TOWARDS A BETTER CARE FOR HEAD AND NECK CANCER PATIENTS AND THEIR PARTNERS

MARINELLA OFFERMAN

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Towards a Better Care for Head and Neck Cancer Patients and their Partners

Op weg naar een betere zorg voor mensen met hoofd-halskanker en hun partners

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In loving memory of my mother

CONTENTS

We are the only animals who can deploy vocal communication for sheer pleasure and recreation, combining it with our two other boasts of reason and humor to produce higher syntheses. To lose this ability is to be deprived of an entire range of faculty:
it is assuredly to die more than a little.

Christopher Hitchens: Mortality. London: Atlantic Books, 2012

CHAPTER 1

GENERAL INTRODUCTION

GENERAL INTRODUCTION

Head and Neck cancer and important gaps in the psychosocial literature

Malignant Head and Neck (H&N) tumors constitute around 5% of the total malignant tumors. In the Netherlands, approximately 2.600 newly diagnosed cases are registered annually and around 800 patients die yearly as a consequence of the disease.[1-2] During the years, substantial literature has been published on the impact to the life of patients with head and neck cancer. As well as experiencing symptoms common to all cancer types, such as pain, H&N cancer can affect the most fundamental activities of daily living, including speech, swallowing, hearing and breathing.[3] Minor disturbances of anatomy by surgery or chemo/radiation therapy may lead to significant dysfunction and disfigurement, and hence to psychosocial complaints.[4]

The work of this thesis further builts on more than twenty years of quality of life research done by our H&N group. We started this work with reviews of studies on physical and psychosocial correlates of head and neck cancer.[4-6] After these literature studies, prospective research followed in which we investigated both physical and psychosocial aspects in the rehabilitation, survival and relapse of head and neck cancer.[7] More recent work from our group on quality of life was the thesis 'Towards effective assessment of the quality of life of head and neck cancer patients in the clinical setting'.[8] In this thesis, it is concluded that more than half of the H&N cancer patients (60%) favored using quality of life questionnaires as a method of communicating their problems to their doctor. Most patients are in favor of completing quality of life questionnaires in the clinic, because it assists them to describe their condition to their doctor. However, only a small percentage (13%) of the H&N clinicians carry out quality of life assessments on a structural basis, because of lack of time or the clinicians did not see the practical relevance of these instruments.

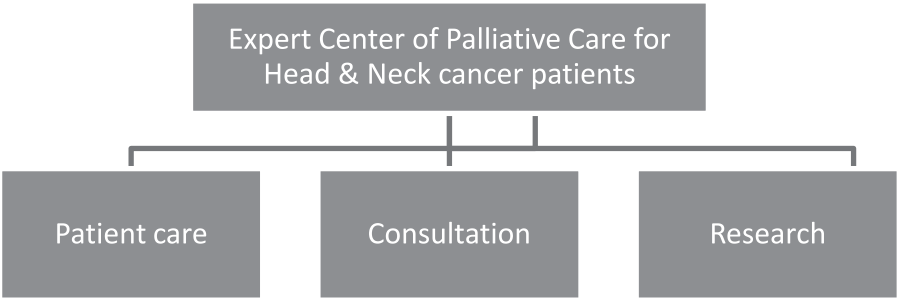
During the years, we started to find out more about the person behind the H&N cancer patient. The next question for our team was: how can we best support the patient in dealing with the consequences of the disease and its treatment? Based on literature, we developed and introduced several innovations in the clinical practice with H&N cancer patients. All of these interventions aim to improve the quality of life of patients. An example of an important project in our H&N team is called the 'Logboek', nowadays known as the 'Zorggids'. This patient dossier contains specific information modules on different care aspects of the disease. It is developed to improve the continuity of information. Patients receiving this logbook seem to be better informed and they experience fewer psychosocial problems and less contradictory information than did patients without the logbook.[9]

Another example of one of our projects improving the psychosocial care for our patients is an ICT-project. This project was part of the thesis 'Supporting Transmural Oncological Care'.[10] Since many different disciplines are involved in H&N cancer cure and care, communication bottlenecks can exist. We developed an electronic health information system to support head and neck cancer patients in their post discharge period at home. With this system, some aspects of quality of life were significantly improved.

A final example of innovation in our care towards patients with H&N cancer is the organization of an Expert Center for H&N cancer patients in the palliative phase in 2005. From the clinical practice and from earlier research within our group we learned that not all aspects of our palliative care were sufficient.[11]

Specifically psychosocial support and patient education needed to be improved. That was the basis of the foundation of our Expert Center. We installed a specialist team consisting of dedicated H&N surgeons, acting as clear contact persons for patients; specialist nurses, psychologists, speech therapists, a pain team of anesthesiologists, a dietician , social workers, and clergymen. Specialized nurses provide information and psychosocial support to patients and their relatives, handle pain management and screen psychosocial needs and other relevant data both for effective allocation of specialized care and for research purposes. These nurses play a pivotal role in the palliative care which leads to a more efficient and effective flow of communication between surgeon, patient and other caregivers. For the main activities of the EC, please see figure 1.

All in all, we have a good overview of important psychosocial aspects of H&N cancer patients and their affected quality of life. However, on certain aspects in the literature there is hardly any, or limited insight into a number of questions in the psychosocial field. In this thesis we refer to these unanswered questions as 'knowledge gaps in literature'. Knowledge gaps are present in all the phases of the disease and treatment process. Let's start with the curative phase. One of the questions we asked ourselves was: what is the impact of the disease on the partner and on the spousal relationship, including intimacy and sexual functioning. Both are underexposed subjects in the head and neck cancer literature. We have chosen to do research among laryngectomees and their partners. In this homogeneous patient group the disease has its impact on both physical and social aspects of life given the loss of natural voice, loss of expressing emotions and the degree of disfigurement. Another issue that we encountered during our work with patients in the curative phase is the way they have to find new meaning in life. Patients have been treated and in a positive scenario they can be cured. However, are they able to live on as they did before? Little is known how patients with head and neck cancer cope with the consequences of the disease. Even less is known about the role of goal disturbance in



Multi disciplinary care with focus on symptom control and psychosocial and spiritual support.

<u>Outpatient clinic</u>: key contact persons: the dedicated Head & Neck cancer surgeons and the specialist nurses.

<u>Clinical care</u>: two rooms specifically equipped for the patients and their caregivers in the (early) palliative phase and the terminal phase on the ward of the Department of Otorhinolaryngology and Head and Neck Surgery in the hospital.

Towards health caregivers in palliative care:

- General Practitioner of the patient in the palliative phase.
- Medical specialist from other departments in the hospital and in other hospitals.
- Hospice / Nursing home.

Published research on the subjects:

- Palliative care in general practice.
- Experience & evaluations of palliative care of next of kin.
- Self-efficacy and goal disturbance in patients and their partners.
- Survival of patients with palliative head and neck cancer.
- Psychosocial aspects of recurrent head and neck cancer.
- Symptom prevalence in the palliative phase and impact on daily functioning.

Current research on the subjects:

- Anxiety in the palliative phase.
- Prediction model risk factors blow-out.
- Prognostic modeling.

Figure 1. Main activities Expert Center of Palliative Care for H&N Cancer

relation to psychological distress in H&N cancer patients and partners. We explored the impact of the disease on the goals people have in life and how this might be related to their perceived quality of life.

As professionals, we are faced with the fact that one fifth of the patients with head and neck cancer develop a recurrence.[12] A valid question we might ask ourselves is what this will do with the mental state of patients? We found out that despite the prevalence of recurrent cancer, psychosocial research on the experience of cancer recurrence and quality of life outcomes after recurrence has been limited.

This is also the case when we look at the most negative scenario for patients, when a patient is diagnosed by the multidisciplinary team with an incurable H&N tumor. We found that little research has been done among H&N cancer patients in the palliative phase of their disease. In order to give the best possible care to this patient group and their family, it is of key importance to know which symptoms occur during this specific phase of the disease, as well as the extent of the impact of these symptoms on the daily functioning of patients. We also have to increase our knowledge of how treatment and support in the palliative phase are experienced by the patients and their families.

In this thesis, several knowledge gaps in psychosocial head and neck (H&N) oncological care are the subject of discussion. This is the first thesis that encompasses psychosocial issues of H&N cancer patients simultaneously during all phases of the disease with inclusion of the partner. It is a novelty that we included psychosocial aspects of the partner of H&N cancer patients and the interaction within the spousal relationship with the patient. More insight into unexplored psychosocial areas is essential for setting up substantiated and efficient interventions for this patient group. This is why we have examined these psychosocial gaps in research; with the explicit intention to use our findings as much as we can for direct implementation in the clinical practice.

The knowledge gaps we have addressed in this thesis are:

1. Changed live goals as a consequence of head and neck cancer.
2. Psychosocial aspects of recurrent head and neck cancer.
3. Head & Neck cancer in the palliative phase:
   a) Prevalence of symptoms of head and neck cancer patients in the palliative phase and the impact on their daily functioning.
   b) The experience of 'standard' palliative care through the eyes of next of kin.
   c) The experience of palliative care after the establishment of an Expert Center for head and neck cancer patients in the palliative phase and their family.
4. Psychosocial problems and quality of life for partners of patients after a total laryngectomy.
5. Impact of a total laryngectomy on the spousal relationship.

The objective of this thesis is to explore psychosocial aspects in the literature for which there is hardly any, or limited insight. The knowledge from this thesis can contribute to further professionalization of care for patients with head and neck cancer and their partners. In some cases we already have implemented some of our interventions, like our Expert Center for palliative care and the work with our specialized nurses. These are examples of ideas that we have adopted into daily practice. In other cases, we are working on the set-up of a pilot intervention like the aftercare project for laryngectomees and their partners, 'Life back on track after a total laryngectomy'. While it is not possible to discuss all the knowledge gaps that exist in the psycho-oncology literature for head and neck cancer, in this thesis we have addressed the knowledge gaps we found to be of significant importance for the care of patients with H&N cancer and their families.

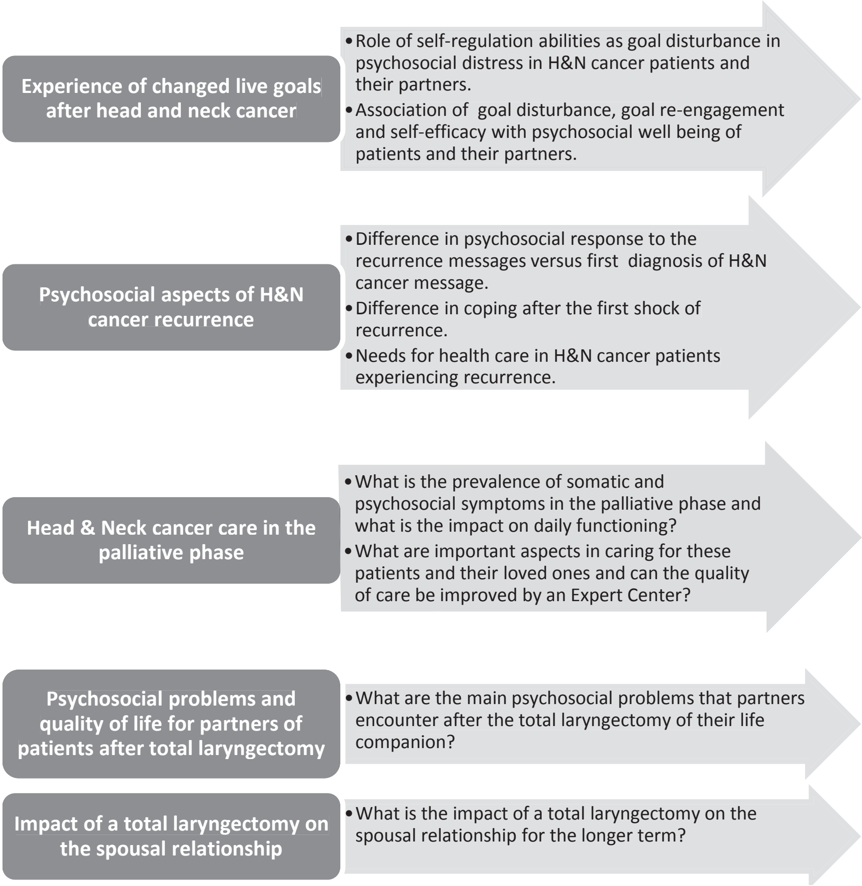


Figure 2. Gaps in literature that form the outline of this thesis

Figure 2 gives a short introduction of the five main gaps that forms the basis of this thesis. Points 3a, b and c are covered together in one gap, called palliative care. The other four gaps are discussed separately.

The experience of changed life goals of head and neck cancer patients

Although researchers are beginning to find out more about problems encountered by patients with Head & Neck (H&N) cancer, the different components influencing their psychosocial well-being still remain poorly understood.[13] Research of the coping and psychological adaptation of H&N cancer patients has gained attention, however, only a few studies have investigated coping in H&N cancer patients.[14] In this research, we used a self-regulation perspective to better understand the experience of psychological distress in H&N cancer patients and their partners. The definition of self-regulation clearly places goals at the center of the processes. People live life by identifying goals and behave in ways aimed at attaining these goals.[15] Little is known about the role of goal disturbance in psychological distress in H&N cancer patients and partners. The present study explored the goals which are important to H&N cancer patients and their partners and whether they experienced disturbances in these goals as a result of the disease. Moreover, we examined the associations of goal disturbance, goal re-engagement, and self-efficacy with levels of psychological distress. The self-regulation abilities, like setting goals and enhancing self-efficacy can be seen in relation to the concept of patient empowerment. In general cancer care, there is a clear development in society stimulating individual choices of patients. More and more patients are seen as an equal partner in the decision-making treatment process. Also after treatment, patients have to be empowered as they will have to learn to deal with the consequences of the disease. In H&N cancer patients and their partners' programs enhancing self-efficacy and empowerment are rare. This current study is the first exploring the self-regulation theory in H&N cancer patients in the curative and palliative phase and their partners. *Covered in chapter 2.*

Psychosocial aspects of recurrent head and neck cancer

A specific psychosocial problem after the treatment of cancer is the experience of fear of both patients and partners that the disease might come back, the so called 'cancer recurrence'. The relapse of cancer is a distressing experience for survivors and their families because once again they have to face the psychosocial effects of cancer. Three main categories have been described explaining survivors' and families' experiences of recurrent cancer in general:[16]

- fear of recurrence during survivorship, which is one of the most frequently mentioned components of distress among cancer survivors. It is often triggered by medical follow-up;

- facing new challenges as a family when cancer recurs, like dealing with the diagnosis of recurrent cancer, living with uncertainty, and facing treatment again;
- distress caused by recurrence.

The findings in the literature discussing whether the recurrence experience is more or less distressing than the message of the primary cancer diagnosis are contradictory and debatable. More research is needed to better understand the psychosocial impact of recurrence as this subject is under-reported in literature. From the few papers on this subject we know that many patients have a wish to discuss their fear of recurrence during the outpatient review. A third of H&N cancer patients at diagnosis reported relatively high levels of fears of recurrence, with 12% still reporting similar levels of fear 6–8 months after treatment. This thesis gives insight into the psychosocial responses of the experience of H&N cancer recurrence and the impact of the illness experience as compared with the impact of the initial diagnosis. With these findings we can further fine-tune our health-care services for the specific group of head and neck cancer patients experiencing recurrence of the disease. *Covered in chapter 3*.

Palliative care for H&N cancer patients

As a large percentage (59%) of the Head and Neck (H&N) cancer patients die as a consequence of their disease,[17] every H&N cancer surgeon will sooner or later be confronted with patients entering the palliative phase. Because of the unique nature of malignancies of the H&N and a variety of tumor related symptoms, special considerations must be given to end-of-life care for these patients and their loved ones.[18-19] A multi-faceted approach for treating and caring for H&N cancer patients in the palliative phase is required.[20] The literature is, however, very scarce on the palliative and end-of-life phase of H&N cancer patients, as well as on experiences of the care that is offered during this phase.[21]

In this thesis, the subject palliative care consists of three separate manuscripts. Together these manuscripts give more insight into the underexposed area of palliative care and provide leads for further professionalization of the care for these patients and their family. We started the subject palliative care with the prevalence of somatic and psychosocial symptoms when patients enter the early palliative phase. We also looked at the impact of these symptoms on their daily functioning. Findings in this research give us a better focus for symptom management, an important task of good palliative care. Another study we did, describes an evaluation of our palliative care through the eyes of the next of kin of our deceased patients. It deals with an evaluation of our medical treatment(s), psychosocial support, communication and experiences of the family including the terminal phase of dying. In between the two research periods, we have set-up an Expert Center for H&N cancer patients in the palliative phase. Once the Expert Center was up and running, we did a follow-up research with a similar set-up. In this second research we made a comparison of the palliative care after the installation of our Expert Center against the care given before this intervention. The pressing question is: can the quality of care of H&N cancer patients in the palliative phase be improved by our Expert Center? *Covered in chapters 4, 5 and 6.*

Psychosocial problems of partners of patients after a total laryngectomy

Head and neck cancer can also have a considerable impact on partners. It is suggested that partners experience an even higher stress level than patients. Partners' distress may be related to the prospect of losing their life companion[22] and to feelings of helplessness that can lead to depression as partners are unable to take a direct role in fighting the cancer.[23] Drabe et al.[24] suggest that anxiety disorders are the most frequently reported psychological disorders amongst (female) partners of H&N cancer patients. This affected psychosocial well-being can hamper adequate care to patients.[25] In a review article on head and neck (H&N) cancer patients in general,[26] it is concluded that there is a lack of publications dealing with the partners' perspective of H&N cancer. Partners provide a crucial role in support of patients with head and neck cancer and more research is needed to explore the levels of distress amongst partners over time.

The literature is particularly scarce when it comes to the psychosocial consequences of a Total Laryngectomy (TL) on partners of patients and on how partners function in their daily life in the long run. The few available studies on the impact of a Total Laryngectomy on partners are mainly old and not all in the English language. This research gives insight into the main problems that partners encounter after the TL of their life companion. In addition to being an explorative analysis of the psychosocial problems and quality of life of partners of laryngectomees, this study also aims to explore the skills people use when dealing with their changed situation (coping). Also the beliefs that partners have about their capabilities (self-efficacy) and goal disturbance related to the consequences of a TL have been explored. *Covered in chapter 7.*

The impact of a total laryngectomy on the spousal relationship

How patients cope with the consequences of cancer depends, among other things, on the interpersonal context of the patient and in particular on the relationship with the partner. More research is needed on the dynamics within the relationship of H&N cancer patient and their partners. When we look at how patients and partners support each other and what the disease means for their relationship we conclude that very little is known about the impact of the consequences of H&N cancer on the spousal relationship. It is suggested that overall quality of life is considerably high in oral cancer patients and their partners living in stable relationships.[27] In a recent research among couples dealing with lung cancer and H&N cancer, it is discussed that patients and partners who engaged in more positive spousal communication experienced less distress.[28] When we look specifically at the impact of a Total Laryngectomy (TL) on the spousal relationship, we must conclude that there is no study to date dealing with that subject. Within this thesis, we discuss the first research exploring the consequences of the TL on the spousal relationship of a large group of laryngectomees and their partners on the long term. *Covered in chapter 8.*

We finish this thesis with a general conclusion with a focus on recommendations (*covered in chapter 9)* for the work in the clinical practice as well as suggestions for future research. In the general discussion of this thesis, two of these initiatives, namely our Expert Center of Palliative Care for H&N cancer patients and a pilot 'Life back on track after a total laryngectomy', are discussed. Our mission with this thesis is to contribute to better understanding of the psychosocial consequences of head and neck cancer for patients and their partners. Based on our key findings, we aim to implement substantiated clinical interventions that will directly help the people affected with head and neck cancer and their families.

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CHAPTER 2

GOAL PROCESSES & SELF-EFFICACY RELATED TO PSYCHOLOGICAL DISTRESS IN HEAD & NECK CANCER PATIENTS AND THEIR PARTNERS

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ABSTRACT

Background

In this cross-sectional study we used a self-regulation perspective to better understand the experience of psychological distress in head & neck (H&N)cancer patients and their partners. We examined which goals they valued and the extent to which patients and partners experience goal disturbance. Furthermore, associations were explored between goal disturbance, goal re-engagement, (goal) self-efficacy, and psychological distress.

Methods

H&N cancer patients and their partners, recruited from the Erasmus Medical Center Rotterdam (N=40), were interviewed and completed questionnaires, assessing the above aspects of the self-regulation theory.

Results

H&N cancer patients and their partners experienced goal disturbance from the disease. Such disturbances were in patients significantly related to more psychological distress. Higher levels of goal re-engagement were related to less psychological distress, again only significantly in patients. More self-efficacy was significantly associated with less psychological distress in both patients and partners.

Conclusion

Self-regulation abilities as goal re-engagement and self-efficacy may be screened and used as target in future psychological interventions, given their potential to decrease perceived psychological distress. In view of elevated levels of goal disturbances in partners, psychological support for caring relatives in such interventions is recommended.

INTRODUCTION

Unlike most cancers, the treatment-related side effects of head and neck (H&N) cancer such as disfigurement, altered speech and inability to swallow are immediately noticeable in social settings.[1] Vital functions can be affected and minor disturbances of anatomy by surgery or chemo/radiation therapy may lead to significant dysfunction and disfigurement, and hence to psychosocial complaints.[2] Recent literature suggests that such psychosocial consequences are not only observed in H&N cancer patients themselves. Especially, when the patient's disease is accompanied by social impairments, the impact of the cancer on the partner's life may be profound.[3] Thus research on the psychosocial consequences of H&N cancer should focus on both patients and their partners.[4] Although researchers are beginning to find out more about problems encountered by patients with H&N cancer, the different components influencing their psychological well-being still remain poorly understood.[5] It has been postulated that it might be fruitful to examine adaptation to a stressful event such as cancer from a self-regulatory perspective.[6,7] Earlier research in patients with a chronic illness suggests that such a self-regulatory theory is a useful framework for reaching better understanding of patients' psychological adaptation to the illness.[8-10] In this research we will use such a self-regulation perspective to better understand the experience of psychological distress in H&N cancer patients and their partners.

Self-regulation theory and the importance of goals

The definition of self-regulation clearly places goals at the center of the processes. Self-regulation looks upon the individual as an active goal striving agent. People live life by identifying goals and behave in ways aimed at attaining these goals.[11] Personal goals do not exist in isolation. As discussed in De Ridder and De Wit[7] they are linked with other goals in a hierarchical structure. Individuals use this structure in order to organize their goals. Mid-order goals are concrete goals that can be achieved within a relative short period. For example, an individual may have a mid-order goal 'to visit terminal ill patients once a week'. This mid-order goal can be linked to a more abstract higher-order goal 'to support others in life'. Having a clear vision of these higher-order goals in life is in itself an important predictor of subjective well-being.[12] Confronting unattainable goals may result in a reduced well-being and psychological distress. This may especially be relevant in the context of having a chronic illness, as the illness may lead to obstacles in the attainment of important goals.[13,14] Studies among cardiac patients suggest that the experience of such goal disturbance is indeed related to more emotional distress, not only in patients themselves but also in their partners.[8,15] Little is known about the role of goal disturbance in psychological distress in H&N cancer patients and partners. Therefore, the first aim of this study is to explore which goals are valued and at the same time examine if patients with H&N cancer and their partners experience goal disturbance and whether this is related to perceived psychological distress.

Goal re-engagement and self-efficacy

The second goal of the study is to explore the role of two factors that have been related to adaptive self-regulation. First, it has been suggested that adaptive self-regulation in the context of obstructed goals depends on the availability of alternative goals.[16] When goals are unattainable, it seems to be important to be able to find renewed purpose in life elsewhere the, so-called goal re-engagement.[17] Goal re- engagement may buffer the negative emotions associated with the inability to make progress towards a desired goal.[18] In this study we will examine to which extent goal re-engagement in H&N cancer patients and their partners is related to their perceived psychological distress.

A second factor that seems to play an important role in adaptive self-regulation is self-efficacy. Self-efficacy refers to a person's belief and confidence to perform certain behavior leading to a desired outcome in a particular situation. It has been stated that such a confidence is a prerequisite for actual performance of adaptive self-regulatory strategies.[19] Self-efficacy has been found to play a central role in psychological well-being in patients with different chronic illnesses.[14,20] Also among H&N cancer patients with facial disfigurement, self-efficacy appeared to be an important asset in controlling psychological distress.[21] In the present study we will focus on two different types of self-efficacy. First, we will examine *self-efficacy beliefs regarding adequate self-management* of a chronic illness.[22] In chronically ill patients, higher levels of this type of self-efficacy were related to patient's perception of better health.[14] Secondly, we will focus on *goal efficacy* which refers to the belief that one has the ability to attain personal goals.[15] Research among cardiac patients found that a greater sense of goal self-efficacy was associated with better psychological well-being.[8,15]

In conclusion, the present study explored the goals being important to H&N cancer patients and their partners and whether they experienced disturbances in these goals as a result of the disease. Moreover, we examined the associations of goal disturbance, goal re-engagement, and self-efficacy with levels of psychological distress. We hypothesized that: (1) H&N cancer patients and their partners experience goal disturbance as a result of the disease; (2) Such goal disturbance is related to more psycho- logical distress in H&N cancer patients and their partners; (3) Goal re-engagement and self-efficacy are both negatively related to psychological distress in H&N cancer patients and their partners.

METHODS

Participants

The sample for this study included twenty adult male patients from which ten were palliative and ten curative cases and who either were treated for head and neck cancer or had received their palliative diagnosis in the Erasmus Medical Center Rotterdam, together with their female partners (N= 40 in total). We decided to include only male patients as the majority in the general H&N cancer population are male and because of possible gender differences in perceiving psychological distress and providing spousal support. In terms of disease phase we decided to work with a cross section of patients treated in Erasmus MC, which are both palliative and curative patients in different disease stages. Patients were included if they finished treatment or received palliative diagnosis at least one month ago. Patients were excluded who were not able to complete questionnaires in Dutch language.

Design and procedure

For this cross-sectional study, data was collected via a battery of validated questionnaires. Regarding the procedure, patients and their partners were recruited and contacted by phone by the H&N surgeon of the Erasmus Medical Center Rotterdam. They were provided with the questionnaire, a letter explaining the content of the study and an informed consent. After receiving informed consent, a date was planned for a home visit to conduct a short interview and to collect the filled-out questionnaires. This was done by one scientific researcher. In total twenty couples were enrolled for this study. One curative patient did not want to cooperate because he found the questions irrelevant. Ten palliative patients called off their participation with main reason: deteriorating physical situation of the patient and some were too busy with other things or in general not interested in participation. This study was approved by the Medical Ethics Commission of the Erasmus Medical Center Rotterdam.

Instruments

Psychological distress

Psychological distress was assessed with the Hospital Anxiety and Depression Scale.[23] This 14-item self-report instrument measures anxiety (seven items) and depression (seven items) using four-point scales. The range for both scales is 0–21. Scores 8–10 indicate possible cases for depression or anxiety, while scores >10 indicate probable cases for depression or anxiety. In a validation assessment of the HADS[22] the reliability for both scales was found to be good. Specifically for head and neck cancer patients, screening for depression can be accurately done with the HADS.[24] Cronbach's alphas in current study were .91 for patients and .77 for partners for anxiety and .83 for patients and .85 for partners for depression.

Goal importance & disturbance

Goal importance & disturbance were assessed with the Goal Facilitation Inventory (GFI).[25] For each of the 26 higher-order "being" goals such as 'being healthy', patients and partners were asked to report the importance and extent of disturbance in their life on a five-point Likert scale, ranging from 1= 'not at all important' to 5= 'very important' and 1='completely disturbed' to 5= 'not at all disturbed' respectively. Cronbach's alpha for goal importance was .82 for patients and .94 for partners. Cronbach's alpha for goal disturbance was .95 for patients and .92 for partners. In addition to higher-order "being" goals, we asked patients and their partners about their mid-order" doing" goals. By means of one item they were asked to indicate their most valued personal goal for the coming months. By means of five items, we also assessed people's perceptions regarding disturbances in five mid-order goals, related to work, household tasks, partner & children, family & friends, and hobbies (answer category 1= not attainable at all to 5= very good attainable). Cronbach's alphas were .85 for patients and .80 for partners.

Goal re-engagement

Goal re-engagement was assessed with the six item subscale Goal Re-engagement developed by Wrosch et al.[16] To cue the goal re-engagement responses, all six items were answered with respect to the most important unattainable goal for respondents since the disease of the patient. The generic sentence that needed to be completed was: "Now I cannot attain this goal any longer.." with example item: 'I seek other meaningful goals'. Cronbach alpha was .92 in both patients and partners.

Self-efficacy related to self-management

Following Lorig et al.[22] and Kuijer and De Ridder[14] we asked patients and partners to answer six items on self-efficacy beliefs regarding achieving health outcomes (e.g. 'How confident are you that you can continue to do your hobbies and recreation?'). All items were measured on a seven-point scale, ranging from 1='no confidence at all' to 7= 'full of confidence'. Cronbach's alpha for this scale was .90 for patients and .84 for partners.

Goal related self-efficacy

Goal related self-efficacy was measured with the Goal And Processes Inventory-Health (GAPI-H-71).[26] This subscale consists of 6 items (e.g. 'It is clear for me how I can attain this goal') using a five-point Likert scale, ranging from 1= 'completely disagree' to 5= 'completely agree'. Cronbach's alpha for the scale was in the patient and partner group .97 and .93, respectively.

Statistical analysis

First, the scales were screened for normality. None of the scales violated the assumption of normality, except for the depression scale of the HADS and the goal efficacy scale, both with one outlier. Following statistical guidelines to reduce the impact of these outliers, we replaced the scores by the mean score plus/minus two standard deviations.[27] Next, standard descriptive statistics and t-tests were performed to examine the mean levels of goal importance, goal disturbance, goal re-engagement, self-efficacy and distress between patients and their partners. In the patient and partner group separately, Pearson product–moment correlation coefficients were used to examine the relationships between goal disturbance of the higher-order goals, goal re- engagement and self-efficacy on the one hand and psychological distress on the other hand.

RESULTS

Sample characteristics

Table 1 summarizes the characteristics of the studied participants.

Descriptives of study variables

See Table 2 for mean scores and standard deviations of the study variables. Using independent-samples t-test, we found no significant differences between patients and partners.

Goal importance and goal disturbance

Table 3 shows mean scores on all 26 higher-ordergoals, regarding importance and disturbance. A rank order was made for the most important higher-order goals, with the top 5 presented in bold in the column "Importance". It can be seen that the goals *being healthy, ensuring my safety, and treating others fairly* are in the top 5 of both patients and their partners. Also some differences can be observed. Patients attached more importance to the goals *understanding the world around me* and *making my own decisions in life*, whereas partners perceived the goals *supporting others* and *fulfilling my duties to others* to be more important.

The following column of Table 3 shows the "Disturbance" of each of the 26 items, measured with the actual disturbance scores. Experiencing bodily pleasure is the most disturbed higher-order goal for both patients and partners. Furthermore we have added an extra column called "Impact" as we also wanted to examine goal disturbance by looking at goals with the greatest impact (importance x disturbance) by the illness. Hereby assuming that an important goal that is being disturbed has a greater impact than a less important goal that is being disturbed. Also here the top 5 are presented in bold.

Table 1. Demographic and medical characteristics of head & neck cancer patients and partners.

Characteristic	Patients (*n*= *20*)	Partners (*n*= *20*)
Gender		
Male	20	0
Female	0	20
Age (M, SD)	60.7 (10.37)	57.6 (11.37)
Education level		
Elementary	7	6
Lower	3	3
Middle	4	9
Higher	6	2
Employment status		
Paid job	6	4
Self-employed person	4	1
Retired	8	1
Housewife	0	13
Volunteer work	0	1
Incapacity for work	2	0
Time of treatment or palliative diagnosis		
<1 year ago	17	-
Beween 1 and 1,5 years ago	3	-
T-stage		
T1	0	-
T2	8	-
T3	7	-
T4	4	-
Tx	1	-
N-stage		
N0	9	-
N1	4	-
N2	5	-
N3	1	-
Nx	1	-
M-stage		
M0	16	-
M1	4	-

Table 2. Descriptive statistics of study variables

	H&N Patients *(n = 20)* Mean (SD*)	H&N Partners *(n = 20)* Mean (SD)
Goal importance	104.23 (10.93)	97.62 (18.86)
Goal disturbance	52.92 (17.86)	56.49 (13.87)
Goal re-engagement	20.05 (5.88)	18.56 (5.15)
Goal efficacy	23.65 (5.31)	21.00 (4.77)
Self-efficacy related to self-management	28.85 (8.26)	28.36 (7.06)
Anxiety	7.69 (4.88)	8.15 (3.34)
Depression	5.65 (3.63)	6.25 (4.46)

* SD= Standard deviation

Table 3 part 1. Ranking of goal importance, disturbance and impact of higher order goals based on mean scores. Impact = importance x disturbance.

	Goals male PATIENTS:	Importance	Disturbance	Impact
1	**being healthy**	**4,60**	2,80	**12,88**
2	treating others fairly	**4,60**	1,20	5,52
3	ensuring my safety	**4,60**	2,10	9,66
4	understanding the world around me	**4,55**	1,50	6,83
5	making my own decisions in life	**4,50**	2,05	9,23
6	**having fun**	4,45	2,35	**10,46**
7	coming up with new ideas	4,45	1,35	6,01
8	keeping up my self-confidence	4,40	1,80	7,92
9	fulfilling my duties to others	4,40	1,70	7,48
10	supporting others	4,40	1,35	5,94
11	**feeling relaxed**	4,20	2,60	**10,92**
12	**experiencing bodily pleasure**	4,15	3,10	**12,87**
13	respecting rules	3,95	1,25	4,94
14	receiving support from others	3,90	1,65	6,44
15	feeling connected to the people around me	3,90	1,55	6,04
16	meeting a challenging standard of performance	3,90	2,60	10,14
17	having daily activities run smoothly	3,90	2,40	9,36
18	**experiencing excitement**	3,80	2,90	**11,02**
19	learning new things	3,75	2,40	9,00
20	reaching a higher level of consciousness	3,68	1,73	6,37
21	doing creative things	3,60	2,35	8,46
22	feeling unique	3,50	1,75	6,13
23	discovering who I truly am	3,50	1,65	5,78
24	doing things better than others	3,25	2,15	6,99
25	feeling a spiritual sense of connectedness	3,21	2,05	6,58
26	obtaining more money or possessions	2,80	2,55	7,14

Table 3 part 2. Ranking of goal importance, disturbance and impact of higher order goals based on mean scores. Impact = importance x disturbance.

