

Head and neck cancer:

Factors related to patient delay in seeking medical care



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Head and neck cancer: Factors related to patient delay in seeking medical care

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In het boek wordt de relatie tussen de vertraging in het zoeken naar medische hulp en de uitkomst van de behandeling van hoofd- en halskanker bestudeerd.

De auteur heeft een uitgebreid onderzoek gedaan naar de factoren die tot vertraging in het zoeken naar medische hulp leiden. Het onderzoek is uitgevoerd bij patiënten met hoofd- en halskanker die zijn behandeld aan het Universitair Ziekenhuis in Utrecht. De resultaten van het onderzoek zijn in dit boek gepresenteerd. Het boek is bedoeld voor artsen, verpleegkundigen en andere medewerkers in de gezondheidszorg. Het boek is ook geschikt voor patiënten en hun familie. Het boek is geschreven in het Nederlands en is voorzien van een samenvatting in het Engels. Het boek is te koop bij de uitgeverij.

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In 1998 en in 2003 werd in de Oude Kerk in Amsterdam een tentoonstelling gehouden met onder andere schilderijen, tekeningen, beeldhouwwerk en keramiek gemaakt door mensen die met kanker zijn geconfronteerd. Deze tentoonstelling werd georganiseerd door de Stichting Kanker in Beeld. Deze stichting van ex-patiënten en hulpverleners is opgericht om patiënten en hun naasten bekend te maken met de mogelijkheden van creatieve expressie bij de verwerking van de diagnose kanker. Van de tentoonstelling in 2003 werd bovengenoemd boek samengesteld. De afbeelding 'Verdriet' op de omslag, gemaakt door M. van der Meij, is één van deze tentoongestelde kunstwerken. De maakster geeft aan dat ze met beeldhouwen is begonnen nadat ze borstkanker heeft gekregen. De beeldjes die ze maakt geven emoties weer die te maken hebben met de verwerking van de diagnose en het gevecht om er weer bovenop te komen.

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Hoofd-halskanker:
factoren gerelateerd aan uitstel in het zoeken van medische hulp

(met een samenvatting in het Nederlands)

Proefschrift

Ter verkrijging van de graad van doctor aan de Universiteit te Utrecht
op gezag van de Rector Magnificus, Prof. Dr. W.H. Gispen
ingevolge het besluit van het College voor Promoties
in het openbaar te verdedigen
op woensdag 1 juni 2005 des middags te 12.45 uur.

door

Debbie Marianne Tromp

geboren op 20 november 1974 te Haarlem

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Aan mijn ouders

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Head and neck cancer

Incidence and risk factors

Tumours of the head and neck make up approximately 4% of all newly diagnosed malignancies (excluding non-melanoma skin cancer), and are the seventh and eleventh most common cancers in men and women, respectively.^{1,2} In the Netherlands approximately 2,500 patients per year are newly diagnosed with head and neck cancer.³

The term 'head and neck' cancer does not refer to a single entity but rather to a diverse spectrum of malignancies that arise from the epithelial lining of the upper part of the aerodigestive tract.⁴ Tumours of the brain, eye, thyroid, skin and (non) Hodgkin's disease are not included in this category. More than 90% of all head and neck tumours are squamous cell carcinoma.⁵ Approximately 32% of the newly diagnosed tumours of the head and neck in the Netherlands occur in the oral cavity, 28% in the larynx, 18% in the pharynx, 8% in the lip, 5% in the major salivary glands, and 9% in the remaining sites (nasopharynx, nasal cavity, paranasal sinus and middle ear).⁴

It has been demonstrated that the most important risk factors for squamous cell carcinoma of the head and neck are tobacco use and excessive alcohol consumption. The combined effect of heavy drinking and smoking increases the risk of developing head and neck carcinoma even more.^{6,7} Patients who smoke and drink have an increased risk of a second primary tumour predominantly in the head and neck, but also in the lungs.⁸ The sex ratio (male/female) for head and neck cancer varies from 6:1 for the larynx to 2:1 for the oral cavity and pharynx.⁹ Since more and more women smoke, the incidence of head and neck cancer is increasing in women.² For both men and women, the incidence of oral and pharyngeal cancer is increasing in the Netherlands, as well as in other European countries.² It has been shown that since the late 1980s the mortality from head and neck cancer has increased in most European countries, most probably as a result of a change in alcohol consumption over the past 30 years.^{7,8}

Increasing incidence of advanced tumours

Head and neck tumours generally present with distinct and early symptoms, such as hoarseness, a lesion in the mouth, or complaints relating to mastication, swallowing and speech. It is therefore reasonable to assume that these symptoms can be clearly recognised by patients or their relatives. Moreover, most of the head and neck locations are easily accessible for examination purposes by a physician or a dentist. Notwithstanding these favourable conditions for the detection of head and neck

Chapter 1

Introduction

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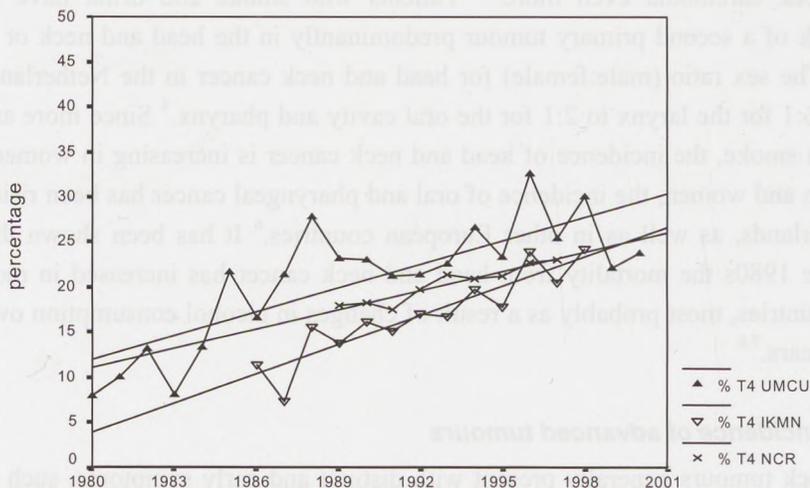
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tumours at an early stage, the proportion of patients presenting with an advanced primary tumour of the head and neck is increasing. A study by Brouha et al. (2003) showed that among all newly diagnosed patients in the University Medical Center Utrecht over the last twenty years, the relative number of patients with an advanced tumour had increased significantly.⁹ In the period 1980-82, one out of nine patients had an advanced tumour (T4), while in the period 1998-2000, this rose to one out of four patients. These results were comparable to regional and national figures in which the same trend of a growing number of patients with an advanced tumour was observed (see Figure 1). International studies also show an increase in more advanced head and neck cancer at the primary site.^{10,11} This is an unfavourable situation as advanced tumours lead to worse survival rates and a poorer quality of life after treatment.^{12,13}

The overall five-year survival rate is approximately 65% of patients with cancer of the larynx and 50% of patients with cancer of the oral cavity or pharynx.⁴ However, the survival rate is largely dependent on tumour stage at diagnosis. Generally, for most sites, the five-year survival rate for small tumours is 70 to 90%, but this rate drops to below 30% for patients diagnosed with large tumours with lymph node metastasis.^{2,12}

Figure 1. Percentage of T4 stage head and neck carcinomas in the University Medical Center Utrecht (UMCU), regional (IKMN), and national (NCR)



UMCU: University Medical Center Utrecht data from 1980 to 2000

IKMN: Netherlands Regional Cancer Registry Mid Netherlands data from 1986 to 1998 including data from UMCU

NCR: Netherlands Cancer Registry data from 1989 to 1997 including data from IKMN

In general, head and neck cancer and its treatment have a huge impact on quality of life. The location of the tumour and the often disfiguring treatment interfere with some of the most fundamental aspects of daily functioning, such as talking, breathing, and eating. Patients have to cope with a range of disease-related symptoms and side-effects of treatment. For example, patients may experience swallowing problems, impairment of speech, pain, or a dry mouth after treatment. Moreover, unlike other forms of cancer, the disfigurement after head and neck cancer surgery cannot be hidden. In particular, patients who are diagnosed with an advanced tumour need extensive and costly treatment, in most cases both surgery and radiotherapy. Patients who have undergone this treatment reported a lower quality of life than those who have undergone either surgery or radiotherapy alone.¹⁴⁻¹⁶ Therefore, to reduce morbidity and mortality as well as treatment costs, early detection of head and neck cancer is extremely important.

Delay in diagnosis

Delay in cancer diagnosis

An impeding factor for early detection of cancer is delay in diagnosis. Diagnostic delay can be defined as the number of days from the awareness of the first symptoms to eventual diagnosis. Considering that the time lag may occur when seeing a physician for symptoms, when being diagnosed with a medical condition, or even when beginning treatment for the condition, both patients and physicians can be “delayers”.¹⁷ Therefore, a distinction is often made between patient delay and professional delay. Patient delay can be described as the time between the awareness of the first symptom and the first medical appointment. Professional delay can be described as the time from the patient’s first medical consultation to the definitive diagnosis. A frequently used cut-off for serious patient delay has been a time period of 3 months or more between symptom discovery and initial seeking of a diagnosis.¹⁸ Previous research involving cancer patients has indicated that, according to this definition, the overall number of patients delaying consultation ranges from 23 to 76%.¹⁹

An important question is whether delay matters, that is, does delay make a difference in prognosis? Several studies regarding various types of cancer indicated that survival is better for cancer patients who had not shown diagnostic delay.²⁰⁻²⁴ That the stage of the disease is the key mediating factor in the delay-survival link has been affirmed by several studies.^{21,25-27} They found that more delay was related to more advanced disease, which in turn leads to worse survival. Thus, for cancers that are

relatively curable when caught at an early stage, delay clearly makes a difference in terms of survival. With regard to head and neck cancer, the results concerning the relationship between delay and tumour stage and survival are inconsistent and are addressed in the next paragraph.

Delay in head and neck cancer diagnosis

Literature shows that among head and neck cancer patients the average total diagnostic delay (the period from the first symptoms until definitive diagnosis) ranged from 3 to 7.5 months,²⁸⁻³⁴ while the median total diagnostic delay ranged from 1.5 to 6 months.^{23,29,34-40} Total diagnostic delay of less than three months was seen in 42-66% of the patients,^{31,36,41-43} while a total delay of more than six months occurred in 21-41% of the patients.^{36,41-44} Ranges of delay were reported of one day to even eight years.^{31,45,46} It can be concluded that there is a large variation between studies, although the different statistical measures that were used to describe delay make the studies hard to compare.

Several studies made a distinction between patient and professional delay,^{23,29,32,34,36,38-40,42,44-49} or focused on describing either patient delay⁵⁰ or professional delay.^{31,35,51,52} Literature shows that the average patient delay among head and neck cancer patients varied from 7.4 weeks to 6 months,^{29,32,34,45-48,50} while the median patient delay varied from 1 to 4 months.^{23,29,36,38-40,42,46,47,49} The percentage of patients who consulted a doctor within 1 month ranged from 37% until 58%^{29,34,36,39,45,47,48,50} and 20-34% postponed seeking medical care for more than three months.^{34,36,45,47,48,50} An exception to this figures were two studies that involved only patients with laryngeal cancer of which only 16% of the patients sought medical care within one month and around 45% postponed medical consultation for more than three months.^{23,38}

Professional delay has been defined as the time between the first medical consultation and definitive diagnosis.^{23,29,39,44-46,49,52} The average professional delay varied in these studies from 22 days to 2 months.^{29,45,46} The median professional delay varied from 11 days to 1.2 months,^{29,39,46,49} and up to 3 months in a study involving only laryngeal cancer patients.²³ Professional delay of less than one month was seen in 44-77% of the patients^{29,39,44,45} and of three months or more in 14-40% of the patients.^{44,45,52}

Other studies divided professional delay into delay between the first medical visit and the first visit to the hospital (so-called general practitioner delay or referral delay) and delay between the first hospital visit and definitive diagnosis or treatment,^{32,38,40,48} whereas others solely describe the first form of professional delay (referral delay).^{31,34,36,47} The average referral delay varied from 8.5 days to 2 months.^{34,36,48} The

median referral delay varied from 2 days to 1.5 months.^{32,36,40} Between 25% and 66% of the patients were referred within one month^{31,34,36,38,47} while 15-50% had referral delay of three months or more.^{31,36,38,47}

Several studies investigated the relationship between delay in diagnosis and disease outcome measures. Most studies used disease stage as an outcome measure,^{28-30,33,34,36-38,41-44,46,49,53,54} but some studies (also) used tumour size,^{34,40,46,47,50} survival rate,^{23,39,46,49,52} local recurrence rate⁵⁵ or tumour volume.⁵⁶

With regard to the stage of the disease, previous studies found that professional delay was positively related to advanced stage disease in oral cancer patients.^{36,42,44,49,54} In patients with pharyngeal or laryngeal cancer it was found that advanced disease was positively related to patient delay^{36,44} or total diagnostic delay.³⁷ In other studies no relationship between diagnostic delay and disease stage at diagnosis was found^{29,30,33,34,38,41,43,46,53} or a reverse relationship was found.²⁸ In studies that investigated tumour size, no significant associations with diagnostic delay were found, except in one study that found a negative relationship between professional delay and tumour size.⁴⁶

Several studies indicated that survival was worse for those patients who had shown patient delay³⁹ or experienced professional delay,^{23,49} although these results were not confirmed in other studies.^{46,52} With regard to delay in starting treatment, it was found that the local recurrence rate was significantly higher for those head and neck cancer patients who started radiotherapy more than six weeks after surgery.⁵⁵ A study among oropharyngeal cancer patients showed a significant tumour volume increase during waiting time for radiotherapy with, as a consequence, an average loss of probability in tumour control of 16-19%.⁵⁶

Although the results suggest that delay matters, these findings are not unequivocal. The discrepancies found between the various studies might be attributed to the different definitions of delay. In addition, actual sign duration and diagnostic delay may not be equal as signs may go unnoticed for a while.⁵⁷ There is also a large variation in the methods used to collect data on diagnostic delay. Most studies used medical records,^{28,33,37,40,41,45,48,52,53,58} some patients' questionnaires^{31,42-44,46} or patients' interview data,^{34,35,47,51} or a combination of both interviews and medical records.^{38,50} A few studies used primary care records,⁴⁹ whether or not in combination with patients' interviews³⁶ or medical records.^{23,39} An aspect that is inherent in studies of patient delay is that the nature of the data is retrospective. This constitutes a threat to the reliability of the findings. A way of enhancing reliability is to use different data sources to verify the course of events with regard to seeking medical care and treatment. Data which is collected directly from the patient could be completed by different data sources, such as the partner of the patient, the general practitioner or

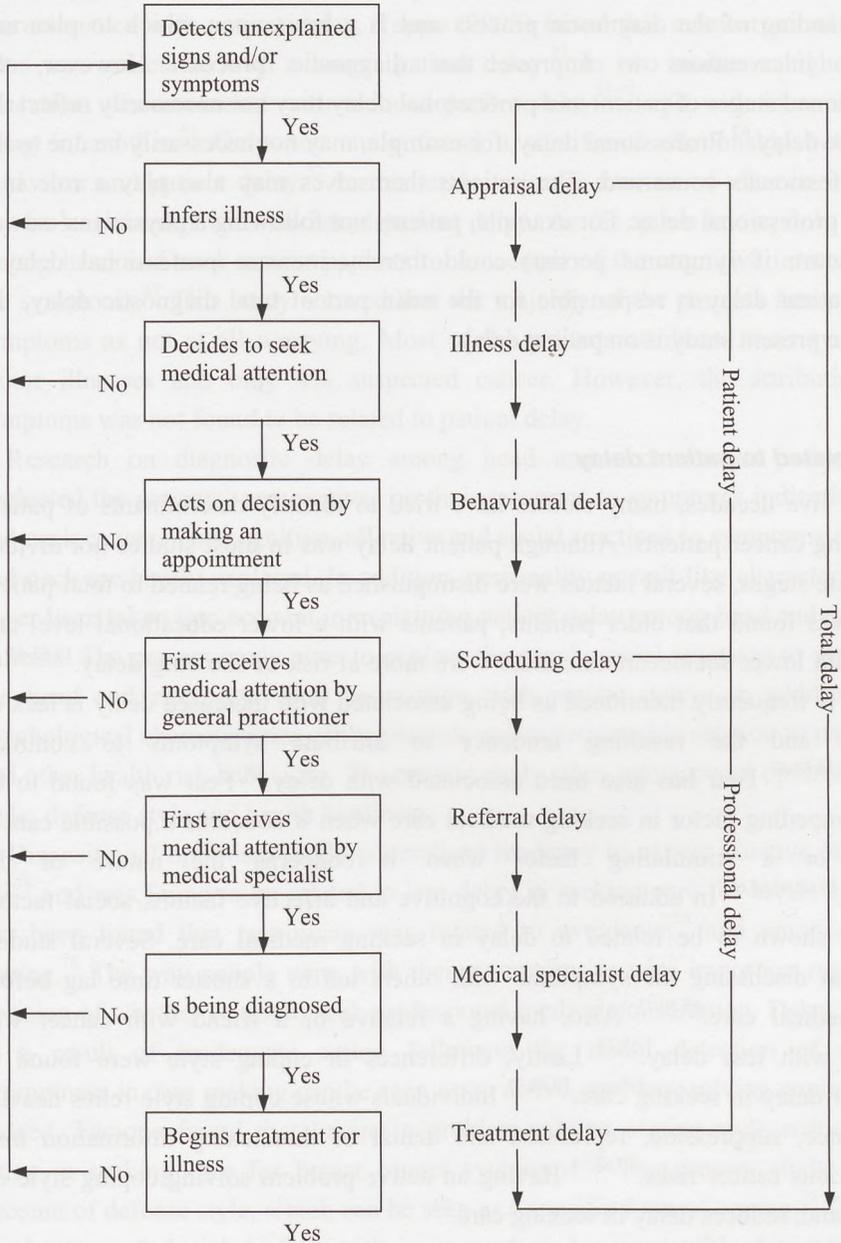
dentist, or medical records. To the best of our knowledge, there are no studies that used information from the partner to verify the data on diagnostic delay, as we intend to in this study.

A conceptual model of delay

For this study a model of delay is used that was proposed by Andersen and Cacioppo (1995) and based on earlier work of Safer *et al.* (1979).^{59,60} In this model, delay is conceptualised as a series of stages, including appraisal, illness, behavioural and scheduling delay (see Figure 2). Each stage is governed by a distinct set of decisional and appraisal processes. Appraisal delay is defined as the period which elapses from the moment an individual detects unexplained signs or symptoms until the moment he or she concludes he or she is ill. This stage of delay, related to the interpretation of the importance and meaning of the symptoms, has been found to account for the bulk of the delay in seeking a cancer diagnosis.⁶¹ In a study of recently diagnosed women with cancer the appraisal interval was approximately 80% of the total patient delay for women with gynaecologic cancer, whereas for women with breast symptoms, a site with a narrower range of symptom diversity, this interval accounted for 60% of the patient delay.⁵⁹ Whereas cancer is a life-threatening disease, it is perceived as a low probability one for many individuals. Thus, the appraisal process may lengthen as people think it is unlikely that their symptoms would indicate a condition as serious as cancer.

Illness delay is defined as the number of days elapsed from the moment individuals conclude they are ill until the day they decide to seek medical help. At this time individuals must decide, for example, whether to seek assistance from others (e.g. physician) or to self-treat the illness. After this, the patient delay is spent in making two remaining decisions. One is the delay between the decision to seek medical attention and acting on this decision by making an appointment with a health professional, which is called behavioural delay. The other is scheduling delay, which is the time that elapses between the person making an appointment and the first provision of medical attention. When scheduling an appointment, both patient characteristics (such as the manner in which the person describes their concerns and symptoms) and medical environment characteristics (such as a physician's waiting list), may modulate the delay incurred. In the model of Andersen and Cacioppo (1995), the period from the first medical appointment until treatment is called treatment delay. To get a better insight in various forms of professional delay, we decided to divide treatment delay into several stages. We distinguished referral delay, medical specialist delay and management delay.

Figure 2. Andersen’s model of total patient delay in which the stages of professional delay are modified for the present study.



Most studies on delay in head and neck cancer patients distinguished between patient and professional delay. However, with a few exceptions of studies concerning professional delay,^{30,35,40,51} very general measures of patient and professional delay were used which made no distinctions between different stages of delay. A classification of delay in clear and distinct categories may serve as a starting point for an understanding of the diagnostic process and is a basis upon which to plan and implement interventions to improve that diagnostic process. However, the aforementioned stages of patient and professional delay may not necessarily reflect the cause of the delay.⁶² Professional delay, for example, may not necessarily be due to the health professionals concerned. The patients themselves may also play a role in a prolonged professional delay. For example, patients not following a physicians' advice (e.g. to return if symptoms persist) could thereby increase professional delay.⁶³ Because patient delay is responsible for the main part of total diagnostic delay, the focus of the present study is on patient delay.

Factors related to patient delay

In the last five decades, many studies have tried to identify determinants of patient delay among cancer patients. Although patient delay was in most studies not divided into separate stages, several factors were distinguished as being related to total patient delay. It was found that older patients, patients with a lower educational level and patients with lower socioeconomic class were more at risk of showing delay.^{19,63-65} A factor that is frequently mentioned as being associated with increased delay is lack of knowledge and the resulting tendency to attribute symptoms to common illnesses.^{18,19,65-67} Fear has also been associated with delay.¹⁹ Fear was found to be either an impeding factor in seeking medical care when it concerns a possible cancer diagnosis or a stimulating factor when it concerns the nature of the symptoms.^{59,60,64,68,69} In addition to the cognitive and affective factors, social factors have been shown to be related to delay in seeking medical care. Several studies showed that discussing the symptoms with others led to a shorter time lag before seeking medical care.^{65,70,71} Also, having a relative or a friend with cancer was associated with less delay.^{18,72} Lastly, differences in coping style were found to account for delay in seeking care.^{19,68,73} Individuals whose coping style relies heavily on avoidance, suppression, repression and denial of threatening information may ignore obvious cancer risks.^{19,68,74} Having an active problem solving coping style on the other hand, reduces delay in seeking care.⁷³

With regard to head and neck cancer, several studies tried to identify correlates of patient delay.^{23,34,35,39,40,46,47,50,51,57} Most of the studies focused on tumour

characteristics, sociodemographics and smoking and drinking behaviour,^{34,35,39,50,51} although some studies also took account of comorbidity and frequency of dental visits.^{23,40,46,57} Experiencing a neck mass as a first symptom was associated with reduced patient delay, while experiencing hoarseness was associated with increased delay.^{23,39,51} Only a few studies found significant associations of the patient characteristics with patient delay. Teppo (2003) found that a lower social economic class was associated with a longer patient delay.²³ In two studies a higher level of education was associated with reduced patient delay^{35,57} and with increased patient delay in another.⁵¹ Only one study found a significant relationship between risk behaviour and patient delay.⁵⁷ In this study, a lower amount of tobacco smoked per day was associated with increased patient delay. As far as we know, only one study among head and neck cancer patients took account of the cognitive interpretation of the symptoms.⁴⁷ This study showed that the majority of the patients interpreted their symptoms as not at all worrying. Most of the patients attributed their symptoms to minor illnesses and only 4% suspected cancer. However, the attribution of the symptoms was not found to be related to patient delay.

Research on diagnostic delay among head and neck cancer patients clearly neglected the patients' perspectives on their reactions to symptoms indicative of head and neck cancer. The cognitive, affective and social reactions to symptoms of the head and neck are hardly explored. In addition, personality or trait like characteristics have never been taken into account in explaining patient delay among head and neck cancer patients. The present study aims to explore the psychosocial reactions to symptoms of the head and neck and their association with patient delay. In addition, several psychological characteristics of the patients are investigated in relation to patient delay and other health risk behaviour. The present study takes into account optimism, coping style, defense style and health hardiness.

Dispositional optimism is the generalised tendency to expect positive outcomes in life⁷⁵ and was found to be related to less delay in seeking care for breast cancer.⁷⁶ It has been found that pessimism was related to avoidance⁷⁷ and emotion oriented coping.⁷⁸ The way people cope with their symptoms is very important regarding the decision of whether or not to seek professional medical consultation. Delay may occur as a result of inadequate action following the initial detection of symptoms. Promptness in care seeking can be seen as an active, problem-solving coping strategy. Indeed, Facione found that having a problem-solving coping style reduced patient delay in seeking care for breast cancer symptoms.⁷³ The present study also takes account of defense style, which can be seen as a specific form of coping.⁷⁹ The defense mechanism of denial is frequently presumed to be responsible for patient delay, especially in the case of unusually long delays.⁶⁸ The assessment of the above-

mentioned psychological factors might be particularly relevant in patients with head and neck cancer, who are frequently heavy to excessive drinkers. The personalities of individuals who consume excessive amounts of alcohol are characterised by a tendency to deny or repress unpleasant events, indifference, depression and to act passively.⁸⁰ This, in turn, may result in a failure to consult a medical professional as soon as suspicious symptoms occur. Alcohol use and cigarette smoking were also found to be related to lower scores on health hardiness.^{81,82} Health hardiness reflects the extent to which individuals are involved in health issues and believe they have control over their health.⁸³ As far as we know, the relationship between health hardiness and seeking medical care for cancer symptoms has never been directly examined. However, it has been found that hardy individuals adapt better to chronic illness⁸⁴ and engage more in health promoting behaviour.^{81,85-87}

Aims of this thesis

A large number of patients who present with head and neck cancer are diagnosed with advanced disease. This has a negative impact on patients' survival and quality of life, as well as on treatment costs. As yet, little is known about the patients' motivation to seek care for head and neck cancer symptoms or, on the contrary, to postpone seeking medical care. In addition, the relationship between psychological characteristics of patients and diagnostic delay has never been addressed among head and neck cancer patients. The present study aims to explore the role of the patient in delay in diagnosis of head and neck cancer and to identify risk factors for presenting with an advanced tumour. The aims of this thesis are:

1. To gain a greater insight into the extent to which different stages of patient delay contribute to total patient delay in head and neck cancer and which psychosocial factors are related to different stages of patient delay.
2. To evaluate which psychological characteristics are related to patient delay, in particular among those patients who have shown health risk behaviour in terms of alcohol use.
3. To determine the relationship between health value and control beliefs with health behaviour of head and neck cancer patients.
4. To gain a greater insight into the role of the patient with regard to delay during the referral process in primary care.
5. To detect risk factors for presenting with an advanced tumour of the head and neck.

Methods

Participants

The results from this thesis are derived from a study carried out from 2000 until 2002 at the University Medical Center Utrecht (UMCU). Patients with newly diagnosed squamous cell carcinoma of the pharynx, larynx or oral cavity were eligible for study inclusion. Patients with a previous malignancy in the head and neck region, cognitive impairments or poor understanding of the Dutch language were excluded. During the inclusion period, 427 patients were recruited of whom 306 (72%) participated. The main reasons for refusing to participate were poor physical or mental condition (30%), a lack of motivation (29%) or an excessive burden (22%). Six patients (5%) who agreed to participate died before the interview took place. The non-participants did not differ from the participants regarding sex, age, tumour localisation and tumour size. The sample of patients included 210 men and 96 women. The participants' ages ranged from 34 to 89 years, with a mean of 62.0 years. There were 117 patients with carcinoma of the larynx, 55 with carcinoma of the pharynx and 134 with carcinoma in the oral cavity. Two hundred and seven patients (68%) presented with a small tumour (T1 or T2) and 99 patients (32%) presented with a large tumour (T3 or T4, according to the TNM classification⁸⁸). With regard to disease stage, 172 patients (56%) were diagnosed with early stage disease (stage I/II) and 134 patients (44%) with advanced stage disease (stage III/IV).

Data collection

Patients were interviewed and completed a questionnaire after diagnosis but before the start of treatment. In addition, in order to detect possible delay not indicated by the patient, the patients' partner or close relative was sent a questionnaire as well as the general practitioner or dentist who the patient initially consulted.

Face-to-face interview

During the semi-structured interview, data were collected on sociodemographic variables (marital status, level of education, employment status, children, religion, etc.) and smoking and alcohol habits. Patients were asked about their care seeking process, symptoms experienced, interpretation of the symptoms, health professional consultations and the period of time taken for each step in the diagnostic process. The interview also included questions concerning previous medical experiences and knowledge of cancer. Patients were asked about the role of others during the care

seeking process. Also life events during the past year (like death of a loved one, removal, problems at work, etc.) and their perceived severity were noted.

