eHealth to support cancer survivors

Development, implementation and evaluation of an interactive portal

Wilma Kuijpers

eHEALTH TO SUPPORT CANCER SURVIVORS

DEVELOPMENT, IMPLEMENTATION AND
EVALUATION OF AN INTERACTIVE PORTAL

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Chapter 1

General introduction

Cancer survivors

Due to advancements in the early detection, diagnosis and treatment of cancer, along with the ageing population, the number of cancer survivors is increasing rapidly [1]. In the Netherlands, numbers are expected to increase from 420.000 in 2009 up to 660.000 individuals in 2020 [2]. Over the years there has been debate about who should be considered a cancer survivor and different definitions have been presented [3]. According to the National Coalition for Cancer Survivorship (NCCS), individuals are a cancer survivor from the moment of diagnosis through the balance of life [4]. This implies that individuals undergoing treatment (usually referred to as cancer patients) are also seen as cancer survivors, which was also suggested by the Institute of Medicine (IOM) in their report “From cancer patient to cancer survivor: Lost in transition” [5]. The National Cancer Institute (NCI) has adapted and expanded the definition of the NCCS by also including family, friends and caregivers [6]. In contrast, the Survivorship Task Force of the European Organisation of Research and Treatment of Cancer (EORTC) has defined a cancer survivor as an individual who has completed his or her primary treatment for cancer and is currently disease-free [7]. We will adhere to the definition of the NCCS in this thesis, which implies that we refer to individuals both during and after treatment when we use the term cancer survivor.

As the majority (62%) of cancer survivors live at least 5 years after diagnosis (“long-term”) [2], with cancer therapies health professionals not only try to maximize cure but also to minimize side effects of treatments [8]. Nevertheless, many survivors suffer from short-term, long-term and/or late effects caused by the cancer itself or cancer treatment, and can therefore be seen as individuals with a chronic disease. These effects can be physical or psychosocial and are likely to have an impact on health status and quality of life [5]. Short-term effects occur during treatment and include, for example, nausea and vomiting, hair loss, pain, and dyspnea; these effects often disappear after treatment completion. Long-term effects refer to side effects of cancer treatment that are persistent, such as pain, fatigue, and anxiety and sexual problems. Late effects emerge months or even years after the end of treatment. Besides an increased risk of cancer recurrence and second malignancies, late effects include, for example, cardiovascular disease, fibrosis, peripheral neuropathy, and cognitive deficits.

Cancer survivorship care

Survivorship care is becoming increasingly important for supporting cancer survivors in coping with these effects. It includes the palliation of persisting symptoms, the prevention of late effects of treatment or second cancers, and health promotion to maximize health status [8]. For palliation, prevention and health promotion, the provision of relevant information is important. The majority of cancer survivors have strong information needs regarding their diagnosis, treatment, rehabilitation and (late) effects [9; 10]. More specifically, they would like to know as much as possible about the characteristics of their disease, the course of treatment, the possible occurrence of (late) effects and what to

do to prevent or overcome them, what their follow-up schedule is and how to develop and maintain a healthy lifestyle. Information needs differ across the cancer trajectory and across people from different age, sex, educational level, ethnicity and stage of disease [11]. As fulfilled information needs are related to satisfaction with care [12], and sometimes even to a better quality of life [13], it is important to provide survivors with information that fits their individual characteristics, preferences and needs to as great an extent as possible.

Many of the short-term, long-term and late effects of cancer and its treatment have a physical component, which makes it increasingly important to adopt a healthy lifestyle in order to maximize health status. Being sufficiently physically active is especially important. A large number of studies have investigated the effects of interventions aimed at stimulating physical activity in cancer survivors both during and after treatment. In general, these studies have found positive effects on physical and psychosocial well-being, including improved physiology and body composition, less fatigue, improved psychological outcomes, better overall health-related quality of life and improvements in specific quality of life domains [14-19]. For breast, colon and prostate cancer, even a reduced risk of cancer recurrence has been reported [20; 21]. Despite these benefits, physical activity norms recommending 150 minutes of moderate intensity, 75 minutes of vigorous intensity or a comparable combination of these two per week [22] are not met by many cancer survivors [23; 24]. Barriers for being sufficiently physically active include health- or treatment related factors (e.g., illness, fatigue, nausea, pain, weakness), environmental factors (e.g., lack of equipment, lack of facilities, weather circumstances, family responsibilities) and personal factors (e.g., no interest, lack of self-discipline, lack of enjoyment, no motivation)[25-27]. It is important to help survivors to overcome these barriers so that they can engage regularly in physical activity. In this regard it is appropriate to provide relevant information and advice that take into account individual characteristics, needs and preferences.

Another important factor in managing the (late) effects of cancer and its treatment is the regular screening for physical and psychosocial symptoms. In part, this can be done with questionnaires in which cancer survivors report about their health status: patient-reported outcomes (PROs). PROs can provide health professionals with information about the symptoms and subjective well-being of a cancer survivor that can be used during the clinical consultation. The results of PRO assessments can also be given to cancer survivors so that they can monitor their own situation. This feedback from PROs often leads to improved symptom detection [28-30], more discussion of problems [28-30], and higher levels of patient satisfaction [29]. However, only a few studies have found a direct impact of PRO information in the clinical practice setting on quality of life [31; 32]. Nevertheless, the detection and discussion of symptoms is likely to lead to more timely and appropriate treatment of self-reported problems and, ultimately, to a better health status and quality of life.

So, when thinking of cancer survivorship care in terms of palliation, prevention and health promotion, it is essential to provide survivors with personal, relevant information during the different stages of the cancer trajectory. Most relevant in this regard are the prevention, detection and management of (late) effects. The promotion of physical activity and the use of PROs are important aspects of survivorship care.

Patient empowerment

As the number of cancer survivors and the accompanying health care costs are increasing, and the time of health professionals is limited, it is a challenge to provide optimal survivorship care. There is a need for a transition from institutional-centered models of health care, in which the focus is on the detection and treatment of acute disease, to more patient-centered models of health care in which cancer survivors are more actively involved in their care [33]. Apart from *being* involved, it is essential that survivors are *willing* to be involved and take responsibility for their own health. Providing relevant information during various stages of the cancer trajectory can be a first, important step to engaging cancer survivors, and getting them to share responsibility for their health. This is often termed “patient empowerment” [34]. The construct of patient empowerment is rather complex and multi-faceted. To optimally design interventions aiming to improve characteristics of patient empowerment, it is essential to have a generally accepted definition. Thus far, research has shown that interventions aimed at improving patient empowerment, regardless of the definition used, can have a positive effect on health behavior and health outcomes. Empowered individuals are more likely to engage in physical activity behavior and self-monitoring, to have a healthy diet and to adhere to treatment. Positive health outcomes that have been observed as a result of increased patient empowerment include, for example, positive changes in blood pressure, body mass index and cholesterol [35]. Although it is expected that increasing patient empowerment will result in reduced health care use and thus reduced health care costs [36; 37], the actual evidence about the impact on costs is scarce [35].

eHealth

To support patient empowerment it can be helpful to implement eHealth applications [38; 39]. In 2001, Eysenbach provided the following definition of eHealth: *“eHealth is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology”* [40]. eHealth applications could be used to exchange information and to support survivors in managing their care. The internet is particularly promising because it enables the easy provision of tailored information that is always accessible, and it offers the possibility of interactivity (i.e., providing feedback based on data provided by a cancer survivor). In the Netherlands, approximately 95% of the

population has daily access to the internet. Actual internet use is highest among younger groups, but even among the elderly, 20% (age 75 and older) to 55% (age 65-75) is using the internet daily, and these numbers are likely to further increase in the coming years [41].

Many studies have investigated the potential of internet-based interventions for both healthy individuals and those with a chronic disease. Literature reviews have shown that these interventions are effective in improving patient empowerment of different patient populations [42], and that they have a significant effect on health behaviors [43]. Specific effects include, for example, improved physical activity behavior in adults [44] and pain reduction in those suffering from chronic pain [45]. For other outcome measures like smoking cessation and weight loss, however, inconsistent results have been found [46; 47]. Nevertheless, it has been shown that internet-based interventions are more effective in improving knowledge and behavior change than offline interventions [48].

A specific eHealth application that is gaining in popularity is the (electronic) patient portal, a system to provide access to health-related information and to allow information exchange and communication in a secure way [49]. More specifically, most patient portals offer access to a patient's electronic medical record, making test results and personal disease information available to patients. In addition, portals could for example be used to provide (tailored) educational materials and an overview of appointments, to exchange e-mails with health professionals, to complete questionnaires, to keep a diary, to order medication, to send online reminders and to provide self-management programs. Thus far, patients are generally satisfied with patient portals, but the evidence for the effect on health outcomes is mixed [49].

Despite the potential benefits of using eHealth in general and patient portals in particular, at the time the project described in this thesis started, only a very limited number of eHealth applications were available for cancer survivors. There was a particular paucity of information about the needs and expectations of cancer survivors and their health professionals regarding eHealth and its preferred design. The overall aim of this project was to develop an interactive portal ("MijnAVL") to empower cancer survivors within the Netherlands Cancer Institute. Furthermore, we aimed to evaluate MijnAVL in terms of use, usability and impact on cancer survivors and health professionals. In this project we focused on breast and lung cancer survivors because of the relatively high incidence of these tumors [2] and their distinct physical characteristics (e.g., aspects of the disease, impairments) and rehabilitation options.

Development and evaluation of eHealth

To develop eHealth applications that are useful and sustainable, the developmental process should include more than just designing a product or service [50]. Too often, project members and software programmers who assume that they understand the needs and skills of end-users develop eHealth applications. This leads to applications that do not fit the requirements of the end-users [51] and to limited levels of clinical

appropriateness and usability [52]. Van Gemert – Pijnen and colleagues have therefore emphasized that, to optimize the uptake of eHealth applications, one should find a good fit between the application itself, the users, sociocultural factors and the organization of the health care system [50]. They have developed a framework that could serve as a guideline for the development of eHealth applications. It is beyond the scope of this thesis to extensively discuss the framework, but we have tried to adhere to the underlying principles as much as possible. These six principles state that the development of eHealth: 1) *is a participatory process*, which means that the involvement of end-users and other stakeholders is essential; 2) *involves continuous evaluation cycles*, it is an iterative process of collecting feedback from end-users; 3) *is intertwined with implementation*, as it is important to take into account possible barriers to implementation from the start; 4) *changes the organization of health care*, as it influences traditional work flow; 5) *should involve persuasive design techniques*, to make sure that the application fits with user characteristics and motivates stakeholders to use the technology; and 6) *needs advanced methods to assess impact*, to be able to assess the impact over time and situations.

Two of these principles (1 and 2) were already highlighted in the nineties and their importance is still acknowledged. The involvement of end-users is essential, as taking into account their characteristics, needs and values is likely to increase the chances of the eHealth application being accepted and actually used in daily (clinical) practice [53]. End-user requirements should be used to develop prototypes of the eHealth application, which could be concepts in PowerPoint in early stages and more functional technology in later stages. The iterative evaluation of these prototypes is essential to detect potential technical problems and problems related to the implementation in the health care system. Solving these problems before the actual implementation will contribute to the final quality of the application [54].

There are many research techniques that could be applied during the development of eHealth applications. In a review on this topic, it has been shown that the decision on what technique to use depends primarily on the stage of development [55]. At an early stage, when the goal is to obtain the opinion of the end-users about intended content or perceived usefulness, techniques like an interview, a questionnaire or a focus group are often most appropriate. In later stages, when usability needs to be assessed, useful techniques include user observations, think-aloud procedures or expert reviews. Interviews, questionnaires, focus groups, expert reviews and think aloud procedures were the most frequently used techniques and that often a combination of techniques is used to obtain as much information as possible [55].

Apart from the application of research during eHealth development, it is also important to evaluate the impact of an eHealth application (principle 6). Thus far, there is a lack of formal studies of sufficient methodological quality that could provide reliable evidence for the impact of eHealth applications and its associated risks and costs [52]. This is due to the fact that the majority of studies are performed in an academic setting, as a

result of which the sustainability of an eHealth application after implementation cannot be guaranteed. The evaluation of eHealth and its implementation should be inherently related [50]. Factors that could be taken into account are related to the application itself (e.g., technical issues), the end-users (e.g., use, experiences, and satisfaction), their environment (e.g., social support) and the health care system (e.g., resources such as time and money). It is often recommended that a mixed methods approach be used in which quantitative and qualitative research techniques are combined [50]. The results that are obtained with these different research techniques can complement each other.

Aim and outline of this thesis

This thesis presents the results of our work to contribute to the knowledge about using eHealth applications for cancer survivors. The overall aim of the thesis was to develop and evaluate an interactive portal to empower breast and lung cancer survivors (“MijnAVL”). This portal is a secured, personal website for cancer survivors of the Netherlands Cancer Institute (Antoni van Leeuwenhoek). Survivors can login to MijnAVL with their DigiD, a safe authentication method related to one’s social security number. The different steps we have taken for the development and evaluation of MijnAVL are shown in Figure 1.1.

Exploration of eHealth applications

We started this project with two systematic literature reviews to explore the field of patient empowerment and eHealth. Chapter 2 describes the results of the review in which we identified existing definitions and conceptualizations of patient empowerment, in general, in order to conceptualize patient empowerment for cancer survivors. Such a conceptualization could be used to optimally design interventions. In this chapter, we also present how eHealth applications could facilitate patient empowerment among cancer survivors. In the second review (Chapter 3) we have explored randomized controlled trials of existing online interventions for patient empowerment in the chronic disease setting and we determined which features are included in such interventions. Subsequently, we discussed how these features could be relevant for cancer survivors.

Development of MijnAVL

Chapter 4 reports on focus group sessions that were conducted with breast and lung cancer survivors and their health professionals to verify the findings from our literature review. We investigated what these groups expect from an interactive portal and which features they would like to have included. Chapter 5 describes the developmental process of MijnAVL, which consisted of interviews about a draft version in PowerPoint and usability tests with a fully functional prototype. With these studies we aimed to develop a system that fulfilled requirements of end-users as much as possible and we also wanted to detect errors before delivering the final version. In Chapter 6 we focus on the presentation of quality of life information via a portal. More specifically, we present the results of a survey of cancer survivors’ and health professionals’ understanding of and preferences for graphical presentation styles of individual quality of life scores.

Figure 1.1 Development and evaluation of MijAVL

Evaluation of MijAVL

Chapter 7 and 8 describe the results of a feasibility study in breast and lung cancer survivors, respectively. In these studies we examine the use of and experiences with MijAVL, as well as possible efficacy. The results are presented for these two subgroups of survivors separately, as they have quite distinct clinical characteristics.

Finally, Chapter 9 provides a general discussion in which we consider the strengths and limitations of our research, place our findings in a broader context, and provide future directions for research and practice.

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Chapter 2

Empowerment of cancer survivors through information technology: An integrative review

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ABSTRACT

Background

Patient empowerment may be an effective approach to strengthen the role of cancer survivors and be helpful to reduce the burden on health care. However, it is not well conceptualized, notably in oncology. Furthermore, it is unclear to what extent IT services can contribute to empowerment of cancer survivors.

Objectives

We aim to define the conceptual components of patient empowerment of chronic patients and especially cancer survivors and to explore the contribution of existing and new IT services to promote empowerment.

Methods

Electronic databases were searched to identify theoretical and empirical articles regarding empowerment. We extracted and synthesized conceptual components of patient empowerment (attributes, antecedents and consequences) according to the integrated review methodology. We identified recent IT services for cancer survivors by reviewing systematic reviews and by an inventory of new services and we related their features and effects to the identified components of empowerment.

Results

Based on 26 articles, we identified 5 main attributes of patient empowerment: 1) being autonomous and respected, 2) having knowledge, 3) having psychosocial and behavioral skills, 4) Perceiving support from community, family and friends, and 5) {van den Berg, 2013 #28}Perceiving to be useful. The latter two were specific for the cancer setting. Systematic reviews of IT services and our additional inventory helped us identify five main categories: 1) educational services (including electronic survivorship care plan services); 2) patient-to-patient services; 3) e-PRO services; 4) multi-component services; 5) portal services. Potential impact on empowerment included knowledge enhancement and to a lesser extent enhancing autonomy and skills. Newly developed services offer promising and exciting opportunities to empower cancer survivors, for instance by providing tailored advice for supportive or follow-up care based on patients input.

Conclusions

We identified five main components of empowerment and showed that IT services may especially contribute to empowerment by providing knowledge. The components of empowerment could be used to develop IT services for cancer survivors. It is important to take into account patients' needs, follow up on these needs and make a service that is attractive and easy to use.

INTRODUCTION

A popular approach to improve the involvement of patients in their care is to provide them with information on how to make a decision about medical treatment (shared decision making) [1]. However, more aspects are important when fully engaging patients regarding their health. A concept that may be particularly relevant in this regard is patient empowerment, which is generally viewed as a multi-level construct with manifestations at the community, group or individual level. Despite its popularity, patient empowerment has no generally accepted definition or conceptualization and it is a rather complex and multifaceted construct. This is illustrated by the differences in various questionnaires that have been developed to measure (aspects of) empowerment [2]. Nevertheless, there is convincing evidence for the effects of improving patient empowerment on health outcomes. Meta analyses show that self-management interventions improve glycated hemoglobin levels (a marker of glycemic control), self-efficacy, and empowerment levels in patients with chronic metabolic diseases [3]. Moreover, these interventions reduce the number of readmissions in heart failure [4] and emergency department visits in asthma [4].

Because of better screening, detection and treatment, the number of cancer survivors is growing rapidly. We will use the term cancer survivor to describe both as the National Coalition of Cancer Survivorship defines cancer survivorship as follows: “from the time of diagnosis and through the balance of life”. In 2008, 28.8 million people worldwide had survived cancer at least 5 years [5]. Cancer and its treatment result in a wide range of physical and psychological challenges, some of which may even appear years later [6]. The current models of survivorship care are likely to lead to rapidly increasing and not sustainable use of health care [7]. Some claim that a stronger role of the patient might be helpful to control costs. New models are emerging that emphasize the importance of supporting patients to engage in self-management activities and to be able to make informed choices about the type of support they need. The challenge is to provide this in a cost-effective way that is either equally effective or more so than traditional models of survivorship care [8]. It seems imperative that cancer survivors need to become (more) effective co-actors in their health care. Existing theories and models of chronic disease management might be relevant to cancer survivors as well but have not been tested rigorously [9, 10]. In this review we therefore focused on the “higher order” concept patient empowerment.

Empowering interventions providing face-to-face support to patients require substantial resources and effort. A promising approach is the use of Information Technology (IT), which enables the provision of easily accessible, up-to-date, and tailored information and automated feedback to patients. Many “empowering” web-based interventions have been developed in the field of chronic diseases (e.g. diabetes, heart failure and chronic obstructive pulmonary disease), but relatively few seem to have been developed for, and rigorously tested in cancer survivors [11].

The objective of the current study is to identify conceptual components of patient empowerment in chronic patients and cancer survivors and to explore the contribution of existing and new IT services to promote their empowerment. This can guide the development of innovative and sustainable e-health services that may improve empowerment in cancer survivorship care.

METHODS

We conducted an integrative literature review using the methodology as proposed by Whittemore and Knafl to conceptualize the construct of empowerment. An integrative review summarizes past empirical and theoretical literature to provide a more comprehensive understanding of a phenomenon or healthcare problem [12]. Accordingly, five steps were undertaken: (1) problem identification (already stated in the introduction); (2) literature search; (3) data evaluation; (4) data analysis; and (5) presentation. In addition, we searched for IT services that could support cancer survivors with regard to patient empowerment. The Preferred Reporting Items for Systematic reviews and Meta-Analysis (PRISMA) statement was checked for relevant items that would aid the reporting of this review [13].

Integrative literature review

Literature search and data evaluation

We performed a literature search in PubMed (Medline), SCOPUS and PsychINFO from January 1990 up to April 2014 to obtain definitions of patient empowerment in general, and specifically in cancer survivors. Search terms included “conceptual”, “theory” and “cancer” either alone or combined, and always in combination with “patient empowerment”. The search query for PubMed is presented in Appendix 2.1. We selected publications for full text review based on screening of titles and abstracts. Articles were selected for inclusion if they met the following criteria: 1) written in English; 2) published in a peer reviewed journal; and 3) being one of the following types of articles: 3a) Articles providing a conceptual or theoretical description of patient empowerment. 3b) Articles providing empirical qualitative data on the concept of patient empowerment in chronic patients or cancer survivors. 3c) Articles describing the development of a questionnaire that aims to measure (aspects of) patient empowerment (both generic and disease specific). 3d) Quantitative articles with empowerment as an outcome that also extensively discuss the conceptual definition of patient empowerment in chronic patients or cancer survivors. Reference lists of selected full texts were screened for additional relevant papers. A second researcher (WK) reviewed all articles for inclusion and in case of disagreement a third researcher (WvH) was consulted for a definite decision.

Data analysis and presentation

A predefined data sheet was used for data extraction. Data were extracted on study characteristics (first author, year of publication, type of research, number of participants involved, type of disease), defining attributes (characteristics), antecedents (events or circumstances that precede a concept) and consequences (phenomena that follow an occurrence of the concept) of empowerment [14]. In order to identify the main attributes, we coded qualifying text elements and these were integrated into common descriptions. A final check of the primary data sources was performed to verify the conceptualization [12]. Findings of the studies specific on cancer were reviewed separately and compared to the findings of the literature on chronic diseases. All aspects of the procedure were verified by a second researcher (WK) to reduce potential bias. Data are presented narratively.

Identification of existing IT services and their potential to support patient empowerment in cancer survivors

We searched the Medline (PubMed) database for papers in English that were published between January 2010 and January 2015. We used medical subject headings and free text terms. A combination of any of the following: "cancer patient", "cancer survivor", "cancer survivorship", and "cancer" was combined with any combination of the following: "ICT", "information and communication technology", "web-based", and "internet". The search query for PubMed is presented in Appendix 2.1. Because there have been several recent, systematic reviews on this topic, we decided not to do a search on primary articles. One author (WG) checked titles and abstracts to determine if articles were potentially relevant to retrieve the full-text article. Reference lists were also searched for additional relevant papers. Full texts were screened by two reviewers (WG and WK) on the following criteria: 1) the paper described a literature review with a systematic and explicit search strategy; 2) the scope of the review concerned supportive IT services; 3) the services focused on adult cancer survivors; and 4) The papers should contain information on the features and effects of the reported IT services (or when these were not reported, obtained this from primary articles).

Apart from the services described in the systematic reviews there also are emerging services that are in early phase of development and have not yet been rigorously tested. We therefore additionally searched Google and PubMed up to April 2014. To our knowledge no formal guidelines exist for surveying e-health systems and applications. We purposely selected three groups of these IT services that may be particularly relevant for cancer survivors (but may be designed for other diseases as well), namely: 1) patient portals, 2) electronic patient reported outcome (e-PRO) systems and 3) IT services related to survivorship care (plans) for cancer patients. Major keywords used were: patient portal(s), patient empowerment, electronic medical record, patient reported outcomes, survivorship care plan, cancer and information and communication technology either alone or in combination. References in reports and articles were checked for citations leading to possible other relevant IT services (snowballing method). Suggestions from

members of our project group were added to this inventory as well. Our inclusion criteria were as follows: We included portal services that at least provided insight into the patients' medical record. With regard to e-PRO systems, we included systems that enable people with cancer to complete symptoms and/or quality of life questionnaires by computer either at home or at the clinic. For the survivorship care support services we included those that were aimed at cancer survivors and provided an electronic survivorship care plan (SCP) or generated one from a digital registry. All IT services had to be in use and not only available as a test or beta version.

From the identified IT services, key features and user interaction aspects were collected from websites, published manuscripts, or by demos of the service when possible. Lastly, convenience sample based site visits were made to developers of the OncoKompas system (VU medical Center, Amsterdam, NL), the ChipSoft patient portal (UMC Utrecht, NL), digital IVF clinic (Radboud UMC, Nijmegen, NL), and the electronic patient reported outcome system of UMC Leiden, NL. The developers of Care Companion (Sanofi Aventis, Gouda, NL) visited us to demonstrate their application. Demo software of the CHES e-PRO (Innsbruck, Austria) system was obtained for review. References to the according services can be found in the Multimedia Appendix 2.2.

The (possible) contribution of identified IT services to attributes of patient empowerment was determined by relating the reviewed features and effects to the attributes of empowerment as identified by the integrative review. Results are presented qualitatively and several exemplary IT services are described in detail.

RESULTS

Integrative literature review

Included studies

The initial search resulted in 2248 hits. After screening titles and abstracts, 94 papers were selected and read in full text. Twenty-two met our inclusion criteria and 4 articles were added by checking reference lists. Eleven reviews were included [15-25]. Nine manuscripts described the development and/or psychometric evaluation of a questionnaire on patient empowerment [26-34] and six qualitative studies described patient empowerment of chronic patients [35-40]. Figure 2.1 shows the literature search and selection procedure.

Conceptualization of patient empowerment

Antecedents, attributes and consequences of patient empowerment of chronic patients, and cancer survivors are presented in Figure 2.2 and are described in more detail here. References to the most illustrative manuscripts are provided.

Figure 2.1 Flowchart of selection of articles according to PRISMA

Antecedents

Antecedents that appeared from the literature were to a large extent based on the excellent review of Holmström et al. [21]. Antecedents are events or circumstances that precede a concept [14]. An antecedent may contribute to the occurrence of the concept, it may be associated with its occurrence or it may need to be present for the concept to occur. Several antecedents of patient empowerment are related to patients themselves. Having a long term condition [24, 29] is a first antecedent of empowerment. Further antecedents on the “patient side” are poor health behaviours that need to be changed, the presence of motivation for action towards desired goals(s) and the ability to self-reflect regarding benefits of behaviour change [21].

There are several antecedents of patient empowerment that relate to health care providers (HCPs) and their approach to patients. When HCPs respect patients’ beliefs and surrender their need to control and decide for patients, they create an atmosphere of mutual trust and respect [17, 18, 20] and shared responsibility [21], which facilitates patient empowerment. Finally, an antecedent to patient empowerment is HCPs’ willingness to provide educational support to patients [17, 21].

ANTECEDENTS OF EMPOWERMENT:

- Patient related
 - Having a long term condition including being a cancer survivor
 - Patient with poor health behavior that needs to change
 - Patient is motivated for action
 - Patient possesses ability to reflect on benefits of behavior change
- HCP related
 - HCPs respect patients' beliefs
 - HCPs surrender need to control and decide for patients
 - HCPs provide education and support
- Atmosphere
 - Shared responsibility between patient and HCP
 - Mutual trust and respect between HCP and patient

ATTRIBUTES OF EMPOWERMENT*:

- Being autonomous and respected (and willingness and ability of HCPs to support this)
- Having knowledge (and willingness and ability of HCPs to share/provide information)
- Having psychosocial and behavioural skills (and HCPs supporting their development)
 - Internal/personal
 - External/interactional
- Perceiving support from community, family and friends
- Perceiving oneself to be useful through having paid employment and/or by contributing to family and friends

CONSEQUENCES OF EMPOWERMENT:

- Improved self-esteem/self-concept
- Increased knowledge of disease and treatments
- Better self-efficacy
- More perceived control
- Better emotional coping
- Better interaction or collaboration with HCPs
- Better self-management
- Better health status
- Better quality of life
- More satisfaction

Figure 2.2 Conceptual components of empowerment in chronic patients including cancer survivors. HCP, health care provider. *A detailed overview of attributes is provided in Tables 2.1 and 2.2.

Attributes

Three main attributes emerged from the literature review concerning chronic patients.

Being autonomous and respected (and willingness of HCPs to support this)

Patients must have the opportunity to make *their own* decisions and choose *their own* health or life goals [15, 17, 19, 23]. This attribute depends, in part, on external factors. For example HCPs need to adjust their position of power to a level that provokes equal participation of the patient, and they need to act as a coach to work towards negotiated health goals [15, 18-20, 24, 25]. Being respected also requires that HCPs share knowledge and resources in such a way that patients feel fully recognized [18, 24].

Having knowledge (and willingness and ability of HCPs to share/provide this)

Having knowledge about one's health situation is another attribute of empowerment. It refers to having knowledge about one's disease [34, 39, 40], about oneself [19, 23], and about available supporting resources [17, 23]. Having more knowledge is expected to enable 'better informed decision making' e.g. about treatments or lifestyle changes [20, 39, 40].

Having psychosocial and behavioural skills (and HCP's supporting their development)

Nearly every article that we reviewed described having skills to positively influence one's situation as an attribute of patient empowerment. These skills could be subdivided into those related to internal thought processes (internal/personal) and those more behavioural and externally oriented (external/interactional). Internal/personal skills are, in general, referred to as personal psychological strengths such as having a sense of self-efficacy, self-esteem, optimism, and personal competence [30, 38] and to the ability to accept and cope with living with a chronic disease [29, 34, 38]. These skills are also related to building the capacity to identify one's needs and psychosocial problems, goal setting, and problem solving [25]. It also refers to the skill of patients to increase and maintain motivation to pursue their health goals [25].

External/interactional skills are needed to positively influence one's current situation by one's own behaviour and/or by interaction with others. These skills are generally related to the effectiveness of patients in managing their disease through (preventive) self-management [19, 23, 27, 28, 31, 34, 39], and effective, collaborative interaction with HCPs, such as negotiating, and asking for clarification [25, 27]. Furthermore, being able to obtain emotional and practical support from family and friends is important [26, 27, 29, 30, 32, 36, 37]. Using or developing these skills may be a challenge for patients who have (had) a life-threatening disease such as cancer. Nevertheless, developing or reinforcing these skills is the hallmark of empowering interventions [25].

Consequences

A diversity of consequences of empowerment was reported in the reviewed literature. Empowerment is associated with increased self-esteem and a better self-concept [16, 17], increased knowledge about disease and treatments [21, 24, 25, 29, 35], more self-

efficacy regarding disease and treatment-related behaviors [16, 18, 21, 25, 36] and more perceived control [16, 17, 25, 29]. It is also associated with better interaction or collaboration with HCPs [21, 31], better disease self-management [21, 24, 25, 31], and improved emotional coping [21, 25, 26, 28]. In more general terms empowerment is related to higher levels of satisfaction [16, 18, 21, 25], better health status [18, 21, 25, 28, 31] and quality of life [16, 18, 25, 36].

Cancer-specific findings

Six papers were specifically aimed at cancer patients: Three methodological papers describing the development and psychometric testing of a questionnaire designed to measure empowerment [26, 27, 30] and three very small scale qualitative studies of which one (Bulsara et al. [36]) was also included in a questionnaire development paper [35-37].

Taken together the cancer-specific papers reflected many aspects already identified from literature on patients with a chronic disease. No cancer-specific antecedents or consequences could be identified from these studies. Most attributes were related to having knowledge and having psychosocial and behavioural skills. Cancer-specific attributes that could be added to the three already described above are: 1) *Perceiving support from community, family and friends*{van den Berg, 2013 #28} [26, 30, 37]; This refers to perceived support from people close to the patient and feelings of acceptance and support from the social community. It is about the availability of support, which makes it slightly different from the earlier identified skill of seeking support from these sources. 2) *Perceiving oneself to be useful through having paid employment and/or by contributing to family and friends* [26]. This attribute refers to the patients' sense of self-worth through having a job or through having the feeling that one is contributing to family or friends or that they may rely on him/her.

Also, one specific sub-attribute could be added to the attribute "having skills": being able to accept the diagnosis [26, 36], and coping with emotions (e.g., anxiety or depression) related to the disease [27].

Identification of existing IT services and their potential to support patient empowerment in cancer survivors

Identified IT services, their features and effects

The initial search identified 216 potentially relevant reviews. We selected 26 reviews for full text screening and 4 met all our inclusion criteria [41-44]. Two reviews concerned cancer in general [41, 42], one was focused on breast cancer [43] and one on prostate cancer [44]. None of the included reviews performed a meta-analysis. The 4 reviews included 46 unique IT services (described in 74 studies). The additional search and expert input yielded additional information on 5 patient portal services, 6 e-PRO services and 3 electronic survivorship care (plan) support systems [45-55] (see Appendix 2.2 for

an overview). IT services could be divided into five categories: 1) educational services (including electronic survivorship care plan services); 2) patient-to-patient services; 3) e-PRO services; 4) multi-component services (which combines two or more of the former); and 5) patient portal services.

Below we report on the main features of the services per category including several examples and a summary of the evidence regarding the effectiveness or hypothesized benefits in supporting the attributes of patient empowerment (as identified in the previous step). For convenience the possible contributions to attributes of empowerment are indicated as follows: being autonomous and respected, **AR**; having knowledge, **HK**; and having skills, **SK**; perceived supported from community, family and friends, **PS**). We felt that IT could not/hardly contribute to the attribute “Perceiving oneself to be useful through having paid employment and/or by contributing to family and friends”; therefore this attribute is not represented here. An overview is presented in Tables 2.1 and 2.2. Because the features of multi-component services were very diverse these are not presented in the tables.

Educational services

These often are interactive systems provided via internet or off-line via computer or CD-ROM. Many provide disease- and treatment-related information to improve knowledge of survivors (**HK**). Some are specifically aimed at improving decision making (**SK**), for example regarding (surgical) treatment for breast or prostate cancer. An example is the Interactive Digital Education Aid (IDEA) intervention [56]; an interactive software program that includes high-quality, three-dimensional animated graphics, patient testimonials, before-and-after photographs, and video explanations from clinical specialists. It is designed to answer general questions about breast reconstruction and to provide detailed explanations of the various techniques, including advantages and disadvantages (**HK**). The intervention has shown to increase the knowledge (**HK**) and satisfaction with treatment choice, compared to a control group.

