Hold on, for each other

Supporting partners of cancer patients via eHealth and positive psychology

Nadine Köhle

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SUPPORTING PARTNERS OF CANCER PATIENTS VIA EHEALTH AND POSITIVE PSYCHOLOGY

Nadine Köhle
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“ *a hero*

is an ordinary individual
who finds the strength
to persevere and endure
in spite of
overwhelming obstacles. “

– Christopher Reeve

CONTENTS

1

GENERAL INTRODUCTION

This chapter is partly based on: Köhle N & Drossaert CHC. (2016). Mantelzorg voor je partner. Tijdschrift Positieve Psychologie, 2, 31-35.

GENERAL INTRODUCTION

Only ten days had passed since the day we celebrated the good news from the PET scan; it seemed like ten years. Ironically, leaving the hospital was difficult because I had adjusted to our routine there and found some comfort in the familiarity of the environment. We were insulated in the hospital, protected from whatever beasts were awaiting us outside. I was afraid to go home, afraid to start down a different road. Granted, home was familiar territory, but it had taken on an entirely different perspective because the occupants had been forever altered. My life would never be the same. My husband had just had his chest opened, a couple of ribs broken and removed, and almost an entire lung excised. I received better instructions when taking home a puppy from the pet store than in taking home a cancer patient from the hospital. I didn't understand a thing about the disease except that it was a very bad one to have. I had the ominous feeling this might be our last Christmas together.

Caregiver fatigue, resulting from staying in the hospital, is a problem for which I still see no solution. When the patient is gravely ill and unable to oversee his own care, you simply cannot depend on an overworked nursing staff to see to his needs. Additionally, there are those in the medical field—as in any other—who are just plain incompetent. I had friends who were willing to stay with Jim, but I believed I needed to be there. By the time he came home from the hospital and my real caregiving began, I was physically and emotionally spent from the hospital stay and the whirlwind that preceded it. It is no wonder I felt unable to cope with caring for him.

I had never taken care of anyone who was seriously ill. My grandparents had died suddenly. When my dad had colon cancer surgery, I was already married and away from home. My children had the usual childhood illnesses, but they were uncomplicated and of short duration.

Nor was I the nurturing, caregiver type. I grew up in a home where no one took to their sick bed unless they were vomiting. Our medicine chest consisted of a small cardboard box in the top of a kitchen cabinet, containing mercurochrome, baby aspirin, calamine lotion, Fletcher's Castoria, and some sort of gooey, multi-purpose, black salve. I don't think we owned a thermometer; my mother used the hand-on-the-forehead method.

I was ill-prepared for the task ahead of me. Jim required around-the-clock care. He was in pain, unable to lie down or even to sleep. Away from the confinement of the hospital, he was beginning to recognize his limitations and wondering how long they would last. I was doing my best to be positive and protect him from any information that might be upsetting to him. There were meals to fix and medications to organize and dispense. He needed help to the bathroom and supervision in the shower. I had to clean his surgical wounds, keep his spirits up and his fever down, and see that he did his breathing exercises. I also had to answer the telephone. That alone required a secretary because the phone rang incessantly—sometime thirty or forty times a day. We finally had to take it off the hook so I could catch an occasional nap.

I realize that caring for the ill or aging is a taxing job, but surely it is easier for those who are not emotionally involved with their patients. When caring for someone we love, we have the same physical demands as the professionals, exacerbated by mental stress. It is this kind of stress that makes our jobs so difficult. No matter how much sleep I got, I was always exhausted. I had no energy left for ordinary activities. I marvel as I see others carry on quite nicely, juggling their regular activities and caring for a family member, but I just couldn't seem to manage more than the one job.

The inevitability and the imminence of death were in the forefront of my mind. I was walking with my nerve-endings and my antennae out, searching for signals and messages that might reassure me of Jim's ultimate recovery. I was in a state of readiness — watchful, wary, and ready to do battle. Fear weighed me down. The "what ifs," so aptly named in Shel Silverstein's poem, invaded my thinking. "What if I spend the next forty years as a widow? What if the cancer is growing right now in the other lung? What if we're living on a pocket of radon gas that caused Jim's cancer? What if my mother dies, too, and I lose them both?" In the wee hours of the morning, I came up with some doozies.

In addition to fear, there was the stress of responsibility. There were so many decisions to be made, mostly by me. I was learning I had to be an advocate, that no one else cared about my husband the way I did.

Excerpt from the book Cancer Journey – A caregiver's view from the passenger seat by Cynthia Zahm Siegfried, pp. 20-23. (Author provided permission to use this excerpt)

This excerpt from *Cancer Journey* by Cynthia Zahm Siegfried illustrates the difficult and challenging situation partners of cancer patients are confronted with. In her memoir, Cynthia describes first-hand the enormous impact that her husband's cancer had on their lives. She is one of the thousands of caregivers overwhelmed every year by the consequences of a partner's cancer diagnosis. In 2015, about 537,797 people were living with cancer in The Netherlands, and every year there are about 100,000 new cases in The Netherlands alone [1]. Prevalence rates are expected to almost double in the next ten years. The effectiveness of cancer treatment has improved steadily, with the result that cancer increasingly becomes a chronic disease. In the past, people with cancer were treated in hospitals and stayed there for a longer period of time. However, during the last years, a shift has occurred; supportive cancer care is becoming more the responsibility of family members, and, in particular, the partners of the cancer patients. Partners fulfill a wide variety of care and support roles, which Cynthia also describes in her book. Partners also perform additional tasks in the household or family situation. They assist the patient with personal care and nursing, accompany their sick family member to medical appointments, help with administrative tasks regarding the patient's medical condition, and frequently provide emotional support [2]. Since the patient is one of the dearest persons in the partner's life to whom they devote most of their time, it is not easy for the partner to sometimes disengage from being the caregiver. Accordingly, the patient's disease and the challenging situation it creates, have a profound impact on the partner's life and future perspectives.

In the personal testimony above, Cynthia describes how she was totally unprepared for the sudden care situation she had to assume. This lack of preparation frequently happens to many people who provide informal care. Partners often indicate that this role has unexpectedly been thrust upon them, just as the disease has been thrust upon the patient. In many cases, partners see the help that they provide not as informal care, but rather care that emerges out of love, affection and, in some cases, a sense of duty [3]. While doing everything to help the patient feel better, the partners often neglect their own feelings and needs. Consequently, partners' positive intentions can also be a trap that undermines their own health and resilience.

Negative and positive impacts of being a partner of a cancer patient

Cancer can have detrimental effects on partners' emotional, physical and social functioning. A review by Stenberg et al. [2] identified more than 200 problems related to the effects of caring for a cancer patient. In Cynthia's reflection, she described that she was afraid of all the possible 'what-ifs' and that she felt emotionally and physically exhausted. These experiences are also described by other partners. They often suffer from anxiety and depression (e.g., [2, 4, 5]), and they frequently feel like being on an emotional roller coaster due to all the different feelings that they are confronted with (such as fear, guilt, uncertainty, helplessness, and frustration) [2]. As a result of their caregiving tasks, partners may also experience physical impairments. The most mentioned physical health problems are pain, disturbed sleep, fatigue, loss of physical strength and weight loss [2]. In addition, the cancer can negatively influence the partners' social lives and their relationship/marriage [2]. Previous research has shown that, while couples in which one partner has cancer are not generally at a greater risk to divorce than the general population [6], partners often do report a loss of intimacy and reduced sexual engagement, communication problems and feelings of inequity [7]. They also experience shifts in tasks and responsibilities, resulting in partners needing to balance multiple roles, which can especially be challenging when they also have to care for children. Sometimes partners need to adjust work hours or even stop working due to their caregiver role. This can result in financial issues generated by a loss of income or savings. Finally, due to their caregiving tasks, partners generally have less time for social activities and social contacts which can result in feelings of isolation [2].

Although a large number of the partners have indicated that they basically experience negative effects of their patient's cancer, other partners have indicated that they have experienced positive changes [2, 8]. Such positive development is often referred to as posttraumatic growth (PTG). PTG refers to a spectrum of positive changes people can experience as a result of a struggle with a trauma (such as a cancer diagnosis) [9]. According to Tedeschi and Calhoun [9] people can experience PTG in five domains: relating to others, new possibilities, personal strength, spiritual change and appreciation of life. In one of our studies, we found that partners of cancer patients especially experience PTG in the following domains: *relating to others*, *personal strength* and *appreciation of life* [10, 11] Partners of cancer patients may feel more related to others, meaning that they are more aware of the relationships they have, see that they can count on others in times of trouble, and exert more effort into their relationships. They may also feel personally stronger and more spiritually connected to something greater than themselves. Moreover, they may have changed their priorities about what is important in life or have more appreciation for what exists in their everyday lives [9]. In addition, partners may see new possibilities. For instance, they feel that they need to establish a new path for their life or they develop new interests.

Existing psychological interventions for partners of cancer patients

As aforementioned, caregivers play an important role in the current health care system. Adequate support for them is not only vital for the caregivers, but also for the patients. Fortunately, there is increasing attention to the demanding situation that caregivers must face. In recent years, a number of interventions for cancer caregivers have been developed. These interventions differ widely with regard to their scope, aim, format and content. A meta-analysis by Northouse et al. [12] analyzed the types of interventions offered to family caregivers of cancer patients. They identified 29 randomized controlled trials in which an intervention for family caregivers was described and tested. According to Northouse et al. [12], the existing interventions can be divided into three types: psychoeducation, skills training and therapeutic counseling. More than half of the interventions fell into the first category. Psychoeducation often focuses on providing information on symptom management and physical and emotional patient care. About 26% of the interventions were skills training, which was primarily focused on developing coping, communication, and problem-solving skills. A small number of the interventions (17%) were therapeutic counseling. The focus of these interventions primarily concentrated on the development of a therapeutic relationship to address worries related to cancer or caregiving (e.g., discussing caregiver’s fears and feelings or identifying patient’s and caregiver’s thoughts and feelings).

Not only the content, but also the duration of the 29 interventions varied widely. The total number of hours ranged from 1.7 to 18 hours; the total number of sessions/contacts varied between 2 to 16 sessions/contacts; and the duration of the interventions varied between 1.2 to 56 weeks from start to finish of the intervention. Regarding the format, Northouse et al. [12] found that most of interventions were offered to the patients and partners together, and the interventions are usually delivered as face-to-face visits in a clinical setting, mostly by nurses (52%). The content of the interventions primarily focused on how caregivers can care for the patient, how they can maintain family and marital relationships, and how they can care for themselves. In most interventions, patient care received the most prominent attention and caregiver care was just a secondary aim.

More recently, Applebaum and Breitbart [13] also conducted a systematic review of interventions for cancer caregivers. They found 49 interventions, which they classified into eight major categories: psychoeducation, problem-solving/skills building interventions, supportive therapy, family/couples therapy, cognitive behavioral therapy, interpersonal therapy, complementary and alternative medicine interventions, and existential therapy. Corresponding with Northouse et al. [12] results, Applebaum and Breitbart [13] found that the existing interventions varied widely with regard to content and duration, and that the interventions were mostly (73%) delivered face-to-face with both the patient and the informal caregiver together.