Patients' questionnaire

The written questionnaire included questions about anxiety and depression, coping, optimism, defense style and health hardiness. These variables were measured with the following standardised questionnaires.

Anxious and depressive symptoms were measured using the *Hospital Anxiety and Depression Scale (HADS)*.^{89,90} This is questionnaire of 14 items of which 7 items measure anxious symptoms and the other 7 items measure depressive symptoms with a 4-point Likert scale. This questionnaire was developed for physically ill patients in general medical out-patients clinics and has been properly validated for cancer patients.^{91,92}

Coping was measured using the *Utrecht Coping List (UCL) (short version)*.⁹³ This questionnaire is widely used in the Netherlands and consists of 17 items measuring five coping styles: active problem solving (5 items), seeking support (5 items), avoidance (3 items), palliative coping (2 items) and religious coping (2 items). Patients indicate the frequency of these habitual coping styles on a 4-point Likert scale, ranging from 'hardly ever' to 'very often'.

Optimism was measured with the *Life Orientation Test (LOT)*.^{75,94} This questionnaire measures generalised optimistic expectancies about outcomes in life. The questionnaire consists of 12 items of which four measure optimism, four measure pessimism and four filler items. The questions are statements on which patients indicate to what extent the items apply to them on a 5-point Likert scale, ranging from 'strongly disagree' to 'strongly agree'.

Defense style was measured using the *Defense Style Questionnaire (DSQ-42)*.^{95,96} This questionnaire consists of 42 items with a 9-point Likert scale measuring mature, immature and neurotic defense mechanisms. The DSQ measures 21 defense mechanisms which can be ordered along several defense levels. The adaptive level consists of mature defenses (e.g. humor, anticipation), while the levels of distortion and denial consist of immature defenses (e.g. idealisation, denial, and projection). For this study an overall defensive functioning score was used which has proven to be a reliable and valid measure of defense style.^{96,97} The higher the score, the more mature relative to immature defense mechanisms the person adopts.

Health hardiness was measured with the *Health Hardiness Inventory (HHI)*.^{82,98} This 35-item scale measures the extent to which individuals are committed to, and involved in, health-related activities, perceive health as controllable and approach potential health stressors as an opportunity for personal growth. The items are belief

statements with a 5-point Likert scale ranging from 'strongly disagree' to 'strongly agree' on which patients indicate to what extent the items apply to them.

Medical data

Data on tumour characteristics, such as tumour localisation and tumour size and stage, were retrieved from the patients' medical records. Tumours were registered according to the International Classification of Diseases for Oncology (ICD-O) and the TNM classification.⁸⁸

Partners' questionnaire

A questionnaire was sent to the patients' partner or a close relative. The questionnaire contained specific questions about the care seeking process of the patient, the referral and any subsequent visits to health professionals until the start of treatment. A reminder letter was sent after three weeks if the partner had not responded. The response rate to this questionnaire was 76%.

General practitioners' / dentists' questionnaire

A questionnaire was sent to the general practitioner or the dentist who the patients initially consulted. They were asked about their policy from the first visit of the patient for the tumour-related symptoms until referral to the medical specialist. A reminder was sent if the general practitioner or dentist had not responded within four weeks, followed by a telephone call if the written reminder had no effect. The response rate to this questionnaire was 94%.

Determination of the stages of delay

The semi-structured interview was used to elicit a detailed history of the course of events from discovery of the first symptoms through to diagnosis and treatment. To gain an insight into the length of the appraisal, illness, behavioural and scheduling stages of delay, patients were asked when they experienced their first symptoms, inferred illness, decided to seek medical attention, and actually made an appointment. Responses that patients gave with regard to patient delay were verified against data from the questionnaires filled in by the patients' partner or family member and the health professional initially consulted. Data provided by the patient were used in the first instance. If the total patient delay reported by the significant other was more than 1 month longer than that reported by the patient, and if the significant other indicated

that the patient postponed seeking medical care, the data provided by the significant other were used.

The date of the first medical contact for cancer-related symptoms was established by the general practitioner or dentist as well as the length of the referral delay. Both the length of the medical specialist delay and the length of management delay as regards starting treatment were inferred from the medical records of the patients.

Outline of the thesis

Chapter 2 focuses on the different stages of patient delay and the reasons for possible delay. It investigates which sociodemographics as well as psychosocial characteristics are related to the various stages of patient delay.

In **chapter 3** differences are evaluated regarding personal characteristics between the patients with and without delay. Patients are compared regarding optimism, coping, health hardiness, defensive functioning and psychological distress. In addition, the moderating role of drinking behaviour is investigated.

In **chapter 4** the relationship is investigated between health value and control beliefs on the one hand and patient delay and quitting smoking and alcohol drinking on the other.

Chapter 5 describes the role of the patient in delay during the referral process. Patients who fail to return to the general practitioner in time are compared to those who returned punctually as regards sociodemographics, tumour characteristics and psychosocial and personal factors.

Chapter 6 assesses which sociodemographic, psychological and disease-related factors can be used to predict presentation with an advanced tumour. Special attention is paid to the role of patient and professional diagnostic delay.

Chapter 7 contains the general discussion.

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Abstract

Many head and neck cancer patients present with advanced stage disease; patient delay in seeking medical attention may impede an early diagnosis. The aim of this study was to explore physical and psychological factors related to patient delay in a Dutch sample of patients with newly diagnosed head and neck cancer. Three-hundred-six patients were interviewed about their care-seeking process between discovery of symptoms and first medical consultation. Data were verified by significant others and general practitioners or dentists. The results showed that 96% of the patients considered their symptoms benign and 78% did not consider themselves ill. The appraisal process accounted for most of the total patient delay. Seventy-eight (27%) patients waited more than 3 months before consulting a physician. Prompt care-seeking was associated with a mass in the neck, knowledge of (head and neck) cancer, and openness about complaints. Heavy drinking, having voice changes or general symptoms, and physician consultation prompted by others were associated with a delay in seeking care. Results suggest that many symptoms of head and neck cancer are not perceived as alarming, even if they are present for a long time. In order to promote early detection, health (education) professionals should be aware of how patients interpret the symptoms accompanying head and neck cancer.

INTRODUCTION

Since early recognition of cancer symptoms and prompt treatment are associated with improved survival,¹⁻⁴ an unnecessary delay in seeking medical attention on the part of patients or caregivers should be avoided. Although a great deal of research has been done to identify the factors associated with delay in seeking medical attention for cancer symptoms,⁵ the number of patients with head and neck cancer presenting with advanced disease appears to have increased over the last twenty years in the Netherlands.⁶ An earlier study has shown that increased patient delay was associated with advanced cancer of the head and neck.⁷ It is important to reduce the number of patients with advanced disease because advanced head and neck cancer carries a high mortality and morbidity.^{8,9}

A number of studies have investigated the delay in seeking medical attention by patients with head and neck cancer, with data being collected retrospectively from patients¹⁰⁻¹² or primary care professionals.^{13,14} However only a few have identified factors, such as socio-economic background and type of symptom, that are significantly correlated with delay in seeking medical advice, and even then the direction of the association is not always consistent.^{11,14} Psychological responses to the symptoms of head and neck cancer, such as illness cognition, are seldom taken into account in such studies.¹² Research on illness cognition has shown that a person's perceptions of illness (symptoms and their meaning [illness identity], expected timelines, causes, consequences, and controllability) guides health behaviour and elicits coping strategies, such as seeking medical help.¹⁵ A strong illness identity and strong controllability are associated with a more vigilant response to health threats.¹⁶

According to Andersen and Cacioppo (1995), the time from the patient's first awareness of symptoms to the first medical consultation can be divided into five consecutive stages: time between the first symptoms and the moment the patient infers illness (appraisal delay); time from illness inference to the decision to seek medical help (illness delay); time from decision to seek medical advice to actually making an appointment (behavioural delay); time from making an appointment to the actual consultation with a physician (scheduling delay); and time from consultation to the start of the treatment (treatment delay).¹⁷ Because different cognitive and affective processes underlie the various steps in the care seeking process, this subdivision of patient delay into stages helps us to identify causes of patient delay.¹⁸

In the present study, patient delay was divided into the above-mentioned stages. To obtain reliable measures of patient delay, we collected data by means of semi-structured interviews with recently diagnosed patients and questionnaires completed by the primary care health professional and a significant other. The aim of the present

study was to explore the psychosocial and behavioural reactions to symptoms of head and neck cancer and their role in delaying diagnosis.

METHODS

Participants

From 2000 until 2002, 427 consecutive patients with squamous cell carcinoma of the pharynx, larynx, or oral cavity diagnosed at the University Medical Center Utrecht were eligible for study inclusion. Patients with a previous malignancy in the head and neck region, cognitive impairments, or poor understanding of Dutch were excluded. Three-hundred-six (72%) patients agreed to participate and were interviewed by one of the investigators just before surgery or at the start of radiotherapy. The main reasons for refusal to participate were poor physical or mental condition (30%), lack of motivation (29%), or too much burden (22%). Six (5%) patients who agreed to participate died before the interview took place. The non-participants did not differ from the participants regarding sex, age, tumour localisation, or tumour status.

Materials

A semi-structured interview was used to elicit a detailed history of the course of events from discovery of the first symptoms through to diagnosis and treatment. To gain insight into the length of the appraisal, illness, behavioural, and scheduling stages of delay, patients were asked when they experienced their first symptoms, inferred illness, decided to seek medical attention, and actually made an appointment. The last stage of Andersen and Cacioppo's model, treatment delay, was omitted in these analyses because this stage deals mainly with professional delay, although patient factors also may play a part in this stage.

Patients were asked about the nature of the first and any subsequent head and neck symptoms (assessment of illness identity), about their attribution of the symptoms (assessment of cause), and about worry about the symptoms and the influence of the symptoms on physical and psychosocial functioning (assessment of consequences). They were also asked what the reason was to seek medical attention (head and neck symptom or other reason), their motivation (self-motivated or motivated by others), and why they delayed inferring illness and going to see a general practitioner or dentist. In addition, patients were asked if they knew about head and neck cancer and cancer in general, if they had former experience with health problems, and with cancer in particular, and if they were open in discussing symptoms with others (for an overview of the interview questions see Appendix 1).

To verify the course of events, a questionnaire was sent to the general practitioner or dentist initially consulted and to a significant other of the patient (response rate 94.1% and 76.2%, respectively). Data on disease characteristics, such as tumour localisation and tumour size, were retrieved from medical records. The tumours were registered according to the International Classification of Diseases for Oncology (ICD-O) and the TNM classification.¹⁹ Because smoking and alcohol use are important risk factors for developing head and neck cancer and also may possibly interfere with seeking medical care, data on these risk behaviours were obtained during the interview.

Data analysis

The data provided by the patient were used primarily. The data of the significant other were used to identify possible delay which was not mentioned by the patient. If the total patient delay reported by the significant other was more than 1 month longer than that reported by the patient and the significant other indicated that the patient postponed seeking medical care, the data provided by the significant other, if available, were used. This was the case for eleven patients, as the majority of patients and significant others agreed over timeframes. The date of the first medical contact for cancer-related symptoms was established by the general practitioner or dentist. Total patient delay was categorised in three categories: more than 3 months, in accordance with other studies; between 1 and 3 months; and less than 1 month, in accordance with the advice with regard to seeking care for head and neck symptoms given by the Dutch Cancer Society.

The symptoms that were mentioned were coded into nine categories: (1) voice change, which includes hoarseness, breaking or fading voice, and “hot potato” voice; (2) lesion on the tongue, mouth, or throat; (3) swelling in the mouth or tongue; (4) neck mass (lump in the neck); (5) ulcer in the mouth, throat, or tongue; (6) pain in the neck, throat, mouth, or ears; (7) irritation in the mouth or throat; (8) swallowing problems, and (9) general symptoms, which includes fatigue, tightness of the chest, cough, “cold”, weight loss, or bleeding. Patient responses to the other questions in the interview (see Appendix 1) were grouped into categories by two investigators. The investigators were blind to patient delay status at the time of coding. If there was disagreement about the categorisation, consensus was reached by discussing the answer in the light of the original interview.

Statistical analysis

Chi-square tests were used to analyse the association between categorised total patient delay, the sociodemographic and risk behaviour characteristics, and the patients'

symptoms and responses to their symptoms. Because no valid cut-offs are available for the various stages of delay, the whole range of delay time data is used when exploring the association between the duration of each stage of delay and sociodemographics, risk behaviours, symptoms and patient's responses. The relationships between the variables and the length of each delay stage were evaluated using Pearson correlations. The positively skewed delay time data were transformed logarithmically to normalise the distribution for statistical analysis. Stepwise multiple regression analyses were used to determine which variables were independently associated with the various stages of patient delay. The criteria for entry and removal were, respectively, $p=0.05$ and $p=0.10$.

RESULTS

The data for 15 of the 306 participants were excluded from the analyses: 8 patients were asymptomatic and their symptoms of head and neck cancer were first detected by a health professional, and 7 patients were symptomatic but the health professional alerted them to their symptoms. There were 117 patients with carcinoma of the larynx, 55 with carcinoma of the pharynx and 134 with carcinoma in the oral cavity. Forty-five per cent of the patients presented with advanced stage disease. The sociodemographic and risk behaviour characteristics are presented in Table 1.

The most commonly reported symptoms were pain in the mouth, throat or ears and voice change, but patients also present with swallowing problems, (ulcerated) lesions, swellings and more general symptoms such as cough or tightness of chest (Table 2). Only 10 patients (4%) attributed their first symptoms to cancer: most patients attributed them to benign causes such as infection, cold, dental problems, or a harmless ulcer or swelling (Table 3). With regard to the consequences of the symptoms, only 16% of the patients perceived their symptoms as being worrisome or as affecting mood or physical functioning. A part of the patients (10%) visited the general practitioner or dentist for another reason, and only mentioned their head and neck symptoms casually. Although most of the patients reported to be known with cancer in general, only 21% had heard of cancer of the head and neck.

The median delay between symptom onset and initial medical presentation was 41 days (range 1 to 1436 days); 1 of 4 patients (26.8%) waited more than 3 months before seeking medical advice. We could not distinguish a separate stage of illness delay in most patients. Only 22% of the patients thought that they were ill before they decided to seek medical help. The others did not infer illness until they had visited the general

Table 1. Characteristics of the study population (first column) and patient delay according to sociodemographics and risk behaviour.

	n (%)	Median delay (days)	Total patient delay (row %)			P _r
			<1 month (n=120)	1-3 months (n=93)	>3 months (n=78)	
Sex						
Male	199 (68)	46	38.7	35.7	25.6	.133
Female	92 (32)	35	46.7	23.9	29.3	
Age group						
<65	176 (60)	38	44.3	34.1	21.6	.046
>65	115 (40)	55	36.5	28.7	34.8	
Living situation						
Living with partner or family	223 (77)	36	44.6	32.4	23.0	.031
Living alone	68 (23)	68	30.9	30.9	38.2	
Education						
Low	141 (49)	51	37.6	33.3	29.1	.602
Middle	95 (33)	39	44.2	28.4	27.4	
High	51 (18)	35	45.1	35.3	19.6	
Employment status						
Employed	97 (34)	38	43.3	36.1	20.6	.335
Unemployed	38 (13)	52	36.8	36.8	26.3	
Retired	109 (38)	47	36.7	31.2	32.1	
Housewife	43 (15)	29	51.2	20.9	27.9	
Smoking						
None	117 (40)	35	44.4	30.8	24.8	.452
1-20 cigarettes/day	63 (22)	45	38.1	39.7	22.2	
>20 cigarettes/day	111 (38)	60	39.6	28.8	31.5	
Alcohol drinking						
0-2 drinks/day	170 (58)	37	43.5	32.4	24.1	.260
3-4 drinks/day	49 (17)	35	46.9	30.6	22.4	
>4 drinks/day	72 (25)	59	31.9	31.9	36.1	

practitioner or dentist for what they thought were "harmless" symptoms. For this reason, in our study appraisal delay is defined as the period between the detection of the first symptoms and the decision to seek medical attention.

Appraisal delay, behavioural delay, and scheduling delay accounted for 94%, 4.6% and 1.4% of the total patient delay, respectively. The reasons for appraisal delay are reported in Table 4. Interpreting the symptoms as innocuous was the most common reason for appraisal delay, followed by symptoms not causing bother, and the patient never visited a doctor quickly or often. Patients who did not delay seeking medical advice mentioned that they did not wait long or that they had monitored their symptoms for a while.

Table 2. Perceived first symptoms according to patient delay

	n	Median delay (days)	Total patient delay (row %)			P _r
			<1 month (n=120)	1-3 months (n=93)	>3 months (N=78)	
Neck mass						
Reported	17	17	76.5	11.8	11.8	.010
Not reported	274	47	39.1	33.2	27.7	
Ulcer						
Reported	22	20	59.1	22.7	18.2	.209
Not reported	269	46	39.8	32.7	27.5	
Pain						
Reported	93	34	47.3	28.0	24.7	.345
Not reported	198	48	38.4	33.8	27.8	
Swelling						
Reported	15	36	40.0	26.7	33.3	.820
Not reported	276	43	41.3	32.2	26.4	
Swallowing problems						
Reported	23	41	34.8	34.8	30.4	.804
Not reported	268	43	41.8	31.7	26.5	
Irritation						
Reported	18	47	44.4	27.8	27.8	.923
Not reported	273	41	41.0	32.2	26.8	
Voice change						
Reported	93	60	28.0	38.7	33.3	.007
Not reported	198	34	47.5	28.8	23.7	
Lesion						
Reported	30	61	26.7	46.7	26.7	.136
Not reported	261	40	42.9	30.3	26.8	
General symptoms						
Reported	27	77	29.6	29.6	40.7	.204
Not reported	264	40	42.4	32.2	25.4	
Number of symptoms						
1	251	40	42.2	31.9	25.9	.606
>1	40	61	35.0	32.5	32.5	

Note: The total number of reported symptoms exceeds the number of patients (N=291) because some patients reported more than one symptom.

Behavioural delay was one week or more in 33 (11%) patients and one month or more in six (2%) patients. The reasons for postponing making an appointment were mostly practical, such as private or work hassles (27%), holidays (21%) or waiting for an already scheduled appointment (15%). A scheduling delay of 1 week or more was mentioned by only 10 patients and was due to waiting times for those patients who decided to consult a dentist (60%) or a medical specialist directly (without first going to their general practitioner) (30%), or to patients' holidays (10%). The scheduling delay never exceeded 1 month.

Table 3. Psychological, behavioural, and interpersonal responses to discovery of first symptoms according to patient delay

	n (%)	Median delay (days)	Total patient delay (row %)			P _r ²
			<1 month (n=120)	1-3 months (n=93)	>3 months (n=78)	
Attribution of first symptom						
Cancer	10 (4)	36	40.0	30.0	30.0	.819
Benign	213 (76)	39	43.2	31.9	24.9	
No idea	56 (20)	58	35.7	32.1	32.1	
Concern about first symptom						
Yes	49 (16)	46	38.8	34.7	26.5	.908
No	234 (84)	41	41.5	31.6	26.9	
Knowledge head and neck cancer						
Yes	55 (21)	30	58.2	23.6	18.2	.011
None or little	209 (79)	52	35.9	35.4	28.7	
Knowledge cancer in general						
Yes	238 (87)	39	43.3	31.5	25.2	.458
No	34 (13)	59	32.4	35.3	32.4	
Limitation in functioning caused by first symptoms						
Yes	41 (16)	68	31.7	36.6	31.7	.395
No	222 (84)	37	42.8	32.4	24.8	
Worse mood caused by first symptoms						
Yes	39 (15)	60	33.3	33.3	33.3	.478
No	225 (85)	39	42.4	32.3	25.3	
Experience with health problems						
Yes	137 (50)	39	41.6	33.6	24.8	.799
None or little	138 (50)	47	40.6	31.2	28.3	
Experience with cancer						
None	68 (25)	41	36.8	42.6	20.6	.071
Yes, self or partner	29 (11)	60	27.6	34.5	37.9	
Yes, family or friends	173 (64)	35	46.8	27.7	25.4	
Openness about complaints/illness						
Yes	209 (75)	36	45.5	31.1	23.4	.138
No	68 (25)	63	32.4	35.3	32.4	
Motivation for attending GP						
Self	245 (86)	35	46.1	31.4	22.4	.000
Other person	40 (14)	96	17.5	32.5	50.0	
Reason for attending GP						
Head and neck symptom	257 (90)	41	42.0	32.7	25.3	.357
Other symptom/complaint	28 (10)	36	42.9	21.4	35.7	

Note 1: missing values range from 6 to 27

Note 2: GP= general practitioner

Table 4. Reasons for appraisal delay for patients with different length of total patient delay

	n	Total patient delay		
		<1 month	1-3 months	>3 months
Interpreted symptoms as innocuous	88	22	35	31
Symptoms not bothersome	31	3	10	18
Never go to the doctor quickly/often	37	6	17	14
Tried to solve it oneself	15	2	11	2
Denial	5			5
Symptoms had varying pattern	5	1	1	3
Distraction by other events	4		2	2
Other persons reassured	2		1	1
Fear	4	1		3
Indolence	2		1	1
Alcohol problem	2			2
Patient did not think he/she had waited long	66	52	11	3
Waited for a moment to see if symptoms will disappear	35	25	9	1

Note: data are frequencies

Several factors were found to be associated with the various stages of delay and total patient delay (Table 5). Total patient delay was positively associated with living alone, heavy alcohol drinking, presenting with voice change symptoms, and being motivated by another person to visit a health professional, whereas it was negatively associated with higher education, a neck mass, being known with head and neck cancer or discussing symptoms with others. The factors affecting appraisal delay overlapped completely with those affecting total patient delay, but besides these eight factors, a few more were significantly related to appraisal delay: more appraisal delay was associated with having general symptoms, experiencing a limitation in physical functioning and having experience with cancer because oneself or the partner has had cancer. Knowledge of cancer was negatively related to appraisal delay.

Behavioural delay was positively associated with being motivated by others to attend a general practitioner or dentist, and negatively associated with being concerned about symptoms and having experience with health problems. Scheduling delay was positively associated with consultation for symptoms other than head and neck symptom, and negatively with consultation motivated by another person.

Table 5. Summary of the factors related to the different stages of patient delay as well as total delay using Pearson correlation coefficients

	Appraisal delay	Behavioural delay	Scheduling delay	Total patient delay
Sociodemographic factors and risk behaviour				
Living situation (alone)	0.12*			0.12*
Education (high)	-0.15*			-0.13*
Alcohol drinking (>4 daily)	0.12*			0.12*
Symptoms				
Voice change (reported)	0.19***			0.18**
Neck mass (reported)	-0.22***			-0.19***
General symptoms (reported)	0.12*			
Patient responses				
Concern (yes)		-0.12*		
Knowledge head and neck cancer (yes)	-0.14*			-0.16*
Knowledge cancer (yes)	-0.12*			
Limitation physical functioning (yes)	0.12*			
Experience with health problems (yes)		-0.14*		
Experience with cancer (yes, self or other)	0.14*			
Openness about symptoms (yes)	-0.16**			-0.15*
Motivation for attending GP (other person)	0.24***	0.18*	-0.12*	0.24***
Reason for attending GP (other reason)			0.12*	

Note 1: p <.05; ** p <.01; *** p<.001

Note 2: Labels between parentheses indicate the highest coded category

Note 3: Values printed in bold belong to variables that were significant in the multivariate regression analyses.

Note 4: GP= general practitioner

All variables were entered stepwise in multiple regression analyses to determine the factors independently related to the stages of delay. Nine variables were independent predictors of appraisal delay ($F(9,236)=7.34$; $p<.000$; $R^2 = 0.24$): alcohol drinking; presenting with voice change, neck mass, or general symptoms; knowledge of head and neck cancer or cancer in general; experience with cancer; openness about complaints/illness; and motivation for attending the general practitioner or dentist. Experience with health problems and motivation for visiting the doctor were independent predictors of behavioural delay ($F(2,263)=6.84$; $p<.001$; $R^2=0.05$). Both motivation and reason for attending the doctor were significant independent predictors of scheduling delay ($F(2,268)=4.18$; $p=.016$; $R^2=.031$). Finally, total patient delay was predicted by five independent predictors ($F(5,241)$; $p<.000$; $R^2=0.15$): presenting with voice change or a neck mass; knowledge of head and neck cancer; openness about complaints/illness; and motivation for attending the general practitioner or dentist. All relationships were in the same directions as stated in the univariate analyses.

DISCUSSION

Total delay

Because patient delay can impede the early detection of head and neck cancer,⁷ this study sought to distinguish various stages of patient delay and their psychosocial predictors. The median total patient delay in our study was 41 days and 26.7% of the patients delayed seeking medical attention for more than 3 months. These results are comparable with those of other interview-based studies of delay in patients with head and neck cancer.^{11,12,20} The retrospective nature of the data, inherent in any study on patient delay, can affect the validity of the data. An attempt was made to limit errors of memory by only including patients who were recently diagnosed and not yet treated, so we did not have to rely on patient's distant recall. In addition, besides the detailed patient's interviews, data were obtained from both the primary care health professional and a significant other. The large agreement between the patients and their significant others gives the confidence that recall bias was minimal. The more so as the present finding with regard to the length of the patient delay are consistent with other studies.

Appraisal delay

Appraisal delay accounted for 94% of the total delay in seeking care for symptoms of head and neck cancer, far more than any other component, which is consistent with (scarce) earlier studies.^{17,18,21} This result also suggests that symptoms and symptom interpretation are the most important factors in the care-seeking process.²² Andersen and Cacioppo (1995) reported that appraisal delay accounted for 80% and 60% of total delay in gynaecological and potential breast cancer patients, respectively.¹⁷ The high percentage of appraisal delay found in gynaecological patients was ascribed to the non-specificity of the symptoms (e.g. fatigue), an explanation which is probably also applicable to our study population of patients with head and neck cancer. In our study, the symptoms of the disease [illness identity] influenced the appraisal process: voice change or general symptoms as a first symptom significantly lengthened the appraisal delay, whereas a neck mass shortened the delay in deciding to seek care. This is in line with previous findings for patients with head and neck cancer.^{11,14} Another explanation can be found in the "shared-benign/singular serious rule", which states that sharing an illness with other people reduces the perception of the seriousness of the health threat.²³ As such, the rather common nature of the general symptoms (such as cough) or symptoms specific for voice change (such as hoarseness) may prolong the appraisal process.

Illness delay

The high percentage of appraisal delay found in this study may be partly due to the definition of appraisal delay used, which included illness delay. Andersen and Cacioppo (1995) found illness delay (the period between the moment one infers illness until the decision to seek care) to account for an additional 10% of the total delay.¹⁷ However, we could not distinguish a separate stage of illness delay in most patients, probably because of the general nature of the symptoms accompanying head and neck cancer. Most of the patients (78%) did not consider themselves ill. Although some of the reported reasons for postponing seeking medical help, such as first trying to solve the problem oneself and never going to the doctor quickly or often, are indicative of illness delay, subsequent analyses showed that these reasons were mentioned to the same extent by patients who did or did not infer they had an illness before the first medical visit. We agree with De Nooijer (2001), who found overlap in the stages as well and stated that “the various stages of the model form a useful framework to structure the process, but they do not exist as such in the minds of the patients”.²¹ In addition, at the time of the interview, which was after the cancer diagnosis, the word ‘illness’ might have had a totally different meaning than at the time the first symptoms were ascribed to common ailments. Further analyses showed that patients for whom a separate illness delay stage could be distinguished were more often worried about their symptoms, had more knowledge about head and neck cancer, attributed their symptoms more often to cancer, and more frequently had a swelling as presenting symptom. It might be that these patients were more involved with their symptoms and had a greater illness awareness before their first contact with a health professional.

Behavioural and scheduling delay

Behavioural delay (time elapsed from the decision to seek care and making an appointment) was not found often. This may be due to the easy accessibility of the Dutch health care system, in which everyone is insured against medical costs. Safer *et al.* (1979) found that concern about the cost of treatment (which is an issue in the USA) was the most important predictor of utilisation delay, encompassing both behavioural and scheduling delay.¹⁸ Scheduling delay (period between making the appointment and the appointment itself) was found in only a few patients who visited a dentist or medical specialist directly; these physicians who often have waiting lists.