Other services contain educational programs about symptoms and how to cope with them (**HK & SK**). For example, the Sleep Healthy Using The Internet (SHUTi) program, is based on a well-validated face-to-face CBT program and includes six interactive modules [57]. It covers aspects of behavior, stimulus control, education and problem prevention (**SK**). SHUTi provides a high degree of individual tailoring and feedback. Automated emails are sent throughout the program to inform the users about next steps as well as to encourage adherence. A small scale two arms RCT (n=14 per group) showed that the intervention significantly improved overall insomnia severity, sleep efficiency, sleep onset latency, soundness of sleep, restored feeling upon awakening and general fatigue.

The electronic survivorship care (plan) support is based on the recommendation of the Institute of Medicine that survivors should be provided with a personalized structured overview of one’s disease, treatments and possible short and long term side effects (**HK**).

Table 2.1 Identified attributes of patient empowerment and the possible contributing role of educational and patient-to-patient IT services

ATTRIBUTES OF EMPOWERMENT	POSSIBLE CONTRIBUTING ROLE OF REVIEWED IT SERVICES	
	Educational services	Patient-to-patient services
Being autonomous and respected (and willingness and ability of HCPs to support this)		
Patients make their own decisions and choose their own health or life goals	o	+ ^e
There is an atmosphere of mutual trust	o	o
HCPs bring their power to a level that provokes equal participation of the patient and act as a coach to work towards negotiated health goals	o	o
HCPs share knowledge and resources in such a way that patients feel fully recognized	++ ^a	o
Having knowledge (and willingness and ability of HCP's to share/ provide information)		
Having knowledge about one's disease and treatments and about oneself	++ ^b	+ ^f
Having knowledge about available supporting resources	++ ^b	+ ^f
Having psychosocial and behavioural skills (and HCP's supporting their development)		
Internal/personal		
Having self-efficacy, self-esteem, optimism, and personal competence	o	o
Ability to accept diagnosis and cope with emotions (e.g. anxiety or depression)	+ ^c	o
Capacity to identify one's needs and psychosocial problems and set goals to improve self-selected goals	o	o
Increase and maintain motivation to pursue health goals	o	o
External/interactional		
Effectiveness of patients in managing their disease through (preventive) self-management	+ ^d	o
Effective collaborative interaction with HCPs, such as negotiating, asking for clarification etcetera	o	o
Being able to obtain emotional and practical support from family and friends	+ ^d	o
Perceiving support from community, family and friends	o	+ ^f
Perceiving oneself to be useful through having paid employment and/ or by contributing to family/friends	o	o

Legend Table 2.1:

HCP, health care provider; ++ = strong positive contribution to empowerment; + = weak positive contribution to empowerment; o = no positive contribution to empowerment. ^a Knowledge and resources are shared between HCPs and patients. ^b Providing Information about e.g. diagnosis, treatments, side effects late effects, follow-up scheme, healthy lifestyle and information on or links to supporting resources. ^c Training programs could enhance coping with emotions. ^d Providing information about diagnosis, treatments, side effects late effects, follow-up scheme, healthy lifestyle and information on or links to supporting resources. Provision of skill building programs to effectively obtain social support. ^e Patients can ask questions regarding their most relevant issues in online communities. ^f Information could be obtained through online communities however quality may be limited. ^g Patients could perceive more support from community (i.e. fellow patients).

Furthermore, it may include information on available resources, recommended follow-up visits and on healthy lifestyle (**AR & HK**). Several electronic SCP initiatives exist. The “Livestrong care plan” provides an online SCP based on the data that patients provide themselves [53]. Patients can then view and/or print their SCP. Other systems such as ROGY Care [55] and “SCP builder” [54] enable health professionals to compose an SCP for survivors based on tumor registry data, manual input or both. The electronic SCP initiatives are hypothesized to contribute to patient empowerment by increasing autonomy through HCPs sharing knowledge about available resources. Furthermore it may enhance patients’ knowledge of their current and future situation. With regard to skill development, SCPs appear to offer limited benefit. Patients might better anticipate side effects and late effects by adopting a healthier lifestyle.

Beneficial effects of educational services related to patient empowerment include increased levels of knowledge, skill development through better decision making, increased levels of satisfaction and (to a lesser extent) a better quality of life. However, the number of high quality studies supporting those claims remains limited [41-44].

Patient-to-patient services

These consist of online support groups or bulletin boards in which patients can exchange experiences with fellow patients and ask their most bothersome issues (**AR, HK & PS**). These services are quite unstructured and the quality of feedback may be limited because fellow patients may have different treatments and may lack proper medical knowledge. An example is the internet peer support offered to a large group of cancer survivors as described by Hoybye et al. [58]. The intervention contained a self-guided space for communication, including an internet discussion forum, a live chat room and a personal message system. Groups would form around a shared cancer diagnosis or particular shared concern in relation to the experience of cancer (**HK, PS**). No therapeutic content or information services were offered within the groups. The intervention did not result in statistically significant improvements of self-reported mood disturbance, adjustment to cancer and self-rated health.

Table 2.2 Identified attributes of patient empowerment and the possible contributing role of reviewed e-PRO services and patient portals

ATTRIBUTES OF EMPOWERMENT	POSSIBLE CONTRIBUTING ROLE OF REVIEWED IT SERVICES	
	e-PRO services	Patient portals
Being autonomous and respected (and willingness and ability of HCPs to support this)		
Patients make their own decisions and choose their own health or life goals	+ ^a	0
There is an atmosphere of mutual trust	0	0
HCPs bring their power to a level that provokes equal participation of the patient and act as a coach to work towards negotiated health goals	+ ^a	0
HCPs share knowledge and resources in such a way that patients feel fully recognized	0	++ ^e
Having knowledge (and willingness and ability of HCP's to share/ provide information)		
Having knowledge about one's disease and treatments and about oneself	+ ^b	++ ^f
Having knowledge about available supporting resources	0	++ ^f
Having psychosocial and behavioural skills (and HCP's supporting their development)		
Internal/personal		
Having self-efficacy, self-esteem, optimism, and personal competence	0	0
Ability to accept diagnosis and cope with emotions (e.g. anxiety or depression)	0	0
Capacity to identify one's needs and psychosocial problems and set goals to improve self-selected goals	+ ^c	0
Increase and maintain motivation to pursue health goals	+ ^c	0
External/interactional		
Effectiveness of patients in managing their disease through (preventive) self-management	0	0
Effective collaborative interaction with HCPs, such as negotiating, asking for clarification etcetera	++ ^d	+ ^g
Being able to obtain emotional and practical support from family and friends	0	0
Perceiving support from community, family and friends	0	0
Perceiving oneself to be useful through having paid employment and/ or by contributing to family/friends	0	0

Legend Table 2.2:

HCP, health care provider; ++ = strong positive contribution to empowerment; + = weak positive contribution to empowerment; o = no positive contribution to empowerment. ^a PROs gives patients the opportunity to identify personally relevant issues and health goals. ^b Providing knowledge of personal symptoms and physical and psychosocial functioning by providing graphic overview of symptom and QoL scores. ^c Identification of personal needs and psychosocial problems by providing graphic overview of symptoms and quality of life scores (with or without reference values). ^d When PRO outcomes are fed back to patients (with coaching statements) it may improve the effectiveness of the encounters with health professionals. ^e Medical knowledge (in the EMR) is shared between HCPs and patients. ^f Providing information about diagnosis, test results, treatments etc. by providing access to (parts of) the EMR (during and after treatment). ^g Providing knowledge about available supporting resources through (tailored) patient educational material. ^h Information could be obtained through online communities however quality may be limited. ⁱ E-consultations may enhance patient provider interaction.

Patient-to-patient services may contribute to empowerment through increased autonomy because patients can ask questions about their most bothersome issues and through increased knowledge about one's health/disease. Furthermore, it may improve perceived support from the community (in this case fellow patients). To date, however, there are few studies available to make firm claims on effectiveness related to patient empowerment. Results of controlled studies range from positive effects on depression, cancer related trauma and perceived stress [59] to no effects and even negative effects (on psychosocial distress and quality of life) [60].

Electronic patient-reported outcomes (e-PRO) services

Several national and international services have been developed whereby cancer survivors can complete (validated) questionnaires about symptoms and/or quality of life issues at home or in the (waiting room of the) clinic. All identified systems possess the ability to (graphically) show data of questionnaires to clinicians, and some have the feature of adding norm values derived from healthy individuals, such as the CHES system [50]. Few services provide (graphic) feedback on scores or outcomes to patients themselves. Most of these systems are not directly integrated with the electronic medical record (EMR) but freestanding database systems that can be linked via a standardized HL7 protocol. The Electronic Self-Report Assessment for Cancer (ESRA-C) system [61] enables patients to score their symptoms and quality of life and get tips for communicating about their most bothersome issues with HCPs (**SK**). Furthermore, patients can review all aspects of their symptoms and quality of life in charts with cut off values (**HK**) and may be better able to identify their personal needs and psychosocial issues (**SK**). A promising new approach is the OncoKompas that provides survivors with an overview of one's health status in terms of a profile indicating whether the patient is either "on-track" or "off track" [52]. This profile is based on a set of validated questionnaires and uses an internal algorithm and cut off values. It also provides advice on how to address problems (**HK**) using a stepped-care algorithm, starting with self-help options (**SK**) and gradually progressing to professional help. It has not been tested in a controlled study. Another promising system is the Electronic patient self-assessment (SAM) system which provides tailored information and graphical feedback to prostate cancer patients post-surgery based on their input [51].

E-PRO systems are hypothesized to contribute to patient empowerment by enabling survivors to identify their most relevant issues (increased autonomy) and by enhancing their knowledge of their current health status and patterns of change in their health over time. Having such information may also increase the effectiveness of the encounters of patients with their HCP; both patients and their HCP may be motivated to talk about the patients (most) bothersome issues. Two RCTs of the ESRA-C have demonstrated its effectiveness in terms of the number of bothersome issues discussed (knowledge and skill of assertive interaction) and a small improvement in symptom distress (coping skill) [61, 62].

Multi-component services

Many services contain a mix of the aforementioned features. Most services combine educational support with patient-to-patient support as described above. One such service is the Comprehensive Health Enhancement System (“CHESS”) [63]. This service provides access to many online services including information services such as breast cancer information, personal stories of fellow patients, a resource guide, discussion groups, ask an expert, live chats, and coaching services [63].

Because this category of services is quite broad, the evidence regarding effects on enhancing empowerment is also variable. There is some evidence that these services contribute to enhanced knowledge and skills (mostly from studies of CHESS). However, other services also show improved knowledge [64] and coping [65] (skill) as a result of educational and patient to patient services.

Patient portal services

Most patient portals offer patients' access to their EMR (**AR & HK**) and provide additional services like tailored patient education (**HK**), questionnaire administration, posing questions electronically to clinicians (e-consultation) (**SK**), making notes/keeping a diary for oneself (**HK**), ordering medication, and appointment keeping (**SK**). Most portals are directly integrated with the EMR, although some are separate applications connecting to the EMR and transfer data to a free standing web-based portal [6]. In the Netherlands portals are secured via a two way authorization procedure, meaning that patients have to provide a personal username and password and consequently have to enter an additional code that is sent to their mobile phone.

No controlled studies have investigated the effect of patient portals on improving aspects of empowerment in cancer survivors, but they may contribute to patient empowerment in several ways. First, by accessing their EMR, patients have the same (clinical) information available as their clinicians, thus potentially enhancing perceptions of being respected and autonomy. Secondly, portals may enhance patients' knowledge of their disease and treatments, either via access to their EMR or via (tailored) patient education. To date, there appears to be limited contribution of patient portals to skill development. E-consultation might enhance the effectiveness of the interaction of patients with their HCPs.

DISCUSSION

By using the integrative review methodology we were able to identify conceptual components of patient empowerment of chronic patients including cancer survivors. We illustrated the various ways in which selected IT services (may) contribute to patient empowerment of cancer survivors. This is a first attempt to link empowerment theory to existing IT services for cancer survivors.

Patient empowerment of cancer survivors

We identified five main attributes related to patient empowerment. The first is “being autonomous and respected (and willingness and ability of HCPs to support this)”. For this attribute, a patient-centred approach seems imperative. Patients need to be regarded as a valuable source of information and the goals that are set should be derived from the patients themselves. These goals could, but do not have to, correspond with the ones based on the health provider’s values. When external factors are neglected (e.g., how clinicians approach patients), it may be difficult to facilitate empowerment in patients. We cannot expect patients to take an active role when that is not supported by the health care environment. It is known that patients in general highly depend on their oncologist which consequently leads to high levels of trust. This high dependency and need for trust might result in a more obedient attitude and reduced autonomy of patients [66].

The second attribute is “Having knowledge” and willingness and ability of HCP’s to share/ provide this”. For this attribute we have to realize that some patients may not want to know all details of their disease and treatments. For example, it is known that people can have different coping styles with regard to information. There are “monitors” (those who attend to threatening information) and “blunters” (those who avoid it). In general, monitors are more physiologically, behaviorally, and subjectively aroused than blunters, and these differences occur primarily under conditions of threat of the sort when cancer risk or diagnosis is at issue [67]. Patients with a blunting coping style may be unable to process the relevant information necessary to make informed decisions regarding treatment or self-care. It is thus important to match the amount of information to the patients’ coping style to reduce their level of stress, because telling patients either more or less than they want to know about a stressor will make it more stressful [67].

The third identified attribute is “*Having psychosocial and behavioural skills (and HCPs supporting their development)*”. In the literature many empowering interventions have been described to enhance survivors’ skills. For example, one could think of a physical activity intervention with motivational interviewing technique [68] to enhance exercise behaviour, or cognitive behavioural therapy (CBT) to restructure dysfunctional ways of thinking to alleviate symptom burden, e.g. CBT for climacteric symptoms [69] or for cancer-related fatigue [70]. Physical activity may be a particularly promising intervention for patient empowerment because in addition to its direct beneficial effects on physical

and psychosocial outcomes in cancer [71], it may also function as a *gateway behavior*, such that improvements in physical activity behavior positively influence other health behaviors, like healthy eating [72]. It may therefore be particularly useful to emphasize physical activity promotion in cancer survivorship.

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The fourth and fifth attributes were derived from cancer specific studies: “Perceiving support from community, family and friends” was highlighted by several papers and delineates the importance of patients not only having skills to obtain support but also the a-priori existence of such sources of support which are strong enough to be perceived as supporting by the patient. This attribute seems to very difficult to facilitate with the use of IT. {van den Berg, 2013 #28} “Perceiving oneself to be useful through having paid employment and/or by contributing to family and friends” highlights the importance of maintaining a sense of self-worth and the importance of returning to work. Return-to-work programs specifically aimed at cancer survivors exist but are still relatively rare [73]. These cancer-specific attributes are highly relevant but appear not to be very actionable by IT services.

Empowerment appears to be a relatively new concept in its application to cancer survivors. This may be due to a recent paradigm shift: many cancer types are no longer regarded as a deadly disease, but as a disease with a chronic nature, requiring on-going support and care. This is highlighted by the fact that existing theories and models of chronic disease management, such as the Chronic Care Model (CCM) and Chronic Disease Self-Management Program have recently been introduced to cancer survivorship [9, 10]. Not surprisingly, many overlap exists between these models and our identified attributes of empowerment. Interestingly, researchers have recently related the CCM to ICT [74, 75], and alterations to the CCM have been proposed to make it more appropriate for eHealth use [75]. These existing models may also be considered for future IT services for cancer survivors.

Recently, others have attempted to conceptualize patient empowerment by systematically reviewing questionnaires purporting to capture patient empowerment [76] and by using a mixed methods approach combining literature review and focus groups [77]. Although these studies have taken a slightly different approach than ours, the findings show great overlap, which strengthens the confidence in our current findings. We found that the attributes of empowerment do not differ much for cancer survivors, compared to patients with a chronic disease, however further in depth research is needed especially on empowerment in dealing with symptom specific aspects and with cancer worries.

Using IT to support patient empowerment in cancer survivors

For patients with a chronic disease we previously found that there are many IT services available that are aiming to increase aspects of empowerment through web-based interventions [11]. Positive effects regarding empowerment were found, mainly related to self-care behavior and measures of self-efficacy [11]. In the current study we

additionally found IT services that could contribute to the empowerment of especially cancer survivors. When we related these services to the earlier identified attributes of empowerment it showed that they contribute to attributes of empowerment differently. Mainly, services were found to contribute to enhancing knowledge of patients regarding their situation but the evidence for enhancing skills is limited. The contribution to the attribute of being autonomous and respected may be present in some tailored services; however it hardly ever is a specific study endpoint which makes it hard to substantiate it. For the different types of IT services we will now discuss points of attention with regard to empowerment of cancer survivors.

Educational services may greatly contribute to patient empowerment by providing patients with knowledge and skills. The approaches taken and the use of IT differs greatly, ranging from interactive decision tools to services that interactively deliver cognitive behavioral therapy to electronically provided survivorship care plans. Although appealing, the empowering potential of the latter service, either generated online or printed from an electronic tumor registry, seems to be mainly restricted to knowledge provision. To date there is very little evidence of the effectiveness of providing patients with a survivorship care plan on aspects of patient empowerment [78]. From focus groups we know that survivors anticipate that they would benefit from SCPs because they provide information about side effects that could occur in the long-term and advice for a healthy lifestyle. They also value having an overview of diagnosis- and treatment-related information [79]. However, when focusing on the potential to empower cancer survivors, providing SCPs may be a too passive approach when it comes to enhancing skill levels. It is expected that when (e-)interventions are offered based on the input of patients (e.g. as is done by the OncoKompas) cancer survivors will gain skills related to their problem areas. This hypothesis, however, needs to be tested in high quality controlled trials. The use of SCPs could be valuable to facilitate information transfer from oncology centers to primary care and between several primary care physicians, especially in countries where the information transfer between these care providers is suboptimal.

Patient-to-patient services seemed to offer little benefit in terms of empowerment and some negative effects have been reported as well. In focus group sessions we found that some survivors would find such a service useful (mainly for practical tips, such as e.g. where to find good wigs), however in general they did not endorse such a feature. Many doubted the quality of the information due to lack of moderation by a HCP and they were also reluctant in sharing their emotions via this medium [79]. On the other hand new peer to peer services such as “Patients like me” seem to grow in popularity, indicating there may be value in it for patients, that has not been studied and recognized yet.

e-PRO services. A recent review shows that routine use of PROs in clinical practice leads to better communication between patient and physician [80], and this benefit may also be expected from e-PRO systems. These systems have the opportunity to immediately

provide relevant (web-based) interventions to alleviate symptoms or improve coping ability for problems indicated on PROs. Of the reviewed IT services these seem to be particularly promising as will be outlined in the following section.

Multi-component services. It remains unclear what positive effects are related to what mix of components, but a study of Baker et al. [63], comparing different versions of the CHESS system (information only vs information + support services vs information, support and coaching services) showed that emotional coping was only enhanced in the first two conditions (contrary to their expectations). The authors state that the full CHESS version may be too complex for survivors and may reduce its effectiveness. In line with this finding, the WebChoice service [81] failed to show major benefits, despite it contains educational, patient to patient and e-PRO services.

Patient portals. Most portals that we reviewed are likely to make some contribution to patient empowerment. A recent systematic review questions the effectiveness of patient portals, as the data to date provide limited evidence for improved health outcomes or reduced costs [82]. Patient portals provide a technical basis for information exchange but (still) seem to be limited in their ability to really tailor content and feedback to patient input, which may limit their effectiveness in terms of skill development. Therefore, they may be enhanced by providing information and educational materials in a tailored way, for example via intelligent algorithms that enable the tailoring according to the user's age, (e)health literacy, coping style, etc. Patient empowerment could also be enhanced by adding tailored interventions (such as online cognitive behavioral therapy).

Promising developments and research priorities

Based on the current study we conclude that services that are able to elicit survivors' most bothersome issues and provide them with guidance to improve these issues have great potential to empower them. Preferably an active attempt to improve or reinforce skills (e.g. their ability to cope with emotions or to deal with fatigue) is used. Services that are particularly promising in this regard are tailored e-PRO systems such as the SAM, ESRA-C and OncoKompas [51, 52, 61]. A significant challenge will be defining thresholds (cut-off values) for (screening) questionnaires of such services, and generating a decision tree with valid and acceptable interventions that align with existing care pathways. The stepped care model, starting with self-management options and gradually progressing to professional help is a promising approach. It is largely unknown what the optimal format for graphically presenting PRO data to cancer survivors and their HCPs is, but researchers are starting to look into this issue [83]. It may be useful to include question prompt sheets that enable patients to formulate their specific questions prior to a medical visit, based on their PRO results. Most e-PRO systems make use of validated quality of life and symptom measures. From an empowerment perspective, it may be useful to supplement these measures with questions that ask patients to identify their most relevant health problems and goals (such as ESRA-C does [61]). Future challenges in this regard will be to

make these services truly aimed at the patients' needs, effective in following up on the identified needs and making these services attractive and easy to use for patients with varying levels of (e)-health literacy and sociodemographic characteristics. An area that was not fully tapped into in this paper, but that also may be promising is that of social media services such as Twitter and Facebook. There is, for example, recent literature indicating that Twitter may be valuable for patients to increase their knowledge [84] and their perceived support from the community [85].

Consequently, several research priorities can be pointed out. First, research needs to focus on how to best measure what survivors identify as key areas or goals that they want to work on regarding their health and how these could be best met by existing health services (either on- or off-line) in preferably a stepped care manner. Second, research is needed to determine the optimal information provision to survivors given their informational coping styles. Third, it is important to determine the key skills that cancer survivors need, as well as the most effective way(s) to enhance these skills, possibly differentiated for different types of cancer. And finally, an important issue with health IT services is that there is a limited uptake. According to a large study in the US (N=3959) overall use ranged from 3% to 78% for online diary keeping and health information seeking on the internet respectively. They also found that older persons, males and those with a lower socioeconomic status were less likely to engage in a number of e-Health activities (Odds ratio ~ 0.5) compared to their counterparts [86]. It therefore may be prudent to study ways to optimize the reach of such services in cancer survivors, for example by using the RE-AIM framework that was developed to guide the widespread adoption and implementation of health interventions [87].

Limitations and strengths

First, regarding the integrative literature search on empowerment, we did not include or exclude articles based on quality criteria, which makes it impossible to objectively assign more weight to one article over another. Furthermore, it is an inherent limitation of the current review that there is a limited number of studies specifically focusing on cancer patients. However, as findings with regard to patient empowerment in the larger body of literature on chronically diseased patient populations were also reflected in the more limited literature specifically focusing on patients with cancer, we can assume that the conceptualisation of empowerment applies to the cancer setting as well. Second, the review of IT services may not include every IT service currently available. This is a rapidly developing area, and thus it is difficult to be comprehensive. Rather, we have provided an overview of some of the more widely publicized IT services that serve cancer survivors. Although there are no established methods for reviewing newly developed IT services, we have suggestions for future attempts. Reviews in this area may be strengthened by searching multiple databases (PubMed, Scopus etc.), having at least two persons evaluating the eligibility and extracting features/functionalities of the services and relate them to predefined quality criteria when available. For example, Williams et al. reviewed

online decision aids and rated them on International Patient Decision Aid Standards (IPDAS) criteria [88]. Finally, our statements regarding the contribution of IT to patient empowerment have been based largely on hypothesized effectiveness, as the current evidence base in this area is quite small.

2

The major strength of this review is that it addresses both the literature on defining patient empowerment, and the literature on current IT services for cancer survivors and their possible contribution to enhancing empowerment. Another strength is the use of the integrated review method, which facilitates inclusion and integration of different sources and types of information (e.g. theoretical and empirical manuscripts) in a single review [12].

Conclusions

In this paper we have identified the key attributes of the concept of patient empowerment for chronic patients including cancer survivors and we have illustrated the ways in which IT services can contribute to enhancing empowerment of cancer survivors. We found that IT services were mainly related to knowledge provision (e.g. about the patients' medical condition) and that active approaches for skill development were limited. Future challenges will be to make these services truly aimed at the patients' needs, effective in following up on the identified needs and making these services attractive and easy to use for patients with varying levels of (e)-health literacy and sociodemographic characteristics.

Appendix 2.1 Electronic PubMed searches

Primary search on Patient Empowerment

((patient empowerment AND ((conceptual) OR (theory) OR (cancer)))

Filter: English

Primary search on IT services for cancer survivors

((((("cancer patient" OR "cancer survivor" OR "cancer survivorship" OR "cancer"))))

AND (((("ict" OR "information and communication technology" OR "web-based" OR "internet"))

Filters: English; Reviews; publication date Jan 2010-Jan 2015

2

Appendix 2.2 Examples of IT services with potential for empowerment of cancer survivors

System name	Key features and user interaction aspects	Integration with electronic medical record (EMR)
Patient portals		
MyChart/EPIC [48]	<ul style="list-style-type: none"> • View test results • View upcoming & past appointments • Fill out pre-visit questionnaires • Schedule appointments • View paperless statements & pay bills online • Upload photos • Connect to home devices • Refill prescriptions • Message securely with providers • View a child's records and print growth charts • Manage the care of elderly parents • View education topics triggered by EHR data • Get a chronic disease summary w/reminders 	Yes
ChipSoft patient portal	<ul style="list-style-type: none"> • Access to parts of the medical record via secure portal • View scheduled and past visits • Provide and change registered patient personal data • Fill out questionnaires prior to a visit by computer at home • presentation of questionnaire data in tables (for both patients and clinicians) • Clinicians can provide patient education for upcoming visits by selecting documents manually • Access for the general practitioner (optional) • Output (e.g. advice) can be tailored based on input data via specific predefined rules and is presented in the portal 	Yes

Appendix 2.2 Continued

System name	Key features and user interaction aspects	Integration with electronic medical record (EMR)
Patient portals		
Digital IVF clinic (digitale IVF poli)	Access to: <ul style="list-style-type: none"> • Planned visits • Outcome of treatment • Laboratory results • Ultrasound results • Letters to general practitioners • Photos of the embryo • Communication with the care team 	No direct integration
Medischegegevens.nl [47]	Access to: <ul style="list-style-type: none"> • Medical data • Letters to general practitioners • Laboratory results • Diagnostic test results • Radiology results (Rontgen pictures) • Add own documents and allergies • Make summary of health history • Provide access to physicians of choice 	No, medical data is extracted to patient portal surrounding
Care companion [46]	<ul style="list-style-type: none"> • Personal care trajectory depicted as a “metro trail” including all important phases of treatment with patient education linked to each “station” • Library • Information about diagnosis • Overview of scheduled visits • Personal notes • Monitoring personal data (e.g. pain of QoL) and graphical presentation • View and update personal data (such as name birth data etc.) 	No direct integration
Electronic patient-reported outcome (e-PRO) systems		
CHES: Computer-based Health Evaluation System [50]	<ul style="list-style-type: none"> • Electronic filling out of quality of life questionnaires by patients on-site via computerized questionnaire (web based input at home is under construction). • Graphical depiction of quality of life scores for different measurements • Addition of reference values and flags for deviant scores • Software can be modified to user requirements (e.g. recording of chemotherapy details in oncological patients). • Graphical overview currently only available for clinician 	No, but database can be linked to EMR via HL7

Appendix 2.2 Continued

System name	Key features and user interaction aspects	Integration with electronic medical record (EMR)
Electronic patient-reported outcome (e-PRO) systems		
Electronic patient reported outcome system of UMC Leiden, NL	<ul style="list-style-type: none"> • Possibility for patients to fill out questionnaire on symptoms and quality of life at home • Graphical overview of domain scores of quality of life for health professionals <p>A hospital employee manually:</p> <ul style="list-style-type: none"> • Sends out questionnaires to patients • Notifies physicians of alarming scores • Physicians are able to view quality of life profile in their own hospital information system 	Yes
Eir, a computer based decision support system [49]	<ul style="list-style-type: none"> • Patients complete symptom assessment at home on an tablet computer prior to consultation • Data is transferred wireless to physician desktop • Physician has an overview of symptoms and complaints prior to consultation • Physician can add treatment and clinical data • Clinical decision support is provided by the system based on input data and is based on international guidelines 	Unknown
Electronic patient self-assessment (SAM) [51]	<ul style="list-style-type: none"> • Patients get invitation by email to fill out validated questionnaires online at preset intervals post-surgery (mainly developed for prostate cancer patients undergoing surgery) • Results of questionnaires are analyzed to provide patients with real-time and, online information about their progress and to provide them with tailored and standardized medical advice • Data could be electronically transferred to the health care provider 	No, but data could be transferred to the clinician electronically

Appendix 2.2 Continued

System name	Key features and user interaction aspects	Integration with electronic medical record (EMR)
Electronic patient-reported outcome (e-PRO) systems		
Electronic Patient reported outcomes from cancer survivors (ePOCS) [45]	<p>This system consists of two key components: QTool and Tracker.</p> <p><i>QTool: Web-based password-protected questionnaire administration and management system</i></p> <ul style="list-style-type: none">• Any PROM can be entered and displayed in various formats (e.g., one or multiple items per screen, tick-box or drop-down menu response options)• Individual PROMs questions can be set to display (or not), dependent on responses to other questions, and to require an answer (or not)• Any combination of PROMs can be assigned to any size patient group, and different groups can complete different PROMs packages simultaneously• PROMs can be set to be accessible to patients at any specific time-points from their diagnosis date, and to be available for any window of time• Entering and setting PROMs is menu-driven and does not require specialist skills <p><i>Tracker: database for monitoring patients' QTool activity and generating study correspondence, which is housed on a secure registry server</i></p> <ul style="list-style-type: none">• All due correspondence is automatically calculated for all patients in the system daily, for every data collection time point (e.g., invitations to complete PROMs, reminders, thank you acknowledgements)• Appropriate pre-programmed communications are automatically selected and populated with the relevant patient's details (e.g., name, address, QTool ID + password)• Prepared communications are generated ready to send as Emails, or to print out as letters, dependent on whether a patient provides an Email address or not.• Any communication can be recorded as unsent (e.g., if a patient is unwell and requests communications are stopped)• All (un)sent communications associated with a patient can be instantly viewed in a table• Notice is provided of patients near-due to complete further PROMs, along with a printable details form (e.g., name, address, NHS number), so administrators may check patient status (e.g., via GP), to ensure it is appropriate to send a PROMs invitation	No, data are merged together with EMR data and then sent to the national cancer repository

Appendix 2.2 Continued

System name	Key features and user interaction aspects	Integration with electronic medical record (EMR)
Electronic patient-reported outcome (e-PRO) systems		
OncoKompas [52]	<ul style="list-style-type: none"> • A personal website that provides a profile of health status (depicted as a compass) is provide based on user input. • Per health status domain it is shown if a person is on track (shown as green, orange or red signs). • When orange or red, then tailored advises (via stepped care order progressing from self-help to suggestions for professional medical intervention). 	No
Electronic survivorship care (plan) support		
Livestrong Care Plan [53]	<p>A personal survivorship care plan (SCP) is generated based on patient input. The SCP contains:</p> <ul style="list-style-type: none"> • Records of medical history. • Specific information about cancer diagnosis and treatment. • Information about possible late effects and signs of a recurrence or new cancer. • A schedule for follow-up health care including screening tests. • Tips on cancer prevention and suggestions for maintaining a healthy lifestyle. • How to find quality health care and other support services. 	No
ROGY Care [55]	<ul style="list-style-type: none"> • A paper based personal survivorship care plan (SCP) is generated based on a registration system for gynecological cancer. The SCP provides tailored information based on personal patient and disease data (e.g., name patient, date of birth, type of cancer, cancer stage, treatment received, providers involved). • Detailed information is provided on the diagnosis, treatment, possible short term and long-term effects of the disease and the treatment and aftercare. • Recurrences, toxicities or other specialists involved in the patient's care are registered in ROGY and automatically updated in the personal SCP. 	No, but is linked to a separate regional cancer registry system for gynecological tumors

Appendix 2.2 Continued

System name	Key features and user interaction aspects	Integration with electronic medical record (EMR)
Electronic survivorship care (plan) support		
Survivorship Care Plan builder [54]	<p>The Survivorship Care Plan Builder will support in quickly creating individualized Care Plans that reflect ASCO guidelines and the recommendations in the IOM (Institute of Medicine) report, From Cancer Patient to Cancer Survivor: Lost in Transition.</p> <p>The Survivorship Care Plan Builder includes:</p> <p>Convenient forms for quickly preparing treatment summaries based on ASCO templates</p> <ul style="list-style-type: none">• Ability to pre-populate forms with data from a cancer registry• Surveillance guidelines• Recommended schedule for follow-up care• Information on managing ongoing effects of cancer treatment• Psycho-social patient assessment• Ability to create custom templates• Ability to include your practice logo• Free technical support	<p>No, but it is possible to export patient data from from C/NExT registry software to the Survivorship Care Plan builder</p>

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Chapter 3

A systematic review of
web-based interventions
for patient empowerment
and physical activity in
chronic diseases:
Relevance for cancer survivors

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ABSTRACT

Background

Patient empowerment reflects the ability of patients to positively influence their health and health behaviour such as physical activity. While interactive, web-based interventions are increasingly used in various chronic disease settings to enhance patient empowerment related to physical activity, such interventions are still uncommon for cancer survivors.

Objectives

To systematically review the literature regarding interactive, web-based interventions with a focus on patient empowerment, physical activity or both for various chronic conditions, and to explore their possible relevance for cancer survivors.