The meta-analyses from Northouse et al. [12] along with the systematic reviews of Applebaum and Breitbart [13] and Ussher et al. [14] have shown that traditional interventions, as described above, can have significant positive effects on multiple outcomes. Caregivers who participated in an intervention reported less caregiver burden, less psychological distress, greater caregiving benefits, higher levels of self-efficacy, better physical functioning, better relational functioning or fewer informational needs. However, despite such promising results, these traditional interventions often bear several limitations. First, as aforementioned, they mostly target the couple, instead the partner alone and, as a consequence, they mainly focus on the care of the patient rather than on the specific needs of the partner [12, 14]. Second, partners hardly use the existing interventions [12-14], which could be a result of poor diffusion and recruitment strategies. For example, caregivers who might benefit the most from an intervention may be excluded from participation through the way they are recruited. It has been suggested that that patients, organizations and health professionals function as “gatekeepers” which means that they – and not the caregivers themselves – decide whether a caregiver should be contacted for participation or not [15]. Other reasons for not using the interventions could be: (1) Partners are not aware of their own health complaints or they deliberately neglect these complaints because the patient’s health is more important to them than their own health [16]. (2) Partners feel guilty or ashamed to ask for help [17]. (3) Interventions do not match their personal needs [14]. (4) The traditional interventions may be too time consuming for them to participate [18]. As previously mentioned, most of the interventions are delivered in person in a clinical setting, and, therefore, partners’ attendance may require the partner to take time off from his or her daily activities. Also it maybe be difficult to arrange meetings in advance for the patient, given their illness and its lack of predictability? Another limitation is that interventions are often not evidence- and/or theory-based, which are highly necessary to ensure the delivery of high-quality support to partners [14].

Approaches from positive psychology

As is clearly illustrated in Cynthia's story, partners of cancer patients are often confronted with negative emotions (such as fear, anxiety and distress) and "what-if" scenarios (such as: "What if the cancer spreads?" or "What if the treatment doesn't help?"). Many partners also forget or neglect their own needs for numerous reasons, such as: the patient's needs are of utmost importance to them, they feel responsible for the patient's recovery, and they would do anything to improve the patient's wellbeing, regardless of cost [19, 20]. For instance, partners might not engage in social and other leisure activities, because they have no time left, or they even feel guilty about doing pleasurable activities while their partner is suffering [2, 21]. Despite this natural human tendency, partners actually might benefit from rediscovering and reorganizing personal values and future perspectives. Approaches from positive psychology that align with these challenges and needs are Acceptance and Commitment Therapy (ACT) and self-compassion.

Acceptance and commitment therapy

ACT [22] is a form of contextual behavior therapy that aims to modify a person's relationship with negative thoughts and feelings rather than the content of such thoughts and feelings. ACT attempts to show people that avoidance and suppression of painful thoughts is counterproductive as this behavior only increases the frequency and importance of such thoughts and feelings leading to psychological distress, which can underpin psychopathology. The goal of ACT is not to remove or "fix" the negative experiences, but to help people to realize what they value in order to live a meaningful life. The six-core therapeutic processes of ACT are: acceptance, being present, cognitive defusion, values, committed action, and self as context. *Acceptance* is the willingness to experience difficult thoughts, feelings, urges and sensations and to make mental and emotional room for them. This process is about helping people to stop struggling with these experiences and instead allow these experiences to simply be as they are. *Being present* refers to a state of mindful awareness of the here and now. *Cognitive defusion* means to disentangle oneself from unwanted thoughts, images and memories. This process tries to show people that the mind continually produces thoughts and that are not necessarily a reflection of reality. *Values* are about all the things in life that really matter. In ACT, they are also often described as "chosen life directions." An awareness of such values is necessary to live a meaningful life. *Committed action* aims to encourage people to do what it takes to live in accordance with their personal values, despite the presence of obstacles (e.g., depressive symptoms). *Self as context*, also referred to as the *observing self*, is the part of us that is able to merely observe; a state in which we are purely aware of everything around, e.g., every thought, feeling, sound, touch, smell and action [23]. These six processes are interconnected, and together they form the *psychological flexibility* of a person. Harris defines *psychological flexibility* as “the ability to be in the present moment with full awareness and openness to [one’s] experience, and to take action guided by [one’s] values” ([24], p.12). ACT has been applied to a variety of conditions such as chronic pain [25], depression and anxiety [26], and psychosis [27]. ACT has also shown positive outcomes for cancer patients [28, 29].

Relevance of ACT for partners of cancer patients

To the best of our knowledge, ACT has not been applied to partners of cancer patients. However, we do strongly feel that ACT can help partners in several ways: (1) Partners can learn how to accept, as opposed to avoid, negative thoughts and feelings. (2) They can learn how to distance themselves from and release unhelpful thoughts, feelings and sensations. (3) ACT can show them how to engage more fully in the present moment. (4) ACT can help partners to be more aware of their personal values in life and their relationship and show them how to live in accordance to those values, notwithstanding the cancer.

Self-compassion

Self-compassion refers to the tendency to be kind and caring towards ourselves when we consider our personal inadequacies, failures, mistakes, or when we are confronted with painful life events that are outside of our control. Neff [30] has operationalized this concept as consisting of three interacting components: self-kindness versus self-judgement, common humanity versus isolation, and mindfulness versus over identification. *Self-kindness* refers to the tendency of being supportive of and caring towards oneself rather than being harshly critical and judgmental. The second component, *common humanity*, is about realizing that difficulties are a part of our lives, that all humans are imperfect, and everyone makes mistakes and engages in dysfunctional behavior. This realization can help us to feel less lonely and isolated when we are feeling sad and struggling with some challenge. The third component, *mindfulness*, refers to the ability of being aware of the here and now. Experiences are noticed in a clear and balanced way, and people try to keep things in perspective when they fail at something that they perceive as important. This is in contrast to over identifying with our failures and/or ruminating or fixating on aspects in our lives that went wrong. A growing body of literature suggests that higher levels of self-compassion are associated with lower levels of anxiety and depression [31]. Self-compassion is also linked to positive psychological outcomes, including happiness, life satisfaction, and optimism [32, 33]. Self-compassion also seems to be a powerful source of coping and resilience in difficult times [34].

Relevance of self-compassion for partners of cancer patients

Remarkably, self-compassion has not been applied to partners of cancer patients. Self-compassion exercises can help partners to extend their caring attention also to themselves. By developing self-compassion, partners can learn that it is also important to be kind and caring towards themselves rather than exclusively offering compassion to their ill partner. Self-compassion exercises can also help partners to cope with feelings of isolation and failure, and may help them to view painful thoughts and feelings with clarity and balance, instead of ruminating and obsessively fixating on them [30].

Relationship between ACT and self-compassion

There is a growing interest in the relationship between ACT and self-compassion. Researchers agree that these two are not two entirely different approaches, but interconnected [35] and that conceptualizations of self-compassion fit well with the ACT model [36]. Hayes stated that (self-)compassion might be the only value that is inherent to the hexaflex model of ACT (Hayes in [37]). Elements of the ACT model are related to the experience of self-compassion, and the processes of ACT are also essential to the roots of self-compassion (Hayes in [37]). Yadavaia, Hayes and Vilardaga [36] describe the parallels between the concepts of self-compassion and ACT. For instance, it seems that the concept of self-kindness, which was defined by Neff [30], is linked to self-acceptance. When people are able to accept difficult experiences, then they are able to be in a profound experience of self-kindness. In addition, mindfulness plays an essential role in ACT as well as in Neff's model of self-compassion. In ACT, mindfulness consists of defusion, acceptance, contact with the present moment and the self as context [38]. Defusion is of particular interest for self-compassion because it can help people to cope with self-criticism. Instead of over identifying with critical thoughts, they allow these thoughts to come and go, without judging them as positive or negative. Tirch, Schoendorff and Silberstein [35] give the following description of the concepts self-compassion, mindfulness and psychological flexibility:

> "Both psychological flexibility and Kirsten Neff's (2003a) conceptualization of self-compassion are multidimensional constructs that involve mindfulness, the experience of an expansive sense of self, and a commitment to serve specific valued aims. In the case of self-compassion, the alleviation of one's own suffering is an explicit aim, and in the case of psychological flexibility, a broader value of alleviating suffering and promoting life-affirming action is inherent" (p.33).

To optimally support partners of cancer patients, we decided to develop an intervention that would be based on a clear theoretical framework. Because we strongly feel that the processes of ACT and self-compassion can be beneficial to partners of cancer patients, we chose these two approaches as the framework for our intervention.

Web-based interventions

In addition to the lack of theory-based interventions, partners also hardly use existing interventions for many reasons, for example, because demanding caregiving tasks leave them little free time. The Internet may be a solution to this problem. Web-based psychological interventions are increasingly being used in the health care system. They have been tested on various groups and seem to be as effective as traditional face-to-face therapies [39]. Web-based interventions have the potential to offer easily accessible, flexible, and cost-effective support [40]. These features may especially be interesting to partners of cancer patients because such interventions may help partners overcome the lack of personal time, financial issues, and reluctance to seek help. In addition, with Web-based interventions, it is possible to match the intervention to an individual partner's needs.

Although the Internet has a great potential to deliver psychological interventions, Web-based interventions for partners of cancer patients remain scarce [41, 42]. Two systematic reviews of Web-based interventions for caregivers of patients were recently published [41, 42]. Together these two reviews found nine studies that were focused on Web-based interventions for cancer caregivers. Three studies examined the effects of Web-based interventions for caregivers of pediatric cancer patients [43-45], the remaining six studies focused on cancer caregivers of adult patients. Of this adult group, three studies focused on the caregivers alone [46-48] and three studies focused on patient/caregiver dyads [49-51]. Regarding the format of the interventions, the researchers found that two interventions were online support groups [43, 44], two were informative websites [48, 51] and the rest was a combination of both online support groups and informative websites [45-47, 49, 50]. Theoretical backgrounds of the interventions were the Transaction Model of Stress and Coping [46], the Flaskerud and Winslow's vulnerable population model [43], the Calgary Family Intervention Model [45], cognitive behavioral therapy [48], and the stress coping framework [51].

Although the quality of the studies varied widely, both systematic reviews [41, 42] came to the conclusion that Web-based interventions can be beneficial in providing information and support and can have a positive influence on the social and psychological outcomes of the caregivers; an analysis that corresponds with the findings of Northouse et al. [52]. Effect sizes of the Web-based interventions for caregivers were comparable with those of traditional interventions for cancer caregivers (e.g., [12]). Despite the advantages of these interventions and such promising results, Web-based interventions for partners (or other caregivers) of cancer patients remain scarce, and more research into the (cost-) effectiveness, the most efficient dosage, and the implementation of these Web-based interventions is needed. Therefore, we decided to develop a Web-based intervention for partners of cancer patients based on the theoretical frameworks of ACT and self-compassion.

Co-creating a web-based intervention

As previously mentioned, Web-based interventions have a great potential to be implemented in the health care system. Yet, despite their possibilities and advantages, there is still room for improvement. Problems of Web-based interventions that often occur are usability problems [53-55] or high attrition rates [56-59]. A possible explanation for these problems is that interventions do not fit the needs and wishes of the (end) users. End users are not, or only nominally, involved in the development process of e-health interventions [60], which are more often developed from the top down. In addition, developers are often more interested in the innovation of new information technologies and, as such, often fail to examine the utility of such novel tools [61] nor how well the technology applies to the use context [60]. To overcome these problems and guarantee the acceptance and use of Web-based interventions, researchers are beginning to acknowledge the importance of actively involving users in the development process [62]. Co-creation is one example of a suitable method to involve the users, combining top-down and bottom-up approaches [63]. Professionals and experts collaborate with (end) users, and together they develop an intervention. The collaboration actually begins with defining the actual health problem, lasts during the development phase, and extends through the intervention's implementation and evaluation [60].

The aim and outline of this thesis

The aim of this thesis is to develop and evaluate a Web-based self-help intervention based on approaches from positive psychology (ACT and self-compassion) for partners of cancer patients. The research questions addressed in this thesis are:

1. Is a Web-based intervention a useful and effective alternative for partners of cancer patients?
2. Are the processes of ACT and self-compassion applicable and beneficial for this target group?
3. Is co-creation useful in the development of a Web-based intervention for partners of cancer patients? And what are our recommendations for future intervention developers?

