

SUMMARY

The main aim of this thesis was to investigate the usefulness of three (eHealth) self-management interventions in clinical practice (1) 'OncoQuest' (OQ), an application to monitor HRQOL, (2) 'Head Matters' (HM), a multimodal guided self-care exercise intervention to prevent speech, swallowing and shoulder problems in HNC patients during and after radiotherapy (RT) alone or in combination with chemotherapy, and (3) 'In Tune without Cords' (ITwC), a self-care intervention to support the rehabilitation of TLPs. The usefulness of these interventions supporting the rehabilitation of HNC patients was investigated, and insights were gained into the factors influencing the usefulness of these interventions.

The purpose of the first study was to evaluate the usefulness of OQ to monitor speech and swallowing outcomes and its impact on QoL and emotional well-being in HNC patients in an outpatient clinic (**chapter 2**). At baseline (at time of diagnosis) and at first follow-up (1 month after end of treatment) HNC patients completed the EORTC QLQ-C30 and QLQ-H&N35 questionnaires and the Hospital Anxiety and Depression Scale, using OQ. No speech or swallowing problems at baseline or follow-up were noted in 23% (speech) and 41% (swallowing) of patients. Twenty-one percent (speech) and 19% (swallowing) had problems at baseline and returned to normal scores at follow-up, while 16% (speech) and 19% (swallowing) had normal scores at baseline but developed problems at follow-up. Forty percent (speech) and 21% (swallowing) had persistent problems from baseline to follow-up. At baseline, speech problems were significantly related to tumor site and emotional distress. At baseline and follow-up, swallowing problems were significantly related to QoL and emotional distress. At follow-up, speech problems were significantly related to QoL, emotional distress, and swallowing problems. It was concluded that monitoring speech and swallowing problems through OQ in an outpatient clinic is feasible. Many patients reported speech and swallowing problems, negatively affecting their HRQOL and emotional well-being.

In the second study the feasibility of HM was investigated, a multimodal guided self-help exercise program (**chapter 3**). During a 6-week course of RT many HNC patients have to endure radiotherapy-induced toxicity, negatively affecting patients' HRQOL. Pretreatment counseling combined with self-help exercises can be provided to inform patients and possibly prevent them from having speech, swallowing, and shoulder problems, and a stiff neck during and after treatment. Participating HNC patients ($n=33$) were asked to follow HM targeting prevention of deterioration of speech, swallowing, and shoulder function during and after treatment with RT alone or in combination with chemotherapy. HM was offered in three different formats, a leaflet, an online and a booklet format. Weekly coaching was provided by a speech and swallowing therapist. Patients filled out a diary to keep track of their exercise activity. To gain insight into possible barriers and facilitators to exercise adherence, reports of weekly coaching sessions were analyzed by two coders independently using qualitative research methods. Results from this study indicated that the guided self-help exercise program HM is feasible among HNC patients undergoing primary or postoperative RT (combined

with chemotherapy) with high uptake (83%) and reasonable adherence rates (64%). The majority of participants (58%) performed at least the minimum number of exercises during 6 weeks, and had moderate to high levels of exercise performance. Exercise performance level was not significantly associated with age ($P=.50$), gender ($P=.42$), tumor subsite ($P=1.00$) or tumor stage ($P=.20$), treatment modality ($P=.72$), or Head Matters format (web-based or paper) ($P=1.00$). Based on the analysis of reports of weekly coaching sessions, patients' perceived barriers to exercise were a decreased physical condition, treatment-related barriers, emotional problems, lack of motivation, social barriers, and technical problems. Patients' perceived facilitators included an increased physical condition, feeling motivated, and social and technical facilitators. The conclusion was that HM, a multimodal guided self-help exercise program is feasible for HNC patients undergoing (chemo) radiation.

