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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 6\(^{th}\) most common
type of cancer. Men are twice as likely to develop HNC as compared to women.

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. Besides tobacco and alcohol use, human papilloma virus infections (HPV) play an increasing role in the origination of mainly oropharyngeal cancers. The risk of developing HNC increases with age. Most patients are diagnosed between the age of 55 and 74.

**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. 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.

**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. 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. For many survivors, problems remain present long after treatment for HNC has finished.

Patient reported outcome measures (PROMs) are developed to assess HRQOL. 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, can function as a reminder for topics to discuss during patient-physician consultations that may be easily overlooked or are difficult to bring up, and can be helpful in tracking changes in survivors experienced symptoms over time. Monitoring HRQOL may lead to more accurately met individual supportive care needs, when PROMs are followed by individual feedback on supportive cancer care to the survivor.

**SUPPORTIVE CANCER CARE**

Supportive care is defined as the prevention and management of the adverse effects of cancer and its treatment. 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. Barriers that impede survivors from obtaining adequate supportive care are a lack of awareness of available services among survivors and HCPs, a lack of identification of survivor’s symptoms and needs, inadequate referral by HCPs, e.g. due to inadequate discussion of symptoms experienced, and changes in the current health care system such as centralization of care and limited time of HCPs. 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. Exhaustion and therefore not wanting to visit other HCPs after an intensive period of cancer treatment can also play a role.

To improve accessibility to supportive care services, cancer survivors are expected to adopt an active role in managing their own care. Self-management interventions such as educational interventions, exercise programs, and (online) self-help interventions can improve cancer patients’ self-efficacy. McCorkle et al. 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. There is growing interest in eHealth among cancer survivors, healthcare providers, healthcare assurance companies, and policy-makers, as a means to improve self-management.

**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. 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. However, there are only few eHealth applications available for HNC cancer survivors. 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.

**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\textsuperscript{68}. Often, there is little attention for the interdependency between end-users, technology and the socioeconomic environment\textsuperscript{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\textsuperscript{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\textsuperscript{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.
REFERENCES