Interpretation of symptoms

Only 3.6% of the patients attributed their symptoms to cancer. Comparable percentages are described for patients with lung (4.1%) and colorectal (9.1%) cancer,

but much higher percentages are reported for patients with breast cancer (35.8%).²⁴ In patients with breast cancer, misattribution of symptoms is an important predictor of patient delay,²⁵ whereas it was not in our study or that of Amir *et al.* (1999) of patients with head and neck cancer.¹² The low percentage of people who attributed their symptoms to cancer could partly be explained by an optimistic bias, that is, some people adopt an innocuous rather than a more serious or threatening explanation for their symptoms.¹⁷ Moreover, people know little about cancer of the head and neck and the accompanying symptoms. Two large population-based studies among Dutch adults showed that knowledge of cancer symptoms was poor, although there was a difference between active recalling and recognition of cancer symptoms.²⁶ These studies showed that the proportion of respondents who actively recalled symptoms of head and neck cancer ranged from 1.6% for swallowing problems to 17.2% for nagging cough or hoarseness. When respondents were asked to select symptoms associated with cancer from a list of general symptoms, this proportion increased, ranging from 37.5% to 53.1%. In our study only 20.8% of the patients knew of head and neck cancer before they were confronted with it.

Predictors of various stages of delay

The subdivision of delay into different stages seems useful for identifying predictors of the various stages of delay. Although appraisal delay accounted for a large proportion of the total patient delay, additional factors were identified, such as experience with cancer as a predictor of appraisal delay. Patients who had another type of cancer themselves or who had a partner with cancer showed more appraisal delay than patients without such first-hand experience. A partner's illness may distract a patient from his/her symptoms or a patient with cancer may consider the risk of developing another cancer as being low. Appraisal delay was also increased by an inability/unwillingness to talk openly about complaints and by being prompted to seek medical help by another person, which is in agreement with literature on patients with breast cancer.^{25,27} Being known with head and neck cancer, or with cancer in general, reduced the appraisal delay. Patients with such knowledge may be more likely to interpret their symptoms as a health threat, which shortens the appraisal period.²⁸ We found that heavy alcohol drinking was related to a longer appraisal delay, a finding not confirmed in other studies.^{11,29} Personalities of individuals using excessive amounts of alcohol are characterised by a tendency to deny or repress unpleasant events, which might be an explanation for the finding that they show a longer delay in appraising their symptoms.³⁰

Concern about the symptoms and experience with health problems were factors that shortened behavioural delay, as was medical visit prompted by others a factor that

shortened scheduling delay. Although the results concerning behavioural and scheduling delay should be interpreted with caution, because there was little variation in the data, they support the suggestion that different processes affect the various stages of patient delay differently.¹⁸ However, it should be borne in mind that a large amount of variance remained unexplained. Although symptoms and responses to symptoms were treated as static variables in the analyses, symptom appraisal is a dynamic process influenced by the (change in) presentation of symptoms and various cognitive, emotional, and social reactions by which individuals form their own representation of their illness. Moreover, while the semi-structured personal interviews elicited detailed information on experienced symptoms and responses, the questions were asked after cancer was diagnosed, at a time the patients may have been in a state of emotional turmoil, which could have affected their ability to recall events. However, this study was conducted to explore cognitive, affective and social processes that underlie delay in head and neck cancer patients, a patient group in which delay is common, but in which the patient's perspective has seldom been taken into account.

Conclusions and implications

Many of the symptoms of head and neck cancer were interpreted by patients as being benign. The somewhat general nature of these symptoms prolonged the appraisal process and hence increased patient delay. Knowledge factors shortened the appraisal process, whereas social factors had a differential effect on appraisal delay.

In the case of head and neck cancer, an important indicator distinguishing between benign and malignant disease is the duration of symptoms. Even so, a large group of patients was not alarmed even though they had had symptoms for a long time. In order to promote early detection, the general public should be alerted to the importance of both the nature and the duration of their symptoms. In addition, health (education) professionals should be aware of how patients interpret the symptoms of head and neck cancer, as this interpretation is indicative of health behaviour.

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Appendix 1

Table A Interview questions regarding the responses to symptoms and possible factors related to delay

-
1. *What did you think was the cause of your symptom(s)?*
 2. *Were you concerned about your symptom(s)?*
 3. *Did your symptom(s) influence your mood?*
 4. *Did your symptom(s) influence your physical functioning?*
 5. *What was the reason to consult a health care professional?*
 6. *Were you motivated by others to consult a health care professional?*
 7. *Were you known with cancer and the consequences when it is not treated?*
 8. *Were you known with cancer of the head and neck?*
 9. *Do you have experience with health problems?*
 10. *Do you have experience with cancer in your family or circle of friends?*
 11. *Do you openly discuss symptoms with others?*
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Abstract

There is a rising incidence of patients presenting with advanced cancer in the head and neck region. Late presentation may be due to a delay in seeking medical attention, which is sometimes surprisingly long. The aim of the present study was to investigate the association between patient delay and the psychological factors of optimism, health hardiness, overall defensive functioning, coping styles and psychological distress in 277 patients with cancer of the head and neck. Significant correlations were found between patient delay and the psychological factors. Twenty-six percent of the patients waited more than three months before seeking medical attention and they reported less optimism ($P=.000$), less health hardiness ($P=.008$), less active coping ($P=.019$) and less seeking support as a coping style ($P=.017$) than patients presenting within three months. Excessive drinkers (5+ alcoholic drinks/day) tended to show more delay than patients who did not drink or were moderate drinkers (0-2 drinks/day) or moderate-heavy drinkers (3-4 drinks/day). Together, the psychological factors could explain 25% of the variance of patient delay in excessive drinkers compared to 21% and 6% in moderate-heavy drinkers and non to moderate drinkers, respectively. These results suggest that psychological factors affect health care seeking behaviour. Health education aimed at the risk group of excessive drinkers should take psychological factors into account that influence their health behaviour.

Introduction

During the last twenty years, there has been a rising incidence of patients presenting with advanced cancer in the head and neck region in the Netherlands,¹ and this has also been seen worldwide.^{2,3} Late presentation may be due to a delay in seeking medical attention, although results regarding the effect of patient delay on tumour stage are contradictory.⁴⁻⁶ Studies showed that 25% to 30% of the patients waited longer than three months before seeking medical care.^{6,7} Patients presenting with cancer in an advanced stage need extensive treatment, which may worsen the quality of life and survival after the therapy.⁸ Therefore, in order to prevent late presentation, it is important to identify the factors associated with delay.

A delay in seeking care could partly be explained by tumour related factors such as the site of the tumour and the type of symptom experienced by the patients. In addition, socio-demographic variables, such as socio-economic class were found to influence patient delay.^{9,10} Psychological characteristics are seldom taken into account to explain patient delay in patients with head and neck cancer and such factors will be the focus of the present study.

The assessment of psychological factors in relation to delay might be particularly relevant in patients with head and neck cancer because of their health behaviour. Patients with head and neck cancer are often heavy to excessive drinkers and smokers. The personalities of subjects using excessive amounts of alcohol are characterised by a tendency to deny or repress unpleasant events, indifference, depression and a tendency to act passively.¹¹ This may result in a failure to consult a medical professional as soon as suspicious symptoms occur and delay in seeking care until it is in an advanced stage.

Past studies in which the relationship between psychological factors and delay in seeking care for cancer symptoms have been investigated have mostly involved breast cancer patients. Relationships between denial and delay were found in some studies, but were not confirmed in others.¹²⁻¹⁴ More recent studies found significant relations between optimism and patient delay¹⁵ and active coping and patient delay.¹⁶ Patients who were optimistic or had an active coping style showed less delay in care seeking for their cancer symptoms. A study which examined the relationship between the psychological factors of health locus of control, hopefulness, repression-sensitisation and anxiety and patient delay found no significant associations.¹⁷

The aim of the present study is to examine patient delay in relation to the psychological factors of optimism, coping style, overall defensive functioning, psychological distress and health hardiness, which have been proven to be related to health behaviour.¹⁸⁻²⁰

Patients and Methods

Patients

From 2000 until 2002, 427 consecutive patients with squamous cell carcinoma of the pharynx, larynx, or oral cavity diagnosed at the University Medical Center Utrecht were eligible for study inclusion. Patients with a previous malignancy in the head and neck region, cognitive impairments, or a poor understanding of Dutch were excluded. Three hundred and six patients (72%) agreed to participate. The main reasons for refusal to participate were poor physical or mental condition (30%), lack of motivation (29%), or too much burden (22%). Six patients (5%) who agreed to participate died before the interview took place. The non-participants did not differ from the participants regarding sex, age, tumour localisation, or tumour size.

Procedure

Participants filled in a questionnaire on psychological measures a few weeks after they were diagnosed, but receiving before treatment. Most patients spent 30 to 60 minutes on completing the questionnaire. They were interviewed about the period of the discovery of the first symptoms until the moment they sought medical attention by one of the investigators just before surgery or at the start of radiotherapy. To verify the course of events in the care seeking process, a questionnaire was sent to the general practitioner or dentist initially consulted and to a significant other, which was in most cases the partner of the patient or otherwise a family member (response rates 94.1% and 76.2%, respectively).

Measures

Patient delay was defined as the time from the first awareness of symptoms to the first medical consultation. The data provided by the patient was used primarily. In cases in which the total patient delay reported by the significant other was more than 1 month longer than that reported by the patient and if the significant other indicated that the patient postponed seeking medical care for a specific reason, such as fear or denial, the data provided by the significant other was used instead. The date of the first medical contact for cancer-related symptoms was established by the general practitioner or dentist. Patient delay was divided into less and more than three months delay in accordance with previous literature (e.g. ²¹).

Optimism was measured by the Dutch version of the *Life Orientation Test (LOT)*,^{22,23} which consists of 8 items and measures generalised optimistic expectancies about outcomes in life. The optimism score is the sum of the 8 items which are rated

on a scale ranging from *strongly disagree* (0) to *strongly agree* (4). Higher scores indicate more optimism.

A Dutch version of the *Defense Style Questionnaire (DSQ-42)*^{24,25} was used to measure overall defensive functioning. The DSQ measures 21 defence mechanisms, each mechanism measured by two items that are rated on a scale from *strongly disagree* (0) to *strongly agree* (8) and which can be ordered along several defence levels. The adaptive level consists of mature defences (e.g. humor, anticipation), while the levels of distortion and denial consist of immature defences (e.g. idealisation, denial, and projection). An overall defensive functioning score was computed which indicates that the higher the score, the more mature defence mechanisms the patient adopts relative to immature ones.

The Dutch version of the *Health Hardiness Inventory (HHI)*^{26,27} was used to measure health hardiness. This 35-item scale consists of belief statements that measure the extent to which individuals are committed to, and involved in, health-related activities, perceive health as controllable and approach potential health stressors as an opportunity for personal growth. Items are rated on a five-point Likert scale ranging from *strongly disagree* (1) to *strongly agree* (5). An overall score was used which indicates that the higher the score, the greater the health hardiness.

Coping styles were measured by a short version of the *Utrecht Coping List (UCL)* consisting of 17 items.²⁸ Coping style is defined as the use of similar behaviours across stressful situations.²⁹ Five coping styles are distinguished: Active coping (5 items), Seeking support (5 items), Avoidance coping (3 items), Palliative coping (2 items) and Religious coping (2 items). Items are formulated as coping behaviours (e.g. *When facing a problem, I ask someone to help me*) rated on a four-point Likert scale ranging from *seldom or never* (1) to *quite often* (4). Scale scores are the sums of the individual items. Higher scores indicate that the specific coping style is more often adopted.

A Dutch version of the 14-item *Hospital Anxiety and Depression Scale (HADS)*^{30,31} was used to measure anxious and depressive symptoms. We used a total sum score of the HADS which can be interpreted as a unidimensional measure of psychological distress.³² Higher scores indicate more psychological distress. A score above the cut-off score of 19 is an indication for a major depressive disorder.

The patient's *age, sex, level of education and living situation* were recorded during the interview. The level of education was recorded as low, middle and high. With regard to living situation, patients were divided into those living alone and those living with a partner or one or more family members.

Smoking and drinking habits were elicited during the interview. Patients were asked if they smoked or drank before diagnosis and, if so, how many cigarettes they smoked or glasses of alcoholic beverages they drank daily. If patients had stopped smoking or

drinking, the moment of quitting was recorded as well as the former cigarette and alcohol intake. Patients were divided into three groups according to their drinking habits³³: non-drinkers to moderate drinkers (0-2 drinks daily, which includes patients who never drank, or stopped drinking); moderate-heavy drinkers (3-4 drinks daily); and excessive drinkers (5+ daily).

Data on disease characteristics, such as tumour localisation and tumour size, were retrieved from medical records. The tumours were registered according to the International Classification of Diseases for Oncology (ICD-O) and the TNM classification.³⁴

Statistics

We used the Statistical Package for Social Sciences (SPSS; Windows 10.0 software) for statistical analyses. Chi-square tests and t-tests were used to compare the patients with less than three months delay and more than three months delay on sociodemographics and psychological factors.

Pearson correlations were computed for all psychological factors and patient delay. Patients with different drinking habits were compared regarding the psychological factors and patient delay by means of univariate variance analysis (ONEWAY). Pearson correlations were computed between the psychological factors and patient delay for groups with different drinking habits. Multiple regression analyses were used to examine the contribution of the psychological factors in explaining patient delay.

Delay in number of days was used. The positively skewed delay time data were transformed with a logarithmic function to normalise the distribution for statistical analysis. Missing data were imputed using a data augmentation procedure.³⁵

Results

Patients

The data of 15 participants were excluded from the analyses: 8 patients were asymptomatic and their symptoms of head and neck cancer were first detected by a health professional and 7 patients were symptomatic but did not seek help for their symptoms. In those cases the health professional alerted them to their symptoms. Another 14 patients did not fill in the questionnaires measuring the psychological constructs and were therefore excluded from the analyses. This left 277 patients.

Table 1. Characteristics of study population ($n=277$)

	n	(%)
Sex		
Male	191	(69)
Female	86	(31)
Age group		
<65	171	(62)
≥65	106	(38)
Living situation		
Living alone	62	(22)
Living with partner or family	215	(78)
Education ^a		
Low	132	(48)
Middle	91	(33)
High	50	(18)
Smoking		
Never	31	(11)
Stopped	82	(30)
0-20 cigarettes	60	(22)
>20 cigarettes	104	(38)
Drinking		
0-2 drinks daily	162	(59)
3-4 drinks daily	48	(17)
>4 drinks daily	67	(24)
Tumour localisation		
Larynx	106	(38)
Throat	49	(18)
Mouth	122	(44)
Tumour size		
T1	95	(34)
T2	90	(33)
T3	33	(12)
T4	59	(21)
Patient delay		
< 3 months	205	(74)
> 3 months	72	(26)

^aSome data are missing

Sixty-nine percent of the patients were male and 62% were under the age of 65 years (Table 1). Fifty-nine percent of the patients were smokers and 83% drank alcohol before diagnosis. One third (33%) of the patients presented with a large tumour (T3 or T4). One in four patients (26%) waited more than 3 months before seeking medical advice. Of the sociodemographic characteristics, only age and living situation were associated with patient delay ($\chi^2 = 7.09$; $p=.008$ and $\chi^2 = 5.12$; $p=.024$, respectively). A greater patient delay was found in patients aged over sixty-five and those living alone. Sex and education were not related to patient delay.

Psychological factors and patient delay

Mean scores and intercorrelations of the psychological measures and patient delay for the total group are presented in Table 2. Patient delay was, although moderate, negatively related to optimism, health hardiness and overall defensive functioning, and positively related to avoidance coping.

Patients who postponed seeking medical advice for more than three months differed from those who did not with regard to optimism, health hardiness, active coping and seeking support as coping style (Table 3). Patients who postponed their first medical consultation were less optimistic, reported less health hardiness and made less use of active coping and seeking support as a coping style. There was a trend in patients with lower overall defensive functioning scores to show more patient delay.

Table 2. Mean scores and Pearson intercorrelations among study variables

	N	M	SD	Possible range	1.	2.	3.	4.	5.	6.	7.	8.	9.
1. Delay	277	90.75	158.57	1-1436									
2. Optimism	264	21.07	5.35	0-32	-0.15*								
3. Health hardiness	251	2.17	0.25	0-3	-0.15*	0.29**							
4. Overall defensive functioning	241	4.17	0.50	0-8	-0.13*	0.37**	0.35**						
5. Active Coping	265	13.25	3.00	5-20	-0.07	0.25**	0.25**	0.31**					
6. Seeking Support	266	10.65	3.20	5-20	-0.08	0.07	0.22**	0.13*	0.27**				
7. Avoidance Coping	266	5.73	1.74	3-12	0.16*	-0.32**	-0.25**	-0.33**	-0.08	-0.06			
8. Palliative Coping	268	4.94	1.34	2-8	0.03	0.16**	0.20**	0.11*	0.26**	0.19**	0.14*		
9. Religious Coping	253	3.50	1.60	2-8	0.06	-0.19**	-0.10	-0.07	-0.08	0.10	0.23**	0.05	
10. Psychological distress	258	13.10	7.77	0-42	0.03	-0.54**	-0.33**	-0.44**	-0.25**	0.05	0.34**	-0.06	0.11

** $p < .01$; * $p < .05$

Note: N indicates the number of patients who completed the questionnaire; M, mean; SD, standard deviation.

Table 3. Mean score comparisons of psychological variables for patients with delay and patients without delay

	Patient delay		t Value
	< 3 months n=205	> 3 months n=72	
Optimism	21.74	19.08	3.75***
Health hardiness	2.19	2.10	2.67**
Overall defensive functioning	4.18	4.05	1.89 [†]
Active Coping	13.48	12.51	2.37*
Seeking Support	10.88	9.83	2.40*
Avoidance Coping	5.46	6.00	-1.42
Palliative Coping	4.90	4.93	-0.18
Religious Coping	3.41	3.75	-1.53
Psychological distress	12.36	13.86	-1.38

***: $p < .001$; **: $p < .01$; *: $p < .05$; [†]: $p < .10$

Drinking habits, patient delay and psychological factors

There was a trend ($p=.064$) for excessive drinkers (5+ daily) to show more patient delay than non-drinkers to moderate drinkers (0-2 daily) or moderate-heavy drinkers (3-4 daily) (Table 4). The mean patient delay for excessive drinkers was 115 days (median 57 days), compared to 83 days (median 36 days) and 83 days (median 33 days) for non-drinkers to moderate drinkers and moderate-heavy drinkers, respectively.

Excessive drinkers showed more psychological distress than moderate-heavy drinkers. Among the excessive drinkers 27% had an indication for a major depressive disorder as compared to 8% among the moderate-heavy drinkers. Excessive drinkers with an advanced tumour did not differ from those with an early tumour with regard to psychological distress. Non-drinkers to moderate drinkers reported more health hardiness and religious coping than the patients who drank three or more drinks daily.

For non-drinkers to moderate drinkers, no significant correlations were found between patient delay and the psychological factors. There was a trend for health hardiness to be related to patient delay ($r=-.14$, $p=.071$). For the moderate-heavy drinkers, avoidance coping was positively related to patient delay ($r=.38$, $p=.008$). Optimism ($r=-.43$, $p=.000$) was negatively related to patient delay in the excessive drinking group. There was a trend for overall defensive functioning and religious coping to be associated with patient delay in this latter group ($r=-.21$, $p=.091$; $r=.23$, $p=.06$, respectively).

Table 4. Mean scores of patient delay and psychological factors for groups with different drinking habits

	0-2 drinks/day N=162	3-4 drinks/day N=48	5+ drinks/day N=67	F value
Patient delay (days)	83	83	115	3.10 [†]
Optimism	21.20	22.02	19.98	2.25
Health hardiness	2.20	2.08	2.13	4.65**
Overall defensive functioning	4.16	4.14	4.13	0.08
Active Coping	13.00	13.27	13.75	1.48
Seeking Support	10.64	10.50	10.60	0.04
Avoidance Coping	5.84	5.33	5.84	1.69
Palliative Coping	4.92	4.79	4.96	0.22
Religious Coping	3.80	3.06	3.09	7.13***
Psychological distress	12.61	10.69	14.57	3.44*

***: $p < .001$; **: $p < .01$; *: $p < .05$; †: $p < .10$

Explaining patient delay with psychological factors

Multiple regression analyses were conducted to examine how much variance in patient delay could be explained by the psychological factors (Table 5). In the total group of patients, the psychological factors could explain 6.2% of the patient delay ($F=1.97$, $p=.044$). The most important explaining variables were optimism and psychological distress. In the case of patients who drank no or moderate levels of alcohol, the psychological factors also explained 6.2% of the patient delay. In this patient group, psychological distress best explained the patient delay. The regression model was not significant. Psychological factors, especially avoidance coping, explained a greater variance in patient delay in the group of moderate-heavy drinkers, although the regression model was still not significant ($R^2 = 20.8\%$; $p=.379$). The psychological factors significantly explained patient delay in the excessive drinking group ($R^2 = 25.3\%$; $p=.040$), with optimism and religious coping as the most important variables. Comparable results were obtained when controlled for age, sex, living situation and education.

If smoking behaviour was taken into account, as an additional health risk behaviour, and analyses were carried out among those patients who drank and smoked before diagnosis, an even greater variance of patient delay could be explained. In the group of patients who drank 3 to 4 drinks a day in combination with smoking ($n=33$) 44% of the variance of patient delay could be explained by the psychological factors. For patients who drank five or more drinks a day in combination with smoking ($n=53$), the psychological factors accounted for 25% of the variance of patient delay. In the case of moderate heavy and excessive drinkers who maintained their drinking and smoking habits after diagnosis ($n=45$), the explained variance of patient delay increased to 39%.

Table 5. Separate multiple regression analyses to explain patient delay for the total group and for groups with different drinking habits

	Total group (n=277)		0-2 drinks/day (n=162)		3-4 drinks/day (n=48)		5+ drinks/day (n=67)	
	β	P value	β	P value	β	P value	β	P value
Optimism	-0.14	0.055	-0.04	0.732	0.01	0.972	-0.55	0.004
Health hardiness	-0.10	0.141	-0.15	0.117	-0.18	0.287	0.06	0.667
Overall defensive functioning	-0.07	0.356	-0.09	0.346	0.09	0.594	-0.01	0.950
Active Coping	-0.02	0.770	-0.03	0.766	-0.17	0.314	-0.01	0.923
Seeking Support	-0.04	0.572	-0.04	0.671	-0.03	0.887	-0.02	0.897
Avoidance Coping	0.10	0.151	0.06	0.504	0.40	0.020	-0.11	0.501
Palliative Coping	0.06	0.320	0.10	0.262	0.01	0.960	-0.03	0.846
Religious Coping	0.01	0.866	0.01	0.892	0.02	0.888	0.22	0.084
Psychological distress	-0.14	0.070	-0.19	0.064	0.09	0.620	-0.17	0.309
Regression model								
Multiple R	0.25		0.25		0.46		0.50	
Explained Variance R ²	6.2%		6.2%		20.8%		25.3%	
F value	1.97	0.044	1.21	0.351	1.11	0.379	2.14	0.040

Values are standardised regression coefficients (β) with significance of t , except for the Regression model where rows represent R and R^2 , and F values and significance of F is displayed.

Discussion

Patient delay is often observed among patients presenting with symptoms of head and neck cancer. Tumour-related and sociodemographic variables can only partly explain patient delay, yet few studies have considered psychological factors as a reason for the delay. Therefore, our study sought to examine the relationships between psychological factors and delay in seeking medical advice after discovery of symptoms related to cancer in the head and neck.

The psychological measures of this study were interrelated in the expected direction, which is an indication of the validity of the measures. Coping style, overall defensive functioning, optimism and health hardiness were shown to be related to patient delay in seeking care. The way people cope with a symptom is very important for the decision as to whether or not to seek professional medical consultation. Promptness in care seeking can be seen as an active, problem-solving coping strategy.¹⁵ Indeed, patient delay was associated with avoidance coping and patients who postponed their medical consultation for more than three months made less use of an active coping style or of seeking support as coping style. This is in agreement with the literature as Facione et al.¹⁶ found those women with an active coping style were less inclined to delay seeking care for a breast symptom.

Defence, which can be seen as a specific form of coping,³⁶ was measured by an overall defensive functioning score. It was found that patients who adopt more immature defences relative to mature defences, showed more patient delay. Denial and other forms of defensiveness are likely to occur when an individual has no means of immediately reducing the threat.³⁷ Denial is frequently presumed to be responsible for patient delay, especially in the case of unusually long delays.³⁸

Optimism was associated with less patient delay in seeking care. Likewise, Lauver and Tak¹⁵ found that, among patients confronted with a breast symptom, optimism was related to prompt care seeking. Optimism has been associated with greater use of active coping, while pessimism has been shown to be related to avoidance.³⁹ In addition, optimism has been related to a greater attention to health threats.⁴⁰

The present study found a negative relationship between patient delay and health hardiness. Thus, patients who were involved in health issues and believed they have control over their health showed less delay. As far as we are aware, the relationship between health hardiness and patient delay has never been directly examined. A related construct, health locus of control, was found not to be related to patient delay in seeking care for breast symptoms, although the sample size was small.¹⁷ Health hardiness has been found to be related to other health behaviours as well. Hardy individuals were found to adapt better to chronic illness⁴¹ and engage more in health

promoting activities such as exercising, dieting and non-consumption of alcohol and cigarettes.⁴²

Patients who drank 5 or more drinks daily tended to show more patient delay than patients who drank less or nothing at all, a finding not confirmed in other studies.^{43,44} Excessive drinkers also showed significantly more psychological distress before treatment. Alcohol intake has been proven to be associated with anxious and depressive symptoms.⁴⁵ Patients who drank 0 to 2 drinks daily showed more health hardiness and reported more religious coping than moderate heavy drinkers (3+ drinks daily), which possibly reflects a difference in lifestyles and values.

Although the psychological measures were only partially capable of explaining patient delay in patients who drank nothing, light, or moderately, they were more important in explaining patient delay in patients drinking more than three drinks a day. This was especially true for excessive drinkers, in which a quarter of the variance in patient delay could be explained by the psychological variables. Further multiple regression analyses showed that in the case of non-drinkers to moderate drinkers, patient delay was associated with the type of symptom experienced, knowledge of cancer and discussing the symptoms with others (data not shown). By contrast, these same factors could hardly explain delay among excessive drinkers. Thus it seems that, among excessive drinkers, psychological characteristics like coping style and general outcome expectancies are indicative for the reaction to a head and neck symptom, regardless of the medical and social situation.

It should be borne in mind that the associations between the psychological factors and patient delay found for the total group were, although significant, small. However, it is meaningful that very general psychological self report measures could explain a specific behavioural measure like a delay in seeking care to such a large degree in a specific group of patients, namely excessive drinkers. When a second health risk behaviour, cigarette smoking, was taken into account, explained variances increased even further, especially in the case of those who continued drinking and smoking after diagnosis.

Other psychological factors that might explain patient delay are guilt or fear about medical judgement. Especially in heavy drinkers these might be important factors in the process of seeking medical care.⁴⁶ In addition, these factors could lead to underreporting of the amount of alcohol consumption, which must be borne in mind when interpreting the findings of this study. Beyond psychological factors, social factors might play a role in the care seeking process. As we have seen, patients who were living with a partner or family showed less delay, possibly because discussing the symptoms leads to patients seeking care earlier.

A threat to the reliability of the findings of this study concerns the time at which the measurements were taken. The questionnaires were completed after cancer was diagnosed, at a time at which the patients may have been in a state of emotional turmoil. Although most of the psychological variables in this study are assumed to be stable over time, it is not possible to exclude reactions to recent events (such as the diagnosis of a major life-threatening disease like cancer) as an explanation for the current reported behaviour.

The results of this study show that patient delay is a serious problem among patients with head and neck cancer, especially among excessive drinkers. The psychological characteristics of these patients seem to influence patient delay. Although the risk group of excessive drinkers is a hard group to reach, health education directed at them should not focus solely on symptoms, but also on outcome expectancies and on supplying information about adaptive coping strategies.

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This chapter discusses the role of health value, control beliefs and psychological distress in the decision-making process of patients with head and neck cancer. The chapter is divided into three main sections. The first section discusses the role of health value in the decision-making process. The second section discusses the role of control beliefs in the decision-making process. The third section discusses the role of psychological distress in the decision-making process. The chapter concludes with a summary of the findings and a discussion of the implications for practice.