Methods

Searches were performed in Pubmed, Embase and Scopus to identify peer-reviewed papers reporting on randomized controlled trials that studied the effects of web-based interventions. These interventions were developed for adults with diabetes, cardiovascular disease, chronic obstructive pulmonary disease, heart failure or cancer. Intervention characteristics, effects on patient empowerment and physical activity, information on barriers to and facilitators of intervention use, users' experiences, and methodological quality were assessed. Results were summarized in a qualitative way. We used the recommendations of the Institute of Medicine (IOM) regarding cancer survivorship care to explore the relevance of the interventions for cancer survivors.

Results

Nineteen papers reporting on trials with 18 unique studies were included. Four studies reported significant, positive effects on patient empowerment and two studies reported positive effects on physical activity. The remaining studies yielded mixed results or no significant group differences in these outcomes (i.e., no change or an improvement for all groups). Although the content, duration and frequency of interventions varied considerably across studies, commonly used elements included: education, self-monitoring, feedback/tailored information, self-management training, personal exercise program and communication (e.g., chat, email) with either health care providers or patients. Limited information was found on barriers, facilitators and users' experiences. Methodological quality varied, with 13 studies being of moderate quality. The reported web-based intervention elements appear to be highly relevant to address the specific needs of cancer survivors as indicated by the IOM.

Conclusions

We identified seven common elements of interactive, web-based interventions in chronic disease settings that could possibly be translated into e-health recommendations for cancer survivors. While further work is needed to determine optimal intervention characteristics, the work performed in other chronic disease settings provides a basis for the design of an interactive e-health approach to improve patient empowerment and physical activity in cancer survivors. This may subsequently improve their health status and quality of life and reduce their need for supportive care.

INTRODUCTION

Due to improvements in cancer screening and cancer treatment, the number of people living with cancer or who have been successfully treated for cancer is increasing rapidly [1]. Those people are often referred to as cancer survivors, and in the Netherlands this population is expected to increase from 419,000 in 2009 to 660,000 in 2020 [2]. Cancer survivors are increasingly approached as individuals with a chronic disease, with either on-going or intermittent impact on their health status and quality of life. Therefore, many of them need supportive and rehabilitation services to alleviate side effects of treatment and to cope with psychosocial problems such as fear of disease recurrence or with physical health problems such as a painful arm after breast cancer surgery. Furthermore, these services can be used for health promotion [3;4]. To minimize the time and costs that are involved in the need for such supportive care due to the raising number of cancer survivors, it may be useful to enhance patient empowerment.

Patient empowerment can contribute to the control over health and health behaviour and is frequently described as having knowledge about one's health, and being able and motivated to influence one's health [5]. It refers to well-informed patients taking responsibility for their own health, to as great an extent as possible, and with expected benefits in terms of improved quality of life [6]. It is expected that increasing patient empowerment will result in a reduced need for support from the health care system, and thus in lower health care costs [7;8].

Another factor that positively contributes to quality of life is physical activity. A number of studies have demonstrated many beneficial effects of physical activity on physical and psychosocial well-being, both during and after cancer treatment [9-11]. So, empowering cancer survivors and enabling them to become or stay physically active is very likely to be beneficial for both patients and society.

A promising medium for facilitating patient empowerment and physical activity is the internet. Easily accessible, up-to-date and tailored information can be provided, often in an interactive way. For example, patients can be asked to provide information via a questionnaire or can pose questions, and this in turn triggers either standardized or tailored feedback from the health care system (given automatically or by a health care provider). The internet is increasingly used for the delivery of these interactive interventions, both for healthy individuals [12] and those with a chronic condition [13]. For cancer survivors, other e-health initiatives do exist, for example online support groups, online patient education programs [14;15], informative tools for decision support and various mobile apps that can be used independent of provider activities. However, there are very few interactive websites that aim to empower cancer survivors, especially in the area of physical activity. Previously researchers have reviewed web-based interventions meant to increase either patient empowerment or physical activity level, and they found

promising results [13;16]. These reviews included studies that were focused primarily on healthy individuals (in some cases sedentary or overweighted)[16] or that aimed at increasing patient empowerment, but not physical activity levels, of individuals with chronic diseases [13]. In view of the increasing number of cancer survivors and the possible role interactive web-based interventions can play in stimulating empowerment and physical activity, it is important to learn from empirical evidence about the efficacy of such interventions in chronic diseases. Considering the comparable chronic nature of these diseases and cancer survivorship, it is plausible that interventions that contribute to managing chronic diseases other than cancer contain elements that are appropriate for cancer survivors as well.

This systematic review has five aims: (1) to describe the characteristics (content, length, frequency, duration) of interactive, web-based interventions in diabetes, chronic obstructive pulmonary disease (COPD), (congestive) heart failure, cardiovascular disease, and cancer; (2) to summarize the effects of these interventions on patient empowerment and physical activity; (3) to identify barriers for and facilitators of the use of web-based interventions and to describe users' experiences with such websites; (4) to assess the methodological quality of the studies reviewed; and (5) to evaluate the possible relevance of these interventions for cancer survivors.

METHODS

Search strategy

We searched the literature in Pubmed, Embase, and Scopus. The search strategy combined four concepts: patient empowerment, physical activity, information technology (IT), and type of chronic disease. For each concept, several search terms were used (see Appendix 3.1). Because we also wanted to identify IT that focussed on either physical activity or patient empowerment, we also searched PubMed for the combination of patient empowerment, IT and type of chronic disease, and separately for the combination of physical activity, IT and type of chronic disease. As this resulted in many duplicates, this dual search strategy was not repeated in Embase or Scopus. To retrieve other relevant publications, we examined the reference lists of the selected publications and of reviews that were excluded based on eligibility criteria.

Eligibility criteria

We used the following inclusion criteria: (a) peer reviewed studies in English describing a randomized controlled trial (RCT), published between 1990 and November 20th 2012; (b) participants were adults and suffered from at least one of the following chronic diseases: cancer, diabetes, heart failure, cardiovascular disease, or chronic obstructive pulmonary disease (COPD); (c) the intervention was web-based and interactive; (d) the intervention group was compared to a similar patient group (receiving another intervention or

usual care); and (e) the study included at least one outcome measure assessing patient empowerment and/or physical activity. For patient empowerment, relevant, related outcomes included self-efficacy, self-management, self-care behaviour, and self-control. For physical activity, relevant outcomes could be based on self-report (e.g., by questionnaire or interview), performance tests, or observation (e.g., accelerometer data).

Selection method

The first author applied the eligibility criteria to the titles and abstracts. When considered relevant or in case of ambiguity, the full publication was reviewed by two authors independently. In case of disagreement, consensus was sought through discussion. When disagreement persisted, the judgement of a third reviewer was decisive.

Data extraction

The following information was extracted from each publication: study characteristics (source and year of publication, country of origin, aim and sample size), patient characteristics (type of disease, age, gender, comorbidities, computer experience, internet use), intervention characteristics (content, duration, frequency, compliance and drop-out rate), outcome measures (instruments used and effects on patient empowerment and physical activity), information about barriers to and facilitators of intervention use, and users' reported experiences with the intervention. The first author independently extracted the data, and the second author checked the data extraction for 20% of the studies to determine inter-rater reliability. This was established by calculating the percentage of agreement. Consensus was reached by discussion. Due to the diversity of outcome measures, sample size and intervention characteristics, it was not possible to conduct a formal meta-analysis.

Quality assessment

The methodological quality of the studies was evaluated, but did not serve as an eligibility criterion. We used a list that was an adapted version of the Cochrane Collaboration Back Review Group [17], which was used previously in a systematic review of internet-based physical activity interventions by van den Berg and co-workers. These authors modified the Cochrane list to better suit the type of studies they examined. For example, the Cochrane list contained the item "description of and acceptable drop-out rate", which was changed into "description of dropout rate plus comparison of dropouts with completers". In addition, they deleted some items because they were not relevant for web-based interventions [16]. For our review, one additional change was made: "Long-term follow-up measurement" was defined as an outcome assessment more than three months after the post-intervention measurement. The final list of criteria included 13 items relating to the selection of patients, the intervention, outcome measurements and statistics. The complete list can be found in Table 3.3, in which the outcomes of the methodological quality assessment are shown.

For each study, all criteria were scored with yes, no, or unclear, resulting in a maximum quality score of 13. In line with other researchers [16], we considered studies obtaining at least two-thirds of the total score (i.e. ≥ 9 points) to be of high quality. Studies scoring 5 to 8 points were rated as moderate quality, and studies scoring lower than 5 points as low quality. Quality assessment was performed by the first author; the second author assessed the quality of a random sample of 4 studies. The inter-rater reliability was calculated as percentage of agreement on 52 aspects (4 x 13 criteria). Disagreements between researchers were discussed to reach consensus.

Evaluation of potential relevance for cancer survivors

To evaluate the relevance of the selected interventions for cancer survivors, we used the five factors included as characteristics of cancer survivorship identified by the Institute of Medicine (IOM): surveillance, management of late effects, rehabilitation, psychosocial support and health promotion [4]. We evaluated whether the interventions reviewed could be mapped onto these five features of cancer survivorship care.

RESULTS

Selection of publications

The initial search yielded 3,438 hits. Based on titles and abstracts, 62 publications were selected. The full text of these 62 publications was reviewed, resulting in a selection of 19 publications that met all eligibility criteria [18-36]. A review of the reference lists of these publications, as well as the reference lists of the excluded reviews did not result in any additional studies. See figure 1 for a flow chart of the selection process. For the cancer setting, we found 46 papers that met several of our inclusion criteria, but not all. Reasons for exclusion were diverse, varying from not being an RCT (for example design papers or non-randomized pilot studies) to inappropriate outcome measures or not being web-based and/or interactive (for example a CD-ROM).

Data extraction

Reviewers' ratings were in agreement for 88% of the data extraction elements of the sample. This can be considered as a high level of agreement according to the guidelines of Landis and Koch [37], and justified the decision to have only one of the authors carry out the data extraction for the remaining studies.

Study characteristics

All papers were published in 2000 or later, with most being published after 2005. The 19 publications described 18 unique studies; two papers by Glasgow et al. described the same study using different assessment points (4 and 12 months) [21;22]. Twelve studies were conducted in the United States. The remaining studies took place in Canada (n=2), Korea (n=1), Norway (n=2) and Australia (together with the U.S.; n=1). Sample sizes at

Figure 3.1 Flow chart of the search process

baseline varied between 15 and 1,665. In the majority of RCTs, one group was exposed to a web-based intervention and was compared to a usual care control group (n=7), an information only condition (n=2), an observational control group (n=1), a face-to-face intervention (n=1), both a print material intervention and usual care (n=1) or both a face-to-face intervention and an information only condition (n=1). In two RCTs, two intervention groups were compared with either a usual care control group or enhanced usual care. In one RCT, two groups receiving a web-based intervention were compared with an information only condition. Finally, in two RCTs, two intervention groups were compared. Those groups received the same basic intervention, but with a different focus (high versus low self-efficacy and lifestyle goals versus structured goals).

Patient characteristics

Studies included patients with diabetes (n=11), heart failure (n=3), COPD (n=1), cardiovascular disease (n=1), cancer (n=1), and mixed patient groups (heart disease, lung disease, type 2 diabetes; n=1). The overall mean age of the participants was 60 years (range 40 - 76 years). For the 18 studies that reported on gender, the median percentage of women was 53% (range 6% - 73%). Seven studies excluded individuals with comorbid

conditions, and six studies provided information about comorbidity (e.g., mean number of comorbid conditions). Only six studies collected information on participants' prior experience with computers and/or internet use. Both computer experience and internet use were assessed with a variety of self-reported questionnaire items, ranging from times per week to years of experience, making it difficult to compare across studies.

Intervention characteristics

Intervention characteristics for both intervention and control groups are described in Table 3.1. The degree of detail provided about the interventions varied greatly across studies. There was large variation in the duration, frequency, and content of the interventions. Duration varied between 1 month and 1 year (mean = 23 weeks, SD = 19 weeks). The (intended) frequency or intensity of the interventions was not clearly described in the majority of the papers. In some papers, a schedule for intervention use was proposed [23;25;36], whereas in other papers only information about actual use was reported (e.g., number of logins, percentage of individuals that used the different intervention elements).

Although the content of the interventions differed, seven elements could be identified that were used in the majority of the interventions, including both those interventions that had significant effects and those that did not. These elements were used in different combinations and were adapted to the specific patient population. The first element was *education*: information about various aspects of the chronic health condition such as medication, nutrition, exercise, coping, and symptom management, provided via electronic newsletters, pamphlets, slides, or a digital library with articles. The second element, *self-monitoring*, involved uploading or registration of data such as blood glucose levels, blood pressure, medication use, food intake and exercise behaviour. In the study of Nguyen and colleagues for example, individuals had to submit real-time information about dyspnea, cough and sputum via their computer or smartphone [29]. This was often followed by the third element, *feedback/tailored information*. Patients received individual advice based on the uploaded data. This included such things as individually tailored exercise advice, or a graphical overview of blood glucose levels. Other forms of tailored information included access to the medical record, medication reminders and tips for overcoming personal exercise barriers. Fourth, interventions could include *self-management training*, involving lessons about the management of symptoms, psychosocial aspects and fatigue. An important aspect of self-management training was goal setting. The fifth element, found only in interventions involving physical activity, was a *personalized exercise program* that was adapted on the basis of self-reported and/or objective physical activity data obtained before and during the intervention. The exercise programs took the individual's needs, preferences and possibilities into account. In the study of McKay and co-workers for example, patients went through a five-step process to select their personal motivators, goals, preferred activities and schedule, and to identify their personal barriers [27]. Elements six and seven both involved *communication*, either

with health care providers or with fellow patients, respectively, using communication routes like e-mail, live chat, videoconferences and discussion boards (forums). Communication with health care providers was often used for questions, encouragement and emotional support, whereas communication with fellow patients was included to share experiences, exchange information and provide support. Additionally, elements that were used in only some studies were an educational quiz and periodic reminders for website use.

The overall percentage of dropouts varied between 0% and 52% (median 17.5%). For the intervention groups (including the control groups that also received a web-based program) the median dropout rate was 19.7% and for the control groups this was 14%. Compliance with the intended intervention varied between 37% and 96% for the eight studies that reported on it. The remaining studies did not report compliance, but described aspects of website use, such as number of logins, percentage of people using a certain feature, minutes per session, or percentage of tasks completed. Intervention use varied greatly between studies and participants. All studies that monitored website use found a decline during the intervention period. There was no obvious relationship between drop-out rates, compliance and website use on the one hand, and patient and intervention characteristics on the other hand.

Table 3.1 Intervention characteristics

Study	Patient group (sample size)	Study design ^a + Focus of intervention	Intervention	Follow-up period
Artinian et al. (2007)	Congestive heart failure (n = 18)	Pilot RCT with an intervention group and a usual care comparison group	Home care monitoring system <ul style="list-style-type: none"> • pamphlet with education about self-care behaviour • medication reminders • questions + response • registration of pill taking 	3 months
Bond et al. (2010)	Diabetes (n = 62)	RCT with an intervention group and a usual care comparison group	Focus on self-management and psychosocial well-being <ul style="list-style-type: none"> • usual care • instructions (about issues regarding disease management) • interaction with study nurse • uploading data & receiving feedback • online educational discussion group • peer support via email and instant messaging 	6 months

Table 3.1 Continued

Study	Patient group (sample size)	Study design ^a + Focus of intervention	Intervention	Follow-up period
Glasgow et al. (2003)	Type 2 diabetes (n = 320)	RCT with 3 intervention groups and an internet information only comparison group (library with articles, automated dietary goal setting, online assessments)	Aspects of information only plus 1) Tailored self-management training • on-line professional suggesting tailored strategies • question and answer with dietician • blood glucose upload and dietary databases plus graphical feedback or 2) Peer support • exchange of information, coping strategies, and emotional support on a forum • live chat • 5 electronic newsletters both 1 and 2	10 months
Glasgow et al. (2010)	Type 2 diabetes (n = 463)	RCT with 2 intervention groups and an enhanced usual care comparison group (health risk appraisal feedback, recommendations of preventive care behaviour)	Self-management program with 1) Minimal support • goal selection • progress recording • feedback • community resources • quiz questions • motivational tips • periodic prompting or 2) Moderate support • aspects of minimal support • follow-up calls • invitation for a group visit with other participants	4 months 12 months
Glasgow et al. (2011)				
Kim & Kang (2006)	Type 2 diabetes (n = 73)	RCT with an intervention group, a print-material comparison group (booklets with tailored exercise strategies), and a usual care comparison group	Physical activity intervention • general information • assessment tools for physical and psychological readiness for exercise • stage-based individual information about goal setting and exercise planning • question-and-answer board • interactive and animated features • exercise test (in the lab), followed by an individualized physical activity prescription	12 weeks

Table 3.1 Continued

Study	Patient group (sample size)	Study design ^a + Focus of intervention	Intervention	Follow-up period
Liebreich et al. (2009)	Type 2 diabetes (n = 49)	RCT with an intervention group and a usual care comparison group	Website and counselling <ul style="list-style-type: none"> • link to clinical practice guidelines for physical activity • interactive features (physical activity logbook, forum, email counselling) • education / tips • weekly topic (e.g., goal setting, time management) 	12 weeks
Lorig et al. (2006)	Heart & lung disease, type 2 diabetes (n = 958)	RCT with an intervention group and a usual care comparison group	Self-management program plus usual care <ul style="list-style-type: none"> • individual exercise program • management of symptoms, fatigue, emotions, problems • motivational email reminders • overview of medications • interaction with moderator • action planning • feedback 	12 months
Lorig et al. (2010)	Type 2 diabetes (n = 761)	RCT with 2 intervention groups (only difference was e-mail support; analysed together) and a usual care comparison group	Self-management program <ul style="list-style-type: none"> • 6 weekly sessions with different topics • bulletin board • exercise logs and monitoring tools • communication with facilitators 	18 months
McKay et al. (2001)	Type 2 diabetes (n = 78)	RCT with an intervention group and an information only comparison group (library articles, glucose tracking plus feedback)	Physical Activity Intervention <ul style="list-style-type: none"> • feedback on baseline activity levels • personalized PA program and PA database • personal coach counselling and support • communication with other intervention participants 	8 weeks
Nguyen et al. (2008)	COPD ^b (n = 50)	RCT with an intervention group and a face-to- face intervention comparison group (same intervention components)	Self-management program <ul style="list-style-type: none"> • education and skills training • tailored exercise planning • self-monitoring of symptoms and exercise • personalized feedback 	6 months

Table 3.1 Continued

Study	Patient group (sample size)	Study design ^a + Focus of intervention	Intervention	Follow-up period
Richardson et al. (2007)	Type 2 diabetes (n = 35)	Pilot RCT with 2 intervention groups (with a focus on either Lifestyle goals or Structured goals)	<p>Pedometer-based walking program with a focus on</p> <ol style="list-style-type: none"> 1) Lifestyle goals (targeting accumulated steps) or 2) Structured goals (only targeting steps taken during bouts of at least 10 minutes with at least 60 steps per minute) <ul style="list-style-type: none"> • access to a personally-tailored Stepping Up to Health web page • tailored motivational messages • tips about managing diabetes • automatically calculated goals (based on pedometer results) • feedback about performance toward goals 	6 weeks
Ross et al. (2004)	Congestive heart failure (n = 107)	RCT with an intervention group and a usual care comparison group	<p>Secure web-interface to three features</p> <ul style="list-style-type: none"> • medical record • educational guide • messaging system • reminders 	12 months
Tomita et al. (2009)	Heart failure (n = 40)	RCT with an intervention group and a usual care comparison group	<p>Self-management program in addition to usual care</p> <ul style="list-style-type: none"> • informational support • recording vital signs and exercise • appraisal support (feedback) • emotional support 	12 months
Trief et al. (2007)	Diabetes (n = 1665)	RCT with an intervention group and a usual care comparison group	<p>Telemedicine case management</p> <ul style="list-style-type: none"> • access to educational materials • upload data on blood glucose and blood pressure readings • videoconference with a nurse case manager and dietician (to educate patients, facilitate goal setting/self-management, and discuss concerns) 	12 months

Table 3.1 Continued

Study	Patient group (sample size)	Study design ^a + Focus of intervention	Intervention	Follow-up period
Wangberg (2008)	Type 2 diabetes (n = 60)	RCT with 2 intervention groups (with a focus on either high or low self-efficacy)	Self-care intervention tailored to either high or low self-efficacy <ul style="list-style-type: none"> • behaviour exercises (including monitoring and graphic feedback) • information • quizzes with feedback • videos of peers • videos of lectures from health personnel 	1 month
Zutz et al. (2007)	Cardiovascular disease (n = 15)	Pilot RCT with an intervention group and an observational control comparison group (no contact with either the research staff or the hospital)	Cardiac rehabilitation program <ul style="list-style-type: none"> • chat sessions with health care professionals • education sessions (slides) • monitoring of blood and exercise • group chat sessions 	12 weeks

^a RCT = randomized controlled trial^b COPD = chronic obstructive pulmonary disease

Outcome measures

Table 3.2 presents patient empowerment and physical activity outcomes and dropout rates. A range of outcome measures was used (e.g., different self-efficacy scales, diverse measures of different forms of physical activity). A total of 13 studies included one or more patient empowerment measures. In four studies, patient empowerment increased significantly ($p < .05$) in the intervention group compared to usual care or observation [19;25;34;36], while in three studies this increase was reported for both groups [18;22;28] (i.e., both the web-based intervention group and the comparison group improved irrespective of receiving a web-based or a face-to-face intervention or usual care). In the study of Nguyen et al., for example, both the individuals receiving the web-based intervention and those having personal contact improved on a measure of self-efficacy [28]. Two studies yielded mixed results, with one of two outcome measures showing a significant increase [24;35]. For example, Wangberg et al. measured both self-efficacy and self-care behavior, but observed improvement only in the latter. The remaining four studies did not observe a significant change in patient empowerment [26;29;31;32] for either the intervention group or the usual care group.

Of 14 studies that assessed physical activity, two reported significant improvement ($p < .05$) for the intervention group compared to usual care [33;36] (e.g., an increase in the number of individuals who exercised regularly or in physical activity behavior). Increases in physical activity were found for both groups in six studies [21-23;27;28;30]. For instance, McKay et al. compared their web-based group with an information only approach. Both groups improved their moderate/vigorous exercise behavior as well as their walking performance. Three studies [24;26;29] found mixed results, with one of their outcome measures being non-significant and the others showing a significant increase. For example, Lorig et al. found no change in aerobic exercise behavior but did observe an increase in stretch/strength exercise [26]. Finally, three studies did not find any effects on physical activity [18;20;25].

Table 3.2 Intervention outcomes and dropout rates

Study	Patient empowerment outcome measure ^c	Patient empowerment outcomes ^{a, c}	Physical activity outcome measure ^c	Physical activity outcomes ^{a, c}	Dropout rate (overall)
Artinian et al. (2007)	<i>Revised Heart Failure Self-Care Behavior Scale</i>	Self-care + ($P = .02$) ^d	<i>6 Minutes Walking Test</i>	Exercise performance - ($P = .42$)	0%
Bond et al. (2010)	<i>Diabetes Empowerment Scale</i>	Self-efficacy + ($P < .05$) ^b	X	X	0%
Glasgow et al. (2003)	X	X	<i>Physical Activity Scale for the Elderly</i>	Physical activity - ($P = .41$)	18%
Glasgow et al. (2010)	<i>Diabetes Self-Efficacy scale</i>	Self-efficacy 4 months	<i>Community Health Activities Model Program for Seniors Questionnaire</i>	Caloric expenditure in physical activity 4 months: + ($P = .04$) ^f	4 months 17.5%
Glasgow et al. (2011)		X			
		12 months + ($P < .10$) ^{b, f}		12 months: + ($P < .05$) ^{b, f}	12 months 22.7%
Kim & Kang (2006)	X	X	<i>Self-report instrument adapted from the 7-day physical activity questionnaire (frequency, duration, intensity)</i>	Metabolic equivalents (MET) x hours/week + ($P < .001$) ^f	0%

Table 3.2 Continued

Study	Patient empowerment outcome measure ^c	Patient empowerment outcomes ^{a, c}	Physical activity outcome measure ^c	Physical activity outcomes ^{a, c}	Dropout rate (overall)
Liebreich et al. (2009)	<i>Likert scale (1-5); 12 items</i>	Self-efficacy - ($P = .31$)	<i>Godin Leisure-Time Exercise Questionnaire (GLTEQ)</i>	MET minutes + ($P = .04$) ^f	10.3%
	<i>Likert scale (1-5); 4 items</i>	Behaviour capacity + ($P = .001$) ^f	<i>GLTEQ</i>	Unweighted minutes + ($P = .01$) ^f	
			<i>Incorporated in GLTEQ (times/week, average time per session)</i>	Resistance training - ($P = .06$)	
Lorig et al. (2006)	<i>Likert scale (1-10)</i>	Self-efficacy - ($P = .06$)	<i>Scale (0-4) measuring minutes of exercise per week</i>	Stretch/strength exercise + ($P = .02$) ^f	18.8%
				Aerobic exercise - ($P = .70$)	
Lorig et al. (2010)	<i>Patient activation measure</i>	Patient activation + ($P = .01$) ^f	<i>A physical activities scale (minutes/week)</i>	Aerobic exercise - ($P > .05$) ^b	15.8%
	<i>Diabetes Self-Efficacy scale</i>	Self-efficacy + ($P = .02$) ^f			
McKay et al. (2001)	X	X	<i>Behavioural Risk Factor Surveillance System</i>	Moderate/vigorous exercise + ($P < .001$) ^d	13%
				Walking + ($P < .001$) ^d	
Nguyen et al. (2008)	<i>Single question on a 0- to 10-point response scale</i>	Self-efficacy + ($P = .02$) ^e	<i>Self-report (frequency & duration)</i>	Endurance exercise + ($P = .001$) ^e	24%
				Strength exercise + ($P < .001$) ^e	
			<i>List of 5 descriptions</i>	Stages of change + ($P = .05$) ^e	
			<i>6 Minutes Walking Test</i>	Exercise performance + ($P = .05$) ^g	

Table 3.2 Continued

Study	Patient empowerment outcome measure ^c	Patient empowerment outcomes ^{a, c}	Physical activity outcome measure ^c	Physical activity outcomes ^{a, c}	Dropout rate (overall)
Richardson et al. (2007)	X	X	Pedometer (Omron HJ-720IT)	Total steps + ($P = .003$) ^e Bout steps + ($P < .001$) ^e	14%
Ross et al. (2004)	Kansas City Cardiomyopathy Questionnaire (Self-efficacy domain)	Self-efficacy - ($P = 0.08$)	X	X	24%
Tomita et al. (2009)	X	X	Self-reported frequency of exercise; participants exercising 2-3 times/week or more were seen as exercisers	Number of exercisers + ($P = .001$) ^f	19.8%
Trief et al. (2007)	Diabetes Self-Efficacy scale	Self-efficacy + ($P < .001$) ^f	X	X	52%
Wangberg (2008)	Perceived Competence Scales	Self-efficacy - ($P = .17$)	X	X	48%
	Summary of Diabetes Self-Care Activities measure	Self-care behaviour + ($P = .026$) ^e			
Zutz et al. (2007)	Likert scoring	Self-efficacy (exercise-specific) + ($P < .05$) ^{b, f}	Minnesota Leisure Time Physical Activity Questionnaire	Physical activity + ($P < .05$) ^{b, f}	6.65%
			Symptom-limited treadmill exercise stress test	Exercise capacity + ($P < .05$) ^{b, f}	

^a + = positive effect; - = no effect^b The researchers did not provide specific P values^c X = not applicable^d Positive effect for both the web-based intervention group and the usual care group^e Positive effect for all intervention groups (web-based or other; study did not include an usual care group)^f Positive effect for the web-based intervention group(s) compared to usual care^g Positive effect for the web-based intervention group compared to a face-to-face intervention

Barriers for and facilitators of intervention use and reported users' experiences

Five studies reported on perceived barriers, whereas no studies reported on perceived facilitators of the use of interactive, web-based interventions. Perceived barriers were typically of a technical nature, including problems with internet connection, slow loading of website, security concerns, discomfort with using the computer or internet, and problems with related hardware (e.g., PDA, monitor). Ten studies described some users' experiences, for example, satisfaction scores and a judgment of intervention content. In general, patient satisfaction was high. The personalized nature of the interventions was often cited by participants as being important. In one study [31], nurses and physicians reported that their workload did not increase as a result of the intervention.

Table 3.3 Methodological quality assessment^a

	1	2	3	4	5	6	7	8	9	10	11	12	13	Total score ^c
Artinian et al. (2007)	✓	X	?	✓	X	✓	?	✓ ^b	X	✓	X	X	✓	6
Bond et al. (2010)	✓	X	?	✓	X	X	✓	✓ ^b	X	✓	✓	X	✓	7
Glasgow et al. (2003)	✓	X	?	✓	X	X	?	✓	X	✓	✓	X	✓	5
Glasgow et al. (2010 + 2011)	✓	✓	?	✓	✓	✓	?	✓	X	✓	✓	✓	✓	10
Kim & Kang (2006)	✓	X	?	✓	X	X	?	✓ ^b	X	✓	X	X	✓	5
Liebreich et al. (2009)	✓	X	?	X	X	✓	?	X	X	✓	X	X	✓	4
Lorig et al. (2006)	✓	X	?	✓	✓	X	?	✓	✓	✓	X	✓	✓	8
Lorig et al. (2010)	✓	✓	?	✓	X	X	?	✓	✓	✓	X	✓	✓	8
McKay et al. (2001)	✓	✓	?	✓	X	X	?	✓	X	✓	X	X	✓	6
Nguyen et al. (2008)	✓	✓	✓	✓	✓	✓	✓	✓	X	✓	X	✓	✓	11
Richardson et al. (2007)	✓	X	?	?	✓	✓	?	X	X	✓	X	X	✓	5
Ross et al. (2004)	✓	✓	?	✓	X	X	?	X	X	✓	X	X	X	4
Tomita et al. (2009)	✓	X	?	✓	✓	✓	?	X	X	✓	✓	✓	X	7
Trief et al. (2007)	✓	X	?	✓	X	X	✓	✓	X	✓	X	✓	X	6
Wangberg (2008)	✓	X	?	✓	X	X	?	✓	X	✓	✓	X	✓	6
Zutz et al. (2007)	✓	X	?	✓	✓	✓	?	X	X	✓	X	X	✓	6

✓ = reported item; X = unreported item; ? = unclear item

^a 1 = specification of eligibility criteria; 2 = method of randomization explained; 3 = treatment allocation concealed; 4 = groups similar at baseline; 5 = explicit description of interventions; 6 = description of compliance; 7 = outcome assessor blinded; 8 = description of dropout + comparison with completers; 9 = long-term follow-up (> 3 months after post-intervention assessment); 10 = timing of outcome assessment comparable; 11 = sample size described with power calculation; 12 = intention-to-treat analysis; 13 = point estimates + measures of variability

^b Dropout rate was 0%

^c Maximum score is 13

Methodological quality

The concordance between reviewers in rating the methodological quality for the sample of papers evaluated was high (90%)[37]. For this reason, the first researcher independently performed the quality assessment for the remainder of the studies. The two papers of Glasgow that described the same study were judged together for methodological quality. Table 3.3 shows that three of 18 studies [21;22;28;29] obtained a score of 9 or higher, indicating good methodological quality. Two studies were of low quality [24;31] and the remaining studies were of moderate quality, with most studies scoring a 5 or 6. All studies specified eligibility criteria and employed a comparable timing of outcome assessment for the different groups. The majority of the studies reported dropout rates, including a comparison between completers and non-completers, and gave point estimates together with measures of variability. Only a minority of studies (maximum n=7) provided information about the method of randomization, described their intervention explicitly, performed a power calculation and used an intention-to-treat approach to the data analysis. Most studies were unclear about concealing treatment allocation and blinding of the outcome assessor. In one study, groups were not similar at baseline, and for one study this was not clear. Only two studies described a long-term follow-up measurement. Because 12 out of 18 studies were of moderate quality, it was not possible to determine whether differences in outcomes were related to methodological quality.

Evaluation of potential relevance for cancer survivors

Our judgement of the relevance of the intervention elements for the cancer survivorship setting was based on their *web-based* application (as opposed to their usefulness, in general). Table 3.4a (the more cancer-related recommendations) and 3.4b (the more health-related recommendations) show how these intervention elements could be mapped onto the recommendations for survivorship care as described by the IOM [4]. Five intervention elements contributed to all recommendations, and two elements (personal exercise program and communication with fellow patients) would only be inappropriate for long-term follow-up/surveillance. The specific content of each element when adapted to the oncology setting depended on the recommendation for which it was used. For example, information provision will differ for surveillance versus healthy lifestyle recommendations. Similarly, a personal exercise plan for rehabilitation after surgery differs from an exercise plan that aims to enhance general physical activity levels.