The first two chapters of this thesis outline two studies that were conducted to explore the needs and wishes of partners of cancer patients regarding the content and design of a Web-based self-help intervention. In the study described in Chapter 2, partners of cancer patients were interviewed in order to examine partners' interest in a Web-based psychological intervention and to identify their needs and wishes regarding such an intervention.

Subsequently, as described in Chapter 3, we conducted a quantitative survey study to see if we could validate the results of the qualitative study. Similar to in the interview study, the aim of this quantitative study was to investigate the partners' needs and preferences regarding a Web-based intervention and their intention of using it. In addition, this study provided answers to whether specific variables, related to the partners' personal characteristics and psychological functioning and the patients' cancer-related characteristics, were associated with the partners' intention of use. The findings of Chapters 2 and 3 also provided input for the design and content of our intervention.

Chapter 4 describes the development of the intervention *Hold on, for each other* and presents the design of the randomized controlled trial to test the intervention's (cost-) effectiveness. In **Chapter 5**, we describe our examination of the role of self-compassion in the understanding of psychological distress and mental wellbeing of partners of cancer patients. This study focused on to what extent self-compassion is associated with psychological distress and positive mental wellbeing in this specific group. In addition, we examined whether self-compassion can add to the understanding of levels of distress and wellbeing after controlling for other psychological resources (i.e., psychological flexibility, mastery and resilience). To provide the reader of this thesis an idea of the intervention's appearance, we presented all the components of the intervention as an **intermezzo**.

Then we returned to our research in **Chapter 6** with a presentation of a qualitative evaluation study about what partners appreciated about *Hold on, for each other,* what they learned from the intervention, and if these learning effects were related to the underlying theories ACT and self-compassion. **Chapter 7** focuses on the quantitative evaluation of the intervention *Hold on, for each other* and describes results of the randomized controlled trial (RCT) in which the effects on psychological distress were examined. Finally, **Chapter 8** contains a summary of the main findings per chapter, a discussion of how the results in the presented studies align with the three research questions, and recommendations for future research.

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2

Needs and preferences of partners of cancer patients regarding a web-based psychological intervention: a qualitative study

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ABSTRACT

Background: Evidence-based, easily accessible, supportive interventions for partners of cancer patients are limited, despite the fact that they often suffer from diminished emotional, social, physical, and relational functioning. To develop a new intervention that will fit their demands, it is important to consult potential users.

Objective: To examine partners' interest in a Web-based psychological intervention and to identify their needs and wishes regarding such an intervention.

Methods: Semistructured interviews were conducted with 16 partners of cancer patients, who varied in terms of age, gender, education, employment, type, and stage of disease. Partners were asked (1) whether they would use a psychological Web-based intervention and which preconditions (maximum time, structure, participate alone or with their partner) it should meet; (2) which functionalities (information, peer support, online psychological counseling) the intervention should contain; and (3) which topics (e.g., taking care of oneself) should be addressed. Data were coded by 2 coders independently.

Results: The need for a Web-based intervention varied. Arguments for being interested in a Web-based intervention included the need for acknowledgement; the need for someone they could talk to; and the need for information, tips, and support. Based on their experiences as a partner of a cancer patient, participants would prefer an intervention that is not too time-consuming (about 1-2 hours a week) and which is based on a "step-by-step" approach, meaning that the content of the intervention should match the stage of their partner's disease. Also, they would prefer a positive approach, which means that the intervention should be a source of hope and energy. Most participants stated that they would prefer to participate without their ill spouse, because they do not want to burden their partners with their own problems. An intervention should contain information and optional peer support. Participants' opinions about online psychological counseling in the intervention were divided. Arguments for online psychological counseling were that a professional could check on them and they were able to ask questions. Arguments against online counseling were that partners were not in need for guidance or they had enough support from usual care. Topics with the highest priority were "coping with feelings and emotions," "should I or shouldn't I spare my partner?," "communicating with each other," "asking for help and refusing help," and "moving on with life after cancer treatment." Furthermore, participants suggested additional topics of "dare to enjoy" and "acceptance of the patient's disease."

Conclusions: A Web-based intervention can be a valuable addition to existing support initiatives for partners of cancer patients. This study provides important information about the content and form of such an intervention. Flexibility and a positive approach seem to be the most important features.

KEYWORDS

Cancer; oncology; partner; needs; web-based interventions; interventions

INTRODUCTION

Partners of cancer patients

Cancer not only affects the patients' lives, but also the lives of their loved ones. Partners of cancer patients may suffer from diminished emotional, social, physical, and relational functioning [1-11]. The couples' relationship often changes because of shifting roles and responsibilities [3,4], feelings of inequality [5,12], reduced social activities, less financial resources [6,7], and a decrease of sexuality and intimacy [8]. Problems often occur when patients and partners avoid talking about the disease, their feelings, and changes in their relationship [9]. Recent studies have shown that clinical levels of psychological distress are highly prevalent in partners of cancer patients (especially in female partners) and can even be higher than the levels experienced by patients themselves [1,2,13]. Cancer can directly and indirectly affect the physical wellbeing of partners [6], because many partners have barely time to relax and they often neglect their own health [9].

Despite the known multiple and serious effects of cancer on partners' lives, the availability of evidence-based, easily accessible, supportive interventions for partners of cancer patients is still limited. The interventions that do exist vary widely in their scope, aims, target groups, intensity, used methods, and theoretical frameworks [9,14,10]. Northouse et al [9] classified the interventions into 3 major types: psychoeducation, skills training, and therapeutic counseling. The majority of the interventions belong to the first type, and these primarily strive to provide information about the optimal patient care. Skills training tries to improve skills regarding coping with the situation, communication, and problem solving. Therapeutic counseling, finally, aims to address concerns regarding cancer or caregiving. The interventions also vary widely in terms of how demanding they are: most interventions are delivered as face-to-face visits, with the majority provided in a clinical setting, they take between 1.7-18 hours; they comprise between 2-16 sessions; and they last for 1.2-56 weeks from first to last session [9]. Most existing interventions are developed for couples (both partners and cancer patients) and since usually no differentiation is made between their needs, the focus is inevitably often on the patients' care and wellbeing. Only a few interventions have primarily addressed partners' wellbeing [9,14]. Furthermore, partners of cancer patients often make no or only limited use of existing interventions [14]. Many of the interventions described in the meta-analysis of Northouse et al [9] and reviews of Ussher et al [14] and Applebaum and Breitbart [10] report difficulties with inclusion or high dropout rates. Reported reasons for low participation are, for example, that partners are often not aware of their own health complaints and that they therefore do not feel in need of support [15]. Participation is also connected to the demands of the illness, when the demands are high (e.g., intensive treatment), existing interventions seem to ask too much from the partners and they will not participate [16]. Other identified barriers to make use of the offered resources are being unaware of existing sources, being reluctant to ask for help or to talk about sensitive topics, and being afraid that their own requests may affect the care of the patient [17]. Another possible explanation may be that the existing interventions do not fit to the specific needs of partners of cancer patients [14]. Ussher et al [14] recommend prior needs assessments before development.

Another recommendation was to examine the potential for using the Internet to deliver interventions to the caregivers of cancer patients [9,10]. The Internet offers new opportunities to deliver easily accessible and (cost-) effective supportive interventions. Possible advantages of Web-based interventions include a low threshold, flexibility, and possibilities to follow the intervention at any time that suits the client [18]. These features might be especially important for partners of cancer patients since they have less time for their own mental and physical health. The Internet also bears the possibility to tailor information and feedback to the individual needs of a client. This may be beneficial to partners of cancer patients because they are only confronted with information that is relevant to them [19]. Despite these benefits, the availability of Web-based interventions for partners of cancer patients is also still limited [20]. To the best of our knowledge, no studies exist that have examined the views and opinions of partners regarding a Web-based intervention.

Aim of the study

Accordingly, the aim of this study was to examine partners' interest in a Web-based psychological intervention and to identify their wishes, desires, and needs regarding such an intervention. This study focused on the following questions: (1) "Is there a need for a Web-based intervention and which preconditions (maximum time, structure, participate alone or with their partner) should it meet?"; (2) "Which functionalities (information, peer support, psychological guidance) should the intervention contain?"; and (3) "Which topics (e.g., taking care of oneself) should be addressed?"

METHOD

Study design and ethical approval

A qualitative research design was chosen to gain insights into the wishes, desires, and needs of partners of cancer patients regarding a Web-based psychological intervention. Semistructured interviews were conducted. The Ethics Committee of the University of Twente (Behavioural, Management, and Social Sciences) provided ethical approval for this interview study and the study was conducted according to the declaration of Helsinki.

Participants and procedures

Partners of cancer patients were recruited in a large hospital in the region of Twente, an area in the east of the Netherlands. A nurse practitioner informed partners of cancer patients of the ongoing study and she handed out information leaflets. In case partners were interested in participating, they had to fill out a reply card with their name and telephone number on it, and return it to the nurse practitioner. Subsequently, the nurse practitioner contacted the researchers so that they could get in touch with the partner. Additionally, partners were recruited through convenience sampling. Partners were people from the network of the researchers and they were called and asked if they wanted to participate in this study. In case they were interested, they received an information leaflet by mail or email and after reading the information they could decide if they still wanted to participate. Once the participants had given their informed consent, they were interviewed. The interviews took place at the participants' homes. There were 2 researchers (NK and SO) that conducted 16 interviews together. Both researchers are psychologists and were trained in conducting interviews. Initially, the researchers proposed to interview the partner alone, without their ill spouse. However, during 3 interviews the (patient) partner was also present, because the partner explicitly wanted the patient to be there. After the 16 interviews data saturation was reached, meaning that no more new information was found [21]. All interviews were audio-recorded—with the prior permission of the participants—and the audiotapes were transcribed verbatim.

Interview scheme and mock-ups

All interviews started by asking participants to introduce themselves and to give a short overview of their partner's disease and how this had affected them personally. After that, partners were asked about their ideas and opinions about a Web-based psychological intervention. As many participants had difficulties conceptualizing the idea of a Web-based intervention, 2 mock-ups of a possible Web-based intervention for partners of cancer patients were shown to the respondents. These mock-ups were based on an existing Web-based intervention called "Living to the full" (Figures 1 and 2 show this) [22-24]. Participants were encouraged to elaborate on their motives for (not) wanting a Web-based intervention. With an open-ended question, we asked the participants which functionalities a Web-based intervention should contain. We continued by asking their opinion about the preselected functionalities: information, peer support, and online psychological counseling. Regarding the preconditions of the intervention, we invited participants to reflect on the following issues: maximum time, structure, and participate alone or with ill partner. Participants were encouraged to motivate their answers and to add other functionalities or preconditions. Finally, we asked partners which topics should be addressed in a Web-based intervention. First, an open question was posed. In addition, the researchers had prepared 9 cards with words of potential topics. These topics were based on literature and suggestions of 5 experts in the field who we have consulted beforehand. The topics were: (1) coping with feelings and emotions; (2) taking care of oneself; (3) sparing your partner or not?; (4) communicating with each other; (5) sexuality and intimacy; (6) asking for help and refusing help; (7) moving on with life after cancer treatment; (8) living with cancer; and (9) if the end is near. Participants were asked to pick those cards which were possibly relevant to them and which should be targeted in a Web-based intervention. Participants were asked to motivate their choice. Also, they were encouraged to add more topics with an extra "empty" card. At the end of the interview, participants completed a short questionnaire about socio-demographics (such as gender, age, education, employment). The interviews took between 40 minutes and 2 hours, with an average duration of 65 minutes.

"Kanker heb je samen", is een bekende uitspraak. Uiteraard gaat er veel zorg en aandacht van u maar ook van familie, vrienden, professionele hulpverleners en dokters naar de patiënt. Maar ook voor partners is het een moeilijke periode, waarin veel verandert en partners te maken krijgen met vragen als: Hoe begeleid ik mijn partner het beste en hoe houd ik het zelf vol? Wat betekent dit voor onze relatie?

