ONLINE PATIENT REPORTED OUTCOME MEASURES
TO FACILITATE SUPPORTIVE CARE
IN HEAD AND NECK CANCER PATIENTS

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ONLINE PATIENT REPORTED OUTCOME MEASURES TO FACILITATE SUPPORTIVE CARE IN HEAD AND NECK CANCER PATIENTS

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Voor Samih en Isra

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1

GENERAL INTRODUCTION

In the past decades, cancer survival rates have increased, resulting in more people living with the consequences of cancer and its treatment than ever before[1]. Cancer and its treatment can have a tremendous impact on cancer survivor's health related quality of life (HRQOL)[2]. Head and neck cancer (HNC) survivors are confronted specifically with symptoms such as dry mouth, problems with swallowing and speaking, fatigue, and psychological issues[3,4]. Monitoring HRQOL in clinical practice by means of patient reported outcome measures (PROMs) can be helpful to identify cancer survivors with problems, concerns and needs[5–7]. Because monitoring alone does not improve survivors' HRQOL[8,9], it is recommended that monitoring is followed by a consult with a health care professional (HCP) to discuss the results and to provide advice on supportive care services[10]. In clinical care the use of PROMs is recommended, but implementing PROMs in routine care remains difficult[11]. Since the rise of the Internet, online applications have become available to monitor HRQOL by means of PROMs, which can also be used as a navigation instrument to personalized supportive cancer care based on cancer survivors' HRQOL. However, little is known about the need for and feasibility of these online tools among (HNC) survivors.

Ideally, innovations as the use of PROMs to facilitate supportive care (whether or not online), should be developed and evaluated according to a participatory design approach, involving all important stakeholders (e.g. survivors, HCPs, policy advisors, health care insurance companies and other experts). Following participatory design principles, the eventual adoption and usage of these applications can be increased. With respect to the maintenance of using PROMs, there is also an urgent need to obtain insight into whether the implementation of such innovative care is durable in the long-term.

In this thesis, we set out to acquire insight into the durable use of PROMs in clinical practice combined with a nurse consultation also at long-term follow-up, to investigate the potential reach of and need for online applications among HNC survivors, and to evaluate the development, usability and feasibility of an online application that HNC survivors can use at home that aims to facilitate access to supportive care.

EPIDEMIOLOGY OF HEAD AND NECK CANCER

Head and neck cancer (HNC) accounts for about 600,000 new cancer cases per year worldwide[1], and approximately 3000 in the Netherlands[12]. It is the 6th most common type of cancer[13]. Men are twice as likely to develop HNC as compared to women[12].

HNC originates from the oral cavity, oropharynx, hypopharynx, larynx, nasal cavity and salivary glands. About 85% of HNC is of squamous cell histology. Tobacco and excessive alcohol use are two important risk factors that cause HNC[14,15]. Besides tobacco and alcohol use, human papilloma virus infections (HPV) play an increasing role in the origination of mainly oropharyngeal cancers[16]. The risk of developing HNC increases with age. Most patients are diagnosed between the age of 55 and 74[17].

TREATMENT OF HEAD AND NECK CANCER

HNC is treated by surgery with postoperative radiotherapy or chemo-radiotherapy, or by upfront chemoradiation, or by bioradiation (combination of cetuximab treatment with radiotherapy). Treatment modality depends on TNM stage (TNM Classification of Malignant Tumors), tumor site and the physical condition of a patient. Generally, early stage HNC (I and II) is treated with single modality, such as surgery or radiation therapy. More advanced stages of HNC (III and IV) are associated with a high risk of local recurrence and distant metastases and therefore require multi-modality treatment, such as surgery followed by (chemo)radiation therapy. Prognosis of HNC is dependent on tumor type, stage and HPV tumor status[18,19]. The five-year survival rates of HNC in the Netherlands range from 31-59% for tumors in the pharynx, 61% in the oral cavity, 68% in the larynx, to 91% in the lip[12].

HEALTH RELATED QUALITY OF LIFE

HNC and its treatment can have a profound impact on a patient's HRQQL. HRQOL is a broad concept that involves physical, psychological and social aspects of quality of life[20,21]. Physically, HNC patients may experience symptoms as dry mouth, oral pain and have problems with speaking, chewing, and swallowing, and experience for instance insomnia or fatigue. Psychologically, patients may face depression and/or anxiety or cognitive decline, and socially patients face possible social isolation or have difficulties to return to work[3,4,22–25]. For many survivors, problems remain present long after treatment for HNC has finished.

Patient reported outcome measures (PROMs) are developed to assess HRQOL[26]. PROMs that are most often used are questionnaires. These questionnaires can be divided into general and disease specific questionnaires. Examples of general PROM questionnaires that are used for the measurement of HRQOL include the SF-36 and EQ5D; examples of cancer specific PROMs to measure HRQOL include the EORTC QLQ-C30 (cancer patients in general) and EORTC H&N35 (HNC specific).

The use of PROMs to measure HRQOL facilitates the identification of symptoms that cancer survivors experience[5,7,27,28], can function as a reminder for topics to discuss during patient-physician consultations that may be easily overlooked or are difficult to bring up[29–31], and can be helpful in tracking changes in survivors experienced symptoms over time[32]. Monitoring HRQOL may lead to more accurately met individual supportive care needs[32], when PROMs are followed by individual feedback on supportive cancer care to the survivor[6,8,9,33–38].

SUPPORTIVE CANCER CARE

Supportive care is defined as the prevention and management of the adverse effects of cancer and its treatment[39,40]. It involves the provision of services to meet physical, psychosocial, informational, practical, spiritual and lifestyle needs from the phase of diagnosis and treatment to (long-term) follow-up phases of cancer. Examples of supportive care are physical therapy, psychological counseling and occupational therapy that can be delivered individually or in a group, face-to-face or via Internet. Currently, many cancer survivors are not taking advantage of supportive care services[41–45]. Barriers that impede survivors from obtaining adequate supportive care are a lack of awareness of available services among survivors and HCPs[46–48], a lack of identification of survivor's symptoms and needs[45,49], inadequate referral by HCPs[44–46,50], e.g. due to inadequate discussion of symptoms experienced[51], and changes in the current health care system such as centralization of care and limited time of HCPs[52,53]. From the survivors' perspective, barriers include the feeling they don't need supportive care services; symptoms experienced are considered as a 'normal consequence' of surviving cancer[45,47]. Exhaustion and therefore not wanting to visit other HCPs after an intensive period of cancer treatment can also play a role[45,47].

To improve accessibility to supportive care services, cancer survivors are expected to adopt an active role in managing their own care[54]. Self-management interventions such as educational interventions, exercise programs, and (online) self-help interventions can improve cancer patients' self-efficacy[55–57]. McCorkle et al[56] defined self-management as "those tasks that individuals undertake to deal with the medical, role, and emotional management of their health condition(s).” Combined with usual care, benefits of self-management options include improvement of quality of life and cost-effectiveness[58]. There is growing interest in eHealth among cancer survivors, healthcare providers, healthcare assurance companies, and policy-makers, as a means to improve self-management[59,60].

eHEALTH

eHealth is described as an emerging field of medical informatics, referring to health services and information delivered or enhanced through the Internet and related technologies[61]. For cancer survivors, eHealth interventions are available that focus on providing information about cancer and cancer treatment, that support survivors in treatment decision-making and that provide support when dealing with for instance physical or psychological problems. Benefits of eHealth interventions include that they are available 24/7, have the potential to be interactive (e.g. by delivering feedback to the survivor depending on the survivor’s input) and can be tailored to the survivors’ needs. A recent meta-review on the effects of eHealth for cancer patients showed evidence for effects on perceived support, knowledge levels, and information competence and indications of evidence for health status and healthcare participation of cancer patients[62]. However, there are only few eHealth applications available for HNC cancer survivors[63–65]. Even less applications incorporate PROMs to enable tailoring advice to individual survivors’ needs.

In 2006, a touch-screen computer-assisted PROMs system (OncoQuest) to monitor HRQOL was developed at the VU University Medical Center, followed by a nurse consultation to discuss the results of the screening with the survivor and provide advice regarding supportive cancer care. With the increased use of Internet and tablets, it became possible to develop tools that can be used from the patients’ home. We developed an online home-based application ‘Oncokompas’ that monitors HNC patients’ HRQOL by means of PROMs, provides personalized advice and referral to supportive care services. In the process of developing OncoQuest and Oncokompas we followed participatory design principles[66,67].

PARTICIPATORY DESIGN IN THE DEVELOPMENT OF eHEALTH APPLICATIONS

To enhance adoption of eHealth applications in clinical practice, it is essential to integrate well-developed research methods during both the development and evaluation of eHealth applications[68]. Often, there is little attention for the interdependency between end-users, technology and the socioeconomic environment[67]. By using participatory design methods in the development of eHealth applications, the effectiveness and usefulness of these applications is expected to be optimized. Participatory design is a method that actively involves users and other stakeholders in the design process of technological solutions[66,67], to make sure that the end product is closely aligned to the users' needs. Participatory design generally consists of several iterative phases: 1) needs assessment or contextual inquiry: the identification of end users needs through active participation of end users, 2) idea generation or value specification: generating ideas following the identification of needs, gaining insight into the perceived benefits and barriers of the application and define requirements, resulting in prototypes that address the end users' needs, 3) testing and retesting, the design phase: testing the prototypes in pilot studies and further developing them before implementation, 4) operationalization: the phase in which the application is introduced into practice and 5) evaluation: assessment of effectiveness and contribution to the quality of care after implementation[66,67].

SUMMARY

In summary, although HNC is a relatively rare disease, the societal impact is high because HNC survivors have to deal with various physical, psycho-behavioral, and social side effects of cancer and cancer treatment, negatively affecting HRQOL. There is a substantial gap in our ability to optimize supportive care targeting HNC survivors. Using patient reported outcome measures (PROMs) and eHealth may be the way forward, but more research is needed on the usefulness of PROMs and eHealth applications among HNC survivors.

AIM OF THIS THESIS

The main aim of this thesis is to investigate the usefulness of online applications to monitor HRQOL by means of PROMs in HNC survivors, in terms of needs, usability, feasibility, adoption, usage, reach, satisfaction and long-term implementation. Furthermore, factors are investigated that may influence the usefulness of these applications.

The research presented in this thesis is based on the following research questions and hypotheses;

1. Currently, in clinical practice cancer survivors are offered PROMs to gain insight into their HRQOL, but the maintenance of using of PROMs in the long term remains unclear. Who is reached, and what types of survivors make use of PROMs? Our hypothesis is that not all survivors are reached, and PROMs are mainly used by cancer survivors that have (many) symptoms and needs.

2. eHealth applications integrating PROMs to monitor HRQOL are upcoming. However, it is unclear what cancer survivors' needs and preferences towards these types of applications are, and whether they are able to use these applications independent (as a self-management instrument) or if they need the support from a health care professional (supported self-management). Our hypothesis is that survivors are positive towards the use of these types of eHealth applications, but that independent use is limited.

3. When there is a need for the use of eHealth applications in cancer survivors, the question of how to develop an application that meets end-users and other stakeholders' needs is important. Our hypothesis is that by using participatory design principles, the feasibility of an application will be optimized.

THESIS OUTLINE

The two main (eHealth) self-management applications studied in this thesis are (1) OncoQuest, a touch screen computer-assisted PROM system to monitor HRQOL among HNC survivors during follow-up care at the outpatient clinic, followed by a nurse consultation, in which the results of the screening are discussed with the patient, and advice regarding supportive cancer care is provided and 2) Oncokompas, an online home-based application in follow-up cancer care which monitors HRQOL via patient reported outcome measures (PROMs) ("Measure"), followed by automatically generated tailored feedback ("Learn") and personalized advice on supportive care ("Act").

In **Chapter 2** the long-term follow-up of implementing PROMs in clinical practice to monitor HRQOL in HNC patients will be investigated. In this study, PROMs are administered through OncoQuest, which was developed in 2006 and implemented in clinical practice from 2008 onwards.

In **Chapter 3** (cancer-related) Internet use of HNC patients in 2015 will be studied, and compared to their (cancer-related) Internet use in 2007. Also, we aim to identify HNC patients' needs regarding eHealth applications.

Chapter 4, 5, and 6 concern the eHealth application Oncokompas. In **Chapter 4**, the acceptability and preferences of HNC survivors towards an eHealth application in follow-up care to monitor HRQOL and target personalized access to supportive care services will be investigated. In **Chapter 5**, HCP's perspectives towards an eHealth application in follow-up care for HNC survivorship care will be investigated through a needs assessment and cognitive walkthrough of the prototype of Oncokompas. These findings are used to further optimize Oncokompas, after which a feasibility study of Oncokompas among HNC survivors is carried out, which is described in **Chapter 6**.

Finally, **Chapter 7** provides a general discussion of the presented studies in which the findings are placed in a broader perspective, and their strengths and limitations, clinical implications and possible future perspectives for research and practice are discussed.

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31

INTERMEZZO

ONCOQUEST: A TOUCH-SCREEN COMPUTER ASSISTED SYSTEM TO MONITOR HEALTH RELATED QUALITY OF LIFE VIA PATIENT REPORTED OUTCOME MEASURES

In 2006, the Department of Otolaryngology- Head & Neck Surgery of VU University Medical Center in Amsterdam started to develop OncoQuest, a touch-screen computer assisted system to monitor health related quality of life via patient reported outcome measures (PROMs) in head and neck cancer patients during follow-up care.

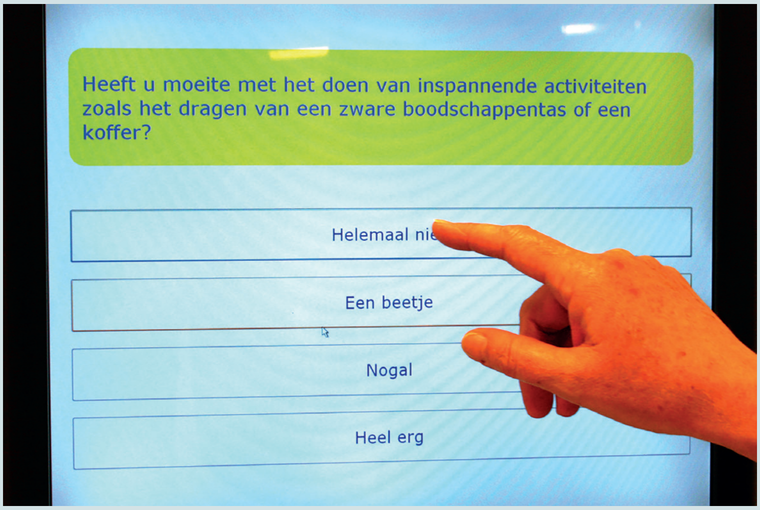
In OncoQuest a patient can monitor his or her health related quality of life (HRQOL) via the EORTC QLQ-C30 and QLQ-HN35 questionnaires and the Hospital Anxiety and Depression Scale (HADS). The EORTC-QLQ-C30 is a cancer-specific questionnaire focused on quality of life[1], the EORTC-QLQ-HN35 module covers specific issues on HNC[2]. The HADS is a self-assessment scale for measuring distress (total HADS score) with two subscales, anxiety (HADS-A) and depression (HADS-D)[3]. The HADS was specifically designed for use in the medically ill.

OncoQuest is organized in three modules: 1) the central database in which the patient's response data are held, archived and organized, 2) the patient response unit which is controlled via touch screen, and 3) analysis and graphical display of the patient's responses.

To log into the system, a patient is asked for his or her hospital identification number, which is checked against the hospital patient information system for confirmation. A patient then gets the questions in OncoQuest presented in full screen mode, in which one question at a time is shown. All questions are multiple choice and mandatory to answer in order to continue to the next question. The next question is automatically displayed once the previous question is answered. Figure 1 shows a screenshot of an OncoQuest question (in Dutch).

After a patient has completed all questions, the results of the subscales of the questionnaires are shown in clear graphics on the computer screen (see figure 2&3), by means of a stand-alone application (OncoQuest viewer), which is linked to the hospital information system. Via this system, the physician of the patient can also view the results.

From 2008 onwards, all HNC patients who are treated with curative intent are invited to use OncoQuest during their regular follow-up visit to the outpatient clinic. The usage of OncoQuest is on a voluntary basis. OncoQuest is available at the outpatient clinic in a separate consultation room with dedicated touch screen computers. If patients need help when using OncoQuest, assistance is available. When a patient has completed all questions in OncoQuest, he or she can choose to discuss the results with a consulting oncology nurse. The nurse can identify and support patients that have problems regarding their HRQOL and/or experience psychological distress. During this consultation, the nurse provides information and advice, and, if needed, supportive care options are discussed.



Heeft u moeite met het doen van inspannende activiteiten zoals het dragen van een zware boodschappentas of een koffer?

Figure 1. Screenshot of an OncoQuest question

Figure 2. Screenshot of graphical display of results in OncoQuest

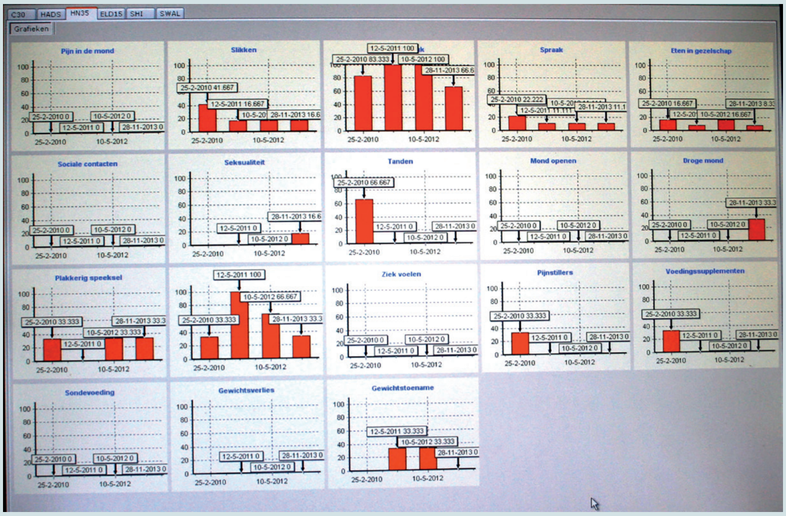


Figure 3. Screenshot of the graphical display of multiple measurements of OncoQuest

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DURABLE USAGE OF PATIENT REPORTED OUTCOME MEASURES IN CLINICAL PRACTICE TO MONITOR HEALTH RELATED QUALITY OF LIFE IN HEAD AND NECK CANCER PATIENTS

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ABSTRACT

Purpose To investigate the long-term follow-up (5 years) of implementing patient-reported outcome measures (PROMs) in clinical practice to monitor health-related quality of life (HRQOL) in head and neck cancer (HNC) patients.

Methods A mixed method design was used. The usage rate of OncoQuest (a touch screen computer system to monitor HRQOL) and the subsequent nurse consultation was calculated among HNC patients who visited the outpatient clinic for regular follow-up, as well as differences between ever users and never users (socio-demographic and clinical characteristics). The content of the nurse consultation was investigated. Reasons for not using (barriers) or using (facilitators) OncoQuest and the nurse consultation were explored from the perspective of HNC patients, and of head and neck surgeons.

Results Usage rate of OncoQuest was 67% and of the nurse consultation 79%. Usage of OncoQuest was significantly related to tumor subsite and tumor stage. Topics most frequently (>40%) discussed during the nurse consultation were global quality of life (97%), head and neck cancer related symptoms (82%), other physical symptoms such as pain (61%), and psychological problems such as anxiety (44%). Several barriers and facilitators to implement PROMs in clinical practice were reported by both patients and head and neck surgeons.

Conclusion Usage of PROMs in clinical practice and a nurse consultation is durable, even 5 years after the introduction. This study contributes to better insight into long-term follow-up of implementation, thereby guiding future research and projects that aim to implement PROMs in clinical practice to monitor HRQOL among (head and neck) cancer patients.

Keywords Head and neck cancer, Patient-reported outcome measures, Screening for psychological distress, Implementation, Health-related quality of life.

INTRODUCTION

In clinical practice, monitoring health-related quality of life (HRQOL) can be helpful to identify cancer patients with problems, concerns, and needs[1–3]. The use of patient-reported outcome measures (PROMs) to monitor HRQOL is feasible and acceptable[4]. Using PROMs allows patients to actively participate in their own care by providing the information they know best and helps clinicians to identify patients' most bothersome issues[3, 5–7]. However, because monitoring alone does not improve patients' HRQOL [8, 9], this needs to be followed by providing individual feedback to the patient and the healthcare provider (HCP) so they can discuss the need for supportive care[10–16]. In addition, collecting HRQOL data by means of PROMs in daily clinical practice is of high importance for research purposes also. PROMs provide data which are unique in detaining the patient's own view on the impact of having cancer, and its treatment, on their HRQOL.

Based on the existing evidence, several evidence-based national guidelines recommend routine HRQOL assessment in clinical practice [e.g.,[17–21]]. Although the importance of monitoring HRQOL in clinical practice is clearly recognized, it remains difficult to implement PROMs in clinical practice. Previous studies showed that following the implementation, usage rates vary from 40 to 73% [22–24]. These results are based on short-term follow-up studies investigating the success of implementation. Knowledge on the long-term implementation is lacking[4, 7].

In 2006, we introduced a computer-assisted PROMs system (OncoQuest) in our clinical practice to monitor HRQOL among head and neck cancer (HNC) patients. Usage rate of OncoQuest in the first year after implementation was 67%[22]. To increase usage rate and the relevance of monitoring HRQOL for the individual patient, from 2008 onwards, we have been using OncoQuest in combination with a nurse consultation.

The overall aim of the present study was to investigate the long-term follow-up of OncoQuest and the nurse consultation, 5 years after the implementation. We investigated the current usage rate of OncoQuest and the nurse consultation among HNC patients, as well as differences between ever users and never users (socio-demographic and clinical characteristics) (aim A). Furthermore, we investigated the content of the nurse consultation (aim B). Also, we explored reasons for not using (barriers) or using (facilitators) OncoQuest and the nurse consultation from the perspective of HNC patients (aim C) and from the perspective of the head and neck surgeons (aim D). This study contributes to better insight into long-term follow-up of implementation.

METHODS

A mixed methods design was used, with quantitative and qualitative research methods. The study was conducted at the Department of Otolaryngology – Head and Neck Surgery, VU University Medical Center in Amsterdam, The Netherlands, between April 2013 and September 2013. According to the Dutch Medical Research Involving Human Subjects Act, ethical approval was not necessary, because this study evaluated regular care and patients were not subjected to procedures or required to follow rules of behavior.

DESCRIPTION OF ONCOQUEST AND THE NURSE CONSULTATION

All HNC patients who are treated with curative intent are offered to use OncoQuest to monitor HRQOL via the EORTC QLQ-C30 and QLQ-H&N35 questionnaires and the Hospital Anxiety and Depression Scale (HADS) (in total 79 items), and to discuss the results by consulting an oncology nurse during follow-up visits after cancer treatment. Patients are also asked permission to use their HRQOL data in OncoQuest for research purposes. OncoQuest is available on dedicated computers with a touch screen in a separate consultation room. Due to logistic reasons, patients fill in OncoQuest after the follow-up visit with their surgeon. When a patient has completed OncoQuest, he or she can discuss the results with the nurse. The results of OncoQuest are available in real time in clear graphics on a computer screen by means of a stand-alone application (OncoQuest viewer), which is linked to the hospital information system. Based on the results, the nurse can identify and support HNC patients with problems regarding HRQOL or psychological distress. In this nurse consultation, the nurse provides information and advice, and, if needed, supportive care options are discussed. Usage is on a voluntary basis.

AIM A: USAGE RATE OF ONCOQUEST AND NURSE CONSULTATION, AND DIFFERENCES BETWEEN EVER USERS AND NEVER USERS

To determine the usage rate of OncoQuest, the number of patients who ever used OncoQuest was divided by the number of all eligible HNC patients. The number of eligible HNC patients (denominator) was counted by reviewing data of patients (all subsites, all stages) who were treated with curative intent (all treatment modalities) at least 3 months earlier and who attended the outpatient clinic during the study period (April–September 2013) through the hospital information system. Patients' usage data—if they used OncoQuest and the number of times they used OncoQuest—was consequently derived from the OncoQuest database. We defined patients as an ever user of OncoQuest if they had used OncoQuest during at least one follow-up visit. We did not limit the usage to the study period, since patients visiting the outpatient clinic are at different stages of their follow-up and could therefore have used OncoQuest in the past.

To determine the usage rate of the nurse consultation, the number of patients who used the nurse consultation during the study period was divided by the number of all patients who used OncoQuest during the study period (current users). We limited the usage of the nurse consultation to the study period, since information on usage of the nurse consultation was not collected earlier.

To gain insight into the characteristics of ever users, current users, and never users of OncoQuest and the nurse consultation, socio-demographic (age, sex) and clinical variables (tumor location, tumor stage, and type of treatment) were obtained from the medical records.

AIM B: CONTENT OF THE NURSE CONSULTATION

To gain insight into the content of the nurse consultation following the use of OncoQuest, a researcher observed all nurse consultations during the study period with patients' consent and filled out a study-specific report form. In this report form, the researcher noted the length of the consultation, the topics that were discussed, and the advice and supportive care options provided by the nurse.

AIM C: BARRIERS AND FACILITATORS

To gain insight into barriers to use OncoQuest and the nurse consultation, a random sample of patients who did not use OncoQuest and the nurse consultation during the current follow-up visit (nonusers), were asked about their reasons. A researcher posted at the consultation room of one of the six head and neck surgeons (based on a circulation scheme). Patients who did not proceed to OncoQuest were approached by the researcher for a short structured interview with predefined answer categories.

The researcher asked patients for their reasons for nonuse of OncoQuest and the nurse consultation, as well as for their suggestions on improvement. The researcher noted the answer as provided by the patient. In addition, the researcher noted the respondents' socio-demographic variables sex and date of birth. Information regarding the number of times patients used OncoQuest ever before the current follow-up visit was derived from the OncoQuest database.

To gain insight into facilitators to use OncoQuest and the nurse consultation, we asked all patients who used OncoQuest and the nurse consultation during the study period (current users) to complete and return a study-specific paper-and-pencil questionnaire. The questionnaire included two questions on age and sex, and four items with predefined answer options (comparable to the questions asked in the interviews with nonusers) regarding reasons to use and added value of OncoQuest and the nurse consultation. Patients were able to choose multiple answers and were invited to elaborate by means of a free-text response. Information regarding the number of times patients had used OncoQuest before the current follow-up visit was derived from the OncoQuest database.

To evaluate patients' satisfaction with the nurse consultation, the questionnaire contained three questions on satisfaction with this consultation. General satisfaction was measured with the Net Promotor Score (NPS) with the question "How likely is it that you would recommend the nurse's consultation to other cancer patients?" (11-point rating scale: 0 (not likely) to 10 (very likely)). The NPS is calculated by subtracting the percentage of detractors (that score 0–6) from the percentage of promotors (that score 9–10). The percentages "passives" that score 7–8 is not included in calculating the NPS. The range of the NPS lies between −100 and +100. A positive score is considered good[25]. Additionally, patients were asked how satisfied they were with respect to the knowledge of the nurse regarding supportive care options, and with respect to her listening skills (11-point rating scales).

AIM D: EXPLORING THE PERSPECTIVE OF THE HEAD AND NECK SURGEONS

Semi-structured interviews were conducted with the head and neck surgeons involved in follow-up visits (N = 6). Interviews included questions concerning the added value and barriers of OncoQuest and the nurse consultation, and recommendations for improvement.

DATA ANALYSES

All statistical analyses were performed using the IBM Statistical Package for the Social Sciences (SPSS) version 22 (IBM Corp. Armonk, NY, USA). For aim A, descriptive statistics were used to describe socio-demographic and clinical characteristics of ever users and never users, as well as the number of times OncoQuest was used. We conducted chi-square tests, independent sample t-tests, and multiple logistic regression analyses to study demographic (age, sex) and clinical variables (tumor subsite, stage, and treatment modality) in relation to usage of OncoQuest and the nurse consultation. A multiple logistic regression model, with a stepwise forward selection procedure, was applied. Variables were added one by one to the multiple regression model, with p value for entry $p < 0.1$. p values < 0.05 were considered statistically significant.

For aim B, descriptive statistics were used to describe the characteristics of the nurse's consultation. For aim C, the answers provided by the patients during the interviews on non-usage were categorized into one of the predefined answer categories. If the answer did not match one of the predefined answer categories, these reasons for non-usage and suggestions for improvement were added. Descriptive statistics were used to summarize reasons, suggestions for improvement, and the number of times these patients had used OncoQuest in the past, and to summarize the facilitators identified in the questionnaire and patients' satisfaction with the consultation. For aim D, the semi-structured interviews were analyzed by thematic analyses.

RESULTS

AIM A: USAGE RATE

During the study period of 6 months, 449 patients who visited the outpatient clinic for their follow-up visits fulfilled the inclusion and exclusion criteria (all eligible HNC patients). The characteristics of these patients are shown in Table 2.1. Of these patients, 303 were defined as an ever user of OncoQuest. To calculate the usage rate of OncoQuest, the number of OncoQuest ever users was divided by all eligible HNC patients (303/449). The usage rate of OncoQuest was 67%, meaning that 67% of the patients used OncoQuest at least once post-treatment. OncoQuest ever users used it between 1 and 11 times after treatment (median 2, interquartile range (IQR) 1–3).

Multivariate analyses showed that tumor stage and subsite were significantly associated with the use of OncoQuest. Patients treated for a tumor stage >I used OncoQuest relatively more often, and patients treated for a tumor stage I used OncoQuest relatively less often. Patients with laryngeal cancer used OncoQuest relatively less often compared to other head and neck subsites (Table 2.2).

During the study period of 6 months, 147 patients used OncoQuest at the time of their follow-up visit (current users), of which 116 (out of 147) also used the nurse consultation (usage rate 79%) (Table 2.3). Age, sex, tumor subsite, tumor stage, and treatment modality were not significantly related to the use of the nurse consultation.

