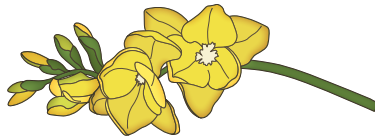# NURSES' SELF-MANAGEMENT SUPPORT FOR PEOPLE FACING INCURABLE CANCER

VINA SLEV

NURSES'
SELF-MANAGEMENT
SUPPORT FOR PEOPLE
FACING INCURABLE
CANCER

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CONTENTS

CHAPTER 1

General introduction

GENERAL INTRODUCTION

Living with cancer is hard in itself, let alone when confronted with an incurable form. Having to live with a life-limiting illness often results in physical and psychological symptoms that could lead to sweeping changes in daily living, such as fewer social interactions, not being able to work, or not being able to do housekeeping tasks.

Self-management is important in letting people live a satisfactory life and in preventing the disease from taking over. This is a daily process in which a patient manages the consequences the disease has on daily life and in which he or she makes decisions about preferred treatment and care. Self-management also applies to the patient's partner, children, or other informal caregivers who might have to cope with a high caregiving burden.

Self-management, however, is not self-evident for everyone, and some people need support, for instance from nursing professionals.

In this general introduction we provide information on patients facing incurable cancer, the essence of self-management and self-management support and the promising role of eHealth in this regard. This is followed by the main research questions and a description of the structure of this PhD thesis about nurse-led self-management support for people facing incurable cancer.

PEOPLE FACING INCURABLE CANCER

Although average survival rates five years after diagnosis increased from 56% in 2001-2005 to 64% in 2011-2015 [1], due to early detection as well as advancements in treatment, cancer was still the main cause of death in the Netherlands in 2017, responsible for 45,206 deaths [2]. The predominant cancer types responsible for deaths are (in decreasing order of frequency): gastro-intestinal cancer, lung cancer, hematological cancers, breast cancer, and male reproductive cancers [3].

When someone is diagnosed with cancer, generally the aim of treatment is curation with optimal health-related quality of life. However, if curative options are lacking or if at some point the cancer can no longer be cured, the care aim shifts to palliation. Palliative care includes life-prolonging treatment and symptom alleviation. The purpose of palliative care is to improve or maintain the health-related quality of life of patients and their families facing a life-threatening illness, through the prevention and relief of suffering by means of treatment of pain and other physical, psychosocial, and spiritual problems [4].

Cancer can cause a rapid physical and/or mental decline, or slow deterioration. The latter implies that people with incurable cancer might still live for a long period of time, e.g. a year or more. This might also be the case for people who have successfully undergone life-prolonging treatment. While the possibility of living longer despite being incurably ill sounds advantageous, it also means that the rest of the patient's life is spent dealing with the impact of the disease.

Impact on patients

Cancer and its treatment have a tremendous impact on the patient as the disease influences the course of daily life in different ways, and consequently the health-related quality of life. Physical symptoms like fatigue and lack of energy prevent the patient from performing activities of daily living such as personal care or housekeeping [5]. Psychosocial problems such as depressive symptoms, worry, and anxiety might prevent the patient from undertaking social activities with family and friends [6]. In addition, visits to the hospital for treatment and checkups change daily routines.

When a patient is confronted with an incurable form of cancer, the patient also has to live with the irreversibility of the situation, alongside the likelihood of dying within a timespan which might be shorter than expected. This could result in additional psychological and social problems like existential uncertainty, fear of dying, and worries about having to leave loved ones behind [7,8].

The physical deterioration, inextricably related to the disease, at some point makes living with incurable cancer even more difficult as the patient is confronted daily with the fact that they cannot do the things they are used to doing. As pain, fatigue and mobility problems become more of an issue, the patient increasingly becomes homebound and dependent on others as the disease progresses. This subsequently affects the health-related quality of life. Ultimately, it is important that the patient knows what their personal values are and what they consider important in life, so they will be able to make educated choices about how they want to spend the rest of their life [7].

Impact on informal caregivers

Cancer affects not only patients, but also their family members. The impact is even greater when the family member is also an informal caregiver, who then has to find a balance between being a caregiver and e.g. a spouse or child of the patient, which puts a strain on familial relationships [9].

Research has shown that informal caregiving is associated with a decrease in general health, physical symptoms such as sleeplessness, psychological problems like depression, and financial consequences due to the intensity and extent of the caring tasks [9-12]. A family member who is also an informal caregiver then has to deal with problems induced by informal caregiving, alongside personal problems related to having an incurably ill loved one, like seeing their loved one suffer and deteriorate physically and mentally [12]. Hence, family members may also have care needs of their own. As the consequences of cancer also extend to informal caregivers, they also have to decide what they consider important in life, and how they want to spend the time left with the patient, and the time ahead without the patient.

In summary, living with cancer is challenging as it heavily influences daily routines and the quality of life of both patients and informal caregivers. The impact, however, is even bigger when confronted with an incurable form, as those affected have to live with the knowledge of losing life or losing a loved one, probably sooner than expected. Self-management is required to maintain a satisfactory life and quality of life by preventing the disease from interfering with daily life.

SELF-MANAGEMENT

In this thesis, a definition of self-management will be used that is inspired by the definitions of Barlow et al. [13] and Bodenheimer et al. [14], namely:

An individual's ability to manage the physical and psychosocial symptoms and to make decisions concerning treatment and/or care, in order to optimally integrate the disease in daily life, and to maintain a satisfactory quality of life despite the disease.

So far, self-management has mainly been used in the context of chronic diseases. This is because self-management is especially important for these patients, as daily care in most cases is a lifetime responsibility [15].

Self-management refers to the ability to manage the disease and the skills required to do so, on a daily basis, at home or in other places, and subsequently to keep control over one's own life and care. Examples are the ability to acquire disease-related information and to use it in decision-making about treatment and care (see the section 'General Model Of Self-Management'). Self-management is about the patient knowing and deciding what they consider necessary for maintaining a satisfactory quality of life, despite being ill, specifically at times when professional help is not available. People only spend a very small part of their lives seeing a healthcare professional, meaning that most of the time they are their 'own' doctor [14].

Although self-management originally referred to patients, the concept also fits informal caregivers as they have to deal with the patient's disease and additionally the consequences of informal caregiving, and the reality of having a loved one who is incurably ill.

Self-management in people facing incurable cancer

Self-management, however, is not exclusive to chronic illnesses, but may also be relevant in patients with incurable cancer. Medical and technological advances enable incurably ill cancer patients to live longer than before, and also spend longer in their home environment. However, as mentioned before, it also means they spend the rest of their lives dealing with the consequences the disease has for daily life. Living with the knowledge of a short life expectancy, uncertainty and, in time, a deterioration in health and quality of life makes it difficult not to let the disease negatively affect daily living [7]. As physical and psychological problems become more prominent, and increasingly interfere with the patient's daily activities and independence, the patient might have to self-manage even more. Besides, an

increasing number of decisions about treatment and care have to be made, leading to more reflections on what the patient values in life, for example spending time at the hospital for treatment and dealing with side effects, or spending time at home with loved ones [7,16]. Self-management, therefore, is also key for people who have been diagnosed with incurable cancer. Besides, the concept fits palliative care, as both are about maintaining quality of life and staying in control for as long as possible, despite being ill [16].

General Model of Self-Management

An essential element of self-management by both the patient and the informal caregiver is having knowledge about the disease and treatment, and knowing their personal preferences in care and life, in order to make well-informed decisions about e.g. whether or not to undergo a certain treatment and its consequences for daily living.

These aspects can be categorized in the following four domains of self-management, described in the General Model of Self-Management [17] as follows:

1. Experience-based knowledge: acquiring knowledge about the health problem. This knowledge is based on general information about the disease and it accumulates as patients draw on their own experience, to become their own, personal field of knowledge. This experience-based knowledge lets the patient deal with the disease and the associated consequences appropriately.
2. Contributing to care: monitoring health, making decisions about the preferred treatment and care, and investing in interventions that help mitigate the consequences of the condition.
3. Living with the condition: living a satisfactory life by coping appropriately with the physical, emotional, and social consequences of the disease.
4. Organization of care and support: finding out about, deciding on and arranging appropriate necessary health care and support.

In order to effectively enable self-management in these domains, having knowledge about people's perspectives on self-management and possible support needs is essential. Various studies concerning these matters have been published. They include studies of Lashbrook et al. [18], Kidd [19] and Northouse et al. [20] on self-management, and Girgis et al. [9] and Lambert et al. [21] on support needs. Research, however, is mostly focused on the curative and survivorship stage (e.g. Lashbrook et al. [18]), focused on specific tumor types, like Kidd on people affected with colorectal cancer [19], or specific symptoms such as fatigue and pain, like Chan et al. [22] and Gibbins et al. [23]. Although studies are accumulating, there is still a

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need for research particularly on self-management and self-management support needs of incurably ill cancer patients and their informal caregivers, according to several reviews on this matter [24-27].

SELF-MANAGEMENT SUPPORT

Throughout this thesis, Wagner et al.'s [28] explanation of self-management support will be used, namely:

A collaborative approach, in which providers and patients work together to define problems, set priorities, establish goals, create treatment plans, and solve problems along the way.

Self-management support requires a partnership between the healthcare professional and the patient and/or informal caregiver. An important aspect of both self-management and self-management support is making the person's wellbeing and quality of life the central aim rather than the disease. Hence, it is crucial that the healthcare professional recognizes, acknowledges, and respects the patient's and informal caregiver's own beliefs and values, and involves them in the management of the disease and the decisions that have to be made regarding treatment and/or care. Given this, suitable providers of self-management support are often nurses.

Nurses and self-management support

Nurses are key healthcare professionals in cancer and palliative care, and important providers of self-management support [16,29,30]. In fact, supporting self-management is due to be integrated in Dutch nursing practice as one of the core competences of nursing professionals by the year 2020 [31]. Nurses often have relatively intense contacts with the patient, and are the ones who see patients on a regular basis, which makes nurses suitable healthcare professionals for supporting self-management [29]. Historically, nurses are those healthcare professionals whose care is not solely focused on medical and physical issues, but also on emotional and psychosocial problems, and on guiding and supporting patients in dealing with these problems. Accordingly, self-management support fits perfectly with the nursing profession.

Several previous studies considered (nurse-led) self-management support for both patients with curable cancer and those with incurable cancer and/or their informal caregivers, e.g. Howell et al. [32], Johnston et al. [16], Hammer et al.

[33], and Kaltenbaugh et al. [34]. However, most previous research reviewed the effectiveness of self-management support interventions, while less attention was paid to nurses' professional perspectives on self-management support and how they provide self-management support.

Knowledge regarding nurses' understanding of self-management support is important as supporting self-management calls for a different approach to the provision of traditional nursing care, namely a collaborative one in which the patient is a partner [14]. Therefore, it is important to know if nurses are competent and properly equipped for supporting self-management.

While suitable and competent providers are vital in effectively contributing to people's self-management, it is also important that support is provided in a sound way, that is to say by actively involving and collaborating with the patient and informal caregiver.

5 A's Behavior Change Model

When structuring self-management support, nurses and other healthcare professionals can use the 5 A's Behavior Change Model (5 A's model) [35-38]. The 5 A's model distinguishes five steps, namely:
1. Assess: assessing the patient's knowledge, beliefs, and behaviors;
2. Advise: advising the patient by providing specific information about the disease and information about the patient's health status in an understandable manner so the patient can relate their self-management skills and behaviors to their health status;
3. Agree: agreeing on goals collaboratively set with the patient and according to the patient's priorities;
4. Assist: assisting the patient by identifying and resolving barriers that hinder the patient in achieving the set goals;
5. Arrange: arranging follow-up via e.g. e-mail or telephone.

The 5 A's model assists healthcare professionals in structuring self-management support within a dynamic and tailored process and forces the healthcare professional to work together with the patient as the third, fourth, and fifth steps in particular emphasize patient involvement and collaboration.

EHEALTH IN SELF-MANAGEMENT AND SELF-MANAGEMENT SUPPORT

Self-management support often involves face-to-face contacts. However, this type of support is increasingly being offered online via the Internet [39]. eHealth tools appear to be a promising option for both self-management support and self-management [40]. In addition, nowadays health care without the use of computer or related technologies is inconceivable.

Due to the lack of a uniform definition and existing definitions encompassing similar elements, we define eHealth, based on Eysenbach's definition [41], as follows:

The provision of information about illness or health care and/or support for patients and/or informal caregivers using computers or related technologies.

People diagnosed with incurable cancer may benefit from eHealth. If a patient is in such poor health or faces mobility problems that prevent the patient from visiting the hospital, eHealth can bring care to the home by means of e.g. e-mail or video chats [42,43].

eHealth is a source of information through which patients can find out about care and support that they can arrange themselves, without the involvement of a healthcare professional. Besides, eHealth can include symptom monitoring, allowing patients to monitor their own health, and facilitating instant feedback on aberrations. This kind of personal information about patients' health status is useful in both self-management and self-management support. In self-management, it enables patients to develop a personal knowledge base which can they can draw on in their own care, and to learn how to manage symptoms. In self-management support, it might enable the support to be aligned with patients' needs, making eHealth valuable for patients as well as healthcare professionals.

Given the growing importance of eHealth in modern health care and its claimed advantages and features, eHealth might be useful in self-management and self-management support. However, more research is needed on its usefulness for people facing a life-limiting illness [44]. Therefore, this thesis will also describe the effects of eHealth on people confronted with cancer, and incurably ill cancer patients' and nurses' opinions about eHealth in the context of self-management and self-management support. Additionally, an eHealth component as part of a nurse-led self-management support intervention will be studied regarding its usefulness to both nurses and patients.

A NURSE-LED SELF-MANAGEMENT SUPPORT INTERVENTION FOR PEOPLE FACING INCURABLE CANCER

In conclusion, incurable cancer can have a huge impact on the daily lives of both patients and informal caregivers. Some people might need support in managing the consequences of their life-limiting illness in order to maintain their quality of life. There is, however, a paucity of research on self-management support and related (eHealth) interventions for this target group, as well as on nurses as providers of self-management support to people facing incurable cancer.

Therefore, in this thesis research a structured self-management support intervention was developed that included an eHealth component. It focused specifically on people confronted with incurable cancer, while considering both the patients' and the providers' perspectives on self-management support.

The number of self-management support interventions focusing particularly on patients with incurable cancer and their informal caregivers is increasing, though still limited [24,26]. Moreover, to our knowledge, only a few of the existent interventions are specifically designed for the providers of self-management support, and most were not developed using a theoretically based model for the provision of self-management support [24].

The self-management support intervention discussed in this thesis is nurse-led, as there are plans to make supporting self-management a core competence for nursing professionals by 2020, and as nurses have a central role in both oncology care and palliative care. The intervention is based on the 5 A's model since the Dutch care standard for self-management [35] recommends the use of this particular model as a framework for the provision of self-management support. Part of the intervention is an eHealth tool to be used by patients, as eHealth tools are a promising means for both self-management and self-management support.

The feasibility of the structured nurse-led self-management support intervention among nurses and patients will be evaluated in this thesis

AIM AND RESEARCH QUESTIONS

The general aim of this thesis is to provide insight into nurse-led self-management support for people facing incurable cancer.

The following main research questions are addressed:

1. a. What evidence exists for the effects of eHealth for patients with incurable cancer and their informal caregivers?
    b. What are cancer patients' and nurses' views on eHealth and its use in the context of self-management and self-management support?
2. How do people facing incurable cancer self-manage the consequences of the disease in their daily lives?
3. How do nurses perceive their competencies and their actual performance in self-management support for people facing incurable cancer?
4. a. What is the feasibility of the structured nurse-led self-management support intervention for patients with incurable cancer?
    b. How do nurses and patients with incurable cancer evaluate this structured nurse-led self-management support intervention?
    c. Are there indications that the self-management support intervention positively influences patient activation and quality of life of patients with incurable cancer?

OUTLINE OF THE THESIS

This general introduction is followed by **Chapter 2,** which presents a meta-review (a systematic review of systematic reviews) regarding the effects of eHealth on patients and informal caregivers confronted with cancer. This chapter addresses research question 1a.

Chapter 3 addresses research questions 1b and 2. It describes how cancer patients self-manage the consequences the disease has for daily life, and what they consider important in self-management and self-management support. Furthermore, patients' perceptions of eHealth in this context are discussed.

Chapter 4 focuses on the way in which nurses support cancer patients and their informal caregivers in their self-management, what nurses consider important in self-management and self-management support, and their opinions on eHealth. This chapter addresses research questions 1b and 3.

How nurses perceive their competencies and their actual performance in self-management support is outlined in **Chapter 5,** which addresses research question 3.

The results of **Chapters 2 to 5** informed the development of a structured nurse-led self-management support intervention. It is evaluated in **Chapters 6 and 7,** which address research questions 4a and 4b, and 4a, 4b, and 4c, respectively.

Chapter 6 reports specifically on the feasibility of the intervention from the perspective of nurses, while **Chapter 7** reports on the feasibility of the intervention from the patients' perspective. This chapter also discusses the possible effects on patient activation and quality of life.

The thesis ends with **Chapter 8**, which gives a summary, reflections on the main findings, methodological considerations, and recommendations for education and practice.

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CHAPTER 2

Effects of eHealth for patients and informal
caregivers confronted with cancer:
a meta-review
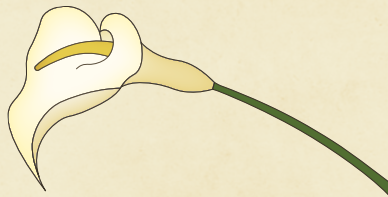
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ABSTRACT

Background: eHealth can be defined as information provision about illness or health care and/or support for patients and/or informal caregivers, using the computer or related technologies. eHealth interventions are increasingly being used in cancer care, e.g. to support patients and informal caregivers in managing symptoms and problems in daily life.

Objectives: To synthesize evidence from systematic reviews on the effects of eHealth for cancer patients or their informal caregivers.

Materials and Methods: A systematic meta-review, in the sense of a systematic review of reviews, was conducted. Searches were performed in PubMed, Embase, CINAHL, PsycINFO, and the Cochrane Library. All steps in the review process were either performed by two reviewers independently or checked by a second reviewer. Disagreements were resolved by consensus.

Results: Ten systematic reviews were included. All reviews focused on the effects of eHealth for patients and none on effects for informal caregivers. Except for one review of high methodological quality, all reviews were of moderate methodological quality. Evidence was found for effects on perceived support, knowledge levels, and information competence of cancer patients. Indications of evidence were found for health status and healthcare participation. Findings were inconsistent for outcomes related to decision-making, psychological wellbeing, depression and anxiety, and quality of life. No evidence was found for effects on physical and functional wellbeing.

Conclusion: There is evidence for positive effects of eHealth on perceived support, knowledge, and information competence of cancer patients. For effects on other outcomes in cancer patients, findings are mainly inconsistent or lacking. This meta-review did not find relevant reviews focusing on or including the effects of eHealth on informal caregivers, which seems a rather unexplored area.

HIGHLIGHTS

- Evidence for effects on perceived support, knowledge, and information competence.
- Indications of evidence for, among more, health status, and patient involvement.
- Inconsistent findings for, among more, psychological outcomes and quality of life.
- No focus on informal caregivers, various disease stages, and specific tumor types.

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INTRODUCTION

Cancer and its treatment make a great demand on patients as well as on informal caregivers. Cancer patients often suffer from problems and symptoms such as pain, fatigue, depression, anxiety, and hopelessness [1]. In addition, their informal caregivers often experience a high care burden, psychological problems, and a decrease in social activities [2]. Professional support can help them in dealing with these symptoms and problems. However, given that many people prefer to keep control over their own life and in view of increasing healthcare costs, it is not self-evident that all support should be given in face-to-face contacts between professionals and care recipients. EHealth may complement or replace traditional professional support to some extent [3,4]. We define eHealth as the provision of information about illness or health care and/or support for patients and/or informal caregivers using computers or related technologies. Our definition is inspired by Eysenbach's well-known statement describing eHealth as "... 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" [5].

Nowadays, various computer-based and internet-based eHealth interventions are available for patients and informal caregivers confronted with cancer. These interventions provide information about cancer and its treatment (e.g. www.oncolink.org), support in decision-making (e.g. www.prostaatkankerkeuzehulp.nl), support in self-management, (e.g. www.oncokompas.nl), support for physical and emotional problems (e.g. www.helpforcancercaregivers.com), and peer support (e.g. www.cancerstories.info).

Given the growing importance of eHealth in modern health care, it is relevant to see what evidence already exists regarding the effects of eHealth in people confronted with cancer. Since several systematic reviews had already been published, we performed a meta-review in which we analyzed and synthesized the evidence from existing reviews. In this meta-review we address the following primary question:

1. What evidence can be derived from existing systematic reviews about the effects of eHealth for patients with cancer and/or their informal caregivers?

The secondary question is:

2. What specific types of eHealth interventions for patients with specific types of cancer and/or their informal caregivers are addressed in the relevant systematic reviews?

MATERIAL AND METHODS

Design

We conducted a meta-review, i.e. a systematic review of reviews. This review type is suitable for describing the quality, discerning the heterogeneity, and identifying lacunas in the current evidence base, since it synthesizes evidence from relevant previous systematic reviews [6].

Eligibility criteria

References were eligible for inclusion if they concerned a literature review that satisfies all of the following four criteria, namely if it:

1. reports on the effects of eHealth. As stated before, we define eHealth as the provision of information about illness or healthcare and/or support for patients or informal caregivers using computers or related technologies;
2. concerns the effects on adult patients diagnosed with cancer and/or their informal caregivers. Reviews that also include studies among non-cancer groups were only eligible for inclusion if they reported the effects on cancer patients separately;
3. is a systematic review. We considered a review 'systematic' if the following criteria were satisfied: (a) search terms are presented; (b) searches are done in PubMed/Medline or Cancerlit and at least one other international literature database;
4. has an overall methodological score of ≥3 (see Section 'Quality assessment').

Search methods and terms

First, we developed a search strategy for PubMed, which is available as supplementary material. Subsequently, we adapted the strategy for searches in Embase, CINAHL, PsycINFO, and The Cochrane Library. For the development and adaption of the search strategies, databases' thesaurus terms for eHealth, cancer, systematic review and meta-analysis or specific 'systematic review filters' were used, as well as free text words describing eHealth. The searches were performed on March 6th 2014.

Review selection

The review selection process consisted of three phases:

1. Screening of titles and abstracts. First, VNS and HRP independently screened the titles and available abstracts of a random selection of 10% of the references identified. The interrater agreement between the two reviewers about the final inclusion and exclusion was 100%. The interrater agreement about whether the three separate inclusion criteria were met, was 99.59% on average. Next, the remaining 90% of the references were divided among VNS and HRP, who each screened the titles and available abstracts of 3600 references. Finally, they discussed the list of references eligible for full text screening as well as references where it was not very clear whether they should be included or excluded.
2. The full texts of all references remaining after the first selection phase were then screened by VNS and ALF independently, using the first three inclusion criteria. The interrater agreement between the two reviewers was high: In 84% of the references they agreed about the final inclusion and exclusion. Discrepancies were discussed until consensus was reached.
3. Subsequently VNS and ALF independently assessed the methodological quality of the references remaining after the second selection phase (see Section 'Quality assessment'). In accordance with the fourth criterion concerning the methodological quality, only studies with a methodological score of 3 or more were finally included.

   Also in this phase, discrepancies were discussed and resolved by consensus.

Quality assessment

After review selection, the methodological quality of the systematic reviews was assessed using the Quality Assessment Checklist for Reviews [7,8]. This checklist is one of the few for which the psychometric properties have been documented [9], and it has been used in other meta-reviews [10,11]. The overall scores on this checklist range from "extensive flaws" (score 1 or 2), to "major flaws" (score 3 or 4), "minor flaws" (score 5 or 6) and "minimal flaws" (score 7). We calculated the average overall score when the overall scores of the VNS and ALF differed by 1 point. Differences of 2 or more points were resolved by consensus.

For the best evidence synthesis (see Section 'Data synthesis'), we classified the scores into three quality categories: "high quality" (score 5–7), "moderate quality" (score 3–4.5) and "low quality" (score 1–2.5).

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Data extraction

A pre-defined data extraction form—encompassing such items as the review aim, cancer type, types of eHealth, and reported outcomes—was used to extract data from the reviews. VNS performed the data extraction and IMVdL or CFU independently cross-checked the extracted information. We only extracted data concerning the effects of eHealth on cancer patients and/or informal caregivers, although some of the reviews had a broader focus, e.g. chronic conditions (including cancer).

Data synthesis

We categorized outcomes into categories including "psychological wellbeing", "depression", "anxiety", "knowledge and information", and "decision-making". The categorization was based on the types of outcomes reported in the reviews.

Pooling of results was impossible because of the large variety of methods used and eHealth interventions studied, and the lack of numeric results in the reviews. We did, however, indicate the level of evidence regarding the effects of eHealth on a specific outcome category, using the criteria displayed in Box 1.

Box 1 *Principles of best evidence synthesis*

Evidence:

Consistent effects on a specific outcome in at least one high quality systematic review, based on at least two underlying effect studies.
This is under the condition that no more than two moderate quality systematic reviews or no other high quality systematic review report conflicting findings.

OR

Consistent effects on a specific outcome in at least three moderate quality systematic reviews, based on at least two underlying effect studies per systematic review.
This is under the condition that no high quality systematic review or no more than two other moderate quality systematic reviews report conflicting findings.

Indications of evidence:

Consistent effects on a specific outcome in one high quality systematic review, based on one underlying effect study.
This is under the condition that no more than two moderate quality systematic reviews and/or no other high quality review report conflicting findings.

OR

Consistent effects on a specific outcome in one moderate quality systematic reviews. This is under the condition that no high quality systematic review and/or no more than two other moderate quality systematic reviews report conflicting or inconsistent findings.

Inconsistent findings:

Inconsistent effects on a specific outcome, when findings of a (number of) high quality systematic review(s) are being contradicted by a (number of) other high quality systematic review(s).

OR

Inconsistent effects on a specific outcome, when findings of a (number of) moderate quality systematic review(s) are being contradicted by a (number of) other moderate quality systematic review(s).

No evidence:

No effects on a specific outcome when a (number of) high quality systematic review(s) did not find effects.

This is under the condition that no other (number of) high quality systematic review(s) or no more than two moderate quality systematic reviews report conflicting findings

OR

No effects on a specific outcome when three or more moderate quality systematic reviews did not find effects. This is under the condition that no other systematic review reports conflicting findings.

No research found:

None of the included reviews examined effects on a specific outcome.

These criteria were inspired by the principles of best evidence synthesis in systematic reviews, as developed by Steultjens et al. [12]. However, we had to adjust the criteria of Steultjens et al. [12] since we conducted a systematic meta-review of reviews rather than a traditional systematic review of RCTs. Adjustments concerned redefining the levels of evidence and corresponding criteria by taking into consideration the methodological quality of the included reviews rather than of the methodological quality of separate RCTs.

RESULTS

Results of review selection and quality assessment

Through the searches, we identified 8157 unique potentially relevant references (Figure 1).

After examining the titles and available abstracts, 50 references remained for screening based on their full text versions. Thirteen review papers turned out to be eligible for inclusion, and were assessed on their methodological quality, subsequently.
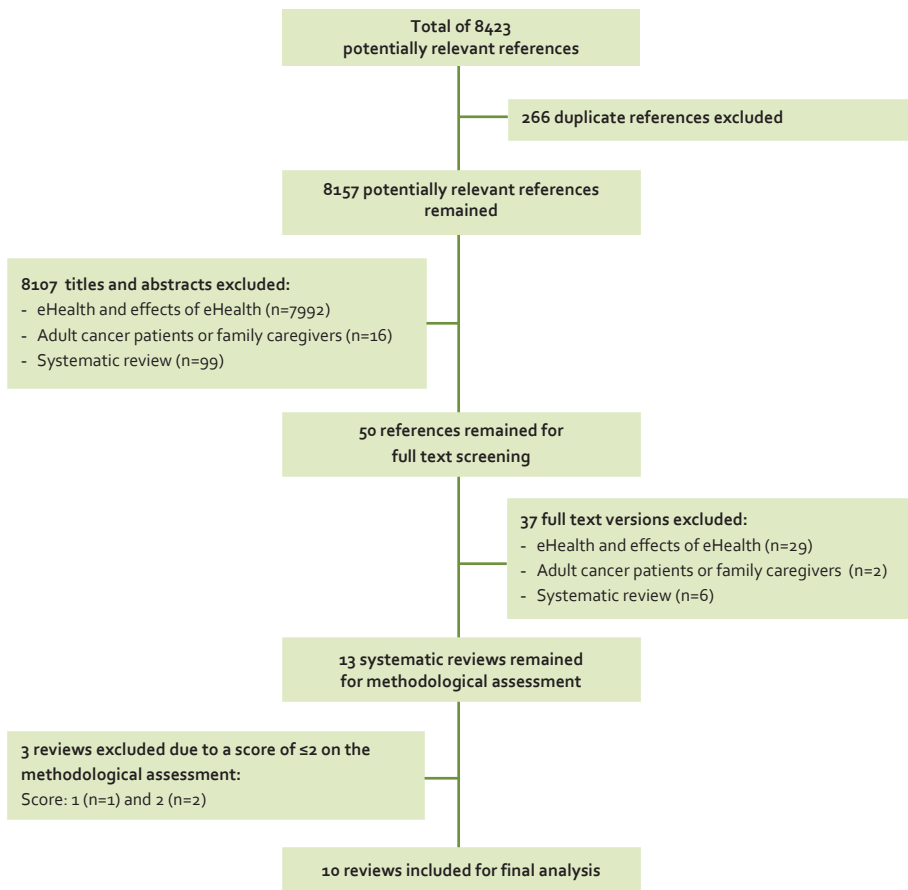

Figure 1 *Flowchart of review selection process*

Table 1 *Methodological assessment scores*

Reference	Methodological assessment scores
Beatty and Lambert [13]	5
Bender et al. [14]	3
Griffiths et al. [15]	3
Gysels and Higginson [16]	4.5
Hoey et al. [17]	4.5
Hong et al. [18]	3
Johansen et al. [19]	3.5
Ryhanen et al. [20]	3.5
Salonen et al. [21]	3.5
Ventura et al. [22]	3

Only one review [13] received a high quality rating, namely 5 points on the checklist used, indicating only minor flaws (Table 1).

Nine reviews [14-22] were judged as likely to have major flaws (score range: 3–4.5). In general, these reviews scored best on items concerning the description and comprehensiveness of searches, and use of explicit inclusion and exclusion criteria. However, most reviews scored poorly on items referring to an independent reference selection and screening and items referring to a methodological appraisal or data synthesis.

Three reviews [23-25] had a very low quality rating of 1 or 2, and were excluded (in accordance with exclusion criterion no. 4 described in Section 'Eligibility criteria') in the end. Consequently, ten reviews remained for inclusion in this meta-review.

General and methodological characteristics of the ten reviews and their underlying studies

Table S1 provides an overview of the ten reviews' main general and methodological characteristics, such as the eligibility criteria used. Table S1 is available as a supplementary material. Only one review [14] explicitly mentioned family caregivers as well as patients in the inclusion criteria. All other reviews explicitly excluded studies about informal caregivers or did not make any statement regarding informal caregivers. Eight reviews exclusively included studies focusing on cancer patients (type unspecified) and two specifically included studies in breast cancer or prostate cancer populations [20,21]. Most of the reviews did not restrict their eligibility criteria to patients in a certain disease stage or clinical stage. Two reviews specified

outcomes in their eligibility criteria, such as distress, emotional wellbeing, and depressive symptoms [13,15].

Table S1 also includes the main characteristics of the reviews' underlying studies. These studies were often RCTs or quasi-experimental studies among patients with breast cancer, prostate cancer, or colorectal cancer, or mixed groups of cancer patients. Only one underlying study also concentrated on patients' partners. There was also great variety regarding the disease stage or clinical stage; studies concerned newly diagnosed patients, patients under treatment, or post-surgery patients. There appeared to be some overlap in the underlying studies included in the ten reviews, since reviews often included the same underlying studies, such as studies of the eHealth intervention known as the Comprehensive Health Enhancement Support System for breast cancer patients (CHESS) [26-29].

Characteristics of the eHealth interventions

Most of the reviews did not clearly define what type of interventions they were interested in. Only Ryhanen et al. [20] gave a definition of the eHealth interventions they focused on, namely "Internet-based patient education as the use of the World Wide Web or with modem connections to a central server for communication for patient education" [20].

All reviews, except for one, included studies concerning internet-based and/or computer-based interventions (Table 2). Bender et al. [14] were the only ones who focused solely on smartphone applications.

Most eHealth interventions studied were multi-component with a mixture of information and support. In some cases, coping skills training [13-15,20] or monitoring and tracking features [14,19,21] were also part of the content. Different forms of support were available like emotional and/or psychosocial support [15,18,21,22], reminders for appointments or medication [14], and psycho-educational strategies [21]. Support was provided through, for example, a 'chat functionality' with healthcare professionals or by other cancer patients (peer support) [13-18,20]. The above-mentioned CHESS eHealth intervention is also multi-component and involves components like information, discussion groups, and treatment decision aids. Only Griffiths et al. [15] separately analyzed and compared single-component eHealth interventions versus multi-component interventions. Single-component eHealth interventions concerned internet support groups, for example, where participants could exchange personal stories.

Table 2   *Characteristics of eHealth interventions in reviews included*

Reference and score methodological assessment	Type of eHealth interventions	Content of eHealth interventions	eHealth intervention period	Organizational setting of eHealth interventions
Beatty and Lambert 2013 [13] 5	• Internet-based cognitive-behavior therapy • Website: asynchronous bulletin board; un-moderated forum.	<u>Information provision</u> • Information provision: common symptoms and side-effects (self-help). <u>Support</u> • Online peer-support (peer support) <u>Other</u> • Six coping-skills training exercises based on Cognitive Behavior Therapy principles (self-help).	• 12 wks	Not reported
Bender et al. 2013 [14] 3	<u>Examples of 8/295 cancer-focused smartphone applications, categorized per purpose:</u> • *awareness*: Pink Ribbon Breast Cancer Wallpaper; • *information provision*: Cancer iOncolex; • *fundraising*: The Ride to Conquer Cancer; • *promotion organizations*: Conquer Cancer Foundation; • *early detection*: Skin Cancer- The Most Accurate Skin Cancer Detector on iPhone; • *disease management* : Cancer Net; • *prevention*: iEat for Life: Prostate Cancer; • *peer support*: Breast Cancer Connect <u>Methods per purpose:</u> • *awareness*: text, images, games, interactive activities (Quiz); • *information provision*: text, eBook, images, videos, search functionality; • *fundraising*: fundraising tools; • *early detection*: text, images, videos, monitoring tools: capture, track images; risk score questionnaires; • *promotion organizations*: text; • *disease management*: appointment tools, lab results storage, self-monitoring/tracking tools, communication tools, question list guidance patient-healthcare professional communication, recording possibilities; • *prevention*: text; images; interactive activities (Quiz); • *peer support*: asynchronous communication tools, GPS locator tracking other members, text, audio.	<u>Information provision</u> • Information provision: disease, diagnosis, symptoms, treatment, prevention, screening, alternative therapy, managing physical, behavioral, psychosocial aspects, charitable organizations. • Communication with healthcare team • Promotion exercise • Promotion healthy eating behaviors <u>Support</u> • Reminders; screening, medication, appointments • Online peer support; personal stories. <u>Other</u> • Skills training/Instructions • Monitoring screening results • (physical and psychosocial) symptom and medication, medical costs tracking.	Not reported	Not reported

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- Top three multimedia formats: visual media-only (36.7%, 108/295); text-only (28.9%, 83/295); text and visual media (22.6%, 65/295).
- Combination multi-media content (31.5%, 93/295).

| Griffiths et al. 2009 [15] 3 | **Internet Support Group: single component interventions:**
- Web-based structured newsgroup moderated psychologist; topic discussion, once a week
- Chat room sessions with experienced leader therapist and 24h access bulletin board
- Public bulletin board, moderated
- Public bulletin board, no information about moderator status
- Public bulletin board

Internet Support Group: multi component interventions:
- Bulletin board, moderated by health professional and art/poetry forum
- Peer-to-peer forum, e-mail communication, electronic questionnaire | **Single-component interventions**
<u>Support:</u>
- Providing emotional support
- In some instances, content was not explicitly reported.

Multi-component interventions
<u>Information provision</u>
- Information provision
- Information + monitoring via electronic questionnaire.

<u>Support</u>
- Peer support
- Self-management advice

<u>Other</u>
- Structured coping skills exercises (stress management, assertiveness + structured problem solving training). | Various:
- 12 wks
- 16 wks, 1.5 hrs. chat room
- 6-8 mths
- variable duration membership: mean 247 days; 44-1001 days
- 6 wks | Not reported |
| Gysels and Higginson 2007 [16] 4.5 | - Comprehensive Health Enhancement Support System (CHESS); 'Take-away tool' providing cancer information, decision making + emotional support
- Computer-based information system; Device for improvement of information transfer and facilitating consent process, during consultation. It provides: general information (intervention 1); personalized information via link between device and patients' medical records (1/2 of patients also accessed general information) (intervention 2)
- Interactive video disk; Device for improvement of information transfer, during consultation. Provides cancer information, treatment choices, explores issues of uncertainty, variations in practice. Operated step-by-step under professional's supervision
- Interactive multimedia program/computer-assisted instruction; Proactive device delivered before and for preparation of consultation. Presentation of information in following formats: text, graphics, narration, music, audio and video clips
- Interactive decision board during consultations; Device for improvement of information transfer, during consultation. Visual aid with written and graphical information. Operated step-by-step under professional's supervision | <u>Information provision</u>
- Some form of research-based information
- Research-based information: explanation relevant terms and concepts; current literature overview; explanation of RCTs; 'Instant Library' with scientific and popular press articles.

<u>Support</u>
- Decision-making tools: Tailored information based on patient provided personal details. Information on treatment options, risks and benefits, clarification of values and understanding outcomes
- Forms of video segments of experiences of others
- Provision of support groups or expert advice
- Awareness raising/empowerment by: repeatedly encouraging to take active role in decision making and disease management; identification of resources like descriptions and contacts services. | Not reported | Various:
- Home-based
- Before consultation
- During consultation |

Table 2 Continued

Reference and score methodological assessment	Type of eHealth interventions	Content of eHealth interventions	eHealth intervention period	Organizational setting of eHealth interventions
Hoey et al. 2008 [17] 4.5	• Peer-support programs • (Facilitated) Bulletin board • Chat room format • Structured group, professionally facilitated • Asynchronous support groups	Support • Peer support	Various: • Ongoing, 24h • 24h, 1 yr • 24h, 12 wks • 24h, 6 mths • 1 p wk, 16 wks	• Home • In some instances, organizational setting was not reported
Hong et al. 2012 [18] 3	• Home-based computer system (CHESS) • (Privately accessed) online bulletin boards • Online cancer forum • Internet/online/electronic support group • General Internet use: especially online/offline communication stimulated by online communication and online information seeking • Internet Discussion group • Online breast cancer discussion board • Peer support system: online discussion, chat room, personal message system (for intervention group) • Online coping group specifically designed for study • E-mail list; breast cancer and cancer-related • Newly designed website (Virtual Cancer Internet Community) • Peer-led and unstructured interventions • Structured intervention and moderated by professional	Information provision • Information provision on cancer and decision making. Support • Online cancer support; mostly online social (emotional or informational support). • Peer support	Various: • 1.5h/wk, 16 wks • 12 wks • 90 min/wk, 30 wks • 27 wks • In some instances, intervention period was not reported	Not reported
Johansen et al. 2012 [19] 3.5	• Electronic Self-Report Assessment-Cancer (ESRA-C): color graphical summary of participant's self-reported symptoms and quality of life issues with predetermined thresholds flagged was printed and handed to clinician immediately before targeted clinic visit. No recommendations offered • Touch-screen survey filled out before oncologist visit. Computer scored answers. Printed summary of report in patient's file for consideration during consultation. Suggested strategies for managing identified issues were included • All patients scheduled for outpatient visit used system on tablet computer for	Support • Enhancing patient–provider communication with electronic self-report assessment for cancer. • Supporting shared decision making • Improving communication and patient wellbeing • In some instances, content was not reported.	Various: • 2 visits (before treatment, 4–6 wks later) • Before visit, 4 times	Various: • Inside Clinic • Outside/ home

reporting symptoms and preferences before consultation. For clinicians, system highlighted patient experienced symptoms incl. severity, degree of bother, importance for patients. Information was printed and handed to the patient and clinician
• Use of "Choice"; interactive tailored patient assessment tool, touchpad tablet PC, for symptom assessments prior to inpatient and outpatient visits. Assessment summary, displaying patient's self-reported symptoms, problems and distress in rank order of patient's need for support, provided to physicians and nurses
Completion of touch-screen Health-related quality of life questionnaires in waiting room before every encounter. Summary handed to physicians.
• Mobile phone system (ASyMS) used in morning, evening and any time patients felt unwell on days 1–14 following first 4 chemotherapy cycles. Completion electronic symptom questionnaire on mobile phone, incl. temperature. Patients immediately received written feedback on mobile phone. Clinicians were advised to contact patients within 1 hour after receiving red alert. The system's alert to physician is based on risk model

Device:
• Computer/tablet
• Mobile phone

Other
• Monitoring: management of chemotherapy-related toxicity.

• 1 consultation
• Up to 1 yr (once per encounter during treatment, once week during hospital stay, once outpatient visit in up to 4 visits)
• Approx. 6 mths
• 4 cycles chemotherapy (12–16 wks)

Table 2   Continued

Reference and score methodological assessment	Type of eHealth interventions	Content of eHealth interventions	eHealth intervention period	Organizational setting of eHealth interventions
Ryhanen et al. 2010 [20] 3-5	**Internet education programs** · Comprehensive Health Enhancement Support System (CHESS) · Self-guided Internet-Based Coping-skills training program to manage symptoms of treatments **Different educational interactive computerized programs** · Options for Treating Breast Cancer · The information and decision profiles · Breast Cancer Genetics Computer Program · The Computerized Decision Aid · Interactive Digital Education Aid · Retratos de la Vida Real (Photographs of Real Life) · Common use of Internet **Computer-based (interactive or multimedia) programs** · Interactive soap opera · CD-ROM · Interactive multimedia program · Interactive computer system/interface **Internet-based programs** · Home computer with modem connection to a central server for communication · (a series of) Webpage(s) · Common use of Internet · Possibilities to chat with other patients or pose questions to health professionals (Internet-based programs) · Text related to breast cancer · Images and sound · Audio and videos · Decision aids · Users able to affect progression of the program	<u>Information provision</u> · Patient education/information provision: breast anatomy, disease, treatment, heredity, prevention, screening. <u>Support</u> · Decision-making with different treatment options/intention to go genetic testing. · Peer-support like stories of other breast cancer patients. <u>Other</u> · Exercises	Not reported	Not reported

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Salonen et al. 2014 [21] 3-5	• Patient Information Programme: computer program, touchscreen or mouse format • Virtual Conversations model: voice-activated interactive computer system. Virtual communication with virtual doctor • Multimedia program: internet or CD-ROM • IT-based informational support: CD-ROM and websites • Interactive Health communication: CD-ROM and websites • Nurse-Driven Intervention: video • Internet: website, Database of Individual Patient Experiences-website • Multimedia features integrate audio, video and computer technology	Information provision • Comprehensive and reliable information provision • Majority of eHealth interventions: providing questions and answers. • Providing knowledge • List of variety of reputable cancer websites. Cancer specialized CD-ROM. • List reputable cancer websites, either breast/prostate cancer. Cancer specialized CD-ROM. • Modules for prostate and breast cancer. Also module hypertension, testis cancer, cervix, bowel. Support • Help with (informed) decision-making treatment • Providing psychosocial support • Providing symptom management strategies • Psycho educational strategies Other • Tracking quality of life-problems and psycho-educational strategies with an assessment • Measuring decision and information preferences	Various: • Multiple viewing; every month during 6 mths, unlimited access, 8 wks period • Single viewing • In some instances, intervention period was not reported	Various: • Clinical environment; hospital • Patients' homes • Partners and spouses in same room, without each other's input • In some instances, organizational setting was not reported

Table 2   Continued

Reference and score methodological assessment	Type of eHealth interventions	Content of eHealth interventions	eHealth intervention period	Organizational setting of eHealth interventions
Ventura et al., 2013 [22] 3	• Prostate Interactive Educational System (PIES); construction not based on needs assessment of target population, user-driven, contains text, audio, video, pictures/graphics and computer-based feedback only • Comprehensive Health Enhancement Support System (CHESS); construction based on needs assessment of target population, user-driven, contains text, audio, video, pictures/graphics and both human and computer-based feedback • Virtual Conversations; construction not based on needs assessment of target population, user-driven, contains audio, video and computer-based feedback only • Interactive Digital Education Aid (IDEA); construction based on needs assessment of target population, user-driven, contains text, audio, video, pictures/ graphics and no interactivity in form of feedback • Computerized Multimedia Interactive Patient Education Aid (CPtDA); construction not based on needs assessment of target population, user-driven, contains text, audio, video, pictures/graphics and computer-based feedback only • Interactive Shared Decision-Making (DM) Program; construction not based on needs assessment of target population, user-driven, contains text, audio, video, pictures/graphics and no interactivity in form of feedback • Multimedia Education Program (MEP); construction not based on needs assessment of target population, not user-driven, contains audio, video, pictures/graphics and no interactivity in form of feedback • Oncology Interactive Educational Series (OIES); construction not based on needs assessment of target population, user-driven, does not contain text, audio, video, pictures/graphics and interactivity in form of feedback • CD-ROM Educational Aid; construction not based on needs assessment of target population, user-driven, contains audio, video, pictures/graphics and no interactivity in form of feedback • Help with Adjustment to Alopecia by Imaging Recovering (HAAIR); construction not based on needs assessment of target population, user-driven, contains video and computer-based feedback only. Other multimedia features are not applicable. • The Interactive Breast Cancer CDROM; construction based on needs assessment of target population, user-driven, contains text, audio, video and computer-based feedback only	Information provision • Informational support Support • Emotional support • Social support • Decision-making • Self-care	Not reported	Various: • Research center • All places • All places and research center

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- The Understanding Cancer CD-ROM; construction not based on needs assessment of target population, user-driven, contains text, audio, video, pictures/graphics and computer-based feedback only
- WebChoice; construction based on needs assessment of target population, user-driven, contains text, audio, video, pictures/graphics and both human + computer-based feedback
- Computerized Educational Tool; construction based on needs assessment of target population, user-driven, contains text and no interactivity in form of feedback
- "A Guide to Your Visit"; construction not based on needs assessment of target population, not user-driven, contains audio, video and interactivity in form of feedback not applicable
- Interactive Videodisc Module; construction not based on needs assessment of target population, user-driven, contains audio, video and no interactivity in form of feedback
- Almost all interventions had format of computer-based tool and were user-driven
- Five underlying studies: intervention based on needs assessment of target population, CHESS, IDEA, The Interactive Breast Cancer CD-ROM, WebChoice and The Computerized Educational Tool

Effects of the eHealth interventions

All reviews except one [14] found studies concerning the effects of eHealth interventions. Bender et al. [14] did not find any study meeting their eligibility criteria, most likely due to their narrow focus on smartphone applications available in Canadian and French online application stores. The results of the nine remaining reviews are presented in Table S2 which is available as supplementary material.

The reviews studied a variety of outcomes and were based on underlying studies using different, mostly multiple, points in time, varying from pre-test, post-test, and follow-up after nine months, to baseline, six weeks, and 12 weeks.

Since many different outcomes were reported, we consider only those outcome categories that are discussed in a majority of the reviews. The level of evidence for each outcome category is summarized in Table 3.

Effects on knowledge and information competence

Evidence exists for positive effects of eHealth interventions on knowledge and information competence (the ability to acquire information as well as to use the acquired information) [16,18,20,21].

Gysels and Higginson [16], who studied the effects of interactive multimedia programs, elaborated on a study describing increased knowledge levels about breast cancer and improvements in information competence in women with breast cancer two months and five months after attending an internet support group, and on women who are non-Caucasian, uninsured or less educated. These findings appear to be supported by Ryhanen et al. [20]. Comparable results were yielded for prostate cancer patients. Hong et al. [18] found some evidence for improvements in information competence, information seeking, and information exchange in a patient population with various types of cancer.

Effects on perceived support

Evidence is also found for positive effects of eHealth interventions on perceived support [16-22].

Table S2 shows that three reviews [17,18,22] described positive effects on the provision of social support and one review [19] on the reduction in perceived needs for support. Two reviews specifically mentioned eHealth interventions positively influencing the provision of social support for breast cancer patients [16,20]. Salonen et al. [21] reported some improvement in informational support to prostate cancer patients and satisfaction with that support. Similar results for breast cancer patients were found by Hoey et al. [17].

Table 3 *Best evidence synthesis*

Reference	Salonen et al. [21] 2014 moderate quality	Beatty and Lambert [13] 2013 high quality	Ventura et al. [22] 2013 moderate quality	Bender et al. [14] 2013 moderate quality	Johansen et al. [19] 2012 moderate quality	Hong et al. [18] 2012 moderate quality	Ryhanen et al. [20] 2010 moderate quality	Griffiths et al. [15] 2009 moderate quality	Hoey et al. [17] 2008 moderate quality	Gysels and Higginson [16] 2007 moderate quality	Level of Evidence
Outcome category											Level of Evidence
Knowledge and Information	+ (3)					+ (3) no effects (1)	+ (9)			+ (5)	Evidence
Support	+ (2)		+ (1) no effects (1)		+ (1)	+ (7)	+ (3)		+ (1)	+ (1)	Evidence
Decision making	+ (3) - (1)		+ (6)				+ (2)			+ (2) no effects (2)	Inconsistent findings
Healthcare participation and Patient involvement			+ (3) no effects (1)			+ (1)	+ (6)		+ (1)	+ (1) no effects (2)	Indications of evidence
Depression	+ (4)				+ (1)	+ (4) - (1) no effects (1)	no effects (2)	+ (4) no effects (2)	+ (3)	no effects (1)	Inconsistent findings
Anxiety					+ (1)		no effects (2)		+ (2)	+ (1) - (1) no effects (2)	Inconsistent findings
Psychological wellbeing	+ (3)	no effects (1)			+ (1) no effects (1)	+ (9) - (1) no effects (4)		+ (1)	+ (1) - (1)		Inconsistent findings

Table 3   Continued

Reference	Salonen et al. [21] 2014 moderate quality	Beatty and Lambert [13] 2013 high quality	Ventura et al. [22] 2013 moderate quality	Bender et al. [14] 2013 moderate quality	Johansen et al. [19] 2012 moderate quality	Hong et al. [18] 2012 moderate quality	Ryhanen et al. [20] 2010 moderate quality	Griffiths et al. [15] 2009 moderate quality	Hoey et al. [17] 2008 moderate quality	Gysels and Higginson [16] 2007 moderate quality	
Quality of life	+ (2)	no effects (1)	+ (4) no effects (1)		+ (1)	+ (1) - (1) no effects (1)			no effects (1)	+ (1)	Inconsistent findings
Health status	+ (1)		+ (4) no effects (2)			no effects (1)				+ (1)	Indications of evidence
Physical wellbeing	no effects (1)					+ (1) no effects (1)			+ (1)		No evidence
Functional wellbeing						no effects (1)					No evidence

+ Positive effects - Negative effects ( ) Number of underlying studies in review included

Effects on decision-making

Findings concerning the effects of eHealth interventions on decision-making are inconsistent [16,20-22].

While two reviews [20,22] solely found positive effects, Gysels and Higginson [16] found mixed results for the effects of interactive multimedia technologies on decision-making by breast cancer patients regarding treatment, namely studies describing positive effects as well as studies describing no effects on breast cancer patients' satisfaction with decision making concerning treatment. Gysels and Higginson explained these mixed findings as a result of the differences between the studied eHealth interventions. Additionally, Salonen et al. [21] described the results of internet and computer-based programs for prostate cancer patients and found that these programs positively influenced not only levels of decision control, and patient involvement in decision-making but also decisional conflict.

