Supporting Transmural Oncological Care

evaluation of a telemedicine system in head and neck cancer

J.L. van den Brink

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Supporting Transmural Oncological Care

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Bijna alles wat je doet is onbelangrijk,
maar het is erg belangrijk dat je het doet.
(Mahatma Gandhi)

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Chapter 1

General introduction

Chapter 1

INTRODUCTION

In The Netherlands nearly 2400 patients are newly diagnosed with head and neck cancer each year.[1] The mainstay of treatment consists of surgery, radiotherapy, or both.

Head and neck cancer and its treatment have a large impact on the patients' quality of life.[2-4] Many patients report physical and psychosocial complaints, even after successful therapy. Physical complaints include speech problems and difficulties with swallowing. Anxiety, mood disorders, fatigue and depression are often reported psychosocial complaints.

Therefore, it has been known for decades that treating the tumour is not enough: the social and emotional adjustment of the patient should also be attended to.[5]

Bottlenecks in the care for head and neck cancer patients

There is evidence that some aspects of the care for head and neck cancer patients could certainly be improved. Care for head and neck cancer patients contains a diagnostic stage, followed by treatment, careful follow-up and rehabilitation after treatment, and -if cure cannot be achieved- palliative care. Symptom control is an important aspect during all stages. We will first outline some of the bottlenecks in head and neck cancer care.

Continuity of care

A previous study in The Netherlands has demonstrated a lack of continuity between the different modalities of care for head and neck cancer.[6] An important issue in this perspective is that many disciplines are involved. In The Netherlands, as many as twenty different disciplines may contribute to the care for head and neck cancer patients, both in- and outside the hospital.[7] In this complex and slightly incoherent organisation, co-operation between the different professionals is suboptimal.[6,7] General practitioners lack experience with head and neck cancer patients and prefer to leave the care to the specialist. On the other hand, specialists often lack information on how the patient is functioning in his or her home environment.

Co-operation between healthcare providers will improve when professionals communicate more frequently, leading to a better demarcation of their jobs.[8]

Improving communication between professionals involved in the care for head and neck cancer patients would therefore result in more continuity of care.

Lack of information on head and neck cancer

General practitioners and other care providers outside the hospital have reported a need for information on head and neck cancer once they are confronted with such a patient.[6]

Head and neck cancer patients themselves also indicate a need for more information.[9] This is especially relevant knowing that a (perceived) lack of information correlates with post-treatment uncertainty, anxiety and depression.[7] Head and neck cancer patients who receive more information on the disease and its treatment experience less psychosocial problems.[7] Even more, the perception of having obtained adequate information from the specialist is an important predictor of positive rehabilitation outcomes in the 2- to 6-year post-treatment period in head and neck cancer patients.[10]

The post-discharge period

For head and neck cancer patients who have been admitted to a hospital for treatment, the period following directly after discharge (the post-discharge period) is characterised by many uncertainties and fear.[11] Discharge is an abrupt end to having care providers nearby; suddenly doctors and nurses are no longer at calling distance. Moreover, attention from friends and relatives often decreases. Many patients fall into a ‘black hole’, with a considerable need for information and social support.[11] Furthermore, problems occurring during the post-discharge period are likely to remain unnoticed until patients are once more seen in the outpatient clinic. This may lead to undesirable delays.

Quality of life in head and neck cancer

During the last decades, quality of life issues in head and neck cancer have increasingly been portrayed in the medical literature.[12] Quality of life is often used as a parameter to compare different treatment modalities for head and neck cancer.[13-21] Most of these studies are retrospective, introducing the likelihood of selection bias. This is illustrated by a prospective study comparing pre-treatment quality of life with three years post-treatment quality of life.[22] After three years only 66% of the initially included head and neck cancer patients were still alive, and patients who died during the study had worse pre-treatment quality of life compared to the survivors. Other researchers came to similar conclusions: quality of life of head and neck cancer patients who died during the fist year after treatment was worse compared to the patients who survived this first year.[23]

Prospective studies on quality of life in head and neck cancer often compare pre-treatment quality of life with quality of life some time after treatment (typically 3 to 12 months after treatment).[23-28] Many authors have found that quality of life improves as more time has passed since diagnosis and/ or treatment.[23,25,29,30]

However, there is still a lack of insight into the quality of life of head and neck cancer patients during the post-discharge period. Therefore, we have studied the quality of life of surgically treated head and neck cancer patients during this post-discharge period. This study will be described in ***chapter 2*** of this thesis. The chapter has the following main questions:

1. does quality of life of surgically treated head and neck cancer patients worsen or improve during the first three months after discharge from the hospital?
2. what patient characteristics are associated with a poorer quality of life?

Communication from the hospital to the general practitioner

Traditionally, general practitioners receive information from hospital specialists by means of progress reports and discharge letters.[31] Researchers have uncovered many bottlenecks in the communication between specialists and general practitioners: letters often arrive too late and are frequently of suboptimal quality,[31,32] which endangers the continuity of care.[6] For example, general practitioners may be confronted with discharged patients before the discharge letter is received.[33] Attempts to improve the quality and timeliness of letters, for example, by replacing them with electronic equivalents, have been undertaken.[34] Communication in head and neck cancer care is also known to be poor.[7] Informing general practitioners more timely could enable them to anticipate better to their patient's discharge, and hence could already improve care. In ***chapter 3*** we will assess how general practitioners value an additional letter (the so called preadmission letter), informing them that one of their patients is *going to be* admitted for head and neck cancer surgery.

Chapter 3 covers the following main questions:

1. do general practitioners value the preadmission letter as data overload?
2. do general practitioners think that the preadmission letter allows them to provide better care to head and neck cancer patients?

Telemedicine

The Institute of Medicine's (IOM) report, entitled *From Cancer Patient to Cancer Survivor: Lost in Transition*, exposes a gap in the follow-up care of cancer patients.[35] Issues raised in the report include coordination between healthcare providers, and monitoring for consequences of cancer and its treatment, including psychosocial needs.

Information and Communication Technology (ICT) has been advocated as a possible solution for the communication and co-ordination needs of healthcare.[36] There is increasing interest in the use of ICT[36] and telemedicine[37] as a means to deliver healthcare.

Telemedicine is the use of information and communication technology to provide healthcare services to individuals who are at some distance from the healthcare provider.[38] Although an abundance of telemedicine literature exists, studies evaluating telemedicine applications are still scarce,[39] have often poor study designs,[40] or are restricted to demonstrating a system's feasibility.[40] Evidence regarding the effectiveness of telemedicine is still limited and not yet conclusive.[38,41-44] Some evidence exists that home-based telemedicine has positive effects on clinical outcomes for management of chronic diseases such as hypertension and HIV/AIDS.[41] Telemedicine applications are also believed to have the potential of enhancing quality of life.[45] Telemedicine evaluations having quality of life as an outcome parameter are still rare, but the results are promising. Out of 4646 telemedicine publications, only 11 addressed quality of life, of which most showed improvements.[46]

Main focus of this thesis

The main focus of this thesis is to investigate whether telemedicine can improve the care for head and neck cancer patients in their post-operative period. This main focus will be the subject of ***chapters 4, 5, and 6***.

A telemedicine system for head and neck cancer patients

Many researchers have argued that information and communication technology is, in principle, able to support the communication and co-ordination needs of medicine.[36,47] System designers, however, have to translate these broad claims into specific objectives that are addressed by systems. That is, when designing a telemedicine system for head and neck cancer patients, the objectives need to be tailored to the needs of that specific population.

Chapter 4 therefore comprises the following main questions:

1. is it possible to tailor the functionality of an information system to the information and communication bottlenecks in head and neck cancer care?
2. how could such a system be evaluated in terms of clinical feasibility and usefulness?

Evaluation of our telemedicine system for head and neck cancer patients

In ***chapter 5 and 6*** we describe the evaluation of our telemedicine system for head and neck cancer patients during the post-discharge period.

In ***chapter 5*** we aim to answer the following main questions:

1. what is the use and appreciation of our system by the patients?
2. what is the use and appreciation of our system by general practitioners?
3. did our system enable the early detection of potential health problems of head and neck cancer patients who were at home after discharge from the hospital?

And in ***chapter 6***:

1. does the use of our telemedicine system objectively influence the quality of life of head and neck cancer patients?

Summary, conclusions and suggestions for future research

In ***chapter 7*** we will summarise chapters 2 through 6, provide conclusions, and do some suggestions for future research.

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Chapter 2

Quality of life during the first three months following discharge after surgery for head and neck cancer; a prospective evaluation

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ABSTRACT

Objective: To identify patients groups that are prone to poorer quality of life (QoL) during the first three months following discharge from the hospital after surgery for head and neck (H&N) cancer.

Design: Prospective evaluation of the QoL of surgically treated H&N cancer patients measured with questionnaires: at discharge, and at six weeks and three months after discharge.

Setting: Department of Otolaryngology and Head and Neck surgery of the Erasmus MC (Erasmus University Medical Centre), a tertiary health care centre in Rotterdam, The Netherlands.

Participants: Ninety H&N cancer patients who had undergone a total laryngectomy, neck dissection or commando procedure.

Main outcome measures: patients' quality of life in 22 different dimensions.

Results: Three patient characteristics associated with poorer QoL during the first three months following discharge from the hospital after surgery for H&N cancer: laryngectomy, lower levels of education, and being single.

Quality of life already improved in eight QoL dimensions during the first three months after discharge, but QoL in the dimensions 'loss of control' and 'physical self efficacy' worsened during this same period.

Conclusions: It is possible to identify patients groups that are prone to poorer QoL during the first three months following discharge from the hospital after surgery for H&N cancer. The results of this study may help care providers working with H&N cancer patients to tailor their rehabilitation programs.

INTRODUCTION

Both head and neck (H&N) cancer and its treatment have a great impact on patients' quality of life.[1,2] Patients are confronted with a life-threatening disease, and also have to deal with consequences for appearance and important functions like breathing, eating, swallowing and speaking.[3]

During the last decades, quality of life (QoL) issues in H&N cancer have increasingly been portrayed in medical literature.[4] QoL often is used as a parameter to compare different treatment modalities for H&N cancer,[5-13] or to compare pre-treatment QoL with post treatment QoL.[3,14-18]

However, little is known on the QoL of surgically treated H&N cancer patients during the first three months following discharge from the hospital: the post discharge period. Yet, from a patient's perspective, this period is characterised by many uncertainties and fear.[19] Discharge is an abrupt end to having care providers nearby; doctors and nurses are no longer available at calling range. Moreover, attention from friends and relatives often decreases. Many patients fall into a 'black hole', with a considerable need for information and social support.[19]

Being able to identify patient groups with poorer quality of life, would permit care providers working in the field of H&N cancer to tailor their rehabilitation programs. To this end, we studied the QoL of surgically treated H&N cancer patients during the post discharge period.

METHODS

In a prospective study, we included patients from June 1999 through August 2000. All patients had undergone surgery for head and neck cancer at the Erasmus MC (Erasmus University Medical Centre), a tertiary health care centre in Rotterdam, The Netherlands. The Erasmus MC has two hospital sites in which head and neck patients are treated. Treatment protocols and surgeons are the same at both sites.

Patients were eligible to participate in this study after one of the following three surgical procedures:

- total laryngectomy (with or without concurrent neck dissection),
- commando procedure (resection of a tumour after mandibular split, with concurrent uni- or bilateral neck dissection, and reconstruction using a flap (pedicle or free vascularised), or
- neck dissection (uni- or bilaterally, with or without concurrent local excision, but without reconstructive flaps).

All patients needed to be able to read and write the Dutch language.

A physician who did not belong to the therapeutic team invited the patients to participate, one day before discharge from the hospital. He asked the patients to complete a questionnaire at three evaluation moments: at discharge, 6 weeks after discharge, and 3 months after discharge. The first questionnaire was provided in the hospital, the second and third were sent by mail and could be returned by mail (free of charge).

All three questionnaires addressed 22 quality of life dimensions. The choice of these QoL dimensions was based on the theoretical model of coping with cancer developed by Van den Borne and Pruyn.[20,21] This model is based on the assumption that uncertainty, negative feelings (e.g., feelings of depression and loneliness), loss of control and threatened self-esteem are the most important psychosocial problems experienced by cancer patients.

The 22 QoL dimensions were measured by means of 22 (sub)scales. Most (sub)scales have been used in previous research.[20,22-25] We developed an additional scale on feelings of insecurity (two subscales) newly for this study. Furthermore, we added some items to the object anxiety scale (fear related to interactions with care providers). To verify the internal reliability of all (sub)scales we computed the reliability coefficients[26] using SPSS 11.0. The reliability coefficient (Cronbach's α) is considered to be too low if <0.60.

Table 1 provides a review of all 22 (sub)scales used in this study. Table 1 shows, for example, that all reliability coefficients (Cronbach's α) were satisfactory (above 0.60).

In the first questionnaire we additionally obtained the following patient characteristics: age, gender, living single or together, highest level of education (on an eight-point scale), hospital site and type of surgical treatment.

Statistical analyses.

We analysed only data of patients who completed all three questionnaires.

For each of the 22 QoL (sub)scales, we determined the associations with the following 7 patient characteristics: type of surgery, evaluation moment, hospital site, gender, living single or together, level of education, and age.

For all (sub)scales, except 5 and 19, repeated measurements ANOVA with SAS PROC MIXED (SAS Institute Inc., Cary, North Carolina, USA, 1999-2001) was used to simultaneously evaluate the associations with type of surgery, evaluation moment, hospital site, gender, living single or together, level of education, and age. For the (sub)scales 6, 13 and 20 outcomes were logarithmically transformed to approximate normal distribution.

For (sub)scales 5 and 19, due to extreme skewness, data were dichotomized: above and below the median value of the mean of the 3 evaluation moments, after having verified that there were no significant differences between these 3 evaluation moments (Friedman's test). For these two dichotomized scales, multivariable logistic regression was used to evaluate the associations with type of surgery, hospital site, gender, living single or together, level of education, and age.

P=0.05 (two sided) was considered the limit of significance.

In subscales 15 through 18 ('physical self efficacy', 'self confidence in oral presentation’, ‘perceived abilities in swallowing and food intake’, and ‘perceived speech abilities’) high scores mean good QoL, whereas in all other (sub)scales high scores stand for poor QoL. To avoid confusion we therefore do not present the results as ‘higher scores’ or ‘lower scores’, but as ‘poorer QoL’ or ‘better QoL’.

Table 1. Review of scales

Scale (number of scale)		Number of items	Minimal score	Maximal score	α*
State anxiety (1)		18	18	72	.95
Object anxiety (2-6)					
2	fear for consequences of the illness	11	11	44	.89
3	fear related to specific head and neck problems	15	15	60	.90
4	fear for (additional) treatment	6	6	24	.91
5	fear for social interactions	3	3	12	.87
6	fear related to interactions with care providers	9	9	36	.94
Feelings of depression (7)		10	10	40	.85
Uncertainty (8-11)					
8	uncertainty, prospects of disease and treatment	9	9	36	.95
9	uncertainty, access to help and problem solving	8	8	32	.91
10	uncertainty, how to handle practical consequences of the illness	11	11	44	.93
11	uncertainty, how to cope with one’s own emotions	7	7	28	.93
Feelings of insecurity (12-13)					
12	insecurity related to accessibility of aid	6	6	24	.77
13	insecurity related to surveillance of the illness by care providers	5	5	20	.76
Loss of control (14)		8	0	8	.78
Self efficacy (15-18)					
15	physical self efficacy	7	7	42	.83
16	self confidence in oral presentation	9	9	54	.78
17	perceived abilities in swallowing and food intake	8	8	48	.72
18	perceived speech abilities	4	4	24	.85
Loneliness (19)		5	5	10	.74
Complaints (20-22)					
20	general psychosocial complains	9	9	32	.92
21	general physical complaints	7	7	28	.67
22	head and neck specific complaints	21	21	84	.85

* Cronbach’s α in this study

RESULTS

During the inclusion period, 120 patients met the inclusion criteria. Twenty-one patients refused to participate, 99 patients were included (response rate of 82.5%). **Table 2** presents the reasons for refusal as provided by the patients.

Ninety out of the 99 included patients completed all three questionnaires: at discharge, six weeks after discharge, and three months after discharge. **Table 3** presents the reasons for not completing all three questionnaires.

Table 2.
Reasons for refusing to participate in this study as provided by the patients (n=21)

Reasons for refusal (number of patients)	
Too much effort to fill in the questionnaires	(14)
Very high age	(1)
Partner with cancer	(1)
Nervousness	(1)
Refuses on principle to participate in any study	(1)
No reason provided	(3)

Table 3. Reasons for not completing all three questionnaires (n=9)

Reasons for not completing all three questionnaires (number of patients)	
Re-admission in hospital for additional treatment	(3)
Death	(2)
Pain and malaise due to bone metastases	(2)
Extreme fatigue	(1)
Being abroad	(1)

Table 4 summarises the patient characteristics from all included patients who completed the three questionnaires (n=90).

All 21 patients in the total laryngectomy group had primary closure of their neopharynx and received a voice prosthesis (Provox®) at the time of their laryngectomy. In four cases a simultaneous uni- or bilateral neck dissection was also conducted.

In the 27 patients requiring a commando procedure, defects were reconstructed with a pectoralis major flap (9 times), a free radial forearm flap (14 times), a fibular free flap (three times), and a local flap (once).

Table 4. Patient characteristics (n=90)

Type of surgery (number and %)		
	total laryngectomy	21 (23)
	commando procedure	27 (30)
	neck dissection	42 (47)
Hospital site (number and %)		
	Erasmus MC, Centre location	59 (66)
	Erasmus MC, Daniel den Hoed oncology clinic	31 (34)
Gender (number and %)		
	male	69 (77)
	female	21 (23)
Living single or together (number and %)		
	single	19 (21)
	together	71 (79)
Highest level of education (number and %)		
	1 (lowest)	3 (3)
	2	19 (21)
	3	26 (29)
	4	13 (14)
	5	9 (10)
	6	5 (6)
	7	9 (10)
	8 (highest)	0 (0)
	missing	6 (7)
Mean age in years (range)		61 (29-84)

Of all 42 neck dissections 38 were unilateral and four were bilateral. In 20 cases an additional local excision was also performed (tongue 13 times, parotid gland twice, alveolar process twice, lip once, skin behind ear once, and floor of mouth once). In four cases the accessory nerve had to be sacrificed, in the remaining 38 cases this nerve could be saved.

Table 5 provides the associations between all 22 quality of life (sub)scales and the 7 patient characteristics. The table shows that ‘age’, ‘gender’ and ‘hospital site’ were significantly associated with only one QoL (sub)scale.

‘Type of surgery’, ‘evaluation moment’ (at discharge, 6 weeks after discharge, and 3 months after discharge), ‘living single or together’, and ‘level of education’ were significantly associated with at least 4 QoL (sub)scales. **Table 6** presents the details of all significant associations for the latter 4 patient characteristics. Since ‘age’, ‘gender’ and ‘hospital site’ were associated with only one QoL (sub)scale, we do not explore these patient characteristics in **Table 6**.

Table 5. P-values of the associations between QOL and patient characteristics (n=90)

	(Sub)scale	Type of surgery	Evaluation moment	Hospital site	Gender	Living single or together	Level of education	Age
1	State anxiety	.007	-	-	-	-	.001	-
2	Fear for consequences of the illness	-	<.001	-	-	-	.023	-
3	Fear related to specific head and neck problems	-	-	-	-	.029	.021	-
4	Fear for (additional) treatment	-	.008	-	-	-	-	-
5	Fear for social interactions	-	-	-	-	-	-	-
6	Fear related to interaction with care providers	-	-	-	-	.014	-	-
7	Feelings of depression	-	-	-	-	-	.026	-
8	Uncertainty - prospects of disease and treatment	-	-	-	-	-	-	-
9	Uncertainty - access to help and problem solving	-	<.001	-	-	-	-	-
10	Uncertainty - how to handle practical consequences of the illness	<.001	<.001	-	-	-	-	-
11	Uncertainty - how to cope with one's own emotions	-	.014	-	-	-	-	-
12	Feelings of insecurity related to accessibility of aid	-	<.001	-	.039	-	-	.003
13	Feelings of insecurity related to surveillance of the illness by care providers	-	-	-	-	-	-	-
14	Loss of control	.034	.029	-	-	-	-	-
15	Physical self efficacy	-	.001	-	-	.037	-	-
16	Self confidence in oral presentation	<.001	-	-	-	.022	-	-
17	Perceived abilities in swallowing and food intake	.033	-	-	-	-	-	-
18	Perceived speech abilities	<.001	.006	.032	-	-	-	-
19	Loneliness	-	-	-	-	.006	-	-
20	General psychosocial complaints	-	<.001	-	-	-	-	-
21	General physical complaints	-	-	-	-	-	-	-
22	Head and neck specific complaints	.007	-	-	-	-	-	-

- Means that the P-value was not significant

Table 6. Summary of all significant associations between the 22 QoL (sub)scales and 4 patient characteristics. ‘X’<‘Y’ means that ‘X’ has poorer QoL than ‘Y’.

