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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 survivors1-5, and is advised in best practices and national guidelines [e.g. 6-11]. Studies have shown that implementation is feasible2,12-14. 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. 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. 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.

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. Explanations that were mentioned included that elderly patients seem to be skeptical towards HRQOL monitoring e.g. because they fear to lose contact with their HCP. 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. 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. 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. 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. 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)\textsuperscript{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\textsuperscript{24–26}, but the applications that are available are acceptable and used by HNC survivors\textsuperscript{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\textsuperscript{22}. Acceptability of HNC survivors is good regarding specific eHealth self-management applications to support them during follow-up care (chapter 4 and 5)\textsuperscript{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\textsuperscript{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 principles31–33, whilst applications that have not used such an extensive development period are often less successful30,34. 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 used35,36. 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 games37. 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.

STRENGTHS 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. 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, 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. Feedback from a HCP is essential 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, 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, particularly when a relatively mild intervention was offered to them. This group needs a more personalized and active approach. 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\textsuperscript{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\textsuperscript{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.
REFERENCES