Effects on healthcare participation and patient involvement

Indications of evidence exist for positive effects of eHealth interventions on healthcare participation and patient involvement in care [16-18,20,22].

Results varied from positive effects to no effects, but mainly involved positive effects. Table S2 shows that positive effects on healthcare participation were experienced by breast cancer patients after two months of using an internet-based program [16-18,20] and by women with breast cancer who are non-Caucasian, uninsured, or less educated [16]. The effect on healthcare participation after two months, however, seemed to dissolve after five months [16]. There also appeared to be no effect on patient involvement during consultations for choosing breast cancer treatment [16]. Ventura et al. [22] described mixed results on healthcare participation but mostly positive ones.

Effects on depression and anxiety

Inconsistent findings were yielded regarding depression [15-21] and anxiety [16,17,19,20].

With regard to the effects on depression, Griffiths et al. [15], Hoey et al. [17], and Hong et al. [18] found positive effects from internet support groups and online cancer support and resources on symptoms of depression in breast cancer patients and survivors. These findings are likely to be strengthened by the result that showed internet support groups to be more successful for patients with breast cancer than for patients with other (non-cancer) diagnoses [15]. However, two reviews [16,18] also reported that the aforementioned finding is likely not to apply to recently diagnosed breast cancer patients [18] and women with early stage breast cancer [16]. Additionally, Griffiths et al. [15] reported no effects of multi-

component internet support groups on breast cancer patients and head and neck cancer patients. With respect to prostate cancer patients, Salonen et al. [21] found positive results for internet and computer-based programs in reducing depression. Electronic symptom reporting in the context of consultation support appeared to reduce depression as well [19].

Four reviews reported varying results concerning effects on anxiety [16,17,19,20]. Ryhanen et al. [20] found no effect of internet and computer-based programs on anxiety among breast cancer patients. Gysels and Higginson [16] seem to contradict this result by reporting that the use of interactive multimedia programs during the discussion of diagnosis and treatment helped reduce anxiety among breast cancer patients. Internet peer support programs [17] and electronic symptom reporting [19] were also found to reduce anxiety in breast cancer patients and cancer patients in general respectively.

Effects on psychological wellbeing
Findings on the effects of eHealth interventions on psychological wellbeing and related outcomes are inconsistent [13,15,17-19,21].

Hoey et al. [17] and Hong et al. [18] found mixed effects and no effects respectively of online cancer support (from peers) on emotional wellbeing [17,18]. Johansen et al. [19] found underlying studies on electronic symptom reporting that demonstrated a positive impact from providing feedback on emotional wellbeing but they found no effect for electronic symptom reporting in general.

Psychological wellbeing was discussed in four reviews [13,15,18,21]. Beatty and Lambert [13] and Salonen et al. [21] present contradictory findings for the effects on psychological distress: Beatty and Lambert argue that online interventions had no impact while Salonen et al. see a positive impact.

Effects on quality of life and health status
Findings on the effects of eHealth interventions on quality of life are inconsistent [13,16-19,21,22].

Some reviews found positive effects [16,19,21], while others did not [13,17] or found mixed results [17,22]. For instance, Gysels and Higginson [16] found one study describing positive effects of internet support groups specifically for women with breast cancer and who are of color, uninsured, or with less education. Johansen et al. [19] described positive effects of electronic symptom reporting on the health-related quality of life. However, Hong et al. [18] studied online cancer support and found no effects on the health-related quality of life, while these authors did find positive effects on the self-reported quality of life. Ventura et al. [22] discussed comparable mixed results.

2

The four reviews reporting on outcomes related to health status presented results that are inconsistent [13,16,18,22]. Two reviews [13,16] found positive effects. However, one review [22] described some studies with positive effects on general health and others with no effects on general health of internet or computer-based programs. Both Ventura et al. [22] and Hong et al. [18] found no effects on the self-rated health status.

Effects on physical and functional wellbeing
No evidence is found for effects of eHealth interventions on physical [13,17,18] and functional wellbeing [18].

One review [18] found mixed results concerning physical wellbeing and another [17] found positive effects. Positive effects specifically concerned reductions in patients' reaction to pain. These findings, however, are contradicted by Beatty and Lambert's high quality review [13] that found no effects on physical wellbeing.

Functional wellbeing was mentioned in only one review and appeared not to be influenced two months after using an online cancer support program [18].

DISCUSSION

This meta-review shows that evidence exists for effects of eHealth on cancer patients' knowledge level, and information competence. Patients' knowledge levels increased as well as their ability to acquire information and to use the acquired information [16,18,20,21]. The use of eHealth also reduced patients' needs for support as it improved provision of support [16–22]. Evidence regarding health status [13,16,18,22], healthcare participation and patient involvement in care is sparse [16–18,20,22], since we found only indications for effects of eHealth on these outcomes. Although results described in the systematic reviews mainly concerned positive effects [13,16–18,20,22], they also reported studies showing no effects on mentioned outcomes. Findings are inconsistent with regard to effects on psychological outcomes (psychological wellbeing [13,15,17–19,21], depression [15–21], and anxiety [16,17,19,20]), quality of life [13,16–19,21,22], and decision-making about treatment or care [16,20–22]. For example, some systematic reviews described positive effects on patients' satisfaction with their decision about treatment, while other systematic reviews found mixed or no effects in this regard. Besides, evidence is lacking for effects on physical [13,17,18] and functional wellbeing [18]. Remarkably, only one review [14] aimed to consider the effects of eHealth for informal caregivers as well as patients. Since this review did not find any effect studies at all, evidence for the effects of eHealth for informal caregivers could

not be obtained. Moreover, of the three reviews that were excluded because of poor methodological quality, two [23,24] did not include studies on the effects of eHealth in informal caregivers of cancer patients. Nevertheless, we do have indications that some research into the effects of eHealth on informal caregivers has already been conducted, e.g. Farnham et al. [30], and Namkoong et al. [31].

The reviews included in our meta-review concerned internet-based and/or computer-based eHealth interventions, the only exception being Bender et al.'s [14] review, which looked at smartphone applications only. The eHealth interventions described in the ten reviews concerned both single-component interventions and multi-component interventions with content that varied considerably. Examples of single-component interventions are websites that only provide information about the disease or treatments. Multi-component interventions, for example, offer information as well as the possibility to 'chat' with healthcare professionals. It is, however, difficult to conclude if the type of eHealth modality, e.g. internet-based or computer-based, moderates possible effects. Moreover, it is also often difficult to determine whether multi-component interventions are more effective than single-component interventions based on the existing systematic reviews. In the case of multi-component eHealth interventions, it is difficult to establish which particular component contributes most to an effect on a certain outcome. In this regard, Griffiths et al.'s [15] results are likely to be the most informative, since they separately reviewed the effects of single-component and multi-component interventions.

A surprising finding is that most of the reviews as well as the underlying studies did not focus on patients in a specific disease or treatment stage. Consequently, we do not know whether eHealth is equally effective for patients in the diagnostic, curative and palliative phase of cancer. The effects of eHealth might be different depending on patients' needs for information and support, which may vary during the disease and treatment trajectory. Cancer patients in the curative phase, for example, may be in more need of information about how to cope with late effects of surgery or chemotherapy, while patients with advanced cancer may want information about the self-management of pain and psychological distress. In future research (both at the level of separate intervention studies and the level of systematic reviews), more attention should be given to the effects of eHealth interventions in relation to the disease stage.

We also found that almost none of the reviews considered patients with specific tumor types, while there may be differences in patients' needs for information and support depending on their diagnosis. People with lung cancer for example, may be more in need of information about dyspnea while women with cervical cancer might appreciate information concerning infertility.

Additionally, we discovered a considerable overlap between four reviews in the underlying studies they included. This may be due to the fact that the Comprehensive Health Enhancement Support System for breast cancer patients is the most researched eHealth intervention among the available eHealth interventions. Hence, in some cases, the reported effects and evidence may apply more to breast cancer patients than to patients with other tumor types. This is all the more reason why future research should concentrate on specific tumor types.

Lastly, demographic characteristics such as age or education were not taken into account by the reviews, while such background characteristics might be important since older people or less educated people may have more difficulties with the use of eHealth.

More tailored eHealth interventions may yield stronger effects. However, more research is needed to confirm this hypothesis.

Strengths and limitations

The strengths of this meta-review are: (1) sensitive search strategies with few limitations and in a range of literature databases; (2) assessment of the methodological quality, which led to the exclusion of systematic reviews of poor quality; (3) a broad range of eHealth interventions and outcomes studied in the reviews included. The latter, however, is also a limitation as it shows heterogeneity. Therefore, findings have to be interpreted with prudence. We decided to perform a meta-review since we believed many systematic reviews concerning eHealth for patients and informal caregivers had already been published. While this assumption was correct for patients, it was not for informal caregivers. None of the reviews we looked at studied eHealth targeting informal caregivers. Given this, it may have been more sensible to separately review eHealth for informal caregivers in a systematic review instead of a meta-review.

CONCLUSIONS

This meta-review based on systematic reviews found evidence for the effect of eHealth on cancer patients' knowledge, information competence, and perception of the support they received. For effects on other patient outcomes the evidence is inconsistent, limited, or seems to point to no effect.

None of the systematic reviews focused on eHealth for informal caregivers of cancer patients. Future systematic reviews should provide insight into the effects of eHealth in informal caregivers in particular. To further demonstrate effects

in patients and/or informal caregivers, researchers should separately analyze and compare single-component and multi-component eHealth interventions. Additionally, future reviews should focus more on comparing the effects of eHealth in different groups of patients, distinguished by treatment stage (curative or palliative) and tumor types, for instance.

Acknowledgements

SUMMARY POINTS

What was already known on the topic

- eHealth might complement professional face-to-face support to people confronted with cancer.
- A variety of eHealth interventions for people confronted with cancer and which focuses on information provision and (peer)support in managing physical and emotional problems, decision-making, and self-management, has already been developed.
- Several systematic reviews on effects of eHealth have already been published. A comprehensive overview of evidence for effects of eHealth on cancer patients and their informal caregivers is absent.

What this study added to our knowledge

- Paucity of high quality systematic reviews.
- Demonstration of (lack of) evidence for effects of eHealth on different outcomes like perceived support, knowledge and information competence, psychological outcomes and decision-making.
- Identification of lacunas in the existent evidence base regarding effects on:
  - informal caregivers of cancer patients;
  - patients with specific tumor types;
  - cancer patients in a specific treatment or disease stage.
- Recommendation to focus future research on the identified lacunas, and separately study different types of eHealth interventions, like single-component and multi-component eHealth interventions.

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2

SUPPLEMENTARY MATERIAL

Search strategy PubMed

For the development and adaption of the search strategies, databases' thesaurus terms for eHealth, cancer, systematic review and meta-analysis or specific 'systematic review filters' were used, as well as free text words describing eHealth.

Search Strategy for PubMed

(telecommunications[Majr] OR "Medical Informatics/education"[Mesh] OR "Medical Informatics/nursing"[Mesh] OR "Medical Informatics/psychology"[Mesh] OR Computer Communication Networks[Majr] OR educational technology[Majr] OR Biomedical technology[Majr] OR Mobile applications[MeSH Terms] OR electronic health records[Majr] OR Health Records, Personal[MeSH Terms] OR Telenursing[MeSH Terms] OR telemedicine[tiab] OR tele?medicine[tiab] OR telehealth[tiab] OR ehealth[tiab] OR e?health[tiab] OR mhealth[tiab] OR m?health[tiab] OR "mobile health" OR telecare[tiab] OR tele?care[tiab] OR ecare[tiab] OR e?care[tiab] OR app care OR teleconsult*[tiab] OR tele?consult*[tiab] OR econsult*[tiab] OR e?consult*[tiab] OR videoconsult* OR video?consult*[tiab] OR telecommunicat*[tiab] OR tele?communicat*[tiab] OR ecommunicat* OR e?communicat*[tiab] OR electronic communicat* OR videocommunicat* OR video?communicat*[tiab] OR telemonitor*[tiab] OR tele?monitor*[tiab] OR e?support[tiab] OR telesupport[tiab] OR "health technology" OR "health care technology" OR wireless[tiab] OR telenurs*[tiab] OR tele?nurs*[tiab] OR "mobile applications" OR e?coach*[tiab] OR elearn*[tiab] OR e?learn*[tiab] OR web?base*[tiab] OR email*[ti] OR e?mail*[ti] OR smartphon*[tiab] OR smart?phon*[tiab] OR mobile phone* OR "tablet computer" OR "tablet computers" OR iphone*[tiab] OR ipad*[tiab] OR text?messag*[tiab] OR internet*[ti] OR online*[tiab] OR "health 2.0" OR tele?health[tiab])

AND

(cancer[Majr] OR neoplasms[Majr] OR medical oncology[Majr] OR carcinoma[Majr] OR Sarcoma [Majr] OR metastasis[Majr] OR cancer*[tiab] OR neoplasm*[tiab] OR "medical oncology"[tiab] OR oncolog*[tiab] OR tumor*[tiab] OR carcinom*[tiab] OR metastas*[tiab] OR Sarcom*[tiab] OR leukem*[tiab] OR leucem*[tiab] OR hodgkin*[tiab] OR lymphom*[tiab])

AND

((((Meta-Analysis[ptyp] OR Review[ptyp] OR systematic[sb]))) OR ((systematic review[ti] OR meta-analysis[pt] OR meta-analysis[ti] OR systematic literature review[ti] OR (systematic review[tiab] AND review[pt]) OR consensus development conference[pt] OR practice guideline[pt] OR cochrane database syst rev[ta] OR acp journal club[ta] OR health technol assess[ta] OR evid rep technol assess summ[ta] OR drug class reviews[ti]) OR (clinical guideline[tw] AND management[tw]) OR ((evidence based[ti] OR evidence-based medicine[mh] OR best practice*[ti] OR evidence synthesis[tiab]) AND (review[pt] OR diseases category[mh] OR behavior and behavior mechanisms[mh] OR therapeutics[mh] OR evaluation studies[pt] OR validation studies[pt] OR guideline[pt] OR pmcbook)) OR ((systematic[tw] OR systematically[tw] OR critical[tiab] OR (study selection[tw]) OR (predetermined[tw] OR inclusion[tw] AND criteri*[tw]) OR exclusion criteri*[tw] OR main outcome measures[tw] OR standard of care[tw] OR standards of care[tw]) AND (survey[tiab] OR surveys[tiab] OR overview*[tw] OR review[tiab] OR reviews[tiab] OR search*[tw] OR handsearch[tw] OR analysis[tiab] OR critique[tiab] OR appraisal[tw] OR (reduction[tw] AND (risk[mh] OR risk[tw]) AND (death OR recurrence))) AND literature[tiab] OR articles[tiab] OR publications[tiab] OR publication[tiab] OR bibliography[tiab] OR bibliographies[tiab] OR published[tiab] OR unpublished[tw] OR citation[tw] OR citations[tw] OR database[tiab] OR internet[tiab] OR textbooks[tiab] OR references[tw] OR scales[tw] OR papers[tw] OR datasets[tw] OR trials[tiab] OR meta-analy*[tw] OR (clinical[tiab] AND studies[tiab]) OR treatment outcome[mh] OR treatment outcome[tw] OR pmcbook) NOT (letter[pt] OR newspaper article[pt] OR comment[pt]))))

Table S1
General and methodological characteristics of reviews included

	General and methodological characteristics of reviews included				General and methodological characteristics of under-lying studies in review	
Reference, first author's country of origin, score meth. assessment	Information sources and dates of coverage	Review objectives	Review's eligibility criteria	Synthesis of results	Number and design	Population
Beatty and Lambert 2013 Australia [13] 5	· Embase (period ?). · MEDLINE (period ?) · PsycINFO (period ?) · CINAHL (1980 - Dec. 2011) · Reference lists of included studies.	To update evidence and to review application of internet to psychological treatment of distress	Inclusion criteria: Published (or in-press) 1980 - December 2011; Adults (18>) with a chronic physical health condition; Self-help internet-based psychosocial therapeutic interventions; Outcome measure: distress, quality of life or wellbeing; RCT, quasi-randomized trial, feasibility RCT study; English language. Exclusion criteria: Conditions included in DSM-IV; Interventions providing information/education only, without therapeutic component; Studies examining computer-based support groups; Case-series and single group pre-post studies.	· Narrative synthesis	· 23 studies included. Only 1 concerned cancer patients. · design: quasi experimental. · conditions: eHealth intervention vs waitlist control group	· population: adult patients with a variety of chronic diseases. Only one study concerned cancer patients: · tumor type: breast · disease/clinical stage: already diagnosed · gender: only female

Bender et al. 2013 Canada [14] 3	To characterize purpose and content of cancer-focused smartphone applications available for use by the general public and evidence on their utility or effectiveness.	*Canadian and French mobile application markets:* • iPhone (App Store) • Android (Google Play) • BlackBerry (App World) • Nokia/Symbian (Ovi) · Date of searches: February 14, 2012 *Health literature databases:* • MEDLINE (1990-June 18, 2012) • Embase • The Cochrane Library; all databases · Dates of coverage: 1990-June 24, 2012 · Reference lists from eligible articles and recent reviews.	*Mobile application market* Inclusion criteria: focus on cancer; focus on cancer patients or survivors, their family caregivers or the general public concerned about cancer; English-language interface; Available for smartphones. Exclusion criteria: Only available on tablet computers; Aimed at health care professionals; Applications related to smoking cessation, radiation exposure, or general symptom management applications. *Health literature search* Inclusion –part 1: Description of evaluation of mobile phone applications for cancer patients/survivors, family caregivers, or the general public; Inclusion of original data on use of mobile phone applications by cancer patients/survivors, family caregivers or the general public; English language. Inclusion final analysis: Description of evaluation of a cancer-focused smartphone applications. Exclusion final analysis: Description of evaluation of: · basic mobile phone and personal digital assistant interventions · reliability of paper vs mobile phone-based assessments; Evaluations of applications tested exclusively on laptops, netbooks or tablet computers.	· Coding scheme for describing purpose of applications, based on seven identified categories of applications. · Applications coded into one category based on their main purpose as describes in store description.	· 295 cancer-focused smartphone applications found. · No studies concerning evaluation of cancer-focused smartphone applications found.	· population: different groups of people: patients; cancer survivors; family caregivers; general public · tumor type: breast; skin; prostate; lung; colorectal; pancreatic; cervical; ovarian; testicular; liver; kidney; brain; pediatric cancers; hematologic cancers; female cancers; cancer in general. · disease/clinical stage: no explicit stage defined. · gender: no explicit focus reported.

Table S1 Continued

General and methodological characteristics of reviews included			General and methodological characteristics of underlying studies in review
Griffiths et al. 2009 Australia [15] 3	• PubMed • PsycINFO • The Cochrane library • Dates of coverage: period before Aug. 2007 • Dates of searches: May 2005 and July 2007 • Reference lists of included studies.	To provide comprehensive overview of effects of Internet Support Groups on depressive symptoms	Inclusion criteria stage 1: Peer-to-peer interaction; At least one of following: online/electronic support groups, online/electronic social or peer support, online/computer-based communication or interaction, collaborative virtual environments or interventions; Support "group" was health/psychology related or article measured health/psychology related outcome in relation to a support group. Inclusion criteria stage 2: Study employed online peer-to-peer support group; Study incorporated either a depression outcome or involved unipolar depression Internet Support Group. Inclusion criteria stage 3: Study reported either quantitative or qualitative empirical data. Exclusion criteria stage 4: No depression outcome or study did not concern Internet Support Group exclusively devoted to depression; Duplicates after second search; Non-English language.	• Possible role of different characteristics and quality explored by comparing samples which reported to have yielded positive statistically significant results with those that did not: Series of Fisher exact tests and Mann-Whitney tests. Data analyzed at comparison rather than study level. • For descriptive purposes, where possible, Cohen's d standardized effect sizes calculated. • Uncontrolled studies: pre-post standardized effect size calculated from mean pre-test and post-test scores and standard deviations. • Controlled studies, study effect size: difference between pre-post effect size control group and pre-post effect size intervention group calculated. • When only t test value for dependent (or equivalent) samples available: no effect size estimated. • When only baseline adjusted means + baseline adjusted difference in change available: no effect sizes calculated.	• 28 studies included. • 7 concerned cancer patients and had various designs. • 7 studies concerned cancer patients. • design: RCT (n=2); controlled trial (n=1); pre-post study (n=4). • conditions (n=3): eHealth intervention vs: wait-list control (n=2); treatment as usual (not further specified, n=1). • control intervention period varied: 12 wks (n=2), 6 wks (n=1). • control group: patients with breast cancer (n=1); patients with breast cancer diagnosed in past 32 mths (n=1); patients with head- and neck cancer (n=1). • gender control group: female (n=2); not reported (n=1).	• population: people with a variety of chronic diseases. • tumor type: breast (n=6); head or neck-cancer (n=1). • disease/clinical stage: breast cancer: diagnosed past 32 mths (n=1) • head or neck-cancer: post-surgery (n=1); no report of stage (n=5). • gender: only female (n=6); not reported (n=1). • other: Inclusion of some rural residents (n=1); Participants joined 1 of 5 frequently used bulletin boards <8 wks previous to participation in study (n=1); Participants joined 1 of 4 frequently used bulletin boards <8 wks previous to participation in study (n=1); Participants who have previously posted on Breast Cancer bulletin board during a particular 1-wk period (n=1); Financial incentive given to patients for participation (n=1).

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Gysels and Higginson 2007 UK [16] 4.5	To assess benefits of interactive multimedia technologies and videotapes for patient education	Inclusion criteria: RCTs; Patient education to improve knowledge, satisfaction, decision making, treatment choice or care management; Videotape or computer programs; Cancer care; Only diagnostic screening procedures.	• Meta-analysis: when sufficient comparable outcome data ≥2 studies; heterogeneity testing using the χ2 test; random-effects model applied.	• 9 studies included. 6 concerned effects of eHealth interventions.	• population: patients (n=6)
• MEDLINE (1966-wk 3 of April 2006)			• Continuous data summarized as weighted mean differences with 95% confidence intervals.	• design: RCT.	• tumor type: breast (n=4); various (n=1); referred for colonoscopy: not specified (n=1).
• Embase (1980 – wk 18 2006)		Exclusion criteria: Studies involving hypothetical choices, informed consent to take part in clinical trial, decisions regarding preventive screening or public health measures; Interventions intended for other purposes than treatment decision making and informed consent; Interventions experimenting with Internet; Focus on children; Non-intervention studies.	• Dichotomous data summarized as odds ratios with 95% confidence intervals.	• conditions: eHealth intervention vs: reading material: Susan Love's Breast Book (n=1); usual care: standard information and (face-to-face) care from multidisciplinary team (n=1); standard education (n=1); brochure (n=1); face-to-face medical consultation (n=1); information booklets (n=1).	• disease/clinical stage: - breast cancer: newly diagnosed (n=1); recently diagnosed (n=1); stage I / II (n=1); histologically confirmed axillary node-negative breast cancer and primary surgery at first consultation for adjuvant systemic therapy (n=1). - various types: started radical radiotherapy (n=1).
• CINAHL (1982 – wk 3 of April 2006)			• Analysis of continuous + dichotomous data altogether: Effect sizes for all outcomes calculated by dividing estimated mean difference or difference in proportions, by sample standard deviation.	• gender control group: female (n=4); mixed (n=2).	- referred for colonoscopy: undergoing colonoscopy (n=1).
• Cochrane Database of Systematic Reviews					• age: <60 years (n=1), not reported (n=5).
• Cochrane Central Register of Controlled Trials					• gender: female (n=4); not reported (n=2).
• Dates of coverage: wk 3 of April 2006					
• Reference lists of included studies.					
• Expert panel's advice on recently published articles or ongoing research.					

Table S1 Continued

General and methodological characteristics of reviews included				General and methodological characteristics of underlying studies in review
Hoey et al. 2008 Australia [17] 4-5	· CINAHL · MEDLINE · PsycINFO · Dates of coverage: (1980-April 2007) · Reference lists of included studies. · Key researchers were contacted for identification additional publications.	To identify different peer support models and examine research assessing their effectiveness	Inclusion criteria: English language; Description of specific program where peers provided direct support to people with cancer; Peer who has been diagnosed and/or treated for cancer; Primary program purpose: to provide support to cancer patients. Exclusion criteria: Not specific peer-support program; Focus on children or adolescents; Educational or therapeutic course run by professionals (incl. supportive expressive therapy); No primarily focus on peer support; Peer support from someone other than person with cancer; No sufficiently detailed program description; Not possible to determine how peer provided support; Not possible to determine if peer support provider had experienced cancer; Editorial or letter concerning program; First-person account of an experience.	· Selected papers classified into one of following pre-determined categories: - non-research theoretical or service usage; papers describing proposed model or specific program+-papers no data containing apart from service usage data - one group descriptive; describing program with data collection, one group only and no experimental design) - non-randomized comparative studies - randomized controlled trials.	· 44 studies included. 7 concerned effects of eHealth interventions. · designs: qualitative (n=4):- telephone interviews (n=2) - face-to-face + online interviews (n=1) - content analysis posted messages (n=1); RCTs (n=2). · conditions: eHealth intervention vs: providing information in form of booklet concerning breast cancer (n=1); wait-list control (n=1). · control group: not explicitly reported (n=2). · population: patients (n=7) · tumor type: breast (n=7) · gender: female (n=7)

| Hong et al. 2012 USA [18] 3 | • PsycINFO
• ERIC
• MEDLINE via PubMed
• Dates of coverage: ?
• Reference lists of included studies. | To systematically review existing studies on outcomes concerning online support or resources | Inclusion criteria: Empirical data (either qualitative or quantitative methods) on use online cancer support/ resources; Reported outcome measures; Focus on adult cancer survivors; English language; Peer-reviewed articles published before July 2010.

Exclusion criteria: Descriptive studies which did not report outcomes; No focus on cancer survivors; Focus on computer-based resources (without access to Internet); review studies; theoretical articles. | Not reported | • 24 studies included.
• design: cross-sectional survey/interview (n=15): focus groups, in-depth interviews, ethnographic case studies, pre-post studies (n=5); RCTs (n=4).
• conditions: online educational control condition (n=1); not reported (n=3).
• control group: patients (n=4)
• gender control group: female (n=3); not report-ed (n=1). | • population: patients (n=24)
• ethnicity: - majority: Caucasian people; - low income woman; African Americans breast cancer (n=1); Latino immigrants breast cancer (n=1).
• tumor type: breast (n=16); colorectal (n=1); prostate/ breast (n=1); various types (n=6)
• disease/clinical stage: majority of studies: various disease/clinical stages, from patients undergoing treatment to survivors post-treatment;
- breast cancer: survivors (n=16), early stage in treatment (n=1); recently diagnosed (n= 1); meta-static (n=1); not reported (n=13); colorectal cancer: early stage (n=1); not reported (n=7)
• age: <65 yrs. (n=3); not reported (n=19).
• gender: female (n=16); male (n=1); mixed (n=2); not reported (n=5). |

Table S1 Continued

	General and methodological characteristics of reviews included				General and methodological characteristics of underlying studies in review	
Johansen et al. 2012 Norway [19] 3-5	Via Ovid: • MEDLINE • Embase • PsycINFO • Cochrane Central Register of Controlled Trials • IEEE Xplore • Dates of coverage: (1990-November 2011) • Date of searches: May 2011 and 2 updates in October and November 2011	To create comprehensive an overview of knowledge focusing on electronic communication between patient and provider to improve health care service quality, and to clarify what has been investigated so far regarding different patient groups, health service innovations, research targets and relevant electronic symptom reporting	Inclusion criteria: original study; patients or parents; Electronically reported symptoms or health information to clinical health care personnel or system, where receiver processed and interpreted data and provided feedback; Reported information had to concern symptoms and health status at time of reporting or during preceding few days; RCT comparing electronic symptom reporting vs control where symptom or health information was not received by health care professionals or systems. Exclusion criteria: Retrospective questionnaires, prevalence surveys, general screening on Internet, tests of medications; Electronic communication requiring simultaneous presence of patient and health care personnel; automatic biometric measurements; voice diary.	• Qualitative content analysis of data • Qualitative analysis of study as whole • Quantitative analysis applied: not reported	• 29 studies included. 6 concerned cancer patients. • design: RCT • conditions: eHealth intervention vs: electronic Self-Report Assessment-Cancer: color graphical summary of participant's self-reported symptoms and quality of life issues with predetermined thresholds flagged. No summary handed to clinician (n=1); Touch-screen survey filled out before oncologist visit. Computer scored answers. No results made available to oncologist (n=1); All patients scheduled for outpatient visit used system on tablet computer for reporting symptoms and preferences before consultation. For clinicians, system highlighted patient experienced symptoms incl. severity, degree of bother, importance for patients. Information was not printed, not provided to the patient and clinician (n=1); Use of "Choice": interactive tailored patient assessment tool; touchpad tablet PC, for symptom	• population: people with different illnesses. • 6 studies concerned cancer patients: • tumor type: leukemia/Lymphoma (n=1); breast, lung/colorectal cancer (n=1); not reported (n=4). • disease/clinical stage: not reported • mean age years 67.7 (n=5): 18–86 (mean 54), 23–77 (mean 56.3), ≥18: mean Intervention: 50.- Control: 49 (I+C/2 = mean 49.5) range not reported: (mean 54.9), >18 (mean 56); mean age not reported, 20–85 years (n=1). • gender: mixed (n=6); female, mean (n=6); female, mean 61.3 % (n=5): female 59.5%, female 59%, female 38%, female 73%, female 76.8%; female % not reported (n=1).

2

assessments prior to inpatient and outpatient visits. Assessment summary, displaying patient's self-reported symptoms, problems and distress in rank order of patient's need for support, was not provided to clinicians (n=1). - attention-control group: Completion of touch-screen Health-related quality of life questionnaires in waiting room before every encounter. No summary provided to physicians.
AND - control group: no touch-screen measurement of Health-related quality of life questionnaires before clinic encounters (n=1); standard care (n=1).

- organizational setting control conditions varied: Inside Clinic (n=5); outside/home (n=1).
- control intervention period varied: 2 visits (before treatment, 4–6 wks later) (n=1); before visit, 4 times (n=1); 1 consultation (n=1); up to 1 yr (once per encounter during treatment, once week during hospital stay, once outpatient visit in up to 4 visits) (n=1); approx. 6 mths (n=1); 4 cycles chemotherapy (12–16 wks) (n=1)
- control group: patients (n=6).
- gender control group: not reported (n=6).

Table S1 *Continued*

	General and methodological characteristics of reviews included		General and methodological characteristics of underlying studies in review
Ryhanen et al. 2010 Finland [20] 3-5	• Cochrane Database of Systematic Reviews (Issue 4, 2008) • CINAHL (1982–2008) • MEDLINE (1950–2008) • PsycINFO (1995–2008) • ERIC (1966–2008) • ScienceDirect (1994–2008) • Social Science Citation Index (1956–2008) • Education Research Complete (1990–2008)	To provide a description of internet and interactive computer-based patient educational programs and analyze their effectiveness	<u>Inclusion criteria:</u> RCTs, clinical trials and quasi-experimental studies; English language; Internet-based patient education as use of World Wide Web or with modem connections to central server for communication for patient education; Use of computer with CD-ROMs. <u>Exclusion criteria:</u> Use of computer for generating written patient education materials and e-mails; Use of computer by health care professionals; Solely examining support groups' efficiency; Focus solely on breast cancer screening.	Not reported	• 14 studies included. • design varied: RCTs (n=9); clinical trials (n=2); quasi-experimental (n=3). • conditions: eHealth intervention vs: brochure (n=1); traditional manner (n=1); discussion of general issues with registered nurse (n=1); eHealth intervention + oral negotiations by counselors vs oral negotiations by counselors (n=2), standard face-to-face prevention consultation (n=1), eHealth intervention + standard patient education vs standard patient education (n=1); lay book (n=1), - eHealth intervention (general internet use and for breast health issues) vs no using internet, - eHealth intervention (general internet use) vs not using internet (n=1), eHealth intervention (internet use for breast health issues) vs not using Internet for breast health issues (n=1); no educational interventions named, being in a waiting-list (n=1); status before use intervention (n=3).	• population: patients (n=11); low risk and high risk patients (n=2); women with high-risk prognosis (n=1). • ethnicity: Caucasian, African American, Hispanic American (n=1); Caucasian and African American (n=1); Spanish speaking (n=1) • tumor type: breast (n=14) • disease/clinical stage: already diagnosed (n=6); newly diagnosed (n=1); under treatment (n=1); stage I or II (n=1); stage I or II after receiving biopsy results (n=1); without evidence of recurrent or previous breast cancer (n=1); women with family or personal histories of breast cancer (n=2): high-risk patients, low-risk patients; high-risk prognosis (n=1). • mean age in years: 52.6 (23-77) • gender: female (n=14) • other: Financial incentive given to patients for participation (n=1)

- control group: patients (n=12); low risk and high risk patients (n=2); high-risk prognosis; younger and older women (n=1); minority and Caucasian group mixed (n=2).
- age control group: mean age in years: 52.4 (24-71).

| Salonen et al. 2014 Finland [21] 3-5 | • Ovid MEDLINE (1948–2011) • Ovid Nursing Database (1948–2011). • Cochrane (1991–2011) • CINAHL (1996–2011) • PsycINFO (1997–2011). • Reference lists of included studies. | To evaluate benefits of best available evidence for Internet use or use of computer-based programs for cancer-related information, emotional or spiritual support | Inclusion criteria: quantitative or qualitative design; prostate cancer patients; English language; Use of computer/Internet/websites with CD-ROMs, when programs were interactive; Outcome was reported qualitatively or quantitatively. Exclusion criteria: Dissemination of prostate cancer risks and screening information; Examination of information resources in prostate cancer treatment; Descriptive studies not reporting outcomes; review studies or theoretical articles. | Not reported | • 18 studies included. 9 concerned effects of eHealth interventions. • designs: RCTs (n=2); pre-post-quasi-experimental (n=1); quasi-experimental (n=2), pre-post studies (n=2); qualitative studies (n=2): - face-to-face interview (n=1), - in-depth interviews (n=1). • conditions: eHealth intervention vs standard care (not further specified, n=1); not reported (n=4). • control group: not explicitly reported (n=5). | • population: patients (n=8); patients and spouses/partners (n=1) • ethnicity: Caucasian (Asian people possibly included); English speaking (French speaking people possibly included). • tumor type: (localized) prostate cancer (n=6); prostate cancer and breast cancer (n=3). • disease/clinical stage: often recently diagnosed. • mean age years 64.1 (n=6): 62.4, 62.2, 65.7, 66.7, 62.3, mean intervention: 62.3 mean control: 67.8 (I+C/2 = mean 65.05); age not reported (n=3). • gender: male (n=5); mixed (n=4). |

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Table S1 Continued

	General and methodological characteristics of reviews included		General and methodological characteristics of underlying studies in review
Ventura et al., 2013 Sweden [22] 3	• PubMed (1950-2012); • CINAHL (1982-2012); • PsycINFO (1872-2012); • Reference lists of included studies.	To gather more knowledge of the design of supportive eHealth interventions and to analyze and synthesize that knowledge in a potential explanatory model for those interventions	<u>Inclusion criteria</u>: participants > 18 years; diagnosed with cancer; starting/undergoing/completed treatment; supportive eHealth systems designed and implemented/facilitated by health professionals; all interventions using videos, CDs or DVDs; Interventions constituted educational and/or support tools. <u>Exclusion criteria</u>: Tools developed for pre-disease period; descriptive analyses of health information websites; Report on development (phase I) or exclusively on usability, acceptability, feasibility (phase II).	• Data analysis: ordering, coding and categorization of primary studies. • Results were summarized and integrated into conclusion regarding research problem. • Data analysis led to identification of patterns, themes and relationships that were synthesized in potential explanatory model	• 29 studies included. • design: one group studies (n=11); experimental design (n=18); two arms studies (n=13), three arms studies (n=2), four arms studies (n=3). • conditions: not reported (n=29). • control group: probably healthy women (n=1); not explicitly reported (n=28).	• population: patients (n=29): Underserved (n=4); low literate, multi-ethnic (n=1); Low-income (n=1); Women with hair loss (n=1); Outpatients (n=1). • tumor type: breast (n=18); prostate (n=2); colorectal (n=2); papillary thyroid (n=1); Various types (n=3): prostate and breast cancer; not reported (n=3). • disease/clinical stage: - breast cancer: newly diagnosed (n=10); recently diagnosed (n=2); stage I + II (n=1); under treatment (n=1); not reported (n=7). - prostate cancer: newly diagnosed (n=4). - papillary thyroid cancer: recently diagnosed (n=1). - colorectal cancer: post-operative with stoma (n=1); not reported (n=1). - starting chemo (n=1). - under cancer treatment/ chemo (n=2). • age: <60 years (n=1); not reported (n=28). • gender: female (n=19); male (n=2); mixed (n=3); not reported (n=5). • other: Home interventions: Researchers made it possible to borrow computer and Internet charges were paid for during intervention period

Table S2
Outcomes, effects, conclusions

Reference and score methodological assessment	Time measurements	Outcomes	Results concerning effects of eHealth	Review's conclusions and reflections concerning effects of eHealth on cancer patients
Beatty and Lambert 2013 [13] 5	• Pre-test and post-test after 12 wks	• Distress • Quality of life • Wellbeing	Psychological wellbeing *No effects on:* • psychological distress • emotional wellbeing Physical wellbeing *No effects* Quality of life *No effects* Health status *Positive effects on:* • global perceived health for people with poor baseline levels	Conclusion • Moderate evidence was found for chronic pain-related distress; however, limited research conducted among cancer patients currently precludes conclusions from being drawn. Reflections • Conclusions concerning lack of evidence for effects on cancer patients might be premature given that only one study was conducted. This limits ability to draw conclusions. • Waitlist designs are weaker as control participants are less likely to seek constructive action compared to alternative control-groups, as they anticipate future therapeutic input. • Tentative evidence was found for online interventions leading to significant improvements of physical symptom/disease-control in cancer patients.

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Table S2 Continued

Reference and score methodological assessment	Time measurements	Outcomes	Results concerning effects of eHealth	Review's conclusions and reflections concerning effects of eHealth on cancer patients
Bender et al. 2013 [14] 3	not applicable	All potentially relevant outcomes	**No research found** • No studies concerning evaluation of cancer-focused smartphone applications were found.	**Conclusion** • Considerable number of cancer-focused applications available. • Lack of evidence base in favor of applications, despite mobile devices offering remarkably low-cost, real-time ways to encourage preventive strategies, monitor behaviors, symptoms physiological indicators and provide interventions. • Focus of future efforts should be on improving and consolidating evidence on utility, safety, effectiveness of mobile cancer applications into a whitelist for public consumption. **Reflections** • Majority targeted breast cancer or cancer in general • Increasing number available health apps • Cancer apps on their own have limited potential value in delivering health behavior-changing interventions. • Focus raising awareness / provision educational information Minority od applications combined information provision with skill-building tools assisting in performance of preventive, detection or self-management behaviors. • Limited use of smartphone's technical capabilities, e.g. audio recording, self-monitoring using photos and automated sensing for tracking. Majority uses textual entry or touch screen completion. • Limited use of assistance through mobile sensing platforms of smartphones in automated logging symptoms or health behaviors. • Effective self-management requires effective communication with + support from healthcare team. Limited use features facilitating communication with healthcare team. Restricted to tools identification, prioritizing questions and journaling apps to take notes. • Limited use of advantage of smartphone's social networking capabilities.

- Lack of evidence on effectiveness and description of procedures/data sources is worrisome.
- Over-representation of breast cancer apps, under-representation of prostate, lung, and colorectal apps.
- Current lack of synthesis of regulations on development, evaluation, reporting standards and criteria for selecting health applications.
- Applications potentially cause distress and harm if provided advice is misleading and unsupervised.

| Griffiths et al. 2009 [15] 3 | Various:
· Baseline, wks
· Baseline, 16 wks, 20 wks
· "Baseline", 6 mths post "baseline"
· Analysis mood; First online post, Last online post
· Baseline, 6 wks, 3 mths | · Depression | <u>Depression and anxiety</u>
Positive effects on:
· reduction of depressive symptoms (single-component interventions)

No effects on:
· depressive symptoms in baseline adjusted mean at 12 wks (multi-component intervention)
· depressive symptoms in baseline adjusted difference at 6 wks and 3 mths (multi-component intervention)

<u>Psychological wellbeing</u>
· possibly small association between board use and improved mood (single-component intervention)

<u>Other</u>
· breast cancer Internet Support Groups are more successful than Internet Support Groups focusing on other diagnoses (Fisher exact test, P = .02) | <u>Conclusion</u>
· There is a need for high-quality research on effect of Internet Support Groups on depression outcomes.

<u>Reflections</u>
· Baseline measures of depression were not predictive dropout
· Predictors for non-adherence: poorer coping anxiety, more fatalistic, less pain interference in life, less perceived change in relationships/personal strength
· No baseline differences in demographics, clinical characteristics, depression severity, posttraumatic growth/psychosocial wellbeing between completers and non-completers.
· There is a paucity of high-quality studies: Minority consisted of controlled studies.
· Results yielded about breast cancer Internet Support Groups being more successful than other types of Internet Support Groups, requires further investigation. Women with breast cancer are known for increased risk of depression. If found effective, breast cancer Internet Support Groups could provide an important mental health self-care and prevention tool for women with breast cancer. However, status of current results are unclear given majority of findings being derived from one research group and underlying studies being typically of low quality. |

Table S2 Continued

Reference and score methodological assessment	Time measurements	Outcomes	Results concerning effects of eHealth	Review's conclusions and reflections concerning effects of eHealth on cancer patients
Gysels and Higginson 2007 [16] 4.5	Various: • Pre- test + 2 post-test surveys (2 + 5 mths follow-up) • In some instances, time measurement was not reported	• Knowledge • Satisfaction • Decision making • Treatment choice • Care management	<u>Knowledge and information</u> *Positive effects on:* • information competence after 2 mths at breast cancer patients • information competence after 5 mths at breast cancer patients • information competence for women with breast cancer and of color, uninsured or those with less education • knowledge at breast cancer patients after receiving information about breast cancer treatment • knowledge at patients who started radical radiotherapy after receiving personalized information • overall information comprehension by colonoscopy patients <u>Support</u> *Positive effects on:* • social support after 5 mths at breast cancer patients • social support for women with breast cancer and of color, uninsured or those with less education <u>Decision making</u> *Positive effects on:* • satisfaction with decision making concerning treatment by breast cancer patients *No effects on:* • decision making concerning treatment by breast cancer patients • satisfaction with treatment decision of breast cancer patients <u>Healthcare participation and patient involvement</u> *Positive effects on:* • healthcare participation after 2 mths at breast cancer patients • healthcare participation for women with breast cancer and of color, uninsured or those with less education	<u>Conclusion</u> • Claims of reprioritizing patient education as essential element of patients' management requires evaluation of interventions at different patient groups and in variety of circumstances. • Educational technology as effective and, in most outcomes, superior to traditional methods. They achieved knowledge improvement. • The interventions did not increase anxiety, and in two interventions, lower levels of anxiety were reported. • Computer interventions have a variable impact on patient involvement in decision making. • Inconsistencies are due to diversity in interventions undertaken. • Included studies present only preliminary evaluations. • Various ways of delivering interventions may affect patient responses and thus the extent of personal communication with health professional are one of factors affecting patient responses. <u>Reflections</u> • Studies are heterogeneous in design, instruments tested, content provided, populations examined, outcomes measured and results obtained. Therefore it is difficult to give general answers regarding effective use of the interventions. • Various ways of delivering interventions may affect patient responses: some interventions were administered with assistance of a health professional during consultation. Advantage: Professional can probe somebody's information requirements, thoughts, mood which a machine is not able to do. Disadvantage: focus on medical encounter and danger that complexity of decision-making process may be overlooked. • Pre-consultation devices still directed towards clinical encounter. However, it allows patients more independence, and better preparation.

2

No effects on:
· healthcare participation by breast cancer patients, after 5 mths
· patient involvement in consultations for choosing breast cancer treatment

Depression and anxiety
Positive effects on:
· reduction of anxiety at breast cancer patients during discussion of diagnosis and treatment

Negative effects on:
· anxiety level at 3 mths at patients who started radical radio-therapy, after receiving general information

No effects on:
· depression scores of breast cancer patients during discussion of diagnosis and treatment
· anxiety at colonoscopy patients

Quality of life
Positive effects on:
· quality of life for women with breast cancer and of color, uninsured or those with less education

Health status
Positive effects on:
· mental health score of breast cancer patients suggesting improvement of health status

· Take-away/in-home instruments have advantage that they are available when and where needed. Less focus on specific decisions and recognize information need outside formal healthcare episodes.

Table S2 Continued

Reference and score methodological assessment	Time measurements	Outcomes	Results concerning effects of eHealth	Review's conclusions and reflections concerning effects of eHealth on cancer patients
Hoey et al. 2008 [17] 4.5	Various: • 6 mths post, 1 yr following • 4 mths post, 8 mths period • Baseline, 16 wks, 20 wks • 3 mth period (monitoring), post-test (Scale) • Baseline, 2, 5 mths post-test • Baseline, 12 wks post-test	All potential-ly relevant outcomes	<u>Support</u> *Positive effects on:* • increase informational and social support post intervention <u>Healthcare participation and patient involvement</u> *Positive effects on:* • increase in healthcare participation at 2 mths <u>Depression and anxiety</u> *Positive effects on:* • reduction in depression • reduction in anxiety • reduction in fear <u>Psychological wellbeing</u> *Positive effects on:* • increase in experience of positive changes *Negative effects on:* • increase in emotional suppression <u>Physical wellbeing</u> *Positive effects on:* • reduction in reaction to pain <u>Quality of life</u> *No effects* <u>Empowerment and coping</u> *Positive effects on:* • participation empowered women through: 1. knowledge, 2. sharing experiences, 3. new social world, 4. social intimacy.	<u>Conclusion:</u> Overall conclusion concerns peer support programs in general: • Very little research has specifically explored effectiveness of peer support programs improving psychological outcomes for cancer patients other than breast cancer patients. Therefore, it may not be appropriate to generalize findings to other cancer populations. • Possible that peer support programs are less likely to impact adjustment and quality of life of breast cancer patients, while an abundance of support is already available for this patient group. • Perhaps new, innovative peer-support programs might be beneficial for other cancer patient groups, particularly those for whom a great deal of support is not available. • Some of mentioned methodological limitations compromise confidence in findings. • RCTs with sufficient statistical power for determining small-moderate effect sizes are particularly lacking. • Given limited level 1 evidence on efficacy of peer-support programs, further research is needed determining whether peer support actually assists cancer patients in adjusting to diagnosis. • Review suggests priority should be given to group Internet peer-support programs, when considering ways of offering peer support. <u>Reflections</u> • It is not possible to determine whether psychosocial benefits are related to group Internet format or to some other factor. • Some peer support programs tested in the RCTs went for a longer time-period than other . An extended period of time may be required to develop relationships and build sufficient rapport to enable people to gain psychosocial benefits from peer support.

Stress
Positive effects on:
• reduction in stress
• reduction in perceived stress
• reduction in post-traumatic stress

Social interaction
Positive effects on:
• sense of altruism
• sense of reward from helping others
• group cohesion

Hope
Positive effects on:
• perceived hope

Sense of helplessness, indifference and uncertainty
Positive effects on:
• reduction in sense of helplessness and indifference
• reduction in uncertainty

Universality
Positive effects on:
• sense of universality

Other
• Overall, results indicate that Internet peer support provided encouragement, empowerment, information and a sense of cohesion.
• Reported positive effects on reducing depression, perceived stress and symptoms of post-traumatic stress suggest that program is possibly effective in reducing psychological distress among breast cancer patients.

• RCTs did not find significant effects on quality of life and coping. This might be result of wide range of outcomes used. Some outcomes are possibly not suitable assessing effectiveness of peer support.
• No RCTs screened patients' psychological adjustment/motivation seeking support prior program. Recruiting people with low levels of psychological distress or who are not open to receiving support, possibly limits potential psychosocial improvements and impact on treatment effect sizes.

2

Table S2 *Continued*

Reference and score methodologi-cal assessment	Time measurements	Outcomes	Results concerning effects of eHealth	Review's conclusions and reflections concerning effects of eHealth on cancer patients
Hong et al. 2012 [18] 3	Various: • Pre-test, post-test, 2-5 mths follow-up • Pre-test, post-test, 1 mth • 12 wks follow-up • 12 wks follow-up, 12 mths • Pre-test, post-test, 6 mths • 1, 6, 12 mths follow-up • 4 mths, 12 mths • In some instances, time measurement was not reported • follow-up pre-post studies variation 1-6 mths. Most 1-3 mths.	All potential-ly relevant outcomes	**Knowledge and information** *Positive effects on:* • information seeking • information exchange • health information competence *No effects on:* • barriers to information **Support** *Positive effects on:* • social support • treatment support • advocacy • greater perceived social support **Healthcare participation and patient involvement** *Positive effects on:* • healthcare participation **Depression and anxiety** *Positive effects on:* • depression/mental health outcomes *Negative effects on:* • depression *No effects on:* • depression **Psychosocial and psychological wellbeing:** *Positive effects on:* • psychosocial wellbeing	<u>Conclusion:</u> • Existing studies show promise for achieving positive effects. • There is inconclusive evidence partly due to lack of rigorous evaluation studies. • There is a call for more studies on online cancer support based on more rigorous design methodology, larger study populations including various cancer survivors and underserved communities. <u>Reflections</u> • Rather limited amount of studies reported outcomes concerning online support for cancer survivors. • There is need for more rigorous studies that evaluate outcomes of online cancer support or resources. • Future studies need to focus on other cancer survivors and males. • Generalizing findings to other cancer survivors could be difficult, because of disproportionate focus on women with breast cancer. • Few studies focus on underserved communities like minorities or people with low social economic status. • Important to assess effects of online resources on other languages. • Cultural appropriateness and literacy must also be considered. • Larger studies need to be developed. • Future studies need to employ more rigorous evaluation design with long-term follow-up periods. • Call for more studies that design online cancer support tailored to different disease stages and which incorporate good quality measures, quantity and approach of online support. • Reported outcomes limited to mainly psychological ones. • It is important to evaluate other aspects like information support and personal empowerment.

- psychological wellbeing in intervention and control group
- reduction of negative emotions
- catharsis
- emotional wellbeing

Negative effects on:
- emotional suppression

No effects on:
- psychosocial outcomes
- psychological wellbeing
- no positive effects on mood disturbance
- emotional wellbeing

<u>Physical wellbeing</u>
Positive effects on:
- reaction to pain

No effects on:
- physical wellbeing

<u>Functional wellbeing</u>
No effects

<u>Quality of life</u>
Positive effects on:
- self-reported quality of life

Negative effects

No effects on:
- health-related quality of life

<u>Health status</u>
No effects
- no positive effects on self-rated health status

<u>Empowerment and coping</u>
Positive effects on:
- empowerment

- It is important to evaluate clinical outcomes.
- Evidence regarding outcomes is inconclusive; 4 RCTs reported insignificant or negative outcomes which might be attributed to methodological flaws. Despite, most participants reported positive online experiences.
- Data are especially needed on mechanisms of online support, psychosocial wellbeing and how online information affects decision making.
- Understudied is impact of different modalities of online access on use of online cancer support.
- Need for studies that focus on online cancer support for other cultures, especially for developing countries.

2

Table S2 Continued

Reference and score methodological assessment	Time measurements	Outcomes	Results concerning effects of eHealth	Review's conclusions and reflections concerning effects of eHealth on cancer patients
			No effects on: • coping • no positive effects on cancer adjustment Stress *Positive effects on:* • stress reduction *No effects* Cancer trauma *Positive effects on:* • cancer trauma measures • posttraumatic growth Social interaction *Positive effects on:* • altruism • personal contacts • group cohesion • loneliness • intimacy • social interaction Hope *Positive effects* Universality *Positive effects on:* • universality	

2

Other

• Cancer survivors were more likely to offer support than asking for it. Technical support was more frequently offered than emotional support

• Empowerment occurred via information exchange, emotional support and sharing experiences.