	(Sub)scale	**Type of Surgery (1)**	**Evaluation moment (2)**	**Living single or together (3)**	**Level of Education (4)**
1	State anxiety	L<N L<C	-	-	L<H
2	Fear for consequences of the illness	-	T1<T3	-	L<H
3	Fear related to specific head and neck problems	-	-	S<T	L<H
4	Fear for (additional) treatment	-	T1<T2, T2<T3, T1<T3	-	-
5	Fear for social interactions	-	-	-	-
6	Fear related to interaction with care providers	-	-	S<T	-
7	Feelings of depression	-	-	-	L<H
8	Uncertainty - prospects of disease and treatment	-	-	-	-
9	Uncertainty - access to help and problem solving	-	T1<T2, T1<T3	-	-
10	Uncertainty - how to handle practical consequences of the illness	L<N L<C	T1<T2, T1<T3	-	-
11	Uncertainty - how to cope with one's own emotions	-	T1<T2, T1<T3	-	-
12	Feelings of insecurity related to accessibility of aid	-	T1<T2, T2<T3, T1<T3	-	-
13	Feelings of insecurity related to surveillance of the illness by care providers	-	-	-	-
14	Loss of control	L<N L<C	T2<T1, T3<T1	-	-
15	Physical self efficacy	-	T3<T1, T3<T2	S<T	-
16	Self confidence in oral presentation	L<N L<C	-	S<T	-
17	Perceived abilities in swallowing and food intake	L<N C<N	-	-	-
18	Perceived speech abilities	L<N L<C	T1<T3, T2<T3	-	-
19	Loneliness	-	-	S<T	-
20	General psychosocial complaints	-	T1<T2, T1<T3	-	-
21	General physical complaints	-	-	-	-
22	Head and neck specific complaints	L<N L<C	-	-	-

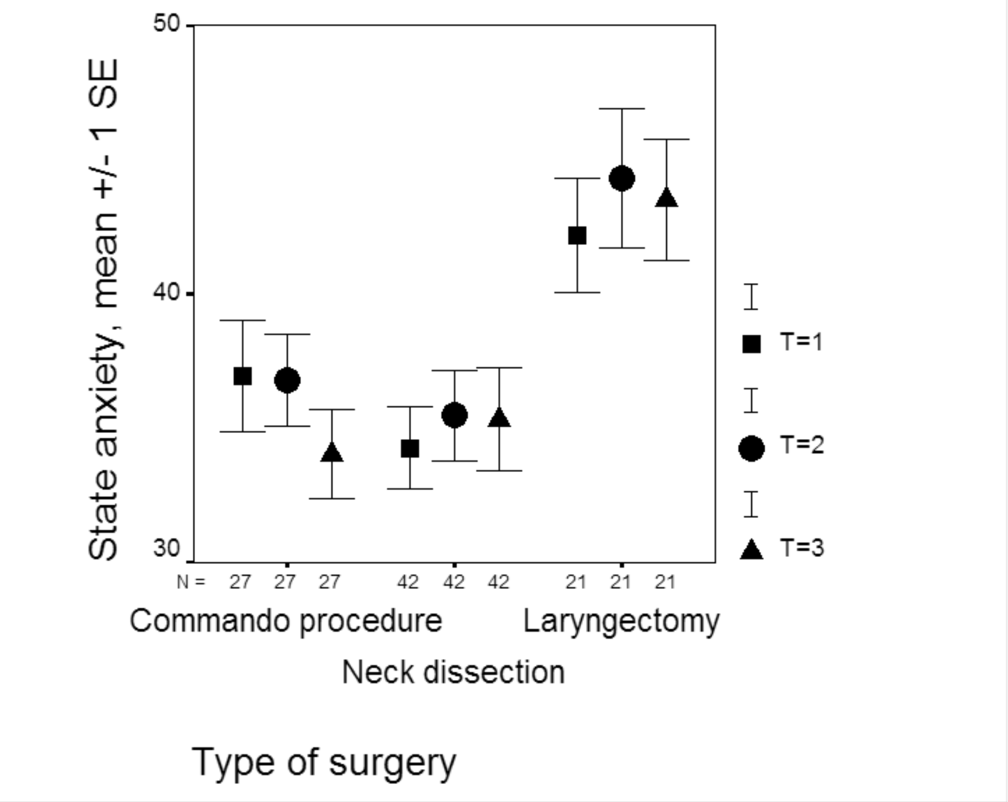
(1) L= laryngectomy, N= neck dissection, C= commando procedure
(2) T1= at discharge, T2= 6 weeks after discharge, T3= 3 months after discharge
(3) Living single (=S) or together (=T)
(4) Level of education ranging from Low (=L) to High (=H)

Table 6 shows that, during the first three months following discharge from the hospital:

- ***Type of surgery*** is significantly associated with 7 of the 22 quality of life (sub)scales. In all 7 associations the total laryngectomy group has the poorer quality of life. Laryngectomees have poorer QoL in the following 7 QoL dimensions: ‘state anxiety’ (Figure 1 gives an example), ‘uncertainty – how to handle practical consequences of the illness’, ‘loss of control’, ‘self confidence in oral presentation’, ‘perceived abilities in swallowing and food intake’, ‘perceived speech abilities’, and ‘head and neck specific complaints’.
- ***Evaluation moment (at discharge, 6 weeks after discharge, and 3 months after discharge)*** is significantly associated with 10 of the 22 quality of life (sub)scales. QoL in the following 8 QoL dimensions improves during the first three months following discharge from the hospital: ‘fear for consequences of the illness’, ‘fear for additional treatment’, ‘uncertainty – how to handle practical consequences of the illness’, ‘uncertainty – how to cope with one’s own emotions’, ‘feelings of insecurity related to accessibility of aid’, ‘physical self efficacy’, ‘perceived speech abilities’, and ‘general psychosocial complaints’. During this same period, QoL in the dimensions ‘loss of control’ and ‘physical self efficacy’ worsens. Quality of life seems to change more between discharge and 6 weeks after discharge than between 6 weeks and 3 months after discharge.
- ***Living single or together*** is significantly associated with 5 of the 22 quality of life (sub)scales. In all 5 associations singles have poorer quality of life. Singles have poorer QoL in the following 5 QoL dimensions: ‘fear related to specific head and neck problems’, ‘fear related to interactions with care providers’, ‘physical self efficacy’, ‘self confidence in oral presentation’, and ‘loneliness’.
- ***Level of education*** is significantly associated with 4 of the 22 quality of life (sub)scales. In all 4 associations patients with lower levels of education have poorer quality of life. Patients with lower levels of education have poorer QoL

in the following 4 QoL dimensions: 'state anxiety', 'fear for consequences of the illness', 'fear related to specific head and neck problems', and 'feelings of depression'.

Figure 1. Mean level of state anxiety (+/- 1 standard error) of the three patient groups at T1, T2, and T3. Note higher levels of anxiety (meaning *poorer* QoL) in the laryngectomy group at all measurement times.



DISCUSSION

This study shows that it is possible to identify patients groups that are prone to poorer QoL during the first three months following discharge from the hospital after surgery for H&N cancer.

In this period, ***type of surgery*** is strongly associated with post discharge QoL. A total laryngectomy is associated with poorer quality of life compared to both commando procedure and neck dissection, even when corrected for evaluation moment, hospital site, gender, living single or together, level of education, and age. Laryngectomees have more anxiety, uncertainty, loss of control, and head and neck specific complains. Moreover, they have lower self efficacy in the areas of speech and swallowing.

Jones et al., who compared QoL of H&N cancer patients treated surgically for H&N cancer found that laryngectomees had relatively few problems.[27] In their study, however, patients were between 4 and 26 months after surgery. It is likely that QoL of laryngectomees improves as they proceed in their rehabilitation programs. This might also be illustrated by Berkhaug et al., who found that approximately 10 years after a laryngectomy QoL is similar between laryngectomees and a general population of patients treated for H&N cancer.[28]

Gibson and others studied QoL of patients following discharge from the hospital after a laryngectomy. They found, like we did, high levels of post-operative anxiety.[29] However, no comparison was made with other H&N patient groups.

We also found that ***evaluation moment*** is strongly associated with post discharge QoL. For ‘loss of control’ and ‘physical self efficacy’ QoL deteriorates after discharge, but QoL in 8 other dimensions already improves during the first three months following discharge from the hospital. Many authors have found that QoL improves as more time has passed since diagnosis and/ or treatment.[15,25,30,31] A recent study shows a deterioration of QoL of H&N cancer patients from baseline (before treatment) to two months from baseline, followed by a recovery at 12 months.[18] As we have not measured pre-treatment QoL, results cannot easily be compared. However, our study shows that QoL in 8 QoL dimensions already improves during the first three months. We therefore assume that the recovery at 12 months post treatment probably already begins during the first three months.

Living single or together also associates with post discharge QoL. As suspected, loneliness is more often reported by singles, but singles also have poorer QoL in 4 other QoL dimensions. Most QoL studies already correct for marital status.

With only a few exceptions,[31,32] thus far most QoL studies do not correct for ***level of education.*** Our study clearly indicates that lower levels of education associate with poorer QoL. We postulate that level of education might be an important patient characteristic determining QoL, which should be corrected for more often in QoL studies.

Age, gender, and hospital site had only minor impact on QoL in our population and study period. The influence of age is under debate. Two recent studies suggest that age has little influence on QoL,[33,34] but results from other researchers contradict these findings.[18,31]

Some authors found poorer quality of life in females.[32] One should bear in mind that in H&N cancer, males outnumber females by far. Our study is no exception to this rule. So in most QoL studies in H&N cancer female groups are small in size.

Our study could have some practical consequences for care providers working with H&N cancer patients:

1. More systematic attention for patients who are single.

Patients who are single are prone to poorer QoL during the first three months following discharge from the hospital. These finding could help care providers working with H&N cancer patients to identify those patients who are in need of additional support during their rehabilitation process. We assume that patients who lack social support from their partner need extra support from their care givers.

2. Tailoring rehabilitation programs based upon 'type of surgery' with special interest on laryngectomees.

During the first three months following discharge from the hospital, laryngectomees have more feelings of uncertainty, anxiety and fear, experience more loss of control and H&N specific complaints, and have lower physical self efficacy compared to both commando procedure and neck dissection patients. In order to reduce anxiety and uncertainty in laryngectomees, more attention should be given to the provision of information, as a (perceived) lack of information correlates with post-treatment uncertainty, anxiety and depression.[35] H&N cancer patients who receive more information on the disease and its treatment experience fewer psychosocial problems.[35] The perception of having obtained adequate information from the specialist even has been identified as an important predictor of positive rehabilitation outcomes in the 2-6 year post-treatment period in H&N cancer patients.[25] We feel that rehabilitation programs for H&N cancer patients should be tailored to the type of surgery the patient has received, with special interest on laryngectomees and focussing on the provision of information.

3. Being alert to the patient's level of education.

As mentioned above, our study shows that lower levels of education associate with poorer QoL. Screening patients for lower levels of education might therefore be a useful tool in order to identify patients who are prone to poorer QoL.

We assume that the QoL of higher educated patients is positively influenced by their abilities to acquire information, as a (perceived) lack of information correlates with post-treatment uncertainty, anxiety and depression.[35] It is likely that higher educated patients acquire information more effectively compared to lower educated people. This raises the question whether lower educated patients should receive information differently compared to higher educated people.

4. Monitoring the patients more closely during the early post discharge period.

An important finding of this study is that QoL in eight QoL dimensions already improves during the first three months following discharge from the hospital, and even during the first six weeks. Despite of this, as mentioned in the introduction, after discharge from the hospital many patients fall into a ‘black hole’, with a considerable need for information and social support.[19] This is also illustrated by the finding that quality of life in the dimensions ‘loss of control’ and ‘physical self efficacy’ worsens following discharge from the hospital. We suppose that this is caused by the fact that patients, during the post discharge period, have experienced the practical limitations in daily life caused by their disease and its treatment. Above, after discharge care providers are no longer available at ‘calling range’. In order to make the fall into the ‘black hole’ as painless as possible intramural professionals could monitor patients more closely, especially in the early post discharge period. On the other hand, family physicians could provide social support by visiting the discharged patient at home regularly, preferably starting immediately after discharge. Social support from family physicians has been reported as an important predictor for QoL in H&N cancer patients.[36]

In an attempt to monitor H&N patients more closely in the post discharge period and in an attempt to improve the co-operation between intramural and extramural care providers, we have developed and implemented an electronic health information support system for H&N cancer patients. We offered this system to H&N cancer patients during the first 6 weeks following their discharge from the hospital.[37,38]

CONCLUSIONS

In this study we found that the following three patient characteristics associate with poorer QoL during the first three months following discharge from the hospital after surgery for H&N cancer: total laryngectomy, lower levels of education, and being single.

Moreover, QoL already improves in eight QoL dimensions during these first three months, whereas QoL in the dimensions ‘loss of control’ and ‘physical self efficacy’ worsens during this same period.

These findings could have the following practical consequences for care providers working with H&N cancer patients, both in hospital and in general practice:

1. More systematic attention for patients who are single.
2. Tailoring rehabilitation programs based upon ‘type of surgery’ with special interest on laryngectomees.
3. Being alert to the patient’s level of education.
4. Monitoring the patients more closely during the early post discharge period.

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Chapter 3

An extra letter, care gets better? Informing general practitioners about planned surgery for head and neck cancer

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ABSTRACT

***Objective*:** To investigate how general practitioners (GPs) value an additional letter from the hospital. This so-called preadmission letter informs the GP about planned surgery for head and neck cancer in one of their patients.

***Design*:** Prospective survey among GPs by means of a questionnaire attached to the preadmission letter.

Setting: Department of Otolaryngology and Head and Neck surgery of a tertiary care centre in The Netherlands and 104 different GPs in primary care.

Participants: All GPs of patients undergoing surgery for head and neck cancer received the preadmission letter during a 1-year study period.

Main Outcome Measures: GPs' appreciation of the received preadmission letter, GPs' opinion on the content of the preadmission letter, and GPs' general opinion on information provided by our hospital.

Results: Of the 145 preadmission letters sent during the study year, 115 questionnaires were returned (response rate of 79%). All GPs positively appreciated receiving the preadmission letter and considered its content relevant. They valued the letter, with a mean mark of 8.3 on a 10-point scale. The majority of the GPs agreed that the preadmission letter allows them to provide better care.

Conclusions: GPs highly appreciate an extra letter informing them about intended surgery for head and neck cancer in one of their patients. Despite the basic content of the preadmission letter (five items only), the majority of GPs consider the information sufficient. The results of this study have led to the implementation of the preadmission letter to GPs of head and neck cancer patients on a permanent basis in our institution.

INTRODUCTION

Head and neck cancer has an enormous impact on the patients' quality of life, frequently including major psychosocial problems.[1] Patients with head and neck cancer, like other oncologic patients, may experience psychosocial problems resulting from fear of the disease and uncertainty about survival.[2] Additionally, in head and neck cancer, problems are often caused by an invasive and mutilating treatment that may lead to speech, eating and swallowing difficulties, as well as problems with appearance.[2] Head and neck cancer patients, consequently, have a considerable need for social support.

In The Netherlands, General Practitioners (GPs) play a prominent role in managing the continuity of information, and in coordinating and supporting the care. However, GPs will be able to provide supporting care only if they are well informed about their patients.

Traditionally, GPs receive information from hospital specialists by means of progress reports and discharge letters.[3] Researchers have uncovered many bottlenecks in the communication between specialists and GPs: letters often arrive too late and are of suboptimal quality,[3,4] which endangers the continuity of care.[5] For example, GPs may be confronted with discharged patients before the discharge letter is received.[6] Attempts to improve the quality and timeliness of letters, for example, by replacing them with electronic equivalents, have been undertaken.[7]

Instead of replacing traditional communications, evidence also exists that increasing the frequency of information exchange can positively influence continuity of care.[5,8] A danger of more frequent communication, however, is data-overload.[3,9]

Communication in head and neck cancer care is also known to be poor.[2] In this paper we assess how GPs value an additional letter (the so called preadmission letter), informing them that one of their patients is *going to be* admitted for head and neck cancer surgery.

METHODS

After a pilot study, we performed a prospective study during a 1-year period at the Department of Otolaryngology and Head and Neck Surgery of the University Hospital Rotterdam (Erasmus MC) in The Netherlands.

During the study year, an extra letter was sent to all GPs whose patients were to undergo surgery for head and neck cancer in one of two hospital locations (Erasmus MC in the city centre, or Erasmus MC-Daniel den Hoed Cancer Centre in the southern district of the city). Routinely, our department sends letters after a patient's first visit to the outpatient clinic and after discharge from the hospital following an examination under anaesthetic or surgical treatment. The extra letter, the so-called preadmission letter, was sent as soon as a date for surgical treatment was set, typically 1 to 2 weeks prior to admission, without changing routine reporting to the GP.

The preadmission letter was written in a predefined format and, in addition to patient and GP identifiers, consists of five items:

1. Diagnosis
2. Planned surgical intervention (e.g., laryngectomy)
3. Planned date of surgery,
4. Hospital location within the Erasmus MC where the patient will be admit (because the Erasmus MC has two different hospital locations where head and neck cancer patients are treated)
5. Expected duration of admission

A questionnaire was attached to all preadmission letters. GPs were invited to complete and return the questionnaire.

The questionnaire covered three main topics: appreciation of the received preadmission letter, opinion on the content of the preadmission letter, and more general opinions on information provided by our hospital. Each main topic was covered by six theses. GPs were asked to score their level of agreement to each thesis on a 5-point scale: strongly disagree (1), somewhat disagree (2), no opinion (3), somewhat agree (4), and strongly agree (5). Additionally, GPs were asked to score the received letter with a mark from 1 to 10 ("I score this letter with the following mark"). If any of the answers needed further explanation, GPs were invited to write down their remarks or suggestions on the back of the questionnaire.

Analyses

In the study, we included all letters that were sent between November 1, 2000, and November 1, 2001, and contained all five items of the predefined format.

For each returned questionnaire, we resolved, from the corresponding letter, the preoperative interval: the number of days between the date the letter was sent and the planned date of surgery. Furthermore, we determined the mean score of agreement, standard deviation, and the number of missing responses for the overall mark and each thesis. In addition, we calculated the percentage of GPs in agreement to each thesis: the number of GPs with a score of 4 or 5 divided by the total number of respondents for that particular thesis. Similarly, the percentages of GPs in disagreement (score of 1 or 2) and with 'no opinion' (score of 3) were calculated. Of the free text remarks, we determined to which thesis they pertained.

To explore a possible relationship between the preoperative interval and GP appreciation (the thesis "the letter arrives at an appropriate time", and overall mark) we performed Spearman's correlation tests.

RESULTS

During the study year, 147 preadmission letters were sent, of which 145 complied with the inclusion criteria: two letters lacked the diagnosis.

One hundred four GPs returned 115 of the 145 questionnaires (response rate of 79%). Of the 115 preadmission letters, 105 (91%) had been sent between 6 and 11 days prior to the planned date of surgery; the mean preoperative interval was 8.2 days (SD 2.2, range 2-16).

On average, GPs rated the preadmission letter with a mean mark of 8.27 (median 8, SD 0.93) on a scale from 1 to 10. Six GPs rated the letter with a 10. One GP gave a mark below 6 as “the letter contained little new information with respect to a previously received letter.”

Table 1 lists the 18 theses contained in the questionnaire, with, for each thesis, the number of received responses, mean score, standard deviation, and percentages of GPs in disagreement or agreement and with “no opinion”.

The upper part of **Table 1** shows the *appreciation of the preadmission letter*. All responding GPs agreed that they appreciate the letter and that they value the letter’s content as relevant. The theses that the letter has “no additional value” and is “a waste of time” were supported by 4.5% and 7.1% of GPs, respectively. Only 1 GP disagreed (0.9%) with the thesis “this letter allows me to provide better care to my patients and/or relatives”, and 13 GPs had no opinion (11.5%).

Table 1. The 18 theses contained in the questionnaire with the number of received responses, mean score, standard deviation, and percentages of general practitioners in disagreement or agreement and with "no opinion"

*Thesis**	*N*	*Mean (SD)*	*Agreement (%)*	*Disagreement (%)*	*No opinion (%)*
Appreciation					
I appreciate this letter. (1)	115	4.97 (0.18)	100.0	0.0	0.0
This letter contains relevant information. (2)	114	4.82 (0.39)	100.0	0.0	0.0
Letters like this have no additional value. (3)	112	1.32 (0.86)	4.5	93.7	1.8
Letters like this are a waste of time. (4)	113	1.45 (0.98)	7.1	86.7	6.2
This letter arrives at an appropriate time. (5)	114	4.04 (1.05)	72.8	8.8	18.4
This letter allows me to provide better care to my patients and/or relatives. (12)	113	4.33 (0.75)	87.6	0.9	11.5
Content					
Mentioning the diagnosis in the letter is useful to me. (6)	115	4.76 (0.62)	96.6	1.7	1.7
Mentioning the planned treatment in the letter is useful to me. (7)	114	4.86 (0.48)	99.1	0.9	0.0
Mentioning the planned date of surgery in the letter is useful to me. (8)	115	4.64 (0.66)	93.9	0.9	5.2
Mentioning the planned hospital location in the letter is useful to me. (9)	115	3.97 (1.10)	63.4	9.6	27.0
Mentioning the expected duration of admission in the letter is useful to me. (10)	115	4.26 (0.94)	79.1	5.2	15.7
I would have liked to receive different or supplementary information. (11)	111	2.03 (2.00)	9.9	66.7	23.4
Other information					
Information from the Erasmus MC regarding my oncologic patients usually reaches me too late. (17)	114	3.51 (1.12)	53.5	16.7	29.8
Information from the Erasmus MC regarding my oncologic patients is usually incomplete. (18)	113	2.69 (1.05)	23.9	42.5	33.6
I would appreciate a similar short letter preceding nononcologic surgery. (13)	115	4.03 (1.02)	77.4	9.6	13.0
I would appreciate a similar short letter after a first outpatient visit. (14)	113	3.88 (1.16)	69.0	14.2	16.8
I would appreciate a similar short letter immediately after hospital discharge. (15)	115	4.49 (0.85)	92.2	5.2	2.6
I would like more information on frequently occurring problems after major oncologic head and neck resections. (16)	111	4.03 (0.83)	73.0	2.7	24.3

* Number indicates order on questionnaire.

