Optimizing cancer care through e-health: status, potential, and adoption

Wessels-van Deursen, J.E.

Chapter 1

General introduction

Current state of cancer and cancer care

Cancer is a growing global health issue. In 2020, the worldwide prevalence of cancer reached approximately 18.1 million cancer cases, with a twofold increase expected by 2070 [1, 2]. Similarly, the number of cancer diagnoses in the Netherlands has increased significantly over the years, from 56,000 new diagnoses in 1989 to almost 130,000 in 2024 [3]. One out of every two Dutch individuals will be diagnosed with cancer at some point in their lifespan, positioning the Netherlands with the second-highest incidence rate in the European Union [4]. Projections for the year 2032 foresee a further increase, estimating 156,000 new diagnoses, with an estimated 1.4 million individuals living with or after a cancer diagnosis in the Netherlands [5, 6].

Several reasons can explain the rising incidence and prevalence of cancer in the Netherlands. The leading cause is the aging of the Dutch population, which has resulted in an increased number of older adults that are living longer [5]. Secondly, the rise is explained by lifestyle-related factors, such as lack of physical activity, overweight, exposure to UV radiation, smoking behaviour, and alcohol consumption [5, 7-9]. For instance, over the next decade, a significant growth is expected in cancers associated with obesity and there is a projected rise of over 30% in skin cancer incidence [5]. Lastly, developments in diagnostic and screening methods have contributed to the early detection of a higher number of cancer cases, including through the Dutch national screening programs for breast, colorectal, and cervical cancer [5, 10].

Cancer globally accounted for 9.7 million deaths in 2022, but survival rates are improving [11, 12]. For instance, in the Netherlands, the five-year survival rates have increased from 56% for women and 42% for men between 1990 and 1994 to 70% for women and 66% for men in recent years [5]. This progress is largely due to developments in treatment and diagnostics (i.e., early detection measures such as population screenings leading to early treatment). As a result, cancer is increasingly being managed as a chronic condition or, in some cases, even cured, rather than being universally fatal [13].

Cancer survivors, defined as individuals who live with cancer from diagnosis until the end of life [14], however, often face many challenges and side effects related to the disease and its treatment. The effects of cancer and its treatment can vary depending on the type of cancer. They may include fatigue, fear, depression, pain, neuropathy, cognitive limitations, sexual dysfunction, employment issues, and social challenges [15-23]. These effects can significantly affect individuals' quality of life. To address the impact of these issues in daily life, support from healthcare providers such as physiotherapists, psychologists, dietitians, and general practitioners is often needed. However, this support is not always readily available or sufficient. This can make it difficult for patients to receive the necessary help and many survivors have unmet needs relating to emotional

and social support, the management of side effects, coping with the fear of recurrence, access to up-to-date information, work support, and smoking cessation support [22, 24-28].

As the demand for care rises due to an increasing number of new diagnoses and a growing population of cancer survivors, the healthcare sector faces the escalating challenge of limited staff capacity, with many healthcare providers experiencing heavier workloads. Projections indicate that by 2060, one in three employees will be required to work in the healthcare sector to meet the demand for care, compared to the current ratio of one in six [29]. Along with capacity issues, the affordability of care is becoming a major concern [5]. The Netherlands ranks among the European countries with the highest per capita cancer-related expenditures, which are anticipated to continue to rise [4]. Expenditures on cancer are projected to increase by an average of 6.2% annually, reaching nearly 14.2 billion euros in 2032 [30]. By 2060, cancer is expected to move from the fifth to the second position on the list of medical conditions with the highest healthcare expenditures [30].

Alongside the rising demand for care, the complexity of care itself is growing due to the rising prevalence of comorbidities among patients [5, 31]. Also, with improving survival rates, certain cancer types become more chronic in nature, requiring prolonged care periods [5]. Additionally, the patient-provider relationship is changing with a growing trend toward more personalized care and empowered self-care [32]. Patients are increasingly seen as collaborative partners who wish to be well-informed and actively involved in the decision-making aspects of their care [33].