• Minorities reported greater benefits than Caucasian people.

• Most studies found positive effects.

• n=5 pre-post studies; n=1 showed mixed outcomes. Specifically after 2 mths CHESS exposure report of better social support, fewer negative emotions, better healthcare participation and health information competence; However, no effects reported on functional and emotional wellbeing or barriers to information

• n=4 RCT studies; n=0 showed positive outcomes for intervention compared to control group.

- 27-wks online support system led to no positive effects on mood disturbance, cancer adjustment or self-related health status. However, psychological wellbeing improved in both intervention and control group

- 12-wks online coping group showed no effect on health-related quality of life or psychological and physical wellbeing. However, a trend of better emotional wellbeing intervention was observed.

- intervention group of online peer support showed more psychological distress and poorer quality of life. There were no differences in perceived social support, self-efficacy or hope

Table S2 Continued

Reference and score methodological assessment	Time measurements	Outcomes	Results concerning effects of eHealth	Review's conclusions and reflections concerning effects of eHealth on cancer patients
Johansen et al. 2012 [19] 3-5	Various: • Equal to duration/ frequency of intervention. • 2 visits (before treatment, 4–6 wks later) • Before visit, 4 times • 1 consultation • Up to 1 yr (once per encounter during treatment, once week during hospital stay, once outpatient visit in up to 4 visits) • Approx. 6 mths • 4 cycles chemotherapy (12–16 wks)	All potentially relevant outcomes	<u>Support</u> *Positive effects on:* • reduction on perceived needs. However, no difference between intervention group and control group. <u>Depression and anxiety</u> *Positive effects on:* • reductions of anxiety levels and depression. However, no difference between intervention group and control group. <u>Psychological wellbeing</u> *Positive effects on:* • positive effect on emotional wellbeing was associated with data feedback *No effects on:* • no association between better emotional wellbeing and instrument completion <u>Quality of life</u> *Positive effects on:* • clinically meaningful improvement and better of health related quality of life. However, no difference between intervention group and control group • association between improvement of health related quality of life and explicit use of health related quality of life data, discussion of pain and role function <u>Symptoms</u> *Positive effects on:* • decrease in symptom distress, over time • decrease in need for symptom management support, over time • patients who reported debilitating physical symptoms at visit 2 are less likely to report debilitating physical symptom visit 3.	<u>Conclusion</u> • So far, research focused on five specific patient groups, among which cancer patients. • The evidence can be structured into four health service innovation categories: consultation support, monitoring with clinician support, self-management with clinician support, and therapy. Most of the research has been conducted within four combinations, among which consultation support innovation in the cancer patient group. <u>Reflections</u> • Cancer patients who receive chemotherapy or radiation therapy (or both) for a period from 6 months to a year could theoretically benefit from both monitoring and self-management approaches. Yet, electronic symptom reporting for this group of patients has mostly been studied in the context of consultation support.

| Ryhanen et al. 2010 [20] 3-5 | Various: • Pre-education, post-education, post-visit • Pre-intervention, post-intervention, post-counselling tests, 6 mths follow-up • Pre-test, post-test, 9 mths follow-up • Pre-operative, pre-surgery, post-surgery • Pre-test, 2 mths, 5 mths follow-up • Pre-test, 12 wks follow-up • Pre-test, post-test 4 mths after • Pre-test and post-test measures, not specified • One measure • Duration of trials: Not specifically reported. | All potentially relevant outcomes | Knowledge and information
Positive effects on:
• increase in knowledge level about breast cancer
• increase in knowledge level due to interactive method
• perceived information competence
• information competence for those who spent more time in the interactive series

Support
Positive effects on:
• increase in social support

Decision making
Positive effects on:
• content of information helped patients to make decisions
• useful in decision-making

Healthcare participation and patient involvement
Positive effects on:
• healthcare participation
• content of information influenced behavioral in taking care of breast health and participate in healthcare

Depression and anxiety
No effects on:
• depression
• anxiety. Anxiety level was higher after face-to-face counselling

Social interaction
Positive effect on:
• decrease in loneliness

Other
• The most common outcome measures were issues related to knowledge and satisfaction-related issues
• Issues pertaining to decision-making and quality of life were also measured.
• Some other issues like social support, coping, stress, loneliness, depression and anxiety were tested. | Conclusion
Results suggest:
• Positive relationship between Internet or interactive computer-based patient education program use and knowledge levels of breast cancer patients. This also has a positive effect patient satisfaction.
• Use of Internet and interactive computer programs are associated with better health information competence. However, use of Internet or interactive computer programs did not independently contribute to enhanced learning outcomes.
• Education method: a) did not affect patient involvement although, b) patients tend to learn more about breast cancer treatment after using multimedia program than after reading a brochure and c) greater proportion of women in intervention group reported they had assumed a significantly more passive role than originally preferred after using interactive computer program.
• Internet can be used to raise knowledge level although results do not show expected outcomes on patients' behavior.
• There is a need to develop and to research Internet-based patient education.

Reflections
• No clear effect of Internet or interactive computer-based patient education on care of breast cancer patients identified, because effects differed across studies.
• Most results were not statistically significant except for knowledge-related issues and some single outcomes.
• Different instruments were used. Most of them were specifically designed for the study, which makes it difficult to compare outcomes.
• Some outcome issues were measured in only one study.
• Outcomes measures varied widely which makes it difficult to establish effects of patient education with Internet or interactive computer.
• Internet or interactive computer-based patient educational programs for breast cancer patients care are effective in increasing patients' knowledge about breast cancer and useful in decision-making regarding participation in care
• The methodological quality of the studies varied widely and in some studies was quite poor. |

Table S2 Continued

Reference and score methodological assessment	Time measurements	Outcomes	Results concerning effects of eHealth	Review's conclusions and reflections concerning effects of eHealth on cancer patients
Salonen et al. 2014 [21] 3-5	Various: • Time diagnosis, 4 mths • Enrolment, 1-2 wks post-intervention, 3 mths later • Pre-post In some instances, time measurement was not reported	All potentially relevant outcomes	Knowledge and information *Positive effects on:* • increase in ability to understand treatment options • better preparation for discussion of treatment options • promotion of knowledge gains Support *Positive effects on:* • improved satisfaction with cancer information for men • marginal improvement of perceived oncologist informational support for men Decision making *Positive effects on:* • increase in levels of decision control after treatment decision in both intervention and control group • reduction of levels of decision conflict after treatment decision in both intervention and control group • increase in patient involvement in decision making *Negative effects on:* • decrease in partner involvement in decision making Depression and anxiety *Positive effects on:* • reduction of depression symptoms Psychological wellbeing *Positive effects on:* • reduction of psychological distress for patients and partners, at 4 mths • reduction of (psychological) distress	Conclusion • This review supports conclusion that computer or Internet-based patient education can improve patients' knowledge, self-efficacy and provide emotional and spiritual support. This conclusion is consistent with other systematic reviews. • Social integration and knowledge sharing occurring through these new technologies possibly increase understanding of disease, treatment options and side effects. • Development on computer and Internet-based programs for prostate cancer patients is still ongoing. • The need to provide more informed and interactive information resources aimed at patients for patient education purposes has underlined benefits of using computer technology to support and improve patients' knowledge during learning process. Reflections • Difficult to compare interventions and their impact, because of dissimilarity of multimedia and single media intervention. • Therefore, no conclusions can be made or any specific advice given for future regarding technology or outcome quality. • The review limitations were based on relatively small number of included articles and included studies contained various methodological weaknesses. This urges for caution in drawing firm conclusions.

2

Quality of life
Positive effects on:
• increase in long-term quality of life related to sexual function-
ing and cancer worry. No difference between intervention and
control group
• prevention of deterioration of functional quality of life and
mental quality of life

Empowerment and coping
Positive effects on:
• patients were more empowered to discuss their disease which
led to ability to control and deal with disease

Table S2 Continued

Reference and score methodological assessment	Time measurements	Outcomes	Results concerning effects of eHealth	Review's conclusions and reflections concerning effects of eHealth on cancer patients
Ventura et al., 2013 [22] 3	All studies longitudinal: • Before-after design • Until 12 mths after inclusion	All potentially relevant outcomes	<u>Support</u> *Positive effects on:* • increase in social support • use of interactive services alone likely improves social support *No effects on:* • social support <u>Decision making</u> *Positive effects on:* • increase in decision making variables <u>Healthcare participation and patient involvement</u> *Positive effects on:* • increase in healthcare participation • association between Caucasian people with early-stage breast cancer and increased healthcare participation *No effects on:* • healthcare participation <u>Quality of life</u> *Positive effects* *No effects* <u>Health status</u> *Positive effects on:* • increase in general health *No effects*	<u>Conclusion:</u> • eHealth interventions that allow informational and supportive needs being satisfied are being designed and implemented and are likely to have positive effects on number of outcomes for individuals with different preferences and priorities. • Even though several communalities could be found in the reviewed interventions, methodological aspects of the design, implementation and evaluation remain unclear. Models and applied theories are needed to clarify such issues, thus enhancing the credibility and applicability of supportive eHealth interventions across target populations. <u>Reflections</u> • Despite similar purposes, interventions analyzed seem to lack common structure linking all aspects of a supportive eHealth program. Lacking such a structure, interventions are difficult to adapt across cultures or cancer patient groups and are barely replicable. • Internet interventions seem to produce favorable change behavior and positive outcomes, although process of achieving them remains unclear. • Overall satisfaction and quality of life are considered being multidimensional variables affected by several factors. These variables thus can hardly be seen as a direct result of supportive eHealth interventions, but more as an ultimate outcome. • Most researchers developed own measurement instruments which might lead to erroneous interpretations of results when comparing several effectiveness reports. Different instruments do not allow comparison across outcomes. • Majority of studies focus on women with breast cancer. Although some studies focus on prostate cancer, gender comparisons regarding intervention use and outcomes are not provided.

2

Health competence and health literacy
Positive effects on:
· increase in health competence
· use of both information and interactive services likely leads to improvements in health competence
· increase in health literacy

No effects on:
· health literacy
· health competence

Empowerment and coping
Positive effects on:
· increase in self-care ability
· improvement in coping

No effects on:
· coping

Overall satisfaction
Positive effects

No effects

Other
· Most commonly measured outcomes: health literacy, incl. various aspects disease, treatment, side-effects knowledge, healthcare services and/or self-care
· Selective use eHealth interventions more likely to predict benefits than total time spent using intervention

CHAPTER 3

Perspectives of cancer patients on self-management activities: an online focus group and interview study

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ABSTRACT

Self-management activities were previously mainly identified in people with chronic conditions. This study explored curable and incurable cancer patients' self-management activities, their support needs and their experiences with eHealth in this regard, through online focus groups and semi-structured individual interviews. All transcripts were analyzed qualitatively. Main themes were categorized using the four self-management domains in the Dutch General Model of Self-Management.

All 24 cancer patients appeared to undertake comparable self-management activities, irrespective of the disease stage. Self-management activities of particular importance include gathering disease and treatment related information (Experience-Based Knowledge), pouring out your heart, accepting the situation and setting limits (Living with the Condition), considering information from the doctor, your own feelings and the consequences of treatments in decision-making (Contributing to Care), and arranging financial assistance and care yourself (Organization of Care). Participants had little need of additional support from, e.g. a nurse. Despite a generally positive attitude towards eHealth, participants stress that it cannot replace personal contacts with nurses or other healthcare professionals.

Nurses and other healthcare professionals should assess self-management activities of particular importance to cancer patients, for optimal self-management support. Additionally, nurses could promote the use of eHealth, being aware that eHealth cannot replace personal contacts.

INTRODUCTION

In the last decade, the concept of self-management has received increasing attention in the scientific and professional literature. Self-management can be described as an individual's ability to manage their physical and psychosocial symptoms and to make decisions concerning treatment and/or care in order to optimally incorporate the disease in their daily life and to maintain a satisfactory quality of life despite the disease [1,2].

Most research in this area has been done on people with chronic diseases such as diabetes and Chronic Obstructive Pulmonary Disease [3-5]. Results show that self-management helps self-efficacy [3] and improves health-related quality of life [5]. Self-management covers several different domains. In the Dutch national care standard on self-management [6], four self-management domains are distinguished as part of the General Model of Self-Management [7]. These are:

1. Experience-Based Knowledge; The patient acquires knowledge about their health problem. This knowledge is based on general information about the disease and it accumulates as they draw on their own experience, to become their own, personal field of knowledge. The patient learns to recognize the disease's progress, the desirable and undesirable effects of the treatment and what has a positive or negative effect on their health. This experience-based knowledge lets the patient deal with the disease and the associated consequences appropriately, and gives them a place in the patient's life.
2. Contributing to care; The patient monitors his health, and makes decisions about the preferred treatment and care. The patient invests in interventions that help him mitigate the consequences of the condition.
3. Living with the Condition; The patient's activities that allow him to live a satisfactory life by coping appropriately with the physical, emotional, and social consequences of the disease.
4. Organization of Care and Support; The patient's activities that enable him to find out about, decide on, and arrange appropriate support and care [6,7].

When undertaking the activities in these domains, patients may require the support of professionals in addition to the support they receive from their family [8]. In addition, eHealth (for example online monitoring applications and personal electronic health records) might be useful in supporting self-management [9-12].

The research literature on the relevance of the above-mentioned self-management domains and sources of support is not as extensive at present for the case of cancer as in the case of chronic diseases such as diabetes. The existent literature is scattered and mostly related to specific tumor types [13-15] and/or

very specific self-management strategies regarding e.g. fatigue, social contacts, everyday life occupations [16-20]. In addition, to our knowledge there have not yet been any studies of self-management and its perceived importance comparing cancer patients who are being treated with curative intent with patients in the palliative stage. Therefore, the objective of the present study was to gain insight into which self-management activities cancer patients undertake, in which self-management domains, at different stages of the disease. The research questions addressed are:

1. a.   Which self-management activities do cancer patients engage in?
    b.   Do patients find self-management activities important, and if so, why?
2. In which domains of the General Model of Self-Management can these activities be categorized?
3. Do cancer patients need support in their self-management from professionals and/or via eHealth?
4. Do cancer patients in the palliative stage differ from patients who are being treated with curative intent with regard to their self-management activities and self-management support needs?

METHODS

Recruitment and sample

Patients were recruited in various ways: from a pre-existing Dutch nationwide panel study of chronic illness, which also included cancer patients in family doctor practices [21]; via outpatient oncology wards; via homecare organizations; and through social media.

The recruitment resulted in a sample of 24 adult cancer patients (12 males and 12 females), with a mean age of 65 years. 11 participants had curable cancer and nine participants had incurable cancer. The disease stage of four participants was unknown. Their background characteristics are shown in Table 1.

All participants signed an informed consent form prior to participating in an online focus group or interview. In accordance with Dutch legislation, the study did not need a review by a medical ethical committee because the participants were not subject to procedures or required to follow rules of behavior [22].

Table 1 *Patient characteristics (n=24)*

	Total (n=24)	Online focus groups (n=14)	Interviews (n=10)
Sex			
Male	12	8	4
Female	12	6	6
Mean age (range)	65 (43-88) (n=20)	63 (47-75) (n=10)	67 (43-88) (n=10)
Educational level			
General secondary education and pre-vocational training	6	5	1
Senior general secondary education and pre-university secondary education	2	0	2
Secondary vocational education	2	0	2
Higher vocational education and university	8	5	3
Data missing	6	4	2
Cancer type			
Prostate	6	5	1
Colorectal	4	0	4
Breast	3	2	1
Hematological	3	0	3
Neuroendocrine	2	1	1
Melanoma	1	1	0
Head and Neck	1	1	0
Data missing	4	4	0
Time since diagnosis			
Less than six months	2	0	2
Between six months and two years	3	0	3
More than two years	15	10	5
Data missing	4	4	0
Treatment aim(s) (could be multiple)			
Curative	11	6	5
Palliative and/or Life Prolonging	10	5	5
Data missing	4	4	0

3

Data collection

In January 2015, three online focus groups were organized: two with patients only and one with patients together with their informal caregivers. In the online focus group that consisted of patients and informal caregivers, only the patients' contributions were analyzed for this paper.

The online focus groups were carried out asynchronously, meaning that participants were able to log in to the website of the online focus group and participate by writing their responses in discussion threads at a time of their choosing, 24 hours a day, and without having to wait for other participants to join the discussion [23]. Privacy was protected by using aliases and personal login names and passwords for logging in to the secure websites of the online focus groups. Participants were not able to see each other; all discussions were in writing.

All online focus group discussions continued for two weeks. Every two days, one or more questions concerning self-management or self-management support were placed online by the moderator (VNS). The discussions were moderated by posting additional questions to clarify participants' responses. Transcripts of the discussions in the online focus groups were generated automatically.

For practical reasons (i.e. avoiding travel time for the patients), we initially planned to solely organize online focus groups. However, after conducting the online focus groups, there was a need for additional information. Therefore, semi-structured individual interviews were conducted as this is a qualitative method suitable for acquiring more detailed information and for understanding interviewees' personal views on certain topics [24]. The individual interviews with newly recruited patients were conducted by the first author (VNS), and at the patient's home (or other preferred place). The individual interviews took 60 minutes on average, and were audio-recorded and transcribed verbatim.

The topics and semi-structured questions for the online focus groups and interviews were derived from the General Model of Self-Management [7] and existing literature, e.g. on patients' supportive needs [25]. Additional questions concerned the use of eHealth in self-management and self-management support. See Box 1 for examples of questions posed in the discussion threads of the online focus groups. Some questions or topics were amended or added to the interview guide during the study on the basis of insights from interim analyses.

Box 1   *Examples of questions posted on the website of the online focus groups*

Physical complaints such as fatigue, pain, and loss of appetite often occur with cancer. These complaints can have consequences for the daily life of someone with cancer and their close relatives.

1. Does this description fit your own experience?
2. If so, what can patients or their close relatives do to deal with physical complaints in their daily life?
3. Would you like information and support from a nurse or other care professional when dealing with physical complaints in your daily life?
4. In this context, what are your views on the usefulness of eHealth, i.e. information and support via the Internet (on the computer, iPad etc.) or via smartphone applications?
5. If you look at the previous questions and the answers, do you think it makes a difference whether someone still has a chance of being cured of cancer or not?

People with cancer have to make decisions about the treatment or care they want, often doing so with their close relatives.

1. Does this description of choices that need to be made about treatments or care fit with your experience? Can you give examples of situations where this happens?
2. Who do you normally discuss such decisions with?
3. How do you make a decision about treatment and/or care?
4. What is important to you when making such a decision?
5. Would you like information and support from a nurse or other care professional when making decisions about treatments or care?

Data analyses

Data analysis of the online-focus-group transcripts commenced immediately after the online focus groups started, following a cyclical process of collecting data, analyzing data, collecting new data, and so on.

All transcripts of the online focus group discussions and the interviews were analyzed qualitatively by first reading and rereading the transcripts, and subsequently by coding them inductively. Next, the themes and subthemes emerging from the inductive analyses of the transcripts were deductively categorized according to the four self-management domains of the General Model of Self-Management (see 'Introduction').

All online-focus-group and interview transcripts were analyzed independently by the first author (VNS) and at least one co-author. The main themes and subthemes were discussed by the analyzing author and co-authors.

RESULTS

Participants' self-management activities

An overview is presented in Figure 1 of the themes resulting from the analyses of the transcripts according to the four self-management domains — Experience-Based Knowledge, Contributing to Care, Living with the Condition, and Organization of Care and Support — in the General Model of Self-Management [7]. The themes are discussed further in the sections below.

Nearly all participants mentioned self-management activities that can be classified in one or more of the self-management domains. Most of the self-management activities mentioned by the participants can be classified in the domains Living with the Condition and Contributing to Care. The next most common domain is Experience-Based Knowledge. Self-management activities that can be classified in the domain Organization of Care and Support were mentioned least often.

Some participants were active in all domains while others were only active in two domains, for example Experience-Based Knowledge and Organization of Care. There were also participants who only appeared to be active in one domain.

Experience-Based Knowledge	Contributing to Care	Living with the Condition	Organization of Care and Support
- Searching for information on the Internet - Talking to peers - Relying on information and advice from a doctor - Basing on own information and previous experience	- Using experience-based knowledge - Weighing up options and taking account of: * own wishes/needs * people around you * consequences of taking/not taking action	- Listening to your body - Pouring out your heart - Letting go and acceptance - Making yourself the priority - Learning to find a balance between doing things yourself and getting help	- Arranging treatment in another hospital - Requesting home care - Engaging other disciplines (medical psychologist, dietician, social worker) - Requesting financial assistance

Figure 1 *Themes categorized in the self-management domains of the General Model of Self-Management*

The degree of involvement in the different domains also seemed to vary between individual participants. For instance, some participants seemed to be 'passive' with regard to the Experience-Based Knowledge domain but 'active' in the Contributing to Care domain. These participants said that they do not actively search for information but they did explain how they take decisions and what is important in this for them.

Experience-based knowledge

According to the General Model of Self-Management, Experience-Based Knowledge means building a knowledge base consisting of general information about the disease and personal experiences with living with the disease.

On the one hand there were participants who said they did not search for information themselves, for example about a treatment. They said they felt no need for this as the information they received from their doctor or nurse was sufficient. Some participants, on the other hand, did actively search for information. They said they obtained the information from a variety of sources, for example talks, patient associations and their websites, and peers as well as through forums for sharing experiences (see too 'Use of and opinions about eHealth').

There seems to be a difference between participants who were being treated with curative intent and participants in the palliative stage of cancer. The latter category of participants generally seemed to be more actively searching for information about the disease, complaints, and treatments. There was less prognosis-related variation in the importance participants attached to information, with both groups often mentioning the same topics (see the following paragraphs).

Searching for information yourself: importance and motivation

Some participants said they actively searched for information themselves about cancer, symptoms, treatments, and side effects. They mentioned that they find it important to have information in order to take the right decisions and to understand the disease and their complaints. This gives them a feeling of certainty and being in control:

"That [knowing what is going on, ed.] gives me a good feeling. Kind of being in control. Of course that's not true at all, but I feel like I'm in control. (...) I want to have an overview of what there is now and what's up ahead. So yes, I think that is a way of … of having a kind of certainty. Like you're in control so you don't need to be afraid of anything." (pat. 13, palliative stage)

These participants also explained that they use the information so that they can take action if anything happens, for example take decisions about a treatment or care, or obtain more new information from the doctor. They draw up a list for example with questions that they would like to ask the doctor in the next consultation. However, this did not work for everyone.

"I'm not the kind of person who drives to the hospital beforehand saying: now I'll ask the doctor that, and then... I do have a few questions but I wait and see what happens. Because I'd already discovered that nine times out of ten, if I was prepared for something it turned out differently. And that brings you disappointments. So I find it very important to approach things with an open mind." (pat. 18, palliative stage)

The participants who were actively gathering information often said this was something they had always done as they were curious and had a thirst for knowledge. This had not changed since they became ill. But this did not apply to all participants, as one participant was more alert about his treatment and care due to previous negative experiences.

"But I saw this go a bit wrong with my father, you know, perhaps that glitch made me think I really don't want that happening to me. Perhaps that's why I keep a close eye on things, you know, why I want to know what chemo I'm getting, I want to know everything. I want to find out about everything." (pat. 15, curative stage)

Patients who actively searched for information themselves often said they did not need any (additional) support in dealing with physical or psychological complaints. However, they often also added that they were not always satisfied with the quality of the support. They mentioned the lack of time for the patient, and lack of understanding and compassion; specialists focused mainly on the disease and the treatment, and did not consider the patient's perspective sufficiently.

Furthermore, patients who had another disease in addition to cancer said that specialists were not aware of each other's involvement and the patients themselves had to point out to the specialists that there was more going on than just the cancer.

Contributing to care
The General Model of Self-Management describes Contributing to Care as activities regarding health monitoring, and making decisions about the preferred treatment and care.

All participants said that having to make decisions about treatment and/or care fitted with their own experience with living with a disease. Some participants also

talked about the considerations underlying the decisions that these participants had made or were still making.

There seems to be a slight difference between participants who were being treated with curative intent and participants in the palliative stage of cancer, whereby participants being treated with curative intent were somewhat less explicit about how they took decisions. When talking about how participants in general take decisions and what is important to them then, both participants who were being treated with curative intent and participants in the palliative stage of cancer mentioned the same topics (see the following paragraphs).

Using experience-based knowledge

Participants often said that they relied on what the doctor advised or told them when taking the final decision for example on whether or not to start a treatment. They said that they assumed the doctors knew what they were doing. Participants who actively searched for information gave examples of situations in which they also took information they had obtained themselves into account when taking a decision about a treatment or care, or even when proposing a treatment themselves.

"[…] in my case, I had a huge hypersensitive reaction to anti-hormone tablets. My oncologist wanted to continue with them but I didn't. I'd been to some talks by oncologists about hormonal therapy and I'd heard there that 50% of women don't need it. So I had side effects from drugs that weren't even definitely going to help me. I had all the side effects mentioned in the Patient Information Leaflet. So I stopped." *(pat. 11, stage unknown)*

Considerations in decisions

When taking a decision, participants also took their own feeling and previous experience with a treatment into account. For example, one participant said that they did not want to undergo a certain treatment again as it had made them very sick in the past. The participant did not want to put themselves and the people around them through this again.

These participants also said they wanted to carry on enjoying life for a while or wanted to continue living with their partner for as long as possible. They also mentioned reasons that had to do with the fact that a treatment needs to have benefits. Participants were still able to enjoy life and do things at the moment. But if this would no longer be possible or if you are no longer able to be yourself and are dependent on help, then that would be the end.

Living with the condition

Living with the condition, as described by the General Model Self-Management, covers activities regarding living a satisfactory life by being able to deal with the physical and emotional consequences of the disease, and the effects the disease has on e.g. family, friends, work, spare time, and recreation.

Participants seemed to cope when having to deal with fatigue, a loss of energy, uncertainty, worries, the fact that they have a (possibly incurable) disease, and the effect it has on their social contacts. However, some participants said they had had support for certain complaints.

There did not appear to be a difference between participants who were being treated with curative intent on the one hand and participants in the palliative stage of cancer on the other in their self-management concerning physical and/or psychosocial complaints and changes in their daily lives. Regarding this self-management domain too, all participants mentioned the same topics (see the following paragraphs).

Listening to your body, scheduling quiet times

Participants who were affected by fatigue and a loss of energy said that they dealt with these complaints by listening properly to their bodies, scheduling frequent quiet times, and picking things up again step by step. Participants said that you can find out what you can and cannot do, what you are and are not capable of by constantly testing your limits and by doing more and more. Changing their daily and/or weekly schedule also helped them get through the day despite their complaints. Participants also said that you had to grab a rest when you needed it.

"I try to plan as much rest as possible but that's not always easy. But I do go to bed early to get plenty of rest. If I'm out during the evening or the entire day then I drink a glass of coke — which I never normally would — and that gives me just enough energy to get through the evening or day." (pat. 14, stage unknown)

Participants who received help and support in dealing with these complaints talked about loved ones who took over household tasks, for instance, or the home care service providing help with personal care and/or a physiotherapist helping them build up their physical fitness again.

Pouring out your heart

Participants who suffered from uncertainty and worries talked about how important it is to pour your heart out and let off steam. It helps you to express what is on your mind and talk about things because then you are rid of it and able to process it.

However, some participants commented that you should not spend too much time talking about such feelings and you need to allow for the fact that not everyone wants to hear this.

"It doesn't improve your outlook and it's important not to have the approaching end dominate your life. That's not only hard for the patient but definitely for your loved ones and partner as well. You also need to be able to laugh." (pat. 5, palliative stage)

Not all participants were able to deal easily or as they wished with complaints such as anxiety or worries, or being ill in general. Indeed, some participants received support from a medical psychologist or social worker.

"I think … well, OK, I just have to accept what I've got. But it's taken a long time. In the hospital, they said, perhaps you should see a medical psychologist? You don't talk about yourself at all. I don't do that very easily, not to strangers. So then I went … but it did actually help." (pat. 23, curative stage)

Letting go, accepting, and remaining positive

Participants who said they did not experience any anxiety or somber moods explained that this was because they "accepted it," "remained in the here and now," "stayed positive," and "went with the flow". This made them feel calm. The same applied for dealing with the fact that they were no longer able or allowed to do the things they were used to doing. Participants who experienced this said that they accepted it.

"You have to look reality square in the face. Just say: guys, I need to get on with my life. What you've got is a loss, you have your weaknesses, and if you can just deal with that and not give up, then you can really get somewhere." (pat. 21, palliative stage)

Changing social network: accepting, stating your limits, learning to give yourself priority, and learning to find a balance being doing something and letting others do it

Participants often said that their social network had changed since they became ill. Some friends and acquaintances had stopped contacting them and no longer visited. Participants stated that they were disappointed and sometimes angry about this. But here too, participants said that they let this go and accepted that people were no longer in contact. Some participants also pointed out how irritating it was that people assumed you were unable or not allowed to do anything anymore now that you were ill, and that these people started to take over from you. They said that you

should do the things you are still able to do yourself and make agreements with the people around you for the things you are not able or allowed to do. Talking about this, one participant said: *"I expect the family to take you seriously and not spare you. I prefer to set my own limits. You should always let someone own the situation for as long as possible. Even if they'll need more and more care." (pat. 14, stage unknown)*

Following on from the above, participants said you should also not stop doing the things that you enjoy. One participant, for example, explained how much joy looking after a grandchild brings, even though it resulted in being exhausted and bone-weary all next day.

Organization of care and support

According to the General Model of Self-Management, the Organization of Care and Support encompasses activities in which the patients find out about and arrange appropriate support and care themselves. Examples are home care or the physiotherapist, as well as financial assistance.

Among the participants who had received different kinds of assistance or care were participants who said they had initiated this themselves as well as participants who had not done so. There were also participants where it was not clear who had taken the initiative. Furthermore, there were participants who had not received any form of support or assistance other than the care they were already getting.

There did not seem to be a difference between participants who were being treated with curative intent and participants in the palliative stage regarding the organization of care and support. The two groups also seemed similar in terms of the different (paramedical) disciplines that were engaged, and the financial measures that were taken.

Participants who organized care or support on their own initiative did so because the care providers did not pay any attention to that aspect or because they were dissatisfied with the support that they were receiving at the time.

"I've always been healthy and know virtually nothing about the Dutch medical system, and I was amazed at times about the lack of communication. I found it difficult to deal with the fact that the brochures were promising all this support… that turned out to be empty words in practice. That caused a lot of stress. Organizing things myself did help me from the point of view of my treatment, but because I don't know the ropes I did sometimes need the help of the oncological nurse who was there, fortunately, and the help of the family doctor. Anyway, I managed it…so OK. But it was a painful learning process." (pat. 6, palliative stage)

The group also included the participants who actively went in search of information and wanted to know everything about their disease and treatment. Some participants, for example, had organized their own treatments and applied for financial aid.

Use of and opinions about eHealth

Some participants said they felt no need for information and support via eHealth. However, they could imagine that others might have that need.

Participants' experience with eHealth mainly took the form of using the Internet as a source of information and reference works, the electronic medical record, and e-mail contact with their doctor about the treatment or specific symptoms, for instance. The participants who actively worked on their experience-based knowledge were also often the participants who used eHealth to a greater or lesser degree. These participants said that when they used the Internet, they tended to look for information in reliable sources and did not generally read the stories of peers.

"I looked up an awful lot on the Internet and I just ignored all the blogs — because that weighs people down; I focused purely on what doctors have written. You do need to read the good things and not what people... Right, because my experience of pain is different to your experience." (pat. 20, palliative stage)

These participants also said that it actually made them distressed as the online forums are often about the somber and negative experiences. In addition, not everything is applicable and it only makes you uncertain.

The fact that information is not always applicable was mentioned by other participants as a reason why they did not use the Internet. Furthermore, there is sometimes so much information that you do not know what is correct.

Participants said that an eHealth application should therefore offer targeted information. No two patients are the same and everyone experiences their illness in a different way, explained one participant. Another participant said that tailored solutions makes all the difference.

The participants who used the Internet as a source of information were also often the ones who made use of their electronic medical record as well. They mentioned advantages such as the fact that you can see at a glance how you are doing, both in the hospital and at home. You can also see your results and the communication between the various specialists and the family doctor.

"I really like the fact now that I'm connected up. That I can see at home if there's a new message or when my appointments are. So I really like that. But also the feeling that you're involved. So if the hematologist writes a letter to my family doctor, I can read it. Or if there are some results, I can see: oh, right, that's going well." (pat. 18, palliative stage)

These participants were also generally positive about the e-mail contact with doctors. The lines of communication were shorter and more focused. It is also useful if you just want to check something about the treatment or a complaint. On top of that, it saves on a trip to the hospital, which helps you feel less of a 'patient'. However, they did not always prefer e-mail and it was not always effective: *"When you talk to a doctor, you say more in ten minutes than you wrote in thirty-five e-mails." (pat. 21, palliative stage)*

Although these participants made use of eHealth, they also stressed that eHealth is not appropriate for everything or all situations. For example, participants mentioned that it was not a good option in situations where there was still a great deal of uncertainty, for 'bad news' talks, or for important results. Personal contact was also needed because sometimes you needed the specialist's ability to empathize or their powers of persuasion when deciding whether or not to start a treatment. But you also needed the personal contact of a nurse passing by who spontaneously asks how you are doing. This is not possible with eHealth.

Participants who were being treated with curative intent had the same views on this subject as participants in the palliative stage of cancer.

DISCUSSION

Irrespective of their disease stage, people who are confronted with cancer mainly seem to undertake self-management activities in the self-management domains of Experience-Based Knowledge, Living with the Condition, and Contributing to Care. They undertake fewer activities in the domain of the Organization of Care and Support.

One of the self-management activities in the Experience-Based Knowledge domain is searching for additional information. Some participants did this because they had a natural curiosity and thirst for knowledge. Others, on the other hand, did this from a need for support: In their eyes, these participants had not received enough information from the doctor or nurse. Participants searched for information themselves because they found it important to be informed and because they wanted to know what their disease involved, what effect the disease would have on them, and what treatments were available. These findings are in line with a longitudinal interview study by Hansen et al. about the illness experiences of patients with hepatocellular carcinoma at the end of life: they also said they had searched for information, in part because they wanted to understand what was happening to their body [15].

People who are confronted with cancer sometimes choose not to undergo a treatment or discontinue a treatment because of the side effects and the desire to maintain their quality of life [15]. People also often weigh up what benefits a treatment will bring against the effect it will have on their lives. Such considerations and decisions fall within the Contributing to Care domain.

Furthermore, it seems that people who are confronted with cancer want to live the life they were used to for as long as possible, even if that costs more effort and time than in the past. A corollary is that they do not want to be treated as a patient or as 'different' by the people around them. Various studies among patients with different kinds of advanced cancer also show that these are key issues when dealing with cancer [18,19,26]. A study by Lewis et al. of how women with metastasized breast cancer deal with their disease showed that they sought to lead as normal a life as possible, for example by starting to do the housework again or by maintaining social contacts and taking part in social activities [18]. The household tasks gave their lives a purpose and value again while the social activities were important for them in making sure that people saw them as a normal person rather than a cancer victim [18].

Despite the importance of aiming for as normal a life as possible and participating in social activities when dealing with cancer, these two goals can be difficult to achieve precisely because of the cancer. The patients in our study said

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that physical symptoms such as fatigue prevented them from continuing to practice certain pastimes or welcome visits from friends and family. The self-management activities that they undertook to deal with this were listening to your body, taking rests, and changing the daily schedule, also mentioned in the study by Peoples et al., investigating how patients with advanced cancer manage their daily lives [19]. Besides changing their daily schedule, patients also made choices about which social activities to take part in and which social contacts to maintain. These choices were also described in a recent study on the impact of changes in social networks cancer survivors [17]. Despite the adaptations people had to make and the difficulty they sometimes had in managing their daily lives, some people said they still had quality of life [17,19]. This is something all the participants in our study also generally said: despite the fact that they were ill and/or had had to make sacrifices, they were satisfied with the life they were now leading.

According to our study, other self-management activities for dealing with being ill and psychological complaints such as uncertainty and worry are talking, letting go, and accepting the situation. This fits with research by Johnston et al., which showed that acceptance let people with incurable cancer manage the disease better and more effectively [26]. In our study too, some patients said they did not suffer from symptoms such as anxiety and uncertainty because they had let go and accepted 'it'. A review of strategies used by survivors of breast cancer, prostate cancer, or colorectal cancer for dealing with their disease also found that patients often focus on acceptance and searching for information [14]. However, there were differences between people in the extent to which they applied these strategies [14] which we also found in our study. These differences are however not related to the disease phase (curative or palliative).

Whether or not people undertake activities within all the self-management domains and which specific activities or strategies they adopt may be related to patients' personal characteristics such as optimism and independence, or sociodemographic characteristics such as age, financial situation, and whether or not they are part of a social network.

Despite their positive comments on eHealth, they also saw downsides. For example, e-mail contact with doctors has advantages such as shorter lines of communication but it is also impersonal and not always practical. In general, eHealth works well for information about treatments, drugs, or side effects. Even so, eHealth is not suitable for all situations, for example situations in which there is still a great deal of uncertainty. These findings are in line with those of Baudendistel et al. [11]. In their research into the role of patients with colorectal cancer in managing their personal electronic health records, the patients mentioned both advantages, such as increasing the patient's personal responsibility for their health,

and disadvantages. For instance, they did not always view the fact that they could see all their personal medical information in a positive light. This was because this could lead to uncertainty or anxiety [11].

Strengths and limitations

A strength of the present study is that we did not simply identify separate self-management activities; instead, we ordered them within a framework that has previously proved its worth in the case of people with chronic diseases such as diabetes but has not been used to this extent for people with cancer.

A methodological concern is possible selection bias. The participants in this study were primarily active, articulate people. This may be why most of the participants in the study had little need of additional support from, for instance a nurse.

The choice for online focus groups automatically meant that people were recruited who used computers and had access to the Internet. These people may have more affinity with eHealth than people without such resources. It also transpired that the patients who were interviewed generally used the computer and the Internet. As a result, the findings about eHealth cannot be automatically extrapolated to people with cancer in general.

CONCLUSION

Participating cancer patients found their self-management activities important for dealing with the disease and letting them take decisions about their treatment and care. Nurses and other healthcare professionals should try to gain insight into self-management activities which are of particular importance to cancer patients, when supporting them in dealing with the consequences of the disease in daily life. In this regard, the General Model of Self-Management can serve as a starting point by ensuring that attention is paid to the individual self-management domains and that support is tailored to the wishes and requirements of the individual patient. As patients with cancer often made use of eHealth, nurses could promote its use, while also being aware that eHealth cannot replace personal contacts.

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CHAPTER 4

Self-management support and eHealth for patients and informal caregivers confronted with advanced cancer: an online focus group study among nurses

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ABSTRACT

Background: Self-management by patients and informal caregivers confronted with advanced cancer is not self-evident. Therefore they might need self-management support from nurses. This article reports on nurses' perspectives on self-management support for people confronted with advanced cancer, and nurses' experiences with eHealth in this context.

Methods: Six online focus groups were organized, with a total of 45 Dutch nurses with different educational levels and working in different care settings. Nurses were asked how they support patients and informal caregivers facing advanced cancer in managing physical and psychosocial problems in their daily life. Questions were also asked regarding the nurses' experiences with eHealth. Transcripts of the online focus group discussions were analyzed qualitatively following the principles of thematic analysis. The main themes derived from the analyses were ordered according to the elements in the 5 A's Behavior Change Model.

Results: Within the scope of self-management support, nurses reported that they discuss the background, personal situation, wishes, and needs of advanced cancer patients ('Assess' in the 5 A's model), and they provide information about cancer and specifically the advanced type ('Advise'). However, nurses hardly give any advice on how patients can manage physical and psychological problems themselves and/or pay any attention to collaborative goal-setting ('Agree'). Neither do they explain how follow-up can be arranged ('Arrange'). In addition, they do not appear to pay much attention to self-management support for informal caregivers. Nurses' attitudes towards eHealth within the scope of self-management support are positive. They see many advantages, such as allowing advanced cancer patients to stay in charge of their own care and lives. However, nurses also explicitly stressed that eHealth can never be a substitute for personal contact between nurses and patients.

Conclusions: Nurses value self-management support and eHealth for advanced cancer patients and their informal caregivers. However, they seem to disregard important elements in the support of self-management, such as providing practical advice, collaborative goal-setting, and arrangement of follow-up. We recommend further promoting and clarifying the essence and importance of self-management support, including self-management support for informal caregivers.

BACKGROUND

Self-management by patients and informal caregivers confronted with a life-limiting illness, such as advanced cancer, is not self-evident. Patients might have limited self-management skills, among more, because of their physical deterioration [1]. Alongside physical symptoms and problems, such as pain, fatigue and loss of appetite, patients also have to deal with psychological problems like anxiety and depressive moods. Symptoms and problems which may be severe and progressive over time in patients with an advanced form of cancer [2]. Besides, research literature suggests that incurably ill patients often lack fundamental knowledge and understanding of the progression of their illness, and have limited insight into care opportunities. Aspects which are important for self-management [3]. Patients may therefore require self-management support from healthcare professionals, such as nursing staff.

Informal caregivers who care for patients may also suffer from problems such as depressed moods, anxiety, and/or a decrease in social activities related to their often high care burden [4].

Hence, both patients and informal caregivers may need self-management support. In this study we use Wagner et al.'s definition of self-management support: "[...] Acknowledging the patients' central role in their care, one that fosters a sense of responsibility for their own health. It includes the use of proven programs that provide basic information, emotional support, and strategies for living with chronic illness. [...] Using a collaborative approach, providers and patients work together to define problems, set priorities, establish goals, create treatment plans and solve problems along the way." [5].

Different models have been developed for self-management and self-management support (e.g. Battersby [6], Battersby et al. [7], Lorig et al. [8,9]). A widely accepted model is the 5 A's Behavior Change Model, originally developed by the U.S. Department of Health [10], further developed by Glasgow et al. [11], and a point of departure for the Dutch national care standard on self-management [12], as well as for other recent research on self-management and self-management support [13]. The 5 A's model (Figure 1) entails five steps, namely:

1. Assess: Assessing the patient's knowledge, beliefs, and behaviors;
2. Advise: Advising the patient by providing specific information about the disease and information about the patient's health status in an understandable manner so the patient can relate their self-management skills and behaviors to their health status;
3. Agree: Agreeing on goals collaboratively set with the patient and according to the patient's priorities;

Five A's Model of Self-Management Support

ASSESS:
Beliefs, Behavior & Knowledge

ADVISE:
Provide specific information about health risks and benefits of change

ARRANGE:
Specify plan for follow-up (e.g., visits, phone calls, mailed reminders)

Personal Action Plan
1. List specific goals in behavioral terms
2. List barriers and strategies to address barriers
3. Specify follow-up plan
4. Share plan with practice team and patient's social support

ASSIST:
Identify personal barriers, strategies, problem-solving techniques, and social/environmental support

AGREE:
Collaboratively set goals based on patient's interest and confidence in his or her ability to change the behavior

Figure 1 *Glasgow et al.'s 5 A's model of self-management support [11]*

4. Assist: Assisting the patient by identifying and resolving barriers that hinder the patient in achieving the set goals;
5. Arrange: Arranging follow-up via e.g. e-mail or telephone.

The model assists healthcare professionals in structuring self-management support within a dynamic and tailored process. The 5 A's model was originally introduced for self-management support for patients. However, we believe the 5 A's model to be relevant for informal caregivers as well.

For self-management support to be effective, it is important that it is provided by suitable healthcare professionals. Nurses in particular are appropriate providers of self-management support since empowering patients and enabling them to understand and cope with their disease or disability, its treatment, and its consequences are core competences for nurses [14,15].

Nurses are indeed main providers of self-management support in practice in the Netherlands and other European countries [16]. Some previous studies focused on

nurses' self-management support for patients with cancer or a variety of chronic conditions, and/or for their informal caregivers (e.g. Johnston et al. [17], Hammer et al. [18], Kaltenbaugh et al. [19], Northouse et al. [20], Verkaik et al. [21], Been-Dahmen et al. [22]). However, these studies often describe effects of interventions rather than nurses' experiences and perspectives on self-management support to people in the advanced stage of an illness, or more specific, in the advanced stage of cancer, which is our main focus. Research on self-management support in people with advanced and ultimately fatal illnesses, apparently is still a rather young research area [23]. To our knowledge, no research has been done on how nurses experience and perceive self-management support specifically to patients and informal caregivers facing advanced cancer. Also the role of eHealth appears unexplored within this specific scope and target group.

For self-management support to be effective, it is essential that it is tailored to the recipient's needs and properly facilitated [24]. In this regard, eHealth in the form of web-based or smartphone applications might be useful, supplementing or (partially) substituting for face-to-face self-management support by professionals. Furthermore, eHealth could be of particular added value for people with reduced mobility and who are too ill to travel [25]. Several studies have already investigated the effects of eHealth for cancer patients and informal caregivers, and their attitudes to eHealth along with the attitudes of various healthcare professionals (e.g. Slev et al. [26], Lubberding et al. [27], Paul et al. [28]). Some studies specifically investigated eHealth for people with life-limiting illnesses (e.g. Johnston et al. [25], Neergaard et al. [29], Collier et al. [30]). However, there appears to be a lack of studies focusing on nurses' opinions about the use of eHealth specifically for self-management support for people confronted with advanced cancer.

We performed an online focus group study to gain more insight into how nurses perceive their role in self-management support for people confronted with advanced cancer and their opinions about the use of eHealth in this regard. The following research questions are addressed in this paper:

1. a.   How do nurses in the Netherlands currently support patients and informal caregivers facing advanced cancer in their self-management of problems and symptoms related to advanced cancer (e.g. pain, fatigue, loss of appetite, sadness/depressive moods, and anxiety, and a high care burden)?

    b.   How would these nurses support the self-management activities of patients and informal caregivers in the ideal situation? Are there any discrepancies between the current situation and the ideal situation?

2. What are experiences and expectations of these nurses regarding the use of eHealth for self-management by or self-management support for patients and informal caregivers facing advanced cancer?

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METHODS

Recruitment and sample

In the Netherlands, three categories of nurses can be distinguished according to their level of education: registered nurses (RN) with secondary vocational education; registered nurses with higher professional education (Bachelor's degree); and 'nurse specialists' with a Master's degree in Advanced Nursing Practice. All three categories of nurses can follow specific continuing education courses in, for instance, oncology nursing or palliative care. Hereafter the term 'nurse' will be used interchangeably for registered nurses with secondary vocational education or higher professional education (Bachelor's degree) and nurse specialists with a Master's degree, unless otherwise specified.

Nurses were eligible for inclusion in the study if they 1) work with patients with advanced cancer on a daily basis, and 2) work in a hospital, home care, transmural care or hospice setting. Nurses were recruited via open calls placed on social media (Facebook, Twitter) and via e-mails directly sent to nurses (n=45) in the authors' own professional network (LinkedIn). Additionally, announcements were placed on the website and the social media account of the Dutch Oncology Nursing Society.

The recruitment resulted in 56 nurses showing their interest in participating in the study. Recruitment via LinkedIn appeared to be most successful as it yielded 36 positive replies. All potentially interested nurses (n=56) were sent an information letter by e-mail explaining the study objectives and methods. Ultimately, 11 of these 56 nurses did not participate due to e.g. personal circumstances or not having enough working experience with people with advanced cancer, or because they did not post any comments to the questions posed in the online focus group. These nurses were considered as non-participants. This resulted in a sample of 45 nurses working in different parts of the Netherlands, and in rural as well as urban areas. None of the participating nurses were close private or professional contacts of the authors. The participants were divided into six online focus groups. Table 1 depicts the participants' characteristics.

Table 1 *Characteristics of the participating nurses (n=45)*

Sex	
Male	1
Female	44
Mean age (range) (n=36)	45.3 (25-62)
Care setting	
Hospital	19
Home care	11
Hospice	9
Other (e.g. transmural)	6
Mean work experience as nurse in years (range) (n=35)	22.4 (3-41)
Highest degree in nursing	
Master's degree in Advanced Nursing Practice	15
Higher professional education (Bachelor's degree)	23
Secondary vocational education	7
Additional education course	
Oncology and/or palliative care	23
No additional course in oncology or palliative care	12
Unknown	10

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Data collection

Data were collected through online focus group sessions. Online focus groups are a relatively new online method for qualitative research using a group of participants [31]. An asynchronous form of the online focus group was used, meaning that participants could log into a secured website and respond to questions of the executive researcher (VNS), and posts of other participants, at times of their choosing, 24 h a day [32]. All online focus groups lasted 2 weeks.

Anonymity and protection of participants' privacy were ensured by using aliases and personal login names and passwords. Six, of which four ran simultaneously, asynchronous online focus groups were organized: one for registered nurses working in a hospital, one for registered nurses working in a home care setting, one for nurse specialists working in a hospital, one for registered nurses working in a hospice and two mixed groups of registered nurses and nurse specialists working in a hospital, home and/or hospice setting. The study started with the first four homogeneous online focus groups. The two heterogeneous online focus groups started 1 week later, while the first four were still running.

Table 2   *Examples of questions posted on the secured websites of the online focus groups*

Physical symptoms such as fatigue, pain and loss of appetite are common in advanced cancer cases. These symptoms can have consequences for people with cancer and their informal caregivers.

• Do you recognize this description?/Is this description familiar?
• What do you do at present to support these patients and/or informal caregivers in dealing with these physical symptoms (=aspects of self-management support)? And how would you want to do this in the ideal situation?
• What are your thoughts on the use of eHealth in this context?

Advanced cancer can be associated with somber moods, anxiety and uncertainty. Both the person with cancer and their informal caregivers may have these feelings.

• Do you recognize this description?/Is this description familiar?
• What do you presently do to help these patients and/or informal caregivers deal with these feelings (=aspects of self-management support)? And how would you want to do this in the ideal situation?
• What advice do you give patients and/or informal caregivers for situations where they would like to talk to a healthcare professional or caregiver but where this is not possible or only to a limited extent?
• What are your thoughts on the use of eHealth in this context?

The decision was made to have both homogeneous and heterogeneous online focus groups in order to provoke discussion and potentially elicit different opinions regarding self-management support and eHealth for advanced cancer patients and their informal caregivers.

Semi-structured open ended questions concerning self-management support in dealing with physical and psychological complaints, and decision making regarding care and treatment were placed in discussion threads on he secured websites of the online focus groups. Some examples of the questions are presented in Table 2.

The posed questions were directly related to the main research questions (see 'Background'), and were based on e.g. the existing literature on the most prevalent symptoms in patients with advanced cancer [2]. The questions were drawn up in consultation with all members of the project group which encompasses, amongst others, four professionals with a nursing background (VNS, CME, ALF and HRWP).

Like in traditional face-to-face focus groups, not everyone had to respond to every question. Nevertheless, on the first page of each online focus group where instructions for participation were set out, and in e-mail alerts which were sent after a new question was posed, participants were asked to login regularly and were stimulated to respond to the presented questions, to comment on other participants' posts, and to look back and respond to previously posed questions.

Data analyses

A qualitative analysis method was used that was inspired by thematic analysis [33,34]. Data analysis of the transcripts commenced as soon as the first online focus groups started, as part of a cyclical process of collecting data, analyzing data, collecting new data and so on.

Every day and multiple times a day, the executive researcher (VNS) logged in into the websites of the online focus groups, to analyze the responses to the questions in the discussion threads. Where appropriate, questions were amended or added to, depending on the responses of participants in the online focus groups. Hence, data collection and data analysis commenced as soon as the first participant responded to the first question placed in the first discussion thread.

First, all transcripts were read and re-read. The full transcripts of the discussions were automatically generated from the websites of the online focus groups, and concerned the literal responses of the participants. Next, open inductive coding was performed in order to identify important themes and subthemes related to the research questions. These themes and subthemes were then deductively categorized in accordance with the 5 A's model for self-management support (see 'Background'). Negative data, i.e. data that did not fit the five A's, were not found. All themes could be ordered using the model. However, it was not always possible to fit themes exclusively in one specific 'A' as it applied to several A's of the 5 A's model.