Table 2.1. Characteristics of the total study population (N=449), and differences between ever users and never users of OncoQuest

	Total N=449	Ever users N=303	Never users N=146
Sex (N, %)			
Male	312	205 (68%)	107 (73%)
Female	137	98 (32%)	39 (27%)
Age in years			
Mean (SD)	63.5 (10.4)	62.9 (10.3)	64.9 (10.5)
Tumor site (N, %)			
Pharynx	165	121 (40%)	44 (30%)
Larynx	141	77 (25%)	64 (44%)
Oral cavity	117	85 (28%)	32 (22%)
Other	26	20 (7%)	6 (4%)
*Tumor stage (N,%)**			
1	139	75 (27%)	64 (51%)
2	65	49 (17%)	16 (13%)
3	54	43 (15%)	11 (9%)
4	149	114 (41%)	35 (27%)
*Type of treatment (N, %)***			
Surgery	128	70 (23%)	58 (40%)
(Chemo-)radiation	238	169 (56%)	69 (48%)
Surgery and (chemo) radiation	83	64 (21%)	19 (13%)

*Data on tumor stage is missing in 42 patients.

**Data on type of treatment is missing in 2 patients.

Table 2.2. Multiple logistic regression analysis of significant variables* of usage of OncoQuest in the total study population (N=407)

	OR	95% CI	P-value
Tumor stage			
Stage 1	1.0		p=0.001
Stage 2	2.6	1.3 – 5.2	
Stage 3	3.3	1.5 – 7.0	
Stage 4	2.4	1.4 – 4.3	
Tumor site			
Larynx	1.0		p=0.013
Pharynx	1.9	1.0 – 3.3	
Oral cavity	2.1	1.2 – 3.7	
Other	3.3	1.1 – 9.7	

*Age, sex, and treatment modality were not significantly associated with usage rate, and therefore not included in these analyses.

Number of patients in these analyses is smaller (N=407) than the total study population (N=449) because of missing data on tumor stage.

Table 2.3. Characteristics of current users (patients who used OncoQuest during the study period) (N=147), and differences between users and non-users of the nurse consultation

	Total N=147	Users N=116	Non-users N=31
Sex (N,%)			
Male	95	76 (66%)	19 (61%)
Female	52	40 (34%)	12 (39%)
Age in years			
Mean (SD)	62.9 (10.4)	62.2 (10.2)	65.8 (11.1)
Tumor site (N,%)			
Pharynx	53	40 (34%)	13 (42%)
Larynx	30	22 (19%)	8 (26%)
Oral cavity	32	28 (24%)	4 (13%)
Other	32	26 (22%)	6 (19%)
*Tumor stage (N,%)**			
1	28	25 (23%)	3 (11%)
2	32	25 (23%)	7 (26%)
3	27	22 (21%)	5 (19%)
4	47	35 (33%)	12 (44%)
Type of treatment (N,%)			
Surgery	34	26 (22%)	8 (26%)
(Chemo)radiation	62	45 (39%)	17 (55%)
Surgery and (chemo) radiation	51	45 (39%)	6 (19%)

*Data on tumor stage is missing in 13 patients.

AIM B: CONTENT OF THE NURSE CONSULTATION

Reports of the nurse consultations were available for 113/ 116 patients. In three cases, there was no report due to logistic reasons. The consultations lasted 2 to 30 min (median 10 min, IQR 7–13 min). Topics most frequently (>40%) discussed during the consultation included global quality of life (97%); head and neck cancer related symptoms such as speech, swallowing, and oral dysfunction (82%); other physical symptoms such as fatigue and pain (61%); anxiety (44%); and depression (41%). The nurse provided practical advice in 23% of the consultations. This advice comprised information on how to cope with current physical or psychological sequelae of cancer and its treatment. In 11% of the consultations, patients received information on, e.g., the website of the Dutch Cancer Society, relevant books, or brochures. Also, 11% of patients were referred to peer support, including patient societies or a community center for cancer patients.

AIM C: BARRIERS AND FACILITATORS TO USE ONCOQUEST AND THE NURSE CONSULTATION

Barriers

In total, 84 HNC patients who did not use OncoQuest at the current follow-up visit were asked to participate in a short structured interview. Two patients did not want to participate, and one was mentally challenged and unable to answer questions. Ten patients indicated that they were not interested in OncoQuest with no further explanation. The majority of the remaining 71 patients were male (N = 52, 73%), and their mean age was 66 years old (range 42–87, SD 9.9). Of these 71 patients, 42 (59%) had used OncoQuest at, least one follow-up visit in the past (ever users), and 29 patients (41%) were never users. Most mentioned reasons for not using OncoQuest were lack of time (N = 29, 41%) and that patients did not have supportive care related questions (N = 14, 20%) (Table 2.4). Suggestions to improve OncoQuest that were mentioned during the interviews related mostly to the user-friendliness, e.g., tailor the questions to the individual patient and limit the number of questions. Patients also mentioned that it would be helpful to have a better explanation of OncoQuest at the start of treatment, and it would be nice to receive feedback during their consultation with the head and neck surgeon.

Table 2.4. Barriers for using OncoQuest (N=71)

	Total N=71, N (%)	Ever users[a] (N=42), N (%)	Never users [b] (N=29), N (%)
Lack of time	29 (41)	15 (36)	14 (48)
No questions regarding supportive care	14 (20)	10 (24)	4 (14)
No change in symptoms	10 (14)	9 (21)	1 (3)
No need	10 (14)	4 (11)	6 (21)
No added value	7 (10)	5 (12)	2 (7)
Emotional problems	6 (8)	5 (12)	1 (3)
Participation in other scientific research	4 (6)	2 (5)	2 (7)
Filled out a similar questionnaire at another department	2 (3)	1 (2)	1 (3)
Parking fee is getting too high / ticket expires	2 (3)	2 (5)	-
Not wanting to use a computer	2 (3)	-	2 (7)
Miscellaneous	13 (18)	8 (19)	5 (17)

Seventy-one patients who did not use OncoQuest at the current follow-up visit (multiple answers possible)

[a] 42 patients who used OncoQuest at a previous follow-up visit, but not at the current follow-up visit

[b] 29 patients who did not use OncoQuest at the present or a previous follow-up visit.

Facilitators

In total, 112 (out of 116) patients who used OncoQuest and the nurse consultation during the study period received a study-specific questionnaire, of which 83 completed the questionnaire. The majority was male (N = 57, 69%), and the mean age was 62 years old (SD 10.2, range 24–87). Most frequent reasons to use OncoQuest were that patients were asked by their HCP (N = 71, 86%), and that patients wanted to contribute to scientific research (N = 34, 41%) (Table 2.5). Most frequently mentioned reasons regarding the added value of OncoQuest were that changes in symptoms and HRQOL over time are monitored (N = 61, 73%), and that symptoms are adequately addressed (N = 39, 47%). Also, some mentioned that by using OncoQuest, they had a clearer overview of what they wanted to ask their HCP (N = 4, 5%). Free text responses yielded no additional reasons to use OncoQuest. With respect to the nurse consultation, the most frequent reasons for usage were being asked to do so (N = 71, 86%) and the opportunity to talk with the nurse (N = 21, 25%) (Table 2.5). Free text responses yielded additional reasons including seeing the nurse's consultation as an automatic consequence following the use of OncoQuest, and a personal and friendly way to discuss the results. As added value of the nurse consultation, patients mentioned the amount of time the consulting nurse had to discuss the OncoQuest results (N = 61, 74%), the personal conversation and advice (N = 29, 35%), and obtaining answers to questions regarding their disease, HRQOL, and symptoms (N = 13, 16%). Overall, patients were satisfied with the nurse consultation, with a Net Promotor Score of 25. The majority highly valued the listening skills of the nurse (11-point scale: median 9, IQR 8–10) and the knowledge of available supportive care (11-point scale: median 8, IQR 8–10).

Table 2.5. Facilitators to use OncoQuest and the nurse consultation (N=83)

OncoQuest	N	%
Being asked by staff	71	86
Contributing to scientific research	34	41
Monitoring changes in quality of life	6	7
Expecting to benefit from using OncoQuest	5	6

Nurse consultation	N	%
Being asked by staff	71	86
Appreciating the conversation with the nurse	21	25
Wanting to discuss results OncoQuest	10	12
Nurse has more time than physician	9	11
Wanting to share their story with the nurse	3	4
Having a question for the nurse	1	1

83 patients who did use OncoQuest and the nurse consultation at the current follow-up visit (multiple answers possible)

AIM D: PERSPECTIVE OF HEAD AND NECK SURGEONS

All six interviewed head and neck surgeons stressed the importance of OncoQuest and the nurse consultation for patients during the follow-up period after treatment. Several themes were mentioned concerning the added value of OncoQuest in clinical practice (Table 2.6). Also, several barriers were mentioned, like a lack of feedback from the surgeon to the patient on the results of OncoQuest may lead to a decrease in patient's motivation to use OncoQuest, and using OncoQuest takes too much time according to their patients. Finally, head and neck surgeons mentioned several improvements that could possibly eliminate these barriers, for example, the provision of feedback to the physician within the electronic patient file (instead of via a standalone application) and enhanced accessibility of OncoQuest for patients (e.g. ability for patients to access OncoQuest online from home) (Table 2.6).

Table 2.6. Facilitators, barriers and suggestions for improvement according to head and neck surgeons (N=6)

Interview topics	Themes
Facilitators of OncoQuest and the nurse consultation	• An enhanced insight into patients' HRQOL • A signalling function for symptoms missed in follow-up consultations • Attention for a wide range of symptoms and concerns (including psychosocial issues) • The possibility to improve (timely) referral to supportive care tailored to individual patients' needs • The opportunity to offer increased (profound) attention to patients • Offering patients the opportunity to have their story heard
Barriers of OncoQuest and the nurse consultation	• Not all patients have a need for OncoQuest (at each follow-up consultation) • The value of repeated use is not clear to patients • Using OncoQuest takes too much time according to their patients • The availability of OncoQuest outcomes during consultation is hampered due to difficulties to trace OncoQuest results at their computer screen • Patients use OncoQuest after the follow-up visit (due to logistic reasons) • A lack of feedback from the surgeon to the patient on the results of OncoQuest may lead to a decrease in patient's motivation to use OncoQuest • Patients' usage of OncoQuest after the follow-up visit to the surgeon (due to logistic reasons) leads to a lack of (accurate) feedback from the surgeon to the patient and to a possible delay in referral to supportive care • OncoQuest may address unsolvable problems (e.g. dry mouth, swallowing problems) possibly leading to a decrease in patients' motivation to use OncoQuest • A lack of structural feedback to the surgeon from what is discussed during the nurse consultation
Suggestions for improvement of OncoQuest and the nurse consultation	• Provision of feedback to the physician within the electronic patient file (instead of via a standalone application) • The provision of extra reminders for physicians during consultation hours so they remember to discuss patients' results • Enhanced accessibility of OncoQuest for patients (e.g. ability for patients to access OncoQuest online from home)

DISCUSSION

The main aim of this study was to investigate the usage of PROMs in clinical practice through a computer-assisted PROMs system “OncoQuest” combined with a nurse consultation, 5 years after the introduction. Study results are discussed within the scope of the RE-AIM framework. The RE-AIM framework is designed to enhance the quality, speed, and public health impact of efforts to translate research into practice and can be used to study the reach, effectiveness, adoption, implementation, and maintenance of healthcare innovations[26].

In this study, we investigated the reach of OncoQuest and the nurse consultation by comparing ever users and never users. The usage rate of OncoQuest remained 67%, the same as at the time of the introduction[22]. This high usage rate, even in the long term, might be explained due to the fact that OncoQuest is combined with a nurse consultation. Among the patients who used OncoQuest, the majority also used the nurse consultation (79%). Other explanations based on our study data might be that the HCPs at the outpatient clinic personally invite patients to make use of OncoQuest and patients’ awareness of usage of OncoQuest data for research purposes also. This suggests that trust, therapeutic alliance, and altruism, as in helping other patients by participating in scientific research, might increase durable participation in monitoring HRQOL by means of PROMs in clinical practice. Usage rate of OncoQuest was significantly related to tumor stage. Patients treated for a tumor stage >I used OncoQuest relatively more often and patients with a tumor stage I used OncoQuest relatively less often. It may be that the never users have a lower need for supportive care and therefore are not likely to use OncoQuest and the nurse consultation.

Although we did not perform a randomized controlled trial on the effectiveness, study results showed that current users were very satisfied and most would recommend OncoQuest and the nurse consultation. HRQOL following cancer treatment was monitored via OncoQuest, and important issues to patients were discussed with the nurse. Patients felt that the nurse truly listened to their concerns and indicated to have faith in the referrals and advice given. These findings confirm earlier studies on the value of using PROMs in clinical practice to improve communication between patients and HCPs[4,6], to identify cancer patients’ most bothersome issues[3], to monitor the course of symptoms as swallowing problems [27,28], and to facilitate screening for psychological distress[2].

With respect to the adoption by care providers, all head and neck surgeons were satisfied with the use of PROMs in clinical practice and the nurse consultation. This high adoption rate by surgeons was important also for patients since our study results showed that one of the facilitators for patients to use OncoQuest and the nurse consultation was to be referred by their HCP. Adoption by HCPs is a key issue in implementing new interventions in cancer care[4,29].

In this study, we explored barriers and facilitators of using OncoQuest and the nurse consultation. Finding the optimal way to implement PROMs in clinical practice is difficult and often creates logistical challenges[15,30,31]. In line with previous studies[15], patients in our study mentioned several barriers, such as no change in symptoms since the previous follow-up visit, and no need for supportive care. To overcome these barriers, we decided 5 years ago that using OncoQuest and the nurse consultation is on a voluntary basis, so that patients can decide themselves whether or not to use this service. This decision in favor of user-friendliness, does, however, hamper us to use the HRQOL data for research purposes.

Finally, this study provided insight into the maintenance of OncoQuest and the nurse consultation among HNC patients. Although the results are positive and usage rate was high, maintenance remains a challenge and needs regular reevaluation. For instance, in our hospital, a new electronic hospital information system was introduced last year, and we are still busy incorporating OncoQuest into this new system.

A strength of this study is that we involved all stakeholders to study the long-term follow-up of OncoQuest and nurse consultation. A weakness is that we did not use the RE-AIM framework upfront to define outcome measures as well as process indicators to study the long-term implementation. In addition, there is a potential bias in comparing the usage rate of OncoQuest as determined in the current study, compared to the usage rate as determined in the first year after implementation of OncoQuest, resulting from differences in study cohorts. Future research is needed to obtain more insights into the uptake of supportive care services after using OncoQuest and the nurse consultation. The likelihood of supportive care uptake by patients is increased when there is a good relationship between the patient and the team of HCPs[32]. Implementing PROMs in clinical practice facilitates this good relationship. OncoQuest is now used in follow-up care and not yet in patients during treatment. The reason is that patients during treatment already have frequent contact with their HCPs. However, an adapted version of OncoQuest specifically targeting patients during treatment may have added value as well, but further research is needed to explore the needs of both patients and HCPs for OncoQuest during treatment. Another area of further research is to provide patients the opportunity to fill out PROMs at home before their follow-up visit. Via an online system, the uptake of using PROMs may be increased. The online use of PROMs at home seems to be feasible for a large percentage of cancer patients[33,34]. This could lead to a better preparation for clinical consultations and a better adherence to medical advice[35], possibly including a better uptake of supportive care services.

CONCLUSION

The majority of HNC patients use PROMs and a nurse consultation in clinical practice, also in the long term. This study contributes to better insight into durable usage of PROMs, thereby guiding future research and other projects that aim to implement PROMs in clinical practice to monitor HRQOL among (head and neck) cancer patients.

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3

THE USE OF eHEALTH IN HEAD AND NECK CANCER PATIENTS: IS IT INCREASING?

Submitted

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ABSTRACT

Purpose To investigate (1) potential increase in Internet use and Internet use to search for information on cancer (content) in head and neck cancer (HNC) patients between 2007 and 2015, (2) which patients are most likely to be Internet users, (3) preferences related to future use of eHealth (community, communication, and care) and (4) use of eHealth in 2015.

Methods A questionnaire was completed by 84 (2007) and 136 (2015) HNC patients. Factors associated with (cancer-related) Internet use were investigated using stepwise logistic regression analyses.

Results Internet use among HNC patients increased from 53% in 2007 to 79% in 2015. Respectively 46% and 59% of these patients used the Internet to search for information on cancer. Younger patients, and patients with a tumor originating from the oral cavity used the Internet more often in 2007. Younger patients, patients with a higher educational level and those with a partner used the Internet more often in 2015. Patients with a higher educational level used the Internet more often to search for information on cancer in 2015. Many patients in both samples (2007 range: 21% to 68% and 2015 range: 16% to 71%) were interested in using eHealth in the future. Use of eHealth in 2015 was limited (range: 0% to 10%).

Conclusion Internet usage of HNC patients increased strongly. Internet was especially used to search for information on cancer. Since many patients were interested in future eHealth use, attention should be paid to ensure adequate awareness among HNC patients.

Key words: Head and neck cancer, Internet usage, eHealth

INTRODUCTION

In cancer care, the supply of eHealth for content, communication, community and care purposes is increasing. These services aim to inform patients on their condition, to communicate online with healthcare providers, to share concerns and experiences with peers in online communities and to support patients in adopting an active role in managing their own care[1,2]. A recent review on the effects of eHealth for cancer patients showed evidence for effects on perceived support, knowledge levels, and information competence and indications of evidence for health status and healthcare participation of cancer patients[3].

To be able to embrace eHealth, patients have to have access to the Internet and have to possess skills to make use of the Internet[4]. However, barriers often mentioned in studies on the engagement of eHealth in cancer care are patients' lack of Internet access or skills to make use of the Internet[5–9].

In the Netherlands, in 2015 overall 94% of the population over 12 years of age had access to the Internet. Of the population over 65 years of age this percentage was lower 78%[10]. In the past years, several studies focused on the percentage of cancer patients using the Internet, showing an increase from 32% to 80% in studies conducted between 2006 and 2012[11–16].

In 2007, we conducted a non-published study among head and neck cancer (HNC) patients on their Internet use and cancer-related Internet use, since we aimed to develop eHealth interventions for HNC patients. In recent years, Internet has become increasingly integrated in the day-to-day life, for instance in the form of Internet banking. Also, eHealth is increasingly deployed in current cancer care. Because of the ever-increasing integration of Internet in daily life and clinical care it is probable that the percentage of HNC patients that use the Internet and (are able to) profit from eHealth has increased. Therefore in 2015 we repeated the study on Internet use and cancer-related Internet use among HNC patients.

The objective of this study was to investigate among patients treated for HNC (1) a potential increase in Internet use and Internet use to search for information on cancer (content) between 2007 and 2015, (2) which patients (based on socio-demographic, clinical characteristics and QOL) are most likely to be Internet users in respectively 2007 and in 2015, (3) to investigate preferences towards future use of other types of eHealth (community, communication, and care) in 2007 and 2015 and (4) which of these types of eHealth were used in 2015.

METHODS

STUDY DESIGN AND SAMPLE

Patients were included from two cross-sectional studies conducted in 2007 and 2015 at the department of Otolaryngology—Head and Neck Surgery of the VU University Medical Center, Amsterdam, The Netherlands. For the 2007 study all HNC patients who were treated between July 2005 and July 2006 were screened for eligibility. Patients were included when they were treated with curative intent for squamous cell carcinoma of the oral cavity, pharynx, larynx, or metastasis of an unknown primary. Exclusion criteria were 1) cognitive impairment, 2) lack of basic fluency of the Dutch language, 3) recurrent loco regional disease or 4) distant metastasis. For the 2015 study all HNC patients who came in for a follow-up consult in February or March 2015 were screened for eligibility. Patients were included when they were 1) treated for HNC (oral cavity, pharynx, larynx, nasal cavity and major salivary glands) with curative intent 3 months to 5 years prior to the follow-up consult, and were 2) 18 years or older. Exclusion criteria were 1) cognitive impairment or 2) insufficient knowledge of the Dutch language.

Patients were asked to fill in a questionnaire at home using paper and pencil consisting of items on socio-demographic variables (age, gender, education, marital status and employment) and measures on Internet use and QOL. Data on diagnosis (tumor type and stage), treatment (surgery, radiotherapy, chemoradiation) and time since diagnosis were retrieved from hospital files.

Ethical approval was not necessary according to the Dutch Medical Research Involving Human Subjects Act, because patients were not subjected to procedures or required to follow rules of behaviour. Written informed consent was obtained from all participants.

MEASURES

Internet use

Internet use, and cancer-related Internet use were assessed based on a questionnaire on Internet use by cancer patients[11]. This questionnaire covers three broad eHealth application areas as defined by Eysenbach[17]: content (searching for health-related information), communication (contact with a physician or health care organization by means of the Internet) and community (sharing concerns and experiences with peers in online communities). Because of the growing interest in eHealth as a means to improve supportive care and self-help, we added items, which we refer to as care.

Patients were asked if they used the Internet. Regarding the content application area, patients who used the Internet were asked if they had ever used the Internet to search for information on cancer. Those who searched for information on cancer were asked additional questions on whose *initiative* they searched for information about cancer (e.g. own initiative or on initiative of their physician), on *timing*; when they searched for information during their cancer trajectory (e.g. right after being diagnosed or during treatment). These patients were also asked which *type of information* they searched for (e.g. type of cancer or consequences of treatment) and if they had been able to trace this information. Patients were asked for the *source of information* (e.g. how often they made use of specific websites, like the website of the Dutch Cancer Society). In addition, the questionnaire contained questions on the *perceived effects* of searching for information on cancer (e.g. on feeling better informed). Patients were also asked if they had ever *discussed the cancer-related information with a care professional* and if this professional appreciated discussing this information.

In addition, for patients who made use of the Internet, the questionnaire contained items on preferences for future use of eHealth for communication (e.g. pose a question to a care professional via Internet), community (e.g. participate in an online support group for HNC patients) and care (e.g. participate in a self-help course) purposes. In the 2015 sample, participants were also asked if they currently made use of eHealth with regard to communication, community and care.

Quality of life

To assess QOL we made use of the EORTC QLQ-C30. The 30-item EORTC QLQ-C30 (version 3.0) includes a global QOL scale (2 items) and 5 functional scales: physical functioning, role functioning, emotional functioning, cognitive functioning, and social functioning. There are three symptom scales (nausea and vomiting, fatigue and pain) and 6 single items relating to dyspnoea, insomnia, loss of appetite, constipation, diarrhoea and financial difficulties. In the present study, the global QOL scale was used. The scores of the QLQ-C30 are linearly transformed to a scale of 0-100, with a higher score indicating a higher level of QOL[18,19].

DATA ANALYSIS

Statistical analyses were performed using the IBM Statistical Package for the Social Science (SPSS) version 22 (IBM Corp., Armonk, NY USA). Descriptive statistics were used to summarize the socio-demographic and clinical characteristics and the data on Internet use and QOL.

We defined cancer-related Internet users as “HNC patients who had searched for information about cancer on the Internet”. Chi-squared tests and independent samples *t*-tests were used to compare socio-demographic, clinical characteristics, type of information searched for and preferences for future eHealth use between the samples. Internet use and cancer-related Internet use in the 2007 study sample and the 2015 study sample was compared via logistic regression, taking into account differences between both study populations.

Stepwise logistic regression analyses were performed to assess the relative importance of the variables (Nagelkerke R^2) that were univariately associated with Internet use, or cancer-related Internet use in 2007 and 2015. In the first block of the regression analysis, the demographic characteristics were entered (age, sex, marital status, education and employment), followed by the clinical characteristic (tumor type) and QOL in the second block.

Statistical significance was assumed when the p value was <.05 (two-tailed).

RESULTS

STUDY SAMPLE

In 2007, 128 patients were eligible for the study of whom 84 responded (66%). In

2015, 294 patients were eligible for the study of whom 136 responded (46%). In this study only those patients were included who completed the items on use of the Internet in general and cancer-related Internet use (2007 N=78; 2015 N=134).

Characteristics of the study samples in 2007 and 2015 are described in Table 3.1. The 2007 sample did not significantly differ from the 2015 sample on demographic characteristics and QOL scores. All clinical characteristics significantly differed between the 2007 and 2015 study sample.

INTERNET USE AND USE OF THE INTERNET TO SEARCH FOR INFORMATION ON CANCER

In 2007, 53% (N=41/78) of the HNC patients made use of the Internet (Table 3.1). Of these, 46% (N=19/41) made use of the Internet to search for information on cancer (Table 3.2). In 2015, 79% (N=106/134) of the HNC patients made use of the Internet (Table 3.1). Of these, 59% (N=62/106) made use of the Internet to specifically search for information on cancer (Table 3.2). Internet use was significantly higher in 2015 *(p*<.001*)* compared to 2007, as was Internet use to search for information on cancer *(p*=.039*)*.

Within the group of patients who used the Internet to search for information on cancer (2007: N=19; 2015: N=62) we asked for the *initiative to search for information on cancer online*. Most patients indicated that they searched for information about cancer on their own initiative (2007: N=14/19, 74%; 2015: N=55/62, 89%). Only some were referred to the Internet by family or friends (2007: N=3/19, 16%; 2015: N=4/62; 7%), by the physician (2015: N=4/62, 7%) or the (oncology) nurse (2007: N=1/19, 5%).

Timing Patients in both study samples searched most often for information about cancer immediately after being diagnosed. In total, 67% (N=12/17) in 2007 and 54% (N=33/61) in 2015 searched for information about cancer daily to several times per week immediately after being diagnosed. During treatment with (chemo-)radiation daily-to-weekly Internet use for cancer-related purposes decreased in 2007 (38%; N=6/18) and in 2015 (26%; N=11/43) (only relevant for those treated with (chemo-) radiation). After treatment, most HNC patients in the 2007 study sample (N=10/19, 53%) indicated to search for information about cancer less than once per month, followed by 8 HNC patients (of the 19 patients) (42%) who indicated to currently not

Table 3.1. Patient characteristics by Internet use (2007 and 2015)

			2007			
	Overall sample N=212	*p*[1]	**Total sample 2007 N=78**	**Internet users N=41**	**Non-Internet users N=37**	*p*[2]
Age in years[*a]*						*<.001*
Mean (SD)	64 (9.8)		64 (10.1)	60 (7.5)	68 (11.0)	
Minimum	37		44	44	45	
Maximum	95		95	75	95	
Sex, n (%)						
Male	148 (70)		57 (73)	26 (63)	31 (84)	
Female	64 (30)		21 (27)	15 (37)	6 (16)	
Marital status[b]						
Together	162 (77)		63 (82)	36 (90)	27 (73)	
Alone	48 (23)		14 (18)	4 (10)	10 (27)	
Education[c]*, n (%)*						
Elementary education	16 (8)		8 (10)	3 (7)	5 (14)	
Lower education	71 (34)		19 (25)	7 (17)	12 (33)	
Secondary education	56 (27)		25 (33)	16 (39)	9 (25)	
Higher education	68 (32)		25 (33)	15 (37)	10 (28)	
Employment[d]*, n (%)*						*.048*
Employed	64 (31)		20 (27)	15 (39)	5 (14)	
Not employed/not able to work	33 (16)		13 (18)	7 (18)	6 (17)	
Retired	111 (53)		41 (55)	17 (44)	24 (69)	
Tumor site[e]		*.005*				*.028*
Oral cavity	62 (29)		19 (24)	14 (34)	5 (14)	
Pharynx	72 (34)		25 (32)	15 (37)	10 (27)	
Larynx	60 (28)		32 (41)	12 (29)	20 (54)	
Other	17 (8)		2 (3)	0 (0)	2 (5)	
Disease stage (UICC)[f]		*.010*				
Stage I	56 (28)		15 (20)	7 (17)	8 (22)	
Stage II	38 (19)		23 (30)	11 (27)	12 (33)	
Stage III	35 (17)		13 (17)	7 (17)	6 (17)	
Stage IV	72 (36)		26 (33)	16 (39)	10 (28)	
Type of treatment[g]		*.022*				
Surgery	42 (20)		10 (13)	5 (12)	5 (14)	
Radiotherapy	57 (27)		28 (36)	10 (24)	18 (49)	
Surgery and chemoradiation	12 (6)		1 (1)	0 (0)	1 (3)	
Surgery and radiation	552 (25)		19 (24)	14 (34)	5 (14)	
Chemoradiation	48 (23)		20 (24)	12 (29)	8 (22)	
Time since treatment, in months[h]		*<.001*				
Mean (SD)	19 (13)		14 (5)	13 (5)	15 (5)	
Minimum	0		5	5	7	
Maximum	58		27	27	25	
Quality of life[i]						
Median (IQR)	83 (67-92)		83 (67-92)	83 (67-83)	83 (67-92)	

1*p<.05 **p<.01 ***p<.001 for chi square test or t-tests comparing the 2007 sample and the 2015 sample

2*p<.05 **p<.01 ***p<.001 for chi square test or t-tests comparing Internet users versus non-Internet users in the 2007 sample

3*p<.05 **p<.01 ***p<.001 for chi square test or t-tests comparing Internet users versus non-Internet users in the 2015 sample

2015			
Total sample 2015 N=134	**Internet users N=106**	**Non-Internet users N=28**	*p*[3]
			<.001
65 (9.6)	63 (8.8)	71 (10.0)	
37	37	52	
91	90	91	
91 (68)	73 (69)	18 (64)	
43 (32)	33 (31)	10 (36)	
			.023
99 (74)	84 (79)	15 (56)	
34 (26)	22 (21)	12 (44)	
			<.001
8 (6)	4 (4)	4 (14)	
52 (39)	34 (32)	18 (64)	
31 (23)	26 (25)	5 (16)	
43 (32)	42 (32)	1 (2)	
			.019
44 (33)	41 (39)	3 (11)	
20 (15)	15 (14)	5 (18)	
70 (52)	50 (47)	20 (71)	
43 (32)	34 (32)	9 (32)	
47 (35)	38 (36)	9 (32)	
28 (21)	21 (20)	7 (25)	
15 (11)	12 (11)	3 (11)	
			.045
41 (33)	33 (33)	8 (32)	
15 (11)	8 (8)	7 (28)	
22 (18)	18 (18)	4 (16)	
46 (37)	40 (40)	6 (24)	
32 (24)	25 (24)	7 (25)	
29 (22)	22 (21)	7 (25)	
11 (8)	8 (8)	3 (11)	
31 (25)	26 (25)	7 (25)	
28 (21)	24 (23)	4 (14)	
21 (15)	22 (15)	21 (16)	
0	0	4	
58	57	58	
83 (67-92)	83 (67-92)	79 (67-83)	

[a] Information on age is missing in 2 patients. [b] Information on marital status is missing in 2 patients.
[c] Information on education is missing in 1 patient. [d] Information on employment is missing in 4 patients.
[e] Information on tumor site is missing in 1 patient. [f] Information on disease stage is missing in 11 patients.
[g] Information on type of treatment is missing in 1 patient. [h] Information on time since treatment is missing in 5 patients. [i] Information on quality of life is missing in 11 patients.