Chapter 4

Medical care seeking and health risk behaviour in patients with head and neck cancer: The role of health value, control beliefs and psychological distress

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Abstract

Health behaviour plays an important role in the development, detection and course of cancer of the head and neck. Relevant health behaviour includes prompt medical care seeking and smoking and drinking cessation after diagnosis. This study examines the relationship between these health behaviours and health value and control beliefs as well as psychological distress. Two hundred and sixty-four recently diagnosed head and neck cancer patients were interviewed about their health behaviour and they filled in a questionnaire on health beliefs and psychological distress. The results showed that one quarter (25%) of the patients had waited more than three months before seeking medical care, 50% had continued to smoke and 80% had continued to drink after the diagnosis. The patients, particularly those who smoked and drank before diagnosis, reported lower levels of health value and perceived health competence than a general population sample with which they were compared. Patients who engaged in patient delay reported a lack of perceived health competence. Psychological distress and lack of perceived health competence were found to be more common among patients who continued to smoke. The implications of these findings are discussed with regard to interventions aimed at promoting these specific health behaviours.

Introduction

Approximately 4% of all cancer patients have cancer of the head and neck, a type of cancer that has become increasingly prevalent in the last two to three decades.¹ Unfortunately, nearly half of the patients with cancer of the head and neck are diagnosed with advanced stage disease and this proportion has been rising over the last twenty years both in European countries and the United States.²⁻⁴ The five-year survival rate of patients with cancer of the head and neck who are diagnosed with early stage disease is 60 to 80%, but this rate drops to below 30% for patients diagnosed with advanced stage disease.⁵ In addition, patients who are diagnosed with advanced disease experience a worse quality of life after treatment.⁶ Therefore, early detection of head and neck cancer is extremely important. An impeding factor for early detection is patient delay in seeking medical care for head and neck cancer symptoms. A frequently used definition of patient delay has been a time period of 3 months or more between symptom discovery and initial seeking of a diagnosis.⁷ On the basis of this criterion, 30% of the patients delay presentation of head and neck cancer symptoms.⁸

The major risk factors for developing cancer of the head and neck are smoking and alcohol consumption.⁹ Besides the effect on the development of cancer of the head and neck, continuing these risk behaviours during or after treatment enhances the negative side-effects of radiation therapy,^{10,11} and increases the risk of postoperative complications¹² and the development of second primary tumours and disease recurrence.^{13,14}

Although it can be concluded that health behaviour plays an important role in the development, detection and course of cancer of the head and neck, the psychological determinants of the relevant health behaviours are rarely examined in this patient group.¹⁵⁻¹⁷ Identifying the psychological correlates of patient delay in seeking medical care and continued smoking and drinking could help guide effective interventions in the case of head and neck cancer patients.

One of the psychological determinants of health behaviour is health-related hardiness which reflects the extent to which individuals are committed to health-related activities, perceive health as controllable and approach potential health stressors as an opportunity for personal growth.¹⁸ Health hardiness is positively related to various health promoting behaviours, such as exercising, dieting and abstinence from alcohol, cigarettes and drugs.¹⁹⁻²¹ In particular, perceived personal control over health and commitment to health have consistently been found to predict health behaviour.²² The most recent instrument for measuring health hardiness is the Health Hardiness Inventory (HHI).²³ In the HHI, the control dimension includes items that reflect the concept of perceived health competence, a domain-specific self-efficacy

construct. Perceived health competence refers to an individual's generalised expectancy regarding the ability to interact effectively with the environment in order to obtain the desired outcome, i.e. to be healthy.^{24,25} In a Dutch validation study of the HHI, four scales were identified which represent the constructs of health value, perceived health competence and two control constructs related to the source of control, namely internal locus of control and external locus of control.²⁶

Locus of control has been frequently studied in relation to health promoting behaviour.^{27,28} It was theorised that individuals with a more internal locus of control as opposed to those with a more external locus of control are more likely to engage in health protective behaviour. However, empirical studies that tested this relationship are not conclusive.^{29,30} Several studies showed that the importance placed on health (i.e. health value) was a more significant variable for predicting health behaviour than locus of control beliefs,^{25,31,32} as were beliefs of self-efficacy or perceived competence.^{24,26,33} It was, however, also theorised that among individuals who face a life threatening disease, which head and neck cancer is, there is little variation in how the value of health is appraised, and that this value placed on health is consistently high.^{25,26}

As mentioned earlier, the health protective behaviours that are important for the survival and quality of life of head and neck cancer patients are prompt care seeking when confronted with symptoms and cutting down on smoking and drinking. With regard to the speed of seeking medical care when one first notices symptoms indicative of a health problem, it was theorised that health value and control expectancies could predict this type of behaviour.²⁵ The more one values health, the more one should be motivated to do something about it when it is threatened. Also, the more one expects that one can successfully carry out health behaviours that lead to favourable health outcomes (that is the higher the perceived health competence), the less reason there is to delay seeking definitive information. With regard to locus of control beliefs, it was hypothesised that people with an internal locus of control orientation may partially blame themselves for the symptom and that this self-blame may lead to avoidance and delay rather than to confrontation. We are only aware of one study that directly examined the relationship between health control beliefs and a delay in requesting medical care.³⁴ In this study no relationship was found between internal locus of control and delay in seeking care for a breast symptom. However, for breast cancer patients the relationship between health risk behaviour and disease is less evident than for head and neck cancer patients.

Internal and external control beliefs were in some studies found to predict smoking cessation in non-clinical samples, but this relationship was not always confirmed in other studies.^{35,36} With regard to alcohol use, it was found that externals engaged more

in excessive drinking than internals.²⁷ Self-efficacy (a related construct to perceived health competence although measured in most studies on a more behavioural specific level) appears to be a strong predictor of abstinence from alcohol and cigarettes.^{28,35,36} We expect that patients with higher levels of internal locus of control, health value and perceived health competence are more likely to change their behaviour, i.e. are more likely to quit smoking or drinking.

Because smoking and drinking are supposed to reduce stress among many individuals, anxious and depressive symptoms might impede people from stopping smoking or drinking during a stressful period. Psychological distress is prevalent among patients diagnosed with cancer of the head and neck.^{37,38} Research on smoking cessation indicated that individuals who showed higher levels of perceived stress were less likely to quit.³⁵ We expect a high prevalence of psychological distress in our sample of head and neck cancer patients and, in addition, that those patients with higher levels of psychological distress are less likely to quit smoking or drinking.

In the present study, health value and control beliefs as well as psychological distress were measured in a sample of head and neck cancer patients. The relationships between health beliefs and the health protective behaviours that are relevant for head and neck cancer patients were examined. In addition, tests were carried out to assess whether psychological distress was related to a lack of behavioural change.

Method

Participants and procedure

The participants were 264 patients with cancer of the head and neck. The patients were asked to participate if they had been recently diagnosed at the University Medical Center Utrecht, a tertiary oncology referral centre in a city in the heart of the Netherlands. Patients with a previous malignancy in the head and neck region, cognitive impairments or poor understanding of the Dutch language were excluded. Participants filled in a questionnaire and were interviewed about the care seeking process a few weeks after diagnosis but before receiving treatment. The sample of patients included 185 males and 79 females. The average age was 60.9 years (SD=11.0). Forty percent of the patients were diagnosed with advanced stage disease.

Measures

Patient's care seeking behaviour

Patient care seeking delay was divided into less and more than a three month delay between symptom discovery and medical care seeking according to previous

literature.⁷ Responses that patients gave with regard to patient delay were verified against data from medical records and questionnaires filled in by the patients' partner or family member and the health professional initially consulted.

Patient's health risk behaviour

Information on smoking and drinking habits before diagnosis, as well as quitting behaviour after they heard the diagnosis were gathered during the interview. Patients were divided into two groups according to their health risk behaviour before the first medical consultation: those showing no health risk behaviour (non-smoking in combination with non to moderate drinking (0-2 drinks a day)) and those showing health risk behaviour (smoking cigarettes or drinking 3 or more drinks daily or both).

With regard to change in health risk behaviour after diagnosis, patients who exhibited health risk behaviour before diagnosis (smoking cigarettes or drinking 3 or more drinks daily) were divided into two groups with regard to their current smoking or drinking behaviour (patients who stopped versus those who continued). The two health behaviour changes were investigated separately, because only half of the smokers also drank heavily. In addition, only a few patients (n=14) changed both health risk behaviours.

Health value and control beliefs

The Revised Health Hardiness Inventory (RHHI-24)²⁶ was used to measure health beliefs. The RHHI is based on the Health Hardiness Inventory (HHI)²³ and contains health belief statements concerning four scales: Health value (six items, e.g. *I take care of my health as a matter of principle*, $\alpha=.74$); Internal locus of control (five items, e.g. *The main thing that affects my health is what I do myself*, $\alpha=.62$); External locus of control (seven items, e.g. *No matter what I do, if I am going to get ill, I will get ill*, $\alpha=.59$); and Perceived health competence (six items, e.g. *I find that efforts to change things I don't like about my health, are ineffective*, $\alpha=.59$). This last scale consists of six of the eight items of the original Perceived Health Competence Scale (Smith, 1995). Items are rated on a five-point Likert scale ranging from *strongly disagree* (1) to *strongly agree* (5).

Psychological distress

The Hospital Anxiety and Depression Scale (HADS)³⁹ was used to measure anxious and depressive symptoms. We used a total sum score of the HADS which can be interpreted as a unidimensional measure of psychological distress. A score above the cut-off score of 19 is an indication of a major depressive disorder.⁴⁰

Statistical analysis

The mean scores on the health value and control scales were compared with a Dutch general population sample from the study of Gebhardt et al.²⁶ using student's t-tests. Both the total patient group and subgroups according to health risk behaviour were compared. Also, the scores on psychological distress were compared with normative data from a non-clinical sample⁴¹ by use of student's t-tests.

To determine differences on the health belief scales between patients who engaged in delay and those who did not, student's t-tests were applied. Patients who changed their smoking or drinking behaviour were compared with those who failed to do so on the health belief scales and psychological distress. Multivariate logistic regression analyses using backward selection were used to determine the most important predictors of patient delay and behaviour change, after controlling for disease stage.

Results

Mean scores on health belief scales and psychological distress

The mean scores on the health belief scales of the total patient group, and the subgroups according to the health risk behaviour before diagnosis, were compared to the general population sample (Table 1). Gebhardt et al.²⁶ found a significant age effect in their sample whose ages ranged from 13 to 97 years. Because the patients in our sample are for the most part older than 45 years, we compared our sample means against the available means belonging to the age categories 45-65 years and 65 years or older.

The mean score on the total HADS scale was 12.37 (SD=7.77) in our sample, as compared to 9.82 (SD=5.98) in the normative, non-clinical sample.⁴¹ This was a significant difference ($t=6.20$, $p<.001$). Of all patients, 19% scored above the cut-off score of 19, which indicates major depression. Seventeen per cent of the male patients scored above the cut-off score, as compared to 4% of the males in the normative sample. Of all female patients, 23% scored above the cut-off score as compared to 9% of the females in the normative sample. In contrast to the normative sample, no significant sex effect was found in our patient sample ($t=-1.05$, $p=.297$). The intercorrelations of the scores on health value and control beliefs and psychological distress are displayed in Table 2.

Patient delay and health value and control beliefs

Fourteen patients were excluded from the analyses regarding patient delay because their symptoms were first detected by a health professional. Sixty-three patients (25%)

Table 1. Mean scores on health belief scales for the total patient group (first column) and the patient group split up according their risk behaviour before diagnosis (second and third column) compared to the general population sample

	Total patient group		No risk behaviour before diagnosis		One or both risk behaviours before diagnosis		General population sample ^a	
	M	(SD)	M	(SD)	M	(SD)	M	(SD)
< 65 years	N=168		n=27		n=141		N=50	
Health value	3.87**	(.65)	4.32	(.48)	3.78***	(.64)	4.17	(.65)
Internal LOC	3.46	(.74)	3.30 [†]	(.80)	3.49	(.72)	3.62	(.67)
External LOC	2.69	(.67)	2.47	(.65)	2.73	(.67)	2.53	(.77)
Perceived health competence	3.37***	(.69)	3.70	(.59)	3.30***	(.69)	3.77	(.62)
> 65 years	N=96		n=46		n=50		N=37	
Health value	4.15	(.72)	4.36	(.60)	3.95 [†]	(.77)	4.25	(.66)
Internal LOC	3.42 [†]	(.80)	3.43	(.78)	3.42	(.82)	3.69	(.87)
External LOC	2.94	(.77)	2.90	(.77)	2.99	(.77)	2.99	(.87)
Perceived health competence	3.26	(.66)	3.36	(.63)	3.17	(.68)	3.41	(.82)

^aDerived from the study by Gebhardt et al. (2001)²⁶

[†]p<.10; * p <.05; ** p <.01; *** p<.001; significance levels of differences in mean scores compared to the general population sample.

Table 2. Intercorrelations between health value and control beliefs and psychological distress

Scale	1.	2.	3.	4.	5.
1. Health value	1				
2. Internal LOC	0.30 ***	1			
3. External LOC	0.05	0.21 ***	1		
4. Perceived health competence	0.26 ***	0.32 ***	-0.32 ***	1	
5. Psychological distress	-0.14 *	-0.15 *	-0.18 **	-0.45 ***	1

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

of the remaining patients waited three months or more before seeking medical help.

The scores for External locus of control and Perceived health competence were significantly different in the case of patients who delayed and those who did not (Table 3). Patients who delayed seeking medical care reported higher levels of External locus of control and lower levels of Perceived health competence. Multivariate logistic regression analyses revealed that, with regard to patient delay, only Perceived health competence was selected as a significant predictor (OR=0.55, p=.010, CI=0.35-0.87). The higher the score for Perceived health competence, the less likely the patient was to delay seeking care.

Table 3. Comparison of patients who did not delay and patients who delayed seeking medical care for 3 months or more using T-tests (n=250)

Scale	Patients without delay n=187		Patients with delay n=63		T (df)
	M	(SD)	M	(SD)	
Health value	4.00	(.66)	3.89	(.75)	1.04 (248)
Internal LOC	3.45	(.76)	3.34	(.78)	1.07 (248)
External LOC	2.72	(.71)	2.94	(.75)	-2.13 (248) *
Perceived health competence	3.37	(.69)	3.11	(.60)	2.64 (248) **

Note. †p<.10; *p<.05; **p<.01; ***p<.001

Health value and control beliefs and psychological distress in relation to smoking and drinking cessation

Of all patients who smoked before diagnosis, fifty percent (79 patients) stopped after they had heard the diagnosis. Those patients who stopped smoking reported higher levels of Perceived health competence than those patients who continued to smoke. There was a trend for patients who stopped smoking to report higher levels of Health value. Patients who continued to smoke reported a significantly higher level of psychological distress (Table 4).

Only a small percentage, namely 20% (n=22) of the patients who drank three or more alcoholic drinks daily before diagnosis, stopped drinking. There was a trend for patients who stopped drinking to have higher scores on the Internal locus of control scale as compared to those patients who continued to drink more than three drinks per day (Table 5). No significant differences in levels of psychological distress were found between patients who stopped drinking and those who continued.

Table 4. Comparison of patients who stopped smoking and patients who continued smoking after diagnosis using T-tests (n=158)

Scale	Patients stopped smoking n=79		Patients continued smoking n=79		T (df)
	M	(SD)	M	(SD)	
Health value	3.90	(.69)	3.72	(.65)	1.72 (156)
Internal LOC	3.46	(.68)	3.43	(.81)	0.25 (156)
External LOC	2.72	(.65)	2.76	(.73)	-0.16 (156)
Perceived health competence	3.37	(.62)	3.13	(.69)	2.30 (156) *
Psychological distress	11.82	(6.89)	16.15	(8.44)	-3.54 (156) ***

Note. †p<.10; *p<.05; **p<.01; ***p<.001

Table 5. Comparison of patients who stopped drinking alcohol and patients who continued drinking after diagnosis using T-tests (n=105)

Scale	Patients stopped drinking n=79		Patients continued drinking n=79		T (df)
	M	(SD)	M	(SD)	
Health value	3.73	(.78)	3.76	(.61)	0.76 (103)
Internal LOC	3.66	(.78)	3.35	(.76)	1.63 (103) †
External LOC	2.75	(.75)	2.77	(.66)	-0.13 (103)
Perceived health competence	3.50	(.73)	3.27	(.66)	1.38 (103)
Psychological distress	13.81	(7.94)	12.67	(7.32)	0.63 (103)

Note. †p<.10; *p<.05; **p<.01; ***p<.001

Multivariate logistic regression analyses revealed that, with regard to continued smoking, psychological distress (OR=1.08, p=.001, CI=1.03-1.25) and Health value (OR=0.65, p=.094, CI= 0.39-1.08) were included in the prediction model. The lower the score for Health value and the more psychological distress, the more likely patients were to have continued smoking. With regard to continued drinking, Internal locus of control was selected (OR=0.58, p=.089, CI=0.31-1.09) as the most important predictor. The lower the score for Internal locus of control, the more likely patients were to have continued excessive drinking. However, Internal locus of control (and also Health value with regard to continued smoking), were only trend significant.

Discussion

The purpose of the present study was to examine the relationship between health value and control beliefs, psychological distress and various health behaviours among a sample of head and neck cancer patients. In this patient group, health behaviours, such as seeking medical care for symptoms, and smoking and drinking behaviour are particularly important because of their influence on the development, detection and the course of the disease.

It was theorised that, in the context of a life-threatening disease, the salience of health and the value placed on it is consistently high.³¹ However, our results do not sustain this assumption. The younger members of our sample of head and neck cancer patients (45 to 65 years of age) scored significantly lower as regards health value than the general population sample of a comparable age. Head and neck cancer patients are known to exhibit health risk behaviour frequently. They are often smokers, frequently

in combination with heavy drinking.⁴² It was shown that for those patients who did not show health risk behaviour before diagnosis, the reported levels of health value were comparable to those of the general population. The group of patients showing one or more health risk behaviours accounted for the difference with the general population sample. The same results were obtained for the health belief scale of perceived health competence. Literature shows that health value and perceived health competence are negatively related to health risk behaviour such as smoking and excessive drinking.^{24,26,28} In the case of older patients (65 years and older), no significant differences in levels of health value and perceived health competence were found when compared to the general population. A plausible explanation for this finding is that the health risk behaviours were less prevalent and less extreme among the older members of the patient group.

The head and neck cancer patients tended to report lower levels of internal locus of control than the general population sample. The confrontation of being diagnosed with serious illness may have led to the perception that one cannot control one's health to the extent regarded as possible before the diagnosis. This explanation was sustained by the fact that the lower levels of internal control are especially observed in those patients who showed no health risk behaviour. It can be argued, however, that the items of the internal locus of control scale are less suitable for patients who are confronted with cancer. Items such as "I am in control of my health" and "I can be as healthy as I want to be" are probably less relevant to those who already consider themselves to be ill.⁴³

In this study, we tried to identify psychological correlates of patient delay in seeking medical care to get a better view of who are at risk for patient delay, since patient delay has negative consequences with regard to disease outcomes. However, inherent to any study of patient delay, one can only measure patient delay retrospectively. A prospective study on delay in seeking medical care is impossible to conduct for practical and ethical reasons. We investigated health-related hardiness (by use of health value and control beliefs statements), as this was assumed to be a personality trait and as such is assumed to be relatively stable over time. However, it must be borne in mind that the health value and control beliefs were measured after patient delay took place and, also, after patients had heard the cancer diagnosis. The confrontation with serious disease might have influenced the responses on the questions posed with regard to health value and control beliefs. Therefore, the conclusions concerning health beliefs in relation to patient delay must be treated with caution.

We could not confirm the hypothesised relationship between health value and patient delay, but we did find that a delay in seeking medical care for symptoms of the

head and neck was related to perceived health competence and external health locus of control. As expected, patients who reported higher levels of perceived health competence were less likely to show delay. In addition, the bivariate analyses showed that patients who delayed seeking care for three months or more reported higher levels of external locus of control. However, the items constituting the external locus of control scale concern beliefs that chance or fate influences one's health and it was suggested that these beliefs are more appropriately conceived as indicators of a lack of perceived personal control than as an external locus of control dimension.²⁵ In addition, in the multivariate analysis the effect of external locus of control was superseded by the effect of perceived health competence. Thus, it seems that patients who experience a lack of perceived health competence or personal control are particularly at risk to delays in seeking medical care. A possible mechanism through which personal control might influence patient delay is that control reduces the appraisal of threat and increases problem-solving and support-seeking strategies.⁴⁴ The items of the perceived health competence scale reflect the incapability of finding effective solutions for health problems. Therefore, to promote early detection, awareness raising as regards head and neck cancer should not only focus on the awareness of symptoms, but also on the steps to be taken once confronted with symptoms. This means discouraging a 'wait and see' attitude and enhancing personal efficacy by showing that one can do something about it, namely seek medical advice. Literature on cancer screening has proven that interventions aimed at enhancing self-efficacy are effective in promoting participation.⁴⁵

The diagnosis of a life threatening disease has been considered a 'teachable moment', a health event that can motivate patients to spontaneously adopt risk-reducing behaviour.⁴⁶ Indeed, the smoking cessation rate of patients faced with serious illness is much higher than the population cessation rate.⁴⁷ In our sample fifty per cent of the patients stopped smoking and twenty per cent stopped drinking heavily after they had heard the diagnosis. These percentages are lower than reported in earlier studies into quitting smoking or drinking among head and neck cancer patients but the period of abstinence was not always comparable.^{16,17} We measured the quitting rate before treatment, which provides us with no information about possible changes in smoking or drinking behaviour after treatment. Longitudinal research is needed to see which patients are long-term quitters and which patients are prone to relapse. However, the moment between diagnosis and treatment is important because abstinence during treatment is beneficial for treatment outcomes. In addition, the contact between various health professionals and the patient is frequent and that offers opportunities for intervention. Apparently, quitting smoking is not easy for many patients and just a doctor's advice about the benefits of quitting does not seem to be

effective. Patients who wish to quit may benefit from some support during this stressful period. We found that psychological distress and a lack of perceived health competence were more common among patients who continue to smoke. Therefore, an intervention aimed at changing smoking behaviour should pay attention to reducing psychological distress and enhancing the patient's personal efficacy.

This cross-sectional data gives us no information about the trend of the effects. It must be borne in mind that health control beliefs and health behaviours may influence each other. In particular, the relationship between self-efficacy and behaviour is probably a reciprocal one. Past successful experiences enhance one's sense of efficacy and this may, in turn, contribute to greater effort to achieve goals in the future.⁴⁸ It has, however, been suggested that it is sooner the case that self-efficacy promotes smoking cessation than vice-versa.⁴⁹

It can be questioned whether self-report measures about smoking and drinking behaviour are reliable, especially with regard to patients who are being treated for a smoking or drinking related illness and who might be under pressure because of social or medical disapproval. In our study, a research psychologist who was not involved in the patients' medical treatment carried out the interview which may have reduced patients' tendency to provide socially desirable answers. Moreover, a recent study has shown that smoking related research using self-reporting alone can reliably be carried out among this particular smoking group.⁵⁰

Finally, our health value and control belief scales, although specific to health are fairly general measures. It has been suggested that they should only properly be used to predict global indices of health behaviours (e.g. leading a healthy lifestyle) rather than specific behaviours such as smoking or alcohol consumption.²⁵ In order to predict specific behaviours, one should also use more behaviourally specific expectancies.³³ Our perceived health competence scale measures self-efficacy related to health, but is still not very specific to the behaviours investigated. However, it was shown that this domain-specific measure was related to various forms of health-related behaviours investigated in this study.

To conclude, head and neck cancer patients frequently show health risk behaviour. Because beliefs regarding control over one's health and psychological distress were found to be related to specific health behaviours, interventions aimed at early detection and behavioural change with regard to smoking and drinking should take these psychological factors into account. Future research should explore these relationships, particularly in the long term.

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Abstract (faint text)

Chapter 5

Patient factors associated with delay in primary care among patients with head and neck carcinoma: a case-series analysis

Methods

Participants

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...of the head and neck region, cognitive dysfunction, ...
excluded. A total of 100 patients (participation rate 70%) ...
The researchers before treatment took place. The main reasons for ...
were poor physical or mental condition (n=36, 36%), lack of ...
or too much burden (n=27, 27%), 56 (56%) patients who agreed to participate ...

Family Practice 2005 (in press)

Abstract

Head and neck cancer patients are often diagnosed with advanced stage disease, while the location is easily accessible for examination or distinct symptoms are present. Professional delay in primary care has been found to affect tumour stage and survival. There has been little research on the role of the patient in delaying referral or diagnosis once the patient has visited a primary health care professional. The aim of the present study is to identify patient-related factors which are associated with delay in primary care and the referral to the hospital. A case-series analysis using semi-structured interviews combined with questionnaires was conducted among 306 consecutive patients newly diagnosed in a tertiary referral centre for head and neck oncology patients in the Netherlands. The main outcome measure was delay in returning to the general practitioner or dentist after the first consultation. Logistic regression analyses were performed to test which patient-related variables made delay more likely. A hundred and fifty-five patients (53%) were not referred or followed up after the first medical contact with the general practitioner or dentist. Fifty per cent (n=78) of them delayed returning to the health professional for more than three weeks. Patients were more likely to delay when they experienced voice change, were not familiar with head and neck cancer, were not suspicious of cancer or were generally not inclined to seek support. To conclude, delay in returning to the health professional is partly dependent on patient-related factors. Therefore, patients should be educated about the possible meaning and expected time-course of the symptoms and be strongly advised to return, or be followed up, within three to four weeks if the symptoms do not disappear. To prevent further delay after referral, the general practitioner or dentist should mediate the visit to the hospital.

Introduction

Early detection of cancer of the head and neck improves survival and quality of life after treatment.¹ However, a large proportion of patients with cancer of the head and neck presents with advanced disease and this proportion has increased in the past twenty years.²⁻⁴ The reason for a patient to be diagnosed with advanced disease can be due to the patient's delay in seeking medical care, misdiagnosis by the general practitioner or dentist in primary care who needs to refer the patient, or mismanagement in diagnosing and treating the patient once s/he attends the hospital. In the Netherlands, most patients first consult a primary care physician (general practitioner or dentist) who refers the patient to an otolaryngologist or oral surgeon in the hospital when the patient cannot be treated in primary care. Professional delay in primary care was found to influence tumour stage and survival.⁵⁻⁷ Most studies that identified factors related to this professional delay focused on tumour-related and doctor-related reasons for delay.⁸⁻¹¹ However, the care seeking behaviour of the patient plays an important role during the referral period, especially when the patient is not referred at the first consultation and needs to decide when to make further appointments.

This study aimed to identify several patient-related factors which have been suggested as influencing professional delay including (a) sociodemographics; (b) previous health experiences; (c) risk behaviour like smoking and alcohol consumption; (d) cognitive interpretation of symptoms; and (e) conflict of responsibilities.¹² Patient interviews as well as information from primary care units were used to determine the relative contribution of the patient in professional delay after the first medical consultation until the first visit in the hospital.

Methods

Participants

Eligible participants were patients newly diagnosed at the Head and Neck Oncology Unit of the University Medical Centre Utrecht between 2000 and 2002 as having squamous cell carcinoma of the head and neck. Patients with previous malignancy in the head and neck region, cognitive impairments, or poor understanding of Dutch were excluded. A total of 306 patients (participation rate 72%) were interviewed by one of the researchers before treatment took place. The main reasons for refusal to participate were poor physical or mental condition ($n=36$; 30%), lack of motivation ($n=35$; 29%), or too much burden ($n=27$; 22%). Six (5%) patients who agreed to participate died

before the interview took place. The non-participants did not differ from the participants regarding sex, age, tumour localisation, or tumour size. The study has been carried out with approval of the Medical Ethical Committee of the University Medical Center Utrecht.

Professional delay

A questionnaire was sent to the general practitioner or dentist whom the participating patients initially consulted. This provided data on the visit(s) of the patient for the tumour-related symptoms, the referral and the first visit to the hospital (response rate 94%). A detailed history of the course of events from the first medical consultation until the first visit to the hospital was elicited during patient interviews and verified by use of a questionnaire sent to a significant other (response rate 76%). To establish the possible delay between the various steps, the data given by the general practitioner or dentist was used primarily. Only visits in which the tumour-related symptoms were brought up were recorded.

Patient factors

During the patient interview the following data were gathered: (a) *sociodemographic data*; (b) *previous health experiences* including the type of health care professional first visited (general practitioner; dentist; medical specialist), patient delay before the first medical consultation (in weeks), previous experience with serious health problems and seeking care (yes; none or little), and previous experience with cancer (none; self/partner; family/friends); (c) *daily consumption of cigarettes and alcohol*; (d) *cognitive interpretation of symptoms* including suspicion of cancer (yes; no), knowledge of head and neck cancer (yes; no) and knowledge of cancer in general (yes; no); (e) *conflict of responsibilities* which was the total score of life events during the past year weighted by the severity rating given by the patient.