The executive researcher (VNS) analyzed all the transcripts for the six online focus groups. To deepen and validate her analyses, two co-authors (HRWP and ALF) each independently analyzed one half of the transcripts. The main themes and subthemes were then finalized through discussion [33]. The interim and final analyses were also discussed with the other authors, who all read at least one transcript.

RESULTS

Number of posts

On average, 41 posts were placed in each online focus group. The number of posts per participant varied from 1 post to 12 posts (on average 6 posts per participant).

Table 3   *Current situation and ideal situation regarding nurses' self-management support in the case of advanced cancer*

5 A's	Current situation		Ideal situation	
	Self-management support for patients	*Self-management support for informal caregivers*	*Self-management support for patients*	*Self-management support for informal caregivers*
Assess	Obtaining an understanding of the patient's background, personal situation, wishes, and needs by initiating a discussion, enabling an open discussion about topics, actively asking follow-up questions, listening	- *	More time	In general: More attention
Advise	Giving information and guidance, advising, listening, and referring the person to other disciplines or organizations	Giving information and guidance, advising, listening	-*	
Agree	Jointly setting goals, letting patients prioritize symptoms themselves	- *	-*	
Assist	Mapping barriers and strategies applied in the past, giving practical tips	-*	-*	
Arrange	Continuity of care	-*	In general: Better cooperation between intramural and extramural healthcare	
Throughout all 5 A's			More attention to self-management support in the home situation	

* no information from online focus groups that relates to the 'A' in question.

Self-management support by nurses

In this section, the themes resulting from the analyses of the transcripts are presented and categorized in the 'Assess', 'Advise', 'Agree', 'Assist,' and 'Arrange' steps in the 5 A's model [11] (Table 3). Table 3 also shows the extent to which the current situation matches the ideal situation, as outlined by the participants in the online focus groups.

Assess

Nurses in all the care settings covered said that when talking to patients with advanced cancer, they always try first to gain an understanding of their background, personal situation, wishes, and needs. Nurses find this important because they can only offer the desired, optimal self-management support if they are aware of the patient's background and issues.

Nurses also said that obtaining a picture of the patient's situation makes things clearer for the patient too, and this helps generate or enhance self-awareness.

"When we ask for information, patients find that they reflect on things more." (nurse specialist)

4

Nurses said that the patient's insight into their own situation and functioning puts the patient more in control of what is happening. This lets the patient take charge and/or stay in charge, which helps in tackling the issues at stake. Nurses also mentioned that if the patient and the informal caregiver have a good picture of the situation, this creates mutual understanding between them. Mutual understanding can improve the communication between the patient and the informal caregiver; any misunderstandings and confusion can be straightened out. This also often improves communication between the patient, the informal caregiver, and the nursing professional.

Nurses assess the patient's issues and support needs by initiating a discussion, making it possible to talk openly about topics, proactively asking follow-up questions, and listening.

"What I do now is first ask what the problem is, how important is it for the patient, get to know the patient well so that I can give advice that suits their situation." (nurse specialist)

Some nursing professionals said that they use screening tools when assessing the patient's symptoms, for example the Utrecht Symptom Diary which is a Dutch translation of the Edmonton Symptom Assessment System [35], and the Lastmeter, the Dutch version of the Distress Thermometer [36].

"What we do, is we let the patient fill out a Utrecht Symptom Diary, so the patient gets insight in the symptoms he suffers from." (hospital nurse)

"In practice, the Distress Thermometer is being used which also gives insight in not immediately discussed feelings." (nurse specialist, in the context of support with dealing with psychological problems)

The screening results can present angles from which to start discussing issues. However, others also emphasized that running through the screening tools should never be an end in itself, that nurses must not blindly trust the figures.

"I am also somewhat anxious about translating complaints or symptoms into scores or numbers. It could be used as a starting point […] but not more than this." (nurse specialist)

The discussion techniques that nurses use to obtain a picture of the patient's background depend on the nature of the issues—physical, psychological, or spiritual/existential. In the case of physical problems, nurses said that actively asking follow-up questions is often the best way to determine the nature and cause of physical symptoms. This is in part because some of these symptoms may be due to psychological or social problems, such as increasing pain caused by too many family visits.

Some also mentioned that it can be necessary to proactively initiate a discussion about anxiety, for example, or somber moods, uncertainty and distress about the prognosis. They say that patients do not always speak out about these feelings, even not to their informal caregivers.

"Getting a conversation going (if people allow that) can make people feel relieved and sometimes they learn how to understand each other's emotions better." (transmural nurse)

According to the nurses, whether the symptoms listed above are eventually discussed in detail depends on the patient's needs.

Nurses added that the actual situation in this regard is close to what they would ideally do. Even so, they stressed that they would like more time—with the exception of a number of home care nurses whose organizations offer the option of 'continuity visits' (home visits following discharge from hospital). Nurses emphasized that with more time, they could assess the patient's interests, needs, wishes, and cognitive capacity better, as well as the disease stage, in order to improve tailoring of self-management support:

"The ideal situation would be that I would be able to find out what skills the patient has that are necessary for self-management and work with the patient and/or informal caregiver to determine interventions that tie in with that." (nurse specialist)

Furthermore, nurses in hospices in particular said that in the ideal situation more attention would be given to assessing the informal caregivers' situation:

"In the ideal situation, we hospice staff would be better informed about the informal caregivers' hobbies, social activities and how they deal with social contacts […] The combination of this [ed. combination of care for a patient and continuing with their 'own' social activities] and ensuring contact with their sick relative in the hospice is so important for the informal caregivers in particular." (hospice nurse)

Advise

Nurses said that helping advanced cancer patients deal with problems and symptoms in their daily lives involves giving them information and guidance, advising them, listening to them, and referring them to other disciplines or organizations. As with 'Assess,' this too is important in engendering and enhancing self-awareness and mutual understanding between the patient, their informal caregivers, and nurses.

Giving information and guidance is relevant for example in dealing with loss of appetite in the palliative phase.

"The loss of appetite often causes a lot of frustration with one another and distress. I try […] to explain how the loss of appetite is part of the disease process. I find that this takes some of the pressure off and that the client and their informal caregivers start to understand each other better again." (transmural nurse)

Nurses said that they provide information repeatedly in different forms (verbally, on paper, and digitally). This gives patients the opportunity to read the information several times, which helps them retain the information. Despite this, nurses felt that providing information deserves more attention. This applies in particular to providing clear, unambiguous information, and clear communication about the prognosis.

Nurses working in hospices sometimes said that they *"[…] involve informal caregivers in the talks as well. They [ed. informal caregivers] are also given support in the form of information about the extent to which symptoms are a part of the final stage of life and how they can continue to give support and care." (hospice nurse).*

Nurses mentioned occasionally that they give practical tips that advanced cancer patients and their informal caregivers can apply at home, mainly with regard to physical symptoms. For example, if a patient is low on energy, nurses advise the patient to draw up a schedule of activities and concentrate on allocating their energy well.

"We explain about dividing energy and taking into account the, to the patient, important moments, e.g. visitors, hobbies, etc. In practice, it appears that the patient mentions having hobbies, but that hobbies get put on hold because of low energy. A daily schedule can help to save enough energy for this." (hospice nurse)

In the case of psychological symptoms, nurses often deliberately refrain from giving advice and offering solutions. They said that somber moods, anxiety, uncertainty, distress, and worry are feelings that cannot be alleviated and that each individual patient deals with this in their own way. Nurses concentrate mainly on listening, acknowledging these feelings, and being there for the patient. According to nurses, these are the best approaches for supporting patients with symptoms of this nature.

"[…] leaving room for everything they are feeling, thinking and experiencing, not giving each other advice and not coming up with solutions. Anything is allowed." (transmural nurse)

Some do give a few tips to the patient, such as talking about the symptoms and looking for diversion.

Furthermore, nurses said that they refer patients to other disciplines, such as a psychologist or spiritual caregiver, to help them deal with psychological problems. Hospice nurses in particular also frequently mentioned pointing out the options for complementary care, such as creative therapy, aromatherapy and massages for both psychological symptoms and physical symptoms. They said that patients derive energy from this.

Nurses gave few examples—even after follow-up questions—of how informal caregivers are supported in dealing with the patient's problems and symptoms or their own problems. Only some hospice nurses and home care nurses gave examples in this regard.

"Informal caregivers' feelings of powerlessness are often an issue here. They already have to hand over a lot of things when their relative is admitted to a hospice. […] We often then look for alternative responsibilities for the relatives […]. For instance, you can explain how to give good oral care. Complementary care, such as giving a hand massage, can also be handed over to relatives to some extent." (hospice nurse)

"We support informal caregivers by listening and giving tips and advices. For example […] by taking the pressure off nutrition. My experience is that informal caregivers feel like they are not giving proper care, if the ill one eats insufficiently. We also offer voluntary palliative care so informal caregivers could unwind a little." (home care nurse)

Agree

According to the 5 A's model, collaborative goal-setting is part of the 'Agree' step. However, nurses barely mentioned setting goals in partnership with an advanced cancer patient and/or informal caregiver, or the use of an individual plan. Nurses did mention that wherever possible they look at what the patient's wishes are and that they let the patient decide which symptoms and/or feelings or problems should be given priority. Nurses emphasized that it is important to do this with the patient because this lets the patient remain in control as much as possible, or puts the patient in control if that was not already the case.

"When getting insight in the patient's problems, it is also important to know what is important to the patient himself, to work on. What does the patient experience as the biggest issues." (nurse specialist)

For example, when decisions have to be taken, nurses support the patient by helping them to draw up a list of advantages and disadvantages and weigh these up against one another, and to write down any questions for the next appointment with the treating physician, family doctor or nurse.

"Patients sometimes ask then what they should do. I can't give them that advice but I can help them to get an overview of everything. It helps enormously if they write this down on paper and e.g. assign a degree of importance." (hospice nurse)

Assist

According to the 5 A's model, an important aspect of this step is assisting in developing plans to meet goals. This also implies mapping any barriers that might prevent the patient or informal caregiver from achieving the goals, deploying interventions and giving practical advice that can help them achieve the defined goals. A number of nurses mentioned that when dealing with patients with advanced cancer, they assess whether there are barriers, for example in dealing with feelings of anxiety, somber moods, and uncertainty, and if so, what strategies the patient has for removing those barriers.

"[…] how did you respond to difficult situations in the past and what helped you then to get back on track?" (home care nurse)

Nurses stated that every patient is unique and deals with their feelings, symptoms and problems in their own way; that is one reason why it is important to put the patient in control when dealing with symptoms. Patients often know best

themselves where their strengths lie. If that is not the case, the patient will need assistance, to be made more aware of their own strengths by becoming actively involved in their own care.

Arrange

Nurses did not explicitly state how they arrange follow-up. The only point made by some is that they sometimes encourage patients to write down goals and questions so that these can be referred back to in a subsequent consultation. Nurses stressed the importance of follow-up primarily in terms of the continuity of care. In the ideal situation it would not just be about the continuity of the care they are delivering; their care would be part of a multidisciplinary collaborative approach within and between intramural and extramural care providers. This would ensure follow-up in the home situation as well.

"Home visits should also be much more effective. This currently depends on the hospital and partnerships with home care organizations. The hospital can also inform the primary care side and make sure the family doctor is aware of the bad news at an earlier stage and that the oncological or palliative care nurse makes contact. So that needs better cooperation between the primary care and the hospital." (home care nurse)

Throughout all 5 A's

Regarding self-management support in the ideal situation, hospital nurses said that self-management support should be extended to include dealing with problems when at home.

"I think one point for improvement would be instructing people in the hospital where they can find information/support themselves to make it easier for them to tackle this when they get home. There should be more continuity here; at the moment the hospital and the home are two separate worlds. [...] More continuity too in information and so on; there are loads of different information sources at the moment and patients can no longer see the wood for the trees." (hospital nurse)

Experiences with and opinions on the use of eHealth in self-management support

Nurses said they do not often use eHealth. They do see potential added value from eHealth, both for general healthcare information and for disease-specific information and practical advice. Some mentioned that it is important that patients can choose their own topics, that the eHealth application has an appropriate design

for the target group, that it is available on smartphones, computers, and tablets, and that there are options for printing.

Nurses also said that eHealth can let patients remain in control, for example if there is a digital symptoms diary or the ability to view your own health record, if it makes it easier to ask a healthcare professional questions, or if it enables online contact with peers.

"Use of a symptoms diary can certainly be worthwhile and could be part of an eHealth program. Using this can also give a patient a better understanding of their symptoms, and they may be able to make their own connections between activities and symptoms." (hospital nurse)

"[…] precisely for those who want to remain self-reliant for as long as possible. A digital patient record with the patient as the owner could be particularly beneficial in letting the patient be in control." (hospice nurse)

Hospital nurses in particular said that eHealth could promote and safeguard the continuity of care if there is a link between the eHealth application and the physician, family doctor, and/or nurses. Moreover this would ensure the accuracy and clarity of the information.

However, nurses also made qualifying remarks. For instance, they repeatedly emphasized that eHealth cannot and should not replace personal contact. They therefore prefer a combination of eHealth and personal contact with a healthcare professional.

Nurses also said that eHealth is not suitable for everybody. Some hospice nurses saw the main potential added value of eHealth in the care of patients in the early palliative phase. Patients often no longer have enough energy to use a laptop or tablet, for example, in the final phase. According to the hospice nurses, eHealth could still have added value for informal caregivers in the terminal phase.

"However, I frequently see patients bringing their tablets, setting up a laptop but subsequently hardly having time/energy for it. Relatives possibly might benefit from it more." (hospice nurse)

Home care nurses said that eHealth is less suitable for the current generation of older patients because they do not know how to use computers and cell phones.

"I frequently deal with (frail) elderly people (+75 years), 99% don't have knowledge of controlling a PC, app or tablet. This would probably be different in the next generation of older people." (home care nurse)

Furthermore, some nurses said that eHealth is more suitable for support in dealing with physical problems than psychological problems. According to nurses, eHealth cannot remove or resolve feelings of somberness, anxiety and uncertainty, although putting tips online on how to deal with this could be worthwhile.

"Of course a program with tips and tricks and elements to cheer people up would be OK. I don't think anything fundamental can be done about somber moods, anxiety and uncertainty." (hospital nurse)

DISCUSSION

Within the scope of self-management support, Dutch nurses pay considerable attention, to the assessment of a patient's background, personal situation, wishes, and needs ('Assess' in the 5 A's model), and to the provision of illness-related information and advice ('Advise' in the 5 A's model). This result is in line with the findings in the study of nurses working with patients with various chronic conditions by Been-Dahmen et al. [22].

Our study, however, also shows that nurses are not inclined to give advice about psychological problems; they tend mainly to listen to the patient and refer them to a psychologist or spiritual caregiver. This also fits with the findings of Been-Dahmen et al. [22], as well as with the systematic review by Ventura et al. [37] of patients receiving palliative care at home and their informal caregivers. That study concluded that nurses and other professionals provide better-targeted support for physical problems than for psychological problems [37].

The findings above are striking as paying attention to psychological problems is actually seen as an essential element of palliative care [38].

It is interesting to note that 'Agree' (collaborative goalsetting) and 'Assist' (assisting patients in achieving their goals) are barely mentioned by the nurses in our study, whereas these are essential aspects of self-management support. Nurses also seem to pay relatively little attention to follow-up as an aspect of self-management support ('Arrange' in the 5 A's model). In a European study of how self-management support is integrated into the care for the chronically ill, Elissen et al. [16] also concluded that collaborative care planning and structured follow-up receive little consideration in practice. These are therefore areas for improvement.

Furthermore, it is noticeable that nurses currently pay little attention in their daily practice to self-management support for informal caregivers. This result is remarkable, given that support for relatives is an essential part of the care of the incurably ill (see the WHO definition) [38] and of self-management support (see Wagner et al. [39]). The above result, however, is not a new finding.

Previous research on oncology and palliative care also pointed to the fact that informal caregivers still are an underserved population [37,40-42]. Explanations for this finding regard: Informal caregiving often is a gradual process, and relatives are not really aware of the fact that they are becoming an informal caregiver. Realization often comes later in the disease trajectory [40]. Once the caregiver role is acknowledged, most informal caregivers find it hard to discuss their own support needs in the presence of the cared-for person [41]. To overcome these barriers, consultations for informal caregivers alone, have to be arranged [41].

Still, there appear to be differences between settings in this regard: Hospital nurses hardly mentioned self-management support to informal caregivers, while some hospice nurses and home care nurses did mention this. Paying consideration to self-management support to informal caregivers, therefore, seems to be more of a matter for the latter mentioned group of nurses. Signs of stress and physical and psychological symptoms in informal caregivers might be more likely to be picked up in the home care or hospice setting [40]. Hospital nurses often mainly see the patient and are busy with technical tasks during the patient's visit to the hospital or outpatient clinic or during treatment. Nurses in home care and hospice care may have a better picture of what the informal caregiver could do to cope with the impact of their relative's illness on their daily lives. Because of the qualitative nature of this study and therefore the small sample size, we should be cautious on reporting 'differences' between nurses. Therefore, above-mentioned findings have to be interpreted with prudence.

Furthermore, this study shows that nurses see benefits from eHealth. However they stress that it should never replace personal contact and that its applicability depends on patients' digital skills, the disease stage and the nature of the problems and symptoms. Other studies [25,29,30] among both doctors and nurses working in palliative care came to similar conclusions. The finding that eHealth can enhance the patient's control over things, for example by letting the patient record and monitor their symptoms online, is also backed up by studies by Collier et al. [30] and Johnston et al. [25]. The nurses in our study do not see a role for eHealth in the self-management of psychosocial problems such as anxiety, uncertainty, and somber feelings. Such views did not emerge in the aforementioned studies and contradict the support on the effectiveness of web-based psychological interventions in diverse patient populations [43,44].

This study indicates that nurses value self-management support. However, sometimes they appear to omit providing practical advice, and they seem to pay little attention to the A's of 'Agree', 'Assist' and 'Arrange' of the 5 A's model. The fact that the steps in the 5 A's model were not explicitly mentioned in the questions in the online focus groups may have contributed to this outcome. Findings might have been different if we asked directly about the A's of the 5 A's model.

We intentionally chose to include practical descriptions of 'self-management' and 'self-management support' rather than definitions, to avoid differences in participants' interpretation of self-management and self-management support. However, the data yielded may have been constrained by the nurses' perception of self-management support. If self-management support in nurses' understanding of the concept, does not include e.g. the provision of practical advice, collaborative goal-setting and arranging follow-up, then perhaps it is logical that these elements were not discussed. Despite, one could expect that at least some nurses would refer to the essence of the steps in the model as the 5 A's model is a starting point in the Dutch national care standard on self-management, and because self-management support is mentioned as a core task of today's nurses, in the national report on nursing roles in the Netherlands [15].

Strengths and limitations of this study

For this study we used a combination of convenience and purposive sampling. To involve nurses with different backgrounds, we approached and eventually included nurses working in various care settings, in different areas of the Netherlands and with differences in years of working experience. We prevented that only nurses with a specific interest in self-management support participated, as we did not use 'providing self-management support' or 'being acquainted with self-management support' as inclusion criteria. None of the participating nurses were close private or professional contacts of the authors.

Another choice made in this study was to opt for online focus groups rather than traditional face-to-face focus groups. This choice was made, primarily for practical reasons: nurses are often very busy and prefer not to spend time traveling to a location for a traditional focus group. In general this worked well. We were able to recruit enough nurses to gain a picture of how nurses offer self-management support for dealing with the symptoms and problems that people may encounter when faced with an incurable form of cancer. Given that the final online focus group did not produce any significant new information, we can assume that we achieved data saturation.

In the course of the 2 weeks that each online focus group was active, we added further in-depth questions. Moreover, we sometimes repeated questions for debate and added a question about a specific example. Some participants did not log in for every new question and this could mean that some of the in-depth questions or repeat questions were not read by all the participants. This is a limitation of online focus groups when compared with traditional face-to-face focus groups.

CONCLUSIONS

The nurses in this online focus-group study value self-management support and eHealth for advanced cancer patients. However, they seem to disregard important elements of self-management support, such as providing practical advice, collaborative goal-setting, and arranging follow-up. At present little consideration is given to self-management support for informal caregivers. We recommend making nurses more aware of the importance of self-management support for both patients and informal caregivers. This awareness could be achieved through targeted (re) training of nurses in self-management support and the 5 A's model using the Dutch national care standard as starting point, and incorporating self-management, self-management support and the 5 A's model as integral part of nursing education.

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Ethics approval and consent to participate

In accordance with Dutch legislation, the study did not need review by a medical ethical committee because the participants were not subject to procedures or required to follow rules of behavior [45].

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CHAPTER 5

Self-management support in patients with incurable cancer: how confident are nurses?

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ABSTRACT

Objectives: To explore how nurses perceive their self-efficacy and performance in supporting self-management among patients with incurable cancer, and whether these perceptions differ between community and hospital nurses.

Sample & setting: 222 hospital nurses (N=94) and community nurses (N=128) working with adult patients with incurable cancer.

Methods & variables: An online survey included the Self-Efficacy and Performance in Self-Management Support instrument. Possible differences in age, gender, work setting, and additional training in oncology between groups were explored.

Results: Nurses felt confident about their self-efficacy, particularly in assessing patients' knowledge and beliefs and in advising about their disease and health status. Nurses felt less confident in their performance, particularly in the use of technology (arranging follow-up care), but also in agreeing on collaborative goals and assisting patients in achieving these goals. Compared to hospital nurses, community nurses reported significantly higher scores on self-efficacy and performance.

Implications for nursing: More effort is needed to increase nurses' confidence in providing self-management support, with a focus on arranging follow-up care with the use of technology and on collaborating with patients in setting and achieving goals.

KNOWLEDGE TRANSLATION

- A discrepancy exists between nurses' (particularly hospital nurses') perceived (high) self-efficacy and (low) performance for supporting self-management among patients with incurable cancer.

- Community nurses are more confident than hospital nurses in supporting self-management.

- Nurses rarely initiate or facilitate follow-up care.

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Living with incurable cancer can have devastating effects on psychological, social, physical, economic, and cultural aspects of a person's life [1,2]. Patients with incurable cancer must cope with life-limiting, changing conditions, as well as the consequences of the disease and treatment in daily life [2-5]. Assisting with self-management might help patients deal with these consequences, improve problem-solving skills, and prepare for death [6-8].

Self-management can be described as a person's ability to manage physical and psychosocial symptoms and to make decisions concerning treatment and/or care to integrate the disease as well as possible into daily life and to maintain a satisfactory quality of life despite the disease [9,10]. At the end of life, self-management focuses on "living with dying"; activities are likely to be beneficial if focused on symptoms or impending death and directed toward emotional and psychological adjustment to the incurable illness. For instance, activities can focus on how to deal with fatigue or pain, how to plan important moments or daily care, and how to rest in between these moments. In addition, changes in personal (physical, emotional, or social) or care aspects (cancer status, treatment, or palliative phase) prompt changes in self-management [5]. Support should acknowledge these possible transitions and be directed toward present and future care needs, quality of life, and other outcomes identified by patients as necessary for self-management [5,11,12].

Literature Review

Self-management support acknowledges patients' central role in their own care, fostering a sense of responsibility for their own health [13]. It uses proven programs that provide adequate information about actual or potential problems, emotional support, and strategies for living with a chronic illness that enable patients to care for themselves in a way they prefer [7,14]. Using a collaborative approach, providers and patients work together to assess problems, set priorities, establish goals, create treatment plans, and solve problems [15]. The role of nurses in supporting self-management in patients with incurable cancer is important [1], and it requires a range of educational, supportive, and communicational competencies [16,17]. These competencies can be distinguished by the phases of the 5 A's model, which include the following [18,19]:

- Assessing the patient's knowledge, beliefs, and behaviors
- Advising the patient by providing specific information about the disease and information about the patient's health status in an understandable manner so that patients can relate their self-management skills and behaviors to their health status
- Agreeing on goals collaboratively set with the patient and according to the patient's priorities

- Assisting the patient by identifying and resolving barriers that make it difficult for the patient to achieve the goals set
- Arranging follow-up (such as by email or telephone)

The five A's are interrelated and provide a structure for self-management support [18].

A precondition for performing self-management support activities is self-efficacy—the confidence a person has in his or her skills and perceived ability to perform the behavior [20]. Self-efficacy as perceived by nurses can be an indicator for the activities they perform; more confidence in skills (e.g. using technology) is a predictor of choices and behavior (e.g. applying technology) [21]. A study with 598 respondents revealed a discrepancy between higher reported self-efficacy and lower reported performance of self-management support activities in a general nursing population [19]. This discrepancy increased in the subsequent phases of the 5 A's model , with larger differences between self-efficacy and performance in the Agree, Assist, and Arrange phases [19,22]. Nurses seem to focus mainly on assessment of background (Assess) and advice and information (Advise) [19,22]; whereby such advice seems restricted to physical problems and psychological problems and receives less attention [23,24]. Activities in the Agree, Assist, and Arrange phases seem to be limited, although these aspects are essential in self-management support [16,25].

Studies using the 5 A's model reported inconsistencies regarding self-management support in patients with chronic illnesses [19,26]. However, knowledge about nurses supporting self-management in people with incurable cancer is still limited. Several studies have suggested that setting and additional training (e.g. in oncology) improve the provision of self-management support [27,28], which is based on the perceptions of nurses or patients. As a result, the current authors expected that nurses caring for patients with incurable cancer would perceive their self-efficacy and subsequent performance as better than nurses caring for patients with chronic conditions. The first aim of the current study was to explore how nurses perceived their self-efficacy and performance in supporting self-management activities in patients with incurable cancer.

In addition, in the Netherlands, the role of nurses in supporting self-management is currently emphasized more for community nurses than for hospital nurses, who focus more on medical treatment [19]. The authors hypothesized that community nurses would have more positive perceptions about their self-efficacy and performance and their support of self-management in the subsequent phases of the 5 A's model. The second aim of the study was to determine to what extent the setting (community versus hospital) affected nurses' perceived self-management support for patients with incurable cancer.

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METHODS

Design and ethical approval

In June 2016, the authors conducted a cross-sectional quantitative study among nurses using an online questionnaire. For such a study, Dutch legislation (Medical Research Involving Human Subjects Act) does not require ethical approval by a medical ethics committee. Study participation was voluntary, and participant consent was assumed upon return of completed questionnaires. The questionnaire data were stored and analyzed anonymously, in accordance with the Dutch Personal Data Protection Act.

Study population

Nurses working in hospitals or the community were selected from a pre-existing research sample, the Nursing Staff Panel. This panel consists of a nationwide representative sample of nursing staff members working in various healthcare sectors. Members of the Nursing Staff Panel are mainly recruited via Dutch employee insurance agencies (with which every healthcare employee is registered). All participants of the Nursing Staff Panel agree to complete questionnaires about issues in nursing on a regular basis (at least twice a year). To recruit participants for this study, the authors sent an email with information about the aim and content of the survey, as well as a link to the questionnaire, to members of the Nursing Staff Panel (N=692) who worked as RNs in the community or at a general or university hospital. One or two email reminders were sent to nonresponders after one and three weeks to improve the response rate. No incentives were provided. After entering the online site, potential participants answered study-specific questions about age, gender, work experience, work setting, and additional training in oncology. If they stated that they had provided care to adult patients with incurable cancer in the past 12 months, they were invited to complete the questionnaire and were included.

Instrument

The primary outcome was a quantification of nurses' self-efficacy and performance in providing self-management support. The authors used the validated Self-Efficacy and Performance in Self-Management Support (SEPSS) instrument, Dutch version [22]. SEPSS consists of six subscales, which are based on the 5 A's model (Assess, Advise, Agree, Assist, and Arrange) and a subscale that addresses the overall

competencies that are necessary in each step of the model, such as respecting the cultural background of the patient, reflecting on their own performance, and recognizing ethical dilemmas [22]. Each subscale of the SEPSS contains six items (a total of 36 items). Self-efficacy, defined as the nurse's belief in his or her ability to perform a specific behavior (i.e. self-management support) was assessed with the statement "I can do this," which was rated on a five-point Likert-type scale ranging from 0 (not at all) to 4 (good). Performance (i.e. the actual behavior) was assessed with the statement "I do this," which was rated on a five-point Likert-type scale ranging from 0 (never) to 4 (always). In the final section, nurses could add free-form text about their needs in terms of improving self-management support for patients with incurable cancer.

In previous studies, the Cronbach alpha was 0.96 for self-efficacy and 0.95 for behavior, respectively [19,22]. In the current study, the Cronbach alpha was 0.96 for both self-efficacy and performance.

Analysis

Data were screened for repetitive response patterns, and questionnaires with less than 10% variation in answers (i.e. identical answers to at least 64 out of 72 items) were excluded from further analysis. In addition, data were screened for missing subscale scores (all subscales were complete).

Descriptive analyses were used for summarizing demographic characteristics of nurses, including age (years), gender (male or female), work experience (years), additional training in oncology (yes or no), and setting (community or hospital).

To determine perceived self-efficacy and performance, the authors computed sum scores for each of the subscales, as well as average sum scores for self-efficacy and performance (range 0–4, indicating not at all or never to good or always). Because the scores on the SEPSS subscales were not normally distributed, nonparametric presentation (median scores with interquartile ranges [IQRs]) and analyses were used to present the scores.

Differences between perceived self-efficacy and performance in each group were calculated with Wilcoxon tests, and differences between community and hospital nurses were calculated using Mann-Whitney U tests. Linear regression analyses were used to estimate the differences in self-efficacy and performance that were associated with the setting (community or hospital). Because age and work experience were correlated (Pearson correlation coefficient= 0.83), only age was included in the model.

All statistical analyses were performed with IBM SPSS Statistics, version 22.0. A p-value of less than 0.05 was considered statistically significant.

RESULTS

A total of 334 members of the Nursing Staff Panel returned the questionnaire (response rate= 48%). Of these, 234 had cared for adult patients with incurable cancer in the previous 12 months. Twelve questionnaires were excluded from analysis, mainly because of repetitive or absent responses. Of 222 questionnaires that were included in the analysis, most were completed by female nurses with a median age of 51 years and median work experience of 25 years (see Table 1). Responders were older than nonresponders (median of 52 and 42 years, respectively, p < 0.001) and had more work experience (median of 25 and 16 years, respectively, p < 0.001). No significant difference in gender was noted between responders and nonresponders.

Table 1   *Sample characteristics*

	Hospital (n=94)		Community (n=128)		p[a]
Characteristic	M	IQR	M	IQR	
Age (years)	50.5	(41-57)	52	(41-58)	0.58
Work experience (years)	25	(15-33)	25	(12-34)	0.54
Characteristic		n		n	p[b]
Gender, female		84		120	0.24
Additional training in oncology and/or palliative care, yes		27		21	0.03
Oncology or palliative care team, yes		17		12	0.06

[a] The p values were based on Mann-Whitney U tests
[b] The p values were based on χ^2 tests
IQR—interquartile range; M—median

Self-efficacy in self-management support

The overall median score for self-efficacy in self-management support was 2.8 (IQR=2.5–3.1) (see Table 2), which was considered almost sufficient, based on the response categories ranging from 0 (not at all) to 4 (good). With respect to the subscales, nurses perceived their self-efficacy as sufficient (median=3) in "assessing patients' knowledge and belief," "advising about disease and health status," and the subscale "overall competencies." The remaining subscales were perceived as almost sufficient.

When focusing on single items, nurses felt least confident with using assistive devices and technology (i.e. eHealth) to provide remote guidance (median=1, indicating not sufficient) and discussing with patients how they can use self-management assistive devices (e.g. a diary) in their daily activities (median=2, indicating more or less competent).

Table 2 Medians and IQRs of hospital and community nurses' perceived self-efficacy and performance

| Subscales | Self-efficacy | | | | | Performance | | | | |
| | Hospital | | Community | | | Hospital | | Community | | |
	Median	IQR	Median	IQR	p	Median	IQR	Median	IQR	p
Assess (N= 222)	3.0	2.5-3.2	3.0	2.8-3.2	0.56	2.0	1.6-2.8	2.7	2.0-3.0	0.001
Advise (N= 218)	3.0	2.5-3.3	3.0	2.5-3.0	0.45	2.2	1.5-2.7	2.3	1.7-2.8	0.18
Agree (N= 213)	2.7	2.2-3.0	2.8	2.3-3.0	0.14	1.3	0.8-2.0	2.2	1.7-2.7	0.000
Assist (N= 211)	2.8	2.2-3.2	2.8	2.5-3.0	0.23	1.8	1.0-2.3	2.2	1.7-2.5	0.002
Arrange (N= 210)	2.4	1.8-3.0	2.8	2.5-3.2	0.000	1.1	0.5-1.8	2.0	1.7-2.5	0.000
Overall (N= 208)	3.0	2.5-3.2	3.0	2.8-3.3	0.02	2.2	1.5-2.8	2.8	2.3-3.2	0.000
Sum score	2.7	2.3-3.1	2.9	2.6-3.1	0.06	1.8	1.3-2.4	2.3	2.0-2.7	0.000

IQR—interquartile range

Note. Self-efficacy was assessed with the statement "I can do this," which was rated on a scale ranging from 0 (not at all) to 4 (good). Performance was assessed with the statement "I do this," which was rated on a scale ranging from 0 (never) to 4 (always).
Note. The p values were based on Mann-Whitney U tests.

Performance of self-management support

The overall median score on performing self-management support was 2.1 (IQR=1.7–2.6), which was considered as occasional performance (response categories ranged from 0 (never) to 4 (always)). With respect to the subscales, nurses reported occasional to frequent performance in overall competencies (median=2.7), assessing patients' knowledge and beliefs (median=2.3), and advising (median=2.2). Nurses reported that they rarely to occasionally arranged follow-up care by email or telephone (median=1.8). They also reported that they never used assistive devices and technology to provide remote guidance to the patient (median=0), rarely discussed how patients could use self-management assistive devices in their daily activities (median=1), and rarely discussed with patients who they will inform about their condition (median=1).

Comparison of community and hospital nurses

Nurses working in the community perceived their self-efficacy in the Arrange phase as higher than nurses working in hospitals (median values=2.8 and 2.4, respectively, p < 0.001). This indicates that community nurses felt more confident in their ability to arrange follow-up contact. After adjusting for gender, age, and additional training, the authors found that community nurses still perceived their self-efficacy in self-management support as higher than hospital nurses (estimated difference= 0.18, 95% confidence interval (CI) (0.04-0.37), p=0.01) (see Table 3).

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Table 3 *Linear regression analysis of perceived self-efficacy and performance*

Subscale	Model 1		Model 2	
	b[a]	95% CI	b[a]	95% CI
Self-efficacy				
Setting (hospital versus community)[b]	0.16	[0.02-0.30]	0.18	[0.04 - 0.33]
Gender (male versus female)[c]	-	-	−0.21	[−0.46 - 0.05]
Age (years)	-	-	0.00	[−0.006 - 0.006]
Additional training (no versus yes)[d]	-	-	0.16	[−0.13 - 0.33]
Performance				
Setting (hospital versus community)[b]	0.47	[0.30-0.64]	0.53	[0.36 - 0.70]
Gender (male versus female)[c]	-	-	−0.40	[−0.71 - −0.10]
Age (years)	-	-	−0.004	[−0.01 - 0.004]
Additional training (no versus yes)[d]	-	-	0.35	[0.14 - 0.55]

[a] Unstandardized
[b] Hospital = 0, community = 1
[c] Male = 0, female = 1
[d] No = 0, yes = 1
CI—confidence interval
Note. Model 1 is setting only (R^2 = 2% for self-efficacy, 12% for performance). Model 2 is setting, gender, age, and additional training (R^2 = 5% for self-efficacy, 19.5% for performance).

Considering perceived performance, community nurses had significantly higher median scores in four out of five subscales of the 5 A's model; the subscale Advise was the only one in which no significant differences were found in perceived performance. After adjusting for gender, age, and additional training, the authors found that community nurses still perceived their performance as higher than hospital nurses (estimated difference= 0.53, 95% CI (0.36-0.7), p < 0.001). Male gender and additional training also made a statistically significant contribution (estimated differences= 0.4 and 0.35, respectively).

Community and hospitals nurses perceived their self-efficacy as higher than their performance. All differences between self-efficacy and performance in the subsequent subscales were statistically significant.

DISCUSSION

Community nurses and hospital nurses reported occasionally performing self-management support activities in patients with incurable cancer and reported their self-efficacy as almost sufficient. Community nurses reported an average of 0.5 points higher in performance (on a five-point Likert-type scale) than hospital nurses, particularly in the phases of assessing, agreeing on goals, and arranging follow-up contact. They also reported 0.2 points higher in self-efficacy.

The self-reported performance and self-efficacy reveal deficits in the self-management support provided by nurses. Self-management support for patients with incurable cancer seems comparable to that given to patients in general. Other studies using SEPSS among university hospital nurses [19] or nurses (including students) from various settings [22] revealed comparable results for self-efficacy. However, in terms of performance, the current results are 0.4 points higher than those in other studies, mainly because of more self-management activities performed by community nurses.

More hospital nurses had additional training in oncology; however, they reported lower self-efficacy and performance. One study suggested that inadequate preparation of student nurses hampers transferring theory of self-management support into practice, as well as a lack of role models and hours of training to increase self-confidence; the study did not include additional training [29]. Another study suggested that the perceived difference between performance (occasional) and self-efficacy (sufficient) is influenced by knowledge about self-management support, role conflict, lack of engagement, and time [8,19,27]. As a result, both initial and additional training should focus not only on medical management and knowledge of medical management, but also on self-management skills and techniques, as well as collaborative and proactive care planning together with the patient [27,29].

The 10% higher scores of community nurses confirm the current authors' hypothesis that these professionals apply self-management support in patients with incurable cancer more often than hospital nurses [19]. In community care, self-management support takes place in the social context of the patient. Community nurses have stronger coordination skills and knowledge of other healthcare providers and services. These competencies might explain the difference between community and hospital nurses in the phases Agree, Assist, and Arrange of the 5 A's model. In particular, hospital nurses did not feel sufficiently confident in arranging follow-up care and hardly ever performed this task.

In patients with incurable cancer, hospital and community nurses felt most confident in assessing patient knowledge, beliefs, and behavior and in advising patients about the disease and health status. This is in line with other studies in cancer and chronic care, which concluded that self-management support focuses

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primarily on personal situations and wishes (Assess) and medical management and treatment compliance (Advise) [16,25,30,31]. Other aspects, such as managing psychosocial problems or planning and documenting care (Agree), are not carried out by nurses [25,32]. From the provider's perspective, coaching skills, which are necessary throughout all phases, are used to a lesser extent [31]. Activities for which the required time and effort are difficult to estimate, such as talking to patients or educating patients and families, are more often omitted and seem to receive the lowest priority [32]. The lowest scores were found for arranging follow-up care (Arrange); nurses hardly initiate or facilitate follow-up care with patients prior to discharge. In nurse education, less attention is given to this aspect [29]. In addition, in some hospitals, follow-up care is arranged by transferring nurses or case managers, which might have contributed to the low scores on the items.

Scores for single items revealed that assistive devices and technology are hardly ever used by community or hospital nurses. Technology may provide opportunities for nurses (related to symptom management, patient education, or training interventions) [8,33]. In an online focusgroup study, nurses expressed a positive attitude toward technology [25]. However, one study reported that nurses and nursing students do not feel self-competent about using technology [34,35]. In addition, technology may not be available in everyday practice, and nurses may not have time to learn about applying technology in patient care. More people are becoming familiar with assistive devices [33], and technology provides opportunities for self-management support. In people with cancer, technologic applications positively affect perceived support, knowledge levels, and information competence [36,37]. Future training should focus on competencies and the possibilities for using technology for supporting self-management in patients with incurable cancer.

Limitations

The data in this study reflect nurses' self-reported perceptions of their self-management support for patients with incurable cancer. These perceptions might not reflect their actual performance. Additional observations may provide a better picture of the actual self-management support.

The response rate was fair (48%) but not high enough to eliminate the risk of selection bias. It may represent an underestimate of the actual response rate of eligible nurses. Nurses may have moved or changed positions in recent months and, consequently, had not been providing care to patients with incurable cancer. Some mentioned this upon returning the survey; others may not have responded for this reason.

In addition, the authors could not include the educational background of nurses in the analysis. The information about education among the Nursing Staff

Panel members is continuously changing because of job rotation and professional development. Not all changes are communicated; as a result, the authors decided not to include this variable.

The SEPPS instrument was limited in that it focuses on self-management support of patients; questions do not include informal caregivers. The latter are crucial in the support of patients with advanced cancer; they may experience psychosocial burdens, strain, or distress [38], and they need support in terms of information, what to expect, and how to manage consequences in daily care [6].

Implications for nursing

The findings of this study indicate that more effort is needed to increase nurses' confidence in supporting self-management. Nurses are not confident in agreeing on goals set collaboratively, in assisting patients in achieving these goals, and in arranging follow-up care. Integrating the 5 A's model in training and in team practice is recommended, with emphasis on the phases Agree, Assist, and Arrange. In addition, specific attention should be given to the use of devices and technology, for which nurses reported a lack of knowledge and a lack of time to learn about.

Future research should focus on developing and evaluating training programs for self-management support skills in nurses and, more specifically, on collaborating with patients in care planning and coaching. In addition, studies should examine preferences and possibilities of applying technology in patients with incurable cancer, from both a nursing and a patient perspective, in hospital and community care. They should also explore the relationship between nurses' self-efficacy to support self-management and patients' self-efficacy to perform it.

CONCLUSION

This cross-sectional study found a discrepancy between nurses' (particularly hospital nurses') perceived (high) self-efficacy and (lower) performance for supporting self-management among patients with incurable cancer. Community nurses were more confident than hospital nurses in supporting self-management in this population. More effort is needed to increase self-management support by nurses, with a focus on arranging follow-up care and use of technology.

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CHAPTER 6

A nurse-led self-management support intervention for patients and informal caregivers facing incurable cancer: a feasibility study from the perspective of nurses

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ABSTRACT

Purpose: Investigation of the feasibility of recruitment through nurses of patients with incurable cancer, and the feasibility (adoption, usage) and nurses' evaluation of a nurse-led self-management support intervention, integrated in continuity home visits and based on the 5 A's Behavior Change Model.

Method: Questionnaire, registrations, evaluation forms, and interviews.

Results: Recruitment was complicated; many patients were ineligible for participation, nurses appeared protective of their patients (gatekeeping), and recruitment during the first continuity home visit appeared to be a barrier as a lot of other issues had to be discussed. The adoption rate was 81%, meaning that 18 out of 22 nurses recruited were willing to use the intervention. The usage rate at the nurse level was 56%, meaning that 10 nurses applied the intervention in full (having applied all five A's) in at least one patient. Nurses used the intervention in full in 21 out of the 36 patients included, implying a usage rate at the patient level of 58%. Nurses' mean general satisfaction score for the intervention was 7.57 (range 0-10). Nurse were especially positive about the 5 A's model, and considered the continuity home visits to be an appropriate setting for the intervention.

Conclusions: Timing of recruitment and gatekeeping complicated recruitment of patients through nurses. Although nurses were positive about the intervention, nurses often not fully applied the intervention. To improve the usage, it is suggested that nurses should first be trained in using the 5 A's model.

HIGHLIGHTS

- Nurses regarded continuity home visits an appropriate setting for the intervention.
- Nurses were positive about the 5 A's model for structuring self-management support.
- Usage rates showed that 'Assist' and 'Arrange' of the 5 A's model are applied least.
- Nurses need extra training in applying the A's Assist and Arrange.

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INTRODUCTION

A variety of self-management interventions have already been designed for people confronted with cancer [1-3]. However, few interventions focus on patients facing incurable cancer who live at home and their informal caregivers, and few focus specifically on self-management support provided by nurses [4,5]. Self-management in cases of incurable cancer is important, although it might be quite challenging, e.g. due to physical and psychological symptoms, and existential issues that may be severe and progressive over time.

When people do not have sufficient self-management skills, guidance in self-management may be needed. eHealth is increasingly proving itself useful in self-management [6-8] and possibly has added value in self-management support [9,10]. However, to our knowledge, no interventions have been developed that combine face-to-face support at home and eHealth.

A structured, nurse-led self-management support intervention for people facing incurable cancer and their informal caregivers was therefore developed, combining personal contact at home with a specialist oncology and/or palliative care nurse, and eHealth. This article reports on its feasibility for nursing practice.

Technological and other medical advances are now letting patients remain in the palliative phase of cancer longer than ever before. This additionally results in the possibility of living in their home environment for longer, often with little or no support from professionals in particular [11]. With symptoms mostly arising at home, the demands made on self-management are high. Self-management by patients facing incurable cancer and their informal caregivers can be rather complex. Self-management can be described as an individual's ability to manage their physical and psychosocial symptoms and to make decisions about treatment and/or care in order to optimally incorporate the disease into their daily life and to maintain a satisfactory quality of life despite the disease [12,13].

Both patients and informal caregivers are confronted with problems and symptoms related to the irreversibility of the disease. Patients are often faced with a variety of problems and symptoms, such as fatigue, pain, lack of energy, loss of appetite, dyspnea and worry [14,15]. Not everyone has the skills to deal with the multifaceted consequences of the disease appropriately in daily life. Self-management support from healthcare professionals may therefore be needed [11].

Self-management support concerns a collaborative approach in which providers and patients work together to define problems, set priorities, establish goals, create treatment plans and solve problems along the way [16].

Nurses are the appropriate healthcare professionals to provide self-management support [2,3]. Historically, nurses are the healthcare professionals whose care is not focused solely on medical and physical issues but also on emotional and psychosocial problems, and guiding and helping patients deal with these problems. Additionally, in the Netherlands, supporting self-management is described in the professional nursing profile document for the year 2020 as a core competence of nursing professionals [17,18].

The use of eHealth tools can be integrated into the self-management support provided by nurses [19]. Inspired by Eysenbach's definition [20], we define eHealth as the provision of information about illness or health care and/or support for patients and/or informal caregivers using computers or related technologies. A meta-review of the effects of eHealth for cancer patients published in 2016, showed evidence for improvement in perceived support, knowledge levels and information competence, as well as indications of evidence for effects on health status and healthcare participation of cancer patients [21]. In addition, previous research has shown that nurses see potential in the use of eHealth in self-management support. However, most of them emphasize that it is should be supplementary to face-to-face self-management support [10,22].

As mentioned before, a structured nurse-led self-management support intervention was developed for people facing incurable cancer and their informal caregivers. The intervention combines personal contact at home with a specialist oncology and/or palliative care nurse, and an eHealth tool for patients (see the 'Intervention' section). The intervention is complex as it 1) targets providers and receivers of the intervention, 2) involves interacting components, namely face-to-face contact, an eHealth component, and customization to individual problems and needs, and 3) multiple outcomes. The Medical Research Council distinguishes several stages for developing, piloting, evaluating and implementing complex interventions [23]. This study discusses the feasibility of the intervention as part of the piloting stage.

This study additionally discusses the feasibility of study recruitment by nurses among people facing incurable cancer. Recruitment is a challenging aspect of conducting research, especially among people with a life-limiting illness such as cancer, and perhaps even more when it is done by healthcare professionals. It is not always possible for researchers to recruit potential participants personally and directly, e.g. due to privacy regulations. In this case, recruitment through healthcare professionals is often the only option. Furthermore, healthcare professionals who best know the patient appear to be the appropriate people to explain about a study and ask the patient to consider participating. While this approach appears feasible, it also has its downsides. Numerous ethical and practical matters complicating patient recruitment have already been studied extensively [24-27], for example the limited

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time available to spend on patient recruitment, fear of damaging the relationship with the patient, and "gatekeeping" (being protective about patients participating in a study due to the burden the research could possibly impose on them), particularly in patients whose physical or mental condition is vulnerable. While many strategies have been proposed to surmount the difficulties [24,26,28-30], recruitment through healthcare professionals and among people facing incurable cancer seems to remain complex. This article aims to add to the dialogue on this intricate matter.

The goal of the present study was therefore twofold: 1) to investigate the feasibility of study recruitment among the target group of home dwelling patients with incurable cancer through nurses, and 2) to investigate the feasibility of the self-management support intervention by determining nurses' adoption and actual usage of the intervention, plus nurses' subjective evaluations of the intervention for the target group of patients with incurable cancer who live at home.

MATERIALS AND METHODS

Intervention

This study addresses the feasibility of a structured nurse-led self-management support intervention. In the earlier development stage, we first conducted a systematic meta-review of eHealth in cancer [21]. Subsequently, to optimize how the intervention could fit patients' and nurses' preferences, online focus groups and individual interviews were conducted [22,31], alongside several expert meetings with oncology and palliative care nurses, medical experts and representatives of patients and informal caregivers.

The structured nurse-led self-management support intervention was integrated into what are known as 'continuity home visits' made by specialist oncology and/or palliative care nurses, for cancer patients who are not yet receiving regular home care. The visit's purpose is to guarantee continuity of care after discharge from hospital and to assess new problems that arise at home [11,32]. A continuity home visit takes 75 minutes on average, depending on the home care organization.

Self-management support as provided in the intervention was structured according to widely accepted 5 A's Behavior Change Model (hereinafter simply the "5 A's model") [33,34], a framework for providing self-management support that underpins the Dutch care standard for self-management [35]. The 5 A's model entails five steps, namely: 1) Assess, 2) Advise, 3) Agree, 4) Assist, and 5) Arrange.

The core of the intervention protocol, a schematic overview of how the five A's are addressed in the intervention, is presented in Table 1. The full version is available from https://nivel.nl/sites/default/files/pdf/interventieprotocol-sms-EN.pdf.

Table 1   Core of the intervention protocol

Schematic overview of the 'Self-management support in incurable cancer' intervention within the continuity home visits

First continuity home visit:
· Introduction and intake looking at the personal situations of the patient and informal caregiver.
· Explanation of continuity home visits and an introduction to Oncokompas and the Informal Care Quick Scan. Point out that using these tools is not mandatory.
· Follow up appointment? Provide information as well about how to reach the nurse.

The emphasis of this first continuity home visit can be on the first A, Assess.

Between the first and second continuity home visits
· In the period between the first and second continuity home visits, the patient and the informal caregiver fill in Oncokompas or the Informal Care Quick Scan as appropriate.

The second and any subsequent continuity home visits:
Oncokompas and Informal Care Quick Scan:
· Find out whether the patient and informal caregiver managed to complete Oncokompas and the Informal Care Quick Scan.
· Find out whether the patient and informal caregiver want to discuss the outcomes of Oncokompas and the Informal Care Quick Scan.

If they have completed Oncokompas and the Informal Care Quick Scan and want to discuss it:
· Follow the steps of the 5 A's model and use the approaches that are applicable for Oncokompas and the Informal Care Quick Scan.
· Also pay attention to any other problems and support needs of the patient and informal caregiver. Do this using the checklist of discussion topics from the right-hand column.

If Oncokompas or the Informal Care Quick Scan have not been completed or if those involved do not wish to discuss them:
· Follow the steps of the 5 A's model and use the approaches that are applicable in the general case.
· Use the checklist of discussion topics from the right-hand column to make an inventory of the problems and self-management support needs of the patient and informal caregiver.

When rounding off the continuity home visit:
· Summarize the discussion and the agreements made together. Also make agreements about feedback to the referrer.
· Leave a copy of the individual care plan with the patient or informal caregiver.
In the second continuity home visit, the emphasis can still be on the A for **A**ssess. But the other A's then also come into play, namely **A**dvise, **A**greeing goals, **A**ssisting in achieving the goals and **A**rranging an individual care plan in which the goals and agreements are recorded.

NB 1: It is not always possible to use all five of the A's in the second continuity home visit. Further **follow-up visits** may sometimes be needed for this.
NB 2: The current Oncokompas covers five subjects: pain, fatigue, depression, anxiety and stress. For making an inventory of the patient's self-management support needs for other complaints and problems that are not detailed in Oncokompas, use the checklist of discussion topics from the right-hand column.
NB3: Use the checklist of discussion topics from the right-hand column as well for making an inventory of the problems and self-management support needs of the informal caregiver.