	Goals female PARTNERS	Importance	Disturbance	Impact
1	ensuring my safety	**4,65**	2,20	10,23
2	**being healthy**	**4,60**	2,25	**10,35**
3	supporting others	**4,60**	1,00	4,60
4	treating others fairly	**4,50**	1,90	8,55
5	fulfilling my duties to others	**4,45**	1,78	7,92
6	receiving support from others	4,30	2,10	9,03
7	**feeling relaxed**	4,25	2,80	**11,90**
8	**having fun**	4,20	2,70	**11,34**
9	keeping up my self-confidence	4,20	2,30	9,66
10	feeling connected to the people around me	4,20	1,90	7,98
11	**having daily activities run smoothly**	4,20	2,75	**11,55**
12	respecting rules	4,10	1,50	6,15
13	understanding the world around me	3,90	2,00	7,80
14	**making my own decisions in life**	3,75	2,90	**10,88**
15	experiencing excitement	3,60	2,60	9,36
16	meeting a challenging standard of performance	3,55	2,05	7,28
17	experiencing bodily pleasure	3,35	3,00	10,05
18	feeling a spiritual sense of connectedness	3,31	2,00	6,62
19	doing creative things	3,25	2,30	7,48
20	discovering who I truly am	3,15	1,80	5,67
21	coming up with new ideas	3,10	2,50	7,75
22	learning new things	3,10	2,50	7,75
23	reaching a higher level of consciousness	2,90	1,95	5,66
24	feeling unique	2,80	1,70	4,76
25	obtaining more money or possessions	2,80	2,35	6,58
26	doing things better than others	2,40	1,70	4,08

In both patients and partners, the illness had a great impact on the goals *being healthy, feeling relaxed*, and *having fun*. In addition, patients also reported an impact on the goals *experiencing bodily pleasure* and *experiencing excitement*, whereas partners reported an impact on the goals *having daily activities run smoothly*, and *making own decisions in life*.

Regarding their mid-order goals (see figure 1), we additionally asked patients and partners to share their most important goal they want to achieve in the coming months. Patients reported that they concentrated mostly on 'building up their physical condition' (n= 6), and 'live life as normal as possible' (n= 6). Specific goals were celebrating marriage, quit smoking or moving to another house (n= 4), leisure time(n= 3) and no

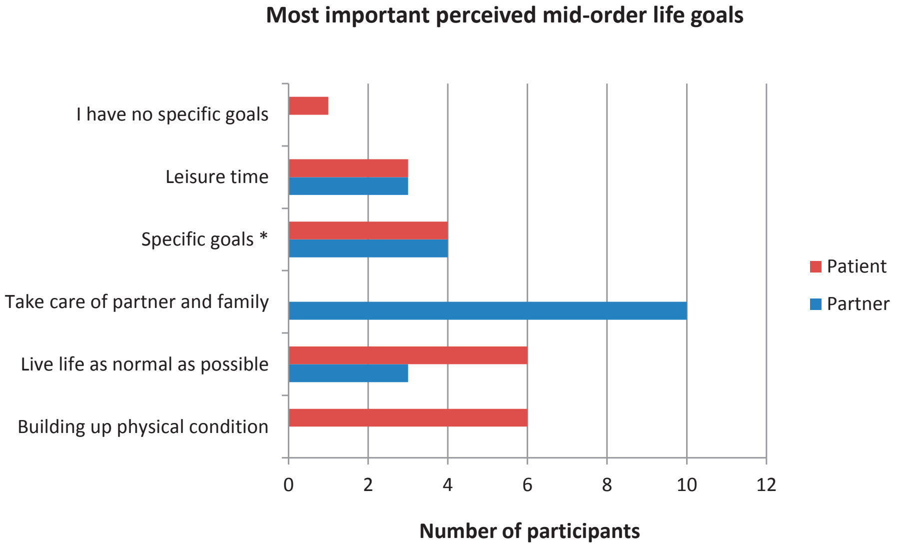

Figure 1. Most important mid-order goals for head and neck cancer patients and their partners.
* Specific goals were celebrating a marriage in the family, quit smoking and moving to a new house.

specific goals (n= 1). For half of the partners (n= 10) the most important goal for the coming months was to take care of their partner and family, followed by specific goals as celebrating marriage, quit smoking or moving to another house(n= 4), live life as normal as possible (n= 3), and leisure time (n= 3).

When patients were asked about attainability of the five domains of mid-order goals since the cancer diagnosis, goals within the area of work, were lowest attainable (mean 2.4), followed by household-related goals (mean 3.3) and hobby-related goals (mean 3.6). For partners, also work-related goals were most difficult to attain (mean 3.1), followed by hobby-related goals (mean 3.2) and goals related to family & friends (mean 3.6).

Psychological distress

The mean score on anxiety and depression for patients was 7.69 (SD 4.88) and 5.65 (SD 3.63) respectively. For partners the anxiety mean score was 8.15 (SD 3.34) and the depression mean score was 6.25 (SD 4.46). The optimal cut-off suggested by Zigmond and Snaith (1983) in their original paper on HADS is >8. In the patient group 35% scored >8 for HADS-Anxiety and 20% of the patients had a score of >8 on HADS-Depression. In the partner group 60% scored >8 on the HADS-Anxiety scale and 30% scored >8 on the HADS-Depression scale.

Relationships of goal disturbance, goal re-engagement, self-efficacy with distress

Goal disturbance

In patients, more goal disturbance was significantly associated with more depression (r= .70, p < .001) and more anxiety (r= .63, p < .01). For partners we found correlations in the same direction but, these associations were not significant (Table 4).

Goal re-engagement

More goal re-engagement was significantly related to lower depression in patients (r= -.47, p < .05). In partners, more goal reengagement was not significantly related to less depression. A trend was found for an association of more re-engagement with less anxiety.

Self-efficacy

In patients, more self-efficacy to achieve health outcomes was significantly related to less depression (r= -.73, p < .001) and less anxiety (r= -.60, p < .01). In addition, more goal self-efficacy was significantly related to less depression (r= -.46, p < .05), with a trend observed for less anxiety. A similar picture was found in partners, with more self-efficacy achieving health outcomes significantly related to less anxiety (r= -.60, p < .01) and less depression(r= -.71, p < .001). Also more goal self-efficacy was significantly related to less depression(r= -.45, p < .05), with a trend observed for less anxiety.

Table 4. Inter correlations among outcome variables in head and neck cancer patients and their partners.

		1	2	3	4	5	6
1	Goal disturbance	-	.22	-.39	-.03	.35	.36
2	Goal re-engagement	-.35	-	.32	.07	-.33	-.16
3	Self-efficacy health outcomes	-.59**	.50*	-	.68**	-.60**	-.71***
4	Goal self-efficacy	-.56**	.61**	.57**	-	-.33	-.45*
5	Anxiety	.63**	-.29	-.60**	-.33	-	.57**
6	Depression	.70***	-.47*	-.73***	-.46*	.85***	-

***p<.001; **p< .01; *p<.05.

Note: Correlations in patients are below the diagonal and those of partners are above the diagonal.

DISCUSSION

This study aimed to examine whether a self-regulation approach could lead to a greater insight into factors related to psychological distress in H&N cancer patients and their partners. Results confirmed our hypothesis that H&N cancer patients and their partners experienced goal disturbance. Such disturbances were especially in cancer patients related to more psychological distress. Also consistent with our hypothesis, more reengaging in alternative goals was related to less psychological distress, but only significantly in patients. Finally, higher levels of self-efficacy were in both patients and their partners related to less psychological distress.

Descriptive analyses clearly demonstrate the presence of psychological problems in this sample of patients as well as in their partners. Both patients and partners reported disturbances in the attainment of their personal goals due to cancer. These levels were comparable with levels of goal disturbance found in another study among cancer patients.[28] Compared to norms from similar aged individuals from a community sample, patients and partners also reported elevated levels of depression and anxiety: these levels were more or less in line with non-oncological general medical patients from medical outpatient clinics at Leiden University Hospital.[29] The rate of 20% of total patients scoring >8 cut-off score is completely in line with Katz et al. [24] who also reported 20% prevalence of clinically significant depression in his study with head and neck cancer patients. Partners in the current study scored in line with another H&N cancer partner group on anxiety.[30] These results emphasize the impact of H&N cancer, not only on the patient but also on the partner.[3-4,31] Such distress in partners maybe related to the prospect of losing their partner and feelings of helplessness which can lead to depression.[30] As it has been found that distressed partners generally show less supportive behaviors towards the patient, [4,32] healthcare professionals should be aware of possible burden of H&N cancer in spouses and may offer integrated psychosocial support.[33]

Regarding goal importance, both patients and their partners found it important to feel healthy and safe and to treat others fairly in their relationships. Patients also found it important to make sense out of the world and to make their own decisions. Regarding the short-term, many patients were focused on building up their physical condition and living life as normal as possible. These results show that patients want to move on with their lives. This is in concordance with recent research indicating that H&N cancer patients strive for returning to a normal lifestyle.[34] In addition, partners attached great interest in giving support to others and fulfilling social and daily duties. Not surprisingly, most partners were currently focused on taking care of their family. This latter finding may be related to the fact that all partners were females mainly taking care of their partner.[35] Least important life goals for both patients and partners were obtaining more money or possessions and doing things better than others.

Correlational analysis confirmed that in male patients, more goal disturbance was significantly associated with higher levels of psychological distress. This is in agreement with previous studies among chronically ill patients.[8-9,15] Although the female partner group experienced similar levels of goal disturbance as patients, the association of goal disturbances with distress was less strong in the female partners. A possible explanation could be found in the difference between male patients and female partners regarding importance of the content of goals. While half of the female partners reported as their most important mid-term goal for the coming months: to take care of their partner and family, male patients primarily concentrate on building up their physical condition. Disturbance of higher-order life goals in female partners seems not to be significantly related to psychological distress as female partners might only focus on their primary short-term goal of 'care taking'. Future research is needed to examine the role of goal disturbance in levels of psychological distress, taking into account both role (patient versus partner) and gender effects.

In accordance with earlier research,[16] we found that more goal re-engagement was associated with less depression, confirming that in case of unattainable goals, the pursuit of meaningful alternatives is of crucial importance for patients 'well- being.[10] As mentioned earlier, this may indicate that patients want to move on with their life.[34] At group level, male patients and female partners showed similar levels of re-engagement, which were comparable with a community sample and a sample of cancer patients.[28,35] The association of goal re- engagement with psychological distress in the female partners was, however, less strong. At this point in time, it can be argued that this has to do with the earlier mentioned importance of the caring role of female partners. We can hypothesize that, as goal disturbance was less strongly associated with a reduced well-being in partners, goal re-engagement may also be less functional for partners' well- being, compared to patients. Being able or not to support and take care of the patient, rather than feeling hopeless and helpless, may be more important or of key importance for partners' well-being.

Higher levels of self-efficacy were in both patients and partners significantly associated with less psychological distress. This confirms earlier research in chronically ill patients.[14,15] Especially, having the confidence to manage and continue things in life such as daily duties, hobbies and social activities appeared to be important for perceived psycho- logical well-being. Therefore, enhancing self-efficacy in H&N cancer patients and their partners, by means of self-management programs for chronic diseases, seems a worthwhile research area.

Limitations

When interpreting the results, several limitations should be mentioned. First, the current study was cross-sectional, thus no conclusions can be drawn about causality. Moreover, the small sample size hampered the use of multivariate statistics. The specific characteristics of the participants may also limit the generalizability of the findings. We included only male patients and their female partners within a fixed period of time from diagnosis and treatment. Despite these limitations, our results add to an underexposed subject of the impact of H&N cancer on caregiver relationships. The study enabled us to understand patients and their partner's perceptions regarding personal goals in life in an in- depth way. Furthermore, this study was strongly driven by the self- regulation theory. Future longitudinal research, using a larger sample, is needed to confirm our findings and further examine the role of self-regulation variables in the psychological adaptation of cancer patients. Dyadic analyses could be of added value, including attention to the seemingly important role of gender in individual distress levels.[36]

Implications for clinical practice & nursing

While the necessity of psychological support has been recognized, it is still rare in H&N cancer units, mainly due to lack of resources required to develop psychological services.[37] Before starting any interventions, a structured screening to assess the levels of distress and needs for support is of key importance. Specifically for H&N cancer patients an efficient aid in screening and referral of patients with psychosocial problems has been developed.[38] It has been proven that this instrument leads to a reduction in consultation time and increases specialists' initiative to discuss psychosocial problems and could be complemented with screening questions related to self-regulation abilities.

Possible psychological support could be seen in self- management programs emphasizing the patients' central role in managing their illness.[39] Examples of such programs enhancing the patient's self-efficacy include psycho- educational interventions, cognitive-behavioral interventions or group interventions.[40] One specific intervention developed for chronically ill patients is the generic Chronic Disease Self-management Program.[41] As our findings indicate that self-regulation abilities such as goal re-engagement and self-efficacy play an important role in psychological well- being in H&N cancer patients and their partners, it seems obvious to target possible future interventions on increasing these capabilities. Before treatment, additional information in the form of a leaflet or DVD[42] could be given, specifically related to psychological consequences of H&N cancer that enhances self-efficacy. An H&N cancer nurse or a psychologist could give information and train patients and partners to engage in attainable life goals and to increase self-efficacy capabilities. A pilot study testing the feasibility of providing a psycho-educational intervention for H&N cancer patients has shown to have beneficial effects.[43] Also support groups for patients and partners seem to improve well-being in various areas such as emotions, pain and enhancing self-efficacy.[44] Future research is needed to confirm the current findings which could serve as the basis for possible psychosocial interventions aiming at increasing psychological well-being of H&N cancer patients and their partners.

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CHAPTER 3

PSYCHOSOCIAL ASPECTS OF RECURRENT HEAD AND NECK CANCER

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INTRODUCTION

The psychosocial impact of recurrent cancer in general

Despite the prevalence of recurrent cancer, psychosocial research on the experience of cancer recurrence and quality of life outcomes after recurrence has been limited. [1-3] Burnet & Robinson indicated in their paper that research on the psychosocial adjustment of cancer has been mainly focussed on *newly* diagnosed cancer patients and not on cancer recurrence experiences.[1] It was more than three decades ago that Weisman suggested that 'strangely enough' little investigation into cancer recurrence has been done, whereas this phase may be the most discouraging that a patient has to face.[4]

Earlier research has found that recurrence of cancer can be equally as stressful as or more stressful than the original diagnosis of cancer.[2] Complex treatment regimes, unclear explanations and exhaustion caused by the accumulation of earlier experiences with cancer may leave families overwhelmed and confused. The relapse of cancer can bring back negative emotions and different psychosocial concerns which could be more intense and different than those after first diagnosis. There is often more uncertainty about the patient's future than at the time of the initial diagnosis and treatment. Vivar et al.[3] suggested that recurrence is a distressing experience for survivors and families because they have to face again psychosocial effects of cancer. The authors identified in their review three main categories that explained survivors' and families' experiences of recurrent cancer:

- Fear of recurrence during survivorship which is one of the most frequently mentioned components of distress among cancer survivors and it is often triggered by medical follow-up.
- Facing new challenges as a family when cancer recurs, like dealing with the diagnosis of recurrent cancer, living with uncertainty and facing treatment again.
- Distress caused by recurrence.

In earlier research it is suggested that knowing the cancer had returned was devastating because, although patients knew the chances of recurrence, they were not prepared for this shock.[2] Individuals are faced with adapting to changing circumstances, living with uncertainty, letting go of some relationships and re-enforcing others, including those with spouses and family.[1] In contrast, other research suggested that levels of distress in patients with recurrence were statistically not significantly different from those of newly diagnosed with cancer.[3] Yang et al.[5] concluded in a mixed cancer population that patients with disease recurrence report gains in their psychological functioning and quality of life. Their hypothesis was that patients' familiarity with the cancer experience would ease the psychological impact at the time of the recurrence diagnosis.

The findings in the literature concerning whether the recurrence experience is more or less distressing than that of the primary cancer are contradictory and debatable. Burnet and Robinson mentioned that the question that is more relevant in this context is: 'What is distressing and upsetting about the recurrence experience and what can healthcare professionals do to help?' [1] More research is needed to better understand the psychosocial impact of recurrence. The goal of this chapter is to shed some more light on the psychosocial aspects of recurrence in head and neck cancer patients, as well as in relation to the first diagnosis. By providing more information about this underreported subject in the literature for head and neck cancer, we hope that health-care professionals can better fine-tune their services for this specific group of cancer patients.

A context of the impact of recurrence in head and neck cancer

Head and neck (H&N) cancer can be described as a psychologically highly traumatic cancer type. Many vital functions, such as mastication, swallowing, speech, taste, smell and appearance can be affected. Even minor disturbances of anatomy by surgery may lead to significant dysfunction and disfigurement, and hence to psychosocial complaints.[6] The survival of head and neck cancer is approximately 50%,[7] with average survival rates at 5 years ranging from zero to 40%.[8] In a retrospective review over a period of five years, 19% of the head and neck cancer patients developed a recurrence. [9] The recurrence risk in orofacial cancer patients is relatively high in comparison to other cancers. [10] One-third of all head and neck cancer patients are confronted with a recurrence at some time in their lives. [11] Patients who develop a recurrent head and neck cancer have a poor prognosis; to a large extent because the initial course of treatment substantially reduces the flexibility and intensity of re-treatment. [12] The main causes of death in patients with advanced head and neck cancer is loco regional recurrence, occurring in approximately 40%-60% of patients. [13,14]

Studies on psychosocial response after head and neck cancer recurrence

A literature search was performed in order to identify the maximum possible number of papers on our topic of psychosocial aspects of head and neck cancer recurrence. With our research team we have set-up in cooperation with a professional research librarian the search terms, as presented in the enclosure, in the databases: PubMed, EMbase, Web of Science and PsycInfo. In total we found 254 articles of which 106 were duplicates, leaving a total of N=148 articles[a]. Of this total amount of 148 papers, the great majority (133) was

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[a] The enclosure of this chapter covers an overview of the search terms in the databases PubMed, EMbase and PsycInfo.

not related to quality of life in head and neck cancer recurrence in terms of psychosocial aspects. In most cases these papers deal with either the meaning of different surgery types or therapy options in the management of recurrent head and neck cancer or with quality of life of patients with recurrent head and neck cancer treated with treatment X or Y.

Of the remaining fifteen papers, we found only one paper that examined psychological response in patients with head and neck cancer recurrence. [15] The key outcomes of this study will be discussed in the next section. Nine papers were dealing with fears of head and neck cancer recurrence, of which the key conclusions will be discussed later in this chapter. One paper specifically discussed the need for close follow-up in patients previously treated for oral/oropharyngeal squamous cell carcinoma as the majority of the patient population were unaware of a return of their disease. [9] The authors conclude that a close follow-up in the first two years is essential.

Additionally, there is a study in which recurrence is also discussed as outcome measure for head and neck cancer patients.[16] With respect to psychosocial predictors, they found that patients who perceived themselves as more physically self-efficacious, were more likely to survive and less likely to have a recurrence. And patients who expressed a higher intensity of negative feelings in regard to their illness were less likely to develop a recurrence than those patients who were unable to express such feelings.

In one study the association between depression and disease recurrence in patients with head and neck cancer is examined.[18] The authors concluded that depressed patients with head and neck cancer may have a higher mortality and disease recurrence rate. Therefore, diagnosis, prevention, and treatment of depression in head and neck cancer may provide an avenue to improve survival.

Furthermore we found one recent review discussing the relevant literature concerning quality of life considerations in treatment of recurrent unresectable head and neck cancer.[8] According to these authors, the management of loco regional recurrence is a complex problem. The best choice for treatment is related to interplay of patient and tumor variables. This paper discusses the background to the question why it is not straightforward to assess and interpret quality of life scores in recurrent head and neck cancer patients. The authors suggest that this group is difficult to assess as many patients are too unwell to comply, which leads to high attrition rates and less possibility for long-term follow-up. Sample sizes are often small and all existing validated quality of life instruments are only suitable for comparing populations of patients and not individual scores. No instrument has been correlated with clinical anchor states in recurrent head and neck cancer so as to direct decisions on the best form of management. This paper concluded that this population has the most to lose if treatment processes cause deterioration in quality of life, owing to their limited lifespan. It is, therefore, of the utmost importance to ensure that they have the highest attainable quality of life even if survival might not be prolonged. All in all results of treatment are poor; thus quality of life outcome should play a major role in the choice of treatment.

To focus on our chapter topic, we share the main thoughts of the one study that examined the psychosocial experience of head and neck cancer recurrence. [15] The authors used a qualitative method and did research with nine head and neck cancer patients of whom three had two or more recurrences. They collected their data by making use of a semi structured interview schedule in a flexible and adaptive approach. The authors identified five core themes. The first three themes were: (a) emotional reactions, such as shock, fear, or denial; (b) reevaluation; such as reappraisal of life; and (c) active coping strategies, such as striving for hope and normality, fighting spirit or thinking positive. The authors called these themes "internal or psychological" effects of cancer recurrence. The other two themes were (d) life changes such as limitations or physical problems; and (e) support, such as positive impact on relations. These two themes were considered as "external" effects of cancer recurrence. An additional theme that was found concerned improvement in relationships, such as more closeness within familial relationships due to the recurrence of the cancer. One of the main conclusions shared in this paper was that even though there was a wide variation of individual differences reported, a common experience of heightened emotional vulnerability was seen across participants with recurrent illness. The level of consequential emotional burden expressed was strongly determined by how patients were able to comprehend, reappraise, and adjust to the circumstances they found themselves in. Furthermore, they said that the patient's journey through specialist services was not always smooth and sometimes added to their burden. Therefore, increased provision of support for both patients who experience recurrence and their caregivers seems to be a vital addition to head and neck oncology services that wish to meet the emotional and psychological needs of their patients. These needs are likely to be complex and significant after a diagnosis of oral cancer recurrence

Studies on fear of recurrence

Earlier studies in different types of cancer patients indicated fear of recurrence as one of the major concerns that cancer survivors report. Distress because of the fear of recurrence in cancer is clearly established in the literature.[3] When we look specifically at the subject of fear of recurrence in the population of head and cancer patients, there is some relatively recent literature available.[10,19-25] The key conclusions of these papers dealing with fear of head and neck cancer recurrence are:

- A majority (80%) of patients expressed their concern about the possibility of recurrence at three months post treatment and 72% of the patients at seven months post treatment.[10]
- Many head and neck cancer patients have a wish to discuss their fear of recurrence concerns during the outpatient review. [19]
- A third of HNC patients at diagnosis reported relatively high levels of fears of recurrence, with 12% still reporting similar levels of fear 6–8 months after treatment.[25]
- Patients aged 65 or above were significantly less concerned about recurrence.[10]
- Carers recorded higher recurrence concerns on average than patients.[21]
- A low level of cancer concern persisted in about half of the long-term head and neck cancer survivors. [20]
- Cancer concern is associated with continued pain, disfigurement and limitations on eating in public.[20]
- Patients who have more severe long-term effects will be more likely to be concerned about the recurrence of their cancer. [20]
- Fear of cancer recurrence after treatment was directly predicted by pre-treatment fears and optimism.[25]
- Future research is required into the triggers of fear of recurrence and to identify the aspects of fear of recurrence and concerns and how best to give information to patients about the likelihood of further disease.[19]

Current Research

To further build on the findings of the scarce literature on psychosocial experiences of head and neck cancer recurrence with the one and only paper,[15] we have set up some further research as follows:

Research question

How can we fine-tune our healthcare services for the specific group of head and neck cancer patients experiencing recurrence of the disease?

Research goal

Obtain knowledge in order to describe the psychosocial responses after the recurrence message and the impact of the illness experience on the life of the patient.

METHODS

Sample

Purposeful criterion- based sampling. This meant that patients were selected in a purposeful way so that it was not a coincidence to be included in the research. We used an up-to-date database with our H&N oncology patients treated in the Erasmus Medical Center Rotterdam, the Netherlands and followed the trend of our data, i.e. the division in our total database of first recurrence tumors belonging to a first primary tumor and second primary tumors. We decided to include ten patients who had recurrence[b] of the illness; eight of them received curative treatment and two patients received palliative treatment (table 1).

Table 1. Demographic and medical data participants N=10

	Sex	Age/ yrs	Nature of tumor	Tumor belongs to	Treatment recurrence
P1	Male	63	2nd primary	-	Curative surgery Jan 2010
P2	Male	83	1st recurrence	1st primary tumor	Curative surgery and RT Oct 2009
P3	Male	72	1st recurrence	1st primary tumor	None, palliative control visits As of Feb 2010
P4	Male	46	1st recurrence	1st primary tumor	Curative surgery Sep 2009
P5	Female	62	1st recurrence	1st primary tumor	Curative surgery Dec 2009
P6	Female	39	1st recurrence	1st primary tumor	None, palliative control visits As off summer 2009
P7	Male	49	1st recurrence	1st primary tumor	Curative surgery and CRT Jan 2010
P8	Male	64	2nd primary	-	Curative RT Nov 2009
P9	Female	74	2nd primary	-	Curative surgery and RT Aug 2009
P10	Male	59	2nd primary	-	Curative RT Nov 2009

RT= radiotherapy; CRT= chemo-radiation therapy

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[b] Medically speaking, a recurrence means that *the same cancer* (related to the first cancer) comes back after some time. However, we defined recurrence from the perspective of the patient, i.e. the patient has been treated successfully for the first cancer experience, and after a period, he experience cancer in the same area for a second time. We therefore included loco-regional second primary head and neck cancer as from the patient perspective, this is recurrence as well, since the disease came back, despite the fact that with a second primary tumor, it is not a recurrence in the pure sense of the word.

Additional inclusion criteria were sufficient knowledge of the Dutch language and no significant cognitive deficits of patients. Patients were selected from our database (figure 1) and their status of loco-regional recurrence was checked by a head and neck surgeon. After this first selection, the candidates were handed over to the specialized head and neck nurses who have regular contact with the patients. They best know if the patient is in a good condition to be interviewed or whether he or she can speak the Dutch language. The nurses made the first contact with the candidates and they asked permission of the patients for a research psychologist to contact them. This psychologist made the second call to the patient and gave further background and an introduction of the interview. And the end of the telephone call an appointment was made for a home visit.

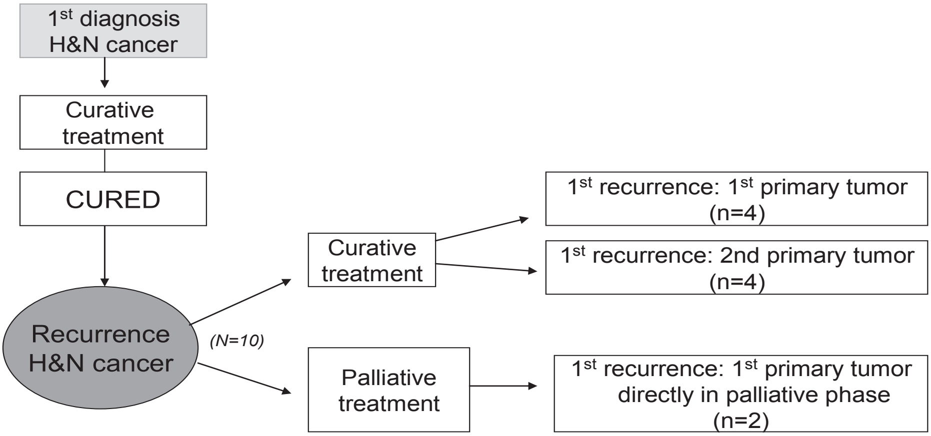

Figure 1. Progression of patients.

Set-up interview

In-depth qualitative interviews were set-up with a well-structured questionnaire containing five main blocks of questions. Each block had a primary question to start the interview with. First there was time for open reactions. Each primary question was then followed by a series of questions to follow-through on the subject.

The five main blocks were:

1) Primary reactions (thoughts, emotions and behavior) of the patient directly after the recurrence message (second diagnosis) given by the surgeon.
2) The differences in primary reactions of the message between the second and first diagnoses.

3) Psychosocial responses in the period from receiving the news of recurrence until now (when the first 'shock' is over).
4) The differences between the second and first diagnoses in terms of psychosocial responses in the period after the first 'shock'.
5) Wants and needs for healthcare in H&N cancer patients experiencing recurrence.

Examples of questions per main block were:

1) What were your first thoughts after the recurrence message? How did you behave? How did the surgeon behave? Can you describe your emotions? With which expectations did you enter the doctor's room? Did you have any idea of why the recurrence took place?
2) Did you enter the doctor's room with another expectation than the first time? Were your feelings or was your behaviour different compared with the first diagnosis?
3) How do you try and cope with your situation of recurrence? Did you think about how you want to spend / change your life from then on? Do you have fear for a second recurrence and possible death?
4) Do you have other thoughts on your mind compared with the first diagnosis? Are the consequences of the disease on your social life and partner different from those from the first diagnosis?
5) What questions did you have when you received the news about the recurrence? What kind of support did you need? Was there room for your emotions? How was the support afterwards? Current needs?

The results and conclusion of the above mentioned research will be described in the following sections. We will go step by step through the process that the patient follows more or less chronologically from the receipt of the recurrence message. The psychosocial consequences after recurrence are described right after the news and in the period following the recurrence message when the first shock has "sunk in". Furthermore, we describe the differences in experience between the first and the second diagnosis of head and neck cancer.

The doctor's message: "The cancer is back"

The main question in this chapter is: Is it even worse for patients getting this message for the second time? Awaiting for a possible diagnosis of cancer, expected or not, can be an important stress factor in itself for both patient and partner. Imagine that you had received the message of a 'diagnosis head and neck cancer' two years ago. After a successful treatment, the doctor said: "We have removed the cancer". You are getting better and better with time and you are returning more or less to your normal lifestyle. This morning you had your control visit. And then the doctor said: "I don't have good news for you. The cancer is back." For some patients this message will come completely out of the blue and for others it is a confirmation of an already anxious foreboding.

For health care professionals, it would be interesting to know whether people experience this second message differently than the first. More knowledge about the psychosocial impact of the recurrent message can better prepare professionals in their work with patients and their partners. This part of the chapter goes deeper into the inner thoughts and feelings of patients who experience head and neck cancer recurrence. It describes the first thoughts, emotions after the message is received and also the patients' own ideas of why the cancer came back. This part of the chapter ends with a description of the experienced difference between the second and the first message of head and neck cancer.

First thoughts after the recurrence message

We asked the participants to describe their very first thoughts when they were in the doctor's room receiving the recurrence message. Four out of ten patients had a resigned attitude, letting things take their course. "*I'll wait and see what happens. I have to follow this treatment, otherwise I will die, the doctor says*."

Three out of ten patients had angry reactions; anger against the professional , such as: "*The doctors did not react adequately earlier on*". Also anger against the situation "*Damn, again an operation, I thought everything was OK and now I have to follow the same process again*…." or anger in the sense of rebellion, as one patient says after receiving a palliative diagnosis as a recurrence message: "*One way or the other, I am going to make it. This does not fit with the idea I had for myself and the future*." Furthermore there were two reactions of disbelief including the question 'Why is this happening to me again' and one reaction of 'shock'.

First emotions after the recurrence message

The participants described their very first emotions after the recurrence message of the doctor. Four out of ten patients had a down-to-earth attitude with feelings of acceptance of the situation. One example is "*I looked at it soberly. I knew from the first time how things were going and I completely entrusted my situation to the doctors again*." Three out of ten patients were distressed and felt sad: "*I roared with sadness and I cried. The doctor tried to calm me down*". Other reactions were: anger, anxiety and powerlessness.

Expectations and explanations of the patient

We asked all participants about what expectations they had when they entered the doctors' room. Four out of ten had a premonition about the cancer coming back. One example is: "*I already had my idea that it was not good as the doctor mentioned before the tests that he saw an abnormality*. *I have known my doctor for more than one year and he does not say something like that when it is not true*."

The complete opposite was reported by the same number of participants; four out of ten persons who were completely shocked as they did not expect the recurrence. "*I thought I was 100% OK, as I had not noticed anything and I did not feel ill. I entered the doctor's room with fresh courage; however, I was thrown of my balance right after the recurrence message.*" The other two reactions were open minded and patients did not have a specific foreboding.

When we asked the participants whether they thought they were completely cured after the first head and neck cancer experience, seven out of ten said that they had the feeling that they were completely cured after the first time. For example: "*After the first treatment, the doctor said that it was gone*." The three others were neutral in their reaction. "*I did not know if I was cured. They never told me that I got rid of it or that (some of) it was still there*". Two of the neutral reactions also mentioned the critical period of five years had not passed; only then you can say you are cured or not, participants said.

We also asked the participants if they had an idea of why the cancer came back. It seems that everyone had his or her own ideas of explanations of the cancer recurrence. One person said that his work in the petrochemical industry might have had negative influence on his health and could have caused the first and second cancers. Another said that cancer runs in the family. The other eight persons did not have such fixed ideas of the origin of the recurrence as the previous two patients, but they either had no idea or had speculative ideas such as: "*Maybe some cells left behind and could have caused the recurrence*" or "*Probably it was not gone in the first place.*"

Reaction of the doctor

We can conclude from all the interviews that the doctors informed the patient of the news of recurrence in a direct manner. All patients' experience was that, in terms of communicating the message, the doctor immediately came to the point. A majority of the patients (eight out of ten) found that in essence a good approach. People in general want the doctor to be honest with them. An example of that approach is: "*I do not have good news for you. If we don't do anything, you have no longer than four months to live*". One person says that it is good that the doctor was straightforward, however, the patient would have liked the doctor to have built up the message a bit more toward the bad news - it was too harsh. One of the patients receiving the message of palliative treatment had the feeling that the doctor, in a figurative sense, had stepped aside. The message was more or less 'This is it'. The doctor could not offer a curative treatment. In addition, the patient had the feeling that the doctor was letting her down in a way by sending her home with this bad message to deal with by herself.

Reaction of the Partner

Four out of ten partners had the same down-to-earth attitude as the patient with feelings of acceptance of the situation. One patient said: "*My partner accepted the situation just as much as I did. That gives me calm and peaceful feeling*." The rest has a variety of reactions such as: anger, sadness, anxiety, loss of control and feeling numb. An example of the latter: "*When we entered the doctors' room my partner had good faith in a positive messages and she cheered me up all the time . When she heard that the cancer was back, she was really stunned*."

Difference recurrence message versus the first message

We asked the participants to describe the differences, if any, between the news of recurrence compared with the news of the first diagnosis of head and neck cancer. We asked this question in terms of possible differences in 'shock' between the two. Half of the respondents found the news of recurrence a bigger 'slap in the face' than the first experience; three out of ten found the opposite and said that the first message was a bigger shock for them. Two out of ten found both messages equally shocking. See table 2.

Table 2. Verbatim reactions after news of recurrence

Shock recurrence message	Example verbatim
Recurrence was <u>bigger shock</u> than the first experience (50%)	*"The second time is a bigger shock because you theoretically know that it can come back but now I really experienced that it did."* *"The second time is a bigger shock because you think why isn't the cancer gone after the first time? I have always lived a healthy life and still I am confronted with cancer twice!"*
Recurrence was <u>less of a shock</u> than the first experience (30%)	*"The first time was a bigger shock because I did not know what cancer was and I thought I was going to die. Now that I have not, I think that the second time I will survive as well."* *"The first time was a bigger shock because that message came totally unexpected whereas the second time was something I always thought of as a possibility."*
Recurrence was <u>equal</u> to first experience (20%)	*"Both experiences were the same in terms of impact, but they are separate from each other. Both times bad luck."* *"Both experiences were equal to each other in terms of shock as both times I already expected it".*

After the recurrence message… how to go on?

