

Digital self-management support for patients with esophageal cancer

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Summary

The impact of being diagnosed with esophageal cancer is high, because patients have to deal with the impact on physical and nutritional status and ultimately on quality of life, especially during the pre-operative period. Currently, people with cancer are expected to take a more active role in their health care, which involves symptom management, adherence to treatment regimens, commitment to appropriate lifestyle changes, and the ability to deal with the psychological and physical consequences of their condition. This so-called self-management is challenging for patients. Receiving adequate support is crucial and providing this support is an important task of healthcare professionals. Self-management support aims to learn patients to actively participate in the management of their chronic condition and is the systematic provision of supportive interventions by healthcare staff to increase patients' skills and confidence in managing their chronic disease, including regular assessment of progress and problems, goal setting, and problem-solving support. With the rising healthcare costs, the increasing number of patients having access to and using the internet, and the rapid development of digital technology, there is growing interest in digital support among cancer patients, healthcare providers, healthcare assurance companies, and policy-makers, as a means to improve self-management. These digital self-management support tools (DSMSTs) can be any kind of digital application (e.g. website, electronic patient file, app) used on any type of digital device (e.g. smartwatch, laptop, tablet, phone) that is applied by physicians in their healthcare practice or by individuals to monitor or improve their health status. Subsequently, there's a demand for new knowledge regarding the experiences and needs of self-management supportive care of patients with potentially curable esophageal cancer planned for surgery and to investigate their preferences towards DSMST. The main aims of this thesis are to:

- I. Explore the effectiveness of digital self-management support interventions in the care plan of cancer patients
- II. Evaluate the outcome of a web-based self-management intervention for esophageal cancer patients in the pre-operative phase
- III. Investigate the (digital) self-management support needs and requirements of esophageal cancer patients in the pre- (and post) operative care.

In **Chapter 2** a systematic review was performed to explore the effectiveness of digital self-management support interventions in the care plan of cancer patients. A total of 19 publications describing 3 types of DSMST were included. Although the content, duration, and frequency of interventions varied considerably across studies, the commonly used elements included an

assessment component, tailored symptom self-management support, an information section, a communication section, and a diary. This review suggested that DSMSTs have a beneficial effect on the quality of life. For effects on other patient outcomes (eg, anxiety and depression, symptom distress, physical activity, dietary behavior, and fatigue), the evidence is inconsistent and limited or no effect was suggested, mainly due to the variety across studies in content, duration, and frequency of the interventions. In addition, the review identified several lacunas in the available body of evidence regarding effects of DSMST on patients with specific tumor types, patients with cancer in a specific disease stage, the design of technology, and especially the design of technology tailored to the patients' needs. This overview provides an initial step to guide clinicians and researchers to focus further research on specific tumor types, to study different types of interventions separately, and assess the effects of specific interventions at different stages of disease progression.

Chapter 3 aimed to investigate the adoption and actual use of a digital dietary monitoring system (DDMS) and its impact on patient satisfaction with the provided hospital care, body weight changes and health-related quality of life (HRQoL) in patients with potentially curable esophageal cancer planned for surgery. The DDMS enabled patients and dietitians to monitor patients' nutritional intake and body weight during the preoperative period. In this prospective observational study, the first 47 included patients received usual nutritional care, and were followed from diagnosis until surgery. After implementation of the DDMS 37 patients were followed, again from diagnosis until surgery. Main outcomes were actual use of the DDMS, by means of adoption and usage measures, overall patient satisfaction (EORTC-INPATSAT32), weight change and HRQoL (EORTC QLQ-C30 and EORTC-OG25). Outcomes were assessed immediately after diagnosis, and 6 and 12 weeks later. The system had an adoption rate of 64% and a usage rate of 78%. No significant effects on patient satisfaction were found at 12 weeks after diagnosis between the intervention and the usual care group. The implementation of the DDMS also had no significant effect on body weight and HRQoL over time. This 'stage of disease'-specific study showed that the DDMS is feasible for many potentially curable EC patients even during neo-adjuvant CRT before surgery.

In **Chapter 4**, we aimed to gain consensus on healthcare professionals' perspectives on self-management support information needs of patients with esophageal cancer during the preoperative phase. Based on the literature, observations of clinical consultations, and hospital patient information leaflets, a survey was created. HCPs were surveyed twice about their opinion on importance of information, from "not essential" to "absolutely essential," using Delphi methods. Topics were included in the second round if predetermined criteria were met. To be included in the final list, topics had to meet criteria for consensus and stability. 64 information items and 6 sources

of support were identified. Survey response rates were 59% (68 out of 116, first round) and 75% thereafter. The final list included 33 topics, including logistical information, expectations for future health condition, complications, follow-up care, nutrition during treatment, and nutrition during recovery as topics with 100% agreement. Consensus on the source of support was reached for face-to-face contact, written information, information video, and a case manager. This study provided a list of important topics, from the perspectives of HCPs, to guide the systematic provision of education to support EC patients' self-management during the preoperative phase.

The aim of **chapter 5** was to gain consensus on the patients' perspectives on the self-management support needs of patients with esophageal cancer during the pre-operative phase. A multicenter Delphi study among patients with esophageal cancer in the pre-operative phase from 8 esophageal (expert) centers in the Netherlands was performed. Participants were surveyed twice. In round 1, participants rated 64 information items and 6 different sources of support from "not essential" to "absolutely essential" on a 1 to 9 Likert scale. Topics were included in the second round if predetermined criteria were met, together with feedback on individual and group scores. To be included in the final list, topics had to meet criteria for consensus and stability. Survey response rates were 84.3% (86 out of 102, round 1) and 73.4% thereafter. The final list included 26 topics, including expectations for future health condition as the one topic considered most important. No consensus on the source of support was reached. This multicenter Delphi study among patients has established a core set for self-management support information needs of patients with esophageal cancer during the pre-operative phase. This core set may direct the systematic provision of education to support the patients' self-management.

The aim of the study in **chapter 6** was to explore experiences of patients with esophageal cancer during curative treatment regarding self-management, relevant aspects of self-management in which they need additional support, and to explore their willingness to use eHealth. 13 semi-structured interviews were held with esophageal cancer patients, (≥ 18 years) who have been treated with neo-adjuvant chemo(radio)therapy followed by surgery, maximally 1 year after surgery. The following themes were discussed: experience-based knowledge, contribution to care, living with the condition, and organization of care and support. Content analysis was used to analyze the data. All four self-management domains were identified. Participants described the diverse experiences with self-management, their need for support, and highlighted feeling unprepared for the postoperative period. Participants are open to the idea of using eHealth in addition to usual care and expressed that (digital) self-management support should be personal, easily accessible, person-centered, and confidential. Differences between patients with esophageal cancer in their expectations and needs

regarding self-management, self-management support and eHealth for self-management purposes are found, indicating that no one approach will meet the needs of all patients at all points in time.

In the general discussion in **Chapter 7**, the main findings and methodological considerations of this thesis are discussed. Furthermore, implications for clinical practice and recommendations for future research are presented.

In conclusion, this thesis has resulted in an improved understanding of the (digital) self-management support needs and requirements of esophageal cancer patients during the pre- (and post-) operative care. In addition, the results from the different studies in this thesis might represent an initial step towards the development of a new (digital) self-management support intervention to support patients with EC.