De Universiteit Twente en VU medisch centrum hebben, met financiële steun van KWF Kankerbestrijding en Stichting Alpe d'HuZes de cursus 'Houvast, voor elkaar' ontwikkeld, voor partners van mensen die kanker hebben (overleefd).

Figure 1. Mock-up of a possible Web-based intervention

Les 1: Omgaan met je eigen gevoelens
Les 2: Hoe zorg je dat je het volhoudt
Les 3: Mijn verstand maakt overuren
Les 4: Wat is nu echt belangrijk?
Les 5: Momenten om van te genieten
Les 6: De kunst van het in gesprek blijven

Aanvullende lessen:
Les 7: Het leven weer oppakken
Les 8: Een goede laatste periode

Je hebt nog geen berichten in het dagboek geschreven...

Figure 2. Mock-up of a personal home page (after participants have logged in).

Data analysis

There were 2 coders (NK and SO) that independently coded all transcripts. First, the coders read and reread all transcripts to familiarize themselves with the content. Then, relevant fragments were selected and coded into one of the 4 main themes: (1) need for Web-based intervention; (2) preconditions; (3) functionalities; and (4) topics. Subsequently, all fragments were further categorized into subthemes using inductive analysis. Inductive analysis means that the subthemes derive from the data, instead of from predefined categories. After every 5 transcripts, the coders met to discuss their categories. When coders disagreed about the categorization, discussion took place until consensus was reached. The final categories were defined on the basis of consensus between the 2 researchers.

RESULTS

Participants

The characteristics of the 16 participants and their ill partners are listed in Tables 1 and 2. Participants were heterogeneous regarding gender, age, education, and employment. The partners of the participants were diagnosed with a variety of cancers, they varied in prognosis, and most of them were not under treatment (2 under surveillance, 6 in recovery) when the interviews took place. There were 3 of the participants that were widow/widower and used recollection to answer our questions.

Table 1. Characteristics of the participants (N=16).

Characteristics	N	%
Gender		
Male	10	62.5
Female	6	37.5
Age		
Mean (SD)	51.7 (12.8)	
Range in years	30-68	
Religious		
No	2	12.5
Yes	13	81.3
Unknown	1	6.3
Children		
No	2	12.5
Yes	14	87.5
Education		
Low	7	43.8
Medium	4	25
High	5	31.3
Employment		
Full- or part-time work	10	62.5
Retired	3	18.8
Disabled	0	0
Other	3	18.8

Table 2. Characteristics of the ill partners (the patients) (N=16).

Characteristics	n	%
Age		
Mean (SD)	52.5 (13.5)	
Range in years	32-71	
Type of cancer		
Lung cancer	1	6
Acute lymphatic leukaemia	1	6
Hodgkin's lymphoma	1	6
Prostate cancer	1	6
Ovarian cancer	1	6
Testicular cancer	1	6
Breast cancer	2	13
Kahler's disease	1	6
Cervical cancer	1	6
Brain tumor	2	13
Skin cancer	2	13
Non-Hodgkin's lymphoma	1	6
Oesophagus cancer	1	6
Undergoing treatment		
Yes	5	31.3
No	11	50.0
Deceased	3	18.8
Prognosis (self-reported)		
Good	6	46.2
Poor	4	30.8
Uncertain	3	23.1

Need for a web-based psychological intervention

There were 2 of the participants that gave no answer to the question if they were in need for some kind of a Web-based intervention. One of them had no Internet access at home and the other did not use the Internet. They also had difficulties in imagining what a Web-based intervention would look like, even after being given a short explanation of a possible intervention and after being shown the mock-ups. We decided nevertheless to continue the interview with these partners, because we thought these might still give us valuable information about, for example, which topics should be addressed in a Web-based intervention for partners of cancer patients.

Among the remaining participants (n=14), the need for a Web-based intervention varied. There were 6 of them that explained that they would like some kind of Web-based intervention, 4 had ambivalent feelings toward such an intervention, and 4 partners were not interested. Participants' arguments for being interested in a Web-based intervention could be divided into 3 categories: (1) the need for acknowledgment; (2) the need for someone you can talk to; and (3) the need for information, tips, and support regarding their specific needs as a partner of a cancer patient, as illustrated in the following citations,

> *I really missed something offered to me as a partner of a cancer patient.* [Female, 63, partner had Oesophagus cancer]

> *Sometimes you need to tell your story. But my friends were all in a different situation, they just became parents or they were pregnant. A totally different life situation. Therefore, they had problems talking to me. And for my part, I didn't want to be a burden to them either.* [Female, 30, partner had skin cancer]

> *I was looking for acknowledgment. Acknowledgment for all the emotions that you experience as a partner of a cancer patient. Fear, anger, helplessness [...]* [Female, 51, partner died of acute lymphatic leukemia]

Participants who had ambivalent feelings toward a Web-based intervention mentioned various arguments. One of them said that she was not sure whether she had the need for an intervention targeting the partner or not. This need actually changed from moment to moment. However, she was sure that she would prefer face-to-face contact instead of Web-based support. Also, for her it felt wrong to spend some personal time while her partner was ill and she mentioned that she was afraid of losing valuable time with him.

> *Time was too valuable to participate in a Web-based intervention because we already knew that he wouldn't get better anymore.* [Female, 55, partner died of lung cancer]

Another participant said that it was difficult for him to give an answer to this question because—at the time his wife was ill—he was not aware of the fact that he actually needed support. His mere focus lied on his wife's health and her needs and he wanted to be the "hero" for her. His own (health) problems were not important to him at all. He said that the choice to make use of such an intervention would depend on the way this intervention would have been offered to him, see the following quote,

> *It is difficult to give an answer to this question, because I think it depends on how such an intervention was offered to me. If it was something like a therapy or help program...? Well look, as partner of a cancer patient you don't know that you are actually in need for help or, rather, you are convinced that you are not in need for help [...] in my opinion, I tried to be the hero. And it doesn't fit in the role of a hero to participate in a help program [...] I think "support" is a more appropriate word to use [...] I would have been interested in something that aims to improve my skills as caregiver.* [Male, 43, partner died of ovarian cancer]

Another participant welcomed the idea of a Web-based intervention for partners of cancer patients, because he was convinced that a lot of partners are in need of such an intervention. However, he was not sure if he also shared that need. In his opinion, he and his wife managed the situation well (they indicated that they had a down to earth approach to cope with the disease), but they were not sure if this way of coping was the most appropriate and effective way. He guessed that he probably would take a look at what such an intervention could offer him. In particular, he would be interested in acknowledgment.

> *But sometimes I am wondering, in the beginning people sometimes said to us "that you can be so down to earth in coping with it (the disease)". Then you can ask yourself "who is the crazy one?". Maybe our approach is not the right one at all.* [Male, 30, partner had non-Hodgkin's lymphoma]

A participant explained that she would only be interested in an intervention that targets effective ways of coping with the disease instead of talking about the situation and problems again and again.

> *If you are there [at a meeting with a psychologist], I've heard that you have to talk about your problems every time [...] You always have to tell the same old story and I think it is important to look forward. It is not necessary to look back at what has happened in the past [...] How can you cope with it? How can you process it without constantly talking about the problem again?* [Female, 68, partner had skin cancer]

There were 4 participants that explained that they were not interested in a Web-based intervention, because they simply were not in need for support. There was a participant, for example, that explained that she is engaged in a variety of social activities (e.g., choir, yoga class) and that the situation is not affecting her in a way that she would need help. Furthermore, she trusts the medical staff of her husband and accordingly she never used the Internet for looking up information about her husband's disease. Other arguments mentioned were that participants think that they were not "the type" to participate in such an intervention, or that they want to spend all their time with their spouse instead of participating in any kind of support. Yet, 2 of the 4 participants were convinced that other partners would be interested in an intervention that targets their specific situation as a partner of a cancer patient. All the arguments regarding the need for a Web-based psychological intervention are listed in Table 3.

Table 3. Arguments regarding the need for a web-based psychological intervention

Variable	Arguments pro	Arguments con
Need for web-based intervention	Need for acknowledgement	Experiencing no problems or not being aware of any problems
	Need for someone you can talk to	Having sufficient support from social network or own coping-strategy seems fine
	Need for information, tips, and support	Not wanting to lose valuable time with ill partner or feeling that it is wrong to spend personal time while partner is ill
		Being afraid of too much negativity through rehashing the problem; intervention seems not appealing

Preconditions of a web-based intervention

There were 4 participants that gave no answer to these questions, because they had no computer at home (n=1), they had no experiences using the Internet (n=1), or they were not able to give an indication (n=2). The majority of the remaining participants (n=10) reported that the intervention should not be too time-consuming. It appeared that partners who are more certain about their need for a Web-based intervention would be willing to spend more time on it. There were 8 participants that mentioned that they could spend about 1-2 hours a week in an intervention,

> *I think that it is really important, so one and a half hours is not too much. This doesn't mean that you have to spend the time without a break.* [Female 58, partner has brain tumor]

There were 2 participants that indicated that they were willing to spend about 3.5 hours a week in such an intervention.

Regarding the structure of the intervention, 3 participants explicitly mentioned that they would prefer a "step-by-step" approach, which means that the content of the intervention should match the stage of their partner's disease. For example, participants did not want to receive information about the terminal phase if their partner had just been given a diagnosis of cancer, as is illustrated by the following quote,

> *Try to look at it step-by-step. This is a tip I received from my brother. Try not to think too far ahead and try to avoid the thought "what if...?" and all the bad scenarios. Be aware of the things that are really important at this moment.* [Male, 43, partner died of ovarian cancer]

Also, participants mentioned that the intervention should have a positive approach. According to them, thinking positively and accentuating what still can be done, instead of what no longer can be done, is a source of hope and energy for both the partner and the cancer patient,

> *[...] as long it is a little bit positive. I'm not interested in the negative things. Because they only result in a depressed mood.* [Female, 68, partner had skin cancer]

There were 8 of the participants that preferred to participate in the intervention without their ill spouse. One of the reasons for this preference is that their ill spouse is not in need for help. Another reason is that they did not want to burden their partners with their own problems, and that they could express their feelings and emotions more freely if they participated in the intervention alone.

> *I would prefer to participate in the intervention on my own. I think this is of added value. I would have the chance to tell my story and show my emotions freely without anyone knowing.* [Male, 30, partner had non-Hodgkin's lymphoma]

Furthermore, one partner argued that partners' and patients' needs are different and that it is therefore difficult to combine both in one intervention,

> *No, for my partner it is different. He really has a different point of view, because he is the patient. And he is focused on himself, and as a partner you have to focus not only on yourself but also on your partner. And you have to manage in daily life. I think that these are two different things.* [Female, 63, partner had Oesophagus cancer]

There were 3 of the participants that felt that it would be important to participate in the intervention together with the ill spouse. They explained that the disease affects the lives of both partners and that it is essential to cope with the situation as a couple.

> *I think you should do this together, because you are in this situation together.* [Female, 58, partner has a brain tumor]

There were 4 interviewees that suggested that participants should be able to choose whether they want to participate alone or together with their partner, for example,

> *I think you should be free in this choice. I have the need to participate in such an intervention, but my partner doesn't. In this case it is not necessary to participate together.* [Female, 30, partner had skin cancer]

Desired functionalities of a web-based intervention

Information

The majority of the participants (n=14) were interested in information (see Table 4). Relevant medical information should come from a reliable source, should be presented in a clear and intelligible way, and it should match their partner's stage of disease. According to 7 participants, it would be sufficient to include links to other reliable websites (e.g., the website of the Dutch Cancer Society). There were 7 participants that doubted if medical information would be actually necessary, because they already received a lot of medical information in the hospital, or because they feared that the presented information would be too general. Alongside the medical information, participants also expressed a need for information and practical tips about what it means to be partner of a cancer patient (this is further described in the section "Important Topics to Be Addressed by the Intervention" and Table 5).