Type of patients' reactions to recurrence

Along with the doctor's news that the cancer is back, the uncertainties come back too. At the top of one's mind, the question often is: 'Can I be cured for the second time?' What are the psychosocial experiences of patients when cancer recurs? How do they deal with this second experience? We asked patients whether anything radically changed in their lives after the news of the recurrence. We clustered the reactions in a characterization of three different types (table 3):

1. The type of person that wants to move with life as normally as possible and try to get back to the same level.
2. The type of person that becomes depressed and cannot get back into the old situation.
3. The type of person that sees the recurrence experience as an event to change one's life perspective.

Table 3. Type of reaction after news of recurrence

Type 1 "move on"	N=8, of whom one patient was in the palliative phase.	*"Actually there hasn't changed that much since the recurrence. The only thing is that I have physical implications which I have to accept. My goal is to come back on track into my old life pattern as much as possible."* *"I don't want to do new things in life, and I don't see life differently. I just want to move back into my old lifestyle.* *"I just want to live my life as I normally do."*
Type 2 "depressed"	N=1 This patient was in the palliative phase.	*"I have nothing to look forward to now I know that I don't have a future anymore. The joy of living disappears bit by bit and I am more withdrawn from other. I feel defeated."*
Type 3 "life change"	N=1	*"I don't want to completely get back to my 'old self'. I used to work more than 60 hours per week. Now I know that I can be replaced at work, I want to enjoy other aspects of life more. I enjoy the moment in itself because you never know how long it takes. I try to do that more consciously than before."*

Eight out of ten patients said that after the first shock of the recurrence, they wanted to move on as before (type 1) even though for many of these patients their lives have been changed in many aspects. Some of them can only eat via tube feeding for the rest of their lives, feel extremely tired or experience psychological distress. However, they try to do their utmost to move on with their lives and find more or less their old lifestyle. One patient was depressed (type 2) and was not able to go on as before; and another patient saw the disease as a turning point to see their life differently (type 3).

Coping with recurrent head and neck cancer

Table 4 gives an overview of the coping styles that patients said they mostly used after the first shock of the news of recurrence in trying to deal with the (consequences of) the situation. The results show that there are several strategies used by patients. The style of coping is not limited by one specific strategy. Only two patients showed one strategy (acceptance); all the rest used two or more strategies to cope with the situation. Furthermore the results show that the patients in the palliative phase (patient 3 and patient 6) used the most coping strategies (four).

Table 4. Coping styles of patients

Coping style	**Patients (N=10)**									
	P1	**P2**	**P3**	**P4**	**P5**	**P6**	**P7**	**P8**	**P9**	**P10**
Put in perspective	X									
Acceptance [1]	X	X			X			X	X	X
Positive attitude	X	X								
Active coping [2]			X			X	X	X		
Step by step coping			X			X				
Turn off feelings							X			
Humor					X		X			
Express feelings			X	X						
Find distraction [3]			X	X	X					
Give up						X				
Hope						X				

1) The coping style that is most frequently used is ‘acceptance’. This strategy is used by six out of ten patients. Patients said: “*Even if the message was bad after my treatment of the recurrent cancer, I accept that. Who am I to say that I will become 90 years old when so many people around me died earlier than me*?” Or another reaction: “*I have just accepted the whole situation and had the feeling to bravely go on*.”
2) Active coping was used by four out of ten patients. Examples of active coping are: “*I try to go on life live normally and be with other people as much as possible. I don’t want to sit in a corner doing nothing*”
3) The coping strategy ‘looking for distraction’ has been used by nearly one third of the patients. Examples of distraction are closely related to active coping: “*I want to find distraction so I returned to my work very quickly as I can’t stay at home*”.

Current fears

We asked all participants whether they have current fears as an open question. When patients asked 'fear for what?' we explained that this could be different aspects of fear such as fear of death, of recurrence, of pain, of control visits, and so on. Six out of ten patients did not experience current fears, versus four out of ten who did experience current fears. One patient in the palliative phase and five patients in the curative phase did not experience fears. Reactions from this group were: "*I don't have fears, not even for pain or death. I would say that it would be a pity when I die", "I don't make myself anxious about fear of second recurrence. I cannot control it so it does not make any sense*", "*I do not fear death. I will see when it is my time to go*".

Four out of ten patients including one in the palliative phase reported to have fears of different backgrounds. One patient described a strong sense of fear of a second recurrence. "*My biggest fear is related to the follow-up visit as my biggest concern is that the cancer has spread. In five months I have my follow-up visit with a lung scan again and for this I worry already.*"

Another patient described his fear of another recurrence. Since the first recurrence there have been stronger thoughts and fears that the cancer can come back for a third time. "*The follow-up visits with the scans, these are very scary.*" Another patient, in a palliative phase, described fear of an agony and fear of her young son that she cannot raise and help grow up. A further patient had fear for the pain that would not go away.

Difference in coping with cancer recurrence versus the first cancer experience

Half of the patients found coping with head and neck cancer more difficult than the first head and neck cancer experience. Patients felt they had more to cope with because of several different feelings, such as feeling more defeated (in case the recurrence meant a palliative diagnosis), feeling that the recurrence was not expected, feeling that the recurrence treatment was harder (for example in the case of patients who had the first time only had surgery and now face surgery including radiation therapy with a lot of

Table 5. Difficulties in coping with recurrence compared with the initial cancer

Equal **N=2**	**Recurrence is less difficult** **N= 3**	**Recurrence is more difficult** **N= 5**
Two patients had equal feelings of coping.	Three patients found coping with recurrence less difficult than the first cancer.	Five patients found coping with recurrence more difficult than with the first cancer.

negative consequences) or because they had more questions, mainly driven by the need for more information on the cause of the disease recurrence (Table 5).

For three patients the coping with recurrence was less difficult than the first experience as there were more feelings of acceptance and there were fewer emotions. For two patients it was equally difficult both times.

Patients' suggestions for the professional

We asked all patients an open question to give us suggestions regarding the best way of informing patients of the news of recurrence.

Seven out of ten patients spontaneously said that doctors in general should come directly to the point. Doctors must be open and honest when answering the patients' questions because they want to know exactly what is going on and what their options are when it comes to treatment. Patients certainly do not want doctors to raise false hope or to disguise any information. Other preferred doctors' skills during the phase of bringing the recurrence message mentioned were:

- The ability to listen well to the patient in case of questions or expressing their wishes.
- The ability to let the patient finish talking.
- The ability to take time for the patient, or at least give the patient *the feeling* that the doctor has time for the patient even if that is not the case.
- The ability to set the right expectations in terms of treatment, for example when the operation is serious or when the radiation treatment will be difficult, especially later in the trajectory.

Additionally, one patient who received a recurrence message, which in this case also mentioned a palliative diagnosis, mentioned that it is very important that doctors tell the patients in such a situation to bring someone with them, so that they are not alone when they receive such a message. When it comes to support right after the message, most patients mentioned that it is of key importance to get a telephone number of a direct contact person who can be called for support and or with questions when the news has "sunk in."

KEY SUMMARY

- The psychosocial aspects of head and neck cancer recurrence are under-reported in the literature.
- One of the main conclusions of the only paper dealing with psychosocial impact of head and neck cancer recurrence was that a common experience of heightened emotional vulnerability was seen across patients with recurrent illness. Increased provision of attention to both patients and partners seems to be a vital addition to head and neck oncology services.
- Our study aims to describe the psychosocial responses of patients after receiving the news of recurrence of head and neck cancer, and the impact of the illness experience as compared with the impact of the initial diagnosis. An in-depth qualitative interview with ten patients was held covering five main aspects:
    1) Primary reactions of the patients directly after receiving the message that the cancer had recurred.
    2) The difference between initial reactions to the news after the second and after the first diagnosis.
    3) The psychosocial response in the period after receiving the news of recurrence.
    4) The difference in psychosocial responses in the period following the first emotional shock after the second and after the first diagnosis.
    5) Suggestions for healthcare professionals in communicating the news of a recurrence.

The key results of the current study were :

- Half of the respondents found that the news of recurrence caused them a bigger shock than the first diagnosis. Three out of ten patients found the news of recurrence less of a shock and two out of ten were equally shocked after receiving the news on both occasions.
- After the recurrence experience, the great majority of patients want to move on with life as normally as possible.
- Half of the patients found coping with the cancer recurrence more difficult than coping with the first diagnosis.
- Four out of ten patients experience fears, especially for a second recurrence. These fears can be triggered by follow-up visits.
- Patients have the need for an explanatory model of the cause of their recurrent disease.

CONCLUDING THOUGHTS

In the literature, little attention has been paid to the psychosocial impact of head and neck cancer recurrence. Only one earlier paper investigated this subject within this specific patient group.[15] The current research reported on in this chapter has added to this by comparing the recurrence situation with the experience of the initial diagnosis to better understand the experiences and their contexts.

We point out that the study results are based on a small sample size. Furthermore, the retrospective method of the research could have caused errors in the recall of information give the timing of the interview after the treatment of the cancer recurrence. To minimize recall bias, we have designed a well-structured questionnaire that we followed for our qualitative interviews. These findings provide useful insights into the under-reported subject of the psychosocial experience of head and neck cancer recurrence. This subject deserves more attention because one-third of all head and neck cancer patients whom we treat will be confronted with a recurrence sometime in their lives. On the basis of the findings of this study, future quantitative research with a larger sample size should be carried out.

Recurrence experiences can broadly be divided in two types. One group of patients manage and cope with the consequences of the disease quite well, while another, more vulnerable, group of patients will need more attention. In the current study half of the patients experienced a bigger shock on receiving the news of the cancer recurrence than on receiving the news of the initial diagnosis. Also, half of the patients found it more difficult to cope with the recurrent cancer than with the initial cancer experience. Both findings strongly suggest that this substantial patient group gets extra attention from healthcare professionals.

Explanations for the larger difficulties experienced in coping with recurrent cancer could be that the recurrence was not expected, or that patients with recurrence were struggling with questions about how the recurrence could have happened. It seemed that everyone had his or her own ideas and explanations of the possible causes of the cancer recurrence. This cognitive process can be explained by the attribution theory within the field of social psychology, introduced by Heider.[26] Attribution means that someone ascribes (attributes) causes to certain events or behaviour. People make attributions all the time. We all try to determine what caused a certain event. There is a general tendency in people to see reality in their own way and to give meaning to it in their own way. When people enter into an insecure situation like a cancer recurrence, there can be a great need for some kind of explanation to provide more control of the insecure situation.

The cognitive process of attribution will be followed by a response of coping. Coping refers to both cognitive and behavioural efforts to manage situations that are perceived as stressful.[27] The majority of the patients were not limited to one coping style and they used a variety of strategies. The most frequently used coping styles were 'acceptance' and 'active coping'. This is in line with earlier research among advanced head and neck cancer patients.[28] These patients used a broad array of coping strategies of which the most prominent were 'religion, acceptance and active coping'. Another finding of this study is that patients who respond to the disease with denial or avoidance may be at heightened risk of psychosocial morbidity. More recently, this finding has been confirmed in a paper indicating that the use of avoidance coping was associated with more depressive symptoms and a worse quality of life. [29]

There is more to say about how people live on after the treatment of head and neck cancer recurrence. The majority of patients did not radically change their life and/or lifestyle after the recurrence experience. Eighty percent said that after the first shock of the recurrence, they wanted to move on with their lives. They wanted to find their old life style level again as much as possible. This is in line with earlier research on goal importance among head and neck cancer patients. The short-term goals were mainly focused on building up physical condition and living life as normal as possible.[30] It is also in concordance with earlier research in head and neck cancer patients in the palliative phase in which patients also strived to return to a normal lifestyle.[31] Furthermore this kind of attitude fits with the logic of the most frequently used coping styles 'acceptance' and 'active coping'.

What do these results mean for healthcare professionals in hospitals? As we concluded, our findings justify extra attention for this vulnerable group of patients who experience the recurrence as a bigger shock and find it more difficult to cope with. This means that professionals should systematically screen which of their patients belong to the 'vulnerable group'. This systematic screening should be part of a fixed procedure or protocol. Earlier research confirmed the efficiency of a specific head and neck cancer screening and referral instrument for patients with psychosocial problems. This screening method was developed at the Erasmus Medical Center, Rotterdam.[32] General suggestions from patients were that doctors should be open and honest and should have good listening skills. Furthermore, they suggested that doctors should carefully observe if their patients experienced strong emotions or clammed up after receiving the message that the cancer had recurred. Physicians should pay attention to these more vulnerable patients and offer them and their partners for the option of another visit in the coming days so that the patient and partner can ask questions that may come up later. Alternatively, additional time with a specialized nurse could be offered in case patients experience the recurrence as a bigger shock, accompanied by strong emotions.

And what do the psychological processes of coping and attribution mean for the patient-doctor communication? First, we stress that although there is often no single straightforward explanation for the cancer recurrence, doctors should realize that patients may need to make sense out of the situation. Patients have the need for an explanatory model of the cause of their recurrent disease. Doctors therefore should, wherever they can, help patients looking for possible explanations. Patients may want to receive information to decrease their feeling of insecurity, to get more control over the situation. Second, during the course of the disease, physicians should ask the patients how they are coping with the situation. Patients who rigidly deny the reality of the disease or refuse to allow themselves to think about it should elicit the physician's concern.[28] We add that denial in itself is not necessarily wrong and could be an adaptive coping response in a given situation, like any other coping style for that matter. Coping is not a static process and how patients react during their disease trajectory can change, also because of changing circumstances. Therefore there is no wrong coping style in itself as each coping style is a means for the patient to deal with her or his distress. It is important to stay in open communication with patients about their coping. One specific question that a doctor can ask is: "*Do you think you are capable of dealing with this situation of cancer recurrence, or do you think you will need additional support from us*?" In this way physicians can understand what the cancer recurrence means to their patients and find out whether patients might get stuck somewhere in the process of dealing with the consequences of the recurrent disease.

Future Research

More research is needed in the following areas:

- Identifying the psychosocial needs of patients after recurrence with different types of cancer and covering both female and male patient groups. Specifically, the literature lacks data on the psychosocial response and the psychosocial needs of head and neck cancer patients experiencing recurrence.
- How to best screen head and neck cancer patients on the fear of recurrence.
- Understanding how best to set up supportive care both for the head and neck cancer patient and the spouse, and for the family dealing with such a traumatic experience as a recurrence.
- How the doctor can help the patients to understand the cause of their recurrent head and neck cancer (need for an explanatory model).

Recommended Reading

- Griffiths MJ, Humphris GM, Skirrow PM, Rogers SN. A qualitative evaluation of patient experiences when diagnosed with oral cancer recurrence. Cancer Nurs 2008;31(4):E11–E17. (This is one of the scarce articles in the literature giving more in-depth insight into patients' psychosocial response to head and neck cancer recurrence.)
- Rogers SN, Scott B, Lowe D, Ozakinci G, Humphris GM. Fear of recurrence following head and neck cancer in the outpatient clinic. Eur Arch Otorhinolaryngol. 2010;267(12):1943– 1949. (This paper makes a direct link with clinical practice and stresses the importance of good screening for fear of recurrence as patients with high fear of recurrence tend to have significant problems associated with their fear.)
- McLarnon C, Kulloo P, Mehanna H, Kelly C, Paleri V. Quality-of-life considerations in treatment of unresectable, recurrent head and neck cancer. Expert Rev Anticancer Ther 2010;10(3):345– 352. (These authors suggest that there are insufficient data on the effects of different treatment modalities on the quality of life of recurrent head and neck cancer patients. This vulnerable group of patients have the most to lose if treatment processes cause deterioration in quality of life because of their limited lifespan.)
- Vivar CG, Canga N, Canga AD, Arantzamendi M. The psychosocial impact of recurrence on cancer survivors and family members: a narrative review. J Adv Nurs. 2009;65(4):724–736. (These authors state that the impact of cancer recurrence is as bad or even more devastating for family members. This review analyses both the psychosocial experience of cancer recurrence for survivors and for their family members.

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ENCLOSURE

Search terms of the literature research.
With these search terms: (head and neck neoplas*[tw] OR neck cancer*[tw] OR mouth neoplasms[mesh] OR otorhinolaryngologic neoplasms[mesh]) AND (recurr*[ti] OR relap*[ti]) AND (psychology, social[mesh] OR psychosocial[tw] OR life style*[tw] OR lifestyle*[tw] OR life change event*[tw] OR stressful event*[tw] OR life experien*[tw] OR psychol*[tw] OR quality of life[tw] OR life qualit*[tw] OR qol[tw]) à we found in PubMed 76 articles.

With these search terms: ('head and neck cancer'/syn OR 'mouth cancer'/syn OR ((neck OR mouth OR otorhinolaryngol* OR head OR tongue OR pharyn* OR hypophar* OR nasopharyn* OR oropharyn* OR laryn* OR otolaryn*) NEAR/3 (neoplasm* OR cancer* OR tumo* OR carcinom*)):ti,ab,de) AND (recurr*:ti OR relap*:ti) AND ('social psychology'/syn OR psychosocial:ti,ab,de OR life style*:ti,ab,de OR lifestyle*:ti,ab,de OR ((life OR stressful) NEAR/3 (event* OR experien*)):ti,ab,de OR psychol*:ti,ab,de OR (quality NEAR/3 life):ti,ab,de OR qol:ti,ab,de) à we found in EMbase: 95 articles, of which remained in EMbase 36 articles after removing all duplicates from PubMed.

With these search terms: (neck OR mouth OR otorhinolaryngol* OR head OR tongue OR pharyn* OR hypophar* OR nasopharyn* OR oropharyn* OR laryn* OR otolaryn*) AND (neoplasm* OR cancer* OR tumo* OR carcinom*) AND (ti=recurr* OR ti=relap*) AND (social AND psychol* OR psychosocial OR life style OR lifestyle* OR ((life OR stressful) AND (event* OR experien*)) OR psychol* OR (quality AND life) OR qol) à we found in Web of Science: 78 articles, of which remained in Web of Science 36 articles after removing all duplicates from PubMed.

With these search terms: (neck OR mouth OR otorhinolaryngol* OR head OR tongue OR pharyn* OR hypophar* OR nasopharyn* OR oropharyn* OR laryn* OR otolaryn*) AND (neoplasm* OR cancer* OR tumo* OR carcinom*) AND (recurr*.ti. OR relap*.ti.) AND (social AND psychol* OR psychosocial OR life style OR lifestyle* OR ((life OR stressful) AND (event* OR experien*)) OR psychol* OR (quality AND life) OR qol) à we found in PsycInfo: 5 articles, of which remained in PsycInfo 0 articles after removing all duplicates from PubMed.

CHAPTER 4

SYMPTOMS OF PATIENTS WITH INCURABLE HEAD AND NECK CANCER: PREVALENCE AND IMPACT ON DAILY FUNCTIONING

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**M. E .Lokker & M. P. J. Offerman are co-first authors on this article.*

ABSTRACT

Background

There is lack of research on symptoms in patients with head and neck cancer in the palliative phase. The aim of this study was to explore symptom prevalence and the impact of these symptoms on daily functioning in patients with incurable head and neck cancer. Also discrepancies between patients and family caregivers are described.

Methods

Questionnaires were used to collect data about symptom prevalence (N=124) and symptom impact (N=24).

Results

We discovered that the symptoms with a high prevalence were fatigue, pain, weakness, trouble with short walks outside and dysphagia. The symptoms with the greatest impact on daily functioning were dyspnea, voice changes, trouble with short walks outside, anger and weakness.

Conclusion

Patients with incurable head and neck cancer experience a great number of different symptoms. Focus on these symptoms by healthcare professionals could further optimize symptom management. In future research, we recommend further validation of the used questionnaires.

INTRODUCTION

Head and neck cancer is known as a psychological highly traumatic cancer type.[1] This is due to potential negative effects of the tumor itself and its treatment on various functions, such as swallowing, speaking, tasting, and smelling, as well as on the appearance of a patient. Head and neck cancer is the fifth most common cancer type worldwide and the most common neoplasm in central Asia.[2] In the United States, head and neck cancer accounts for 3% of malignancies; in The Netherlands, it accounts for nearly 5%.[3,4] The average age of patients affected with head and neck cancer is 63 years. More than two thirds of this patient group are men.[4] Significant risk factors for the occurrence of head and neck cancer are the use of tobacco and alcohol.[5]

Approximately 25% to 30% of patients with head and neck cancer will at a certain moment reach the palliative phase.[3,6] Knowledge about experiences in the palliative phase of head and neck cancer is limited.[7] The palliative phase begins when cure is no longer possible or when curative treatment is refused and ends with the patient dying.[8] Earlier research among palliative patients with head and neck cancer showed a mean duration for the palliative phase of approximately 6 months.[7] During this phase, the number and intensity of symptoms can influence the quality of life of a patient negatively. Palliative care aims to improve the quality of life of patients and their family caregivers by adequately dealing with occurring symptoms, known as "symptom management." [9] In this research, symptoms are defined as all complaints expressed by a patient as a result of a progressing disease or the consequences of the treatment for that disease. Patients with cancer in the palliative phase are frequently confronted with multiple and simultaneously occurring symptoms.[10–15] A systematic review of the literature (2007)[16] about symptom prevalence in patients with cancer in general during the palliative phase, revealed 5 somatic symptoms occurring in more than 50% of patients during the palliative phase. These somatic symptoms were: fatigue, pain, lack of energy, weakness, and appetite loss. However, this research only included a very small group of patients (5%) suffering from a head and neck tumor. Therefore, the possibility to generalize the results from this review to the entire population of patients with head and neck cancer is limited.

In another article (1997)[13] on symptom prevalence, patients with head and neck cancer were included, however, this research focused on somatic symptoms only in the terminal phase. The 5 most frequently reported symptoms were: weight loss, pain, feeding difficulties, dysphagia, and cough. Symptoms in the very last part of the palliative phase (the terminal phase), however, are not fully representative for the entire palliative phase. This is confirmed by a review of patients with cancer in general,[16] showing a difference between the prevalence of symptoms occurring in the last 2 weeks of living and symptoms that occur during the period prior to those weeks. Research among patients with head and neck cancer in general also indicates that, besides somatic issues, more than one third of patients are also confronted with psychological problems.[17] In a recent study of surviving relatives of patients with head and neck cancer, two thirds of the relatives claimed that the patient was depressed and had a need for better psychosocial support during the palliative phase.[6] When it comes to symptom report, earlier research suggests that family caregivers in comparison with patients often over-estimate patient symptoms.[18–21] These studies, however, did not include patients with head and neck cancer.

In order to deliver good health care, it is important to know which symptoms occur during a specific disease or disease phase, as well as the extent of their impact on daily functioning. In this article, "symptom impact" refers to: "the impact that symptoms have on daily functioning of an individual patient." The premise is that such an impact is either neutral or negative.

The current study focused on: (1) the prevalence of symptoms in patients with head and neck cancer during the palliative phase; (2) the impact of those symptoms on daily functioning of patients; and (3) discrepancies between patients and family caregivers with reference to how they individually score the occurrence of symptoms as well as their evaluation of the impact on daily functioning.

MATERIALS AND METHODS

Design

This cross-sectional descriptive study consisted of a retrospective and a prospective element. The first research question was answered by making use of retrospectively collected data. The other two questions were answered by examining prospective data. This study was approved by the Medical Ethics Committee of the Erasmus Medical Centre Rotterdam.

Setting

At the Erasmus Medical Centre Rotterdam, a university medical center in The Netherlands treating around 600 patients newly diagnosed with head and neck cancer every year, palliative care is given by a specialist palliative team for patients with head and neck cancer. This team consists of head and neck surgeons, specialized nurses, speech therapists, pain specialists, dietitians, social workers, and clergymen. Each year, approximately 130 new patients are registered by the palliative team. Since October 2006, as part of the standard working procedure, data is structurally gathered from patients with a head and neck tumor in the palliative phase. Since that date, all new patients are being requested by the specialized nurses to fill out a questionnaire, the Palliative Checklist (Pal- C), once during their palliative phase. In most cases, this happens shortly after receiving the diagnosis of their palliative status. Follow-up of patients by the palliative team is done regularly, both in the outpatient clinic as well as by telephone. During about half of these medical telephone contacts, the family caregiver speaks on the patient's behalf. This occurs because of issues such as difficulties with speech, pain, and physical weakness of the patient.

Participants and procedure

Patients with a primary head and neck tumor in the palliative phase treated in the Erasmus Medical Centre Rotterdam were included. Patients who were younger than 18 years, unable to speak or write in Dutch, mentally incompetent, or participating in another study at the same time were excluded. Participants were divided into 2 groups: the prevalence group and the symptom impact group.

1. *The prevalence group*

This group consists of all patients who completed a Pal-C (instrument described in detail below) between October 2006 and October 2008.

2. *The symptom impact group*

For this prospective part of our study, patient's main family caregivers were also included. Because of the limited number of available patients and the limited average life expectancy, a convenience sample was chosen. From February 2009 up to May 2009, patients were approached by the specialized nurses of the palliative team. After they had given written informed consent, participants were requested to separately fill out a questionnaire which is called the Palliative Symptom Impact list (Pal-SI), as mentioned below.

Data collection 'prevalence group'

Socio-demographic data was gathered from the electronic patient file. Prevalence of symptoms was measured using the Pal-C. This questionnaire provides insight into the prevalence of 30 separate symptoms. The Pal-C was developed in 2006 by the Expert Centre of Palliative Care for Head and Neck Cancer of the department of Otorhinolaryngology and Head and Neck surgery of the Erasmus Medical Centre in Rotterdam. The instrument consists of 53 questions, of which the first fifteen questions are from the EORTC QLQ-C15-PAL.[22,23] The remaining 38 questions of the Pal-C are based on the Integral Checklist.[24] The Integral Checklist is a questionnaire that was developed as an instrument for systematic screening of psychosocial and physical problems in ambulatory cancer patients. The Pal-C is meant to obtain an impression of the situation as experienced by the patient during the past week. The Integral Checklist has been used previously in a study with cancer patients in all phases of disease, including patients with head and neck cancer.[24] Completion of the questionnaire requires approximately 20 minutes. The Pal-C in its current form has not been tested on validity and/or reliability. However, the Pal-C was primarily used to support the gathering of information about the patient's health in a non- burdensome way and turned out to be a very practical instrument for that purpose and for referral to other specialists.

Data collection 'symptom impact group'

Socio-demographic data of patients were gathered from the electronic patient file. Caregivers socio-demographic data; gender, their relationship to the patient and their age, were gathered by making use of questionnaires.

Impact of symptoms was measured using the Pal-SI. This instrument was developed, for this study, by the Expert Centre of Palliative Care for Head and Neck Cancer of the department of Otorhinolaryngology and Head and Neck surgery of the Erasmus Medical Centre in Rotterdam. To enable comparison of data, the Pal-SI covers the same symptoms and uses equal formulation as in the Pal-C. The Pal-SI consists of two parts. Part A contains the 30 symptoms from the Pal-C. By answering 'yes' or 'no', the patient can indicate whether or not the specific symptom occurred in the previous week. In part B, the patient is asked to rate all symptoms present on an 11 point numeric scale (NMS), indicating the impact of a specific symptom on daily functioning. (0= 'no impact', 10= 'unbearable impact').

Specifically for family caregiver's, a family caregiver's version of the Pal-SI was available. This version differs from the original Pal-SI on two aspects: 1) to prevent missing values the answer option 'do not know' was added; and 2) all questions were formulated from the perspective of the family caregiver, i.e. instead of asking: "Have you had pain", the family caregiver's version states "Do you think the patient had pain". It took approximately 15 minutes to complete the Pal-SI.

Statistical analysis

The socio-demographic data, the prevalence of symptoms, and the impact of those symptoms were described by way of descriptive statistics. The socio-demographic data of patients from the prevalence group were statistically tested using the independent samples t test (age), chi-square test (sex, tumor location, and treatment), and the Mann–Whitney test (duration of palliative phase). The socio-demographic data with reference to the patients from the symptom impact group were statistically tested using the Mann–Whitney test. In order to compare the prevalence and the symptom impact data of the patients and their family caregivers per pair, the Wilcoxon matched pairs test was performed. Nonparametric tests were used when data was not normally distributed. With reference to the symptom impact group, this was the result of the limited number of cases. The significance level was set at 5%. For the analysis of the data, the statistics program SPSS v 14.0 was used.

RESULTS

Description of "prevalence group"

Between October 2006 and October 2008, 310 new patients were registered with the specialized nurses for palliative care. After exclusion, 220 patients were approached, of which 124 (56%) completed the Pal-C. Two percent of questions were not filled in. The reasons for exclusion and nonresponse are indicated in Figure 1.

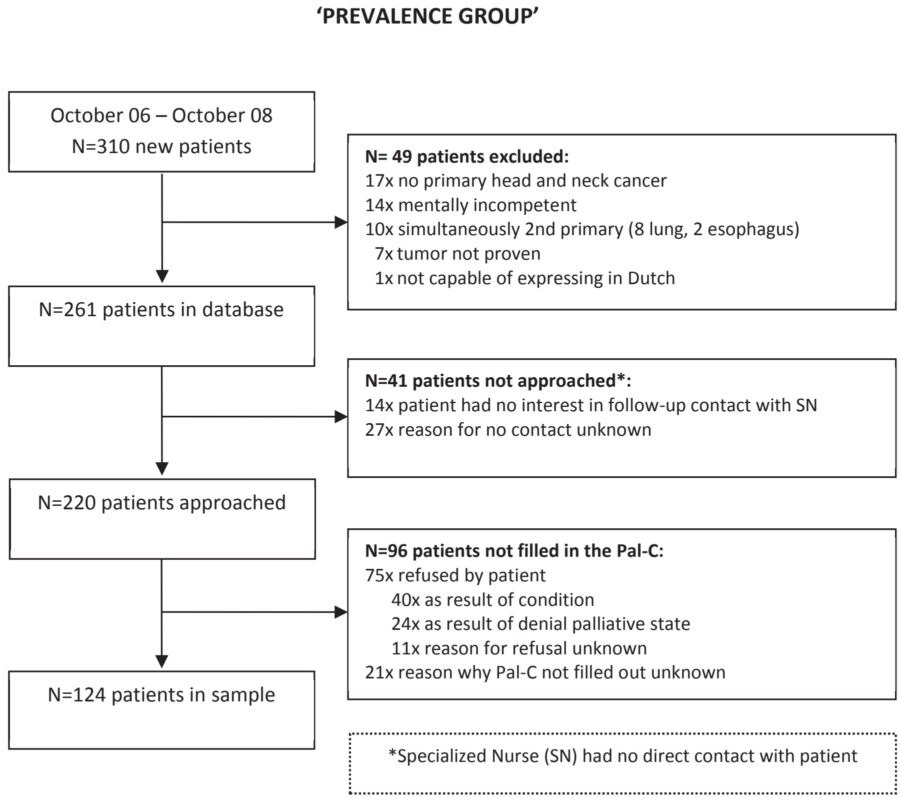

Figure 1. Prevalence group

Refer to Table 1 for socio-demographic data. Patients who completed a Pal-C (Pal-C+) were significantly different from those who did not complete a Pal-C (Pal-C-) on 3 aspects. The Pal-C+ group (1) consisted of more men; (2) were subjected to more extensive palliative treatment; and (3) their duration of the palliative phase was longer, with a median discrepancy of more than 100 days.

Table 1. Socio-demographic data *Prevalence Group*

	% (no. of patients) by group*									
Characteristic	Pal-C+ group (n=124)				Pal-C- group (n=137)				p value	
Age, average (interval)	68y	(39-90 y)			66y	(28-98 y)			.203	
Sex										
Male	73	(91)			61	(83)			**.019**	
Female	27	(33)			39	(54)				
Location of Tumor										
Oral cavity	24	(30)			20	(28)			.724	
Oropharynx	26	(32)			30	(41)				
Larynx	11	(14)			13	(18)				
Hypopharynx	13	(16)			14	(19)				
Nasopharynx	2	(3)			2	(3)				
Nasal fossa	11	(14)			6	(8)				
Other**	12	(15)			15	(20)				
Treatment	All phases		Palliative phase		All phases		Palliative phase		A	P
No treatment	8	(10)	50	(62)	17	(23)	70	(96)	.067	**.017**
Surgery	2	(3)	2	(2)	3	(4)	0	(0)		
Radiotherapy (RT)	32	(39)	35	(43)	19	(26)	22	(30)		
Chemotherapy (CT)	0	(0)	7	(8)	0	(0)	6	(8)		
Surgery + RT	35	(43)	2	(2)	33	(45)	0	(0)		
Surgery + CT	1	(1)	0	(0)	0	(0)	1	(1)		
Surgery + RT + CT	7	(9)	1	(1)	15	(21)	0	(0)		
Chemotherapy + RT	15	(19)	5	(6)	13	(18)	2	(2)		
Time interval between start of pall phase and Pal-C, median (interval)	61 days (0-1682)				X					
Duration palliative phase	169 days (9-2621) **Φ**				62 days (1-652) **Δ**				**.000**	

Abbreviation: Pal-C, Palliative Checklist; RT, radiotherapy. * Except as otherwise stated. ** Tumors of the skin, salivary glands, ear and trachea. Φ: based on 109 patients. Δ : based on 128 patients.

Description of "symptom impact group"

Between February 2009 and May 2009, 116 new patients were registered with the specialized nurses. Of the total of 56 patients who met all the inclusion criteria, 24 patients (43%) and 24 family caregivers completed a Pal-SI. For 3% of the questions, no answer was given. The reasons for exclusion and nonresponse are indicated in Figure 2. Refer to table 2 for socio-demographic data. Patients from the Pal-SI+ group were not significantly different from the patients of the Pal-SI- group. Family caregivers were, on average, 60 years old (32–77 years). Their relation to the patient was that of the husband/wife (17), daughter/son (5), friend (1), and brother (1).