In addition, patients were asked about tumour and symptom-related factors like the nature of the first and any subsequent symptoms of the head and neck ('voice change', 'lesion', 'swelling', 'neck mass', 'pain', 'irritation', 'swallowing problems', and 'general symptoms' (e.g. fatigue, tightness of the chest, weight loss)), and whether the patients experienced any physical limitation because of their symptoms.

Patients filled in a questionnaire which comprised questions about the following psychological constructs: (1) *Optimism* was assessed with the Life Orientation Test (LOT)^{13,14} measuring generalised optimistic expectancies about outcomes in life; (2) *Overall defensive functioning* was assessed with the Defense Style Questionnaire (DSQ-42),^{15,16} measuring the extent to which people adopt more mature defence mechanisms (e.g. humor, anticipation) relative to immature ones (e.g. idealisation,

denial, and projection); (3) *Health hardiness* was assessed with the Health Hardiness Inventory (HHI)^{17,18} measuring the extent to which individuals are committed to health-related activities, perceive health as controllable, and approach potential health stressors as an opportunity for personal growth; (4) *Coping style* was assessed by a short version of the Utrecht Coping List (UCL),¹⁹ measuring active coping, seeking support, avoidance coping, palliative coping, and religious coping; and (5) *Anxious and depressive symptoms* were assessed with the Hospital Anxiety and Depression Scale (HADS).²⁰

Data were analysed using SPSS version 10.0. The summary statistics for the continuous data are presented by using the mean, median and (interquartile) range. Logistic regression analyses were used to investigate the association between delay and patient and tumour-related factors. Continuous delay data were compared using the Mann-Whitney U-test.

Results

Table 1 shows the characteristics of the study population. The period in primary care until referral ranged from 0 to 176 weeks with a median of 2 weeks (mean 6 weeks).

Of the 295 patients who initially consulted a health professional other than an otolaryngologist or oral surgeon, 112 patients (38%) were referred at the first visit to an otolaryngologist or oral surgeon in the hospital. One of these patients did not effectuate the referral and returned to the general practitioner 4.5 months later. Of the 183 non-referred patients, 28 patients were scheduled for a follow-up appointment of which fifty per cent were eventually referred within 12 days, and 80% within one month. The other 155 patients were eventually referred with a median delay of six weeks (Figure 1).

The 155 non-referred, non-scheduled-up patients needed to return to the general practitioner or dentist on their own initiative and did so with a median delay of 3 weeks (mean 7 weeks, interquartile range 2-8 weeks). Patients decided to return to the health professional because symptoms persisted in spite of treatment (38%) or without being treated (15%), symptoms deteriorated (22%), or because the patient was advised to return if symptoms would persist (6%). Ten per cent of the patients postponed a second consultation for more than four months. Table 2 lists the reasons for waiting to go back to the health professional. Those patients who had received treatment or were advised to wait for a specific period usually returned within 3 weeks. Holidays, interpreting the symptoms as innocent, the idea that the health professional could not be of any help and fear were some of the reasons to postpone a second consultation.

Table 1. Characteristics of the study population

Characteristic	Patients	(n=306)
Sex		
Men	210	(69%)
Women	96	(31%)
Age group		
<65	186	(61%)
≥65	120	(39%)
Cohabitation		
Living alone	69	(23%)
Living with partner or family	237	(77%)
Education ^a		
Low	147	(49%)
Middle	101	(33%)
High	54	(18%)
Daily cigarette intake		
Never	31	(10%)
Stopped	89	(29%)
0-20 cigarettes	69	(23%)
>20 cigarettes	117	(38%)
Daily alcohol intake		
Never	34	(11%)
Stopped	20	(7%)
0-2 units daily	126	(41%)
3-4 units daily	52	(17%)
>4 units daily	74	(24%)
Tumour localisation		
Glottis	78	(25%)
Supraglottis	41	(13%)
Pharynx	55	(18%)
Oral cavity	134	(44%)
Tumour size		
T1	107	(35%)
T2	100	(33%)
T3	36	(12%)
T4	63	(21%)
Physician first visited		
General practitioner	252	(82%)
Dentist	36	(12%)
Otolaryngologist/Oral surgeon	11	(4%)
Other medical specialist	7	(2%)

^aSome data are missing

Figure 1. Flow-chart of management in primary care of patients eventually diagnosed of having cancer of the head and neck

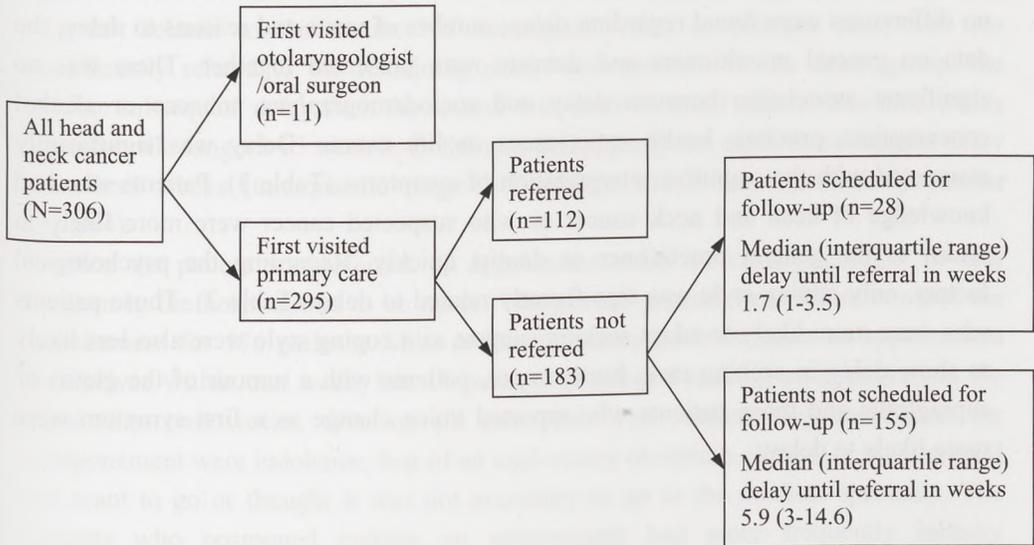


Table 2. Frequency of reasons to postpone returning to the health professional initially consulted for a head and neck symptom for the second time according to delay (longer than 3 weeks)

Reason for waiting ^a	Delay	Non-delay
Patient did not think he had waited long	2	8
Waited for the effect of the course of treatment	6	34
Waited until test period was over		4
Waited for a scheduled appointment for other complaints/symptoms	1	3
Waited until symptoms disappeared	6	7
Doctor could not help the first time	5	
Holidays	6	
Interpreted symptoms as innocuous	8	1
Symptoms were not bothering	3	
Reassurance at first visit	2	1
Fear	3	
Medical problems of patient or family	1	1
Did not want any investigations	1	
Indolence	1	
Alcohol problem	1	
Forgot referral to otolaryngologist	1	

^aNot available for all patients

On the basis of the median duration of three weeks between the first and second visit in primary care, patients were divided into two groups representing delay and non-delay patients. Because only a small part of the patients first visited a dentist, and no differences were found regarding delay, number of visits and reasons to delay, the data on general practitioners and dentists were presented together. There was no significant association between delay and sociodemographics, tobacco or alcohol consumption, previous health experiences or life events. Delay was significantly associated with the cognitive interpretation of symptoms (Table 3). Patients who had knowledge of head and neck cancer or who suspected cancer were more likely to return to the general practitioner or dentist quickly. Regarding the psychological factors, only coping style was significantly related to delay (Table 3). Those patients who were more likely to adopt seeking support as a coping style were also less likely to show delay in seeking care. Furthermore, patients with a tumour of the glottis or supraglottis and those patients who reported voice change as a first symptom were more likely to delay.

Table 3. Association between cognitive interpretation of symptoms, psychological factors, and tumour-related factors and delay in seeking medical care for the second time (more than 3 weeks).¹

Variable	Delay	Non-delay	Odds ratio (95% CI) ²
Cognitive interpretation of symptoms			
Knowledge of head and neck cancer			
No	52 ³ (56%)	41 (44%)	1
Yes	15 (33%)	31 (67%)	0.38 (0.18 to 0.80)
Suspicion of cancer			
No	73 (54%)	63 (46%)	1
Yes	2 (14%)	12 (86%)	0.14 (0.03 to 0.67)
Psychological factors			
Mean score Coping style seeking support (SD)	10.22 (2.71)	11.57 (3.56)	0.86 (0.77 to 0.97)
Tumour/symptom related factors			
Tumour site			
Glottis	23 (64%)	13 (36%)	1
Supraglottis	16 (64%)	9 (36%)	1.01 (0.35 to 2.90)
Pharynx	14 (40%)	21 (60%)	0.38 (0.14 to 0.98)
Oral cavity	24 (40%)	35 (59%)	0.39 (0.17 to 0.91)
Symptom voice change			
Not reported	70 (64%)	40 (36%)	1
Yes	20 (44%)	25 (56%)	2.3 (1.1 to 4.8)

¹Only significant results are displayed

²CI: Confidence interval

³Values are numbers (percentages) unless stated otherwise

Ninety-nine patients (54%) were referred after the second visit. Forty-one patients (22%) were referred after the third visit, 27 (15%) after the fourth visit and 17 (9%) after five visits or more. Delay in returning to the health professional for a second time was not related to the number of subsequent visits in primary care, but was significantly related to the remaining delay until referral. In the delay group, the median subsequent delay from the second visit until eventual referral was nine weeks (interquartile range 3-15 weeks). In the non-delay group the median subsequent delay was three weeks (interquartile range 2-7 weeks), which was significantly shorter ($p=.004$).

Once the patient was referred, an appointment with the otolaryngologist or oral surgeon in the hospital had to be made. The general practitioner or dentist made the appointment for 176 patients. Most of the remaining patients made an appointment themselves within one week, but 14 patients postponed making an appointment for more than two weeks, even up till one year. The reasons they mentioned for postponement were indolence, fear of an exploratory operation, illness, or that they did not want to go or thought it was not necessary to go to the medical specialist. The patients who postponed making an appointment had more frequently initially consulted the primary care health professional for another reason than their head and neck symptom ($P=.001$) and had shown more patient delay before the initial visit ($P=.020$).

The waiting period between the making of the appointment and the first visit with the otolaryngologist or oral surgeon in the hospital ranged from 0 to 11.5 weeks. If the general practitioner or dentist made the appointment the median waiting time (4 days, range 0-35 days) as compared to that if the patients did so themselves (10 days, range 5-74 days) was significantly shorter ($P<.001$).

Discussion

Summary of main findings

Patients with symptoms of head and neck cancer who are not referred or followed up after the first medical consultation, which in our study comprised half of the patients, are at risk for increased professional delay. They need to decide for themselves when to return to the health professional. Postponing the second consultation is not uncommon, as in our study half of the patients who were not referred or followed up returned after more than three weeks and 10% even delayed for more than four months. In addition, patients who delayed the second consultation were prone to further delay in any subsequent consultations. Several tumour and patient factors were

identified to be related to delay in returning to the health professional. Patients who experienced voice change were at risk for delay. Besides, not being familiar with head and neck cancer, or not being suspicious that the symptoms might indicate cancer increased the risk of delay in returning to the health professional. Patients who were generally not inclined to seek support when confronted with a problem were also more at risk for delay. Even after referral, long delays occurred because patients did not immediately effectuate their referral or because waiting times to see the otolaryngologist or oral surgeon in the hospital were long. These latter delays were prevented when the general practitioner or dentist mediates the first visit to the hospital.

Comparison with other research

It was found that patients with the interrelated tumour characteristics of a carcinoma of the larynx or experiencing voice change, more often postponed a second consultation. These factors were found to influence professional delay in primary care in other studies as well, although in these studies professional delay was defined as the delay until the eventual referral.^{7,10} Possibly, the physical functioning of these patients was not disturbed, and patients were therefore not bothered by their symptoms which lead them to delay consultation.

Besides tumour-related factors, several patient-related factors were found to influence delay in returning to the general practitioner or dentist. Those patients who did not have any knowledge of head and neck cancer and were not suspicious of cancer were more likely to postpone a second consultation. This was also reflected in the reasons for postponement. A reason that was frequently mentioned was that the patients interpreted their symptoms as innocent, partly because they were reassured at the first visit. This is in agreement with Kantola et al.⁶ who suggested that a false sense of security causes patients to postpone a second consultation. Other patients were not bothered by their symptoms or gave priority to holidays, which gives the impression that these patients were also not alarmed by their symptoms. Patients who made less use of the seeking support coping style and thus were not used to ask for support from others were more at risk of delay. The way people cope with a symptom is very important for the decision to seek professional medical consultation.²¹

Once the decision about referral was made, most of the patients immediately made an appointment with the otolaryngologist or oral surgeon in the hospital or such an appointment was made by the general practitioner or dentist. The benefits of this action of the health professional, which can probably also be undertaken by an assistant, are twofold. It not only prevents further delay due to the patient waiting to effectuate the referral but also shortens the waiting time before the patient is seen by

the medical specialist. General practitioners should pay extra attention to those patients who had already shown patient delay before the first visit, as well as those who consulted for another main reason than the head and neck symptom, as those patients were prone to delay in effectuating the referral.

Strengths and limitations of the study

To the best of our knowledge, this is the first study on delay in primary care among patients eventually diagnosed as having cancer of the head neck, which takes into account the patient's perspective. The study was exploratory and has identified issues for further research. The strength of the present study is that the interview data were verified against data from the general practitioner or dentist and a significant other of the patient. In this way, recall bias was minimised.

The main limitation of the study is directly related to the method used to recruit participants. Only patients who were eventually diagnosed with cancer were included in the study. Therefore, no data were available regarding the false positives, patients who were referred that did not have cancer, but had other causes for their complaints. In addition, no data were available of patients who were not referred and who did not have cancer, the true negatives, in which presumably the complaints subsided. The symptoms accompanying head and neck cancer are very prevalent in primary care, but the times they indicate malignancy are infrequent. The persistence of the symptoms is an important indicator of possible malignancy. Therefore, health professionals should be extra cautious when symptoms persist, especially among patients with a risk of malignancy due to heavy smoking and drinking. In our study, only six percent of the patients (who were not referred or followed up) indicated that they returned to the health professional because they were advised to return if symptoms persisted. Although we cannot be sure that there were not more patients who were given this advice, it is striking that such a small number of patients indicated this as the main reason to seek medical help for a second time. This result may give a reason to doubt whether the advice that was given to the patients had really come across.

Implications for clinical practice

It can be concluded that cancer of the head and neck is not always detected at the first professional consultation. Because delay in returning to the health professional is partly dependent on patient-related factors, such as coping style and the cognitive interpretation of symptoms, patients should be educated about the possible meaning of their symptoms and should be strongly advised to return within three to four weeks if symptoms do not disappear. In addition, it is recommended that general practitioners or dentists should follow up patients who experience symptoms that are suspicious of

cancer of the head and neck.^{22 23} To prevent further delay, the general practitioner or dentist should contact the otolaryngologist or oral surgeon in the hospital with a view to arranging the first visit to the hospital.

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Chapter 6

Patient and tumour factors associated with advanced carcinoma of the head and neck

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Methods

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Patients diagnosed with squamous cell carcinoma of the larynx (ICD-146, 148), or oral cavity (ICD-141, 142-145) were included in the study. All patients were newly diagnosed at the University Medical Centre Utrecht during a two-year period beginning 1 December 2000. Data were collected during an interview, which was performed between diagnosis and the start of therapy, using a standardized

Abstract

This study identifies patient and tumour related factors associated with advanced carcinoma of the head and neck. Special attention was paid to the role of patient and professional diagnostic delays. Three-hundred and six patients newly diagnosed with carcinoma of the pharynx, larynx and oral cavity were included in the study. Logistic regression analyses were used to identify the risk factors for presenting with an advanced tumour. Multivariate analysis found that having a pharyngeal carcinoma (OR 22.68; $P=.000$), an oral carcinoma (OR 6.51; $P=.000$), or a supraglottic carcinoma (OR 8.12; $P=.000$), patient delay > 3 months (OR 3.47; $P=.001$) and having a doctors' contact for another reason than the head and neck symptom (OR 0.20; $P=.022$) were predictive of presenting with an advanced tumour. These results suggest that beyond tumour-related factors, the patients' care seeking behaviour contributes to an increased risk of being diagnosed with an advanced tumour of the head and neck.

Introduction

Head and neck cancers are an increasing health problem in the Netherlands. Not only are incidence rates increasing, the proportion of patients presenting with an advanced primary tumour has also been rising over the last twenty years, as is the case in other European countries and the United States.¹⁻³ This is an unfavourable situation as advanced tumours lead to worse survival rates and a poorer quality of life after therapy.^{4,5} Therefore, to reduce mortality and morbidity it is important that tumours are diagnosed at an early stage.

Several studies have been published documenting risk factors for advanced head and neck cancer.⁶⁻¹⁰ Both tumour-related factors, such as localisation and type of presenting symptoms, and patient-related factors, such as age, sex, marital status and smoking behaviour, were found to be related to advanced disease. Because of the time-dependent progression of tumour growth, several studies investigated the relationship between the duration of symptoms until diagnosis and the clinical stage of the tumour at diagnosis. The results with regard to this so-called diagnostic delay as a risk factor for advanced disease were contradictory. Most studies made a distinction between patient delay in seeking professional health care and professional delay in diagnosing cancer. Carvalho (2002) found mixed results regarding the relationship between patient delay in seeking medical care and disease stage, dependent on disease site. Allison (1998) and Carvalho (2002) found a significant positive association between professional delay in diagnosing oral cancer and the stage of the tumour, while Wildt (1995) found a negative relationship. Other studies found diagnostic delay to have no significant effect on tumour stage, but sample sizes were small or no distinction was made between patient and professional delay.¹¹⁻¹³

In this study, total diagnostic delay was subdivided into patient delay and two forms of professional delay, namely referral delay and medical specialist delay. The different forms of delay were tested for their independent effect on tumour size. In addition, we evaluated the relationship of several patient-related and tumour-related factors with tumour size at diagnosis.

Methods

Patients diagnosed with squamous cell carcinoma of the larynx (ICD-161), pharynx (ICD-146, 148), or oral cavity (ICD-141, 143-145) were included in the study. Patients were all newly diagnosed at the University Medical Centre Utrecht during a two-year period beginning 1 December 2000. Data were collected during an interview, which was performed between diagnosis and the start of therapy, using a standardised

questionnaire. Data were collected on sociodemographic data, smoking and drinking behaviour, and previous medical experiences and knowledge of cancer, together with information regarding symptomatology, interpretation of the symptoms, health professional consultations and the period of time taken for each step in the diagnostic process. Responses on patient and professional delay were verified against data from medical records and questionnaires filled in by the patients' partner or family member and the health professional initially consulted.

Patient delay was defined as the time elapsed between symptom discovery and the first medical contact with a medical doctor or dentist concerning that symptom. Referral delay was defined as the period between the first medical contact with the general practitioner or dentist and the first contact with the medical specialist. Medical specialist delay was defined as the period from the first contact with the medical specialist until definitive diagnosis. Total delay was defined as the period between symptom discovery and definitive diagnosis. Fifteen patients were excluded from the investigation of patient delay because their symptoms of head and neck cancer were first detected by a health professional. Eighteen patients who immediately consulted a medical specialist, and thus were not referred by a general practitioner or dentist were excluded from the investigation of referral delay.

Data on tumour characteristics were collected from the patients' medical records. Tumours were registered according to the International Classification of Diseases for Oncology (ICD-O) and the TNM classification.¹⁴ Tumours were coded as advanced if they were classified as T3 or T4 according the T-classification. Tumour stage was subdivided into stage I-II (T1 or T2 and N0) and stage III-IV (T3, T4 or N>0).

Statistical analysis

Odds ratios (ORs) for diagnosis of an advanced tumour and their respective 95% confidence intervals (CIs) were estimated using univariate logistic regression analyses containing categorical independent variables. Stepwise multiple logistic regression analysis was used to build a model of variables which could best explain the risk of presenting with an advanced tumour. The relationships between various forms of delay were examined using Pearson product moment correlations after transforming the variables into a logarithmic scale to correct for the skewness in the distributions.

Results

A total of 306 patients were included in the study, comprising 210 men and 96 women. The participants' ages ranged from 34 to 89 years, with a mean of 62.0 years. There

were 117 patients with carcinoma of the larynx, 55 with carcinoma of the pharynx and 134 with carcinoma in the oral cavity. Two hundred and seven patients (68%) presented with a tumour classified as T1 or T2 and 99 patients (32%) presented with a tumour classified as T3 or T4. When tumour positive lymph nodes were taken into account, 172 patients (56%) were diagnosed with stage I/II and 134 patients (44%) with stage III/IV.

Table 1 provides the crude ORs for presenting with an advanced tumour (T3 or T4) by sociodemographics and smoking and drinking behaviour. This data suggests that there is a trend for male patients to have an increased risk of being diagnosed with an advanced tumour ($p=.064$). Furthermore, the risk of an advanced tumour appears to be greater among those who drank five or more alcoholic beverages a day and those who smoked 20 or more cigarettes a day, although again the significance is marginal ($p=.076$ and $p=.052$ respectively). The combined effect of heavy smoking and drinking was tested, but was not proven to be significant. Age, marital status, education and employment status seemed not to be associated with tumour size at presentation.

Table 1. Odds Ratios (ORs) with 95% Confidence Intervals (CIs) for diagnosis of an advanced tumour (T3/T4) by sociodemographic variables and smoking and drinking behaviour

Variable	Category	T1-2/ T3-4	OR	(95% CI)
Sex	Male	135/75	1.00	(ref.)
	Female	72/24	0.60	(0.35-1.03)
Age	<65	123/63	1.00	(ref.)
	≥65	84/36	0.84	(0.51-1.37)
Marital status	Married	160/70	1.00	(ref.)
	Single	47/29	1.41	(0.82-2.42)
Education	Low	94/53	1.00	(ref.)
	Middle	70/31	0.79	(0.46-1.35)
	High	41/13	0.56	(0.28-1.14)
Employment status	Employed	67/34	1.00	(ref.)
	Unemployed	22/19	1.70	(0.81-3.57)
	Retired	83/32	0.76	(0.43-1.36)
	Housewife	32/13	0.80	(0.37-1.72)
Alcohol consumption	Never	25/9	1.00	(ref.)
	Stopped	12/8	1.85	(0.57-6.00)
	0-2 drinks/day	91/35	1.07	(0.45-2.51)
	3-4 drinks/day	38/14	1.02	(0.39-2.72)
	≥5 drinks/day	41/33	2.24	(0.92-5.44)
Tobacco consumption	Never	25/6	1.00	(ref.)
	Stopped	63/26	1.72	(0.63-4.68)
	0-20 cig/day	47/22	1.95	(0.70-5.44)
	≥20 cig/day	72/45	2.60	(0.99-6.84)

Table 2. Odds Ratios (ORs) with 95% Confidence Intervals (CIs) for diagnosis of an advanced tumour (T3/T4) by tumour variables

Variable	Category	T1-2/ T3-4	OR	(95% CI)
<i>Localisation</i>	Glottis	72/6	1.00	(ref.)
	Supraglottis	23/16	8.35	(2.92-23.83)
	Pharynx	20/34	19.43	(7.19-52.53)
	Oral cavity	91/43	5.67	(2.29-14.06)
<i>Presence of symptoms</i>	1	179/80	1.00	(ref.)
	≥2	22/18	1.83	(0.93-3.60)
<i>Voice change</i>	Not reported	124/83	1.00	(ref.)
	Yes	83/16	0.29	(0.16-0.53)
<i>Lesion</i>	Not reported	170/83	1.00	(ref.)
	Yes	37/16	0.89	(0.47-1.68)
<i>Pain</i>	Not reported	161/52	1.00	(ref.)
	Yes	46/47	3.16	(1.89-5.28)
<i>Dysphagia</i>	Not reported	199/84	1.00	(ref.)
	Yes	8/15	4.44	(1.82-10.87)
<i>General symptoms^a</i>	Not reported	188/91	1.00	(ref.)
	Yes	19/8	0.87	(0.37-2.06)
<i>Swelling</i>	Not reported	198/92	1.00	(ref.)
	Yes	9/7	1.67	(0.61-4.63)
<i>Irritation</i>	Not reported	194/94	1.00	(ref.)
	Yes	13/5	0.79	(0.28-2.293)
<i>Neck mass</i>	Not reported	194/95	1.00	(ref.)
	Yes	13/4	0.63	(0.20-1.98)

^a General symptoms include fatigue, tightness of the chest and weight loss

Patients with a tumour of the pharynx, of the oral cavity or of the supraglottis are diagnosed significantly more often ($p=.000$) as having an advanced tumour than patients with a tumour of the glottis (Table 2). Especially among the patients with a tumour of the pharynx, a large proportion (62%) presented with an advanced tumour. There was a trend for patients who experienced more than one symptom from the beginning of symptoms to be diagnosed with an advanced tumour ($p=.080$). Patients who reported pain or dysphagia as a first symptom were more likely to be diagnosed with an advanced tumour ($p=.000$ and $p=.001$, respectively), while patients who reported voice change were less likely to be diagnosed with an advanced tumour ($p=.000$).

The ORs for an advanced tumour associated with previous knowledge and experiences and with reactions to the symptoms are shown in Table 3. Knowledge of cancer in general decreased the risk of being diagnosed with an advanced tumour ($p=.034$). In addition, patients with previous experience with serious health problems

and seeking care had a reduced risk of being diagnosed with an advanced tumour ($p=.036$). Furthermore, patients who went to the doctor for a main reason other than their head and neck symptom were diagnosed significantly less frequently with an advanced tumour ($p=.002$).

Table 3. Odds Ratios (ORs) with 95% Confidence Intervals (CIs) for diagnosis of an advanced tumour (T3/T4) by knowledge factors, previous experiences and reactions to symptoms

Variable	Category	T1-2/ T3-4	OR	(95% CI)
<i>Knowledge of head and neck cancer</i>	None	133/55	1.00	(ref.)
	Yes	42/16	0.92	(0.48-1.78)
	Little	19/13	1.66	(0.76-3.58)
<i>Knowledge of cancer in general</i>	No	19/16	1.00	(ref.)
	Yes	181/70	0.46	(0.22-0.94)
<i>Experience with health problems</i>	None or little	91/53	1.00	(ref.)
	Yes	109/37	0.58	(0.35-0.97)
<i>Experience with cancer</i>	None	42/27	1.00	(ref.)
	Yes, self or partner	20/10	0.78	(0.32-1.91)
	Yes, family or friends	131/54	0.64	(0.36-1.14)
<i>Attribution of first symptom</i>	Cancer	8/2	1.00	(ref.)
	Benign	150/69	1.84	(0.38-8.89)
	No idea	40/19	1.90	(0.37-9.82)
<i>Concern about first symptom</i>	No	170/74	1.00	(ref.)
	Yes	30/19	1.46	(0.77-2.75)
<i>Main reason for visiting GP</i>	Head and neck symptom	164/92	1.00	(ref.)
	Other symptom	38/4	0.19	(0.07-0.55)

Table 4 shows the association between the various forms of delay and presenting with an advanced tumour. Patients who delayed seeking care for more than three months had an increased risk of being diagnosed with an advanced tumour compared with patients who consulted within the first month ($p=.049$). Furthermore, patients with a total diagnostic delay of more than three or nine months were twice as likely to be diagnosed with an advanced tumour than patients who had a total delay of less than three months ($p=.044$ and $p=.050$ respectively). Delay due to the general practitioner or dentist, or due to the medical specialist appeared not to be related to tumour size. Patient delay related positively to total delay ($r=0.75$, $p<.01$) as did referral delay ($r=0.56$, $p<.05$) and medical specialist delay ($r=0.36$, $p<.05$). Patient delay was not significantly related to either form of professional delay. Referral delay was moderately related to medical specialist delay ($r=0.15$, $p<.05$).