With respect to the *content of the preadmission letter*, the GPs indicated that they find the diagnosis, planned treatment, and planned surgery date more useful than the hospital location and expected duration of the admission. Moreover, only 9.9% of the GPs agreed that they “would have liked to receive different or supplementary information.”

The lower part of **Table 1** shows more general opinions of the GPs regarding *information provided by our hospital*. Information from our hospital regarding oncologic patients was considered “too late” and “incomplete” by more than half of the GPs (53.5%) and by nearly one in four GPs (23.9%), respectively. In general, the GPs had a positive attitude toward the idea of also receiving similar short letters at other occasions, especially immediately after hospital discharge (92.2%).

Thirty-eight GPs made 49 additional free text remarks:

Two remarks related to the thesis “this letter arrives at an appropriate time”. Both GPs stated that they would have liked the letter earlier.

Seven remarks related to the thesis “I would have liked to receive different or supplementary information”. GPs suggested to add the name and telephone number of the specialist in charge and outlining the extent to which the specialist had informed the patient. Furthermore, some GPs would have welcomed a more extensive description of the diagnosis and the treatment.

Thirty-one remarks related to the possibility of receiving similar short letters on other occasions. In 26 remarks, the GPs indicated that they would welcome the following information in such letters: (differential) diagnosis, treatment or therapy, (potential) complications, medication, and prognosis. Five GPs emphasised that frequent communication is more important in oncologic care than in ordinary otolaryngologic care.

The remaining nine remarks were general remarks that did not directly relate to any of the theses.

The preoperative interval was not significantly correlated with GP appreciation.

DISCUSSION

In this study, we assessed how GPs value an additional preadmission letter, which informs them that one of their patients *is going to be* admitted for head and neck cancer surgery.

The GPs value the preadmission letter highly. The GPs rated the letter with a mean of 8.27 on a scale from 1 to 10, and all GPs agreed that they appreciate the letter. Furthermore, the results do not support the hypothesis that GPs consider this extra communication as data overload: only few GPs agreed that the letter is a waste of time and had no additional value. On the contrary, the majority of GPs (87.6%) indicated that the preadmission letter allows them to provide better care to their patient and/or relatives. Our study, however, was not designed to uncover whether they consider currently provided care (that is, without the preadmission letter) as inadequate or *how* the letter enabled them to provide better care. We speculate that the preadmission letter enables GPs to anticipate upcoming events: questions of patients and relatives can be more adequately responded to and visits can be planned or can take place earlier.

GPs' appreciation of the preadmission letter showed no correlation with the interval between the date of surgery and the date of sending the letter. From this, we conclude that GPs consider actually receiving the letter as more important than the timing on which they receive the letter. Although some GPs indicated that they would have liked the letter earlier, this was not possible because, in those cases, the date of surgery had not been set earlier. For our hospital, these findings imply that we will continue sending the letters on the day that the date of surgery is set.

Despite the basic and simple format of our preadmission letter, the majority of GPs consider its contents useful. The preadmission letter informed the GP of the diagnosis, planned surgical intervention, date of surgery, expected duration of admission, and hospital location. Of these, the GPs especially valued the items diagnosis, planned surgical intervention, and planned date of surgery. We therefore believe that inclusion of few items results in highly appreciated preadmission letters.

However, some GPs indicated that they would have liked to receive supplementary information. First, GPs suggested adding the name and telephone number of the specialist in charge. Apparently, GPs often have difficulty in finding the responsible person among the many involved care providers: in head and neck cancer, up to 20 different disciplines may be involved.[2] This stresses the importance of also having a clearly identifiable contact person in hospital, for example, by assigning a treatment coordinator for the intramural care of each patient. Adding the name and telephone number of the contact person could improve the preadmission letter.

Second, GPs suggested adding the extent to which the specialist had informed the patient. In this respect, our hospital follows the national regulations, stating that the care provider "should inform the patient clearly" and "be guided by what is reasonable for the patient to know," unless "the patient has expressed the wish not to be informed."

Many GPs indicated a positive attitude towards also receiving a preadmission letter in nononcologic surgery. From this study, however, we cannot conclude that GPs will equally appreciate preadmission letters in other patient groups: GP appreciation may have been biased by the fact that, in general practice, head and neck cancer is rare. Also, many GPs in our study indicated that the usual communications from our hospital often arrive too late. Therefore, timely information at other points in time could decrease appreciation of the preadmission letter.

However, problems in communication are not unique to head and neck cancer.[10] Therefore, we believe it is worthwhile to study the value of preadmission letters in other patient groups as well.

The results of this study have led to the implementation of the preadmission letter to GPs of head and neck cancer patients on a permanent basis in our institution.

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Chapter 4

An information system to support the care for head and neck cancer patients

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ABSTRACT

Goals of work: The potential of Information and Communication Technology (ICT) as a method to improve care is widely acknowledged. However, before ICT can be used in a specific patient population, the needs of that population should first be made explicit. In this paper we aim to explore the feasibility and functionality of an electronic information system to support head and neck (H&N) cancer care.

Patients and methods: We describe communication and information bottlenecks in supportive care for H&N cancer patients. These bottlenecks were used to determine the functionality of an electronic health information support system.

Main results: We discern three perspectives of problems in H&N cancer care: lacking communication among professionals, lacking information about the disease and its treatment, and lacking supportive measures to reduce uncertainty and fear in patients. To support care, an information support system can facilitate (1) c*ommunication* among all professionals involved and between professionals and patients, (2) professionals' and patients' access to *information*, (3) *contact with fellow sufferers*, and (4) early detection of patient problems by means of *monitoring*. Based on these analyses we subsequently built such a system and established a setting for evaluation.

Conclusions: Information and communication technology can be tailored to address the communication and information bottlenecks in supportive H&N cancer care. As we aim to investigate whether care for H&N cancer patients may benefit from ICT, we are currently performing a clinical evaluation study.

INTRODUCTION

In The Netherlands approximately 2350 patients are newly diagnosed with head and neck (H&N) cancer each year.[20] The mainstay of treatment consists of surgery and radiotherapy, singly or in combination.

Head and neck cancer has an enormous impact on the patients' quality of life.[5] Many patients report both physical and psychosocial complaints, even after successful therapy. Physical complaints include pain, speech problems, a dry mouth and throat, and difficulties with swallowing. Anxiety, mood disorders, fatigue and depression are frequently reported psychosocial complaints. Furthermore, owing to the nature of the illness and its often disfiguring treatment, patients frequently experience blows to their body image and self-esteem. Therefore, it has been known for decades that performing an adequate operation and reconstruction alone are not enough. The social and emotional adjustment of the patient should also be attended to.[4]

The wide range of physical and psychosocial complaints caused by H&N cancer and the multidisciplinary treatment it requires make integral, supportive[15] and shared care an absolute necessity.[11] Shared care is a situation in which physicians and other healthcare professionals jointly treat the same patient. Researchers, however, report that in shared care situations communication both between and within the professions concerned is often is suboptimal.[11] As a result, care and its supportive care processes are not integrated into a meaningful whole.[9]

Information and communication technology (ICT) has often been advocated as a tool that could de used to improve communication between and with professionals providing shared care.[11] However, little is known about whether or how care for H&N cancer patients could de improved by ICT.

In this paper we share our experiences in the development of an electronic health information support system dedicated to the care of H&N cancer patients.

We first describe the information and communication bottlenecks surrounding the care of H&N cancer patients. We subsequently outline how ICT could possibly support the care processes by tackling these bottlenecks. Next, we describe the system that we have developed specifically for H&N cancer care. We close with a brief discussion of the system's present status, its ongoing evaluation, and the expected added value in supporting H&N cancer care.

INFORMATION AND COMMUNICATION BOTTLENECKS IN THE CARE FOR HEAD AND NECK CANCER PATIENTS

Many researchers have argued that ICT is, in principle, capable of supporting the communication and co-ordination needs of medicine.[1,2] System designers, however, have to translate these broad claims into specific objectives that are addressed by systems. That is, when designing a system for H&N cancer care, the objectives need tailoring to the needs of that specific population. We will discuss the needs of H&N cancer care from three different perspectives: communication among professionals, information about the disease and its treatment, and supportive measures to reduce uncertainty and fear in patients in the post-discharge period.

1. Communication among professionals

At present, as many as twenty different disciplines may be involved in the diagnosis, treatment and care of H&N cancer patients, both in- and outside hospital.[19] Researchers report that, in this complex and somewhat chaotic organisation, co-operation between different professionals is suboptimal.[19,21]

General practitioners (GPs) rarely see H&N cancer patients, and they lack experience in dealing with these patients: GPs often prefer to leave their care to specialists.[21] Specialists, however, lack information on how the patient is doing in his or her home environment. Problems occurring after discharge from hospital are especially likely to remain unnoticed until patients are seen in the outpatient clinic. This may lead to delays in involvement of a doctor. Continuity of care in H&N cancer patients is poor[21] and would be improved if specialists were better informed on how these patients are doing at home and if GPs were able to confer easily with hospital-based professionals.

Courtens and Crebolder report that oncological care is poorly co-ordinated.[3] Care providers rarely agree on who is responsible for which of the tasks involved. Courtens concludes that the involvement of larger numbers of professionals increases the need for co-ordination and supportive care measures and argues that poor co-ordination is caused by difficulties in communication. Other researchers also report that co-operation is improved when professionals communicate more frequently and their jobs are better demarcated.[18]

To summarise, the continuity of care in H&N cancer patients needs to be improved, and this in turn can be achieved by improving communication between professionals.

2. Information

GPs need general information concerning H&N cancer once they are confronted with such a patient. Other care providers outside hospitals also require information; 75% of district nurses, for example, report needing information about cancer of the larynx.[21]

Head and neck cancer patients themselves also indicate a need for more information. Nearly one in four of such patients (23%) reports receiving poor information from the hospital about possibilities for care after discharge.[5] Moreover, 73% receive little or no significant information and 59% receive little or no support from their GP.

A (perceived) lack of information correlates with post-treatment uncertainty, anxiety and depression.[19] Head and neck cancer patients who receive more information on the disease and its treatment experience fewer psychosocial problems.[19] The perception of having obtained adequate information from the specialist is an important predictor of positive rehabilitation outcomes in the 2- to 6-year post-treatment period in H&N cancer patients.[6]

To summarise, there is a clear need for patients and professionals to receive information on the disease and its treatment.

3. Uncertainty and fear

From a patient's perspective, the period following discharge from hospital is characterised by many uncertainties and fear.[16] Discharge is an abrupt end to a period when care providers have been nearby all the time; suddenly doctors or nurses are no longer within calling distance. The amount of attention from friends and relatives often decreases. Many patients fall into a 'black hole', with a considerable need for information and social support.[16]

Dealing with uncertainty and fear is complicated by the fact that many H&N cancer patients experience difficulties in speech. After removal of the larynx, for example, patients need to learn an alternative method of speech; it can take several weeks until patients speak clearly enough to communicate by telephone.

Seeking information is an important means to reduce uncertainty.[14,17] Patients prefer to seek information through formal sources, such as specialists. However, there is information, e.g., what the further development of the illness will be like, that patients cannot obtain through formal sources. In such cases the patient will seek information through informal sources, such as fellow sufferers.[14] A fellow sufferer provides the patient valuable opportunities to compare his or her situation with someone else's. Cancer patients who have had contact with fellow sufferers are less uncertain; higher numbers of contacts with fellow sufferers correlate with lower levels of uncertainty.[17]

To summarise, contact with fellow sufferers is an important means to reduce uncertainty.

Chapter 4

FUNCTIONAL REQUIREMENTS FOR AN INFORMATION SUPPORT SYSTEM IN HEAD AND NECK CANCER CARE

On the basis of the information and communication bottlenecks described, we decided that a system should:

1. Facilitate c*ommunication* between all professionals involved and between professionals and patients,
2. Provide *information* to professionals and patients,
3. Facilitate contact with fellow sufferers,
4. Facilitate the early detection of patient problems by means of *monitoring*.

Various considerations underlay our thoughts as we sought to determine how the functionality of such a system could be achieved.

First of all, ICT is preferable to use of the telephone, because many H&N cancer patients experience speech difficulties and ICT allows nonspoken communication. While paper-based systems have shown to benefit patients,[19] ICT allows faster and more tailored information exchange.

Secondly, even though some of the care providers have access to information systems (e.g., hospital information systems and GP information systems), these systems are generally not compatible with each other. More importantly, patients are usually not authorised to access these systems. We therefore decided that integration with existing systems fell outside the scope of our objectives.

Thirdly, development via web technology would directly enable widespread use.

Chapter 4

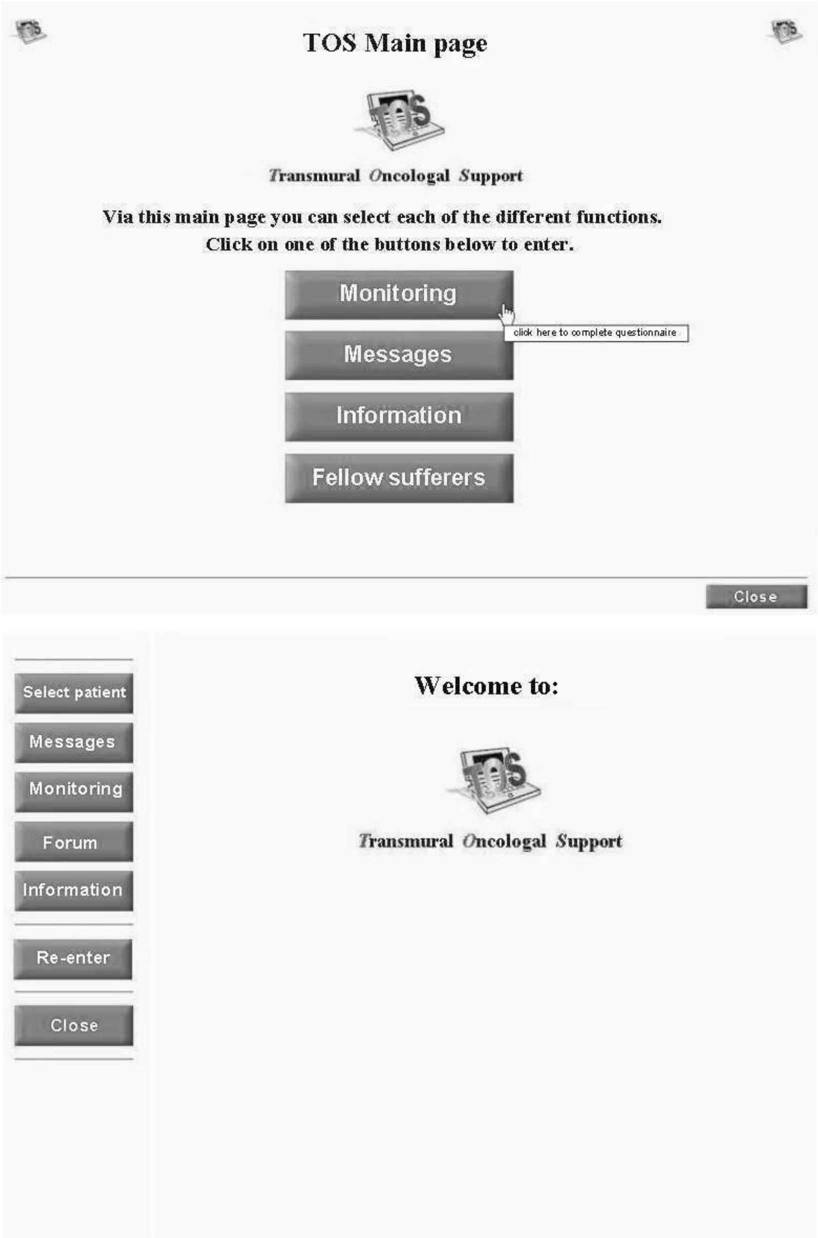
FUNCTIONAL DESCRIPTION OF THE ELECTRONIC HEALTH INFORMATION SUPPORT SYSTEM

We developed an electronic health information support system, which can be used transmurally by all professionals involved and all patients. The objective of the system is to support care of H&N cancer patients after their discharge from hospital. The system relies on Internet technology and can be run from every computer with Internet Explorer version 5.0 or higher.

The system has four main functions:

- Communication,
- Information,
- Contact with fellow sufferers,
- Monitoring.

In the sections below we will describe these functions in more detail. It should be noted, however, that access to the functions ‘communication’ and ‘monitoring’ is restricted to authorised users only, whereas the functions ‘information’ and ‘contact with fellow sufferers’ are readily accessible to anyone with access to the Internet. Furthermore, the user interface is tailored to the type of user. This is illustrated by **Figure 1**.



TOS Main page

Transmural Oncologal Support

Via this main page you can select each of the different functions.
Click on one of the buttons below to enter.

Welcome to:

Transmural Oncologal Support

Figure 1. The translated screen captures illustrate the different interfaces of the main screen for patients (left) and GPs (right). The buttons and letters are larger in the patient interface. GPs have additional functionality, such as selecting a patient for which the GP is authorised.

1. Communication

To facilitate communication, patients and professionals can create ‘messages’. For each message, the user has to indicate the subject and the type of message. The possible message types are ‘report’, ‘question’, ‘answer’, ‘medication change’ and ‘other’. Message types are used to track and follow-up messages. The messages themselves are in free text.

Messages are not sent from one user to another user. Instead, all messages are stored centrally; patients each have their own ‘postbox’, to which authorised users have access. This allows both patients and professionals to read all patient-related messages. **Figure 2** shows the message overview presented to a user consulting the message history.

Thus, the message functionality allows patients and all care providers involved not only to communicate with each other, but also to be informed about each other’s communications.

2. Information

To provide information to both professionals and patients, we developed a website containing general information on cancer, information on H&N cancer, treatment of H&N cancer, rehabilitation after treatment and links to other relevant websites. To ensure that all information on the web site is reliable, experts in the field of H&N cancer have carefully reviewed the information. The main screen of the system has a direct link to this website, to allow easy access for patients and care providers.

Message overview

There is/are **10** message(s) regarding [redacted]

Date	Function	Subject	Feature
16-11-2000 11:32	Speech therapist	Speech therapy	Question
16-11-2000 11:33	Speech therapist	Speech therapy	Question
13-11-2000 16:05	Head and Neck surgeon	Outpatient visit	Report
13-11-2000 11:29	Patient	Questionnaire completed	Notice
9-11-2000 12:02	Member Support Team	Alert	Report
8-11-2000 13:53	Patient	Questionnaire completed	Notice
6-11-2000 11:48	Member Support Team	Alert	Report
4-11-2000 14:33	Patient	Questionnaire completed	Notice

Figure 2. Translated screen capture of the message overview presented to a user when consulting the message history. In this example the overview shows 8 (out of 10) selected messages of a single patient. By clicking on the date/ time box, the user opens the free text message for reading.

3. Contact with fellow sufferers

To enable contact with fellow sufferers, we created a forum. The forum can be accessed both via the main screen of the system and via a link on the website.

Patients can discuss any subject, either anonymously or under their own names. In this patient population surgery may have caused significant disfigurement, resulting in initial reluctance to engage in face-to-face contacts. Especially for patients who experience barriers in face-to-face contacts, anonymous and easily accessible contact with fellow sufferers via a forum provides a welcome extra dimension.

4. Monitoring

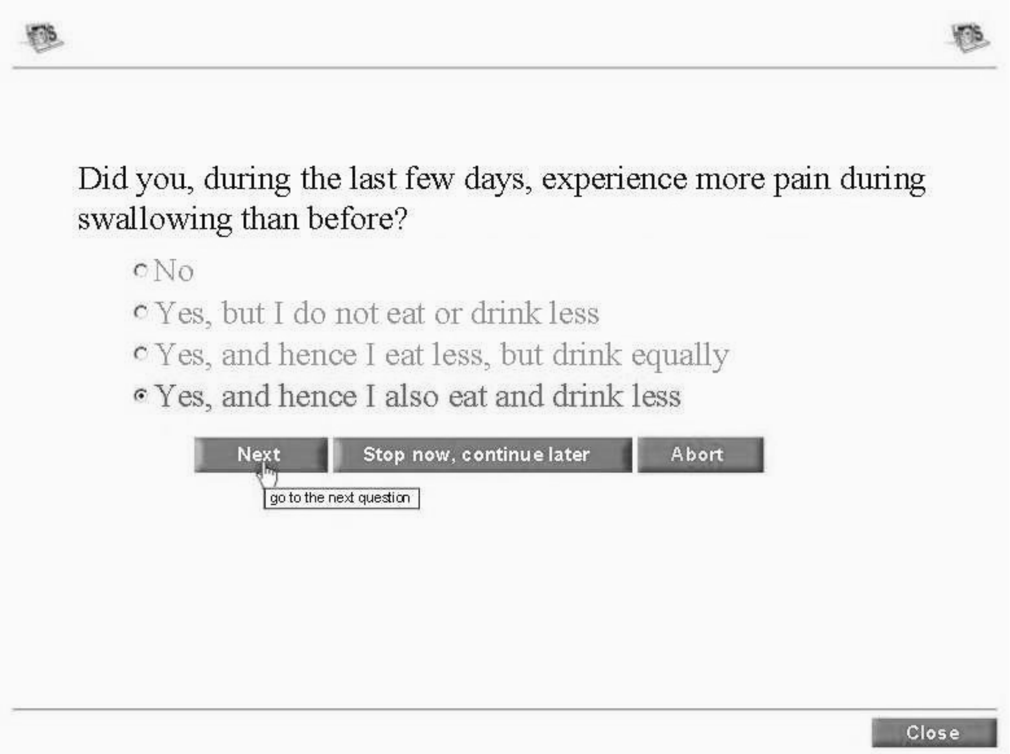
To gain insight into the medical and psychological status of the patient at home, and make detection of potential problems possible, patients are regularly prompted to complete an electronic questionnaire after logging in. The questions asked depend on the type of surgery that a patient has undergone, and all relate to potential problems in the period after discharge from the hospital. The frequency with which questions are presented as elements in a questionnaire varies from twice a week to once every four weeks. Most questions are presented with multiple-choice answers, but some are open questions that are answered in free text. Questions are asked one by one. **Figure 3** shows an example.