‘SYMPTOM IMPACT GROUP’

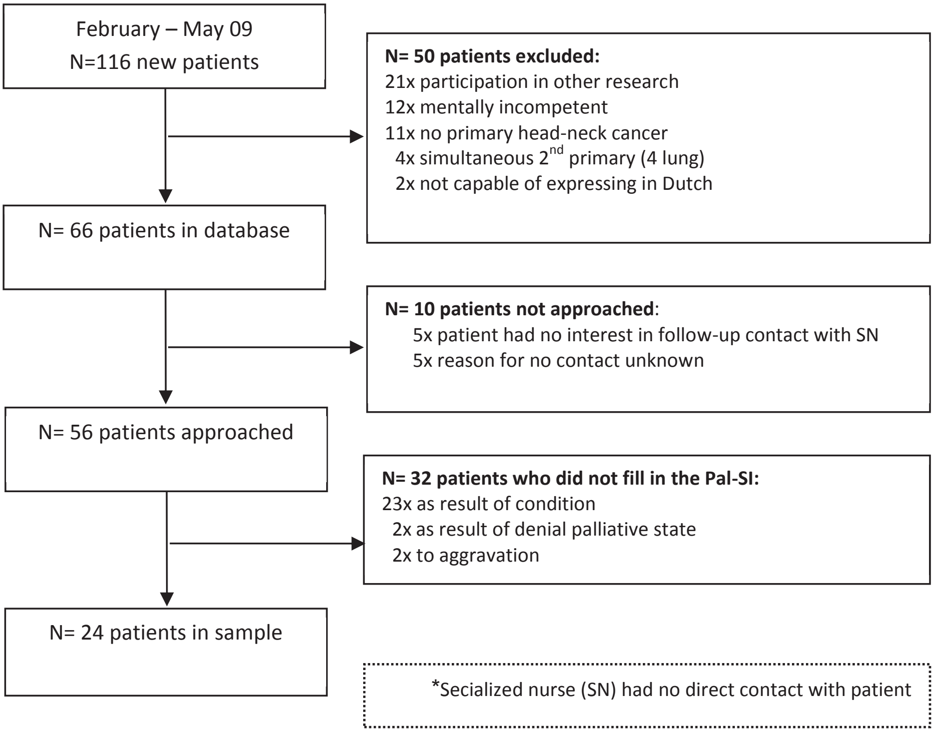

Figure 2. Symptom Impact Group

Prevalence of symptoms in “prevalence group”

All results obtained from the Pal-C are described in Table 3. Patients reported an average of 14 different symptoms (interval 0–26), of which there were 10 somatic symptoms and 4 psychosocial symptoms. Fatigue had the highest prevalence (81%), followed by pain

Table 2. Socio-demographic data *Symptom Impact Group*

Characteristic	% (no. of patients) by group				
	Pal-SI + group (n=24)		Pal-SI- group (n=42)		p value
Age (average/interval)	66 y	(29-90 y)	67 y	(38-98 y)	.957
Gender					
Male	50	(12)	64	(27)	.260
Female	50	(12)	36	(15)	
Tumor location					
Oral cavity	33	(8)	21	(9)	.823
Oropharynx	17	(4)	19	(8)	
Larynx	8	(2)	14	(6)	
Hypopharynx	4	(1)	12	(5)	
Nasopharynx	0	(0)	5	(2)	
Nasal fossa	17	(4)	12	(5)	
Other*	21	(5)	17	(7)	

Treatment	All phases		Palliative phase		All phases		Palliative phase		All phases p value	Palliative phase p value
No treatment	4	(1)	38	(9)	10	(4)	45	(19)	.797	.615
Surgery	4	(1)	4	(1)	2	(1)	2	(1)		
Radiotherapy (RT)	21	(5)	42	(10)	21	(9)	38	(16)		
Chemotherapy (CT)	0	(0)	13	(3)	0	(0)	10	(4)		
Surgery + RT	42	(10)	0	(0)	41	(17)	0	(0)		
Surgery + CT	0	(0)	0	(0)	2	(1)	0	(0)		
Surgery + RT + CT	17	(4)	4	(1)	12	(5)	0	(0)		
Chemotherapy + RT	13	(3)	0	(0)	12	(5)	5	(2)		
Time interval between start of pall phase and Pal-SI (average/interval)	270 days (17-1024))				X					

Abbreviation: Pal-SI, Palliative Symptom impact list; RT, radiotherapy. * Tumors of the skin, salivary glands, ear and trachea.

(75%), weakness (75%), trouble with short walks outside (65%), and dysphagia (59%). Frequently reported psychosocial symptoms were worrying (61%), sadness (57%), tenseness (52%), depressed mood (52%), and powerlessness (50%).

Prevalence of symptoms in "symptom impact group"

All results obtained from the Pal-SI are described in Table 4. The patient and his/her family caregiver differed significantly from one another for the occurrence of 4 symptoms: difficulty sleeping (patient 29% vs caregiver 13%; p= .046), dyspnea (21% vs 42%; p= .025), powerlessness (75% vs 46%; p= .046), and anxiety (29% vs 50%; p= .034).

Table 3. Prevalence of symptoms n=124 from the Pal-C.

Symptoms	% of patients	(no/total no of patients)	Symptoms	% of patients	(no/total no of patients)
Fatigue	81	(101/124)	Dyspnea	41	(51/123)
Pain	75	(93/123)	Coughing after eating/ drinking	38	(47/122)
Weakness	75	(93/123)	Need for help with everyday functioning	30	(37/123)
Trouble with short walks outside	65	(81/123)	Nausea	29	(36/121)
Dysphagia	59	(73/123)	Wound in neck or face	22	(27/124)
Difficulty speaking	57	(71/123)	Unpleasant smell/ stench	19	(24/123)
Difficulty sleeping	56	(70/124)	Worrying*	61	(75/118)
Head and Neck edema	56	(69/122)	Sadness*	57	(71/118)
Daily activities restricted as a result of pain	53	(66/121)	Depressed mood*	52	(65/123)
Weight loss	53	(66/124)	Tenseness*	52	(65/122)
Voice changes	52	(64/123)	Powerlessness*	50	(62/117)
Constipation	48	(60/123)	Anger*	39	(48/116)
Shortness of breath	48	(59/123)	Anxiety*	32	(39/117)
Need to stay in bed/chair during day	48	(59/123)	Trouble expressing oneself*	24	(30/118)
Appetite loss	53	(66/119)	Feelings of shame*	12	(15/118)

Abbreviation: Pal-C, Palliative Checklist.
* Psychosocial symptoms.

Impact on daily functioning from "symptom impact group"

According to the patients, dyspnea, voice changes, trouble with short walks outside, anger, and weakness, all had, in decreasing order, a large impact on daily functioning. The score for the symptom impact on daily functioning of the patient differed significantly between the patients and their family caregivers on 5 symptoms: trouble with short walks outside (patient NMS 5.5 vs caregiver NMS 6.7; p= .047), difficulty sleeping (4.7 vs 5.3; p= .042), powerlessness (4.4 vs 3.8; p= .031), trouble expressing oneself (3.3 vs 4.9; p= .014), and anxiety(5.1 vs 4.5; p= .015).

Table 4. Part 1. Results Symptom Impact Group n=24 from the Pal-SI.

Symptoms	Prevalence, % (n)					Symptom impact, average (interval)				
	Patients		Close relatives		*p* value	Patients		Close relatives		*p* value
Somatic										
Trouble with short walks outside	25	(6/24)	38	(9/24)	.083	5,5	(2-9)	6,7	(3-9)	.047
Need to stay in bed/chair during day	21	(5/24)	25	(6/24)	.317	3,8	(1-6)	4,8	(1-8)	.102
Need for help with everyday functioning	13	(3/24)	13	(3/24)	1.00	4,0	(3-5)	5,0	(5)	.180
Shortness of breath	38	(9/24)	33	(8/24)	.705	3,4	(1-7)	4,5	(2-8)	.561
Pain	54	(13/24)	58	(14/23)	.317	4,9	(2-10)	5,5	(1-10)	.109
Difficulty sleeping	29	(7/24)	13	(3/24)	.046	4,7	(1-10)	5,3	(2-10)	.042
Weakness	42	(10/23)	50	(12/22)	.705	5,2	(1-1-0)	4,6	(1-10)	.476
Appetite loss	21	(5/23)	13	(3/23)	.059	5,0	(1-8)	6,0	(2-8)	.414
Nausea	25	(6/24)	17	(4/22)	.317	3,4	(1-5)	2,0	(1-3)	.223
Constipation	21	(5/24)	25	(6/22)	.564	4,8	(2-10)	4,8	(2-10)	.102
Fatigue	92	(22/24)	79	(19/23)	.317	4,5	(1-10)	4,8	(1-10)	.796
Daily activities restricted as result pain	33	(8/24)	25	(6/23)	.317	5,0	(1-10)	4,5	(2-6)	.313
Head and Neck edema	25	(6/23)	29	(7/22)	.655	4,3	(1-7)	4,9	(1-10)	.465
Wound in neck or face	13	(3/24)	17	(4/23)	.564	5,0	(5)	5,3	(3-9)	.102
Unpleasant smell/ stench	4	(1/24)	17	(4/24)	.083	5,0	(5)	4,3	(2-6)	.068
Dyspnea	21	(5/24)	42	(10/24)	.025	7,0	(3-10)	4,6	(1-8)	.234
Difficulty speaking	54	(13/24)	54	(13/24)	1.00	4,9	(2-10)	4,7	(1-9)	.648
Dysphagia	54	(13/23)	42	(10/22)	.405	5,0	(1-10)	6,2	(3-10)	.813
Coughing after eating/drinking	33	(8/23)	42	(10/24)	.666	4,1	(1-7)	5,0	(1-10)	.055
Voice changes	38	(9/24)	50	(12/24)	.257	5,9	(1-10)	4,8	(1-10)	.698
Weight loss	25	(6/24)	29	(7/23)	.317	3,8	(1-8)	4,9	(1-8)	.131
Psychosocial										
Tenseness	38	(9/24)	33	(8/23)	1.00	3,9	(1-10)	4,1	(2-6)	.858
Depressed mood	46	(11/24)	38	(9/21)	.317	3,9	(2-7)	3,1	(2-5)	.088
Powerlessness	75	(18/24)	46	(11/21)	.046	4,4	(1-10)	3,8	(2-7)	.031
Worrying	63	(15/24)	63	(15/21)	.083	4,4	(1-8)	4,4	(1-8)	.368
Trouble expressing oneself	25	(6/24)	42	(10/23)	.157	3,3	(2-7)	4,9	(2-8)	.014
Feelings of shame	13	(3/24)	4	(1/24)	.317	2,3	(1-5)	2,0	(2)	.461
Anxiety	29	(7/24)	50	(12/21)	.034	5,1	(2-8)	4,5	(2-8)	.015
Anger	29	(7/24)	42	(10/23)	.180	5,3	(3-7)	4,2	(1-8)	.609
Sadness	71	(17/24)	54	(13/24)	.102	4,6	(1-9)	6,0	(2-9)	.338

Abbreviations: Pal-SI, Palliative Symptom impact list.

DISCUSSION

In the first part of this research, we explored symptom prevalence in 124 patients with incurable head and neck cancer. Within this sample, "fatigue" was the somatic symptom most prevalent (81%), followed by pain (75%), weakness (75%), trouble with short walks outside (65%), and dysphagia (59%). To our knowledge, no comparative figures are known for symptom prevalence in patients with incurable head and neck cancer. Prior studies among head and neck cancer survivors, a few years after their curative treatment, indicate diverging percentages for the prevalence of fatigue (33% to 48%),[25,26] pain (10% to 43%), [25–28] and dysphagia (17% to 76%). [25–28] For the prevalence of weakness and trouble with short walks outside, no comparative figures were found. We hypothesize that symptoms experienced by patients in the palliative phase are not consistent with those experienced by cancer survivors because of the difference of disease phase, location/ presence of the tumor, and tumor treatments.

The four most prevalent symptoms experienced by patients with head and neck cancer in the palliative phase are consistent with the results of a systematic review in 25,074 patients with cancer in general during the palliative phase.[16] Despite a probable difference in etiology of various symptoms as a result of different primary diagnoses, it seems that the most prevalent symptoms during the palliative phase are independent of the primary diagnosis.

In this study, a distinction was made between somatic and psychosocial symptoms. Despite the assumption that psychosocial symptoms occur less frequently in palliative patient with cancer in general,[17] it has been shown that these symptoms play an important role in the assessment of quality of life in patients with head and neck cancer.[29–33] The 5 most frequently reported psychosocial symptoms in our study were: worrying (61%), sadness (57%), tenseness (52%), depressed mood (52%), and powerlessness (50%). The prevalence figures for psychosocial symptoms found in our study are higher for the symptoms: worrying, sadness, tenseness, and anxiety compared with the findings of 2 other studies. The article by van den Beuken et al. [34] studied a subpopulation of 25 patients with incurable head and neck cancer during their treatment and found a prevalence of 25% for worrying, 17% for tenseness, and 8% for anxiety. In the overall incurable oncological population, Teunissen et al[16] found a prevalence of 36% for worrying, 39% for sadness, and 30% for anxiety. These discrepancies between our findings compared with other studies could be explained by the use of different terminology, measuring instruments, and sample selection. For example, van den Beuken[34] included patients who were all still receiving some form of (palliative) treatment aimed at symptom control, such as surgery, radiotherapy, or chemotherapy during the palliative phase of their illness. Whereas we studied a group of patients of which only a small portion was receiving such treatment and the larger portion was not. Receiving treatment, even if this treatment is of a palliative nature, can place patients more in a fighting mode and less open to feelings and negative emotions such as worrying. Teunissen et al[16] used a broad population of patients in the palliative phase, which could also lower the prevalence of these results because we know that patients with head and neck cancer psychologically suffer more[1] and have been associated with higher levels of depression and anxiety.

The least occurring psychosocial symptom (12%) was "feelings of shame." We find this remarkable because head and neck cancer and its treatment can lead to mutilations and disfigurement, and therefore one would expect a higher prevalence for this specific symptom. It could be possible that patients already coped with these consequences when they occurred earlier on during the curative phase. Another reason for the low prevalence of feelings of shame may be related to the specific characteristics of the majority of patients with head and neck cancer: men over 60 years of age, generally with a lower socioeconomic background. Especially sex and age might influence the importance of appearance. Our findings are consistent with a study of patients after a laryngectomy, in which 14% of patients reported experiencing feelings of shame.[35]

In the second part of this research, we explored the impact of symptoms on daily functioning of patients with incurable head and neck cancer. We also looked at discrepancies between patients and their family caregivers with respect to how they score symptom occurrence and symptom impact on daily functioning. The symptoms dyspnea, voice changes, trouble with short walks outside, anger, and weakness, all have, according to the patients in the symptom impact group, a significant impact on daily functioning.

Furthermore, we found that family caregivers of patients with head and neck cancer during the palliative phase frequently overestimate the occurrence of somatic symptoms as well as the impact from those symptoms on daily functioning of patients. In two thirds of cases, although not always significant, the prevalence and the symptom impact score for somatic symptoms were systematically estimated higher by the family caregivers compared to the patients. However, when it comes to psychosocial symptoms, we see a reverse trend. Both symptom prevalence as well as symptom impact was underestimated by family caregivers. Approximately 50% of the symptom prevalence and the symptom impact score are indicated higher by the patients compared with family caregivers. These findings are not consistent with studies in patients receiving oncology treatment during the palliative phase, in which family caregivers more frequently overestimated psychosocial symptoms compared to somatic symptoms.[19–21] Research indicates that the degree of consistency between patients and their caregivers depends on the health condition of the patient in question. Just a slight consistency can be found when the health of the patient is very good or very bad.[36] A potential explanation for the discrepancy between patients and family caregivers could be underreporting of symptoms by patients. Patients do not wish to worry their caregivers and hence are very careful when communicating about their symptoms and/or the intensity of those symptoms.[18,20,21,37] Whether or not the discrepancy between patients and their family caregivers in our study can be explained by this is unclear and requires further investigation.

It is remarkable that family caregivers indicated that dyspnea was present, twice as often as the patients did. In case of a head and neck tumor, dyspnea is a potentially realistic threat. It is likely that fear of suffocation makes the family caregivers more aware of possible signs of dyspnea. In addition, a lot of patients with head and neck cancer trivialize their dyspnea because the progression happens gradually. Our result is consistent with prior research among patients with lung cancer during the palliative phase.[18]

Limitations

The cross-sectional method of current study is inapt to obtain a definite conclusion about the entire palliative phase. Practical achievability of a longitudinal approach within a palliative population, however, is limited and hence very difficult to realize.[38,39] Despite the fact that the Pal-C and the Pal-SI are well used and practical instruments for gathering information in the least possible intrusive way, the lack of validation is a limitation. Another limitation was the 44% nonresponse within the prevalence group. Non-responding patients had a significant shorter life expectancy and seemed to have a much worse condition than responding patients. Generalization of the results from the prevalence group should therefore be done carefully. The large number of nonresponse (more specifically, patients that dropped out because of their weak condition) within this group, however, also confirms how vulnerable this specific cancer population group is. Finally, the option to work with an occasional random sample for investigating the symptom impact group means that patients were selected. The number of patients and caregivers is too limited to generalize results to the entire population. However, the gained insight has resulted in a number of discrepancies between patients with head and neck cancer and their caregivers, and patients suffering from other malignant dysfunctions.

CONCLUSION

Implications for clinical practice

This is the first study investigating the prevalence of symptoms in patients with head and neck cancer and their impact on daily functioning during the palliative phase reported by patients themselves and their family caregivers. These patients experience a large number of different symptoms. We found that most frequently reported somatic symptoms were fatigue, pain, weakness, trouble with short walks outside, and dysphagia, which is consistent with research involving a wide palliative cancer population. In the psychosocial area, these are worrying, sadness, tenseness, depressed mood, and powerlessness. For these symptoms, there are no comparative prevalence figures yet available. The symptom with the greatest impact on daily functioning, according to patients, is dyspnea. According to the caregivers, this is the symptom "trouble with short walks outside." For a number of symptoms, the mutual discrepancies between patients and their caregivers are significant.

These results were limited due to several aspects such as a relatively low accrual rate, mainly because of the condition of patients and the use of a non-validated questionnaire. Future research should, therefore, be focused on replication of our results with further validation of the used questionnaire. We do, however, believe that the results give valuable insight into symptoms experienced by patients with head and neck cancer in the palliative phase and their impact on daily functioning of those patients, a subject that is clearly underexposed in research. Furthermore, we suggest that care for patients with head and neck cancer in the palliative phase should include targeted screening. This screening should focus on highly prevalent symptoms as fatigue and psychosocial symptoms which, because they are less visible, may now receive less attention. We also suggest that in the relationship between healthcare workers and patients and their caregivers, attention should be paid to the discrepancies between patients and caregivers found in this study. By making this difference in perception open for discussion, patients and caregivers can become more aware of this within their relationship. Insight regarding possible discrepancies may contribute to better and targeted health care and hence improve the quality of life of patients with head and neck cancer and their caregivers.

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CHAPTER 5

EXPERIENCE OF PALLIATIVE CARE FOR PATIENTS WITH HEAD AND NECK CANCER THROUGH THE EYES OF NEXT OF KIN

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ABSTRACT

Background

Little is known about how palliative care is experienced by patients with head and neck cancer and their relatives. The aim of this retrospective study was to analyze this care from the point of view of surviving relatives.

Methods

Fifty-five surviving relatives of patients with head and neck cancer treated at our department were enrolled in this study. Forty-five returned a completed questionnaire.

Results

Medical treatment during the palliative stage was judged as sufficient in most cases, but was often felt to be intrusive. The majority of patients had more need for psychosocial and physical support. Contact between head and neck surgeon and patient was sufficient. Many relatives found information about the terminal stage unsatisfactory.

Conclusion

Not all aspects of palliative care for head and neck cancer patients are sufficient and improvements are, in our setting, necessary, specifically within the psychosocial field. This supports the initiation of our Expert Center to improve quality of life in the palliative stage.

INTRODUCTION

In the literature, little attention has been paid to palliative care for patients with head and neck cancer.[1] In the palliative stage of disease, cure is no longer possible or pursued. Approach with this patient group is aimed at prevention and relief of both physical and psychosocial suffering. We consider the palliative phase to be the period from the moment the patient is diagnosed with an incurable head and neck tumor, or chooses not to be treated, until death. During this stage, the patient can still undergo palliative treatment, such as surgery, radiotherapy or chemotherapy.

Palliative patients in the Netherlands generally prefer to be taken care of at home.[2] As a consequence, general practitioners (GPs) are usually the key providers of palliative care.[3] Patients with head and neck tumors may, apart from general symptoms accompanying terminal cancer, develop swallowing, speech and airway problems, bleeding and possibly dramatic changes of appearance. As a consequence, both physical and psychosocial functioning is limited, which influences the Quality of Life (QoL) of palliative patients and their families. Since these patients are mainly ambulatory throughout the palliative stage, specialized attention needs to be home based. Palliative care does not stop after the patient dies. The care should also include support of relatives in the bereavement period.

In the department of Otorhinolaryngology and Head & Neck Surgery of the Erasmus University Medical Centre, approximately 700 new patients with head and neck cancer are treated annually. In the Netherlands, head and neck oncology is concentrated in mostly academic head and neck centers. One third of patients treated in these centers die as a consequence of their disease. To reduce physical and psychosocial suffering in this group, systematic screening, follow-up, and support are essential. A review by Hearn and Higginson[4] demonstrated that the use of specialized palliative care teams for advanced patients with cancer improved symptom control, patient and carer satisfaction, and reduced hospital admissions. Another review also revealed positive effects for patients and carers in hospital-based teams.[5] In the summer of 2005, an Expert Center of Palliative Care for Head and Neck cancer patients became operational in our department. This palliative team consults mainly during the ambulatory stage. The team consists of head and neck surgeons, specialized nurses, speech therapists, a pain team, dietician, social workers, and clergymen. The objectives of the expert centre are good symptom control, consultation towards other caregivers, research, targeted information, structural support of patient and family and research. To achieve these objectives, intensive care is needed besides the current medical treatment by a specialist. Since most specialists can generally not provide such intensive care, a joint clinic was realized with the employment of 3 specialized palliative care nurses. In this joint clinic, the head and neck surgeon is in charge of somatic treatment and instruction of the specialized nurse. Furthermore, nurse handles social guidance, wound care, information, and consultation. In addition, care is improved through the use of a palliative checklist and provision of targeted information. Little is known about how close family experiences the palliative and terminal stages and the period of mourning. In the literature available, [6,7] it is suggested that relatives of patients, who were well supported during the palliative stage had fewer psychological problems, a shorter period of mourning and less anger than relatives of patients who were not well supported. No studies have been performed that specifically concern patients with head and neck cancer.

The aim of our study was to increase our knowledge of how treatment and support are experienced by relatives of palliative patients with head and neck cancer during the palliative stage and after death. The care of the palliative patient with head and neck cancer was evaluated through the eyes of the relatives, before the start of the Expert Center.

PATIENTS AND METHODS

Inclusion Criteria

Surviving relatives or close friends (the first contact person noted in the medical dossier) of patients with incurable head and neck cancer diagnosed or treated in our department were included in this study. All patients had a histologically proven malignancy of the head and neck area. Sixty-one palliative patients died because of their disease between January 2003 and July 2004.

Procedure

First, we announced this study to the relatives by telephone and we asked for their participation. Of 4 patients, relatives could not be located. Of 2 patients, relatives were excluded because they did not speak Dutch. After confirmation of the relative, we sent a letter confirming their participation and explaining the aim of the study once more. With the letter, a written questionnaire was included. This questionnaire consisted of 64 semi-structural questions, 6 open questions, and 16 general statements on palliative care. Questions were categorized as medical treatment, psychosocial support, information, and education and terminal stage. Relatives who did not return the questionnaire were reminded by telephone. In total, 55 relatives consented to participation. Forty-five returned a completed questionnaire, resulting in a response-rate of 82%. Reasons for not participating were lack of time or the sensitive nature of the subject. Descriptive, correlational statistics, and cross tab-analysis were done using SPSS 12.0.1.

RESULTS

Socio-demographic Data of Patients and Relatives

The average palliative period lasted 4 months. Socio-demographic data of patients are shown in Table 1. The study population answering the questionnaire was in most cases the surviving spouse (53%) or offspring (29%), see figure 1. Almost all (91%) relatives 'often' to 'always' accompanied the patient during their hospital visits. Two thirds discussed the situation 'often' with the patient; one third discussed it 'sometimes'.

Table 1. Socio-demographic data of patients (n = 45).

Characteristic	No. of patients (%)
Age (median/range)	66 y (24-82 y)
Sex	
Male	34 (76)
Female	11 (24)
Marital status	
Single	11 (24)
With partner	34 (76)
In living offspring	
Yes	6 (14)
No	37 (86)
Palliative period (median/range)	4 mo (1-16 mo)
Main stay in palliative period	
At home	36 (82)
Hospital	8 (18)
Nursing home	1

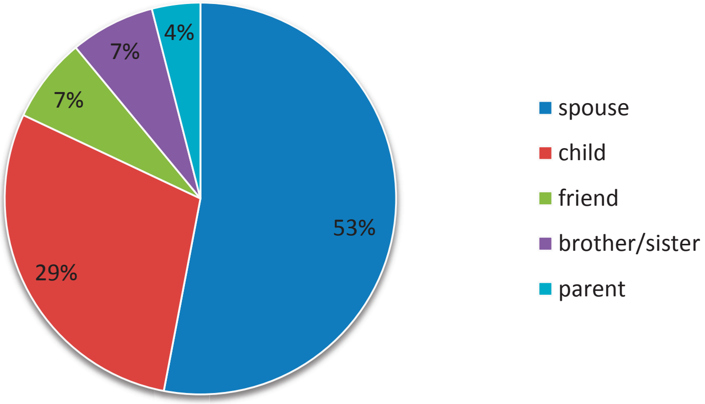

Figure 1. Relatives answering the questionnaire.

Psychosocial Support during the Palliative Stage

According to more than half of the relatives (54%), the 'overall' care and support of the Erasmus MC head and neck oncology was 'good' to 'very good'. One third (32%) judged the care and support as 'reasonable' and the remaining felt it was as 'poor'. The relatives reported that 67% of the patients were sometimes or often depressed. In 69% of the cases, it was felt that patients needed better psychosocial support during the palliative stage. Satisfaction of psychosocial support is summarized in table 2. In only 23% of the cases, there was spiritual support. Patients who did not receive spiritual support judged the psychosocial support from the head and neck department less satisfactory. The most important finding was that in only half of the cases, psychosocial support of our department was experienced as sufficient. There was a positive correlation between psychosocial support of the general practitioner (GP) and the head and neck surgeon (r= .337, p=.05).

Table 2. Satisfaction of support of family, Erasmus MC, and general practitioner.

	% of total patients	
Type of support	Satisfaction with received support	Dissatisfaction with received support
Support from family	96	4
Discussing disease in family	86	14
Psychosocial support head and neck department	51	49
Psychosocial support general practitioner	70	30

Medical Treatment during the Palliative Stage

A great majority of the patients (79%) needed medical treatment. Treatment provided by the head and neck department was judged as satisfactory by 81%, while treatment provided by the GP was judged as satisfactory in 67%. Half of the surviving relatives thought that the patient experienced the medical treatment as too intrusive. In 2%, treatment was given without informed consent. Cross tab analysis demonstrated that in case of consent on medical treatment, this was less often experienced as too intrusive than if the patient was not well informed. See table 3.

Table 3. Crosstab-analysis between agreement in care and finding the treatment too intrusive

	No. (%) by whether treatment was thought to be too intrusive		
Accordance in care	No	Yes	Total
No	7 (33)	10 (50)	17 (41)
Yes	14 (66)	10 (50)	24 (59)
Total	21 (100)	20 (100)	41 (100)

Communication and Information during the Palliative Stage

Contact with Head and Neck Surgeon and General Practitioner. Half of the patients were mainly treated by 1 head and neck surgeon during the palliative treatment process. Nearly one fifth (19%) rotated extensively and approximately on third (30%) rotated sometimes between head and neck surgeons. More than half of the relatives (59%) judged the contact between patient and head and neck surgeon as 'good' to 'very good'. The remaining judged it as 'poor' (9%) to 'reasonable' (32%). Overall scores of the judgment of contact with the GP were similar to those with head and neck surgeon. There was a positive relation between having a single attending surgeon and a positive evaluation of the psychosocial support of the head and neck department (r= .353, p= .05). Additionally, there was a positive relation between continually visiting the same head and neck surgeon and how contact with the surgeon was experienced (r= .440, p= .01). Visiting the same head and neck surgeon did not influence the opinion of the patient about medical treatment (r= .130).

Information during the Palliative Stage. The judgment of quality, quantity and understanding of information provided by the head and neck surgeon about the medical condition of the patient is shown in Table 4. More than half of the relatives judged the provided information as 'good' to 'very good'. However, there still is room for improvement, particularly in quantity and quality of information.

Table 4. The judgement of quality, quantity and understanding of info provided by the head and neck surgeon about the medical condition of the patient

	No. (%) by perceived grade of info provided by head and neck surgeon*				
Aspects of given info.	Poor	Reasonable	Good	Very good	Total
Quality	4 (9)	12 (27)	25 (57)	3 (7)	44 (100)
Quantity	6 (13)	14 (31)	20 (45)	5 (11)	45 (100)
Understandability	2 (5)	9 (20)	30 (68)	3 (7)	44 (100)

** Where participants did not respond to a question, percentages were calculated out of the total number of responses.*

Experience of the Surviving Relative Themselves

Nearly two thirds (62%) of the surviving relatives themselves judged the total care and support from the Erasmus MC for themselves as 'good' to 'very good' versus one third (31%) that judged the total care package as 'reasonable' to 'poor'. Contact with the head and neck surgeon was judged as follows: 16% rated 'very good', 34% rated 'good', 27% rated 'reasonable', and 18% rated 'poor'. Thirty-three per cent of the surviving relatives said that the head and neck surgeon did not pay sufficient attention to them. More than half (58%) claimed that the psychosocial support from the head and neck department in respect to problems of the relatives themselves was insufficient.

The Terminal Phase of Dying

Half (53%) of the patients died at home. Thirty-eight per cent of the patients died in the hospital and 9% in a nursing home. According to the relatives, one tenth were not informed that their disease was incurable and the treatment was palliative. Half of the relatives (49%) said that symptoms related to the terminal stage were not discussed with the patient. Patients who were better informed about the stage of dying found psychosocial support more sufficient (r= .782, p= .01) and were better prepared for death (r= .570, p= .01). No relation was found between better information and acceptance of dying.

Psychosocial support during the phase of dying was judged as insufficient in two thirds (63%) of the cases. Two thirds of the relatives said the caregivers did not mention support in bereavement. Three fourths (78%) of the relatives reported that the head and neck department did not contact them after the death of their spouse. Almost none (5%) of the relatives received support from the head and neck department during bereavement.

DISCUSSION

Previous publications indicate that relatives of patients who are well supported during the palliative stage of disease have fewer psychological problems, a shorter period of mourning, and less anger than relatives of patients who were not well supported.[6,7] Additionally, family members report that patients prefer comfort over life-lengthening treatments, even though most patients were treated aggressively.[8] In this study, two thirds of the relatives claimed the patient was depressed and had a need for better psychosocial support. Therefore, an important task for the Expert Center is to provide psychosocial support and education, especially during the stage of dying, to both patient and relative. This care is given by our palliative team (head and neck surgeons, specialized nurses, speech therapists, pain team, dietician). Since most specialists generally cannot provide such intensive care, besides somatic treatment, some of these specific tasks can be taken care of by a specialized nurse. This nurse can extensively discuss the disease, problems, expectations and the period of death. Costs and logistic factors may, however, limit the availability of care by a specialized nurse. Trained volunteers may well be used to fill this gap in the future. These volunteers can be a 'listening ear' and are easily accessible, while the specialized nurse can focus on medical support or arrange further consultation. Many questions raised cannot be answered by any of the caregivers because of insufficient knowledge about the terminal stage. It is always uncertain how long this stage will last and how patients will die. Further studies on prognostic factors in palliative patients must generate more information about this in the future.

According to our results, half of the surviving relatives thought that the patient experienced the medical treatment as too intrusive. This also confirms that communication between patient and physician is not optimal. Physicians in our department are mostly focused on curative treatment. The approach in the curative stage differs from the one in the palliative stage. This can lead to too many diagnostic procedures and too little attention to psychosocial symptoms of palliative patients. A study by Koedoot et al [9] showed that medical oncologists frequently do not discuss the option of watchful waiting when proposing palliative chemotherapy. They concluded that patients often do not receive sufficient information to make an adequate treatment decision. Treatment options should be well explained to both patient and relatives. Furthermore treatment should be based on a common palliative pathway protocol. The objective of these protocols is to access somatic and psychosocial symptoms with minimal interventions and treat them accordingly.

In large centers, patients may at different times be treated by different attending physicians. This study demonstrates that it is very important for patients with terminal head and neck cancer to be treated and supported by one single attending specialist. Other studies also show that interpersonal continuity of care is important to the majority of patients, particularly those in vulnerable groups.[10] Within the Expert Center, a policy is made to appoint a single head and neck surgeon to each palliative patient. We must realize, however, that head and neck cancer treatment is a multidisciplinary approach.

Communication between different caregivers is often inadequate.[11] Little is known about communication within a multidisciplinary team. In our institution, a logbook was developed [12] to improve continuity of information in cancer care in the curative stage. This resulted in better informed patients and caregivers, leading to a reduction of psychosocial problems.

Limitations of our study are that feedback of surviving relatives regarding the experiences of palliative patients, such as coping, symptom control and judgment of care, is only an estimate of reality in terms of patient experience, which may be biased. Furthermore in most cases more than a year had passed between death and the answering of the questionnaire. Specific head and neck cancer problems, such as swallowing, speech and airway problems, were not explored in this study. In the near future, prospective studies involving palliative patients themselves and their specific concerns will be used to evaluate our Expert Center.

CONCLUSION

Medical treatment of the head and neck department was felt to be sufficient in the majority of the cases. Psychosocial support and patient education need to be improved, particularly during the last stage of life. This can be achieved through deployment of a specialized nurse, support by a single attending specialist and new standardized protocols and means of communication resulting in a better continuity of care. Medical treatment is frequently experienced as too intrusive. A common palliative pathway protocol with minimal interventions and targeted treatment must help to avoid this. To support relatives during the palliative stage and bereavement period, a special support program is necessary.

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CHAPTER 6

EXPERIENCE OF PALLIATIVE CARE FOR PATIENTS WITH HEAD AND NECK CANCER THROUGH THE EYES OF NEXT OF KIN: IMPACT OF AN EXPERT CENTER

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ABSTRACT

Background

Literature is scarce on the palliative care experiences of patients with head and neck cancer and their families. We report our experience in this patient population after the establishment of our Expert Center.

Methods

We administered a questionnaire to 40 surviving relatives of patients with head and neck cancer after the establishment of our Expert Center and compared the results to a similar group of surviving relatives of patients with head and neck cancer before the establishment of our Expert Center.

Results

Since the establishment of our Expert Center, we found: an improved evaluation of the psychosocial support offered; better contact between head and neck surgeons, the patients and families; and improvement in the quantity of information in the palliative phase. Some relatives however, reported that patients received treatment against their wishes and life was not made as comfortable as possible.

Conclusion

Important aspects of palliative care, such as psychosocial support and contact between patient and surgeon, have been improved since the establishment of our Expert Center.