Table 4. Odds Ratios (Ors) with 95% Confidence Intervals (Cis) for an advanced tumour according to various forms of delay

Variable	Category	T1-2/ T3-4	OR	(95% CI)
<i>Patient delay</i>	< 1 month	87/33	1.00	(ref.)
	1-3 months	60/33	1.45	(0.81-2.60)
	≥ 3 months	46/32	1.83	(1.00-3.35)
<i>Referral delay</i>	< 1 month	107/50	1.00	(ref.)
	1-3 months	49/28	1.22	(0.69-2.17)
	≥ 3 months	35/18	1.10	(0.57-2.13)
<i>Specialist delay</i>	< 1 month	56/26	1.00	(ref.)
	1-3 months	116/62	1.15	(0.66-2.01)
	≥ 3 months	35/10	0.62	(0.27-1.43)
<i>Total delay</i>	< 3 month	52/14	1.00	(ref.)
	3-9 months	110/59	1.99	(1.02-3.89)
	≥ 9 months	45/26	2.15	(1.00-4.60)

Multiple logistic regression was used to select the variables that could best explain the risk of presenting with an advanced tumour. Those factors with an univariate significance of $p < .30$ were used in the analyses. The significant variables in the multifactorial model were patient delay, tumour site and the reason for consulting the GP or dentist (Table 5). The model demonstrates that (1) patients with patient delay between 1 and 3 months have twice, and patients with a patient delay > 3 months have 3.5 the odds for an advanced tumour of those patients with a patient delay < 1 month; (2) supraglottic, oral and especially pharyngeal tumours are associated with higher odds (8.12, 6.51, and 22.68, respectively) for an advanced tumour than glottic tumours and (3) patients who consulted the doctor for another reason than their head and neck symptom have one fifth the odds of an advanced tumour when compared to patients who visited their doctor because of head and neck symptoms.

Table 5. Multifactorial model for the odds ratio (OR) estimates for advanced tumour size (T3-T4)

Variable	Category	OR	(95% CI)	P value
<i>Patient delay</i>	1-3 months	2.00	(0.98-4.06)	.056
	≥ 3 months	3.47	(1.62-7.44)	.001
<i>Localisation</i>	Supraglottis	8.12	(2.52-26.23)	.000
	Pharynx	22.68	(7.74-66.46)	.000
	Oral cavity	6.51	(2.46-17.19)	.000
<i>Reason for visiting GP</i>	Other symptom	0.20	(0.05-0.79)	.022

Disease stage as an outcome variable

The same analyses were carried out to estimate the odds ratios for being diagnosed with advanced stage cancer (stage III or IV) according to the study variables. Being male was no longer a risk factor for advanced disease (OR=0.94, $p=.796$). None of the other sociodemographic factors were associated with disease stage. As with tumour size, drinking more than four alcoholic drinks a day increased the risk of advanced stage disease significantly (OR=2.67, $p=.026$) compared to patients who never drink. However, the odds ratio for smoking more than 20 cigarettes a day was no longer significant (OR=1.50, $p=.322$). With regard to the tumour variables results comparable with tumour size were obtained, except for the symptom variable neck mass. Patients who experienced a neck mass as a first symptom were diagnosed with advanced disease significantly more frequently (OR=10.69, $p=.002$) compared to patients who did not report that symptom. With regard to the knowledge factors, previous experiences and reactions to the symptoms, the same results were obtained as with tumour size. Finally, the various forms of delay were not related to tumour stage.

Discussion

In this study we investigated which patient-related and tumour-related factors were associated with an advanced tumour in the head and neck. The most important factors that independently explained tumour size were tumour localisation, the reason to consult a doctor and patient delay.

Patients with a tumour of the supraglottic, oral cavity and especially the pharynx were diagnosed with an advanced tumour significantly more frequently than patients with a tumour of the glottis, as established in other studies.^{8,15} Apparently, glottic tumours are accompanied by early symptoms. The symptoms that accompanied the advanced tumour were pain and dysphagia, while voice change was more often seen in patients eventually diagnosed with a small tumour. With regard to the stage of the disease (stage I/II or III/IV), the same factors predict late stage disease. The relations between the symptoms and tumour status could be explained by the fact that specific symptoms are related to a specific disease site. This was confirmed by the finding that in the multifactorial model only tumour site was selected as an important variable explaining patient delay, while the symptom variables were no longer significant.

Female patients, patients with knowledge of cancer and patients with experience of health problems were at a lower risk of being diagnosed with an advanced tumour. These factors were no longer significant in the multifactorial model, which indicates that these effects were at least partly mediated by the significant variables in the

multivariate model. Heavy smokers and drinkers were at a higher risk of presenting with an advanced tumour. However, these variables were not significant in the multifactorial model, although smoking remained a risk factor at borderline significance. In other studies, advanced disease stage was related to tobacco use,^{7,9} alcohol use¹¹ or the combination of alcohol and tobacco use.¹⁶

The reason for consulting a health professional was found to be a predictor of the size of the tumour. Patients who consulted their general practitioner or dentist for a main reason other than their head and neck symptom, and only mentioned their head and neck symptom casually, were at a lower risk of being diagnosed with an advanced tumour. This effect was independent of patient delay. Thus, the time that elapsed between the first symptom and the first medical contact was not per se shorter for these patients and cannot as such serve as an explanation for this finding. Apparently, these patients were not disturbed or alarmed by their symptoms, which possibly indicates that these patients had less aggressive tumours.

Although it seems logical to assume that the time that elapses between the occurrence of symptoms and final diagnosis will influence tumour size, results regarding this relationship are not unequivocal. Only a few studies analysed the relationship between diagnostic delay and the T-classification of the tumour, thus tumour size, instead of the TNM-classification that includes the status of the lymph nodes and distant metastasis as well. In our study we found a higher risk of presenting with an advanced tumour (T3 or T4) in the case of patients who delayed seeking care for more than three months. Although patient delay is a subjective measure, in this study the measurement error was minimised by validating the data against other data sources. The two forms of professional delay (referral delay and medical specialist delay) were not found to be related to tumour size, but again, total diagnostic delay was positively related to tumour size. These findings were not confirmed in other studies.^{10,12,17} With regard to the stage of the disease, no associations between different forms of delay and advanced stage cancer were found in our study. Carvalho and Allison found that patient delay was related to advanced stage cancer for patients with carcinoma of the hypopharynx and larynx, and pharynx, respectively. In the case of oral cavity patients they both found that increased professional delay was related to advanced stage cancer. In other studies the relationship between diagnostic delay and disease stage at diagnosis was not confirmed.^{6,11,13,18} The failure to demonstrate the presence of a relationship between patient delay and disease stage can be explained by the fact that stage is not only determined by tumour size, but also by the status of the lymph nodes. Patients who experience a neck mass as a first symptom are often alarmed and seek care immediately.¹⁸ These patients are diagnosed as having advanced stage cancer, while their primary tumour might still be small.

In this study, total diagnostic delay was divided into patient delay and two forms of professional delay. In the univariate analyses, both patient delay and total diagnostic delay were significant risk factors for an advanced tumour. However, patient delay and total delay were highly correlated and in the multifactorial model only patient delay was significant. Of the different forms of delay, patient delay seemed to be the most important with regard to the size of the tumour. It was speculated that patients who showed a long patient delay, and therefore presented with an advanced tumour, would show less professional delay because the tumour is easily recognised.⁹ Although there seemed to be a trend that a shorter medical specialist delay was associated with advanced tumours, no relationship was found between patient delay and the two forms of professional delay. Thus, in our study, increased patient delay did not subsequently decrease the professional delay.

From the findings of this study it can be concluded that among patients with cancer of the head and neck, patients with oral, supraglottic, but especially pharyngeal carcinoma are at increased risk of being diagnosed with an advanced tumour. In addition, patient delay increases the risk of an advanced tumour, while a medical check-up for a reason other than head and neck symptoms decreases the risk of an advanced tumour. Thus, although tumour related factors seem to be important, the behaviour of the patient is also a critical factor that influences tumour status and therefore should not be neglected. In order to prevent advanced disease, the population should be well informed regarding the identification of symptoms of head and neck cancer. Special attention should be paid to high-risk subjects with excessive smoking and/or drinking habits.

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Chapter 7

General discussion

Introduction

Head and neck cancer accounts for approximately 4% of all newly diagnosed cancers, and the incidence rate (especially of oral and pharyngeal cancer) is still rising. Head and neck cancer has a huge impact on quality of life, and survival is poor, particularly for those patients who present with advanced disease. Unfortunately, the incidence of patients who present with an advanced tumour has increased over the last twenty years.

Despite progress in diagnostic and therapeutic options for advanced head and neck cancer, the prognosis of patients with advanced tumours is still modest and treatment still has a major impact on quality of life. Therefore, preventive actions to improve early detection of cancer are becoming more and more important with a view to increasing the number of tumours discovered at an early stage.

An important factor for early detection of head and neck cancer is delay in diagnosis. Many studies have investigated this diagnostic delay in head and neck cancer patients. However, the patient's perspective regarding the process of seeking medical care is seldom taken into account. It is still the case that little is known about the patients' motivation to seek care for head and neck cancer symptoms or, on the contrary, to postpone seeking medical care. In addition, the relationship between psychological characteristics of patients and diagnostic delay has never been addressed among head and neck cancer patients.

This is the first study to investigate the patient's perspective with regard to diagnostic delay in head and neck cancer. The patient's perspective is important because the patient is the main decision maker in the care seeking process. This is true not only before the first medical consultation, but also thereafter. After all, we found that half of the patients have to decide themselves whether to seek medical care or not. In addition, this study takes into account data from the general practitioner and the patient when establishing the possible diagnostic delay. The high response rate of these two parties enhances the reliability of the findings regarding the length of the different stages of delay.

The present study aims to explore the role of the patient in delays in diagnosing head and neck cancer and to identify risk factors for presenting with an advanced tumour. In this final chapter, the major findings are further outlined and considered in a transfer perspective. The methodological issues are discussed and implications for health education and clinical practice as well as recommendations for future research are made.

Chapter 7

General discussion

Introduction

Head and neck cancer accounts for approximately 4% of all newly diagnosed cancers, and the incidence rate (especially of oral and pharyngeal cancer) is still rising. Head and neck cancer has a huge impact on quality of life, and survival is poor, particularly for those patients who present with advanced disease. Unfortunately, the incidence of patients who present with an advanced tumour has increased over the last twenty years.

Despite progress in diagnostic and therapeutic options for advanced head and neck cancer, the prognosis of patients with advanced tumours is still modest and treatment still has a major impact on quality of life. Therefore, preventive actions to improve early detection of cancers are becoming more and more important with a view to increasing the number of tumours discovered at an early stage.

An impeding factor for early detection of head and neck cancer is delay in diagnosis. Many studies have investigated this diagnostic delay in head and neck cancer patients. However, the patient's perspective regarding the process of seeking medical care is seldom taken into account. It is still the case that little is known about the patients' motivation to seek care for head and neck cancer symptoms or, on the contrary, to postpone seeking medical care. In addition, the relationship between psychological characteristics of patients and diagnostic delay has never been addressed among head and neck cancer patients.

This is the first study to investigate the patient's perspective with regard to diagnostic delay in head and neck cancer. The patient's perspective is important because the patient is the main decision maker in the care seeking process. This is true not only before the first medical consultation, but also thereafter. After all, we found that half of the patients have to decide themselves when to return to the health professional. In addition, this study takes into account data from the general practitioner and the partner when establishing the possible diagnostic delay. The high response rate of these two parties enhances the reliability of the findings regarding the length of the different stages of delay.

The present study aims to explore the role of the patient in delays in diagnosing head and neck cancer and to identify risk factors for presenting with an advanced tumour. In this final chapter, the major findings are further outlined and considered in a broader perspective. The methodological issues are discussed and implications for health education and clinical practice as well as recommendations for future research are made.

Risk factors for presentation with advanced carcinoma

Most previous studies that focused on examining the effect of diagnostic delay on disease outcome used disease stage as an outcome measure.^{e.g.1-3} To determine the disease stage, both tumour size and local and distant metastases were taken into account. However, we were particularly interested in tumour size, since the patients with complaints related to large size tumours could possibly have been diagnosed earlier.

We found that the most important risk factors that independently explained tumour size were tumour localisation, the reason to consult a health professional and patient delay in consulting a health professional (Chapter 6). Patients with a tumour of the supraglottic, oral cavity and especially the pharynx were diagnosed significantly more frequently with an advanced tumour than patients with a tumour of the glottis. This finding was confirmed in other studies.^{4,5} Apparently, glottic tumours are accompanied by early symptoms.

Patients who consulted their general practitioner or dentist for a main reason other than their head and neck symptom and only mentioned their head and neck symptom in passing were at a lower risk of being diagnosed with an advanced tumour. This effect was independent of patient delay. Thus, the time that elapsed between the first symptom and the first medical contact was not by definition shorter for these patients and cannot as such serve as an explanation for this finding. It seems that these patients were not disturbed or alarmed by their symptoms, which possibly indicates that these patients had less aggressive tumours.

In the present study, univariate analyses showed that heavy smokers and drinkers were at a higher risk of presenting with an advanced tumour. However, these variables were not significant in the multifactorial model, although smoking remained a risk factor of borderline significance. In other studies, advanced disease stage was related to tobacco use,^{2,6} alcohol use⁷ or the combination of alcohol and tobacco use.⁸

In our study, total diagnostic delay was divided into patient delay and two forms of professional delay: referral delay and medical specialist delay. Referral delay was defined as the time from the first visit to the general practitioner's or dentist's until the first contact with the medical specialist. Medical specialist delay was defined as the time between the first contact with the medical specialist and the definitive diagnosis. We found that in the univariate analyses, both patient delay and total diagnostic delay were significant risk factors for an advanced tumour. However, patient delay and total delay were highly correlated and in the multifactorial model only patient delay emerged as a predictor. Thus, of the different forms of delay, patient delay seemed to be the most important in predicting the size of the tumour. A confounder variable in

the relationship between diagnostic delay and tumour size is tumour growth rate. However, there is no uniformly recognised direct measure of tumour growth rate.⁹ An accurate but difficult measure to obtain was used by Waaiker et al (2003), who measured tumour volume increase by evaluating CT scans at two different points in time.¹⁰

Thus, although tumour related factors, such as localisation of the tumour, appear to be important, the behaviour of the patient during the care seeking process is also a critical factor that influences tumour status.

Stages of patient delay

Our study showed that patient delay is not uncommon among patients with head and neck cancer (Chapter 2, 3, 4). More than one quarter of the patients postponed seeking medical care for three months or more. This is within the range seen in other studies.¹¹⁻

¹³ In order to gain a better understanding of the different steps in the process of detecting symptoms and seeking medical help, the model of patient delay developed by Andersen was used as a framework.¹⁴ This model distinguishes the following delay stages in the care seeking process: appraisal delay, illness delay, behavioural delay and scheduling delay.

Although the model was useful in structuring the steps in the care seeking process of the patients in our study, we encountered a problem when distinguishing the stage between the appraisal of symptoms and behavioural action. In this illness delay stage, patients were expected to have already inferred illness and to have decided whether or not to seek medical assistance or self-treat the disease. However, when we asked the patients when they inferred illness, almost eighty per cent referred to a date that coincided with the first medical visit or thereafter. Thus, most of the patients did not consider themselves ill before they sought medical help. This finding might be related to the nature of the symptoms accompanying head and neck cancer (such as hoarseness, sore throat or swallowing problems). These are often ascribed to common ailments like the flu, a cold, or voice strain. Only a few studies on patient delay distinguish the various stages of delay.¹⁴⁻¹⁷ These studies demonstrated that segmenting the total patient delay period into sequential stages of delay can facilitate the search for specific causes of delay. This allows a differentiation to be made of disparate causal factors that come into play as the person's reactions, decisions and behaviours unfold during the different steps in the care seeking process. However, these studies recognised the difficulty of accurately registering the different stages in retrospect. Ristvedt en Trinkaus (2004) found that, among their sample of rectal cancer

patients, some did not infer illness before the first medical consultation.¹⁷ Hence, they were unable to distinguish an illness delay stage for this part of the patients. In the study by de Nooijer et al (2001) it was stated that “although it (the model of patient delay) is a useful model to structure delay, it does not exist in the mind of the patients”.¹⁶ We suggest that the question we asked the patients to distinguish illness delay (*that is*: when did you realise you were ill?) had a completely different meaning after cancer diagnosis. Patients who had not realised that their symptoms might be indicative of cancer, have to place the past experiences regarding these symptoms in a different and new reference frame. Our results provide some evidence for this, as the twenty per cent of patients who distinguished illness delay indicated that, before the first medical visit, they were more worried, had more knowledge of head and neck cancer, attributed their symptoms more often to cancer and more frequently experienced a swelling as a first symptom (Chapter 2). Thus, it seems that these patients had greater illness awareness before their first contact with a health professional. It can therefore be suggested that for those patients of whom we could not distinguish the illness delay stage, the cognitive mapping of the steps of the care seeking process *no longer* exist in their mind because they were overwhelmed by the diagnosis of cancer. This is confirmed by the finding that among the reasons to postpone medical consultation, reasons indicative of illness delay (such as indolence, tried to solve the problem oneself, never went to the doctor quickly) were actually reported in this group of patients (Chapter 2). It has also been suggested that recall could be impaired due to the emotional turmoil of the cancer diagnosis.^{14,16} The issue of recall bias is elaborated in more detail in the paragraph on possible methodological limitations.

It was found that appraisal delay (which in our study is defined as the time that elapses between detection of the first symptoms and the decision to seek medical care, including both appraisal and illness delay) accounts for the greater part of the total patient delay (Chapter 2). Appraisal delay concerns the interpretation of the importance and meaning of the symptoms. It was suggested that the appraisal process may lengthen as people think it is unlikely that their symptoms indicate a condition as serious as cancer.¹⁴ In our study, the main reason for delay is indeed that patients interpreted their symptoms as innocuous (Chapter 2). Only a small percentage (4%) of the patients ascribed the symptoms to cancer. The common nature of the symptoms (e.g. sore throat, hoarseness) may lead to a low risk perception of serious disease.¹⁸ Also, earlier studies showed that the less specific the symptoms, the longer the appraisal delay.^{14,19} This finding was confirmed in our study, since the symptoms influenced appraisal delay: voice change or general symptoms as a first symptom

lengthened the appraisal delay, while experiencing a neck mass shortened the delay in deciding to seek care (Chapter 2).

Behavioural delay and scheduling delay in making an appointment were not found very often in our study population (Chapter 2). An earlier study in the USA showed that concern about the cost of treatment (which is an issue in the USA and was not (yet) in the Netherlands) was the most important predictor of these forms of delay.¹⁵ This finding emphasizes that, when comparing delay among several studies, one must take into consideration the geographic locations of the studies, as the health care systems and cultures of different countries could contribute to the variability in patient and professional delay.⁹

Patient factors related to delay

Personal characteristics

Earlier studies that took into account patient characteristics in relation to delay focused mostly on sociodemographical characteristics.^{e.g.20-22} To the best of our knowledge, personal characteristics and their relationship with delay has not yet been explored in head and neck cancer patients. In our study we found that patient delay was related to personal characteristics like coping style, defense style, health hardiness and optimism (Chapter 3, 4, 5).

The way people cope with a symptom is very important for the decision as to whether or not to seek professional medical consultation. Promptness in care seeking can be seen as an active, problem-solving **cop**ing strategy.²³ Indeed, in our study, patient delay was positively associated with avoidance coping, and patients who postponed their medical consultation for more than three months made less use of an active coping style or of seeking support as coping style (Chapter 3). Moreover, patients who postponed returning to the general practitioner or dentist for a second consultation were the ones who made less use of seeking support as a coping style (Chapter 5). This is in agreement with the literature as Facione et al. found that those women with an active coping style were less inclined to delay seeking care for a breast tumour symptom.²⁴ Although the items of the seeking support coping style measured with the Utrecht Coping List reflect both seeking instrumental support and emotional support, in the case of seeking medical care for symptoms, seeking support (particularly instrumental support) is similar to active coping.

Defense style, which can be seen as a specific form of coping,²⁵ was measured by an overall defensive functioning score which reflects the extent to which people adopt more mature defense mechanisms (e.g. humour, anticipation) relative to immature

ones (e.g. idealisation, denial, and projection). It was found that patients with a lower score on overall defensive functioning, who thus adopt more immature defenses relative to mature defenses, showed more patient delay. Denial and other forms of defensiveness are likely to occur when an individual has no means of immediately reducing the psychological threat.²⁶ Denial is frequently presumed to be responsible for patient delay, especially in the case of unusually long delays.²⁷ Although the Defense Style Questionnaire contains items measuring denial, it is a global measure which gives an indication of how individuals tend to react in a variety of situations. There might be a gap between the defense mechanisms one usually adopts and the one used in a specific situation. As such, the Defense Style Questionnaire gives us little information about possible denial in this specific process of seeking care for head and neck symptoms.

The present study found a negative relationship between patient delay and overall **health hardiness** (Chapter 3). Therefore, patients who were involved in health issues and believed that they had control over their health showed less delay. As far as we are aware, the relationship between health hardiness and patient delay has never been directly examined. A related construct, namely health locus of control, was found not to be related to patient delay in seeking care for breast symptoms, although the sample size was small.²⁸ When examining the construct of health hardiness in more detail, we found that especially the control dimension was related to patient delay (Chapter 4). Patients who delayed seeking medical care reported higher levels of external locus of control and lower levels of perceived health competence. The items constituting the external locus of control scale concern beliefs that chance or fate influences one's health. It has been suggested that such beliefs are more appropriately conceived as indicators of a lack of perceived personal control than as an external locus of control dimension.²⁹ The items of the perceived health competence scale reflect the inability of finding effective solutions for health problems. Thus, it seems that patients who experience a lack of personal control and efficacy with regard to health issues are particularly at risk as regards delays in seeking medical care. A possible mechanism through which personal control might influence patient delay is that control reduces the appraisal of threat and increases problem-solving and support-seeking strategies which, in turn, reduces delay in seeking medical care.³⁰

We found that **optimism** was associated with less patient delay in seeking care. Likewise, Lauer and Tak found that, among patients confronted with a symptom possibly related to breast cancer, optimism was related to prompt care seeking.²³ An explanation for this finding might be that optimism has been related to a greater attention to health threats.³¹ In addition, optimism has been associated with greater use of active coping, while pessimism has been shown to be related to avoidance.³² Our

results confirm this relationship between optimism and coping (Chapter 3). In our study, optimism was operationalised as a personality trait, that is dispositional optimism which is the general expectation that good things will be plentiful in the future and bad things scarce.³³ It can be suggested that if you expect things to turn out right for you, you do not have to be afraid of possible consequences of your actions, in this case seeking care for possible cancer symptoms. However, it is suggested that there is a downside to optimism if it is too unrealistic, as described by Weinstein (1989) with respect to people's perception of personal risk for illnesses and mishaps.³⁴ When people are asked to provide a percentage estimate of the likelihood, in comparison with peers, that they will someday experience an illness or injury, most underestimate the risks.³⁵ A recent study showed that dispositional optimism was inversely associated with perceived risk of breast cancer. However, for most women, their perceived risk significantly exceeded their actual risk, which led the authors to conclude that optimists are less likely to overestimate their risk of breast cancer.³⁶ It is not known, but possibly not likely, that these results can be generalised to head and neck cancer, as this type of cancer is less known and receives less media attention and that has an influence on risk perception.

The above-mentioned measures of coping, defense style, health hardiness and optimism are very general self-report measures and reflect the way people on the whole think and act. We related these measures to a situation-specific behaviour, namely patient delay, and although significant relationships were detected, one cannot be surprised that these associations were weak. During the interview we tried to explore more situation-specific factors that might play a role in the process of seeking care for head and neck cancer symptoms. We identified several social, cognitive and emotional factors that were related to delay in seeking medical care.

Social, cognitive and emotional factors

We found that increased patient delay was seen in patients who lived alone, who were unable or unwilling to talk openly about complaints and who were prompted by others to seek medical care (Chapter 2). This is in agreement with literature on patient delay among breast cancer patients.^{37,38} It seems that social interaction stimulates care seeking for head and neck symptoms, although the finding that being prompted by others was associated with more delay suggests otherwise. However, from the interviews it appeared that it is likely that those patients who were prompted by others were prevented from yet further delay. This was sustained by the finding that for a number of patients, the patient's partner eventually scheduled a medical appointment because the patient neglected to do so.

Other factors that were found in our study to be related to patient delay concerned the interpretation of the symptoms, as already mentioned above. We found that patients who knew about head and neck cancer before they were confronted with it, showed not only less delay in seeking medical care for the first time, but also in returning for a second consultation (Chapter 2, 5). Also, patients who were suspicious of cancer returned more quickly to the general practitioner for a second consultation (Chapter 5). Literature suggests that patients with knowledge of cancer and cancer symptoms may be more likely to interpret their symptoms as a health threat, which shortens the appraisal period.³⁹ In our study sample, only 21% reported that they knew about head and neck cancer. Two large population based studies among Dutch adults show that the knowledge of cancer symptoms was poor, although there was a difference between active recalling and recognition of cancer symptoms.⁴⁰ They found that the percentage of respondents who actively recalled head and neck cancer symptoms ranged from 1.6% in the case of swallowing problems to 17.2% in the case of nagging cough or hoarseness. When respondents had to recognise head and neck cancer symptoms, these percentages increased and ranged from 37.5% to 53.1%, although they resemble the percentages of respondents who linked non-cancer symptoms incorrectly to cancer.

There is recurring evidence that there are two kinds of “delayers”: delayers out of lack of knowledge and delayers out of fear.^{14,17,41} The first group believes that their symptoms are not serious and will clear up on their own. The second group is concerned that their symptoms are serious, but are then immobilized by fear, resulting in avoidance behaviour. These reasons for delay correspond with different stages of the care seeking process. The first reason (thinking that the symptom is not serious) lengthens the appraisal process and hence contributes to appraisal delay. The second reason (fear) may lengthen the action phase and increase illness and behavioural delay. The point at which the individual recognises that the symptom could be serious is a critical psychological turning point in the time prior to seeking help.¹⁷ We could not distinguish this critical turning point (recognition of the seriousness of the symptoms) for the majority of the patients. Therefore, it seems that the delayers in our sample of head and neck cancer patients are mostly delayers out of lack of knowledge. However, there were a few patients who indicated that they realised their symptoms could be serious but did not seek help out of fear or denial (Chapter 2). That we only found a few patients who delayed out of fear or denial might be due to the fact that fear or denial is not easy to measure, especially not retrospectively. We only registered denial when it was reported by the patient, but probably these patients are exceptional as they were able and willing to recognise their denial. It can be argued that the appraisal process of all patients who appraised their symptoms as being innocuous for three months or more was influenced by some sort of defensive bias.¹⁸

We tried to identify different predictors of delay for the various stages in the care seeking process. Because appraisal delay almost completely overlaps total patient delay, nearly the same predictors were identified for appraisal delay as for total patient delay (Chapter 2). However, we were able to identify a few unique predictors of behavioural delay. Although the reported reasons to postpone making a medical appointment were mostly practical (such as private or work hassles, or holidays) we found that concern about the symptoms and having experience with health problems and seeking care decreases delay at this stage. These findings support the suggestion that different processes affect the various stages of patient delay differently. However, due to the small variation in the data, the results concerning behavioural delay should be interpreted with caution.

Alcohol use and cigarette smoking

Alcohol use and cigarette smoking, and especially the combination of both, are important risk factors for developing head and neck cancer. Therefore, these health risk behaviours are very common among head and neck cancer patients. In our study sample, 59% were current smokers and 29% had smoked in the past. Eighty-three per cent drank regularly alcoholic beverages, of which 20% drank three to four units of alcoholic beverages per day and 30% five or more units of alcoholic beverages a day.

It has been suggested that, among patients who are confronted with a life-threatening disease, the value they place on health is consistently high.⁴² However, we found that patients who showed one or both health risk behaviours (smoking, or drinking three or more units alcohol per day) had lower scores on health value beliefs than a general population sample (Chapter 4). This difference with the general population was not found for those who did not smoke or drink alcohol before diagnosis. In addition, patients who showed health risk behaviour scored lower on perceived health competence. This scale of the Health Hardiness Inventory reflects the individual's generalised expectancy regarding the ability to interact effectively with the environment in order to obtain the desired outcome, i.e. to be healthy⁴³, and in previous studies as well was found to be negatively related to health risk behaviour such as smoking and excessive drinking.^{29,43,44} We found that excessive drinkers also showed a long patient delay (Chapter 3). It seems that the fact that someone drinks excessively may simply be one manifestation of some larger pattern of (harmful) health-related behaviour. Ouellette (2001) suggests a possible mechanism through which health hardiness (which is a composite of health value and control beliefs) promotes healthy behaviour: the higher the score of individuals on health value and

control beliefs, the less the chance that events are appraised pessimistically as stressful or threatening.³⁰ We found that patient delay could be well predicted by pessimistic beliefs among excessive drinkers (Chapter 3). It might be that fatalistic ideas over outcomes and the perceived inability to exhibit healthy behaviour impedes appropriate care seeking among excessive drinkers.