Questions are tailored to the individual circumstances of a patient. The questions depend on type of operation, time elapsed since discharge, and answers given to previous questions. As an illustration of the last, the question ‘Do you cough particularly while drinking?’ is only asked when the patient has indicated that coughing has increased.

All possible patient answers are classified as being ‘normal’ (not alarming) or ‘abnormal’ (pointing to a possible problem or complication). This classification allows for the detection of situations that need attention. For example, the answer to the question about ‘pain during swallowing’ that indicates that the patient is eating and drinking less is classified as abnormal.

After answering all questions in a questionnaire, the patient can review the answers given and send the questionnaire to his or her ‘postbox’. A message with type ‘completed questionnaire’ is then automatically added to the message overview.

Every time the patient logs into the system, the date a questionnaire was last completed is checked. When the patient is eligible to answer a new questionnaire a prompt appears reminding the patient to do this.



Did you, during the last few days, experience more pain during swallowing than before?

- ○ No
- ○ Yes, but I do not eat or drink less
- ○ Yes, and hence I eat less, but drink equally
- ● Yes, and hence I also eat and drink less

Figure 3. Translated screen capture of a question that is asked during monitoring. In this example, the patient answers the question: ‘Did you, during the last few days, experience more pain during swallowing than before?’ by: ‘Yes, and hence I also eat and drink less’. The answer is highlighted after it has been selected.

The monitoring questionnaires were based on the experiences of senior ENT-surgeons and on an inventory of patient problems occurring in the six weeks following discharge from hospital.

Alerts

The system would be meaningless if added information were to go unnoticed. Therefore, the system automatically generates alerts in specific circumstances. Alerts are e-mail messages generated by the system and sent to predefined e-mail addresses. Alerts are generated when:

- a message contains a question, that is to say when the type of the message is 'question',
- one or more answers in the questionnaire are classified as 'abnormal', thus pointing to a possible problem,
- patients have not completed their questionnaire for 4 days or more.

All alerts are sent (by e-mail) to a support team in the hospital. This support team consists of two specialised nurses trained in home care technology and palliative care. The team responds to alerts following a predetermined protocol. On working days alerts generated before 16:00 are responded to the same day. A response usually consists of contacting (by telephone) the author of the message that triggered the alert. Additional actions to alerts are, for example:

- Making an extra appointment for the patient with a professional in hospital (e.g., the specialist),
- Giving the patient information or providing social support,
- Asking the GP to visit the patient,
- Asking the patient follow-up questions,
- Suggesting that the patient should discuss a problem with a particular professional.

After a response to an alert, the support team documents the event as a new message in the patient's 'postbox'.

PROTECTION OF PATIENT DATA

For transfer of data, we make use of the services of a secure intranet supplied by the leading medical data exchange provider in The Netherlands.

For storage of the data, we could not make use of the facilities in our hospital: the hospital information system provides no access for patients and professionals outside the hospital. Therefore, we decided to store the data in a database hosted by the provider. This, however, required explicit permission by the hospital, as the privacy regulation prohibits the removal of patient data to any site outside the hospital premises. Permission was granted on the basis of the provider's security measures. Important aspects in these measures were: (1) physical protection of the database, (2) use of the secure medical intranet, and (3) the authorisation and authentication procedures.

In addition, the standard guidelines for research were followed: we obtained permission from the Medical Ethical Committee and all participating patients gave informed consent.

RESEARCH SETTING AND EVALUATION

To be able to assess the clinical feasibility and usefulness of the system, we designed a research setting.

Patients that have undergone a laryngectomy (removal of larynx), a commando-procedure (removal of a tumour in the mouth or throat by splitting the lower jaw), or a neck dissection (removal of the lymph nodes in the neck) are eligible to participate. Further requirements are that patients are able to read and write Dutch and have a telephone at home.

In our research setting, we offer patients taking part a laptop with modem to be used at home for a period of 6 weeks after discharge. Before discharge, a medical student visits the patient in the hospital, and under his supervision the patient practices using of the system. In addition, members of the support team personally introduce themselves to the patient.

The laptop is programmed to launch the dial-in connection directly and go straight to the main screen of the system. The telephone number is free of charge. All care providers involved receive information on how to use the system and are provided with passwords for access. For all users a telephone helpdesk is available during office hours.

In the evaluation we assess patients' Quality of Life (QoL), use and appreciation of the system by all users, and its utility in the detection of potential problems. We use validated questionnaires[6,7] for QoL parameters such as uncertainty, feelings of depression, anxiety, and physical complaints. To determine use, all user actions are stored in a log file. Users receive a questionnaire asking about their subjective appreciation of the various functions of the system and the overall system. Furthermore, we track down all problems occurring in the post-discharge period, and determine when and how they are attended to.

Where possible, results will be compared to those obtained in a control group of similar H&N cancer patients who do not have access to our system.

A formal cost-benefit analysis will not be part of the evaluation. The following data, however, illustrate the various costs in term of hard and software:

A laptop costs about € 1500. With a standard depreciation period of 3 years, one laptop can serve about 20 different patients.

Development of the system took approximately 200 man-days. Two notes are needed to place this amount into perspective. The first is that many functions were implemented on a meta-level, which means that adapting the system to a different patient category will not require additional programming. Secondly, with currently available standard Internet routines, we believe that developing such a system now would take considerably fewer man-days.

The annual fee for hosting and maintenance by a commercial company is about € 5000. This amount may vary with the number of patients participating.

The dial-in telephone connection, which is free of charge to the patient, costs €15 per week per patient, based on an estimated average of 60 minutes' use.

GENERAL DISCUSSION

Multiple care providers from different disciplines are involved in the care of cancer patients; for H&N cancer patients, as many as twenty different disciplines may be involved.[19] Integral, supportive and shared care by a multidisciplinary team requires reliable and timely exchange of information between health care professionals and patients. Unfortunately, many studies have shown that in practice communication is far from ideal, and ICT is often advocated as a solution. However, information systems need to be tailored to the specific needs of the population under scrutiny. In this paper we have explored the feasibility and functionality of an electronic information system to support H&N cancer care.

In H&N cancer care many communication bottlenecks exist. The period following discharge, in particular, is a communication 'pitfall': the patient is transferred from being well looked after in a hospital bed to the home environment, where more and different care providers become involved, who usually have little experience of caring for patients with H&N cancer.

ICT could help reduce these bottlenecks. Electronic messaging may stimulate care providers and patients to give each other information. Patients and GPs may find answers to their questions when they are provided with readily accessible information resources. Electronic monitoring can emulate the alert bell at the hospital bed, and a forum or discussion group could provide social support. Thus, ICT seems an attractive option to support the care processes by facilitating communication, especially since many H&N cancer patients experience speech difficulties.

It should be realised, however, that communication is not automatically improved when it is done electronically. ICT is not a solution in itself, but merely a tool that can support human communication by weakening the inhibitions that sometimes prevent it. The monitoring functionality of our system, for example, provides the patient with the means to inform the care providers of even minor worries. Yet, when alerts occur, personal contact (e.g., by telephone) is necessary, as (a) not all details of the patient's condition can be captured by standard formulations of questions and answers, and (b) the response (e.g., explanation or reassurance) needs to be tailored to the specific problem(s) of that patient. Thus, the system does not replace direct human communication, its strength lies in its aforementioned ability to weaken the inhibitions that might otherwise prevent patients from communicating with their caregivers.

We built an information support system tailored to the communication and information bottlenecks encountered in the care of H&N cancer patients. The system contains four functions: communication, information, contact with fellow sufferers, and monitoring. Other researchers have reported on similar functions. Electronic messaging between care providers, for example, has been in use since the early 1990s. Internet sites with health information, including health discussion groups, abound. Projects in which patients access their electronic medical record, send e-mails to their doctors or send data to be monitored (either via the Internet, e.g., blood glucose levels, or via special devices, e.g., www.healthhero.com) have also been described. We are unaware, however, of any existing system that combines the four functions incorporated into the one described in this paper, all of which may be needed to support H&N cancer care.

Moreover, many telemedicine projects are flawed by the lack of adequate evaluation[13] and restriction of research goals to proof of the feasibility of implementing new technology.[12] We emphasize that we built the system to gain insight into its added value, and not to push technology. Therefore, we introduced the system into a research setting and are currently evaluating the system. From the evaluation we hope to learn more about the system's feasibility and utility.

With respect to feasibility, we will firstly determine to what extend health care professionals have been able to incorporate such a system into their daily practice. Secondly, we will gain insight into the question of whether oncological patients, who are in a stressful and eventful situation, are in a position to collaborate in our initiative. It should also be realised that computer literacy is low among the targeted patient population (the mean age of the first 30 enrolled patients is 59 years, 23 had little or no computer experience). Although the low computer literacy required us to provide laptops for the patients, we also believe that use of the system will make extrapolation of the results and experiences recorded to other patient groups simpler. Thirdly, in all users we will evaluate the subjective appreciation of the system, and hope to gain more insight into other limitations and (perceived) dangers of the use of our system.

With respect to utility, we focus on two other aspects. The first refers to the ability to detect problems arising in the home situation with the aid of the system. The second involves determining the impact on patients' quality of life.

Although evaluation of ICT in medicine is generally considered as complex,[10] understanding of the benefits, disadvantages and risks is important. We hope that our evaluation will add to that understanding. Especially as the information and communication bottlenecks described are not unique to H&N cancer care, such insights might also be valuable outside the H&N cancer domain.

Determining whether the described system's functionality is also applicable to and useful for other categories of patients needing supportive care will be the subject of future research.

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Chapter 5

Involving the patient:
a prospective study on use, appreciation and effectiveness of an information system in head and neck cancer care

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ABSTRACT

Objective: To determine use, appreciation and effectiveness of an electronic health information support system in Head and Neck (H&N) cancer care.

Design: A prospective evaluation study. The evaluated system has four different functions: (1) c*ommunication* amongst health care providers and between health care providers and patients, (2) *information* for health care providers and patients, (3) *contact with fellow sufferers*, and (4) *monitoring* of discharged patients by means of electronic questionnaires. Evaluation of the system was done both objectively using automatically created log files and stored messages, and subjectively by using paper questionnaires from patients and general practitioners (GPs).

Setting: Department of Otorhinolaryngology and Head and Neck surgery of a tertiary health care centre in The Netherlands. The system was put at patients' disposal for a period of six weeks following discharge from the hospital after surgery for H&N cancer, and was additional to standard care.

Participants: Head and Neck cancer patients, hospital physicians, members of a hospital based support team, GPs, district nurses and speech therapists.

Main outcome measures: Actual use of the system by patients and health care providers. Patients' appreciation for each of the system's four different functions. GPs' appreciation for the system. Capability to detect potential patient problems with the system.

Results: The system was used by 36 H&N cancer patients, 10 hospital physicians, 2 members of the support team, 8 GPs, 2 district nurses, and 2 speech therapists. The total number of patient-sessions was 982: an average of 27.3 sessions per patient during the 6 week study period.

In total, 456 monitoring questionnaires were completed. The support team in hospital responded with 231 actions. In 16 cases, an extra appointment was made for a patient with the hospital physician. Out of these cases, immediate action was considered necessary 8 times.

Patients appreciated the system highly, rating it with an average score of 8.0 on a 10-point scale. All patients used the monitoring function, and rated ‘monitoring’ with a mean score of 8.0 on a 10-point scale. Least used and appreciated was the ‘contact with fellow sufferers’ function.

Only 8 out of possible 36 GPs used the system, rating it with an average of 5.6 on a 10-point scale.

Conclusions: The electronic health information support system was used intensively and highly appreciated by H&N cancer patients. The system enabled the early detection of occurring health problems that required direct intervention. Information and Communication Technology (ICT) can play an additional role in the management of patients, also in a relatively elderly and computer illiterate patient population.

INTRODUCTION

Many researchers have argued that Information and Communication Technology (ICT), in principle, is able to solve the communication and co-ordination needs of health care.[1,2] However, adequate evaluation of most ICT-projects in health care is lacking,[3] and research goals are often limited to proving the feasibility of implementing new technology.[4] Besides, evaluation of ICT in health care is generally considered as complex.[5]

In Head and Neck (H&N) cancer care many information and communication bottlenecks exist.[6,7] A well-recognised problem in multidisciplinary H&N cancer care is that as many as twenty different disciplines may be involved in the management of a patient.[6] When many care providers are involved, inter professional communication often is sub-optimal.[8] As a result, care is rarely functionally integrated.[9] Especially the period following discharge is a communication 'pitfall': the patient is transferred from a well looked after hospital bed to the home environment, where the care providers usually have little experience in H&N cancer.

Based on an analysis of the information and communication bottlenecks in H&N cancer care we designed, and subsequently built, an electronic health information support system.[10]

In this paper, we report the actual use of the system. We focus on two questions. First, we assessed patient involvement by investigating the use and appreciation of the system by the patients. Second, we explored whether the system enabled the early detection of potential health problems of patients who were discharged from the hospital after surgery for H&N cancer.

METHODS

Functional description of the electronic health information support system

Prior to the study, we developed an electronic health information support system for H&N cancer patients and their health care providers. The system was designed to:

1. facilitate c*ommunication* between all involved health care providers and between health care providers and patients,
2. provide *information* to health care providers and patients,
3. facilitate *contact with fellow sufferers*,
4. facilitate the early detection of patient problems by means of *monitoring*.

Access to the functions 'communication' and 'monitoring' was restricted to authorised users only, whereas the functions 'information' and 'contact with fellow sufferers' were readily accessible to anyone with access to the Internet.

In this paper, only a limited description of the system's functionality is given. An extensive description of this system, including an overview of the bottlenecks in H&N cancer care, and considerations on the protection of patient data, can be found elsewhere.[10]

Communication. Both patients and health care providers were able to create 'messages'. For each message, the user indicated the subject and the type of message. A message could be typified as 'report', 'question', 'answer', 'medication change' or 'other'. Messages themselves were in free text.

Messages were not sent from one user to another, but all messages were stored centrally; each patient had an own 'P.O. box' to which authorised users had access. This allowed both patients and authorised health care providers to read all patient-related messages. **Figure 1** shows the message overview presented to a user when consulting the message history.

Message overview

There is/are **10** message(s) regarding [redacted]

Date	Function	Subject	Feature
16-11-2000 11:32	Speech therapist	Speech therapy	Question
16-11-2000 11:33	Speech therapist	Speech therapy	Question
13-11-2000 16:05	Head and Neck surgeon	Outpatient visit	Report
13-11-2000 11:29	Patient	Questionnaire completed	Notice
9-11-2000 12:02	Member Support Team	Alert	Report
8-11-2000 13:53	Patient	Questionnaire completed	Notice
6-11-2000 11:48	Member Support Team	Alert	Report
4-11-2000 14:33	Patient	Questionnaire completed	Notice

Figure 1. Translated screen capture of the message overview presented to a user when consulting the message history. In this example the overview shows 8 (out of 10) selected messages of a single patient. By clicking on the date/ time box, the user opens the free text message for reading.

Information. Information for patients and health care providers was supplied by a specially developed website containing general information on cancer, information on H&N cancer, treatment of H&N cancer, rehabilitation after treatment, and links to other relevant websites. Experts in the field of H&N cancer had first carefully reviewed the information to ensure its reliability.

Contact with fellow sufferers. To enable contact with fellow sufferers, we created a forum. Patients could discuss any subject, either anonymously, or under their own name.

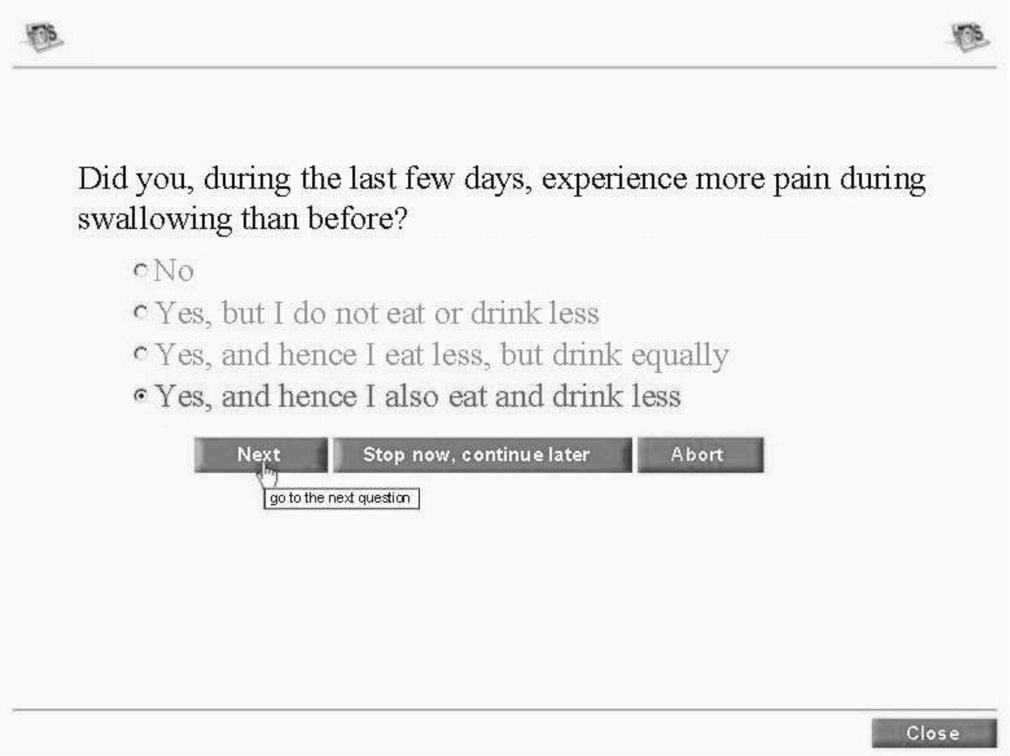
Monitoring. Patients were asked to complete electronic monitoring questionnaires on a regular basis after they were discharged from the hospital. Questionnaires provided information about the medical and psychological condition of the patient at home. The content of the questionnaire depended on the type of surgery that a patient had undergone, the time elapsed since discharge, and previous answers given by the patient. Most questions were of the multiple-choice type. A few questions could be answered in free text; for example, when patients had any questions or worries. **Figure 2** shows an example of a question that is asked during monitoring.

Every time a patient had completed an electronic questionnaire, a message was automatically added to the patient's personal ‘P.O. box’, indicating that the patient had completed a questionnaire. By clicking on this message users could read all answers given by that patient.

E-mail alerts. All possible patient answers of the multiple-choice type had in advance been classified as being ‘normal’ (not alarming) or ‘abnormal’ (pointing to a potential problem or complication). All answers in free text were considered ‘abnormal’ as they could contain questions or worries from the patient.

Every time a completed questionnaire contained one or more ‘abnormal’ answers, or whenever any user had sent a message of the type ‘question’, the system automatically generated an e-mail alert, which was sent to a support team in the hospital. This support team consisted of two nurses specialised in home care technology. The team responded according to a predetermined protocol. This protocol described which action should be undertaken in which circumstances. For example, the support team might make an extra appointment for the patient with the specialist, inform or reassure the patient, or arrange for the GP to visit the patient. Members of the support team always contacted the patient by phone and added a message (‘report’) to the patient’s personal ‘P.O. box’.