Table 3.4a Proposed application of intervention elements that could enhance cancer survivorship care based on findings from this review (cancer-related recommendations)

Elements of web-based intervention	Recommendations for survivorship care	
	Long-term follow-up/surveillance	Management of (late) effects
Education	<ul style="list-style-type: none">• Information about reasons for surveillance• Recommendations for self-screening	Information about possible late effects of cancer treatment
Self-monitoring	Reporting results of self-screening	Upload of relevant vital signs (e.g., pain scores, blood values)
Feedback/Tailored information	<ul style="list-style-type: none">• A personal follow-up schedule with frequency and type of screening• Feedback on reported self-screening	Advice for managing (late) effects as identified by self-monitoring data
Self-management training	Training aimed at performing regular self-screening	Training to learn to cope with late effects of cancer treatment
Personal exercise program	X	Individual exercise advice to prevent or reduce (late) effects, taking into account a survivor's specific needs and preferences
Communication with health care provider	Possibility to ask questions about follow-up and self-screening	
Communication with fellow patients	X	Possibility to ask questions about symptoms and how to deal with them Share experiences and tips about managing (late) effects

Table 3.4b Proposed application of intervention elements that could enhance cancer survivorship care based on findings from this review (health-related recommendations)

Elements of web-based intervention	Recommendations for survivorship care		
	Rehabilitation	Psychosocial support	Health promotion
Education	Information about the importance of and possibilities for rehabilitation	Information about possible psychosocial problems and possibilities to solve them	Information about the importance of and ways to obtain a healthy lifestyle
Self-monitoring	Upload of relevant vital signs (e.g., blood pressure, lung function) or exercise behaviour (either self-reported or objective)	Questionnaire(s) measuring psychosocial aspects	Upload of relevant data such as food intake and exercise behaviour
Feedback/Tailored information	Rehabilitation advice based on self-monitoring data	Advice for dealing with psychosocial problems as identified with questionnaires; following the stepped care principle	Health advice based on uploaded data; following the stepped care principle
Self-management training	Training to learn to sustain doing rehabilitation exercises	Training aimed at coping with psychosocial problems like anger, fear or frustration	Training aimed at obtaining and sustaining a healthy lifestyle
Personal exercise program	Individual exercise advice aimed at rehabilitation, taking into account a survivor's specific needs and preferences	Individual exercise advice, taking into account a survivor's specific needs and preferences	Individual exercise advice, taking into account a survivor's specific needs and preferences
Communication with health care provider	Possibility to ask questions about rehabilitation	Possibility to ask questions about psychosocial problems; receiving support	Possibility to ask questions about exercise advice
Communication with fellow patients	Share experiences and tips about rehabilitation	<ul style="list-style-type: none"> • Share experiences and tips about dealing with psychosocial problems • Provide support 	<ul style="list-style-type: none"> • Share experiences and tips about health behaviour • Provide support

DISCUSSION

In this paper we have reviewed systematically the empirical literature on web-based interventions for people with diabetes, COPD, heart failure, cardiovascular disease and cancer, and have evaluated their potential relevance for cancer survivors. Nineteen publications covering 18 unique studies were included in this review. The RCTs varied greatly in content, duration and frequency. Four studies found significant, positive effects on patient empowerment and two studies reported positive effects on physical activity. The remaining studies reported mixed results or no significant differences between intervention and comparison groups (i.e., either both groups or neither group improved) on these outcomes. The information we could obtain about barriers and facilitators for intervention use and users' experiences was limited. Nevertheless, we identified seven elements that were common for the majority of interventions: education, self-monitoring, feedback/tailored information, self-management training, personal exercise program and communication (with either health care providers or fellow patients). We were able to map these elements onto e-health features for the recommendations for survivorship care of the IOM.

The seven common intervention elements were used in different combinations and were adapted to the specific patient population. It is therefore not possible to make a judgment about the individual contribution of these elements to intervention outcomes. Future studies should be more structured, in order to determine the role of individual intervention elements and should also take the duration and frequency of interventions into account. In most studies no intervention schedule was prescribed. Rather, the intensity, frequency and duration of website use were determined by the participants themselves. In contrast, structured rehabilitation programs usually have schedules to which patients are expected to adhere (e.g., performing moderate intensity physical activity (running or cycling) for 30 minutes, three times a week, during a 12-week period). It is debatable whether web-based interventions should or should not have a structured program, but it is conceivable that a certain combination of duration and frequency is optimal for achieving improved patient empowerment and physical activity. A recent review of web-based interventions for type 2 diabetes [38] indicated that interventions of longer duration (more than 12 weeks) resulted in better outcomes, and it is likely that the same is valid for cancer survivors. However, future studies need to confirm this.

The relative importance and value of intervention elements, duration and frequency on outcomes is not yet clear. Other factors may also have played a role in the large variation in patient empowerment and physical activity outcomes observed in the studies reviewed. These include the different measurement tools that were used within and between studies, different sample sizes and different periods between the start of the intervention and the post-intervention measurement. To facilitate future meta-analyses, new investigations should preferably use uniform outcome measures and time intervals

for the outcome assessment. The need for a uniform measure of patient empowerment was also pointed out in a paper that discussed the role of assessing patient empowerment in health care evaluation [39].

Another issue to be considered is that, in the majority of studies where no significant differences between groups were observed, significant, positive effects were found for all groups. In many of these studies, the comparison group(s) received an intervention as well. This may have limited the possibility of detecting an effect in favour of the web-based interventions. More generally, it is becoming increasingly difficult to establish appropriate control groups, because the usual care situation is evolving rapidly. Although previous studies have shown that effects on knowledge and behaviour change were higher for individuals using a web-based intervention than for individuals using a non-web-based intervention [40], more work is needed to determine whether this also applies to cancer survivors.

It would have been useful if the RCTs reviewed had provided more information on barriers and facilitators for intervention use. Insight into these factors is very important, because web-based interventions are often characterised by high drop-out rates [41]. Drop-out can refer to patients being lost to follow-up or to patients not using the intervention. Bennett and Glasgow indicated that an important reason for drop-out is loss of interest [42]. Furthermore, two literature reviews showed that peer support, counsellor support, e-mail and phone contact, frequent website updates, record keeping, and individualized feedback were related to sustained intervention use (and conversely, to less drop-out) [43;44]. Most of these components were present in the studies included in the current review. The mean percentage of drop-outs in the web-based intervention groups of the studies reviewed was 20%, which is comparable to the dropout rate found in another review (21%) [40]. More research on program adherence is needed. Or, in other words, it should be determined “what works and why” [44].

The assessment of the methodological quality of the studies reviewed suggests a number of areas in which there is room for improvement. Future RCTs in the field of web-based interventions could be improved by clearly describing the method of randomization, concealment of treatment allocation and an adequate description of sample size calculation. Additionally, researchers should preferably describe explicitly their intervention(s), including specific information about intervention elements, length, frequency and duration. Studies should carry out the statistical analysis on an intention-to-treat basis (as opposed to only analysing the participants who completed the intervention). This is important because participants who complete an intervention may differ from those who do not, as a result of which intervention effects may be over- or underestimated. Because it is often the goal to not only enhance patient empowerment and facilitate a physically active lifestyle in the short-term, but to sustain these outcomes over a longer period of time, it is important that RCTs include not only immediate post-intervention outcome assessment, but also longer-term follow-up assessments.

Web-based interventions are being developed at a rapid pace. This is also true for web-based interventions for cancer survivors. In this review we identified only one paper in the cancer field that met our eligibility criteria. Recently, however, positive results of a web-based intervention to reduce depression in cancer survivors [45], and of a web-based, tailored education program to reduce cancer-related fatigue and anxiety [46] have been reported. Several additional RCT's of web-based interventions for cancer patients are currently on-going (www.clinicaltrials.gov). It is likely that in several years there will be sufficient, mature studies to facilitate a formal meta-analysis to more precisely determine the effects of web-based interventions for both chronic diseases and cancer, rather than the more qualitative review presented here.

Although we identified 7 elements of e-health interventions that may be relevant for cancer survivors, based on the available evidence, we could not determine which of these elements are the most important and effective. It is also unclear which combinations of intervention elements would be optimal. However, the benefit of the educational element for cancer survivors is supported by a review which showed that cancer survivors who received sufficient information reported a better quality of life [47]. An emerging approach in cancer survivorship that may encompass or incorporate many of the intervention elements described in the e-health literature is the use of a survivorship care plan. Such a plan includes a summary of the individual patient's diagnosis and treatment, as well as recommendations for appropriate follow-up care [4]. Currently, survivorship care plans are typically provided on paper, and consequently are quite static documents. There is no reason why they cannot be adapted for e-health use, including interactive elements.

Conclusion

In conclusion, our review suggests that web-based, interactive interventions have a beneficial effect on patient empowerment and/or physical activity in people with various chronic conditions. Program elements that were frequently observed included education, self-monitoring, feedback/tailored information, self-management training, personal exercise program and communication (with either health care providers or fellow patients). Although the results of these studies did not necessarily differ from those of traditional interventions, it is likely that the elements increased patient centeredness and efficiency of the interventions. Empowered individuals who are physically active are likely to have a better health status and quality of life, so the use of interactive internet interventions in this field would appear to be promising. Further research is needed to establish optimal intervention characteristics and specific effects in cancer survivor populations. Future studies should also identify perceived barriers for and facilitators of the use of web-based interventions. The studies that have been conducted in other chronic diseases are likely to constitute a basis for the development of an interactive, web-based intervention to effectively empower the rapidly growing number cancer survivors.

Appendix 3.1 Search strategy in PubMed

#1	("patient empowerment" OR "empowerment" OR "self- efficacy" OR "mastery" OR "self-management" OR "self-control" OR "self-confidence" OR "perceived control" OR "perceived competence" OR "competence" OR "power" OR "self-determination" OR "enhanced control" OR "patient participation" OR "motivation" OR "locus of control")
#2	("physical exercise" OR "physical activity" OR "exercise" OR "physical training" OR "active lifestyle" OR "activities of daily living")
#3	("ict" OR "information and communication technology" OR "web-based" OR "internet" OR "information technology" OR "online" OR "computer assisted" OR "telemedicine" OR "telecommunication" OR "computer assisted instruction" OR "user-computer interface" OR "computerized")
#4	("cancer patient" OR "cancer survivor" OR "cancer survivorship" OR "cancer" OR "chronic obstructive pulmonary disease" OR "diabetes" OR "heart failure" OR "cardiovascular disease")
#5	#1 AND #2 AND #3 AND #4
#6	#1 AND #3 AND #4
#7	#2 AND #3 AND #4

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Chapter 4

An interactive portal to
empower cancer survivors:
A qualitative study on user
expectations

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ABSTRACT

Purpose

Portals are increasingly used to improve patient empowerment, but are still uncommon in oncology. In this study we explored cancer survivors' and health professionals' expectations of possible features of an interactive portal.

Methods

We conducted 3 focus groups with breast cancer survivors (n=21), 2 with lung cancer survivors (n=14) and 4 with health professionals (n=31). Drafts of possible features of an interactive portal were presented as static screenshots: survivorship care plan (SCP), access to electronic medical record (EMR), appointments, e-consultation, online patient community, patient reported outcomes (PROs) plus feedback, telemonitoring service, online rehabilitation program and online psychosocial self-management program. This presentation was followed by an open discussion. Focus groups were audiotaped, transcribed verbatim and data were analysed using content analysis.

Results

Important themes included fulfilment of information needs, communication, motivation, quality of feedback and supervision. Cancer survivors were primarily interested in features that could fulfil their information needs: SCP, access to their EMR and an overview of appointments. Health professionals considered PROs and telemonitoring as most useful features, as these provide relevant information about survivors' health status. We recommend to minimally include these features in an interactive portal for cancer survivors.

Conclusions

This is the first study that evaluated the expectations of cancer survivors and health professionals concerning an interactive portal. Both groups were positive about the introduction of such a portal, although their preferences for the various features differed. These findings reflect their unique perspective and emphasize the importance of involving multiple stakeholders in the actual design process.

INTRODUCTION

Improvements in cancer screening and treatment in combination with an ageing population lead to a rapid increase of the number of people that is diagnosed with cancer or that has been successfully treated for cancer (cancer survivors) [1]. Approximately 60% of them survive at least 5 years after diagnosis and they often experience a range of symptoms and functional limitations that affect their daily lives and their well-being [1,2]. The majority of cancer survivors has strong information needs related to diagnosis, treatments, side-effects and lifestyle factors [3,4].

To cope with these challenges, it seems imperative to provide cancer survivors with the knowledge, skills and motivation to positively influence their health status, which is commonly referred to as patient empowerment [5]. The internet has shown to be effective in this regard [6], because it can easily provide personal information and health interventions. In the health care setting, this is often done through secured portals, online applications with a personal login, often directly connected to the hospital's electronic medical record.

To date, very little is known about the appropriate specifications of such a portal in the oncology setting. To obtain this information, we conducted a systematic literature review regarding portals for patients with a chronic disease. We identified 7 features that were commonly used and evaluated their relevance for cancer survivorship care following the recommendations of the Institute of Medicine [2]. These seven features included: education, self-monitoring, feedback/tailored information, self-management training, a personal exercise program, and communication with either health professionals or patients [7].

However, with our review we found only limited information on user experiences and -preferences, and the available information was not specific to oncology practice. It is thus unknown what cancer survivors and their health professionals expect from an interactive portal. The involvement of end users in the developmental process of a technology increases the likelihood that the technology actually will be used [8]. Therefore, the aim of this study was to explore the expectations of an interactive portal among cancer survivors and health professionals by means of focus groups.

MATERIALS AND METHODS

Participants

We conducted separate focus groups with breast and lung cancer survivors and health professionals to obtain their unique viewpoints. Breast and lung cancer survivors were chosen because of the relatively high incidence of these tumors [9] and their distinct physical components (e.g., disease characteristics, impairments) and rehabilitation options. We purposively sampled survivors to ensure a range in sociodemographic and

clinical characteristics such as age and treatment stage [10]. Eligibility criteria included: (1) being adult; (2) undergoing curative treatment or within 5 years of treatment completion (without metastases); (3) being able to understand and speak Dutch; and (4) having at least minimal experience with computers and internet. For practical reasons, potentially eligible survivors were either approached by a nurse practitioner (breast) or with an informational letter followed by a phone call (lung). Those willing to participate were scheduled for a focus group session and received a confirmation letter.

All health professionals involved in the care for breast or lung cancer survivors were approached by an email in which we explained the purpose of the study. Those who were interested were scheduled for a focus group session. The Institutional Review Board designated this study as health care quality improvement, exempting it from formal review and informed consent procedures.

4

Focus group procedures

The focus groups took place in our institute and were facilitated by two of the researchers (WK and WG). Participants verbally consented to audiotaping of the session and completed a short questionnaire about their sociodemographics (including internet use and experience). Subsequently, the topic of the focus group was introduced and, to facilitate an open discussion, it was emphasized that participants were free to express their opinions and that both positive and negative responses were respected.

In order to help cancer survivors to become familiar with the opportunities of an interactive portal, we demonstrated drafts of nine possible features of such a portal using screenshots with pictures showing examples of graphs, content and exercises (see Table 4.1). Those features were based on the ones we identified in our literature review [7] [Marshall, 1996 #9] and they were presented one-by-one. Subsequently we had an open discussion to obtain all possible viewpoints regarding each particular feature.

For health professionals, the focus groups also included a demonstration, covering similar features as were presented to patients. In addition to an open discussion, we also posed specific questions on the possible impact of the interactive portal on their job performance (e.g., “How could the interactive portal, as presented, make you more efficient at work?”).

Analyses

We generated verbatim transcriptions of the audiotaped sessions and two researchers (WK and RL) read all the transcriptions to familiarize themselves with the data. Using content analysis [11], WK and RL independently selected all meaningful text fragments of two randomly selected manuscripts. All text fragments were discussed, and after resolving discrepancies, RL selected the text fragments of the remaining transcripts and discussed them with WK. Subsequently, WK and RL assigned codes to the text fragments,

Table 4.1 Possible features of an interactive portal

Feature	Description
Survivorship care plan (SCP)	Tailored information about diagnosis, treatment, follow-up and health promotion
Access to the electronic medical record (EMR)	Insight into personal medical information (e.g., on diagnostic tests, treatments, and correspondence)
Appointments	Overview of past and future appointments, the possibility to make and/or change appointments
E-consultation	Secured e-mail communication with health professionals
Online patient community	Discussion forum that facilitates communication with fellow survivors
Patient-reported outcomes (PROs) and related feedback	Self-reported data on health status, followed by an overview of results and additional information
Telemonitoring of physical parameters	Body worn sensors that measure and upload data on e.g. blood pressure or heart rate that can be accessed by survivors and health professionals
Online rehabilitation program	Information, homework assignments and self-reports to improve physical functioning and physical activity
Online psychosocial self-management program	Psycho education, homework and self-reports to decrease distress (e.g., symptoms of anxiety or depression)

reflecting the words of the participants in a more abstract way. Finally, the number of codes was reduced by combining similar codes into more comprehensive themes [11] by RL. For example, codes like 'exchange of information' and 'sharing experiences' were combined into the theme 'communication'. All themes were discussed with WK, and in case of persisting disagreement, the judgment of a third researcher (WG) was decisive. The expectations (themes) per feature resulted in a recommendation whether or not to include each feature in an interactive portal for cancer survivors and under what conditions.

RESULTS

Participants

We conducted three focus groups with breast cancer (n=21) and two with a total of 14 lung cancer survivors. Their mean age was 52.9 (range 27-76) and 61.6 (range 52-79) years, respectively. Further characteristics are shown in Table 4.2.

In the four focus groups with health professionals (n=31) individuals from medical (n=7; e.g. radiotherapists, nurse practitioners), paramedical (n=10; physical therapists, dieticians, etc.) and psychosocial professions (n=14; e.g. social workers, psychiatrist) were represented. Their mean age was 45.5 years (range 24-62) and 81% were female. They had been working in the institute for 13 years on average (range <1-30). Computer- and internet skills were self-rated as being quite good (mean = 5.1 on a 7 point scale).

Table 4.2 Characteristics of cancer survivors

	Breast cancer (n=21)	Lung cancer (n=14)
Characteristic	n (%)	n (%)
Gender		
Male	0 (0)	7 (50)
Female	21 (100)	7 (50)
Treatment stage		
<1 year after treatment	9 (43)	14 (100)
>1 – 5 years after treatment	12 (57)	0 (0)
Education		
Low (primary school)	0 (0)	2 (14)
Middle (high school/vocational education)	14 (67)	5 (36)
High (college/university)	7 (33)	7 (50)
Marital status		
Single	6 (29)	2 (14)
Married/cohabiting	15 (71)	12 (86)
	Mean (range)	Mean (range)
Computer skills ^a	5.4 (1-7)	4.6 (2-7) ^b
Internet skills ^a	5.4 (1-7)	4.5 (2-7) ^b

^a Assessed on a 7-point scale ranging from very bad (1) to very good (7)

^b Based on n = 13 (one participant did not have a computer/internet)

Focus group results

Results are presented per feature. Expectations of breast and lung cancer survivors were generally comparable, unless explicitly stated differently. The themes that emerged and quotes from participants are highlighted in *italics*. In addition to these themes, several requirements and concerns that were identified are reported. Finally, we present recommendations for an interactive portal for cancer survivorship.

Survivorship care plan

Two themes related to the SCP emerged: *fulfillment of information needs* and the *opportunity to re-read information*. The majority of cancer survivors expressed a need for information about side effects that could occur on the long-term, about what to expect in the future and advice for a healthy lifestyle. They also appreciated the overview of diagnosis and treatment information; it seems useful to re-read this information.

"I would like to know what I can expect. And why I am feeling certain things and if they could be caused by the treatment. You cannot call the hospital for everything. So it is handy to have this information there [on the portal]"
(cancer survivor)

Several health professionals indicated that the SCP could be useful to *provide information* that cancer survivors need, for example about the period after treatment completion:

"I think it can really help people if there is a kind of path, well, especially if they have completed treatment, we often hear from people 'what to do now?' and that they need some grip." (nurse practitioner)

Access to the EMR

The *opportunity to re-read information* also applied to having access to their personal EMR. Most cancer survivors especially appreciated the possibility to access the results of medical examinations online:

"And sometimes, when you have been to your doctor, you are thinking 'what exactly did he say?'. Then it would be convenient to have a look."

Another theme that emerged was *communication*; some survivors indicated that the accessibility of information from the EMR could help to improve communication with either their family or their health professionals:

"Now, I sometimes don't know how to say things [to my family], as a results of which I cannot explain disease-related issues properly. This [access to the EMR at home] would be perfect, a good aid."

The last theme was *anxiety*. Both cancer survivors and health professionals anticipated that access to the EMR could evoke many questions due to a lack of understanding. Survivors indicated that an explanation of medical jargon was required and all participants agreed that the medical information should only be accessible after a consultation with a health professional. Some were worried about security and privacy issues.

"Yes, an explanation would be convenient. Yes, because who would understand all these numbers? I mean, not everyone is familiar with hemoglobin levels and what they mean."

Appointments

Two themes emerged concerning appointments: *fulfillment of information needs* and *ease of use*. Cancer survivors expressed the need for an overview of past and future appointments for example for this practical reason:

"It would be practical to see the history of all my appointments. I have been needing this information for my insurance company several times as well."

Some suggested to receive a short report of each appointment, although the majority recommended that this would fit better in the EMR and some indicated that they were not in need of such a report. Ease of use was expected from the possibility to make and change appointments online. Health professionals indicated that this feature was not relevant to them.

E-consultation

Communication and *quality of feedback* were the emerging themes. Many cancer survivors expected that communication would improve because when sending an email, you have time to formulate your questions and you can ask questions that you forgot about during a consultation:

“During appointments with my doctor, I always feel stressed. E-consultation would provide me with a way of asking questions that I did not think of during the visit.”

However, some of them thought that a phone call would be more efficient. Similarly, health professionals anticipated that it would be time-consuming to answer emails. Both survivors and health professionals worried about the quality of feedback of the answers that could be provided or obtained via email, as this would be sensitive to misinterpretation.

*“If you do not see people, their facial expression or [hear] the tone of asking something, then it can be very difficult to provide a correct answer”
(physical therapist)*

Requirements included a limited response time (survivors) and a central email box per profession in order to structure the responses (health professionals).

Online patient community

Again, *communication* and *quality of feedback* were important themes. Survivors assumed that an online patient community could be used to share experiences with others, although they were interested in exchanging practical information (e.g., about how to obtain wigs), rather than in sharing emotions. Survivors and health professionals doubted the quality of feedback that could be provided via a forum. As a result, all participants indicated that it would be important to have a moderator who could check, and, if necessary, adjust messages.

“All types of messages are placed in such a community. I think that you, that you [as a hospital] cannot take the responsibility for the ideas that patients exchange” (social worker)

Also, they pointed out that several cancer associations already have such a community, which would make a hospital-based one redundant.

PROs and related feedback

Relevant themes were *knowledge about health status, communication and motivation of health professionals*. The information that could be retrieved from PROs would increase survivors' and professionals' knowledge about the health status of survivors. It was expected that communication would improve through feedback from the PROs, because consultations could be better prepared:

"By doing this [completing a PRO], you can better inform your doctor about how you are exactly doing, and it prevents skipping important health aspects during a consultation" (cancer survivor)

On the other hand, various survivors doubted the motivation of health professionals to have a look at their PROs, due to the extra time that may be needed. This was supported by health professionals; they doubted about who would be responsible for checking and discussing PROs.

Telemonitoring of physical parameters

Survivors indicated that using telemonitoring would increase the *knowledge about their health status*. Health professionals agreed on this, and expected that telemonitoring could be especially useful for specific rehabilitation goals:

"I can really imagine, for return to work for example it is about ergonomics and physical capacity and so on. And what would be more efficient than monitoring someone at work, seeing how someone arranges his schedule, and being able to give feedback, like: 'you've been working on the computer for 3 hours now, you'd better do some exercises'." (physical therapist)

However, breast cancer survivors indicated that you should be well *motivated* to use telemonitoring, which was illustrated by their argument that they would only use it if it is medically imperative:

"I would really limit this to what you were saying, lung function, that is really important to monitor. But I would not make it too technical, and I do not want to see online that I should go for a walk or something."

Online rehabilitation program

The opportunity to *fulfill information needs* about rehabilitation by obtaining (survivors) or *providing* (professionals) accessible information was appreciated. This information could include movies of exercises and personal advice. Survivors and health professionals

both believed that online rehabilitation requires a strong *motivation of survivors* to read the information and to exercise at home. Survivors thought that *supervision* is important to ensure that exercises are performed correctly:

"If you only have those pictures [as instruction for exercise], I think... sometimes it is not clear what you have to do exactly, and if you really do the wrong exercise then the pain only increases."

Online psychosocial self-management program

All participants thought that face-to-face *supervision* would be necessary to solve mental problems. Like a lung cancer survivor stated:

"But well, in case of anxiety or depression, which are mental problems, you know. Sometimes you express a problem but the actual problem is different and only a professional can determine what exactly is wrong with you."

However, participants also acknowledged that such a program could be used for less severe problems, possibly as supplement to usual care. Furthermore, health professionals could provide relevant information to *fulfill an information need* of survivors (e.g. assignments to learn to cope with emotions).

Table 4.3 shows a summary of the expectations (themes) per feature, a recommendation whether to include each feature in an interactive portal for cancer survivors or not and under what conditions.

DISCUSSION

In this qualitative study we investigated breast and lung cancer survivors' and health professionals' expectations of an interactive portal to empower cancer survivors. The focus groups have resulted in useful feedback regarding different possible features. Important themes that emerged were the fulfillment of information needs, the opportunity to re-read information, anxiety, quality of feedback, communication, motivation and supervision. Based on participants' feedback we recommend that an interactive portal for cancer survivors at least includes a SCP, access to the EMR, appointments, PROs and related feedback, and telemonitoring (all under certain conditions).

Survivors were most positive about features that could provide them with personally relevant information, including a SCP, access to their EMR and appointments. Health professionals considered PROs and telemonitoring as most useful from their perspective, possibly enabling them to improve medical decision making. Their preferences for different features may reflect differences in the perceived value of an interactive portal. Survivors

Table 4.3 Overview of expectations (themes) and resulting recommendations

Feature	Cancer survivors	Health professionals	Recommendation
Survivorship Care Plan	Fulfillment of information needs (+) Opportunity to re-read information (+)	Provision of relevant information (+)	Include
Access to EMR	Opportunity to re-read information (+) Communication (+) Anxiety (-)	Anxiety (-)	Include, as long as anxiety is minimized (e.g., by including a medical dictionary and by first discussing results in a consultation)
Appointments	Fulfillment of information needs (+) Ease of use (+)	Not applicable	Include
E-consultation	Communication (+/-) Quality of feedback (-)	Communication (-) Quality of feedback (-)	Exclude
Online patient community	Communication (+/-) Quality of feedback (-)	Quality of feedback (-)	Exclude, and add a link to existing communities instead
PROs + feedback	Knowledge of health status (+) Communication (+) Motivation of health professional (-)	Knowledge of health status (+) Communication (+) Motivation of health professional (-)	Include, as long as health professionals are being stimulated to discuss the results
Telemonitoring	Knowledge of health status (+) Motivation of survivor (+/-)	Knowledge of health status (+)	Include, especially for lung cancer survivors
Online rehabilitation program	Fulfillment of information needs (+) Motivation of survivors (-) Supervision (-)	Provision of relevant information (+) Supervision (-)	Exclude, unless a combination with face-to-face meetings is possible
Online psychosocial self-management program	Fulfillment of information needs (+/-) Supervision (-)	Provision of relevant information (+/-) Supervision (-)	Exclude, unless a combination with face-to-face meetings is possible

anticipate using an interactive portal to improve (knowledge about) their health status. In contrast, health professionals anticipate using the portal to improve the provision of care by having access to PRO and telemonitoring information about their patients' symptoms and (self-reported) functional status. Survivors' expectations regarding telemonitoring of physical parameters differed, which could be related to differences in socio demographic characteristics, disease characteristics and different treatments with associated (side) effects [12]. Lung cancer survivors may perceive the possible benefits of monitoring vital data after lung resection, in contrast to breast cancer survivors, who (in general) receive less extensive surgery and have an overall better health status.

The concern that survivors expressed about the limited quality of feedback that they would receive via e-consultations is comparable to a study on patients' experiences with web-based communication with their health professionals. Patients prefer e-consultation for specific purposes (e.g., prescription renewals, basic medical content), and face-to-face communication for others (e.g., information about treatment, questions about side-effects) [13]. We did not anticipate survivors' negative view of a hospital-based online patient community, as the literature on online cancer support groups suggests that individuals who participate in such groups tend to cope more effectively with their disease [14], have less depressive feelings and improved social contacts [15]. Possibly our participants are not aware of the potential benefits of using these communities, and they also referred to already existing patient communities that could be used.

Most cancer survivors and health professionals indicated that they would require face-to-face supervision for rehabilitation and psychosocial support. Studies in the fields of chronic pain and rheumatology also found that participants anticipate on the value of face-to-face supervision of a health professional [16,17]. Furthermore, it is known that several contacts with a therapist result in less dropout and better adherence to treatment programs [18], which implies that combining an internet program with face-to-face support would be a good compromise. This will increase the motivation of cancer survivors, which will contribute to empowerment. Other empowerment-related aspects like knowledge and skills are sufficiently covered by the remaining recommended features.

This study has methodological limitations that should be addressed. First, the focus groups were conducted in a single center and participating cancer survivors were limited to those with breast and lung cancer after active treatment, which may restrict the generalizability of our results. However, we used a purposive sampling procedure to include participants with a variety in sociodemographic and clinical variables and the number of participants was reasonable for qualitative research. Furthermore, survivors indicated that the features that they endorsed could also be useful during treatment. Second, we were not able to include medical oncologists in the focus groups due to their busy schedules. Although we do not have any reason believe that their perspective would be substantially different from that of those health professionals who did participate in

the focus groups, this is something that cannot be ruled out entirely. Finally, except for one lung cancer survivor, all participants had at least minimal experience with computers and internet. Obviously, these individuals are most likely to actually start using an interactive portal. However, it is important to further investigate the expectations of inexperienced individuals, to be able to develop a portal that can be widely used.

Despite these potential limitations, our study is, to our knowledge, the first to systematically investigate the views of cancer survivors and their health professionals regarding an interactive portal. The information that we have generated regarding their expectations can inform the design and implementation of an interactive portal in oncology practice. A next step would be to explore the technical and practical possibilities in order to develop and test prototypes. Subsequently, the feasibility of using an interactive portal in clinical practice should be established. Once this is achieved, the (cost-) effectiveness of using an interactive portal on both patient-related and professional-related aspects can be evaluated. At the patient level, outcome measures should include patient empowerment, compliance with treatment and follow-up advice, satisfaction with care and health-related quality of life. At the professional level, relevant outcome measures would be workload and job efficiency, awareness of patients' symptoms and functional limitations, and satisfaction with the care process.

Conclusion

Cancer survivors' and health professionals' expectations of an interactive portal were obtained by a qualitative approach. Expectations differed slightly between breast and lung cancer survivors and to a larger extent between survivors and health professionals. More work is needed regarding prototyping and feasibility testing to develop a user-friendly portal that has the potential to effectively empower cancer survivors.

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Chapter 5

Development of MijnAVL,
an interactive portal to
empower breast and lung
cancer survivors:
An iterative, multi-stakeholder
approach

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ABSTRACT

Background

To empower cancer survivors we are developing MijnAVL (MyAVL), an interactive portal. Literature review and focus groups yielded the selection of features such as access to the electronic medical record (EMR), patient reported outcomes (PROs) and related feedback and a physical activity support program.

Objective

To present a final design of MijnAVL based on (1) health professionals' evaluation of proposed features; (2) cancer survivors' evaluation of a first draft; and (3) cancer survivors' evaluation of a functional online prototype.

Methods

Professionals from various disciplines gave input for the content of and procedures related to MijnAVL. Subsequently, sixteen cancer survivors participated in an interview to evaluate content and graphic design of a first draft (graphicized by screenshots). Finally, seven survivors participated in a usability test with a fully functional prototype. They performed predefined tasks (e.g., logging in, finding a test result, completing a questionnaire) while thinking aloud. Descriptive statistics and simple content analysis were used to analyse the data of both the interviews and the usability tests.

Results

Professionals supported access to the EMR (e.g., histology reports, lab results and their letters to general practitioners). They also informed the development of PROs and the physical activity support program. Based on the first draft, survivors selected the preferred graphic design, approved the features and provided suggestions for the content (e.g., explanation of medical jargon, more concise texts, notification by emails). Usability tests revealed that it was relatively easy to navigate through the website and to use the different features. Recommendations included, among others, a frequently asked questions section and the use of hyperlinks between different parts of the website.

Conclusions

We present the final design of MijnAVL, an interactive portal to empower breast and lung cancer survivors. The development of MijnAVL was performed iteratively and involved multiple groups of end-users. This approach resulted in a usable and understandable final version, which effectiveness should be determined in further research.

INTRODUCTION

Background

People diagnosed with cancer or who have been successfully treated for cancer (cancer survivors) often experience a range of physical (e.g., fatigue, pain) and psychosocial health problems (e.g., distress, disruption of work and social relationships) as a result of their disease and its treatment [1]. The majority of cancer survivors want to know as much as possible about their diagnosis, treatment, side effects and health promotion [2, 3]. Also, although we know that physical activity can have positive effects on both the physical and psychosocial well-being of cancer survivors [4, 5], many survivors do not meet physical activity norms [6, 7]. To cope with the cancer-related problems, fulfil information needs, and promote physical activity, efforts are required to enhance patients' knowledge, skills and motivation to positively influence their health, often referred to as patient empowerment [8].

In the Netherlands, 94% of the population has daily access to the internet. Among the elderly, this varies from 20% (age 75 and older) to 55% (age 65-75) and it is expected that these figures will continue to increase [9]. Apart from information, online interventions can be provided via the internet, and these e-health initiatives are likely to increase patient empowerment [10]. To empower breast and lung cancer survivors of the Antoni van Leeuwenhoek hospital, part of the Netherlands Cancer Institute (a comprehensive cancer centre in Amsterdam), we are developing "MijnAVL" (MyAVL), a personal, interactive portal. In developing the portal, we have initially focused on the population of breast and lung cancer survivors because of their distinct disease characteristics, impairments, rehabilitation needs and options and the relatively high incidence of these tumors [11]. The focus on breast and lung cancer relates primarily to the specific content of the portal, but not to its design features or overall functionality. We expect that the design and functionality of the portal will be applicable to a wide range of cancer survivors.