Table 4. Arguments and preferences regarding the various functionalities of a Web-based psychological intervention.

Variable		Arguments pro	Arguments con	Preferences
Functionalities				
	Information	Being informed about all aspects of disease	Information overload	Medical and practical information is preferred
		Being informed about what it means to be a partner of a cancer patient	Information usually too general	From reliable source
		Practical tips can be helpful		Be clear and intelligible
				Match partner's stage of disease
				Links to relevant websites are sufficient
	Peer support	Acknowledgement	No time to support others	Possibility to read experiences and tips of other partners
		Confirmation	Problems with managing own problems	Possibility to participate (anonymously) on web-based platforms
		Support	Doubting helpfulness of peer support	
		Someone who will listen	Afraid of being confronted with negative experiences	
	Online psychological counseling	Signaling	Professionals' advices in the hospital are sufficient	Feedback tailored to personal situation
		Improving motivation	No further support is needed	Feedback from reliable person
		Possibility to ask questions	Term 'psychological guidance' is too heavy	
			No need; satisfied with regular healthcare	

Table 5. Relevant topics for a Web-based intervention, according to the partners (n=16).

Topic	N
Coping with feelings and emotions	16
Should I or shouldn't I spare my partner?	16
Communicate with each other	16
Asking for help and refusing help	16
Moving on life after cancer treatment	16
Sexuality and intimacy	13
Taking care of oneself	10
Living with cancer	10
The end is near	10

Peer support

The majority of the participants (n=10) were interested in some form of peer support (see Table 4). They were looking for acknowledgment, confirmation, support, and someone who would listen to them, as expressed by these quotes,

> *Look for other partners of cancer patients. They will understand you immediately and can help you. You will definitively find acknowledgment.* [Female, 51, partner died of acute lymphatic leukemia]

> *The information you receive is valuable, because everyone is looking for confirmation [...] You are doing something instinctively, but you are uncertain if this is the right thing to do. You want to know how other partners handle it.* [Female, 63, partner had Oesophagus cancer]

> *Often it is enough that somebody is listening. People often only want to tell their story.* [Female, 51, partner died of acute lymphatic leukemia]

Opinions about the best form of peer support varied, however. Some indicated that it would be sufficient to read about experiences of partners of cancer patients. Others wanted to actively participate on Web-based platforms (whether anonymously or not), because they wanted to share their experiences with other partners of cancer patients or they appreciated the personal contact for understanding, support, and acknowledgment.

However, a group of participants were not sure about their interest in contact with peers (n=4) or they were not interested in peer support at all (n=2). Arguments against peer support were that it was enough for them to cope with their own situation and that they did not have time to support others.

> *I don't know how other partners handle this issue, but I definitely had no time for it [...] I'm not sure how much capacities I had left at that moment to listen to another person's story. But I guess very little.* [Male, 43, partner died of ovarian cancer]

In addition, they doubted whether experiences of other partners of cancer patients would be helpful to them, and they were afraid to be confronted with negative experiences, as illustrated with the following quotes.

> *I have to confess that I tried to avoid peer support, because there were always people with even worse stories. And if you are in a period of hope and the other person is in a period of despair, this can negatively affect your own mood and hope.* [Male, 43, partner died of ovarian cancer]

> *I think that peer support about medical issues can be negative. It scares people about situations, which might not have been come up yet.* [Male, 30, partner had non-Hodgkin's lymphoma]

Online psychological counseling

There were 2 participants that gave no answer to this question. Of the remaining participants, opinions about online psychological counseling varied (see Table 4). There were 9 participants that were positive about some kind of online psychological counseling. First, they liked the idea that a professional could check on them and would be able to signal if something went wrong (e.g., if their mental health was deteriorating).

> *I think this is quite important. Imagine that someone is writing something in a depressed tone. Then a psychologist would be able to intervene and check on him or her.* [Male, 30, partner had non-Hodgkin's lymphoma]

Second, they thought that a personal online counselor could improve their motivation to complete the Web-based intervention, and third they liked the idea that they would be able to ask questions, as illustrated in the following quotations.

> *No obligations and flexibility are necessary, but it is also important that there constantly is someone who - how should I call it - someone who wakes you up if necessary.* [Male, 43, partner died of ovarian cancer]

> *Yeah, I think that people need this and that they would like the idea to rely on it (the psychological guidance) [...] The website shouldn't just say: "Deal with it". It is necessary,*

> *well look, if they pick a topic and have a lot of questions about it, then these questions need to be answered.* [Female, 58, partner has a brain tumor]

However, 3 of the participants also mentioned that they would prefer feedback that is focused on their personal situation. General feedback would not be enough to satisfy their needs. Furthermore, 1 participant mentioned that he would prefer guidance from a person he knows, definitively someone who is capable, and knows how things work. There were 3 interviewees who also mentioned that online psychological counseling should not be mandatory, but offered as a possibility.

There were 5 participants (3 of these were generally not in need of a Web-based intervention) that were not interested in online psychological counseling, because they had no need for it or they were already satisfied with the help given by doctors and nurses in the hospital and they felt they did not need any further support.

We encouraged participants to bring up any other functionalities. However, they didn’t come up with anything else.

Important topics to be addressed by the intervention

As described earlier, participants were asked to choose topics that were relevant to them and should be addressed in a Web-based intervention. Participants reported that all the proposed topics were valuable to partners of cancer patients. However, they emphasized the importance of the topics “coping with feelings and emotions,” “should I or shouldn’t I spare my partner?” “communicating with each other,” “asking for help and refusing help,” “moving on with life after cancer treatment,” and “sexuality and intimacy” (see Table 5). Furthermore, 4 participants suggested an additional topic “dare to enjoy”. The topic refers to enjoying those things that they still can do, instead of regretting what they cannot do anymore. This is an important source of hope and energy for the cancer patient as well as for the partner. There was 1 participant that added the topic “acceptance of the patient’s disease”. She had difficulties accepting their partner’s disease and she wished to get some help with that process.

DISCUSSION

Need for a web-based intervention

In this study, we examined partners' interest in a Web-based psychological intervention, and their needs and wishes regarding such an intervention. We found that the need for a Web-based intervention varied. Arguments for being interested in a Web-based intervention were: (1) the need for acknowledgment; (2) the need for someone who would listen; and (3) the need for information, tips, and support. Arguments against such an intervention were: (1) not experiencing any problems or not being aware of any problems; (2) having sufficient support from the social network or their own coping-strategy seems fine; (3) not wanting to lose valuable time with their partner or feeling that it's wrong to spend some personal time while the partner is ill; and (4) being afraid of too much negativity through rehashing the problem or an intervention seems not appealing. These results correspond with findings of previous research among cancer caregivers. For example, Harding and Higginson [25], Ussher et al [14], and Northouse et al [9] have found that many informal cancer caregivers are not asking for help, because they are often not aware of their own needs and problems, and they are mainly focused on the wellbeing of the patient. We think that it is of the utmost importance that we create more awareness for the challenging situation partners (or other caregivers) of cancer patients are confronted with every day. Both partners and the general public should be alerted (e.g., through awareness campaigns) about the effects and consequences that often come along with a diagnosis of cancer. Also, partners should be informed about the different possibilities to receive help (e.g., social workers, psychologists, nurse practitioners, Web-based interventions), as some partners in our study explicitly stated that they were not aware of any initiatives. By offering (information about) different kinds of support, we can ensure that everyone receives that kind of support that he or she needs and prefers. For some cancer caregivers, it is probably enough to be acknowledged that cancer may also affect their lives. Others may wish to consult a psychologist or they have a good relationship with their general practitioner, medical staff, or they receive sufficient support from their network. We think that a Web-based intervention can help caregivers who have little time to seek help; who experience a high threshold to consult a psychologist; who want to stay anonymous; or who want to check if they are in need for support before actually seeking help from a health care professional.

In our sample, we have seen that most of the partners had no or only little experience with e-Health interventions and also there were misconceptions about psychological interventions in general (e.g., the idea that psychologists only want to rehash the problem). To inform partners about the possibilities of a Web-based intervention and to overcome misconceptions, we would recommend the use of both written and visual (e.g., demonstration video) information about the content and nature of such an intervention.

We can conclude that partners of cancer patients differ in their opinions about the need for a Web-based (or any other) psychological intervention. Our data suggest that more awareness for the situation of cancer patients is needed, and information about existing options for support is lacking. In addition, our data show that there is a considerable group of partners who would be interested in a Web-based psychological intervention.

Preconditions

Overall, participants reported that an intervention should not be too time-consuming. They were afraid of losing valuable time with their partners and they also emphasized that they were already challenged with managing caregiving responsibilities and everyday tasks. According to the participants, they were able to spend about 1 to 2 hours a week on a Web-based intervention. For the successful implementation of such an intervention, it is important to meet the specific needs of the partners. The advantages of Web-based interventions (low threshold, high accessibility, flexibility) will be useful to fulfill these needs.

As far as the content of the intervention is concerned, the participants in our study would prefer a step-by-step approach. This means that the content should match the patient's stage of disease. The participants would also prefer a positive approach. They explained that they are confronted with enough misery (almost) every day and that it would be important that a Web-based intervention would also focus on positive things in life and in their specific situation. They indicated that such an intervention should be a source of hope and energy. This preference fits in with the developments in the field of psychology. Psychology traditionally focused on dysfunction. Positive psychology, in contrast, aims to focus on the positive features that make life worth living such as hope, optimism, happiness, and wellbeing [26]. Accordingly, we think that it could be of great value if an intervention for partners of cancer patients is based on concepts stemming from positive psychology, such as acceptance, values, resilience, mindfulness, and self-compassion.

As described earlier, most available supportive interventions aim at the couple (patient and partner) and usually no differentiation is made between their needs [9,14]. However, we have found that most of our participants would prefer to participate alone. They doubted that patients' and partners' needs could be combined in a single intervention. A small group of participants would prefer to participate together with their ill spouse because the disease affects both their lives. These participants explained that it is essential to cope with the situation together. According to these different preferences, we would recommend a flexible approach (participating alone versus participating together) for a future Web-based intervention for partners of cancer patients.

Desired functionalities

Participants in our study indicated that a Web-based psychological intervention should contain information as well as peer support. We found that participants were mainly interested in information and practical tips about all aspects of the disease and the consequences of being a partner of a cancer patient, coming from a reliable source. Previous research among partners of cancer patients has shown similar findings [27,28]. However, some partners in our study doubted if medical information is necessary for a Web-based intervention. They indicated that they have already received a lot of information in the hospital, or they feared that the information would be too general. Other researchers reported a similarly wide range of information needs of partners of cancer patients [7,29,30]. The different preferences regarding information needs should be considered in a Web-based intervention for partners.

Most participants were interested in peer support because they were looking for acknowledgment, confirmation, support, and someone who would listen. However, their wishes regarding the type of peer support varied. Whereas some participants would prefer the possibility to merely read experiences and tips of other peers and to stay anonymous, other participants preferred to actively participate in Web-based platforms. Rozmovits and Ziebland [30] also showed the general need for peer support in a study on the information needs of cancer patients. In this study, participants reported that having access to the experiences of peers was generally positively valued because it results in reduced feelings of fear and isolation during their illness, and it was both informative and reassuring. Furthermore, van Uden-Kraan et al [31] found that active participation in a Web-based support group by sending postings and nonactive participation by mere reading of postings from others are equally effective.