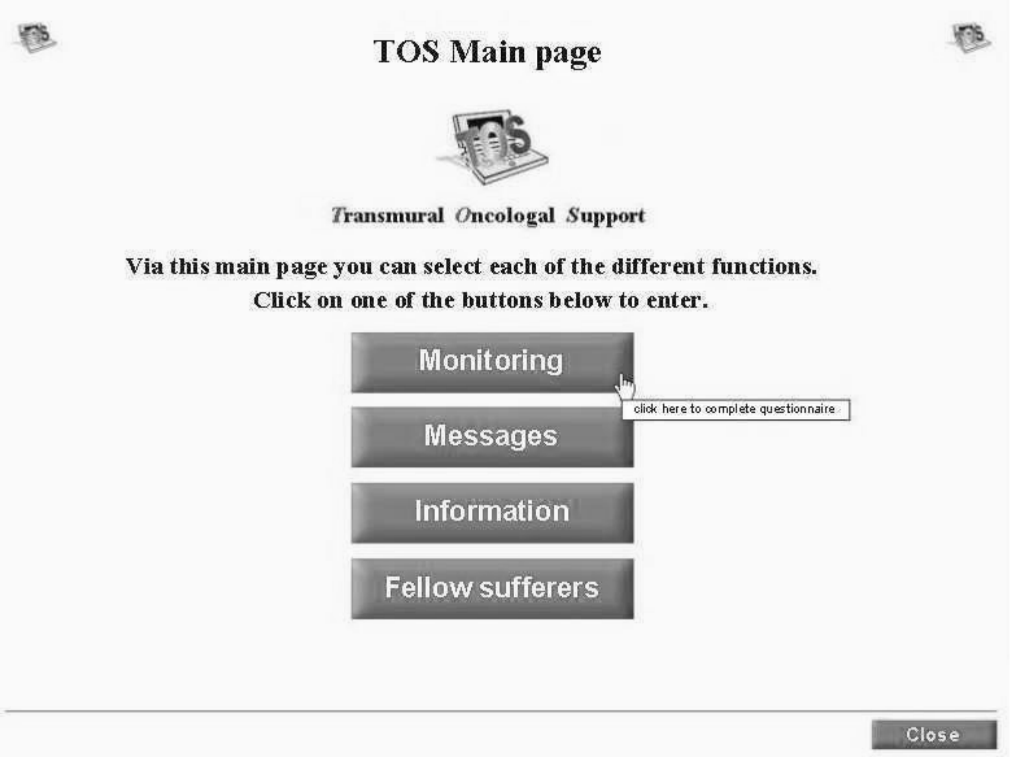
Whenever a patient had *not* filled in the electronic monitoring questionnaire for 4 days or more, the system also automatically sent an e-mail alert to the support team.



Did you, during the last few days, experience more pain during swallowing than before?

- ○ No
- ○ Yes, but I do not eat or drink less
- ○ Yes, and hence I eat less, but drink equally
- ● Yes, and hence I also eat and drink less

Figure 2. Translated screen capture of a question that is asked during monitoring. In this example, the patient answers the question: 'Did you, during the last few days, experience more pain during swallowing than before?' by: 'Yes, and hence I also eat and drink less'. The answer is highlighted after it has been selected.



TOS Main page

Transmural Oncologal Support

Via this main page you can select each of the different functions.
Click on one of the buttons below to enter.

Figure 3. Translated screen capture of the main screen for patients.

Research setting

Patients were included from September 2000 to February 2002.

Patients were eligible to participate when they had undergone:

1. a laryngectomy (removal of the speech organ),
2. a commando-procedure (removal of a tumour in the mouth or throat by splitting the lower jaw), or
3. a neck dissection (removal of the lymph nodes in the neck).

Patients furthermore needed to be able to read and write Dutch, and have a phone at home. All surgeries were performed at the Daniel den Hoed Oncology Hospital of Erasmus MC (Erasmus University Medical Centre), a tertiary health care centre in Rotterdam, The Netherlands.

Included patients received standard care: scheduled visits to our outpatient clinic, typically at 2 and 6 weeks after discharge. Additionally, we offered patients a laptop personal computer with modem to be used at home for a period of six weeks from discharge. Before discharge, a medical student instructed the patient in the hospital and supervised while the patient practised the use of the system. Furthermore, the members of the support team personally introduced themselves to the patient.

The laptop was programmed to launch the dial-in connection on start-up and go to the main screen of the system. This main screen gave access to each of the four different functions (**Figure 3**). The phone-in number was free of charge. All involved health care providers also received information on how to use the system and they were provided with access passwords. GPs could enter the system using their own computer or via the patient's laptop. For all users a telephone helpdesk was available during office hours.

Evaluation

Patients who refused to participate in our study were requested to indicate their reason. We asked all included patients to provide the following data:

- the type of surgery that the patient had undergone,
- gender, age, and marital status,
- level of education (on an 8-point scale), and
- experience with computers ('none', 'a little', 'quite a bit' or 'a lot').

Evaluation of the system was conducted in two different ways:

1. by analysing the log files and by evaluating all messages and e-mail alerts,
2. by means of a paper based questionnaire addressing the use and appreciation of the system.

System use. The system created automatic log files. From these log files, we determined:

- who had used the system and when,
- the number of sessions for each user (every new entry into the system by any single user was defined as ‘a session’),
- the average number of sessions (as well as standard deviation and range),
- the average duration (and range) of the patients’ sessions.

Messages. We counted the total number of messages. For all patient messages, we determined the type (e.g., ‘question’, ‘report’) and content of each message. Messages from health care providers were analysed in a similar way. Furthermore, the average number of completed electronic monitoring questionnaires per patient was computed.

Monitoring. We determined the percentage of electronic monitoring questionnaires that had evoked one or more e-mail alerts (pointing at potential patient problems), and we explored which questions had evoked how many e-mail alerts.

Actions of the support team. By reading all free text messages sent by the support team and the health care providers, we analysed what types of action the support team had undertaken. Next, we explored all messages created by the ENT physicians in order to determine whether the system had been able to detect patient problems that required direct medical intervention.

Questionnaires addressing use and appreciation of the system. When patients returned their laptop computer at around six weeks after discharge, they were asked to complete a paper questionnaire addressing use and appreciation of the system. At the same time, GPs were sent a similar questionnaire that could be returned by mail free of charge.

The patients’ questionnaire contained 22 questions, mostly multiple-choice. Amongst others, patients were asked to describe which of the system’s four functions they had used and how they valued each function separately, as well as the system as a whole (by giving a score from 1 to 10). Average, median and range for all scores were computed.

The GPs' questionnaire contained 16 questions, mostly multiple-choice. We asked GPs who had used the system, to rate the system on a 10-point scale, and to indicate whether they had used their own computer or the patient's laptop. All GPs were asked whether they expected that ICT would increasingly play an important role in transmural oncological care.

RESULTS

During the inclusion period, 59 patients met the inclusion criteria. From these 59 patients, 20 refused to participate (inclusion of 66%). Of the 20 patients who refused to participate 15 were male and 5 were female.

Table 1 lists the reasons for refusal. Three patients stopped shortly after inclusion; 2 were too tired to participate, and one patient died. Thus, 36 patients remained for evaluation of the electronic health information support system.

Table 1. Reasons for patients' refusal to participate in this study

Reason for refusal	Number of times
computer phobia	9
tiredness / needing some rest	4
does not like the idea of filling in paper questionnaires	2
looks after demented parent	1
moving house	1
partner does not allow patient to have access to a computer	1
no time (company ownership)	1
afraid for theft of laptop computer	1

Table 2. Patients' characteristics.

Number	**Operation type**	**Gender**	**Age**	**Marital status**	**Level of education**	**Computer experience**
01	neck dissection	m	68	married	3	none
02	neck dissection	f	70	married	2	none
03	laryngectomy	m	53	married	3	none
04	laryngectomy	f	78	widow	5	none
05	commando	m	51	married	7	a little
06	laryngectomy	m	74	married	3	quite a bit
07	laryngectomy	m	49	single	5	a lot
08	laryngectomy	m	68	widower	3	none
09	neck dissection	m	64	married	2	none
10	neck dissection	m	51	married	3	none
11	laryngectomy	m	67	married	2	none
12	laryngectomy	f	52	married	3	none
13	laryngectomy	m	54	married	4	quite a bit
14	commando	m	38	divorced	6	a lot
15	laryngectomy	m	68	single	2	none
16	laryngectomy	f	44	married	2	none
17	neck dissection	m	57	married	3	a little
18	neck dissection	m	65	divorced	6	some
19	commando	f	52	married	3	a little
20	neck dissection	f	54	married	3	a little
21	neck dissection	m	53	married	3	none
22	laryngectomy	m	74	married	4	a little
23	neck dissection	m	39	married	8	a lot
24	neck dissection	f	57	widow	4	none
25	commando	f	74	married	4	none
26	laryngectomy	m	55	married	2	none
27	laryngectomy	m	64	married	4	none
28	commando	m	70	married	6	quite a bit
29	neck dissection	m	73	married	7	a little
30	neck dissection	m	58	married	3	a little
31	commando	m	51	married	3	none
32	neck dissection	f	57	divorced	4	quite a bit
33	laryngectomy	m	71	single	7	none
34	commando	m	54	married	3	none
35	neck dissection	m	41	married	8	a lot
36	neck dissection	f	56	married	3	none

Level of education; 1: no education, 2: elementary school, 3: lower technical school, 4: secondary education, 5: middle technical training, 6: high school / college, 7: higher education, 8: university level.

Table 2 describes the patients' characteristics (n=36): 26 patients were male, 10 patients were female, and the average age was 59 years (range 38-78). Twenty of the 36 patients (56%) had no experience with computers before participation.

System use. Ten hospital physicians, 7 GPs, 2 speech therapists, 2 district nurses, 2 members of the support team, one medical student, and one researcher used the system. Total number of sessions for GPs, speech therapists, hospital physicians and support team members were 13, 32, 158, and 460, respectively.

All 36 patients used the system. The total number of patient-sessions was 982. The average number of sessions per patient was 27.3 (SD 18.4, range 4-69) in the 6 weeks study period. On average, a patient-session lasted 12 minutes. The longest patient-session lasted 1 hour and 38 minutes. Of all patient-sessions, 16 percent took place after office hours (between 19.00 and 7.00).

Messages. In total, 994 messages were sent, of which 456 were results of monitoring questionnaires answered by patients.

On average, each patient completed 12.6 questionnaires. In addition to monitoring questionnaires, 21 patients sent additional messages. These 21 patients, on average, sent 4.5 messages. Half of these messages contained a question, and half were personal reports on how the patient was doing. Two patients sent a 'test question' to test the response.

Hospital physicians sent, on average, 2.6 messages per patient. For 2 patients they did not send any messages. Messages included discharge reports, patient visits reports, and answers to patient questions. In 4 cases a message was used to communicate results of tests.

Six GPs sent on average 2.0 messages; 3 of these messages were questions.

For 9 patients the speech therapists sent messages: in those cases the average was 2.9 messages.

Monitoring. Of the 456 monitoring questionnaires, 187 (41%) evoked an e-mail alert as a result of 'abnormal answers'. In 2 patients none of the monitoring questionnaires evoked such an alert. **Table 3** shows the questions in the monitoring questionnaire that had evoked e-mail alerts.

Table 3. Subjects of questions generating e-mail alerts.

Subject of question*	**Number of e-mail alerts**
pain during swallowing	52
open question about worries	36
open item to let something be known	34
coughing in relation to food intake or cannula insertion	32
speech problems	30
shortness of breath	27
requesting additional information	25
pain in head and neck	21
problems with dental prosthesis	20
problems with insertion of cannula	18
difficulties in swallowing	18
psychosocial issues (7 different questions)	17
lumps or swelling in the head and neck region	16
viscous mucus	13
pain in shoulder	13
tiredness/fatigue	8
skin sensitivity	7
dry mouth	7
runny nose	6
nasal regurgitation	4
hearing difficulties	3
loss of taste	3
problems in contacting care providers	1

*Most questions informed about a ‘deteriorating situation since last time’.

Actions of the support team. For 34 of the 36 patients the team had to respond to questions or e-mail alerts: in total 231 actions. In 81.7% of the 231 cases requiring action, the patient's question could be answered, advice could be given, the patient could be reassured, or the patient already had an appointment to be seen in hospital within a short time.

In 17 cases, an extra appointment was made for the patient: 6 times the same day, 7 times within 2 days, 3 after more than 2 days, and once with the GP. In 8 of the 16 hospital cases the ENT physician considered it necessary to undertake direct further action, after having seen the patient. Leaking speech prostheses were replaced twice, in three cases the patient was referred to physiotherapy, one patient received antibiotics for a wound infection, one patient received a nasogastric feeding tube, and one patient was referred to a dietician.

During the study period 3 patients had additional problems requiring action. These problems were detected during regular outpatient visits and had not been picked up by monitoring. One patient was admitted for blood transfusion (for low haemoglobin), in one patient the oral flap had become dehiscent, and another patient required a nasogastric feeding tube.

For 17 patients, the team had to contact the patient to enquire why the patient had not posted any monitoring questionnaires for 4 days or more.

Results from the patients' questionnaire. All 36 patients filled in the paper-based questionnaire on use and appreciation of the system.

Table 4 shows the subjective patients' view on use and appreciation of the system. The table shows, for example, that of the 36 patients that used the monitoring function, 33 were aware of having received responses from the support team, and 31 (94%) of these 33 patients were satisfied with the response. Furthermore, the average score of all patients for the monitoring function was 8.0 on a 10-point scale.

Table 4. Use and appreciation of the electronic health information support system by patients.

Functionality	**Number (percentage) of patients that used the functionality**	**Percentage of satisfied patient users (numbers)**	**Mean score (range)**
monitoring	36 (100%)	94% (31/33)	8.0 (2-10)
ask questions	23 (64%)	91% (21/23)	7.8 (1-10)
read messages	27 (75%)	89% (24/27)	7.7 (4-10)
contact with fellow sufferers	3 (8%)	67% (2/3)	6.7 (6-8)
information	22 (61%)	91% (20/22)	7.8 (1-10)
		overall score for ‘the system as a whole’:	8.0 (4-10)

Table 5 shows the other 15 topics in the patients’ questionnaire. The table shows, for example, that 9 patients (25%) encountered (technical) problems while using the system. In these cases, the patients reported that: their system ‘didn't work anymore’ (3 times), was ‘too slow’ (3 times), the ‘password’ had been ‘forgotten’ (once), ‘handling the mouse was difficult’ (once), and that the computer ‘refused to switch off’ (once). The helpdesk solved 8 of these 9 problems by phone, in one case the patient’s laptop was replaced.

Sixteen patients made additional remarks at the end of their questionnaire. Five patients explicitly regretted the fact that they had to return their laptop; they would have liked access to the system for a longer period of time. Seven patients simply gave additional positive remarks. One such remark was: "I am just very glad I could participate. It gave me a substantial feeling of security and I will miss this".

Table 5. Additional questions asked in the patients' questionnaire.

Question	**Patients' answers (percentages)**
Did you find it difficult to learn how to use the laptop computer?	not difficult at all (61%) somewhat difficult (28%) rather difficult (3%) very difficult (8%)
Did use of the system result in increased knowledge about your illness and/or treatment?	yes (64%) no (36%)
Did use of the system affect the way in which you have been feeling during the past few weeks?	yes, a positive effect (64%) yes, a negative effect (0%) no effect (33%)
Do you feel that health care providers, by using the system, have kept a better eye on your illness?	yes (86%) no (14%)
Do you feel that use of the system has enabled you to communicate better with health care providers?	yes (75%) no (25%)
Do you feel that use of the system has led to earlier detection of encountered problems?	yes (53%) no (41%) open (6%)
Would you advise other patients in similar situations to use the system as well?	yes (89%) no (11%)
Did you encounter any technical problems while using the system?	yes, … (25%) no (75%)
Do you believe that computers have the potential to improve communication and co-operation between health care providers?	yes (86%) no (0%) don't know (14%)
Did you find it annoying to fill in electronic monitoring questionnaires regularly?	no, not at all (92%) yes, somewhat (8%) yes, a lot (0%)
Being able to contact health care providers in hospital by means of the system provided a feeling of security:	yes, a lot (72%) yes, somewhat (11%) no (17%)
If the phone-in number had not been free of charge, I would have used the system:	less often (11%) just as much (86%) more often (3%)
Do you have any suggestions on how to improve the system?	yes, … (25%) no (75%)
As a result of the last few weeks, do you plan to buy a computer of your own?	yes, I already bought one(3%) yes, but I didn't buy one yet (22%) no (75%)
Do you have any additional remarks?	yes, … (44%) no (56%)

Results from the GPs' questionnaire. From the 36 GPs, 31 returned their questionnaire (response rate of 86%).

Eight of these 31 GPs had used the system: 2 using their own computer, 6 using the patient's laptop. The fact that 8 GPs claimed to have used the system, whereas the log files showed only 7 GPs may be the result of one GP using the system with the patient's laptop (with the patient's username and password).

The 23 GP's who didn't use the system explained that: there had been no reason to use the system (12 times), GPs had no time for this (7 times), there had been no contact with the patient (twice), the GP had lost the instructions and password (once) or was not aware of the existence of the system (once).

Seven GPs rated the electronic health information support system with an average score of 5.6 on a 10-point scale (range 1-9). Of the 31 responding GPs, 19 GPs (61%) expected that ICT will increasingly play an important role in transmural oncological care, and 9 GPs (29%) had 'no opinion' on this.

DISCUSSION

Involving the patient in the care process using ICT is an active area of research.[11-13] Internet sites with health information, including health discussion groups, are abundant.[14-16] Projects where patients access their electronic medical record,[17] send e-mails to their doctors,[18-20] or send data to be monitored,[21,22] have also been described.

In this paper, we evaluated an electronic health information support system that provides the patient with the ability to communicate with their health care providers and with fellow sufferers, gives the patient access to Internet information, and allows the early detection of potential patient problems. We assessed whether patients used and appreciated the system, and whether the system enabled the early detection of potential patient problems.

The patients in our study used the system intensively (all patients used the system with an average of 4 to 5 times a week). Patients also appreciated the system highly (average overall score of 8.0 on a 10-point scale, and 89% would advise other patients in similar situations to use the system as well). This, despite their high average age, and the fact that all patients were recovering from an (often mutilating) operation for H&N cancer. Although there may have been some inclusion-bias (11 patients indicated computer related reasons for non-participating), the patients in the study group in majority were still relatively computer-illiterate (56% had no previous computer experience).

The system did allow the early detection of occurring patient problems: in 8 of the 36 patients direct medical actions by the hospital physician were required. This means that in one out of four patients, the system detected patient problems that had not (yet) been discovered during regular outpatient visits. Without the system, these problems could also have been discovered, but later. By then, they possibly could have resulted in adverse events: for example, leaking speech prostheses may cause airway infections. In addition, a wide variety of other issues emerged in which the patient needed reassurance. However, not all problems came to light through the system: 3 action-requiring patient problems were identified during routine hospital visits. This finding suggests that ICT should be complementary to, rather than replace, current practice.

GPs in The Netherlands have a long history of ICT use[23] and electronic messaging.[24,25] Of the GPs in our study, 61% believed that ICT will increasingly play an important role in transmural oncological care. It is therefore disappointing to observe that only 25% of the GPs used the system. This finding may be explained by the fact that the system was not integrated with the GP's own information system.

Literature shows that contact with fellow sufferers can be beneficial to oncological patients.[26,27] Of the four available functions, however, patients used and appreciated ‘contact with fellow sufferers’ the least. A possible explanation for this finding might be the timing of our study. The first 6 weeks after discharge may well be too soon for patients to appreciate exchanging experiences with other patients, for example because most attention and energy is still needed for recovering from the operation.

In our study, patient satisfaction for the ‘monitoring’ and ‘ask a question’ functions were high: 94% and 91%, respectively. Although patients were asked to fill in electronic monitoring questionnaires 2 to 3 times a week, the fast majority (92%) indicated that they found this ‘not at all’ annoying. The timing of our study may explain these findings. Whereas discharge normally brings an abrupt end to having health care providers nearby, the ‘monitoring’ and ‘ask a question’ functions emulated the ‘hospital bell by the bed’ in their home environment. This is also illustrated by the finding that most patients (83%) believed that being able to contact care providers by means of the system had provided a feeling of security.

Most patients found learning how to use of the system not difficult at all (61%). Although personal instruction and the system's ease of use may have contributed, general knowledge in relation to patient satisfaction with telemedicine applications is still limited[28] and requires further research, for example, on the influence on quality of care and life, and on cost effectiveness. The fact that, in this study, an elderly, relatively computer illiterate patient group, in an uncertain phase of their life, appreciated the additional value of ICT in their care shows that such groups should not be excluded.

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Chapter 5

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Chapter 6

Impact on quality of life of a telemedicine system supporting head and neck cancer patients: a controlled trial during the postoperative period at home

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Submitted

ABSTRACT

Background: Telemedicine applications are believed to have the potential of enhancing the quality of life of patients, but studies evaluating telemedicine applications are still scarce. The evidence regarding the effectiveness of telemedicine is limited and not yet conclusive.

Methods: Between 1999 and 2002 we conducted a prospective controlled trial evaluating the effects of a telemedicine application on the quality of life of head and neck cancer patients, using quality of life questionnaires that covered 22 quality of life parameters. All patients had undergone surgery for head and neck cancer at the Erasmus MC, a tertiary university hospital in The Netherlands. Patients in the intervention group were given access to an electronic health information support system for a period of six weeks starting at discharge from the hospital.

Results: In total, 184 patients were included of whom 39 entered the intervention group. Of the 22 studied quality of life parameters, five showed significantly improved quality of life in the intervention group as compared to the control group at the end of the intervention. At 6 weeks after the end of the intervention, only one of these five quality of life parameters remained significantly different.

Conclusions: This study adds to the sparse evidence that telemedicine may be beneficial for the quality of life of cancer patients.

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Chapter 7

Summary, conclusions, discussion and suggestions for future research

Chapter 7

SUMMARY

The general introduction (**chapter 1**) provides the background to the central theme of this thesis: can telemedicine improve the care for head and neck cancer patients?

In **chapter 2** we assessed the quality of life of head and neck cancer patients during the first three months after discharge from the hospital after surgery. The studied population consisted of 90 head and neck cancer patients who had undergone a total laryngectomy, neck dissection or a commando procedure. During the first three months after discharge, the quality of life already improved for 8 out of 22 variables, but for two variables the quality of life worsened during the same period. We furthermore found three patient characteristics to be associated with a lower quality of life: laryngectomy, lower levels of education, and being single.