Features of MijnAVL

The features of MijnAVL are primarily based on a literature review of web-based interventions for patient empowerment and physical activity in various chronic diseases. We identified features of interactive portals that are likely to be relevant for cancer survivors, including: education, self-monitoring, feedback (tailored information), self-management, personal exercise program, and communication with professionals and/or fellow patients [12]. Subsequent focus groups revealed that health professionals were most interested in portal features that would provide them with relevant information about the health status of their patients, while cancer survivors preferred the features that could fulfil their information needs. These preferences led to the following set of requirements for MijnAVL: (1) *patient education* (relevant information about diagnostic tests, treatments and rehabilitation opportunities); (2) *an overview of past and future appointments*; (3) *access to the electronic medical record* (EMR; reports of diagnostic tests

and lab tests, letters to general practitioners, etc.); (4) *patient-reported outcomes (PROs) and related feedback for patients*: symptom and health-related quality of life outcomes including a summary of scores, accompanied by relevant information on the different outcomes (e.g. background information and tips for fatigue); and (5) *a physical activity support program*: tailored physical activity advice based on a set of questionnaires.

Survivors can access MijnAVL by providing their DigiD username and password accompanied by a code that is sent to their cell phone. DigiD is a safe authentication method related to one's social security number, that is used primarily (but not exclusively) by various governmental services.

The objective of the current study was to describe the development of MijnAVL by "translating" the proposed set of requirements into final content and design based on: (1) health professionals' evaluation of content; (2) cancer survivors' evaluation of a first draft of screenshots (interviews); and (3) cancer survivors' evaluation of a functional prototype through usability tests.

5

METHODS

MijnAVL was developed using a stepwise approach involving both health professionals and cancer survivors from our institute, as this increases the likelihood of the portal being accepted and actually used in daily practice [13, 14]. The Institutional Review Board exempted this study from formal review and all cancer survivors provided written informed consent.

Health professionals' evaluation of content

We obtained health professionals' feedback during various sessions in which the proposed portal features were presented in PowerPoint. With regard to access to the EMR, we organised group sessions for breast and lung cancer separately and in both sessions approximately 10 professionals participated (medical oncologists, surgeons, radiotherapists, nurse practitioners). We discussed which parts of the EMR should be accessible and under what conditions. After we had constructed a first draft of MijnAVL, these professionals participated again in a group session. Seven professionals joined a group session to discuss when PROs should be completed and what type of feedback should be provided to both health professionals and survivors. In addition, we had individual interviews with a medical oncologist, two surgeons, a nurse practitioner and a social worker about the feedback that could be provided based on PRO scores. The advice to be given in the physical activity support program was written and discussed in collaboration with 5 physical therapists and a rehabilitation physician.

Cancer survivors' evaluation of a first draft (semi-structured interviews)

Cancer survivors were eligible when they were adult, under curative treatment or within 3 years of treatment completion, had a basic fluency in Dutch and had at least minimal experience with computers and internet. We organised semi-structured interviews until saturation of qualitative data occurred (i.e., no new information came up) [15]. Ten breast and six lung cancer survivors with a mean age of 61.4 (SD = 9.8; range 45-77) years participated; 75% was female. The majority was highly educated and fourteen individuals had been using the internet daily for more than two years.

Participants completed a questionnaire on sociodemographics and verbally consented to audiotaping of the session. Subsequently, the researcher (WK or WG) presented screenshots with two types of graphic design and examples of the intended content of MijnAVL. In a semi-structured interview we focused on portal design and content, especially regarding access to the EMR, PROs and the physical activity support program. Participants also reported what they considered to be the most positive and negative aspects of the portal, and suggestions for possible improvements.

The interviews were analysed by a simple content analysis [16] of the notes taken by the researcher and, if notes were not sufficient, listening back the audiotapes. The data were structured according to each feature of MijnAVL or the category graphic design. The results from these semi-structured interviews were used to develop a functional prototype of the portal. Before conducting the usability tests, the technical functioning of MijnAVL was rigorously tested in numerous iterations by the research team.

Cancer survivors' evaluation of a functional online prototype (usability tests)

Eligibility criteria and recruitment procedures were identical to those of the semi-structured interviews. We organized individual sessions in a lab setting until saturation occurred [15]. Five female breast cancer and 2 male lung cancer survivors, with a mean age of 50.6 (SD = 5.7; range 44-61) years, participated in a usability test. They all had been using the internet for more than two years and about half had graduated from college or university.

First, participants completed a questionnaire on sociodemographics and agreed to audiotaping of the session. Then they performed various tasks, including logging on to the portal, completing a questionnaire digitally, checking future appointments and finding the results of a lab test. During task performance they were encouraged to think aloud, which provided insight into how they were performing these tasks [17]. After completion of the tasks, the researcher asked about the positive and negative aspects of the portal. Finally, participants completed a questionnaire on their expectations regarding the portal (based on the Unified Theory of Acceptance and Use of Technology; UTAUT [18]) and on anticipated effects on patient empowerment (based on the Patient Activation Measure [19]). Data analysis was similar to that of the interviews, except for adding usability as a category to organise the data. Results were used to produce the final design of MijnAVL.

RESULTS

Health professionals' evaluation of content

Access to the EMR

The majority of health professionals supported patients' access to the reports of lab tests, histological examinations, and letters from the hospital to general practitioners. However, they expected that this information would evoke anxiety and many questions. Therefore, professionals involved in lung cancer care especially had reservations about showing radiology reports, specifically due to ambiguous test results and the generally poor prognosis of lung cancer survivors. They indicated several conditions for providing test results: development of an accompanying medical dictionary, introductory texts for each report and a delay of two weeks before sharing the test results online (to ensure that test results are personally discussed with patients first).

PROs and related feedback

Health professionals recognized the potential benefits of PROs (being aware of a patients' symptoms and quality of life), but they also expected an increased workload due to having to discuss these various issues with their patients in more detail than might typically be the case. Patients should preferably complete PROs at diagnosis, after completion of treatment, and at each follow-up visit. Health professionals preferred having PRO data summarized graphically, with clear indication of problem areas (especially worsening of symptoms), the clinical significance of scores and suggestions for referral. They were reluctant about automated advice to patients about different symptoms, because they believed that the aetiology of many symptoms is too complex to allow for standardized advice. It was therefore decided to provide patients with an overview of the PRO results, supplemented by more general information and advice related to each domain of the questionnaire. For example, if a survivor reported clinically relevant levels of fatigue, (s)he would be directed to information on cancer-related fatigue. Professionals from all relevant disciplines assisted in drafting this type of information.

Physical activity support program

Because the support offered in the program was relatively non-specific (i.e. it is aimed at increasing general levels of physical activity), we opted for a stand-alone, computerized system (providing advice based on a questionnaire). Factors that were covered in the physical activity questionnaire were "stage of change", nutritional status, possible contraindications for physical activity, treatment phase (during or after treatment), tumour type (breast or lung cancer), whether the patient is participating in a supervised exercise program and, if yes, whether (s)he wishes to receive additional information on physical activity. Two well-known theoretical models were used to generate the physical activity advice: Social Cognitive Theory [20] and Theory of Planned Behaviour [21]. All information and advice was written in a collaboration between the researchers, the physical therapists and the patient education service of the hospital.

Cancer survivors' evaluation of a first draft (semi-structured interviews)

In general, participants were positive about MijnAVL and the majority was familiar with the DigiD authentication method to log in. Major positive aspects of MijnAVL were involvement in the health care process and the accessibility of information (transparency), whereas negative aspects were too lengthy texts and use of medical jargon.

Access to the EMR

Access to the EMR was appreciated, but concerns were also raised about being able to understand the information provided, and the potential worry or upset that could result. These concerns appeared to be justified, as most patients understood less than half of the information provided in the radiology and pathology reports. However, this improved when they were provided with a dictionary of terms. Results of clinical lab tests were easier to understand because reference values were already provided in the tables. Some participants wanted to receive additional contextual information, for example, which specific blood test values indicate that one is able to receive a new cycle of chemotherapy or how blood markers are related to lifestyle factors (such as cholesterol levels). Access to the letters to the general practitioner were considered as a good summary by some, and one participant would like to be provided with the treatment plan and results from multidisciplinary meetings.

PROs and related feedback

Participants wished to receive a notification (e.g., text message, email or a notification on the homepage of MijnAVL) when they needed to complete a questionnaire. Most participants were able to understand graphical summaries of the PROs, and there was no clear preference for line charts versus bar charts. The majority wanted to see changes over time; both positive and negative.

Physical activity support program

Eleven (of sixteen) participants expected that this would increase awareness of the importance of being physically active during and directly after treatment. Five were already quite physically active and would not need such a program. Participants expected to receive information on which activities are allowed (or discouraged) during treatment, and more personal information on rehabilitation and reimbursement of rehabilitation programs. The examples of this type of information and advice were judged to be interesting, understandable, reliable, of appropriate length and quite motivating. An example of a graph presenting the amount of physical activity undertaken (based on self-report) during the past week was relatively easily understood.

Graphic design

The preferred homepage contained large buttons with icons that indicated the features of MijnAVL; this was perceived as highly accessible. The favourite content page was divided into several 'blocks' of main text with the possibility to click for more information.

Participants liked that the information was illustrated by visual images. Recommendations and resulting changes in portal design and content are shown in Table 5.1.

Table 5.1 Recommendations and changes in the portal design and content based on semi-structured interviews with cancer survivors (N = 16)

Recommendation	Adjustment(s)
Graphic design	
The term 'physical activity advice' is not very appealing.	Physical activity advice was changed to 'keep fit'.
The overall look of MijnAVL is somewhat boring.	A photo was added to the background to improve the overall visual attractiveness.
The large red text box indicating patient number, name and date of birth should be displayed on the homepage only.	The text box was deleted from all pages except for the homepage. Instead, identical information was displayed on top of the menu on the left.
Provide the specific location in the hospital in the overview of appointments.	None (technically not possible).
Content: Access to the EMR	
Provide detailed information about the different elements of the blood (What does that abbreviation mean? What is the function of this element?).	A link to the website of the Dutch Society of Clinical Chemistry and Laboratory Medicine (NVKC), containing this information, was included.
The information from the EMR should be provided in a way that a layman can understand.	A medical dictionary was created.
Content: PROs and related feedback	
It is necessary to receive a notification when you have to fill out a questionnaire.	An email will be sent when a new questionnaire needs to be filled out.
Content: Physical activity support program	
The explanatory text accompanying the graph with physical activity information is too complicated.	It is technically not (yet) possible to include graphs, so the information is provided in a table. The explanatory text was adjusted and simplified accordingly.

Cancer survivors' evaluation of a functional online prototype (usability tests)

Five (of seven) participants mentioned the overview of appointments to be the most positive aspect of MijnAVL, followed by access to the EMR, the reliability of the information, and the fact that all information is gathered at a single location. Less positive aspects included concerns about possible computer hacking and the comprehensibility of information from the medical record. MijnAVL was rated as 7.9 on a 10-point scale (10 = excellent). Suggestions for additional features included an option to ask questions online (e-consult) and a frequently asked questions section (with both portal-related and cancer-related issues).

Access to the EMR

Participants highly appreciated the accessibility of information from the EMR, especially the possibility to read over information. The standard dictionary with medical terms on MijnAVL was helpful, but did not contain all words that participants were looking for. The clinical lab results were relatively easy to understand, although deviating values should be highlighted.

PROs and related feedback

Participants were content with the possibility of completing PROs online instead of in the hospital. There were some complaints about response options and three participants thought that the questionnaire was too long, but as we are using validated questionnaires these factors could not be changed. All were able to interpret their scores per domain as shown in the tables and valued the availability of information and advice on many aspects of quality of life.

Physical activity support program

Five participants thought that they would benefit from the tailored advice of the program; the remaining two indicated that they were already intrinsically motivated to be physically active. One explicitly mentioned that it is good to incorporate a specific goal such as the Dutch Norm of Physical Activity. Some questions of the questionnaire related to the program were hard to answer, for example on the amount of physical activity in the past week (recall problems). The table showing the amount of high and moderate intensive exercise was clear to everyone.

Graphic design

Participants were satisfied with the clear, simple and accessible layout. Letter type and font size were good and the menu bar on the top of the page was perceived as convenient. It was recommended to place the most important information at the top of each page, and keep the information as concise as possible. Many participants noted that they were inclined to skip the introductory texts and first look for the 'real' information (e.g., a table with their personal quality of life scores).

Usability

All participants managed to log in to the website, although one experienced problems due to the browser used. They were able to navigate through MijnAVL with little or no help and typically used the menu bar on top of the page to go to other features of MijnAVL. The menu on the left was used to navigate within a single feature. Participants made several navigation errors. One tried to find the results from a mammogram by clicking on the appointment during which the mammogram was taken, while this information could be found in the EMR. Three experienced difficulties with finding the quality of life questionnaire to be filled out, as well as with finding the additional information on quality of life domains. Most of them first visited the "Keep fit" page to find the physical activity

questionnaire, as they associated this with physical activity. Actually, this one could be found under the button 'questionnaires'. The final task, logging out from MijnAVL, was no problem. An overview of recommendations and adjustments based on the functional prototype are shown in Table 5.2.

Table 5.2 Recommendations and adjustments based on usability tests (N=7)

Recommendation	Adjustment(s)
Graphic design	
The button to log in should be placed on top of the login page.	The button to log in was moved to the top of the login page, followed by instructions on what to do when you forgot your password or you need to request a DigiD account.
Introductory and/or explanatory information should be provided in a pop-up.	None (technically not possible yet).
Content: Access to the EMR	
The denomination 'medical imaging' is not clear and should be changed into 'radiology'.	This term was not changed, as 'medical imaging' also contains the results of nuclear medicine.
The meaning of the letters L (low) and H (high) accompanying clinical lab results should be elucidated.	The introductory text was extended with a sentence explaining the meaning of L and H.
It would be convenient if you could search in the medical dictionary.	Planned for a next phase (technically not possible yet).
The menu on the left should only contain these test results that you have actually received.	Planned for a next phase (technically not possible yet).
Content: PROs + related feedback	
You have to scroll a lot when filling out the questionnaires.	None (technically not possible).
The educational materials should be placed in alphabetic order.	Planned for a next phase (technically not possible yet).
Content: Physical activity support program	
A hyperlink to the physical activity questionnaire is required on the "Keep fit" page when physical activity support has not yet been provided.	This hyperlink was added.
User performance	
More direct hyperlinks between the different features would be helpful.	These hyperlinks were added where possible.
A section with frequently asked questions would be helpful.	A list with frequently asked questions related to login procedures and who to approach in case of questions was added.
Informational movies would make MijnAVL more attractive.	Planned for a next phase (due to time restrictions).

Expectations

Table 5.3 shows the results of the questionnaire on expectations of MijnAVL (based on UTAUT) and expected effects on patient empowerment. All statements were rated on a 5-point scale ranging from 1 (completely disagree) to 5 (completely agree).

Table 5.3 Expectations based on UTAUT and expected effects on patient empowerment (N = 7)

	Negative ^b N	Neutral ^b N	Positive ^b N
Statements based on UTAUT^a			
Using MijnAVL will contribute positively to my feelings of control with regard to my health status	1	1	5
MijnAVL will be easy to use	0	0	7
People who are important to me would think that I should use MijnAVL	3	4	0
I have the knowledge and resources to use MijnAVL	0	0	7
I will be able to use MijnAVL	0	0	7
I feel positive about MijnAVL	0	0	7
Using MijnAVL will evoke emotional feelings	2	1	4
I intend to use MijnAVL	0	1	6
Statements related to patient empowerment^a			
By using MijnAVL...			
... my knowledge about my disease, treatment and effects will increase	0	3	4
... I can take an active role in my own health care	1	4	2
... I am confident I can help to prevent or reduce problems associated with my health	2	3	2
... I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself	4	0	3
... I am confident that I can tell a doctor concerns I have even when he or she does not ask	1	2	4
... I will be motivated to maintain lifestyle changes	1	6	0

^a All statements were rated on a 5-point scale ranging from 1 (completely disagree) to 5 (completely agree)

^b Negative = score 1 + 2; Neutral = score 3; Positive = score 4 + 5

DISCUSSION

In this paper we have described the development of the final design of MijnAVL, an interactive portal to empower cancer survivors. Health professionals provided feedback on the proposed content of and conditions required for MijnAVL, and contributed to the development of information and advice. Cancer survivors participated in interviews to evaluate a first draft of screenshots and performed usability tests with a functional

prototype. Their suggestions concerning graphic design, content and usability were taken into account as much as possible in generating the current version of MijnAVL, within the limits imposed by technology and time (see Figure 5.1-5.3).

In general, both health professionals and cancer survivors were positive about the development of MijnAVL. Cancer survivors appreciated the features that provide them with relevant information, and especially the overview of appointments and access to their EMR. However, it is known that patients, in general, do not fully understand their medical records [22]. This could explain why they indicated that a dictionary or some other type of aid was needed to understand all the information in the EMR. Other studies have also shown that an explanation of medical jargon, abbreviations and acronyms and additional information on tests and results [23] or an online dictionary [24] are useful and necessary tools. Although the participants in this study have provided a suggestion in this regard (e.g., that it should be possible to search in the dictionary), further research is needed to determine the specific content and optimal format of these tools.

5

Related to this, health professionals expected that patients' access to the EMR would lead to an increased workload, because patients would find it difficult to understand the medical information and it could evoke anxiety and many questions. Indeed, based on a usability test, study participants expected, that using MijnAVL would evoke emotional feelings. However, these expectations may not be justified, as several studies have shown that giving cancer patients access to their EMR does not increase anxiety levels [25, 26]. Furthermore, Rodriguez and colleagues [27] have shown that, according to 75% of the physicians and nurses participating in their study, workload did not increase after the implementation of patients' access to laboratory results. The fear of an increased workload also applied to the introduction of PROs, due to the expected time needed to prepare consultations and discuss results. However, previous trials have shown that the use of PROs does not increase the duration of consultations [28, 29].

Survivors' feedback regarding PROs and the physical activity support program was more diverse. While the majority saw value in these features of the portal, some did not. It is important that participants not only value the usability of MijnAVL, but that they are also aware of its aim (increasing patient empowerment). In this study, survivors anticipated that using MijnAVL would only moderately improve empowerment (Table 5.3). It may have been difficult for them to judge the actual value of MijnAVL and its interactive features based on a usability test only. An alternative explanation could be that the features need further adjustment and fine-tuning to enhance their effectiveness.

Our results indicated that professionals were primarily interested in PRO scores indicating a worsening of symptoms, whereas survivors preferred to see both worsened and improved scores. This could be due to their different perspectives: professionals need to help the patient to reduce symptom burden, while survivors apparently want to monitor

Figure 5.1 MijnAVL: Homepage

Figure 5.2 Interactive feature of MijnAVL: PROs

changes in their symptom experience and functional health, both positive and negative. When feeding back the results of PROs to both health professionals and survivors, it is important to take into account their unique preferences. What also needs to be fine-tuned, is the way in which information is provided. Survivors suggested for example that educational materials should be placed in alphabetic order, which is not yet possible due to technical restrictions. However, we acknowledge the importance of providing information in the most convenient manner.

Limitations

Several possible limitations of this study need to be considered. First, the number of participants in this study was relatively small (16 and 7 participants in the interviews and usability tests, respectively). However, the last sessions did not reveal any new issues (saturation), so we assume that these numbers were sufficient. Furthermore, for usability testing it is not unusual to limit the sample size to 6-12 individuals [30]. Second, participants were probably more likely to be interested in and able to use MijAVL than those who declined (response bias). Indeed, important reasons for non-participation were not having a computer and disinterest, suggesting that our sample may well be

Figure 5.3 Interactive feature of MijnAVL: Physical activity support program

representative of the target population of computer literate patients who have interest in such a system. It is a challenge to motivate and enable the non-participants to use MijnAVL in order to benefit from its features. Finally, this was a single centre study conducted in a specialized cancer centre. The results may not be entirely applicable to other settings, in which the treatment of cancer is just one of many different disciplines.

Strengths

An evident strength was that we used a multi-stakeholder approach in which all relevant end-users were involved. Both health professionals and cancer survivors provided feedback during the developmental process of MijnAVL, ensuring that the portal fits their needs as much as possible. Second, the development of MijnAVL included multiple iterations, with the results of the previous iteration being incorporated in the next prototype. We were able to detect possible problems regarding content and design at an early stage and to adjust MijnAVL accordingly, resulting in a user-friendly portal.

Although similar initiatives have been undertaken successfully in other chronic disease areas such as diabetes, congestive heart failure and chronic obstructive pulmonary disease [12, 31, 32], the use of information technology (IT) to enhance patient empowerment is relatively new in the field of oncology. The features of MijnAVL reflect different trends that are currently seen in oncology, such as electronic symptom monitoring (e.g., [33,

34]), hospital-based systems to provide patient education and, to a lesser extent, access to medical record information. MijnAVL incorporates these various features, targeting different aspects of cancer survivorship simultaneously. We anticipate that the portal will enhance empowerment by increasing survivors' knowledge and understanding of their disease and its treatment, by providing personally relevant information, by allowing them to self-monitor their symptoms and functional health, and by providing tools for becoming more physically active. We are currently conducting a pilot study to evaluate the extent to which the effects of MijnAVL on empowerment and satisfaction.

Conclusion

In this paper we have described an iterative approach, involving all relevant stakeholders and end-users, to developing MijnAVL. Content and usability were improved based on the feedback of participants, which has resulted in a user-friendly portal with the potential to empower cancer survivors. On-going and future research is needed to evaluate the efficacy of MijnAVL in daily clinical practice in terms of meeting the information needs of cancer survivors and health professionals, in enhancing patient empowerment, and ultimately in contributing to the quality of life of cancer survivors.

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Chapter 6

Patients' and health
professionals' understanding
of and preferences for
graphical presentation styles
for individual level EORTC
QLQ-C30 scores

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ABSTRACT

Purpose

To investigate patients' and health professionals' understanding of and preferences for different graphical presentation styles for individual level EORTC QLQ-C30 scores.

Methods

We recruited cancer patients (any treatment and diagnosis) in four European countries and health professionals in the Netherlands. Using a questionnaire, we assessed objective and self-rated understanding of QLQ-C30 scores and preferences for five presentation styles (bar and line charts, with or without color coding, and a heat map).

Results

In total, 548 patients and 227 health professionals participated. Eighty-three percent of patients and 85% of professionals self-rated the graphs as very or quite easy to understand; this did not differ between graphical presentation styles. The mean percentage of correct answers to questions objectively assessing understanding was 59% in patients, 78% in medical specialists and 74% in other health professionals. Objective understanding did not differ between graphical formats in patients. For non-colored charts, 49.8% of patients did not have a preference. Colored bar charts (39%) were preferred over heat maps (20%) and colored line charts (12%). Medical specialists preferred heat maps (46%) followed by non-colored bar charts (19%), whereas these charts were equally valued by other health professionals (both 32%).

Conclusions

The substantial discrepancy between participants' high self-rated and relatively low objective understanding of graphical presentation of PRO results highlights the need to provide sufficient guidance when presenting such results. It may be appropriate to adapt the presentation of PRO results to individual preferences. This could be facilitated when PROs are administered and presented to patients and health professionals electronically.

INTRODUCTION

Patient-reported outcomes (PROs) are frequently used as outcome measures in cancer clinical trials and in observational studies. More recently they have also been introduced into daily clinical practice, where they provide clinicians and nurses with information about the symptom experience, functional health, and subjective well-being of patients that can be used during the clinical encounter. Although this feedback from PROs often leads to improved symptom detection [1-3], more discussion of problems [1-3], and higher levels of patient satisfaction [2], only a few studies have found a direct impact on quality of life (QoL) [4; 5].

Electronic data collection systems have been developed to facilitate the introduction of PROs in daily clinical practice. The major advantages of these electronic systems are that they facilitate efficient data collection and that PRO results are directly available [6]. Most recently, PRO data collection systems have been integrated into web-based patient portals and can be integrated into the electronic medical record. The use of an electronic data collection system facilitates graphical presentation of the PRO results. Graphs are especially useful for the display of dynamic data, such as change over time [7].

To date, only limited information is available regarding how best to graphically summarize and display the results of PROs for both patients and health professionals. Several studies have investigated patients' and health professionals' understanding of graphically presented quality-of-life data at the group level, as obtained in clinical trials. These studies have shown that patients are most accurate in interpreting simple line graphs compared to simple bar charts or more complex graphs [8; 9], and that professionals prefer line graphs presenting change over time [10].

Individual PRO results are most likely to be presented as absolute scores at fixed time points. Although this allows for calculating and displaying change over time, the interpretation of an absolute score at a single time point is more challenging. The interpretation of absolute scores can be facilitated through the use of clinical thresholds that allow one to classify individual patients as a "case" [11]. The caseness thresholds may reflect a priori decision rules regarding symptom severity or may be related to external criteria or percentiles from general population or patient reference groups. Such thresholds can be integrated into graphical displays of PRO results using color-coding methods that indicate the severity or clinical importance of a symptom or problem [12-14].

Given the paucity of studies on the graphical presentation of individual level PRO results, the aim of the current study was to investigate patients' and health professionals' understanding of and preferences for different graphical presentation styles for the EORTC QLQ-C30, a questionnaire frequently used to assess QoL in cancer patients [15]. In addition, we asked patients and health professionals their opinions about general aspects of PRO data collection and use in daily clinical practice.

METHODS

Patient survey

Procedures

A cross-sectional sample was recruited from the Netherlands Cancer Institute (the Netherlands), Mount Vernon Cancer Centre, Basingstoke & North Hampshire Hospital (both United Kingdom), Kufstein County Hospital (Austria) and the Jagiellonian University Medical College (Poland). We aimed to obtain a heterogeneous sample consisting of patients with any type of cancer who were receiving or had received treatment (chemotherapy, radiation therapy, surgery). Patients were approached by mail (followed by a reminder by mail) or at the outpatient clinic and were asked to complete a questionnaire. The Institutional Review Board of each participating center approved the study following local standards and patients provided written informed consent where required. We obtained clinical data (cancer site, cancer stage) from the (electronic) medical record and sociodemographic data (age, sex, marital status, education) via the questionnaire. Patients were randomly assigned to one of five versions of this questionnaire. The allocation of patients and the topic areas covered by the study questionnaire are summarized in Figure 6.1.

EORTC QLQ-C30

Patients first completed the EORTC QLQ-C30 to become familiar with a quality of life instrument. The QLQ-C30 contains five functioning scales (physical, social, role, cognitive, and emotional), nine symptom scales (fatigue, nausea/vomiting, pain, dyspnea, sleeping disturbances, appetite loss, constipation, diarrhea and financial impact), and a global QoL scale [15]. Response choices range from 1 (not at all) to 4 (very much), with the exception of the two items of the global QoL scale, where responses range from 1 (very poor) to 7 (excellent). All scale scores are linearly transformed to a 0–100 scale. For the functioning scales and the global QoL scale, a higher score represents a higher level of functioning or QoL. For the symptom scales, a higher score represents more symptom burden.

Graphical presentation styles

Based on their randomization patients received one of five frequently used graphical presentation styles: non-colored and colored bar charts and line charts, and a heat map (see Figures 6.2a–e).

We included both non-colored and colored charts to assess preferences separately for charts using and not using color-coded reference values. The graphs contained hypothetical data from four assessment points for four QLQ-C30 scales: physical and emotional functioning, fatigue and pain. For each graph, we assessed the *objective* understanding of absolute scores by asking patients to rate the extent of the problem (none/mild, moderate or severe). These questions on absolute scores were only presented

Figure 6.1 Flowchart of the patient questionnaire

Figure 6.2a-e Five graphical presentation styles for physical functioning used in this study

to patients who received a survey with colored graphs. To assist patients in understanding the graphs, we added a description explaining the meaning of the colors (green – no/mild; orange – moderate; red – severe). *Objective understanding* of change scores was assessed with these questions: “Overall, over the 4 time points, how did health status change?” (overall change; continuous worsening, continuous improvement, fluctuation between improvement and worsening) and “How did the health status change from 10.09.2012 to 22.10.2012?” (specific change; worsened, no change, improved). We assessed *subjective* understanding with the following question: “How easy or difficult was it for you to understand the graphs?” (1-4 scale, ranging from very easy to very difficult).

Regarding preferences, we made a distinction between non-colored and colored charts. Patients had to choose from among the two non-colored charts or from among the three colored charts, depending on the questionnaire they received (i.e., they were not given all five charts, but just the two non-colored or the three colored ones). We also asked for their preference regarding three different directional indicators (indicating whether a score of 100 is good or bad): plus and minus signs (see Figures 2a-e), green and red arrows or a green arrow pointing in the direction of better scores.

General aspects of PRO data collection and use

The last section of the questionnaire consisted of general questions on the use of PROs in clinical practice (e.g., “How often would you be willing to complete a questionnaire during treatment about how you are feeling?”).

Health professional survey

Procedures

All health professionals from the Netherlands Cancer Institute involved in patient care were eligible to participate. They were invited via email to complete an online questionnaire using SurveyMonkey [16] about the use and interpretation of PROs. Reminders were sent after 3 weeks.

Sociodemographics and introduction

The survey began with questions about participant characteristics and previous experience with QoL data. The EORTC QLQ-C30 was displayed to familiarize the respondents with such questionnaires and to provide a context for the remainder of the survey.

Graphical presentation styles

We introduced the five graphs (both non-colored and colored; Figure 6.2a-e) and asked the respondents to rank them in order of preference. Each respondent was then shown graphs with data for four assessment points for the QLQ-C30 physical functioning and fatigue scales in the format which (s)he had indicated was his/her first preference. The questions to assess professionals’ objective and subjective understanding of the

graphically presented QLQ-C30 data were identical to those posed to patients. We also asked for their preference regarding different directional indicators, and provided space for general comments.

General aspects of PRO data collection and use

Finally, we asked the health professionals whether they believe that PRO questionnaires are useful for obtaining information about the health status and well-being of their patients. If the answer was positive, we posed follow-up questions on the use of PROs in clinical practice (e.g., “How often would you like to receive PRO information about a patient during treatment?”; “Do you think it is useful to have access to PRO results via the electronic medical record?”). If the initial response regarding usefulness of PROs was negative, they were asked to explain their rating.

Statistical analyses

We used descriptive statistics for sociodemographics, clinical data and the general questions. For each question assessing understanding, we calculated the percentage of participants with a correct answer. In addition, we calculated the mean number of correct answers for questions on the understanding of absolute scores, for questions on change over all four time points, for questions on specific change and a total score of all correct answers. For patients, the maximum number of correct answers was 12 (4 domains $\times$ 3 questions) and for health professionals 6 (2 domains $\times$ 3 questions). We used Kruskal-Wallis tests to compare the number of correct answers to the questions assessing absolute scores, overall change and specific change as a function of the graphical presentation styles. We used the Mann-Whitney U test to assess differences in understanding as a function of profession (medical specialists versus nurses and other health professionals combined). Using t-tests, we compared differences in understanding of functioning scales and symptom scales, in understanding of professionals with and without previous experience with PROs, in understanding of men versus women and in understanding of younger versus older participants. One way ANOVA was used to test whether objective understanding was influenced by educational level. We calculated the percentage of respondents who expressed a preference for each of the graphical presentation styles and used the Chi-square statistic to assess differences in preferences. We considered p -values below 0.05 to be statistically significant. All analyses were performed using the Statistical Package for the Social Sciences (SPSS) version 22.

RESULTS

Patient survey

Sociodemographics

A total of 548 patients participated (the Netherlands: $n = 236$, Austria: $n = 151$, Poland: $n = 100$, United Kingdom: $n = 61$). The mean age was 60.6 years (SD 12.3) and 54% was female. The most common diagnoses were breast cancer (25.7%), colorectal cancer (12.8%) and lung cancer (11.7%), and 61.2% of patients had UICC stage III or IV disease. Approximately three-quarter of the patients were on active treatment at the time they completed the questionnaire. Further patient characteristics are shown in Table 6.1.

Table 6.1 Patient characteristics ($N = 548$)

Age	Mean (SD)	60.6 (12.3)
	Range	19-89
Sex	Female	54.0%
	Male	46.0%
Education	Compulsory or less	31.2%
	Post compulsory	41.6%
	University or college	27.3%
Employment status	Full-time job	20.4%
	Part-time job	10.2%
	Homemaker	7.4%
	Retired	36.3%
	Unemployed	3.7%
	Student	0.2%
	Other	11.8%
UICC stage	I	9.9%
	II	28.9%
	III	24.4%
	IV	36.8%
Cancer site (primary)	Breast cancer	25.7%
	Colorectal cancer	12.8%
	Lung cancer	11.7%
	Head & neck cancer	8.0%
	Prostate cancer	7.4%
	Non-hodgkin lymphoma	7.3%
	Stomach/Esophageal cancer	6.6%
	Gynecologic cancer	6.0%
	Other	14.5%
Treatment status	On treatment	74.3%
	Off treatment	25.7%

Graphical presentation styles

Randomized allocation of patients to the five graphical presentation styles resulted in 20.6% of the patients receiving non-colored bar charts, 21.7% receiving non-colored line charts, 19.7% receiving colored bar charts, 18.6% receiving colored line charts and 19.3% receiving heat maps (see Fig. 6.2a–e).

Table 6.2 shows patients' preferences for the different graphical presentation styles. For those receiving non-colored charts, almost half of the patients did not have a preference ($\chi^2 = 30.5$, $p < 0.001$). For patients who received colored charts, bar charts were favored ($\chi^2 = 49.2$, $p < 0.001$).