INTRODUCTION

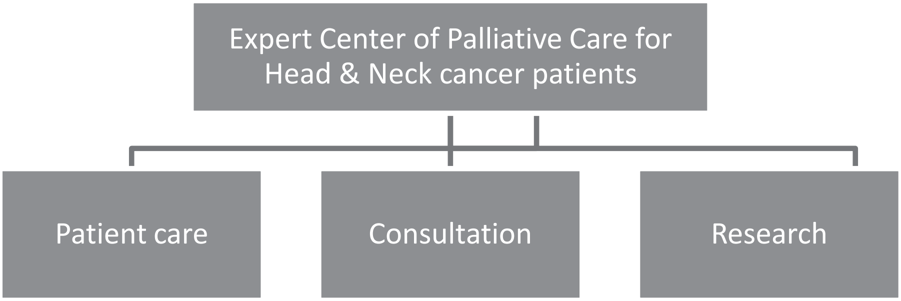
Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems; physical, psychosocial and spiritual.(1) As a large percentage (59%) of the Head and Neck (H&N) cancer patients die as a consequence of their disease(2) every H&N cancer surgeon will be confronted with patients entering the palliative phase. The issues of pain and symptom control, psychosocial distress and spiritual issues in H&N cancer patients during the end-of-life phase need to be addressed across the continuum of care.(3) Because of the unique nature of cancer of the head and neck and a variety of cancer related symptoms, special considerations must be given to end-of-life care for these patients and their loved ones. (4)

Palliative care of H&N cancer patients and their families experiences during this phase remains an underexposed subject in literature. To address this, our team at the Erasmus Medical Center Rotterdam had previously set-up an evaluation study of HNC patients' experience of palliative care. This study was done through the eyes of relatives of these patients, the patients themselves having died between January 2003 and July 2004. (5) From this research it was concluded that not all aspects of care during the palliative phase were sufficient. Specifically psychosocial support and patient education and information needed improvement. Based on our own experiences and on the experiences of other specialists, our HNC team set up an Expert Center (EC) in 2005 to address this issue. This EC is dedicated to the palliative care of HNC patients and their families or significant others. The mission of the EC is to improve the quality of life of the patient in the palliative phase. This was achieved by offering structured attention to patients and their families physical and psychosocial needs. Because, in general, knowledge of the palliative phase of head and neck cancer is limited, the EC additionally sought to provide an important consultancy role for other caregivers. The goals of this Center, as shown in table 1, were achieved by installing a specialist team consisting of dedicated

Table 1. Objectives Expert Center of Palliative Care for H&N Cancer

1. Support and facilitate optimal physical condition of the patient by providing good symptom control.
2. Provision of targeted information about the palliative phase for the patient and his family.
3. Provide structural (psychosocial) support to patient and family.
4. Consultation with other caregivers in (home based) palliative care.
5. Help to realize the wish of patients to die at home.
6. Research on palliative care.
7. Reduce unnecessary hospital admissions & interventions.

HNC surgeons, acting as a clear contact person for patients; specialist nurses, psychologists, speech therapists, a pain team of anesthesiologists, a dietician, social workers, and representatives of the religious profession. A joint clinic was set up with two specialist palliative care nurses on the staff of seven Head and Neck surgeons. The nurses provide information and psychosocial support to patients and relatives, handle pain management and screen psychosocial needs and other relevant data for effective allocation of



Multi disciplinary care with focus on symptom control and psychosocial and spiritual support.

Outpatient clinic: key contact persons: the dedicated Head & Neck cancer surgeons and the specialist nurses.

Clinical care: two rooms specifically equipped for the patients and their caregivers in the (early) palliative phase and the terminal phase on the ward of the Department of Otorhinolaryngology and Head and Neck Surgery in the hospital.

Towards health caregivers in palliative care:

- General Practitioner of the patient in the palliative phase.
- Medical specialist from other departments in the hospital and in other hospitals.
- Hospice / Nursing home.

Published research on the subjects:

- Palliative care in general practice.
- Experience & evaluations of palliative care of next of kin.
- Self-efficacy and goal disturbance in patients and their partners.
- Survival of patients with palliative head and neck cancer.
- Psychosocial aspects of recurrent head and neck cancer.
- Symptom prevalence in the palliative phase and impact on daily functioning.

Current research on the subjects:

- Anxiety in the palliative phase.
- Prediction model risk factors blow-out.
- Prognostic modeling.

Figure 1. Main activities Expert Center of Palliative Care for H&N Cancer

specialized care and for research purposes. In addition they offer consultation to e.g. General Practitioners (GP's) who rarely see such cases in their daily practices. These nurses play a pivotal role in the palliative care, ensuring more efficient and effective communication between surgeon, patient and other caregivers. For the main activities of the EC, please see figure 1.

The start of the palliative phase is defined as the period from the moment the patient: is diagnosed by the multidisciplinary team to be suffering from incurable cancer of the head and neck, or chooses not to be treated; until death. In the palliative stage of the disease, treatment is aimed at prevention and relief of symptoms, resulting in the best possible quality of life. During this phase, however, the patient may still undergo palliative treatment, i.e. surgery, radiotherapy or chemotherapy.

The objective of this follow-up study was to evaluate the interventions given by our newly established EC to head and neck cancer patients in the palliative phase, again through the eyes of the relatives of the deceased patients. Additionally, a comparison was made of the palliative care after the installation of our EC against the care given before this intervention. The results of the period prior to the EC were published in 2008 by Ledeboer et al. (5)

MATERIALS AND METHODS

Sample

Included for this study were surviving relatives and other contact persons[c] of patients with incurable head and neck cancer diagnosed or treated in our department. All patients had a histologically proven malignancy of the head and neck area. One completed questionnaire was excluded from this study, as the patient died from a second primary lung cancer with metastases and should not have been included in this study. Those who did not participate did so for the following reasons: they were not reachable, they lacked the time or were emotionally unable to talk about this subject. The total population was N= 40 for this cross sectional retrospective study.

Procedure

Relatives were contacted by a surgeon by telephone and were asked to participate in the study. After approval by the relative, a letter was sent confirming their participation and explaining the aim of the study once more. Included with the letter was a written ques-

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[c] This is the first contact person noted in the medical dossier.

tionnaire. This questionnaire was exactly the same as the one used in our first research evaluating our palliative care before the set-up of the Expert Center. (5) The questionnaire consisted of 64 semi-structural questions, 6 open questions, and 16 general statements on palliative care. Questions were categorized under medical treatment, psychosocial support, information, and education and terminal stage. Relatives who did not return the questionnaire were reminded by telephone. In total, N=62 relatives were included for participation. N=41 returned a completed questionnaire, resulting in a response rate of 66%.

Statistical Analysis

Statistical analyses included descriptive statistics, Pearson correlational statistics, and cross tab-analysis were done using SPSS 17.0.

RESULTS

Patient characteristics

The average palliative period for this study was 3 months. Socio demographic data of the patients is shown in table 2. The questionnaire was answered by spouses (44%), children (34%), a sibling (11%) or other contact person (11%). See table 2.

Descriptive Analyses

Psychosocial support during the palliative stage

Satisfaction with psychosocial support in the palliative phase is summarized in table 3. Support from the family of the patient and support from the GP are both judged in line with the period before the establishment of the EC. More than two thirds of the surviving relatives (68%) in the current research indicated that the palliative psychosocial support from the Head and Neck department was satisfactory. Before the establishment of the EC, 51% of the surviving relatives found this psychosocial support satisfactory.

Medical treatment during the palliative stage

The medical treatment provided by the HNC department was judged to be satisfactory by the majority of the respondents (77%) however this percentage was lower than in the previous research (81%). One out of eight surviving relatives (13% versus 2% before the EC) thought that the patient received treatment against their wishes. In addition more relatives (11%) found that the HNC department did not do everything they could to make life for the patient as comfortable as possible, see table 4.

Table 2. Socio-demographic data and clinical characteristics of patients

	Study before EC (2008)		Study after EC (current)	
	N	%	N	%
Sex	34	76%	27	68%
Male	11	24%	13	32%
Female	45	100%	40	100%
Mean Age (SD)	66 (12,7)		73 (13,4)	
Marital Status				
Single[1]	11	24%	19	47%
With partner	34	76%	21	53%
Total	45	100%	40	100%
In living offspring				
Yes	6	14%	5	14%
No	37	86%	31	86%
Total	43	100%	36	100%
Palliative phase (median/range)	4 mo (1-16 mo)		3 mo (0-13 mo)	
Main stay in palliative period				
At home	36	82%	21	53%
Hospital	8	18%	5	12%
Nursing home / hospice	1	0%	14	35%
Total	45	100%	40	100%
Questionnaire answered by:				
spouse	24	53%	18	44%
child	13	29%	14	34%
brother/sister	3	7%	4	11%
other	5	11%	4	11%
Total	45	100%	40	100%

[1] This can also mean 'widow'

Table 3. Satisfaction with (psychosocial) support from family, hospital and General Practitioner (GP)

	Study BEFORE Expert Center	Study AFTER Expert Center	-/+
Satisfied with support from family.	96%	93%	-3%
Satisfied with discussing disease in the family.	86%	80%	-6%
Satisfied with psychosocial support H&N department	51%	68%	**+17%**[2]
Satisfied with psychosocial support GP.	70%	67%	-3%
Patient is not 'sometimes' or 'often' depressed.	33%	32%	-1%

[2] The figures in boldface represent differences above 10%.

Table 4. Medical treatment

	Study BEFORE Expert Center	Study AFTER Expert center	-/+
Satisfied with medical treatment H&N department.	81%	77%	-4%
Satisfied with medical treatment from the GP.	67%	73%	+6%
Medical treatment was not too intrusive.	50%	44%	-6%
H&N department did everything possible to make life for the patient as comfortable as possible	75%	64%	**-11%**
Patient did not receive treatment against wishes.	98%	87%	**-11%**

Nearly two out of three relatives in the current study (67%) reported that the patient was seen by the same HNC surgeon (clear contact person) versus 49% before the installation of the EC. Before the EC, 19% rotated 'extensively' between H&N surgeons. After the installation of the EC this figure decreased to 8%.

Communication and information during the palliative stage

Satisfaction with the communication and the information received during the palliative stage is summarized in table 5. A substantial proportion of the surviving relatives in the current study (78%) reported a good to very good[d] contact between the patient and the HNC surgeon. This compares with 59% before the EC was set up. 75% of the GP's considered this contact to be (very) good as against 59% before the EC. Start-up. There was also an improvement in terms of quantity of information (+17%) provided by the surgeon, however, not it's understandability (-8%), see table 5.

Table 5. Communication and Information during the palliative stage

	Study BEFORE Expert Center	Study AFTER Expert Center	-/+
Contact between patient and H&N surgeon judged as: 'good' to 'very good'.	59%	78%	**+19%**
Contact between patient and GP judged as: 'good' to 'very good'.	59%	75%	**+16%**
Quality of communication and information judged as: 'good' to 'very good'.	64%	67%	+3%
Quantity of communication and information judged as: 'good' to 'very good'.	56%	73%	**+17%**
Understandability of communication and information judged as: 'good' to 'very good'.	75%	67%	-8%
Surgeons or nurses discussed with patients and relatives whether the care was in agreement with their wishes.	56%	63%	+7%

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[d] This question was measured on a four-point scale, ranging from 1='bad' to 4='very good'.

Experience of the surviving relatives

80% of the surviving relatives reported a (very) good contact between the patient and the HNC surgeon compared with 50% before the EC was established. Only 5% of the surviving relatives judged the contact with the HNC surgeon to be 'poor' as compared to 18% before the EC. The percentage of surviving relatives who judged the psychosocial support from the HNC department to be insufficient, from 58% before the EC to 34% after it was established. For further details, see table 6.

Table 6. Experience of the surviving relatives

	Study BEFORE Expert Center	Study AFTER Expert center	-/+
The total care and support from the Erasmus MC judged as 'good' to 'very good.	62%	54%	-8%
The doctors give sufficient attention to relatives.	67%	68%	+1%
Psychosocial support from the H&N department was not insufficient in respect to problems of relatives themselves.	42%	66%	**+24%**
Contact with the H&N surgeon judged as 'good' to 'very good'.	50%	80%	**+30%**
Contact with the H&N surgeon was not judged as 'poor'.	82%	95%	**+13%**

The terminal phase

The surviving relatives experiences of the terminal phase are summarized in table 7. More relatives were contacted after the death of the patient since the installation of the EC. Before, 22% of the relatives reported being contacted by the H&N department compared to 59% after the installation of the EC. The psychosocial support during the terminal phase and afterwards was also judged more positively. 37% of the surviving relatives said this support was sufficient before the EC. This percentage increased to 64% after the installation of the EC. More than half of the relatives (60%) further reported that they received good information from the H&N department about the dying process versus 43% before the EC.

Since the introduction of the EC more patients have died in a nursing home (9% before the EC and 40% since the start of the EC). Fewer patients died in hospital. Before the EC 38% of patients died in hospital. Since its establishment this percentage has dropped to 18%. See figure 2.

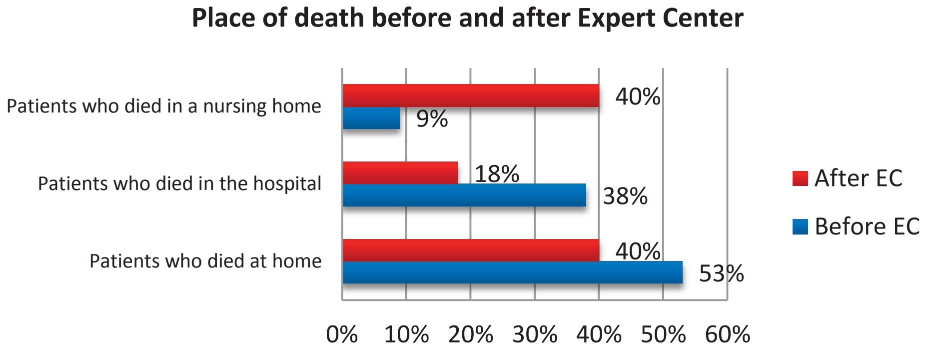

Figure 2. Place of death before and after the installation of the Expert Center

Table 7. Terminal Phase of Dying

	Study BEFORE Expert Center	Study AFTER Expert center	-/+
Long enough before death and clear enough for the patient that he/she would die from H&N cancer.	83%	95%	**+12%**
Relatives received good information from H&N department about the dying process.	43%	60%	**+17%**
Patients were not informed that their disease was incurable and treatment was palliative.	10%	10%	0%
Symptoms related to the terminal stage were discussed with the patient.	51%	63%	**+12%**
Psychosocial support during the phase of dying and afterwards was sufficient.	37%	64%	**+27%**
Relatives had the feeling of being well prepared for the death of the patient.	57%	62%	+5%
The caregivers from H&N department did mention support in bereavement.	35%	48%	**+13%**
The H&N department did contact the relative(s) after the death of the patient.	22%	59%	**+37%**
Relatives received support from the H&N department during bereavement.	5%	18%	**+13%**

DISCUSSION

The aim of this study was to describe the experiences of Head and Neck cancer (HNC) patients with regard to the palliative care they received after the set-up of our Expert Center (EC). The reported experiences are according to the next of kin of the deceased patients. We further compared the findings of this study with those from the same research done prior to the existence of the EC. The question being: are we on the right track with our EC palliative care?

Results suggest that our *psychosocial support* receives higher praise since the establishment of the EC. Improved results in this area could be explained by the work of our specialized nurses, a key element of whose work is the provision of psychosocial support to patients and partners. Another main finding was that after the establishment of the EC a considerably higher percentage of surviving relatives reported a (very) good *contact between the patient and the HNC surgeon and between the partner and the HNC surgeon*. This improved relationship could be explained by the allocation of one specific surgeon to each patient during the palliative phase. Correlational analysis revealed a significantly positive relationship (r= 62; p= .00) between the two variables. Crosstab analysis further revealed that of all patients who "often" or "always" saw the same HNC surgeon, 88% had a "good to very good" relationship with their HNC surgeon. The current results show that since the establishment of the EC, patients have been more frequently allocated to the same surgeon during the palliative phase. Before the start of the EC one fifth (19%) rotated extensively between HNC surgeons. After the establishment of the EC this dropped to 8%. It is part of the policy of the EC to allocate one HNC surgeon to each patient in the palliative phase. We believe that patients having one dedicated surgeon to whom they report their issues feel safer and more comfortable and thus can build a trustworthy relationship. A dedicated surgeon remains more alert to possible (symptom) changes in the patient. In that way not only the best possible support but also continuity of care can be offered. While the General Practitioner is the most easily accessible professional caregiver for a patient in the palliative phase, good contact with the HNC surgeon is important given the specific tumor related symptoms that HNC patients are confronted with.(4) Since the establishment of the EC General Practitioners are able to consult our specialized nurses in order to improve home-based palliative care.(6)

We also received a better evaluation for the quantity of the communication and information during the palliative phase. This could also be explained by the presence in the team of the specialized nurse. Besides verbal information given after the doctor's visit, they provide various brochures from the National Cancer Association which deal with the palliative phase.(7) However, fewer relatives found the communication and information understandable than prior to the set-up of the EC, indicating that there is room for improvement of the content of the given information. One suggestion would be to provide in the palliative phase a similar type of 'care guide' to the one used for curative HNC patients in the preoperative phase. (8) Based on our practical experiences, this could include items for patients in the palliative phase such as: wound care, pain, nausea, sleeping difficulties, psychosocial well-being, resuscitation policy and aftercare for relatives. A source of targeted information covering different aspects of care for the patient in straightforward terms, may well solve the issue of clarity for patients and their relatives.

After the establishment of the EC, there were more positive experiences reported in *the terminal phase* too. Firstly, more relatives were contacted after the death of the patient. This is directly related to the presence of the specialist nurses who are responsible for this task. Though some relatives report that the HNC department did not contact them after the death of the patient. A study of the digital patient files indicates that the specialized nurses had contact with the family of the deceased patient in 95% of the cases. A possible explanation for the discrepancy between facts and perceived experience could be the period of stress in which surviving relatives find themselves after the death of the patient, which renders them unable to recall this contact. Another possible explanation could be that the person who completed the questionnaire was not the one contacted by the specialized nurses. Based on this experience we have changed our policy. We express our condolences in writing during the first week. Telephone contact is made no earlier than three weeks after the death of the patient.

The psychosocial support provided during the terminal phase and afterwards was judged more positively. 63% of the surviving relatives judged this support as insufficient before the establishment of the EC and this percentage dropped to 36% after the EC came into being. A considerably higher proportion of relatives indicated they had received good information from the H&N department about the process of decease as well as support from the HNC department during bereavement. It is of key importance for every physician to weigh the side effects of interventions in the palliative phase against the life expectancy of the patient. A major goal of end-of-life care for terminal head and neck cancer patients must be recognition of the limitations of further therapeutic approaches and to start the best supportive therapy at a reasonable point in time. Talking to patients about the remaining life span is a difficult task for every physician and is often avoided. (4) Physicians should be encouraged to talk to their terminally ill patients about the status and incurability of the disease as early as possible. This in order to facilitate patient and family decision making on how to prepare for the impending end of life.(9) Accurate prognostic modelling could be helpful in informing and supporting HNC patients in the palliative phase (6,10) Research on individualized prognostic counselling is currently being done in our department. In light of the relatively short span of life, the wishes of the patients and next of kin play a pivotal role. There was no perceived improvement in this area of care. After the establishment of the EC, there were more relatives (11%) than in the period before the EC who reported that the patient received treatment against his or her wishes. More relatives also expressed that the HNC department did not do everything in its power to make life for the patient as comfortable as possible. In general the mind-set of surgeons is focused on (curative) treatment, as doctors are educated to cure people. In a recent Dutch study by Visser (11) among 726 doctors, 62% stated that in their opinion terminally ill patients are over treated in the final phase of their life. It would appear that doctors are generally inclined to choose a specific course of treatment because a considerable number of patients do not accept the fact that they are going to die. The family may also request life prolonging treatments. However, this does not explain the lack of improvement over the past few years on the issues of unwanted over-treatment. It is our opinion that patients have become more critical. An empowered is more alert to shortcomings in care and can communicate his or her feelings on this more easily.

Before the establishment of the EC, more than one third of the patients died in hospital. This is now no more than one fifth. Forty percent of the patients died at home and more and more patients died in a nursing home. An important goal of the EC is to help accommodate the patient's wishes as to where he or she wants to die. This is often at home. This can be achieved by consulting professional caregivers such as the General Practitioner and the partner/family via our specialized nurses so that home-based palliative care can be arranged. In a recent study within our team it was concluded that patients who were guided by one of our specialized nurses were more likely to die at home or in a hospice than in a hospital. In those cases where one of our specialized nurses was involved, the number of hospital admissions also decreased. (6) We acknowledge that nearly half of this patient group was single, which makes it more difficult to help to realize their wish to die at home. In the days before the EC and with no specialized nurses, patients were often admitted to our hospital in a very bad state mainly due to lack of symptom control. These patients often died shortly after admission. Now the specialized nurses maintain close contact with the patient, his family and other caregivers. In this way the necessary care and treatment can be better anticipated and patients can be admitted at an earlier stage to a nursing home or hospice. Our experience from clinical practice shows that the number of emergency admissions to our hospital reduced due to this policy of careful monitoring by specialized nurses and - pro-active counseling on symptoms in the outpatient clinic. Less emergency care and fewer hospital admissions therefore seem to be cost effective in the whole palliative phase.

It is important to note that palliative care involvement need not immediately precede death. The stigma of palliative care involvement as "giving up" should be replaced with a positive movement towards better control of symptoms and facilitating a proactive role for patients and families. (12) Care for HNC patients in the early palliative phase should therefore include targeted screening focusing on frequently occurring symptoms such as fatigue and psychosocial symptoms which being less immediately apparent, may be given less attention. (13)

This retrospective study has its limitations. We cannot consider this to be an evaluation study in the pure sense of the word. We do not know if the measured improvements can be attributed for 100% to the Expert Center. We have to take into account certain historical effects. To begin with the shift from doctor-centered to patient-centered (palliative) care, in which patients are increasingly seen as an active partner. It is possible that the experience of palliative care has improved because of the trend of shared decision making in oncology in which professionals are being encouraged to actively involve patients in discussions of possible treatment options.(14,15) Another limitation is that the feedback given concerns subjective, and thus possibly biased, comments from the relative of the deceased patient. However, despite these limitations, our results contribute to the very underexposed subject of palliative and end of life care of HNC patients. We also emphasize the difficulty of doing research with patients in the palliative and specifically in the terminal phase of their disease. Due to ethical considerations and the physical and mental state of patients at the end of their lives, it seems logical to include direct relatives in this research. The above mentioned findings provide us with valuable information for our palliative care.

CONCLUSION

The literature is very scarce on experiences of palliative and end-of-life care for Head and Neck cancer (HNC) patients. Still it is worthwhile to pay attention to this patient group as a large percentage of the head and neck cancer patients die as a consequence of their disease. Every HNC surgeon will be confronted sooner or later in his career with patients entering this phase. In this study we described an evaluation of the interventions given by our Expert Center (EC) to HNC patients in the palliative phase, through the eyes of their next of kin. In addition, a comparison was made of palliative care since the establishment of our EC versus palliative care prior to its existence. In this way we sought to analyze if certain aspects of palliative care given by the HNC department have improved since the set-up of the EC. The approach adopted by our EC with one dedicated HNC surgeon per patient, focusing on structural symptom control together with specialized nurses coordinating care and consultation; has led to increased appreciation of our psychosocial support (including the phase of dying), better contact between patients and HNC surgeons and to more patients being able to die where they wish to.

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CHAPTER 7

PSYCHOSOCIAL PROBLEMS AND QUALITY OF LIFE FOR PARTNERS OF PATIENTS AFTER TOTAL LARYNGECTOMY

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ABSTRACT

Background

Literature about the psychosocial impact on partners of patients who have undergone a total laryngectomy (TL) is lacking. This explorative study provides a broad picture of this impact.

Methods

N=144 partners completed questionnaires assessing the psychosocial impact of a TL. Measures used were health related quality of life, anxiety & depression, fear, goal disturbance, hopelessness, caregiver burden, coping strategies, self-efficacy and cancer locus of control.

Results

A considerable number of partners of laryngectomees experience impact on their social life and their sexual relationship. Also, the tendency of other people to neglect their laryngectomized life companion, affects partners negatively. Clinical levels of anxiety and depression were found in around 20% of partners. Their deepest fear concerns the death of their partner.

Conclusion

A TL has a considerable impact on the psychosocial life of partners of laryngectomees. The findings from current research sets the stage for subsequent research to better understand the psychosocial problems of partners of laryngectomees and the needed interventions to improve quality of life for both patients and partners.

INTRODUCTION

Research has traditionally focused on the impact of cancer on patients. However, the impact of a cancer diagnosis on caregivers is well recognized. The one caring for the cancer patient (most often the partner) experiences a myriad of strains due to the many aspects of life affected by cancer, including communication, nursing care, financial concerns, and emotional conflicts.[1, 2, 3] Partners are more at risk when they lack a supportive network of their own and when there are relationship difficulties with the patient.[4] In a review of Hagedoorn et al [5] it is suggested that a difference in psychosocial well-being between patients and partners can be explained by gender differences. Women report more psychological distress than men, irrespective of their role as patient or partner. From the literature on partners in general cancer care it can be concluded that although partners' psychosocial wellbeing has received considerable attention in the literature, most studies have a limited sample size and many studies focus on either female partners of men with prostate cancer, or on male partners of women with breast cancer.[2\]

Head & Neck (H&N) cancer in general has a considerable impact on partners. It is suggested that partners experience an even higher psychological stress level than patients. Partners' distress may be related to the prospect of losing their life companion [6] and to feelings of helplessness that can lead to depression. [7] Drabe et al. [8] suggest that anxiety disorders are the most frequently reported psychological disorders amongst (female) partners of H&N cancer patients. This affected psychosocial well-being can hamper adequate care to patients.[9]

The literature is very scarce when it comes to the psychosocial consequences of a Total Laryngectomy (TL) on partners of patients. The available studies dealing solely with the impact of a TL on partners are mainly older studies.[10, 11, 12] Two more recent studies are written in the German language.[13,14] The earliest study we found on the impact of a TL on spouses [10] described the reactions of wives related to the TL of their husband. Key examples of these reactions were: low spirit after surgery, difficulties with adjustment to their husbands' voice loss, negative reaction to the first sight of their husbands' stoma and decreased communication between husband and wife. Caregiver stress and burden has been signalled especially at the time of diagnosis and during the first months of the laryngectomy.[11] These researchers conclude that male partners are less inclined to report feelings of hopelessness and that they give another interpretation to their 'supporting role'. It seems that they spend less time with the patient during the first crisis period than female partners of patients do. It is suggested that spouses were more anxious than their laryngectomized partners. However, only very few spouses made use of a psychological treatment.[13] In a review on the impact of caregiving for adults with tracheostoma or laryngectomy, partners were found to report negative personal changes, and to experience even more depression, fatigue and anxiety than the patients themselves did.[12] The researchers of this review emphasized the dearth of studies on caregivers of patients within this population.

In conclusion, the available studies on the impact of a TL on partners are scarce, mainly old and not all in the English language. An overview of the psychosocial problems that partners experience after a TL and how partners function in their daily life in de long run is missing. The objective of our current study is to address these gaps in knowledge within a large research group of partners. In addition to being an explorative analysis of the psychosocial problems and quality of life of partners of laryngectomees, this study also aims to explore the skills people use when dealing with their changed situation (coping). Also the beliefs that partners have about their capabilities (self-efficacy) and goal disturbance related to the consequences of a TL have been explored.

PATIENTS AND METHODS

Sample

Procedures

This study was part of a larger project funded by the Michel Keijzer Fund of the Dutch Patients' Association for Laryngectomees, the NSvG.[e] All respondents were members of this organization. As the NSvG could not discriminate between members with and without a partner, all members received an introduction letter explaining the background and goal of this study, including an apology for sending the letter in case the person did not have a partner. The letter included a reply card for obtaining informed consent. Reply cards were sent free of charge to the NSvG who made address stickers of the participants. Participants then received a written questionnaire separate for laryngectomees and partners and a free of charge reply envelope. Follow-up telephone contacts were done in case the research team did not receive the questionnaires of participating couples. In figure 1 an overview is presented of the number of people approached and reasons for exclusion.

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[e] This study investigated the psychosocial consequences in patients who have undergone a total laryngectomy, their partners and the impact on their relationship. Insight on these aspects will be leading in the formulation of recommendations for interventions aiming to increase QoL of patients and their partners.

Participants

Eligible for this study were partners of laryngectomized patients who are member of the Dutch Patients' Association for Laryngectomees from whom we received written informed consent. As shown in figure 1, all members of the NSvG were approached and from N= 169 partners we received an informed consent of which N=25 partners refused to participate or had to be excluded after all. Of these 25 partners: 14 did not send the questionnaire back after several follow-up contacts. This was without a specific reason. Furthermore 11 partners decided not to participate with the following reasons: illness or death of partner (5), partners filled in less than half of the questionnaire (3), time consuming (1), did not find the questions relevant (1) or did not feel being a partner of "a patient" (1). In total N=144 partners of laryngectomees participated in this study.

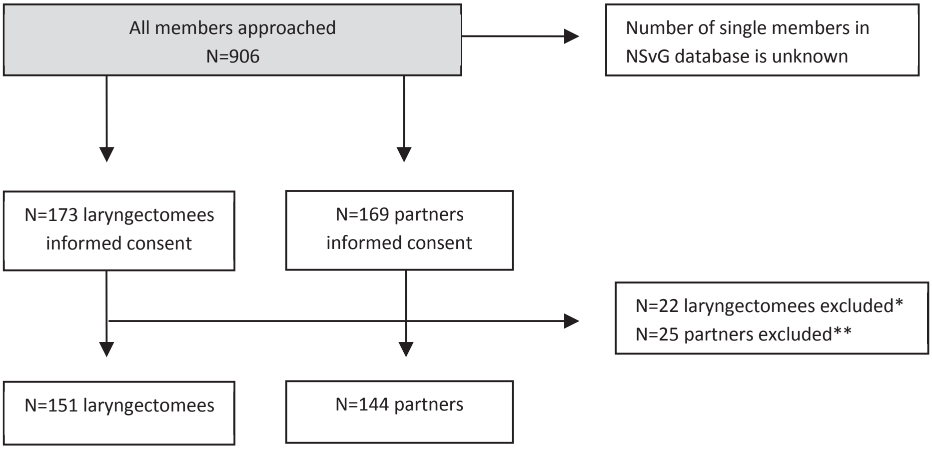

Figure 1. Particiapants

* N=22 laryngectomees were excluded: 14x did not send questionnaire after telephone contact, 8x decided not to participate with reasons: 4 serious ill, 1 died, 2 questions not relevant and 1 question too intimate.

** N=25 partners were excluded: 14x did not send questionnaire after telephone contact, 11x decided not to participate with the following reasons: 4 husband ill, 1 husband died, 3 filled in less than half of the questionnaire, 1 too much time, 1 could not answer the questions, 1 does not feel being a partner of a patient.

Measurements

The basis of the studied concepts in this cross-sectional study is the theoretical model of coping with cancer introduced by Pruyn[15] and Van den Borne and Pruyn.[16] This model is based on the literature about coping with stress associated with cancer. In this model Quality of Life (QoL) is described by four psychosocial key issues experienced by all cancer patients.[f] On top of these negative experiences, also the positive outcomes of a

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[f] The key psychosocial issues in this model are: 1) uncertainty, 2) negative feelings such as fear and depression, shame, hopelessness 3) loss of control and 4) threat to self-esteem.

traumatic event as a laryngectomy will be described by making use of the concept 'post-traumatic growth'.[17] During the past decade this concept has been increasingly studied in cancer populations. However, until now it has been unexplored in the research of oral cancer patients in general [18,19] and not at all explored specifically in patients who have undergone a TL and their partners.

The present study first describes the general QoL of partners of laryngectomees in terms of negative feelings as anxiety, depression, fear and loss of control.[g] Secondly, a descriptive analysis is made of skills to cope with the consequences of these feelings. The following criteria have been used to select the measurements: a) validated scales, b) total length of battery of questionnaires and c) specificity in problems for head & neck cancer and more specific for laryngectomy. Related to the latter criteria we decided to develop specific instruments, and used these parallel to internationally used and validated questionnaires.

Psychosocial problems and quality of life outcome variables

Quality of Life for partners was measured with the EORTC Quality of Life Questionnaire (QLQ-C30) Dutch version 3 for cancer patients.[20] The scores are transformed to a scale of 0-100, with a high score implying a high level of functioning or global QoL. Cronbach's alpha in the current study was .85.

Anxiety & Depression were assessed with the Hospital Anxiety and Depression Scale, HADS.[21, 22] The HADS was specifically designed for use in the medically ill and has been widely used in patients with head and neck cancer. This 14-item self-report instrument measures anxiety (seven items) and depression (seven items) using four-point scales. For both anxiety and depression we have used the cut off values recommended by Zigmond & Snaith, classifying each person according to a clinically tested classification method of psychiatric morbidity. The scoring range for the 14 items was 0 to 3. For both subscales the scoring range varied from 0-21. Scores <8 were categorized as "normal". Scores between 8-10 indicated a "possible depression or anxiety disorder" and scores >10 indicated a "probable depression or anxiety disorder". For the mean scores, see table 2. Cronbach's alphas in the current study were .86 for anxiety and .82 for depression.

Loss of control was measured by 23 statements, based on a loss of control scale developed for cancer patients.[16] 'Loss of control' is defined as the inability to manage and influence events. It concerns the feeling of losing grip on the situation and is divided in

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[g] Uncertainty of the disease is not included in this study, as this is closely related to a patient's lack of information and questions he or she has about the disease and treatment. As this population concerns long-term survivors, we focused more on the other aspects of negative experiences.

different areas of life, such as daily functioning, physical functioning, social functioning, emotional functioning, general functioning and material possibilities. A factor analysis revealed high scores for three factors: 1) 'disruption of daily life' with Cronbach's alpha of .74, 2) 'feeling bad' with Cronbach's alpha .77 and 3) 'irritation with regard to other people neglecting the patient' with a Cronbach's alpha of .53. Higher scores indicate a greater loss of control.

Fear was measured by a 32-item scale. People with cancer may experience three types of anxiety. 'Personal trait anxiety' and 'state anxiety' refer to a more general and indefinable state of mind. A more specific form of anxiety is "fear", and refers to a concrete threatening object or situation; in this case in relation to the disease (i.e. laryngectomy). People go in fear of new treatments, or fear of dying. Because of the specificity, the concept of fear is very useful/ informative for this research, as it gives concrete directions for professional care. The original scale consists of 11 items on a 4-point scale ranging from 1 (no fear at all) to 4 (very much fear).[16] For our current research in this population 21 items were added. A factor analysis revealed high scores for three factors: 1) 'fear of situations in which the (laryngectomized) partner cannot talk with other persons/people' with Chronbach alpha of .84, 2) 'fear of new treatments of the patient' with Chronbach alpha of .88 and 3) 'fear of deterioration of the relationship and tension in the family' with Chronbach alpha of .82. Higher scores indicate more fear.

Goal disturbance was captured following Offerman et al.[23] through one question on five domains in life. We asked partners of laryngectomees about their perception regarding disturbances in five goals, related to: work, household tasks, partner & children, family & friends, and hobbies. The partners indicated whether their goals were still attainable, even though their life companion had undergone a laryngectomy. Answers were given on a range of category 1 (not attainable at all) to 5 (very well attainable). Chronbach alpha for the total scale was .84.

Hopelessness/Helplessness was assessed with the Mental Adjustment to Cancer Scale developed by Watson et al.[24] and was tested in a Dutch version with six items by Braeken et al.[25] Scores range from 6-24 and the cut-off score is $\geq$11. Chronbach alpha in current study was .87 Higher scores indicate more feelings of hopelessness/helplessness.