Possible methodological limitations

During the two-year accrual period of the study, 427 patients were eligible for study inclusion. A total of 306 patients eventually participated, resulting in a participation rate of 72%. It may be that this rate was lowered because we not only collected data from the patients themselves, but also requested information from their partner or close relative and their general practitioner or dentist. There were no differences detected regarding sex, age and tumour characteristics between the participants and non-participants. However, we do not know if there was a selection bias regarding diagnostic delay. There might be an underrepresentation of those who themselves delayed seeking medical care and did not want to discuss or be confronted with this topic. On the other hand, patients with prolonged professional delay may actually be more keen to talk about their situation because they are unhappy at not having been referred quickly. We tried to minimise this selection bias by not explicitly referring to delay in diagnosis in the information letter, but by stating that we are investigating, in more general terms, factors related to seeking a diagnosis for head and neck cancer. In addition, we have no information about possible diagnostic delay of those six patients who were diagnosed with advanced disease but who died before treatment.

The second possible methodological limitation is the retrospective nature of data regarding diagnostic delay. Recall bias may not only influence the recollection of the various steps of the care seeking process, as described earlier, but also the recollection of the length of the various stages of delay. The recall of the pre-diagnostic period might be hampered by the emotional turmoil of the cancer diagnosis. To overcome the limitations of retrospective interviewing, a prospective cohort study should be carried out in which participants and their symptoms are followed. However, an enormous sample size would be required to ensure the inclusion of people who detect possible head and neck cancer symptoms. In addition, it would be ethically impossible to allow participants to behave as they would have normally done once symptoms are recorded. An attempt was made to limit errors of memory by only including patients who were recently diagnosed and not yet treated. Thus, as a consequence, we did not have to rely on patients' distant recall. In addition, we collected complementary information from

the patients' general practitioner or dentist, and from the patient's partner. From the general practitioners and dentists we received the exact dates of the patients' visits, which was stored in their medical records. The partners' report of the care seeking process of the patient was used to detect possible patient delay that was not mentioned by the patient. However, the patients' interview report was used primarily, since the partner could only give information about possible delay once symptoms became overtly perceptible or were discussed openly.

Another reason why patients might distort their memories, or underreport delay, is because of guilt or shame over a long delay. We have tried to overcome this by ensuring that the interviews were conducted by a research psychologist who is not involved in the patients' medical treatment. The findings of this study regarding the lengths of delay are consistent with other studies^{11,12} and the fact that a fair number of patients reported very long delay times suggests that it is not probable that delay was underreported. However, it is inevitable that an ethical dilemma is encountered when questioning procrastination behaviour since, as a researcher, one does not want to leave the patient behind with a feeling that the situation they are in is partly their own fault because they did not act appropriately.

The retrospective nature of the study may not only affect recall bias regarding diagnostic delay, but also concerns the personal characteristics which we tried to measure with the self-report questionnaires. Patients completed the questionnaires after cancer was diagnosed. Although most of the psychological variables measured by these questionnaires are assumed to be stable over time, it is not possible to exclude reactions to recent events (such as the diagnosis of a major life-threatening disease like cancer) as an explanation for the current reported behaviour.

Suggestions for future research

From the present study we can infer some directions and implications for future research. The first recommendation regards the theoretical model of patient delay used in this study. It appears to be difficult to distinguish the various steps in the care seeking process when questions are asked retrospectively. This is especially so when individuals do not recognise the seriousness of their symptoms. It might be possible to identify the different steps in the care seeking process for apparently common symptoms as well but then, when asking questions retrospectively, attention should be paid to the formulation of the interview questions regarding illness delay. Another possibility that would facilitate the reconstruction of the care seeking process would be to ask the patients at an earlier point in time, for example at the general practitioners'

or during the first visit to the medical specialist. By distinguishing illness delay more effectively, one could also acquire a better view of the length of the appraisal process. In addition, it enables identifying factors related to appraisal delay as well as illness delay, which may guide interventions to improve early detection of cancer. A different point is that the name of the model assumes that each patient has shown patient delay. An alternative could be that it is referred to as a model of stages of care seeking for medical symptoms instead of stages of *delay*.

This study was undertaken to identify possible causes of delay in diagnosis of head and neck cancer. From the interview it appeared that a lack of knowledge of head and neck cancer was an important impeding factor during several stages of delay. However, our interview questions were explorative in nature, and we used crude categories to distinguish patients with or without general knowledge of head and neck cancer. Future research should use more comprehensive and standardised questionnaires to determine the level of knowledge of several aspects head and neck cancer. It would be interesting to study the knowledge of head and neck cancer symptoms as well as knowledge of treatment and treatment outcomes in relation to patient delay. In addition, research should focus on the awareness of the risk factors for developing head and neck cancer, such as alcohol use and cigarette smoking.

Another aspect which deserves further examination is denial and its influence on seeking medical care for head and neck cancer symptoms. The few studies that exist on denial and patient delay among cancer patients are mostly case studies and, as such, give us no information of the extent of this phenomenon.²⁷ In this study we only took into account overtly reported denial, which might be the tip of the iceberg. In this patient group in particular, which has a large proportion of heavy drinkers, future studies should use objective measures with which more subtle manifestations of denial can be observed and noted.

A few possible causes of delay, which have hardly been examined among cancer patients, deserve attention in future research. The first is risk perception, as a low risk perception may lead to delay in seeking care. This is of special interest with regard to head and neck cancer because of the obvious risk factors of this type of cancer. It would be of interest to study the perception of risk in relation to the personality trait of optimism. Another aspect is past habits with regard to seeking medical care. Past care seeking behaviour might influence both patient and professional delay. Frequent visitors to general practitioners' may show little patient delay, but may experience a longer professional delay before hospital referral. This might be particularly important with regard to head and neck cancer because of the common nature of the symptoms.

Future studies that examine the relationship between diagnostic delay and tumour size should consider taking tumour growth rate into account. However, more research is needed to establish a uniform measure of tumour growth rate.

A recommendation which we wish to make and which is more specifically related to our study is to perform a follow-up measurement to examine the long-term effect of diagnostic delay on survival. Besides, little is known about the consequences of delay on the well-being of patients. Patient or professional delay may increase feelings of guilt or distress which may have a negative effect on treatment outcomes and quality of life. Because delay is common, more research is needed to examine these relationships and explore these possible negative consequences of delay.

Practical implications: towards prevention of advanced tumours

The present study revealed that patient delay among head and neck cancer patients is not uncommon. Sometimes dramatically long delays were detected. Diagnostic delay, and especially patient delay, was found to be related to presentation with more advanced tumours (Chapter 6). Therefore, reducing patient delay in seeking medical care for head and neck cancer symptoms is extremely important. The more so as we found that patient delay was more often seen in patients who lived alone since this constitutes an ever increasing section of society.⁴⁵

Many of the symptoms of head and neck cancer were interpreted as being innocuous and this lengthened the appraisal delay. Only a small percentage of the patients knew about head and neck cancer, and an even smaller percentage attributed their symptoms to cancer. Therefore, health education aimed at the early detection of cancer should educate the public about the specific symptoms accompanying head and neck cancer. The problem, however, is that the symptoms which might indicate head and neck cancer are common (such as hoarseness, an oral lesion, or a sore throat). An important indicator which distinguishes benign and malignant disease is the duration of symptoms. As a consequence, the general public should not only be alerted to the importance of the nature of the symptoms, but also to the duration of these symptoms. In addition, we found that patient delay was seen more often among those patients who experience a low perceived health competence and thus find it difficult to find effective solutions for health problems. Therefore, to promote early detection, awareness raising as regards head and neck cancer should not only focus on the awareness of symptoms, but also on the steps to be taken once confronted with symptoms. This means discouraging a 'wait and see' attitude and enhancing personal efficacy by showing that one can do something about it, namely seek medical advice. The advice should be to seek medical care if symptoms persist for more than three or four weeks. The messages might include cognitive aspects such as the consequences of delay and strategies for making decisions to seek care.

Individuals who smoke and drink alcohol have an increased risk of developing head and neck cancer and, in addition, of being diagnosed with advanced disease. Therefore, the health education messages should be mainly directed at this group of possible future cancer patients. The excessive drinkers in our patient group showed a long patient delay in seeking medical care. In this patient group, holding pessimistic beliefs was a strong predictor of patient delay. Health education aimed at early detection of head and neck cancer in this group should not focus solely on symptoms, but also on positive outcomes of the desired behaviour such as minimal treatment and good prognosis.

One of the current means for promoting early detection is through a leaflet about cancer early warning signals, provided by the Dutch Cancer Society and distributed among general practitioners and chemist's. However, some members of our patient group, especially those with a long delay, indicated that they seldom visit a general practitioner. The current health education on early detection of cancer will probably not reach this group of patients. Increased access to new technologies, such as the Internet and interactive CD-ROM, open a window of opportunity to reach a large population and can be used to promote health behaviour through (tailored) interventions.⁴⁶ Special attention should be paid to reaching a specific target group of high risk individuals who are heavy smokers and drinkers.⁴⁷ For example, Internet sites on which it is possible to seek information actively about the meaning of symptoms should integrate information about risk factors, duration of symptoms and steps to be taken. General public health campaigns or general practitioners who are aware of their patients' smoking and drinking behaviour should address high risk individuals and refer to the available information.

Moreover, after diagnosis, the patients who smoke or drink alcohol deserve special attention. It was shown that only some of these patients were able to stop smoking or drinking after diagnosis, while quitting would have been highly beneficial for the treatment outcome. Apparently, quitting smoking and drinking is not easy for many patients and a doctor's advice on its own about the benefits of quitting does not seem to be very effective. We found that psychological distress and a lack of personal control were factors that impeded smoking and drinking cessation. Patients who wish to quit may benefit from some professional support during this stressful period. An intervention aimed at changing these health risk behaviours should pay attention to reducing psychological distress and enhancing the patient's personal control.

Our last recommendation concerns the general practitioner and dentist. The results of this study have shown that cancer of the head and neck was not always detected at the first professional consultation (Chapter 5). Because delay in returning to the health professional is partly dependent on patient related factors, such as a seeking support coping style and the cognitive interpretation of symptoms, patients should be informed

about the possible meaning of their symptoms and should be strongly advised to return within three to four weeks if symptoms do not disappear. In addition, it is recommended that general practitioners and dentists should actively follow up patients who experience symptoms that raise any suspicions of cancer of the head and neck if they do not return for the follow-up appointment. This policy is particularly important for patients who are heavy smokers and drinkers, as they have an increased risk of developing head and neck cancer. Furthermore, it was shown that patients who, after referral, needed to make an appointment with the hospital themselves, were confronted with waiting lists or waited, sometimes for even an extremely long time, to effectuate the referral. The latter was seen especially among those who went to the general practitioner for a primary reason other than their head and neck symptom. Therefore, to prevent further delay, the general practitioner or dentist should contact the otolaryngologist or oral surgeon in the hospital with a view to arranging the first visit to the hospital.

Conclusions

On the basis of our results we can conclude that patient delay is common among head and neck cancer and affects tumour size at diagnosis. Therefore, this study aimed to identify factors that impede early presentation. It was found that most of the delay occurred during the appraisal of the meaning and importance of the symptoms. The common nature of the symptoms led patients to think that their condition was not serious. In addition, more personal characteristics such as lack of personal control, avoidance coping and pessimism were associated with patient delay, especially among heavy drinkers. Future research is needed to unravel the complex process of seeking care for head and neck cancer symptoms and the causal factors of delay during the different steps in this process. However, it is recommended that the general public, and in particular those high risk individuals who are heavy smokers and drinkers, are educated about the nature and duration of head and neck cancer symptoms, the risk factors relevant to developing head and neck cancer, the steps to be taken once confronted with head and neck cancer symptoms, and the benefits of early detection. In addition, general practitioners should bear in mind that patients might delay returning for a second consultation if symptoms persist, especially those patients who are not inclined to seek support or who did not recognise the seriousness of their symptoms. General practitioners should consider actively following up patients who present with symptoms that might be indicative of head and neck cancer, particularly when these are individuals with a high risk of developing head and neck cancer.

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Summary

Head and neck cancers are an increasing health problem in the Netherlands. Not only are incidence rates increasing, the proportion of patients presenting with an advanced primary tumour has also been rising over the last twenty years, as is the case in other European countries and the United States. This is an unfavourable situation as advanced tumours lead to worse survival rates and a poorer quality of life after therapy. Therefore, to reduce mortality and morbidity it is important that tumours are detected at an early stage. An impeding factor for early detection of cancer is delay in diagnosis. Delay in seeking a diagnosis or treatment may occur during care seeking for the detected symptoms, referral to a medical specialist by a general practitioner, diagnosing the condition, or starting the treatment. A frequently made distinction is the one between patient delay and professional delay. Patient delay is defined as the time lag between the detection of the symptoms and the first medical consultation. Professional delay is the time lag between this first medical consultation and definitive diagnosis or treatment. The results of previous studies regarding the relationship between diagnostic delay and disease outcome among head and neck cancer patients are not unequivocal. However, previous studies on delay among patients with head and neck cancer have indicated that delay in diagnosis is common, and sometimes even surprisingly long. It has also been shown that patient delay accounts for a great part of the total diagnostic delay. However, in identifying factors that are related to this patient delay among patients with head and neck cancer, the patient's perspective with regard to the care seeking process has been mostly neglected. In addition, patients' characteristics, other than sociodemographical factors, have seldom been investigated in relation to delay in seeking care for head and neck cancer symptoms. This thesis focused on two central questions, i.e.: (1) which patient-related factors are related to a delay in diagnosis of head and neck cancer? and (2) what are the risk factors for presenting with an advanced carcinoma of the head and neck?

Summary

In chapter 1, an overview is given of the results of previous studies on diagnostic delay among head and neck cancer patients. In addition, a model of patient delay is presented which distinguishes various steps in the care seeking process for detected symptoms. This model was used in this study to structure the care seeking process of the patients with head and neck cancer into different stages in which patient delay may occur. The following delay stages are described by this model: (1) appraisal delay, which is the time between the first symptoms and the moment the patient starts illness; (2) illness delay, described as the time from illness inference to the decision to seek medical help; (3) behavioural delay, the time from the decision to seek medical help to

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In **chapter 1**, an overview is given of the results of previous studies on diagnostic delay among head and neck cancer patients. In addition, a model of patient delay is presented which distinguishes various steps in the care seeking process for detected symptoms. This model was used in this study to structure the care seeking process of the patients with head and neck cancer into different stages in which patient delay may occur. The following delay stages are described by this model: (1) appraisal delay, which is the time between the first symptoms and the moment the patient infers illness; (2) illness delay, described as the time from illness inference to the decision to seek medical help; (3) behavioural delay, the time from the decision to seek medical help to

actually making an appointment; (4) scheduling delay, which is the time between the making of the appointment and the actual consultation; (5) referral delay; the time between the first medical consultation with the general practitioner and the visit to a medical specialist in the hospital; (6) medical specialist delay; which is the time which elapses between the first consultation with the medical specialist and the definitive diagnosis; and (7) management delay, the time between diagnosis and the beginning of treatment.

The participants in this study were recently diagnosed head and neck cancer patients, their partner (or significant other), and their general practitioner or dentist. Between 2000 and 2002, a total of 306 patients who were diagnosed at the University Medical Center Utrecht (UMC Utrecht) with cancer of the larynx (n=117), the pharynx (n=55) or oral cavity (n=134) were included in the study (participation rate 72%). The sample comprised 210 men and 96 women. The participants' ages ranged from 34 to 89 years, with a mean of 62.0 years. Two hundred and seven patients (68%) presented with a small tumour (T1 or T2) and 99 patients (32%) presented with a large tumour (T3 or T4). With regard to disease stage, 172 patients (56%) were diagnosed with early stage disease (stage I/II) and 134 patients (44%) with advanced stage disease (stage III/IV).

Semi-structured interviews were held with all patients before treatment was started. The interview contained questions about the care seeking process, symptoms experienced, interpretation of the symptoms, health professional consultations and the period of time taken for each step in the diagnostic process. The interview also included questions concerning sociodemographic characteristics, smoking and alcohol habits, previous medical experiences and knowledge of cancer. Patients were also asked about the role of others during the care seeking process. In addition to the interview, patients filled in a questionnaire which contained measures of optimism (Life Orientation Test), coping style (Utrecht Coping List), defense style (Defense Style Questionnaire), health hardiness (Health Hardiness Inventory) and psychological distress (Hospital Anxiety and Depression Scale).

To verify the course of events with regard to the care seeking process and to detect possible delay not indicated by the patient, the patients' partner or a close relative was sent a questionnaire as well as the general practitioner or dentist who the patient initially consulted. The partners' questionnaire contained specific questions about the care seeking process engaged in by the patient, the referral and any subsequent visits to health professionals until the start of treatment. The response rate to this questionnaire was 76%. General practitioners and dentists were asked about their policy from the first visit of the patient for the tumour-related symptoms until referral to the medical specialist. The response rate to this questionnaire was 94%.

To start with, the various steps in the care seeking process of patients with head and neck cancer were explored. The aim of **chapter 2** was to determine the length of the various stages of patient delay as described in the above mentioned model, as well as to explore the psychosocial and behavioural reactions to symptoms of head and neck cancer and their relationships with (the various stages of) patient delay. It appeared that the most commonly reported symptoms were voice change and pain in the mouth, throat or ears, but patients also presented with swallowing problems, (ulcerated) lesions, swellings and more general symptoms, such as a cough or tightness of chest. Almost all the patients (96%) considered their symptoms benign and 10% of the patients even consulted the health professional for another main reason than the head and neck symptom. Only 21% of the patients knew of head and neck cancer before they were confronted with it themselves. Of all patients, 78% did not consider themselves ill before seeking medical consultation. Therefore, we could not distinguish the stage of illness delay. As a consequence, we changed the definition of appraisal delay to include illness delay.

We found that the median total patient delay between the awareness of the first symptoms and the first medical consultation was 41 days. Seventy-eight (27%) patients waited more than 3 months before consulting a physician. The appraisal process accounted for most of the total patient delay. Behavioural delay and scheduling delay were not common. If behavioural delay occurred, it was mostly for practical reasons, such as holidays or private or work hassles. Scheduling delay due to waiting lists occurred among some patients who first visited a medical specialist or dentist. We found that prompt care-seeking was associated with a mass in the neck, knowledge of (head and neck) cancer, and openness about complaints. Heavy drinking, voice changes or general symptoms (like a cough or fatigue), and consultations with physicians prompted by others were associated with a delay in seeking care. In conclusion, this study demonstrated that many symptoms of head and neck cancer are not perceived as alarming, even if they are present for a long time. Therefore, the cognitive interpretation of head and neck cancer symptoms should be taken into consideration by health (education) professionals aiming at early detection of cancer.

The aim of the study in **chapter 3** was to investigate the association between patient delay and the psychological factors of optimism, health hardiness, defense style, coping styles and psychological distress. Significant differences were found between patients who sought medical care within three months and those who postponed seeking medical attention for three months or more. Patients who postponed seeking medical care reported less optimism, less health hardiness, less active coping, and less

seeking support as a coping style than patients presenting within three months. A large proportion of the patients were heavy to excessive drinkers and drank three or more units of alcoholic beverages a day. Excessive drinkers (5+ alcoholic drinks/day) tended to show more patient delay than patients who did not drink or were moderate drinkers (0-2 drinks/day) or moderate-heavy drinkers (3-4 drinks/day). We found that alcohol drinking was a moderator variable in the relationship between the psychological factors and patient delay in seeking medical care. Together, the psychological factors could explain 25% of the variance of patient delay in excessive drinkers compared to 21% and 6% in moderate-heavy drinkers and non-to-moderate drinkers, respectively. In particular, pessimistic beliefs were associated with greater delay among excessive drinkers. From this study it can be concluded that psychological factors affect health care seeking behaviour, in particular among excessive drinkers.

In **chapter 4** the relationship between health hardiness and health behaviour was examined in more detail. Besides delay in seeking medical care, smoking and drinking behaviour after diagnosis were also taken into account. All of these three health (risk) behaviours play an important role in the development, detection and course of cancer of the head and neck. The health hardiness questionnaire contains four subscales, reflecting health value and control beliefs. With regard to smoking and drinking cessation after diagnosis, psychological distress was also taken into account. The results showed that around one quarter of the patients had waited more than three months before seeking medical care. Fifty per cent of the patients who smoked before diagnosis continued to smoke after diagnosis, and 80% who drank three or more alcoholic drinks daily continued to drink the same amounts after the diagnosis. Those patients who smoked and/or drank before diagnosis, reported lower levels of health value and perceived health competence than a general population sample with which they were compared. Patients who engaged in patient delay reported less perceived health competence than patients who did not delay seeking medical care. Higher scores of psychological distress and lower scores of perceived health competence were found to be more common among patients who continued to smoke as compared to those patients who quit smoking. The implications of these findings are discussed with regard to interventions aimed at promoting early detection of cancer and quitting smoking among head and neck cancer patients.

Little research has been carried out into the role of the patient in delaying referral or diagnosis once the patient has visited a primary health care professional. Therefore, **chapter 5** describes patient-related factors that are associated with delay in primary care and the referral to the hospital. The study showed that 155 patients (53%) were

not referred to a medical specialist or followed up after the first medical contact with the general practitioner or dentist. These patients needed to decide for themselves when to return to the health professional. Fifty per cent (n=78) of these patients delayed returning to the health professional for a second consultation for more than three weeks and 10% even delayed for more than four months. In addition, patients who delayed the second consultation were prone to further delay in any subsequent visits. Patients were more likely to delay when they experienced voice change, were not familiar with head and neck cancer, were not suspicious of cancer or were generally not inclined to seek support. Even after referral, long delays occurred because patients did not immediately effectuate their referral or because there were long waiting times to see the otolaryngologist or oral surgeon in the hospital. These latter delays were prevented when the general practitioner or dentist mediated the first visit to the hospital. This study demonstrated that delay in returning to the health professional is partly dependent on patient-related factors. This delay can possibly be reduced by educating patients about the possible meaning and expected time-course of the symptoms. In addition, patients should be strongly advised to return to, or be followed up by, the general practitioner or dentist if the symptoms do not disappear.

The study described in **chapter 6** identifies patient and tumour-related factors associated with advanced carcinoma of the head and neck. The study paid special attention to the role of patient and professional diagnostic delays. Multivariate analysis revealed that patients with a tumour of the supraglottis, oral cavity and especially the pharynx were at an increased risk of being diagnosed with an advanced tumour, as compared to patients with a tumour of the glottis. In addition, patient delay of three months or more increased the risk of an advanced tumour, while a medical check-up for a reason other than head and neck symptoms decreased the risk of an advanced tumour. Thus, in addition to tumour-related factors, the patients' delay in seeking care contributed to an increased risk of being diagnosed with an advanced tumour of the head and neck. These findings underline the importance of patient behaviour as a critical factor that influences tumour size and therefore should not be neglected.

Chapter 7 discusses the results of the different studies described above. This chapter also includes methodological considerations, recommendations for further research and practical implications. Limitations are discussed with regard to response rate and the retrospective nature of the data, in particular the issue of recall bias which might have distorted the memories of the care seeking process. As regards future research, it was suggested that special attention should be paid to a more detailed operationalisation of the theoretical stages of patient delay. This applies particularly in

the case of care seeking processes for apparently common symptoms, since in such processes the illness delay stage is hard to identify. Furthermore, research on denial, risk perception and past care seeking behaviour in relation to delay would be very useful for a better understanding of the phenomenon of patient delay in seeking care for head and neck cancer symptoms. In addition, it would also be interesting to study the negative consequences of patient and professional delay for the patient, such as feelings of guilt or distress and, in the long-term, survival. Practical recommendations for health education are described. Based on the results it was suggested that, to promote early detection, awareness raising as regards head and neck cancer should not only focus on the awareness of symptoms and their duration, but also on the steps to be taken once confronted with it. This means discouraging a 'wait and see' attitude and enhancing personal control by showing that one can do something about it, namely seek medical advice. Special attention should be paid to individuals who smoke and drink and who are as such at risk of developing head and neck cancer and delaying seeking medical help. Because holding pessimistic beliefs was a strong predictor of delay in excessive drinkers, health education messages might include positive outcomes of the desired behaviour (that is early consultation) such as minimal treatment and good prognosis. While, after the first medical visit, delay in returning to the health professional was found to be partly dependent on patient-related factors, it was recommended that general practitioners and dentists strongly advise their patients to return if symptoms persist, or (actively) follow up patients with suspicious symptoms.

In conclusion, patient delay is common among cases of head and neck cancer and affects tumour size at diagnosis. The awareness that perceived symptoms were indicative of head and neck cancer was low. It is recommended that the general public, and in particular those high risk individuals who are heavy smokers and drinkers, are educated about the nature and duration of head and neck cancer symptoms, the risk factors relevant to developing head and neck cancer, the steps to be taken once confronted with head and neck cancer symptoms, and the benefits of early detection.

Samenvatting

Hoofd-halskanker wordt een steeds groter gezondheidsprobleem in Nederland. Niet alleen stijgt het totaal aantal mensen dat gediagnosticeerd wordt met deze vorm van kanker, maar ook het percentage patiënten dat zich niet een goede terugkoppeling bij de afgelopen twintig jaar genoeit. Dit is een ongunstige ontwikkeling omdat een diagnose van een grote tumor gepaard gaat met een kleinere overlevingskans en een slechtere kwaliteit van leven na de behandeling. Om ziekte- en sterftekansen te reduceren is het daarom belangrijk dat de hoofd-halskanker ontdekt wordt in een vroeg stadium. Een belangrijke factor voor vroegtijdige ontdekking van kanker is een vertraging in de diagnostiek van de tumor. Vertraging in de diagnostiek van de tumor of behandeling ervan kan optreden tijdens het hulp-zoeken voor de ontdekte symptomen, het doorverwijzen naar de medische specialist, het vaststellen van de diagnose of het beginnen van de behandeling. Vaak wordt onderscheid gemaakt tussen 'patient delay' (patiëntvertraging) en 'professional delay' (professionele vertraging). 'Patient delay' is de tijd die verstrijkt tussen het gewaar worden van de symptomen en het eerste bezoek aan een arts. De periode vanaf deze eerste medische consultatie tot aan de definitieve diagnose of het begin van de behandeling wordt aangeduid als 'professional delay'. Alhoewel er eerdere onderzoeken over vertraging in de diagnostiek bij hoofd-halskankerpatiënten met een eenduidig verband is gebonden tussen vertraging en gezondheidsuitkomsten, bleek wel dat vertraging in de diagnostiek vaak voorkomt en soms zelfs verrassend lang kan zijn. Dit deed onderzoekers in ook gebieden dat 'patient delay' een groot deel uitmaakt van de totale vertraging in de diagnostiek. Echter, in de studies naar factoren die gerelateerd zijn aan 'patient delay' bij hoofd-halskanker is het perspectief van de patiënt met betrekking tot het hulpzoekproces zelden overgenomen. Tevens zijn persoonlijk, Sociaal-demografische factoren zelden onderzocht in relatie tot uitstel bij hulp zoeken voor hoofd-halskankersymptomen. Dit proefschrift richt zich op twee centrale vragen, te weten: (1) Welke psychologisch-geassocieerde factoren hangen samen met een vertraging in de diagnostiek van hoofd-halskanker? En (2) wat zijn de uitkomstmaten voor een diagnose van een grote tumor in het hoofd-halsgebied?