Table 6.2 Preferences for graphical presentation styles

Non-colored charts	Patients^a (N=232)	Medical specialists (N=86)	Nurses (N=141)^b
	<i>Frequency</i>	<i>Frequency</i>	<i>Frequency</i>
Bar charts	30.3%	18.9%	32.0%
Line charts	19.9%	21.6%	18.0%
No preference	49.8%	NA	NA
Colored charts	Patients^a (N=316)	Medical specialists (N=86)	Nurses (N=141)^b
	<i>Frequency</i>	<i>Frequency</i>	<i>Frequency</i>
Bar charts	38.9%	12.2%	4.0%
Line charts	11.5%	1.4%	14.0%
Heat map	19.8%	45.9%	32.0%
No preference	29.9%	NA	NA

^a Numbers in this column add up to 200% because patients either judged the non-colored or the colored charts. For both types of charts, the total adds up to 100%.

^b Nurses and other health professionals

Table 6.3 Objective understanding (percentage of patients answering correctly)

Domain	Absolute score^a (N=316)	Overall change (N=548)	Specific change (N=548)
Physical functioning	44.4%	62.1%	72.2%
Emotional functioning	60.4%	72.8%	76.7%
Fatigue	42.8%	54.6%	52.6%
Pain	51.9%	60.5%	57.3%
Total ^b	49.8%	63.5%	65.3%

^a Calculated for group C/D/E (colored charts) only

^b These numbers reflect the percentage of correct answers (mean number of correct answers divided by the maximum possible number of correct answers)

The mean number of correct answers to the twelve questions assessing objective understanding was 7.0 (59%); for absolute scores this was 2.0 (out of 4), for overall change 2.5 (out of 4) and for specific change 2.6 (out of 4). Functioning scales were better understood than symptom scales (absolute scores $t = 3.08$, $p = 0.002$; overall change $t = 4.91$, $p < 0.001$; specific change $t = 9.93$, $p < 0.001$). Table 6.3 shows, for each question, the percentage of participants with a correct response. These results did not differ significantly between the different graphical presentation styles (not shown in tabular form).

Objective understanding did not differ significantly between men and women. Younger patients (below the median age of 62 years) were better in understanding specific change than older patients ($t = 4.15$, $p < 0.001$). For both specific change ($F = 14.705$, $p < 0.001$) and overall change scores ($F = 6.591$, $p = 0.002$), we found an effect of educational level. Posthoc pairwise comparisons indicated that patients with a university or college degree were better in understanding specific and overall change scores than patients with lower educational levels.

A much higher percentage (83%) of respondents reported that they found the graphs (very) easy to understand; this did not differ between groups ($\chi^2 = 6.76$, $p = 0.149$).

With regard to directional indicators, one third of patients (34.8%) did not have a preference and 34.4% preferred the green and red arrows. These percentages were significantly higher than the percentage of patients preferring the green arrow indicating better scores (23.4%) and plus and minus signs (7.3%); $\chi^2 = 102.1$, $p < 0.001$.

General aspects of PRO data collection and use

The majority of patients (75.8%) believed that PROs are a good way to provide their professional caregivers with information about how they are feeling. Completing such a questionnaire at home was favored over completing it in the hospital (39.0% versus 16.2%; 44.8% had no preference). About half of patients (46.9%) were willing to spend 15 to 30 minutes to complete PROs and would prefer to receive oral feedback on PRO results from a health professional (49.7%). The largest group of patients would like to complete PROs once a month during treatment (35.9%) and once every three months after treatment (30.0%). The preferred comparison group was one's own previous results (40.9%). Further details are given in Table 6.4.

Table 6.4 General aspects of PRO data collection and use

	Patients (N=548)	Health professionals (N=227)
Frequency during treatment		
Never	6.3%	5.1%
Every week	16.9%	7.0%
Every two weeks	18.0%	12.7%
Every month	35.9%	47.1%
Less than once a month	20.9%	28.0%
Frequency after treatment		
Never	9.7%	5.0%
Every month	20.5%	4.4%
Every three months	30.0%	47.8%
Every six months	23.2%	31.4%
Every year	16.5%	11.3%
Preferred comparison group ^a		
None	41.3%	6.6%
Other cancer patients	33.7%	26.9%
Healthy individuals	15.5%	24.7%
Previous personal results	40.9%	55.5%

^a Percentages may exceed 100% because giving more than one answer was allowed

Health professional survey

Sociodemographics

A total of 227 health professionals completed the online questionnaire. The mean age was 45.2 (SD 10.8) years and 76.4% was female. The largest group consisted of nurses (53.7%) followed by medical specialists (37.9%; e.g., medical oncologists, radiotherapists, surgeons, pulmonologists), and paramedical professionals (8.4%; e.g., physical therapists, social workers). For analysis purposes, we combined nurses, nurse specialists and paramedical professionals into a single group (“nurses and other health professionals”) and compared this combined group with medical specialists.

Graphical presentation styles

Thirty-two percent of all health professionals indicated that they had previously used PROs (typically QoL questionnaires) in a clinical study, and 48.0% reported using PRO results to inform patients about the possible (adverse) effects of treatment. About half of the professionals (56.3%) had used individual level QoL information in daily clinical practice.

Preferences for graphical display of QLQ-C30 results (all professionals) are shown in Table 6.2. There was a significant difference between professional groups. Forty-six percent of medical specialists preferred the heat map whereas other health professionals preferred the heat map and non-colored bar charts equally (32% for both) ($\chi^2 = 16.9$, $p = 0.002$).

The mean number of correct answers to the six questions assessing objective understanding was 4.7 (78%) for medical specialists and 4.4 (74%) for nurses and other health professionals. Understanding of overall change did not differ significantly between functioning and symptom scales ($t = 1.68$, $p = 0.095$). Specific change was understood better for functioning scales ($t = 4.11$, $p < 0.001$), whereas absolute scores were better understood for symptom scales ($t = -3.92$, $p < 0.001$). Table 6.5 shows the percentage of professionals who accurately interpreted the information summarized in the graphical displays. Understanding of overall and specific change scores did not differ significantly as a function of profession, but a significantly greater percentage of medical specialists than nurses and other professionals interpreted absolute scores accurately (72.6% versus 52.9%; $U = 816.5$, $p = 0.024$). Understanding did not differ significantly between those with and without previous experience with PROs. Regarding graphical presentation style, we found a significant difference for overall change scores, with the non-colored bar charts being interpreted correctly more often than the other graphical displays ($\chi^2 = 16.9$, $p = 0.023$; data not presented in tabular form).

Table 6.5. Objective understanding (percentage of professionals answering correctly)

Domain	Absolute score		Overall change		Specific change	
	Medical specialists (N=86)	Nurses ^a (N=141)	Medical specialists (N=86)	Nurses ^a (N=141)	Medical specialists (N=86)	Nurses ^a (N=141)
Physical functioning	64.3%	40.4%	75.7%	84.2%	98.6%	98.0%
Fatigue	81.0%	65.4%	64.2%	81.1%	89.7%	83.5%
Total ^b	72.6%	52.9%	69.4%	82.1%	94.1%	90.7%

^a Nurses and other health professionals

^b These numbers reflect the percentage of correct answers (mean number of correct answers divided by the maximum possible number of correct answers)

A high percentage (85%) of the health professionals indicated that the graphs were (very) easy to understand; this did not differ significantly between professions or graphical presentation styles. Both medical specialists (44.9%) and other health professionals (64.4%) preferred the green and red arrows as directional indicators. However, the second choice for medical specialists was the green “better” arrow (34.8%) whereas for nurses, the second choice was the graph with the plus and minus signs (19.8%); $\chi^2 = 24.47$, $p < 0.001$).

About 13% of health professionals responded to the open-ended question with a comment about the way in which the QLQ-C30 is scored, with higher scores being better for functional scales and worse for symptom scales. Some respondents indicated that they would prefer the use of a uniform direction for scoring, while others stressed the importance of highlighting this distinction more clearly to avoid confusion.

General aspects of PRO data collection and use

A large majority (87.8%) of health professionals believed that PROs are a useful way to obtain information about how their patients are feeling. Nearly all professionals (96.3%) indicated that it would be useful to access the results of PROs via the electronic medical record and many (76.5%) would wish to receive an alert when scores indicated a clinically relevant deterioration in functioning or increase in symptoms. Those who did not consider PROs to be useful reported having had negative experiences with such data, not having the time to review and discuss PRO results with their patients, and/or not wanting to bother their patients with completing questionnaires. Almost half of the professionals would like their patients to complete PROs once a month during treatment and once every three months after treatment. The majority preferred to compare a patient's current scores with his/her previous scores. Further information is provided in Table 6.4.

DISCUSSION

In this study we investigated cancer patients' and health professionals' understanding of and preferences for graphical presentation styles for individual level PRO data obtained using the EORTC QLQ-C30 questionnaire. Patients' objective and self-rated understanding were similar for the five graphical presentation styles, although they had a slight preference for bar graphs. Health professionals preferred heat maps, followed by non-colored bar charts and non-colored line charts. Their understanding of overall change was better for non-colored bar charts, and medical specialists were more accurate than other professionals in interpreting absolute scores. Self-rated understanding was substantially higher, and did not differ significantly between professions or graphical presentation styles.

Compared with previous studies, the objective understanding of the patients in our study was relatively low; it varied from 42.8% to 76.7%. In previous studies using group-level data, these figures did not fall below 80% [8; 17]. As educational levels of patients appear to be comparable across the different studies, this is not likely to explain these differences. However, in a study using individual-level data, the percentage of correct answers varied from 64-96% [18], which is also higher than the percentages we found. This rules out that the differences in observed understanding are caused by the use of group-level versus individual-level data. Possibly the lower levels of understanding are due to the different types of graphical formats that were used in the studies.

Professionals' understanding varied from 52.9% to 94.1%, which is relatively low compared to the results of a recently published mixed-methods study showing that oncologists answered 90-100% of questions correctly [18]. This difference might be due to the fact that we included professionals with different backgrounds, whereas in the mixed-methods study only oncologists were included. However, with some exceptions, professionals' understanding of the PRO results presented graphically was much higher than that of patients. We suspect that this may be due to their familiarity with interpreting data, in general, as well as to the fact that some of the health professionals had had previous experience with PROs, in general, and the QLQ-C30, in particular. Within the group of health professionals, we found that medical specialists were better in interpreting absolute scores than nurses and other health professionals, possibly because medical specialists are more accustomed to interpreting numerical data and charts. Many participating professionals indeed indicated that they had previous experience with PROs, for example in clinical practice. As we only recruited professionals from the Netherlands Cancer Institute, a comprehensive cancer center, these results may not be representative of health professionals, in general.

It is noteworthy that the self-rated understanding of both patients and health professionals was much higher than objectively measured understanding. Respondents may have answered the question assessing their self-rated understanding in a socially desirable way, providing an overly optimistic view. This is in line with two studies on lay understanding of medical terms [19; 20]. Self-rated understanding in this study did not differ as a function of graphical presentation style, whereas previous research has shown that line graphs were self-rated as easiest to understand [8].

Our findings regarding preferences are not in line with findings from studies on group-level data, which report that line graphs are preferred by patients and professionals [8; 10] or with a study on individual-level data in which line graphs were also preferred [18]. However, in those studies the selection was not made from a set of chart types fully comparable to the options used in our study. This discrepancy may reflect a methods effect; if different combinations of graphs would be used, preferences might also differ.

We found that both patients and professionals preferred PROs to be completed once a month during treatment and every three months after treatment. The higher frequency during treatment seems reasonable, given that one could expect more fluctuation and change in symptoms and functional health during this period. These findings are in line with the considerations of Snyder and colleagues regarding the implementation of PROs in clinical practice [11]. In addition, respondents in both groups indicated that they would prefer to compare current scores with a patient's previous scores. Detecting worsening of symptoms and deterioration in functioning is particularly important in order to provide relevant care in a timely manner.

Our study has several limitations that need to be considered. First, although we investigated five graphical presentation styles, these did not represent all possible styles. Furthermore, patients were not shown all types, but only the non-colored or the colored ones (to prevent an exposure effect). Second, we only used hypothetical data, which might have led to an underestimation of objective understanding. Some patients explicitly indicated that the graphs were not representative of their health situation at the indicated time points. This suggests that these patients may have answered the questions with their own health status in mind, which could have been different from the health status shown in the graphs. Possibly their interpretation would be more accurate if these patients were to be provided with graphs reflecting their own health status. Another limitation of the study is that we were only able to survey health professionals from a single hospital.

Our study also had a number of strengths, including the use of a variety of graphical presentation styles, the use of colored and non-colored graphics, and inclusion of patients from a number of countries, with different diagnoses, and both on- and off-treatment. We were also able to include a sizeable number of health professionals representing a variety of professions.

Because particularly patients' objective understanding was relatively low, it is important to learn more about how patients interpret and understand their individual graphically displayed PRO results. What are they thinking when they view such results? What information draws their attention? What do they understand and what do they not understand? These questions could be addressed via interviews in which patients are asked to verbalize what they are thinking when presented with graphs to interpret (a "think aloud" exercise [21]) and/or to reflect on their thinking process in retrospect. The results of such a qualitative study could be used to develop educational materials to help patients better understand their PRO results. For example, a tutorial video could be developed in which instructions are provided about the interpretation of PRO results. Special attention should be paid to the interpretation of functioning versus symptom scales, as our study as well as another study [18] showed differences in understanding between these types of scales. Such a video could also include a test to assess whether a patient fully understands the graphs. Comparable materials could be developed for professionals. Such a tutorial should not only focus on interpretation, but also on how to best provide care to and/or refer patients with clinically relevant QoL scores. In a previous study, professionals indeed indicated that they required help interpreting QoL data, and especially the clinical relevance of those data [10].

Conclusion

In this study we investigated patients' and health professionals' understanding of and preferences for different graphical presentation styles of individual PRO results. Our results indicate that, although patients and health care professionals generally believe that they understand PRO results summarized in graphical displays, in fact, their level of understanding is considerably lower. Thus future studies are needed to better understand the causes of misunderstanding, and to determine how to optimally present PRO results in a graphical form. This information could be used to develop educational materials that help to optimize interpretation. Because we did not find a clear preference for a certain graphical presentation style, choosing different styles for different individuals should be considered. This could be facilitated by using electronic systems to collect and feedback PROs.

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Chapter 7

eHealth for breast cancer
survivors: Feasibility and
preliminary evidence on the
efficacy of an interactive
portal

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ABSTRACT

Background

MijnAVL is an interactive portal including patient education, overview of appointments, access to the electronic medical record (EMR), patient-reported outcomes plus feedback and physical activity support. With this study we aimed to evaluate the feasibility of MijnAVL and to generate preliminary evidence on its efficacy among breast cancer survivors.

Methods

We included survivors currently or recently treated with curative intent. They completed questions on sociodemographics, patient activation (PAM), quality of life (SF-36), and physical activity (IPAQ). MijnAVL could be used noncommittally for four months. Log data were collected retrospectively and participants completed questions on acceptability, satisfaction and the PAM, SF-36 and IPAQ.

Results

Ninety-two women (mean age 49.5 years, 59% on-treatment) participated. Their mean number of logins was 8.7. Overview of appointments (80% of participants) and access to the EMR (90%) were most frequently used and most highly valued. Average website user satisfaction was 3.8 on a 5-point scale. Although participants reported having more knowledge and experiencing more control of their situation after using MijnAVL, PAM scores did not change significantly. Three domains of the SF-36 (role functioning – emotional, mental health and social functioning) and median vigorous physical activity improved significantly over time. The burden of MijnAVL for professionals was limited.

Conclusions

User experiences were positive and exposure to MijnAVL was accompanied by improvements in three quality of life domains and vigorous physical activity. Tailored features may be needed to enhance the usefulness and efficacy of MijnAVL. Research with a controlled design is needed to confirm our findings.

INTRODUCTION

Cancer survivors are individuals who are either in or after the primary treatment phase [1] and they are often considered to have a chronic disease. They may suffer from acute (e.g., nausea, hair loss, pain), long-term (e.g., fatigue, anxiety, sexual problems) and late effects (e.g., second malignancies, cardiovascular disease) caused by cancer or its treatment. These effects often have an impact on health status and quality of life and might even require professional help [2]. Current models of health care, with a focus on detection and treatment of acute disease, seem no longer sustainable given the increasing number of people with a chronic disease like cancer [3]. Additionally, the time of health professionals is limited and the costs involved in professional help are rising.

A transition to patient-centered models of care in which cancer survivors play a more active role in their care process is needed. This could be referred to as ‘patient empowerment’, which implies that cancer survivors’ autonomy is respected by health professionals and that survivors have the knowledge and the skills needed to positively influence their health status [4]. Research has shown that interventions aimed at improving patient empowerment can have a positive effect on health behavior and health outcomes [5].

To support patient empowerment it may be helpful to utilize information and communication technologies in health care (eHealth) [6, 7]. An important advantage of eHealth is that tailored information and interventions can be easily provided. In the Netherlands, about 95% of the population has access to the internet and its use is highest among younger age groups. Therefore, breast cancer survivors are an appropriate target population for eHealth services. To date, eHealth applications for breast cancer survivors have focused primarily on online (peer) support [8], patient education [9] or singular aspects of empowerment, such as psychological adjustment [10].

In the Netherlands Cancer Institute (Antoni van Leeuwenhoek hospital; AVL) we have developed an eHealth application to support cancer survivors during the whole cancer trajectory (“MijnAVL”; MyAVL in English). MijnAVL is a secured portal that provides survivors with personalized information, insight into their health status and tailored physical activity advice. The aim of this study was to evaluate the feasibility of MijnAVL and to generate preliminary evidence on its efficacy among breast cancer survivors.

METHODS

Participants and procedures

We invited women with histologically confirmed breast cancer who were currently receiving curative treatment (surgery, radiotherapy and/or chemotherapy) or had received such treatment 3-12 months earlier. They received a letter in which the

purpose of the study was explained, followed by a call from the researchers to discuss participation and check further eligibility criteria (i.e., having a computer and internet, mastery of the Dutch language). Women with cognitive disorders or emotional instability were excluded. Those declining participation were asked to indicate their main reason for non-participation. The Institutional Review Board approved the study and participants provided written informed consent.

We used a pre-posttest design. Upon completion of the baseline questionnaire participants could access MijnAVL noncommittally for 4 months, after which they were asked to complete a post-test questionnaire. We organized a focus group with a random selection of participants to obtain more detailed feedback about MijnAVL. Health professionals (medical oncologists, surgeons, radiotherapists and nurse specialists) were asked to complete a questionnaire about the impact of MijnAVL on their work.

Intervention

The development, content and layout of MijnAVL have been described in detail previously [11, 12]. It includes personalized educational material (e.g., about their disease, their treatment, and possible side effects) and an overview of appointments. Users can also access parts of their electronic medical record (EMR) including radiology, pathology and lab results, conclusions from multidisciplinary meetings and a medication overview; all supported by a dictionary. Additionally, users are asked to complete patient-reported outcomes (PROs) about their quality of life at regular intervals. Both participants and health professionals are provided with a summary of the PRO scores. The physical activity support program automatically provided tailored advice based on a set of questionnaires assessing physical activity levels and motivation. A screenshot of the homepage of MijnAVL has been presented in Figure 5.1.

Assessments

The use of MijnAVL (number and duration of logins, pages visited, questionnaires completed) was automatically logged per participant and clinical information (UICC stage, type of treatment, time since treatment) was obtained from the EMR.

Baseline questionnaire

First, sociodemographics such as marital status, education level and employment status were obtained. Internet use was measured in terms of frequency and duration. The Dutch version of the eHealth Literacy Scale (eHEALS) was used to assess users' ability to find and evaluate online health information. The eHEALS score ranges between 0 and 40; 40 being the highest score [13]. Expectations were measured with questions covering aspects derived from the Unified Theory of the Acceptance and Use of Technology (UTAUT) framework: ease of use (e.g., "MijnAVL will be easy to use"), usefulness (e.g., "MijnAVL will be a valuable supplement), attitude (e.g., "It will be a good idea to use MijnAVL"), social norm (e.g., "People who are important to me will encourage me to use MijnAVL"),

self-efficacy (e.g., “I have the ability to use MijnAVL”) and intention (e.g., “I intend to use MijnAVL as often as needed”) [14]. Response options ranged from 1 (completely disagree) to 7 (completely agree).

Preliminary data on the impact of MijnAVL was examined with three validated questionnaires. The patient activation measure (PAM) was used to measure patient empowerment in terms of knowledge, skills and confidence in self-management [15]. It consists of 13 questions with response options varying from 1 (strongly disagree) to 4 (strongly agree). Responses are converted to a total score ranging from 0- 100, with higher scores representing more activation.

Quality of life was assessed with the Short-Form 36-Item Health Survey (SF-36), which consists of eight scales (e.g., physical functioning, mental health and vitality) that are scored from 0 to 100, with higher scores being more favorable [16].

Physical activity was assessed with the International Physical Activity Questionnaire (IPAQ), which measures the frequency (days a week) and duration (minutes) of physical activity during the last seven days in the following domains: work, transportation, work at home and leisure activities [17]. Different levels of exercise (walking, moderate, vigorous, total) were calculated and expressed in Metabolic Equivalent of Task (MET)-minutes per week (a product of exercise intensity and duration).

Post-intervention questionnaire

Participants reported on their use (e.g., frequency, duration, features used) of MijnAVL. Satisfaction with MijnAVL was measured with the website user satisfaction questionnaire (WUS), assessing 11 dimensions of satisfaction such as information comprehensibility, ease of use and web site structure [18]. Experiences were assessed with questions based on the UTAUT framework that were an adapted version of the ones that were used to measure expectations at T0 (i.e., rewritten in the past tense). We also posed specific questions on acceptability per feature, for example, about the quality, timing and comprehensibility of information and about the usefulness of the feedback on PROs and physical activity questionnaire. These questions could be answered on a 1-5 scale (completely disagree - completely agree). Participants rated the different features of MijnAVL and finally completed the PAM, the SF-36 and the IPAQ.

Focus group

We discussed experiences with MijnAVL more thoroughly and gathered information on possible improvements and facilitators of long-term use. The focus groups were audio-taped and notes were taken.

Questionnaire health professionals

Involved professionals received a short questionnaire about the impact of survivors' access to MijnAVL on their work (e.g.: "Did you receive questions about MijnAVL and its content?"; "Did your workload increase?").

(Statistical) analyses

We used descriptive statistics to characterize the study sample in terms of clinical and sociodemographic variables, and to report expectations, satisfaction, experiences, use and measures of preliminary efficacy. We used the Chi-square statistic and Student's t-tests to examine possible differences between the groups on- versus off-treatment in clinical and sociodemographic characteristics at baseline, as well as in expectations and experiences. We assessed changes over time on the PAM and the SF-36 with paired-samples t-tests, and on the IPAQ with the Wilcoxon Signed Rank test. These tests were also used to perform subgroup analyses (on- versus off-treatment). We also checked, on an individual level, whether physical activity levels increased or decreased. We considered p-values <0.05 to be statistically significant and used the Statistical Package for the Social Sciences (SPSS) version 22.

Notes from the focus groups were combined with the qualitative comments from the questionnaires to highlight the most important issues. Health professionals' questionnaire responses were summarized using descriptive statistics and a qualitative analysis of answers to the open-ended questions.

RESULTS

7

Participants

Ninety-two women agreed to participate (response rate 35%), of which 59% were on-treatment. Those off-treatment had completed primary treatment, on average, 6.2 (SD=3.0) months earlier. The sociodemographic and clinical characteristics of the sample are reported in Table 7.1. Participants' mean age was 49.5 (SD=11.4) years, the majority was highly educated and had a job. All participants had undergone surgery, and 80% had adjuvant treatment. Ninety-six percent had used the internet for more than 3 years, 86% was using it daily and mean eHealth literacy was 30.8 (SD=4.4). Sociodemographic characteristics did not differ significantly between those on- and off-treatment. The primary reasons for non-participation were the anticipated emotional burden (27%), too little experience with computers/internet (17%), and lack of time (11%). The post-intervention questionnaire was completed by 87% of participants.

Table 7.1 Baseline characteristics (N=92)

Characteristic	%
Marital status	
Relationship, living together	64.1
Relationship, not living together	8.7
Single	19.6
Divorced	5.4
Widow	2.2
Education	
Compulsory or less	6.5
Post compulsory	20.7
University or college	72.8
Employment status	
Full-time job	28.2
Part-time job	40.0
Homemaker	4.7
Retired	10.6
Unemployed	4.7
Voluntary work	1.2
Disabled	10.6
UICC stage	
Ductal Carcinoma In Situ (DCIS)	11.0
I	28.6
II	45.1
III	15.4
Type of treatment	
Surgery	19.1
Surgery + Radiotherapy	21.3
Surgery + Chemotherapy	15.7
Surgery + Chemotherapy + Radiotherapy	43.8
Hormonal therapy	56.2
Immunotherapy	7.9

Expectations and experiences with MijnAVL

Participants' expectations and experiences, based on UTAUT, are shown in Table 7.2. Expectations were generally high, except for social norm. Experiences regarding social norm and intention were significantly lower than the expectations. For the remaining components (except for self-efficacy), experiences were comparable to expectations.

Table 7.2 Expectations of and experiences with MijnAVL

UTAUT component	Expectation	Experience	<i>p</i> -value
	Mean (SD)	Mean (SD)	
Ease of use	5.89 (0.91)	5.71 (1.17)	.228
Usefulness	5.13 (0.95)	4.86 (1.34)	.097
Attitude	6.10 (0.89)	5.89 (1.13)	.087
Social norm	4.16 (1.39)	2.82 (1.50)	.000
Self-efficacy	6.29 (0.80)	6.36 (0.81)	.524
Intention	6.43 (0.70)	5.55 (1.62)	.000

Use

About 75% of participants indicated that it was easy or very easy to log on to MijnAVL, and 90% used MijnAVL without any assistance. Use statistics are shown in Table 7.3. Use varied widely across participants; the number of logins ranged from 0-62 and the duration of use from 2-38 minutes. Participants on-treatment used MijnAVL and its features more often than those off-treatment (except for accessing quality of life scores); however the visits of those off-treatment lasted longer. PRO completion rates were high and similar for those on- and off-treatment (77% and 83%, respectively). The overview of appointments and the EMR were accessed most frequently and used by the largest number of participants (80% and 90%, respectively).

Table 7.3 Use of MijnAVL

	On-treatment (N=46)	Off-treatment (N=37)	Rating (N=92)
	Mean (SD)	Mean (SD)	1-10 scale
Number of logins	10.9 (12.7) ^a	5.6 (3.7) ^{b,c}	Not applicable
Mean duration of login	11.3 (6.5)	15.2 (8.9) ^d	Not applicable
Patient education	4.0 (6.3)	1.8 (1.3) ^d	6.9
Overview of appointments	8.8 (11.2)	3.3 (2.1) ^c	8.7
Access to EMR	8.7 (11.3)	3.8 (3.0) ^c	7.9
Quality of life scores	3.5 (3.9)	2.4 (2.3)	6.8
Physical activity support program	4.4 (3.7)	2.4 (1.8) ^c	6.1

^aN=54, ^bN=38, ^cdifferent from on-treatment; *p* < .001, ^ddifferent from on-treatment; *p* < .05

Satisfaction

The overall mean score for the WUS was 3.8 (SD=0.44) on a 1-5 scale. The domains ease of use, website structure and accuracy were particularly highly valued. MijnAVL as a whole was rated 7.6 on a 1-10 scale, with the overview of appointments and access to the EMR being rated highest.

Acceptability of MijnAVL was good in terms of perceived usefulness and comprehensibility; although the graphical presentation of PRO results was less well understood and the information from the EMR raised questions for about 40% of participants. The EMR information and educational materials did not lead to anxiety for the majority of participants, and most participants indicated that access to this information increased their knowledge about and control over their disease. Participants reported that the patient education and physical activity advice could be improved by adapting it more to one's personal situation and by making the advice more interesting, concise and motivating. Participants expressed appreciation for the opportunity to complete PROs at home, but some indicated disappointment that their health professional(s) did not discuss the results with them.

Preliminary data on efficacy

An overview of the outcome measures at baseline and post-intervention is presented in Table 7.4. Scores on the PAM did not change significantly over time. Three domains of the SF-36 improved significantly over time: role functioning–emotional ($p=.021$) and mental health ($p=.000$) improved for those during treatment and social functioning for those after treatment ($p=.001$). Median vigorous physical activity increased significantly from 0.0 to 360.0 MET-minutes per week for the total group ($p=.017$), although this effect was not apparent in the subgroup analyses. However, the total amount of physical activity actually decreased over time for about half of those on-treatment, and for about one-third of those off-treatment.

Focus group results

Results indicated that participants ($n=6$) were pleased with having access to information and being able to re-read information. At the same time, they indicated that the educational materials, feedback and advice could benefit from tailoring and could be presented in a more visually attractive manner. Participants also expressed interest in being able to make and change appointments online and in obtaining access to the full EMR. They felt that providing regular updates and having their health professionals encourage them to use MijnAVL could contribute to sustained use.

Questionnaire for health professionals

Twenty-four professionals, including medical oncologists, surgeons, radiotherapists and nurse specialists (response rate 73%) completed the questionnaire. Thirty-eight percent indicated that their patients who had access to MijnAVL asked questions about

Table 7.4 Outcome measures

	On-treatment (N=38)		Off-treatment (N=35)		Total group (N=73)	
	Baseline	Post-intervention	Baseline	Post-intervention	Baseline	Post-intervention
PAM		Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Score 0-100	62.7 (13.2) ^a	61.5 (16.8) ^a	62.7 (13.2) ^b	60.1 (13.7) ^b	62.7 (13.1) ^d	60.9 (15.4) ^d
SF-36						
Physical functioning	82.2 (20.8)	80.4 (18.3)	82.5 (14.1)	83.4 (14.6)	82.4 (17.8)	81.8 (16.6)
Role functioning – physical	45.4 (42.3)	41.4 (42.4)	52.9 (46.1)	62.9 (41.7)	49.0 (43.0)	51.7 (43.2)
Role functioning – emotional	58.6 (42.6) ^a	77.0 (38.0) ^{a,*}	72.4 (36.6)	80.0 (38.1)	65.3 (40.1) ^e	78.5 (37.8) ^{e,+}
Vitality	57.4 (18.2) ^a	59.1 (17.0) ^a	58.4 (17.8)	61.0 (16.0)	57.9 (17.9) ^e	60.0 (16.4) ^e
Mental health	66.3 (14.9) ^a	77.4 (14.5) ^{a,*}	73.6 (16.1)	75.4 (14.8)	69.8 (15.8) ^e	76.5 (14.6) ^{e,+}
Social functioning	69.4 (21.7)	78.0 (21.7)	73.2 (18.5)	83.2 (17.4) ⁺	71.2 (20.2)	80.5 (19.8) ⁺
Bodily pain	71.3 (27.6)	74.6 (18.2)	79.1 (17.8)	75.0 (24.1)	75.0 (23.6)	74.8 (21.1)
General health	55.0 (21.1)	55.9 (19.4)	59.1 (15.3)	62.0 (15.8)	57.0 (18.5)	58.8 (17.9)
IPAQ (MET-min/week)		Median (Range)	Median (Range)	Median (Range)	Median (Range)	Median (Range)
Walking	330.0 (0-19404)	651.8 (0-9890)	627.0 (0-3762) ^c	462.0 (0-10866) ^c	396 (0-19404)	594 (0-108660)
Moderate activity	832.5 (0-13220)	1039.5 (0-8310)	1835.0 (0-6800) ^c	2430.0 (0-11220) ^c	1420 (0-13220)	1560 (0-11220)
Vigorous activity	0.0 (0-9600)	360.0 (0-8160)	0.0 (0-4920) ^c	405.0 (0-7080) ^c	0 (0-9600)	360 (0-8160) ⁺
Total activity	1921.5 (0-25569)	2542.5 (0-13374)	3326.0 (0-13106) ^c	4005.0 (0-17598) ^c	2793 (0-25569)	3724.2 (0-17598)

^aN=37, ^bN=31, ^cN=33, ^dN=68, ^eN=72, ^fN=71, *different from baseline; p<0.05, ⁺different from baseline; p<.01

the program (e.g., about the overview of appointments, login procedures, access to the EMR). Twenty-one percent indicated to receive questions about the content of the EMR (e.g., requests for explanation of jargon, interpretation of reports). Thirty-six percent reviewed their patients' PRO results and some discussed those results with their patients. One-quarter believed that their patients having had access to MijnAVL led to an increased workload (ranging from several to more than ten minutes).

DISCUSSION

The results of this study support the feasibility of MijnAVL, an interactive portal, for breast cancer survivors. Use varied widely between participants, with highest levels of use being observed for those on-treatment. The scores on the UTAUT components and the WUS indicated that satisfaction with MijnAVL was relatively high, with overview of appointments and access to the EMR being most highly rated. Although both the questionnaire and focus group results suggested that participants perceived having more knowledge and control over their disease due to exposure to MijnAVL, the PAM scores did not reflect such change over time. Participants' scores on three quality of life domains and their level of vigorous activity improved significantly from pre- to post-intervention. The focus group yielded useful feedback for improving MijnAVL (particularly the need to further tailor the information provided). Health professionals indicated that, although some patients asked questions about MijnAVL, it led to only a modest increase in workload.