Despite the positive effects of peer support, some partners of our study indicated they had no interest in contact with other peers. They explained that they struggle with their own situation and that they did not have time to support others. Besides, they doubted whether the experiences of other partners would be helpful to them. These results are in line with various previous studies [32,33]. It seems that partners have ambivalent feelings toward peer contact: they do feel the need, yet they are afraid of being confronted with negative stories of other peers. Therefore, we would advocate that a future Web-based intervention for partners of cancer patients should offer the possibility to get in touch with peers. However, we would recommend a flexible approach in participation where partners will be able to engage in the type of contact with peers that actually matches their wishes (participation vs nonparticipation; active vs passive peer support) and type of peer support (e.g., Web-based platform vs private messages).

The need for online psychological counseling during participation in a Web-based intervention varied. Most of our participants liked the idea that a professional would guide them through the intervention, but others rate the presence of a professional as unnecessary. We can conclude that there are different preferences regarding psychological guidance. Recent studies have revealed that personal guidance is essential for the effectiveness of, and adherence to, eHealth interventions [34-37]. Yet, there is no consensus about the amount or form of support. For example, a study on the self-help intervention "Living to the full" with email support has indicated that short support messages were as effective as more extensive counseling [38], and a study of Kelders [39] has shown that automated support (consisting of a weekly feedback message) was as effective as a weekly feedback message given by a personal online counselor. However, more research in this field is needed to, for example, examine whether personal guidance is more effective for certain groups of partners. For a Web-based intervention for partners of cancer patients, it would definitely be useful if the different preferences regarding online psychological counseling could be considered.

Topics

Our participants agreed about the relevance of all the mentioned topics. They were especially interested in topics like "coping with feelings and emotions," "should I or shouldn't I spare my partner?" "communicating with each other," "asking for help and refusing help," and "moving on with life after cancer treatment". Furthermore, participants suggested extra topics of "dare to enjoy" and "acceptance of the disease".

In line with the fact that partners are (often) unaware of their own health complaints and therefore do not ask for help [9,14,40], participants in this study rated the topic "taking care of oneself" as less important than the other topics. Based on these outcomes, we think it is essential that an intervention targeting this group should be framed as informal and easily accessible support, from a positive perspective.

Limitations

There are some limitations to this study. First of all, this qualitative study was performed with a rather small number of respondents. We aimed to explore the needs and wishes of a group as heterogeneous as possible. We feel that we have succeeded in this effort as a wide range of people (in terms of gender, age, type, stage of disease, treatment) participated. However, the selective group of participants may not be representative for all partners of cancer patients. Therefore, it may be worthwhile to develop a quantitative questionnaire based upon the outcomes of this study, to corroborate the results in a larger sample of partners of cancer patients. In a quantitative study, it would also be possible to identify variables (e.g., gender, age, type, stage of disease, treatment) that are related to the intention to make use of a Web-based intervention.

Second, during recruitment, partners were told (in the information leaflet) that the interview was about a Web-based intervention. This could have led to selection bias. It might have been that partners of cancer patients who were not (regularly) using the Internet would have been less likely to participate.

Third, it should be noted that during 3 interviews the patient was also present. We agreed to this when the partner wanted their spouse to be present. However, it could have been possible that the presence of the patient had influenced the partner’s answers. Perhaps they were more cautious talking about their personal needs and wishes in order to protect their partner’s feelings.

Fourth, we have to note that 3 of our participants were widow/widower and that they used recollection to answer our questions, whereas the other participants used their current state. We asked the 3 partners to report on what would have been helpful to them in case their partner was still alive. We do not know for sure if these answers would have been the same when their partners were still alive, but it appears from our study results that the opinions of these 3 participants are in line with those of the other participants.

At last, it might have been difficult for partners to decide upon their interest in an intervention that does not exist yet. Also, the majority of the participants had no experience with e-Health interventions. We have tried to overcome these problems by using mock-ups. The participants responded well to these mock-ups and they said that these were helpful during the interview. We would therefore recommend the use of mock-ups, prototypes, or demonstrations to other researchers that are willing to develop a Web-based intervention.

Conclusions

We conclude that a Web-based intervention can be a valuable addition to existing support initiatives for partners of cancer patients. Furthermore, it is important that there is more awareness for the challenging situation partners of cancer patients are facing. This study yields important information about the content and form of a Web-based intervention for partners of cancer patients. In particular, flexibility and a positive approach seem to be the most important features. Also, information should be provided about the content and nature of an intervention in order to overcome misconceptions.

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Conflicts of interest

None declared.

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3

A web-based psychological intervention for partners of cancer patients: interest, influencing factors and preferences

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Submitted

ABSTRACT

Objective: A diagnosis of cancer can have detrimental effects on the wellbeing of partners of cancer patients. Despite the advantages of eHealth, Web-based interventions to support partners of cancer patients are scarce. This study aimed to examine partners' intention to use a Web-based psychological intervention, explore their wishes regarding such an intervention, and identify factors related to their intention.

Methods: 168 partners of cancer patients completed a questionnaire which queried personal characteristics, cancer-related characteristics of the patients, partners' psychological functioning (psychological distress, positive mental health, caregiver strain), intention to use a Web-based intervention, and wishes regarding preconditions and functionalities of such an intervention.

Results: Nearly half (48%) of the partners would make use of a Web-based intervention (35% maybe and 13% definitely). Partners who intended to participate were significantly younger (P = .014), used the internet more often (P = .041), and perceived more caregiver strain (P = .020). Multinomial logistic regression analysis showed that age was the only significant predictor of the intention to take part in a Web-based intervention. Most partners preferred an intervention that takes less than 1 hour a week, lasts for five weeks or more, and contains information as well as peer support. Half of the partners would like to receive online guidance by a personal counselor.

Conclusions: Approximately half of the partners were interested in a Web-based intervention, especially those who were younger. A Web-based intervention targeting this group should be flexible in use and contain information, peer support, and the option of online guidance.

KEYWORDS

cancer; oncology; partner; distress; Web-based interventions; survey study

INTRODUCTION

A diagnosis of cancer has a profound impact not only on the patients but also on their partners. In addition to providing informal care and emotional and practical support, partners also have to deal with their own emotions and often struggle to maintain their work, educational and family life. This balancing act is highly demanding, often creating detrimental effects on the partner's physical, mental and social health (e.g. [1-5]).

To help partners face the challenges that accompany their partner's cancer diagnosis and treatment, supportive psychological interventions (e.g. psychoeducation, skills training, cognitive behavior therapy, peer support) targeting this particular group are needed (e.g. [2, 6]). A recent meta-analysis [7] and two systematic reviews [8, 9] have found a number of such interventions. However, these interventions have some limitations. First, most of the interventions aim at the couple instead of the partner alone, and, as a consequence, these interventions primarily focus on the caregiving role and not so much on the caregivers' wellbeing. Second, they often have difficulties reaching the target audience [7-11], indicating that these interventions may not completely meet the partners' needs and wishes [8]. A systematic assessment of partners' needs prior and during the development of an intervention is, therefore, recommended [8, 12, 13].

The Internet can be a useful medium for psychological interventions, because of its numerous advantages, such as its ability to reach a broad audience, its flexibility, interactivity, cost-effectiveness, and anonymity [14-16]. The anonymity and flexibility of the Internet, for example, could help partners of cancer patients to overcome the threshold of seeking professional support. Despite the benefits of the Internet, and promising results of a recently developed Web-based intervention for cancer patients and their family caregivers [17, 18], Web-based interventions for partners of cancer patients remain scarce [6].

In light of this need and the current lack of viable solutions, we were interested in developing a low-threshold Web-based psychological intervention for partners of cancer patients. In an earlier qualitative study, we examined partners' interest in a Web-based psychological intervention and their needs and wishes regarding such an intervention. We found that such an intervention can be a valuable addition to existing interventions for partners of cancer patients. The study revealed that the personal interest in participating in such an intervention varied, and it yielded insights into the content and form such a Web-based intervention might implement [19]. We found that an intervention should not be too time-consuming, the content should be matched to the stage of the patient's disease, flexibility and a positive approach were important, and an intervention should contain information and optional peer support. Because of the small and selective study group of the earlier study, we could not generalize these findings, and therefore we conducted this quantitative study. The first aim of the present study was to investigate the partners' needs and preferences regarding the preconditions (maximum time and duration, participate alone or together with patients), functionalities (information, peer support, personal guidance by professional), and content of such an intervention and to examine their intention to use it. To be able to examine if certain partners are more in need of an intervention, or would be more willing to accept a web-based intervention, we also aimed to identify variables that are associated with the intention to use a web-based intervention. Thus far, no previous studies have examined predictors of interest in Web-based interventions among caregivers of cancer patients. However, Mosher et al [20] examined factors (including caregiver demographics, patient medical factors and caregivers' distress) that were associated with face-to-face support service use among caregivers of lung cancer patients. They found that only the patients' receipt of chemotherapy was a predictor of the caregivers' mental health service use. From studies among population- and patient-based samples we know that health related internet use is associated with younger age [21-23], female gender [21, 23], higher educational levels [22, 23], work employment [22], and greater distress symptoms [23]. To gain a better understanding in predictive factors, this study aimed to identify variables (partner's personal characteristics and psychological functioning (psychological distress, positive mental health, caregiver strain) and the cancer-related characteristics of the patient) that may be associated with the intention to use a Web-based psychological intervention.

METHODS

Study sample and procedure

A Web-based and a paper version of a survey were used to collect data. The only inclusion criteria were that the participant be a partner of a cancer patient or cancer survivor and 18 years or older. The data were collected from November 2012 to May 2013. The questionnaire was distributed in The Netherlands in two participating hospitals, one online forum, one hospice and two centers where cancer patients and their families could receive, for example, (peer) support, advice, information, and training on how to cope with the disease. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The study protocol was checked by the Medical Ethical Committee of the VU University Medical Center (Amsterdam). They decided that according to the Dutch Medical Research Involving Human Subjects Act, ethical approval was not necessary, because the partners of cancer patients were not subjected to procedures or required to follow rules of behavior.

Questionnaire

Partners’ personal characteristics and cancer-related characteristics of the patients

Partners’ personal characteristics that were assessed included: age, gender, country of birth, education, employment, computer- and internet use, and frequency of internet use. Regarding the patient’s disease, we asked partners about the type of cancer, time since diagnosis, and phase of disease. The latter was measured with one question: “Which statement describes best the current situation of your partner?” Partners could reply with one of the following: (1) “My partner is still in treatment and we have good hope that he/she will recover.” (2) “The treatment is completed and we are moving on with our lives.” or (3) “My partner is unlikely to be cured.” We also asked the partners if they are or had been consulting a psychologist or counselor because of the patient’s disease.