Table 3.2. Patient characteristics by cancer-related Internet use (2007 and 2015)

	2007			
	Total Internet users N=41	**Cancer related Internet users N=19**	**Non-cancer related Internet users N=22**	*p*[1]
Age in years[*a]*				
Mean (SD)	60 (7.5)	58 (6,8)	61 (8,0)	
Minimum	44	44	49	
Maximum	75	66	75	
Sex, n (%)				
Male	26 (63)	12 (63)	14 (63)	
Female	15 (37)	7 (37)	8 (36)	
Marital status[b]				
Together	36 (90)	18 (95)	18 (86)	
Alone	4 (10)	1 (5)	3 (14)	
Education[c]*, n (%)*				
Elementary education	3 (7)	0 (0)	3 (14)	
Lower education	7 (17)	2 (11)	5 (23)	
Secondary education	16 (39)	7 (37)	9 (41)	
Higher education	15 (37)	10 (53)	5 (23)	
Employment[d]*, n (%)*				
Employed	15 (39)	6 (35)	9 (41)	
Not employed/not able to work	7 (18)	4 (24)	3 (14)	
Retired	17 (44)	7 (41)	10 (45)	
Tumor site[e]				
Oral cavity	14 (34)	4 (21)	10 (46)	
Pharynx	15 (37)	9 (47)	6 (27)	
Larynx	12 (29)	6 (32)	6 (27)	
Other	0 (0)	0 (0)	0 (0)	
Disease stage (UICC)[f]				
Stage I	7 (17)	3 (16)	4 (18)	
Stage II	11 (27)	5 (26)	6 (27)	
Stage III	7 (17)	2 (11)	5 (23)	
Stage IV	16 (39)	9 (47)	7 (32)	
Type of treatment[g]				*.022*
Surgery	5 (12)	1 (5)	4 (23)	
Radiotherapy	10 (24)	6 (32)	4 (18)	
Surgery and chemoradiation	0 (0)	0 (0)	0 (0)	
Surgery and radiation	14 (34)	3 (16)	11 (50)	
Chemoradiation	12 (29)	9 (47)	3 (14)	
Time since treatment, in months[h]				
Mean (SD)	13 (5)	12 (4)	14 (5)	
Minimum	5	5	7	
Maximum	27	19	27	
Quality of life				*.027*
Median (IQR)	83 (67-83)	83 (75-100)	71 (50-83)	

[1] *p<.05 **p<.01 ***p<.001 for chi square test or *t*-tests comparing cancer-related Internet users versus non-cancer-related Internet users in the 2007 sample

[2] *p<.05 **p<.01 ***p<.001 for chi square test or *t*-tests comparing cancer-related Internet users versus non-cancer-related Internet users in the 2007 sample

2015			
Total Internet users N=106	**Cancer related Internet users N=62**	**Non-cancer related Internet users N=44**	*p*²
63 (8.8)	62 (8.7)	64 (9.0)	
37	37	44	
90	78	90	
73 (69)	40 (65)	33 (75)	
33 (31)	22 (36)	11 (25)	
84 (79)	49 (79)	35 (80)	
22 (21)	13 (21)	9 (21)	
4 (4)	2 (3)	2 (5)	
34 (32)	15 (24)	19 (43)	
26 (25)	16 (26)	10 (23)	
42 (32)	29 (47)	13 (30)	
41 (39)	25 (40)	16 (36)	
15 (14)	9 (15)	6 (14)	
50 (47)	28 (45)	22 (50)	
34 (32)	23 (37)	11 (26)	
38 (36)	20 (32)	18 (42)	
21 (20)	11 (18)	10 (23)	
12 (11)	8 (13)	4 (9)	
33 (33)	20 (33)	13 (33)	
8 (8)	2 (3)	6 (15)	
18 (18)	14 (23)	4 (10)	
40 (40)	24 (40)	16 (41)	
25 (24)	16 (26)	9 (21)	
22 (21)	12 (19)	10 (23)	
8 (8)	3 (5)	5 (12)	
26 (25)	16 (26)	10 (23)	
24 (23)	15 (24)	9 (21)	
22 (15)	20 (14)	23 (15)	
0	0	4	
57	55	57	
83 (67-92)	79 (65-85)	83 (67-92)	

2007 [b] Information on marital status is missing in 1 patient. [c] Information on education is missing in 1 patient. [d] Information on employment is missing in 2 patients. [h] Information on time since last treatment is missing 2 patients. [i] Information on quality of life is missing in 1 patient.

2015 [a] Information on age is missing in 1 patient. [e] Information on tumor site is missing in 1 patient. [f] Information on disease stage is missing in 7 patients. [g] Information on type of treatment is missing in 1 patient. [h] Information on time since treatment is missing in 1 patient.

search for cancer-related information. In the 2015 study sample most HNC patients (N=27/62, 44%) indicated to currently not search for cancer-related information, followed by 23 HNC patients (of the 62 patients) (37%) who indicated to search for information about cancer less than once per month.

Type of information Patients in both samples most often searched for information about their tumor type, type of treatment and (consequences) of treatment. Most patients were able to find the information they searched for (Table 3.3). The 2007 study population searched significantly (*p*=.038) more often for general consequences of the cancer treatment.

Sources of information The majority of patients (2007: N=17/19, 89%; 2015: N=55/62, 89%) searched for information about cancer via a search engine. Websites used by over half of patients concerned: websites of hospitals (2007: N=13/19, 68%; 2015: N=37/59, 63%), websites of health organizations (2007: N=12/19, 63%; 2015: N=39/61, 64%) and university websites (2007: N=10/19, 53%; 2015: N=19/60, 32%). In addition, in the 2015 study sample 63% (N=38/60) indicated to make use of the patient information website of the Dutch Cancer Society, which was not launched yet in 2007.

Perceived effects Most patients of the 2007 population (N=12/18, 67%) and about one third of the 2015 population (N=22/61; 36%) felt better informed after searching for cancer-related information online. In total 5 patients (of the 18 patients) (28%) of the 2007 population and 3 patients (of the 61 patients) (5%) of the 2015 population felt better informed, although new questions had arisen. Consulting the Internet did not influence the frequency of physician visits (2007: N=13/18, 72%; 2015: N=54/62, 87%).

Discussion with health care professional Several patients (2007: N=9/18, 50%; 2015: N=29/62; 47%) had ever discussed the cancer-related information with a health care professional (respectively with a physician (2007: N=8/9, 89%; 2015: N=25/29, 86%), oncology nurse (2007: N=1/9, 11%; 2015: N=7/29, 24%), or GP (2007: N=3/9, 33%; 2015: N=10/29, 34%). Most patients were of the opinion that health care professionals appreciated discussing this information (2007: 75% physician, 100% oncology nurse, 67% GP; 2015: 96% physician, 100% oncology nurse, 89% GP).

ASSOCIATIONS BETWEEN INTERNET USE AND CANCER-RELATED INTERNET USE AND DEMOGRAPHIC, CLINICAL CHARACTERISTICS AND QOL

Results of stepwise regression analyses are provided in Table 3.4. In 2007, Internet use was significantly associated with age and tumor subsite, explaining 33% of the variance. Younger HNC patients and patients with a tumor originating from the oral cavity used the Internet significantly more often compared to older patients and patients with a tumor originating from the larynx. The number of patients who made use of the Internet for cancer-related purposes was too small to conduct a stepwise regression analysis.

In 2015, Internet use was significantly associated with age, educational level and marital status, explaining 33% of the variance. Patients who were younger, who had a higher educational level and who had a partner used the Internet significantly more often. Cancer-related Internet use was significantly associated with educational level explaining 6% of the variance. Patients who had a higher educational level used the Internet significantly more often for cancer-related purposes.

Table 3.3. Cancer-related Internet use

	2007 (N = 19)			2015 (N = 59-62)		
	Searched for and found N (%)	Search for and not found N (%)	Not searched for N (%)	Searched for and found N (%)	Search for and not found N (%)	Not searched for N (%)
Information on cancer and treatment						
Type of cancer	19 (100)	-	-	56 (90)	3 (5)	3 (5)
Treatment	18 (95)	1 (5)	-	42 (69)	2 (3)	17 (28)
Treatment guidelines	9 (47)	1 (5)	9 (47)	15 (25)	1 (2)	45 (74)
Trials/research	5 (26)	1 (5)	13 (68)	5 (8)	2 (3)	54 (89)
Alternative medicine	3 (16)	2 (11)	14 (74)	4 (7)	6 (10)	52 (84)
Options for supportive care	n.a.	n.a.	n.a.	4 (7)	4 (7)	52 (87)
Information on health-care						
Where to find a good oncologist	2 (11)	2 (11)	15 (79)	6 (10)	4 (7)	52 (84)
Which hospital is best	6 (32)	-	13 (68)	11 (18)	5 (8)	46 (74)
Information on patient support						
Patient association	2 (11)	-	17 (90)	6 (10)	2(3)	54 (87)
Cancer support groups	5 (26)	1 (5)	13 (68)	10 (16)	-	52 (84)
Patient activities in region	2 (11)	-	17 (90)	3 (5)	1 (2)	58 (94)
Information on consequences of cancer and treatment						
Consequences of treatment in general*	18 (95)	1 (5)	-	39 (64)	2 (3)	20 (33)
Consequences for sexuality	2 (11)	-	17 (90)	7 (11)	1 (2)	54 (87)
Fatigue	8 (42)	-	11 (58)	13 (21)	3 (5)	46 (74)
Other symptoms experienced as a consequence of treatment	n.a.	n.a.	n.a.	19 (32)	3 (5)	38 (64)
Lifestyle and health	n.a.	n.a.	n.a.	19 (32)	-	41 (68)
Consequences for future parenthood	n.a.	n.a.	n.a.	2 (3)	-	57 (97)
Other types of information searched for						
Health care insurance coverage	3 (16)	-	16 (84)	24 (39)	3 (5)	34 (56)
Financial consequences	1 (5)	-	18 (95)	6 (10)	1 (2)	53 (88)
Legislation (e.g. insurances, compensation)	n.a.	n.a.	n.a.	17 (28)	3 (5)	40 (67)
Cancer and genetics/ heritability	n.a.	n.a.	n.a.	10 (17)	3 (5)	47 (78)
End of life	4 (21)	-	15 (79)	5 (9)	1 (2)	53 (90)
What I can do myself	6 (32)	1 (5)	12 (63)	17 (27)	5 (8)	40 (65)

*p=.038

n.a. = not available

Table 3.4. Logistic regression analysis for Internet use and cancer-related Internet use in 2007 and 2015

		Model step 1, odds ratio (95% CI)	Model step 2, odds ratio (95% CI)	Nagelkerke R^2
Internet use 2007				
Step 1 Demographics				0.25
Age (continue)		0.93 (0.86-1.00)*	0.93 (0.86-1.00)*	
Sex				
	Male	Reference	Reference	
	Female	1.71 (0.48-6.05)	1.68 (0.45-6.28)	
Education				
	Low	Reference	Reference	
	High	2.40 (0.19-7.34)	2.42 (0.75-7.88)	
Employment				
	Not employed	Reference	Reference	
	Employed	1.01 (0.24-4.58)	0.96 (0.20-4.54)	
Step 2 Clinical characteristics				0.33
Tumor site				
	Larynx		Reference	
	Oral cavity		5.03 (1.22-20.66)*	
	Pharynx		2.38 (0.69-8.23)	
Internet use 2015				
Step 1 Demographics				0.33
Age		0.93 (0.88-0.99)*		
Marital status				
	Alone	Reference		
	Together	3.07 (1.10-8.57)*		
Education				
	Low	Reference		
	High	4.59 (1.59-13.19)**		
Employment				
	Not employed	Reference		
	Employed	1.98 (0.46-8.53)		
Cancer-related Internet use 2015				
Step 1 Demographics				0.06
Education				
	Low	Reference		
	High	2.42* (1.07-5.45)		

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

PREFERENCES REGARDING FUTURE USE OF eHEALTH

In both study samples, many patients who made use of the Internet were interested in using eHealth for communication, community and care in the future (range 2007: 21% to 68%; range 2015: 16% to 71%) (Table 3.5). No significant differences were found in preferences regarding future use of eHealth when comparing the study samples. Patients were especially interested in using eHealth to communicate with health care organizations and professionals: obtaining access to their own test results (2007: N=26/38, 68%; 2015 N=75/104, 71%) and medical record (2007: N=26/38, 68%;

2015: N=71/104, 68%), followed by requesting a prescription (2007: 22/38, 58%; 2015 N=66/102, 65%) and making an appointment online (2007: N=24/38, 63%; 2015: N=65/104, 63%). About half of the patients would like to have contact with their own physician (2007: N=21/38, 55%; 2015: N=60/104, 58%) by email. With respect to using eHealth for community purposes HNC patients showed less interest. A minority (2007: N=10/38, 26%; 2015: N=14/104, 14%) was interested in contacting other patients online.

Most items on preferences regarding care purposes where only asked in 2015. The most preferred functionalities concerned obtaining an online overview of supportive care options (N=53/104, 51%), followed by monitoring symptoms online (N=51/104, 49%) and receiving personalized advice (N=50, 48%). Participating in online self-help courses was less popular (N=17/104, 16%). In 2007 and 2015 respectively 21% (N=8/38) and 25% (N=26/103) indicated to be interested in doing self-tests online.

Table 3.5. Preferences for future use of eHealth for communication, community and care purposes (2007; N= 38 / 2015; N=102-104)*

	2007			2015		
	Yes (n, %)	Neutral (n, %)	No (n, %)	Yes (n, %)	Neutral (n, %)	No (n, %)
Communication						
Access to own health record	26 (68)	2 (5)	10 (26)	71 (68)	18 (17)	15 (14)
Access to own test results	26 (68)	2 (5)	10 (26)	75 (71)	11 (10)	18 (17)
e-mail with my physician	21 (55)	6 (16)	11 (29)	60 (58)	25 (24)	19 (18)
e-mail with nurses	15 (40)	7 (18)	16 (42)	47 (44)	26 (25)	31 (30)
Request prescriptions	22 (58)	8 (21)	8 (21)	66 (65)	20 (20)	16 (16)
Request tests	20 (53)	8 (21)	10 (26)	54 (52)	22 (21)	28 (27)
Make an appointment with own physician	24 (63)	5 (13)	9 (24)	65 (63)	18 (17)	21 (20)
Pose question to physician via a forum	11 (30)	11 (30)	15 (41)	27 (26)	24 (23)	53 (51)
Review care professional	n.a.	n.a.	n.a.	39 (38)	35 (34)	30 (29)
Report complaints	18 (47)	9 (24)	11 (29)	47 (45)	33 (32)	24 (23)
Receive reminders in support of the treatment	10 (26)	14 (37)	14 (37)	51 (50)	21 (20)	31 (30)
Suggest ideas for improvement of treatment	19 (50)	10 (26)	9 (24)	44 (43)	34 (33)	25 (24)
Community						
Chat with other patients	10 (26)	7 (18)	21 (55)	14 (14)	18 (17)	72 (69)
Care						
Do self-tests	8 (21)	9 (24)	21 (55)	26 (25)	25 (24)	52 (51)
Monitor symptoms	n.a.	n.a.	n.a.	51 (49)	26 (25)	27 (26)
Receive personalized advice	n.a.	n.a.	n.a.	50 (48)	19 (18)	35 (34)
Receive a personalized overview of supportive care	n.a.	n.a.	n.a.	53 (51)	24 (23)	27 (26)
Participate in an online self-help course	n.a.	n.a.	n.a.	17 (16)	28 (27)	59 (57)

*no significant differences were found for chi square tests comparing the 2007 and the 2015 study sample in preferences regarding the future use of eHealth
n.a. = not available

TYPES OF eHEALTH USED IN 2015

We asked the HNC patients in the 2015 study sample, who made use of the Internet (N=106), for their current use of eHealth (Table 3.6). Overall eHealth was used at a limited level (range: 0% to 10%). With respect to the use of eHealth for communication purposes, in total 11 patients (of the 106 patients) (10%) had ordered medication online, 4 patients (of the 106 patients) (4%) had made an appointment online with their physician or hospital and 6 patients (of the 106 patients) (6%) had asked their physician a question online. For community purposes, some of the patients (N=8/106; 8%) had at some time read along with an online patient support group and even less (N=3/106; 3%) had actively participated in by sending postings. None of the patients were in contact with peers via chat or Facebook. With respect to the use of the eHealth for care, 4 patients (of the 105 patients) (4%) had ever searched for options for supportive care online. None (of the 106 patients) had participated in an online self-help course.

Table 3.6. Usage of eHealth for communication, community and care purposes by Internet users (2015) (N=105-106)

	n	%
Communication		
Make an appointment with a health care professional or organization	4	4
Pose question to my health care professional via the Internet	6	6
Order medication	11	10
Search for a health care professional review	5	5
Post a health care professional review	1	1
Community		
Read along with an online support group	8	8
Send posting to online support group	3	3
Contact via chat / Facebook	0	0
Care		
Participation in a self-help course	0	0
Search for supportive care options	4	4

DISCUSSION

In this study, we investigated the increase in Internet use and in Internet use to search for information on cancer in HNC patients between 2007 and 2015 and aimed to identify which HNC patients (based on socio-demographic and clinical characteristics and QOL) were most likely to be Internet, and cancer-related Internet users. Results revealed that Internet use in general and for cancer-related purposes significantly increased. Younger HNC patients and patients with a tumor originating from the oral cavity used the Internet more often in 2007. Younger patients, patients with a higher educational level and those with a partner used the Internet more often in 2015. Patients with a higher educational level used the Internet more often for cancer-related purposes in 2015.

As hypothesized the proportion of Internet users among HNC patients has strongly increased between 2007 and 2015. While just over half of the HNC patients in 2007 used the Internet, the far majority used the Internet in 2015. This is comparable to the increase in the Dutch population of 65 years and older from 48% percent in 2007 to 78% in 2015[10]. Additionally, study results are concurrent to the increase in level of Internet use among HNC patients in the UK from 32% in 2006 to 54% in 2010[13].

Our study confirmed previous findings on the impact of age and education[11–16,20,21] on Internet use. Younger patients used the Internet more often in 2007 and 2015. The 2015 study sample showed that patients with a higher educational level used the Internet more often. Level of education is considered as the most consistent determinant in "digital divide" research[22]. People with a lower educational level have less means to access the Internet[23] and have lower levels of Internet skills[24].

Study results also showed an increase in use of the Internet to search for cancer. HNC patients specifically made use of the content application area of the Internet, by seeking information on cancer online. These results are in line with results of a study among Dutch patients treated for laryngeal cancer[25] and with study results of Rogers et al.[13] among HNC patients in the UK. Literature shows that informational needs of HNC patients often remain unmet[26–28]. A recent study by d'Souza[26] disclosed that although the doctors were the main source of information, HNC patients often experienced difficulties in understanding and retaining the information. Induced by their informational needs, HNC patients possibly search the Internet to look for information on cancer. Future research is needed to gain insight in which HNC patients are able to find adequate information on the Internet.

This study also aimed to investigate preferences towards future use of other types of eHealth among HNC patients. Strikingly, we did not find differences in preferences for future use of eHealth between both samples. We expected less interest in eHealth in 2007, because of inexperience with and no proper idea about what eHealth would withhold. An explanation for the current results, based on Rogers diffusion of innovation theory, which explains how technology spreads[29], might be that the 2007 study sample consisted of innovators, early adopters and the early majority who were the first to engage in Internet usage, while the 2015 sample also includes the late majority. Especially, the group of innovators and early adopters are people who are open for new innovations.

Patients were especially interested in eHealth for communication and care purposes.

eHealth applications for these types of purposes are available for HNC patients[30], however as is confirmed in our study in 2015, actual engagement remains low. A range of approaches to support successful integration of eHealth in clinical care have been suggested, amongst others: (1) *Participatory design* including patients and HCPs in the development process to carefully match their needs[31,32], (2) *Schooling and gaining experience*, including instructions for patients on usage of eHealth services that ask for a more diverse range of skills[4,33], (3) *Finding ambassadors* to promote eHealth services, and[33] (4) Focus on *financing opportunities and evidence of effectivity* of these types of eHealth[33]. The degree of success of these approaches has yet to emerge from future research.

A limitation of this study is its cross-sectional design and the moderate response percentage (2007: 65% and 2015: 46%). The findings of this study are also limited by the small sample size, the fact that patients were included from a single center and that we did not study digital health literacy skills.

CONCLUSION

Internet use among HNC patients has strongly increased between 2007 and 2015. Younger HNC patients and patients with a tumor originating from the oral cavity used the Internet more often in 2007. Younger patients, patients with a higher educational level and those with a partner used the Internet more often in 2015. Patients with a higher educational level used the Internet more often for cancer-related purposes in 2015. Since many patients were interested in future eHealth use, attention should be paid to ensure adequate awareness among patients.

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IMPROVING ACCESS TO SUPPORTIVE CANCER CARE THROUGH AN eHEALTH APPLICATION: A QUALITATIVE NEEDS ASSESSMENT AMONG CANCER SURVIVORS

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ABSTRACT

Aims and objectives To gain insight into cancer survivors' needs towards an eHealth application monitoring quality of life and targeting personalized access to supportive care.

Background Supportive care in cancer addresses survivors' concerns and needs. However, many survivors are not taking advantage of supportive care provided. To enable cancer survivors to benefit, survivors' needs must be identified timely and effectively. An eHealth application could be a solution to meet patients' individual supportive care needs.

Design A qualitative approach.

Methods Thirty cancer survivors (15 head and neck and 15 breast cancer survivors) participated. The majority were female (n=20, 67%). The mean age was 60 (SD 8.8) years. Mean time interval since treatment was 13.5 months (SD 10.5). All interviews were audio-recorded and transcribed verbatim. During the interviews, participants were asked about their unmet needs during follow-up care and a potential eHealth application. Data were analyzed independently by two coders and coded into key issues and themes.

Results Cancer survivors commented that they felt unprepared for the post-treatment period and that their symptoms often remained unknown to care providers. Survivors also mentioned a suboptimal referral pattern to supportive care services. Mentioned advantages of an eHealth application were as follows: insight into the course of symptoms by monitoring, availability of information among follow-up appointments, receiving personalized advice and tailored supportive care.

Conclusions Cancer survivors identified several unmet needs during follow-up care. Most survivors were positive towards the proposed eHealth application and expressed that it could be a valuable addition to follow-up cancer care. Relevance to clinical practice. Study results provide care providers with insight into barriers that impede survivors from obtaining optimal supportive care. This study also provides insight into the characteristics needed to design, build and implement an eHealth application targeting personalized access to supportive care from the survivors' perspective. Future studies should address the viewpoints of care providers, and investigate the usability of the eHealth application prototype to facilitate implementation.

Key words: Aftercare, Self-care, Telemedicine, Tertiary prevention

INTRODUCTION AND BACKGROUND

It is increasingly recognized that the impact of cancer does not end after cancer treatment[1]. The number of cancer survivors expressing unmet needs is reportedly highest in the post-treatment period[2,3], indicating a need for a review and provision of adequate supportive cancer care. Supportive care in cancer entails the prevention and management of adverse effects of cancer and its treatment[4], across the survivorship continuum, to address cancer survivors' concerns and needs[5]. However, many survivors are not taking advantage of supportive care provided, despite proven benefits[6–9].

Several studies have identified patients' barriers that impede their engagement in supportive care services. It has been suggested that services are under utilized because of lack of awareness among both survivors and care providers[10,11].

Survivors' barriers to using supportive care include subjective judgments about their need for these services. Problems related to diagnosis and treatment of cancer care are often considered to be a normal consequence[8,10]. Additionally, survivors are sometimes not willing to be referred because of the long treatment period after which they do not wish or are too exhausted to visit other care providers[8,10]. Also, care providers have a tendency to inadequately refer to supportive care[7,8]. Cancer survivors' declined well-being and psychosocial functioning often remain unrecognized[8,12], because of fragmentation in cancer care. Care providers often have a limited availability of relevant information regarding each patient's well-being[8], and communication between health care team members is frequently poor[13]. Additionally, care providers may find some symptoms, such as psychosocial issues, more difficult to discuss, which may contribute to low referral rates[14].

To enable more cancer survivors to benefit from supportive care, survivors' needs must be identified in a timely and effective manner[11,15]. Tailoring of interventions to each cancer survivors' symptoms and needs is argued to be a prerequisite for their successful rehabilitation[3].

Several studies have shown that using patient-reported outcomes (PRO's) facilitates identification of symptoms and serves as a reminder for topics to be discussed and allows for identifying and tracking changes over time[13,16]. Carlson et al. (2012)[17] stated that monitoring of symptoms may result in more accurately meeting each individuals' supportive care needs. However, there is less evidence that screening alone leads to reducing cancer survivors symptom burden[18,19]. Additional efforts are needed to enhance the effect[20].

An eHealth application integrating patient-reported outcome measures (PROMs) to monitor quality of life, followed by personalized advice and referral to supportive care services, could be a solution to meet cancer survivors' individual supportive care needs. Although eHealth applications monitoring quality of life by means of PROMs are available in oncology[8,21,22], as are websites which offer patient education and supportive care options[23], to our knowledge, no such application acts as a navigation instrument to personalized supportive cancer care.

For eHealth applications to become useful and effective, they have to address the end-users' needs. To ensure adequate uptake we followed participatory design principles, meaning that cancer survivors were involved in each step of the development process of the eHealth application[24,25]. The aim of this study was twofold. First, we wanted to gain insight into unmet needs of cancer survivors during regular follow-up care regarding their post-treatment symptoms and the current pattern of referral to supportive care services. Secondly, we wanted to investigate cancer survivors' acceptability and preferences towards an eHealth application monitoring quality of life, offering personalized advice and referring to supportive care services.

METHODS

SAMPLE AND PROCEDURE

This study focused on head and neck cancer (HNC) and breast cancer (BC) survivors. These groups were explored because of the contrast between the types of cancer (a relatively rare type of cancer that mainly affects men versus a more common type that mainly affects women) and its treatment with different side effects on quality of life. HNC and BC survivors that attended the outpatient clinic of the VU University Medical Center in Amsterdam, The Netherlands, were invited to participate. Eligibility for the study included that they (1) were 18 years or over, (2) had completed their curative treatment for cancer between three months and five years prior to the interview, (3) were able to communicate in Dutch. The survivor's clinician introduced the study to eligible patients. If a survivor expressed interest, he or she was approached by one of the researchers for further details about the study, and agreement to participate. In total, 37 survivors were invited, of whom 15 HNC and 15 BC survivors gave written informed consent. Reasons mentioned for nonparticipation included difficulty speaking after total laryngectomy, and not wanting to be burdened. Mean age of participants was 59.7 years (SD 8.8). Mean time interval from completion of treatment was 13.5 months (SD 10.5). An overview of the demographics of the participants is shown in Table 4.1.

Participants were interviewed at a preferred location. The duration of the interviews lasted between 35 minutes and 95 minutes (median 59.5). Interviews were audio-recorded with the participant's consent, and transcribed verbatim. After 30 interviews, data saturation was reached, meaning that no new information of value was obtained.

ETHICS STATEMENT

The study was approved by the Medical Ethics Committee of VU University Medical Center. All participating patients provided written informed consent to participate in the study.

INTERVIEW STRUCTURE

The interviews were conducted using a semi-structured interview schedule (Table 4.2), consisting of a set of standardized interview questions, while allowing flexibility in how and in what order questions were asked, and in whether and how particular areas were pursued with different respondents.

Topics and questions were derived from the literature[25] and clinical experience of our team. In addition, participants were asked to provide information about demographics and cancer treatment. During the interviews, more information about a possible eHealth application was conveyed to cancer survivors by means of mock-ups of screenshots of the layout and design of a possible application, including monitoring of symptoms, personalized advice and offering supportive care options.

Table 4.1. Demographic, health and Internet use characteristics (N=30)

	Head and Neck Cancer	Breast Cancer
Sex (n, %)		
Female	5 (33)	15 (100)
Male	10 (67)	- (0)
Age in years		
Mean (SD)	58 (7)	61 (10)
Minimum	48	49
Maximum	74	88
Marital status (n, %)		
Single	-	2 (13)
Living together	2 (13)	-
Married	10 (67)	9 (60)
Widow(er)	3 (20)	3 (20)
Divorced	-	1 (7)
Education (n, %)		
Low	8 (54)	9 (60)
Middle	5 (33)	5 (33)
High	2 (13)	1 (7)
Labor (n, %)		
Paid job	7 (46)	6 (40)
Unpaid job	-	2 (13)
Retired	4 (27)	3 (20)
Unemployed	4 (27)	4 (27)
Time since last treatment (months)		
Mean (SD)	11 (9)	15 (12) *
Minimum	5	3
Maximum	35	48
Treatment (n, %)		
Surgery	2 (13)	-
Radiation therapy	6 (40)	-
Chemotherapy	-	-
Combination of radiation therapy and surgery	3 (20)	8 (54)
Combination of chemotherapy and radiation therapy	3 (20)	-
Combination surgery, chemotherapy and radiation therapy	1 (7)	2 (13)
Combination of surgery, radiation treatment, and hormone therapy	-	2 (13)
Combination of surgery, radiation treatment, chemotherapy and hormone therapy	-	3 (20)
Internet use (n, %)		
Yes	14 (93)	14 (93)
No	1 (7)	1 (7)
Use of internet for health related purposes (n, %)		
Yes	5 (33)	9 (60)
No	10 (67)	6 (40)

* 1 missing

Table 4.2. Interview topics

Topics	Key questions
Unmet needs during regular follow-up care:	*Post-treatment symptoms* • How do you feel about the information you received regarding possible remaining symptoms after cancer treatment? • Based on your experience with follow-up care, how would you describe the support you received concerning your post-treatment symptoms? *Current use of supportive care* • What is your experience with referral to supportive care and use of supportive care options? • What type of supportive care would you like to receive?
Acceptability and preferences towards an eHealth application:	*eHealth application* • Do you think you would use an eHealth application in supportive cancer care if one was available to you? • What are your preferences and requirements regarding an eHealth application? *Monitoring quality of life* • What are your thoughts about being able to monitor your own health status by means of an eHealth application? *Offering personalized advice* • How would you feel about receiving personalized advice regarding your post-treatment symptoms by means of an eHealth application? *Referring to personalized supportive care service* • What are your thoughts about finding supportive care services tailored to your personal needs and current health status?