The table below provides a structure for the continuity home visits, using the A's from the 5 A's model.

Self-management support according to the 5 A's model	Example questions	Checklist of discussion topics

Assessing the need for support

General approaches for assessing the need for support
- Fit in with the personal situations of the patient and/or informal caregiver.
- If Oncokompas was used, ask about any other problems as well, that they may have that did not come to the fore in Oncokompas. Use the checklist in the right-hand column.

Approaches for assessing needs using Oncokompas:
- Use and discuss the results of Oncokompas for support needs in dealing with pain, fatigue, depression, anxiety and/or stress using the example questions in the adjacent column.

Approaches for assessing needs using Informal Care Quick Scan:
- Use and discuss the results of Informal Care Quick Scan for determining the issues that the informal caregiver would like support for.
- Ask the informal caregiver what areas they are experiencing problems in. Use the checklist in the right-hand column.
- Ask the informal caregiver if they know which people and organizations can be asked for help.

General example questions for assessing the need for support:
- What do you think is important in life?
- What's the most important thing for you right now?
- Could you tell me about your illness and its treatment?
- Is your illness or treatment causing problems or restrictions in your daily life? In what areas?
- What would you like to tackle or change?
- What can you do for yourself and where do you need help?

Example questions for assessing the need for support using Oncokompas:
- Have you looked at your individual results?
- What subjects from the result would you like to discuss?
- Is there anything you would like to tackle or change?

Example questions for assessing the need for support using Informal Care Quick Scan
- Have you looked at the recommendations from the Informal Care Quick Scan?
- Are there any questions you'd like to ask about the results?
- Is there anything you would like to tackle or change?

Situation of the patient and/or informal caregiver:
- *Physical problems*
- *Social problems*
- *Mental problems*
- *Spiritual issues*
- *Other*

Need for:
- support;
- information;
  - related to the illness;
  - care related to e.g. care providers, individual care options, support in regulatory matters (or aspects relating to rules) such as e.g. asking for care under the Social Support Act (Wmo) or Long-Term Care Act (Wlz).

For more details, please refer to the 'Discussion Topics Checklist for Home Visits in the Palliative Phase'.

Advising and providing information

Approaches for providing advice based on the results of Oncokompas:
- Use and discuss recommendations and additional sources from Oncokompas using the example questions from the adjacent column.

General approaches for providing advice:
- If Oncokompas or the Informal Care Quick Scan was used, advice and information should also be given about subjects that are not discussed in Oncokompas or the Informal Care Quick Scan. Please refer to the checklist in the right-hand column.
- Remember that the recommendations have to be usable and easy to implement in daily living, without additional assistance from the care provider, unless the nature of the problem dictates otherwise.
- Ask what more the patient and/or informal caregiver wants to know.
- Use understandable language and adjust the amount of information.
- Encourage them to ask questions and allow the time and scope for them to do so.
- Get them to retell ("reproduce") the information as they understand it.
- Also ask whether they would like to receive more information, e.g. as hardcopy or by e-mail.

Example questions for advice based on Oncokompas:
- Have you looked at the advice and information sources in Oncokompas?
- For which topics do you want to discuss the advice or information?
- Do you think that the advice given is appropriate for your symptoms?
- What additional sources of information have you been offered?
- Are there some sources of information that you have already used?
- Do you have any questions after reading the recommendations or additional sources?

Once again, you can fit the above-mentioned topics for this step of the 5 A's model in with the 'Discussion Topics Checklist for Home Visits in the Palliative Phase'.

Agreeing goals

General approaches for agreeing goals:
- Encourage the patient and/or informal caregiver to state achievable, concrete goals for handling issues in daily life that are associated with their illness or its treatment. If necessary, help them to formulate achievable targets.
- Weigh up together the quality of life objectives (the things they find important in their own lives) and what is needed for the medical treatment.

Example questions for agreeing goals:
- What do you currently find most important in your life?
- What is the most important thing for you right now?
- What problems would you like to tackle that are consequences of your illness or treatment?
- What, according to you, would be needed for tackling those issues? When would you be satisfied?
- What are the positives of the various options for tackling the problems? What are the negatives and where are the bottlenecks?
- Would you like me (or someone else) to help you make decisions about how to tackle the issues?

Idem

Assisting in achieving the goals

General approaches for assisting in achieving the goals:
- Make an inventory of any factors that will help or hinder the patient and/or informal caregiver in achieving the goal.
- Also discuss strategies for dealing with the obstacles.
- Make an inventory of whether these strategies have previously been successful and the possible causes in cases where they were not.
- Make an inventory of whether any additional support is needed (e.g. from a psychologist or associated non-medical professionals).

Example questions for assisting in achieving the goals:
- What would help you to tackle your problems?
- And what obstacles are preventing you from tackling them?
- Have you encountered these obstacles previously in the past? How did you deal with them then? Did that approach help you? If not, are you able to say why not?
- Do you have ideas about how you could tackle the issue in some other way?
- What can you do for yourself and where do you need assistance?

Idem

Arranging an individual care plan

General approaches for arranging:
- Record the agreements that have been made in an individual care plan for the patient and/or informal caregiver.
- Get the patient and/or informal caregiver to state or write down goals and agreements themselves, in terms that are as concrete as possible.
- Leave a copy of the individual care plan with the patient and/or informal caregiver.
- Encourage the patient and/or informal caregiver to manage the individual care plan themselves.

Idem

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Additional to face-to-face support the intervention comprises the use of two tools: a prototype of Oncokompas tailored to incurably ill cancer patients covering five topics (pain, fatigue, depression, anxiety and stress) and the Informal Care Quick Scan (in Dutch: Quick Scan Mantelzorg). Oncokompas is a web-based self-management instrument that aims to increase what patients know about the impact of cancer, help patients to identify support needs for cancer-related problems, and facilitate access to supportive care [6,36-38]. The Informal Care Quick Scan is a short questionnaire that provides a picture of informal caregivers' care burden, inspired by the "3-minute check" [39].

The intervention was also aligned with the Discussion Topics Checklist for Home Visits in the Palliative Phase (in Dutch: Checklist Gespreksonderwerpen Huisbezoek in de Palliatieve Fase), covering topics relating not only to physical and mental problems but also to the need for practical support [40]. This is an existing checklist that can be used to assess the problems and self-management support needs of the patient and informal caregiver.

Study sample and procedures

Nurses from four Dutch homecare organizations were purposefully recruited through the co-authors' professional networks between October 2016 and December 2016. They were invited to participate in this study. Nurses were eligible to take part in the study if they a) were specialist oncology or palliative care nurses who had followed additional training in oncology and/or palliative care, and b) made continuity home visits to incurably ill cancer patients.

Nurses first received an informational letter about the feasibility study and information about the structured nurse-led self-management support intervention by e-mail. After showing interest in participation, nurses were informed in person by the researcher (VNS) about the study, the self-management support intervention and the intervention protocol.

Additionally, nurses were asked to recruit eligible patients and informal caregivers for a parallel pre-test/post-test study into the preliminary effects of the self-management support intervention in patients (described in De Veer et al. [41]).

A card stating the eligibility criteria and recruitment procedures was handed out during the first meeting. Several meetings at each homecare organization followed during the study, to monitor recruitment. The experiences of team members at their own organization and elsewhere were shared at these meetings; facilitators and barriers to recruitment were identified and scripts to facilitate further recruitment were provided. Moreover, nurses received a financial incentive for every five patients recruited. In addition, newsletters about recruitment progression were sent to the nurses.

A mixed-method design was used, including 1) a short questionnaire on nurses' sociodemographic and work-related characteristics; 2) nurses' recording of background characteristics on all patients newly referred for continuity home visits. Data was the most complete for the period from January 2017 to March 2017, as all organizations provided records of newly referred patients for this period. This information has therefore been used to describe the characteristics of newly referred patients and the recruitment rate; 3) a study-specific evaluation form comprising items about the application of the self-management support intervention, an estimate of the time needed for applying the intervention, the application of the five A's during the continuity home visits, and the suitability of Oncokompas and the Informal Care Quick Scan for patients and informal caregivers respectively. Nurses were asked to fill in the evaluation form for every patient included in the study, and; 4) interview data about the design of the intervention, and recruitment of patients and informal caregivers.

Semi-structured interviews with the nurses were conducted by VNS and CFvU. These interviews were conducted by phone, were audio recorded with the interviewee's permission and transcribed verbatim. An interview guide was used to structure the interviews (see Box 1 for examples of the questions asked).

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Box 1 *Examples of questions asked during the interviews*

- How satisfied are you with the intervention? (0-10)
- What do you think of the 5 A's model?
- What do you think of the fact that the intervention is offered during a home visit? Do you think this is a correct/suitable moment?
- What do you think of the combination of structured personal support and eHealth?
- Do you have suggestions for improving the intervention?
- Could you say how you felt about recruiting clients and relatives for the study?

All participating nurses (see Figure 1) were asked to take part in an interview. Four nurses declined to take part as they had not recruited any patients and consequently did not apply the intervention.

To gain a picture of nurses' subjective evaluations, nurses who had three or more of their patients participating in the study (meaning three possibilities to apply the intervention) were asked how satisfied they were with the intervention on a scale ranging from 0 (not satisfied) to 10 (very satisfied).

Outcome measures

The structured nurse-led self-management support intervention was defined being feasible in the event of adoption and usage rates of 64%, and a mean satisfaction score of at least 7. The adoption and usage rates were based on rates reported in previous studies [8,42]. The usage rate was determined at both the nurse level and the patient level.

Adoption
The adoption rate was defined as the percentage of nurses who agreed to participate and were thus willing to use the self-management support intervention during continuity home visits.

Usage at the nurse level
The usage rate at the level of the nurse was defined as the percentage of nurses who applied the intervention in full, meaning they applied every A from the 5 A's model (namely Assess, Advise, Agree, Assist and Arrange) in at least one patient.

Usage at the patient level
The usage rate at the level of the patient was defined as the percentage of patients for whom the nurses applied the intervention in full, meaning they applied every A from the 5 A's model (namely Assess, Advise, Agree, Assist and Arrange) in providing self-management support to the patient.

General satisfaction
Nurses' general satisfaction with the intervention was assessed based on the mean score of study-specific question "How satisfied are you with the intervention?" (11-point Likert scales from 0 (poor) to 10 (good)).

Data analyses

Descriptive statistics were used to describe the adoption, usage and general satisfaction. Analyses were performed using SPSS Statistics 23 (IBM SPSS Statistics).

All interview transcripts were read and re-read in order to get familiar with the data. Information about the design of the intervention and study procedures was selected and summarized into a list of main themes by the first author, VNS. The list was discussed with CFvU and disagreements were solved by consensus.

RESULTS

Study sample

Each of the four homecare organizations had a special team consisting of on average five specialist oncology and/or palliative care nurses. All nurses (n=22) were invited to participate. During the study, four nurses dropped out, leaving a study sample of 18 (see Figure 1).
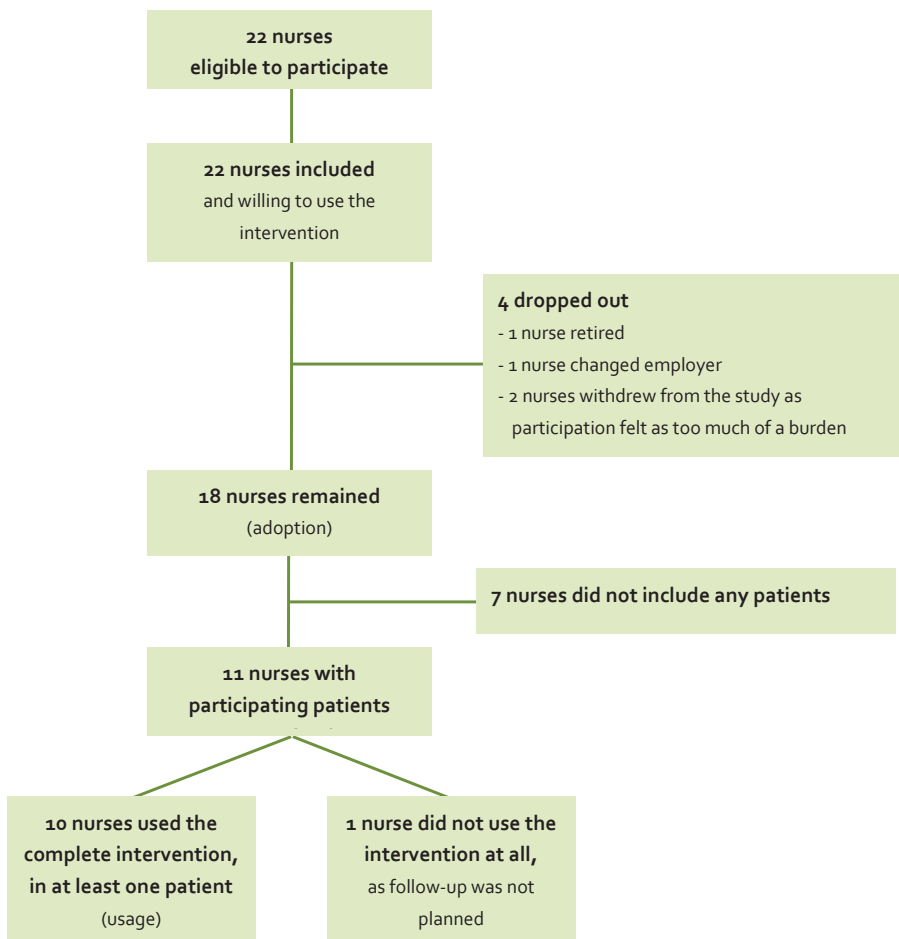
Figure 1   *Flow chart for the nurses*

The majority of the participating nurses had Bachelor's degrees in nursing and had completed oncology and/or palliative care training. The average work experience was 27.11 years. These nurses' background characteristics are presented in Table 2.

Table 2 *Characteristics of the participating nurses*

	Total (n=18)
Gender (female)	17
Mean age in years (SD)	50.06 (6.97)
Mean work experience as a nurse in years (SD)	27.11 (6.95)
Highest degree in nursing	
Higher professional education (Bachelor's degree)	10
Secondary vocational education	5
In-service nursing education	3
Additional education courses	
Oncology and/or palliative care	14
Palliative care and haematology/oncology certificate	2
Haematology/oncology and haematology certificate	2

Feasibility of study recruitment through the nurses

Nurses were asked to record how many patients were newly referred for continuity home visits, whether they were eligible according to the inclusion criteria used and if so whether they were indeed asked to participate. These records were most complete in the period from January 2017 to March 2017, as all the organizations provided records of newly referred patients for this period (the total recruitment period lasted 17 months). This information therefore provides the best indication of the feasibility of study recruitment.

A total of 195 newly referred patients were registered in the above-mentioned period. Of these 195 patients, a total of 94 (48%) were ineligible, mainly because they did not meet the inclusion criterion of "having incurable cancer". Of the 109 patients who did meet the inclusion criteria according to the nurses, 67 (61%) were asked by the nurse to participate. Of these 67 patients, a total of 37 (55%) stated that they were interested or might possibly be interested in participating. The remaining 45% who were not interested mostly did not give a reason for not being interested, according to the nurses. Not having much energy was the most widely mentioned reason given by those who did provide one.

For patients who met all the inclusion criteria, nurses stated they often struggled with the recruitment and mentioned several reasons. They explained that they sometimes forgot about recruitment as they were occupied with other things like e.g. a reorganization in the homecare organization. Furthermore, the timing of recruitment – namely during the first continuity home visit – was a major barrier. The first visit's main purpose is getting to know the patient, gaining the patient's trust, building a relationship, and introducing the organization and the continuity home visits. To the nurses, it felt inappropriate to ask patients if they were interested in participating in the study as well. Patients were already having to deal with so much, the nurses explained, and some patients were in denial of their diagnosis.

"It depends on the patients; I do sometimes find it awkward. If you notice that people are not really ready yet even to mention the word palliative and are still so focused on recovering, then I am very cautious." (Nurse 6)

As an alternative, nurses opted for patient recruitment during the second home visit or at the hospital, which is usually where patients are first informed about continuity home visits.

Nurses also stated that they decided for some patients before even asking that participation would be too much of a burden, e.g. elderly or fragile patients or patients who had to cope with physical symptoms like fatigue or those who had just heard their prognosis.

"What I find tricky about it is that I'm already feeling it in and it's sometimes a burden for the client, shall we say. [...] I'm well aware of how some people don't like questionnaires, and here's another list..." (Nurse 9)

However, nurses also revealed that some patients were interested in the study, when they had expected the opposite.

Furthermore, nurses also pointed out that patients with incurable cancer were referred for the continuity home visits rather late in the disease trajectory. In such a late stage, those patients were often mentally and physically unable to fill in a questionnaire (e.g. people who already appeared to be in the terminal stage of cancer), making them ineligible for study participation.

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Feasibility of the intervention

Adoption
All 22 eligible nurses were willing to use the self-management support intervention during continuity home visits. However, four nurses changed their minds shortly after (see Figure 1). Therefore, the adoption rate was 81% (18/22).

Usage at the nurse level
Ten out of 18 participating nurses used the complete intervention, meaning that they applied every A from the 5 A's model (namely Assess, Advise, Agree, Assist and Arrange) in at least one patient (see Table 3 for details). The usage rate at the level of the nurses was therefore 56%. One nurse did not have the opportunity to apply the intervention, as no follow-up occurred. The other seven nurses did not have patients who participated in the study (see Figure 1).

Usage at the patient level
A total of 69 patients were included in this feasibility study of whom 36 completed the study. Nurses applied every A of the 5 A's model (namely Assess, Advise, Agree, Assist and Arrange) in 21 patients. This implies a usage rate of 58%, taken at the patient level (see Table 3 for details). In seven patients, only four A's were applied. Three A's were applied in one patient. Nurses did not use the intervention at all (no A's applied) in five of their patients. Reasons mentioned for this were a follow-up not being planned, or follow-up taking place by phone. Data on two other patients was missing as no evaluation forms were filled out.

Data from nurses' evaluation forms about all 36 patients revealed that the A's that were applied most often were Assess and Advise, namely in 29 patients. The A's applied least often were Assist and Arrange, namely in 25 patients (see Table 3). Some nurses explained that goals and follow-up were written in a care plan. In most cases, the care plan was discussed with the patient and the practice team that provided daily care.

Table 3 *Detailed overview of usage at the nurse and patient levels*

Usage at the nurse level	Usage at the patient level	Number of A's applied	Assess	Advise	Agree	Assist	Arrange
Nurse 1	Patient 1	5	x	x	x	x	x
Nurse 2	Patient 2	5	x	x	x	x	x
	Patient 3	5	x	x	x	x	x
	Patient 4	5	x	x	x	x	x
Nurse 3	Patient 5	5	x	x	x	x	x
Nurse 4	Patient 6	5	x	x	x	x	x
Nurse 5	Patient 7	5	x	x	x	x	x
	Patient 8	5	x	x	x	x	x
	Patient 9	5	x	x	x	x	x
Nurse 6	Patient 10	5	x	x	x	x	x
Nurse 7	Patient 11	5	x	x	x	x	x
	Patient 12	5	x	x	x	x	x
	Patient 13	5	x	x	x	x	x
Nurse 8	Patient 14	5	x	x	x	x	x
Nurse 9	Patient 15	5	x	x	x	x	x
	Patient 16	5	x	x	x	x	x
	Patient 17	5	x	x	x	x	x
	Patient 18	5	x	x	x	x	x
	Patient 19	5	x	x	x	x	x
Nurse 10	Patient 20	5	x	x	x	x	x
	Patient 21	5	x	x	x	x	x
	Patient 22	4	x	x	x	x	-
	Patient 23	4	x	x	x	-	x
	Patient 24	4	x	x	x	-	x
	Patient 25	4	x	x	x	-	x
	Patient 26	4	x	x	-	x	x
	Patient 27	4	x	x	x	x	-
	Patient 28	4	x	x	x	x	-
	Patient 29	3	x	x	x	-	-
Total number of patients in which the A is applied:			**29**	**29**	**28**	**25**	**25**
	Patient 30	0	No follow-up				
	Patient 31	0	Follow-up by phone				
	Patient 32	0	No follow-up				
	Patient 33	0	No follow-up				
	Patient 34	0	Follow-up by phone				
	Patient 35	-	Missing				
	Patient 36	-	Missing				

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Nurses' subjective evaluation of the intervention

Nurses were generally positive about the intervention. They said the intervention fitted current practice and helped to support and to promote self-management. The mean score for general satisfaction was 7.57 (range 7-9) (SD 0.79) (n=7).

Following the intervention took as much time as usual care, on average 69 minutes (data available on 22 patients). However, nurses reported that in four patients, the time normally spent on continuity home visits was exceeded by 14 minutes.

Evaluation of the 5 A's model

Nurses approved the choice of the 5 A's model. They pointed out that the steps in the model correspond with current practice. Despite that familiarity, nurses said that it raised awareness about how they currently structure their self-management support.

"It does make clear exactly what steps you're taking. Otherwise you're doing it a bit more subconsciously, but now you're a bit more aware of what you're doing. And you're also paying a bit more attention to discussing the care plan and what my role in it can be for that person. I do try to pay a bit more attention to that in this case." (Nurse 7)

Evaluation of Oncokompas

Nurses were ambivalent about the added value and suitability of Oncokompas for their patients.

Nurses said on the one hand that Oncokompas lets people take action themselves, like looking up information about their symptoms at any time they prefer, and that it helps them get a grip on their situation. Additionally, nurses said that Oncokompas helps them to address their patients' needs better.

"Things are then offered in Oncokompas too. […] And then, in your role as an oncology community nurse, you can help them by saying okay did you think of this, or that? Take mindfulness, for example: if that's the result, it's available there, or there… So you can use your own social map again." (Nurse 17)

On the other hand, nurses also said that Oncokompas is not really suitable for their patient group, e.g. patients are too tired to use Oncokompas or do not have sufficient Internet skills. Nurses also remarked on the usability of the tool, e.g. the registration procedure was considered rather complicated. In addition, they indicated that the tool lacked use of multimedia, which made it predominantly usable for patients who are textually oriented. Despite, nurses still saw potential in Oncokompas, e.g. for patients who do not appreciate home visits or who do not prefer support in person by e.g. a nurse.

Evaluation of the Informal Care Quick Scan

Nurses were positive about the incorporation of the tool in the intervention. They said that the Informal Care Quick Scan encouraged them to pay more attention to the informal caregivers. This might result in the informal caregiver feeling more acknowledged, according to the nurses.

"By filling in the Informal Care Quick Scan, they are getting some acknowledgement. That really gives them a feeling of OK, you're coming for me too. It's great if you can show them 'I'm coming to you, I'm there for you too' by having them complete a questionnaire like that." (Nurse 13)

In addition, nurses indicated that discussing the outcomes of the tool allowed conversations about the burden of care to be focused more specifically.
However, nurses shared that sometimes they did not have the opportunity to discuss the results with the informal caregiver because of the (limited) timespan of the home visit.

Evaluation of the suitability of the setting

Nurses saw continuity home visits as a suitable setting and saw specialist oncology and/or palliative care nurses as the appropriate healthcare professionals to apply the intervention.

They stated that following the intervention in general and the steps of the 5 A's model specifically requires time and calm that may be absent in other settings such as hospitals.

"Making an inventory is always possible; you can do your intake then as well. Although I know that's not really what the time is for. You really need a lot of time to do this thoroughly and carefully, following the model. And it's exactly the calmness and the time that we have during home visits that makes them so suitable." (Nurse 3)

Nurses stated that an outpatient clinic might perhaps be an appropriate setting as well. However, they also said that an important advantage of continuity home visits is the possibility of supporting and seeing the patient in their own home.

"You really get a lot more extra information. Yes, someone is in their own environment so you soon see, for example, how people interact with each other. I mean, if there are two of them, and there are often children there too. Well, I always reckon that gives a lot of information." (Nurse 7)

Nurses said that nurses specialized in oncology and/or palliative care nurses in particular – are the appropriate healthcare professionals for this, considering their specific focus on people confronted with incurable cancer. They pointed to the additional oncology and/or palliative care training in which nurses are trained in paying attention to four dimensions (physical, psychological, social and spiritual or existential), communicating about death and dying and other palliative care topics, and their expertise in oncology.

Personal support and eHealth: a good combination or not?

In general, nurses emphasized the importance of considering the patient's preference.

Some nurses preferred support in person, others were in favor of a combination. Nurses who preferred support in person explained that face-to-face contact makes in-depth conversations easier and allows a better assessment of the patient's situation, which lets nurses respond better to care and/or support needs.

Nurses who preferred a combination said that eHealth complements personal contact and that it saves time.

"Well, actually, the client has already done some preparatory work so that you already have the specific questions out in the open. And if you only do it verbally, you need a little while just to find out what the questions are." (Nurse 5)

DISCUSSION

Feasibility of study recruitment through nurses

Study recruitment through nurses turned out to be challenging, resulting in a lengthy recruitment period; it took 17 months in total to include a sample of 69 patients. Based on our results, three possible explanations for this are 1) that patients who were referred for continuity home visits often did not meet the eligibility criteria for the current study, 2) inappropriate timing of recruitment, and 3) nurses often functioning as a "gatekeeper".

Many newly referred patients appeared either to be in the curative phase or already in such a late stage of the disease trajectory that they were not eligible for participation in this feasibility study and a parallel pre-test/post-test study of the preliminary effects in patients (described in De Veer et al. [41]).

Furthermore, recruitment during the first continuity home visit was inconvenient, as the purpose of that visit is getting to know the patient and building a relationship.

Additionally, nurses found it inappropriate to ask patients if they were willing to participate in a study.

In addition, in line with earlier studies [24,27,29,43], nurses often (unconsciously) functioned as a 'gatekeeper'. They said they were making assessments for their patients that participating in the parallel pre-test/post-test study would be too burdensome. To reduce gatekeeping among nurses, the benefits for patients of participating in research should be emphasized, such as patients' desire to give something back to research and society, and the possibility that they themselves could benefit from the intervention being studied [44,45].

Feasibility of the nurse-led self-management support intervention

The current study provides insight into the feasibility of a structured nurse-led self-management support intervention for patients living at home who are facing incurable cancer (and their informal caregivers). Although 18 nurses were willing to use the intervention (an adoption rate of 81%), the usage rate at the nurse level was 56%, and the usage rate at the patient level 58%. This implies that the intervention is not feasible, as the desired adoption and usage rates of 64% were not achieved [8,42]. However, nurses were positive about the intervention, giving it a general satisfaction score of 7.57.

Nurses were especially positive about the 5 A's model that was used for structuring the self-management support. The most widely applied A's were Assess and Advise, while the least commonly applied were Assist and Arrange. These findings are comparable with those of previous studies, which additionally showed that Agree is often forgotten as well [22,46-49]. Moreover, this corresponds with findings from the parallel pre-test/post-test study, which showed that patients perceived these A's as being applied less often by their nurse [41].

The A's of Agree and Assist in particular are important and representative for the collaborative approach in self-management support. Future training in self-management support should therefore pay extra attention to nurses' competencies in agreeing goals with the patient that are based on the patient's needs, assisting the patient in achieving the goals set, and arranging follow-up care.

The "Informal Care Quick Scan" tool was considered by the nurses to be a valuable part of the intervention, as it made sure self-management support could be provided for informal caregivers and elicited areas of concern that showed the burden on the caregiver. Nurses said that the eHealth tool Oncokompas might be a useful addition to face-to-face self-management support. Nurses stated that discussing the outcomes of Oncokompas allowed quicker assessment of patients' problems

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and needs and helped them to tailor their self-management support better. Given the general positive attitude of nurses towards incorporating Oncokompas and the Informal Care Quick Scan in the self-management support intervention, it should be worth the effort of investing in these tools.

Continuity home visits were felt to be a suitable setting for the intervention, as these visits are specifically for cancer patients and are carried out by specialist oncology and/or palliative care nurses. In addition, the setting seemed appropriate because one aim of these visits is to provide advice, instructions and education about symptoms, care and support [11,32]. Promoting self-management fits very well with this aim.

However, as said, many patients referred for the continuity home visits were in a rather late stage of the disease trajectory. This might imply that the setting is, in this regard, not the most appropriate one. Perhaps if continuity home visits are to be part of standard practice and offered to all cancer patients living at home irrespective of the prognosis or disease stage, the intervention would be available for more patients who are in an earlier stage of the palliative phase of the disease. It is therefore recommended that research should be conducted into which patients are currently missing out on an intervention and if they could possibly benefit from it.

Strengths and limitations

A strength of this study is that developing and pilot testing the nurse-led self-management support intervention means that knowledge is being accumulated about integrating self-management support and care for people with incurable cancer [4].

Moreover, many of the existing interventions involve a healthcare professional as a teacher and expert in self-management, instead of focusing on the collaboration between the patient and the healthcare professional, which is typical of self-management support [5,16]. Incorporating the 5 A's model as the framework for structuring self-management support emphasizes the role of the healthcare professional or nurse as working with the patient and assisting their self-management.

A limitation of this study is the rather strict definition of the usage rate at the patient level, which was defined as nurses applying all of the A's (namely Assess, Advise, Agree, Assist and Arrange) of the 5 A's model. It is important to be aware of the fact that providing self-management support is a dynamic and collaborative process between the healthcare professional and the patient or informal caregiver. This implies that it is possible that an aspect such as 'Assist' may not be applied, e.g. when the patient does not need help in achieving the agreed goals. Not applying

one or more steps of the 5 A's model does not necessarily mean that the intervention is unfeasible in practice. Furthermore, it should be noted that we did not define 'applied' any further, meaning that no data was collected about the extent to which the nurse applied each aspect. It is consequently unknown if a nurse merely mentioned the possibility of e.g. agreeing on goals, or if goals were actually discussed and agreed.

CONCLUSION

Inconvenient timing of recruitment and gatekeeping hampered the feasibility of study recruitment through nurses. It is recommended that future research should focus more on appropriate recruitment planning and strategies to overcome gatekeeping, in order to optimize recruitment by nurses.

Although 18 nurses were willing to use the self-management support intervention, and generally evaluated the intervention positively, the usage rate was moderate. To improve the usage rate further, it is recommended that nurses should be trained in the use of the 5 A's model; especially in the A's that were least applied, namely helping the patient achieve the goals set (Assist) and sorting out follow-up care (Arrange).

Ethical considerations

The study was conducted according to procedures of the local ethics committee of the VU University Medical Center, Amsterdam [50]. All participants provided informed consent.
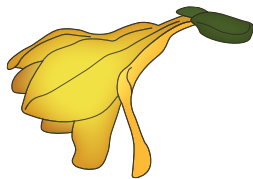
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CHAPTER 7

A structured self-management support intervention for patients with incurable cancer, led by nurses: does it work, according to patients?

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ABSTRACT

Objectives: To gain an understanding of the perceptions of patients with incurable cancer of a new nurse-led self-management support intervention with an integrated eHealth application (Oncokompas) and its potential effectiveness.

Sample and setting: Patients (n=36) receiving support at home.

Methods and variables: A pre/post-test mixed-method design with a period of twelve weeks between the tests and qualitative interviews with 11 patients post-test. Outcome measures were the perceived application of the intervention, patients' satisfaction, patient activation and quality of life (QOL).

Results: Patients gave the intervention an average general satisfaction score of 7.2. Most of the patients (85%) were satisfied with the assessment of their needs and the advice received. They valued the nurses' expertise and the assistance provided at their homes. A quarter of the patients (25%) used Oncokompas. No statistically significant changes in patient activation and QOL were found.

Implications for nursing: This intervention can be used for encouraging self-management by people with incurably cancer. Further refinement and tailoring is desirable. Offering the intervention as early in the palliative phase as possible is recommended.

KNOWLEDGE TRANSLATION

- People with incurable cancer value nurse-led self-management support from a specialist nurse at their own home.

- The value of Oncokompas, the eHealth tool in the intervention, seems to depend on the patient's state of health.

- After twelve weeks, patient activation and quality of life were not improved.

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INTRODUCTION

Medical advances are letting patients with incurable cancer live independently longer than before. Living with the knowledge of a limited life expectancy, uncertainty, and (in the longer term) deterioration of health may make it difficult not to let the disease negatively affect daily living and may result in loss of self-management capacities [1,2]. In this regard, self-management support can be helpful. The aim of this study is to gain an understanding of how patients with incurable cancer perceive a new nurse-led self-management support intervention with an integrated eHealth application and its potential effectiveness on patient activation and quality of life (QOL).

Self-management is a dynamic, interactive daily process that individuals use for managing their illness [3] and refers to a person's ability to manage physical and psychosocial symptoms and to make decisions concerning treatment and/or care to integrate the disease as well as possible into daily life and to maintain a satisfactory quality of life despite the disease [4,5]. Prerequisites for self-management include knowledge about the disease and being able to acquire, select and use appropriate information and help, both professional and other kinds [4-6].

Self-management, however, is not easy for everyone and some people need help managing the consequences of their disease on daily life. Self-management is challenging for people with incurable cancer who have to deal with physical deterioration and a limited life expectancy [1,2]. These patients may need self-management support. Self-management support is a collaborative approach in which providers and patients work together to define problems, set priorities, establish goals, create treatment plans and solve problems along the way [7,8]. In the Netherlands, assisting self-management by patients is part of the scope of nursing practice [9]. Nurses may therefore be the appropriate professionals to provide that self-management support.

Existing self-management interventions mainly focus on patients with chronic diseases such as diabetes, COPD, and rheumatoid arthritis, while patients with cancer, and particularly incurable cancer, have received less attention [10-13]. In addition, most of the interventions are not aimed at nurses who provide self-management support.

A structured nurse-led self-management support intervention for people facing incurable cancer was developed (https://nivel.nl/sites/default/files/pdf/interventieprotocol-sms-EN.pdf) involving face-to-face contacts and an optional eHealth component. eHealth is the provision of information about illness or health care and/or support for patients and/or informal caregivers using computers or

related technologies [14]. The face-to-face contacts were integrated into 'continuity home visits' by a specialist oncology and/or palliative care nurse for patients who are not yet receiving regular home care [15,16]. The nurse's self-management support during the visits was structured according to the five steps of the 5 A's model [17,18]. Currently, in the Netherlands, the 5 A's model is increasingly being adopted and integrated into care standards, nursing education and interventions in self-management support (e.g. Beck et al. [19] and Huis in het Veld et al. [20]).

The optional eHealth component to be used by patients was 'Oncokompas', a web-based self-management instrument for monitoring various QOL aspects by means of Patient-Reported Outcome Measures (PROMs), followed by automatically generated tailored feedback and personalized advice about supportive care services [21-23].

In this study, we tested the feasibility of the intervention from the patient's perspective. The feasibility among nurses has been described elsewhere [24] and showed a high adoption rate (intention to use) of 81%. Nurses' subjective evaluation of the intervention was positive (general satisfaction score of 7.57 out of 10). The usage rate (actual usage) was, however, lower than expected (56%), which suggests that the intervention did not fit nurses' self-management support practice sufficiently well.

The central aim of the current study was to gain an understanding of how people with incurable cancer evaluate the self-management support intervention. A secondary aim was to obtain a picture of the possible effects of the intervention on patient activation and QOL. Patient activation can be described as the individual's knowledge, skills, and confidence for managing their health and healthcare [25]. Activated patients are patients who believe they have important roles to play in self-managing their care, collaborating with providers, and maintaining their health. Studies have demonstrated that patient activation positively affects various health-related self-management behaviors and is associated with improved health outcomes [26-31].

The following research questions are addressed in this paper:

1. Do patients recognize that the nurses applied elements of the 5 A's model, i.e. assessed their knowledge, beliefs and behaviors related to their health, gave advice, collaboratively set goals, helped achieve these goals, and arranged a care plan and follow-up?
2. Are patients satisfied with how the nurse applied elements of the 5 A's model and how do patients generally evaluate the self-management support intervention?
3. How is Oncokompas used and evaluated by patients as an extra service?
4. Are there indications that the self-management support intervention positively influences patient activation and the QOL of patients with incurable cancer?

METHODS

Study sample and procedures

The sample size is calculated based on an expected Cohen's D effect size of 0.4 for patients, an alpha of 0.05, a power of 0.8, and a two-tailed t-test. The power analysis based on the short version of the Patient Activation Measure (PAM) resulted in a sample of 52 patients. Taking into account a drop-out rate of 30% [32], 68 patients had to be included.

A convenience sample was used. Between November 2016 and May 2018, eligible patients were invited to participate in this study by nurses from four home care organizations in the Netherlands. Patients were eligible for study participation if they met the following inclusion criteria: a) were 18 or older; b) had an incurable form of cancer; c) were mentally and physically able to fill out a questionnaire at the time of recruitment; d) had sufficient verbal and written mastery of Dutch; and e) were a new referral for a continuity home visit.

A pre-post design was used with a questionnaire at baseline (T0) and twelve weeks later (T1).

Eligible patients were asked by their nurses to participate in the study during the first continuity home visit and received an informed consent form and the baseline questionnaire. Patients' participation was confirmed as soon as the signed informed consent form and the baseline questionnaire were received. Subsequently, a registration hyperlink for Oncokompas was sent by e-mail to patients who provided an e-mail address. Prior to the second continuity home visit, these patients were asked to complete Oncokompas.

Research ethics and patient informed consent

Under Dutch legislation, the study did not need review by a medical ethical committee because the participants were not subject to procedures or required to follow rules of behavior [33]. All patients gave written informed consent to participate.

Measures

A study-specific questionnaire was put together comprising items about sociodemographic and clinical factors (T0), items about the application of the self-management support intervention in general and satisfaction with it, and about Oncokompas specifically (follow-up (T1)), and scales for the patient's activation and quality of life (T0 and T1).

Recognition of the 5 A's model being applied by the nurse was measured at T1 with statements about the five A's. Each A of the model was operationalized into a single behavior. Patients were asked to indicate whether they were satisfied with the extent to which the nurse applied the following behaviors: "I am satisfied with the extent to which…"

- "…the nurse spoke to me about my experiences (problems, wishes and needs)" (Assess).
- "…the nurse provided information (information, advice and tips)" (Advice).
- "…the nurse set goals together with me for handling my problems or being able to cope with them better" (Agree).
- "…the nurse offered assistance solving the daily problems due to my illness" (Assist).
- "…the nurse made an individual care plan with me containing agreements for the continuation of care" (Arrange).

The response options were a 5-point Likert scale (strongly disagree to strongly agree) and a sixth category of 'not applied'. Perceived application of the five A's was operationalized as the percentage of patients indicating that every A of the 5 A's model was applied by the nurse.

Satisfaction with the five A's was assessed using the Likert scale mentioned above. In addition, patients rated their satisfaction with the overall intervention and the nurse's support on 11-point Likert scales from 0 (very poor) to 10 (very good).

Use of Oncokompas was defined as the percentage of patients who actually used Oncokompas as intended, based on logging data from the application. In the patient questionnaire, users of Oncokompas rated their satisfaction on an 11-point Likert scale from 0 (very poor) to 10 (very good). Non-users were asked why they had not used Oncokompas (open question).

Patient activation was measured with the Patient Activation Measure (PAM) as a 13-item PROM on knowledge, skills, and confidence about self-management of the patient's own health or chronic condition. Patients were asked to say how much they agreed with various statements on a 4-point Likert scale (strongly disagree to strongly agree) or to indicate that the item was not applicable. The total score was transformed to a standardized activation score ranging from 0 to 100 [34]. The Dutch translation of the PAM has good internal consistency (Cronbach's alpha=0.88) and a moderate test-retest reliability (r=0.47) [35].

Quality of life (QOL) was measured using the EORTC QLQ-C15-PAL [36]. The European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire-Core 15-Palliative (EORTC QLQ-C15-PAL) contains 15 items. It was developed as an abbreviated tool for assessing the QOL in patients receiving palliative care [37]. It includes two functional scales (physical and emotional), two

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symptom scales (pain and fatigue), five single items (dyspnea, insomnia, loss of appetite, nausea/vomiting, and constipation) and an overall QOL item. Symptoms and functioning are assessed using 14 items (Q1–14) on a 4 point Likert scale (1—not at all, to 4—very much). Overall QOL is rated from 1 (very poor) to 7 (excellent). Each scale/item is converted to a score ranging from 0 to 100. Although the EORTC QLQ-C15-PAL has been developed partly with Dutch patients and professionals, information about the psychometric properties of the Dutch translation has not been published. In several other countries, the EORTC QLQ-C15-PAL proved to be reliable and valid [38-42].

Box 1   *Topics addressed in the interviews and central questions asked*

- *Motivation*: Why did you decide to participate in the intervention?
- *Experiences with the intervention*: How did you experience participation in the intervention?
- *Experienced effects of the intervention*: Has the intervention helped you?
- *Satisfaction with the intervention*: In the questionnaire, you rated the intervention at <number>. Why?
- *The content of the intervention*: What do you think of the combination of personal support and use of Oncokompas?
- *Assess*: In the questionnaire, you said you were <.....> satisfied with the extent to which the nurse spoke to you about your experiences (problems, wishes and needs). Why?
- *Advise*: In the questionnaire, you said you were <.....> satisfied with the extent to which the nurse provided information (information, advice and tips). Why?
- *Agree*: In the questionnaire, you said you were <.....> satisfied with the extent to which the nurse set goals together with you for handling your problems or being able to cope with them better. Why?
- *Assist*: In the questionnaire, you said you were <.....> satisfied with the extent to which the nurse offered assistance solving the daily problems due to your illness. Why?
- *Arrange*: In the questionnaire, you said you were <.....> satisfied with the extent to which the nurse made an individual care plan with you containing agreements for the continuation of care. Why?
- *Satisfaction with the nurse*: In the questionnaire, you rated the support provided by the nurse at <number>. Why?
- *Satisfaction with Oncokompas*: In the questionnaire, you rated Oncokompas at <number>. Why?
- *Attitude towards self-management*: How do you feel about someone explaining/advising you about what you yourself could do to deal with the disease and the consequences it has for your daily living?

To obtain a picture of patients' experiences with the self-management support intervention, semi-structured interviews were held among a sub-sample of patients (n=11). Patients who had completed the T1 questionnaire were contacted and asked to participate. An interview guide was used to structure the interviews (Box 1). The interviews were conducted by phone, took about 45 minutes, were audio-recorded with the interviewee's permission, and transcribed verbatim.

Data analyses

Analyses were performed using SPSS Statistics 23 (IBM SPSS Statistics). We used descriptive statistics for reporting on perceived application of the A's of the 5 A's model, Oncokompas usage rate, and general satisfaction. To assess the effects of the self-management support intervention on patient activation and QOL, paired t-tests were conducted. Statistical significance was assumed when $p < 0.05$ (two-tailed). All interview transcripts were read and re-read for familiarization with the data. Information about the self-management support intervention in general and Oncokompas specifically was selected and summarized in a list of main themes by AdV and VNS. All text fragments were arranged by theme and placed in Excel, after which AdV and VNS discussed the conclusions for each theme. Disagreements in coding and conclusions were solved through consensus.

RESULTS

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Study sample

Out of 131 patients who showed interest in participating in the study, 69 (53%) were included as they gave informed consent and returned the To questionnaire (Figure 1). Reasons for non-participation included that we lost contact with the patient after several reminders (n=13), that patients found themselves (physically and/or mentally) incapable of participating (n=9), and that patients were too late returning the To questionnaire and informed consent, namely prior to the second continuity home visit (n=7) (Figure 1).

In total, 33 out of 69 patients (48%) dropped out during the study, leaving a study cohort of 36 patients. The main reason for dropping out was the death of the patient (n=23) (Figure 1).

131 patients expressed interest in participating

62 non-participants (multiple reasons possible)
- Unable to reach patient (n=3)
- Unknown; contact with patient lost (n=13)
- Incapable of participating (n=9)
- No T0 questionnaire and informed consent returned (n=2)
- Too tired (n=6)
- Not interested (n=5)
- Too late to participate as second continuity home visit had taken place already (n=7)
- No energy (n=3)
- Wanting to focus on other things than the disease (n=3)
- No reason mentioned (n=3)
- Did not like the way in which the T0 questions were asked (n=2)
- T0 questionnaire was too confrontational (n=2)
- Too burdensome (n=2)
- Patient's situation was too hectic to also participate (n=2)
- Patient had already participated in numerous other studies (n=1)
- Patient formally ended care via continuity home visits (n=1)
- Not incurably ill (n=1)

69 patients completed the T0 questionnaire and returned the informed consent

33 patients dropped out
- Passed away (n=23)
- Retracted from study (n=10)
  - No energy (n=3)
  - No reason mentioned (n=2)
  - Wanting to focus on other things than the disease (n=2)
  - Patient has been transferred to another care provider (n=2)
  - No response after multiple T1 reminders (n=1)

36 patients completed the T1 questionnaire

Figure 1   *Flow of participants*

Characteristics of the study sample

No significant differences were found between the participants and those who dropped out in terms of age, sex, marital status, education, occupational status, time since diagnosis, treatment modality, or PAM score (Table 1). Significant differences were found for the aim of the received care as perceived by the patients. Participants more often indicated that slowing down tumor growth was the aim, whereas symptom relief and wellbeing were more common among those who dropped out. Significant differences were also found for physical functioning, fatigue, appetite loss, and overall QOL (better among participants). This reflects a poorer state of health among those who dropped out group and is in line with the large number of deaths in the drop-out group.

Table 1 *Demographic and health characteristics of the participants (n=36) and those who dropped out (n=33)*

	Participants[3]		Drop outs[3]		
	n	%	n	%	p[4]
Age (n=67)					
60 years or younger	11	32%	8	24%	0.719
61 – 70 years	14	41%	14	42%	
71 years or older	9	27%	11	33%	
Gender (n=69)					
Female	18	50%	14	42%	0.528
Male	18	50%	19	58%	
Time since diagnosis (n=69)					
Less than 6 months	17	47%	16	49%	0.397
Between 6 months and two years	8	22%	11	33%	
More than two years	11	31%	6	18%	
Education (n=69)					
Primary: elementary, middle	16	44%	14	42%	0.848
Secondary: high school, vocational college	12	33%	10	39%	
Tertiary: Bachelor's and Master's degree	8	22%	9	18%	
Occupational status (n=69)					
Employed	6	17%	7	21%	0.630
Unemployed	30	83%	26	79%	
Cancer treatment (surgery, chemotherapy, radiation or hormones) (n=69)					
Yes	30	83%	25	76%	0.434
No	6	17%	8	24%	
Aim of received care					
Slowing down tumor growth, yes (n=53)	18	62%	8	33%	0.037
Symptom relief and general wellbeing, yes (n=53)	12	41%	17	71%	0.032
Mean PAM score (0-100) (SD) (n=62)	57.2 (14.1)		51.5 (9.5)		0.072

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Table 1   *Continued*

	Participants[3]		Drop outs[3]		
	n	%	n	%	p[4]
Mean QLQ-C15-PAL (0-100) (SD)					
Physical functioning[1] (n=69)		82.1 (20.6)		64.6 (24.8)	0.002
Emotional functioning[1] (n=69)		71.8 (27.0)		65.2 (30.7)	0.345
Dyspnea[2] (n=69)		25.0 (32.2)		33.3 (31.2)	0.280
Pain[2] (n=69)		37.0 (29.0)		42.9 (32.6)	0.430
Insomnia[2] (n=69)		36.1 (37.7)		32.3 (31.7)	0.655
Fatigue[2] (n=68)		44.0 (24.0)		56.3 (23.1)	0.036
Appetite loss[2] (n=69)		25.9 (33.0)		44.4 (37.0)	0.031
Nausea and vomiting[2] (n=69)		25.0 (30.2)		35.4 (34.3)	0.187
Constipation[2] (n=68)		12.4 (23.0)		22.2 (27.2)	0.111
Overall quality of life[1] (n=69)		67.6 (18.7)		56.6 (23.9)	0.036

[1] High scores represent high functionality or higher quality of life
[2] High scores represent high symptomatology or lower quality of life
[3] Due to rounding, not all percentages add up to 100
[4] T-test and χ2 tests, two-sided p-value

Perceived application of the intervention

The following results are for the 36 patients who participated at T1. According to almost three fourths of the patients (74%, 25 out of 34, 2 missing), the nurse applied the intervention in full, meaning that every A of the 5 A's model was applied. Three patients (9%) indicated that none of the A's were applied during the continuity home visits. Figure 2 shows that Agree, Assist, and Arrange were the A's that were least recognized.

Satisfaction with the Intervention

Best appreciated were the nurse's assessment of a broad range of actual and potential problems of the patient as well as their family members and the recommendations of the nurse (Figure 2).

"...someone who comes round to your home and takes a good look at your issues, so that you can have a right good talk about them. That's valuable to me." (respondent 31)
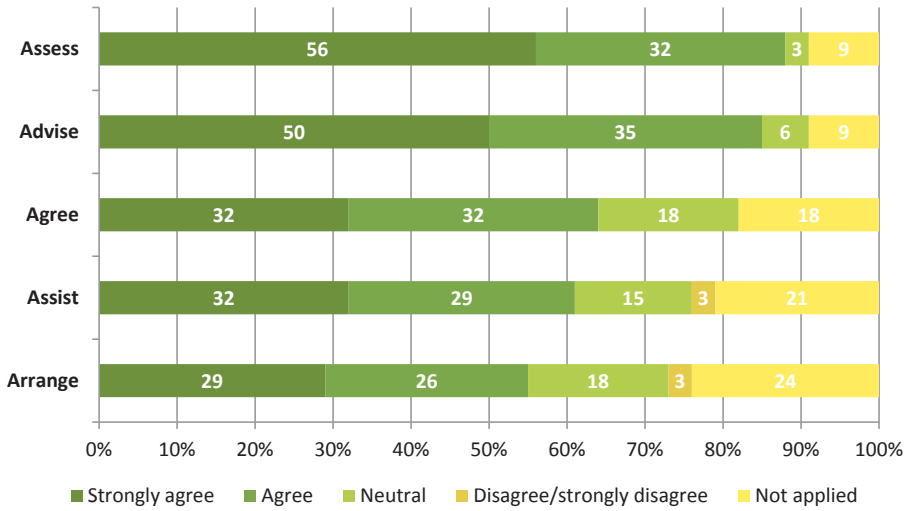
Figure 2 *Extent to which patients agreed with the statements on satisfaction about elements of the 5 A's model ("I am satisfied with the extent to which...") (n=34, 2 missing)*

"...you're not only ill, as my oncologist said to me, but you've both got to cope with the disease, because it has a big impact." (respondent 79)

Some patients did not appreciate all the topics the nurse put forward; those concerning the terminal phase in particular were confrontational.

"...the facts are always being driven home... that small glimmer of hope that you've still got, the one thing you're clinging onto in life... the hard truth is rammed home and that can be pretty tricky to cope with... I think that people do benefit from not having whatever hope is left taken away from them." (respondent 11)

Patients mentioned all kinds of subjects that the nurse gave advice about, such as practical advice on how to arrange a taxi, medical and other aids, or domestic help, information about possible places for dying or how to deal with symptoms, as well as advice on how to involve family and friends in the care.

"It's nice that you don't have to search the whole Internet to find exactly where you need to be at: she knows the answers and will show you the way... Some people simply feel too ill to go Googling." (respondent 11)

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Patients were generally also satisfied with the other A's of the intervention, if applied (Agree, Assist, and Arrange – see Figure 2). In the interviews, patients stated that they perceived these A's as less necessary. When asked if goals had been set, one patient (11) answered that there were no goals as "*I don't know what the future will bring.*" Arrangements consisted mostly of appointments for further contact or that the patient agreed to contact the nurse when their state of health worsened. As one respondent (70) remarked: "*...when it gets that far... that you'll have a fixed contact then, someone you've gotten to know.*"

Patients gave the structured nurse-led self-management support intervention an average general satisfaction score of 7.2 on a scale from 0 (very bad) to 10 (very good) (range 0-10, SD 2.0). The average score for support by the nurse was 7.9 (range 1-10, SD 1.7) These broad ranges indicate large differences in how much the intervention was appreciated.