Partners’ psychological functioning

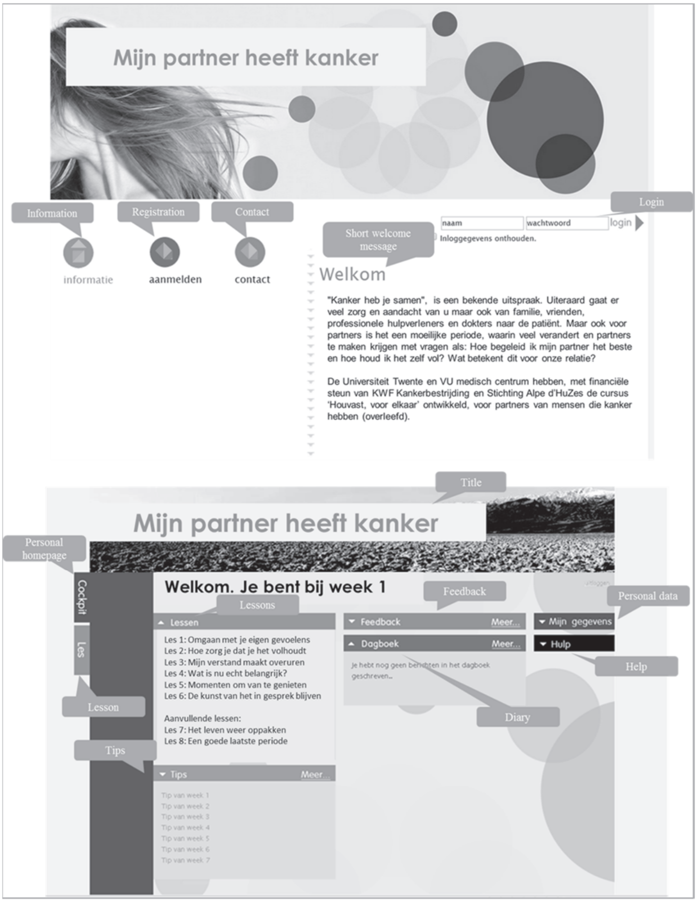
Psychological distress was assessed with the Hospital Anxiety and Depression Scale (HADS) [24]. This questionnaire measures the presence and severity of anxiety (7 items) and depressive symptoms (7 items). Responses are rated on a 4-point Likert scale (0-3). Anchor points for the Likert items vary depending on the item (e.g. “I feel cheerful” scores as 0 most of the time to 3 not at all; and “I can sit at ease and feel relaxed” scores as 0 definitively to 3 not at all). Items scores were summed into a score for the HADS total (Cronbach’s $\alpha = .91$), anxiety ($\alpha = .85$) and depression ($\alpha = .86$). The cutoff score for both subscales is ≥ 8 for the identification of doubtful cases and ≥ 11 for definitive cases [24].

Positive mental health was assessed with the Mental Health Continuum-Short Form (MHC-SF) [25, 26]. This 14-item questionnaire measures three dimensions of positive mental health: emotional wellbeing (3 items; Cronbach’s $\alpha = .84$), psychological wellbeing (6 items; $\alpha = .84$), and social wellbeing (5 items $\alpha = .82$). Partners rated the frequency with which they had experienced certain feelings in the past month on a 6-point Likert scale (1 = never to 6 = every day). Scale scores were computed for the subscales as well as for the total scale ($\alpha = .93$), by averaging the scores on all relevant items.

Caregiver strain was assessed with the 13-item Caregiver Strain Index (CSI) [27]. The CSI contains at least one item for each of the following major domains: employment, financial, physical, social and time. Each item can be answered with ‘yes’ (1) or ‘no’ (0). A CSI-score is computed by counting the number of ‘yes,’ resulting in a score from 0 to 13. A score of ≥ 7 indicates caregiver strain [27]. In the present study, the Cronbach’s α for the CSI was .84.

Intention to use a web-based intervention and wishes regarding such an intervention

To give partners an idea about what a Web-based intervention for partners of cancer patients might look like, we added a short description and two mock-ups of a possible Web-based intervention (see Figure 1). In our previous interview study [19], we experienced that using mock-ups facilitated partners to elaborate on their wishes. After the mock-ups and the description, partners were asked if they would make use of such an intervention (answer choices: no/maybe/yes). They could further explain their answers in a textbox. In addition, partners who responded either 'maybe' or 'yes' to the possibility of using a Web-based intervention were asked which preconditions the intervention should meet (maximum time per week and participation alone or with their ill partner), which functionalities the intervention should contain (information, peer support, and online psychological guidance by a counselor), and which topics should be addressed. Based on literature, suggestions of experts in the field and the results of the previous interview study [19], we created a list of eleven topics and we asked partners to rate their interest on a scale from 0 = not interested to 4 = interested). The topics were: (1) coping with emotions; (2) taking care of oneself; (3) sparing your partner or not?; (4) communication with patient; (5) communication with children; (6) communication with care providers; (7) sexuality and intimacy; (8) asking for help and refusing help; (9) moving on with life after successful cancer treatment; (10) living with cancer; and (11) if the end is near. Partners were also encouraged to add more topics in a textbox.



"Kanker heb je samen", is een bekende uitspraak. Uiteraard gaat er veel zorg en aandacht van u maar ook van familie, vrienden, professionele hulpverleners en dokters naar de patiënt. Maar ook voor partners is het een moeilijke periode, waarin veel verandert en partners te maken krijgen met vragen als: Hoe begeleid ik mijn partner het beste en hoe houd ik het zelf vol? Wat betekent dit voor onze relatie?

De Universiteit Twente en VU medisch centrum hebben, met financiële steun van KWF Kankerbestrijding en Stichting Alpe d'HuZes de cursus 'Houvast, voor elkaar' ontwikkeld, voor partners van mensen die kanker hebben (overleefd).

Welkom. Je bent bij week 1

Les 1: Omgaan met je eigen gevoelens
Les 2: Hoe zorg je dat je het volhoudt
Les 3: Mijn verstand maakt overuren
Les 4: Wat is nu echt belangrijk?
Les 5: Momenten om van te genieten
Les 6: De kunst van het in gesprek blijven

Aanvullende lessen:
Les 7: Het leven weer oppakken
Les 8: Een goede laatste periode

Tip van week 1
Tip van week 2
Tip van week 3
Tip van week 4
Tip van week 5
Tip van week 6
Tip van week 7

Je hebt nog geen berichten in het dagboek geschreven...

Short description of a possible Web-based intervention for partners of cancer patients

As a partner of a cancer patient you can log in to the secure website of the Web-based intervention (see Figure 1). After logging in, you enter your personal homepage (see Figure 2). On this homepage you find an overview of the different components of the intervention, e.g. its lessons. The lessons contain information and tips, and experiences of other partners of cancer patients. Furthermore, you can do exercises or keep a diary. When you have read lesson 1 and you have done the accompanying exercises, you can share your experiences about this lesson with a psychologist or counselor. Accordingly, you will receive feedback on your experiences, and questions will be answered.

Figure 1. Mock-ups of a possible Web-based intervention (top), personal homepage (after logging in) and description (bottom).

Statistical analyses

Quantities, percentages and mean scores were calculated for the partner's personal characteristics and the cancer-related characteristics of the patient, along with the partner's psychological functioning, intention to use a Web-based intervention, and preferences regarding such an intervention. Chi-square tests and Kruskall-Wallis tests were used to compare three groups: 1) partners with no intention to use a Web-based intervention, 2) partners with an intention to use such an intervention, and 3) partners who would maybe make use of it. Variables that were significantly associated with the dependent variable (intention to use a Web-based intervention) were entered into a multinomial logistic regression analysis. All reported p values were two-sided, and a value of $p < 0.05$ was considered to be statistically significant. Data were analyzed using the Statistical Package for the Social Sciences (IBM SPSS 20.0 for Windows, Chicago, IL, USA). Free-text responses were used as illustrations, offering further insights into the quantitative data.

RESULTS

Partners' personal characteristics and cancer-related characteristics of the patients

A convenience sample of 168 partners filled out the questionnaire, 23 via the Web-based version and 145 via the paper version. An overview of the partners' personal characteristics and cancer-related characteristics of the patient is shown in Table 1. Nearly all partners (93%) had computer- and home Internet access, and 67% used the Internet on a daily basis.

Partners' psychological functioning

Table 2 presents the results of the partners' psychological functioning. Twenty-two percent of the partners had an increased risk for depression and 37% for an anxiety disorder. Probable presence of a depression or anxiety disorder was found in 10% and 16% of the partners, respectively. The mean score on the total MHC-SF was 4.2 on a scale from 1 to 6, indicating a rather positive score on mental health. A third (33%) experienced caregiver strain.

Table 1. Partners' personal characteristics and partner cancer-related characteristics: Total and subtotals divided by intention to use Web-based intervention (*N* = 168)

	Intention to use the Web-based intervention								
	Total (n = 155-167)		No (n = 71-83)		Maybe (n = 53-55)		Yes (n = 19-20)		*P*^{a}
	n	%^{2}	n	%^{2}	n	%^{2}	n	%^{b}	
Personal characteristics									
Gender (n = 167)									.579
Female	81	49	39	47	27	49	12	60	
Male	86	52	44	53	28	51	8	40	
Age, mean (S.D.), years (n = 164)	59.2 (11.5)		60.7 (10.3)		59.0 (11.4)		51.6 (13.5)		.014*
Country of birth (n = 167)									.885
The Netherlands	157	94	77	93	52	95	19	95	
Other	10	6	6	7	3	6	1	5	
Children (n = 167)									.078
No / or living away from home	133	80	69	83	43	78	12	60	
Yes, living at home	34	20	14	17	12	22	8	40	
Education (n = 167)									.509
Low	73	44	42	51	20	36	9	45	
Middle	50	30	22	27	16	29	6	30	
High	44	26	19	23	19	35	5	25	
Employment (n = 167)									.094
Employed > 20 hours a week	54	32	25	30	17	31	11	55	
Unemployed / retired	113	68	58	70	38	69	9	45	
Relationship with patient (n = 167)									.349
Married and/or living together	158	95	80	96	51	93	20	100	
In a relationship but living apart	9	5	3	4	4	7	-	-	
Computer access, yes (n = 167)	155	93	74	88	54	98	19	95	.080
Internet access, yes (n = 167)	155	93	74	88	54	98	19	95	.080
Frequency of internet use (n = 155)									.041*
Almost every day	103	67	45	61	37	69	15	79	
Several days in a week	31	20	11	15	15	28	3	16	
About one day in a week	10	7	7	10	2	4	1	5	
Less than one day a week	3	2	3	4	-	-	-	-	
(Previous) contact with a psychologist or counselor (n=164)	28	17	15	18	6	11	5	25	.294
Cancer-related characteristics of the patient									
Type of cancer (n = 166)									.451
Breast cancer	44	27	20	28	18	33	1	5	
Lung cancer	25	15	13	18	8	15	3	15	
Head-and-neck cancer	23	14	11	16	3	6	5	25	
Leukemia	16	10	7	10	5	10	3	15	
Lymphoma	12	7	5	7	3	6	2	10	
Cancer of bone marrow	11	7	6	9	4	8	1	5	
Colon cancer	9	5	4	7	3	6	1	5	
Prostate cancer	9	5	3	4	5	10	1	5	
Skin cancer	8	5	1	1	2	4	2	10	
Other[c]	9	5	1	1	4	8	1	5	

[a] Kruskal-wallis test for age, time since diagnosis, and how often contact with healthcare professional; chi-square tests for the remaining variables

[b] Percentages may not total 100 due to rounding

[c] Seven different kinds of cancer

*p < .05

Table 1 (continued). Partners' personal characteristics and partner cancer-related characteristics: Total and subtotals divided by intention to use Web-based intervention (*N* = 168)

			Intention to use the Web-based intervention						
	Total (n = 155-167)		No (n = 71-83)		Maybe (n = 53-55)		Yes (n = 19-20)		P^a
	n	%^{2}	n	%^{2}	n	%^{2}	n	%^{b}	
Time since diagnosis (n = 167)									.349
< 3 months ago	14	8	8	10	4	7	2	10	
3-6 months ago	10	6	3	4	7	13	-	-	
6-12 months ago	20	12	11	13	7	13	1	5	
1-5 years ago	87	52	43	52	27	49	11	55	
5-10 years ago	27	16	12	15	8	15	6	30	
>10 years ago	9	5	6	7	2	4	-		
Current treatment (n = 161)									.782
No current cancer treatment	81	50	43	54	23	44	8	40	
Chemotherapy	39	24	20	25	14	27	4	20	
Radiation treatment	2	1	1	1	0	0	1	5	
Chemotherapy combined with other treatment	2	1	1	1	0	0	1	5	
"Drugs" not specified	9	6	4	5	3	6	2	10	
Hormonal therapy	9	6	4	5	4	8	1	5	
Treatment graft-versus-host disease	6	4	3	4	2	4	1	5	
Other	13	8	4	5	6	12	2	10	
Self-reported phase of disease (n = 167)									.789
Patient is still in treatment with curative intent	58	34.7	30	36.1	20	36	5	25	
Treatment with curative intent is completed; patient is recovered	63	37.7	33	39.8	19	35	8	40	
Patient will (probably) not get better anymore	46	27.5	20	24.1	16	29	7	35	