Ratings of experiences with MijnAVL were somewhat lower than expectations beforehand. The focus group confirmed that MijnAVL did not fully live up to the expectations, primarily because information and advice were not sufficiently tailored to individual needs. Two literature reviews have also indicated that tailored information matching user needs is an important feature of successful eHealth interventions [19, 20]. Nevertheless, participants expressed high levels of satisfaction with MijnAVL and used it quite regularly, particularly individuals on-treatment. This probably reflects the fact that, during treatment, more relevant information including updates of the patients' EMR was available, thus leading to more logins [21].

Because use of MijnAVL was on a voluntary basis, it was not possible to calculate adherence rates. However, the dropout rate was relatively low compared to other eHealth interventions [22] and the completion rate of PROs was relatively high. This may reflect the fact that MijnAVL is directly linked to the EMR, and thus may be perceived by patients as being an integral part of the health care process; something that has been found to be an important characteristic of successful eHealth applications [20]. Another factor that might have contributed to the sustained use of MijnAVL was the use of automatic email reminders for the completion of questionnaires [23]. To further improve the use of

MijnAVL it might be beneficial not only to provide more tailored information and advice, but also to facilitate social support, to have health professionals encourage their patients to use the system, and to provide feedback (e.g., regarding PRO data) [19, 21].

Linkage to the EMR is an important feature of MijnAVL. Importantly, clinical staff supported sharing test results and other EMR information, with the exception of their personal notes. Post-intervention, about 40% of professionals indicated that participants had posed questions about MijnAVL, half of which were about medical topics. Twenty-five percent of the health professionals indicated some increased workload due to their patients using MijnAVL. This is in contrast with an earlier study that indicated no increased workload resulting from patients' access to lab test results [24]. This difference could be due to the fact that MijnAVL provided access to a wider range of EMR data. Additional studies are needed to better understand the impact of portals such as MijnAVL on the content and processes of care. It would be particularly useful to conduct observational studies, that document the actual (versus self-reported) influence of portals on doctor-patient communication.

Despite predominantly positive experiences with MijnAVL, the effects we measured on patient empowerment, quality of life and physical activity were relatively modest. Although participants indicated that they felt better informed because of their exposure to MijnAVL, this did not translate into increased levels of patient empowerment, at least as measured by the PAM. It may be that the PAM is not sufficiently sensitive to changes in empowerment over time, and that more specific questions are needed to detect such changes. It may also be the case that only a relatively brief exposure to a patient portal such as was the case in the current study may be insufficient to facilitate increased feelings of empowerment. Similarly, the modest observed improvement in quality of life and physical activity over time may be due to the relatively short exposure to MijnAVL, as well as to the absence of sufficiently tailored information. The impact of MijnAVL may be enhanced by combining its interactive features with face-to-face contacts that can increase motivation and adherence [11].

In the next version of MijnAVL we intend to incorporate more tailored information and advice based on individual information needs. Such needs may vary as a function of age, sex, educational level, ethnicity and stage of disease [25]. We also intend to link PRO data with clinical pathways and treatment guidelines, using a stepped care approach, starting with self-management options, followed by referral to more formal forms of intervention and care, where appropriate. Finally, the physical activity support program could be improved by taking greater account of personal (e.g., preferred type of exercise) and environmental (e.g., support, resources) factors when providing advice. It may be particularly important to attend to the needs of those who use the portal during the period of active treatment, as we observed a decrease in the amount of physical activity in half of this group.

Our study has several limitations that need to be considered. First, all participants were experienced internet-users. This may, to some degree, overestimate the feasibility and accessibility of the program, limiting generalizability to the larger population of cancer survivors. Second, the absence of a control group and of information about participants' use of other (educational) tools or mobile apps does not allow us to attribute the observed efficacy to the use of MijnAVL. Third, the data on physical activity were based on self-reports, which are known to be less reliable than objective measures such as accelerometers [26]. Despite these limitations, our study nevertheless is one of the first to investigate the feasibility of an interactive portal for breast cancer survivors that is fully integrated into the care trajectory and the hospital information system. In addition, the objective log data provided reliable information on the actual use of the portal.

Conclusion

Our findings suggest that MijnAVL is a feasible eHealth application for breast cancer survivors that has the potential to improve quality of life and physical activity levels. MijnAVL could be further improved by including more visually attractive and tailored information, where possible adapted to individual information needs. Research with a controlled design and including more specific outcome measures is needed to further document the effects of such an interactive portal.

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Chapter 8

Supporting lung cancer
patients by eHealth:
A pilot study of the feasibility,
use and impact of an
interactive portal

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ABSTRACT

Objectives

ICT-based supportive services for lung cancer patients are scarce. “MijnAVL” is an interactive portal for cancer patients that aims to strengthen empowerment of lung cancer patients. The objective of this study was to evaluate the feasibility of MijnAVL and to generate preliminary evidence on its impact when used by lung cancer patients.

Materials and Methods

We included lung cancer patients currently or recently treated with curative intent, surgery or (chemo)-radiotherapy. At baseline, they completed a questionnaire on sociodemographics and effect measures, such as the patient activation (PAM), health-related quality of life (HRQOL) (SF-36), and physical activity (IPAQ). MijnAVL could be used noncommittally for 4 months. Log data were analyzed retrospectively and participants completed questions on acceptability, satisfaction and effect measures.

Results

We included 37 patients (mean age 59.6 years). Mean number of logins was 11.2 with a mean duration of 12.9 minutes. Eighty-nine percent of patients indicated that MijnAVL was easy to use and 82% was positive about using it; 69% saw MijnAVL as a valuable addition to the care and 56% indicated that it helped to have more control over their health. MijnAVL as a whole was rated 7.8 on a 10-point scale. Patient activation scores decreased slightly over time from 64.8 to 59.4 ($p=0.049$), while the SF-36 and the IPAQ showed no significant changes, although vigorous physical activity tended to increase.

Conclusion

“MijnAVL” is feasible and user-friendly, multifunctional eHealth program for patients with lung cancer. The features of the current version of the program most often used and valued by patients are the overview of appointment-keeping, access to the EMR, and PRO questionnaire administration. Additional efforts are needed to increase the effect of the program in terms of patient empowerment, and to increase the attractiveness, perceived value and use of the patient education and physical exercise elements of the program.

INTRODUCTION

To date, eHealth services have been developed primarily for breast and prostate cancer populations [1]. Although lung cancer has a high symptom burden, we could find only one report on an eHealth service that supports these patients [2]. To strengthen empowerment of lung cancer patients in the Netherlands Cancer Institute (NKI- Antoni van Leeuwenhoek Hospital, abbreviation in Dutch “AVL”) we developed an interactive portal (“MijnAVL”; “MyAVL” in English). It includes patient education, an overview of appointments, access to the electronic medical record, patient-reported outcomes with related feedback, and tailored physical activity support. We developed MijnAVL following a stepwise approach: literature review [3], focus groups with patients and health professionals [4], acceptability testing based on mock-ups and usability testing of functional prototypes [5]. The aim of this pilot study was to evaluate MijnAVL’s feasibility and to generate preliminary evidence on its impact when used by lung cancer patients.

MATERIALS AND METHODS

Patients and recruitment

We included patients with Non Small Cell Lung Cancer (NSCLC) who were currently being treated or who had completed primary, curative treatment 3 to 12 months earlier. Treatments included surgery, radiotherapy, concurrent chemoradiotherapy or a combination of these. Patients provided written informed consent and the study procedures were approved by the local Institutional Review Board.

MijnAVL intervention

The content of MijnAVL, including screenshots of its features, have been described in detail previously [5]. In short, it includes five features: 1) personalized patient education material (health professionals provide the most timely and suitable patient education materials); 2) an overview of past and upcoming appointments; 3) access to the electronic medical record (EMR), including blood tests, physiological test results (e.g., lung function), pathology reports, and letters to the general practitioner and other hospitals (with medical test results made available with a two week delay; 4) patient-reported outcomes (PROs) and related feedback (i.e., a graphical and tabular overview of scores and related background information on quality of life domains); and 5) tailored physical activity advice based on a set of questionnaires assessing physical activity levels, motivation and possible contra-indications. MijnAVL could be used noncommittally for 4 months. A screenshot of the homepage of MijnAVL was provided in Figure 5.1.

Assessments

At baseline, participants completed a questionnaire on sociodemographics and effect measures; patient activation (PAM) [6-8], quality of life (SF-36) [9], and physical activity

(IPAQ) [10]. After four months, log data on actual use were analysed retrospectively and participants completed questions on self-reported use, satisfaction (Website User Satisfaction questionnaire; WUS), acceptability (a questionnaire based on the Unified Theory of Acceptance and Use of Technology; UTAUT [11] and the effect measures PAM, SF-36 and IPAQ. Physical activity was expressed as Metabolic Equivalent of Task (MET) minutes/week for moderate, vigorous and total activity. To evaluate acceptability per component of the portal, questions were posed on aspects like level of personalization, level of comprehensibility and level of anxiety. The response scale of these questions ranged from 'strongly disagree' to 'strongly agree'. Patients also rated the different components on a scale from 1 to 10 (higher scores being more positive rating). Finally, a focus group was held with 5 participants to further discuss the pros and cons of using MijnAVL and its features.

Analyses

Data on feasibility (use, satisfaction and acceptability) were analysed descriptively. Data on the PAM, SF36 were presented as means (SD) and the IPAQ as median (IQR). The PAM, SF-36 and IPAQ questionnaires were scored according to standard scoring procedures. Pre- and post-test scores were compared by a paired samples t-test except for the IPAQ, which was tested with the Related samples Wilcoxon signed rank test. Analyses were performed with SPSS version 22.

RESULTS

Feasibility

Between January 2014 and August 2015 we invited 123 patients to participate, 37 of whom agreed to do so (16 women). Most common reasons for declining were: having little computer/internet experience (n=14), emotionally too burdensome (n=12), and not having a computer or internet access (n=9).

Mean age of the subjects was 59.6 (SD=8.4) years. Eighty percent was on-treatment and patients had NSCLC stage I (37%), II (14%) or III (49%). Treatments included surgery (34%), chemoradiotherapy (29%), radiotherapy (20%), or a combination of these (18%). Seventy-nine percent of participants had used the internet more than 3 years and 91% used it (almost) daily.

The mean number of logins during the four month study period was 11.2 (SD=9.1; range 0-30) with a mean duration of 12.9 (SD=13.9; range 1-77) minutes. Of the PROs that were provided in MijnAVL, on average, 83% (SD 35%) were completed. Overview of appointments, access to EMR, and questionnaires were used most frequently, with an average of 7.5 (SD=7.0), 6.7 (SD=4.7) and 6.7 (SD=5.0) logins, respectively. The remaining components, patient education, quality of life scores and Keep Fit were accessed less

often, with an average of 1.9 (SD=2.4), 3.7 (SD=3.1) and 3.1 (SD=2.5) views, respectively. On average, 2.3 (SD=2.5) PROs were completed (82.0%; SD=35.5%). The mean number of Keep Fit questionnaires filled out was 2.0 (SD=1.3). No significant differences in these variables were noted between patients on- and off-treatment.

Acceptability data, as measured with the UTAUT-based questionnaire indicated that 93% of patients found MijnAVL easy to use, 56% reported that it contributed to a sense of control over their health and 69% indicated that it was a valuable addition to their health care experience. Eighty-two percent was satisfied with MijnAVL and 80% intended to continue using it. Sixty-one percent reported being better informed via access to the EMR, and 43% reported an enhanced sense of control over their disease. Average satisfaction rating (WUS scores) across domains was 3.9 on a 5-point scale. Key issues that emerged from the acceptability questions and focus group are presented in Table 8.1.

Preliminary data on impact

Patient activation (PAM) scores actually decreased slightly over time from 64.8 (SD=14.2) to 59.4 (SD=11.6) ($p=0.042$). For the SF-36 we found no significant changes over time. Levels of physical activity did not change significantly, but vigorous physical activity tended to increase over time: from a median of 0 (IQR=0-840) to 240 (IQR=0-1140) MET-minutes per week ($p=.053$).

DISCUSSION

MijnAVL, an eHealth program developed in an oncology setting, was found to be feasible, easy to use and useful by the majority of the lung cancer patients. Access to the EMR and the overview of appointments were evaluated very positively and used quite frequently. We expected positive effects of access to the EMR in terms of improved knowledge, autonomy, self-efficacy, and patient-clinician communication [12]. Our results supported this, in part: 61% reported that this information enhanced knowledge of their disease and 43% indicated that it enhanced their sense of control over their disease. In general, patients indicated that they would prefer access to their full medical record and immediate access to medical test results, as soon as they have been discussed with the patient. Reassuringly, and similar to other studies [13, 14], very few patients reported that having access to the EMR led to feelings of (mild) anxiety. At the same time and unexpectedly, our measure of patient empowerment (the PAM) indicated no improvement over time. In fact, there was a significant, albeit small decrease in PAM scores. Quite unexpectedly we found a slight decrease on the PAM over time. It is doubtful whether this mean change of 5 points is clinically relevant. (the average PAM scores remain within the same “level” of empowerment) [7]. It may also be that the PAM does not measure aspects of empowerment that are most relevant for cancer patients. The effect of MijnAVL on empowerment may be increased by adding features focused specifically on coping and symptom control [17].

Table 8.1 Acceptability of MijnAVL as a whole and its components.

MijnAVL component	Used this feature (self-report) (n, %)	Rating (1-10), mean (SD)	Key remarks, issues and suggestions for improvement
MijnAVL as a whole	N.A.	7.8 (0.9)	<ul style="list-style-type: none"> • The two-step authorization procedure (with username, password and SMS authentication) was found to be burdensome. • Issues with non-Windows operation system (i.e., iOS). • Frequency of use declined due to infrequent updates.
Patient education	11/28 (37%)	7.1 (1.5)	<ul style="list-style-type: none"> • Patients indicated that too few documents were available. • Some indicated that content could be more tailored to specific complaints of patient.
Appointments	25/28 (83%)	8.2 (1.2)	<ul style="list-style-type: none"> • No major issues; very comprehensible and useful. • Past appointments were found to be useful for reimbursement purposes.
Access to the EMR	24/28 (80%)	7.1 (1.1)	<ul style="list-style-type: none"> • Although many patients found the information useful and comprehensible, it also raised questions or anxiety in some cases. • Not all data of the EMR could be accessed. Some wanted to see more. • The delay of 2 weeks before showing test results was perceived as too long by some patients. The delay should be indicated more clearly in the portal. • Data from other hospitals could not be seen via MijnAVL.
PROs and feedback	21/28 (70%)	7.4 (1.0)	<ul style="list-style-type: none"> • Graphs and tables with scores were comprehensible and valued by patients as these give insight into their quality of life over time. • Some indicated that PROs were somewhat unpleasant or confronting to complete or took too much time to complete. • PROs were not often discussed during medical consultations, which disappointed some patients.
Keep Fit	8/28 (27%)	7.2 (0.8)	<ul style="list-style-type: none"> • Reminded several patients of the importance of physical activity • Advice was sometimes perceived as too general and could be more tailored. • Recalling the amount of physical activity during the past week (needed for the questionnaire) was not always easy. • Some expressed desire for free text option to express their concerns/needs in this respect. • Some expressed the need for information on services (e.g. physiotherapy) that are specialized for cancer patients.

Despite the large potential benefits of exercise [15], the physical activity support program was used by only one-third of participants. Those who received intensive treatment (e.g., chemoradiotherapy) were particularly unlikely to use the program. On the other hand, we saw a marked, albeit non-significant, increase in vigorous physical activity. We observed relatively good “compliance” with completing PROs during the study period, which may be due to the fact that the PROs are perceived as part of their integrated care [16]. The accessibility of MijnAVL may be further enhanced by simplifying the authorisation/access procedure (Table 8.1).

Conclusions

“MijnAVL” is feasible and user-friendly, multifunctional eHealth program for patients with lung cancer. The features of the current version of the program most often used and valued by patients are the overview of appointment-keeping, access to the EMR, and PRO questionnaire administration. Additional efforts are needed to increase the effect of the program in terms of patient empowerment, and to increase the attractiveness, perceived value and use of the patient education and physical exercise elements of the program.

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Chapter 9

General discussion

Background

Many cancer survivors suffer from short-term, long-term and late effects that are due to cancer itself or its treatment. These effects are likely to impact their health status and quality of life in a negative way [1]. They often need long-term care, which makes their trajectory more or less comparable to people with a typical chronic disease such as diabetes or COPD. However, the growing population of cancer survivors, the accompanying health care costs, and the limited time of health professionals make it challenging to provide this long-term care. There is an urgent need for more patient-centered care models in which cancer survivors are actively involved and take more responsibility for their health [2]. This approach is commonly referred to as patient empowerment [3].

Research has shown that eHealth could be useful to enhance patient empowerment in individuals with chronic diseases [4], but at the start of this project hardly any eHealth applications were available for cancer survivors. Therefore, our aim was to develop, implement and evaluate an interactive portal (“MijnAVL”) for breast and lung cancer survivors. The studies we conducted have yielded useful and important knowledge about the application of eHealth for cancer survivors. We have described the different steps that could be taken to develop and evaluate such an application. In this final chapter we will reflect on the main findings, discuss methodological considerations, and describe implications for future research and practice will be described.

Reflection on main findings

Exploration of eHealth applications

To determine which features of eHealth applications could be relevant for cancer survivors, we obtained information about online tools for individuals with a chronic disease. We identified seven common features of eHealth applications that could also be used to deliver aspects of cancer survivorship care: i.e. education, self-monitoring, feedback/tailored information, self-management training, a personal exercise program, and communication with either health professionals or fellow patients (Chapter 3). One could argue whether it is plausible to make this leap from chronic diseases to cancer, as there still is a substantial number of individuals with progressive disease who will eventually die from cancer [5]. Furthermore, among cancer survivors, worries might be more prominent than among individuals with other chronic diseases. Even after completion of primary treatment, they frequently report on worries about possible recurrence, the risk of second malignancies, symptoms and the future in general [6]. These cancer-related worries require special attention when developing eHealth applications for cancer survivors, which was also highlighted in the focus groups we conducted (Chapter 4). The other features from our literature review were however verified by cancer survivors, confirming that the approach taken was an acceptable one.

eHealth was a relatively new topic in cancer survivorship only a few years ago, but in the past years the number of applications that aim to support cancer survivors has increased considerably. In our more recent literature review (Chapter 2), we identified 46 unique applications that could be divided into five categories: educational services, patient-to-patient services, e-PRO services, multi-component services and portal services. The majority of these applications were developed for breast and prostate cancer survivors, which might be related to their high incidence and survival rates [5]. The overview was not comprehensive, as many eHealth applications are developed and implemented without being scientifically tested (and thus could not be retrieved from scientific literature). We also did not take into account smartphone apps, which are rapidly growing in number and popularity, but often lack a scientific basis [7]. Our review showed that most of the applications supported the enhancement of knowledge about health status and health care, and that a minority led to skill development, autonomy and support. To further increase the effect on these empowerment-related aspects, eHealth applications need to be adapted and improved. We will elaborate on this in the section ‘implications for clinical practice and implementation’.

Development of MijnAVL

To verify the findings from our literature review, we conducted focus groups with cancer survivors and their health professionals separately to obtain their unique viewpoints (Chapter 4). This was the first study to explore the needs and expectations of these specific populations regarding an eHealth application. The participants in the focus groups had no or hardly any experience with eHealth, so their feedback was primarily based on their expectations. Nevertheless, they were very well able to discuss the (dis)advantages of the features we presented and to make a comparison with usual care. Important themes that emerged from the qualitative analyses included the fulfillment of information needs, communication, motivation, quality of feedback, and supervision. This resulted in the recommendation that an interactive portal for cancer survivors should at least include tailored information, access to the EMR, an overview of appointments, PROs and related feedback, and telemonitoring of parameters of physical functioning (all under certain conditions). These recommendations formed the foundation for the technical development of MijnAVL.

The next steps in the iterative approach were discussions about the content of MijnAVL (with health professionals), interviews about a prototype in PowerPoint, and usability tests with a functional prototype (both with cancer survivors; Chapter 5). Professionals informed the development of access to the EMR, PROs and the physical activity program, which has strengthened the quality of these features and led to commitment among professionals. The interviews and the usability tests provided useful feedback about graphic design, content and ease of use to develop an optimal version of MijnAVL that could be used in the evaluation study. In parallel to the aforementioned steps, with a survey study we showed that survivors’ and health professionals’ self-rated understanding

of different graphical presentation styles of individual-level PRO results was substantially higher than their objective understanding. As preferences differed across individuals, it would be appropriate to adapt the graphical presentation to individual preferences (Chapter 6).

An important issue that emerged during the development of MijnAVL was the comprehensibility of information. Professionals as well as survivors doubted whether survivors could understand the information from the EMR and the results of the survey study indicated that educational support is very important when giving access to PRO results. Previous studies have also shown that lay understanding of medical jargon is limited, and that individuals overestimate their understanding [8; 9]. As an explanation of medical jargon, abbreviations and test results, or an online dictionary are necessary aids [10; 11], we added a medical dictionary to MijnAVL as a first step. Unfortunately we could not include all desired changes and support in MijnAVL before the start of the evaluation study, due to constraints in terms of time and technology. This illustrates the tension that exists between the development of eHealth on the one hand and its evaluation on the other hand, which is usually characterized by a mismatch between rapidly evolving technology and the need for more time-consuming evaluations [12]. However, it could also be the other way around, with the technology not yet being sufficiently advanced to meet all user needs.

Evaluation of MijnAVL

To evaluate the feasibility and preliminary efficacy of MijnAVL, we conducted a study with a pre-posttest design (Chapters 7 and 8). Survivors were relatively satisfied and provided useful suggestions to make the portal even more attractive and beneficial. We did not find an effect on patient empowerment as measured by the PAM for breast cancer survivors, and a small deterioration for lung cancer survivors. However, in the focus groups post-intervention and in the questions related to the specific features of MijnAVL, survivors reported that they had more knowledge about and felt more in control of their disease and some felt better able to ask their health professional questions. This points out the potential of MijnAVL to contribute to empowerment-related aspects. Breast cancer survivors showed significant improvements on three quality of life domains and they increased their levels of vigorous activity. For lung cancer survivors we did not find a change in quality of life and physical activity. These findings should be interpreted carefully, because we did not include a control group and we do not know about participants' use of other information sources and supportive interventions.

The contradictory finding that patient empowerment as measured by the PAM did not improve, but that participants indicated to have more knowledge and feel more control, might question the suitability of the PAM for this intervention or for this population. In the validation process of the original questionnaire approximately 80 cancer patients were involved [13], so it is unlikely that the PAM is not appropriate for the cancer setting

at all. Possibly the questions were too general, making it hard to detect differences in empowerment as the result of using MijnAVL. It was for example to be expected that participants' answers to the question "I know what each of my described medications do" did not change, as this information was not extensively presented in the portal. More specific questions, focusing on aspects that are likely to be changed by the use of MijnAVL may increase the chance of detecting an effect of the intervention.

It is also possible that we did not find an increase in PAM score because the intervention, i.e., the use of MijnAVL, was not efficacious enough to enhance (aspects of) patient empowerment as identified in our literature review (Chapter 2): 1) being autonomous and respected by health professionals; 2) having knowledge; 3) having psychosocial and behavioral skills; 4) perceiving support from community, family and friends; and 5) perceiving oneself to be useful (e.g., for society or family). This review showed that the impact of eHealth applications on empowerment is especially related to knowledge enhancement, which probably also applies to MijnAVL as its features mainly provide information. It could be that the physical activity support program has led to some skills development, but that the PAM was not sufficiently sensitive to detect these differences. To further increase the impact of MijnAVL, it would be beneficial to provide survivors with more personalized (tailored) information, advice, and skill developing programs, as it is known that this leads to stronger intervention effects [14; 15].

A final question related to our findings regarding patient empowerment is whether, despite the trend towards more patient-centered models of health care, survivors actually *want* to be empowered. It is imaginable that a substantial number of individuals who face a (potentially) life-threatening disease choose to follow the recommendations of their health professional. Related to this, it could be that cancer treatment had such an impact on individuals that they were not able to properly process the information on MijnAVL and act upon it. This means that levels of empowerment would be higher in individuals off-treatment, but this was not supported by our data. Possibly subgroups of individuals with different levels of empowerment could be identified based on other characteristics such as self-efficacy, knowledge, perceived control and health literacy [16]. In clinical practice it should be taken into account that not all individuals want to and will be empowered to the same extent, which requires a different approach of for example providing information and (shared) decision making for different individuals.

The finding that quality of life and physical activity did not substantially change may be due to the limited ability of MijnAVL to positively affect these outcomes. It could also be that the negative impact of cancer treatment and its consequences was stronger than the positive effects that could have been obtained by using MijnAVL (i.e., scores may even have deteriorated without using MijnAVL). As mentioned before, a more tailored approach may increase the efficacy of MijnAVL; this will be further discussed in the section 'Implications for clinical practice and implementation'. Another relevant issue,

which also emerged in the focus groups (Chapter 4), is the potential role of face-to-face contacts with health professionals. It is known that several contacts with a professional in addition to an eHealth intervention result in less dropout and better adherence to treatment [17; 18]. Research has also shown that patients value face-to-face supervision, which most likely leads to more motivated individuals and better intervention effects [14]. Therefore it would be worthwhile to consider a combination of eHealth and face-to-face contacts to enhance the impact on quality of life and physical activity.

An evident strength of the evaluation study was that the dropout rates were only 13% (breast cancer) and 19% (lung cancer). This is rather low compared to other eHealth interventions [19] and might be due to the connection of MijnAVL to the hospital information system. This makes the use of MijnAVL part of the health care process, which is an important characteristic of successful eHealth applications [15]. Also the email reminders for the completion of questionnaires might have contributed to the low dropout rates [20]. Factors that might even further improve adherence include social support (from peers, counselors or family and friends), regular updates, a more personal approach (with tailored advice and feedback), and tools for self-management [14; 15; 17].

Methodological considerations

The limitations of the specific studies have already been described in the respective chapters. Here we will address several issues that offer useful suggestions to improve eHealth research and implementation.

Generalizability

In our studies we included breast and lung cancer survivors from the Netherlands Cancer Institute. Despite some differences in baseline characteristics (i.e., breast cancer survivors were younger, all female, more often single, and higher educated), the majority of findings were comparable for these groups. Therefore MijnAVL is very likely to be suitable for other tumor types as well. We also found some differences: lung cancer survivors expressed a stronger need for telemonitoring of physical functioning parameters (Chapter 4), they were more positive about the physical activity support program, but their rating of access to the EMR and their self-efficacy to use MijnAVL were lower (Chapters 7 and 8). Given these differences between breast and lung cancer survivors it is, important to explore the unique needs and expectations of individuals with other tumor types regarding an eHealth application. A focus group will be the most appropriate research method here. In such a focus group one could verify the current features and thoroughly explore additional needs.

Participants versus non-participants

The response rates for the evaluation study were relatively low: 35.5% for breast and 29.8% for lung cancer survivors. These numbers probably are not fully representative for the number of individuals willing to use an eHealth application, as the research aspects (e.g., the completion of evaluation questionnaires) were also reported to be a barrier. Unfortunately, we do not have information about the sociodemographic and clinical characteristics of non-participants, which hinders a comparison with participants. Such a comparison would have provided insight into factors that may influence the willingness to use an eHealth application, giving useful leads on how to stimulate and support the use of MijnAVL. We know however that about 25% declined because of emotional reasons, for example that it would be too much in addition to the treatment or that it would be too confronting to see all disease-related information again. For these individuals, it should be emphasized that the use of MijnAVL is noncommittal and that it encompasses more than having access to the EMR. Other reasons for non-participation included limited experience with computers and internet (21%) and not having a computer (12%). Although eventually everyone in the Netherlands will have a computer or laptop, there will always be individuals with limited skills. It is very important to support these individuals in using eHealth, for example by offering regular training sessions.

Non-controlled evaluation study

The pre-posttest design without a control group of our evaluation study impeded the attribution of effects to the use of MijnAVL. In clinical research a randomized controlled trial (RCT) is the most frequently used design to investigate the effectiveness of interventions as it has minimal bias and thus provides the strongest level of evidence. In eHealth research, however, RCTs may not be the most appropriate method as these trials are rather time-consuming [21]. eHealth applications are susceptible to rapid changes in technology, so by the time the results of an RCT are available, the content, features and platform of an application may be out-of-date. Additional drawbacks of RCTs in eHealth research are that it is impossible to blind participants for the intervention, that it might be hard to assure that the intervention group is actually using the intervention and that the control group could be contaminated by for example other websites or apps [22]. Despite the disadvantages of RCTs in this field, an eHealth version of the CONSORT checklist has been developed, describing which information should be included when reporting on RCTs evaluating eHealth applications [23]. This checklist is meant to facilitate the progress of eHealth research and suggests that RCTs are still valued. We will further elaborate on this in the next section.

Implications for future research and practice

The future of eHealth faces many challenges related to both research and practice. In this section we will first discuss implications for eHealth research, followed by practical implications.

Implications for research

In our evaluation study several reasons for non-participation were reported, including emotional reasons and limited computer/internet skills. It is important to obtain more insight into these factors, because this could eventually help to increase the use of MijnAVL (and eHealth applications in general). It should be examined why survivors feel emotionally unable to use eHealth, and how this barrier could be overcome. Individuals with limited skills could be asked what kind of aids they need to become able to use an eHealth application. Qualitative research methods such as interviews and focus groups will be most appropriate here, as with these techniques more detailed information could be gathered. The UTAUT framework, which we also applied in several of our studies (Chapter 5, 7, 8), could be used as a basis for this type of research. An exploration of the different components of this framework will provide a rather complete view of the (anticipated) acceptance of an eHealth application.

Given the limitations of RCTs in eHealth research, it is questionable whether this would be the best next step following the pre-posttest design we used. A clear vision on alternative research designs is lacking, so possibly RCTs will be unavoidable to determine the effects of eHealth applications in terms of clinical outcomes and health behavior. However, to keep up with the rapidly developing technologies, the efficiency and speed of eHealth evaluations should be improved, for example by conducting small-scale studies with a focus on the most relevant outcomes [21]. It is recommended to use proximal outcomes that are not only (clinically) relevant but also sufficiently sensitive and responsive to be detected, for example self-efficacy [21]. An appropriate strategy would be to conduct an RCT to determine the effectiveness of an eHealth application, while within that trial addressing research questions that could be answered with a small part of the participants only (e.g., which features do they prefer? What are the levels of use and adherence? How could information best be tailored?).

An important proximal outcome measure is patient empowerment, as it is known that empowered individuals are more likely to engage in healthy behavior and often show better health outcomes [24]. In addition, individuals may value to be empowered even if their health status does not optimally improve by using an eHealth application [25]. A systematic review on the psychometric properties of empowerment measures has shown that there is little evidence for the reliability and responsiveness of these measures [26]. Additionally, as there is a substantial overlap with other related constructs, the authors recommended that a clear definition of patient empowerment is necessary to develop a reliable, valid and responsive measure [26]. In Chapter 2 we have provided a conceptualization of empowerment for cancer survivors. To our knowledge, three cancer-specific questionnaires to measure patient empowerment have been developed [27-29], but these questionnaires do not fully cover all aspects of this conceptualization. Therefore, the next step should be to develop a questionnaire that captures all characteristics of empowerment. The questions should be really specific, focusing on concrete aspects such as knowledge and feelings of autonomy, to increase the likelihood of detecting change.

Instead of only focusing on effectiveness, it is important to also evaluate how and why an eHealth application works [30]. In such an evaluation the interests of different stakeholders such as clinicians, patients, funders and policy makers should be taken into account. A combination of quantitative and qualitative research would be most appropriate to understand the impact of eHealth applications on its users and the organization [30]. In our evaluation study we have combined questionnaires and focus groups. The questionnaires provided structured information about experiences, satisfaction and effects and the focus groups led to more detailed information about the (dis)advantages of MijnAVL, its uptake and use, and reasons for the effects that were or were not found. Although the use of questionnaires might be more practical (e.g., less time-consuming, easier to analyze) than focus groups, especially this qualitative research is likely to result in clues and concrete suggestions for the further improvement of an application.

A final recommendation for eHealth research is to involve health professionals. Evaluation studies tend to focus on patients, as they usually are the primary users of an eHealth application. However, the introduction of an eHealth application in clinical practice is likely to also have an impact on the role of health professionals and their work. After the evaluation study 22% of health professionals indicated to experience an increased workload, which was primarily due to survivors asking questions about MijnAVL. The PROs were only used by a minority, indicating that the adoption is not yet optimal. Further research should elaborate on the impact of eHealth applications on the work of health professionals, for example by using qualitative methods to obtain more insight into barriers and facilitators for adoption. The impact could also be assessed objectively by audiotaping consultations in order to analyze the content and duration.

Implications for clinical practice and implementation

A major issue with eHealth applications is that many of them do not make it through the pilot phase (i.e., they are developed and evaluated for research purposes but not implemented for day to day use). To improve the sustainability of eHealth applications, the optimal fit between technology, users and sociocultural context needs to be created and sufficient resources like money and time should be available [30]. An important factor in this regard is the compatibility of eHealth applications with relatively new tools like smartphones and tablets. The number of people using these tools is increasing rapidly, and therefore it is essential that new eHealth applications are responsive (i.e., the display format could be adapted to the tool that is being used). At several moments during the development and evaluation of MijnAVL, participants indeed indicated that this would lower the threshold for using an application, as it enables them to basically use it everywhere.