In the third study adherence, and exercise performance levels and its associated factors in HNC patients ($n=50$) following HM during and after treatment with SW-IMRT (combined with chemotherapy) ((C)SW-IMRT) were investigated (**chapter 4**). Adherence (percentage of patients who kept up exercising) and exercise performance level (categorized as low: ≤ 1 , moderate: 1-2, and high: ≥ 2 time(s) per day, on average) were assessed using patient-completed diaries. Associations between 6- and 12-week exercise performance levels (low vs moderate/high), and age, gender, tumor site and stage, treatment, format, amount of coaching sessions and baseline HNC specific symptoms (EORTC QLQ-H&N35) were investigated. Changes in exercise performance levels in relation to each of these symptoms (at weeks 1 to 6, and at 12 weeks) were analyzed. Six- and 12-week adherence rates were 70% and 38% respectively. Exercise performance levels were most frequent low (during 6 weeks: 40%; during 12 weeks: 54%), and decreased over time (during 6 weeks: 34% moderate and 26% high; during 12 weeks: 28% moderate and 18% high). The addition of chemotherapy to SW-IMRT (CSW-IMRT) was the only factor significantly associated with low exercise performance level during six weeks ($P=.015$) and 12 weeks ($P<.001$). The conclusion was that adherence to a guided home-based prophylactic exercise program was high during (C)SW-IMRT but dropped afterwards. Exercise performance levels varied and were especially low in patients treated with chemotherapy in combination with SW-IMRT.

In **chapter 5** the development process of a web-based self-care program (ITwC) for patients after total laryngectomy according to a participatory design approach was described. A needs assessment was conducted with laryngectomees ($n=9$) and their partners ($n=3$) by means of a focus group interview. In 4 focus group sessions, a requirement plan was formulated by a team of health care professionals ($n=10$) and translated into a prototype. An eHealth application was built including illustrated information on functional changes after total laryngectomy as well as video demonstrations of skills and exercises. Usability of the prototype was tested by end users (laryngectomees; $n=4$) and expert users (speech therapists; $n=10$). Interviews were held to elicit the intention to use and the desired implementation strategy. Six main self-care topics were identified: (1) nutrition, (2) tracheostomy care, (3) voice prosthesis care, (4) speech rehabilitation, (5) smell

rehabilitation, and (6) mobility of head, neck, and shoulder muscles. Speech therapists expressed concerns regarding tailored exercises, indicated a positive intent to implement the intervention in routine care, and expressed a need for guidance when implementing the intervention. End users and expert users appreciated the content completeness and multimedia-based information built into the application. The participatory design is a valuable approach to develop a self-care program to help meet users' needs.

In **chapter 6** the feasibility of ITwC, and factors associated with satisfaction were investigated in clinical practice. HCPs were invited to participate and to recruit TLPs. TLPs were informed on the self-care education program ITwC after which they gained access. A study specific survey was used (at baseline T0 and post intervention T1) on TLPs' uptake. Usage, satisfaction (general impression, willingness to use, user-friendliness, satisfaction with self-care advice and strategies, Net Promoter Score (NPS)), sociodemographic, and clinical factors were analyzed. HCPs of 6 out of 9 centers (67% uptake rate) agreed to participate and recruited TLPs. In total, 55 of 75 TLPs returned informed consent and the baseline T0 survey and were provided access to ITwC (73% uptake rate). Thirty-eight of these 55 TLPs used ITwC and completed the T1 survey (69% usage rate). Most (66%) TLPs were satisfied (i.e., score ≥ 7 (scale 1–10) on 4 survey items) with the self-care education program (mean score 7.2, SD 1.1). NPS was positive (+5). Satisfaction with the self-care education program was significantly associated with (higher) educational level and health literacy skills ($P=.004$, $P=.038$, respectively). No significant association was found with gender, age, marital status, employment status, Internet use, Internet literacy, treatment modality, time since total laryngectomy, and quality of life. The online self-care education program ITwC supporting early rehabilitation was feasible in clinical practice. In general, TLPs were satisfied with the program.

In the general discussion (**chapter 7**) of this thesis the main findings, methodological considerations, and implications for clinical practice were described, followed by directions for future research. The general conclusion of this thesis was that applying a participatory design approach has led to useful, user-friendly and feasible (online) self-management interventions and that OQ, HM, and ITwC proved to be useful, feasible, and satisfactory in clinical practice. Results of the studies conducted showed that part of the HNC patients prefer to receive the intervention via a book format. Therefore, HM and ITwC were also made available via a book format with DVDs of video exercise demonstrations, but it is expected that this may increase intervention costs. Through the studies described in this thesis a better understanding of the usefulness of (eHealth) self-management interventions among HNC patients was achieved, but the potential of these interventions should be further explored. More research is needed to increase adherence and to gain insight into the multitude of factors that contribute to poor exercise adherence. Also, more research on the efficacy and cost-effectiveness, as well as the implementation of these new interventions in clinical practice is warranted.