Patients greatly appreciated specialist oncology and/or palliative care nurses visiting them. The patients interviewed generally perceived this as pleasant because of the nurses' expertise, empathy, and time for the patient. They also valued the fact that the visits were at the patient's home, as this led to a more relaxed and open conversation.

"...at the hospital, you're immediately just another patient. And the smell, and all the sick people you see around you – that always makes me so sad." (respondent 31)

"...at home, well, it's cozier, more homey, more relaxing. Maybe the relaxing part comes first. You make a coffee or a tea and then we can have a cozy chat about it." (respondent 126)

Use and evaluation of Oncokompas

In total, 59 patients (out of 69=86%) provided an e-mail address and were sent a registration link for Oncokompas. According to logging data, 35 patients (51%, drop-outs included) registered, and 17 patients (25%, drop-outs included) used Oncokompas. Whereas patients in the drop-out group and patients in the study cohort provided an e-mail address equally often, fewer drop-out patients registered (36%) than patients in the study cohort (64%). Twelve percent of the patients in the drop-out group (4 out of 33) used Oncokompas, compared to 36% of the patients in the study cohort (13 out of 36). Six patients stated at T1 that they had discussed their scores with the nurse. At T1, 18 patients from the study cohort gave reasons for not using Oncokompas; these were that their physical condition was too poor or they were too tired (n=4), no interest in using Oncokompas (n=4), recurrent hospital admissions or visits (n=2), technical problems (n=2), not receiving access to Oncokompas (n=2),

not remembering that Oncokompas was available (n=1), no Internet (n=1), did not understand Oncokompas (n=1), did not know Oncokompas (n=1).

The average score for Oncokompas was 6.5 with large differences in scores (range 1-9, SD 1.9). In the interviews, patients noted that the value of Oncokompas is related to personal preferences (patients e.g. remarked that the topics in Oncokompas did not really fit their situation) and to the disease burden.

"…so you've got to be up to it, be in good enough shape physically and mentally just to sit there with your PC or tablet and look everything up." (respondent 72)

Generally they preferred a nurse and believed Oncokompas could sometimes have an added value.

"For me, personal contact is what matters and Oncokompas can then be a nice extra on top of that." (respondent 26)

Changes in Patient Activation and QOL

There was no statistically significant change in patient activation (PAM score) or QOL (QLQ-C15-PAL scores) after the intervention (Table 2).

Table 2 *Mean and standard deviation scores for patient activation (PAM) and QOL scales (QLQ-C15-PAL) at pre-test (To) and post-test (T1)*

	n	To	T1	p
PAM	30	57.6 (14.4)	53.0 (9.5)	0.054
QLQ-C15-PAL				
Physical functioning[1]	30	84.1 (20.8)	76.3 (27.2)	0.072
Emotional functioning[1]	30	69.4 (28.1)	76.1 (17.9)	0.178
Dyspnea[2]	30	23.3 (31.7)	20.0 (22.5)	0.501
Pain[2]	30	34.4 (28.3)	26.7 (28.2)	0.080
Insomnia[2]	30	36.7 (37.5)	28.9 (30.0)	0.182
Fatigue[2]	30	43.9 (22.5)	46.7 (27.5)	0.517
Appetite loss[2]	30	24.4 (32.7)	24.4 (28.9)	1.00
Nausea and vomiting[2]	30	25.6 (28.6)	24.4 (28.9)	0.861
Constipation[2]	28	10.7 (18.3)	19.0 (27.9)	0.109
Overall quality of life[1]	30	67.2 (16.7)	66.7 (15.8)	0.865

[1].High scores represent high functionality or higher quality of life
[2] High scores represent high symptomatology or lower quality of life

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DISCUSSION AND CONCLUSION

Discussion

The present study provides an understanding of patients' evaluation of a structured nurse-led self-management support intervention with optional use of Oncokompas, and the preliminary effects on patient activation and quality of life. The results showed a mean satisfaction score of 7.2 for the intervention as a whole, with patients being particularly satisfied with the assistance from the nurse (7.9). Patients greatly valued the expertise and attitude of the nurse, the time available for a quiet conversation, and the visits in their own home. This is in line with previous studies on specialist home palliative and cancer care professionals [43,44] reporting that competent specialist care was perceived as reassuring by patients and increased the self-perceived ability to deal with symptoms [43]. Furthermore, earlier research revealed that visits by healthcare professionals to the patients' own homes were often greatly appreciated by people facing a life-limiting disease, as such visits provide a sense of security [44,45].

Oncokompas was less highly valued (mean score 6.5). Other studies of Oncokompas showed mean scores of 6.9 and 7.3 respectively from breast cancer survivors [46] and head and neck cancer survivors [22]. Some patients interviewed in the present study considered Oncokompas to add little value as the topics discussed did not really fit their situations, whereas others appreciated Oncokompas greatly. In addition, other studies found differences between people in the use and intended use of eHealth. People with lower educational levels and with complex, unstable health conditions were found to be less open to eHealth than people with higher educational levels and less complex health conditions [47,48]. Perceptions such as the belief that eHealth will help, the perceived ease of use of an eHealth tool, the extent to which the results of an eHealth tool are easily observed, and self-efficacy were found to be strongly related to the use of eHealth [22,47,49]. In addition, our results suggest that patients lose interest in eHealth as they become weaker. Future research into the relationship between the added value of Oncokompas and advanced disease is desirable.

The nurse-led intervention to enhance self-management was structured using five steps, Assess, Advise, Agree, Assist and Arrange. Three fourths of the patients (74%) recognized these steps as being applied by their nurse. Nurses particularly assessed problems, wishes and needs and gave information and advice. Setting goals, nurses' assistance in achieving these goals and arranging future care were less often applied, according to patients. This corresponds to what nurses themselves in this study indicated they had applied during the study period [24]. A recent study

among nurses showed that nurses felt confident in assessing and advising, but less confident in agreeing on goals, assisting patients in achieving these goals and arranging follow up care [50]. The general skill level of the nurses may play a role in nurses feeling confident in applying the five steps.

This study also evaluated the potential effectiveness of the intervention on patient activation and QOL. Patient activation is a prerequisite of self-management behavior. High patient activation was found to be associated with higher engagement in advance care planning [51], which is an important aspect of qualitatively good palliative care and self-management in terms of patients contributing to their care. The mean activation scores in our group were 58 (T0) and 53 (T1), corresponding to mean activation scores of people who rated their own health as poor or fair [25]. The post-test activation scores of our group were lower than the mean score found for breast cancer survivors (61 at T1 [46]). An explanation might be that feeling empowered and self-efficacy are less important for patients with a life-limiting illness as they are for other patient groups [52]. Still, there are indications that there might be room for improvement in patient activation.

The intervention did not improve the QOL, as no statistically significant changes were found across the study period of twelve weeks. It could be argued that even maintaining or slowing down the decline of patient activation and QOL might be a positive effect of the intervention. However, due to the absence of a control group, it is unknown what these patient outcomes would have been without the intervention. Additional information from professionals at T0 and T1 about the functional status of the patient (measured with e.g. the Palliative Performance Scale) could also have helped interpret our results.

Strengths and limitations

A major strength is that the structured nurse-led self-management support intervention studied is one of the few interventions that offers self-management support for people with incurable cancer and which is specifically developed for the healthcare professional [10,11,52]. Moreover, considering the recent review by Wakefield et al., this appears to be the first study with a pre-test and post-test design among people facing a life-limiting illness that included a relatively large group of patients [52].

Furthermore, our study also illustrates the difficulty of carrying out intervention studies with people with incurable cancer. The low activation scores and the high percentage of deceased patients in the drop-out group shows the extreme vulnerability of our study group, and sets limits on the feasibility of such studies. In addition, patient recruitment turned out to be challenging, given that it took

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17 months to include 69 patients. This is partly due to newly referred patients for continuity visits being either too ill to participate or being treated with curative intent, timing of recruitment, and because of nurses' "gatekeeping" behavior [24]. Our recruitment and drop-out data of 50% can help future studies estimate the number of people with incurable cancer required.

Another strength of this study is the mixed-method design, providing an in-depth picture of patients' experiences with distinct features of the intervention such as the home setting, specialist nurses supporting self-management, and Oncokompas.

Limitations are the small sample size and the lack of a control group, which may have made it difficult to test differences between T0 and T1. Subsequently, no firm conclusions can be made about the efficacy of the intervention. Further research should be carried out with a control group and larger numbers of patients.

Implications for nursing practice and research

The intervention was appreciated by both nurses [24] and patients with incurable cancer for structuring self-management support and enhancing self-management of disease-related problems and needs. Using a model that distinguishes various domains of self-management, such as the Dutch General Model of Self-Management [18,53], could further improve the potential effectiveness of the intervention. This model distinguishes four self-management domains: 'Experience-Based Knowledge', 'Living with the Condition', 'Contributing to Care,' and 'Organization of Care and Support'. Nurses could use these domains to systematically assess problems and needs within each domain and further tailor their self-management support.

Oncokompas can be offered to patients for optional use, as some patients appreciated the eHealth tool. The prototype of Oncokompas for patients in the palliative phase of the disease that was used in this study has been developed further and is currently being tested in a randomized controlled trial [54]. Nurses stated that discussing the outcomes of Oncokompas allowed quicker assessment of patients' problems and needs and helped them to tailor their self-management support better [24]. As patients' intentions to use eHealth depend strongly on their perceptions and expectations of eHealth [22,47,49], it is important that nurses help their patients with using Oncokompas by for instance explaining the use and showing the possibilities, as well as showing the possible gains of using Oncokompas.

It is advisable to offer the intervention as early in the palliative phase as possible. Patients' perspectives of their deteriorating physical and mental health may make them lose faith in how they themselves could still take control of matters. If it is offered earlier in the palliative phase, patients will have more time to learn how

to self-manage and how they can stay in control over their life and their care, and subsequently maintain their quality of life. Using the Palliative Performance Scale score (or something similar) might assist in establishing a continuum of when such an intervention is helpful and when it is not. This needs further research.

Conclusion

People with incurable cancer gave a positive assessment of the nurse-led self-management support intervention, although the usage of Oncokompas was rather low. The intervention did not positively influence patient activation and QOL. Offering patients the intervention in an earlier phase would probably enhance the efficacy of the intervention.

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CHAPTER 8

Summary and general discussion
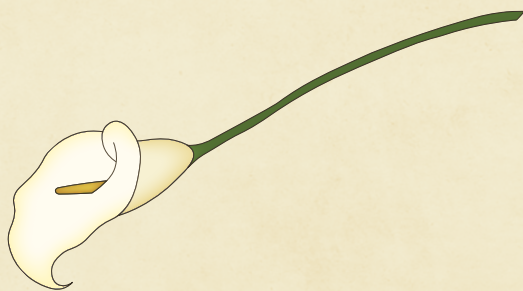
This final chapter summarizes and reflects on the main findings, discusses general methodological strengths and limitations, and provides recommendations for future research and practice.

SUMMARY

The general aim of this thesis is to provide insight into nurses' self-management support for people facing incurable cancer.

The definition of *self-management* used in this thesis was inspired by the definitions of Barlow et al. [1] and Bodenheimer et al. [2]. It is formulated as:

An individual's ability to manage the physical and psychosocial symptoms and to make decisions concerning treatment and/or care, in order to optimally integrate the disease in daily life, and to maintain a satisfactory quality of life despite the disease.

Self-management support refers to:

A collaborative approach in which providers and patients work together to define problems, set priorities, establish goals, create treatment plans, and solve problems along the way [3,4].

eHealth can be part of self-management and self-management support. The following definition of *eHealth*, which is based on Eysenbach's definition [5], was used:

The provision of information about illness or health care and/or support for patients and/or informal caregivers using computers or related technologies.

The first main question addressed in this thesis was:

1. a. **What evidence exists for the effects of eHealth for patients with incurable cancer and their informal caregivers?**
   b. **What are cancer patients' and nurses' views on eHealth and its use in the context of self-management and self-management support?**

To gain insight into the existing evidence on the effects of eHealth tools in cancer care, a meta-review of relevant systematic reviews was conducted (**Chapter 2**). Ten systematic reviews were included, all focusing on the effects of eHealth for cancer patients. No systematic reviews about the effects of eHealth on informal caregivers of people with cancer were found.

Evidence was found for effects on perceived support, knowledge levels, and the information competence of cancer patients. Findings regarding effects on decision-making, psychological wellbeing, depression and anxiety, and quality of life were inconsistent.

The large majority of the eHealth tools studied were meant for a rather broad target group of people with cancer and did not focus on a specific disease stage, such as the palliative stage. Furthermore, eHealth was often just one component in a multi-component intervention, and effects were rarely analyzed separately. This means that it was not always clear which component was responsible for an effect.

Next, cancer patients' views on eHealth were investigated. In three online focus groups and 10 semi-structured individual interviews, both patients with curable cancer and patients with incurable cancer were asked about their experiences with and views on eHealth (**Chapter 3**). Generally, patients' attitudes towards eHealth were positive. eHealth was deemed useful for looking up information about treatments, drugs, or side effects, and for online communication with healthcare professionals. However, patients with curable cancer as well as those with incurable cancer emphasized that eHealth cannot fully replace face-to-face contact with healthcare professionals.

Furthermore, nurses' views on eHealth in the context of self-management and self-management support were explored in six online focus groups with 45 nurses from various care settings (**Chapter 4**). Nurses explained that they see advantages in eHealth, e.g. the possibility of looking up disease-specific information, and monitoring symptoms via digital symptom diaries, allowing patients to stay in charge of their own care and lives. In addition, nurses said that whether or not eHealth is feasible for incurable cancer patients depends on their digital skills, the disease stage, and the severity and nature of their problems and symptoms. Nurses also highlighted advantages in terms of continuity of care when both patients and healthcare professionals have direct access to the eHealth application. Despite this, in an online survey of nurses' self-management support competencies and performance, nurses reported they do not feel confident in using eHealth, and never use eHealth to provide remote support (**Chapter 5**). In addition, they reported that they rarely discuss with their patients how the patients could use eHealth in their daily activities.

Like the patients, the nurses stressed that eHealth cannot fully substitute for personal contact between them and patients.

The second main research question addressed was:

2. How do people facing incurable cancer self-manage the consequences of the disease in their daily lives?

In three online focus groups and 10 semi-structured individual interviews, insight was obtained into the self-management activities of both patients with curable cancer and patients with incurable cancer (**Chapter 3**). The data that were gathered were analyzed qualitatively. The main themes derived from the analyses were categorized using the four domains of the Dutch General Model of Self-Management [6,7]. All cancer patients appeared to undertake comparable self-management activities, irrespective of the disease stage. The self-management activities mostly encompassed:

- Gathering information about the disease and treatments (which fits the 'Experience-based knowledge' domain in the General Model of Self-Management);
- Accepting your situating, pouring out your heart and setting limits (which fits the 'Living with the condition' domain);
- Taking into account information from the doctor, your own feelings, and the consequences of undergoing (or not undergoing) treatment (which fits the 'Contributing to care' domain).

Arranging home care, financial assistance, or other forms of care and support (fitting the 'Organization of care and support' domain) was not mentioned as often.

Patients considered their self-management activities important in dealing properly with the disease and making decisions about treatment and care.

The third main research question addressed was:

3. How do nurses perceive their competencies and their actual performance in self-management support for people facing incurable cancer?

In six online focus groups with nurses working in various settings and with different educational qualifications, nurses were asked how they currently support incurably ill cancer patients and informal caregivers in managing and dealing with the physical and psychosocial consequences of the disease, and how they would support them in the ideal situation (**Chapter 4**).

The online focus groups were analyzed qualitatively, and themes were categorized according to the steps of the 5 A's Behavior Change Model (5 A's model) [7,8]: Assess, Advise, Agree, Assist, and Arrange. The model assists healthcare professionals in structuring self-management support.

The nurses turned out to give most attention to assessing incurable cancer patients' personal situation, wishes, and needs ('Assess' in the 5 A's model), and providing information on cancer, specifically incurable cancer ('Advise' in the 5 A's model). The other A's, Agreeing on goals, Assisting patients in reaching the goals set, and Arranging follow-up, were mentioned less frequently as part of nurses' self-management support. Nurses also said that, in the ideal situation, they would have more time to spend with the patient in order to optimally tailor self-management support to the patient's needs. Additionally, nurses said that they would pay more attention to involving informal caregivers.

In a subsequent online survey among a nationwide sample of 222 hospital and community nurses, nurses' competencies and confidence in providing self-management support to incurably ill cancer patients were examined. In the questionnaire, the steps of the 5 A's model were explored (**Chapter 5**). The results showed that the nurses felt sufficiently confident about their ability to assess patients' situation and needs ('Assess' in the 5 A's model), and to provide information on cancer and treatment ('Advise' in the 5 A's model). Nurses had close to sufficient confidence in their ability to agree on goals ('Agree' in the 5 A's model), assist in achieving the goals set ('Assist' in the 5 A's model), and arrange follow-up ('Arrange' in the 5 A's model).

In line with the online focus groups discussed in **Chapter 4**, it was found that 'Assess' and 'Advise' were the elements of self-management support most often applied by nurses. Also, in line with the online focus groups, the survey established that nurses were less likely to set goals collaboratively with patients ('Agree' in the 5 A's model). The same applies for assisting patients in achieving their goals ('Assist') and arranging follow-up care ('Arrange'). These latter elements of the 5 A's model turned out to be the least applied in practice, and were also the A's about which nurses felt least self-confident.

The survey results discussed in **Chapter 5** also revealed differences between care settings: community nurses appeared to have more confidence in their ability to support self-management and performed self-management support more often than hospital nurses.

The aforementioned findings informed the development of a nurse-led self-management support intervention for people facing incurable cancer. The self-management support intervention consisted in part of face-to-face contacts between patients and specialist oncology and/or palliative care nurses in the setting

of existing 'continuity home visits'. Such home visits are performed to guarantee continuity of care after hospital discharge, and to ensure the timely identification of problems.

The purpose of the intervention was to guide nurses in supporting self-management among people with incurable cancer, and at the same time to foster self-management among people facing incurable cancer.

The nurse-led self-management support intervention was structured according to the steps of the 5 A's model. In addition to the face-to-face contacts, two tools were used: a prototype of the eHealth tool Oncokompas, adapted for patients in the palliative phase, and the Informal Care Quick Scan (in Dutch: Quick Scan Mantelzorg) for informal caregivers. Oncokompas is a web-based self-management instrument that aims to increase patients' knowledge about the impact of cancer, to assist patients in identifying supportive care needs regarding cancer-related problems, and to facilitate access to supportive care. In Oncokompas, patients can monitor their quality of life with Patient-Reported Outcome Measures (PROMs), followed by automatically generated tailored feedback [9-12]. The Informal Care Quick Scan is a short questionnaire that provides information on informal caregivers' care burden.

The fourth main research question addressed in this thesis was:

4. a. **What is the feasibility of the structured nurse-led self-management support intervention for patients with incurable cancer?**
   b. **How do nurses and patients with incurable cancer evaluate this structured nurse-led self-management support intervention?**
   c. **Are there indications that the self-management support intervention positively influences patient activation and quality of life of patients with incurable cancer?**

This fourth research question was answered in a mixed-method study consisting of two parts, namely a feasibility study among nurses (**Chapter 6**) and a feasibility study among patients (**Chapter 7**). Data were collected through forms completed by nurses for this study on new referrals for continuity home visits, and through questionnaires and interviews with nurses and patients.

The feasibility study among 22 nurses revealed that the nurse-led self-management support intervention was feasible in some respects but not feasible in others (**Chapter 6**). On the one hand, the intervention was feasible, as 18 of the 22 recruited nurses were willing to use the intervention during continuity home visits. This is a rather high adoption rate of 81%. In addition, nurses evaluated the intervention positively with a mean general satisfaction score of 7.6 (range of 0-10),

and they said that the intervention fits with current practice. In individual interviews, nurses were particularly positive about the inclusion of the 5 A's model. Nurses considered the continuity home visits as an appropriate setting for the intervention, as more time is available for the patient and informal caregiver than e.g. in a hospital.

On the other hand, the intervention was not feasible in all respects, as only some of the nurses (10 out of 22) used the full intervention, meaning they applied every A of the 5 A's model in at least one patient. This is a usage rate of 56% at the nurse level. The usage rate at the patient level was 58%, as the nurses used the intervention fully for 21 of the 36 included patients. In line with previous sub-studies, the A's that were applied least were 'Assist' and 'Arrange'.

Nurses were divided about whether or not eHealth (in this case Oncokompas) was useful as an integrated part of the intervention. Half of the nurses were in favor of the combination of eHealth and face-to-face support (as in the intervention), while the other half preferred face-to-face support only (**Chapter 6**). With regard to Oncokompas, the first half of the nurses said that it complements face-to-face self-management support, as discussing Oncokompas outcomes allowed a quicker assessment of patients' problems and needs. Additionally, they said that it helped them to better tailor their self-management support. This motivation also applied to the Informal Care Quick Scan, the questionnaire used to assess informal caregivers' care burden.

The feasibility study among nurses **(Chapter 6)** also showed that the recruitment of patients for the study was challenging for nurses. Participating nurses were asked to recruit their patients for the parallel feasibility study among patients (**Chapter 7**). The nurses found study recruitment challenging, particularly during the first continuity home visit, as a lot of other issues had to be discussed as well. Furthermore, nurses appeared to be protective of their patients (gatekeeping), and were consequently hesitant about asking patients to participate in the study.

The sub-study among the incurably ill cancer patients (n=36) showed that the patients were positive about the nurse-led self-management support intervention (**Chapter 7**). They evaluated the support with a mean score of 7.2. Patients emphasized the importance of having a specialized nurse who supported them in their own home environment during continuity home visits. The majority (74%) of the patients felt that their nurses supported their self-management in full, meaning that every A of the 5 A's model was applied. Following from patients' reports, it appeared that assistance from the nurse in reaching the goals agreed upon ('Assist' in the 5 A's model), and making follow-up arrangements ('Arrange') were applied less frequently than self-management support in the sense of assessing patients' situation and needs ('Assess'), and providing information ('Advise'). This finding is in line with findings from other sub-studies (**Chapters 4, 5, and 6**). Oncokompas, as part of the self-management support intervention, was only used by 13 out of 59

patients who provided an e-mail address for this purpose. Patients were ambivalent about Oncokompas. Some were positive but said that the information and advice provided in Oncokompas did not quite fit their situation. However, these patients explained that they see potential for its use by patients who are in a different situation, e.g. patients with more prominent symptoms.

The sub-study among patients (**Chapter 7**) also examined whether there were indications of effects of the intervention on patient activation and quality of life. No statistically significant changes in patient activation and quality of life were found. However, due to the absence of a control group, it is unknown what these patient outcomes would have been in patients who did not receive the intervention.

Reflections on main findings

eHealth to facilitate self-management and self-management support
Multiple studies in this thesis examined eHealth in the context of self-management and self-management support. Our systematic meta-review showed evidence for positive effects on perceived support, knowledge levels, and information competence (**Chapter 2**).

In addition, in the qualitative sub-studies, both cancer patients and nurses were generally positive about the potential of eHealth (**Chapters 3 and 4**). However, patients and nurses also emphasized that eHealth cannot fully replace face-to-face contacts. Moreover, the feasibility study (**Chapters 6 and 7**) showed that patients were not unanimous about the added value of the eHealth tool Oncokompas, which was part of the self-management support intervention. Some patients said that it was not very useful to them, although they expected that Oncokompas could be more helpful for other patients, e.g. those with more prominent symptoms and problems.

Although eHealth tools such as Oncokompas may not be helpful for all patients or in all situations, eHealth has the potential to aid self-management, considering the evidence from previous research for positive effects on knowledge levels and information competence (**Chapter 2**). Use of eHealth also fits with the trend that patients increasingly use the Internet for looking up information about the disease, symptoms, treatment, and side effects (**Chapter 3**). Besides, eHealth is often a source of information that is available round the clock and allows patients to acquire information at their time of preference, letting them learn how they can deal adequately with the consequences of their disease.

A prerequisite for the usefulness and effectiveness of eHealth appears to be tailoring it to the patient's needs and disease stage [3,13,14]. 'Tailoring' was embedded in Oncokompas. Nevertheless, patients said that the information in Oncokompas

did not completely fit their individual situation. Various other studies in comparable target groups also indicated the necessity of tailoring in eHealth [15,16]. For example, a promising teleconsultation intervention for people with a life-limiting illness appeared unsuccessful in reducing the symptom burden; this was probably because the desired frequency of the teleconsultations was not discussed with the patient and a strict pre-defined assessment form was used, which did not give much opportunity for the patient to describe their symptoms and needs in their own words [14].

When eHealth is used as an integral part of self-management support by nurses, tailoring is also necessary from the perspective of nurses. In the feasibility study (**Chapter 6**), nurses varied in the extent to which they found Oncokompas helpful. Nevertheless, some of the nurses mentioned that it assisted them in self-management support following the steps of the 5 A's model, as discussing Oncokompas outcomes allowed a better assessment of patients' problems and needs ('Assess'), and consequently tailoring of information to the patient's needs ('Advise').

A challenge, however, is that not all nurses feel confident enough to use eHealth, as for instance was shown in **Chapter 5**. This is in line with other recent research demonstrating that nurses do not make full use of the potential of eHealth [17], in part because of unfamiliarity with the benefits of eHealth, and a lack of confidence on how to integrate eHealth in daily practice. Nurses are often not fully confident of having the skills to use eHealth for, e.g. recognizing and determining the patients' situation [18]. This points to the necessity of relevant training in eHealth for nursing staff.

Cancer patients' self-management

This thesis draws a picture of cancer patients' main self-management activities. Irrespective of whether the cancer is curable or incurable, cancer patients mentioned the same self-management activities of gathering information, accepting your situation, setting limits in what you want to do yourself to prevent others from taking over, and taking into account your own feelings, information from the doctor, and the consequences of undergoing (or not undergoing) treatment (**Chapter 3**). Patients considered these activities important for dealing adequately with the disease, and making well-informed decisions about treatment and care.

These results, as well as previous studies among cancer patients [19-21], point to commonalities among patients, irrespective of the disease stage. Certain self-management activities, like gathering information about the disease and treatment options, seem to be related to personal characteristics and traits, for example curiosity or an eagerness to learn [2,22,23].

However, there might be a decline in self-management activities and competencies as death approaches. Physical and mental deterioration and uncertainty about the course of the disease might cause patients to lose faith in

their self-management competencies [24,25]. Patients might also have other priorities, for instance negotiating personal and care relationships [24]. This may explain why we could not find positive effects for the nurse-led self-management support intervention on patient activation (**Chapter 7**), an important factor in self-management behavior [26,27].

Nurses' self-management support

A main finding of this thesis is that nurses working with incurable cancer patients often do not follow all the steps of the 5 A's model [8]. Nurses pay least attention to agreeing on goals with the patient ('Agree'), exploring whether or not the patient needs help in achieving the goals set or any other assistance ('Assist'), and making arrangements for follow-up ('Arrange') (**Chapters 4, 5, 6, and 7**). One explanation for these results is that nurses feel less confident in applying these A's compared to assessing a patients' situation and needs ('Assess'), and advising and providing information ('Advise'). Another possible explanation could be that not all nurses are yet used to the collaborative nature of self-management support in which the patient is a partner and an expert on their own healthcare preferences, values, and goals [2,3,28]. Such collaboration is particularly important in the A's of 'Agree', 'Assist' and 'Arrange', and in this regard the nurse is more of a partner and coach, not just the medical expert like in traditional nursing care.

Van Hooft et al. studied nurses' perspectives on self-management support, fitting different nursing roles, namely that of a coach, clinician, gatekeeper, and educator [29]. The roles of clinician and educator, in which professional knowledge is more important than patients' experiences [29], seem to fit well with traditional nursing care. These roles appear to relate strongly to the frequently applied 'A' of 'Advise', as providing information and transferring professional knowledge to patients seem important to nurses who assume these roles [28,30]. It is plausible that many nurses are not yet used to the shift in nursing roles, and that they do not yet see themselves as a coach and the patient as an equal partner. This could be a result of nurses not yet being properly trained in the support of self-management, as was suggested in previous studies of nurses' self-management support behavior [31], and more specifically in goal setting with chronically ill patients in primary care [31,32].

To conclude, the findings in this thesis strongly indicate that self-management support is not yet fully integrated in nursing care for incurable cancer patients, and extra training is therefore needed. It is important to educate nurses in the essence of self-management support, and to help them to acquire confidence in providing self-management support, through training and self-management support interventions specifically designed for nurses.

Essential components of the self-management support intervention in this thesis

The self-management support intervention was informed by the results of the different sub-studies in this thesis and it was developed in close collaboration with specialist oncology nurses working in practice. This approach meant it was possible to develop a practical intervention appreciated by both the providers and the recipients.

The feasibility study (**Chapters 6 and 7**) identified valuable and essential components of the intervention. First is the use of the 5 A's model. Although not all steps of the 5 A's model were applied, nurses did appreciate the 5 A's model as the point of departure for the self-management support intervention. The model helped them to structure their self-management support and raised awareness about how they currently provide self-management support (**Chapter 6**). The use of a model or framework is strongly recommended when developing a complex intervention, such as our self-management support intervention [33]. The 5 A's model was chosen as the framework for the intervention as it is in line with self-management support as described by Wagner et al. [3,4,8]. It is also integrated in the Dutch care standard of self-management [7]. When choosing a certain model or approach for self-management support, it is important that the model emphasizes the partnership and collaboration between patients and nurses, which is the essence of self-management support [3,4,34,35]. This seemed to be particularly important in the self-management support intervention studied in this thesis, given that self-management support is not yet fully integrated in the care for people with incurable cancer.

A second essential component of the intervention is to have specialist nurses as providers of self-management support. To ensure the practical effectiveness of an intervention, it is important to consider who should provide the self-management support given the recipients of the self-management support, and the appropriate setting [33]. The literature shows that nurses are key in both cancer care and palliative care [36,37]; in particular, specialized and advanced nurses are the main providers of a variety of cancer interventions [38].

Both nurses themselves and their patients regard nurses as the most appropriate providers for the studied self-management support intervention because of the nurses' specific expertise (**Chapters 6 and 7**). These results are in line with other studies of specialist home palliative care and cancer care professionals [39,40]. Competent specialist care reassures patients and increases their self-perceived ability to deal with the symptoms [39].

A third essential component concerns the setting. The self-management support intervention was implemented within continuity home visits by specialist oncology and/or palliative care nurses. Patients as well as nurses considered the home environment to be an appropriate setting for the intervention (**Chapters 6**

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and 7). This is in line with previous research on home palliative care, demonstrating that patients with a life-limiting disease often greatly appreciate visits by healthcare providers to their own home, as this provides a sense of security [40,41]. The patient's home environment is also an appropriate setting because self-management is a daily process that generally takes place at home.

Methodological considerations and recommendations for research

This thesis is based on a combination of qualitative and quantitative research studies, including a systematic meta-review, online focus groups, interviews, and questionnaires. The added value of such an approach is the enrichment of data through the use of multiple methods and data sources. This provides more in-depth insights [42], which is important for a better understanding of the effects, challenges, and opportunities in self-management support for people facing incurable cancer.

Another strength is the involvement of both nurses and patients. Involving all important stakeholders is key when aiming for research that is useful for practice [33]. From the outset, patients were involved as research participants to gain insight into important self-management activities and support needs (**Chapter 3**). Furthermore, nurses working in different care settings, i.e. the hospital and the community, participated in sub-studies discussed in **Chapters 4 and 5**, which gave a picture of their perception of self-management support and current self-management support practices. Moreover, the self-management support intervention was developed in close collaboration with specialist oncology nurses working in practice. Including both providers and recipients of self-management support led to a useful intervention, ready for application in practice.

Another strength is the fact that a feasibility study was performed. Such studies are an essential part of the process of developing, evaluating, and implementing a complex intervention, according to the Medical Research Council in the UK [33]. Feasibility studies can be used to explore suitable recruitment strategies and attainable sample sizes, for example [33,43]. Also, feasibility studies are important for acquiring information about the suitability of the developed intervention for practice, and for gaining insight into the added value for stakeholders [33,43].

A limitation concerns the limited involvement of informal caregivers. However, we incorporated a tool for informal caregivers (the Informal Care Quick Scan) in the self-management support intervention. We also included informal caregivers in the systematic meta-review on eHealth (**Chapter 2**), but no relevant review studies were found on eHealth targeting informal caregivers of people with cancer. This suggests two points for attention for future research, namely the need for more insight into

1) the effects of eHealth for informal caregivers of people with incurable cancer, and 2) their self-management activities and perceived self-management support needs in dealing with the consequences of the disease of their relative in daily life.

Recruitment of an incurably ill target group is always challenging. The feasibility study (**Chapter 7**) showed that the group of eligible patients with incurable cancer who received continuity home visits was rather small. This resulted in a long recruitment period of 17 months for inclusion of 69 patients of which 36 actually participated in the study. This implies that the chosen setting for the intervention might not have been the most appropriate one from the perspective of rapid recruitment, although it was deemed an appropriate setting from a care perspective.

Choosing a setting with sufficient eligible patients is particularly important in a randomized controlled trial (RCT), which is considered an important next step after a feasibility study [33]. An RCT requires a substantially larger sample than a feasibility study to guarantee sufficient statistical power. Hence, recruitment of sufficient patients will probably be even more challenging when an RCT is to be conducted. In this regard, it should be noted that an RCT is currently being conducted among patients visiting outpatient clinics to determine the effectiveness of Oncokompas for incurably ill cancer patients [44].

Recommendations for education and practice

1. Educate nurse students in self-management support
This thesis describes experiences and challenges regarding nurses' self-management support for people with incurable cancer (**Chapters 4, 5, and 6**). One challenge is that not all nurses feel competent enough to use eHealth as part of their self-management support.

To increase nurses' competencies, it is important that self-management support (including the use of eHealth) receives more attention in basic nursing education. An advantage in this regard is that the topic of self-management support receives explicit attention in the new nursing Bachelor's program [45]. Nursing curricula are being adapted to incorporate this issue, and a handbook for nursing education and a related website on nurse-led self-management support [46,47] have been developed. It is recommended that these should be used in basic education for nursing students as well as in continuing education, e.g. for oncology and palliative care nursing.

In addition, a usable instrument has been developed for measuring competencies relevant to self-management support. This instrument is the SEPSS (Self-Efficacy and Performance in Self-management Support) [48], which is based on the 5 A's

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model and was used in the sub-study described in **Chapter 5**. This instrument might also be usable for measuring the effects of self-management support education on nurses' competencies.

2. Use the 5 A's model, but optimize the steps of Agree, Assist, and Arrange

For registered nurses working in practice, it is advisable for their self-management support to be based on the 5 A's model, as this thesis revealed that nurses were positive about this model. Nurses said that it helped them to structure their self-management support, and additionally that the model fits current nursing practice (**Chapter 6**). Moreover, the 5 A's model is also recommended in the Dutch care standard of self-management [7], for instance, and the aforementioned handbook and website [46,47], and it is used in self-management support interventions for other target groups [49,50].

However, as described earlier, nurses often do not apply important elements of the 5 A's model that are essential in self-management support, namely agreeing goals with the patient ('Agree'), assisting in achieving the goals agreed ('Assist'), and arranging follow-up support and care ('Arrange'). Nurses should therefore pay extra attention to these particular elements, and if necessary receive training in applying these A's.

3. Pay specific attention to self-management support for incurable cancer patients

The large majority of existent self-management interventions focus on patients with chronic diseases like diabetes, COPD, or rheumatoid arthritis, or cancer survivors, while patients with incurable cancer have received less attention [34,38,51-53]. In addition, most of the interventions are not aimed at self-management support and the providers of this support [34].

The self-management support intervention studied in this thesis could be used to stimulate nurses' self-management support for incurable cancer in practice (see Appendix). The fact that nurses evaluated the intervention positively and indicated that the intervention fits current practice is further backing for this recommendation.

4. Tailor support

In the feasibility study, only a few of the patients used the eHealth component (Oncokompas) of the intervention. Several patients said that the information provided did not quite fit their situation.

Tailoring to individual requirements is key in self-management support. In this regard, it is important that eHealth applications provide opportunities to meet the varying individual needs and problems of patients. One way of doing this is to let patients choose topics about which they would like information through option menus, as included in Oncokompas. However, tailoring within eHealth applications has its limits; e.g. face-to-face prompts and supports are absent when delivering messages via technology, possibly leading to a lack of nuance [54].

The more recent eHealth applications offer all sorts of interactive technologies which facilitate tailoring. People's ability to use this broad spectrum of applications depends on a diverse range of skills [55]. This implies that eHealth might not be suitable in all situations and across the total patient population. In line with the approach chosen in the self-management support intervention, it is recommended that eHealth should not fully replace personal contact between care professionals and patients. It is up to both nurses and patients to decide to what extent and in what way they use eHealth.

5. Start with self-management support and continuity home visits in good time

The feasibility study revealed, among other things, that incurably ill cancer patients in the early palliative stage were underrepresented in the continuity home visits (**Chapters 6 and 7**). It is recommended to facilitate support as early in the palliative care trajectory as possible. Considering the perceived value of the continuity home visits, it is also recommended that referrals for these visits should be integrated into standard cancer care so all cancer patients living at home will have the opportunity to receive at least one or two continuity home visits. If continuity home visits are made in good time, patients will have more time to learn how to self-manage. Consequently, patients could profit from self-management support for a longer period of time and stay in control of their lives and care for longer.

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APPENDIX INTERVENTION PROTOCOL

INTERVENTION PROTOCOL FOR 'SELF-MANAGEMENT SUPPORT IN INCURABLE CANCER'

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CONTENTS

1. INTRODUCTION

1.1   Background and definition of self-management

Patients are living for longer with cancer, making it especially important to deal with the consequences of the disease in daily life. In this sense, self-management in the sense of *"dealing with the condition (symptoms, treatment, physical, psychological and social consequences and the associated changes in lifestyle) so that the condition is fitted into a way of life as well as possible"* is important (LAZ, 2012). Self-management fits in with people's need to keep control over their own lives and care situations for as long as possible.

However, not everyone is equally skilled in this and some people need support in self-management. There has been little attention so far to self-management support for incurably ill patients with cancer and their informal caregivers. This was the reason why the research institute NIVEL (the Netherlands Institute for Health Services Research), the Vrije Universiteit Amsterdam and the Amsterdam UMC have jointly developed an intervention for self-management support for this target group. That intervention is described in this protocol.

1.2   Who is this intervention intended for?

This intervention is intended for and will be implemented by specialist oncology and/or palliative care nursing staff.

1.3   What setting is the intervention used in?

The specialist nurse carries out the intervention during what are known as 'continuity home visits'. These are visits made to the homes of people living at home who do not have regular care or nursing at the time of the notification. These visits are intended to make the transition between care at hospital and care in the home situation as small as possible and to provide guidance for patients and informal caregivers during the course of the illness and the disease trajectory.

1.4   What is the purpose of the intervention?

The intervention focuses on helping people cope with the consequences and symptoms of incurable cancer in daily life, so that patients and informal caregivers can retain control for as long as possible over their lives and the care that they

receive, and can continue to lead the life they have in mind, despite the illness. We are referring here to adult patients and their adult informal caregivers (largely the partner, an adult child or another member of the family).

2. THE 'SELF-MANAGEMENT SUPPORT IN INCURABLE CANCER' INTERVENTION

Self-management support comprises providing guidance for patients and informal caregivers about self-management. The intervention from this protocol is primarily about helping them recognize, monitor and resolve/reduce complaints and problems themselves.

Among other things, self-management support includes tips and recommendations that the patient can apply themselves the next time, without intervention by the nursing staff (please refer to the boxed text for examples).

Example 1: The nurse gives the patient tips about what they can do to relieve pain complaints, such as taking a warm bath. When the patient notices next time that the pain complaints are worsening and then takes a warm bath because it helped the previous time, that is an example of self-management.

Example 2: The nurse recommends to the informal caregiver that they should contact others in the same situation, with the tip that they should visit a walk-in center. If the informal caregiver then finds a walk-in center for themselves and goes to it, that is self-management.

The 'Self-management support in incurable cancer' intervention comprises partly personal contacts and partly eHealth. It uses a number of existing products or approaches: the 5 A's model, the *Discussion Topics Checklist for Home Visits in the Palliative Phase* (in Dutch: Checklist Gespreksonderwerpen Huisbezoek in de Palliatieve Fase), *Informal Care Quick Scan* (in Dutch: Quick Scan Mantelzorg) and *Oncokompas*. These are explained below.

2.1   The 5 A's model

The 5 A's model has been designed to help healthcare providers and structure to self-management support (CBO, 2014). The 5 A's model covers Assess, Advise, Agree, Assist and Arrange (see Box 1).

Box 1   *Brief description of the 5 A's model*

A **Assess** the need for support

A **Advise** and provide information about the problems encountered

A **Agree** achievable goals and helping the care user to set them

A **Assist** in coping with personal barriers that may prevent the goals from being achieved and making an inventory of extra support that may be required

A **Arrange** an individual care plan that records the goals and the agreements made about the care and how it will be provided.

The 'Self-management support in incurable cancer' intervention is aligned to these five A's (see also the schematic overview at the end of this protocol in Section 2.5).

2.2   Alignment with the Discussion Topics Checklist for Home Visits in the Palliative Phase

In the intervention, we also aim for alignment with the Discussion Topics Checklist for Home Visits in the Palliative Phase. This is an existing checklist that is used by many nurses. It describes subjects that can be discussed during a continuity home visit (see the right-hand column in the table at the end of this protocol in Section 2.5). This covers topics relating not only to physical and mental problems but also to the need for practical support.

2.3   Use of Oncokompas and the Informal Care Quick Scan

In the intervention, patients are asked whether they would complete Oncokompas. Informal caregivers are asked if they would complete the Informal Care Quick Scan. Nurses are also asked to include the results of Oncokompas and the Informal Care Quick Scan in the self-management support. We explain below what Oncokompas and the Informal Care Quick Scan involve.

Oncokompas for patients

Oncokompas is an online self-management tool that assists patients in finding and obtaining the optimum 'customized' guidance. It was originally developed for patients who were being given curative treatment[1]. An adapted and less extensive version is available for patients with incurable cancer, in which the following <u>five topics</u> are tackled: pain, fatigue, depression, anxiety and stress.

Oncokompas comprises three steps – measure, learn and act:

Step 1 (measure) involves completing short questionnaires about possible problems

Step 2 (learn) comprises a personalized result for the patient, based on the short questionnaires that have been completed. The result gives an indication of the nature and severity of the problems.

Step 3 (act) covers information about the sources of assistance and the available care that the patient can use.

Informal Care Quick Scan – for informal caregivers

The intervention also uses the Informal Care Quick Scan, inspired by the '3-minute check' developed by Markant (Markant/Prezens, 2014). The Informal Care Quick Scan is a short questionnaire consisting of ten questions that the informal caregiver can use to see if they are still able to cope with informal care or whether they are threatening to become overwhelmed. Based on the score (10 to 22 points), the informal caregiver is given information about the degree of overburdening and follow-on steps recommended.

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1   You can watch a clip about Oncokompas on https://www.youtube.com/watch?v=BGEzrr3pbag

2.4   Practical implementation of the intervention within continuity home visits

The first continuity home visit

In the *first continuity home visit*, after the introduction and after an inventory has been made of whether a further continuity home visit is needed, the nurse provides information about the intervention, including the use of Oncokompas and the Informal Care Quick Scan.

The nurse explains the purpose, content and working method of Oncokompas to the patient. The nurse explains the purpose, content and working method for the Informal Care Quick Scan to the informal caregiver.

Note: state that the intervention is suitable for any patient and informal caregiver and that using Oncokompas or the Informal Care Quick Scan is not mandatory.

Between the first and second continuity home visits

In the period between the first and second continuity home visits, the patient and the informal caregiver fill in Oncokompas/the Informal Care Quick Scan.

The second and any subsequent continuity home visits

At the start of the second continuity home visit, it is important to find out whether the patient and informal caregiver succeeded in completing Oncokompas/the Informal Care Quick Scan and whether they want to discuss the results with the nurse. If that is the case, the nurse then discusses the responses and results together with the patient and/or informal caregiver. For the first two A's (Assess and Advise) in the left-hand column of the schematic overview that follows (Section 2.5), there are ideas about how the nurse can discuss the results of Oncokompas and the Informal Care Quick Scan. The nurse can still also use this column if the patient or informal caregiver does <u>not</u> want to discuss the results of Oncokompas/the Informal Care Quick Scan with the nurse or if the instruments have not been completed.

In the discussion of the results of the instruments, it is important that the nurse is also <u>alert</u> to any other problems or needs that may be playing a role and in which self-management and self-management support could be important. After all, not all potential problems and support needs come to the fore in Oncokompas. The Informal Care Quick Scan also requires the nurse to make an inventory themselves of the areas within which the informal caregiver is experiencing problems. To do this, the nurse uses the right-hand column of the diagram (Section 2.5) in which the discussion topics for the continuity home visits are listed. The nurse can also use this column if the patient or informal caregiver does <u>not</u> want to discuss the results of Oncokompas/the Informal Care Quick Scan with the nurse or if the instruments have <u>not</u> been completed.

2.5 Schematic overview of the implementation of the intervention

The schematic overview given below will help guide and give structure to self-management support at continuity home visits, according to the steps from the 5 A's model and based on concrete example questions and subjects.

Points for further attention:

- It is important that the nurse follows the steps and uses the ideas from the schematic overview as much as possible. It is however not always possible to use all five of the A's within a single continuity home visit. Self-management support according to the 5 A's model is a cyclic process that results in tailored care. If the first or second continuity home visit is not followed up with another visit, it may then for example be the case that the A of Agree – drawing up goals together with the patient – no longer applies.
- Which subjects and how many are discussed during a continuity home visit depends strongly on the needs of the patient and/or informal caregiver.
- If Oncokompas or the Informal Care Quick Scan have not been completed or those involved do not wish to discuss them, you can still use the schematic overview.

Schematic overview of the 'Self-management support in incurable cancer' intervention within the continuity home visits

First continuity home visit:
• Introduction and intake looking at the personal situations of the patient and informal caregiver.
• Explanation of continuity home visits and an introduction to Oncokompas and the Informal Care Quick Scan. Point out that using these tools is not mandatory.
• Follow up appointment? Provide information as well about how to reach the nurse.

The emphasis of this first continuity home visit can be on the first A, Assess.

Between the first and second continuity home visits
• In the period between the first and second continuity home visits, the patient and the informal caregiver fill in Oncokompas or the Informal Care Quick Scan as appropriate.

The second and any subsequent continuity home visits:
Oncokompas and Informal Care Quick Scan:
• Find out whether the patient and informal caregiver managed to complete Oncokompas and the Informal Care Quick Scan.
• Find out whether the patient and informal caregiver want to discuss the outcomes of Oncokompas and the Informal Care Quick Scan.

If they have completed Oncokompas and the Informal Care Quick Scan and want to discuss it:
• Follow the steps of the 5 A's model and use the approaches that are applicable for Oncokompas and the Informal Care Quick Scan.
• Also pay attention to any other problems and support needs of the patient and informal caregiver. Do this using the checklist of discussion topics from the right-hand column.

If Oncokompas or the Informal Care Quick Scan have not been completed or if those involved do not wish to discuss them:
• Follow the steps of the 5 A's model and use the approaches that are applicable in the general case.
• Use the checklist of discussion topics from the right-hand column to make an inventory of the problems and self-management support needs of the patient and informal caregiver.

When rounding off the continuity home visit:
• Summarize the discussion and the agreements made together. Also make agreements about feedback to the referrer.
• Leave a copy of the individual care plan with the patient or informal caregiver.
In the second continuity home visit, the emphasis can still be on the A for **A**ssess. But the other A's then also come into play, namely **A**dvise, **A**greeing goals, **A**ssisting in achieving the goals and **A**rranging an individual care plan in which the goals and agreements are recorded.

NB 1: It is not always possible to use all five of the A's in the second continuity home visit. Further **follow-up visits** may sometimes be needed for this.
NB 2: The current Oncokompas covers five subjects: pain, fatigue, depression, anxiety and stress. For making an inventory of the patient's self-management support needs for other complaints and problems that are not detailed in Oncokompas, use the checklist of discussion topics from the right-hand column.
NB 3: Use the checklist of discussion topics from the right-hand column as well for making an inventory of the problems and self-management support needs of the informal caregiver.

The table below provides a structure for the continuity home visits, using the A's from the 5 A's model.

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Schematic overview Continued

Self-management support according to the 5 A's model	Example questions	Checklist of discussion topics

Assessing the need for support.
 	
General approaches for assessing the need for support
• Fit in with the personal situations of the patient and/or informal caregiver.
• If Oncokompas was used, ask about any other problems as well, that they may have that did not come to the fore in Oncokompas. Use the checklist in the right-hand column.
 	
Approaches for assessing needs using Oncokompas:
• Use and discuss the results of Oncokompas for support needs in dealing with pain, fatigue, depression, anxiety and/or stress using the example questions in the adjacent column.
 	
Approaches for assessing needs using Informal Care Quick Scan:
• Use and discuss the results of Informal Care Quick Scan for determining the issues that the informal caregiver would like support for.
• Ask the informal caregiver what areas they are experiencing problems in. Use the checklist in the right-hand column.
• Ask the informal caregiver if they know which people and organizations can be asked for help.
	General example questions for assessing the need for support:
	• What do you think is important in life? What's the most important thing for you right now?
	• Could you tell me about your illness and its treatment?
	• Is your illness or treatment causing problems or restrictions in your daily life? In what areas?
	• What would you like to tackle or change?
	• What can you do for yourself and where do you need help?
	
	Example questions for assessing the need for support using Oncokompas:
	• Have you looked at your individual results?
	• What subjects from the result would you like to discuss?
	• Is there anything you would like to tackle or change?
	
	Example questions for assessing the need for support using Informal Care Quick Scan
	• Have you looked at the recommendations from the Informal Care Quick Scan?
	• Are there any questions you'd like to ask about the results?
	• Is there anything you would like to tackle or change?
		Situation of the patient and/or informal caregiver:
		• Physical problems
		• Social problems
		• Mental problems
		• Spiritual issues
		• Other
		
		Need for:
		• support;
		• information;
		  • related to the illness;
		  • care related to e.g. care providers, individual care options, support in regulatory matters (or aspects relating to rules) such as e.g. asking for care under the Social Support Act (Wmo) or Long-Term Care Act (Wlz).
		
		For more details, please refer to the 'Discussion Topics Checklist for Home Visits in the Palliative Phase'.

Advising and providing information *Approaches for providing advice based on the results of Oncokompas:* • Use and discuss recommendations and additional sources from Oncokompas using the example questions from the adjacent column. *General approaches for providing advice:* • If Oncokompas or the Informal Care Quick Scan was used, advice and information should also be given about subjects that are not discussed in Oncokompas or the Informal Care Quick Scan. Please refer to the checklist in the right-hand column. • Remember that the recommendations have to be usable and easy to implement in daily living, without additional assistance from the care provider, unless the nature of the problem dictates otherwise. • Ask what more the patient and/or informal caregiver wants to know. • Use understandable language and adjust the amount of information. Encourage them to ask questions and allow the time and scope for them to do so. • Get them to retell ("reproduce") the information as they understand it. Also ask whether they would like to receive more information, e.g. as hardcopy or by e-mail.	*Example questions for advice based on Oncokompas:* • Have you looked at the advice and information sources in Oncokompas? • For which topics do you want to discuss the advice or information? • Do you think that the advice given is appropriate for your symptoms? • What additional sources of information have you been offered? • Are there some sources of information that you have already used? • Do you have any questions after reading the recommendations or additional sources?	Once again, you can fit the above-mentioned topics for this step of the 5 A's model in with the 'Discussion Topics Checklist for Home Visits in the Palliative Phase'.

Agreeing goals

General approaches for agreeing goals:
- Encourage the patient and/or informal caregiver to state achievable, concrete goals for handling issues in daily life that are associated with their illness or its treatment. If necessary, help them to formulate achievable targets.
- Weigh up together the quality of life objectives (the things they find important in their own lives) and what is needed for the medical treatment.