DATA-ANALYSIS

Data were analyzed independently by two coders (SL and CvU). Both coders separately read all transcripts several times to familiarize themselves with the data. Unmet needs in current follow-up care regarding post-treatment symptoms and referral to supportive care were extracted. Citations about motives for use, nonuse and preferences towards the eHealth application were independently selected and coded into key issues and themes by the coders. Subsequently, the coders met to discuss their findings and resolve differences. Key issues and themes were refined and sub themes were identified. A single coder (SL) examined the raw data again to ensure the robustness of the analytical process and to confirm that all data were reflected in the coding[26]. We followed the consolidated criteria for reporting qualitative research (COREQ) to ensure the accuracy of this qualitative study[27].

All quotes provided in this article were translated from Dutch into English. To ensure anonymity all identifying information has been removed from the quotes.

RESULTS

UNMET NEEDS DURING FOLLOW-UP CARE

Several unmet needs of survivors in follow-up care regarding post-treatment symptoms and current referral to supportive care services emerged from the analysis of the transcripts (Table 4.3).

Attention paid to symptoms post-treatment

Unprepared for post-treatment period. Almost all survivors mentioned that they *experienced unexpected persisting or new symptoms* after treatment. Their assumption was that they could go back to normal life after finishing cancer treatment.

Many survivors indicated that they were *uninformed about possible persisting or new symptoms* after cancer treatment. Several mentioned that they didn't receive information about symptoms, while others indicated that their physician may have informed them but they didn't register it:

> *"It is when treatment is finished that you fall apart. You think you have reached the finish line. But it is only the beginning, and that is something that they (physicians) have probably told us, but that you don't expect."*

Post-treatment symptoms remain unknown to care providers. Survivors indicated that they were hesitant in informing their care providers about their post-treatment symptoms. Some mentioned to experience *emotional barriers*, such as not wanting to complain after having survived cancer. They accepted the symptoms because they considered themselves lucky to have survived cancer and its treatment:

> *"When you know you have that disability you can make a fuss about it. However, to me it is not a big deal because I feel I came out of cancer treatment very well considering that I survived."*

Practical barriers to informing their physicians about their symptoms were mentioned, e.g. not having an appointment when symptoms emerged. Survivors indicated it was not always clear to them who to contact in case of emerging symptoms, and they often did not want to bother their doctor with something possibly trivial. Besides, survivors reported doubts about whether symptom care should involve their physician:

> *"I don't blame the hospital for not offering extensive symptom care, since I didn't expect this of them. I expect the hospital to provide me with physical care. Other types of care I will find on my own."*

Survivors indicated being reluctant to mention their symptoms due to *health care barriers*. They indicated that the time they actually spent with their physician during a consultation was too short to ask their questions:

> *"In the (name hospital) a doctor's consultation lasts six minutes, and then it's over. That is very brief. (...) I always intend to ask this or that, but eventually I don't ask anything and before I know it I am outside the doctor's office."*

Survivors perceived consultations often as tense, because of possible cancer recurrence. They considered follow-up consultations as not comforting, and protocol-oriented, not leaving much room to mention their symptoms.

<u>A complete patient's overview is missing.</u> Cancer survivors experienced a lack of overview of their health status. They indicated *a lack of coordination*; there was no complete picture of a survivor's symptoms:

> *"Everybody (the care providers) acts like, this is my job: up to here and no further."*

Regarding the *attitude of physicians towards symptoms and supportive care* several survivors described a wait-and- see approach from their physicians towards their symptoms:

> *"When you mention your symptoms to your physician, you're told that these symptoms may last for a year, but will eventually pass. When you receive this answer for one symptom you mention, it withholds you from bringing up other symptoms because you will receive the same answer."*

Survivors mentioned physicians often view symptoms as a common consequence of cancer. They indicated that many aspects during follow-up care, e.g. sexuality and psychosocial symptoms, were not addressed since their *physician's focus was directed towards the physical aspects of the disease.*

Current referral to supportive care

Supportive care services referrals. Some survivors mentioned to be referred to supportive care. According to them, referrals within the hospital were limited to protocol instructions and consisted of physical therapy, psychological treatment, occupational therapy, a pain clinic and a dental hygienist.

No optimal referral to supportive care services. Survivors indicated to experience a lack of initiative from the hospital towards symptoms and were often advised to visit their general practitioner. They indicated that especially referrals to mental or spiritual supportive care services, services in their own surroundings and complementary services were lacking:

> *"I especially missed a referral to a mental health care professional (...) so I found help on my own and am seeing a therapist. But if you don't take that action yourself, you remain burdened by your psychological symptoms."*

Other supportive care options used by participants, such as art therapy or self-help interventions targeting anxiety, were retrieved on their own initiative.

Table 4.3. Overview of key issues and themes regarding survivors' experienced flaws in regular follow-up care

	Key issues	Themes
Attention paid to symptoms post-treatment	**Unprepared for post-treatment period** Unexpected persisting or new symptoms after treatment	• Duration of symptoms • Variation in symptoms (mild to severe) • Specific symptoms
	Uninformed about possible persisting or new symptoms after treatment	• No information received • Information overload at start of treatment • Missed/did not hear information
	Symptoms post-treatment stay unknown to care providers Emotional barriers	• Not wanting to complain after surviving cancer • Thinking symptoms belong to cancer treatment • Not wanting to dramatize their symptoms
	Practical barriers	• Not wanting to burden their doctor • Not knowing who to contact • Doubts about whether symptom care is involved in regular follow-up care • No appointment in the hospital when symptoms emerge
	Health care barriers	• Follow-up consult is too short • Follow-up consult is too tense • Follow-up consult offers too little comfort • Follow-up consult is too much protocol oriented
	A complete survivor's overview is missing Lack of coordination	• No complete picture of a survivor's symptoms • A cancer survivorship plan is missing
	Physicians attitude towards symptoms and supportive care	• Wait-and-see approach • Symptoms are part of the package • Post-treatment symptoms belong to general practitioner
	Physician's focus on physical aspects	• Often overlooked aspects include: psychosocial symptoms, a survivor's environment, financial issues due to cancer, hereditariness, and sexuality.
Current referral to supportive care	Supportive care services referred	• Referral by physician limited to protocol instructions: physical therapist, psychologist, dental hygienist, dietician, pain department within the hospital.
	No optimal referral to supportive care services	• Lack of action towards symptoms from physicians • Lack of referral to alternative supportive care services • Lack of referral to mental/spiritual support • Limited to advice of visiting their GP • Additional supportive care options found by survivors on their own initiative • Limited referral to supportive care in survivor's own surroundings

ACCEPTABILITY AND PREFERENCES TOWARDS AN eHEALTH APPLICATION

An eHealth application monitoring quality of life, offering personalized advice and referral to supportive care services was appealing to most participants. They viewed it as a possible improvement of the rehabilitation process. HNC survivors especially were positive about such an eHealth application, while BC survivors were more divergent in their opinion. Almost all participants stressed it should not be a substitute to care as usual, but an addition.

Cancer survivors mentioned various motives for use, non- use and preferences towards the functionalities of this eHealth application (Table 4.4).

Two of the survivors interviewed, indicated they did not use the Internet at all. Their results are left out of consideration in the following paragraphs.

Monitoring quality of life through an eHealth application

About half of the survivors interviewed had a positive attitude towards monitoring. Some survivors indicated monitoring would enable them to track whether their symptoms are improving or worsening:

> *"It makes it clearer. I do think by myself, how did I feel a month ago, and then come to the conclusion that I feel a little better now. But I can imagine that monitoring is nice because it provides a clear picture. Because if you feel lousy today you have the feeling that you always feel lousy."*

Other survivors mentioned monitoring could give them a peace of mind, and a feeling of control over their own recovery. Monitoring was indicated to stimulate them to act upon their symptoms, for instance by addressing these when visiting their physician:

> *"Yes I think that it is very good (to monitor quality of life), because there are a lot of symptoms that are too vague to discuss with your physician. These symptoms also make you feel; well I have had an anesthetic and that takes time, it'll be okay. It would be a good thing to have a tracking system for these symptoms."*

Early identification of problems was another motive for monitoring, according to survivors interviewed. However, some mentioned that monitoring could also lead to projecting symptoms onto themselves that they did not experience before.

A motive not to monitor symptoms mentioned was not having enough remaining symptoms. Respondents figured a patient had to have multiple symptoms over a longer period of time, for monitoring to become useful:

> *"I have insufficient remaining symptoms to monitor. Monitoring is valuable to a person that is still experiencing symptoms of cancer treatment, to enable him to see the course of his symptoms."*

Also, survivors feared monitoring would mean they had to answer screening questions not applicable to their situation.

Respondents indicated to prefer to receive feedback about their results and information on what is normal regarding their symptoms so they can compare their own recovery to what could be expected:

> *"When I don't receive feedback about something that I filled out I lose my motivation to fill anything out. (. . .) I want to receive feedback. That you also see yourself compared to other survivors or a previous overview of yourself."*

Personalized advice through an eHealth application

Personalized advice through an eHealth application was appealing to cancer survivors. Motives towards the use of tailored advice mentioned were not having to browse the Internet for information and as a result not being confronted with the negative sides of cancer needlessly:

> *"I don't believe browsing the Internet would have a positive effect on me. I think the focus would soon shift towards negative things you encounter. And then you are confronting yourself with misery and start to think; "That could also happen to me". That wouldn't be good for me."*

Other motives for use included being able to consult the application for the information in between hospital follow-up consultations. Also, having personalized information on aspects often overlooked in the hospital was seen as an advantage by survivors.

However, survivors also mentioned some motives not to use personalized advice. HNC survivors especially mentioned doubts concerning the degree of tailoring that is possible:

> *"I believe every individual is different and that the same is true for diseases. The course of a disease is different for everybody (. . .) You can put all that (personalized advice) online, but it has to address just you."*

Other threats that survivors mentioned were receiving the wrong information, and possibly a wrong diagnosis by misuse. Survivors indicated receiving too much information could lead to increased anxiety. Some survivors mentioned they did not need advice because they received enough information from the hospital.

Survivors pointed out that the information should be reliable, coming from a trustworthy source (preferably their own hospital). They wished to receive information on and strategies to cope with various aspects of their life influenced by cancer (treatment) impact, and identified symptoms, e.g. sexuality, a loss of taste and appetite, and quitting smoking and alcohol use as important aspects to be addressed. Survivors indicated to appreciate to learn about when they can expect symptoms to subside.

They also mentioned to prefer to receive reassuring information, and tips and tricks from expert survivors. The information provided should comply with the information given by their physician and should be easily comprehensible.

Overview of tailored supportive care services through an eHealth application

Generally, survivors interviewed expected advantages in receiving supportive care information tailored to their specific needs. Mentioned motives for use included the ability to find supportive care options on their own, and to take actions towards their symptoms:

> *"I eventually found everything on the web, I searched for all the information by myself. But I think a big help in finding supportive care options would have been if someone had pointed me in the right direction."*

Table 4.4. Overview of key issues and themes concerning the acceptability and preferences towards an eHealth application

Acceptability and preferences towards an eHealth application	
Monitoring quality of care through an eHealth application	**Motives for use:** • Enhances the insight into your symptoms • Symptoms become more concrete • Enables you to monitor the course of symptoms • Gaining a feeling of control over your symptoms • Stimulates you to act upon your symptoms • Enables you to notice your symptoms earlier
Personalized advice through an eHealth application	**Motives for use:** • No overflow of (irrelevant) negative information • Accessibility to personalized advice from home environment • Availability of personalized advice/information in between appointments • Information supply on aspects not often mentioned or overlooked in the hospital • All information on one website • Low threshold to gain access to personalized information
Supportive care services through an eHealth application	**Motives for use:** • Receiving tailored supportive care options • Ability to find supportive care options independently • Ability to take actions towards symptoms • Supportive care services available at all times • Prevents you from having to 'Google' • 24/7 availability of overview supportive care services

Participants mentioned that referrals to supportive care services in their own surroundings and access to a wide variety of options, including mental/spiritual supportive care options, would be beneficial:

> *"The way I see it, what you (the hospital) are for is the medical part, and the other things I can get here (home town). I don't want to go to (hospital city) that is too much of a burden."*

Survivors also mentioned motives why they were not interested in this functionality. Some assumed that services could only be offered in the hospital. Others had the impression that there was nothing they could do to improve their symptoms or indicated

Motives for non-use: • Raise awareness to symptoms you didn't know you had / projecting symptoms onto yourself • Only applicable when having symptoms which remain present • Own ability to feel from your own body how you are doing • Too much focus on the disease • Having to answer non applicable screening questions	**Preferences:** • Feedback about results • Being able to compare yourself to what is normal
Motives for non-use: • Doubts towards degree of tailoring/nuance possible • Lack of trust in accurateness of automatically generated personalized advice • Increases feelings of insecurity by receiving too much information • Enough information received from physicians	**Preferences:** • Personalized reliable information/ tailored to specific symptoms/patient • Information on impact of symptoms on other life aspects • Information about the degree of seriousness and duration of symptoms • Reassuring information • Tips and tricks from expert survivors • Information complies with information from physicians • Availability of a helpline
Motives for non-use: • Supportive care can only be offered in the hospital • Nothing can be done to enhance symptoms • Enough possibilities for supportive care offered by physicians • Trust in doctors to inform about supportive care options • Acceptance of remaining symptoms as part of cancer • Being able to find supportive care services without support	**Preferences:** • Receiving supportive care options in own surroundings • Access to a variety of supportive care services • Availability of complementary medicine supportive care options

they had enough options offered to them. Some also indicated to trust their doctor to inform them about any possibility:

> *"When they tell me, come back in two months, I believe that they know what is best."*

DISCUSSION

This study investigated the unmet needs of cancer survivors and their acceptability and preferences towards an eHealth application monitoring quality of life, providing personalized advice and an overview of tailored supportive care services.

UNMET NEEDS AND CURRENT REFERRAL TO SUPPORTIVE CARE SERVICES

The results of this study showed that cancer survivors experience unmet needs regarding post-treatment symptoms. Besides, several barriers for adequate referral to supportive cancer care were identified. These results are in line with previous studies focusing on unmet needs of cancer survivors[28] and add some interesting aspects from the survivors' perspective. Several survivors indicated to receive minimal response from their physicians concerning their needs and therefore searched for services themselves. Others indicated to rely on their physicians' expertise. In both cases, this may lead to survivors receiving suboptimal care for symptoms where treatment does exist[10]. To provide optimal supportive care, different models are used, varying widely from country to country and within countries. For example, in the UK, every cancer patient should have a nominated key worker to help with the identification of needs and referral to supportive care services. A holistic needs assessment tool is adapted by some clinical teams to adequately meet patients' needs[29].

A fundamental aspect of most of the supportive care models, is stimulating care providers to initiate a dialogue about potential referrals with survivors who are interested in these services[10,18]. However, a key barrier identified is a failure of care providers to link treatment to supportive care needs[20]. By automating this process by means of an eHealth application, the barrier may be settled.

ACCEPTABILITY AND PREFERENCES TOWARDS AN eHEALTH APPLICATION

In general this study found support for the potential value of the proposed eHealth application in follow-up cancer care.

Monitoring quality of life

About half of the survivors indicated to have a positive attitude towards monitoring. Several perceived advantages, e.g. the ability to monitor the course of symptoms and to act upon these symptoms, are comparable to results of previous studies[13,16,21]. Notable advantages of monitoring mentioned by survivors, suggest that monitoring can make a valuable contribution in supporting cancer survivors performing self-management tasks, including adjusting to and managing symptoms and consequences of cancer and cancer treatment to minimize negative impact on quality of life[30].

A significant consideration, when monitoring symptoms identified by survivors in our study, is that it is only useful when remaining symptoms are present, so that survivors are not burdened by non-relevant questionnaires. Therefore, questionnaires should be tailored to a survivors' situation and needs[13,16,21]. By tailored testing or computerized adaptive testing (CAT), sequence questions or intensification questions are selected on basis of what is known from previous questions. The main advantage is that far fewer questions need to be asked to still obtain reliable results. The eHealth application to be developed could benefit from including CAT. However, due to the level of sophistication needed when developing a CAT, it is not widely available yet.

Personalized advice

Personalized advice linked to the results of monitoring quality of life, via an eHealth application is viewed positively in our study. This complies with findings from a previous study concluding that patients are increasingly seeking for personalized health advice online[23]. According to patients, interactive components, make eHealth instruments more appealing[31].

A main advantage of tailored advice survivors mentioned in our study was not being confronted with needless negative information. Previous literature supports this finding[23,31]. Survivors indicated they wanted to be in control of the information they accessed[23] and not be forced to see upsetting information when they did not feel ready for it[31]. Many survivors doubted the degree of tailoring possible. Doubts could possibly be explained by the fact that participants were often from the generation in which Internet does not play an eminent role. This might indicate they are less familiar with possibilities concerning tailoring, which could have contributed to their skepticism towards the level of accuracy. However, previous studies regarding computer- tailored feedback and interventions have shown acceptability of tailoring, even among older cancer survivors[32].

Supportive care services

The results of our study demonstrated that most cancer survivors are positive towards receiving supportive care options through an eHealth application, consistent with their symptoms and tailored to their needs. In directing the patient to optimal supportive care the application fits into the current cancer care navigation movement in which attention is paid towards ensuring cancer survivors receive adequate follow-up and supportive care[33]. Concurrent with our findings, Davis et al. (2009)[34] found that survivors prefer navigation services to continue throughout the continuum of cancer care into long-term survivorship care.

An important condition for success mentioned was that the eHealth application should provide options in the survivors' own surroundings. This entails far-reaching consequences, such as creating an extensive list of available supportive care options throughout its target area. Since this information is not readily accessible it proposes a challenge to translate this information into an eHealth application, and maintain its usability by keeping the information up to date.

It is expected that the eHealth application will not be suitable for all cancer survivors, such as older survivors and survivors with limited trust in eHealth. In line with previous studies, we found that survivors often have more trust in physicians than in eHealth applications to provide relevant advice[35]. It is possible that survivors value the human-component in their doctor-patient relationship and have fears about the impact an eHealth application would have on this relationship. This latter argument concurs with the preference of survivors to use the application additionally to traditional care, and not as a substitute.

Because of the qualitative nature of this study and therefore the small sample size, we should be cautious on reporting 'differences' between the patient groups. As mentioned in the results section, BC survivors seem to be more divided in their opinion towards the added value of an eHealth application. HNC survivors seem to be especially doubtful towards the degree of tailoring that is possible through an eHealth application. This might be explained by the fact that HNC survivors can be faced by a larger variety of symptoms compared to BC survivors. Nevertheless, a quantitative sequel study is needed to detect possible differences between the patient groups and to study if these are clear and consistent.

LIMITATIONS

The findings of this qualitative study are limited by the fact that interviewed survivors were included from a single center. Also, the BC survivors were included from the radiation therapy department, which is why all BC survivors included in the study received radiation therapy, leading to a skewed BC survivor sample. This could have affected the representativeness of the sample, and therefore the ability to generalize on the results obtained.

In addition, during the interviews survivors only gained an abstract idea of the eHealth application. It was difficult for some cancer survivors to visualize and interpret the functionalities the application could encompass. In an upcoming usability study with a prototype of the eHealth application the functionality will be investigated.

CONCLUSION

Interviewed cancer survivors experienced a variety of barriers in obtaining supportive cancer care, such as suboptimal referral. Most survivors were positive towards an eHealth application that enables them to monitor quality of life, provides personalized advice, and supports them in finding tailored supportive care. According to survivors included in our study, such an application could be a solution to several of the identified barriers in finding and obtaining optimal supportive care. To develop a useful eHealth application, a next step in the participatory design process is to address the needs of other stakeholders, e.g. care providers. Involving all stakeholders in the development of the eHealth application will enhance the chance of succeeding in improving current follow-up cancer care.

RELEVANCE TO CLINICAL PRACTICE

This study showed that care providers do not always succeed to link cancer survivors' symptoms and unmet needs to optimal supportive care, due to several barriers. Study results offer care providers insight into the barriers that cancer survivors indicated to experience, such as a short consultation time with their care provider, not having an appointment when symptoms emerge, and not wanting to complain about possible trivial symptoms. Care providers may benefit from this data, by applying them to improve follow-up care, including optimizing referral to supportive care.

An eHealth application could support cancer survivors as well as care providers by eliminating barriers that can impede obtaining supportive care. Study results give insight into the characteristics needed to design, build and implement a useful eHealth application targeting personalized access to supportive care from the survivors' perspective. Due to the rapid expansion of web-based applications, analyzing the perspective of potential users is important in developing and designing a successful eHealth application. An additional benefit is that the eHealth application can invite cancer survivors to participate in more self-management tasks, leading to more accurately met needs while at the same time relieving the increasing pressure on the health care system.

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5

HEALTHCARE PROFESSIONALS’ PERSPECTIVES TOWARD FOLLOW-UP CARE AND AN eHEALTH APPLICATION IN HEAD AND NECK CANCER SURVIVORSHIP CARE

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ABSTRACT

Background Although many cancer survivors could benefit from supportive care, they often do not utilize such services. Previous studies have shown that the use of patient-reported outcome measures (PROMs) could be a solution to meet cancer survivors' needs, for example through an eHealth application that monitors quality of life and provides personalized advice and supportive care options. In order to develop an effective application that can successfully be implemented in current health care, it is important to include health care professionals in the development process.

Objective The aim of this study was to investigate health care professionals' (HCP) perspectives toward follow-up care and an eHealth application, Oncokompas, in follow-up cancer care that monitors quality of life via PROMs, followed by automatically generated tailored feedback and personalized advice on supportive care.

Methods HCPs involved in head and neck cancer care (N=11) were interviewed on current follow-up care and the anticipated value of the proposed eHealth application (Step 1). A prototype of the eHealth application, Oncokompas, was developed (Step 2). Cognitive walkthroughs were conducted among health care professionals (N=21) to investigate perceived usability (Step 3). Interviews were recorded, transcribed verbatim, and analyzed by 2 coders.

Results HCPs indicated several barriers in current follow-up care including difficulties in detecting symptoms, patients' perceived need for supportive care, and a lack of time to encourage survivors to obtain supportive care. HCPs expected the eHealth application to be of added value. The cognitive walkthroughs demonstrated that HCPs emphasized the importance of tailoring care. They considered the navigation structure of Oncokompas to be complex. HCPs differed in their opinion toward the best strategy to implement the application in clinical practice but indicated that it should be incorporated in the HNC cancer care pathway to ensure all survivors would benefit.

Conclusions HCPs experienced several barriers in directing patients to supportive care. They were positive toward the development and implementation of an eHealth application and expected it could support survivors in obtaining supportive care tailored to their needs. The cognitive walkthroughs revealed several points for optimizing the application prototype and developing an efficient implementation strategy. Including

HCPs in an early phase of a participatory design approach is valuable in developing an eHealth application and an implementation strategy meeting stakeholders’ needs.

Key words: Head and neck cancer, Health-related quality of life, Implementation, Patient-reported outcome measures, Screening for psychological distress

INTRODUCTION

Many cancer survivors have to manage the adverse effects of cancer and its treatment. Head and neck cancer (HNC) specifically has an impact on survivors compared to other cancers. In addition to symptoms such as fatigue, HNC survivors are confronted with oral dysfunction, voice, speech, and swallowing problems, and related social withdrawal and psychological distress. These may negatively impact on quality of life (QOL)[1,2] and increase the need for supportive care.

Supportive care in cancer entails the prevention and management of the adverse effects of cancer and its treatment across the survivorship continuum[3,4]. Although many cancer survivors, including HNC survivors, could benefit from supportive care, they often do not utilize such services[5–8]. Barriers that stand in the way of obtaining supportive care include a lack of awareness of these services and a lack of identification of survivors' symptoms and supportive care needs[9–11].

The use of patient-reported outcome measures (PROMs) has been identified as a possible facilitator to detecting survivors' symptoms[12]. Monitoring symptoms may be helpful in addressing survivors' individual supportive care needs[13]. A prerequisite for its success is that monitoring should be followed by adequate referral to supportive care. An eHealth application integrating PROMs to monitor QOL, followed by automatically generated tailored feedback and personalized advice on supportive care options, could be an alternative solution to meet cancer survivors' individual needs. The proposed eHealth application could also be a helpful tool to enhance self-management among HNC survivors.

In a previous study, we investigated the attitude and preferences of cancer survivors toward an eHealth application targeting personalized referral to supportive care services[14]. The results of this needs assessment showed that survivors were indeed interested in this option of self-management support and believed that the eHealth application could eliminate barriers experienced in current follow-up care, for example, a minimal response from physicians concerning their needs and having to search for services themselves. The results also highlighted considerations and requirements concerning the application, for example, doubts about the degree of tailoring and the need for the application to be an addition to rather than a substitute for traditional care[14].

In order to develop an effective eHealth application and ensure adequate uptake, it is important to include all stakeholders, including health care professionals (HCPs), during the entire developmental phase, following an iterative participatory approach[15]. Therefore, the main aim of this study was to investigate HCPs' perspectives toward an eHealth application in follow-up cancer care, which monitors QOL via PROMs (Measure), followed by automatically generated tailored feedback (Learn), and personalized advice on supportive care (Act). The results of this study are intended to contribute to further development of a participatory design approach enabling the development of effective eHealth applications that meet stakeholders' preferences and needs.

METHODS

A mixed methods study design was used consisting of 3 steps (Figure 5.1). We investigated HCPs' perspectives toward current follow-up care and toward the proposed eHealth application (Step 1) through a qualitative needs assessment. Next, we developed a prototype of the eHealth application (Step 2). Subsequently, we evaluated the application by means of cognitive walkthroughs (CWs) by health care professionals and investigated HCPs' opinions about usability and conditions for implementation (Step 3).

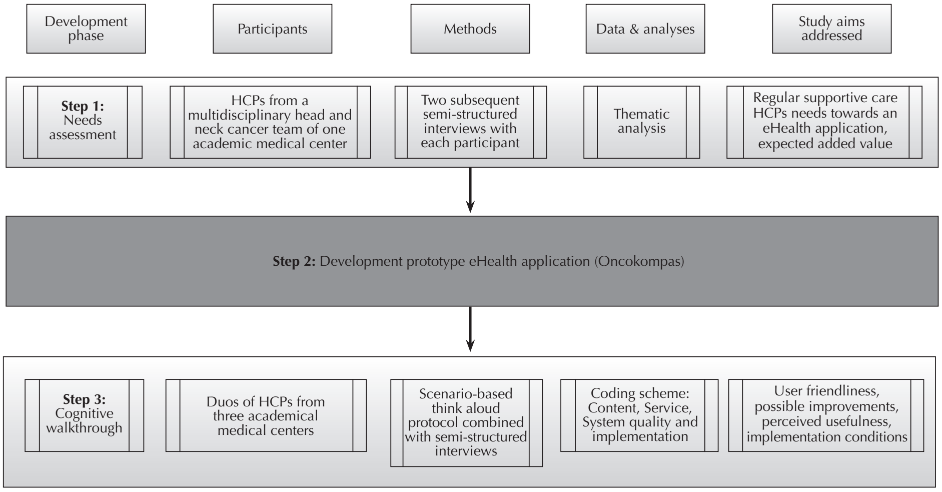

Figure 5.1. Study design

STEP 1: NEEDS ASSESSMENT

HCPs (N=11) were recruited from a multidisciplinary team involved in the care of HNC patients at the VU University Medical Center in Amsterdam, The Netherlands. We made use of purposive sampling. After permission from the department head, we requested study participation from a heterogeneous sample of HCPs. The final sample consisted of an oral and maxillofacial surgeon, head and neck surgeon, oncologist, radiation oncologist, medical social worker, physiotherapist, dental hygienist, dietician, speech therapist, and 2 oncology nurses. Participating HCPs' experience in working with cancer patients ranged from 2 years and 3 months to 25 years (mean 13.38 years). HCPs were interviewed twice. An overview of the topics is shown in Table 5.1.

Table 5.1. Topics discussed in the needs assessment interviews

Needs assessment	
Topic	**Example question**
Current follow-up care: assessing symptoms and supportive care needs	• How do you assess patient's symptoms and quality of life? • What difficulties do you encounter when assessing patient's symptoms and quality of life? • How do you assess patient's supportive care needs? • Do you refer patients to supportive cancer care options? • To which supportive care options do you refer patients? • What difficulties do you encounter when referring patients to supportive cancer care options?
Added value of an eHealth tool in follow-up care for HCPs	• How may an eHealth application be supportive/fit into in your current role in follow-up cancer care?

The first interview covered questions about current follow-up care (assessing patient's symptoms and need for supportive care). The second interview covered questions about the expected added value for HCPs of an eHealth tool aimed at improving supportive care. In this second interview, more information about the proposed application was conveyed (e.g., examples of personalized advice texts and supportive care options).

In total, 22 interviews were conducted, which lasted between 24 and 50 minutes (median 35, SD 7.24). All interviews were recorded and transcribed verbatim.

STEP 2: DEVELOPMENT OF THE PROTOTYPE eHEALTH APPLICATION

A prototype of the eHealth application, "Oncokompas", was developed based on the results of the needs assessment among HCPs (from this study) and survivors[14]. Existing applications were used as examples to build the application[16,17]. First, the results of both needs assessments were discussed with the development team (Web designers and programmers), to translate these needs into requirements. The Web designer and programmers used their expertise to translate these requirements into a prototype of Oncokompas. During regular "demo sessions", these requirements were revisited to ensure a proper translation into the prototype. The contents of Oncokompas were developed together with teams of experts consisting of cancer survivors, medical specialists, and paramedics (refer to the "Results" section for more details on Oncokompas).

STEP 3: COGNITIVE WALKTHROUGHS

The cognitive walkthroughs (CWs) consisted of an expert-based usability evaluation followed by semi-structured interviews. The HCPs who participated in the needs assessment in Step 1 were complemented by a psychologist, a spiritual counsellor, and a patient advisor. We also included 3 head and neck surgeons, a radiation oncologist, 2 oncology nurses, and a health scientist from 2 other academic hospitals.