E-health technology as a means to optimize cancer care

To ensure the sustainability of healthcare and (further) improve the care for people with cancer, the exploration of new and innovative approaches is needed. One such approach is the integration of e-health technologies. E-health is a broad term encompassing a wide range of activities that use electronic means to provide health-related information, resources and services [34]. The World Health Organization defines e-health as "the use of information and communications technology to support health and health-related fields" [35]. This entails technology for collecting, registering, analyzing, exchanging, utilizing, and communicating information, such as mobile applications, wearables and sensors, online patient portals, and telemedicine [36, 37]. Shaw and colleagues describe three interrelated domains of e-health: "health in our hands," which involves using e-health technologies to monitor, track, and inform health; "interacting for health," which utilizes digital technologies to enable communication among health professionals and between them and their patients; and "data enabling health," which involves collecting, managing, and using health data [38].

E-health can potentially contribute to optimizing cancer care, with three specific ways highlighted. First, e-health can enhance the quality of care. To illustrate, a randomized controlled trial conducted by Basch et al. [39] included more than 700 patients with advanced cancer undergoing chemotherapy who were randomly assigned to either weekly monitoring via electronic tablets or receiving usual care. The intervention group subjected to electronic monitoring showed less decline in health-related quality of life (HRQoL), had fewer hospital admissions, and extended overall survival at 7 years follow-up compared to those receiving usual care [39]. Other ways e-health can improve care quality is by facilitating improved communication between patients and healthcare providers, promoting shared decision-making, supporting self-management among survivors, and offering better access to disease and treatment-related information [40-44].

Secondly, e-health can enhance patient engagement throughout the care process by empowering individuals to take control of their health and actively adopt healthier behaviors. This enhanced empowerment can be achieved, for instance, by sharing clinical information and treatment goals with patients through personal electronic records or by using e-health to better monitor and manage the symptom burden of patients. A review by Penedo et al. demonstrated the feasibility and efficacy of the use of mobile applications to deliver evidence-based interventions during and after cancer treatment, including interventions designed to enhance pain coping skills, fatigue management, sleep quality, and overall health-related quality of life (HRQoL), and to decrease psychological distress [45-50].

Lastly, e-health can optimize cancer care by enhancing care efficiency, for example, by avoiding unnecessary diagnostic or therapeutic procedures and delegating or simplifying (administrative) tasks [40, 51, 52]. Also, the application of artificial intelligence (AI)-based analytic tools holds promise for increasing diagnostic insights in oncology, which could improve the workload of healthcare providers [53].

Challenges of e-health implementation

Besides the large potential of e-health in cancer care, there are challenges of its practical implementation. First, although healthcare continues to evolve and new methods are being explored, solid scientific evidence for the benefits of e-health remains limited [54]. In essence, this means that "(...) decisions on health IT development and implementation are based on 'what we think makes sense, what we can afford, what vendors recommend…' - and not on scientific evidence" [55]. Similarly, while many interventions have been developed for cancer survivors, a comprehensive overview of these interventions and the scientific evidence for their effectiveness is still lacking. Having such an overview would be valuable, as it would help stakeholders, including

healthcare providers, identify evidence-based interventions that have been proven effective for cancer survivors.

Furthermore, many e-health interventions are being pilot tested, but often, they fail to become a structural part of routine care [56]. E-health initiatives may gain initial momentum; however, factors such as the lack of long-term funding structures pose a significant risk to their sustainability and successful implementation [57]. Also, for e-health to become a structural part of care, there must be a clear fit between e-health services and the needs of individuals and groups [58]. In line with this, research showed that there is an association between e-health adoption and individuals' positive attitude towards the technology and its perceived added value [59-61]. Therefore, understanding the views of stakeholders, including patients and healthcare providers, on the potential of e-health in cancer care is crucial for successful e-health implementation. Their feedback can help tailor e-health interventions to better meet the needs of patients and survivors and determine how they can provide most value in optimizing cancer care.