In **chapter 3** we described a prospective survey among 104 different general practitioners evaluating the general practitioners' opinions on a received preadmission letter, informing the general practitioner that one of their patients was *going to be* admitted into hospital for surgery for head and neck cancer. Results from this study indicated that general practitioners appreciated this extra letter highly. Apparently, the letter was not considered as data overload. Despite the basic content of the preadmission letter, the majority of general practitioners considered its information as adequate.

In **chapter 4** we first provided an analysis of the information and communication bottlenecks in head and neck cancer care, which have been used to determine the functionality of a telemedicine system. Based on these problems we decided that a system should:

1. facilitate *communication* between all involved professionals, and between professionals and patients,
2. provide access to *information* for professionals and patients,
3. allow *contact with fellow sufferers* as a means to reduce uncertainty,
4. enable the early detection of patient problems by means of *monitoring.*

The chapter furthermore dealt with the issue of 'protection of patient data'. The last section of **chapter 4** described the research setting to assess the clinical feasibility and usefulness of the telemedicine system.

The evaluation of our telemedicine system (**chapters 5 and 6**) focused on the use and appreciation of the system by all users, on the system's effectiveness in detecting potential patient problems, and on the system's effects on quality of life. Whenever possible, results were compared to a control group of similar head and neck cancer patients who received standard care, without access to the telemedicine system.

In **chapter 5** we described the use, appreciation and effectiveness of our telemedicine system. In total, 36 head and neck cancer patients and their healthcare providers, including 8 general practitioners, made use of the system. The system was used intensively by patients, with an average of 4-5 times a week.

Patients appreciated the system highly, rating it with an average score of 8.0 on a 10-point scale. Best used and appreciated was the 'monitoring' function, least used and appreciated was the 'contact with fellow sufferers' function.

As a result of the 'monitoring' and 'ask a question' functions, the support team in the hospital arranged 16 extra appointments for patients with the hospital physician. Out of these cases, immediate action was considered necessary 8 times.

Only 8 out of potentially 36 general practitioners used the system, rating it with an average of 5.6 on a 10-point scale.

In **chapter 6** we presented the effects on the patients' quality of life. Patients in the intervention group, who used the telemedicine system for 6 weeks, had a better quality of life at the end of the intervention for 5 out of 22 variables, compared to the control group who did not have access to the system. At three months after discharge, and thus 6 weeks after taking away the telemedicine system, 4 of these 5 quality of life variables did not differ significantly any longer between intervention and control groups.

CONCLUSIONS

In summary, the main conclusions from chapters 2, 3, 4, 5, and 6 are:

1. Quality of life of surgically treated head and neck cancer patients in general improves during the first three months after discharge from the hospital.
2. It is possible to identify patient groups that are prone to a poorer quality of life during the first three months following discharge from the hospital after surgery for head and neck cancer.
3. General practitioners highly appreciate an extra letter informing them about intended surgery for head and neck cancer for one of their patients.
4. Most general practitioners believe that an extra letter informing them about intended surgery for head and neck cancer for one of their patients allows them to provide better care.
5. Information and communication technology can be tailored to address the communication and information bottlenecks in head and neck cancer care.
6. A telemedicine system designed to support the care for surgically treated head and neck cancer patients during the post-discharge period is highly appreciated by patients who have used this system.

7. Our telemedicine system enables the early detection of health problems that require direct medical intervention during the post-discharge period of surgically treated head and neck cancer patients.
8. A telemedicine system can be used and appreciated by a relatively elderly and computer illiterate patient population.
9. In our study, the telemedicine system did not resolve the communication bottlenecks between hospital and primary care.
10. Use of our telemedicine system during the post-discharge period improves the quality of life of surgically treated head and neck cancer patients.

DISCUSSION AND SUGGESTIONS FOR FUTURE RESEARCH

Chapter 2 identified three patient characteristics to be associated with a lower quality of life: laryngectomy, lower levels of education, and being single. These results lead to the following recommendations:

- more attention should be given to patients who are single,
- more attention should be given to the provision of information, especially to laryngectomees,
- patients should be screened for lower levels of education.

Future research could focus on the possibility (and effects) of tailoring rehabilitation programs with respect to quality of life.

Chapter 3 showed that communication between hospital and primary care should be more frequent and timely, at least in the eyes of the general practitioners. The finding that general practitioners highly appreciated a basic paper letter indicates that information exchange between hospital and primary care remains an important issue.

Whether general practitioners will likewise appreciate preadmission letters in other patient groups cannot be concluded from our results. Appreciation may have been influenced by the fact that, in general practice, head and neck cancer is rare. Also, many general practitioners indicated that the usual communications from our hospital often arrive late. Therefore, more timely information from the hospital could reduce the present appreciation of the preadmission letter.

However, problems with communication to the general practitioner are not unique to head and neck cancer. Therefore, future research could focus on the value of preadmission letters in other patient groups as well. Comparing the appreciation of electronic versus non-electronic preadmission letters could also be valuable.

The results of **chapter 3** have led to the implementation of the preadmission letter to general practitioners of head and neck cancer patients as a routine procedure in Erasmus MC - Daniel den Hoed Oncology Hospital.

Chapter 4 deals with the specification of a telemedicine system which fulfils the need for specific information and communication in head and neck cancer care. It is interesting to realise that demands for electronic systems with regard to protection of patient data are more strict in comparison with patient data on paper. **Chapter 4** also gives an introduction for **chapters 5 and 6** in which we present the results from the evaluation of our telemedicine system in head and neck cancer care.

Despite the fact that all patients were recovering from an -often mutilating- operation for head and neck cancer and notwithstanding their high average age, in **chapter 5** we observed that patients used our system frequently, and appreciated it highly. This indicates that elderly patients should not be excluded from telemedicine systems.

In **chapter 5** we furthermore found that our system detected patient problems that had not (yet) been discovered during regular outpatient visits. Without the system, these problems might also have been discovered, but later. By then, they could have resulted in adverse events. However, not all problems manifested by using the system: three action-requiring patient problems were identified during routine hospital visits. This finding suggests that information and communication technology should be complementary to, rather than replace, current practice.

General practitioners in The Netherlands have been using information and communication technology and electronic messaging already for many years. Therefore, it may be disappointing to observe that only 25% of the general practitioners used our system. The explanation might be that our system was not integrated with the general practitioner’s own information system. It can be understood that most general practitioners refused to use a separate system for just one of their many patients.

Literature shows that contact with fellow sufferers can be beneficial to oncological patients. Of the four available functions, however, patients used and appreciated ‘contact with fellow sufferers’ the least. A possible explanation for this finding might be the timing of our study. The first six weeks after discharge may well be too soon for patients to appreciate exchanging experiences with other patients, for example, because most attention and energy is needed for recovering from the operation.

The timing of our study may also explain why most patients believed that being able to contact care providers by means of the system had provided them a feeling of security, and that they found it ‘not at all’ annoying to fill in electronic monitoring questionnaires 2 to 3 times a week. Whereas hospital discharge normally brings an abrupt end to having health care providers nearby, the ‘monitoring’ and ‘ask a question’ functions simulated the 'hospital bell by the bed' in their home environment. This brings up an interesting question: was the system itself highly appreciated or was this appreciation in fact the result of established contacts (by phone or face to face) with real healthcare providers in the hospital?

From **chapter 6** we concluded that the use of a telemedicine system can improve the quality of life of head and neck cancer patients, and that our study adds to the sparse evidence that telemedicine may be beneficial for the quality of life of cancer patients. In our trial, the studied population suffered from a specific form of cancer. Surgery for head and neck cancer is often accompanied by speech problems, a factor that may have contributed to the positive influence on quality of life of our telemedicine system. Thus, we do not know whether results can be extrapolated to other forms of cancer.

One should realize that the results of **chapters 5 and 6** were obtained in a research setting where most involved hospital healthcare providers were enthusiastic about the idea of a telemedicine system for head and neck cancer patients. Our telemedicine system has not been implemented into routine patient care. Feasibility of implementing the telemedicine system into routine patients care has not been studied. It is possible that practical considerations, like the amount of available time, or the availability of a person to instruct the patients on how to use the system, could be important disincentives.

Moreover, costs will play an important role. One can wonder whether equipping patients with a laptop is the most effective way of spending the limited amount of money that is available. However, in the near future, purchasing laptops will not be necessary anymore as internet access at home will become common place.

Our telemedicine system has shown its capacity in improving the quality of life of patients. This raises the question how much we, as a society, are willing to pay for better quality of life.

Telemedicine could also save costs by enabling earlier discharge from the hospital, or if telemedicine could prevent complications that result in expensive re-admissions into hospital.

As evidence regarding the effectiveness of telemedicine is limited, and information technology will increasingly become part of everyday life, more research in this area should be high on the agenda.

In the light of this thesis, studies are needed that address issues such as:

1. determining the optimal length of time for telemedicine support,
2. cost-benefits of telemedicine in routine patient care,
3. long term quality of life effects of telemedicine,
4. the potential of telemedicine to safely establish earlier discharge of patients from the hospital.

The protocol for patient monitoring (see appendix) has been used by the University of Louisville School of Medicine in Louisville, Kentucky, for their study on a telemedicine system in head and neck cancer, funded by the National Institutes of Health.

We trust that the results from our research will also be used to start new projects on the evaluation of telemedicine for other patient groups, for example, patients with more commonly found tumours such as breast cancer or lung cancer, patients with chronic diseases or chronic pain, or patients in the palliative stage.

Hoofdstuk 8

Samenvatting, conclusies, discussie en aanbevelingen voor vervolgonderzoek

Hoofdstuk 8

SAMENVATTING

In de algemene inleiding (**hoofdstuk 1**) wordt achtergrondinformatie gegeven over het centrale thema van dit proefschrift: kan telegeneeskunde de zorg voor hoofd-halskankerpatiënten verbeteren?

Hoofdstuk 2 beschrijft de kwaliteit van leven van geopereerde hoofd-halskankerpatiënten gedurende de eerste drie maanden na hun ontslag uit het ziekenhuis. De onderzochte patiëntenpopulatie bestond uit 90 hoofd-halskankerpatiënten die een laryngectomie, halsklierdissectie, of commando-operatie hadden ondergaan. Gedurende de eerste drie maanden na ontslag uit het ziekenhuis verbeterden 8 van de 22 kwaliteit van leven variabelen, maar gedurende dezelfde periode verslechterden ook 2 kwaliteit van leven variabelen. Verder bleken drie patiëntkarakteristieken geassocieerd te zijn met een slechtere kwaliteit van leven: laryngectomie, lagere opleidingsniveaus, en alleenstaand zijn.

Hoofdstuk 3 behandelt een prospectieve evaluatie onder 104 verschillende huisartsen naar hun opinie omtrent een door hen ontvangen brief uit het ziekenhuis, waarin werd aangekondigd dat één van hun patiënten opgenomen *zou gaan worden* voor een operatie i.v.m. hoofd-halskanker. Deze brief, het zogenaamde 'bericht van voorgenomen opname', werd door de huisartsen als zeer positief gewaardeerd; zij zagen dit bericht kennelijk niet als een overdaad aan informatie. Ondanks de beperkte informatie die werd gegeven in het 'bericht van voorgenomen opname' bleken huisartsen de gegeven informatie voldoende te vinden.

Hoofdstuk 4 begint met een analyse van de informatie- en communicatieknelpunten in de zorg voor hoofd-halskankerpatiënten. Deze knelpunten zijn gebruikt om de functionaliteit van een telegeneeskundesysteem te bepalen. We besloten dat het telegeneeskundesysteem:

1. *communicatie* mogelijk moet maken tussen alle betrokken hulpverleners, en tussen hulpverleners en patiënten,
2. *informatie* moet verschaffen ten behoeve van hulpverleners èn patiënten,
3. *lotgenotencontact* mogelijk moet maken om onzekerheid te reduceren,
4. problemen bij de patiënt vroegtijdig moet opsporen d.m.v. *monitoren.*

Het hoofdstuk behandelt verder het onderwerp van 'de bescherming van patiëntengegevens'. Het laatste deel van **hoofdstuk 4** gaat over de opzet van het onderzoek waarmee we de klinische haalbaarheid en bruikbaarheid van ons telegeneeskundesysteem hebben onderzocht.

De evaluatie van ons telegeneeskundesysteem (**hoofdstuk 5 en 6**) richt zich op het gebruik van, en de waardering voor het systeem door gebruikers, op de bruikbaarheid van het systeem om problemen bij de patiënt vroegtijdig op te sporen, en op mogelijke effecten op de kwaliteit van leven van patiënten. Indien mogelijk, werden de resultaten vergeleken met een controlegroep van vergelijkbare hoofd-halskankerpatiënten die het telegeneeskundesysteem niet hadden gebruikt.

In **hoofdstuk 5** beschrijven we het gebruik van, de waardering voor, en de bruikbaarheid van ons telegeneeskundesysteem. In totaal hebben 36 hoofd-halskankerpatiënten en hun hulpverleners, waaronder 8 huisartsen, het systeem gebruikt. Patiënten gebruikten het systeem zeer intensief, met een gemiddeld gebruik van 4 tot 5 keer per week.

Patiënten waardeerden het systeem ook zeer positief: patiënten gaven het systeem gemiddeld een 8,0 als cijfer. Het meest gebruikt en gewaardeerd was de functie 'monitoren', het minst gebruikt en gewaardeerd was de 'lotgenotencontact' functie.

Als reactie op het monitoren en op vragen van patiënten maakte het steunteam in het ziekenhuis 16 extra poliklinische controleafspraken bij een arts van de afdeling KNO. In 8 van deze 16 gevallen werd directe medische actie noodzakelijk geacht.

Slechts 8 van de 36 huisartsen hebben het systeem gebruikt. Huisartsen gaven het systeem gemiddeld een 5,6 als cijfer.

In **hoofdstuk 6** presenteren we de resultaten van de studie naar de effecten van ons telegeneeskundesysteem op de kwaliteit van leven van patiënten. Patiënten in de interventiegroep, die het systeem 6 weken hadden gebruikt, bleken aan het eind van de interventie voor 5 van de 22 variabelen een betere kwaliteit van leven te hebben in vergelijking met een controlegroep zonder toegang tot het telegeneeskundesysteem. Drie maanden na ontslag, en dus 6 weken na het einde van de interventie, bleken 4 van deze 5 verschillen in kwaliteit van leven tussen de interventiegroep en de controlegroep verdwenen.

CONCLUSIES

Samenvattend zijn de belangrijkste conclusies van hoofdstuk 2 tot en met 6:

1. De kwaliteit van leven van geopereerde hoofd-halskankerpatiënten verbetert in het algemeen tijdens de eerste drie maanden na ontslag uit het ziekenhuis.
2. Het blijkt mogelijk om groepen van hoofd-halskankerpatiënten te identificeren met een verhoogde kans op slechtere kwaliteit van leven na ontslag uit het ziekenhuis volgend op een operatieve behandeling.
3. Huisartsen waarderen een ‘bericht van voorgenomen opname’ zeer, waarin wordt aangekondigd dat één van hun patiënten geopereerd *zal gaan worden* voor hoofd-halskanker.
4. De meeste huisartsen zijn van mening dat zo’n ‘bericht van voorgenomen opname’ hen in staat stelt om betere zorg aan hun hoofd-halskankerpatiënten te verlenen.
5. Informatie- en communicatietechnologie kan worden toegesneden op informatie- en communicatieknelpunten in de zorg voor hoofd-halskankerpatiënten.

6. Een telegeneeskundesysteem dat ontworpen is om de zorg voor geopereerde hoofd-halskankerpatiënten te ondersteunen wordt zeer positief gewaardeerd door patiënten die dit systeem gebruikt hebben na ontslag uit het ziekenhuis.
7. Ons telegeneeskundesysteem blijkt in staat om medische en actiebehoevende problemen vroegtijdig op te sporen bij geopereerde hoofd-halskanker-patiënten na ontslag uit het ziekenhuis.
8. Een telegeneeskundesysteem kan gebruikt èn gewaardeerd worden door een oudere patiëntenpopulatie met weinig computerervaring.
9. In onze studie is het niet gelukt om de communicatiekloof tussen ziekenhuis en huisarts te overbruggen met behulp van een telegeneeskundesysteem.
10. Gebruik van ons telegeneeskundesysteem verbetert de kwaliteit van leven van geopereerde hoofd-halskankerpatiënten na ontslag uit het ziekenhuis.

DISCUSSIE EN AANBEVELINGEN VOOR VERVOLGONDERZOEK

Hoofdstuk 2 liet zien dat de volgende drie patiëntkarakteristieken geassocieerd waren met een slechtere kwaliteit van leven: laryngectomie, lagere opleidingsniveaus, en alleenstaand zijn. Naar aanleiding van deze resultaten deden wij de volgende aanbevelingen:

- patiënten die alleenstaand zijn behoeven meer aandacht,
- informatieverstrekking aan patiënten, met name aan gelaryngectomeerden, moet worden verbeterd,
- patiënten zouden gescreend moeten worden op lagere opleidingsniveaus.

Toekomstig onderzoek zou zich kunnen richten op de mogelijkheid (en effecten) van het op maat maken van revalidatieprogramma’s om kwaliteit van leven te verbeteren.

Hoofdstuk 3 liet zien dat de communicatie vanuit het ziekenhuis met de huisarts vaker en eerder zou moeten plaatsvinden, althans volgens de huisartsen. De bevinding dat huisartsen een gewone 'papieren' brief zeer positief waarderen laat zien dat informatie-uitwisseling tussen ziekenhuis en huisarts een belangrijk onderwerp blijft. Of huisartsen een 'bericht van voorgenomen opname' net zo zouden waarderen bij andere patiëntengroepen kan niet worden afgeleid uit onze resultaten. De waardering kan beïnvloed zijn doordat hoofd-halskanker betrekkelijk zeldzaam is in de eerste lijn. Daarnaast gaven huisartsen aan dat de gangbare berichtgeving vanuit ons ziekenhuis vaak te laat plaatsvindt. Indien deze gangbare berichtgeving tijdiger zou plaatsvinden, zou dit de waardering voor het 'bericht van voorgenomen opname' kunnen verminderen.

Problemen met de communicatie tussen ziekenhuis en huisarts zijn echter niet uniek voor hoofd-halskanker. Daarom zou vervolgonderzoek zich kunnen richten op de waardering van een 'bericht van voorgenomen opname' bij andere patiëntengroepen. Daarnaast zou het vergelijken van de waardering voor geschreven versus elektronische communicatie nuttig kunnen zijn.

De resultaten van **hoofdstuk 3** hebben ertoe geleid dat het 'bericht van voorgenomen opname' aan huisartsen een vast onderdeel van de reguliere zorg geworden is voor hoofd-halskankerpatiënten in het Erasmus MC – Daniel den Hoedkliniek.

De specificaties van een telegeneeskundesysteem dat voldoet aan de specifieke behoeften aan informatie en communicatie in de zorg voor hoofd-halskankerpatiënten werden behandeld in **hoofdstuk 4**. Het is boeiend om te beseffen dat de eisen ten aanzien van de bescherming van patiëntengegevens strikter zijn voor elektronische gegevens dan voor gegevens op papier. **Hoofdstuk 4** vormt tevens een inleiding voor de **hoofdstukken 5 en 6**, waarin we de resultaten laten zien van de evaluatiestudie van ons telegeneeskundesysteem ten behoeve van hoofd-halskankerpatiënten.

Ondanks het feit dat alle patiënten aan het herstellen waren van een -vaak mutilerende- operatie voor hoofd-halskanker, en ondanks hun gemiddeld hogere

leeftijd, liet **hoofdstuk 5** zien dat patiënten ons telegeneeskundesysteem frequent gebruikten en zeer positief waardeerden. Dit suggereert dat telegeneeskundesystemen niet moeten worden onthouden aan oudere patiënten.
In **hoofdstuk 5** vonden we verder dat ons systeem in staat bleek om problemen bij de patiënt op te sporen die (nog) niet ontdekt waren tijdens de reguliere controles op de polikliniek. Zonder het telegeneeskundesysteem zouden deze problemen waarschijnlijk ook wel aan het licht gekomen zijn, maar later. In de tussentijd zouden de problemen geleid kunnen hebben tot ongewenste complicaties. Echter, niet alle problemen werden ontdekt met behulp van het systeem: drie actiebehoevende problemen werden pas ontdekt tijdens reguliere controles op de polikliniek. Deze bevinding laat zien dat informatie- en communicatietechnologie aanvullend kan zijn aan reguliere zorg, maar waarschijnlijk niet de reguliere zorg kan vervangen.

Nederlandse huisartsen maken reeds vele jaren gebruik van informatie- en communicatietechnologie en elektronische berichtgeving. In dit licht bezien is het enigszins teleurstellend om vast te stellen dat slechts 25% van de huisartsen ons systeem heeft gebruikt. Een mogelijke verklaring is dat ons systeem niet geïntegreerd kon worden met de door huisartsen gebruikte huisartsen-informatiesystemen. Het is begrijpelijk dat de meeste huisartsen geen zin hadden om een apart systeem te gebruiken voor slechts één van hun vele patiënten.

Uit eerdere publicaties kan worden afgeleid dat lotgenotencontact een gunstig effect kan hebben op kankerpatiënten. Echter, ‘lotgenotencontact’ bleek de minst gewaardeerde en minst gebruikte functie van ons telegeneeskundesysteem. Een mogelijke verklaring voor deze bevinding is het tijdstip waarop onze studie plaatsvond. De eerste zes weken na ontslag uit het ziekenhuis zouden wel eens te vroeg kunnen zijn om het delen van ervaringen met lotgenoten te waarderen, bijvoorbeeld omdat patiënten hun energie nog volop nodig hebben voor het herstel van de operatie.