All but one of the usability evaluations were conducted in pairs of health care professionals because this was expected to increase "thinking out loud" by the participants. HCPs were asked to "walk through" the application guided by scenarios and user tasks from the end-users' viewpoint. Following the usability evaluations, we interviewed the HCPs on the implementation process (Table 5.2)

Table 5.2. Overview of CW scenario's tasks and interview topics

Scenario example	This scenario involves a 66-year-old female head- and neck cancer patient. She is experiencing (the onset of) depression as well as stress at home. Furthermore, she has diarrhea, she does not use a feeding tube or nutritional drinks. She has mild dysphagia and moderate loss of taste and smell.
CW tasks	Task 1: Monitor disease problems by (a) filling out the PROMs in *Oncokompas* and (b) send the completed questionnaires Task 2: View your personal well-being profile in *Oncokompas* Task 3: Use personalized well-being profiles to find information regarding your physical condition related to your tumor Task 4: Find personalized advice on an aspect of interest to you, and (b) take action upon this advice Task 5: Find more information in *Oncokompas* regarding a particular supportive care option of your choice and (b) open and view the website of a recommended supportive care provider
Semi-structured interview topic: Implementation Oncokompas	• What role do you think you could have in the usage of *Oncokompas* by patients? • How do you think *Oncokompas* could be implemented in the regular follow-up care procedure? • Do you intend to refer your patients to *Oncokompas* when available?

In total, 11 CWs were conducted, which lasted between 68 and 120 minutes (median 82, SD 14.54), and were recorded using Morae software (Morae version 2.1, TechSmith).

DATA ANALYSIS

All needs assessment interviews and CWs were analyzed by thematic analysis[18]. Both coders (SDL and CvU) read all transcripts to familiarize themselves with the data. The coders independently selected citations from the transcripts of all needs assessment interviews relating to current follow-up cancer care and needs of HCPs with respect to an eHealth application. These were coded into themes.

To analyze the usability of Oncokompas, we made use of the CW transcripts, supported by the Morae recordings. In total, 9 transcripts were coded by 2 coders. Initial codes for the CWs were generated focusing on system quality (ease of use), content quality (usefulness and relevance), and service quality (the process of care provided)[15,19,20]. Additionally, both coders independently selected citations for 9 of the semi-structured interviews concerning the implementation process and coded these into categories. The remaining 2 CW transcripts were coded by 1 coder (SDL).

Next, the 2 coders met to review the extracted citations and themes from the needs assessment interviews and CWs. Disagreements were resolved through consensus, which was reached on all citations and themes. They developed 2 frameworks (one for the needs assessment and one for the CWs), in which the themes were identified and subthemes defined. After coding, the raw data were examined again to ensure the robustness of the analytical process and to ensure that all the data were reflected in the coding[21]. Quotations were translated from Dutch into English and anonymized.

RESULTS

STEP 1: HEALTH CARE PROFESSIONALS' NEEDS ASSESSMENT

Current Follow-Up Care: Assessing Symptoms and Supportive Care Needs

HCPs indicated that during consultations they typically ask the cancer survivors about their symptoms and undertake a physical examination. A few indicated they also asked their patients to complete PROMs. Furthermore, when preparing for the consultations, HCPs indicated that they consulted with their colleagues, as well as the electronic hospital information system (Table 5.3).

HCPs mentioned several difficulties in assessing survivors' symptoms and in the referral process to supportive care services. They mentioned they are able to address only a limited scope of issues during the consultation due to limited time. In addition, all HCPs said they tend to focus on their own field of expertise, for example, physicians indicated that they do not feel capable of assessing a survivor's psychological well-being:

> *"In an open setting you will of course ask: "Are there any things you'd like to discuss?" I think that works fine as a first move to also allow space for the psychological aspects, but of course you do ask things like: "How is your weight?," "What about the pain?"."*

Another difficulty according to HCPs is that they do not want to burden the survivor with unnecessary questions about irrelevant or irreversible symptoms, for example, problems with salivary glands due to radiation therapy. In addition to this, they indicated that they lack a complete picture of survivors' symptoms and quality of life. This comes about due to survivors' hesitancy in mentioning all their symptoms and issues, as well as due to fragmentation in clinical care (e.g., no insight into the patient information system of the other HCPs involved).

HCPs indicated that care for HNC patients in The Netherlands is provided by multidisciplinary teams during treatment. However, follow-up care is generally provided only by physicians who continue to follow-up on the cancer survivor regularly. Physicians said they were hesitant to refer survivors to supportive care. In cases of mild symptoms, they provide the survivor with personal advice themselves. Where there are cases of severe symptoms, they refer survivors to other HCPs. The supportive care services that HCPs make their referrals to are often limited to other HCPs in the same hospital. When referral takes place to services outside the hospital, these mainly include specialized centers for cancer survivors, cancer rehabilitation programs, allied health services in the region, or the survivor's general practitioner.

HCPs also described barriers in referral to supportive care. They reported a lack of overview of the availability of supportive care services. Also, practical barriers in referral were mentioned, including a lack of time to encourage survivors to obtain supportive care:

Table 5.3. Overview of key issues and themes from the needs assessment

Key Issues	Themes
Detecting symptoms and need for supportive care	
Assessment of survivor's symptoms	
Consulting survivor	Verbal questioning (based on checklist or according to protocol) Observing and physical examination (according to protocol) Wait and see what symptoms survivor describes Use of PROMs (OncoQuest)
Consulting colleagues	
Consulting patient information system	
Barriers in determination	
Limited scope of issues being raised during consultation	Limited consultation time Limited skills or expertise of health care professional Limited responsibility of health care professional
Do not wish to burden the survivor by asking about…	Irrelevant symptoms 'Irreversible' symptoms caused by treatment
No complete picture of a survivors' symptoms	Patients do not mention all symptoms Fragmentation in care
Current referral to supportive care options	
Supportive care services referred	
Available services within the hospital	Allied health services i.e. physical therapist, dietician
Services outside hospital	Specialized cancer centers Cancer rehabilitation program Allied health services in the region General practitioner
Barriers in referral	
Lack of options	Lack of overview of available and adequate supportive care
Practical barriers in referral	Lack of time to encourage survivors to obtain supportive care Referral to region complicated due to lack of expertise on HNC Referral only possible through physician
No need of survivor to be referred	Survivor is unwilling to be referred Survivor already has adequate supportive care

Table 5.3. Continued

Key Issues	Themes
Expected added value of eHealth application in follow-up care for HCPs	
Increases insight into symptoms	
Provides a complete picture of a patients' symptoms	Provides insight into the interdependence of patients' symptoms Signal function: creates awareness of the severity of symptoms In support of their own observation/impression of HCP By monitoring symptoms ability to serve as treatment outcome
Improved (preparation for) consultation	Low threshold to speak up about specific issues / symptoms Option to target questions regarding specific symptoms Option to elaborate on and prioritize symptoms
Personalized advice/information	
Provides tailored information	More detailed information than provided by physician Back up for advice provided by HCP Supportive to information provided by HCP
Platform to deliver additional care	Informative support to self-management advice Availability of physical therapy exercises
Increases insight into QOL domains	Improved knowledge in QOL domains out of HCPs' expertise
Insight into supportive care options	Increased insight into supportive care options
Additional service in follow-up care	Showcase for hospital

> *"What I usually do, is just say "this is available," and if it will do some people good, they will give it a go if I want them to. In itself, that's fine, but it is tricky, as you only have a short amount of time during a consultation. You have to encourage people too and that is often the problem."*

Referral to allied health services in the region was considered complicated due to a lack of expertise in HNC. Finally, HCPs indicated there was a perceived lack of need by the survivor to be referred, either due to unwillingness or due to the health care professionals' assumption that the survivor already had adequate support.

Health Care Professionals' Views on a Proposed eHealth Application in Follow-Up Cancer Care

Most HCPs expected an eHealth application to provide added value for themselves in their practice, particularly in terms of follow-up care with the aim of optimizing supportive cancer care (Table 5.3). They hoped by using an eHealth application such as this to monitor survivors, to obtain an increased insight into these patients' symptoms. In addition, the application could help detect survivors with severe symptoms. HCPs indicated that they anticipated the application could serve as a tool during their consultations, help prioritize symptoms, and support them in elaborating on and targeting questions toward symptoms.

Personalized information and advice for survivors provided by an eHealth application was expected to have an added value, if tailored to tumor type or treatment. HCPs indicated they expected this information to be supportive or supplementary to the information they provided to patients. HCPs expected that the application could also serve as a platform to deliver additional care, such as self-management advice and physical therapy exercises. Another benefit expected was an increased insight into various quality of life domains that were not part of the HCPs' specialty.

Insight into supportive care options available could be improved by means of an eHealth application. Finally, HCPs expected the application to be an additional service for survivors in follow-up care, which could serve as a showcase for the hospital.

STEP 2: PROTOTYPE OF ONCOKOMPAS

The prototype Oncokompas was developed in Step 2. Oncokompas was developed as an online computer application. It consists of the following 3 components: (1) Measure, (2) Learn, and (3) Act. In the "Measure" component, cancer survivors can independently complete PROMs targeting the following QOL domains: physical functioning, psychological functioning, social functioning, healthy lifestyle, and existential issues. A specific domain containing topics for head and neck cancer patients is available, in addition to those general domains for cancer survivors (Table 5.4).

On the basis of the interview results, specific PROMs, validated questionnaires (or subscales) if available, were selected by the project team in collaboration with teams of experts. This selection was based on Dutch practice guidelines and literature searches. Data from the "Measure" component are processed in real-time and linked to tailored feedback to the cancer survivor in the "Learn" component. All algorithm calculations are based on available cutoff scores or are defined based on Dutch practice guidelines, literature searches, and/or consensus by teams of experts. A compass metaphor is used in the "Learn" component to summarize overall well-being. Once overall well-being has been presented, feedback is provided to the participant on the risk level for the topics (eg, depression, fatigue) by means of a 3-color system: green (no elevated well-being risks), orange (elevated well-being risks), and red (seriously elevated well-being risks). Cancer survivors receive elaborate personalized information on the outcomes. For instance, taking depression, information is provided on the symptoms of depression and the proportion of cancer survivors who suffer from depressive symptoms. Special attention is paid to evidence-based associations between outcomes. For example, feedback on the association between depression and fatigue is provided if a participant has an orange or a red score on depression as well as on fatigue. The feedback in the "Learn" component concludes with comprehensive self-care advice (tips and tools). All this advice is tailored to the individual cancer survivor, for example, tailored to age (e.g., survivors over 70 years of age receive an adapted advice on exercising), gender (e.g., advice on sexuality issues differ between men and women), and comorbidity (e.g., dietary advice differs for diabetic patients).

Table 5.4. Overview of Oncokompas topics

Psychological quality of life	Physical quality of life	Social quality of life	Healthy lifestyle	Existential issues	Head and neck cancer
Anxiety and depression	General everyday life	Social life	Alcohol	Life questions	Swallowing
Fear of recurrence	Pain	Relationship with partner	Physical activity	Religion	Speech
Subjective cognitive functioning	Sexuality	Relationship with children	Dietary intake	Future perspective	Oral function
Stress	Sleep quality	Financial circumstances	Weight		Neck and shoulder function
	Body image	Patient-physician communication	Smoking		Loss of smell and taste
	Fatigue	Return to work			Head and neck cancer specific lymphedema
	Diarrhea				Nutritional drink / Tube feeding
	Lack of appetite				
	Dyspnea				
	Nausea or vomiting				
	Constipation				
	Hearing & tinnitus				

In the "Act" component, survivors are provided with personalized supportive care options based on their PROM scores and expressed preferences (e.g., preference for individual therapy versus group therapy). If a participant has elevated well-being risks (orange score), the feedback includes suggestions for self-help interventions. If a participant has “seriously elevated well-being risks” (red score), the feedback includes advice to contact their own medical specialist or general practitioner. If survivors want to share their results with their caregiver, they are able to “print their results to PDF” and either bring these with them (hard copy) during their consultation with the caregiver or email these results to the caregiver.

A clickable demo of the application (in Dutch) or an animation video (in Dutch and English) is available on the Oncokompas website.

STEP 3: COGNITIVE WALKTHROUGHS

Technical errors occurred in 2 of the 11 CWs but were subsequently resolved. HCPs strengths and weaknesses concerning quality of the system, content, and service are presented in Table 5.5.

System Quality

HCPs’ opinions toward the accessibility of Oncokompas varied. Many HCPs indicated that Oncokompas may not be useful for a group of HNC survivors, due to limited eHealth literacy skills, lack of motivation, and older age. Others emphasized the usefulness of eHealth applications for HNC survivors, through the elimination of social barriers, such as difficulty speaking and shame about facial scarring. The 24/7 availability from home was considered important (see Table 5.5).

According to the majority of HCPs, the ease of use of Oncokompas was suboptimal because of the complicated navigation structure. HCPs mentioned that the interface was too busy for the target group. Complicating aspects included too much scrolling and unclear progress in the “Measure” component of Oncokompas. Positive aspects included a self-explanatory walkthrough of the application and the option to quit and save the questionnaire halfway through.

HCPs suggested the level of tailoring needed to be improved, for example, with respect to the advice provided. They considered the advice as distant and general, which could make it unclear to the survivor that the information had been tailored to their situation. Some mentioned that as participants are forced to monitor all symptoms, they might receive information on symptoms irrelevant to them. The provision of tailored advice, in contrast to surfing the Web was considered positive:

> *“As I see it, the advantage of the program is that it makes the piles of available information accessible.”*

Finally, HCPs suggested including reminders to encourage participants into action.

Content Quality

HCPs believed there was tension between the application goal and the use of evidence-based PROMs. The use of evidence-based PROMs requires participants to fill out more questions than needed to obtain personalized advice. However, the evidence-based content of the application was valued by HCPs. The application mostly followed HCPs own professional standards with respect to enquiring about symptoms and the provision of advice, which dovetailed with their advice to potential end users. In other words, the advice given in the application was the advice that HCPs expected to be provided (see Table 5.5):

> *“When I look at it, it provides the advice that I would expect to be provided.”*

HCPs varied in their opinion regarding content comprehensibility. The “Measure” component was considered difficult by some HCPs, as was the use of abstract terminology (e.g., “well-being profile”). Others were positive about the different comprehensibility levels at which information was provided to participants. They complimented the formulation of advice texts and the different levels of information provided by the application (so-called read more options):

> *“I believe that most people are able to gauge their own level pretty well. And people who cannot fully grasp this information, soon think, well, I have read all the tips, that will do.”*

The content was considered to be complete by most HCPs. They were positive about the completeness of the QOL aspects included, their interdependence, and the diversity in supportive care options provided. Others indicated that the content was superfluous in that some information is provided to participants several times throughout Oncokompas. Some believed information was missing, for example, costs of supportive care options.

Table 5.5. System, content and service quality *Oncokompas* (strengths and weaknesses)

Strengths	Weaknesses
SYSTEM QUALITY	
Ease of access • Suitable for survivors: 1) that already take good care of themselves, 2) are well-educated, 3) younger people, 4) have a next of kin who can help • Suitable for HNC population: 1) are retired, 2) are able to book vacations online, 3) new population: HPV virus, 4) eHealth may limit the impairments HNC survivors may face • Available in between HCP consults • 24 hours availability from the home situation	**Ease of access** • Not suitable for survivors that: 1) do not speak Dutch or are illiterate, 2) are cognitive or visually impaired, 3) are elderly, 4) have no internet access or a lack of eHealth literacy skills, 5) are not motivated, 6) do not take care of their well-being, 7) have few symptoms • Not suitable for HNC population: 1) don't like to read 2) low educational level • The application is built in Flash and therefore not suitable for use on tablets
Ease of use • Clear navigation structure: simple lay-out, clear main menu	**Ease of use** • Unclear navigation structure: interface too busy, too much scrolling required
Tailoring / customization • Possibility to skip the sexuality topic is positive • Survivors can choose between supportive care options which is of added value	**Tailoring / customization** • Survivor should decide which symptoms to monitor • Information, advices provided is / are too general • Unclear that advice is tailored to the specific survivor
Conditioning • Option to print the results to share these with the HCP • Patients receive concrete, interesting and tailored advice: asset to surfing	**Conditioning** • Lack of a trigger to return to the application • Lack of a 'check' if the survivor has taken action • System should provide reminders to take action
CONTENT QUALITY	
Evidence-based • Use of validated PROMs: reliable • Evidence-based content, advices and supportive care options provided in line with HCPs' expectations	**Evidence-based** • Tension between goal *Oncokompas* and usage of validated PROMs
Comprehensibility • Clear questioning: comprehensible questions • Information and supportive care options offered at different levels of understanding • Advice easy to follow; when complicated accurate referral to HCP	**Comprehensibility** • Complicated questioning: multi-interpretable, similar, difficult, inappropriate intonation and formulation • Complicated answering categories • Difficult and abstract terminology • Difference unclear between advised and alternative supportive care options

Table 5.5. Continued

Strengths	Weaknesses
CONTENT QUALITY	
Complete • Complete picture: all QOL aspects included • In-depth questioning • Visibility of interdependence of QOL domains, • Complete overview supportive care options • Survivors can choose between different supportive care options	**Incomplete** • Clear introduction to PROMs is missing • Too little focus on interdependence between domains • No perspective offered about the "normal" population • Missing (information on) supportive care options: e.g. regional options, whether you need a referral, costs, inclusion in a quality register, option to get in contact **Over complete** • Too much text to read when you are ill/ recovering • Information is provided twofold • Including flyers: more information leads to more questions • Too many supportive care options provided
SERVICE QUALITY	
Perceived usefulness "identification of symptoms" • Symptoms may become more clear by means of PROMs • Leads to clarification of request for help	**Perceived lack of usefulness "identification of symptoms"** • Lack of nuance in identifying symptoms • Impossible to tailor system as much as a consultation
Perceived usefulness "informing participants" • Generates new insights and knowledge for survivors • Recognition: validation of survivors feelings • Approachable for mild symptoms and delicate topics, survivors do not want to burden their physician with	**Perceived lack of usefulness "informing participants"** • Easier for survivors to contact outpatient clinic • Possibly wrong information gathering by wrong clicks • Difficult for already tired participants to act upon personalized advice
Perceived usefulness "referring participants" • More specific, earlier, easier referral to supportive care • Survivor can take initiative in asking for a referral • Referral to own physician supports survivors to discuss symptoms with their physician	**Perceived lack of usefulness "referring participants"** • Leads to confusion when many advices are prompted • During consultation problems are easier to prioritize • Not clear for survivors what to do after finishing *Oncokompas* • Success depends on the assertiveness of the survivor
Perceived usefulness "overall service" • Support in post-treatment period • Increased patient empowerment • Increased attention for QOL of survivors • Improved preparation for consultation with physician	**Perceived lack of usefulness "overall service"** • Increased workload HCPs • Increased worries about symptoms that survivors were not aware of and an increased focus on cancer • Symptoms discussed in *Oncokompas* not mentioned to HCPs

Service Quality of Oncokompas

HCPs were positive about the usefulness of Oncokompas in identifying symptoms, especially by providing patients with a complete picture of their well-being and insight into the interdependences, leading to a clarification of request for help:

"Oncokompas is useful...by broadening the insight of patients and clarifying to them when the time has come to ask for help. Instead of having just us as health care professionals ask and explore, it can enable patients to become more pro-active in that respect."

HCPs' concerns included that Oncokompas lacks nuance and may not be as tailored as a personal consultation with a HCP (see Table 5.5).

HCPs also indicated that they expected benefits in informing participants by creating an opportunity to receive information on sensitive topics. Others mentioned that survivors may be reluctant to use the application for information, because it is easier for them to contact the outpatient clinic. Some HCPs expected that participants might receive inaccurate or irrelevant information if they inaccurately navigated through the application:

> *"Well, with only a few wrong clicks, you can end up with the strangest of information. That does worry me a bit."*

HCPs indicated that the application could support participants by referring them to appropriate supportive care options compatible with their symptoms. Some HCPs mentioned concerns regarding whether participants would know what to do next. They expected participants to get lost in the supportive care options available to choose from, possibly leading to a lack of action.

HCPs also mentioned to expect some overall benefits for future participants, such as empowerment and increased engagement:

> *"I can imagine this patient is wondering, "Do I have to bother my physician about that?" And when she receives the information from Oncokompas, she sees, "Yes, I*

> *should bother my physician about that.".*"

According to HCPs, the application could also help participants be better prepared for their consultations. Concerns mentioned by HCPs included an expected increase in workload and more consultations with HCPs due to participants' increased insight into whom to turn to with their symptoms. Some HCPs mentioned that Oncokompas could possibly lead to participants' continuing to obsess about their disease instead of helping them move on with their life or that emotions surrounding their cancer could (re)surface. Another negative consequence mentioned by HCPs was that participants might not seek the expertise of a HCP concerning their symptoms if they had already received information from the application.

Implementation of Oncokompas

Most HCPs mentioned a positive intention to refer their patients to Oncokompas. All HCPs agreed that if the application were to be implemented in daily clinical practice, it should be offered to survivors through a routine procedure in a care pathway. Physicians believed that referral to the application should take place from different sources, including outside the hospital (e.g., by the Dutch Cancer Society). HCPs suggested possibilities to increase awareness, such as providing a demo in the waiting room (see Table 5.6).

HCPs differed in their opinion toward the best strategy to implement the application in clinical practice. Several HCPs believed that Oncokompas should be implemented as a self-management instrument (independent use by survivors), while others stressed the use as a *supported* self-management instrument (with support from a HCP).

Implementation as a self-management instrument was expected to stimulate survivor empowerment and to support survivors in defining their own route to relieving their symptoms and increasing their quality of life. Furthermore, HCPs mentioned that survivors are responsible for their own well-being. HCPs indicated that referral of survivors to their physician by means of Oncokompas in case of severe symptoms would relieve them from the responsibility to take action on symptoms they may not know are present. HCPs argued that with a self-management application, survivors' privacy would remain intact. They expected survivors to answer more truthfully if they knew their physician would not have access to the data:

Table 5.6. CW's Implementation

Procedure introducing OK to patient	
Accurate introduction of Oncokompas • According to a routine, to prevent that survivors that may benefit from *Oncokompas* are not referred	• Through 1) a flyer, 2) a website, 3) posters in waiting area, 4) a demo of *Oncokompas* • Included in a care pathway (eg after dismissal) • At set times/moments (eg after dismissal) • Responsibility introduction with one person • Availability of a trigger for introduction for HCPs so it cannot be forgotten
Implementation as self-management application	**Implementation as supported self-management application**
Stimulates survivor empowerment • Survivors have to take action themselves • Enables survivors to indicate priorities during consultation • Survivor determines how to handle symptoms and not the physician • Survivor needs to be motivated to address his complaints, otherwise stimulation by HCP will not be effective	*Responsibility well-being patients with HCP* • Self-management not fully accepted in health care • Responsibility well-being always (partially) with HCP • HCP responsible when survivor receives suboptimal care • QOL difficult to act upon by HCPs if they don't have insight into results • Important that symptoms unrelated to a specific specialty (eg anxiety, fatigue) receive attention and are noticeable
Survivor is responsible for own well-being • Responsibility lies with survivor to take action upon symptoms • Referral by *Oncokompas* in case of suboptimal QOL relieves HCPs' responsibility • Survivor can bring printed results to consultation	*Feedback through access Oncokompas or system alert* • HCPs are interested in *Oncokompas* results of survivors • Feedback creates opportunity to discuss results during consultation • HCPs want an alert when survivor has a suboptimal QOL and does not take action • Survivor without printer cannot take results to HCP
Privacy of survivor is protected • Survivor is able to choose what to share with the HCP • No social desirability because HCP cannot view results • HCPs doubt whether survivors would like their results known by HCPs	*Problems surrounding privacy survivors* • Survivors need to be well informed about who has access to their information and give consent • Some aspects of *Oncokompas* are of no importance to HCPs (such as financial issues) • IT issues (accessibility) in how *Oncokompas* would be safe to use for HCPs
Difficult to discuss results during regular consultation • Time pressure • Other priorities during consultation (cancer recurrence) • Problems in prioritizing during consultation	*Requires action from HCP* • Survivors expect HCP to be aware of their results • Lack of HCPs' action may lead to disappointment and have a negative impact on doctor-patient relation • Dependence of survivor in doctor-patient relationship requires action from HCPs

"When a patient wants to share their results, that would be nice, but I think the additional value also lies in that he has the opportunity to keep it to himself."

Finally, HCPs expected that they could get around difficulties in discussing Oncokompas results during their regular consultations (eg, difficulties due to time pressure and the priority to check for cancer recurrence) by offering HNC survivors access to Oncokompas as an unsupported self-management application.

Other HCPs indicated that Oncokompas should be implemented as a *supported* self-management tool because the responsibility of survivors' well-being always remains with the HCP. HCPs wished to receive feedback through access to Oncokompas or a system alert. They wanted to use the results to discuss these and prioritize symptoms during their consultations. HCPs indicated they were aware that when Oncokompas is implemented as a supported self-management tool, this requires action from the HCPs in cases where survivors receive negative results from the application. HCPs mentioned that they might not always be able to fulfill this expectation, possibly leading to survivor disappointment:

> *"It might be that it raises false expectations in the patient. As surely there will be times that I won't come round to it and if the patient then expects, the doctor will have a quick read when I am there and we are going to discuss what I have filled in, then that is a bit hard on the patient."*

DISCUSSION

PRELIMINARY FINDINGS

This study investigated HCPs' perspectives toward current follow-up care and the added value of an eHealth application monitoring QOL via patient-reported outcome measures (PROMs; Measure) followed by automatically generated tailored feedback (Learn), and personalized advice on supportive care (Act).

BARRIERS IN REFERRAL TO SUPPORTIVE CARE AND HEALTH CARE PROFESSIONALS' ACCEPTANCE OF AN EHEALTH APPLICATION

The results of this study showed that current referral to optimal supportive care is limited due to several barriers, such as limited consultation time and a lack of overview of supportive care options. Our data support previous studies that have obtained insights into these barriers[7–9,22,23]. Furthermore, HCPs clearly indicated they expected survivors to mention their symptoms. However, previous studies have shown that survivors themselves also experience barriers possibly resulting in unmet needs[8,10,14]: emotional barriers, such as not wanting to complain after surviving cancer, and practical barriers, such as not wanting to burden their physician. By automating the referral process to supportive care by means of an eHealth application, a barrier such as not wanting to burden their physician may be removed. In general, HCPs expected that the proposed eHealth application could optimize the referral to supportive care.

CONTENT, SYSTEM, AND SERVICE QUALITY OF ONCOKOMPAS

Overall, HCPs were most pleased with the service quality of the application but mentioned several considerations regarding its system and content quality.

Our study showed that HCPs concluded that Oncokompas was useful for a limited group of (HNC) survivors. A frequently mentioned barrier was lack of Internet access, which is remarkable as a large majority of the Dutch population (90.4%) has access to the Internet; 80% of 65-75 year olds indicated they used the Internet[24]. Therefore, access to the Internet seems to have become less of a barrier and the emphasis should be on developing an application congruent with eHealth literacy skills of end users. The needs assessment among cancer survivors showed that they required the application to be easily comprehensible[14].

HCPs in our study underlined the importance of tailoring the application. In the needs assessment among cancer survivors, tailoring was also deemed important. Patients, however, mentioned doubts about the degree of tailoring that is possible[14]. According to HCPs, a lack of tailoring could lead to a loss of interest, possibly leading to nonadherence[25]. HCPs suggested that only select topics of concern to a user should be provided to improve tailoring.

Considering the content quality of Oncokompas, the majority of issues mentioned were related to the use of PROMs. Usage of PROMs resulted in overlap between items (as individual items cannot be deleted from validated PROMs). Additionally, HCPs mentioned comprehensibility issues: they assessed several PROMs as too difficult. Although we strived for readability at the 10thgrade level in all texts in the “Learn” and

"Act" components of Oncokompas, validated PROMs are not always at this reading level.

This study demonstrated that most HCPs expect that the application will support survivors in obtaining appropriate and timely supportive care tailored to their symptoms[14]. This is in line with results of the needs assessment among cancers survivors. They expected similar advantages in receiving information on supportive care options tailored to their specific needs, for example, the ability to find supportive care options on their own and to take actions toward their symptoms[14]. In directing the HNC survivor to optimal supportive care, Oncokompas meets the objective of the current cancer care navigation movement toward ensuring cancer survivors receive adequate follow-up and supportive care[26,27]. However, some HCPs in our study doubted whether survivors would know what to do after completing Oncokompas. They expected that HNC survivors could get lost in the supportive care options they can choose from, possibly leading to a lack of action. Given the evidence that more options and choice equals more stress and less action[28], the number of supportive care options that Oncokompas offers to the participant is limited to 3 recommendations.

IMPLEMENTATION OF eHEALTH

HCPs differed in their opinion whether Oncokompas should be implemented as a self-management application or a *supported* self-management application. The consequences of implementation on existing working procedures were discussed in interviews with those who preferred to implement Oncokompas as a *supported* self-management application, for example, incorporating an alert system in the hospital patient information system. Other HCPs were of the opinion that survivors are responsible for their own well-being and that because of the importance in empowering the survivor and respect for the survivor's privacy, the application should be implemented as a stand-alone self-management instrument. Wiggers et al[29] reported that implementing a *supported* self-management eHealth application in routine clinical practice increases the complexity of existing working procedures, possibly leading to low uptake of an eHealth application. This barrier may be avoided when implementing the application as a self-management tool. Both options offer advantages in clinical practice: supported self-management applications may be more suitable for survivors who lack eHealth literacy skills, while other cancer survivors may be more empowered by a stand-alone self-management instrument. Consequences of both options need to be studied further.

STRENGTHS AND LIMITATIONS

This study is limited due to the small number of HCPs involved. Another limitation is that it might have been difficult for HCPs to view an eHealth application from the survivors' perspective. However, the use of a participatory design approach, including HCPs from different academic hospitals as well as combining these results with cancer survivors' perspectives[14], covered all main aspects. The added value of usability research is limited when weaknesses are mentioned that could have been prevented in the design process. Because there are no similar applications in oncology, the results of our study add value and can be used as a guide for designing other applications. A strength of this study is that we also gained insight into implementation requirements of eHealth in clinical practice.