Post-traumatic growth was assessed with the Posttraumatic Growth Inventory (PTGI),[17] consisting of 21 items divided over five factors. Factor a) 'Relating to others' consists of 7 items with Chronbach alpha of .85, factor b) 'New possibilities' consists of 5 items with Chronbach alpha of .81, factor c) 'Personal Strength' consists of 4 items with Chronbach alpha of .83, factor d) 'Spiritual change' consists of 2 items with Chronbach alpha of .42, and factor e) 'Appreciation of (own) life' consists of 3 items with Chronbach alpha of .75. Answers are rated from 0 ('I did not experience this change as a result of the TL') to 5 ('I experienced this change to a very great degree as a result of the TL'). Higher scores indicate more posttraumatic growth.

Caregiving positive and negative reactions / experiences were assessed with the Caregiver Reaction Assessment (CRA), developed by Given and colleagues.[26] This assessment consists of 24 items and five subscales. Scale 1) 'disrupted living schedules' has 5 items and Chronbach alpha of .85, scale 2) 'health problems' has 4 items and Chronbach alpha of .67, scale 3) 'financial strain' has 3 items and Chronbach alpha of .61, scale 4) 'lack of family support' has 5 items and Chronbach alpha of .57, and scale 5) 'self-esteem' has 7 items and Chronbach alpha of .75. The first 4 scales assess negative experiences of caregiving. The 5th scale measures the impact of caregiving on the self-esteem of the caregiver. This validated tool uses a five-point Likert scale, with responses ranging from 'strongly agree' to 'strongly disagree'. A higher score means a stronger impact on the experiences of the caregiver (either negative or positive).

Coping strategies, self-efficacy and goal disturbance

Coping was assessed with the Brief COPE,[27] using 14 subscales, with two items per subscale. Each item is rated on a four-point response scale ranging from 1 ('I haven't been doing this at all') to 4 ('I have been doing this a lot'). Subscales are: 1) 'Self-distraction', Cronbach's alpha .48, 2) 'Active coping', Cronbach's alpha .57, 3) 'Denial', Cronbach's alpha .56, 4) 'Substance use', Cronbach's alpha .91, 5) 'Use of emotional support', Cronbach's alpha .60, 6) 'Use of instrumental support', Cronbach's alpha .58, 7) 'Behavioral disengagement', Cronbach's alpha .27, 8) 'Venting', Cronbach's alpha .55, 9) 'Positive reframing', Cronbach's alpha .57, 10) 'Planning', Cronbach's alpha .61, 11) 'Humor', Cronbach's alpha .44, 12) 'Acceptance', Cronbach's alpha .68, 13) 'Religion', Cronbach's alpha .93 and 14) 'Self-blame', Cronbach's alpha .13. Higher scores on a specific coping style reflect a higher use of this coping style.

Self-efficacy refers to a person's belief and confidence that performing certain behavior will lead to a desired outcome. Self-efficacy has been found to play a central role in psychological well-being in patients with different chronic illnesses [28] and also in H&N cancer patients.[29-30, 23] Following Lorig et al.[31] and Kuijer and De Ridder [28] all items were taken together. Factor analysis for partners revealed three factors of self-efficacy: 1) 'Self-efficacy in good contact with partner/patient', Cronbach's alpha .91, 2) 'Self-efficacy in having and keeping good contact with others', Cronbach's alpha .80 and 3) 'Self-efficacy in good care for stoma', Cronbach's alpha .65. All items were measured on a seven-point scale, ranging from 1 ('no confidence at all') to 7 ('full of confidence').

Cancer Locus of Control. The perception that the cause of specific events may be attributed to personal (internal control) or situational (external control) elements is called 'locus of control'. Cancer Locus of Control was assessed with the Cancer Locus of Control scale.[16] For this study we asked the partner about the cause and the course of the disease of the patient. The scale consist of 13 items and has 3 subscales: 1) 'Cancer patients' internal locus of control with respect to the *cause* of the illness', Cronbach's alpha .86, 2) 'Cancer patients' internal locus of control with respect to the *course* of the illness', Cronbach's alpha .85 and 3) 'Patients' religious control', Cronbach's alpha .85. A higher score on a specific style of control reflects a higher use of this style of control.

Statistical methods

After screening for normality, descriptive statistics were calculated according to standard procedures, using SPSS 15.0. Reliability analysis of the scales was performed and the Cronbach alpha's are presented in the section measurements. Factor analysis was performed for the specifically for this research developed or adapted scales for data reduction, and in order to better understand the structural composition of the scales. Furthermore, we calculated correlations between socio- demographic variables and psychosocial problems of partners in order to detect vulnerable persons.

RESULTS

Sample characteristics

The age of partners varied from 42 to 87 years with a mean age of 66 years. 84% of the partners were female. Further demographic characteristics are presented in table 1.

Quality of life and psychosocial outcomes

Quality of life. The partners reported a good quality of life. On a range from 1 (=very bad) to 7 (=excellent), 90% of the partners report a figure 5 or higher.

Anxiety & depression were reported by partners of laryngectomees (table 2) with mean scores within the normal range as stated in the original study of Zigmond and Snaith.[21] Clinical levels of anxiety were found in total of 29% partners, of which 12% reported a probable mood disorder and 17% a possible mood disorder. Clinical levels of depression were found in 20% of all partners of which 6% reported a probable mood disorder and 14% a possible mood disorder.

Table 1. Sample characteristics of the partners of laryngectomees

	Partners	
	N	**%**
Gender		
Male	23	16
Female	121	84
Total N	144	
Current age (mean, SD)	66 (9,1)	
Level of education		
Primary	20	14
Lower secondary	38	27
Middle secondary	60	42
Higher secondary/ university	25	17
Children		
Yes	128	90
No	15	10
Living situation		
With partner	130	91
With partner and child(ren)	11	8
Other (LAT)	2	1

Table 2. Results HADS partners

Scale	Mean (SD)	Normal	> cut-off *possible* mood disorder	> cut-off *probable* mood disorder
HADS-Anxiety	5,6 (4,0)	71%	17%	12%
HADS-Depression	4,0 (3,6)	80%	14%	6%

Psychosocial problems. More than half of the partners (56%) feel irritated that people communicated over the head of the laryngectomee directly to the partner[h]. Also, one third of the partners (35%) report visiting social events less frequently. Furthermore, 31% of all partners had less sexual contact since the TL of their partner. Furthermore, more than one out of four partners: are uncomfortable that other people neglect their partner (28%) and cannot have the same leisure as before since the laryngectomy (28%), see figure 2. Important *fear aspects* of partners deal with worries about their partner. First of all, nearly one third of all partners (31%) report to have fear for the death of their partner (31%). One quarter have fear when their partner needs to communicate in a

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[h] *Feelings of shame* in partners were also explored. Many feelings of shame in the pure sense of the words were not reported by partners. Also here it concerns mostly how others view the laryngectomee, just like with the concept loss of control. Nearly 20% of the partners have feelings of shame in case others direct their speech to them and not to the laryngectomee.

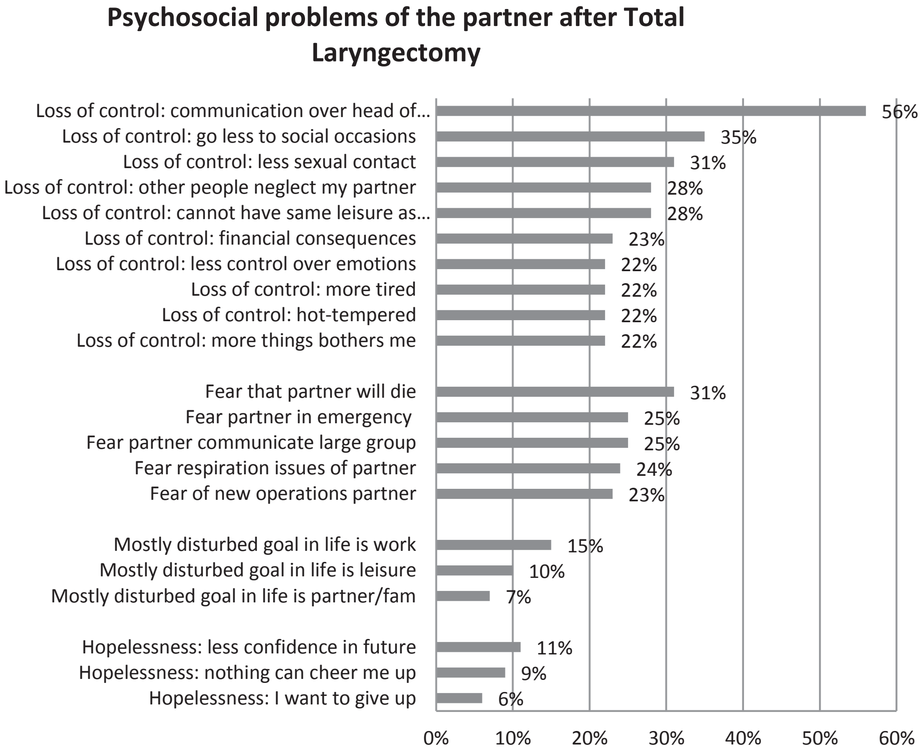

Figure 2. Results psychosocial problems for partners of patients after total laryngectomy

large group or they have fears when their partner is involved in an emergency situation. *Goal disturbance* reported by the partners is mainly in the area of work (15%). Another important area are leisure activities; these were reported to be disturbed for 10% of all partners. *Feelings of Hopelessness/ Helplessness*. The most frequently reported feeling was having less confidence in the future (11% of the partners). 9% of the partners report that nothing can cheer them up and 6% want to give up.

Posttraumatic growth. Nearly half of all partners (49%) experience more appreciation of life since the TL of their life companion. The same percentage of partners report that they feel stronger than they thought they were (48%), which means a greater feel of personal strength. Another 45% says that they are better in facing difficulties since the laryngectomy of their life companion. For more details, see figure 3.

Coping. Key coping strategies for partners are 'accepting the situation' as people learn to live with their situation and accept the reality that the disease has happened. Also positive coping strategies are shown by more than half of all partners. These partners look for something good in what happened (64%) and they try to see their situation more positive (51%).

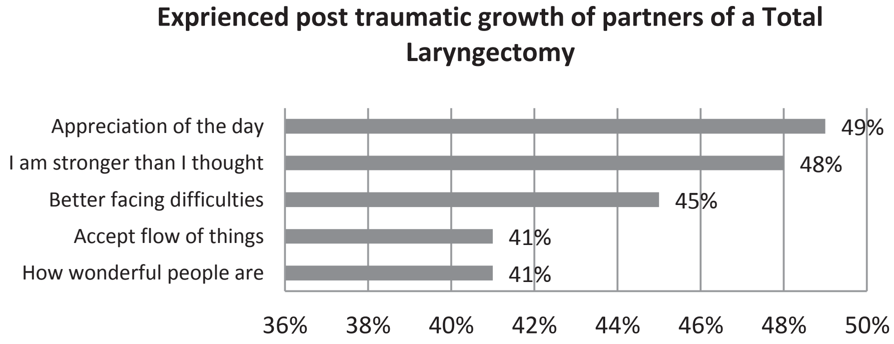

Figure 3. Results posttraumatic growth for partners of patients after total laryngectomy

Cancer Locus of Control. More than one third of the partners believe that the persons who have undergone a total laryngectomy themselves can influence the course of the disease by living healthy (35%) and by fighting against the illness (35%) and follow the prescriptions of the physician (34%). These high frequencies are all related to the internal locus of control with respect to the course of the disease. Only a few partners report internal locus of control related to the cause of the disease, for example: 'that my partner became ill is partly his own fault'.

Self-efficacy. In general it can be said that partners have a good sense of self-efficacy. They show lower self-efficacy specifically in the relationship with their life companion. One out of six partners (17%) has low self-efficacy in having sex with their life companion because of fear for respiration problems. Furthermore, 15% of all partners have low self-efficacy to go out to dinner with the laryngectomee. And one out of ten partners has low self-efficacy in good communication with their life companion. See figure 4.

Generally speaking, the majority of the partners enjoy caring for their life companion who has undergone a TL. Many of the partners (78%) first of all find it important to take care of their life companion, and even 4 out of 5 partners (85%) enjoys doing so. A great part (78%) also feels healthy enough to take care of their life companion and caregiving makes them feel good about themselves (77%).

On the other hand, for one out of four partners (26%) all their activities are centred on the care for their life companion. One out of five partners (22%) visits their family and friends less since they take care of the laryngectomee. Furthermore, one out of

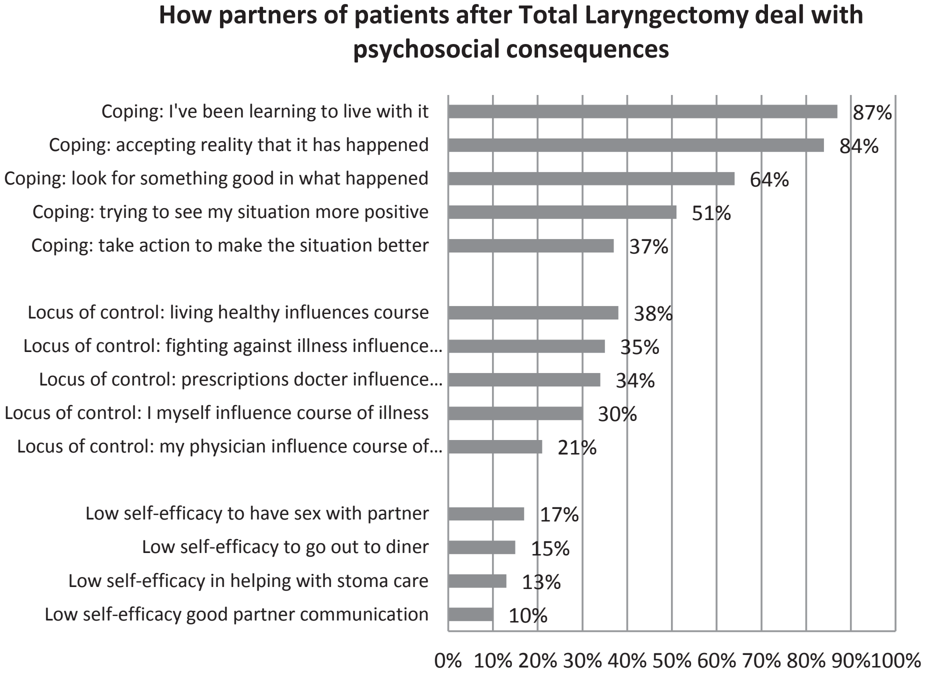

Figure 4. How partners of patients after total laryngectomy deal with the psychosocial consequences

six partners (16%) report that others have dumped the caretaking onto them and that their family has left them alone to take care of their life companion. Another 13% of all partners feels tired all of the time since they take care of their laryngectomized life companion. For more details, see table 3.

Association between demographic characteristics and research variables

In order to get a clearer picture of which aspects could be relevant for intervention in the clinical practice, the relationships between socio demographic data are described. We used three stable variables: gender, age and education and looked at the relationships with the psychosocial problems experienced by the partners of laryngectomees. Using these stable variables is an easy way to quickly identify vulnerable persons who will need extra (psychosocial) attention.

Significant correlations with gender, age and education:

As presented in table 4, female partners of laryngectomees experienced more depression than male partners (r= -.20; p=.02). They also experience more fear for new treatments than male partners (r= -.18; p=.03).

Table 3. Caregiving to laryngectomees

Subscales: five domains Caregiver Reaction Assessment	
Disrupted schedule	
My activities are centred on the care for my partner.	26% (N= 141)
I visit family and friends less since I have been caring for my partner.	22% (N= 139)
I have eliminated things from my schedule since caring for my partner.	13% (N= 138)
I have to stop in the middle of my work or activities to provide care.	11% (N= 142)
The constant interruptions make it difficult to find time for relaxation.	6% (N= 139)
Financial problems	
Financial resources are adequate (reversed).	69% (N= 137)
It is difficult to pay for the care of my partner.	6% (N= 138)
Caring for my partner puts a financial strain on me.	4% (N= 137)
Lack of family support	
My family works together at caring for my partner (reversed).	33% (N= 131)
Others have dumped caring for my partner onto me.	16% (N= 138)
My family (brothers, sisters, and children) left me alone to care for my partner.	16% (N= 137)
It is very difficult to get help from my family in taking care of my partner.	10% (N= 134)
Since caring for my partner, I feel my family has abandoned me.	7% (N= 140)
Health problems	
I am healthy enough to take care of my partner (reversed).	78% (N= 142)
Since caring for my partner, it seems like I’m tired all of the time.	13% (N= 138)
It takes all my physical strength to care for my partner.	12% (N= 142)
My health has gotten worse since I’ve been caring for my partner.	7% (N= 138)
Self-esteem	
I really want to care for my partner.	85% (N= 136)
I enjoy caring for my partner.	84% (N= 141)
Caring for my partner is important to me.	78% (N= 142)
Caring for my partner makes me feel good.	77% (N= 141)
I feel privileged to care for my partner.	70% (N= 139)
I will never be able to do enough caregiving to repay my partner (reversed).	14% (N= 136)
I resent having to care for my partner (reversed).	1% (N= 138)

The percentages ‘agree’ and ‘strongly agree’ are grouped together in the total percentage

Older partners versus younger ones reported more health problems with regard to the care for their laryngectomized life companion (r= -.18; p=.04). On the other hand, older partners show more appreciation of their life than younger partners (r=-.25; p=.01).

Higher educated partners experience less feelings of hopelessness/ helplessness (r= -.18; p=.04) than partners with a lower educational background.

Table 4. Correlations

		1.	2.	3.	4.	5.	6.	7.	8.	9.
1.	Gender	-								
2.	Age	-.11	-							
3.	Education	-.26**	.22*	-						
4.	Anxiety	-.14	-.10	-.05	-					
5.	Depression	-.20*	-.10	-.05	.94**	-				
6.	Fear new treatment	-.18*	-.04	-.12	.15	.05	-			
7.	Posttraumatic growth	-.02	.25**	.09	-.01	-.05	-.00	-		
8.	CRA health problems	.05	-.18*	-.07	.18*	.14	-.02	-.05	-	
9.	Hopelessness	-.04	-.02	-.18*	.28**	.29**	.18	-.03	.40**	-

DISCUSSION

Despite the importance of the role of the partner as key supporter for cancer patients in general and the fact that oral cancer can be understood as an interpersonal experience between patients and partners,[32] only very few studies have addressed the impact of a total laryngectomy (TL) on spouses. The aim of the current study is to explore the main psychosocial consequences after a TL for a large group of partners of laryngectomees. Generally speaking, the partners in the current study experience a good global health related quality of life (QoL). The majority of the partners (85%) also enjoy caring for their partner. Furthermore, partners in the current study experience post-traumatic growth after the experience of the TL. More specifically, nearly half of the partners report more appreciation of their life in general and they experience a sense of personal inner strength after the laryngectomy of their life companion.

Just as we know from earlier research in oral cancer patients; when doing QoL research it is important to look at specific affected domains in the life of the partners of laryngectomees. The consequences are mainly present in the social life of partners and during communication with the life companion and other people. More than half (56%) of the partners have problems with the fact that other people do not see their life companion as a full speaks partner anymore, neglecting the laryngectomee in social settings. Partners feel irritated that people communicated over the head of the laryngectomee directly to them. This feeling is much stronger amongst partners than for the laryngectomees themselves (37%)[i]. Also more

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[i] This study focusing on the partner, however, we also explored the psychosocial impact of the laryngectomees themselves. Whenever there are striking differences between patients and partners, these will be shortly mentioned in the discussion of this study.

than one third of the partners go less frequently to social occasions and cannot have the same leisure as before, which is in line with experiences of laryngectomees. Furthermore, partners report consequences of a TL within the spousal relationship. More specifically they experience less sexual contact and intimacy after a TL. This is in line with the very scarce research existing on sexuality and a TL.[33-35] Future research is needed to give more insight in the underlying causes of sexual (dis)functioning of laryngectomees and their partners.

The consequences of the TL are also evident in individual anxiety levels. Clinical levels of anxiety were found in a total of 29% of the partners versus 21% of the laryngectomees. These results confirm earlier research among head and neck cancer patients and their partners, in which the partner also demonstrated higher levels of anxiety compared with patients.[7-9] Within current research, the greatest fear for partners is the death of their laryngectomized life companion. For the laryngectomees themselves this fear of death was surprisingly not even in their top 10 of fears. An explanation could be that laryngectomees are much more focused on getting on with their life as they were used to live it. Their fears are more related to deterioration of their personal situation and in parallel they fear to become (more) dependent on others. Partners on the other hand were faced with the prospect of losing their life companion. Also, partners are unable to take a direct role in fighting the cancer, which can result in more feelings of anxiety and helplessness.[7] Partners also fear other things connected to the laryngectomy of their life companion. One out of four partners fears for example that their laryngectomized life companion is not able to save himself in emergencies that he[j] is not able to communicate in a large group, or that he will experience serious respiration problems.

During the years, we have enlarged our knowledge of the psychosocial consequences for patients after a TL. As a next step, it seems rather logic to know more about the psychosocial consequences of a TL for their partners as well. That is, if one assumes that the spouse is an integral part of the rehabilitation process. It is suggested that the impact of a TL on spouses is an important component in the course of the treatment and living life after that.[36] Not only the patient, but also the partner has to be prepared for an adapted life after a TL. Healthcare professionals should begin with including the partner in the basic support they offer to patients in the (pre- and post-) treatment phase. This is especially important because we know that the distress in spouses can be higher than in patients, and because only a fraction of these partners seem to seek professional help.[13] The risk could be that partners of laryngectomees neglect their own psychosocial problems. This has consequences; on the one hand they then cannot be the best source of support for the patient in the long term and, on the other hand, they will run the risk of developing medical or psychosocial issues

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[j] In this paper the person who has undergone a laryngectomy is referred to as 'him' of 'he'. However this can be both male and female.

themselves. Healthcare professionals should not only implement structural screening for patients but for their partners as well. Distinct measurements have to be developed for the partners. Psychosocial well-being and relational functioning needs to be part of structural partner screening. Also sexuality and intimacy should be included, because we know from the research that exist on this subject, that H&N cancer negatively influences sexual life.[33, 37, 38] This study gives insight into the psychosocial impact of a TL for partners. For a broader perspective, we also gave laryngectomees the same questionnaire and differences between the two groups were reported in experienced psychosocial problems, like:

- The partners reported a higher mean score on the anxiety scale of the HADS (mean 5,6) than the laryngectomees (mean score 4,7);
- For the partners the highest score on fear is fear for the death of their laryngectomized life companion. 31% of the partners experience this fear versus 17% of the laryngectomees themselves;
- For the partners the highest score on loss of control has to do with the fact that other persons do not treat the laryngectomee as a full person to communicate with (56% of all partners versus 37% of all laryngectomees). These partners feel (more than laryngecomtees) irritated that people communicated over the head of the laryngectomee directly to the partner;
- For certain aspects the laryngectomees showed a more active way of coping with the consequences of the TL: they try to see their situation in a positive light, they actively try to improve their situation and they receive more comfort and support from someone. They also use more humor as a coping strategy.

Health care professionals should be more alert about these differences between patients and partners. They can use the differences to address various issues, so that they can best prepare both the patient and the partner for their functioning in their daily life after a TL. In the context of this study, it is of key importance for doctors to keep a good balance in the attention for both patients and their partners, with their own specific problems. From our clinical experience with this patient group and their known speech problems, the doctor must be watchful when partners lead the conversation for the patient. Partners can sometimes be overprotective,[39] which the patients in general experience as negative for the relationship. On the other hand it is important for health care professionals to keep a sharp look-out on the problems that partners encounter after a TL. More research is needed to better understand how professionals can best empower laryngectomees and their spouses in their partner relation and broader social life. Health care professionals should also pay specific attention to vulnerable partners, which are female, the ones with a lower educational background and older partners.

These people are more at risk for a negative impact of the TL on their individual psychosocial well-being.

Before concluding, several limitations of the current study should be considered. As this study is cross-sectional, no conclusions can be drawn about causality. The fact that our study included only members of the Dutch Patients' Association for Laryngectomees may limit the generalizability of the findings as these participated couples might not be representative for the entire population of laryngectomees and their partners. The major strength of this study is the sample of N=144 partners and N=151 laryngectomees and the fact that our results add to an underexposed subject of the impact of a laryngectomy on the partner.

Future research is needed on the impact of a TL on the spousal relationship. The research should include a better understanding of sexual (dys) functioning. It should also include a better understanding of the effects of psychosocial interventions aiming at improvement of the quality of life for laryngectomees and their partners.

CONCLUSION

Using the general Quality of Life-scale partners of laryngectomees reported a good overall QoL. At first sight there are no differences with normal healthy people. However, when looking closer, partners of laryngectomees do experience a variety of psychosocial problems. Around one out of seven partners experiences a possible mood disorder, feelings of hopelessness, disturbed goals in life and negative experiences with respect to the role of caregiver they fulfill for their life companion. Even a more substantial part, namely between one quarter to one third, experience loss of control with respect to several aspects of life and they are afraid of losing their life companion. These data justify screening partners of laryngectomees for psychosocial problems and helping those who are in need of additional support. The results of this study give insights into the underexposed subject of impact of a TL on the partner of the patient. These results and the ones of future studies can be used to develop a structural screening program. Such a screening program would enable health care professionals to better help more partners in dealing with the consequences of the laryngectomy of their life companion.

Conflict of interest statement

None declared

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CHAPTER 8

IMPACT OF A TOTAL LARYNGECTOMY ON THE SPOUSAL RELATIONSHIP

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Submitted for publication

ABSTRACT

Background

The current study is the first that deals with a broad exploration of the long term impact of a Total Laryngectomy (TL) on the (intimate) relationship within a large group of laryngectomees and their partners.

Methods

151 laryngectomees and 144 partners completed questionnaires assessing the impact of a TL on their relationship.

Results

The TL has a profound impact on certain aspects of the relationship. Negative change is found on sexual functioning, communication and feelings of laryngectomees of being depend. Laryngectomees often received the needed support of their partner, however, the partners themselves do not always receive the support they find important.

Conclusion

A TL has a considerable impact on the spousal relationship. The findings of his explorative study sets the stage for structural screening on the need for support for both patients and their partners. Sexuality and intimacy should be part of this screening.

INTRODUCTION

How patients cope with the consequences of cancer depends among others on the interpersonal context of the patient and in particular with the one of the partner. The partner can play an active role in the treatment decisions and is seen as the most important source of support for cancer patients. [1-3] It is also the person closest to the patient that can give family support on a daily basis. Earlier research among laryngeal cancer patients concluded that social and family support is an important factor in improving patients' self-confidence and satisfaction, playing an important role in recovering useful phonation, psychological adjustment, and global quality of life.[4] The consequences of treatment of the larynx and specifically a Total Laryngectomy (TL) with the permanent loss of the natural voice, can greatly disrupt social and family living.

On the other hand, the cancer experience can also be of influence on the well-being of partners.[5] Caregivers of cancer patients, who are most often the partners, experience a range of problems like social, emotional, communication and health-related problems—as well as significant burden related to caregiving and a reduced well-being.[6] Moreover, partners of cancer patients are confronted with the potential loss of their partner, but at the same time they provide the patient with instrumental and emotional support.[7] Roles and responsibilities of patients and partners can therefore change. Research on cancer family caregiving is evolving towards an emphasis on the caregiver-patient dyad. Patients cannot be conceptualized simply as a source of stress for their caregivers, they also provide utility. Neither can caregivers be conceptualized simply as a source of help for patients.[8] Considering the life changes required by a laryngectomy, the role of the caregiver should be seen broader, for instance in the adaptation process of the patient and family.[9] In an earlier review, the importance of understanding cancer from a relationship perspective has been stressed. The closeness of the relationship is seen as an important determinant of patient and partner psychological adaptation to cancer.[10] Patients in stronger dyadic relationships reported less distress than those in more dysfunctional relationships.[11] Persons with low marital quality reported clinically elevated levels of symptomatology compared to those with high marital quality.[12] Relationships characterized by protective buffering and overprotection on the other hand were negatively correlated with marital satisfaction.[13]

Little is known about the impact of head and neck (H&N) cancer on the spousal relationship. In one of the scarce papers dedicated to dyadic adjustment in oral cancer patients and their partners, it is suggested that overall quality of life is high in oral cancer patients and their partners for those living in stable relationships.[14] There is no literature available that describes the relationships between certain socio demographic factors, such as gender and age, of laryngectomees and their partners that can be of influence on the spousal relationship. This would be helpful in predicting persons 'at risk' and will enable a quick identification of vulnerable persons. In a recent article about research among couples dealing with lung cancer and H&N cancer it is discussed that patients and partners who engaged in positive spousal communication experienced less distress.[15] These researchers suggested that H&N cancer may pose unique barriers to open spousal communication because of self-blame and shame for causing the cancer. Such open discussion of the illness in the family has been studied by our group in the 90's. An open discussion about the illness in the family can be seen as an indication of support within the family. Support within the family is a predictor of positive rehabilitation outcome in H&N cancer patients. The more openness in the discussion about the experience of the patient, the fewer negative feelings as depression, loneliness and anxiety and less loss of control patients report.[16] In a review of Fletcher BS et al.[8] it is concluded that a lack of communication can increase psychological burden and distress not only in patients but also in caregivers. Furthermore there is limited research about the intimate aspect of the spousal relationship following head and neck cancer.[17] Given the anatomical site and the degree of disfigurement of H&N cancer this is remarkable.[18] Recent research has been done among 42 head and neck cancer patients, of which 11 were larynx/hypopharynx patients.[19] All 42 patients reported that the disease negatively impacted their sexual relationships, including half of them rating the effects as extremely negative. Naturally, when we try to look at specific subgroups of patients, the literature about the impact of a TL on the spousal relationship becomes more scarce. Although it is said that coming to terms with a laryngectomy is largely a social phenomenon[20], there is just a handful of papers dealing with the impact of a TL on the spousal relationship including intimacy and sexuality. No study to date investigates the long term impact of a TL on the spousal relationship. In earlier days, our team has published an article on the rehabilitation outcomes of long-term survivors treated for head and neck cancer in general. We found that laryngectomees reported more sexual problems (44%) than T1 larynx patients (23%) who only received radiotherapy and also more sexual problems than H&N cancer patients who received radical surgery called a 'commando procedure' (10%).[16] In 2008 Singer and colleagues concluded otherwise.[21] They reported that sexual difficulties, which are common after laryngeal cancer surgery, are not caused by the type of oncological treatment but rather by the cancer itself. Knafo et al.[22] wrote in reference to the paper of Singer et al.[21] that such a conclusion requires other study methods.

The purpose of the study is to explore long term follow up consequences of a TL on the spousal relationship in a large group of laryngectomees and their partners. Furthermore we have explored which partner support patients and partners find important to give and actually receive. We also describe in current research significant relationships between socio demographic data and the experienced change in the quality of the spousal relationship.

PATIENTS AND METHODS

Procedures and participants

This study was part of a larger project funded by the Michel Keijzer Fund of the Dutch Patients' Association for Laryngectomees, the NSvG. This study investigated the psychosocial consequences in patients who have undergone a TL, their partners and the impact on their relationship. All respondents were members of this association. As the NSvG could not discriminate members not having a partner, all members received an introduction letter explaining the background and goal of this study, including an apology in case person did not have a partner. The letter included a reply card for obtaining informed consent. Reply cards were sent free of charge to the NSvG. Participants then received a written questionnaire separate for laryngectomees and partners and a free of charge reply envelope. Follow-up telephone contacts were done in case the research team did not receive the questionnaires of participated couples. In figure 1 an overview is presented of the number of people approached and reasons for exclusion.

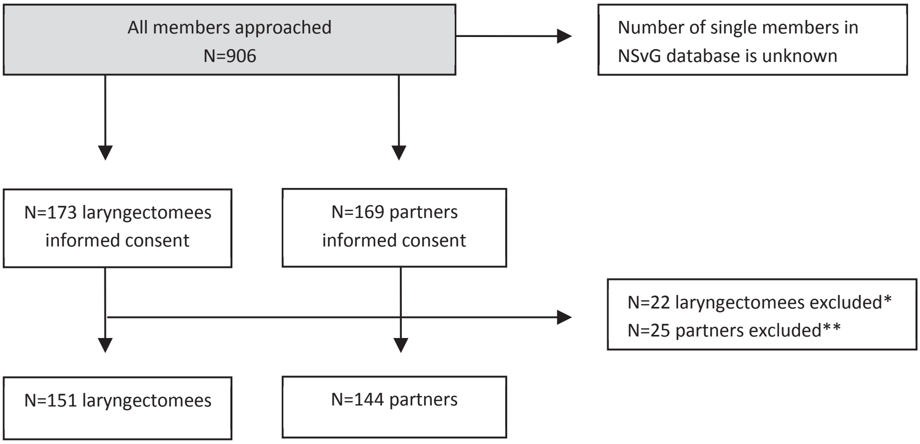

Figure 1. Particiapants.

* N=22 laryngectomees were excluded: 14x did not send questionnaire after telephone contact, 8x decided not to participate with reasons: 4 serious ill, 1 died, 2 questions not relevant and 1 question too intimate.

** N=25 partners were excluded: 14x did not send questionnaire after telephone contact, 11x decided not to participate with the following reasons: 4 husband ill, 1 husband died, 3 filled in less than half of the questionnaire, 1 too much time, 1 could not answer the questions, 1 does not feel being a partner of a patient.

Measurements

Change in quality of spousal relationship. To measure possible changes since the laryngectomy in the quality of the relationship with the partner, we developed a questionnaire with 16 items. The aspects representing the quality of spousal relationship were framed in the question: "Since the laryngectomy – the aspects of the relation - with my partner have been changed". The patient and partner could respond: a) did not change b) have been improved c) have been deteriorated. Factor analysis for both laryngectomees and partners revealed two factors of change in the relationship with the partner: 1) change in the quality of the relationship in general and 2) change in the quality of the sexual relationship. Higher scores mean an improvement of the relationship. Cronbach alpha for laryngectomees for the general relationship was .93 and for the sexual relationship .83. For partners this was .91 and .94 respectively.

Furthermore we have added 5 single items measuring the influence of the consequences of a TL on the spousal relationship. Every single item begins with: "Since the laryngectomy I experience:" Example item:: "That I became more dependent of my partner". These single items were measured on a four-point scale, ranging from 1= 'do not agree at all' to 4= 'totally agree'.

Additional questions on sexuality and intimacy were posed with the following items from three different scales.

1) EORTC H&N35 sexuality scale. The EORTC QLQ-H&N35 [23] measures health related QoL for H&N cancer patients. The module incorporates seven multi-item scales that assess pain, swallowing, senses (taste and smell), speech, social eating, social contact and sexuality. For this research only the sexuality scale was used. The two questions of the sexuality scale are "Have you felt less interest in sex?" and "Have you felt less sexual enjoyment?" These were both measured on a four-point Likert scale range from 1= not at all to 4= very much. The Cronbach alpha for this scale for laryngectomees was .91.

2) FEAR scale sexuality. The question: "Do you have fear for deterioration or decrease in sexual contact with your partner?" is part of the Fear scale consisting in total of 32 items. The original scale consists of 11 items on a 4-point scale ranging from 1= no fear at all to 4= very much fear.[24] For current research 21 specific items for laryngectomees only related to TLE were added for this population.