Het tijdstip waarop onze studie plaatsvond zou ook wel eens kunnen verklaren waarom de meeste patiënten een gevoel van veiligheid ontleenden aan de mogelijkheid om via het telegeneeskundesysteem contact te kunnen maken met hulpverleners in het ziekenhuis, en waarom patiënten het ‘helemaal niet vervelend’ vonden om twee tot drie keer per week een elektronische vragenlijst in te vullen. Terwijl ontslag uit het ziekenhuis normaliter een abrupt einde betekent van het in de buurt hebben van hulpverleners, simuleerden de ‘monitoren’ en ‘stel een vraag’ functies de alarmbel bij het ziekenhuisbed, maar nu in de thuisomgeving. Dit werpt een interessante vraag op: werd het systeem zelf nu zo hogelijk gewaardeerd of was deze waardering feitelijk voor het gerealiseerde contact (per telefoon of tête-à-tête) met hulpverleners in het ziekenhuis?

Uit **hoofdstuk 6** concludeerden we dat het gebruik van een telegeneeskundesysteem de kwaliteit van leven van hoofd-halskankerpatiënten kan verbeteren. Wij zijn van mening dat onze studie enig bewijs toevoegt aan het zeer spaarzame bewijs dat telegeneeskunde een gunstig effect kan hebben op de kwaliteit van leven van kankerpatiënten.

Ons onderzoek werd verricht bij patiënten met een heel specifieke vorm van kanker; de behandeling van hoofd-halskanker leidt geregeld tot problemen met het spreken. Dit kan invloed hebben gehad op het geconstateerde positieve effect van ons telegeneeskundesysteem op de kwaliteit van leven van de patiënten. We weten derhalve niet of onze resultaten extrapoleerbaar zijn naar andere vormen van kanker.

U dient zich te realiseren dat de resultaten van **hoofdstukken 5 en 6** werden behaald in een onderzoekssetting, waarin veel van de betrokken hulpverleners sympathie hadden voor het idee van een telegeneeskundesysteem voor hoofd-halskankerpatiënten. Ons telegeneeskundesysteem werd niet geïmplementeerd in de reguliere zorg. De haalbaarheid van implementatie van ons telegeneeskundesysteem in de reguliere zorg hebben we ook niet bestudeerd. Het is mogelijk dat praktische problemen zoals onvoldoende beschikbare tijd bij hulpverleners, of het niet beschikbaar zijn van iemand om de patiënten te instrueren in het gebruik van het systeem, belangrijke obstakels kunnen vormen.

Daarnaast speelt geld een belangrijke rol. Men mag zich afvragen of het kopen van een laptop voor patiënten de meest effectieve manier is om met het beperkte beschikbare geld om te gaan. Echter, in de nabije toekomst zal het aanschaffen van laptops niet langer nodig zijn omdat toegang tot internet in de thuissituatie gemeengoed zal worden.

Nu gebleken is dat ons telegeneeskundesysteem in staat blijkt om de kwaliteit van leven bij patiënten positief te beïnvloeden komt tevens de vraag naar voren hoeveel wij, als maatschappij, bereid zijn te betalen voor verbeteringen in kwaliteit van leven. Telegeneeskunde zou overigens ook kosten kunnen besparen, bijvoorbeeld door vervroegd ontslag uit het ziekenhuis mogelijk te maken, of door het voorkomen van complicaties die anders hadden geleid tot kostbare heropnames in het ziekenhuis.

Omdat het bewijs naar de effectiviteit van telegeneeskunde nog steeds beperkt is, en omdat informatie- en communicatietechnologie in toenemende mate een onderdeel zal gaan uitmaken van ons dagelijks leven, zou meer onderzoek op dit gebied hoog op de agenda moeten staan.

In het kader van dit proefschrift bevelen wij het volgende vervolgonderzoek aan:

1. het bepalen van de optimale tijdsduur van de ondersteuning met behulp van telegeneeskunde,
2. kosten-batenanalysen van telegeneeskunde in de reguliere patiëntenzorg,
3. lange termijn kwaliteit van leven effecten van telegeneeskunde,
4. de mogelijkheid om met een telegeneeskundesysteem veilig vervroegd uit het ziekenhuis ontslagen te kunnen worden.

Het protocol voor het monitoren van patiënten (zie de appendix) is gebruikt door de ‘University of Louisville School of Medicine’ in Louisville, Kentucky, bij hun studie naar een telegeneeskundesysteem voor hoofd-halskankerpatiënten, betaald door ‘the National Institutes of Health’.

We vertrouwen erop dat de resultaten van onze studie ook gebruikt zullen gaan worden bij nieuwe projecten waarin telegeneeskunde geëvalueerd zal gaan worden bij andere patiëntengroepen, zoals bijvoorbeeld patiënten met meer voorkomende vormen van kanker zoals borst- of longkanker, patiënten met chronische aandoeningen of chronische pijn, of patiënten in de palliatieve fase.

Appendix

Protocol for patients’ monitoring

Appendix

ELECTRONIC MONITORING OF PATIENTS WITH HEAD AND NECK CANCER IN THE POSTOPERATIVE STAGE (AFTER DISCHARGE FROM THE HOSPITAL)

Introduction

One of the elements of our project is the electronic monitoring of patients in the period after discharge from hospital.

The primary aim of electronic monitoring is the early detection of possible problems and complications in the period following discharge. However, we hope that monitoring, next to the other applications of the electronic information system – contact with fellow sufferers, communication, and information – may contribute as well to reducing a patient's negative feelings, such as anxiety, uncertainty and 'sense of insecurity'.

A support team has been instituted to respond to the patient's answers to the questionnaire. Possible actions are, for example: making an (earlier) appointment for the patient with the ENT-specialist, giving the patient information, consoling the patient, asking the GP to visit the patient, asking the patient follow-up questions, providing emotional support, etc.

We attach great importance to the patient's autonomy, i.e. whenever feasible it is the patient's decision to receive further information or not, or be brought into contact with a care provider or not. Only if medical reasons dictate that the specialist must see the patient, for instance, such options are out of the question.

The attached protocol gives the possible answers to the questionnaire with the corresponding actions to be undertaken by the support team. After taking action, the support team will generate a message for the perusal of the patient and the care providers.

This protocol was prepared by a project group, consisting of Prof. dr. J.F.A. Pruyn, Dr. M.F. de Boer, Dr. P.W. Moorman, and Drs. J.L. van den Brink. Dr. L.-A. van der Velden critically evaluated the protocol, resulting in several modifications agreed on in joint consultation.

Appendix

Set-up of the monitoring system

The patients respond to questions tailored to their profiles. For example: those who have undergone a laryngectomy will be asked about the speech prosthesis, whereas commando-patients will not receive questions on this topic.

The questions are geared to possible problems a patient may have to face. More precisely: the questions relate to symptoms; it is essential to know how a specific symptom relates to the underlying problem or treatment consequence. For example, after a laryngectomy the patient is provided with a speech prosthesis. If this is leaky, fluid will enter the trachea when the patient drinks, and coughing will be the result. The question "are you coughing when you drink" therefore informs after the symptom coughing when drinking. The concept is thus as follows:

laryngectomy » speech prosthesis » leakage » specific symptom.

However, a laryngectomy patient's coughing is not always caused by a leaky speech prosthesis. Coughing may also result from irritation of the tracheal cannula, infections, dry air irritation, side effects of medication, and so on. The questions included in the questionnaire therefore aim at differentiating as much as possible between the different causes of a specific symptom (e.g., coughing), down to a level that makes clear what action to take. To this end the questions may be followed by one or more additional questions if necessary.

Format for electronic monitoring:

Symptom:
Underlying problem:
Group(s): Total Laryngectomy (TL), Commando Procedure (CP), Neck Dissection (ND)
Question, if necessary followed by additional question(s):
Question:
No:
Yes:
Frequency:
Support Team (ST) action(s):

Appendix

****

Symptom: Not applicable; necessary in a number of questions.
Underlying problem:
Group(s): TL, CP, ND
Question, if necessary followed by additional question(s):
Question: Did you, during the past two weeks, undergo one or more radiation sessions?
No:
Yes:
Frequency: once a week
ST-action(s): Not applicable; is applicable in various other questions.

****

Symptom: Fatigue (9)
Underlying problem:

- Cancer, operation, chemotherapy or radiotherapy
- Persistent stress resulting from having cancer
- Anemia
- Hypothyroidism
- Other

Groups: TL, CP, ND
Question, if necessary with additional question(s)
Question: Did you, during the past week, experience extreme fatigue?

No:	no action
Yes, but not as much as the week before:	no action
Yes, more than the week before:	actions 1-4

Frequency: once a week
ST-action(s):

1. Look at the answer to the question on radiation.
2. Phone patient and explain that fatigue is common in cancer patients, and possibly goes with the radiation therapy (see also the section on fatigue in the patient information set). Support the patient by providing ‘a listening ear’.
3. If patient undergoes radiation therapy: call the patient and suggest reporting the complaint to the radiotherapist at the next check-up.
4. If patient does not undergo radiation therapy: ask the family physician for hemoglobin test and inform patient that this is going to happen. (At check-up the (ENT-)specialist may feel the need for thyroid gland function testing, but this is the specialist’s responsibility. It is not routinely done in every patient, and therefore need not be mentioned to the patient). If patient has appointment in the hospital within a few days, hemoglobin testing could alternatively be done at this occasion.

Deactivate the question on fatigue.

Appendix

****

Symptom: Food moves down poorly/gets stuck (18)
Underlying problem:

- Stenosis of neopharynx
- Fibrosis, edema, recurrence, radiation reaction
- Reconstruction using e.g. pectoralis major lap

Groups: TL, CP, ND
Question, if necessary with additional question(s):
Question: Did you, during the last few days, have the feeling, more than before, that your food moves down poorly or gets stuck?

No: no action
Yes, only when eating: no action
Yes, both when eating and drinking: additional question 1
Additional question 1: Did you hence also drink much less?
No: action 1
Yes: action 2

Frequency: twice a week
ST-action(s): Look also at the answer to the question on 'pain when swallowing'; that protocol then has precedence over action 1.

1. If not radiation therapy: make appointment for patient with ENT-resident within one week; the resident may next call in the specialist or dietitian if necessary. Phone patient to inform him or her about the appointment. If radiation therapy: check whether patient has specialist check-up within one week. if not, move up the appointment. Advise patient to report the problem to the radiotherapist and recommend switching to liquid diet and pureed food, and inform him or her about the extra appointments.
2. Make appointment for patient with ENT-resident for the same or the next day, in view of dehydration risk. Inform the patient about this extra appointment and explain that it serves to find out what the problem is and if he or she is still ingesting enough fluid. Ask the patient to note down the oral intake and to bring the information. The resident may next call in the dietitian.

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Symptom: food comes out of the nose
Underlying problem:

- Stenosis
- Fibrosis, edema, recurrence, radiation reaction
- Reconstruction
- Palate-insufficiency

Groups: CP, ND
Question, if necessary with additional question(s):
Question: Did you, during the past week, have the experience, more than before, that when you swallowed food it came out of the nose?

No: no action
Yes: action 1

Frequency: once a week
ST-action(s):
Check whether the patient undergoes radiation therapy.

1. If necessary (if patient has no short-term appointment) move up the appointment with the ENT-physician or radiotherapist to within two weeks, to check whether for instance dehiscence of the pectoralis major lap has developed. Phone patient to inform him or her about the appointment and recommend pinching the nose when swallowing.

Appendix

****

Symptom: Pain when swallowing (18/29)

Underlying problem:

- Inflammation, ulcer, dehiscence, neuralgia (mechanical/edema) due to radiotherapy
- Mucositis and/or Candidiasis

Groups: TL, CP, ND

Question, if necessary with additional question(s):

Question: Did you, during the last few days, experience more pain during swallowing than before?

No: no action
Yes, but I do not eat or drink less: action 1
Yes, and hence I eat less, but drink equally: action 2
Yes, and hence I also eat and drink less: action 3

Frequency: twice a week

ST-action(s):

Check whether the patient undergoes radiotherapy.

1. Make an appointment for the patient with the radiotherapist or ENT-physician within one week, in order to investigate the cause. Phone patient to inform him or her about the appointment, and recommend pureed food. If patient undergoes radiation therapy: advise rinsing with chamomile.
2. Similar to action 1; in addition, arrange appointment with the dietitian if not yet done (fluid food) and inform patient about this appointment.
3. Make appointment for the patient with specialist or resident for the same or the next day (risk of dehydration) and inform patient about this appointment.

****

Symptom: Shortness of breath without coughing (15)

Underlying problem:

- Crusts, foreign body, narrow stoma, recurrence
- Cardiac or pulmonary

Group: TL

Question, if necessary with additional question(s):

Question: Did you, during the last few days, experience more shortness of breath or breathing problems than before?

No: no action
Yes, and I also coughed more: action 1
Yes, but I did *not* cough more: additional question 1

Additional question 1: Do your symptoms stop after using saline solution?
No: action 2
Yes: action 3

Frequency: twice a week

ST-action(s):

1. Follow the actions mentioned in the question on coughing.
2. Make an appointment for the patient with the ENT-resident within one day, to investigate the cause. Phone patient to inform him or her about the appointment. Explain that the appointment serves to investigate the cause of this increasing ‘tightness of the chest’.
3. Make an appointment with the resident for check-up (eliminate pathology) within one week. Phone patient to inform him or her about this appointment and recommend more frequent use of saline solution (prevents breathing problems by better coughing up mucus or crusts).

Appendix

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Symptom: Shortness of breath without coughing (15)
Underlying problem:

- Edema, tumor, inflammation
- Cardiac or pulmonary
- Other

Groups: CP, ND
Question, if necessary with additional question(s):
Question: Did you, during the last few days, experience more shortness of breath or breathing problems than before?
No: no action
Yes, and I also coughed more: action 1
Yes, but I did *not* cough more: action 2
Frequency: twice a week
ST-action(s):

1. Follow the actions mentioned in the question on coughing
2. Ask the family physician to call on the patient regarding this complaint (further investigation of cause). Phone patient to inform him or her that the family physician was notified of this increasing 'tightness of the chest' without coughing.

****

Symptom: Cannula does no longer fit
Underlying problem: Narrowing of tracheostoma
Group: TL
Question, if necessary with additional question(s):
Question: Do you have any problems inserting your cannula?
Inserting causes no problems: no action
Inserting is difficult, but I can still manage: action 1
Inserting is no longer possible: action 2
I don't insert it any more, but I could manage: additional question 1
Additional question 1: We recommend you briefly insert the cannula once a day to check if it still fits, unless your specialist told you that you don't have to do this any more. Did your specialist tell you that you don't have to insert the cannula any more?
No: no action
Yes: action 3
Frequency: twice a week
ST-action(s):

1. Make an appointment for the patient with resident within one week to investigate the cause. Phone patient to inform him or her about this appointment. Please advise the patient to leave the cannula in place 24 hours a day and to oil it before insertion.
2. Make an appointment for the patient with (ENT-)physician within 24 hours, preferably the same day (airway may be jeopardized). Phone patient to inform him or her about this appointment, and explain that it serves to investigate if the tracheostoma has become too narrow. Please ask the patient to bring the cannula to the appointment.
3. Deactivate this question.

****

Symptom: Viscous mucus in mouth or throat
Underlying problem:

- Stasis due to impaired swallowing mechanism
- As a result of radiation therapy: less saliva + radiation reaction

Groups: TL, CP, ND
Question, if necessary with additional question(s):
Question: Did you, during the past week, experience more (thick) mucus in your mouth or throat than before?
No: no action
Yes: additional question 1
Additional question 1: Would you like to be called about this for explanation or advice?
Yes: action 1 or 2
No: no action
Frequency: once a week
ST-action(s):
Check whether the patient undergoes radiotherapy.

1. If radiotherapy: Please ring patient and recommend rinsing with chamomile; advise patient to report the problem to the radiotherapist at the next check-up.
2. If not radiotherapy: Make appointment for the patient with speech therapist (if not yet made) to provide swallowing recommendations and (tongue) training, and inform speech therapist on nature of the complaint. Then phone patient to inform him or her about this appointment, and explain that the speech therapist will assess whether swallowing can improve and whether training could be useful.

****

Symptom: Coughing (20)

Underlying problem:

- Infectious (aspiration)
- Radiation reaction
- Bleeding / recurrence
- Pulmonary
- Other

Groups: CP, ND

Question, if necessary with additional question(s):

Question: Did you, in comparison with the days before, experience more coughing or bad fits of coughing

No: no action
Yes, and I also cough up things: additional question 1
Yes, and I do not cough up things: additional question 2

Additional question 1: Do you cough especially when drinking or also at other times?

I cough especially when drinking: action 2
I cough all day: action 3

Additional question 2: Would you like to be called about this for explanation or advice?

Yes: action 1
No: no action

Frequency: twice a week

ST-action(s):

Check whether the patient undergoes radiotherapy.

1. Please call the patient and suggest he or she consult the family doctor if the non–productive coughing does not wear off within a few days (to investigate cause).
2. Make an appointment with the speech therapist (if not yet made) within one week (it might be a question of aspiration). If appointment has been booked already: inform the speech therapist about the patient's symptom: coughing when drinking.
3. Please ring the patient and ask the following additional questions: Are you feverish? What is the color of the sputum you are coughing up? In case of fever, yellow, green or brown sputum make appointment with ENT-resident for the same or the next day (treatment of infection might be necessary). The resident could request an X-thorax. Phone patient to inform him or her about this appointment.
4. Similar to action 2, but without appointment with speech therapist.

Appendix

****

Symptom: Coughing (20)

Underlying problem:

- Leakage of speech prosthesis or fistula above stoma (aspiration)
- Irritation cannula
- Infection
- Nose function lacking
- Granulation tissue around Provox
- Radiation mucositis
- Recurrence
- Pulmonary

Group: TL

Question, if necessary with additional question(s):

Question: Did you, in comparison with the days before, experience more coughing or bad fits of coughing?

No: no action
Yes, and I also cough up things: additional question 1
Yes, and I do not cough up things: additional question 2

Additional question 1: Do you cough especially when drinking or also at other times?
I cough especially when drinking: action 1
I cough all day: action 2

Additional question 2: Do you cough especially when inserting the cannula?
Yes: action 3
No: additional question 3

Additional question 3: Would you like to be called about this for explanation or advice?
Yes: action 4
No: no action

Frequency: twice a week

ST-action(s):

1. Make appointment for Provox consultation hour with ENT-physician for the same or next day (to assess whether speech prosthesis is leaking). Phone patient to inform him or her about this appointment. Please recommend patient to use 'thick fluid' instead of 'thin fluid' until then (for instance yogurt, but no coffee). If patient has a plug it could be inserted into the speech prosthesis; then there will be no leakage (but also no speech).
2. Please call the patient and ask the following additional questions: Are you feverish? What is the color of the sputum you are coughing up? In case of fever, yellow, green, brown or bloody sputum make appointment with ENT-resident for the same or the next day (treatment of infection might be necessary). Phone patient to inform him or her about this appointment. If the patient has clear or white sputum and no fever, please recommend frequent dripping with saline solution. In order to fit on a stoma filter, please notify speech therapist where patient is treated.
3. Please console patient by telephone, and recommend oiling the cannula before inserting (salad oil, olive oil, or baby oil).
4. Please call the patient and suggest he or she consult the family physician if the non-productive coughing does not wear off within a few days (to investigate cause).

Appendix

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Symptom: Pain in the mouth when wearing dentures, or ill-fitting dentures.
Underlying problem:

- Ill-fitting dental prosthesis owing to altered anatomy after operation
- Pain from radiation reaction

Groups: TL, CP, ND
Question, if necessary with additional question(s):
Question: Is wearing your dentures more painful than before, or do your dentures no longer fit properly?

No:	no action
Yes:	action 1

Frequency: once a week
ST-action(s):

1. Please call the patient and recommend to wear the dentures as little as possible and to report the problem to the specialist at the next check-up. The specialist will decide whether it's time to make an appointment with the dentist (there is no point until the swelling has subsided). Ask the patient to take the dentures to the dentist on the next appointment.

Deactivate the question.

****

Symptom: Cannot speak clearly / Cannot make oneself understood
Underlying problem:

- Edema
- Organ parts, of the tongue for instance, have been removed
- Hypoglossal nerve dysfunction
- Inability to use dentures
- Feelings of embarrassment, etc

Groups: CP, ND
Question, if necessary with additional question(s):
Question: Do you have problems speaking clearly?

No:	no action
Yes, and over the past week it worsened:	action 1
Yes, but I had problems already and over the past week it didn't worsen:	additional question 1

Additional question 1: Would you like to be called about this for explanation or advice?

Yes:	*action 2*
No:	*no action*

Frequency: once a week
ST-action(s):
Check whether the patient undergoes radiation therapy.

1. Make appointment for the patient with the specialist within one week to investigate cause, and phone patient to inform him or her about the appointment.
2. Check whether the patient is seen by a speech therapist. If not: make an appointment with speech therapist, provided patient agrees to this, and inform the patient about the appointment. If patient already sees speech therapist: recommend he or she reports the problem to the speech therapist.

****

Symptom: Cannot speak clearly / Cannot make oneself understood
Underlying problem:

- Edema
- Organ parts, of the tongue for instance, have been removed
- Hypoglossal nerve dysfunction
- Inability to use dentures
- Speech prosthesis blocked
- Narrow PE-segment
- Hypertrophy cricopharyngeal muscle
- Feelings of embarrassment, etc

Group: TL
Question, if necessary with additional question(s):
Question: Do you have problems speaking clearly?