CONCLUSION

HCPs experienced a variety of barriers in the current organization of supportive cancer care, such as a lack of overview of options. HCPs expected that the use of an eHealth application that monitors QOL and provides automatically generated personalized advice and referral to supportive care options may be helpful in eliminating some of these barriers. However, they also highlighted some concerns. They mentioned that the application may not be useful for all HNC survivors due to limited eHealth literacy and an older age. Cognitive walkthroughs revealed several points for optimizing the prototype of the application, including improved tailoring. HCPs expected several advantages for survivors: insight into the interdependence of symptoms for cancer survivors, (earlier) referral to adequate supportive care, and increased patient empowerment. Finally, useful recommendations for developing an efficient implementation strategy appeared from the interviews. It can be concluded that including HCPs in an early phase of a participatory design approach is valuable in designing an eHealth application and an implementation strategy that meets stakeholders' needs.

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31

INTERMEZZO

ONCOKOMPAS: AN eHEALTH SELF-MANAGEMENT APPLICATION TO MONITOR HEALTH RELATED QUALITY OF LIFE, PROVIDE PERSONALIZED ADVICE AND SUPPORTIVE CARE OPTIONS

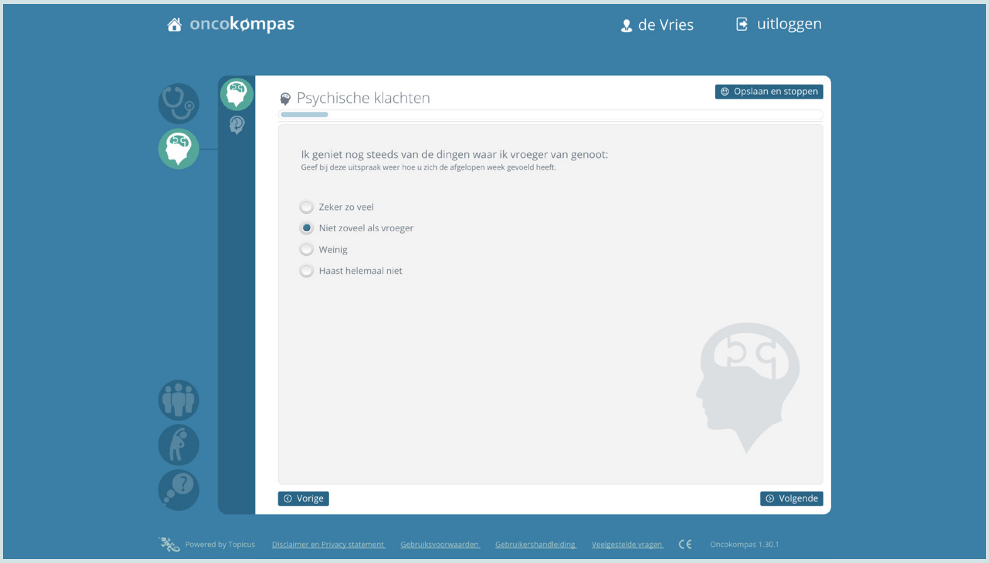
In 2011, the Department of Otolaryngology – Head & Neck Surgery of VU University Medical Center in Amsterdam, started to develop Oncokompas; an eHealth application to monitor health related quality of life, provide personalized advice and supportive care options to cancer survivors, after they have finished their treatment for cancer. The screenshots presented in this section are extracted from the most recent version of Oncokompas.

DESCRIPTION OF ONCOKOMPAS

Oncokompas consists of three components; 'Measure', 'Learn', and 'Act'. Oncokompas starts with a log-in procedure, in which a first-time user is asked to create an account to log in.

Measure

After the log-in procedure is completed, a user enters the 'Measure' component of Oncokompas. In this component, PROMs targeting the following quality of life domains are presented to users: physical functioning, psychological functioning, social functioning, lifestyle and existential issues. These domains are completed with a tumor specific domain containing specific PROMs for HNC survivors. Users are asked to complete all questions, by means of dynamic questionnaires. This means that the system automatically determines whether intensification questions or sequence questions are appropriate. Figure 1 shows a screenshot of a question in Oncokompas (in Dutch).



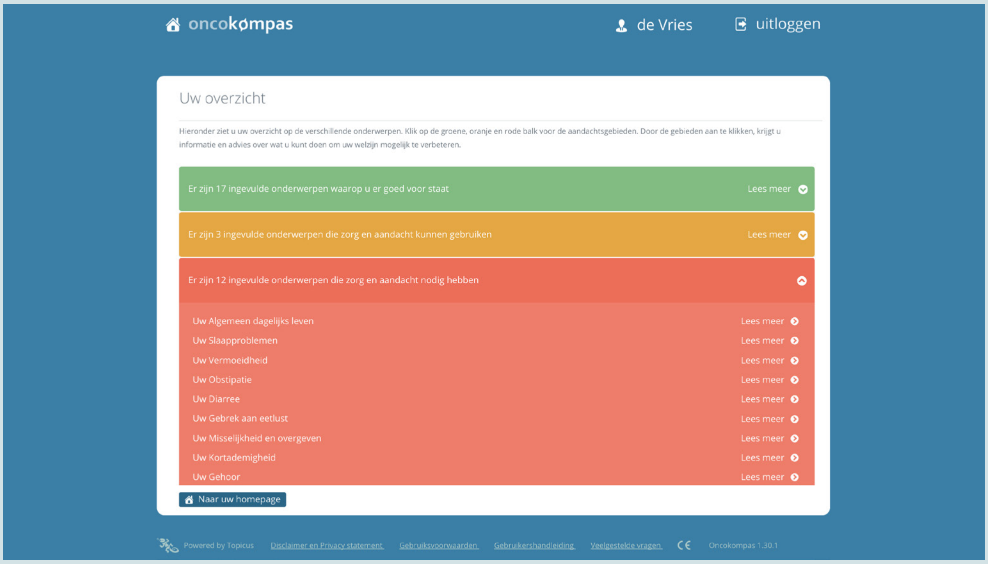
Ik geniet nog steeds van de dingen waar ik vroeger van genoot:
Geef bij deze uitspraak weer hoe u zich de afgelopen week gevoeld heeft.

○ Zeker zo veel
● Niet zoveel als vroeger
○ Weinig
○ Haast helemaal niet

Figure 1. Screenshot of "Measure" component Oncokompas.

Learn

After the user completes the PROMs, the data from the "Measure' component are processed in real-time and linked to tailored feedback to the user in the "Learn" component. This feedback is provided through algorithm calculations, which are based on available cut-off scores, Dutch practice guidelines, literature searches and/or consensus by teams of experts. The user receives general feedback and specific feedback on the levels of the addressed topics in the PROMs (e.g. depression), by means of a 3-color system: green (no elevated well-being risks), orange (elevated well-being risks) and red (seriously elevated well-being risks) (figure 2). The elaborated information is followed by specific attention for clusters of interrelated symptoms, e.g. depression and anxiety (figure 3). The feedback in the "Learn' component concludes with comprehensive self-care advice (tips and tools). In figure 4 a screenshot of personalized advice is shown (in Dutch). These advices are all tailored to the individual user.



Uw overzicht

Hieronder ziet u uw overzicht op de verschillende onderwerpen. Klik op de groene, oranje en rode balk voor de aandachtsgebieden. Door de gebieden aan te klikken, krijgt u informatie en advies over wat u kunt doen om uw welzijn mogelijk te verbeteren.

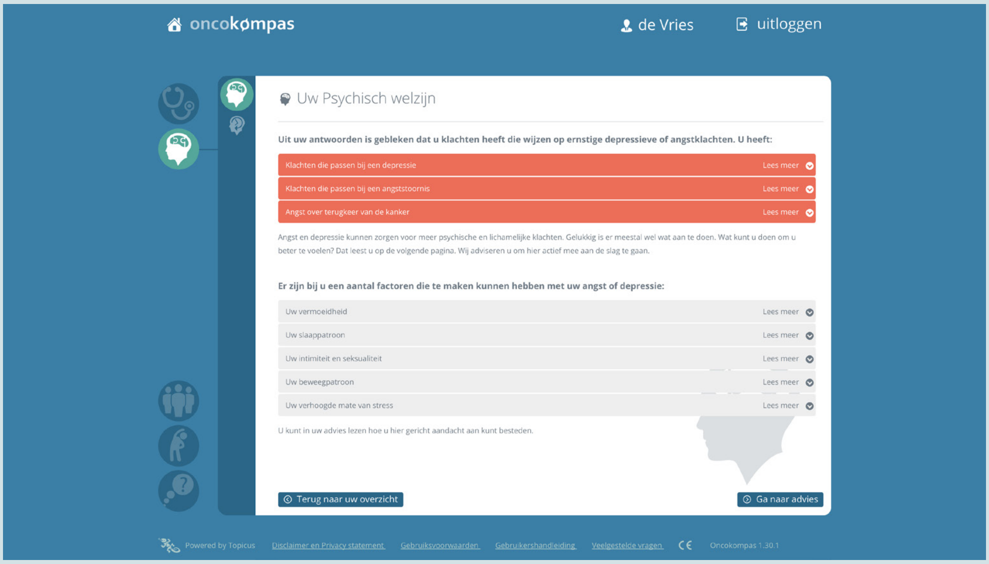
Er zijn 17 ingevulde onderwerpen waarop u er goed voor staat

Er zijn 3 ingevulde onderwerpen die zorg en aandacht kunnen gebruiken

Er zijn 12 ingevulde onderwerpen die zorg en aandacht nodig hebben

- Uw Algemeen dagelijks leven
- Uw Slaapproblemen
- Uw Vermoeidheid
- Uw Obstipatie
- Uw Diarree
- Uw Gebrek aan eetlust
- Uw Misselijkheid en overgeven
- Uw Kortademigheid
- Uw Gehoor

Figure 2. Screenshot of general feedback overview by means of the 3-color system in Oncokompas.



Uw Psychisch welzijn

Uit uw antwoorden is gebleken dat u klachten heeft die wijzen op ernstige depressieve of angstklachten. U heeft:

- Klachten die passen bij een depressie
- Klachten die passen bij een angststoornis
- Angst over terugkeer van de kanker

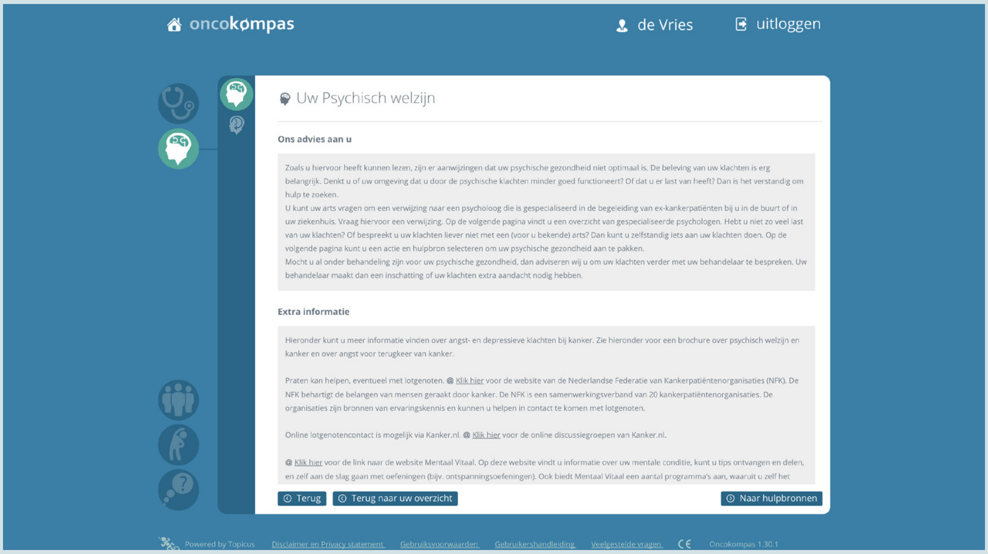
Angst en depressie kunnen zorgen voor meer psychische en lichamelijke klachten. Gelukkig is er meestal wel wat aan te doen. Wat kunt u doen om u beter te voelen? Dat leest u op de volgende pagina. Wij adviseren u om hier actief mee aan de slag te gaan.

Er zijn bij u een aantal factoren die te maken kunnen hebben met uw angst of depressie:

- Uw vermoeidheid
- Uw slaappatroon
- Uw intimiteit en seksualiteit
- Uw beweegpatroon
- Uw verhoogde mate van stress

U kunt in uw advies lezen hoe u hier gericht aandacht aan kunt besteden.

Figure 3. A screenshot of feedback about interrelated clusters of symptoms in Oncokompas.



Uw Psychisch welzijn

Ons advies aan u

Zoals u hiervoor heeft kunnen lezen, zijn er aanwijzingen dat uw psychische gezondheid niet optimaal is. De beleving van uw klachten is erg belangrijk. Denkt u of uw omgeving dat u door de psychische klachten minder goed functioneert? Of dat u er last van heeft? Dan is het verstandig om hulp te zoeken.
U kunt uw arts vragen om een verwijzing naar een psycholoog die is gespecialiseerd in de begeleiding van ex-kankerpatiënten bij u in de buurt of in uw ziekenhuis. Vraag hiervoor een verwijzing. Op de volgende pagina vindt u een overzicht van gespecialiseerde psychologen. Hebt u niet zo veel last van uw klachten? Of bespreekt u uw klachten liever niet met een (voor u bekende) arts? Dan kunt u zelfstandig iets aan uw klachten doen. Op de volgende pagina kunt u een actie en hulpbron selecteren om uw psychische gezondheid aan te pakken.
Mocht u al onder behandeling zijn voor uw psychische gezondheid, dan adviseren wij u om uw klachten verder met uw behandelaar te bespreken. Uw behandelaar maakt dan een inschatting of uw klachten extra aandacht nodig hebben.

Extra informatie

Hieronder kunt u meer informatie vinden over angst- en depressieve klachten bij kanker. Zie hieronder voor een brochure over psychisch welzijn en kanker en over angst voor terugkeer van kanker.

Praten kan helpen, eventueel met lotgenoten. @ Klik hier voor de website van de Nederlandse Federatie van Kankerpatiëntenorganisaties (NFK). De NFK behartigt de belangen van mensen geraakt door kanker. De NFK is een samenwerkingsverband van 20 kankerpatiëntenorganisaties. De organisaties zijn bronnen van ervaringskennis en kunnen u helpen in contact te komen met lotgenoten.

Online lotgenotencontact is mogelijk via Kanker.nl. @ Klik hier voor de online discussiegroepen van Kanker.nl.

@ Klik hier voor de link naar de website Mentaal Vitaal. Op deze website vindt u informatie over uw mentale conditie, kunt u tips ontvangen en delen, en zelf aan de slag gaan met oefeningen (bijv. ontspanningsoefeningen). Ook biedt Mentaal Vitaal een aantal programma's aan, waaruit u zelf het

Figure 4. A screenshot of personalized advice in Oncokompas.

Act

After a user finishes the "Learn" component, they are automatically directed to the "Act" component. In the "Act" component, users are provided with personalized supportive care options, based on their PROM scores and the preferences they expressed (e.g. preference for personal contact or supportive care via the Internet). If a user has received an orange score in the "Measure" component, relating to elevated well-being risks, the feedback includes suggestions for (guided) self-help interventions. If a user has seriously elevated well-being risks and received a red score, the feedback includes an advice to contact their own medical specialist or general practitioner. The user is able to print their Oncokompas results if they want, and bring these with them when they visit their HCP for a consultation.

PARTICIPATORY DESIGN CYCLE

A participatory design approach was used to develop Oncokompas, which, among others, consisted of a needs assessment among HNC patients (Chapter 4) and health care professionals (HCPs) (Chapter 5), and testing of a prototype. This test among HCPs is described in Chapter 5. To ensure that patients' needs are met, we also conducted a study to test the usability of Oncokompas among HNC patients. Here, the study on usability testing among HNC patients is described.

Table 1. Results of the usability test focusing on system, content and service quality (strengths and weaknesses)

Strengths	Weaknesses	Adaptations
SYSTEM QUALITY		
Ease of access • Log-in procedure is clear • 24/7 accessibility from home is positive	**Ease of access** • Log-in procedure is unclear • Log-in procedure takes too long	Simplified log-in procedure
Ease of use User friendly: • Clear page lay-out • Log in structure Clear navigation structure: conveniently arranged menu, easy to find/select information, use of tab button to navigate through the application	**Ease of use** Not user friendly: • More instructions needed • System is too slow • Font size is too small • Occurrence of technical errors Unclear navigation structure: too much scrolling, no insight into progress, inconveniently arranged menu, not clear how to navigate between steps	Scrolling is limited Insight into progress provided by means of a progress bar
Design • Possibility to monitor improvements in QOL	**Design** • Possibility to skip feedback • Application is lengthy	Questions have been revisited to reduce length of Oncokompas. Tunneling has been added to combine feedback and advice on topics
Tailoring/customization • Clear that 'compass'/advice and profile texts are tailored to the personal situation of user • Stepwise supportive care plan	**Tailoring/customization** • Unclear that picture/advice / profile texts are tailored to personal situation • User misses tailoring to type of cancer	Cancer specific modules have been added
CONTENT QUALITY		
Accuracy • Score is congruent with own perception • Dynamic questions make it more efficient	**Accuracy** • Score is not congruent with own perception; answer options / supportive care services are not tailored enough • Through self-reported health survivors can paint a better picture of themselves than their actual situation	
Complete • Appropriate number of questions, relevant topics are presented	**Overcomplete:** • Seemingly similar questions, too much text **Incomplete:** • No insight into problems that are interrelated, supportive care options incomplete	Similar questions have been eliminated as much as possible

Table 1. Continued

Strengths	Weaknesses	Adaptations
CONTENT QUALITY		
Comprehensibility • Clear questioning: comprehensible questions • Information is clear and understandable • Supportive care facilities are clear	**Comprehensibility** • Complicated questioning; difficult, multi-interpretable, inappropriate intonation and formulation • Complicated answering categories	Where possible answer categories have been altered to enhance comprehensibility, more information is added to unclear questions
Evidence-based • The provided information confirms and scientifically proves things survivors already know	**Evidence-based** • User experiences information in tool as not scientific • No congruence between well-being score and perceived health by survivor	
SERVICE QUALITY		
Perceived usefulness 'identification of symptoms' • Confirmation of how participant is feeling • Provides insight into personal situation – aspects to work on • Important to monitor QOL at all stages- enhances awareness	**Perceived lack of usefulness ' identification of symptoms'** • Confronting • Only applicable if you have symptoms	
Perceived usefulness 'informing participants' • Participants can learn about options to improve QOL	**Perceived lack of usefulness 'informing participants'** • Personalized feedback does not motivate to seek help	
Perceived usefulness ' referring participants' • Provision of tools and options to participant • Added value for people that don't look for help • Overview of supportive care facilities is handy/valuable	**Perceived lack of usefulness ' referring participants'** • Supportive care is irrelevant when options are already made use of • No need for extra support -enough help available	
Perceived usefulness 'overall service' • Oncokompas supports patients in difficult times • Oncokompas stimulates self-management (24/7 home availability) • Oncokompas provides extra support in follow-up care • Reliable information and tailored system	**Perceived lack of usefulness ' overall service'** • Oncokompas is offered too late in process • Participant has the need for personal contact instead of an online tool • Participant is self-regulating thus does not need Oncokompas.	Oncokompas is offered to cancer patients after diagnosis instead of after treatment

The usability tests focused on identifying the system quality (ease of use), content quality (usefulness and relevance) and service quality (the process of care provided) of the application[1–3]. This study has not been published and is therefore described here in more detail.

The study was carried out with 18 HNC patients (16 male, 2 female). Mean age of the participants was 59 years. Cancers survivors were asked to “walk through” the application guided by user tasks (e.g. logging in, filling in questionnaires) from the end-users’ viewpoint. Participants were asked to think out loud. The usability tests were recorded using Morae software (Morae version 2.1, TechSmith). The transcripts were analyzed by 2 coders, who met to review their codes, and resolved disagreements through consensus on all codes.

The results of the usability study with cancer survivors are shown in Table 1. Main outcomes were that many patients were able to use Oncokompas, but that several aspects should be refined. Concerning the system quality of the application, cancer survivors mentioned that the navigation structure of the application was unclear and much scrolling was required. Other participants found the application user friendly. Towards the content quality of the application, participants mentioned they felt there were many ‘double’ questions, and questioning was sometimes difficult to understand. Others mentioned they found the questions comprehensible and that relevant topics were addressed by the application. Regarding the service quality of Oncokompas, some participants had doubts towards the added value of Oncokompas in follow-up cancer care, and mentioned it would only be helpful when symptoms are present. Others were very positive, and indicated that Oncokompas provides insight into the survivors HRQOL and options to improve this. Also, they found insight into supportive care options valuable, and saw Oncokompas as supportive during follow-up care, and a stimulant to self-management.

Based on the findings of the usability studies, the prototype of Oncokompas was built into a full application, in which adaptations described in Table 1 were made. This application was used in the feasibility study of Oncokompas (see chapter 6 for a detailed description of the feasibility study).

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6

FEASIBILITY OF AN eHEALTH APPLICATION "ONCOKOMPAS" TO IMPROVE PERSONALIZED SURVIVORSHIP CANCER CARE

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ABSTRACT

Purpose The purpose of this study was to investigate the feasibility of an online self-management application (Oncokompas) among cancer survivors. In Oncokompas, cancer survivors can monitor their quality of life (QOL) via participant reported outcome measures (PROMs) (“Measure”), which is followed by automatically generated individually tailored feedback (“Learn”) and personalized advice on supportive care services (“Act”).

Methods A pretest-posttest design was used, conducting a survey before providing access to Oncokompas, and 2 weeks after, followed by an interview by a nurse. Adoption was defined as the percentage of cancer survivors that agreed to participate in the study and returned the T0 questionnaire. Implementation was defined as the percentage of participants that actually used Oncokompas as intended (T1). General satisfaction was assessed based on the mean score of three study-specific questions: (1) general impression of Oncokompas, (2) the user-friendliness, and (3) the ability to use Oncokompas without assistance (10-point Likert scales). Furthermore, satisfaction was measured with the Net Promotor Scale (NPS).

Results Oncokompas was feasible with an adoption grade of 64%, an implementation grade of 75–91%, a mean satisfaction score of 7.3, and a positive NPS (1.9). Socio-demographic and clinical factors and QOL were not associated with satisfaction. Several facilitators and barriers related to the feasibility of Oncokompas were identified.

Conclusion Oncokompas is considered feasible, but has to be further improved. In order to enhance feasibility and increase satisfaction, we have to balance the time it takes to use Oncokompas, measurement precision, and tailoring towards personalized advices.

Key words: eHealth, lifestyle, neoplasms, quality of life, self-management, supportive cancer care

INTRODUCTION

Cancer and cancer treatment have a large impact on quality of life (QOL). Head and neck cancer (HNC) has a specific impact on survivors. In addition to symptoms such as fatigue, HNC survivors are confronted with oral dysfunction, speech and swallowing problems, and related social withdrawal and psychological distress. All of these symptoms can deteriorate quality of life[1,2] and increase survivors’ needs for supportive care services. Several recent papers report on the need for improving survivorship cancer care[3,4], to enhance quality of life and diminish societal discrimination.

It is essential that cancer survivors have access to optimal supportive care services including self-management options. Access to supportive care may be hampered by current changes in the health-care system, e.g. limited time of health care providers and centralization of care[5]. To improve accessibility, cancer survivors are expected to adopt an active role in managing their own care. Self-management is defined by McCorkle et al.[6] as “those tasks that individuals undertake to deal with the medical, role, and emotional management of their health condition(s).”. Alongside usual care, self-management options can be (cost-)effective and improve quality of life[3]. Although there is evidence that supportive cancer care can be effective, referral rates are low and many survivors have unmet needs. Innovating supportive cancer care includes incorporation of self-management and eHealth, implementation of evidence-based approaches to monitor QOL[7,8], and redesign of the organization of supportive care according to participant centered models of care (e.g. the chronic care model, disease management, stepped care)[3,7,9].

We developed an eHealth application “Oncokompas” with the aim to facilitate and innovate the access to supportive cancer care. In OncoKompas cancer survivors can monitor their QOL by means of participant reported outcome measures (PROMs) (“Measure”), which is followed by automatically generated tailored feedback (“Learn”) and personalized advice on supportive care services (“Act”). To ensure sustainable implementation of Oncokompas we followed participatory design principles. Cancer survivors and health care professionals (HCPs) were involved in each step of the development process[10–12] (Figure 6.1). A qualitative assessment of needs among cancer survivors and HCPs (*step 1*) showed that cancer survivors are interested in an eHealth application that targets personalized access to supportive care and that HCPs expect that an eHealth application could optimize survivorship care[13]. A prototype of the eHealth application, “Oncokompas”, was developed. Existing applications were used as examples to build the application[14,15]. Oncokompas was developed together with mixed teams consisting of cancer survivors and medical specialists as well as allied health professionals. In *step 2* the usability of a prototype was tested among both cancer survivors and HCPs, targeting system quality (ease-of-use), content quality (usefulness and relevance) and service quality (the process of care provided)[16,17]. HCPs raised several points for improvement regarding the ease-of-use and usefulness of the application, resulting in improved persuasiveness and improved tailoring. Usability tests among cancer survivors identified some weaknesses in the user interface that resulted in adjustments, e.g. clearer user instructions[18]. Based on these findings, the prototype of Oncokompas was optimized. The next step (*step 3*) in the developmental cycle of Oncokompas, is to investigate the feasibility in clinical practice.

The purpose of the present study was to investigate the feasibility of Oncokompas: adoption (intent to use Oncokompas), usage (actual use of Oncokompas), and satisfaction with Oncokompas among cancer survivors. Secondary aims were to investigate which socio-demographic and clinical factors are associated with the feasibility of Oncokompas, and to obtain insight in possible barriers and facilitators of the feasibility of Oncokompas.

This feasibility study will provide insight into factors that contribute to the development and usage of eHealth applications among head and neck cancer survivors.

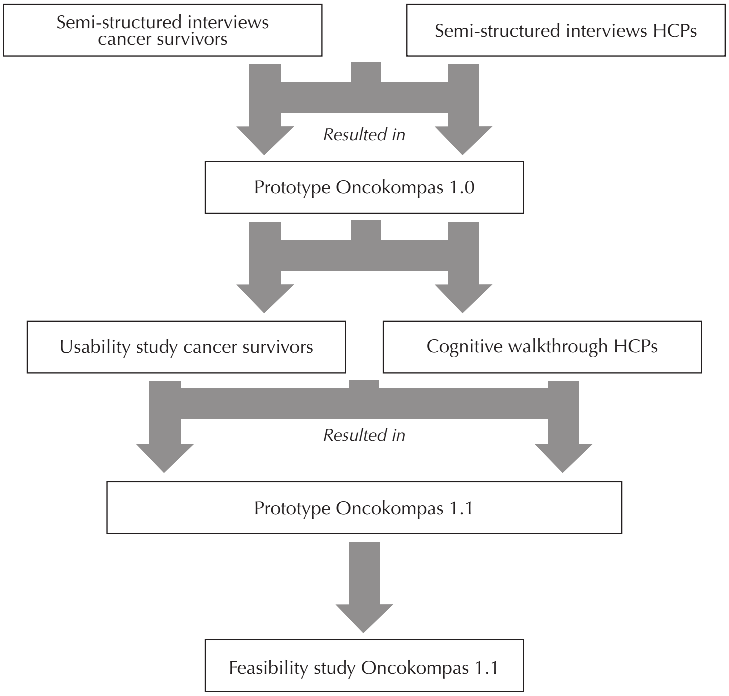

Figure 6.1. Flow chart development process Oncokompas based on participatory design principles

METHODS

A pretest-posttest design was used, conducting a survey before providing cancer survivors access to Oncokompas (T0), and two weeks after (T1). After participants completed the T1 survey, they were interviewed by a nurse specialized in oncology to obtain more in-depth insight into the feasibility of Oncokompas.

STUDY SAMPLE AND PROCEDURES

Between January and July 2013, all eligible cancer survivors from the Departments of Otolaryngology-Head and Neck Surgery from VU University Medical Center, Amsterdam, University Medical Center Leiden, and University Medical Center Maastricht, The Netherlands were invited by an oncology nurse or head and neck surgeon. Participants were eligible if they (1) were treated for head and neck cancer with curative intent with a maximum of 2 years prior, (2) were 18 years or older, (3) were able to write, read, and speak Dutch, (4) had some Internet experience, and (5) had access to the Internet at home.

If participants agreed to participate, they were asked to complete and return a paper-and-pencil questionnaire (T0). Subsequently, participants were contacted to provide them with a login code for Oncokompas at home. An interview was scheduled with an oncology nurse from their hospital 2 weeks later. Prior to their appointment with the nurse, cancer survivors were asked to fill in the post-test questionnaire (T1). During the consultation with the nurse, attention was paid to perceived usefulness of the tailored advice and personalized referral to supportive care services, as provided by Oncokompas. Oncology nurses made standardized interview reports. The scheme consisted of two main components: part A for survivors who completed Oncokompas and part B for survivors who did not complete Oncokompas. Key questions included in part A comprise the following: (1) “How would the survivor describe their experience with Oncokompas?”, (2) “Did the survivor view their personalized advice and supportive care options? If not, why?”, and (3) “Did the survivor find the results applicable to their personal situation?”. Key questions included in part B comprise the following: (1) Why did the survivor not complete Oncokompas?”, (2) “What should be changed in the application to enable the survivor to complete Oncokompas?”, and (3) “What aspects did the survivor miss in Oncokompas that prevented the survivor to complete the application?”. Nurses completed the scheme during the consultation with the survivors and supplemented these following the consultation.

Technical support was offered by two researchers (SL and FJ) when problems occurred with the access or use of Oncokompas. The researchers recorded an entry in a logbook with each technical problem.

The study was conducted according to regular procedures of the local ethical committee of the VU University Medical Center, Amsterdam. All participants signed informed consent.