3) LOSS OF CONTROL sexuality. Following the loss of control[k] scale [24] that has been earlier used in H&N cancer patients [25] we only used the questions concerning the spousal relationship related to the life since the treatment, i.e. the TL. These are three statements concerning sexuality and intimacy. The statements with answer categories no/yes are: a) "Since the laryngectomy, I have less sexual contact with my partner", b) "Since the laryngectomy, I became physically less attractive" and c) "Since the laryngectomy, I find it difficult that I am mutilated".

Important manners of spousal support was measured using an own developed list consisting of ten statements, introduced with the question: "How important do you find receiving the below mentioned manners of spousal support". An example of a statement about spousal support is: "I find it important that my partner listens to me". Statements were answered on a four-point scale ranging from 1= not at all important to 4= very important. With the exact same statements, the question was asked: "Do you receive this manner of spousal support?" with three answer categories: 'No', 'Yes, sometimes' and 'Yes, (almost) always'. Cronbach alpha in current study for laryngectomees was .86 and for partners .85.

Openness to discussion of the illness in the family. Openness to discuss the illness in the family was assessed by a scale of Van den Borne & Pruyn[24] validated by Mesters et al.[26] and used in H&N cancer patients.[25] These items were measure on a four-point scale, ranging from 1= agree very much to 4= not agree at all. For the purpose of this research, we have added five items for the partner only, representing their perspective. Higher scores reflect more openness to discuss the illness in the family. Cronbach alpha in current study for laryngectomees was .86 and for partners .89.

Co morbidity was defined as the existence of one or more diseases in addition to the total laryngectomy. For example heart disease, diabetes or rheumatoid arthritis. We asked the question: "Do you have another physical disease at the moment". Based on the answers we categorized these as: 0= no, 1= yes, 1 co morbidity, 2= yes, 2 co morbidities and 3= yes, 3 co morbidities.

Statistical methods

In this study we have worked with validated scales of which some were used in total and for others we have added additional items that measure specific aspects of the TL. In the last case, factor analysis was performed to construct scales, using SPSS 15.0. This

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[k] Loss of Control is defined as the inability to act on events, to deal with events, and to cope with events because of one's illness (Van den Borne & Pruyn, 1985) because of one's illness.

analysis was also done for our own developed scales. These scales have the advantage to be tailored to the specific disease, i.e. the TL, but they also come with the disadvantage of a lack of norm scores. When items could not be converted into scales, we used the individual items of the questionnaires. Using individual items increases the number of outcomes and therefore the changes on false positives. In order to reduce the changes on false positives, we used a conservative approach and presented only the most prominent results. We started the analysis of the individual items by ranking the items that represent the most positive change for the patients and their partners, and followed with the items that represent the most negative changes. In this explorative analysis, difference between patients and partners are only described in case of substantial discrepancies. In order to explore whether there are clinical relevant subgroups, we looked if the factor found in the factor analysis correlated with gender, age, education and co morbidity using Pearson correlations.

RESULTS

Sample characteristics

The demographic characteristics of laryngectomees and their partners are presented in table 1.

The influence of the total laryngectomy on the relationship

The influence of the laryngectomy on the spousal relationship reveals both negative and positive consequences. An example of a positive consequence can be seen in figure 2 that shows that 1 out of 5 laryngectomees and partners reported that their spousal relationship has been improved since the laryngectomy. This positive finding must be weighed against the observation that the majority of the respondents reported no improvement or deterioration in the relationship. Furthermore, a part of both laryngectomees and partners became closer in their relationship instead of growing apart. More specifically since the laryngectomy: one third of the laryngectomees and partners 'stand together', laryngectomees (29%) and partners (28%) 'show understanding for each other' and they adapt to each other (30% laryngectomees and 26% partners). Unfortunately, such positive changes were less common than negative changes. The most negative change in quality of spousal relationship was on sexual aspects of the relationship, dependency of the partner and communication between laryngectomees and partners (figure 3). One out of three laryngectomees and partners reported a decline in the sexual relationship and diminished sexual mood since the laryngectomy. In relation to this also roughly one out of five of both groups reported since the laryngectomy deterioration in the intimacy

Table 1. Sample characteristics laryngectomees and partners

	Laryngectomees		Partners	
	N	%	N	%
Gender				
Male	129	85	23	16
Female	22	15	121	84
Total N	151	100	144	100
Current age (mean, SD)	68 (9,7)		66 (9,1)	
Level of education				
Primary	29	19	20	14
Lower secondary	28	19	38	27
Middle secondary	52	34	60	42
Higher secondary/ university	42	28	25	17
Children				
Yes	137	91	128	90
No	14	9	15	10
Living situation				
With partner	134	89	130	91
With partner and child(ren)	12	8	11	8
Different (LAT)	4	3	2	1`
Treatment			-	-
Surgery + radiotherapy	126	83	-	-
Surgery only	13	9	-	-
Surgery + radiotherapy + chemotherapy	12	8	-	-
Treatment history				
Less than 1 year	15	10	-	-
1-3 years ago	29	19	-	-
4-6 years ago	28	19	-	-
7-10 years ago	21	14	-	-
More than 10 years ago	57	38	-	-

in their relationship in general. For one out of five laryngectomees and partners, sex with the partner is hampered by fear for respiration problems.

Furthermore one out of five laryngectomees and partners reported deterioration in the communication with each other. Also the expression of emotions has been worsened since the laryngectomy and understanding each other within the relationship. The accordance between patients and partners is in the ranking of the negative items still prominent, but less than with the positive items. The most prominent example of discordance is that one third of the patients find themselves more dependent of their partner while partners do

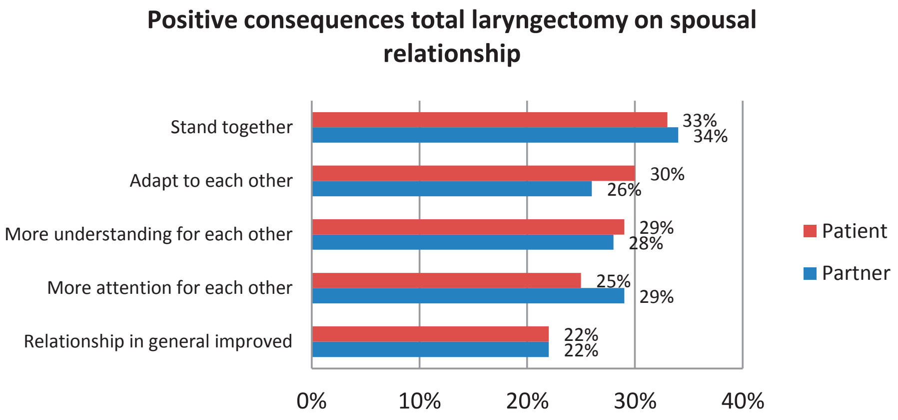

Figure 2. Positive consequences of a TL on the relationship between laryngectomees and partners

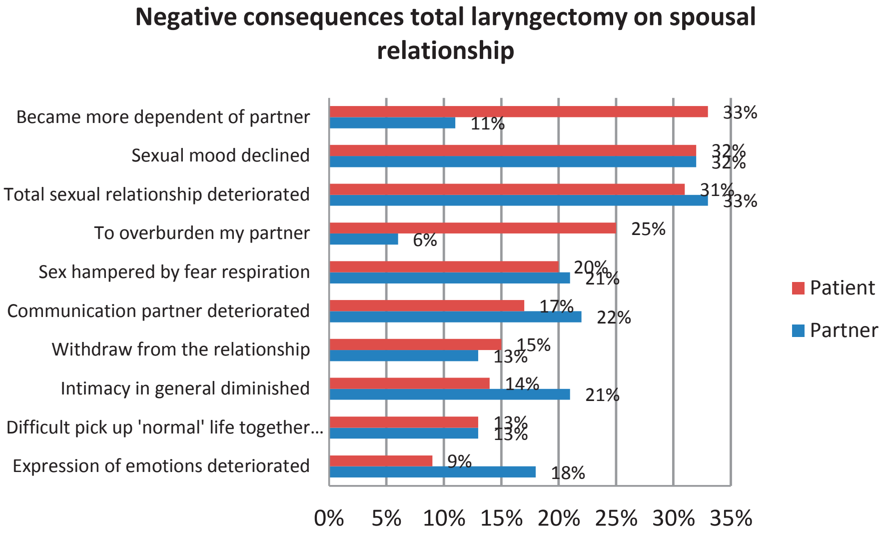

Figure 3. Negative consequences of a TL on the relationship between laryngectomees and partners

not. This is understandable, as the patients have a deteriorated health while the partners have remain in their normal health. The same applies for being a burden to the other. A remarkable difference is that partners report that the expression of emotions in the spousal relationship has been deteriorated more than the patients do, as well as with intimacy. Despite all these negative changes, only a few of the laryngectomees and partners have problems to get on with their (normal) lives together with the partner.

Additional questions on the subjects intimacy & sexuality

In line with the findings above, one third of the people who have undergone a TL reported that they have less sexual interest and almost 40% said that they have less sexual enjoyment since the laryngectomy (table 4). Nearly one quarter of the laryngectomees (24%) felt that they became physically less attractive since the laryngectomy and find it difficult to be mutilated (22%). Looking to both laryngectomees and partners, 44% of the laryngectomees and 31% of the partners said that they have less sexual contact with the partner since the laryngectomy. Furthermore, one quarter of the laryngectomees

Table 2. Questions about sexuality EORTC H&N35, FEAR scale and LOSS OF CONTROL-scale

EORTC H&N35 SEXUALITY SCALE (items for laryngectomees only)		Laryngectomees		Partners	
		N	%	N	%
Have you felt less interest in sex?	Not at all	57	39%	-	-
	A little	39	26%	-	-
	Quite a bit	31	21%	-	-
	Very much	21	14%	-	-
EORTC H&N35 SEXUALITY SCALE (items for laryngectomees only)		Laryngectomees		Partners	
		N	%	N	%
Have you felt less sexual enjoyment?	Not at all	55	37%	-	-
	A little	35	24%	-	-
	Quite a bit	28	19%	-	-
	Very much	29	20%	-	-
FEAR scale		Laryngectomees		Partners	
		N	%	N	%
Do you have fear for deterioration or decrease in sexual contact	Not at all	79	55%	90	64%
with your partner?	A little	30	21%	32	23%
	Quite a bit	15	11%	9	6%
	Very much	19	13%	9	6%
LOSS OF CONTROL scale		Laryngectomees		Partners	
		N	%	N	%
Since the laryngectomy, I have less sexual contact with my partner:	No	83	56%	98	69%
	Yes	65	44%	44	31%
Since the laryngectomy, I became physically less attractive:	No	113	76%	-	-
	Yes	35	24%	-	-
Since the laryngectomy, I find it difficult that I am mutilated:	No	116	78%	-	-
	Yes	32	22%	-	-

(24%) and one out of eight partners (12%) reported to have fear for deterioration or decrease in sexual contact with the partner. See table 2.

Partner support

Both laryngectomees (95%) and partners (86%) find it (very) important that the partner listens to them. They also both find it important that the partner tries to understand them (90% laryngectomees and 94% partners, see table 3). On top laryngectomees (86%) find it important that the partner gives him elbow-room. Furthermore, partners find it important 'to get an arm around them' (86%). More than 80% laryngectomees receive the manners of support they find important. This is far less in partners (see table 3). This is most clear when we look at the need for partners 'to feel an arm around them'.

Table 3. Important and received manners of spousal support

	Importance partner support (%) *		**Received partner support ** (%)**		**Difference importance vs received**	
How important do you find that…..	**L**	**P**	**L**	**P**	**L**	**P**
Your partner listens to you	95% (N=147)	86% (N=141)	79% (N=146)	59% (N=139)	-16	-27
Your partner tries to understand you	90% (N=146)	94% (N=140)	77% (N=146)	51% (N=140)	-13	-43
Your partner gives you elbow-room	86% (N=146)	84% (N=140)	66% (N=144)	62% (N=138)	-20	-22
Your partner puts an arm around you	77% (N=145)	86% (N=140)	47% (N=138)	36% (N=138)	-30	-50

L= Laryngectomees, P= partner
* The categories "Rather" to "Very" important are grouped together.
** The answer is "Yes, (almost) always does my partner provide this kind of support

Openness to discussion of the illness in the family. There is a clear need to improve the openness to discuss the illness in the family. 43% of the laryngectomees and partners reported that the family always wants to hear from them that they are doing well. Almost one third of the laryngectomees talk as little as possible about (the consequences of) the laryngectomy because they don´t want to upset their family. 40% of the partners reported that their partner and children hardly talk about how the burden of the laryngectomy must be for them (figure 4).

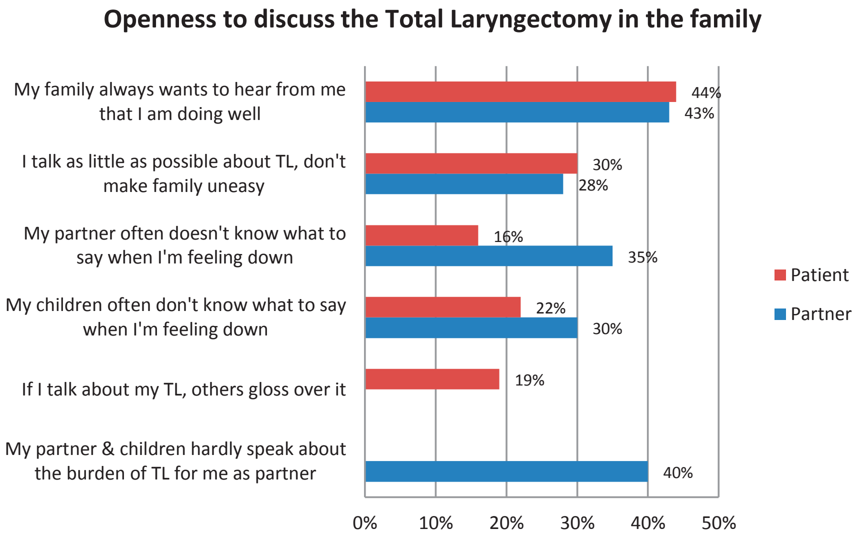

Figure 4. Openness to discuss the Total Laryngectomy in the family

Association between demographic characteristics and research variables

Correlations with gender

With regard to relations with their partner, female laryngectomees experience more a deterioration of their sexual relationship after the TL (r=-.20; p=.01) with more sexual problems (r= .18; p=.05) then men. Furthermore, female laryngectomees find that there is less openness in discussing the laryngectomy in the family (r=-.18; p=.03).

Correlations with age

Older laryngectomees reported less issues with their sexual functioning then younger ones (r=-.30; p=.00).

Correlations with education

Higher educated laryngectomees and higher educated partners both showed a statistically significant better quality of the relationship, although the effect size of education is modest. First, a higher education is positively related to openness of discussing the laryngectomy in the family (r=.19; p=.03). Higher educated laryngectomees also experience less negative influence on their sexual relation (r=.21; p=.02). We also see that higher educated partners experience less negative influence of the laryngectomy on their relationship.

Correlations with co morbidity

Laryngectomees with more co morbidity also experience more problems in sexuality (r=.33; p=.00). Although not significantly related, there is a trend between more co morbidity in laryngectomees and less openness in discussing the laryngectomy in the family. See table 4.

Table 4. Intercorrelations among outcome variables in laryngectomees and their partners

	Variable	1.	2.	3.	4.	5.	6.	7.	8.
1.	Gender	1	-.11	-.26**	-	-.05	.11	-	-.09
2.	Age	.22**	1	.22*	-	.01	-.10	-	.08
3.	Education	-.17*	-.04	1	-	.05	.08	-	.12
4.	Co-morbidity	-.11	-.24**	.02	1	-	-	-	-
5.	Change general relation	.01	-.07	-.00	-.01	1	.29**	-	.03
6.	Change sexual relation	-.20*	-.08	.21*	-.10	.06	1	-	-.01
7.	Less sexuality	.18*	-.30**	-.13	.33**	-.01	-.55**	1	-
8.	Openness to discuss	-.18*	.13	.19*	-.16	.19*	.29**	-.27**	1

** p< .01 and * p<.05

Note: correlations in laryngectomees are below the diagonal and those of their partners are above the diagonal.

DISCUSSION

The aim of the current study was to examine the psychosocial impact of a Total Laryngectomy (TL) on the spousal relationship. Our study is the first to our knowledge that deals with a broad exploration of the impact of a TL on the (intimate) relationship in the long term in a large group of laryngectomees and their partners.

The explorative nature of the present study has its limitations. First of all, it is a cross-sectional study, which doesn't make it possible to make firm statements about causality. Also the fact that our study included only members of the Dutch Patients' Association for Laryngectomees may limit the generalizability of the findings. It might be the case that the participated couples are not fully representative for the entire population of laryngectomees and partners. Furthermore, we have to judge the severity of the problems on the frequencies of the responses. We do not precisely know what the disutility of the frequent reported problems is. The face value, based on the content of the items, suggest nevertheless that the problems are not only frequent, but also serious. Another shortcoming is that through the large number of variables there is a high chance on false positives. Because of the lack of existing questionnaires on the impact of a TL on the spousal relationship, we have used a number of questionnaires which have not yet well developed scales and norm scores. We therefore used a conservative approach by presenting only the most prominent results. The major strength of this study is the sample size of laryngectomees and partners and the fact that our results add to an underexposed subject of the (long term) impact of a laryngectomy on the spousal relationship.

For the majority of the couples, their relationship in general remained the same after the TL. One fifth of them even report a better spousal relationship after the TL than before. This perceived positive relationship change in our patient group is in line with results of earlier studies in different cancer types[27] and in breast cancer patients.[28] In this research, couples reported that the cancer had brought them closer together. Nevertheless, a TL has a great psychosocial impact on people directly involved. The negative change in the spousal relationship is first of all related to feelings of more dependency of the partner. This seems understandable as the impact of the consequences of the disease and its treatment on vital functions as speech and eating, social life and in some cases also on continuation of work with financial consequences.

Another negative consequence of the TL is reflected in the intimate relationship. One out of three laryngectomees and partners reported less sexual contact with their partner than before the disease. This is in line with Singer et al. [21] who described reduced libido and sexual enjoyment as a common problem after laryngeal cancer surgery. It is also in line with earlier research of our own group in which we concluded that from the head and neck cancer patients, the ones who underwent a TL had a substantial lower rate of sexual contacts than patients who underwent radiotherapy alone.[16] Not exclusively for laryngectomees, however, for H&N cancer patients in general also sexuality and intimacy problems were identified in more recent studies.[18,19,29] For current study we would like to present possible reasons for the negative consequence of the sexual relationship after a TL. For part of the laryngectomees and partners, the sex is hampered by fear for respiration problems. Also one out of four laryngectomees find themselves physically less attractive because of the mutilated surgery after laryngeal cancer. Earlier studies also concluded that embarrassment about physical appearance is one of the many difficulties that laryngectomized patients have to deal with. [30-33] Communication with the partner, the openness to discuss the consequences of the illness in the family and the expression of emotions are vulnerable aspects of the spousal relation after the TL. In an old study examining the reactions of wives' to their husband's laryngectomy, part of the wives (44%) also reported decreased spousal communication.[34] More recently Manne et al. [35] concluded that lung cancer and H&N cancer patients engaging in more positive spousal communication experienced less distress.

What does this all mean for the clinical practice?
The loss of sexuality and intimacy can add for cancer patients a profound burden that is often magnified by the lack of discussion about this problem.[36] This and the considerable impact of a TL on certain aspects of the spousal relationship warrant good and structural screening for both patients and their partners. Sexuality and intimacy should be part of this screening. It is important to note that this does not only concerns decreased frequency of sexuality, but also the experience itself, feelings of fear especially for respiration problems, shame related to the stoma and mutilation and the feeling of not being a complete man or woman anymore are important reasons why a sexual relationship can change after a TL. Disfigurement and dysfunction as a result of H&N cancer and its treatment can cause people to feel less attractive.[37] Although it is encouraged in earlier research with laryngectomees[21] to discuss issues about sexuality and intimacy so that patients can disclose their concerns during medical consultations, we acknowledge the difficulty of discussing these subjects by clinicians. Suggested reasons are lack of time and lack of experience and preparation.[38,39] However, patients with all kinds of cancer, not just those with cancers affecting fertility and sexual performance, want open communication about intimacy and sexuality. All patients are entitled to the option of discussing intimacy and sexuality with a member of their treatment team.[40] From the findings of our research, we suggest to pay special attention to younger laryngectomees related to sexual problems. They report more negative impact of the TL on their sexual relationship than older laryngectomees. This is in line with earlier research among a group of general head and neck cancer patients.[18] They also concluded that younger patients experienced relatively more problems with sexual functioning than older patients. One of the possible explanations from these researchers was that younger laryngectomees might have higher expectations of their sexual functioning in general. Our thinking is that the specialist nurse would be an approachable professional for the patient to talk about the intimate issues. These nurses, who in general have more time for the patient than the surgeon has during the medical consultation, have the experience to provide emotional support and they are a trustworthy partner for the patient to communicate with. They also stay in direct contact with both the surgeon and other specialists in case the patient needs to be referred to another specialist such as a social worker or a psychologist. In order to deliver care to the 'whole person behind the patient' it is of key importance to first simply acknowledge this aspect of life along with other key areas of function, no different than pain and fatigue.[41]

Apart from younger laryngectomees, specific attention during screening should be paid to other vulnerable persons, which are female laryngectomees, and the ones with a lower educational background and laryngectomees with co-morbidity. These people are more at risk for a negative impact of the TL on their spousal relationship. Another important subject for discussion and screening is openness to discuss the consequences of the TL with the partner and the family. A considerable part of laryngectomees and partners talk as little as possible about the TL because they do not want to upset others. In those cases when they do talk about it with their family, nearly on fifth of them report that the family quickly change the subject or the family wants to hear from them that they are doing well. To actually discuss illness related matters openly in the family is found to be an important predictor of positive rehabilitation outcomes in head and neck cancer patients.[25] The more openness to discussion patient's experience, the fewer negative feelings such as depression and anxiety, and less loss of control they report. Another recommendation is that there should also be paid additional attention to the lack of spousal support by the patients towards the partners. Especially partners show the highest discrepancy between the received spousal support of the laryngectomized partner versus the manners of spousal support they find important. Finally, professional care givers should remember that there is a substantial group of laryngectomees reporting feelings of dependency of the partner and the feeling to overburden the partners after a TL. Both patients and partners should be prepared, as a team, by professionals on the possible changes in their life after a TL. Open discussion on the daily consequences and share experiences with fellow H&N cancer patients and members of the patient organisation can be of help.

CONCLUSION

The aim of the current study was to examine the psychosocial impact of a Total Laryngectomy (TL) on the spousal relationship. Recent research indicated that more information is required on the H&N cancer patient-partner relationship and how best to support it.[42] Our results shed light on an underexposed subject of the psychosocial impact of a TL on the spousal relationship.

The majority of the couples in current study experienced that their relationship remained the same. However, we cannot simply conclude that patients and partners both are doing well after the surgery. A closer look reveals that a TL has a profound impact on certain aspects of the spousal relationship. Negative change is mainly on sexual functioning, communication and the expression of emotions and feelings of laryngectomees of more dependence of their partner.

Laryngectomees often received the needed support of the partner, however, partners themselves do not always receive the support they find important. A considerable part of laryngectomees and partners do not often discuss the consequences of the TL within their family because they do not want to upset others. In those cases when they do talk about it, nearly one fifth of them report that others quickly change the subject. As the consequences of a TL reach further than the individual impact on the patient, it is of importance to involve the partner as early as possible in the treatment and after care process. Professionals should prepare patients and partners on possible changes in the social and relational context. During hospital visits specialized nurses can be of help in stimulating open communication about psychosocial consequences. They can ask questions to patients and partners on how they discuss the consequence of the TL on their relationship and they can facilitate open communication about the impact of the TL on possible changes in roles and dependency of the partner and on the intimate relationship. Structural screening for both patients and partners can be of help in signalling psychosocial issues so that patients and partners can be referred to specialized help.

Conflict of interest statement

None declared

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CHAPTER 9

GENERAL DISCUSSION

GENERAL DISCUSSION WITH FOCUS ON RECOMMENDATIONS

This thesis aims to contribute to a better care for Head and Neck cancer (HNC) patients and their partners. In doing so, a broad understanding of the psychosocial consequences of HNC is essential. The objective of this thesis is to explore psychosocial aspects in the literature for which there is hardly any, or limited insight. In other words, we focus on what is unknown or not fully clear in literature for this patient group, the so called 'knowledge gaps'. Knowledge gaps are present in all phases of the disease and treatment process. This is the first thesis that encompasses psychosocial issues of HNC patients simultaneously during all phases of the disease, with inclusion of the partner and the interaction within the spousal relationship with the patient.

After a brief discussion of the concept of Good Psychosocial Care, in which the results of the studies in this thesis are embedded, we continue this chapter with recommendations for the clinical practice as well as suggestions for future research.

Good Psychosocial Care

We describe Good psychosocial Care against the background of the theoretical model of coping with cancer developed by van den Borne and Pruyn.[1] This model gives a classification of issues to which all sorts of psychosocial problems experienced by cancer patients in general, can be assigned:

1. Uncertainty
2. Loss of control
3. Negative feelings such as anxiety and depression
4. Threatened self-esteem

Good Care for HNC patients and their partners should help reduce these psychological problems. Good Care could consist of three basic aspects in the work of professionals in oncological care which can be embedded in the model of coping with cancer in the following way, see figure 1. These basic aspects of Good Care should be integrated during all contacts between patients and healthcare professionals.

An important condition for Good Care is 'integral care' as defined by Pruyn et al.[2] Integral care is first of all based on the idea that the patient is the central person in the whole process of disease and treatment. Integral care is also based on the fact that the medical treatment (cure) and supportive care are geared to one another. In this way the patient experiences the whole period from the diagnosis until possible palliative treatment and end-of-life care as one streamlined process. Based on this vision of Good Care, we devel-

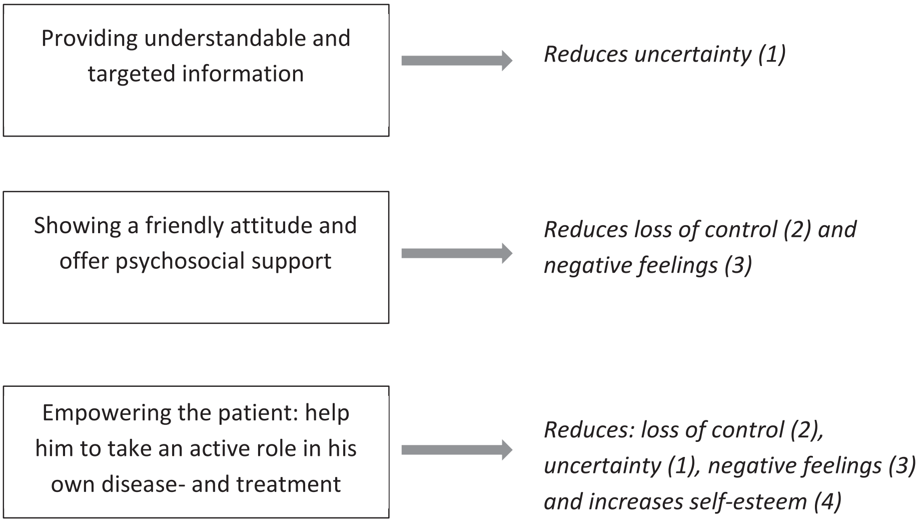

Figure 1. Basic aspects in Good Care for HNC patients and their partners

oped a brochure entitled: 'Good care for people with head and neck cancer: a patient's perspective of the quality criteria

(*Goede zorg voor mensen met kanker in het hoofd-halsgebied: kwaliteitscriteria gezien vanuit de patiënt*).[3] This brochure is a mix of propositions of Good Care: 1) as wished by the patient and 2) based on current national guidelines and protocols, supported by the Dutch Association of laryngectomees NSvG and Stichting Klankbord and authorized by the NWHHT (the Dutch Society for Head and Neck Oncology).

With the above mentioned concept of Good Care in mind and the new findings from our studies, general recommendations for clinical practice are given in this chapter as well as suggestions for specific interventions.

Recommendations for the clinical practice

General recommendations

Screening for psychosocial problems

Based on the results of several of our studies in this thesis (**chapters 2, 3, 6, 7 and 8**), it is recommended that HNC patients should be structurally screened on different aspects of psychosocial well-being and on relational functioning. The objective of this screening is to detect vulnerable people who will need (extra) treatment and support. Care for HNC patients in the early palliative phase should include targeted screening (**chapter 4**) focusing on frequently occurring symptoms such as fatigue and psychosocial symptoms which, as they are less immediately apparent, may be given less attention.

Specific attention for the partner

Healthcare professionals should include the partner in the basic support they offer to patients. This is especially important because we know that the distress in spouses can be higher than in patients. In those circumstances, partners cannot be the best source of support for the patient and they also run the risk of developing medical of psychosocial issues themselves. From our study presented in **chapter 7** we know that a Total Laryngectomy (TL) has a considerable impact on the psychosocial life of partners of laryngectomees. We recommend that:

- Health care professionals should not only implement structural screening for patients but for their partners as well. This means that:
    - Distinct screening instruments have to be developed and systematically used for the partners. Screening for psychosocial problems is necessary at moments when the patient is vulnerable and might be in need for help. In general this is during radical changes in a person's life, like right before treatment of the patient, when a recurrence is detected and after a palliative diagnosis.
    - Professionals should be aware of differences in the individual psychosocial problems experienced by patients and partners, including attention to caregiver burden on the one hand and overprotection of partners on the other hand.
- If a partner is in need for help, this should be offered directly or the partner should be referred to a specialist.
- The partner should be actively involved during consults between patient and professional. Also written information is (partly) directed to the partner.

Specific attention for the impact of a TL on the spousal relationship

Little is known about the impact of HNC on the spousal relationship. From research in general cancer care, it is suggested that the closeness of the relationship is seen as an important determinant of patients' and partners' psychological adaptation to cancer.[4] From the results of our study presented in **chapter 8**, we learned that a Total Laryngectomy has a profound impact on certain aspects of the relationship. Negative change is found on sexual functioning, communication and feelings of laryngectomees of being dependent on others.

It is recommend that:

- The treatment team of the patient, specifically the specialized nurse, should pay attention to the impact of the treatment on the spousal relationship. Open communication should be stimulated about possible consequences for intimacy and sexuality.
- Good and structural screening should be performed for both patients and their partners, including sexuality and intimacy problems that might be experienced after treatment for HNC.

Evaluation of Good Care

To guarantee the high standard of Good Care, it is recommended that care is systematically evaluated. Specifically communication aspects need regular evaluation, as complaints of patients towards healthcare professionals working in hospitals are mainly dealing with communication issues. Verbal communication between health care professionals and patients should be regularly evaluated with specific attention for bringing bad news, communication in case of HNC recurrence and communication in the palliative phase.

Stimulating dialogue concerning the pitfall of overtreatment in the palliative phase

The findings of our studies dealing with palliative care presented in **chapters 5 and 6,** reveals that it is difficult to change the mindset of surgeons. Surgeons are generally focused on (curative) treatment. Given our findings, it is recommended to stimulate a dialogue between different healthcare professionals (cure AND care based), as head and neck surgeons and nurses about the pitfall of over-diagnosis and overtreatment during the palliative phase. During this dialogue, it should be stressed that the patient is and will be *the* central person and that he should be involved as such during the whole palliative phase. Healthcare professionals should be encouraged and trained to talk to their terminally ill patients about the status and incurability of the disease as early as possible.[5] Treatment options should be well explained to both patients and relatives.

Patients should be offered opportunities to share their boundaries and preferences as to how and where to be treated and to spend their last period of life.

Targeted patient information available

Based on our concept of Good Care it is recommended that apart from the standard information such as brochures, patients should also receive relevant information from their patient dossier including the proposal for treatment. In this way the patient is best empowered and can share the information with the family. For patients in the palliative phase, we recommend a similar type of 'care guide' to the one used for curative HNC patients in the preoperative phase should be developed.

Special attention for patients with recurrent H&N cancer

The findings of our study on HNC recurrence, presented in **chapter 3**, show that patients who experience HNC recurrence can be broadly divided in two types. One group of patients manage and cope with the consequences of the disease quite well, while another, more vulnerable, group of patients will need more attention as they experienced a bigger shock on receiving the news of the cancer recurrence than on receiving the news of the initial diagnosis. Also, half of the patients found it more difficult to cope with the recurrent cancer than with the initial cancer experience. It is recommended that during the course of the disease, health care professionals should pay specific attention to the way patients experience and cope with the message of recurrent cancer. Additional time with a specialized nurse is recommended when patients experience the recurrence as a bigger shock. Doctors should, wherever they can, help patients in looking for possible explanations for the recurrence of HNC and discuss the limitations of medical imaging research and control visits in relation to the recurrence.

Specific recommendations

Next to these general recommendations, two specific recommendations are discussed, which can be seen as interventions. The first intervention is called: the Expert Center of Palliative Care for HNC and the second intervention is called: Life back on track after a Total Laryngectomy (TL).

Expert Center Palliative Care for Head and Neck Cancer Patients

With the Expert Center Palliative care, presented in **chapters 5 and 6** we envisioned to offer palliative care organized as closely as possible in the home environment of the patient. We aim with the Expert Center at a better quality of life for patients in the palliative phase and for their family. This is achieved by providing structured attention to patient's physical and psychosocial needs. A joint clinic was set-up with Head and Neck surgeons and specialist palliative care nurses.

Since the set-up of the Expert Center, the psychosocial support received better evaluations from the next of kin of patients **(chapter 6)**. This could be explained by the work of specialized nurses for whom psychosocial support is a key element of their work. During their patient care, these nurses: provide information and psychosocial support to patients and relatives, handle pain management and screen psychosocial needs and other relevant data both for effective allocation of specialized care and for research purposes. It is recommended to work with these specialized nurses who are positioned as the link between the patient and the hospital and the GP. This set-up leads to a more efficient and effective flow of communication between patient, surgeon and other caregivers. Another important task of the Expert Center is the consultation role of the specialized nurses towards professional caregivers, such as General Practitioners (GP). The GP is the important contact person in the home environment for the patient. However, head and neck cancer accounts for nearly 5% of all malignant tumors in the Netherlands.[6] In his daily practice, a GP sees only four head and neck cancer patients in his whole working life. That means that experience of GP's in care for patients in this phase, is limited.

Another main finding of our study, performed after the establishment of the Expert Center **(chapter 6)** was that a higher percentage of relatives reported an improved relationship between patients and HNC surgeons as well as between partners and HNC surgeons. This was explained by the allocation of one fixed surgeon per patient during the palliative phase. Based on the findings of our studies done on the evaluation of palliative care **(chapters 5 and 6)**, it is recommended working with dedicated one on one HNC surgeons aiming at closely monitoring of symptoms. With the objective of careful monitoring home-based palliative care can be arranged. An important consequence of careful monitoring is that we can also better meet one of the main wishes of patients in the palliative phase; namely to be able to die at their preferred place, often their own home or a hospice. When a specialized nurse is involved, we have seen that the number of hospital admissions per patient decreased.[7] Also the emergency admissions dropped dramatically. As it is a common fact that the majority of patients want to spend the palliative phase at home, we may see this as a positive contribution to improve the quality of life of the patient. On the other hand this policy seems to be cost effective for the hospital. Palliative care should be based on the individual needs and strength of the patient and family. With good information, preparation, psychosocial support and close monitoring of symptoms, the patient and family are in control of the disease process and the choices they made.