Also, the implementation of e-health innovations is often hindered by low user uptake (i.e. the first acceptance and initial use of the technology) and adoption (i.e. full integration of the technology in daily life) in the long term [32, 62-64]. Digital self-management interventions, for example, have the potential to meet the needs of cancer survivors, and complement or even substitute traditional care. However, the impact of many of these interventions is still limited, primarily due to their restricted reach [65, 66]. Besides, there are significant differences concerning e-health usage among diverse groups of users. Particularly older individuals or those with lower income or educational levels are less likely to use e-health interventions [67-69]. This may cause e-health to widen existing health inequalities [32, 52]. One of the causes of these differences in usage is the varying levels of e-health literacy and technological ability among patients and healthcare providers. Individuals with limited digital literacy may encounter difficulties in accessing, utilizing, and benefiting from technology-driven cancer care [67, 70]. The low usage rates and differences in e-health usage among different user groups underscores the importance of investigating the factors that are related to the uptake and adoption of e-health interventions among cancer survivors as well as to explore potential differences across diverse survivor groups.

Dissertation objective

This dissertation aims to investigate how cancer care can be optimized by incorporating e-health through an exploration of three main research questions:

1. What is the current scientific base for e-health interventions for Dutch cancer survivors?
2. What are the perspectives of cancer survivors and healthcare providers on the potential

value of e-health in optimizing cancer care?
3. What factors are related to cancer survivors' uptake and adoption of e-health interventions?

Dissertation outline

To answer the first research question, a systematic review is conducted to provide an overview on the types of e-health interventions available for Dutch cancer survivors, their key characteristics, and the empirical evidence regarding their impact on population health, quality of care, and per capita costs (**Chapter 2**) [71].

To answer research question 2, the perspectives of cancer survivors, healthcare providers, and managers on the potential of e-health in optimizing colorectal cancer care in the Netherlands are explored. The aim is to gather insights from individuals who will use e-health technologies in practice. Their knowledge and experiences are important in considering which technology can potentially improve cancer care and how. **Chapter 3** describes a qualitative study among healthcare providers and managers in colorectal cancer care. The study aims to identify opportunities for improvement within the colorectal cancer (CRC) care pathway using e-health and to examine how these opportunities can affect population health, quality of care, per capita costs, and staff experiences [72]. **Chapter 4** presents a qualitative study among Dutch CRC survivors. It aims to gather insights on how to improve care for CRC survivors and how e-health technology could be utilized to improve CRC care delivery from the patient's perspective.

The last research question focuses on the factors that relate to the uptake and adoption of e-health, with a particular focus on digital self-management interventions. **Chapter 5** describes a mixed-methods study involving interviews and an online questionnaire among cancer survivors. It examines what cancer survivors need for improved uptake and adoption of digital self-management interventions and whether sociodemographic and clinical characteristics influence these needs. **Chapter 6** discusses a quantitative study that uses the OncoAppstore as a case study. The OncoAppstore is a landing page that is a central hub for evidence-based digital applications designed for cancer survivors and their relatives [73]. Users of the OncoAppstore receive a digital health credit, a personal budget they can use to access digital applications. The study aims to examine the differences in uptake of digital self-management interventions among diverse groups of cancer survivors by comparing users of the OncoAppstore with the general population of cancer survivors in the Netherlands.

The closing chapter (**Chapter 7**), reflects on the findings of this dissertation, contextualizes them, and discusses the methodological choices made. It also provides implications for policy and practice and future research recommendations.

Embedding of the dissertation

This doctoral dissertation was embedded in the Dutch national E-healthmonitor, which has been conducted since 2021 by the Dutch National Institute for Public Health and the Environment (Dutch abbreviation: RIVM) in collaboration with the Netherlands Institute for Health Services Research (Dutch abbreviation: Nivel) and the National eHealth Living Lab (NeLL) of the Leiden University Medical Center (LUMC). The Dutch Ministry of Health, Welfare, and Sport commissioned the E-health monitor, now known as the Digital Care Monitor (in Dutch: Monitor Digitale Zorg). The monitor aims to provide an overview of the current availability and use of e-health services, as well as their developments over time [74]. Additionally, the monitor offers insights into the role of e-health in addressing several societal challenges. The monitor conducts annual panel surveys and qualitative research on socially relevant themes.

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