INTERVENTION “ONCOKOMPAS”

Oncokompas can be considered as both a screening and a monitoring tool and consists of three components: (1) measure, (2) learn, and (3) act. In the “Measure” component, cancer survivors can independently complete PROMs targeting the following QOL domains: physical functioning, psychological functioning, social functioning, healthy lifestyle, and existential issues. Besides these domains for cancer survivors in general, a specific domain, containing topics for head and neck cancer patients, is allocated (Table 6.1). Specific PROMs were selected by the project team in collaboration with teams of experts, based on Dutch practice guidelines and literature searches. Data from the “Measure” component are processed in real-time and linked to tailored feedback to the cancer survivor in the “Learn” component. All algorithm calculations are based on available cut-off scores, or they are defined based on Dutch practice guidelines, literature searches, and/or consensus by teams of experts. In the “Learn” component, a compass metaphor is used to summarize overall well-being. Following this, feedback is provided to the participant on the level of the topics (e.g., depression and fatigue) by means of a three-color system: green (no elevated well-being risks), orange (elevated well-being risks), and red (seriously elevated well-being risks) (first-degree algorithms). Cancer survivors receive elaborated personalized information on the outcomes, e.g., on the topic depression, information is provided on the symptoms of depression and the proportion of cancer survivors who suffer from depressive symptoms.

Special attention is paid to clusters of interrelated symptoms. For example, feedback on the association between depression and fatigue is provided, if a participant has an orange or a red score on depression as well as on fatigue. The feedback in the “Learn” component concludes with a comprehensive self-care advice (tips and tools). All these advices are tailored to the individual cancer survivor (second-degree algorithms).

In the “Act” component, survivors are provided with personalized supportive care options, based on their PROM scores and expressed preferences (e.g., preference for individual therapy versus group therapy) (third-degree algorithms). If a participant has elevated well-being risks (orange score), the feedback includes suggestions for self-help interventions. If a participant has “seriously elevated well-being risks” (red score), the feedback includes an advice to contact their own medical specialist or general practitioner.

In appendix 1, a worked example of Oncokompas using a case study is presented. For a clickable demo of the application (in Dutch) or an animation video (in Dutch and English), please visit www.oncokompas.nl.

OUTCOME MEASURES

A study-specific survey was composed with items on socio-demographic and clinical factors, a QOL questionnaire (assessed at baseline (T0)), and items on usage and satisfaction (assessed at follow-up (T1)).

Table 6.1. Overview of Oncokompas topics

Psychological quality of life	Physical quality of life	Social quality of life	Healthy lifestyle	Life questions	Head and neck cancer
Anxiety and depression	General everyday life	Social life	Alcohol	Life questions	Swallowing
Fear of recurrence	Pain	Relationship with partner	Physical activity		Speech
Subjective cognitive functioning	Sexuality	Relationship with children	Dietary intake		Oral function
Stress	Sleep quality	Financial circumstances	Weight		Neck and shoulder function
	Body image	Patient–physician communication	Smoking		Loss of smell and taste
	Fatigue	Return to work			Head and neck cancer specific lymphedema
	Diarrhea				Nutritional drink/ Tube feeding
	Lack of appetite				
	Dyspnea				
	Nausea or vomiting				
	Constipation				
	Hearing and tinnitus				

Adoption, usage, and satisfaction

Adoption was defined as the percentage of cancer survivors that agreed to participate in the study and returned the T0 questionnaire and informed consent.

Usage was defined as the percentage of participating cancer survivors that actually used Oncokompas as intended based on the item “Did you fill out and use Oncokompas?” (T1).

General satisfaction was assessed based on the mean score of three study-specific questions: general impression of Oncokompas, the user-friendliness, and the ability to use Oncokompas without assistance (10-point Likert scales: 0 (poor) to 10 (good)). Furthermore, satisfaction was measured with the Net Promoter Score (NPS) with the question “How likely it is that you would recommend Oncokompas to other cancer survivors (10-point Likert scale: 0 (not likely) to 10 (very likely)). The NPS was calculated by dividing the percentage of promoters (who score 9–10) minus the percentage of detractors (who score 0–6). The percentage “passives” (who score 7–8) is not included in calculating NPS. The NPS ranges between –100 and +100. A positive score is considered good[19].

Additionally, the satisfaction of participants on the three components of Oncokompas was assessed (measure, learn, and act).

Moderating factors

Socio-demographic (age and gender) and clinical variables (tumor location, tumor stage, type of treatment, and comorbidity) were drafted by a physician from the medical records. Comorbidity was assessed by the use of the Adult Comorbidity Evaluation 27 (ACE-27), a validated chart built instrument, resulting in a total comorbidity score of none, mild, moderate, or severe[20].

The 30-item EORTC QLQ-C30 (version 3.0) includes a global health-related quality of life (HRQOL) scale (two items) and five functional scales: physical functioning, role functioning, emotional functioning, cognitive functioning, and social functioning. There are three symptom scales (nausea and vomiting, fatigue, and pain) and six single items relating to dyspnea, insomnia, loss of appetite, constipation, diarrhea, and financial difficulties. In the present study, the HRQOL scale was used. The scores of the QLQ-C30 are linearly transformed to a scale of 0–100, with a higher score indicating a higher level of HRQOL[21].

Facilitators and barriers

After the participants completed the T1 survey, they were interviewed by an oncology nurse to obtain more in-depth insight into barriers and facilitators of the feasibility of Oncokompas.

To evaluate technical issues interfering with the feasibility of Oncokompas, the entries in the helpdesk logbook were evaluated on the type of problem encountered, and if and how the problem was solved.

DATA ANALYSES

Descriptive statistics were used to summarize the adoption, usage, and satisfaction. Oncokompas was defined feasible in case of an adoption and usage grade of more than 50 %, a mean satisfaction score of at least 7, and a positive Net Promoter Score.

This definition of feasibility is based on adoption and usage rates reported in previous studies on eHealth applications[22].

Correlations between satisfaction with Oncokompas and gender (male vs. female), age (<65 vs. >64 years), comorbidity (none/mild vs. moderate/severe), tumor subsite (oral cavity/oropharynx vs. hypopharynx/larynx vs. other), tumor stage (stage I/II vs. stage III/IV), and treatment modality (surgery alone vs. surgery plus (chemo)radiation vs. (chemo) radiation) were examined using chi-square tests. The outcome variable satisfaction with Oncokompas was not normally distributed and was therefore dichotomized into two categories: a score from 0 to 6 and a score of 7 and higher. The association between satisfaction with Oncokompas and QOL was analyzed using Mann-Whitney U tests. Statistical analyses were performed using the Statistical Package for the Social Sciences (IBM SPSS Statistics 20). For all analyses, p values <0.05 (two-tailed) were used as criterion for statistical significance.

The structured interview reports by the oncology nurses were analyzed by thematic analyses. Barriers and facilitators towards feasibility of Oncokompas were extracted from the reports and those that were mentioned at least five times are reported. The entries in the logbook with technical difficulties were categorized by type of problem that was encountered. The number of unique problems was counted.

RESULTS

ADOPTION AND USAGE

In total, 106 HNC survivors were asked to participate in the study. The adoption grade was 64%: 68 out of 106 intended to use Oncokompas and gave informed consent and returned the T0 survey. Reasons for non-consent included a lack of time of the patient and no willingness to travel to the hospital for the nurses' consultation.

In total, 12 participants dropped out during the study (17.6%), leaving a study cohort of 56 participants (Table 6.2). The reasons for dropout included cancer recurrence (n = 2), entering palliative care (n = 2), family circumstances (n = 1), comorbid illness (n = 1), tiredness due to which Oncokompas could not be used (n = 1), evaluating the questions in Oncokompas as too confronting (n = 1), insufficient Internet skills according to the participant (n = 1), and not able to reach participants by telephone (n = 3). Of the 56 participants (56 out of 68) who completed the study, 51 survivors filled out Oncokompas completely and as intended (usage grade 91%). In total, five of these participants indicated that they received assistance while filling out Oncokompas (with the help of my spouse (*N* = 4) or with the help of my daughter (*N* = 1)). Two survivors indicated to have used Oncokompas partially (3.6%). They mentioned that they only filled out the ‘Measure’ component in Oncokompas. Three other survivors (5.4%) indicated not to have used Oncokompas due to technical reasons; one participant indicated to be hindered by a bug when using the application, while the other two participants indicated that because of a bug in the application they could not continue. Of the participants who encountered technical problems, one survivor contacted the helpdesk. Despite provision of assistance, this participant was not able to complete Oncokompas. Usage grade thus lies between 75% (51 out of 68 participants (including dropouts)) and 91% (51 out of 56 participants (excluding dropouts)) who used Oncokompas as intended.

SATISFACTION

Most of the participants were satisfied with Oncokompas in general (60.4%, mean score 6.8, SD 1.2). Participants evaluated Oncokompas as user-friendly (76.0%, mean score 7.1, SD 1.6). Participants were able to use Oncokompas without assistance (90.6%, mean score 7.8, SD 1.7). The mean satisfaction score was 7.3 (SD 1.5). The Net Promoter Score of Oncokompas was positive 1.9, consisting of 21% promoters, 19% detractors, and 60% passives.

Regarding the feasibility of the “Measure” component, almost all participants answered all PROMs (98%). For some participants, the PROMs were intrusive (21%), confusing (29%), or difficult to answer (37%). Confusing and difficult questions mentioned by survivors included questions related to God and religion. Questions about sexuality were found intrusive. Almost all participants (94%) viewed their well-being profile in the “Learn” part of Oncokompas. To most participants, the description of their results was clear and understandable (84%) and easy to find in the application (81%). More than half of the participants evaluated the information as applicable to themselves (61%), but less than half evaluated the information of added value for their own health status (43%). More than half of the participants (61%) indicated that the overall picture regarding their results (the compass metaphor) did not add much. Most participants viewed their personalized advices (71%), and these advices were evaluated as clear

(85%) and complete (68%). The amount of supportive care options provided in the "Act" component was considered to be exactly right to most participants (71%) or too much (23%). More than half of the participants (57%) indicated to be interested in one or more of the offered supportive care options and almost a third of these participants subsequently did take action accordingly (29%). The majority indicated to return to Oncokompas in the future to view their personalized advices and actions once again (71%)

Table 6.2. Demographic and health characteristics of the participating participants (*N*=56)

	n	%
Sex (n, %)		
Female	22	39.3
Male	34	60.7
Age in years		
Mean (SD)	59.05 (9.85)	
Minimum	25	
Maximum	77	
Tumor site (n, %)		
Oral cavity and oropharynx	30	53.6
Hypopharynx and larynx	12	21.4
Other	14	25.0
Comorbidity (ACE-27) (n, %)		
None	16	28.6
Mild	17	30.4
Moderate	18	32.1
Severe	5	8.9
Type of treatment (n, %)		
(Chemo) radiation therapy ((C)RT)	27	48.2
Surgery	13	23.2
Surgery + (C)RT	16	28.6
Time since treatment (in months)		
Mean (SD)	12.32 (6.5)	
Minimum	0	
Maximum	24	
Quality of Life (EORTC QLQ C-30)		
Mean (SD)	76.33 (16.49)	
Minimum	33.33	
Maximum	100	

The helpdesk was contacted for a total of 21 unique problems. The problems mainly consisted of difficulties logging on to the application: due to a browser problem ($n = 2$), loss of password ($n = 2$), expiration of security certificate of the application ($n = 3$), use of a tablet (n = 2), blockage by firewall (n = 2), no compliance of the computer with application requirements (n = 1), and other reasons (n = 5). Furthermore, an error message appeared (n = 2) and the button to print the results was not visible (n = 2).

FACTORS ASSOCIATED WITH SATISFACTION WITH ONCOKOMPAS

Satisfaction with Oncokompas was not significantly associated with age (X^2 (1, N = 53) = 0.26, p = 0.61), gender (X^2 (1, N = 53) = 0.58, p = 0.45), tumor location (X^2 (2, N = 53) = 5.49, p = 0.06), tumor stage (X^2 (1, N = 53) = 0.00, p = 0.97), type of treatment (X^2 (2, N = 53) = 3.38, p = 0.19), comorbidity (X^2 (1, N = 53) = 0.034, p = 0.85), and HRQOL (p = 0.35).

BARRIERS AND FACILITATORS

In total, seven barriers towards the feasibility of Oncokompas were mentioned at least five times (Table 6.3): (1) The application did not fully take into account other diseases that participants suffered from, (2) the amount of information in the application was too much, (3) items regarding existential issues were difficult to answer and too much oriented towards religion, (4) participants did not find the results completely applicable to their personal situation (they experienced their symptoms in a different way), (5) participants found a lapsed time of 2 years since treatment to introduce the application too long (these participants often already found a solution to the experienced problems or learned to live with them), (6) the description of participant's overall well-being was suboptimal, either considered confronting or meaningless, and (7) participants found some items in the application confusing making it difficult to answer them truthfully.

Six facilitators were mentioned at least five times (Table 6.3): (1) the user-friendliness of the application, (2) it's informative nature, (3) the provision of a clear overview to the participant of their personal situation and options, (4) the clarity of the items in the questionnaire, (5) the usefulness of the application in general, and (6) the particular usefulness of the application for participants who are very ill or experience many symptoms.

Table 6.3. Barriers and facilitators (mentioned at least five times)

Barriers	No. of times mentioned	Facilitators	No. of times mentioned
The application did not fully take into account other diseases that participants suffered from	11	The user-friendliness of the application	13
The amount of information in the application was too much	9	The informative nature of the applications	7
Items regarding existential issues were difficult to answer and too much oriented towards religion	9	The provision of a clear overview to the participant of their personal situation and options	6
Participants did not find the results completely applicable to their personal situation.	8	The clarity of the items in the questionnaire.	6
Participants found a lapsed time of 2 years since treatment to introduce the application too long	7	The usefulness of the application in general	5
The description of participant's overall well-being was suboptimal	6	The particular usefulness of the application for participants who are very ill or experience many symptoms	5
Participants found some items in the application confusing making it difficult to answer them truthfully.	6		

DISCUSSION

The aim of this study was to investigate the feasibility of the eHealth application Oncokompas aiming to facilitate and innovate cancer survivorship care. Our results show that Oncokompas is feasible with an adoption grade of 64%, a usage grade between 75% and 91%, a mean satisfaction score of 7.3, and a positive Net Promoter Score. Almost all participants were able to use Oncokompas. The few participants that weren't able to use Oncokompas seemed to be hindered by insufficient eHealth skills. These findings are in line with previous studies that examined the feasibility of eHealth applications in clinical practice showing that eHealth applications are acceptable to many participants but not to all[19–22].

Our study showed no associations with socio-demographic factors. Also in previous studies no significant associations between use of eHealth and gender were found[21,23,24]. Previous studies revealed mixed results concerning the association between age and use of eHealth applications[21–25]. Increased age seems to be associated with less use of the internet, although this association has become less strong in recent years, probably due to the availability and increased familiarity of internet[22]. A review by Or and Karsh revealed that most studies did not show significant relationships between eHealth acceptance and age[21]. Our study results match these findings.

In our study there were no significant associations between satisfaction with Oncokompas and clinical factors or QOL. Previous studies that focused on health and treatment factors showed that participants who use eHealth are healthier than participants who don’t use eHealth[26,27]. A better health status seems to lead to a better acceptance of internet applications[28]. However, in other studies the opposite was found[29,30].

Other factors than socio-demographic and clinical factors and QOL may be of more interest in investigating why participants use (or not use) eHealth applications. Adoption rate of eHealth can be predicted by the way an eHealth application is rated in terms of usefulness and ease of use, and the self-efficacy of participants regarding information technology[21,31]. In the present study, only participants with sufficient (self-reported) computer skills were included. Facilitators associated with the feasibility of Oncokompas included the user-friendliness of the application, and it’s informative nature. Ease of use was also determined in previous studies as an important factor for the acceptance of eHealth applications[21]. Important barriers included the feeling that the results did not completely reflect the personal situation, the large amount of information in the application, and difficulties answering some of the items. The barrier regarding the time investment required to complete the application has been reported in previous studies as well. Length and information overload have been found to be important reasons to quit using an online application[32–34]. Individualized feedback has been found to be related to sustained intervention use and less dropout[35,36].

A strength of our study is that we used mixed methods, providing in-depth insight into the feasibility of eHealth applications in clinical practice.

In the present study only participants were included with access to the Internet at home. Therefore, we do not have good insight into the representativeness of our study sample. The positive attitude of participants towards Oncokompas might not be generalizable to all HNC survivors. Another limitation concerns the small sample size, which may have hampered testing the associations. Finally, in this study participants had access to the eHealth application for only two weeks. Further research is needed on the feasibility in the longer term.

CONCLUSIONS

Oncokompas is considered feasible, but our results also show that improvements can be made to enhance the feasibility and increase the satisfaction among cancer survivors. The PROMs can be further investigated and possibly be reduced. It is also important to look at the phrasing of individual items, because of the barrier that answering some of the items was difficult to participants. However, in order to ensure accuracy of the individualized feedback, we have to balance the time it takes to use Oncokompas, measurement precision, and tailoring towards a personalized tool. It is clear that any eHealth application will not be suitable for all participants, due to different needs, preferences, and coping styles of cancer survivors. It is worthwhile to obtain more insight into how further tailoring of eHealth applications and more sophisticated marketing strategies can be applied leading to applications that are attractive to more participants and hereby increase adoption and usage.

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7

GENERAL DISCUSSION

The overall aim of this thesis was to investigate the usefulness of online applications to monitor health related quality of life (HRQOL) by means of patient reported outcome measures (PROMs) in head and neck cancer (HNC) survivors in follow-up care. In this final chapter, the main findings are summarized. Then, findings are discussed in broader perspective with a focus on usage of PROMs in clinical practice, online PROMs assessment and self-management, and the development of eHealth applications according to a participatory design approach. Also, implications for clinical practice are addressed and recommendations for future research are provided. This chapter ends with a general conclusion.

SUMMARY OF THE MAIN FINDINGS

Usage of PROMs administered via OncoQuest, a touch screen computer-assisted PROM system, to monitor HRQOL in clinical practice combined with a nurse consultation in HNC survivors is durable, even 5 years after implementation. The usage rate of OncoQuest was 67% and equal to the rate of usage at the time of introduction. This percentage, although relatively high, also implies that not all survivors are reached by PROMs. Results of the study confirm our first hypothesis as postulated in Chapter 1, that PROMs are more frequently used by cancer survivors that have (many) symptoms and needs. Survivors with early staged cancer, and those who do not experience changes in their HRQOL make less use of PROMs. To enhance the reach for those patients who need it, administering PROMs at home, via the Internet, was suggested by HNC survivors and health care providers (HCPs) to be a possible solution (Chapter 2). Therefore, the Internet use among HNC survivors was investigated. A study group who participated in a survey study on Internet use in 2007 (when eHealth applications were not yet wide-spread) was compared with a study group in 2015 (when many more eHealth applications were available). The Internet use among HNC survivors increased from 53% in 2007 to 79% in 2015. Of these survivors, in 2007 and 2015 respectively 46% and 59% used the Internet to search for information on cancer. Almost 70% of the HNC survivors in both 2007 and 2015 were interested in using eHealth in the future, especially eHealth applications targeting communication (e.g. access to own health record and test results). Approximately 15-25% were interested in online communities (e.g. participation in an online peer support groups). About half of the survivors in 2015 would like to have access to an online system to monitor their HRQOL at home by means of PROMs and receive personalized information on supportive care (chapter 3). These findings confirm our second hypothesis as postulated in Chapter 1, that HNC survivors are positive towards the use of eHealth applications in clinical practice to monitor their HRQOL. Feedback on the results of filling in online PROMs was, however, considered a prerequisite for its use by HNC survivors (chapter 4). Therefore independent use of an eHealth application administering PROMs online will be limited to the capability of the eHealth application to integrate PROMs with adequate feedback and personalized advice. We explored more in-depth the need for such an online system that HNC survivors can use to monitor HRQOL, and which provides personalized information on supportive care, as well as the system, content and service requirements that should be fulfilled to fit the needs of HNC survivors and HCPs. Expected advantages of an online home-based application mentioned by HNC survivors were insight into the course of symptoms by monitoring, availability of information between follow-up appointments, receiving personalized advice, and tailored supportive care (chapter 4). HCPs were also positive toward the development of an online home-based application and expected it could support survivors in obtaining supportive care tailored to their needs, and diminish barriers HCPs encounter in directing survivors to supportive care (chapter 5). Based on these positive findings, a prototype of an online home-based application, Oncokompas, was built and tested among survivors and HCPs in respectively usability tests (see Intermezzo Oncokompas, page 130-139) and cognitive walkthroughs (chapter 5). The quality of the system, content and service of Oncokompas that should be optimized according to survivors and HCPs included the navigation structure and tailoring the advice to the survivor's personal situation. Subsequently, Oncokompas was further optimized, and a feasibility study showed that Oncokompas is feasible in clinical practice with a good adoption and implementation grade, and good satisfaction among HNC survivors (chapter 6). These findings confirm our third hypothesis as postulated in Chapter 1, that using a participatory design approach contributes to the development of an eHealth application that is feasible in clinical practice.

DISCUSSION OF THE MAIN FINDINGS

PROMS IN CLINICAL PRACTICE

The use of PROMs in clinical practice has been found to be beneficial for cancer survivors[1–5], and is advised in best practices and national guidelines [e.g. [6–11]]. Studies have shown that implementation is feasible[2,12–14]. This thesis showed that usage of

PROMs remains high, even 5 years after implementation (67%). However, in general, implementation of PROMs in clinical practice is lagging behind in many (HNC) cancer centers because of the challenges that have to be solved. In the EORTC manual by Wintner et al.[6] it is recommended to follow a tailored implementation strategy for successful integration of PROMs in clinical practice. For instance, it is important to understand current practice before applying integration strategies, and to evaluate the integration process and outcome[6]. The successful usage rate of OncoQuest (chapter 2) can in all likelihood be attributed to a tailored implementation strategy. However, although a usage rate of 67% is good, this might be further increased. The studies conducted in this thesis showed several practical implications concerning selection and timing of PROM assessments, which might help to a further increase of users. In the choice of PROMs, important aspects are to limit the length (chapter 4) and reduce the complexity of the PROMs (chapter 5). Also, it is important to optimize the timing of the use of the PROMs, e.g. before the consultation with the HCP (Chapter 2), for instance by completing the PROMs at home after which the results are discussed with a HCP in the hospital[6].

With respect to the reach of PROMs in clinical practice, there are some subgroups of survivors that are less likely to use PROMs. Survivors with early staged HNC were less likely to use PROMs. Additionally, those survivors who never made use of OncoQuest indicated that they had no need because they did not experience a change in their symptoms (chapter 2). These results are in line with findings from our needs assessment among HNC and breast cancer survivors towards an eHealth application monitoring QOL by means of PROMs (chapter 4) in which survivors indicated that monitoring of symptoms is only useful when symptom burden is high.

Previous literature showed that older cancer patients are less interested in using (web-based) PROMs[2,15,16]. Explanations that were mentioned included that elderly patients seem to be skeptical towards HRQOL monitoring[2] e.g. because they fear to lose contact with their HCP[6]. This latter finding was also found in our needs assessment among HNC survivors, though not limited to elderly survivors (chapter 4). The question rises how to reach these subgroups. Older survivors can be informed on the supplemental nature of PROMs in clinical practice and that this does not substitute personal face-to-face care, to minimize their fear of losing contact with their HCP when using a PROM system[2]. Survivors with early staged cancer and those who do not experience symptoms or changes in HRQOL may be informed that usage is not obligatory but that they are welcome to use PROMs whenever they feel a need.

ONLINE PROM ASSESSMENT AND SELF-MANAGEMENT

Online applications to complete PROMs at home have benefits such as 24/7 availability, easy accessibility in case of doubts towards the severity of symptoms in between HCPs appointments, and they can be interactive and tailored to the survivors' needs. An obvious requisite is that survivors have access to the Internet. Internet use among HNC survivors has increased tremendously in the past 10 years up to 79% in 2015 (chapter 3). Other studies have also found a great increase in Internet use by the general population since 2007[17]. These findings confirm that an important precondition needed for online PROM collection (access to Internet) most often is satisfied, at least in the Netherlands. Most survivors were positive towards the use of online PROMs and eHealth (chapters 2,3,4,5,6). An important aspect however, when using PROMs in clinical practice, is that the survivors' results should be discussed with a HCP. Screening alone without feedback has been identified as insufficient to improve survivor's HRQOL[18–20]. In this thesis, survivors greatly valued the nurse consultation following the use of OncoQuest (chapter 2), but there was also a need for easier access to a PROM system. Also, HCPs indicated to want easier accessibility of a PROMs system for survivors, e.g. by access online from home (chapter 2) to improve the use of PROMs in clinical practice. However, feedback after completing (online) PROMs is a prerequisite for its use (chapter 4). A possibility is that after completing PROMs online, survivors discuss the results during a visit in the clinic or via a telephone consultation. An alternative would be to provide cancer survivors with a self-management tool that facilitates using PROMs in combination with automated feedback.

There are several advantages of such self-management applications compared to use of a PROMs system during a visit to the hospital, e.g. the high flexibility in use in time and place, and the ability to for survivors to optimally prepare for their consultation so they better understand their HCPs by formulating adequate questions and understanding the response of the HCP[21,22]. Expected effects by survivors and HCPs of the use of an online home-based application focused on improving HRQOL included enhanced insight into occurring symptoms, a signaling function towards worrying symptoms and timely referral to supportive care services (chapter 3,4). They expect such an application can eliminate unmet needs and identified barriers, such as relying on the physician's expertise, and a lack of HCPs to link treatment to supportive care needs (chapter 4)[23]. HCPs differed in their opinion whether survivors should be supported by HCPs when using such a self-management application, or that survivors should be able to use the application as a stand-alone application.

Currently, self-management applications (including PROMs) for HNC survivors are scarce[24–26], but the applications that are available are acceptable and used by HNC survivors[25,27]. More self-management applications are becoming available for the general public, as well as for (head and neck) cancer survivors, and the knowledge of survivors on existing self-management applications is also growing[22]. Acceptability of HNC survivors is good regarding specific eHealth self-management applications to support them during follow-up care (chapter 4 and 5)[21,22,28]. Therefore there were good reasons to develop an eHealth application to assess PROMs and provide immediate feedback and supportive care options, which can be accessed from home. To develop a sound and potentially effective application, the development should be done thoroughly and include the needs and preferences of end-users to enable optimal implementation.

USING PARTICIPATORY DESIGN PRINCIPLES IN THE DEVELOPMENT OF AN eHEALTH APPLICATION

Participatory design principles can be used to optimize the effectiveness and usefulness of eHealth applications by involving end-users and other stakeholders throughout all stages of the development process of an eHealth application[29,30]. Participatory design principles were followed in developing the eHealth self-management application Oncokompas, meaning that cancer survivors and healthcare professionals (HCPs) were involved in each step of the development process. This approach resulted in an eHealth application which fits the needs of survivors and HCPs. Oncokompas was tested on feasibility in a multi-center study among HNC survivors (chapter 6). Following participatory design principles showed to result in a feasible eHealth application (Oncokompas), with a good adoption (64%) and implementation grade (75-91%), good satisfaction among HNC survivors (7.3 on a scale from 0-10) and a positive Net Promotor Score. Facilitators associated with the feasibility included the user-friendliness of the application and the information it provided. Barriers mentioned included an overload of information in the application, and that co-morbidity was not considered when survivors received feedback. These barriers were taken into account to improve the application, by reducing the number of PROMs and improving tailoring to the specific situation of the survivor.

Survivors' and HCPs involvement throughout all stages of the development of the application probably helped in ensuring the application met the end users' needs, and was found easy to adopt, and useful for both survivors and HCPs (chapter 4,5,6). The approach of participatory design proved useful and provided important insights into survivors and HCPs perceived usefulness of the application (chapter 2,4,5,6).

Other eHealth applications have also been found useful after the use of participatory design principles[31–33], whilst applications that have not used such an extensive development period are often less successful[30,34]. The use of participatory design principles is important, since the manner in which survivors and HCPs view the usefulness and ease of use of an eHealth application, and their self-efficacy in using the application can predict to what extent the application will be used[35,36]. The studies in this thesis indicated that the use of participatory design principles reflects a successful way to develop an eHealth application that is durable and useful in clinical practice (chapter 3, chapter 6, [31–33]), as survivors are satisfied with the developed applications. However, the question remains whether participatory design leads to the development of more effective applications. A recent study has revealed that in the development of serious digital games for healthy lifestyle promotion, there was no evidence that using participatory design principles led to the development of more effective games[37]. Although this finding does not indicate there is evidence for no effect of participatory design principles, combined with the lack of other studies demonstrating effect, it does warrant future research on this topic.

Besides effectiveness, another important factor is whether participatory design leads to increased use of developed applications. The development of a useful application does not automatically ensure a wide reach of the application among end-users. Acceptance and implementation issues play a role in whether the application is used as intended. Acceptance towards both OncoQuest and Oncokompas in this thesis was found to be good among both cancer survivors and HCPs (chapter 2,4,5,6). To ensure optimal implementation and consistency of delivery of the application as intended, HCPs played a role in defining the implementation strategy currently used, by indicating requirements for implementation. Requirements mentioned contained implementation according to a routine, e.g. in a care pathway at a set moment, provision of promotional material (availability of a flyer, website, demo, poster in the waiting area), availability of a trigger for HCPs to offer Oncokompas so it cannot be forgotten, while taking into account existing time constraints. HCPs were, however, divided in their opinion towards the best strategy to implement Oncokompas in clinical practice; as a self-management application (independent use by users) or a *supported* self-management application (with support from a HCP) (chapter 5). The optimal implementation strategy for Oncokompas, and delivery of Oncokompas to cancer survivors in clinical practice in the long term, is currently further investigated and will provide us with insight in evidence of effect of participatory design principles on actual use of developed applications.

STRENGHTS AND LIMITATIONS

The studies presented in this thesis add important information to the literature on the subject of eHealth applications to monitor HRQOL by means of PROMs in HNC survivors. A strength of this thesis, is that we investigated the needs and preferences of all stakeholders involved in follow-up cancer care for HNC survivors, and studied adoption, usage, acceptability of and satisfaction with (online) applications towards monitoring HRQOL in clinical practice. Involving the target population and clinical setting in the process of development of an eHealth application is critical in intervention development research[38]. Another strength of this thesis is that both qualitative and quantitative research methods were used in the identification of needs, preferences and satisfaction with the applications described in this thesis. Thirdly, factors that facilitate or hamper the usefulness of eHealth applications and insight into implementation requirements in clinical practice were identified, providing directions for future studies to optimize the further development and implementation of eHealth applications.