'Life back on track' after a Total Laryngectomy

The intervention of our Expert Center above mentioned, based on the knowledge gap of palliative care, is already in place. With another intervention, of which the basis further builds on the findings of studies we have done with laryngectomees and their partners **(chapters 7 & 8)**, we are in a pilot phase. The working title of this oncological after care intervention is called 'Life back on track' after a Total Laryngectomy. This intervention is meant as after care for laryngectomees and their partners. Our proposal to the Dutch Patient Organization the NSvG was to set up this initiative together with the Academic Hospitals in the Netherlands. In order to get a clear picture of the content of this intervention and to determine the feasibility of such a project, the NSvG first want to set-up a pilot intervention. The results of this pilot can be leading for a possible national approach.

The basic idea is to let this intervention be a fixed part of the total oncological after care of laryngectomees and their partners. This intervention would be initiated by the Dutch Association of laryngectomees NSvG and organized in close cooperation with the hospital. In our opinion, this (group) intervention can best take place in the hospital so that all laryngectomees, also the ones who do not have a membership of the NSvG, are covered. In terms of timing, this intervention can best be offered after the first control visit in the hospital. Then the total medical treatment is finished. Some patients experience this period as a 'black hole'. Patients are no longer in the 'fighting mode' against the disease and there is more room for emotional coping. Now that the treatment team is no longer structurally visited, the patient may also experience the feeling to be on his own or the feeling to be left alone. Patients, together with their partners, have to pick up their normal life again. With this intervention we want to prepare patients and their partners for this 'new' life after a TL in the best possible way. Such an intervention is in line with the recent directive 'Cancer rehabilitation' [8] drawn up by the Integral Cancer Center Netherlands (Integraal Kankercentrum Nederland IKNL). This guideline describes the rehabilitation care of adult patients with cancer, during and after treatment. For HNC specifically, the NKI/AVL set-up a revalidation program for patients who received surgery and or radio- chemotherapy and who are physically and mentally capable to attend such a program.

This pilot program 'Life back on track' after a TL, is different from the above rehabilitation programs as we:

- Offer after care support to all patients who had undergone a TL and their direct family.
- Structurally include the partner during the whole program and also suggest specific partner modules.
- Besides offering medical information[I] the emphasis is on psychosocial consequences.

[I] Question & answer sessions with for example surgeons, speech therapists and dieticians

Because of the impact of the consequences of a TL on daily life on the one hand and the rarity of the disease on the other hand, it could be helpful to also include other family members such as children, parents or brother/sister and inform them as well how to best deal with the consequences of a TL. Focus should be on both physical and psychosocial consequences of the treatment. Before ideas are shared for the content for such an aftercare intervention, first some key insights are discussed. These insights are based on additional (regression) analyses we have performed and support our ideas of this intervention.

Involving the partner - additional (regression) analyses
From earlier studies, discussed in this thesis, among laryngectomees, it is concluded that the patient sees his partner as the key source of support. However, partners are not only the persons delivering care for the patient. They also are in need for support for themselves. In the studies discussed in **chapters 7 and 8** of this thesis, we investigated the impact of the TL on the partner and on the impact of the TL on the relationship between patients and partners. In order to identify predictors for interventions aiming at improving the quality of life of laryngectomees, their partners and their relationship, we have done some additional regression analyses. The outcome of the regression analyses reveals that certain aspects of quality of life of the partner can explain the perceived quality of life of laryngectomees. The other way around is also true: certain aspects of quality of life of the laryngectomee can explain quality of life dimensions of the partner. When laryngectomees experience less fear, their partners reported less feelings of depression. When the laryngectomee experiences less social support, the partner reported a lower quality of life. In short, the quality of life of the patients seems to be (cor)related with quality of life of partners and vice versa. Patients 'function' better in life with a partner who is also doing well and the partner also experiences a better quality of life when the patient is doing well. All in all, the findings of these analyses justify the recommendation to closely involve the partner and possible other family members for this after care therapy.

The basic assumption of this intervention is to offer support to all patients who had undergone a TL and to their direct family. This intervention is based (primarily) on one group session organized in the hospital and initiated by the Dutch Association of laryngectomees NSvG. We have chosen for a group session, as we have learned from earlier research dealing with contact between fellow cancer patients,[1] that these contacts can lead to a decrease in negative feelings and uncertainty and to an increased feeling of self-esteem. With this intervention we want to empower laryngectomees and their partners to stand up for themselves, speak with them how to best support each other and openly discuss possible issues between patients and partners and help prepare them to pick up their life after the laryngectomy.

The main thinking of the content of this intervention fits in the theoretical approach of the Multi Systemic Theory (MST). MST is a home- and community-based family therapy originally designed for youths presenting antisocial behavior and their families. It uses evidence-based interventions to intervene directly in the systems and processes related to the adolescents' antisocial behavior.[9,10] The MST therapy is based on an ecological model of treatment that views each child as part of a network of systems (i.e. the individual, family, peers, school, neighborhood) that interact to influence behavior.[11] Learning from this evidenced based intervention, we also see the patient clearly in relation to his direct network, i.e. his or her partner, child(ren), family and friends. We could use aspects of the Multi Systemic Therapy in order to learn the 'system' of the patient how to best cope with the consequences of the disease and its treatment. How to best support the patients in such a way that for example the well-being of partners and a possible overburden of caregivers is not ignored. Indeed, MST has already been adapted to other groups with chronic medical conditions like diabetes.[12,13]

To conclude the basic assumption of this intervention, not only does the patient have to adapt to a new life after the TL. Patients and partners have to deal with certain consequences after a TL. It is however not only the patient, but the whole system around the patient that has to find new ways to live their normal life. During this adaptive process there should be room for each other's wishes with regard to how to live life, including work, social life, intimate relationship and how to deal with changes in life. Openly discussing the individual consequences of the disease and how goals in life are changed for certain patients and partners since the TL, should be part of this intervention.

In order to determine the *content and the feasibility* of this intervention, we have set-up earlier a focus group session attended by a multidisciplinary group of professionals[m]. Based on a set of modules developed during qualitative research with laryngectomees, professionals, looking from their own area of expertise, shared their opinion about which subjects should be emphasized and included.

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[m] The focus group was attended by: one laryngectomee and his partner, a head and neck surgeon, two speech therapists, one dietician, one organization consultant, two specialized oncology nurses and two psychologists.

Based on the findings of our research done with laryngectomees and partners and based on the findings of this focus group, we think of the following subjects to be covered in the group session:

1. Medical information
2. Psychosocial support for patients and partners
3. Impact on the spousal relationship
4. Impact on the social life of laryngectomees and partners
5. Specific consequences of the TL for the partner
6. Enhancing self-management and patient empowerment
7. Revalidation and re-integration of patients
8. The patient organization & experience expert

For this intervention, it is not only the professional caregiver but also the patient organization taking on part of the responsibility to deliver support to laryngectomees and partners. Across all the above mentioned modules we see an important role for the 'experience expert' of the Dutch Association of laryngectomees, the NSvG. These experts already do important work by providing pre-operative information on a regular basis. They can also share their experiences during this after care intervention. The role of the patient organization and specifically for the experience experts is of key importance. This kind of cooperation that combines the knowledge of experts from an academic hospital with real life expertise seems to be a powerful way to give the best possible support to patients and their partners.

Recommendations for future research

Based on the results of the studies in this thesis, the following recommendations for future research are made.

Recommendations during all phases of the disease:

- The study dealing with the (caregiving) burden of the partners of laryngectomees and the impact of a Total Laryngectomy on the spousal relation in this thesis **(chapters 7 and 8)**, should be replicated in other larger groups of patients with HNC. Because of the required number of patients to be included, a multi-center approach is necessary.
- Patient and partner empowerment, self-management, self-efficacy and goal setting should be subjects of study in all phases **(chapter 2)**. Also the supportive role of professionals in these aspects should be explored.
- Training programs aimed at improvement of communication between professionals and their patients should be evaluated on their effectiveness **(chapters 3, 5 and 6)**.

Curative treatment and After Care:

- Depending of the results from the earlier mentioned after care intervention 'Life back on Track' **(chapter 9)**, an effect study with a randomized control design is desirable.

Recurrence:

- A comparative study on psychosocial well-being between patients with recurrent HNC and patients with no recurrence should be performed. More information on the quality of life and psychosocial functioning of these two groups may give us more insight into the care needs and wishes **(chapter 3)**.
- Explorative psychosocial research within larger samples of patients with recurrent HNC should be performed to better understand how professionals can further fine-tune their health care services for the specific group of head and neck cancer patients experiencing recurrence of the disease **(chapter 3)**.

Palliative phase:

- Validated questionnaires specific for the palliative phase should be developed **(chapter 4)**. Specifically prospective studies are needed during which palliative patients themselves are involved (instead of the next of kin in our studies as presented in **chapters 5 and 6** in order to evaluate the palliative care.

To come to conclusion, there is room to improve the head and neck cancer psychosocial care. This is especially true for partners of patients with head and neck cancer. By strengthening the position of the partner, both the patient and the partner can benefit in their way of living with the consequences of the disease and its treatment. In further improvement of the psychosocial care for head and neck cancer patients it is recommended to include the partner and to pay attention to the relationship between both.

The recommendations discussed in this chapter may, at first sight, seem to imply additional costs in terms of labor and/or money. Many of the general recommendations, however, are not an issue of money or more manpower, but of a different mindset. It is not necessarily a matter of spending more time with a patient, but of spending the same time differently!

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CHAPTER 10

SUMMARY / SAMENVATTING

SUMMARY

This thesis aims at contributing to a better care for Head and Neck cancer (HNC) patients and their partners. In doing so, a broad understanding of the psychosocial consequences of HNC is essential. The objective of this thesis is to explore psychosocial aspects in the literature for which there is hardly any, or limited insight, the so called 'knowledge gaps'.

The knowledge gaps we have addressed in this thesis are:

- Changed live goals as a consequence of head and neck cancer **(chapter 2)**.
- Psychosocial aspects of recurrent head and neck cancer **(chapter 3)**.
- Head & Neck cancer in the palliative phase:
    - ▪ Prevalence of symptoms of head and neck cancer patients in the palliative phase and the impact on their daily functioning **(chapter 4)**.
    - ▪ The experience of 'standard' palliative care through the eyes of next of kin **(chapter 5)**.
    - ▪ The experience of palliative care after the establishment of an Expert Center for head and neck cancer patients in the palliative phase and their family **(chapter 6)**.
- Psychosocial problems and quality of life for partners of patients after a total laryngectomy **(chapter 7)**.
- Impact of a total laryngectomy on the spousal relationship **(chapter 8)**.

This is the first thesis that encompasses psychosocial issues of HNC patients simultaneously during all phases of the disease with the novelty to include psychosocial aspects of the partners of the patients and the interaction within the spousal relationship.

Chapter 2

This chapter aims to examine whether a self-regulation approach could lead to a greater insight into factors related to psychological distress in HNC patients and their partners. We examined which goals in life they valued and the extent to which patients and partners experience goal disturbance. Furthermore, associations were explored between goal disturbance, goal re-engagement, (goal) self-efficacy, and psychological distress.

Results confirmed our hypothesis that HNC patients and their partners experienced goal disturbance from the disease. Such disturbances were especially in patients significantly related to more psychological distress. Also consistent with our hypothesis, more reengaging in alternative goals was related to less psychological distress, but this association was statistically significant only in patients. More self-efficacy was significantly associated with less psychological distress in both patients and partners. Having the confidence to manage and continue things in life such as daily duties, hobbies and social activities appeared to be important for perceived psychosocial well-being. In this study it is concluded that self-regulation abilities as goal re-engagement and self-efficacy may be screened and used as target in future psychological interventions, given their potential to decrease perceived psychological distress. In view of elevated levels of goal disturbances in partners, psychological support for caring relatives in such interventions is recommended.

Chapter 3

The study in this chapter describes the psychosocial responses of patients after receiving the news of recurrence of head and neck cancer, and the impact of the illness experience as compared with the impact of the initial diagnosis. Half of the patients found that the news of recurrence caused them a bigger shock than the first diagnosis. And also half of the patients found coping with the cancer recurrence more difficult than coping with the first diagnosis. Four out of ten patients experienced fears, especially for a second recurrence, sometimes triggered by follow-up visits. These findings justify extra attention for this vulnerable part of the patient group. Furthermore, patients have the need for an explanatory model of the cause of their recurrent disease. Doctors therefore should, wherever they can, help patients in looking for possible explanations for the recurrence of HNC and discuss the limitations of medical imaging research and control visits in relation to the recurrence. Doctors also should ask patients how they are coping with the situation. If patients rigidly deny the reality of the disease or refuse to allow themselves to think about it, this should elicit the physician’s concern. It is important to stay in open communication with patients about their coping. With the findings of this study we can further fine-tune our health-care services for the specific group of head and neck cancer patients experiencing recurrence of the disease.

Chapter 4

There is lack of research on symptoms in head and neck cancer patients in the palliative phase. In the first part of this chapter symptom prevalence was explored in patients with incurable head and neck cancer. In the second part we looked at the impact of these symptoms on the daily functioning of the patients. Also discrepancies between patients and their family caregivers were described with respect to how they score symptom occurrence and symptom impact on daily functioning. Patients with incurable head and neck cancer experience a great number of different symptoms. Somatic symptoms with a high prevalence were fatigue, pain, weakness, trouble with short walks outside, and dysphagia, which is consistent with research involving a wide palliative cancer population. In the psychosocial area, the symptoms are worrying, sadness, tenseness, depressed mood, and powerlessness. Symptoms with the greatest impact on daily functioning were dyspnea, voice changes, trouble with short walks outside, anger and weakness. Care for patients with head and neck cancer in the palliative phase should include targeted screening. This screening should focus on highly prevalent symptoms such as fatigue and psychosocial symptoms which, because they are less visible, may now receive less attention Focus on these symptoms by healthcare professionals could further optimize symptom management.

Chapter 5

Little is known about how palliative care is experienced by patients with HNC and their relatives. The aim of this study was to analyze this care from the point of view of the next of kin of HNC patients. Psychosocial support and patient education need to be improved, particularly during the last stage of life. Contact between head and neck surgeon and patient was sufficient. Many relatives found information about the terminal stage unsatisfactory. Medical treatment during the palliative stage was judged as sufficient in most cases, but was often felt to be intrusive. Not all aspects of palliative care for head and neck cancer patients were sufficient and improvements are necessary, specifically within the psychosocial field. This supports the initiation of our Expert Center to improve quality of life in the palliative stage.

Chapter 6

The aim of this study was to describe the experiences of HNC patients with regard to the palliative care they received after the set-up of our Expert Center (EC). The reported experiences are according to the next of kin of the deceased patients. Furthermore, we compared the findings of this study with those from the same research done prior to the existence of the EC. We found: an improved evaluation of the psychosocial support offered; better contact between HN surgeons, the patients and families; and an improvement in the quantity of information in the palliative phase. Some relatives, however, reported that patients received treatment against their wishes and life was not made as comfortable as possible. The approach adopted by our EC with one dedicated HNC surgeon per patient focusing on structural symptom control together with specialized nurses coordinating care and consultation has led to increased appreciation of our psychosocial support (including the phase of dying), better contact between patients and HNC surgeons and to more patients being able to die where they wish to.

Chapter 7

Literature is lacking about the psychosocial impact on partners of patients who have undergone a total laryngectomy (TL) and on how partners function in their daily life in the long run. The aim of the current study is to explore the main psychosocial consequences after a TL for a large group of partners of laryngectomees. Partners of laryngectomees experience a variety of psychosocial problems. Around one out of seven partners experienced a possible mood disorder, feelings of hopelessness, disturbed goals in life and negative experiences with respect to the role of caregiver they fulfil for their life companion. Even a more substantial part, namely between one quarter to one third, experience loss of control with respect to several aspects of life and they are afraid of losing their life companion. These data justify screening partners of laryngectomees for psychosocial problems and helping those who are in need of additional support. The results of this study give insights into the underexposed subject of impact of a TL on the partner of the patient. These results and the ones of future studies can be used to develop a structural screening program. Such a screening program would enable health care professionals to better help more partners in dealing with the consequences of the laryngectomy of their life companion. The findings from current research support the idea of screening the partners. A better understanding of their psychosocial problems is needed to develop interventions to improve quality of life for both patients and partners.

Chapter 8

This study is the first that deals with a broad exploration of the long term impact of a Total Laryngectomy (TL) on the (intimate) relationship within a large group of laryngectomees and their partners. Also significant relationships between socio demographic data and the experienced change in the quality of the spousal relationship were described. The majority of the couples in current study experienced that their relationship remained the same. However, a closer look reveals that a TL has a profound impact on certain aspects of the spousal relationship. Negative change is mainly on sexual functioning, communication and the expression of emotions and feelings of laryngectomees of being depended on other people. Laryngectomees often received the needed support from their partner, however, the partners themselves do not always receive the support they find important. As the consequences of a TL reach further than the individual impact on the patient, it is of importance to involve the partner as early as possible in the treatment and after care process. Professionals should prepare patients and partners on possible changes in the social and relational context. The considerable impact of a TL on the spousal relationship warrants structural screening for both patients and partners.

Chapter 9

After a discussion of the concept of Good Care, in which the results of the studies in this thesis are embedded, this thesis ends with recommendations for the work in the clinical practice as well as with suggestions for future research. A key conclusion is that healthcare professionals should include the partner in the basic support they offer to HNC patients. By strengthening the position of the partner, both the patient and the partner can benefit in their way of living with the consequences of the disease and its treatment. In further improvement of the psychosocial care for head and neck cancer patients it is recommended to include the partner and to pay attention to the relationship between patient and partner.

SAMENVATTING

Het doel van dit proefschrift is een bijdrage te leveren aan een betere psychosociale zorg voor mensen met hoofd-halskanker en hun partners. Daarvoor is een goed inzicht in de psychosociale gevolgen van hoofd-halskanker van groot belang. In dit proefschrift worden de psychosociale aspecten van hoofd-halskanker geëxploreerd waarover in de literatuur weinig tot geen inzicht in is; de zogenaamde kennislacunes in de literatuur.

De kennislacunes die in dit proefschrift aan de orde komen zijn:

- Veranderde levensdoelen als gevolg van hoofd-halskanker **(hoofdstuk 2)**.
- Psychosociale aspecten van een recidief hoofd-halskanker **(hoofdstuk 3)**.
- Hoofd-halskanker in de palliatieve fase:
    - ▪ Prevalentie van symptomen bij hoofd-halskanker patiënten in de palliatieve fase en de invloed op het dagelijks functioneren **(hoofdstuk 4)**.
    - ▪ Ervaringen met palliatieve zorg door de ogen van nabestaanden **(hoofdstuk 5)**.
    - ▪ Ervaringen met palliatieve zorg door de ogen van nabestaanden: de invloed van een Kennis Centrum **(hoofdstuk 6)**.
- Psychosociale problemen en kwaliteit van leven van partners van gelaryngectomeerden **(hoofdstuk 7)**.
- Invloed van een totale laryngectomie op de relatie tussen gelaryngectomeerde en partner **(hoofdstuk 8)**.

In dit proefschrift wordt, anders dan in eerder gedaan onderzoek, de psychosociale problematiek behandeld die kan optreden gedurende alle mogelijke fasen van het ziekte- en behandeltraject. Een ander nieuw element is dat de psychosociale gevolgen voor partners van patiënten en de interactie tussen patiënt en partner worden meegenomen.

Hoofdstuk 2

De studie die wordt besproken in hoofdstuk 2 heeft als doel meer inzicht te krijgen in de factoren die bijdragen aan het psychosociaal welbevinden en aan de kwaliteit van leven van mensen met hoofd-halskanker en hun partners. Dit wordt gedaan tegen de achtergrond van de theorie van zelfregulatie. Onderzocht is in hoeverre hoofd-halskanker van invloed kan zijn op de persoonlijke doelen die mensen nastreven in hun leven. Kanker kan ervoor zorgen dat persoonlijke doelen, die voor de diagnose vanzelfsprekend waren, ineens onhaalbaar zijn. Hierdoor worden mensen gedwongen hun doelen bij te stellen of los te laten. Sommige mensen ervaren psychische problemen, omdat ze het moeilijk vinden hun doelen bij te stellen. In deze studie is de samenhang onderzocht tussen doelbelemmering, het zoeken naar alternatieve doelen, het vertrouwen dat men heeft in het eigen vermogen (self-efficacy) en het psychosociaal welbevinden.

Hoofd-hals kankerpatiënten en hun partners ervaren doelbelemmering als gevolg van de ziekte. Bij patiënten is dit significant gerelateerd aan een mindere mate van psychosociaal welbevinden. De vaardigheid om doelen te kunnen loslaten en je te richten op alternatieven was gerelateerd aan een beter psychosociaal welbevinden. Dit was eveneens gerelateerd aan het vertrouwen dat mensen hebben in hun eigen kunnen (self-efficacy), zoals het vertrouwen in staat te zijn nieuwe contacten te leggen of het stoma goed te verzorgen. Zelfregulatievaardigheden, zoals het stellen van doelen en het kunnen bijstellen of loslaten van doelen en self-efficacy, kunnen worden ingezet tijdens interventies die beogen het psychosociaal welbevinden van mensen te vergroten. Het zou daarom nuttig zijn deze vaardigheden mee te nemen in de screening van patiënten en hun partners.

Hoofdstuk 3

In hoofdstuk 3 wordt verslag gedaan van een studie die de psychosociale gevolgen beschrijft van patiënten met een recidief van hoofd-halskanker. Er wordt een vergelijking gemaakt tussen de psychosociale impact van de boodschap van een recidief en de impact van het eerste slecht nieuws bericht. In dit kwalitatieve onderzoek blijkt dat de helft van de patiënten het nieuws van een recidief als een grotere schok ervaart dan het nieuws van de primaire diagnose. Ook vindt de helft van de patiënten het moeilijker om met de gevolgen van een recidief van een hoofd-halstumor om te gaan dan met de gevolgen van een primaire diagnose. Vier van de tien patiënten ervaart angst voor een tweede recidief, een angst die soms wordt aangewakkerd door controlebezoeken in het ziekenhuis. Deze bevindingen geven aanleiding voor verder onderzoek en tot extra aandacht voor deze kwetsbare groep patiënten. Wanneer mensen in een onzekere situatie terechtkomen, zoals het ervaren van een recidief, is het wenselijk dat artsen binnen hun mogelijkheden zoeken naar eventuele verklaringen voor het recidief als ook de beperkingen aangeven van onderzoek en controles in relatie tot het kunnen vaststellen van een recidief. Ten aanzien van de opvang na het bericht van het recidief is het aan te bevelen dat artsen in open gesprek blijven met hun patiënten en hen expliciet vragen hoe zij omgaan met deze situatie.

Hoofdstuk 4

Er is een gebrek aan onderzoek data die de symptomen beschrijven van hoofd-hals kankerpatiënten in de palliatieve fase. Het eerste deel van dit hoofdstuk is erop gericht meer inzicht te krijgen in de prevalentie van symptomen bij hoofd-halskanker patiënten in de palliatieve fase. In het tweede deel van het hoofdstuk wordt verslag gedaan van de invloed van deze symptomen op het dagelijks functioneren van de patiënten. Ook worden mogelijke verschillen tussen patiënten en hun naasten in aanwezigheid van symptomen gerapporteerd. Patiënten met hoofd-halskanker in de palliatieve fase ervaren een groot aantal verschillende symptomen. *Somatische* symptomen met een hoge prevalentie waren vermoeidheid, pijn, zich slap voelen, moeite met een korte wandeling buiten en slikklachten. De symptomen op *psychosociaal* gebied met een hoge prevalentie zijn in aflopende volgorde: piekeren, gevoelens van verdriet, gespannenheid, neerslachtigheid en machteloosheid. De symptomen met de grootste *invloed op het dagelijks functioneren* waren in aflopende mate: benauwdheid, veranderde stem, moeite met een korte wandeling buiten, boosheid en zich slap voelen. Bij de zorgverlening voor mensen met hoofd-halskanker in de palliatieve fase verdient het aanbeveling aandacht te besteden aan gerichte screening ten aanzien van veelvoorkomende symptomen, zoals vermoeidheid en psychosociale symptomen. Deze laatste zijn niet altijd direct zichtbaar en krijgen mogelijk minder aandacht dan ze verdienen.

Hoofdstuk 5

Er is weinig bekend over de ervaringen van hoofd-hals kankerpatiënten en hun naasten met de palliatieve zorg die vanuit het ziekenhuis wordt geboden. Het doel van deze studie was om meer inzicht te krijgen in de ervaringen van hoofd-hals kankerpatiënten met deze zorg, door de ogen van hun nabestaanden. Aspecten die in de palliatieve zorg aandacht behoeven zijn psychosociale steun en voorlichting, in het bijzonder gedurende de terminale fase. Het contact tussen de patiënt en de hoofd-hals oncoloog werd als voldoende beoordeeld. In de meest gevallen werd de medische behandeling in de palliatieve fase ook als voldoende beoordeeld. Echter, deze behandeling werd door de helft van de patiënten als te belastend ervaren. Een groot deel van de nabestaanden vond de verkregen informatie over de terminale fase onvoldoende. Verbeteringen zijn in het bijzonder nodig op het gebied van psychosociale steun. Deze bevindingen ondersteunen het initiatief voor de oprichting van een Kenniscentrum Palliatieve Zorg dat de kwaliteit van leven van patiënten in de palliatieve fase zo hoog mogelijk probeert te houden.

Hoofdstuk 6

De studie die in hoofdstuk 6 wordt besproken, beschrijft de ervaringen van hoofd-hals kankerpatiënten met de palliatieve zorg ná de oprichting van een Kenniscentrum Palliatieve Zorg hoofd-hals oncologie. De ervaringen worden beschreven aan de hand van onderzoek onder de nabestaanden van deze patiënten. De onderzoeksopzet was dezelfde als die van het onderzoek dat in hoofdstuk 5 is besproken, namelijk de ervaringen met de palliatieve zorg vóór de oprichting van een Kenniscentrum Palliatieve Zorg. Ná oprichting van het Kenniscentrum werd psychosociale ondersteuning als beter ervaren; een beter contact tussen de patiënt en de behandelend arts, een beter contact tussen de naaste en de behandelend arts en een verbetering ten aanzien van de hoeveelheid informatie die de behandeld arts aan de patiënt gaf over de medische toestand. Een aantal nabestaanden gaf aan dat de behandeling of de onderzoeken van de patiënt in strijd waren met zijn of haar wensen en dat de afdeling KNO niet al het mogelijke voor de patiënt heeft gedaan om het hem of haar zo comfortabel mogelijk te maken. Sinds de oprichting van het Kennis Centrum heeft de nieuwe werkwijze met de toewijzing van één hoofdhals-oncoloog per patiënt en de aanstelling van verpleegkundig consulenten die de palliatieve zorg coördineren, geleid tot een verhoogde waardering van de psychosociale ondersteuning en een beter contact met de hoofd-hals oncoloog. Ook heeft deze werkwijze geleid tot een groter aantal patiënten dat niet in het ziekenhuis overlijdt, maar op een plek waarvoor de patiënt van te voren zijn voorkeur had uitgesproken, zoals thuis, een verzorgingstehuis of een hospice.

Hoofdstuk 7

Er is in de literatuur weinig bekend over de invloed van een Totale Laryngectomie (TL) op de partners van patiënten en over hoe deze partners op de lange termijn functioneren. De studie die in dit hoofdstuk wordt besproken, exploreert de psychosociale consequenties voor partners van patiënten na een TL. Partners van gelaryngectomeerden ervaren een verscheidenheid aan psychosociale problemen na een TL van hun levensgezel. Een op de zeven partners ervaart een mogelijke stemmingsstoornis, gevoelens van hopeloosheid, verstoorde levensdoelen en een zeker mate van overbelasting door de zorg voor de gelaryngectomeerde. Een op de vier tot een op de drie partners ervaart sinds de TL van hun levensgezel een mate van controleverlies in hun leven, o.a. op sociaal gebied. Zo gaat ongeveer een derde van hen minder vaak naar sociale gelegenheden en kan iets meer dan een kwart in zijn of haar vrije tijd niet meer doen wat hij of zij voorheen wel deed. Meer dan de helft van de partners vindt het storend dat anderen zich over het hoofd van de gelaryngectomeerden heen tot hen wenden. Verder heeft een derde tot een kwart van de partners er last van dat meer mensen de gelaryngectomeerde negeren. Ook op emotioneel gebied zijn er voor de partner gevolgen merkbaar na de TL. Bijna een derde van de partners heeft angst voor de dood van hun gelaryngectomeerde partner. Deze data rechtvaardigen de keuze om partners van gelaryngectomeerden mee te nemen in screening naar hun psychosociaal welbevinden om te bepalen of zij al dan niet (extra) steun nodig hebben.

Hoofdstuk 8

In hoofdstuk 8 wordt verslag gedaan van een studie die als eerste de lange termijn gevolgen beschrijft van een Totale Laryngectomie (TL) op de echtelijke relatie in een grote groep gelaryngectomeerden en hun partners. Significante verbanden worden beschreven tussen socio-demografische variabelen en de ervaren verandering in de relatie. Een groot deel van de gelaryngectomeerden en partners ervaart dat de algehele relatie na de TL gelijk is gebleven. Echter, als gekeken wordt naar deelaspecten van de relatie blijkt dat de TL diepere effecten heeft, voornamelijk op het seksueel functioneren, de communicatie en het uiten van emoties. Ook ervaren gelaryngectomeerden binnen hun relatie meer gevoelens van afhankelijkheid. Als het gaat om partnersteun geven gelaryngectomeerden aan dat ze in de meeste gevallen alle vormen van steun die zij belangrijk vinden ook daadwerkelijk van hun partner krijgen. Bij de partners is het niet altijd zo dat zij de ondersteuningsvormen die zij belangrijk vinden ook krijgen. Aangezien de gevolgen van een TL niet alleen invloed hebben op de patiënt, is het belangrijk de partner zo spoedig mogelijk in het traject van zorg te betrekken. Zorgverleners moeten zowel patiënten als partners voorbereiden op mogelijk veranderingen na een TL in het sociale leven en binnen hun relatie. De aanzienlijke impact die een TL op de echtelijke relatie lijkt te hebben, rechtvaardigt een structurele screening van patiënten en partners.

Hoofdstuk 9

Na een korte uiteenzetting van het concept Goede Zorg waarin de resultaten van dit proefschrift zijn ingebed, eindigt dit proefschrift met een aantal aanbevelingen voor in de klinische praktijk en met suggesties voor toekomstig onderzoek. Een belangrijke conclusie is dat zorgverleners de partner daadwerkelijk moeten includeren in hun basale steun aan hoofd-hals kankerpatiënten. Door de positie van de partner en het “systeem” rondom de patiënt te versterken, kunnen zowel patiënt als partner beter worden voorbereid op het leven met de consequenties van een ingrijpende behandeling. Het is aan te bevelen dat hulpverleners in de screening en bij hun zorg aandacht hebben voor de gevolgen van de TL op de partner en op de relatie tussen de gelaryngectomeerde en de partner. Veel van de algemene aanbevelingen die in dit hoofdstuk worden gegeven, impliceren niet noodzakelijkerwijs additionele kosten. Het is niet een kwestie van meer tijd besteden aan de patiënt, maar om dezelfde tijd op een andere manier aan te wenden.

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ABOUT THE AUTHOR

Marinella Offerman, daughter of Krijn Offerman and Ria Offerman - van der Raad and younger sister of Peter Offerman, was born on March 24, 1971 in Vlaardingen. A graduation at high school SG Spieringshoek Schiedam and a study Economics at the Haagse Hogeschool, was the basis for a 12 year long career at Procter & Gamble (P&G) during which an intensive internal training program followed. She started as marketing assistant, was appointed to assistant manager public relations and in 2000 she got promoted to head of the department consumer relations Netherlands and Belgium. End 2004 she decided to leave P&G to pursue a career in health care. She went to the Leiden University to study Psychology and during the first years she had a hospitality agreement with the Erasmus MC department Otorhinolaryngology and Head & Neck surgery and has done work in research psychosocial oncology, palliative care and patient information and communication. In 2008 Marinella graduated cum laude with a Master in Science Psychology. The same year she started to work fulltime at the Head & Neck surgery department. She did research with Head and Neck cancer patients in different disease stages. For her research with laryngectomees, the team received a four year funding of the Michel Keijzer Fund of the NSvG. She also supported other health care professionals in different quality projects and research aiming to improve the care for patients with head and neck cancer, she coordinated the work of specialized nurses, gave lectures in communication skills to medical students and translated this work to the clinical practice. Marinella Offerman lives together with Anton Duijndam on the premises of the family business, the Riding School 'Manege de Prinsenstad', Delft.

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10. **Offerman MP**, Pruyn JFA, de Boer MF, van Busschbach JJ, Baatenburg de Jong RJ. Psychosocial problems and quality of life after total laryngectomy for partners. Submitted for publication.

11. **Offerman MP**, Pruyn JFA, de Boer MF, van Busschbach JJ, Baatenburg de Jong RJ. Impact of a total laryngectomy on the spousal relationship. Submitted for publication.

12. ‘t Hoen CAC, Georges JJ, Gamel CJ, de Boer MF, Pruyn JFA, **Offerman MP**. The experience of anxiety in head and neck cancer patients in the palliative phase. Submitted for publication.

*De **beste** arts*
*is niet altijd de **beste** voorlichter.*
Een verpleegkundige
is daarin vaak veel beter.

Er wordt om de vragen van seksbeleving heen gedraaid.
Bij het vrijen heb je je handen nodig en kan je niet praten.
Dus geen mooie, lieve woordjes.
*Het is een ‘**STILLE**’ belevenis geworden.*

Ik vind dat men de huisartsen en de thuiszorg
een betere kijk op een laryngectomie moet geven
en een cursus laten volgen.
Ze weten er veel te weinig van.

Partners worden te veel als ***‘aanhang’***
van de patiënt beschouwd.
Echte nazorg of steun aan
partners is minimaal.

HET ZOU PRETTIG ZIJN ALS ER IETS MEER AANDACHT IS VOOR DE PARTNER.
VOORAL IN HET BEGIN IS HET ERG ZWAAR EN ZOU JE IEMAND WILLEN HEBBEN DIE JE AANHOORT
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OOK THUIS MOET ALLES DOORGAAN.

Er moet meer naar de psychische kanten
van een laryngectomie worden gekeken.
Voor de KNO-arts is de operatie geslaagd,
dus met de rest moet je maar mee leren leven.

Wij zouden graag veel meer duidelijkheid krijgen over de gevolgen van
stembandlozen via een hele concrete uitleg voor familie en vrienden.
Dat is voor velen een groot struikelblok
daardoor krijg je veel eenzaamheid en onbegrip.

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TOWARDS A BETTER CARE FOR HEAD AND NECK CANCER PATIENTS AND THEIR PARTNERS

MARINELLA OFFERMAN