No:	no action
Yes, and over the past week it worsened:	action 1
Yes, but I had problem already and over the past week it didn't worsen:	additional question 1

Additional question 1: Would you like to be called about this for explanation or advice?

Yes:	*action 2*
No:	*no action*

Frequency: once a week
ST-action(s):

1. Make appointment for the patient with ENT-resident within one week to check speech prosthesis (speech problems may be caused by increased airflow resistance of the speech prosthesis and may be remedied by thoroughly cleaning or replacing the speech prosthesis). Phone patient to inform him or her about the appointment.
2. Check whether the patient is seen by a speech therapist. If not: make appointment for the patient with speech therapist and inform the patient about the appointment. If patient is already seen by speech therapist (which is highly likely), recommend patient to report the problem to the speech therapist. Please explain to the patient that speech rehabilitation after a larynx extirpation may be a long-lasting process and that radiation therapy may temporarily impair speech.

****

Symptom: Loss of taste (26)

Underlying problem:

- Radiation
- Part of the tongue removed

Groups: CP, ND

Question, if necessary with additional question(s):

Question: Is your sense of taste less intense than before?

No: no action
Yes: additional question 1

Additional question 1: Would you like to be called about this for explanation or advice?

Yes: action 1
No: no action

Frequency: once every four weeks (= one time)

ST-action(s):

Check whether the patient undergoes radiation therapy.

1. If radiation therapy: explain to the patient that this is normal when undergoing radiation therapy, and that he or she should wait and see to what extent it will recover spontaneously. Refer also to the information about radiation available on the website. If not radiation therapy: please recommend patient to report this problem to the specialist at the next check-up (no need to move the appointment up).

****

Symptom: Loss of taste (26)

Underlying problem:

- Radiation
- No longer breathing through the nose

Group: TL

Question, if necessary with additional question(s):

Question: Is your sense of taste less intense than before?

No: no action
Yes: additional question1

Additional question 1: Would you like to be called about this for explanation or advice?

Yes: action 1
No: no action

Frequency: once every four weeks (= one time)

ST-action(s):

Check whether the patient undergoes radiation therapy.

1. If radiation therapy: explain to the patient that this is normal when undergoing radiation therapy, and that he or she should wait and see to what extent it will recover spontaneously. Refer also to the information about radiation available on the website. If not radiation therapy: make appointment for the patient with speech therapist for smell training; if appointment was made already please report to speech therapist. Phone patient to inform him or her about the appointment. If patient is seen by a speech therapist who has no experience with smell training, please ask speech therapist to consult with a specialized speech therapist.

****

Symptom: Pain (29)

Underlying problem: Manifold, including:

- Post neck dissection pain
- Myalgia
- Shoulder pain
- Temporomandibular disorders (TMD)
- Functional
- Recurrence
- Other

Groups: TL, CP, ND

Question, if necessary with additional question(s):

Question: Did you, during the past week, experience more severe pain than before?

No:	no action
Yes, and the pain is somewhere in my head or neck :	action 1
Yes, and the pain is in my shoulders:	action 2
Yes, and the pain is NOT in my head, neck or shoulders:	action 3

Frequency: once a week

ST-action(s):

Please refer also to the question on swelling in the neck, this protocol has precedence.

Check whether the patients undergoes radiation therapy.

1. Move up appointment with radiotherapist or ENT-physician (within one week, exclude pathology), and phone patient to inform him or her about the appointment.
2. Please ring the patient to ask whether he or she has physiotherapy. If not, consult with specialist about possible benefit of physiotherapy, and (if benefit) ask the family physician to prescribe this. Also inform the patient about this.
3. Please give the patient a call and ask what the problem is. Next ask the family physician to visit the patient (investigate cause, start treatment if necessary). Phone patient to inform him/her about this.

Appendix

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Symptom: Swelling in the neck
Underlying problem:

- Edema
- Recurrence of tumor
- Abscess
- Hematoma
- Seroma

Groups: TL, CP, ND
Question, if necessary with additional question(s):
Question: Did you, during the last few days, notice one or more swellings or lumps that were not there before?
No: no action
Yes: additional question 1
Additional question 1: Are you feverish?
Yes: action 1
No: additional question 2
Additional question 2: Does the swelling decrease during the day?
Yes: action 2
No: action 1
Frequency: twice a week
ST-action(s):

1. Make appointment for the patient with ENT-resident for the same day or the next to exclude pathology. Phone patient to inform him or her about this appointment and explain that the doctor will try to find out what is the matter.
2. Make appointment for the patient with ENT-resident within one week to exclude pathology. Phone patient to inform him or her about this appointment and explain that the doctor will try to find out what is the matter. Meanwhile reassure the patient that it is probably a matter of edema.

****

Symptom: Runny nose
Underlying problem: No breathing through the nose
Group: TL
Question, if necessary with additional question(s):
Question: Do you, more than before, frequently have a runny nose?
No: no action
Yes: additional question 1
Additional question 1: Would you like to be called about this for explanation or advice?
Yes: action 1
No: no action
Frequency: once every four weeks (= one time)
ST-action(s):

1. Please give the patient a call and reassure him or her: explain that this problem results from the intervention because breathing is no longer through the nose, and that eventually it will ease off by itself. Recommend the patient to report the problem to the specialist at the next regular check-up.

****

Symptom: Skin feels numb
Underlying problem:

- Postoperatively: nerves transected
- Polyneuropathy

Groups: TL, CP, ND
Question, if necessary with additional question(s):
Question: Does your skin, more than before, feel numb in places?
No: no action
Yes, somewhere on my head and/or neck : additional question 1
Yes, somewhere else on my body additional question 2
Additional question 1: Would you like to be called about this for explanation or advice?
Yes: action 1
No: no action
Additional question 2: Would you like to be called about this for explanation or advice?
Yes: action 2
No: no action
Frequency: once every four weeks (= one time)
ST-action(s):

1. Please call the patient and reassure him or her: explain that the numb feeling is a result of the intervention (nerves have been cut). The body area that feels numb will eventually become smaller by itself, and besides, habituation will occur in the places where the skin remains numb. However, this process might take as long as a year.
2. Please recommend patient to report this to the specialist at the next check-up (no need to move the appointment up).

****

Symptom: Deafness
Underlying problem:

- Perceptive (e.g. presbyacusis)
- Conductive (otitis media, cerumen, etc.)

Groups: TL, CP, ND
Question, if necessary with additional question(s):
Question: Do you have the feeling that your hearing is less acute than before?
No: no action
Yes: additional question 1
Additional question 1: Would you like to be called about this for explanation or advice?
Yes: action 1
No: no action
Frequency: once every four weeks (= one time)
ST-action(s):

1. Please give the patient a ring. Make appointment for the patient with ENT-resident to examine the ears and determine the usefulness of additional audiometry.

****

Symptom: Dry mouth
Underlying problem: Reduced saliva production as a result of radiation therapy
Groups: TL, CP, ND
Question, if necessary with additional question(s):
Question: Do you more often have a dry mouth than before the operation?

No:	no action
Yes:	additional question 1

Additional question 1: Would you like to be called about this for explanation or advice?

Yes:	*action 1*
No:	*no action*

Frequency: once every four weeks (= one time)
ST-action(s):
Check whether he patient undergoes radiation therapy.

1. If radiation therapy: Please call the patient and explain that this is a normal radiation side effect. Recommend the patient to report the problem to the specialist at the next check-up. Also ask the patient to make an appointment with the hospital dentist after radiation therapy has finished. The dentist may prescribe artificial saliva. If not radiation therapy: Call the patient, and recommend reporting the problem to the specialist at the next check-up (investigate cause / give advice)

****

Symptom: Uncertainty, defined as a (personally experienced) need of information
Underlying problem:

- As a result of the cancer (threatened self-image, loss of control, negative feelings, uncertainty)
- As a result of the treatment

Groups: TL, CP, ND
Question, if necessary with additional question(s):
Question: Would you, next to the information already given to you, like to receive additional information? Information about your disease, treatment, the way in which fellow sufferers cope with their disease, and so on. If your answer is ‘yes’, we will phone you.

No, I don’t need this:	no action
Yes, I would like to know more about something or other:	action 1

Frequency: once a week
ST-action(s):

1. Please phone the patient and try to find out what information he or she wishes to receive. Dependent on the nature of the question you may want to consult with the medical professionals involved or others. Act according to the circumstances, as this cannot be fully protocolised. You may also want to refer the patient to the information available in the logbook or on the website.

****

Symptom: State of tension, Anxiety, Agitation

Underlying problem:

- As a result of cancer
- Another cause, for instance (already existing) relational problems

Groups: TL, CP, ND

Question, if necessary with additional question(s):

Question: Did you, during the past week, experience tension, anxiety, or other feelings of restlessness more intensively than before?

Not at all: no action
Yes, a little: no action
Yes, a lot: additional question 1

Additional question 1: Would you like to talk about this with someone? For instance your specialist or family physician, a fellow sufferer, a psychologist, social worker, or spiritual adviser. If your answer is 'yes', we will give you a ring.

No, there's no need: no action
Yes, I would like to talk about it with someone: action 1

Frequency: once a week

ST-action(s):

1. Please phone the patient and try to find out with whom he/she would like to talk, or if the patient doesn't know, who would be the right person. Ask the patient what exactly he or she is anxious about. Ask if the patient himself or herself has an idea why he or she is increasingly troubled by anxiety or feelings of restlessness. Next make an appointment for the patient if the preferred person is not the family physician. If the patient would like to talk with the family physician, please ask the family physician to get in touch with the patient.

****

Symptom: Being in despair about the future

Underlying problem:

- As a result of the cancer (threatened self-image, loss of control, negative feelings, uncertainty
- Another cause
- Fear for remittance of the disease

Groups: TL, CP, ND

Question, if necessary with additional question(s):

Question: Did you, during the past week, worry seriously about your future more than before?

Not at all: no action
Yes, a little : no action
Yes, a lot : additional question 1

Additional question 1: Would you like to talk about this with someone? For instance your specialist or family physician, a fellow sufferer, a psychologist, social worker, or spiritual adviser. If your answer is 'yes', we will give you a ring.

No, there's no need: no action
Yes, I would like to talk about it with someone: action 1

Frequency: once a week

ST-action(s):

1. Please phone the patient and try to find out with whom he/she would like to talk, or if the patient doesn't know, who would be the right person. Ask if the patient himself or herself has an idea why he or she is increasingly worried about the future. Next make an appointment for the patient if the preferred person is not the family physician. If the patient would like to talk with the family physician, please ask the family physician to get in touch with the patient.

Appendix

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Symptom: Dejection, Worrying, Having difficulty falling asleep

Underlying problem:

- As a result of the cancer
- As a result of the treatment
- Another cause

Groups: TL, CP, ND

Question, if necessary with additional question(s):

Question: Did you, during the past week, suffer more than before from dejection, worrying or having difficulty falling asleep?

Not at all: no action

Yes, a little: no action

Yes, a lot: additional question 1

Additional question 1: Would you like to talk about this with someone? For instance your specialist or family physician, a fellow sufferer, a psychologist, social worker, or spiritual adviser. If your answer is 'yes', we will give you a ring.

No, there's no need: no action

Yes, I would like to talk about it with someone: action 1

Frequency: once a week

ST-action(s):

1. Please phone the patient and try to find out with whom he/she would like to talk, or if the patient doesn't know, who would be the right person. Inform after the cause. Next make an appointment for the patient if the preferred person is not the family physician. If the patient would like to talk with the family physician, please ask the family physician to get in touch with the patient.

****

Symptom: Feeling that others fail to understand what you're going through, Feeling to be all on your own

Underlying problem:

- As a result of the cancer
- As a result of the treatment
- Another cause

Groups: TL, CP, ND

Question, if necessary with additional question(s):

Question: Did you, during the past week, have the feeling more than before that you're all on your own, or that others fail to understand what you're going through?

Not at all: no action

Yes, a little: no action

Yes, a lot: additional question1

Additional question 1: Would you like to talk about this with someone? For instance your specialist or family physician, a fellow sufferer, a psychologist, social worker, or spiritual adviser. If your answer is 'yes', we will give you a ring.

No, there's no need: no action

Yes, I would like to talk about it with someone: action 1

Frequency: once a week

ST-action(s):

1. Please phone the patient and try to find out with whom he/she would like to talk, or if the patient doesn't know, who would be the right person. Inform after the cause. Next make an appointment for the patient if the preferred person is not the family physician. If the patient would like to talk with the family physician, please ask the family physician to get in touch with the patient.

****

Symptom: Difficulty accepting yourself for what you are
Underlying problem:

- As a result of the cancer
- As a result of the treatment
- Another cause

Groups: TL, CP, ND
Question, if necessary with additional question(s):
Question: Did you, during the past week, have more difficulty accepting yourself for what you are than before?

Not at all: no action
Yes, a little: no action
Yes, a lot: additional question1

Additional question 1: Would you like to talk about this with someone? For instance your specialist or family physician, a fellow sufferer, a psychologist, social worker, or spiritual adviser. If your answer is 'yes', we will give you a ring.

No, there's no need: no action
Yes, I would like to talk about it with someone: action 1

Frequency: once a week
ST-action(s):

1. Please phone the patient and try to find out with whom he/she would like to talk, or if the patient doesn't know, who would be the right person. Inform after the cause. Next make an appointment for the patient if the preferred person is not the family physician. If the patient would like to talk with the family physician, please ask the family physician to get in touch with the patient.

****

Symptom: Problems with appearance, Reluctance to go out
Underlying problem:

- As a result of the cancer
- As a result of the treatment
- Another cause

Groups: TL, CP, ND
Question, if necessary with additional question(s):
Question: Did you, during the past week, experience more problems relating to your appearance or your reluctance to go out than before?

Not at all: no action
Yes, a little: no action
Yes, a lot: additional question1

Additional question 1: Would you like to talk about this with someone? For instance your specialist or family physician, a fellow sufferer, a psychologist, social worker, or spiritual adviser. If your answer is 'yes', we will give you a ring.

No, there's no need: no action
Yes, I would like to talk about it with someone: action 1

Frequency: once a week
ST-action(s):

1. Please phone the patient and try to find out with whom he/she would like to talk, or if the patient doesn't know, who would be the right person. Inform after the cause. Next make an appointment for the patient if the preferred person is not the family physician. If the patient would like to talk with the family physician, please ask the family physician to get in touch with the patient.

Appendix

****

Symptom: Problems relating to contact with care providers
Underlying problem:

- Care provider is busy
- Care provider has insufficient expertise
- Disturbed relationship between care provider and patient
- Other

Groups: TL, CP, ND
Question, if necessary with additional question(s):
Question: Do you have more problems in getting along with one or more care providers involved in your treatment than before? If your answer is 'yes' we will give you a ring.

No:	no action
Yes:	action 1

Frequency: once every two weeks
ST-action(s):

1. Please call the patient and ask what the problem is. Ask the patient if he or she would like to discuss it with the caregiver(s) in question. If not, be a good listener, if yes, consult with the caregiver(s) in question about possible follow-up steps.

****

Symptom: Various 1
Underlying problem: Various 1
Groups: TL, CP, ND
Question, if necessary with additional question(s):
Question: Do you have any other questions or are there other things you worry about? If your answer is 'yes' we will give you a ring.

No:	no action
Yes, namely… :	action 1

Frequency: twice a week
ST-action(s):

1. If necessary please consult with care provider(s) in question. Call the patient if necessary. Act according to the circumstances.

****

Symptom: not applicable; concluding question
Underlying problem: Not applicable
Groups: TL, CP, ND
Question, if necessary with additional question(s):
Question: Is there anything else you would like to let us know?

No:	no action
Yes, namely…… :	action 1

Frequency: twice a week
ST-action(s):

1. Dependent on the nature of the remark(s): please consult with care provider(s) in question. Call the patient if necessary. Act according to the circumstances.

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Dankwoord

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Leden van de stuurgroep:
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Prof. dr. ir. J.H. van Bemmel
Prof. dr. C.D.A. Verwoerd
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Dr. P.W. Moorman
Dr. F.G. van den Brink
Mr. J.M.M. van den Brink-Wijnans
Dr. M.H. van den Brink-Wieringa

Prof. dr. ir. J.H. van Bemmel
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Curriculum Vitae

Curriculum Vitae

Jacobus Leonardus (Jaap) van den Brink was born in Nijmegen on March 11th 1970. In 1988 he passed his final exams at the Dominicus College in Nijmegen and that same year he started medical studies at the University of Nijmegen. During his studies he was member of the Faculty governing body for one year and of the Faculty advisory committee for 2 years. In 1994 he graduated from medical school, followed by a research project and an elective at the ENT department of the St Radboud University Hospital in Nijmegen, with Prof. dr. P. van den Broek. After completing his medical studies in January 1997, he worked for one year as SHO at the ENT department of the Queen Alexandra Hospital in Portsmouth, UK.
During 1998 he worked as non-training registrar at the ENT - Head and Neck Oncology department at the Daniel den Hoed Oncology Hospital, in Rotterdam. From October 1998 he held a double appointment as research registrar at the department of ENT of the University Hospital of Rotterdam and the department of Medical Informatics of the Erasmus University of Rotterdam, working on the research for this thesis. From August 2001 to August 2005 he specialised as ENT surgeon at the University Hospital of Rotterdam (subsequently renamed Erasmus University Medical Centre), under the supervision of Prof. dr. L. Feenstra. The training included three rotations of 5 months each at the Zuider Hospital, Rotterdam, Gooi-Noord Hospital, Blaricum, and Leyenburg Hospital, The Hague, under the supervision of Dr. L.J.J.M. Boumans, Dr. S. van der Baan, and Dr. E. Rijntjes, respectively. During his training he was president of the national ENT registrars Union for two years. In 2003 he received the Erasmus EMD award for the best scientific contribution to the EMD conference in The Netherlands. From September 2005 he has been working as Fellow in Paediatric Otolaryngology at the Sophia Children's Hospital of the Erasmus University Medical Centre, and is looking forward to starting as ENT surgeon at the TweeSteden Hospital in Tilburg and Waalwijk from May 29th 2006, where T.L. Dijkstra, J.C.R. van Drie, and A.M.L. den Heeten-van Gemert will be his new associates.

He has been married to Dr. Marjan Henriet van den Brink-Wieringa since November 21st 1998. They have three children: Willem (2001), Hanna (2003), and Jolijn (2005).

Curriculum Vitae

Jacobus Leonardus (Jaap) van den Brink werd geboren op 11 maart 1970 te Nijmegen. In 1988 behaalde hij zijn eindexamen Gymnasium ß aan het R.K. Lyceum Dominicus College te Nijmegen. In hetzelfde jaar begon hij met zijn studie geneeskunde aan de Katholieke Universiteit Nijmegen. Tijdens zijn studie was hij onder andere 1 jaar lid van het faculteitsbestuur en was hij gedurende 2 jaar lid van de faculteitsraad. In 1994 werd het doctoraalexamen behaald, waarna hij een wetenschappelijke stage volgde op de KNO-afdeling van Prof. dr. P. van den Broek in het Academisch Ziekenhuis Nijmegen St Radboud. Tijdens zijn co-schappen werd hier ook het keuze co-schap KNO gevolgd. Na zijn artsexamen in januari 1997 was hij gedurende 1 jaar werkzaam als senior house officer op de KNO-afdeling van het Queen Alexandra Hospital te Portsmouth, Verenigd Koninkrijk. In 1998 werkte hij als AGNIO op de afdeling KNO/ Hoofd-Hals chirurgie van de Daniel den Hoedkliniek in Rotterdam. Vanaf oktober 1998 had hij een dubbelaanstelling bij de afdeling KNO van het Academisch Ziekenhuis Rotterdam en de afdeling Medische Informatica van de Erasmus Universiteit Rotterdam en was zijn hoofdtaak het verrichten van het wetenschappelijk onderzoek waarvan dit proefschrift verslag doet. Vanaf augustus 2001 tot en met augustus 2005 specialiseerde hij tot KNO-arts in het Academisch Ziekenhuis Rotterdam, in deze periode omgedoopt tot Erasmus MC, met als opleider Prof. dr. L. Feenstra. Drie perifere stages van elk vijf maanden werden in deze periode gevolgd in het Zuiderziekenhuis, ziekenhuis Gooi-Noord en het Leyenburg ziekenhuis (B-opleiders respectievelijk: Dr. L.J.J.M. Boumans, Dr. S. van der Baan en Dr. E. Rijntjes). Tijdens zijn specialisatie was hij gedurende twee jaar voorzitter van de landelijke KNO-assistentenvereniging. In 2003 ontving hij de Erasmus EMD prijs voor de beste wetenschappelijke presentatie tijdens het 13^{e} symposium 'Huisarts, Specialist en het Elektronische Medisch Dossier'. Vanaf augustus 2005 tot 1 mei 2006 is hij werkzaam als fellow in het Erasmus MC, locatie Sophia, met als aandachtsgebied de Paediatrische KNO. Vanaf 29 mei 2006 zal hij met veel genoegen gaan werken als KNO-arts in het TweeSteden ziekenhuis in Tilburg en Waalwijk, waar hij zich zal associëren met collegae T.L. Dijkstra, J.C.R. van Drie en A.M.L. den Heeten-van Gemert.

Sinds 21 november 1998 is hij gehuwd met Dr. Marjan Henriet van den Brink-Wieringa. Uit dit huwelijk kwamen drie kinderen voort: Willem (2001), Hanna (2003) en Jolijn (2005).