Example questions for agreeing goals:
- What do you currently find most important in your life?
- What is the most important thing for you right now?
- What problems would you like to tackle that are consequences of your illness or treatment?
- What, according to you, would be needed for tackling those issues? When would you be satisfied?
- What are the positives of the various options for tackling the problems? What are the negatives and where are the bottlenecks?
- Would you like me (or someone else) to help you make decisions about how to tackle the issues?

Idem

Assisting in achieving the goals

General approaches for assisting in achieving the goals:
- Make an inventory of any factors that will help or hinder the patient and/or informal caregiver in achieving the goal.
- Also discuss strategies for dealing with the obstacles.
- Make an inventory of whether these strategies have previously been successful and the possible causes in cases where they were not.
- Make an inventory of whether any additional support is needed (e.g. from a psychologist or associated non-medical professionals).

Example questions for assisting in achieving the goals:
- What would help you to tackle your problems?
- And what obstacles are preventing you from tackling them?
- Have you encountered these obstacles previously in the past? How did you deal with them then? Did that approach help you? If not, are you able to say why not?
- Do you have ideas about how you could tackle the issue in some other way?
- What can you do for yourself and where do you need assistance?

Idem

Arranging an individual care plan
General approaches for arranging:
- Record the agreements that have been made in an individual care plan for the patient and/or informal caregiver.
- Get the patient and/or informal caregiver to state or write down goals and agreements themselves, in terms that are as concrete as possible.
- Leave a copy of the individual care plan with the patient and/or informal caregiver.
- Encourage the patient and/or informal caregiver to manage the individual care plan themselves.

Idem

8

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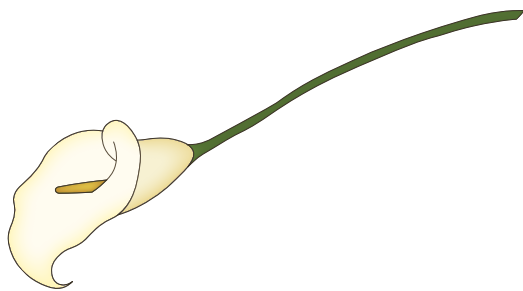
Nederlandse samenvatting

NEDERLANDSE SAMENVATTING

Dit proefschrift geeft inzicht in zelfmanagementondersteuning voor mensen die geconfronteerd zijn met ongeneeslijke kanker, aangeboden door verpleegkundigen.

De definitie van *zelfmanagement* in dit proefschrift is geïnspireerd door de definities van Barlow et al. [1] en Bodenheimer et al. [2], en luidt als volgt:

Het vermogen van een individu om te kunnen omgaan met lichamelijke en psychosociale problemen, en beslissingen te kunnen nemen over behandeling en/of zorg, met het doel om de ziekte optimaal, met behoud van kwaliteit van leven, in het dagelijks leven in te passen.

Zelfmanagementondersteuning verwijst naar:

Een collaboratieve benadering, waarbij zorgverleners en patiënten samenwerken bij het inventariseren van problemen, stellen van prioriteiten, stellen van doelen, opstellen van behandelplannen en het oplossen van problemen [3,4].

Bij zelfmanagement en zelfmanagementondersteuning kan gebruik worden gemaakt van eHealth. De definitie van *eHealth* in dit proefschrift is gebaseerd op de definitie van Eysenbach [5] en luidt:

Het verstrekken van informatie over ziekte of gezondheidszorg en/of ondersteuning aan patiënten en/of mantelzorgers met gebruik van de computer of aanverwante technologieën.

In dit proefschrift zijn vier overkoepelende onderzoeksvragen beantwoord in vijf deelonderzoeken.

De eerste overkoepelende onderzoeksvraag was:

1. a. **Wat voor bewijs bestaat er voor de effecten van eHealth op patiënten met ongeneeslijke kanker en op hun mantelzorgers?**
   b. **Wat zijn de meningen van kankerpatiënten en verpleegkundigen over eHealth en het gebruik daarvan in de context van zelfmanagement en zelfmanagementondersteuning?**

Om zicht te krijgen op in hoeverre er bewijs bestaat voor de effecten van eHealth in de oncologische zorg is een meta-review over bestaande relevante systematische literatuurstudies uitgevoerd (**Hoofdstuk 2**).

Tien systematische literatuurstudies voldeden aan de inclusiecriteria en waren gericht op de effecten van eHealth op kankerpatiënten. Systematische literatuurstudies over de effecten van eHealth op mantelzorgers van patiënten met kanker waren er echter niet.

Uit de meta-review is gebleken dat er bewijs is voor effecten van eHealth op ervaren ondersteuning, kennis en informatievaardigheden. De bevindingen over effecten op besluitvorming, psychisch welbevinden, depressie, angst en kwaliteit van leven waren tegenstrijdig.

Het merendeel van de eHealth-interventies was gericht op een meer algemene groep van kankerpatiënten en minder op een patiëntengroep in een bepaalde ziektefase, zoals bijvoorbeeld de palliatieve fase. Daarnaast betrof eHealth vaak één onderdeel binnen een interventie bestaande uit verschillende onderdelen. Doordat zelden de effecten van de verschillende onderdelen waren gerapporteerd, is het niet altijd duidelijk welk onderdeel van een dergelijke interventie verantwoordelijk was voor een gevonden effect.

In een volgend deelonderzoek zijn aan de hand van drie online focusgroepen en tien semigestructureerde individuele interviews, de meningen van kankerpatiënten over eHealth geëxploreerd (**Hoofdstuk 3**). Aan zowel patiënten met een te genezen vorm van kanker als patiënten met ongeneeslijke kanker is gevraagd naar hun ervaringen en meningen met betrekking tot eHealth.

Patiënten stonden over het algemeen positief tegenover eHealth. eHealth werd bruikbaar gevonden voor het opzoeken van informatie over behandelingen, medicatie of bijwerkingen, en voor online communiceren met zorgverleners. Beide groepen patiënten benadrukten echter dat eHealth persoonlijk contact met zorgverleners niet zal kunnen vervangen.

Ook de meningen en ervaringen van verpleegkundigen over eHealth in het kader van zelfmanagement en zelfmanagementondersteuning zijn in kaart gebracht (**Hoofdstuk 4**). Vijfenveertig verpleegkundigen uit verschillende settings namen deel aan zes online focusgroepen, waarin zij onder meer vertelden voordelen van eHealth te zien; eHealth biedt mogelijkheden om ziektegerelateerde informatie op te zoeken en symptomen via digitale symptoomdagboeken te monitoren. Hierdoor kunnen patiënten meer de regie houden over de zorg en hun leven.

Verpleegkundigen gaven verder aan dat de geschiktheid van eHealth voor, in het bijzonder, ongeneeslijk zieke kankerpatiënten, afhangt van hun digitale vaardigheden, de ziektefase en de ernst en aard van de klachten en symptomen.

Verpleegkundigen benoemden ook voordelen van eHealth voor de continuïteit van zorg, wanneer zowel patiënten als zorgverleners directe toegang tot een eHealth applicatie hebben. Desondanks gaven verpleegkundigen in een online vragenlijstonderzoek over verpleegkundige competenties voor zelfmanagementondersteuning en het toepassen hiervan, te kennen dat zij weinig vertrouwd zijn met eHealth en het ook nooit gebruiken om ondersteuning op afstand te bieden (**Hoofdstuk 5**). Bovendien vermeldden verpleegkundigen dat zij zelden met hun patiënten bespreken hoe zij eHealth bij hun dagelijkse activiteiten kunnen gebruiken.

Net zoals patiënten onderstreepten ook verpleegkundigen dat eHealth persoonlijk contact tussen hen en hun patiënten niet kan vervangen.

De tweede overkoepelende onderzoeksvraag beantwoord in dit proefschrift was:

2. **Hoe gaan mensen die geconfronteerd zijn met ongeneeslijke kanker om met de gevolgen van de ziekte voor het dagelijks leven?**

Aan de hand van drie online focusgroepen en tien semigestructureerde individuele interviews, is in kaart gebracht welke zelfmanagementactiviteiten mensen met een te genezen vorm of een ongeneeslijke vorm van kanker ondernemen (**Hoofdstuk 3**). De verzamelde gegevens werden op kwalitatieve wijze geanalyseerd. De uit de gegevens afgeleide hoofdthema's zijn ingedeeld in de vier aandachtsgebieden zelfmanagement van het Generiek Model Zelfmanagement [6,7]. Alle kankerpatiënten, ongeacht de ziektefase, lijken overeenkomstige zelfmanagementactiviteiten uit te voeren. De activiteiten omvatten voornamelijk:

- opzoeken van informatie over de ziekte en behandelingen (passend bij het aandachtsgebied 'Ervaringskennis' van het Generiek Model Zelfmanagement);
- loslaten en accepteren, je hart luchten en grenzen stellen (passend bij het aandachtsgebied 'Leven met de ziekte');
- rekening houden met informatie van de arts, je eigen wensen/behoeften en de consequenties van het al dan niet ondergaan van een behandeling, bij het nemen van beslissingen (passend bij het aandachtsgebied 'Eigen aandeel in de zorg').

Zelfmanagementactiviteiten zoals het regelen van thuiszorg, financiële tegemoetkomingen of andere vormen van zorg en ondersteuning (passend bij het aandachtsgebied 'Organiseren van zorg –en hulpbronnen') zijn minder vaak genoemd.

Een derde onderzoeksvraag die in dit proefschrift is onderzocht, was:

3. **Hoe beoordelen verpleegkundigen hun competenties voor zelfmanagement-ondersteuning en hun daadwerkelijke zelfmanagementondersteuning aan mensen die geconfronteerd zijn met ongeneeslijke kanker?**

In zes online focusgroepen werden verpleegkundigen met verschillende opleidingsniveaus en werkzaam in verschillende settings, gevraagd hoe zij patiënten met ongeneeslijke kanker en hun mantelzorgers ondersteunen bij het omgaan met de lichamelijke en psychosociale gevolgen van de ziekte. Daarnaast werd hen ook gevraagd hoe zij dit in de ideale situatie zouden doen (**Hoofdstuk 4**).

Gegevens zijn volgens de principes van kwalitatief onderzoek geanalyseerd en de geïdentificeerde thema's zijn ingedeeld in de stappen van het 5A model [7,8], namelijk Achterhalen, Adviseren, Afspreken, Assisteren en Arrangeren. Het 5A model is ontworpen om zorgverleners te helpen structuur te geven aan zelfmanagementondersteuning.

De meeste aandacht blijkt uit te gaan naar het achterhalen van de behoeften en wensen van patiënt met ongeneeslijke kanker en het beoordelen van diens persoonlijke situatie ('Achterhalen' in het 5A model), en het geven van informatie over het hebben van een ongeneeslijke vorm van kanker in het bijzonder ('Adviseren' in het 5A model). De overige A's die minder vaak zijn genoemd betreffen het Afspreken van haalbare doelen, het Assisteren van de patiënt bij het behalen van de gestelde doelen, en het Arrangeren en maken van afspraken over het vervolg van de ondersteuning.

Verpleegkundigen vertelden verder dat zij, in de ideale situatie, meer tijd met de patiënt zouden willen hebben om hun zelfmanagementondersteuning optimaal op de patiënt te kunnen afstemmen. Daarnaast gaven zij te kennen meer aandacht te willen geven aan het betrekken van mantelzorgers.

In een volgend online vragenlijstonderzoek onder een landelijke steekproef van 222 verpleegkundigen werkzaam in het ziekenhuis of in de wijk, is het vertrouwen dat men zelf goed in staat is om zelfmanagementondersteuning te geven onderzocht, alsook of zij daadwerkelijk zelfmanagementondersteuning aanbieden. Dit is in kaart gebracht aan de hand van een vragenlijst die de stappen uit het 5A model volgt (**Hoofdstuk 5**).

De resultaten lieten zien dat de verpleegkundigen voldoende vertrouwen hadden in hun vermogen om te achterhalen wat de behoeften van patiënten zijn en diens persoonlijke situatie te beoordelen, en te adviseren en informeren over de ziekte en gerelateerde problematiek (resp. 'Achterhalen' en 'Adviseren' in het 5A model). Het vertrouwen was redelijk voor wat betreft de A's van Afspreken van

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doelen, Assisteren bij het halen van gestelde doelen en het Arrangeren van het vervolg van de ondersteuning.

Wat betreft de daadwerkelijke toepassing van de stappen uit het 5A model, lijken de uitkomsten van dit onderzoek de resultaten van de online focusgroep studie besproken in **Hoofdstuk 4**, te ondersteunen. Uit het vragenlijstonderzoek bleek namelijk eveneens dat de A's van 'Achterhalen' en 'Adviseren' de elementen van zelfmanagementondersteuning zijn die het vaakst door de verpleegkundigen werden toegepast. Voor het gezamenlijk afspreken van doelen geldt hetzelfde, namelijk dat deze stap ('Afspreken' in het 5A model) ook in het vragenlijstonderzoek als minder vaak toegepaste stap naar voren kwam. Ook het assisteren bij het behalen van gestelde doelen ('Assisteren') en het afspreken van het vervolg van de ondersteuning ('Arrangeren') bleken de minst vaak toegepaste elementen van zelfmanagementondersteuning. Een resultaat dat ook uit de online focusgroep studie naar voren kwam en door het vragenlijstonderzoek is bevestigd.

In het vragenlijstonderzoek zijn ook verschillen tussen zorgsettings geëxploreerd (**Hoofdstuk 5**): Wijkverpleegkundigen bleken meer vertrouwen te hebben in hun eigen vermogen om zelfmanagementondersteuning te geven en zij bieden de ondersteuning ook vaker aan dan ziekenhuisverpleegkundigen aan. Deze uitkomst was van waarde bij de ontwikkeling van een zelfmanagementondersteuning-interventie aangeboden door verpleegkundigen aan mensen geconfronteerd met ongeneeslijke kanker.

De interventie bestond uit persoonlijke contacten tussen patiënten en verpleegkundigen gespecialiseerd in oncologische en/of palliatieve zorg. De interventie vond plaats in de context van bestaande 'continuïteitsbezoeken', dat wil zeggen huisbezoeken om de continuïteit van zorg te waarborgen na bijvoorbeeld ontslag uit het ziekenhuis en om tijdig eventuele problemen te signaleren.

Het doel van de interventie is het begeleiden van verpleegkundigen bij het bieden van zelfmanagementondersteuning en tegelijkertijd bijdragen aan het zelfmanagement van mensen met ongeneeslijke kanker en van hun direct betrokken naasten. De Nederlandse versie van het interventieprotocol is vindbaar via deze link https://nivel.nl/sites/default/files/pdf/interventieprotocol-zmo-NL.pdf

De verpleegkundige zelfmanagementondersteuninginterventie was gestructu-reerd aan de hand van de stappen uit het 5A model. Aanvullend op de persoonlijke contacten was het gebruik van twee instrumenten: een prototype van het eHealth instrument Oncokompas dat speciaal voor patiënten in de palliatieve fase is aangepast, en de Quick Scan Mantelzorg voor mantelzorgers.

Oncokompas is een online zelfmanagement instrument dat tot doel heeft bij patiënten de kennis over de impact van kanker te vergroten, hen te ondersteunen bij het herkennen van ondersteuningsbehoeften ten aanzien van kankergerelateerde

problematiek, en toegang tot ondersteunende zorg te faciliteren. Met Oncokompas kunnen patiënten hun kwaliteit van leven monitoren aan de hand van zgn. Patient Reported Outcomes Measures (PROMS), gevolgd door automatisch gegenereerde en op de patiënt afgestemde feedback [9-12].

De Quick Scan Mantelzorg is een korte vragenlijst die inzicht geeft in mantelzorgers hun zorgbelasting.

Een vierde onderzoeksvraag die in dit proefschrift is beantwoord, luidde:

4. a. **Wat is de haalbaarheid van de gestructureerde verpleegkundige zelf-managementondersteuninginterventie voor patiënten met ongeneeslijke kanker?**
   b. **Hoe beoordelen verpleegkundigen en patiënten met ongeneeslijke kanker de gestructureerde verpleegkundige zelfmanagementondersteuning-interventie?**
   c. **Zijn er indicaties dat de zelfmanagementondersteuninginterventie patiënt activatie en kwaliteit van leven bij patiënten met ongeneeslijke kanker positief beïnvloedt?**

Deze laatste onderzoeksvraag is onderzocht in een haalbaarheidsonderzoek onder verpleegkundigen (**Hoofdstuk 6**) én patiënten (**Hoofdstuk 7**). Hiervoor zijn zo wel kwalitatieve als kwantitatieve onderzoekmethoden en verschillende bronnen gebruikt, namelijk registraties van nieuwe aanmeldingen voor continuïteitsbezoeken, vragenlijsten en interviewgegevens afkomstig van verpleegkundigen en patiënten.

Het haalbaarheidsonderzoek onder 22 verpleegkundigen liet zien dat de toepassing van de verpleegkundige zelfmanagementondersteuninginterventie in de praktijk in sommige opzichten wel maar in andere opzichten niet haalbaar was (**Hoofdstuk 6**). De interventie was aan de ene kant haalbaar omdat 18 van de 22 verpleegkundigen bereid waren om de interventie tijdens de continuïteitsbezoeken toe te passen, en de adoptiegraad daarmee hoog was (81%). Bovendien beoordeelden de verpleegkundigen de interventie positief met een gemiddelde tevredenheidsscore van 7.6 (schaal 0-10), en gaven zij aan dat de interventie bij de huidige praktijk aansluit. In individuele interviews vertelden de verpleegkundigen dat zij vooral positief waren over het 5A model. Verder beschouwden zij de continuïteitsbezoeken als de geschikte setting voor de interventie, omdat meer tijd voor patiënten en mantelzorgers beschikbaar is dan in bijvoorbeeld een ziekenhuis.

Aan de andere kant was de interventie niet in alle opzichten haalbaar; Slechts een deel van de verpleegkundigen (10 van de 22) heeft de volledige interventie (bij minstens één patiënt) toegepast. Daarnaast is de volledige interventie niet bij alle

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patiënten maar bij slechts 21 van de 36 patiënten die hebben deelgenomen aan het haalbaarheidsonderzoek toegepast. In lijn met de hiervoor besproken deelonderzoeken waren de A's van 'Assisteren' en 'Arrangeren' het minst vaak toegepast.

Verpleegkundigen waren verdeeld over de bruikbaarheid van eHealth (in dit geval Oncokompas) als onderdeel van de interventie. De ene helft had een voorkeur voor een combinatie van eHealth en persoonlijk contact (zoals de interventie), terwijl de andere helft juist de voorkeur had voor alleen persoonlijk contact (**Hoofdstuk 6**).

Wat betreft Oncokompas gaf de eerstgenoemde groep aan dat het een aanvulling is op persoonlijk contact, omdat het bespreken van de uitkomsten van Oncokompas een snellere beoordeling van de problemen en behoeften van de patiënt mogelijk maakt. Hierop aansluitend zeiden verpleegkundigen dat het hen heeft geholpen om de zelfmanagementondersteuning beter op de patiënt af te stemmen. Dit gold overigens ook voor de Quick Scan Mantelzorg, de vragenlijst die inzicht geeft in de zorgbelasting bij mantelzorgers.

Aanvullend op de haalbaarheid van de interventie, is ook de haalbaarheid van de werving via verpleegkundigen onderzocht (**Hoofdstuk 6**). Aan deelnemende verpleegkundigen was gevraagd of zij patiënten wilden werven voor het parallelle haalbaarheidsonderzoek onder patiënten (**Hoofdstuk 7**). De verpleegkundigen vonden de werving die tijdens het eerste continuïteitsbezoek moest plaatsvinden een uitdaging. Dit, omdat tijdens dit bezoek ook veel andere zaken worden besproken. Daarnaast bleken verpleegkundigen hun patiënten te beschermen (gatekeeping) en aarzelend te zijn in het vragen van hun patiënten voor deelname aan het onderzoek.

Het deelonderzoek onder ongeneeslijk zieke kankerpatiënten (n=36) toonde aan dat patiënten positief waren over de verpleegkundige zelfmanagement-ondersteuningintervbente; Zij gaven de ondersteuning een 7.2 gemiddeld (schaal 0-10) (**Hoofdstuk 7**). Patiënten vonden het belangrijk dat een verpleegkundige gespecialiseerd in oncologie en/of palliatieve zorg de ondersteuning aan huis bood.

Uit de evaluaties van de patiënten bleek dat het merendeel (74%) vond dat de verpleegkundige hun zelfmanagement volledig ondersteunde, in de zin dat elke A uit het 5A model was toegepast. Daarnaast bleek dat zelfmanagementondersteuning in de zin van ondersteuning bij het behalen van gestelde doelen ('Assisteren') en arrangeren van het vervolg van de ondersteuning ('Arrangeren'), minder vaak gebeurde dan zelfmanagementondersteuning in de zin van het achterhalen van de problematiek, behoeften en wensen van de patiënt ('Achterhalen') en adviseren en informeren over de ziekte en problematiek ('Adviseren'). Deze bevinding komt overeen met de bevindingen van de andere deelonderzoeken (**Hoofdstuk 4, 5 en 6**).

Oncokompas, als onderdeel van de zelfmanagementondersteuninginterventie, was gebruikt door slechts 13 van de 59 patiënten die voor dit doel hun e-mailadres hadden verstrekt. Patiënten waren ambivalent over Oncokompas; Sommigen waren positief maar legden uit dat de informatie en adviezen die Oncokompas hen gaf, niet echt op hen van toepassing waren. Desondanks zagen zij wel potentie in het gebruik van Oncokompas door patiënten die zich in een andere situatie bevinden, bijvoorbeeld patiënten met meer geprononceerde symptomen.
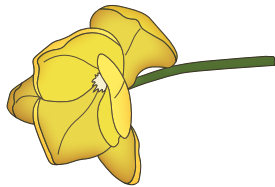
In het deelonderzoek onder patiënten (**Hoofdstuk 7**) is ook onderzocht of er indicaties zijn van effecten van de interventie op patiënt activatie en kwaliteit van leven. Er zijn geen statistisch significante veranderingen in patiënt activatie en kwaliteit van leven gevonden. Door het ontbreken van een controlegroep, is het echter onbekend wat de effecten op deze uitkomstmaten waren geweest bij patiënten die de verpleegkundige zelfmanagementondersteuninginterventie niet hebben ontvangen. Hierdoor kunnen geen vergelijkingen tussen patiëntgroepen worden gemaakt.

Het laatste hoofdstuk (**Hoofdstuk 8**) vat de belangrijkste uitkomsten samen. Ook bevat dit hoofdstuk methodologische reflecties en aanbevelingen voor onderwijs en praktijk. De belangrijkste aanbevelingen zijn om zelfmanagementondersteuning nog meer in het verpleegkundig onderwijs te integreren, en praktiserende verpleegkundigen te scholen in het bieden van zelfmanagementondersteuning volgens het 5A model, met bijzondere aandacht voor de A's van Afspreken, Assisteren en Arrangeren. Verder wordt aanbevolen om zelfmanagementondersteuning aan mensen met ongeneeslijke kanker meer te stimuleren en eerder aan te bieden. Zo kunnen patiënten eerder van deze ondersteuning gebruikmaken en uiteindelijk langer de regie over hun leven en zorg houden. De introductie van de ontwikkelde zelfmanagementondersteuninginterventie in de praktijk kan helpend zijn bij het realiseren van deze aanbeveling. Tot slot is het belangrijk dat de zelfmanagementondersteuning, in het bijzonder als eHealth wordt gebruikt, zo veel mogelijk op de wensen en de behoeften van de patiënt is afgestemd.

9

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Rezumat

REZUMAT

Scopul general al acestei teze este de a oferi o privire în ajutorul self-management al asistenților medicali pentru bolnavii cu cancer incurabil.

Definiția termenului *self-management* folosit în această teză a fost inspirată de definițiile lui Barlow et al. [1] și Bodenheimer et al. [2], și este formulată ca:

O abilitate individuală de a aborda simptomele fizice și psihosociale și de a lua decizii referitor la tratamentul și/sau grija, pentru a integra boala optimal în viața zilnică și a menține o calitate satisfăcătoare a vieții în ciuda bolii.

Ajutorul self-management se referă la:

O abordare colaborativă în care pacienții și îngrijitorii colaborează în a defini problemele, a decide prioritățile, stabilesc ținta, crează planuri de tratament și soluționează problemele pe parcurs [3,4].

eHealth poate fi un element din self-management și ajutorul self-management. Următoarea definiție *eHealth* bazată pe definiția lui Eysenbach [5] folosită:

Înzestrarea informațiilor despre boală sau îngrijire și/sau suport pentru pacienți și/sau îngrijitorii informali folosind computer sau tehnologii înrudite.

În această teză sunt răspunse patru întrebări globale, în cinci sub-studii.
Prima întrebare adresată a fost:

1. a. **Ce dovadă există în efectele eHealth pentru pacienții cu cancer incurabil și îngrijitorii informali?**
    b. **Care este opinia bolnavilor de cancer și a asistentelor medicale despre eHealth și folosirea lui în context cu self-management și ajutorul self-management?**

Pentru a obține o privire în datele existente despre efectele instrumentelor eHealth în cancer, a fost condusă o meta-recenzie a studiilor sistematice de literatură (recenzii) relevantă (**Capitolul 2**). Zece recenzii s-au concentrat pe efectele eHealth pentru pacienții cu cancer. Nu a fost găsită nicio recenzie sistematică despre efectele eHealth referitor la îngrijitorii informali a persoanelor cu cancer.

A fost găsită dovada pentru efectele în ajutorul primit, nivelul cunoştinţelor şi competenţa informaţiilor bolnavilor de cancer. Cele aflate referitor la efectele în luarea deciziilor, bunăstarea psihologică, depresie şi anxietate şi calitatea vieţii au fost inconsistente.

Marea majoritate a instrumentelor eHealth studiate, s-au adresat unui grup larg avizat cu cancer dar nu s-a concentrat pe stadiul specific al bolii ca de exemplu faza paliativă. Mai departe, eHealth a fost adesea doar un component intr-o intervenţie multicomponentă şi efectele au fost rareori analizate separat. Aceasta înseamnă că nu a fost evident care component a fost responsabil unui efect.

În continuare, opiniile pacienţilor cu cancer în legătură cu eHealth au fost investigate. Trei grupuri online şi zece interviuri semi-structurate, deopotrivă pacienţi cu cancer curabil şi pacienţi cu cancer incurabil, au fost întrebaţi despre experienţa lor şi părerea lor despre eHealth (**Capitolul 3**). În mod general atitudinea pacienţilor referitor la eHealth, a fost pozitivă. eHealth a fost apreciată ca folositoare în informaţii despre tratamente, medicamente, efecte secundare şi comunicarea online cu personalul medical profesional. Oricum, pacienţii cu cancer vindecabil şi incurabil, au subliniat faptul că eHealth nu poate substitui în întregime contactul direct cu personalul medical.

În continuare, părerea asistentelor medicale despre eHealth în contextul self-management şi ajutorul self-management a fost cercetat în şase grupuri online cu 45 de asistente din diferite cazuri de îngrijire (**Capitolul 4**). Asistentele medicale au explicat că ele văd avantaje în eHealth ca de exemplu în a căuta informaţii specifice despre boală şi monitorizarea simptomelor prin agenda simptomelor, permiţând pacienţilor să fie conştienţi referitor la viaţa lor şi grija acordată. În completare, asistentele medicale au menţionat ca dacă eHealth este realizabil sau nu, pentru pacienţii cu cancer incurabil depinde de abilităţile lor digitale, stadiul bolii, gravitatea şi natura problemelor şi a simptomelor lor. Asistentele medicale au scos în evidenţă avantajele, în termeni de continuitate a îngrijirii, când deopotrivă pacienţii şi personalul medical au direct acces la aplicaţiile eHealth. Potrivnic acestora, intr-o examinare online a compeţentei în ajutorul self-management al asistentelor medicale, acestea au declarat că nu sunt încrezătoare în a folosi eHealth şi nu folosesc niciodată eHealth pentru a acorda sprijin de la distanţă (**Capitolul 5**). În continuare, asistentele medicale au raportat că au discutat foarte rar cu pacienţii cum pot folosi eHealth în activitatea zilnică.

La fel ca pacienţii, asistentele medicale au accentuat faptul că eHealth nu poate substitui în întregime contactul dintre ele şi pacienţi.

A doua întrebare adresată anchetei principale a fost:

2. Cum cei care înfruntă cancerul incurabil abordează consecințele bolii în viața de zi cu zi?

În trei grupuri online și în zece interviuri individuale semi-structurate s-a obținut o privire în activitățile self-management deopotrivă a pacienților cu cancer incurabil și vindecabil (**Capitolul 3**). Informațiile culese au fost analizate în mod calitativ. Subiectele principale derivate din aceste analize au fost împărțite folosind cele patru domenii ale Modelului General Olandez de Self-Management [6,7]. Se pare că toți bolnavii de cancer au adoptat activități self-management comparabile, indiferent de stadiul bolii. Activitățile self-management conțin în principal:

- Colectarea informațiilor referitor la boală și tratament (care se potrivește cu 'Cunoștințele Bazate pe Experiență' domeniu în Modelul General de Self-Management);
- Acceptarea situației, descărcarea inimii și trăsând limite (care se potrivește cu domeniul 'Trăind viața cu boală');
- Ținând cont de informațiile doctorului, starea personală și consecințele urmării (sau neurmării) tratamentului (care se potrivește cu domeniul 'Contribuția la îngrijire').

Organizarea îngrijirii la domiciliu, asistența financiară, sau alte forme de îngrijire și suport (încadrându-se în domeniul 'Organizarea îngrijirii și suport') nu a fost destul de des menționată.

Pacienții au considerat activitățile lor self-management importante în a acționa cum se cuvine, referitor la boală și în a lua decizii în tratament și îngrijire.

A treia întrebare de bază în cercetarea adresată, a fost:

3. Cum asistentele medicale percep competența lor și realizările reale în ajutorul self-management celor confruntați cu cancer incurabil?

În șase grupuri online cu asistente medicale activând în diferite scenarii și cu calificări educaționale diferite, au fost întrebate cum ajută în mod curent bolnavii cu cancer incurabil și îngrijitorii informali în abordarea de a face față consecințelor fizice și psihosociale a bolii și cum ar ajuta în situații ideale (**Capitolul 4**).

Grupurile online au fost analizate calitativ și temele au fost împărțite în concordanță cu etapele 5 A modelul de schimbare a comportamentului (5 A model) [7,8]: Evalua (Assess), Recomanda (Advise), Stabili (Agree), Asista (Assist)

și Planifica (Arrange). Modelul ajută personalul îngrijitor în a structura ajutorul self-management.

Se pare că asistentele medicale au acordat cea mai mare atenție în a evalua situația personală, dorințele și necesitățile pacienților cu cancer incurabil ('Evalua' în modelul 5 A) și oferind informații despre preponderența în cancerul incurabil ('Recomanda' în modelul 5 A). Celelalte A-uri, Stabilirea țintelor, Asistența pacienților în a realiza ținta propusă și Planificarea următoare, au fost mai puțin menționate ca o parte din ajutorul self-management al asistentelor medicale. Asistentele medicale de asemenea au spus că în situații ideale, ar avea mai mult timp de acordat pacienților pentru a croi în mod optim ajutorul self-management necesar cerințelor pacienților. În completare, asistentele medicale au spus că vor acorda mai multă atenție în a implica îngrijitorii informali.

În un chestionar național online, a testului în 222 de asistente medicale de spital și comunități ale asistentelor medicale, a fost examinată competența asistentelor și încrederea de a oferi ajutorul self-management pacienților cu cancer incurabil. În chestionar au fost investigate etapele modelului 5 A (**Capitolul 5**). Rezultatele au arătat că asistentele medicale au manifestat suficientă încredere în abilitățile lor de a evalua situațiile și cerințele pacienților ('Evalua' în modelul 5 A) și de a oferi informații despre cancer și tratament ('Recomanda' în modelul 5 A). Asistentele medicale au fost aproape de suficient în încrederea abilităților lor de a stabili ținte ('Stabili' în modelul 5 A), a asista în realizarea țintelor propuse ('Asista' în modelul 5 A), și a planifica ingrijirea care urmeaza ('Planifica' în modelul 5 A).

Pe aceeași linie cu grupurile online discutate în Capitolul 4, s-a constatat că 'Evalua' și 'Recomanda' au fost elementele de ajutor self-management care au fost destul de des aplicate de asistentele medicale. De asemenea, pe aceeași linie cu grupurile online anterior, ancheta a arătat că asistentele medicale au stabilit mai puțin probabil țintele în colaborare cu pacienții ('Stabili' în modelul 5 A). Același lucru se aplică și în ajutorul pacienților în realizarea țintelor lor ('Asista') și stabilirea țintelor în grija care urmează ('Planifica'). Aceste elemente din urmă, ale modelului 5 A s-au dovedit a fi cel mai puțin aplicate în practică și au fost A-urile în care asistentele medicale au avut mai putină încredere.

Rezultatele anchetei discutate în **Capitolul 5** au scos la iveală diferențe intre felurile îngrijirii, asistentele medicale de comunitate, se pare că au mai multă încredere în abilitățile lor de ajutor self-management și au folosit acesta mai des decât asistentele medicale de la spital.

Constatările anterior menționate au dat curs dezvoltării intervenției ajutorului self-management al asistentelor medicale față de bolnavii cu cancer incurabil. Intervenția ajutor self-management constă în parte din contactul direct dintre pacienți și asistentul oncolog și/sau a asistentelor paliative în situațiile de vizite continue la domiciliu. Astfel

de vizite la domiciliu sunt efectuate în a garanta continuitatea îngrijirii după ieșirea din spital și a asigura identificarea în timp a problemelor.

Scopul intervenției a fost de a ghida asistentele medicale în ajutorul self-management al bolnavilor cu cancer incurabil și în același timp a motiva self-management bolnavilor cu cancer incurabil.

Intervenția ajutorului self-management al asistentelor medicale a fost structurată în concordanță cu etapele din modelul 5 A. În completarea contactului direct, doua instrumente au fost folosite: un prototip din eHealth Oncokompas, adaptat pacienților în faza paliativă și Informal Care Quick Scan pentru îngrijitorii informali. Oncokompas este un instrument self-management în Internet care are ca scop dezvoltarea cunoștințelor pacienților în impactul cu cancer, de a ajuta pacienții în identificarea necesităților îngrijirii cu privire la probleme adiacente cancerului și de a facilita accesul la îngrijirea necesară. În Oncokompas, pacienții pot urmări calitatea vieții lor cu "Patient-Reported Outcome Measures (PROMs) (Măsurătorile ce decurg din raportările pacientului) urmate de o concluzie automată și bine croită [9-12]. Informal Care Quick Scan este un scurt chestionar care oferă informații despre povara îngrijitorilor informali.

A patra întrebare esențială pusă în această teză a fost:

4. a. **Care este fezabilitatea intervenției ajutorului self-management al asistentelor medicale față de pacienții cu cancer incurabil?**
    b. **Cum evaluează asistentele medicale și pacienții cu cancer incurabil, această intervenție de ajutor self-management al asistentelor medicale?**
    c. **Sunt indicații că intervenția ajutorului self-management influențează pozitiv activarea pacienților și calitatea vieții a pacienților cu cancer incurabil?**

A patra întrebare în cercetare a fost răspunsă în un studiu de metode mixte compuse din două parți și anume: un studiu de fezabilitate adresat asistentelor medicale (**Capitolul 6**) și un studiu de fezabilitate adresat pacienților (**Capitolul 7**). Datele au fost colectate prin formulare completate de asistentele medicale cu referință la continuitatea vizitelor pacienților la domiciliu și prin chestionare și interviuri cu asistentele medicale și pacienți.

Studiul de fezabilitate a 22 de asistente medicale a arătat că intervenția asistentelor cu ajutor self-management a fost fezabilă în anumite situații și deloc fezabilă la celelalte (**Capitolul 6**). Pe de o parte, intervenția a fost fezabilă, căci 18 din 22 de asistente medicale au fost dispuse să folosească intervenția pe parcursul continuității vizitelor la domiciliu. Aceasta înseamnă un procentaj acceptat mare de

81%. În completare, asistentele medicale au evaluat pozitiv intervenția, cu un scor satisfăcător, medie de 7.6 (scala 1-10) și au declarant că intervenția e în acord cu practica curentă. În interviuri individuale, asistentele medicale s-au exprimat în mod particular, pozitiv, referitor la introducerea modelului 5 A. Asistentele medicale au considerat continuitatea vizitelor la domiciliu ca un cadru propice pentru intervenție, aceasta asigurând mai mult timp disponibil pacienților și îngrijitorilor informali, ca de exemplu în spital.

Pe de alta parte, intervenția nu a fost fezabilă în toate privințele dat fiind că doar câteva asistente medicale (10 din 22) au folosit în totalitate intervenția, aceasta însemnând că au aplicat fiecare A din modelul 5 A în cel puțin un pacient. Aceasta înseamnă un procentaj de folosire de 56% la nivelul asistentelor medicale. Procentajul de folosință la nivelul pacienților a fost de 58%, când asistentele medicale au folosit intervenția în totalitate la 21 din cei 36 de pacienți incluși. În linie cu sub-studiile anterioare A-urile care au fost aplicate cel mai putin au fost 'Asista' și ' Planifica'.

Asistentele medicale s-au scindat în doua tabere referitor dacă eHealth (în acest caz Oncokompas) a fost folositor ca o parte integrată a intervenției. Jumătate din asistentele medicale au fost în favoarea combinației eHealth și ajutorul direct (ca în intervenție), în timp ce cealaltă jumătate a preferat doar ajutorul direct (**Capitolul 6**). Cu privire la Oncokompas primul grup susține că acesta complementează ajutorul self-management direct. Comentariul rezultat din Oncokompas a acordat o mai rapidă evaluare și în a ajusta suportul self-management a problemelor și necesităților pacienților. Această motivare este aplicată și în Informal Care Quick Scan, chestionarele care au fost folosite în evaluarea greutăților îngrijitorilor informali.

Studiul de fezabilitate în asistentele medicale (**Capitolul 6**) a arătat de asemenea că alegerea pacienților pentru studiu, a fost o provocare pentru asistentele medicale. Asistentele medicale care au participat, au fost rugate în a selecta pacienții lor în studiul de fezabilitate în pacienți în paralel (**Capitolul 7**). Asistentele medicale au găsit în selectare o provocare, în mod particular la prima lor vizita de continuitate la domiciliu pe când de discutat au fost mai multe teme. Mai mult, asistentele medicale au protejat pacienții (portița de scăpare) și au ezitat în mod consecvent în a solicita pacienților participarea la studiu.

Sub-studiul în pacienții cu cancer incurabil (n=36) a arătat că pacienții au reacționat pozitiv referitor la intervenția asistentelor medicale cu ajutorul self-management (**Capitolul 7**). Ei au dat o notă medie de 7.2. Pacienții au accentuat faptul de a avea o asistentă specializată, la domiciliu, care sa-i ajute în mediul lor familiar pe timpul continuității vizitelor. Majoritatea pacienților (74%) au remarcat din plin ajutorul asistentelor medicale, aceasta însemnând că fiecare A din modelul

5 A au fost implementate. Urmând raportările pacienților, se pare că ajutorul asistentelor medicale în realizarea țintelor stabilite ('Asista' în modelul 5 A) și de a face planificări ('Planifica') au fost mai puțin frecvent aplicate decât ajutorul self-management în sensul evaluării situației și necesității pacienților ('Evalua'), și de a oferi informații ('Recomanda'). Aceasta constatare este pe aceeași linie cu alte sub-studii (**Capitolul 4, 5 și 6**). Oncokompas ca parte din intervenția ajutorul self-management, a fost folosită doar de 13 din cei 59 de pacienți care au oferit o adresă e-mail pentru acest scop. Reacția pacienților despre Oncokompas a fost ambivalentă. Unii au fost pozitivi dar au spus că informațiile și sfaturile oferite de Oncokompas nu s-au potrivit situației lor. Oricum, acești pacienți au explicat că văd un potențial pentru pacienți care sunt în alte situații de exemplu pacienți cu mai multe simptome mai proeminente.

Sub-studiul intre pacienți (**Capitolul 7**) a examinat de asemenea și dacă sunt indicii referitoare la efecte ale intervenției în activarea pacienților (patient activation) și calitatea vieții. Statistic nu s-au găsit schimbări semnificative în activarea și calitatea vieții pacienților. Oricum, datorită absenței unui grup de control, este necunoscut care ar fi fost rezultatul în cazul pacienților care nu au beneficiat de intervenție.

Ultimul capitol (**Capitolul 8**) conține împreună principalele constatări. Acest capitol conține și reflecții metodologice și recomandări pentru învățământ și aspectul practic. Cele mai importante recomandări sunt ca ajutorul self-management să se integreze mai mult în educația medicala a asistentelor medicale și școlarizarea asistentelor medicale în funcție, de a oferi ajutorul self-management conform modelului 5 A cu o atenție deosebita spre A-urile stabileste, asista și planifica. Mai departe, va fi recomandat oamenilor cu cancer incurabil să li se ofere ajutor self-management ca mai multă stimulare din timp. Astfel, pacienții pot apela mai devreme la acest ajutor și în final pot ține mai mult în regie viața și grija acordată. Introducerea interventiei in ajutorului self-management în practică, poate fi ajutător în realizarea acestei recomandări. În încheiere, este important ca ajutorul self-management să fie ajustat pe necesitățile și dorințele pacienților cât de mult posibil în mod specific, când eHealth este implementat.

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9

Kesimpulan

KESIMPULAN

Disertasi ini memberi wawasan dalam sokongan self-management bagi orang yang berkonfrontasi dengan penyakit kanker yang tak dapat disembuhkan, dan yang ditawar oleh jururawat.

Definisi dari *self-management* di disertasi ini diinspirasi oleh definisi Barlow dll. [1] dan Bodenheimer dll. [2] dan ada sebagai berikut:

Kemampuan seorang individu untuk tangani kesulitan fisik dan psikis sosial, dan dapat mengambil keputusan mengenai pengobatan dan /atau perawatan, dengan tujuan supaya penyakit optimal disesuaikan dengan hidup sehari-hari, sedangkan kualitas hidup dipertahankan.

Sokongan self-management dirujuk kepada pendekatan kolaboratif:

Pemberi perawatan dan pasien bekerja sama dengan inventarisasi kesulitan, menentukan prioritas, menetapkan tujuan, menyusun rencana pengobatan dan mengatasi kesulitan [3,4].

Pada self-management dan sokongan self-management dapat dipergunakan dari eHealth. Definisi *eHealth* dalam disertasi ini berdasar atas definisi Eysenbach [5] dan ada sebagai berikut:

Memberikan informasi mengenai penyakit atau perawatan kesehatan dan/atau sokongan kepada pasien dan/atau si pemberi perawatan ini dengan mempergunakan komputer atau teknologi yang lain berada hubungan dengannya.

Dalam disertasi ini ada empat pertanyaan penyelidikan mempunyai hubungan yang diberikan balasan dalam lima bahagian penyelidikan.

Pertanyaan penyelidikan pertama yang berhubungan adalah:

1. a. **Bukti apa ada mengenai efek eHealth bagi pasien berpenyakit kanker yang tak dapat disembuhkan dan bagi si pemberi perawatan ini?**
   b. **Pasien berpenyakit kanker dan jururawat punya perasaan apa mengenai eHealth dan penggunaannya dalam konteks self-management dan sokongan self-management?**

Supaya mengetahui sesuatu dan tahu bukti apa efeknya eHealth ini ada dalam perawatan onkologi beberapa penilaian dilaksanakan tentang studi kesusasteraan yang sistematis dan relevan (**Bab 2**).

Sepuluh studi kesusasteraan yang sistematis menyesuaikan dengan persyaratan tergolong kelompok tertentu dan ditujukan pada efek eHealth mengenai pasien berpenyakit kanker. Studi kesusasteraan yang sistematis mengenai efek eHealth pada si pemberi perawatan dari pasien berpenyakit kanker tidak ada.

Dari beberapa penilaian itu ternyata bahwa ada bukti bagi efek eHealth berdasar atas sokongan, pengetahuan dan kemampuan informasi yang berakhli. Pengalaman mengenai efek pada mengambil keputusan, perasaan dan kehidupan baik secara psikis, depresi, ketakutan dan kualitas hidup berlawanan.

Bahagian terbesar perantaraan eHealth ini lebih dituju kepada kelompok umum pasien berpenyakit kanker daripada kelompok pasien dalam fase penyakit tertentu seperti umpamanya fase paliatif. Selain dari itu eHealth sering bermuat sebahagian dalam perantaraan yang terdiri dari berbagai bahagian. Oleh karena efek berbagai bahagian ini jarang dilaporkan, tidak selalu jelas bahagian yang mana perantaraan tertentu mengakibatkan efek terdapat itu.

Dalam penyelidikan bahagian yang berikut pendapat pasien berpenyakit kanker diperiksa mengenai eHealth melalui tiga kelompok fokus online dan sepuluh wawancara pribadi (**Bab 3**). Baik kepada pasien berpenyakit kanker yang dapat disembuhkan maupun kepada pasien berpenyakit kanker yang tak dapat disembuhkan ditanya apakah pengalaman dan pendapatnya mengenai eHealth.

Pada umumnya pasien bersikap positif mengenai eHealth. eHealth dirasa berguna untuk mencari informasi tentang pengobatan, medikasi atau efek sampingan, dan untuk berkomunikasi online dengan mereka yang memberi perawatan. Akan tetapi kedua kelompok pasien ini pun menegaskan bahwa eHealth tidak bisa menggantikan hubungan pribadi dengan mereka yang memberi perawatan itu.

Juga pendapat dan pengalaman jururawat mengenai eHealth terlihat dari self-management dan sokongan self-management dikemukakan (**Bab 4**). Empat puluh lima jururawat dari berbagai bidang turut serta dalam enam kelompok fokus online. Mereka menceritakan antara lain mengenai keuntungan eHealth; eHealth memberi kemungkinan untuk mencari informasi berhubungan dengan penyakit dan bermonitor gejala melalui buku harian digital. Dengannya pasien dapat menguasai perawatan dan hidupnya.

Kemudian jururawat berpendapat bahwa kelaikan eHealth, teristimewa, bagi pasien berpenyakit kanker yang tak dapat disembuhkan, tergantung dari kemampuannya digital, fase penyakitnya, keparahan dan watak keluhannya serta gejalanya.

Jururawat ini pun menyebut keuntungan eHealth bagi kelangsungan perawatan, jika pasien maupun pemberi perawatan langsung dapat masuk aplikasi eHealth. Walaupun itu jururawat memberitahukan, dalam penyelidikan daftar pertanyaan online tentang kemampuan jururawat untuk sokongan self-management dan diterapkannya, bahwa mereka tidak begitu ketahui eHealth dan tidak pernah gunakanya supaya berikan sokongan dan bantuan dari jarak (**Bab 5**). Lagi pula jururawat memberitahukan bahwa mereka jarang bicarakan dengan pasien bagaimana eHealth dapat digunakan pada kegiatannya sehari-hari.

Sama seperti pasien jururawat tegaskan bahwa eHealth tidak dapat menggantikan hubungan pribadi antara mereka dan pasiennya.

Pertanyaan penyelidikan kedua yang berhubungan dibalas dalam disertasi ini adalah:

2. Bagaimana orang yang berkonfrontasi dengan penyakit kanker yang tak dapat disembuhkan tangani akibat penyakit ini dalam hidup sehari-hari?

Dengan tiga kelompok fokus online dan sepuluh wawancara pribadi diselidiki kegiatan self-management yang mana dilakukan orang yang berpenyakit kanker yang dapat disembuhkan atau tak dapat disembuhkan (**Bab 3**). Keterangan dan data ini yang dikumpul dianaliserkan secara kualitas. Tema terpenting ditarik dari keterangan dan data yang dibagi dalam empat bidang perhatian self-management itu dari Kerangka Generik Self-management [6,7]. Semua pasien berpenyakit kanker, dalam fase penyakit apapun, tampaknya melaksanakan kegiatan self-management yang sama. Kegiatan ini termuat terutama:

- Mencari informasi mengenai penyakit dan pengobatan (yang cocok dengan bidang perhatian 'Pengetahuan melalui pengalaman' dari Kerangka Generik Selfmanagement);
- Melepaskan dan menerima, membuka hati, dan membatasinya (yang cocok dengan bidang perhatian 'Hidup dengan penyakit');
- Memperhitungkan informasi dokter, keinginan/kebutuhan sendiri dan akibatnya mengalami pengobatan atau tidak, waktu mengambil keputusan (yang cocok dengan bidang perhatian 'Sumbangan sendiri dalam perawatan').

Kegiatan self-management seperti mengurus perawatan di rumah, persediaan keuangan atau rupa lain dalam perawatan kesehatan dan sokongan ini (yang cocok dengan bidang perhatian 'Mengorganiserkan sumber perawatan dan bantuan') jarang disebut.

Pertanyaan penyelidikan ketiga yang berhuhungan diperiksakan dalam disertasi ini, adalah:

3. **Bagaimana jururawat menilaikan kemampuannya mengenai sokongan self-management dan sokongan self-management yang benar-benar bagi orang yang dikonfrontasi dengan penyakit kanker yang tak dapat disembuhkan?**

Dalam enam kelompok fokus online jururawat ini yang berpendidikan nivo berbagai-bagai dan bekerja di bidang berbeda-beda, ditanya bagaimana mereka menyokong dan membantu pasien dengan penyakit kanker ini yang tak dapat disembuhkan serta si pemberi perawatan itu dengan mengatasi akibat fisik dan psiko-sosial penyakit ini. Selain dari itu ditanya pun bagaimana mereka membuatnya dalam keadaan ideal (**Bab 4**).

Keterangan dan data menurut unsur penyelidikan kualitatif dianaliserkan dan tema yang penting untuknya dibagikan dalam tahap model 5 A [7,8], yakni mencari tahu (Assess), menasehatkan (Advise), menjanjikan dan menentukan (Agree), membantu (Assist) serta mengatur dan mengurus (Arrange). Model 5 A ini dirancang supaya pemberi perawatan ditolong memberi struktur kepada sokongan self-management.

Ternyata perhatian terutama diberikan pada mencari tahu kebutuhan dan keinginan pasien berpenyakit kanker yang tak dapat disembuhkan serta menilaikan keadaan pribadinya (mencari tahu (Assess) dalam model 5 A) dan memberikan informasi mengenai rupa penyakit kanker teristimewa yang tak dapat disembuhkan (menasehatkan (Advise) dalam model 5 A). Huruf A yang lain yang kurang sering disebut adalah menjanjikan dan menentukan (Agree) tujuan yang dapat dicapaikan, membantu (Assist) pasien jika tujuan tertentu harus dicapaikan, serta mengatur dan mengurus (Arrange) lalu membuat janji mengenai turutan sokongan/pertolongan itu.

Jururawat terus menceritakan, dalam keadaan ideal, bahwa mereka ingin mempunyai waktu lebih untuk bergaul dengan pasien supaya sokongan self-management seoptimal dicocok dengan pasien. Disampingnya mereka beritahukan, memberikan perhatian lebih kepada si pemberi perawatan supaya mereka turut serta.

Dalam penyelidikan daftar pertanyaan online yang berikut, sebagai percontoh di negeri, untuk 222 jururawat yang bekerja di rumah sakit atau di wilayah, maka kepercayaan jururawat ini diperiksa, apakah mereka sendiri mampu memberikan sokongan self-management, pun apakah sokongan self-management benar-benar ditawarkan. Ini dicatat melalui daftar pertanyaan menuruti tahap model 5 A (**Bab 5**).

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Hasilnya bahwa jururawat mempunyai kepercayaan cukup atas kemampuannya mencari tahu kebutuhan pasien serta menilaikan keadaan pribadi lalu menasehatkan dan menginformasikan penyakit dan kesulitan yang bersangkutan (ya itu mencari tahu (Assess) dan menasehatkan (Advise) dalam model 5 A). Kepercayaan cukup baik mengenai menjanjikan dan menentukan (Agree) tujuan, membantu (Assist) supaya tujuan dapat dicapaikan serta mengatur dan mengurus (Arrange) turutan sokongannya.