Although in the Netherlands internet access rates are approximately 95% [31], there is still a substantial number of individuals that have no or only limited skills to use the internet or related technology (i.e., low eHealth literacy). These individuals should be

involved in the development and implementation of eHealth applications to ensure that the technology fits their skills. Other solutions to support use include offering regular training sessions or providing online tutorials to help people to use the application and its specific features. It is also likely that there are individuals who are not interested in and/or not motivated to use an eHealth application. The challenge is to offer applications that are perceived to be useful and easy to use, for example by using persuasive design techniques. This includes principles such as primary task support (e.g., self-monitoring, tailoring), dialogue support (e.g., rewards, similarity), system credibility support (e.g., trustworthiness, authority), and social support (e.g., social comparison, normative influence)[32]. With these principles, eHealth applications can be designed in such a way that they fit the characteristics and needs of the users, which is likely to lead to the motivation to reinforce, change or shape attitudes and/or behaviors [32].

However, it is likely that a number of individuals will never develop the skills or the motivation to use eHealth. The inequalities that arise as the result of these differences in digital skills and the use of eHealth applications are often referred to as the digital divide [33]. The field of eHealth is quickly developing and eHealth applications are probably becoming increasingly effective in supporting health care. As all individuals should have equal rights regarding the (quality of) care they receive, the digital divide may become an issue. It will be hard to provide individuals who are less digitally skilled with the same information, advice and interventions as individuals using eHealth, for example because tailoring is much more difficult without the use of technology. This again highlights the need to offer help to less skilled individuals to enable them to use and take advantage of eHealth.

Individuals with different levels of eHealth literacy have different needs regarding eHealth applications, which is a good example to illustrate that the ‘one size fits all’ principle does not apply to eHealth. The most important recommendation from the evaluation study was that all information and advice should be as personal (tailored) as possible, which implies that it should be adapted to individual characteristics such as age, gender, educational level, and information needs. This requires that individuals are screened on these characteristics, for example by completing a questionnaire the first time they log on to an eHealth application. The answers to such a questionnaire could be analyzed using algorithms, which are computations that combine the different answers to select the information matching an individual’s characteristics. We already developed algorithms for the physical activity support program, and they would also be very useful to provide specific advice based on PROs. In order to do so, the scores on PROs should be classified into different categories (e.g., no problem, moderate problem, severe problem) and the change over time should be monitored. Based on the (change in the) severity of the problem individuals could be referred to educational materials, self-management programs or a health professional for the relevant domains. Such a stepped care approach has already been proven to be useful in mental health care, for example to treat depression [34]. Possibly it is also useful to provide psychosocial support to cancer survivors.

In addition to the personalization of information and advice through the use of algorithms, the content and graphic design MijnAVL could be further improved. Content-wise, survivors would like to see a more central role for nutrition, for example personal information and advice based on a questionnaire or hyperlinks to reliable websites on this topic. Furthermore, they indicated to be interested in new developments in cancer research and treatment, and especially the personal relevance. Related to this, personal information about the detection, prevention and treatment of short-term, long-term and late effects that one could expect was desired. Regarding graphic design, all patient education and advice should be presented more visually, for example with pictures and movies. However, individuals might have different preferences for the visual display of information (Chapter 6), which should be taken into account. Finally, a more practical suggestion was to add the possibility to make and change appointments online.

If an eHealth application fits the needs of end users, they are more likely to adopt it, which is essential for the successful implementation of eHealth in clinical practice. It is known from the literature that technical, social, personal and environmental factors play an important role in this regard and that they are often interrelated [30]. More specifically, the adoption of an eHealth application will only occur when its value is perceived by the users and when it is easy to learn and easy to use the application. This was supported by our research, in which survivors indicated to place great value on being regularly informed about the benefits of MijnAVL, preferably by their health professionals. Health professionals initially were resistant to the introduction of MijnAVL, but by involving them in the developmental process we were able to overcome this barrier. The challenge remains to find such a fit between the relevant factors that it leads to the optimal adoption of eHealth.

In 2014, the Dutch Ministry of Health has established targets for the use of eHealth. In 5 years, 80% of individuals with a chronic disease should have online access to their EMR, 75% of the elderly and chronically ill should be able to engage in self-monitoring and everyone should have the opportunity to use web-consultation [35]. The Ministry of Health and the industry are willing to invest a lot of money to reach these targets. Money is needed to purchase, develop, evaluate and maintain technology, to fulfill requirements for implementation (for example to train clinicians and patients) and to reimburse individuals in need for an application. Although many researchers have suggested that eHealth applications are cost-effective, up till now, insufficient data on the costs have been published to draw firm conclusions [36; 37]. Especially the lack of evidence on cost-effectiveness could be problematic, as investors frequently want to be sure in advance that an eHealth application is worthwhile to reimburse. It is also important that the costs in terms of time and effort could be justified in relation to the value of an eHealth application. Obviously, some clinical aspects of health care such as medical examinations are difficult to substitute by eHealth. However, one should carefully consider which tasks could be substituted by eHealth, which tasks could be performed more effectively by using eHealth and what the possible consequences of an eHealth application are.

Concluding remarks

The research as described in this thesis has yielded useful information about the potential of using eHealth to support cancer survivors. We have provided an overview of the different steps that could be taken to develop and evaluate an interactive portal for breast and lung cancer survivors. From the evaluation study it can be concluded that this portal is a user-friendly and feasible application that has the potential to support cancer survivors. It can be improved to enhance the actual benefits in terms of empowerment, quality of life and physical activity, for example by providing more tailored information and advice. Apart from improving the portal itself, several challenges remain. The main challenge in eHealth research is to intertwine development and research, using research methods that are of good quality but not too time-consuming. Regarding eHealth implementation, challenges are to make applications that are user-friendly for individuals with different characteristics, to optimize the reach, adoption and use of eHealth applications and to guarantee (ongoing) funding.

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Chapter 10

Summary

Nederlandse samenvatting (Summary in Dutch)

Dankwoord (Acknowledgments)

List of publications

About the author

SUMMARY

Nederlandse samenvatting (Summary in Dutch)

Dankwoord (Acknowledgments)

List of publications

About the author

SUMMARY

Due to better detection techniques and treatments, the number of cancer survivors is increasing. As many of them experience short-term, long-term or late effects of cancer and its treatment, they are often seen as individuals with a chronic disease. Patient empowerment and eHealth are often proposed as useful means to support this growing population of cancer survivors. The aim of this thesis was to develop an interactive portal ("MijnAVL") that could support breast and lung cancer survivors.

Patient empowerment and an exploration of eHealth applications

Although patient empowerment is a popular construct that could be effective in improving health outcomes, it is also rather complex and multi-faceted. In order to optimally design interventions or (eHealth) applications and to evaluate whether they indeed have an impact on characteristics of empowerment, it would be essential to have a generally accepted definition. In Chapter 2 we described the results of an integrative literature review in which we analyzed existing definitions of patient empowerment to conceptualize patient empowerment for cancer survivors. We identified three main attributes of patient empowerment: 1) being autonomous and respected; 2) having knowledge; and 3) having psychosocial and behavioral skills. Two attributes that specifically applied to the cancer setting were added: 4) perceiving support from community, family and friends; and 5) perceiving oneself to be useful through having paid employment and/or by contributing to family and friends. Factors that could trigger patient empowerment, so-called antecedents, included for example the presence of a chronic disease, the motivation to change poor health behavior and an atmosphere of mutual trust and respect as created by health professionals. Consequences of patient empowerment include for example increased knowledge about disease and treatments, higher levels of self-efficacy and better interaction with health professionals.

In the same chapter, we present the results of a literature review in which we explored the possibilities of existing eHealth applications to support (aspects of) patient empowerment. The applications that we identified could be divided into five categories: 1) educational services; 2) patient-to-patient services; 3) e-PRO services; 4) multi-component services (combining two or more of the former); and 5) patient portal services. The number of studies that could really show an effect of these applications on patient empowerment was limited. The main benefit was an increase in knowledge, while effects on autonomy and skill development were less pronounced. Future research should try to establish the effect of eHealth applications on patient empowerment. Regarding the development and improvement of these applications, it is important to take into account the characteristics and needs of patients and follow up on these needs.

At the time the project as presented in this thesis started, there was only a very limited number of eHealth applications available for cancer survivors. To inform the development

of the interactive portal, we conducted a systematic literature review of existing eHealth applications for patient empowerment in the chronic disease setting, of which the results were presented in Chapter 3. Based on 18 unique randomized controlled trials we identified seven features that were commonly used: education, self-monitoring, feedback/tailored information, self-management training, personal exercise program, and communication with either health professionals or fellow patients. We also explained how these features could be used for cancer survivorship care. However, based on the available information, we could not determine which features or combinations of features were the most effective. In addition, this review did not result in information about the needs and expectations of cancer survivors and their health professionals regarding an eHealth application.

Development of MijnAVL

To obtain this information, we organized focus groups to elaborate on the findings from our literature review. The focus groups were conducted with breast cancer survivors, lung cancer survivors and health professionals separately (Chapter 4). We presented screenshots with drafts of possible features of MijnAVL: survivorship care plan, access to the electronic medical record, an overview of appointments, e-consultation, online patient community, patient-reported outcomes plus feedback, telemonitoring service, an online rehabilitation program, and an online psychosocial self-management program. This was followed by an open discussion to collect all possible viewpoints regarding each feature. The most important themes that resulted from our qualitative analysis were fulfillment of information needs, communication, motivation, quality of feedback, and supervision. Results also showed that cancer survivors were especially positive about features that could provide them with relevant information (survivorship care plan, access to the medical record, overview of appointments). Health professionals were primarily interested in PROs and telemonitoring, as these features could provide them with information about the health status of their survivors. The findings from this study formed the basis for the development of MijnAVL.

This developmental process, as described in Chapter 5, consisted of three types of activities: 1) discussions with health professionals about the proposed features; 2) interviews with cancer survivors about a first draft in PowerPoint; and 3) usability tests with cancer survivors using a functional online prototype. Health professionals from various disciplines provided feedback in multiple sessions, in which we focused on access to the electronic medical record, PROs and the physical activity support program. They for example pointed out several conditions for giving survivors access to test results, indicated that they were reluctant about automated advice to survivors based on quality of life scores and they assisted in writing the physical activity advice. The interviews with cancer survivors using a draft in PowerPoint primarily yielded useful information about the graphic design and about what should be improved content-wise. They also provided suggestions to optimize the usefulness of the features, for example the need

for a dictionary to be able to understand the information from their medical record and the desire to receive a notification in case of new information or the request to complete a questionnaire. Based on these results, a functional online prototype was developed that was used for usability testing. Participants performed several tasks with the portal while thinking aloud, which provided insight into how they were performing these tasks. The usability tests showed that it was relatively easy to navigate the website and to use the different features. Taking into account the feedback from the usability tests, a final version of MijnAVL was developed.

Given the opportunities of eHealth applications to visually display information, we decided to zoom in on one particular feature of MijnAVL (PROs plus feedback) and investigated patients' and health professionals' understanding of and preferences for different graphical presentation styles of individual PRO results (Chapter 6). We included a cross-sectional sample of 548 patients from four European countries (the Netherlands, Austria, Poland and the United Kingdom) and 227 health professionals from the Netherlands Cancer Institute. With a questionnaire we assessed self-rated and objective understanding of individual-level quality of life scores and preferences for five graphical presentation styles. Results showed that self-rated understanding was substantially higher than objective understanding. Objective understanding did not differ between graphical formats in patients, whereas in health professionals overall change scores were interpreted correctly more often when using non-colored bar charts. For non-colored bar charts, almost half of patients did not express a preference. Colored bar charts (39%) were preferred over heat maps (20%) and colored line charts (12%). Medical specialists preferred heat maps (46%) followed by non-colored bar charts (19%), whereas other health professionals equally valued these chart types (32%). The results of this study suggested that there is a need to provide sufficient guidance when presenting such results to patients and health professionals. In addition, it might be useful to adapt the graphical presentation of PRO results to individual preferences.

Evaluation of MijnAVL

Finally, we performed a study to evaluate the feasibility and preliminary efficacy of MijnAVL. At baseline, participants completed a questionnaire about sociodemographics, their expectations of MijnAVL, and three efficacy measures: patient empowerment (PAM), quality of life (SF-36) and physical activity (IPAQ). After the noncommittal use of MijnAVL for four months, they completed a questionnaire about their satisfaction, the PAM, SF-36 and IPAQ and log data were collected retrospectively. In Chapter 7 the results for the 92 breast cancer survivors that participated were reported. Their mean age was 49.5 years and 59% was on-treatment. The mean number of logins was 8.7, with a mean duration of 13.1 minutes. The overview of appointments (80% of participants) and access to the EMR (90%) were most frequently used and valued highest. The overall score for website user satisfaction was 3.8 on a 1-5 scale and especially ease of use, structure of the website and accuracy scored high. PAM scores did not change over time, but participants indicated

that they were better informed about their disease and felt more control due to the information from the EMR. Three domains of the SF-36 significantly improved (i.e., role functioning – emotional, mental health and social functioning domains). Median vigorous physical activity significantly increased from 0 to 360 MET-minutes per week. The burden of MijnAVL for health professionals was limited.

In Chapter 8 the results of the 37 lung cancer survivors that participated were presented. Their mean age was 59.6 years and they logged in 11.2 times on average, with a mean duration of 12.9 minutes. Eighty-two percent was positive about the use of MijnAVL and 56% indicated that they perceived more control over their health. Website user satisfaction was rated 3.9 on a 5-point scale, with ease of use and website structure scoring highest. All features were frequently used and rated 7 or higher on a 10-point scale. The score on the PAM significantly decreased over time from 64.8 to 59.4, which implies patient activation decreased over time. For the SF-36 and the IPAQ the scores did not significantly over time, although vigorous activity tended to increase. The results of the evaluation in both breast and lung cancer survivors indicated that MijnAVL is a feasible eHealth application for these populations. The preliminary efficacy could only be partly substantiated and primarily for breast cancer survivors, which might be due to the intervention itself or the (insensitivity of) outcome measures. MijnAVL could be further improved by including more visually attractive and tailored information, where possible adapted to individual information needs. Research with a controlled design and including more specific outcome measures is needed to adequately assess the effects of such an interactive portal.

In chapter 9, the findings of our studies are discussed in the context of existing literature and in terms of methodological considerations, ultimately leading to recommendations for future research and practice related to the use of eHealth in general and for cancer survivors in particular.

Concluding remarks

Our research has produced useful information about the use, feasibility and potential efficacy of eHealth for breast and lung cancer survivors. To maximize the benefits, the information and advice should be tailored to individual characteristics as much as possible. Besides the necessity to improve our eHealth application itself, several challenges remain. In eHealth research, solutions are needed to find a balance between the quick development of new applications and the time-consuming evaluations. In eHealth implementation, the challenges are to develop applications that are user-friendly and effective for individuals with different characteristics, to obtain sufficient funding and to optimize the adoption and use of eHealth applications.

Summary

NEDERLANDSE SAMENVATTING (SUMMARY IN DUTCH)

Dankwoord (Acknowledgments)

List of publications

About the author

NEDERLANDSE SAMENVATTING (SUMMARY IN DUTCH)

Door de steeds vroegere opsporing en verbeterde behandeling van kanker, in combinatie met de vergrijzing van de bevolking, neemt het aantal (ex-)kankerpatiënten sterk toe. De meerderheid (62%) is vijf jaar na de diagnose nog in leven, maar velen van hen ervaren klachten als gevolg van de tumor of de behandeling hiervan. Klachten die op korte termijn optreden maar vaak verdwijnen na afronding van de behandeling zijn bijvoorbeeld misselijkheid, haaruitval, pijn en kortademigheid. Er zijn ook klachten die aanhouden, de zogenoemde lange termijn klachten, zoals pijn, vermoeidheid, angst en seksuele problemen. Dan zijn er nog klachten die maanden of zelfs jaren na afronding van de behandeling kunnen optreden (late effecten): bijvoorbeeld het risico op de terugkeer van kanker, cardiovasculaire problemen, fibrose, neuropathie en cognitieve problemen. Vanwege deze klachten worden (ex-) kankerpatiënten vaak gezien als personen met een chronische ziekte. Patient empowerment (actieve betrokkenheid en verantwoordelijkheid) en eHealth (het gebruik van communicatie- en informatietechnologie) worden vaak aangedragen als middelen om (ex-)kankerpatiënten te ondersteunen bij de omgang met deze ziekte. Het doel van het project zoals beschreven in dit proefschrift was om een interactief portaal ("MijnAVL") te ontwikkelen om (ex-) borstkankerpatiënten en (ex-) longkankerpatiënten te ondersteunen.

Patient empowerment en een verkenning van eHealth-toepassingen

Patient empowerment is een populair concept dat kan bijdragen aan het verbeteren van gezondheidsuitkomsten, maar het is ook een complex en veelzijdig concept. Om interventies en eHealth-toepassingen zo goed mogelijk te ontwikkelen en om te evalueren of ze daadwerkelijk effect hebben op aspecten van empowerment, is het essentieel om een algemeen geaccepteerde definitie te creëren. In Hoofdstuk 2 zijn de resultaten beschreven van een literatuuronderzoek waarin we bestaande definities van patient empowerment voor zowel kanker als andere chronische ziekten hebben geanalyseerd. Deze definities zijn geïntegreerd om tot een conceptualisering van patient empowerment voor (ex-)kankerpatiënten te komen. We hebben 3 hoofdkenmerken van empowerment geïdentificeerd: 1) autonoom zijn en behandelaars hebben die deze autonomie respecteren; 2) het hebben van kennis; en 3) het hebben van psychologische en gedragsvaardigheden. Daarnaast vonden wij twee kenmerken die specifiek waren voor de oncologie: 4) het ervaren van steun van de maatschappij, familie en vrienden; en 5) het gevoel hebben nuttig te zijn, bijvoorbeeld door een betaalde baan of door het helpen van familie en vrienden. Er zijn verschillende factoren die een trigger kunnen zijn voor patient empowerment. Deze zogenoemde antecedenten zijn bijvoorbeeld het hebben van een chronische ziekte, de motivatie om slecht gezondheidsgedrag te veranderen en een gevoel van wederzijds vertrouwen en respect tussen (ex-)kankerpatiënt en behandelaar. Gevolgen van patient empowerment zijn bijvoorbeeld meer kennis over ziekte en behandeling, meer eigen effectiviteit en een verbeterde interactie met behandelaars. In hetzelfde hoofdstuk werden de resultaten gepresenteerd van een literatuuronderzoek

naar de mogelijkheden van bestaande eHealth-toepassingen om bij te dragen aan (aspecten van) empowerment. De gevonden applicaties konden ingedeeld worden in vijf categorieën: 1) educatieve applicaties; 2) applicaties via welke patiënten met elkaar kunnen communiceren; 3) applicaties om online patiënt gerapporteerde uitkomsten te verzamelen; 4) applicaties bestaande uit minimaal twee van de voorgaande applicaties; en 5) patiëntenportalen. In slechts een beperkt aantal studies kon het effect van deze applicaties op patient empowerment worden aangetoond. Meestal betekende dit een toename van kennis, en soms een versterkt gevoel van autonomie of de ontwikkeling van vaardigheden. Er is meer onderzoek nodig om het effect van eHealth-toepassingen op patient empowerment vast te stellen. Voor de ontwikkeling en verbetering van deze applicaties is het belangrijk om rekening te (blijven) houden met de kenmerken en behoeftes van (ex-)kankerpatiënten.

Om informatie te verkrijgen voor de ontwikkeling van het interactieve portaal hebben we een systematisch literatuuronderzoek uitgevoerd naar eHealth-toepassingen om empowerment van patiënten met een chronische ziekte te stimuleren. Hierbij werden alleen gerandomiseerde, gecontroleerde studies geïncludeerd. De resultaten van dit review werden beschreven in Hoofdstuk 3. We hebben zeven functionaliteiten geïdentificeerd die veel voorkwamen in de 18 gerandomiseerde, gecontroleerde onderzoeken: educatie, zelfmonitoring, feedback/informatie op maat, zelfmanagement, een persoonlijk beweegprogramma en communicatie met behandelaars en/of medepatiënten. We hebben ook beschreven hoe deze functionaliteiten gebruikt zouden kunnen worden in de zorg voor (ex-)kankerpatiënten. Op basis van de beschikbare informatie konden we echter niet vaststellen welke (combinaties van) functionaliteiten het meest effectief waren. Ook was er vrijwel geen informatie beschikbaar over de behoeftes en verwachtingen van een eHealth-toepassing onder (ex-)kankerpatiënten en hun behandelaars.

Ontwikkeling van MijnAVL

Om dieper in te gaan op de bevindingen van het literatuuronderzoek en de bovengenoemde behoeftes en verwachtingen in kaart te brengen, hebben we groepsgesprekken georganiseerd. Deze focusgroepen werden uitgevoerd met (ex-)borstkankerpatiënten, (ex-)long-kankerpatiënten en behandelaars afzonderlijk (Hoofdstuk 4). We lieten de deelnemers een presentatie zien met mogelijke functionaliteiten van MijnAVL: nazorgplan, toegang tot het elektronisch medisch dossier, een afsprakenoverzicht, e-consult, online patiënten forum, patiënt gerapporteerde uitkomsten (vragenlijsten) met feedback, telemonitoring, een online revalidatieprogramma en een online psychosociaal zelfmanagementprogramma. Na de presentatie van elke functionaliteit was er een open discussie waarin alle mogelijke standpunten werden besproken. De meest belangrijke thema's die uit de kwalitatieve analyse naar voren kwamen, waren: het vervullen van informatiebehoefte, communicatie, motivatie, kwaliteit van feedback en supervisie. De (ex-) kankerpatiënten waren in het bijzonder positief over de functionaliteiten die hen kunnen voorzien van relevante informatie (nazorgplan, toegang tot het elektronisch

medisch dossier, afsprakenoverzicht). Behandelaars hadden voornamelijk interesse in patiënt gerapporteerde uitkomsten en telemonitoring, omdat deze functionaliteiten informatie verschaffen over de gezondheidstoestand van hun patiënten. De bevindingen van deze studie vormden de basis voor de ontwikkeling van MijnAVL.

De ontwikkeling van MijnAVL, zoals beschreven in Hoofdstuk 5, bestond uit drie verschillende activiteiten: 1) discussies met behandelaars over de beoogde functionaliteiten; 2) interviews met (ex-)kankerpatiënten over een eerste versie in PowerPoint; en 3) gebruikerstesten door (ex-)kankerpatiënten met behulp van een werkend prototype. Behandelaars van verschillende disciplines gaven feedback in meerdere sessies, waarin de focus lag op de toegang tot het elektronisch medisch dossier, patiënt gerapporteerde uitkomsten en de module om fysieke activiteit te stimuleren. Ze stelden bijvoorbeeld een aantal voorwaarden waaronder (ex-) kankerpatiënten toegang zouden kunnen krijgen tot hun elektronisch medisch dossier, gaven aan dat ze terughoudend waren over geautomatiseerd advies op basis van de patiënt gerapporteerde uitkomsten en ze hielpen bij het schrijven van de adviezen om fysieke activiteit te stimuleren. De interviews met (ex-)kankerpatiënten leverden voornamelijk nuttige informatie op over het design van MijnAVL en over mogelijkheden om de inhoud te verbeteren. De deelnemers deden ook suggesties om de waarde van de functionaliteiten te optimaliseren, bijvoorbeeld het toevoegen van een woordenboek om de informatie uit het elektronisch medisch dossier te kunnen begrijpen en de wens om een notificatie te ontvangen in het geval van nieuwe informatie of een nieuwe in te vullen vragenlijst. Op basis van deze resultaten werd een functioneel prototype ontwikkeld voor de gebruikerstesten. Deelnemers voerden verschillende taken uit met MijnAVL terwijl ze hardop dachten; hierdoor kregen we inzicht in hoe ze de taken uitvoerden. De gebruikerstesten toonden aan dat de functionaliteiten relatief makkelijk te gebruiken waren. De verkregen feedback werd gebruikt om een definitieve versie van MijnAVL te ontwikkelen.

eHealth-toepassingen bieden veel mogelijkheden om informatie (op maat) te visualiseren, bijvoorbeeld het grafisch weergeven van de resultaten van patiënt gerapporteerde uitkomsten. We hebben daarom onderzoek gedaan naar hoe (ex-)kankerpatiënten en behandelaars verschillende grafieken interpreteren en welke grafiekvorm hun voorkeur heeft (Hoofdstuk 6). Een steekproef van 548 patiënten uit vier Europese landen (Nederland, Oostenrijk, Polen en Engeland) en 227 behandelaars uit het Antoni van Leeuwenhoek heeft deelgenomen aan het onderzoek. Met een vragenlijst hebben we zowel het objectieve en het subjectieve (zelf gerapporteerde) begrip als de voorkeuren voor vijf verschillende grafiekvormen in kaart gebracht (gekleurde en niet-gekleurde lijngrafieken en staafdiagrammen en een zogenoemde “heat map”, waarbij de achtergrondkleuren betekenis geven aan de score). De resultaten lieten zien dat het zelf gerapporteerde begrip groter was dan het objectieve begrip. Voor patiënten verschilde het objectieve begrip niet voor de verschillende grafiekvormen, terwijl behandelaars de totale verandering vaker correct interpreteerden wanneer er niet-gekleurde staafdiagrammen werden gebruikt.

Van de patiënten die de niet-gekleurde grafieken beoordeelden, had bijna de helft geen voorkeur; de voorkeuren voor niet-gekleurde staafdiagrammen en lijngrafieken waren respectievelijk 30% en 20%. De patiënten die de gekleurde grafieken beoordeelden, hadden een voorkeur voor gekleurde staafdiagrammen (39%) in vergelijking met de heat map (20%) en gekleurde lijngrafieken (12%). Waar medisch specialisten een duidelijke voorkeur hadden voor de heat map (46%), hadden andere behandelaars niet alleen een voorkeur voor de heat map, maar ook voor niet-gekleurde staafdiagrammen (beide 32%). De resultaten van dit onderzoek impliceren dat er behoefte is aan voldoende toelichting wanneer de resultaten van patiënt gerapporteerde uitkomsten grafisch aan patiënten en behandelaars gepresenteerd worden. Verder kan het nuttig zijn om de grafische weergave aan te passen aan individuele voorkeuren.

Evaluatie van MijnAVL

Tenslotte hebben we de haalbaarheid en het voorlopige effect van MijnAVL onderzocht. Deelnemers vulden eerst een vragenlijst in over hun achtergrondkenmerken, hun verwachtingen van MijnAVL en drie uitkomstmaten: patient empowerment (PAM), kwaliteit van leven (SF-36) en fysieke activiteit (IPAQ). Vervolgens konden zij vier maanden vrijblijvend gebruikmaken van MijnAVL en na afloop hiervan vulden zij een vragenlijst in over de haalbaarheid, hun tevredenheid en de drie uitkomstmaten (PAM, SF-36, IPAQ). Log data werden retrospectief verzameld. In Hoofdstuk 7 zijn de resultaten beschreven voor de 92 (ex-) borstkankerpatiënten die hebben meegedaan. Hun gemiddelde leeftijd was 49.5 jaar en 59% was onder behandeling. Gemiddeld werd er gedurende de vier maanden 8.7 keer ingelogd, met een gemiddelde duur van 13.1 minuten. Het afspraken overzicht (80% van de deelnemers) en de inzage in het medisch dossier (90%) werden het vaakst gebruikt en het meest gewaardeerd. De tevredenheid met MijnAVL in totaal werd gemiddeld beoordeeld met een 3.8 op een schaal van 1 tot 5 en met name de gebruiksvriendelijkheid, de structuur en de nauwkeurigheid van de website werden goed beoordeeld. De scores op de PAM veranderden niet over tijd, maar de deelnemers gaven wel aan dat ze beter geïnformeerd waren over hun ziekte en meer controle ervoeren door de inzage in het medisch dossier. Drie domeinen van de SF-36 verbeterden significant (rolbeperkingen – emotioneel probleem, mentale gezondheid en sociaal functioneren) en de mediane hoeveelheid intensieve fysieke activiteit nam toe van 0 naar 360 Metabolic Equivalents of Task (MET)-minuten per week. De belasting voor behandelaars was beperkt.

In Hoofdstuk 8 zijn de resultaten beschreven van de 37 (ex-)longkankerpatiënten die aan het onderzoek hebben meegedaan. Hun gemiddelde leeftijd was 59.6 jaar en ze hebben gemiddeld 11.2 keer ingelogd met een gemiddelde duur van 12.9 minuten. Tweeëntachtig procent was positief over het gebruik van MijnAVL en 56% gaf meer controle over de gezondheid te ervaren. Websitetevredenheid werd beoordeeld met 3.9 op een 5-puntsschaal; de gebruiksvriendelijkheid en de structuur van de website scoorden hierbij het hoogst. Alle onderdelen van MijnAVL werden regelmatig gebruikt

en beoordeeld met een 7 of hoger op een 10-puntsschaal. De score op de PAM nam significant af van 64.8 naar 59.4, wat betekent dat patiënt activatie (in termen van kennis, vaardigheden en zelfmanagement) licht afnam over de tijd. Voor de SF-36 en de IPAQ vonden we geen significante veranderingen over de tijd, alhoewel intensieve fysieke activiteit neigde toe te nemen.

De resultaten van de evaluatie bij zowel (ex-)borstkankerpatiënten als (ex-)longkankerpatiënten hebben aangetoond dat MijnAVL een geschikte eHealth-toepassing is voor deze populaties. De voorlopige effectiviteit kon slechts gedeeltelijk aangetoond worden; dit kan het gevolg zijn van de relatief kleine aantallen patiënten, van de interventie of van de (on)gevoeligheid van de gebruikte uitkomstmaten. MijnAVL kan verder verbeterd worden door meer visueel aantrekkelijke en gepersonaliseerde informatie toe te voegen, rekening houdend met de individuele informatiebehoefte. Onderzoek met een gecontroleerd design en meer specifieke uitkomstmaten is nodig om de effecten van een interactief portaal in kaart te brengen.

In Hoofdstuk 9 worden de bevindingen van onze studies besproken in de context van bestaande literatuur. Ook worden methodologische overwegingen besproken, om vervolgens te komen met aanbevelingen voor vervolgonderzoek en voor de praktijk, gerelateerd aan het gebruik van eHealth in het algemeen en voor (ex-)kankerpatiënten in het bijzonder.

Conclusie

Ons onderzoek heeft nuttige informatie opgeleverd over het gebruik, de haalbaarheid en de mogelijke effecten van eHealth voor overlevenden van borst- en longkanker. Om de voordelen van eHealth te maximaliseren dienen de informatie en adviezen die worden aangeboden zoveel mogelijk toegespitst te worden op de kenmerken van een individu. Naast de noodzaak om eHealth-toepassingen te optimaliseren, zijn er ook andere uitdagingen. Voor eHealth onderzoek is het belangrijk om een balans te vinden tussen de snelle ontwikkeling van nieuwe technologie en de vaak tijdrovende evaluatie hiervan. Voor de implementatie van eHealth zijn de uitdagingen om gebruiksvriendelijke applicaties te ontwikkelen die effectief zijn voor personen met verschillende kenmerken, om voldoende financiering te verkrijgen (voor zowel onderzoek als implementatie) en om de adoptie van eHealth-toepassingen te optimaliseren.

Summary

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DANKWOORD (ACKNOWLEDGMENTS)

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DANKWOORD (ACKNOWLEDGMENTS)

Mijn boekje is af! Dit moment leek altijd eindeloos ver weg, maar nu is het de hoogste tijd om aan mijn dankwoord te beginnen. Dit proefschrift was er niet gekomen zonder de bijdrage en support van velen. Een aantal van hen wil ik hier in het bijzonder bedanken.

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LIST OF PUBLICATIONS

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Manuscripts included in this thesis:

Kuijpers W, Groen WG, Oldenburg HAS, Wouters MWJM, Aaronson NK, van Harten WH. eHealth in breast cancer survivors: Feasibility and preliminary efficacy of an interactive portal. *Revisions submitted to JMIR*

Groen WG, Kuijpers W, Oldenburg HAS, Wouters MWJM, Aaronson NK, van Harten WH. Supporting lung cancer patients by eHealth: Feasibility and preliminary efficacy of an interactive patient portal. *Submitted*

Groen WG, Kuijpers W, Oldenburg HAS, Wouters MWJM, Aaronson NK, van Harten WH. Empowerment of cancer survivors through information technology. *J Med Internet Res* 2015;17(11):e270

Kuijpers W, Giesinger JM, Zabernigg A, Young T, Friend E, Tomaszewska IM, Aaronson NK, Holzner B. Patients' and health professionals' understanding of and preferences for graphical presentation styles for individual level EORTC QLQ-C30 scores. *Qual Life Res*, 2015; Open access, DOI: 10.1007/s11136-015-1107-3

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Giesinger JM, Kuijpers W, Young T, Tomaszewski KA, Friend E, Zabernigg A, Holzner B, Aaronson NK. Thresholds for clinical importance for four key domains of the EORTC QLQ-C30: Physical functioning, emotional functioning, fatigue and pain. *Submitted to Health and Quality of Life Outcomes (November 2015)*

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Wilma Kuijpers was born on December 7, 1984 in Beverwijk, the Netherlands. She graduated from high school at the Augustinus College in Beverwijk (2003) and obtained her Bachelor's Master's degree in Human Movement Sciences at VU University in Amsterdam, with a specialization in Sport Psychology. She subsequently obtained a Master's degree in Social Psychology at VU University in Amsterdam in August 2010. From November 2010 onwards Wilma worked on her PhD project at the Netherlands Cancer Institute (Antoni van Leeuwenhoek). She was involved in the development, implementation and evaluation of an interactive portal for cancer survivors. Her research activities were supervised by Prof. Dr. Wim H van Harten and Prof. Dr. Neil K Aaronson and have resulted in this thesis. Since November 2015 Wilma is employed as a social scientific researcher at ResCon, a research and consultancy agency specialized in behavior change related to health and sustainability.

The end