The studies presented are also subject to some limitations towards the methodologies used. First, we did not measure the Internet/eHealth skills of participating HNC survivors in the feasibility study, which may have affected the use of eHealth or self-management applications. Recently, a questionnaire has become available to measure digital health literacy[39], which can be used in future studies to minimize this potential bias. Another limitation is that we did not investigate the potential effectiveness of Oncokompas in the feasibility study. A feasibility study among breast cancer survivors revealed that Oncokompas is likely to be effective to improve patient activation (Melissant, 2017, in press). Currently, a RCT is ongoing to investigate the efficacy and cost-utility of Oncokompas in clinical practice in HNC survivors, breast, colorectal survivors and survivors of lymphoma. Thirdly, the needs assessment among HCPs revealed that some HCPs advocate for Oncokompas as a supported self-management application and others as an unsupported self-management application. In the feasibility study, we investigated the feasibility of Oncokompas as a *supported* self-management application (Oncokompas was offered by nurses and results were discussed with nurses) and we therefore do not have insight yet into the feasibility of Oncokompas as an unsupported self-management application.

IMPLICATIONS FOR CLINICAL PRACTICE

Internationally, guidelines recommend the administration of PROMs in clinical practice to monitor HRQOL and distress in cancer survivors[6–11,40–42]. Feedback from a HCP is essential[43,44] and this may be difficult to integrate logistically to benefit optimally from the PROM data collection. The present thesis showed that implementing a PROMs system to monitor HRQOL (OncoQuest) combined with a nurse consultation is feasible and durable five years after implementation; HNC survivors were positive regarding the use of this intervention. For those HNC survivors who want to use a self-management application at home, Oncokompas is now available. Information on the effectiveness of Oncokompas to improve patient activation and on cost-effectiveness is expected by the end of 2018. Although advantages of self-help programs for cancer survivors have been identified[45], previous literature has shown that a specific group of HNC survivors may not benefit from such interventions, and showed a high level of drop-out[20], particularly when a relatively mild intervention was offered to them. This group needs a more personalized and active approach[20]. These findings show that besides a (supported) self-management application, there probably remains a need for the use of a PROMs system like OncoQuest in clinical practice.

For the optimization of the use of PROMs in clinical practice, it is recommended that research regarding PROMs in clinical practice is synthesized and shared on a national level between researchers and HCPs, and that the provision of this type of care to cancer survivors in the Netherlands is standardized on a national level to ensure all HNC survivors receive the same standard of care and can profit from new available research findings. Besides the immediate advantages of PROM collection for cancer survivors, the collection of PROMs is also important for the registration of the quality of care for HNC survivors (NWHHT registration) in the Netherlands and the possibility to improve quality of care.

RECOMMENDATIONS FOR FUTURE RESEARCH

Research in this thesis provides good insight into the use of a touch-screen computer-assisted PROMs system and the possibility of a self-management application for HNC survivors in terms of acceptability and feasibility. Following the RE-AIM model[46,47], this gives an indication of the reach (R) of a new intervention, and provides a good starting point for future research to assess the effectiveness (E) of the innovation through a RCT. According to the RE-AIM program it is also important to study adoption (A), Implementation (I) and Maintenance (M), to ensure that an evidence-based intervention will be optimally implemented in care in a structural way. Currently this research is ongoing with regard to Oncokompas.

It is important to study possible moderators that may influence the effectiveness and implementation of new interventions such as self-management and eHealth. This way, the target population can be identified more precisely and ultimately the reach and adoption can be improved.

An online home-based application (e.g. Oncokompas) can invite cancer survivors to participate in more self-management tasks, leading to more accurately met needs while at the same time relieving the increasing pressure on the health care system. Introducing the application as a self-management application could be the most effective way, in which the application is supplemental to care as usual. If the application is introduced as a supported self-management application, this could lead to complex working procedures and therefore a low adoption among HCPs[48], however some cancer survivors may need extra support in using the application. Research should focus on identifying the foundation of implementing a supported self-management versus a self-management application. It is important to investigate barriers and facilitators regarding adequate implementation of eHealth applications in clinical practice. Also important after implementation is to evaluate the maintenance after a period of time to identify the sustainability and possible adjustments to be made to maintain the eHealth application's effectiveness for cancer survivors.

CONCLUSION

Collection of PROMs in clinical practice by means of computer-assisted PROMs system (OncoQuest) described in this thesis proved to be feasible in clinical practice, and durable after five years. The consultation with the nurse as part of OncoQuest was of added value in the experience of participating survivors, but implicates logistical challenges. Another option towards PROM collection and providing personalized advice and supportive care options to cancer survivors that could diminish logistical challenges in implementing PROM collection in clinical practice, is an online (supported) self-management application that can be used from home. Internet use among HNC survivors has increased up to 79% in 2015, so this does not appear to be a barrier for online PROMs collection for a least a substantial group of survivors. Since feedback is essential in PROMs collection to improve survivors HRQOL, an online application should provide automated tailored feedback to be of additional value. Such an application was developed following participatory design principles (Oncokompas) and found feasible in clinical practice.

Results from this thesis showed that both a computer-assisted PROMs system (OncoQuest) and an online home-based application (Oncokompas) are found either durable and/or useful. Either application will, however, not reach all cancer patients. Partly since survivors that experience many symptoms and needs mainly use them, but also because not all cancer survivors use the Internet or are comfortable using the Internet. These findings show that besides implementing a (supported) self-management application, there remains a need for the use of a computer-assisted PROMs system like OncoQuest in clinical practice with immediate feedback from a HCP.

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SUMMARY

Chapter 1 presents the general introduction of this thesis. First, this chapter provides a description of head and neck cancer and its treatment options, as well as a description of the impact of this type of cancer on patients' health related quality of life (HRQOL). Secondly, the use of patient reported outcome measures (PROMs) to measure HRQOL in clinical practice is described as well as supportive care services and self-management options. Specific attention is paid to enhance accessibility of supportive care services and self-management through eHealth. Participatory design principles are described that are expected to optimize the effectiveness and usefulness of the eHealth applications. In chapter 1 the two main eHealth self-management applications in this thesis are presented: OncoQuest and Oncokompas. After this introduction, the goal of this thesis is described: to investigate the usefulness of online applications to monitor HRQOL by means of PROMs in HNC survivors, in terms of needs, usability, feasibility, adoption, usage, reach, satisfaction and long-term implementation, and factors that may influence the usefulness of these applications. Also, the hypotheses of this thesis are presented: (1) not all cancer survivors are reached by PROMs, but PROMs are mainly used by cancer patients with many symptoms and needs, (2) survivors are positive towards eHealth applications, but independent use is limited, and (3) by using participatory design principles in the development of eHealth applications, the feasibility of these applications is optimized.

In *Intermezzo OncoQuest*, the first of the two main (eHealth) self-management applications that were investigated in this thesis, OncoQuest, is described. OncoQuest is a touch-screen computer assisted system to monitor health related quality of life via patient reported outcome measures. It is usually followed by a consultation with the nurse to discuss the results of the screening. OncoQuest is available at the outpatient clinic in a separate consultation room with dedicated touch screen computers.

Chapter 2 describes the long-term follow-up of implementing PROMs in clinical practice using OncoQuest to monitor HRQOL in HNC survivors investigated via a mixed-methods design. The usage rate of OncoQuest and the subsequent nurse consultation were calculated among HNC survivors who visited the outpatient clinic for regular follow-up appointments. Differences between ever-users and never-users of OncoQuest were investigated, as well as the content of the nurse consultation. Reasons for not using (barriers) or using (facilitators) OncoQuest and the nurse consultation were explored from the perspective of HNC patients, and of head and neck surgeons.

Usage rate of OncoQuest was 67% and subsequent usage of the nurse consultation 79%. Tumor subsite and tumor stage were significantly related to usage of OncoQuest. The most frequently discussed topics during the nurse consultation were global quality of life (97%), head and neck cancer related symptoms (82%), other physical symptoms as pain (61%) and psychological problems as anxiety. The conclusion of the study was that 5 years after implementation, usage of PROMs in clinical practice combined with a nurse consultation is durable. This study contributes to better insight into long-term follow-up of implementation, thereby guiding future research and projects that aim to implement PROMs in clinical practice to monitor HRQOL among (head and neck) cancer patients.

Chapter 3 reports on the potential increase in Internet use and Internet use to search for cancer related information in HNC survivors between 2007 and 2015. It also describes the survivors that are most likely to use Internet, preferences of survivors towards future use of eHealth, and the use of eHealth in 2015. HNC survivors completed questionnaires. Factors associated with (cancer-related) Internet use were investigated using stepwise logistic regression analyses. Results showed that Internet use among HNC survivors increased from 53% in 2007 to 79% in 2015. The Internet was used to search for information on cancer by respectively 46% and 59% of these survivors. In 2007, survivors that were most likely to use the Internet were younger survivors, and survivors with a tumor originating from the oral cavity. In 2015, younger survivors, survivors with a higher educational level and survivors with a partner used the Internet more often. Also, in 2015 survivors with a higher educational level used the Internet more often to search for information on cancer. Future use of eHealth was appealing to many survivors in both samples (2007 range: 21%-68% and 2015 range: 16%-71%). The use of eHealth in 2015 was limited (range: 0-10%). The results of this study indicate that Internet use among HNC survivors has increased strongly. Internet was especially used to search for information on cancer. Since many survivors were interested in future eHealth use, attention should be paid to ensure adequate awareness among HNC survivors.

Following participatory design principles, in *chapter 4* the needs of cancer survivors towards an eHealth application monitoring quality of life and targeting personalized access to supportive care were investigated through a qualitative study. In total, 30 cancer survivors (15 HNC, 15 breast cancer) were interviewed regarding their unmet needs during follow-up care and the potential of an eHealth application. Data were analyzed independently by two coders and coded into key issues and themes. Cancer survivors mentioned they felt unprepared for the post-treatment period, and that often their remaining symptoms remained unknown to HCPs. They also mentioned that referral to supportive care services was suboptimal. An eHealth application had various advantages according to survivors interviewed; insight into the course of symptoms by monitoring, availability of information between follow-up appointments, and receiving personalized advice and tailored supportive care options. Cancer survivors identified several unmet needs during follow-up care. Most survivors were positive towards the proposed eHealth application and expressed that it could be a valuable addition to current follow-up cancer care. The study results provide insight into barriers that impede survivors from obtaining optimal supportive care. This study also provides insight into the characteristics needed to design, build and implement an eHealth application targeting personalized access to supportive care from the survivors' perspective.

Chapter 5 describes the perspectives of HCPs toward follow-up care and the possibility of an eHealth application in follow-up care, that monitors HRQOL by means of PROMs, followed by personalized advice and feedback on available supportive care options. The study consisted of three steps. In step 1, HCPs were interviewed on current follow-up care and the anticipated value of an eHealth application. In step 2, a prototype of the eHealth application was developed following the results from the current needs assessment among HCPs and the previous needs assessment among cancer survivors described in chapter 4. In step 3, cognitive walkthroughs (CWs) were conducted with the HCPs to investigate the perceived usability of the application. Several barriers in current follow-up care were identified by HCPs, such as difficulties in detecting survivors' symptoms, survivors' perceived need for supportive care, and a lack of time to discuss opportunities of supportive care with survivors. An eHealth application was expected to be of added value to follow-up cancer care, and HCPs expected it could support survivors in obtaining supportive care tailored to their needs. The CWs of the prototype of Oncokompas emphasized the importance of tailoring care. HCPs considered the navigation structure of Oncokompas to be complex. The opinion of HCPs towards the optimal strategy to implement the application in clinical practice differed (as a self-management application vs. a supported self-management application), but all HCPs agreed that the application should be incorporated in the HNC care pathway to ensure all survivors can benefit. The conclusion from the study was that HCPs experienced several barriers in directing patients to supportive care. They were positive toward the development and implementation of an eHealth application and expected it could support survivors in obtaining supportive care tailored to their needs. The CWs revealed several points for optimizing the application prototype and developing an efficient implementation strategy. Including HCPs in an early phase of a participatory design approach is valuable in developing an eHealth application and an implementation strategy meeting stakeholders' needs.

In *Intermezzo Oncokompas*, the development cycle of the self-management application Oncokompas is described. In Oncokompas, cancer survivors can monitor their HRQOL via PROMs, which is followed by automatically generated individually tailored feedback, and personalized advice on supportive care. Also, the results of the usability study that was conducted with Oncokompas are described.

In *chapter 6* the feasibility of Oncokompas was investigated among HNC survivors, through a pretest-posttest design study. A survey was conducted among survivors before providing access to Oncokompas, and two weeks after, followed by an interview by a nurse. Implementation was defined as the percentage of participants that actually used Oncokompas as intended. General satisfaction was assessed based on the mean score of 3 study specific questions: 1) general impression of Oncokompas, 2) the user-friendliness, and 3) the ability to use Oncokompas without assistance (10-point Likert scales). Furthermore, satisfaction was measured with the Net Promotor Scale (NPS). Oncokompas was found feasible with a good adoption grade (64%), implementation grade (75-91%), and mean satisfaction score of 7.3, and a positive Net Promotor Score (1.9). No relationship was found between socio-demographic and clinical factors and HRQOL with satisfaction. The study revealed several facilitators and barriers regarding the feasibility of Oncokompas. In conclusion, Oncokompas was found feasible, but several areas for improvement were mentioned, including balancing the time it takes to use Oncokompas, measurement precision, and tailoring towards personalized advices.

Finally, in *chapter 7*, the main findings, methodological considerations and clinical implications are addressed and recommendations for future research are given. The main findings as described in this chapter follow the hypotheses that were stated in the introduction. First, this chapter elaborates on the finding that the use of PROMs in clinical practice by means of a computer-assisted PROMs system (OncoQuest) is feasible and durable in clinical practice, and that mainly survivors with many symptoms and supportive care needs seem to use this application. Secondly, the option is discussed of a home-based online self-management application to overcome the logistical barriers that may impede survivors from using an application at the outpatient clinic. To improve survivors' HRQOL, feedback following PROM collection is essential; therefore an online application should provide automated tailored feedback to be of additional value. Recommendations for future research include further investigation of (possible moderators that influence) the effectiveness and barriers and facilitators regarding adequate implementation of interventions like OncoQuest and Oncokompas, to enhance the reach and adoption of these applications in routine care.

Overall, it is concluded that both a computer-assisted PROMs system at the outpatient clinic (OncoQuest) and an online home-based application (Oncokompas) are useful tools that supplement supportive care provided by health care professionals.


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SAMENVATTING

SUMMARY IN DUTCH

Het eerste hoofdstuk omvat de algemene introductie van dit proefschrift. In dit hoofdstuk wordt een beschrijving gegeven van hoofd-halskanker en de behandelopties hiervoor, evenals de impact die dit type kanker kan hebben op de kwaliteit van leven van deze patiënten. Daarnaast worden het gebruik van patiënt gerapporteerde uitkomst maten (patient reported outcome measures: PROMs) om kwaliteit van leven te meten en mogelijke opties voor begeleidende zorg en zelfmanagement beschreven. Specifieke aandacht wordt gegeven aan het verbeteren van de toegankelijkheid van begeleidende zorg opties en zelfmanagement door het gebruik van eHealth. Hierbij worden participatieve benaderingen in het ontwikkelproces geschetst waarvan verwacht wordt dat deze de effectiviteit en bruikbaarheid van eHealth applicaties verbeteren. In hoofdstuk 1 worden de twee eHealth zelfmanagement applicaties die centraal staan in deze thesis benoemd: OncoQuest en Oncokompas. Na deze introductie wordt het doel van dit proefschrift beschreven; het onderzoeken van de bruikbaarheid van online applicaties om de kwaliteit van leven van hoofd-halskanker patiënten te monitoren middels het gebruik van PROMs, op het gebied van zowel behoeften, gebruiksvriendelijkheid, haalbaarheid, adoptie, gebruik, bereik, tevredenheid en implementatie op de lange termijn, en factoren die de bruikbaarheid van deze applicaties zouden kunnen beïnvloeden. Daarnaast worden de hypothesen van dit proefschrift gepresenteerd: (1) niet alle patiënten met kanker maken gebruik van PROMs; deze worden meestal gebruikt door patiënten met veel symptomen en (zorg)behoeften, (2) patiënten zijn positief omtrent het gebruik van eHealth applicaties, maar er wordt slechts beperkt gebruik van gemaakt, (3) door gebruik te maken van een participatieve benadering in de ontwikkeling van eHealth applicaties kan de haalbaarheid van deze applicaties geoptimaliseerd worden.

In *Intermezzo OncoQuest*, wordt de eerste van de twee eHealth zelfmanagement applicaties die in dit proefschrift zijn onderzocht (OncoQuest) beschreven. OncoQuest is een touch screen computersysteem dat erop gericht is het welzijn van patiënten met kanker te verbeteren door hun kwaliteit van leven te monitoren via vragenlijsten. OncoQuest wordt gevolgd door een gesprek met een verpleegkundige om de resultaten van de screening te bespreken. OncoQuest is beschikbaar in de polikliniek, in een aparte ruimte waarin speciaal voor OncoQuest beschikbare touch screen computers opgesteld staan.

Hoofdstuk 2 rapporteert de uitkomsten van de evaluatie op de lange termijn van het implementeren van het gebruik van PROMs in de klinische praktijk door middel van OncoQuest, om de kwaliteit van leven van hoofd-halskanker patiënten te monitoren. Hierbij is gebruik gemaakt van zowel kwalitatieve als kwantitatieve onderzoeksmethoden. De mate van gebruik van OncoQuest en het verpleegkundig consult werd onderzocht onder hoofd-halskanker patiënten die de polikliniek bezochten voor regelmatige nazorg afspraken. Verschillen tussen gebruikers en niet gebruikers van OncoQuest werden onderzocht, evenals de inhoud van het verpleegkundig consult. Redenen om OncoQuest en het verpleegkundig consult niet te gebruiken (barrières) of wel te gebruiken (facilitators) werden onderzocht vanuit het perspectief van hoofd-halskanker patiënten en hoofd-halskanker chirurgen. De mate van gebruik van OncoQuest onder patiënten was 67%, en van het verpleegkundig consult 79%. De locatie en gradatie van de tumor waren significant gerelateerd aan het gebruik van OncoQuest. De meest besproken onderwerpen tijdens het verpleegkundig consult betroffen de algemene kwaliteit van leven (97%), hoofd-halskanker symptomen (82%), andere fysieke symptomen zoals pijn (61%) en psychologische problemen zoals angst. De conclusie van de studie was dat vijf jaar na implementatie, het gebruik van PROMs in de klinische praktijk gecombineerd met een verpleegkundig consult duurzaam is. Deze studie geeft een inzicht in de lange-termijn follow-up van de implementatie van PROMs in de klinische praktijk, en geeft daarbij richting aan toekomstig onderzoek en projecten die tot doel hebben om PROMs in de klinische praktijk te implementeren om de kwaliteit van leven van (hoofd-hals)kanker patiënten te monitoren.

In *hoofdstuk 3* wordt de potentiële toename van internet gebruik, en internetgebruik voor het zoeken van informatie over kanker onder hoofd-halskanker patiënten tussen 2007 en 2015 onderzocht. Dit hoofdstuk beschrijft tevens de groep patiënten die het meest geneigd is om internet te gebruiken, voorkeuren van patiënten betreffende toekomstig gebruik van eHealth, en het daadwerkelijke gebruik van eHealth in 2015. Hiervoor werden door hoofd-halskanker patiënten vragenlijsten ingevuld. Factoren geassocieerd met (kanker-specifiek) internetgebruik werden onderzocht door middel van een stapsgewijze logistische regressie analyse. Uit de resultaten blijkt dat internetgebruik onder hoofd-halskanker patiënten is toegenomen van 53% in 2007 naar 79% in 2015. Internet werd gebruikt om informatie over kanker te zoeken door respectievelijk 46% en 59% van deze patiënten. In 2007 maakten voornamelijk jongere patiënten en patiënten met een tumor in de mondholte gebruik van internet. In 2015 maakten jongere patiënten, patiënten met een hoger opleidingsniveau en patiënten met een partner meer gebruik van internet. Ook maakten in 2015 patiënten met een hoger opleidingsniveau meer gebruik van internet om informatie over kanker te zoeken. Toekomstig gebruik van eHealth was voor veel patiënten in beide groepen aantrekkelijk (2007 range 21-68%, en 2015 range 16-71%). Het gebruik van eHealth in 2015 was beperkt (range 0-10%). De resultaten van deze studie tonen aan dat het internetgebruik onder hoofd-halskanker patiënten sterk toegenomen is. Internet werd met name gebruikt om informatie over kanker op te zoeken. Aangezien veel patiënten geïnteresseerd waren in toekomstig eHealth gebruik, dient er aandacht besteed te worden aan de bewustwording over eHealth mogelijkheden onder hoofd-halskanker patiënten.

In *hoofdstuk 4* zijn, volgens de stappen van de participatieve ontwikkel benadering, de behoeften van hoofd-halskanker patiënten met betrekking tot een eHealth applicatie die hun kwaliteit van leven monitort en erop gericht is hen persoonlijke toegang te geven tot begeleidende zorg opties, onderzocht middels een kwalitatieve studie. In totaal zijn 30 patiënten met kanker (15 hoofd-halskanker en 15 borstkanker patiënten) geïnterviewd over hun (onvervulde) zorgbehoeften tijdens hun nazorg traject en over de potentie van een eHealth applicatie. Data werden geanalyseerd door twee onafhankelijke codeurs, en gecodeerd in belangrijke onderwerpen en thema's. Patiënten benoemden dat zij zich onvoorbereid voelden voor de periode na behandeling, en dat hun symptomen vaak niet bekend waren bij zorgprofessionals. Ze noemden ook dat de verwijzing naar begeleidende zorg suboptimaal was. Een eHealth applicatie bood volgens hen verschillende voordelen: inzicht in het verloop van hun symptomen door deze te monitoren, beschikbaarheid van informatie tussen twee nazorg afspraken in, en het ontvangen van persoonlijk advies en begeleidende zorg afgestemd op hun behoeften. De patiënten identificeerden verschillende onvervulde behoeften tijdens de nazorgfase van hun behandeling. De meeste patiënten waren positief omtrent de voorgestelde eHealth applicatie en duidden aan dat het een waardevolle toevoeging zou kunnen zijn aan de huidige nazorg. Deze studie resultaten geven inzicht in barrières die ervoor zorgen dat patiënten geen optimale begeleidende zorg ontvangen. Deze studie geeft tevens inzicht in de elementen die nodig zijn om een eHealth applicatie gericht op het geven van persoonlijk advies en toegang tot begeleidende zorg vanuit het perspectief van de patiënt te ontwerpen, ontwikkelen en implementeren.

In *hoofdstuk 5* zijn de perspectieven van zorgprofessionals onderzocht omtrent nazorg en de mogelijkheid van een eHealth applicatie in de nazorgfase van de behandeling voor hoofd-halskanker, die de kwaliteit van leven monitort door het gebruik van PROMs, gevolgd door persoonlijk advies en feedback omtrent begeleidende zorg opties. Deze studie bestond uit drie stappen. In stap 1 werden zorgprofessionals geïnterviewd over de huidige zorg tijdens de nazorgfase en de verwachte toegevoegde waarde van een eHealth applicatie. In stap 2 werd een prototype van de eHealth applicatie ontwikkeld volgens de resultaten van het behoeftenonderzoek onder zowel de zorgprofessionals, als het eerdere behoeftenonderzoek onder patiënten zoals beschreven in hoofdstuk 4. In stap 3 werden 'cognitive walkthroughs' (CW's) uitgevoerd onder de zorgprofessionals om de verwachte bruikbaarheid van de applicatie te onderzoeken. Verschillende barrières in de nazorgfase werden geïdentificeerd door zorgprofessionals, waaronder barrières bij het vaststellen van de symptomen van patiënten, de behoefte van patiënten aan begeleidende zorg, en een gebrek aan tijd om mogelijkheden van begeleidende zorg met patiënten te bespreken. Verwacht werd dat een eHealth applicatie van toegevoegde waarde zou zijn gedurende de nazorgfase, en zorgprofessionals verwachtten dat het patiënten zou kunnen ondersteunen in het vinden van begeleidende zorg afgestemd op hun persoonlijke behoeften. De CW's waarin gebruik gemaakt werd van het prototype van Oncokompas benadrukten het belang van zorg op maat. Zorgprofessionals vonden de navigatiestructuur van Oncokompas complex. De mening van zorgprofessionals betreffende de beste implementatiestrategie verschilde (als een zelfmanagement applicatie vs. een zelfmanagement applicatie met ondersteuning door een zorgprofessional). Alle zorgprofessionals waren van mening dat de applicatie ingebed zou moeten worden in het zorgpad voor hoofd-halskanker patiënten om ervoor te zorgen dat alle patiënten ervan zouden kunnen profiteren. De conclusie van de studie was dat zorgprofessionals verschillende barrières ervoeren in het verwijzen van patiënten naar begeleidende zorg. Ze waren positief over de ontwikkeling en implementatie van een eHealth applicatie, en verwachtten dat het patiënten kan ondersteunen in het vinden van begeleidende zorg afgestemd op hun persoonlijke behoeften. De CW's brachten belangrijke punten naar voren voor het verbeteren van het prototype van de applicatie, en het ontwikkelen van een efficiënte implementatie strategie. Het betrekken van zorgprofessionals in een begin stadium van een participatieve ontwikkelingsbenadering is waardevol bij het ontwikkelen van een eHealth applicatie en een implementatie strategie die voldoet aan de behoeften van de belanghebbenden.

In *Intermezzo Oncokompas* wordt de ontwikkelingscyclus van de zelfmanagement applicatie Oncokompas beschreven. In Oncokompas kunnen kanker patiënten hun kwaliteit van leven monitoren via PROMs, gevolgd door automatisch gegenereerde individueel persoonlijke feedback, en persoonlijk advies omtrent begeleidende zorg opties. Ook worden de resultaten van de bruikbaarheidsstudie die is uitgevoerd met Oncokompas beschreven.

In *hoofdstuk 6* is de haalbaarheid van Oncokompas onder hoofd-halskanker patiënten onderzocht, door middel van een pretest-posttest design studie. Bij patiënten werd voorafgaand aan toegang tot Oncokompas en twee weken daarna, een vragenlijst afgenomen, gevolgd door een interview met een verpleegkundige. Implementatie werd gedefinieerd als het percentage deelnemers dat gebruik maakte van Oncokompas zoals bedoeld. Algehele tevredenheid werd vastgesteld op basis van de gemiddelde score van 3 studie specifieke vragen: 1) algehele indruk van Oncokompas, 2) de gebruikersvriendelijkheid, 3) de mogelijkheid om Oncokompas te gebruiken zonder assistentie (op een 10-punt Likert schaal). Daarnaast werd tevredenheid gemeten met de Net Promotor Score (NPS). Oncokompas werd haalbaar bevonden, met een goede adoptie graad (64%), implementatie graad (75-91%), en gemiddelde tevredenheidsscore van 7,3, en een positieve Net Promotor Score (1,9). Er werd geen relatie gevonden tussen tevredenheid en socio-demografische factoren, klinische factoren, en kwaliteit van leven. Concluderend werd Oncokompas haalbaar bevonden, maar werden verschillende verbeterpunten genoemd, waaronder het balanceren van de tijd die het kost om Oncokompas in te vullen, de meetprecisie, en het ontvangen van toegespitst persoonlijk advies.

Tot slot worden in *hoofdstuk 7* de belangrijkste bevindingen, methodologische aspecten en klinische implicaties genoemd en adviezen voor toekomstig onderzoek gegeven. De belangrijkste bevindingen beschreven in dit hoofdstuk volgen de hypothesen die in de introductie zijn benoemd. Als eerste wijdt dit hoofdstuk uit over de bevinding dat het gebruik van PROMs in de klinische praktijk door middel van een computersysteem (OncoQuest) haalbaar en duurzaam is in de klinische praktijk en dat vooral patiënten met veel symptomen en behoefte aan begeleidende zorg hiervan gebruik maken. Als tweede wordt de optie van een online zelfmanagement applicatie die vanuit huis gebruikt kan worden bediscussieerd, om de logistieke barrières die patiënten met kanker ervan zouden kunnen weerhouden om een dergelijke applicatie te gebruiken te verminderen. Om de kwaliteit van leven te verbeteren is feedback na het verzamelen van PROMs essentieel; om deze reden zou een online applicatie automatisch gegenereerde feedback op maat moeten bevatten om van toegevoegde waarde te zijn. Aanbevelingen voor toekomstig onderzoek omvatten onder andere verder onderzoek naar (mogelijke moderatoren die van invloed kunnen zijn op) de effectiviteit en barrières en facilitators ten aanzien van adequate implementatie van interventies zoals OncoQuest en Oncokompas, om de reikwijdte en adoptie van dit soort applicaties in de zorg te vergroten.

De conclusie van dit proefschrift is dat zowel een computersysteem gebruik makend van PROMs op de polikliniek (OncoQuest), als een online applicatie vanuit huis (Oncokompas) bruikbare instrumenten zijn om de zorg gegeven door zorgprofessionals te ondersteunen.


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ABOUT THE AUTHOR

Sanne Duman-Lubberding was born on October 13th 1982, in Apeldoorn, the Netherlands. In 2000 she completed her secondary education (VWO) at Cals College, Nieuwegein. Subsequently, she traveled to the USA for a 'High School Year' at Unity High School in Balsam Lake, Wisconsin, and received her High School Diploma in 2001. From 2001 until 2006 she studied Psychology at VU University Amsterdam, and graduated in clinical psychology. After graduation, she started working as a junior researcher at VU University Medical Center, EMGO+ Institute for Health and Care Research, as part of the Patient Safety Research Group. The Patient Safety Research Group was a close collaboration between VU University Medical Center, EMGO+ Institute for Health and Care Research and the Netherlands Institute for Health Services Research (NIVEL). From 2008 she continued to work as a member of the Patient Safety Research Group for NIVEL. In 2011, she started as a PhD candidate at VU University Medical Center, department of Otolaryngology-Head and Neck Surgery. She coordinated the research about the development and evaluation of Oncokompas, as described in this thesis. From 2012 until 2016 she combined her PhD candidacy with the post-master healthcare training program for psychologists ('GZ-opleiding') at Zaans Medical Center. From January 2017 she works as a GZ-psychologist at Schiphol Detention Center (DCS), where she provides psychological treatment and counseling for prisoners and refugees. She is married to Fesih, and together they are blessed with two children; Samih and Isra.


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'*Het werd, het was, het is gedaan*'.