Mengenai penerapan benar-benar tahap dari model 5 A ini, tampaknya penghasilan penyelidikan ini mengkuatkan hasil studi kelompok fokus online yang dikemukan di **Bab 4**. Dari penyelidikan daftar pertanyaan yakni pun ternyata bahwa huruf A dari mencari tahu (Assess) dan menasehatkan (Advise) adalah unsur sokongan self-management, yang terbanyak kali diterapkan oleh jururawat. Menjanjikan dan menentukan tujuan bersama artinya yang sama, ya itu tahap ini (menjanjikan dan menentukan (Agree) dalam model 5 A) kurang sering dikemukan dalam penyelidikan daftar pertanyaan. Juga membantu mencapaikan tujuan tertentu (Assist) dan mengatur dan mengurus turutan sokongan (Arrange) ternyata itulah unsur yang paling kurang diterapkan dari sokongan self-management itu. Hasil yang pun dikemukan dari kelompok studi fokus online dan ditetapkan oleh penyelidikan daftar pertanyaan itu.

Dalam penyelidikan daftar pertanyaan juga ditunjuk perbedaan antara bidang perawatan (**Bab 5**): Ternyata jururawat di wilayah mempunyai kepercayaan lebih atas kemampuannya sendiri untuk memberikan sokongan self-management dan sokongan ini ditawar seringkali daripada jururawat di rumah sakit. Penghasilan ini penting pada perkembangan perantaraan sokongan self-management yang ditawar oleh jururawat kepada orang yang berkronfontasi dengan penyakit kanker yang tak dapat disembuhkan.

Perantaraan terdiri dari hubungan pribadi antara pasien dengan jururawat berakhli perawatan onkologi dan/atau paliatif. Perantaraan diadakan di konteks kunjungan kelangsungan berarti kunjungan di rumah supaya kelangsungan perawatan dijaminkan, misalnya sesudah keluar dari rumah sakit dan kesulitan pada tepatnya dapat ditemukan serta diberitahukan.

Tujuan perantaraannya adalah memimpin jururawat pada memberikan sokongan self-management dan sekaligus memberi sumbangan kepada self-management orang berpenyakit kanker yang tak dapat disembuhkan dan yang langsung bersangkutan.

Perantaraan sokongan self-management dari jururawat berstruktur melalui tahap model 5 A. Menambahkan hubungan pribadi ini adalah penggunaan dua alat: prototipe eHealth alat Oncokompas yang disesuaikan spesial untuk pasien dalam fase paliatif, serta alat Informal Care Quick Scan ('Quick Scan Pemberian

Perawatan').

Oncokompas adalah alat self-management online, yang bertujuan memperkayakan pengetahuan mengenai impak kanker kepada pasien, menyokong mereka supaya mengetahui kebutuhan sokongan terhadap kesulitan bersangkutan dengan kanker, dan berfasilitas perawatan bersokongan. Dengan Oncokompas pasien dapat memonitor kualitas hidup melalui yang disebut 'Patient Reported Outcomes Measures' (penghasilan dan pengukuran dilapor oleh pasien), diturut oleh 'feedback' (umpan balik) yang otomatis dituju kepada dan cocok bagi pasien. [9-12].

Alat Informal Care Quick Scan ('Quick Scan Pemberian Perawatan) adalah daftar pertanyaan yang pendek yang diberi pengetahuan mengenai pajak perawatan pemberi perawatan itu.

Pertanyaan penyelidikan yang keempat dalam disertasi ini adalah:

4. a. **Apakah perantaraan sokongan self-management dari jururawat yang berstruktur bagi pasien yang berpenyakit kanker tak dapat disembuhkan dapat mencapaikan tujuannya?**
   b. **Bagaimana jururawat dan pasien yang berpenyakit kanker tak dapat disembuhkan menilaikan perantaraan sokongan self-management dari jururawat yang berstruktur ini?**
   c. **Apakah ada indikasi bahwa perantaraan sokongan self-management ini diberikan pengaruh positif kepada pasien untuk beraktif online membicarakan penyakitnya dan kepada kualitas hidup bagi pasien yang berpenyakit kanker tak dapat disembuhkan?**

Pertanyaan penyelidikan terakhir ini diperiksa dalam penyelidikan mengenai mencapaikan tujuannya diantara jururawat (**Bab 6**) dan pasien (**Bab 7**). Untuknya digunakan metode penyelidikan kualitatif maupun kuantitatif serta berbagai-bagai sumber, ya itu pendaftaran pemberitahuan baru untuk kunjungan kelangsungan, daftar pertanyaan dan keterangan dan data wawancara dari jururawat dan pasien.

Penyelidikan mencapaikan tujuan ini diantara 22 jururawat ditunjukkan bahwa penerapan perantaraan sokongan self-management ini di praktek pada beberapa pihak tentu tujuan dicapaikan akan tetapi pada beberapa pihak lain tidak (**Bab 6**). Perantaraan pada satu pihak dapat dicapaikan oleh karena 18 dari 22 jururawat sedia menerapkan perantaraan waktu kunjungan kelangsungan ini, maka pengukuran pengangkatan meninggikan (81%). Apa lagi jururawat menilaikan perantaraan ini sebagai positif rata-rata dengan skor kepuasaan 7.57 (skala 0-10), dan mereka beritahukan bahwa perantaraan bersambungan dengan praktek sekarang ini.

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Dalam wawancara pribadi diceritakan oleh jururawat bahwa mereka positif mengenai model 5 A. Kemudian dianggap kunjungan kelangsungan ini sebagai lingkungan cocok bagi perantaraan ini, oleh sebab ada lebih waktu untuk pasien dan pemberi perawatan daripada umpamanya di rumah sakit.

Di pihak lain beberapa sudut perantaraan tujuannya tidak dicapaikan; hanya sebahagian jururawat (10 dari 22) menerapkan perantaraan selengkapnya (sekurang-kurangnya dengan satu pasien). Selain dari itu perantaraan selengkapnya bukan diterapkan pada semua pasien, melainkan hanya pada 21 dari 36 pasien, yang turut serta dalam penyelidikan mencapaikan tujuan ini. Melihat kepada penyelidikan bahagian dikemukakan sebelumnya huruf A dari membantu (Assist) dan mengatur dan mengurus (Arrange) diterapkan paling kurang.

Jururawat tidak setuju, pendapatnya dibagi-bagi mengenai penggunaan eHealth (mengenai Oncokompas) sebagai bahagian perantaraan. Sebahagian ingin berkombinasi eHealth dan hubungan pribadi (seperti perantaraan), sedangkan sebahagian lain ingin hubungan pribadi saja (**Bab 6**).

Mengenai Oncokompas kelompok pertama sudah diberitahukan bahwa inilah tambahan pada hubungan pribadi, oleh karena membicarakan penghasilan Kompas Onko mengakibatkan penilaian cepat dari kesulitan dan kebutuhan pasien. Kemudian ditambah oleh jururawat bahwa inilah membantu mereka menyesuaikan sokongan self-management pada pasien. Ini juga sama bagi 'Quick Scan' Pemberi Perawatan, daftar pertanyaan yang diberi pengetahuan tentang pajak perawatan untuk pemberi perawatan.

Bersambungan dengan mencapaikan tujuannya di perantaraan, pun diselidiki apakah rekrutan melalui jururawat dapat dicapaikan (**Bab 6**). Kepada jururawat yang turut serta ditanya apakah mereka ingin merekrut pasien bagi penyelidikan mencapaikan tujuan yang sama ini (**Bab 7**). Jururawat berpendapat bahwa rekrutan ini yang selama kunjungan kelangsungan pertama harus dilakukan, sebagai tantangan. Oleh karena pada kunjungan pertama juga hal-hal yang lain dibicarakan. Disampingnya ternyata jururawat melindungi pasiennya ('gatekeeping') dan ragu-ragu bertanya turut serta dalam penyelidikan ini.

Penyelidikan bahagian di antara pasien berpenyakit kanker yang tak dapat disembuhkan (n=36) ditunjukkan bahwa pasien positif mengenai perantaraan sokongan self-management dari jururawat; mereka memberikan sokongan angkah 7.2 rata-rata (skala 0-10) (**Bab 7**). Pasien merasa penting bahwa jururawat berakhli dalam onkologi dan/atau perawatan paliatif memberikan sokongan di rumah. Dari penilaian pasien ternyata bahwa sebahagian terbesar (74%) merasa jururawat menyokong self-management nya sepenuh-penuhnya, sehingga setiap huruf A dari model 5 A diterapkan. Selain dari itu ternyata sokongan self-management jika dimaksud sokongan mencapaikan tujuannya yang tertentu (membantu) Assist))

dan mengatur dan mengurus turutuan sokongan (Arrange), terjadi kurang sering daripada sokongan self-management jika dimaksud mencari tahu kesulitannya, kebutuhan dan keinginan pasien (Assess). Pendapat ini bersama dengan pendapat di penyelidikan bahagian yang lain (**Bab 4, 5 dan 6**).

Oncokompas, sebagai bahagian perantaraan sokongan self-management digunakan hanya oleh 13 dari 59 pasien, yang untuk tujuan ini memberikan alamat e mail. Perasaan pasien mengenai Oncokompas berlawanan; ada yang merasa positif tetapi jelaskan bahwa informasi dan nasehat yang diberikan Oncokompas bukan diterapkan, bukan dimaksud bagi mereka. Walaupun begitu mereka merasa ada potensi jika pasien menggunakan Oncokompas yang berada dalam keadaan lain, seumpamanya pasien yang bergejala kuat dan jelas.
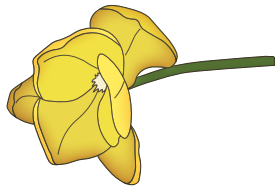
Dalam penyelidikan bahagian diantara pasien (**Bab 7**) juga diperiksa apakah ada indikasi hasil perantaraan bagi pasien mengenai beraktif online dan kualitas hidup. Tidak terdapat perubahan statistis yang berarti bagi pasien mengenai beraktif online dan kualitas hidup. Oleh karena tidak ada kelompok yang dapat periksa dan cek semua ini, tidak diketahui apakah efek pengukuran penghasilan ini bagi pasien yang tidak terima perantaraan sokongan self-management dari jururawat ini. Maka itu persamaan antara kelompok pasien tidak bisa dilakukan.

Bab yang terakhir (**Bab 8**) ada kesimpulan penghasilan terpenting. Pun dimuat renungan dan anjuran metodologis buat pendidikan dan praktek. Anjuran terpenting adalah menyatukan dan membawakan sokongan self-management lebih lagi dalam pendidikan jururawat dan menyekolahkan jururawat berpraktek sedang sokongan self-management ditawarkan menurut model 5 A, dengan perhatian istimewa bagi menjanjikan dan menentukan (Assess), membantu (Assist), mengatur dan mengurus (Arrange). Kemudian dianjurkan untuk mendorong serta memberikan duluan sokongan self-management ini kepada orang yang berpenyakit kanker tak dapat disembuhkan. Demikian pasien dapat gunakan sokongan ini dan pada akhirnya sendiri menentukan dan berkuasa mengenai hidup dan perawatannya. Introduksi perantaraan sokongan self-management ini dalam praktek dapat menolong mewujudkan anjuran ini. Terakhir penting bahwa sokongan self-management ini, teristimewa jika eHealth digunakan, dicocok dengan keinginan dan kebutuhan pasien.

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About the author

List of publications

ABOUT THE AUTHOR

Vina Slev (1983), half Romanian and half Moluccan, was born and raised in Leiden. After completing pre-university high school education in 2002 at the Stedelijk Gymnasium in Leiden, she moved to Groningen to study Law at the University of Groningen. Two years later, she decided to switch subject and started studying Nursing at Hanze University of Applied Sciences in Groningen. She obtained her Bachelor's degree in 2008. The final stage of that degree was a Bachelor's thesis on, among other things, nurses' role in the medical and forensic examination of victims of sexual assault. For this thesis, she received the Vroukje Admiraal award for the best thesis of the year, and a grant from Zorgplein Noord.

As Vina's goal became to initiate research within the field of forensic nursing, she enrolled in the Forensics, Criminology, and Administration of Law Master's program at Maastricht University to expand her knowledge of forensic disciplines and criminal law. As a follow-up to her Bachelor's thesis, she wrote her Master's thesis about legal aspects related to the introduction of a forensic nurse in the medical and forensic examination in sexual assault cases. She obtained her Master's degree in Law in 2009.

In 2011, Vina followed the Evidence-Based Practice Master's program at the University of Amsterdam, to increase her chances of a career as a scientific researcher. Vina took a side-step from forensic nursing as her second Master's thesis discussed the medical and psychiatric health of immigrants, and factors associated with exemption from the obligatory citizenship trajectory. Two years later she obtained her Master's degree in Science.

Vina commenced her PhD project at the Netherlands Institute for Health Services Research (Nivel) in 2014. In 2015, she moved to the End-of-Life Research Group at the VU University Medical Center in Amsterdam to continue working on her PhD, which she completed in 2020.

In 2018, Vina started working at the municipal public health service of Amsterdam, where she currently holds a position as a researcher within the field of forensic medicine and forensic nursing. Her ultimate goal is to contribute to forensic nursing in the Netherlands, among other things by developing a forensic nursing research program.

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Dankwoord

DANKWOORD

Vrijdag 28 februari 2020 is het zo ver! Ik ga promoveren!

Mijn promotietraject heeft mij veel geleerd en gebracht; Het heeft mij laten zien dat goed en zuiver onderzoek doen in de dagelijkse praktijk een uitdaging is. Daarnaast heeft het voor mij bevestigd dat het van essentieel belang is om alle belanghebbende partijen bij zowel de opzet als de uitvoering van het onderzoek te betrekken. Alleen dan kan onderzoek van waarde zijn voor de praktijk en de doelgroep én kan het vanuit methodologisch perspectief slagen.
Velen hebben mijn promotietraject mogelijk gemaakt en ervoor gezorgd dat er nu een proefschrift ligt waar ik trots op ben. Deze mensen wil ik graag bedanken.

Allereerst wil ik alle **onderzoeksdeelnemers** bedanken. Zonder jullie openheid, gastvrijheid, betrokkenheid, tijd en inzet zou dit proefschrift er niet zijn geweest. Jullie hebben voor mij bevestigd hoe belangrijk het is om onderzoek met en onder de doelgroep uit te voeren. Dank jullie wel!

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Nelly, mijn steun en toeverlaat. Jij bent de copromotor die ik iedere promovenda/promovendus toewens. Jij bent begripvol, invoelend, eerlijk en recht voor z'n raap. Onze samenwerking voelde als één tussen copromotor en promovenda én als één tussen collega's. Jij was een 'collega' waarmee ik kon sparren en keer op keer kon discussiëren over de definities van 'adoption' en 'usage'. Jij was ook een 'collega' met wie ik veel heb gelachen en bij wie ik via diverse kanalen mijn hart kon luchten, via e-mails, telefoongesprekken, what's appjes en tijdens treinritjes. Daarnaast was jij een 'copromotor' die nuanceert, aanwijzingen geeft en die jou laat leren door uit te leggen en niet door over te nemen. Dank je wel dat ik van jou mocht leren, dat ik mijn hart kon luchten, dat jij er altijd voor mij was. Oftewel, dank je wel voor alles!

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Malika en Sacha van het VUmc, jullie ben ik extra veel dank verschuldigd. Jullie hebben ontzettend veel werk uit handen genomen zoals tientallen vragenlijsten uitprinten, in enveloppen doen, posten, weer in ontvangst nemen en invoeren, en belletjes plegen en mailtjes sturen. Weet dat jullie onmisbaar waren en dat ik jullie enorm dankbaar ben!

Tot slot wil ik graag de leden van de leescommissie en corona bedanken, **prof. dr. Riper, prof. dr. van Dijk, prof. dr. van Meijel, prof. dr. van Dulmen, dr. van Staa en prof. dr. Onwuteaka-Philipsen**. Hartelijk dank voor de bereidheid om mijn proefschrift te beoordelen en kritische vragen op te stellen voor mijn verdediging.

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Allereerst en in het bijzonder **Judith,** collega en maatje van het eerste uur. In 2014 zijn wij tegelijkertijd met een gelijksoortig promotietraject gestart. Sparren en discussiëren over zelfmanagement, zelfmanagementondersteuning, het 5A model en gevreesde promotievragen kon ik logischerwijs dan ook alleen en het beste met jou. Dit waren overigens niet de enige onderwerpen waaraan wij veel woorden en tijd hebben besteed; Wij hadden het over van-al-les en wij sprongen veelvuldig van de hak op de tak. Hoe vaak hebben wij elkaar wel niet de vraag gesteld hoe wij nu ook alweer bij dit (niet-werkgerelateerde) onderwerp zijn uitgekomen. Lieve Judith, jij bent de topper en ik ben trots op jou! Dank je wel dat ik lief en leed met jou kon delen onder het genot van (heel veel) thee en cappuccino's en muffins. Bedankt voor het kleuren van mijn promotietraject!

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Sommigen van jullie heb ik ook buiten werktijd nog gezien maar ik hoop jullie echter allemaal nog eens te zien; Wie weet bij de volgende promotie of een Dode hoek reünie...

Het overgrote deel van mijn promotietraject heb ik doorgebracht met de bewoners van kamer G-423 en daarom wil ik jullie extra bedanken. Wij zijn totaal verschillend maar toch werkte het. Het werkte motiverend, inspirerend en ontspannend. Het was nooit saai en er waren, soms verrassende, gedeelde interesses die voor genoeg gespreksstof zorgden zoals muizen, (kinder)tv serie tunes, motoren, Formule 1, technomuziek, Backstreet Boys, gamen en het/mijn dating leven. **Eva, Marianne, Ian en Judith**, dank jullie wel voor de gekkigheid, gezelligheid en voor de luisterende oren binnen en buiten de muren van G-423. Het was een fantastische tijd! Trouwens, wanneer en bij wie is het volgende etentje?

Brahim, dank je wel voor het regelen van cadeaubonnen, inkoopordernummers, enveloppen en...het delen van jouw passie! Het was erg leuk om jou in actie te zien tijdens de Guo Shu Cup en hierover (na) te praten met een glas mint thee.
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De afgelopen jaren zijn voor mij een periode van terugblikken en vooruitblikken geweest. Een blik in het verleden op wat ik allemaal heb gedaan, de keuzes die ik heb gemaakt en waar het tot heeft geleid. Maar ook een kijkje in de toekomst naar wat de volgende stap zou kunnen zijn. Graag gebruik ik de volgende pagina's om te reflecteren.

Hoe kom je daar waar je uiteindelijk wilt zijn? Hoe kom je bij het beroep dat je zogezegd je leven lang zou kunnen en willen uitoefenen?

Sommigen weten het al van kleins af aan en worden uiteindelijk de piloot, huisarts of astronaut die ze willen worden. Ik wist het ook van kleins af aan maar huisarts ben ik niet geworden. Hoe kom je er dan?

Nooit had ik gedacht dat ik onderzoeker zou worden, dat ik binnen het forensische vakgebied zou werken en dat ik een sterke affiniteit met forensische verpleegkunde zou ontwikkelen. Ik ben er dan ook van overtuigd dat mijn gevoel en mijn genen mij hiernaar toe hebben geleid. Bij alles weet ik deed volgde ik mijn gevoel. En hoewel mijn keuzes op het moment zelf soms onlogisch leken, bleek dat achteraf niet het geval. Integendeel, als je terugkijkt en het van een afstandje bekijkt dan is het best samenhangend geweest en leidde het allemaal naar één doel. Het is eigenlijk precies zoals het citaat van Steve Jobs, de oprichter van Apple:

"You can't connect the dots looking forward; you can only connect them looking backwards. So you have to trust that the dots will somehow connect in your future. You have to trust in something - your gut, destiny, life, karma, whatever."

Graag neem ik jullie even mee terug in de tijd. Onderweg bedank ik alle andere mensen die in mijn leven en loopbaan belangrijk zijn (geweest).

Basisschool en middelbare school

Dat projecten mij enthousiast maken, bleek al in groep 4 te zijn opgemerkt. Althans, zoals is af te leiden uit mijn rapporten. Ik werkte er thuis aan en nam materiaal mee. Inspiratie haalde ik uit mijzelf, mijn hobby's of uit 'het documentatiecentrum'. Allerlei onderwerpen zijn dan ook de revue gepasseerd zoals bijvoorbeeld Roemenië, de Zuid-Molukken, couveusekinderen, Unicef, de kolibrie, taal en communicatie, orchideeën en geneeskunde. Ook spreekbeurten houden vond ik erg leuk; Over viool, het KNMI en zwakzinnigen en over de werkstukken die ik had gemaakt.

Afgaande op mijn rapporten, bleek ik op de basisschool al een aantal onderzoeks-vaardigheden te bezitten. Zo kon ik al aardig schrijven en moeilijke dingen goed uitleggen. Vooral het laatste was later nog een veelvuldig gegeven compliment. En dat terwijl ik daar juist soms over twijfel.

Er waren uiteraard ook wel wat leerpunten, zoals een tekst beter structureren en opbouwen, en de inhoud beter afstemmen op de titel. Wat ik persoonlijk toch wel grappig vind om te constateren, is dat leerpunten van toen stiekem ook nog aandachtspunten van nu zijn. Zeker wanneer ik een onderwerp erg interessant vind, wil ik nog weleens buiten de kaders van mijn onderzoeksvraag gaan.

Of het altijd een positief gegeven was dat ik ook thuis aan mijn werkstukken werkte, dat weet ik zo net nog niet. Was het omdat ik het zo leuk vond of misschien ook omdat ik in tijdnood kwam? Thuis en laat doorwerken deed ik namelijk ook nog op de middelbare school. Ik doe dat overigens nog steeds weleens. Zeker ook wanneer ik het onderwerp leuk vind, maar soms ook omdat ik mijn deadlines anders niet haal. Ik ben nogal perfectionistisch. Dit is een kracht maar ook een valkuil. Het kan namelijk een efficiënte werkhouding in de weg staan. Hoe dan ook, ik heb goede hoop dat ik er vooral nog een kracht van kan maken.

Tijdens mijn middelbare schooltijd, inmiddels zo'n 24 jaar geleden, heb ik de eerste vriendschappen gesloten die nu nog steeds belangrijk voor mij zijn.

Hanneke, wij zaten samen met Nienke en Aniek, en later ook met Lotte, in klas 1b. Toen wij gingen studeren verloren wij elkaar uit het oog. Vijf jaar later kwamen wij via MSN weer met elkaar in contact en ontmoetten wij elkaar bij Rock Werchter. Niet zoals afgesproken bij, ik meen, een bepaalde lantaarnpaal maar een kwartier eerder bij de wasbakken. Hoe hilarisch was dat! Het was eigenlijk gelijk weer als vanouds en wij bleven contact houden en elkaar opzoeken, waar wij ook woonden. Een paar jaren voor de start van mijn promotietraject kwam ik niet alleen meer bij jou maar ook bij Eelco op bezoek. Hoewel het normaliter ontspannen en gezellig avonden waren, was één keer anders dan anders. Ik moest jullie namelijk vertellen dat ik niet op jullie bruiloft kwam. Tijdens mijn eerste congresbezoek in Kopenhagen mocht ik namelijk een mondelinge presentatie geven over mijn onderzoek. Iets wat je, zeker als junior onderzoeker, het liefst wilt wanneer je naar een congres gaat. Ik voelde mij vereerd dat ik bij jullie bruiloft mocht zijn en ik vond het dan ook niet makkelijk om mee te delen dat ik jullie dag moest missen. Jullie reactie was ontzettend lief en begripvol. Daar ben ik jullie dankbaar voor. Net als alle daaropvolgende etentjes, lunches, borrels en kopi luwak-momenten waarin wij onder meer volop oude herinneringen ophaalden, ik het over de leuke kanten van mijn promotietraject kon hebben maar ook over de minder leuke kanten. Dank voor het luisterende oor en de oude en nieuwe herinneringen!

Nienke, Aniek, Lotte en Annemarie, ik vind het bijzonder dat wij elkaar na al die jaren nog steeds zien. De dynamiek binnen onze vriendschap is logischerwijze veranderd maar ondanks dat en dat wij in verschillende delen van het land wonen,

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heeft onze vriendschap de tand des tijds doorstaan en is het met ons meegegroeid. Dank voor alle mooie momenten, onze gezellige etentjes en lunches waarvan ik hoop dat er nog vele zullen volgen.

Niet alleen is de vriendschap in zijn totaliteit veranderd maar ook de vriendschappen binnen de vriendschap. Dat geldt in het bijzonder voor die van ons, **Nienke**. Onze vriendschap heeft mij veel geleerd over mijzelf. Daar zal ik jou mijn leven lang dankbaar voor zijn. Ik wil jou ook bedanken voor de tientallen telefoongesprekken waarin jij mij keer op keer duidelijk maakte dat het echt wel een prestatie is, dat promotietraject, en dat jij zo trots op mij bent. Telefoongesprekken waarin mijn respect voor jou overigens met elke minuut groeide. Jij bent ontzettend sterk en een vechter. Ik ben trots op jou!

Rechten aan de RUG in Groningen

Na het behalen van mijn middelbare school diploma verhuisde ik in 2002 naar Groningen voor de studie Rechten. Ik had graag Geneeskunde willen studeren. Maar omdat dit niet haalbaar was gezien mijn cijfers voor de bètavakken, moest ik over een alternatief nadenken. Mijn vader opperde destijds of Rechten mij niet wat lijkt. Een van de studies die mijn Roemeense opa ook heeft gevolgd. Ja, dat leek mij wel wat en dan in het bijzonder Internationaal Recht want ik wilde veel reizen (wat een prachtige gedachte!).

Aanvankelijk vond ik het een interessante studie maar uiteindelijk kon alleen het Strafrecht mij boeien. Maar ja, voordat je je kon specialiseren moest je toch ook echt alle andere vakken hebben gehaald.

Aangezien ik na twee jaar nog steeds niet mijn propedeuse binnen had, besloot ik in 2004 te stoppen met de Rechtenstudie en de overstap te maken naar HBO-Verpleegkunde (HBO-V).

Van Rechten naar Verpleegkunde, een nogal vreemde wissel. Ja en nee. Het was namelijk de studie die het dichtst bij Geneeskunde lag. Bovendien zit ook het verpleegkundige beroep in de familie; Mijn Molukse opa, moeder, tantes en een van mijn ooms waren allemaal verpleegkundige of verzorgende.

De beslissing om te stoppen met Rechten en te kiezen voor HBO-V was niet echt moeilijk maar dit aan mijn ouders vertellen wel. Ze waren het er niet helemaal mee eens en vonden het jammer. Of ik het niet nog wilde proberen. Nee, dat was geen optie. Ik had mijn besluit genomen. Ik vond de Rechten studie niet interessant genoeg en ik wilde het niet langer voortzetten, ook niet op het HBO.

HBO-V aan de Hanze in Groningen en Politie Groningen

Ik had besloten om HBO-V te doen, omdat deze studie aldus dicht bij Geneeskunde lag en omdat de onderwijsmethode mij aansprak; Er werd namelijk veel in projecten gewerkt. Daarnaast dacht ik dat studiebegeleiding wel zou helpen, omdat mijn aanname was dat je dan een schop onder je kont kreeg als jij je deadlines niet zou halen én dat je meer begeleid zou worden in plannen en planningen halen. Dat was dus niet het geval.

De studiewissel was hoe dan ook een goede keuze geweest, want ik vond de opleiding echt leuk en het paste goed bij mij. Ik ben best een zorgzaam type. Met plezier liep ik mijn stages in binnen –en buitenland en werkte ik aan verschillende projecten.

In mei 2007 ging ik met Jopie, studiemaatje van het eerste uur, en nog een ander studiegenootje naar bureau Zeden van de Politie Groningen. Voor een derdejaars project wilden wij informatie hebben over of slachtoffers van seksueel misbruik later zelf ook seksueel misbruik plegen. Ik had tegelijk maar mijn stoute schoenen aangetrokken en gevraagd of zij misschien ook stageplekken hadden. Mijn interesse in het Strafrecht was namelijk weer aangewakkerd.

Een stage was wat lastig maar er was nog wel een onderzoeksvraag die Zeden graag beantwoord zou willen zien. Het betrof de vraag of een eventuele verplaatsing van de onderzoekskamer waar het sporenonderzoek en het medisch onderzoek bij slachtoffers van zedendelicten wordt afgenomen, een kwaliteitsverbetering zou kunnen inhouden. Of ik hier ook interesse in had. Absoluut! Ik moest nog wel even bedenken hoe ik het verpleegkundige aspect in het geheel kon verwerken. Maar dat vond ik juist het uitdagende.

Binnen het onderzoek bekeek ik aanvullend wat de huidige rol van de verpleegkundige binnen het forensisch en medisch onderzoek was, en onderzocht ik of en zo ja wat voor rol de verpleegkundige in de toekomst zou kunnen hebben.

Een paar maanden later had ik een goedgekeurde onderzoeksopzet, was mijn afstudeeronderzoek bij de politie een feit, en was ik weer 'terug' naar het (straf)recht.

Uiteindelijk is het een mooi afstudeeronderzoek geworden, waarin -al zeg ik het zelf- mijn kwaliteiten als onderzoeker al goed zichtbaar werden. Dat anderen dit ook vonden, bleek uit de nominatie en uiteindelijk ook het winnen van de Vroukje Admiraal prijs voor beste scriptie van de Academie voor Verpleegkunde van het jaar 2008. Een grappig gegeven: Mijn moeder zei later nog dat ik het altijd al leuk vond om werkstukken te maken en hier ook mooie cijfers voor kreeg.

Tijdens dit afstudeeronderzoek werd voor mij steeds meer duidelijk dat ik onderzoek wilde doen, en in het bijzonder naar de rol van forensisch verpleegkundigen bij het zedenonderzoek. Na mijn afstuderen in 2008 besloot ik Verpleegkunde 'los' te laten en mij in te schrijven voor de master Forensica, Criminologie en Rechtspleging.

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Dit om meer kennis te vergaren over 'het forensische'. Ik had de toelatingstoets gehaald (waar die twee jaren Rechten wel niet goed voor zijn geweest!) en in de zomer van 2008 verhuisde ik naar Maastricht.

Voordat ik overga naar de volgende (post-Groningen) periode, wil ik eerst nog een aantal mensen bedanken die een essentiële bijdrage aan mijn academische carrière hebben geleverd, nog voordat ik ging promoveren.

Dat ik dit HBO-V afstudeeronderzoek kon uitvoeren en dat het zo een succes is geworden is dankzij jullie Siemen, Klaas, Thea en Marijke.

Siemen, mijn HBO-V scriptie -en stagebegeleider. Ik heb natuurlijk geen vergelijkingsmateriaal maar ik ben ontzettend blij dat ik jou als begeleider heb gehad. Jij wist en zag precies wie ik was, hoe ik was, waar mijn sterke punten lagen en waar niet. Nog belangrijker was dat jij jouw begeleiding daarop afstemde en zo mijn ontwikkeling als onderzoeker hebt gefaciliteerd.

Jij hebt mijn scriptie ingestuurd voor de Vroukje Admiraal prijs. Wat een verrassing was het toen jij mij dit vertelde! En een mooie opsteker toen het met mijn psychiatrie-stage wat minder ging. Samen met de positieve beoordeling van mijn scriptie was de uiteindelijke winst een extra bevestiging van mijn capaciteiten als onderzoeker en een grote motivatie om hierin door te gaan. Veel dank voor jouw vertrouwen en kundige begeleiding!

Klaas en Thea, mijn scriptiebegeleiders vanuit de politie. Ten eerste, dank dat jullie het mij toevertrouwden om het belangrijke onderzoek te doen naar de kwaliteit van het forensisch en medisch onderzoek bij slachtoffers van zedendelicten. Ten tweede, dank voor de mogelijkheid om tijdens de HBO-V al de eerste serieuze onderzoekservaring op te doen. Jullie hebben het mogelijk gemaakt dat mijn afstudeeronderzoek goed in elkaar zat (dat durf ik nu ook van mijn eigen onderzoek te zeggen). Ik kon alle belanghebbenden interviewen, heb de onderzoekskamer in Groningen mogen zien en ben samen met jullie naar Amsterdam geweest om te zien hoe daar het een en ander geregeld was. Ten laatste, dank voor jullie waardering voor het door mij verrichtte werk. Jullie hebben dit op meerdere manieren geuit maar een van de dingen die mij is bijgebleven was de eindpresentatie. Het was een ware gebeurtenis met alles erop en eraan. Familie en vrienden mochten aanwezig zijn, er was catering geregeld, jullie collega maakte foto's, de presentatie mocht gefilmd worden en na afloop kreeg ik een prachtige mega bos bloemen. Sommige dingen lijken misschien futiliteiten maar ik vond het super dat dit allemaal werd geregeld voor in mijn ogen 'slechts' een afstudeeronderzoek. Terugkijkend was deze dag eigenlijk een miniverdediging. Niet alleen waren jullie en Siemen aanwezig maar ook een aantal collega's en een forensisch arts. Ik kreeg kritische vragen,

maakte kennis met meningen die niet overeenkwamen met die van mij en moest daar (uiteraard) ter plekke op reageren.

Het gewicht dat jullie hebben gegeven aan de eindpresentatie beschouw ik als een grote blijk van waardering en een groot compliment. Veel dank voor jullie vertrouwen en alles wat jullie hebben gedaan om van mijn afstudeeronderzoek een succes te maken! **Marijke** van GGD Amsterdam, jij leerde mij over de 'forensisch verpleegkundige' en de zogenaamde SANE-nurse in onder meer de Verenigde Staten. Dit is een speciaal opgeleide verpleegkundige die het sporenonderzoek en medisch onderzoek bij slachtoffers van zedendelicten tot haar taak heeft. Jouw invloed en inzet bleef niet beperkt tot mijn afstudeeronderzoek. In de daaropvolgende jaren betrok jij mij namelijk meerdere malen bij forensisch verpleegkundig pionierswerk zoals onder meer het initiatief voor het opzetten van een beroepsvereniging. Daarnaast introduceerde en promootte jij mij bij Tina en Kees. Heel erg bedankt voor alles! Het is van onmiskenbaar belang geweest!

Ook tijdens mijn studententijd heb ik een aantal bijzonder lieve mensen leren kennen die ik graag wil bedanken.

Gezegd wordt dat je studententijd de mooiste tijd van je leven is en dat je er volop van moet genieten. Dat is gelukt! En vooral door de volgende lieve meiden: **Gemma**, stapmaatje van het eerste uur. Wij leerden elkaar kennen tijdens de KEI-week. Toen ik jou aansprak waren wij allebei op zoek naar het huis van onze KEI-mama -en papa's. Wij bleken in dezelfde KEI-groep te zitten. Al lachend kwamen wij binnenlopen en men dacht dat wij elkaar al kenden, omdat wij zo een lol hadden. Niets was minder waar... Wat hebben wij een mooie tijd gehad als meubilair van 't Feest en iets later &zo. Vaak met z'n tweeën maar ook net zo vaak met z'n drieën met Marjan. Jij bent misschien wel de meest onbaatzuchtige persoon die ik ken. Jij doet vanalles voor een ander en doorkruist hiervoor zelfs heel het land. Jij staat altijd voor een ander klaar, ook wanneer jij jezelf het hardst nodig hebt. Ik koester wat wij hebben meegemaakt en wat jij voor mij hebt gedaan! Dank je wel voor alles! **Mirjam**, studiemaatje van Rechten. Na het allereerste werkcollege bood jij aan om een keer samen te eten. Ik vond dat zo ontzettend lief; Wij hadden pas net kennis gemaakt en jij kende mij niet eens. Ik voelde mij zo welkom en het maakte dat ik mij direct op mijn gemak voelde in mijn nieuwe (studie)omgeving. Dank je wel voor jouw vriendschap toen en ook na mijn switch naar Verpleegkunde. Ik kon mij goed voorstellen dat ons contact zou verwateren nu wij niet meer dezelfde studie volgden. Maar het bleef! En daar ben ik erg dankbaar voor. Ik bewonder jou om jouw veerkracht, jouw nuchterheid en positiviteit. Maar ook jouw creativiteit en jouw praktische inslag. Jij denkt aan dingen waar ik niet zo snel aan denk. Ik ben dan ook

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blij dat jij mijn ceremoniemeester bent. Dank je wel hiervoor, en dat ik altijd mijn hart bij jou en ook bij Johannes heb kunnen luchten. Ik waardeer onze vriendschap enorm en daarbij ook jouw familie die het een en ander voor mij heeft gedaan en met wie ik ook bijzondere momenten heb mogen meemaken. Dank jullie wel!

Jopie en Elske, wij kennen elkaar van HBO-V en zaten de eerste twee jaar bij elkaar in de werkgroep. Wat een mooi stel waren wij met z'n drieën. Nog net niet gehaat door het andere deel van de werkgroep. Nee, dat is overdreven. Maar dat wij anders waren dan de rest, dat was ons meerdere maken duidelijk gemaakt. Ach ja, wij konden er alleen maar heel hard om lachen. Zonder jullie waren mijn HBO-V jaren niet zo gezellig geweest!

Jopie, jij bent mijn HBO-V studiemaatje van het eerste uur. Wij waren onafscheidelijk vanaf de eerste minuut, Jut en Jul. Met uitzondering van drie stages en onze Bachelor scriptie, deden wij alles samen met als onvergetelijke momenten de RPM -en spinninglessen en de koffietjes met Amaretto in Sint-Niklaas. Oftewel, onze buitenlandstage in België. Ook onze projectsamenwerkingen zijn memorabel: Medestudenten mocht best met ons meedoen maar ze moesten zich wel een soort van aan onze regels houden. Wij tolereerden geen meelifters. Wij waren een 'match made in heaven' en jij weet dan ook als geen ander hoe ik toen, als onderzoeker in de dop, was. Jij bent een doorzetter die geen genoegen neemt met minder. Jij hebt hard gewerkt om te komen waar jij nu bent en daar bewonder ik jou voor! Dank je wel voor de onvergetelijke HBO-V tijd! Ook al zien wij elkaar niet meer zo vaak. Altijd voelt het vanaf de eerste seconden als vanouds. Dat vind ik bijzonder mooi!

Elske, dank je wel voor jouw vriendschap! Ondanks dat wij soms heel lang niet kunnen afspreken, is het vaak als de dag van gisteren als wij elkaar weer zien! Ook wij waren meerdere keren samen in de kroeg te vinden, hebben meerdere keren de dansvloer onveilig gemaakt en het ons net niet toegeëigend. Ik heb veel respect voor jou. Iedere keer verbaas jij mij: Net wanneer ik denk dat jij het al druk genoeg hebt met je baan, doe jij er nog even een studie bij. Ja, je baan biedt daar soms ook wel ruimte voor maar toch, jij doet het er wel gewoon naast. Ik vind het knap en ik doe het jou niet na!

Master Forensica, Criminologie en Rechtspleging in Maastricht

In 2008 verhuisde ik naar Maastricht en startte ik aldus met de master Forensica, Criminologie en Rechtspleging aan de Faculteit der Rechtsgeleerdheid. Vastberaden en tamelijk overtuigd van de toegevoegde waarde van de forensisch verpleegkundige bij zedenzaken, liet ik mijn master scriptie aansluiten bij een van mijn eigen aanbevelingen uit mijn HBO-V scriptie; Onderzoek naar juridische aspecten (onder meer beroepsgeheim en aansprakelijkheid) die verbonden zijn aan

de eventuele introductie van de forensisch verpleegkundige bij het sporenonderzoek en medisch onderzoek bij zedendelicten. Ook dit is een goed onderzoek geworden met aanbevelingen die nader onderzoek waard waren en nog steeds zijn.

In 2009 behaalde ik mijn master diploma. En wat nu? Gedreven als ik was benaderde ik het Nederlands Forensisch Instituut (NFI) en de Landelijke Expertgroep Zeden. Het onderzoek dat ik in Groningen had verricht wilde ik namelijk graag landelijk uitrollen. Ik merkte echter dat het best lastig is om als eenling en zonder opdrachtgever, jouw onderzoeksplannen aan de man te krijgen. Daarbij, hoe interessant een onderzoeksvoorstel ook mag zijn, als er geen behoefte is en er geen financiële middelen zijn dan houdt het op.

Tja, wat nu. Hoewel ik het even heb geprobeerd was werken als verpleegkundige voor mij geen optie meer. Ik had geen vertrouwen (meer) in mijzelf en mijn bekwaamheid. Bovendien wilde ik zo ontzettend graag in het onderzoek verder, dat ik mij op de dagen waarop ik nog als verpleegkundige werkte zelfs wat ontheemd voelde. Het paste niet meer.

Op een gegeven moment liet mijn moeder een advertentie over de Master Evidence Based Practice bij de Universiteit van Amsterdam zien. Die master zag eruit als een die ik moest volgen, wilde ik als onderzoeker aan het werk kunnen. Wel wilde ik van tevoren weten of ik kon afstuderen op een systematic review over de forensisch verpleegkundige bij zedenzaken. Tijdens de voorlichtingsdag besprak ik dit dan ook direct even met de voorzitter van de master.

Master Evidence Based Practice (EBP) en GGD Amsterdam

In 2011 startte ik met EBP. Al vanaf de eerste dag wist ik dat dit het was. Hier moet ik zijn, dit is wat ik wil! Dat gevoel en die wetenschap wens ik iedereen toe.

Ik was laaiend enthousiast en op mijn eerste studiedag heb ik Marijke's leidinggevende gemaild. Ik had gevraagd om een gesprek over eventuele stage-mogelijkheden in het kader van een Pilot Zeden waarover Marijke mij had verteld of voor mijn systematic review idee. Uiteindelijk werd mij een stageplek aangeboden voor het laatstgenoemde.

Vanwege bepaalde afstudeereisen waaraan mijn systematic review moest voldoen, moest ik het onderwerp 'forensische verpleegkunde' helaas loslaten. GGD Amsterdam vroeg vervolgens of ik interesse had in de uitvoering van een reeds bestaand onderzoeksvoorstel. **Manon**, dank je wel dat ik jouw en Jeroens onderzoeksvoorstel over de medische en psychische gezondheid van aanvragers van ontheffing van het inburgeringsexamen mocht oppakken. Dit voelde als een compliment. Ook veel dank voor het gevoel dat jij mij toen hebt gegeven, namelijk dat ik een collega was en niet slechts de stagiaire.

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Mijn afstudeeronderzoek is uiteindelijk een goed onderzoek geworden, waaruit bovendien een publicatie is voortgekomen.

Op 7 oktober 2013 mocht ik mijzelf 'klinisch epidemioloog' noemen en was het zo ver om te solliciteren voor mijn eerste baan als onderzoeker. Want hoe graag wij het ook allemaal wilden, ik kon helaas niet bij GGD Amsterdam blijven. Hoewel het ontzettend jammer was, zei de optimist in mij dat het wel goedkomt en dat ik, als het moment daar is, vast wel weer terugkom.

Ik was al enorm blij met wat jullie, **Tina en Kees,** voor mij hadden gedaan. Jullie hebben ervoor gezorgd dat ik stappen kon zetten in mijn academische carrière door onder meer deze EBP-stageplek aan te bieden voor mijn 'forensische verpleegkunde-plannen'. En toen dit niet kon doorgaan, hebben jullie mij iets anders aangeboden. ik zal jullie hier altijd dankbaar voor zijn.

Tina, jou ben ik nog extra dankbaar voor jouw begeleiding. Hoe bedenk je het, Tina en Vina? Om maar niet te spreken over andere toevalligheden. Ook jij bent een begeleider die ik iedereen toewens. Jij bent iemand die jou laat leren door eerst aanwijzingen te geven over hoe het ook anders kan. Ik kon ontzettend fijn met jou sparren. Wij zaten volgens mij altijd op één lijn. Ik kan mij namelijk niet meer niet herinneren dat dit niet zo was. En anders heb ik het als zodanig ervaren dat mijn mening en ideeën er óók mogen zijn. Ook bij jou voelde ik mij meer collega dan stagiaire. Dank je wel voor het vertrouwen en dat jij mij vrijwel vanaf onze eerste ontmoeting in 2009, onder jouw vleugels hebt genomen!

Promoveren in Utrecht en in Amsterdam

Ik ging aldus solliciteren en bij mijn tweede brief was het raak. Het ging om de functie van een junior onderzoeker op de onderwerpen verpleegkundige zelfmanagementondersteuning aan mensen dementie en mensen met een ongeneeslijke vorm van kanker. Dit lijkt wellicht weer een afwijkende richting maar ook dit paste in het straatje, alleen op een andere manier.

De vacature sprak mij direct aan omdat het over verpleegkundigen ging en er een stukje eHealth bij zat. Ik 'koos' voor de doelgroep mensen met een ongeneeslijke vorm van kanker vanwege mijn stage-ervaring op een oncologie-afdeling en -hoe vreemd het misschien klinkt- het verdrietige gegeven dat een oom twee jaren eerder aan de gevolgen van deze ziekte was overleden. Dat ik ook affiniteit met zelfmanagementondersteuning en zelfmanagement had is overigens ook niet zo gek. Insiders zouden kunnen weten waarom.

Het promotieonderzoek lijkt misschien ver van de forensisch verpleegkundige af te staan maar niets is minder waar. Zelfmanagementondersteuning en zelfmanagement zijn namelijk ook belangrijk voor slachtoffers van zedendelicten en daarmee ook zeker van belang voor forensisch verpleegkundigen.

Op 5 november 2013 had ik mijn eerste gesprek en op 11 november mijn tweede. Dat ik was aangenomen hoorde ik een dag later en op 2 januari 2014 startte ik samen met Judith dit nieuwe avontuur bij het Nivel in Utrecht. Een jaar later verhuisden wij naar het VUmc, naar de Levenseindezorg-groep van Bregje.

Op 31 december 2017 liep mijn contract bij het VUmc af en moest ik mijn promotietraject in mijn vrije tijd afmaken. Dit hield echter ook in dat ik weer moest solliciteren.

Weer terug bij GGD Amsterdam

Nog voordat ik mijn eerste sollicitatiebrief had geschreven, werd ik op 2 november 2017 gebeld door Tina en Manon. Of ik beschikbaar ben en het zie zitten om bij GGD Amsterdam te komen werken. Jaa!! Ik was ontzettend blij! Ik zei het al: Op een dag, als het moment daar is, dan zal ik weer teruggaan naar het 'forensische'.

Donderdag 3 januari 2018 was mijn eerste dag. Het klinkt misschien gek maar het was als thuiskomen. Wat een warm welkom heb ik gehad van **EGZ-collega's en FGMA-collega's**. Dank hiervoor en voor jullie interesse in mijn promotietraject!

Udo, ook jou wil ik hier in het bijzonder voor bedanken, net als jouw vertrouwen in mij als nieuwe collega.

Tina en Manon, nogmaals wil ik jullie bedanken maar nu als 'collega'. Dank voor het meeleven en voor jullie steun tijdens de laatste jaren van mijn promotietraject! Daarnaast veel dank dat jullie mij 2 november gebeld hebben. Ik ben nog steeds blij dat ik de 'V' in team MTV ben. Ik vind het bijzonder leuk om te merken hoe goed wij elkaar aanvullen en op elkaar zijn ingespeeld! Met z'n drieën verzetten wij bergen en ik hoop dit nog een heel lange tijd met jullie te kunnen doen! We rock!

Alles gebeurt met een reden en niets is voor niets.
Alle keuzes die ik heb gemaakt, hebben ervoor gezorgd dat ik nu doe wat ik het liefst doe. Hoe spannend het op dat moment misschien ook was en hoe onlogisch het soms ook leek, terugkijkend zijn het de beste en meest logische keuzes geweest die ik heb kunnen maken.

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Tot slot rest mij alleen nog om mijn familie en de belangrijksten, mijn ouders, te bedanken.

Lieve familie, dank voor jullie enorme betrokkenheid bij alles wat ik doe en heb gedaan! In verschillende samenstellingen waren jullie bij verscheidene successen: van afzwemmen, viooloptredens, afdansen en balletvoorstellingen tot presentaties, diploma-uitreikingen en straks mijn verdediging.
Frank, jou wil ik nog in het bijzonder bedanken. Dank dat ik mijn studententijd thuis bij jou mocht starten totdat ik een kamer had gevonden. Het was een mooie tijd met veel inspirerende en leerzame verhalen over jouw werk bij de politie en Gran Turismo (de TVR Tuscan was het paradepaardje, toch?). Jouw tip om bij Zeden langs te gaan bleek van goud.

Iubită familie, mulțumesc pentru suportul şi mesajele voastre. Mă simt onorată şi deosebit de fericită că veniți în Olanda la susținerea tezei mele de Doctorat!

Kepada yang terhormat Keluarga yang baik dan manis dari Kamarian, Ambon, Jakarta dan Bali. Sayang bukan banyak kali, kami saling bertemu, sampai sekarang hanya dua kali. Tetapi kali-kali itu menjadi kenangan dan peringatan yang istimewa. Saya diterima dengan baik dan saya rasa senang seperti sudah kenal lama, seperti di rumah sendiri. Perasaan dan temuan itu saya anggap tinggi, karena hatiku sangat senang. Harap temuan yang tentu akan datang dengan Keluarga baik dan manis itu dapat diteruskan.

Liefste papa, veel van mijn eigenschappen zie ik ook bij jou terug en dan heb ik het niet alleen over de muzikaliteit. Wij zijn beiden tegendraads en koppig. Met elkaar in discussie gaan dat kunnen wij dan ook als geen ander. Iets waar mama soms een beetje gek van wordt. Bij het vertalen van de samenvatting kwam ik erachter dat wij ook goed zijn in dingen onderschatten; "Oh... morgen heb het ik wel af. Het is nog maar één pagina.". Morgen: "Nee, dán heb ik het zeker klaar.". Wat ik óók van jou heb is mijn optimisme. Jij bent alles maar vooral ook de vader die jou uit de put helpt door jou ervan te verzekeren dat alles goed komt en dat jij de mooiste en slimste op deze aardbol bent. Dat wil iedere dochter horen wanneer het tegenzit. Het zijn jouw woorden maar ik wil ze hier vereeuwigd hebben: "Tu eşti...Sufletul meu şi viaţa mea."

Optimisme en nuchterheid en relativering zijn elkaar versterkende eigenschappen. Die laatste twee heb ik vooral van jou, **liefste mama**. Jij bent de moeder die van 'het doorzetten' is en die jou uit de put helpt door te relativeren. Overigens net zoals papa, sta jij altijd voor anderen klaar. Jij bent niet te beroerd om anderen te helpen

maar er zijn grenzen. Zelfstandigheid is voor jou een groot goed. Probeer het eerst zelf en als het niet lukt vraag dan om hulp. Dat is dan ook een instelling die ik vooral van jou heb overgenomen. Jij bent liefdevol streng en eerlijk. En niet te vergeten ook lekker gek en bijdehand. Iets wat niet iedereen van jou kent, en wat ook niet iedereen van mij kent. Het rustige en beleefde met een scherp randje (iets wat ooit eens over mij is geschreven in een ander dankwoord), dat heb ik van jou.

Liefste papa en mama, ondanks dat jullie het niet altijd eens zijn geweest met mijn keuzes of hoe ik het een en ander heb aangepakt, hebben jullie mij altijd gesteund. Jullie hebben mij altijd de mogelijkheid gegeven om mijzelf te ontplooien en te ontdekken wie ik ben en wat ik wil doen. Jullie hebben zelden "nee" gezegd. Zonder jullie steun, vertrouwen en ook strenge woorden had ik hier niet gestaan.
Voor mij was het dan ook vanzelfsprekend om jullie als mijn paranimfen, tijdens mijn verdediging, naast mij te hebben. Ik heb vaak genoeg alleen in de spotlights gestaan. Het is tijd dat jullie er ook in staan.
Ik kan niet anders dan dankbaar zijn voor ouders zoals jullie.
Door jullie ben ik wie ik ben.
Ik ben blij met wie ik ben en een groter goed is er niet.
Ik houd van jullie!

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