Samenvatting

In hoofdstuk I is een overzicht gegeven van de uitkomsten van eerdere studies met betrekking tot vertraging in de diagnostiek bij hoofd-halskanker. Tevens wordt een model gepresenteerd dat de verschillende stappen beschrijft die doorgelopen worden bij het zoeken van medische hulp voor patiënten met hoofd-halskanker. Dit model is in dit onderzoek gebruikt om het hulpzoekproces van patiënten met hoofd-halskanker te structureren. Het model onderscheidt verschillende stadia waarin 'patient delay' plaats

Samenvatting

Hoofd-halskanker wordt een steeds groter gezondheidsprobleem in Nederland. Niet alleen stijgt het totaal aantal mensen dat gediagnosticeerd wordt met deze vorm van kanker, maar ook het percentage patiënten dat zich met een grote tumor presenteert is de afgelopen twintig jaar gestegen. Dit is een ongunstige ontwikkeling omdat een diagnose van een grote tumor gepaard gaat met een kleinere overlevingskans en een slechtere kwaliteit van leven na de behandeling. Om ziekte- en sterftecijfers te reduceren is het daarom belangrijk dat de hoofd-halstumor ontdekt wordt in een vroeg stadium. Een belemmerende factor voor vroege ontdekking van kanker is een vertraging in de diagnostiek van de tumor. Vertraging in de diagnostiek van de tumor of behandeling ervan kan optreden tijdens het hulp zoeken voor de ontdekte symptomen, het doorverwijzen naar de medisch specialist, het vaststellen van de diagnose of het beginnen van de behandeling. Vaak wordt onderscheid gemaakt tussen 'patient delay' (patiëntuitstel) en 'professional delay' (professionele vertraging). 'Patient delay' is de tijd die verstrijkt tussen het gewaar worden van de symptomen en het eerste bezoek aan een arts. De periode vanaf deze eerste medische consultatie tot aan de definitieve diagnose of het begin van de behandeling wordt aangeduid als 'professional delay'. Alhoewel uit eerdere onderzoeken over vertraging in de diagnostiek bij hoofd-halskankerpatiënten niet een eenduidig verband is gebleken tussen vertraging en gezondheidsuitkomsten, bleek wel dat vertraging in de diagnostiek vaak voorkomt en soms zelfs verrassend lang kan zijn. Uit deze onderzoeken is ook gebleken dat 'patient delay' een groot deel uitmaakt van de totale vertraging in de diagnostiek. Echter, in de studies naar factoren die gerelateerd zijn aan 'patient delay' bij hoofd-halskanker is het perspectief van de patiënt met betrekking tot het hulpzoekproces zelden meegenomen. Tevens zijn persoonlijke kenmerken anders dan sociodemografische factoren zelden onderzocht in relatie tot uitstel bij hulp zoeken voor hoofd-halskankersymptomen. Dit proefschrift richt zich op twee centrale vragen, te weten: (1) Welke patiëntgerelateerde factoren hangen samen met een vertraging in de diagnostiek van hoofd-halskanker? En, (2) wat zijn de risicofactoren voor een diagnose van een grote tumor in het hoofd-halsgebied?

In **hoofdstuk 1** is een overzicht gegeven van de uitkomsten van eerdere studies met betrekking tot vertraging in de diagnostiek bij hoofd-halskanker. Tevens wordt een model gepresenteerd dat de verschillende stappen beschrijft die doorlopen worden bij het zoeken van medische hulp voor ontdekte symptomen. Dit model is in dit onderzoek gebruikt om het hulpzoekproces van patiënten met hoofd-halskanker te structureren. Het model onderscheidt verschillende stadia waarin 'patient delay' plaats

kan vinden. De volgende stadia worden beschreven in dit model: (1) 'appraisal delay', de tijd tussen de ontdekking van de eerste symptomen en het moment dat men denkt dat men ziek is; (2) 'illness delay', de tijd die verstrijkt tussen het beseft ziek te zijn en het besluit om medische hulp te zoeken; (3) 'behavioural delay', de tijd tussen het besluit om hulp te zoeken en het daadwerkelijk maken van een afspraak; (4) 'scheduling delay', de tijd tussen het maken van de afspraak en het plaatsvinden van het consult; (5) 'referral delay', de tijd tussen de eerste medische consultatie en de eerste afspraak bij de medisch specialist; (6) 'medical specialist delay', de tijd tussen het eerste bezoek bij de medische specialist tot de diagnose; en (7) 'management delay', de tijd tussen diagnose en de start van de behandeling.

De deelnemers aan dit onderzoek waren patiënten die recent gediagnosticeerd waren met hoofd-halskanker in het Universitair Medisch Centrum Utrecht in de periode december 2000 en december 2002, hun partner (of een andere persoon uit hun naaste omgeving) en hun huisarts of tandarts. 306 van de 427 patiënten die in deze periode gediagnosticeerd werden hebben deelgenomen aan het onderzoek (respons: 72%). Van deze patiënten hadden er 117 een kwaadaardige tumor het strottenhoofd, 55 een kwaadaardige tumor in de keelholte en 134 een kwaadaardige tumor in de mondholte. In totaal deden 210 mannen en 96 vrouwen mee, variërend in leeftijd van 34 tot 89 jaar. 207 patiënten werden gediagnosticeerd met een kleine tumor (T1/T2) en 99 patiënten met een grote tumor (T3/T4). De ziekte werd bij 172 patiënten (56%) gediagnosticeerd in een vroeg stadium (stadium I/II) en bij 134 patiënten (44%) in een laat stadium (stadium III/IV).

De deelnemende patiënten werden voorafgaand aan de behandeling geïnterviewd. Het interview bestond uit semi-gestructureerde vragen over het hulpzoekproces, de ervaren symptomen, de interpretatie van de symptomen, medische consultaties en het tijdsverloop van elke stap in het diagnostisch proces. Het interview bevatte tevens vragen over sociodemografische kenmerken, rook- en drinkgedrag, eerdere ervaringen op medisch gebied en kennis van kanker. Ook werd gevraagd of andere mensen een rol hadden gespeeld bij het hulpzoekproces. Naast dit interview vulden patiënten ook een vragenlijst in waarmee verschillende persoonlijke factoren gemeten werden, te weten optimisme (Life Orientation Test), copingstijl (Utrecht Coping Lijst), afweerstijl (Defense Style Questionnaire), gezondheidsgerelateerde gehardheid (Health Hardiness Inventory) en angstige en depressieve symptomen (Hospital Anxiety and Depression Scale).

Om de gang van zaken met betrekking tot het hulpzoekproces te verifiëren en mogelijke vertraging die niet genoemd was door de patiënt op te sporen, werd ook een vragenlijst gestuurd naar de partner van de patiënt en de huisarts of tandarts die de patiënt in eerste instantie raadpleegde. De vragenlijst voor de partner bevatte gerichte

vragen over het hulpzoekproces van de patiënt, de verwijzing, en elk daaropvolgend medisch bezoek tot aan de start van de behandeling. De respons op deze vragenlijst was 76%. De huisarts of tandarts werd gevraagd naar hun beleid vanaf het eerste bezoek van de patiënt voor de aan de tumor gerelateerde klachten tot de verwijzing naar de medisch specialist. De respons op deze vragenlijst was 94%.

Allereerst hebben we de verschillende stappen in het hulpzoekproces van hoofd-halskankerpatiënten onderzocht. Het doel van **hoofdstuk 2** was om de duur van elk stadium waarin uitstel kan voorkomen te bepalen alsmede te onderzoeken welke psychosociale factoren en reacties op de hoofd-halssymptomen gerelateerd waren aan 'patient delay' in elk stadium van het hulpzoekproces. Stemverandering en pijn in de mond, keel of oren bleken de meest genoemde symptomen te zijn, maar patiënten rapporteerden ook slikproblemen, zweertjes of plekjes in de mond, zwellingen en meer algemene symptomen zoals vermoeidheid, hoest, verkoudheid of benauwdheid op de borst. Bijna alle patiënten (96%) interpreteerden hun symptomen als onschuldig en 10% van de patiënten bezocht de huisarts of de tandarts zelfs in eerste instantie voor een andere reden dan het hoofd-halssymptoom. Slechts 21% van de patiënten was bekend met hoofd-halskanker voordat ze er zelf mee geconfronteerd werden. Van alle patiënten had 78% niet het idee dat ze ziek waren op het moment dat ze medische hulp zochten. Om die reden konden we het 'illness delay'-stadium niet onderscheiden. Als gevolg daarvan hebben we de definitie van 'appraisal delay' zodanig veranderd dat dit stadium ook het 'illness-delay'-stadium omvatte. De mediane duur tussen de gewaarwording van de eerste symptomen tot aan het eerste bezoek aan de huisarts of tandarts bleek 41 dagen te zijn. Meer dan een kwart van de patiënten (27%) wachtte drie maanden of meer met het raadplegen van een huisarts of tandarts. 'Appraisal delay' was verantwoordelijk voor het grootste gedeelte van het totale 'patient delay'. 'Behavioural delay' en 'scheduling delay' kwamen niet vaak voor. Als er sprake was van 'behavioural delay' was dit meestal vanwege praktische redenen, zoals werk- en privébeslommeringen. 'Scheduling delay' kwam alleen bij sommige patiënten voor die in eerste instantie een medisch specialist of tandarts raadpleegden en te maken hadden met een wachtlijst. In dit onderzoek bleek tijdig hulp zoeken gerelateerd te zijn aan het hebben van een knobbel in de nek als symptoom, kennis van (hoofd-hals)kanker en openheid over de ervaren symptomen. Het hebben van stemverandering of algemene symptomen (zoals hoest of vermoeidheid), zwaar alcoholgebruik, en door een ander aangespoord zijn om hulp te zoeken bleek gerelateerd aan meer uitstel in het zoeken van medische hulp. Uit deze studie kan geconcludeerd worden dat de symptomen die gepaard gaan met hoofd-halskanker niet als alarmerend ervaren worden, zelfs niet als ze een lange tijd aanhouden. De cognitieve interpretatie van hoofd-halssymptomen is

een belangrijke factor om rekening mee te houden bij het vormgeven van gezondheidsvoorlichting die gericht is op de vroege ontdekking van kanker in het hoofd-halsgebied.

Het doel van **hoofdstuk 3** was om de relaties te onderzoeken tussen 'patient delay' en verschillende persoonlijke factoren, te weten optimisme, afweerstijl, copingstijl, angstige en depressieve symptomen en gezondheidsgerelateerde gehardheid ('health hardiness'; ervaren controle en betrokkenheid m.b.t. gezondheid). De resultaten lieten zien dat personen die langer dan drie maanden gewacht hadden met het zoeken van medische hulp op verscheidene aspecten verschilden van de personen die binnen drie maanden een arts consulteerden. Personen die meer dan drie maanden gewacht hadden met het zoeken van medische hulp rapporteerden lagere scores op optimisme en gezondheidsgerelateerde gehardheid en maakten over het algemeen minder gebruik van probleemoplossende coping of steun zoeken als copingstijl. Een groot gedeelte van de patiënten was bovenmatig tot zwaar drinker. Uit de resultaten bleek dat zware drinkers (5 of meer eenheden per dag) langer wachtten met het raadplegen van een arts dan bovenmatige drinkers (3-4 eenheden per dag) of patiënten die niet of matig dronken (0-2 eenheden per dag). We vonden dat alcoholgebruik voor de diagnose een moderator variabele was in de relatie tussen de persoonlijke factoren en uitstel in het zoeken van medische hulp. Regressieanalyses lieten zien dat 25% van de variantie van 'patient delay' verklaard werd door de persoonlijke factoren bij de groep die zwaar dronk vergeleken met 21% en 6% bij respectievelijk de groep die bovenmatig en niet of matig dronk. Vooral pessimisme droeg significant bij aan de verklaring van 'patient delay' in de groep van zware drinkers. Uit deze studie kan geconcludeerd worden dat, in het bijzonder bij zware drinkers, persoonlijke factoren van invloed zijn op het hulpzoekgedrag voor hoofd-halssymptomen.

In **hoofdstuk 4** is de samenhang tussen gezondheidsgerelateerde gehardheid en gezondheidsgedrag nader in beeld gebracht. Naast het hulpzoekgedrag voor symptomen is ook het rook- en drinkgedrag na de diagnose in aanmerking genomen. Deze drie gezondheidsgedragingen spelen een belangrijke rol in de ontwikkeling, ontdekking en het verloop van de ziekte hoofd-halskanker. De vragenlijst waarmee gezondheidsgerelateerde gehardheid gemeten wordt ('Health Hardiness Inventory') bestaat uit vier subschalen. Deze schalen weerspiegelen algemene opvattingen over de waarde die gehecht wordt aan gezondheid en de ervaren controle over gezondheid. Tevens zijn angstige en depressieve symptomen (psychologische spanning) gemeten en gerelateerd aan het rook- en drinkgedrag na de diagnose. Uit de resultaten kwam naar voren dat een kwart van de patiënten meer dan drie maanden had gewacht met het

zoeken van medische hulp voor de ervaren symptomen. De helft van de patiënten was doorgestaan met roken na de diagnose en 80% van de mensen die voor de diagnose drie of meer eenheden alcohol per dag dronken, bleven dezelfde hoeveelheid alcohol drinken na de diagnose. De patiënten die rookten en/of drie of meer eenheden alcohol per dag dronken rapporteerden minder waarde te hechten aan gezondheid ('health value') en minder waargenomen competentie met betrekking tot gezondheidsgedrag ('perceived health competence') in vergelijking met een steekproef uit de algemene populatie. Patiënten die meer dan drie maanden gewacht hadden met het zoeken van medische hulp rapporteerden minder 'perceived health competence' dan patiënten die wel binnen drie maanden hulp hadden gezocht. Ook werden lagere scores op 'perceived health competence' en hogere scores op psychologische spanning vaker gevonden bij patiënten die doorgingen met roken na de diagnose. Dus de mate waarin mensen zichzelf in het algemeen in staat achtten om gedragingen uit te voeren die goed zijn voor hun gezondheid was gerelateerd aan uitstel bij hulp zoeken en het doorgaan met roken. Echter bij het doorgaan met roken speelde psychologische spanning een grote rol.

Er is weinig onderzoek gedaan naar de rol van de patiënt bij vertraging in de verwijzing of diagnostiek wanneer de patiënt eenmaal een (huis-)arts bezocht heeft voor de symptomen. Dat is de reden waarom in **hoofdstuk 5** een studie wordt beschreven naar de relatie tussen patiëntgerelateerde factoren en vertraging in de eerstelijns (huisarts/tandarts). Uit de resultaten bleek dat 155 patiënten (53%) niet bij het eerste consult werden doorverwezen naar een medisch specialist of een vervolgspraak kregen. Deze patiënten hebben zelf moeten beslissen wanneer ze terug zouden gaan naar de huis- of tandarts voor een tweede consultatie. De helft van de patiënten wachtte langer dan drie weken met teruggaan naar de huis- of tandarts. Tien procent wachtte zelfs langer dan vier maanden. Daar komt bij dat de patiënten die wachtten met teruggaan voor een tweede consultatie ook meer kans hadden op verdere vertraging bij daaropvolgende bezoeken. Uitstel in het teruggaan naar de huis- of tandarts kwam vaker voor bij mensen die last hadden van stemverandering (heesheid), die niet bekend waren met hoofd-halskanker, die niet het vermoeden hadden dat de symptomen op kanker zouden kunnen duiden en die over het algemeen niet geneigd waren om hulp te zoeken wanneer ze met een probleem geconfronteerd werden. Uit de resultaten is ook gebleken dat zelfs na de verwijzing naar de medisch specialist nog lange vertragingen optraden omdat patiënten geen initiatief namen om een afspraak te maken of omdat de wachttijden voor de kno-arts of de kaakchirurg lang waren. Deze laatstgenoemde vertragingen werden voorkomen wanneer de huis- of tandarts zelf de eerste afspraak met de specialist in het ziekenhuis maakte. Deze studie heeft laten zien

dat vertraging bij het teruggaan naar de huis- of tandarts deels afhankelijk is van patiëntgerelateerde factoren. Mogelijk kan deze vertraging gereduceerd worden als de patiënten bij hun eerste bezoek worden voorgelicht over de verwachte tijdsduur van de symptomen en wat het kan betekenen als de klachten langer aanhouden. Patiënten met symptomen die mogelijk kunnen duiden op hoofd-halskanker zouden door de huis- of tandarts met klem geadviseerd moeten worden terug te komen als de klachten langer aanhouden, of zouden standaard een vervolgspraak moeten krijgen.

In **hoofdstuk 6** is een studie beschreven naar de risicofactoren om gediagnosticeerd te worden met een grote tumor in het hoofd-halsgebied. Zowel tumorgerelateerde als patiëntgerelateerde factoren werden geanalyseerd. In het bijzonder werd de rol van vertraging in de diagnostiek (zowel 'patient delay', 'professional delay' als totale vertraging) onderzocht. Multivariate logistische regressie liet zien dat patiënten met een tumor in de supraglottis, de mondholte, maar vooral in de keelholte een verhoogd risico hadden om gediagnosticeerd te worden met een grote tumor vergeleken met patiënten met een tumor in de glottis. Tevens verhoogde 'patient delay' van meer dan drie maanden de kans op een grote tumor, terwijl een medische consultatie voor een andere hoofdreden dan het hoofd-halssymptoom de kans op een grote tumor verkleinde. Uit deze resultaten kan geconcludeerd worden dat naast tumorgerelateerde factoren ook uitstel in het zoeken van medische hulp bijdraagt aan het verhoogde risico om gediagnosticeerd te worden met een grote tumor in het hoofd-halsgebied. Deze bevindingen ondersteunen het belang van het hulpzoekgedrag van de patiënt als een kritische factor met betrekking tot tumorgrootte en zou daarom niet verwaarloosd moeten worden.

In **hoofdstuk 7** zijn de resultaten van de hierboven beschreven studies in samenhang beschouwd. Daarnaast zijn methodologische overwegingen en aanbevelingen voor verder onderzoek en de praktijk beschreven. De beperkingen van het onderzoek werden beschouwd met betrekking tot de mogelijke selectieve deelname aan het onderzoek en de retrospectieve aard van de gegevens. In het bijzonder werd aandacht besteed aan recall bias waardoor de herinneringen aan het hulpzoekproces vervormd zouden kunnen zijn. Wat betreft de implicaties voor verder onderzoek werd gesuggereerd dat bij de operationalisatie van de verschillende stadia van het 'patient delay model' vooral aandacht besteed moet worden aan het stadium van 'illness delay' aangezien in dit onderzoek bleek dat dit stadium in het hulpzoekproces moeilijk te onderscheiden was. Daarnaast zou onderzoek naar risicoperceptie, ontkenning en eerder hulpzoekgedrag meer inzicht kunnen geven in het fenomeen 'patient delay' bij hoofd-halskankerpatiënten. Tevens werd geconstateerd dat onderzoek naar de

negatieve gevolgen van 'patient delay' en 'professional delay' op aspecten als schuld- en angstgevoelens, en op de lange termijn overleving, van belang zou zijn. Verder zijn praktische aanbevelingen geformuleerd met betrekking tot gezondheidsvoorlichting aangaande de vroege ontdekking van hoofd-halskanker. Op basis van de resultaten van deze studie werd gesuggereerd dat, om vroege ontdekking van hoofd-halskanker te stimuleren, gezondheidsvoorlichting zich niet alleen zou moeten richten op de aard en de duur van de symptomen die gepaard gaan met hoofd-halskanker, maar ook op de stappen die ondernomen dienen te worden als mensen geconfronteerd worden met deze symptomen. In het bijzonder zou de voorlichting gericht moeten zijn aan mensen die roken en zwaar drinken aangezien deze mensen een verhoogd risico lopen om hoofd-halskanker te krijgen en 'patient delay' te vertonen. Omdat het hebben van pessimistische opvattingen een sterke voorspeller was van 'patient delay' bij zware drinkers, zouden de positieve uitkomsten, zoals een goede prognose en minimale behandeling bij een vroege ontdekking van een tumor, benadrukt moeten worden. Ook werden een aantal aanbevelingen voor de huisarts en de tandarts beschreven. Omdat vertraging in het maken van een tweede afspraak met de huisarts of tandarts deels afhankelijk was van de patiënt worden huisartsen en tandartsen geadviseerd om hun patiënten met klem te adviseren terug te komen als de symptomen aanhouden, of om zelf met de patiënten die verdachte symptomen hebben een vervolgspraak te maken.

Geconcludeerd kan worden dat uitstel in het zoeken van medische hulp vaak voorkomt bij hoofd-halskankerpatiënten en dat dit 'patient delay' invloed heeft op de grootte van de tumor bij diagnose. Het besef van patiënten dat de door hen ervaren symptomen op hoofd-halskanker duiden bleek minimaal. Daarom is aanbevolen de algemene bevolking, en in het bijzonder de risicogroep van zware drinkers en rokers, voor te lichten over de aard en de duur van symptomen die kunnen duiden op hoofd-halskanker, over de risicofactoren voor het krijgen van deze vorm van kanker, over de te nemen stappen wanneer men deze symptomen gewaar wordt en over het nut van vroege ontdekking van deze vorm van kanker.

Voor het schrijven van een proefschrift heb je de steun van anderen nodig. De vele mensen die direct of indirect een bijdrage geleverd hebben aan de totstandkoming van dit proefschrift wil ik langs deze weg dan ook graag bedanken. Een aantal van deze mensen wil ik in het bijzonder bedanken.

Allereerst de patiënten die hebben deelgenomen aan het onderzoek. Een onderzoek gaat of valt niet met de bereidwilligheid van mensen op wie het onderzoek betrekking heeft. Ik ben dan ook alle patiënten zeer erkentelijk voor hun deelname aan het onderzoek en hun openhartige verhalen. De kracht die vele patiënten ten tone spreidden in deze voor hen moeilijke periode heeft mij erg geïnspireerd. Ook de partners en andere naasten van de patiënten wil ik bedanken voor hun belangrijke deelname aan het onderzoek.

Een woord van dank gaat levens uit naar de huisartsen en tandartsen die hebben meegewerkt aan het onderzoek. Ik was blij verrast dat, ondanks hun drukke werkzaamheden, bijna alle huisartsen en tandartsen bereid waren de vragenlijsten in te vullen.

Zonder de waardevolle begeleiding van mijn begeleidingscommissie was dit proefschrift nooit tot stand gekomen.

Prof. dr. G.J. Hordijk, uw niet afhettende interesse in het onderzoek heb ik zeer gewaardeerd. Ik weet dat u een volle agenda heeft, maar tijdens onze besprekingen was daar nauwelijks iets van te merken. U nam altijd alle tijd om mee te denken over het 'grote numoren-onderzoek'. Uw vragen over wat de resultaten zouden kunnen betekenen voor de klinische praktijk leerden mij om met een kritische blik naar de uitkomsten te kijken.

Dankwoord

Prof. dr. J.A.M. Winnubst, beste Jacques, ik wil je bedanken voor de kans die je mij gegeven hebt om dit onderzoek uit te mogen voeren. Je gaf me veel vrijheid om mijn eigen ideeën omtrent het onderzoek te ontwikkelen, maar op de achtergrond was je altijd aanwezig met goede raad. Je bood de planning altijd goed in de gaten, en verdankt dat dem vaak uit, het gaf je altijd veel bijk van vertrouwen in het eindresultaat.

Dr. J.R.J. de Leeuw, beste Rob, als co-promotor heb je veel tijd in dit onderzoek gestoken en daarvoor wil ik je hartelijk danken. Je was altijd bereid om mee te denken over kleine en grote stappen in het onderzoek. Je kritische houding en je proefjes hebben in grote mate bijgedragen aan de kwaliteit van dit onderzoek. Je nam je als onderzoeker zeer betrokken bij de patiëntengroepen van je onderzoek en hun belang is

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Prof. dr. J.A.M. Winnubst, beste Jacques, ik wil je bedanken voor de kans die je mij gegeven hebt om dit onderzoek uit te mogen voeren. Je gaf me veel vrijheid om mijn eigen ideeën omtrent het onderzoek te ontwikkelen, maar op de achtergrond was je altijd aanwezig met goede raad. Je hield de planning altijd goed in de gaten, en ondanks dat deze vaak uit liep gaf je altijd veel blijf van vertrouwen in het eindresultaat.

Dr. J.R.J. de Leeuw, beste Rob, als co-promotor heb je veel tijd in dit onderzoek gestoken en daarvoor wil ik je hartelijk danken. Je was altijd bereid om mee te denken over kleine en grote stappen in het onderzoek. Je kritische houding en je precisie hebben in grote mate bijgedragen aan de kwaliteit van dit onderzoek. Je toont je als onderzoeker zeer betrokken bij de patiëntengroepen van je onderzoek en hun belang is

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Curriculum Vitea

Debbie Tromp werd geboren op 20 november 1974 in Haarlem. Na het behalen van het VWO diploma aan het Atheneum College Hageveld te Heemstede, studeerde zij vanaf 1993 Psychologie aan de Universiteit Leiden. In 1997 werd zij aangesteld als student-assistent bij de Vakgroep Onderwijs- en Jeugdstudies van de opleiding Pedagogiek. In 1998 studeerde zij cum laude af met als afstudeerrichting Methoden en Technieken van Onderzoek. Tot december 2000 was zij aangesteld bij dezelfde universiteit als wetenschappelijk medewerker bij de Vakgroep Onderwijs- en Jeugdstudies en de Vakgroep Klinische en Gezondheidspsychologie waar zij meewerkte aan onderwijs en diverse onderzoeksprojecten. Vanaf december 2000 tot mei 2004 werkte zij in het Universitair Medisch Centrum Utrecht bij de sectie Medische en Gezondheidspsychologie. Zij werkte als onderzoeker aan het door het Koningin Wilhelmina Fonds gesubsidieerde onderzoeksproject "Increasing incidence of advanced carcinoma of the head and neck: factors associated with patient and professional delay" dat resulteerde in dit proefschrift. Sinds augustus 2004 werkt zij als docent Onderzoek en Statistiek bij de Hotelschool Den Haag.

1. De term 'patient delay' wordt gebruikt voor de periode tussen de eerste klachten en de eerste medische consultatie die ertoe leidt tot de diagnose die voor lang gewacht hebben met hulp zoeken.
2. Voorlichting met betrekking tot de vroegtijdige ontdekking van hoofd-halskanker zou niet te worden beperkt tot de sportclub waar ik de afstudeer.
3. De gezondheidszorg wordt efficiënter als mensen en patiënten samen communiceren over wat zij van elkaar verwachten.
4. Met het oog op de gevolgen van 'patient delay' kan men zich afvragen of een maatregel als de eigen bijdrage of co-actieve regeling voor de gezondheidszorg kostenbesparend zou zijn.
5. 'Vraagstukken over' zou niet alleen op de gezondheidszorg betrekking kunnen hebben, maar ook op ontwikkelingsbijstand.
6. Het verhandelen van informatie van het internet is niet hetzelfde als het verzamelen van kennis die op zijn beurt is uitgewerkt met deze informatie tot plannen.
7. Alleen degenen die de juiste besluiten nemen en de wereld van de gezondheidszorg de wereld veranderen.
8. Van promovenda hier is vooral veel over gezegd.

Stellingen behorende bij het proefschrift

**Head and neck cancer:
Factors related to patient delay in seeking medical care**

1. Mensen die lang wachten met het zoeken van medische hulp voor hoofd-hals symptomen hebben bij diagnose vaker een grote tumor dan mensen die niet lang wachten. (dit proefschrift)
2. Hoofd-halskankersymptomen worden niet als alarmerend ervaren. (dit proefschrift)
3. Pessimistische zware drinkers wachten langer met het zoeken van medische hulp dan optimistische zware drinkers. (dit proefschrift)
4. Mensen die bekend zijn met hoofd-halskanker zoeken eerder medische hulp dan mensen die nog nooit van deze ziekte gehoord hebben. (dit proefschrift)
5. Stoppen met roken is belangrijk voor een goed behandelresultaat bij hoofd-halskankerpatiënten, maar psychologische spanning verhindert dit. (dit proefschrift)
6. De term 'patient delay' voor de periode tussen de eerste klachten en de eerste medische consultatie doet onrecht aan de patiënten die niet lang gewacht hebben met hulp zoeken.
7. Voorlichting met betrekking tot de vroege ontdekking van hoofd-halskanker zou niet te vinden moeten zijn bij de apotheek maar in de slijterij.
8. De gezondheidszorg wordt efficiënter als artsen en patiënten zouden communiceren over wat ze van elkaar verwachten.
9. Met het oog op de gevolgen van 'patient delay' kan men zich afvragen of een maatregel als de eigen-bijdrage of no-claim regeling voor de gezondheidszorg kostenbesparend zal zijn.
10. 'Vraaggerichte zorg' zou niet alleen op de gezondheidszorg toegepast moeten worden maar ook op ontwikkelingshulp.
11. Het verzamelen van informatie van het internet is niet hetzelfde als het vermeerderen van kennis als er geen kader is aangeleerd om deze informatie in te plaatsen.
12. Alleen diegenen die de illusie hadden dat ze de wereld konden veranderen hebben de wereld veranderd.
13. Van promoveren leer je vooral veel over jezelf.

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