[a] Kruskal-wallis test for age, time since diagnosis, and how often contact with healthcare professional; chi-square tests for the remaining variables

[b] Percentages may not total 100 due to rounding

*p < .05

Table 2. Partners' psychological functioning (psychological distress, mental health, and caregiver strain). Total and subtotals divided by intention to use a Web-based intervention (*N* = 168)

	Intention to use the Web-based intervention				
	Total (n = 168)	No (n = 84)	Maybe (n = 55)	Yes (n = 20)	*P*[a]
	Mean (S.D.)	Mean (S.D.)	Mean (S.D.)	Mean (S.D.)	
Psychological distress					
HADS total (n = 161)	11.2 (7.2)	10.8 (7.5)	11.1 (6.5)	12.6 (7.3)	.486
Depression (n = 163)	4.5 (3.8)	4.4 (4.0)	4.4 (3.5)	4.9 (3.7)	.686
≥ 8 (%)	22.1	23.5	11 (20)	21.1	.888
≥ 11 (%)	10.4	11.1	4 (7)	15.8	.543
Anxiety (n = 161)	6.7 (4.0)	6.4 (3.9)	6.7 (3.8)	7.8 (4.2)	.378
≥ 8 (%)	36.6	32.1	21 (38)	55.6	.172
≥ 11 (%)	15.5	13.6	7 (13)	27.8	.264
Mental health					
MHC-SF total (n = 164)	4.2 (1.0)	4.2 (1.0)	4.3 (0.9)	4.1 (1.2)	.959
Emotional wellbeing (n = 166)	4.6 (1.1)	4.6 (1.1)	4.8 (0.9)	4.3 (1.3)	.326
Social wellbeing (n = 165)	3.8 (1.2)	3.9 (1.2)	3.8 (1.2)	3.8 (1.4)	.837
Psychological wellbeing (n = 165)	4.3 (1.1)	4.3 (1.9)	4.4 (0.9)	4.3 (1.4)	.857
Caregiver strain					
CSI (n = 154)	5.1 (3.5)	4.9 (3.3)	4.6 (3.4)	7.1 (3.5)	.020*
≥ 7 (%)	33.0	32.0	28.6	45.0	.413

[a] chi-square test for scores ≥ 8 and ≥ 11 on hads depression and hads anxiety; ≥ 7 caregiver strain; kruskall-wallis test for remaining scores

*p<.05

Partners' intention to use a web-based intervention, preconditions, functionalities and relevant topics

Of all the partners who answered the question regarding their intention to use a Web-based intervention (n=159), 53% (84/159) had no intention of using a Web-based intervention, 35% (55/159) would "maybe" make use of an intervention and 13% (20/159) "definitively" would use one. A sub-sample of partners (n=22) who had *no* intention to use a Web-based intervention further explained their reply with one or several of the following arguments: (1) having no need for an intervention or already receiving sufficient support from personal network (n=18); (2) online character of the intervention is not appealing (because they, for example, think that this kind of support is too impersonal) (n=7); (3) not wanting to be confronted with the whole situation (n=1); and (4) being afraid that such an intervention would form an additional burden (n=1). Four partners of this group also reported that although they were not interested themselves, they did like the idea that such an intervention would become available.

Of the 20 partners who indicated that they would *definitively* make use of a Web-based intervention, nine explained their answer as follows: (1) they felt that it was important that partners receive support, because of the highly challenging and emotional time they were experiencing, and that an intervention could be another source of information and support (n=5); and (2) they would like the easy accessibility of a Web-based intervention, its flexibility and its anonymity (n=4).

Thirteen partners who would *maybe* make use of an intervention also further explained their choice. Their arguments were similar to the above mentioned arguments for and against the use of a web-based intervention. For example, they felt that they did not need any intervention at the moment (n=7), but at the same time, eight partners indicated that they would be happy if such an intervention were available. A few (n=5) reported referred to the online nature of the intervention (either for or against).

In Table 3, the partners' preferences regarding the preconditions, functionalities, and relevant topics of a Web-based intervention are shown. Of the partners who indicated that they would (maybe) make use of a Web-based intervention, 82% felt that the intervention should take less than 1 hour a week, 56% of the partners thought that the intervention should have a duration of 5 weeks or more, and 57% would prefer that at least some parts of the intervention be addressed to the partner alone. The majority of the partners felt that an intervention should contain information (82%) and peer support (72%). Partners differed in their preferences regarding the need for having online contact with a professional counselor. Half of the partners considered such contact as important. The partners' preferences regarding the preconditions and functionalities were not associated with the partner's self-reported phase of their ill partner's disease.

Partners were interested in the majority of the proposed topics. They were especially interested in the topics 'living with cancer', 'if the end is near', and 'communication with the patient'. They were the less interested in the topic 'sexuality and intimacy'. Only five partners suggested an additional topic. Four partners would like to receive more information about financial matters, practical support (if they could get support with household chores or what to do when you have your own business), and availability of (professional) support close to their homes. One partner would like to receive information about how to get more understanding from the social network.

Associated factors

We examined differences between those who (maybe) intended to use a Web-based intervention and those who did not with respect to their personal characteristics and the cancer-related characteristics of the patients (Table 1), as well as to their personal psychological functioning (Table 2). Partners who intended to use a Web-based intervention were significantly younger (*P* = .014), used the internet more often (*P* = .041) and perceived more caregiver strain (P = .020). The intention to use the intervention was not associated with the patient's cancer-related characteristics nor with the partners' psychological distress or positive mental health.

The variables of age, frequency of internet use, and caregiver strain were included in the multinomial logistic regression analyses (MLRA). Together these variables significantly predicted the intention to use a Web-based psychological intervention ($\chi^2(12) = 33.17$, $p < .001$), accounting for about 22% of the variance (Cox and Snell R^2). MLRA showed that only age was a significant predictive factor, $\chi^2(2) = 7.03$, $p = .030$ (frequency of internet use $\chi^2(2) = 15.05$, $p = .058$; and caregiver strain $\chi^2(2) = 4.85$, $p = .089$). Compared with the group of partners who had no intention of participating in Web-based psychological interventions, partners who did want to participate were younger (odds ratio .97, 95%; Confidence Interval .89 - .99).

Table 3. Partners' (who would maybe or definitively intend to participate in a Web-based intervention) preferences regarding preconditions, functionalities and topics of a Web-based intervention (N = 71 - 74)

	n	%[a]
Preconditions		
Maximum time per week		
Less than 30 minutes per week	32	46
30 minutes to 1 hour a week	25	36
1 - 2 hours a week	11	16
3 - 4 hours a week	1	1
More than 4 hours a week	-	-
Maximum number of weeks		
1 - 2 weeks	13	20
3 - 4 weeks	16	24
5 - 6 weeks	10	15
More than 6 weeks	27	41
Participation alone or with ill partner		
Alone	19	28
Some parts alone and some parts together	20	29
Together	30	44
Functionalities		
Information		
Unimportant	13	18
Important	60	82
How should information be presented		
On website	34	47
Via link to other relevant websites	39	53
Peer contact (chat, forum, discussion board)		
Unimportant	21	28
Important	53	72
Personal guidance with professional		
Unimportant	37	50
Important	37	50
How often personal contact with professional (per week)		
No contact	29	40
1 time a week	39	54
2 times a week	3	4
More often	1	2
Topics (range 0-4), mean (S.D.)		
Living with cancer	3.1 (1.0)	
The end is near	3.1 (1.0)	
Communication with patient	3.0 (1.1)	
Coping with feelings	2.8 (1.1)	
Sparing your partner or not?	2.8 (1.0)	
Moving on with life after cancer treatment	2.8 (1.1)	
Asking for help and refusing help	2.7 (1.0)	
Communication with children	2.7 (1.5)	
Taking care for oneself	2.6 (1.2)	
Communication with care providers	2.6 (1.2)	
Sexuality and intimacy	2.4 (1.3)	

[a] Percentages may not total 100 due to rounding

DISCUSSION

Our study indicates that the interest in a Web-based supportive intervention varied. 53% of the partners was not interested in such an intervention, 35% would maybe be interested and 13% would definitively be interested. Of those who were (maybe) interested in an intervention, the majority would prefer an intervention that takes less than one hour a week, lasts up to five weeks or more and contains information and peer support. About half of the partners would like to use a Web-based intervention under the guidance of a professional counselor. The partners were interested in topics about what it means to live with cancer or when you know that the patient will not get better anymore. Or topics that were related to the communication with the patient (and also with children and care providers); how to cope with emotions; if they should or should not spare their ill partner; how to move on with life after a successful cancer treatment; how to ask for help or refuse help; how to take care of yourself; and matters regarding sexuality and intimacy. These results regarding the precondition, functionalities, and content of a Web-based intervention are in line with the outcomes of our earlier qualitative study in which we interviewed sixteen partners of cancer patients about their needs and wishes regarding such an intervention [19].

Existing supportive interventions for cancer caregivers are mostly delivered as face-to-face visits in the clinical setting [7]. We expected that Web-based interventions would be welcomed by partners of cancer patients because of the flexibility and accessibility of such interventions, helping partners of cancer patients to overcome any reluctance in seeking help and/or allowing them more choice as to when to seek help within the time restraints of their (caregiving) tasks and responsibilities [14, 28]. In the present study, 48% of the partners were (maybe) interested in a Web-based intervention, which is higher than reported by Mosher et al. [20]. In their study, 29% of caregivers of lung cancer patients, of whom the majority (65%) were spouse/partners, were willing to attend a support group or talk to professionals. Our result is, however, comparable to the percentage found in a study by Skleranova et al. [1], who reported that 48% of caregivers of patients with various cancers would intend to take part in supportive face-to-face intervention if it were offered. Based on the responses from the partners in our study, it appeared that some partners found the idea of a Web-based intervention particularly appealing, as it was flexible and convenient, whereas others rejected the idea of a Web-based intervention because of its impersonal character. Based on these findings, we conclude that both Web-based and face-to-face interventions have value when attempting to reach all partners of cancer patients.

Most supportive interventions currently available target the couple (patient and partner), instead of the partner alone [7]. In the current study, however, we found that less than half (44%) of the partners would prefer to participate in the intervention together with the patient. The majority (57%) would like to participate alone or they prefer that at least some parts of the intervention be addressed to them alone, which is in line with the results of Mosher et al. [20] who found that only 15% (7/46) of the lung cancer caregivers were interested in couples counseling and only 19% (14/72) were interested in family counseling. Partners of terminally ill patients might prefer to participate alone in an intervention because of the especially challenging tasks of discussing their fears in presence of the patient about losing them and/or the strain they experience due to their caregiving tasks. However, in our sample, we found no similar relationship of the partner's self-reported phase of the patient's disease. Nevertheless, these results should be interpreted with caution because of the small sample size. In our earlier qualitative study, the majority of the partners also indicated that they would prefer to participate in the intervention without the patient because they doubted that patients' and partners' needs could be combined in one supportive intervention. However, other partners preferred to participate together with the patient, because the cancer affects both their lives, and they needed to cope with the situation together [19]. Because of the different preferences, we recommend that future (Web-based) interventions for partners of cancer patients offer a flexible approach allowing them to choose whether they want to participate alone or together with the patient.

Age was the only significant predictor of the intention to use a psychological Web-based intervention. This finding is in accordance with previous studies showing that younger people are using the Internet and Web-based interventions more often [21, 22, 29]. Interestingly, gender was not associated with the intention. On the basis of prior research [21, 23] we had hypothesized that female partners would be more interested in a web-based intervention. Phase of disease was not associated with the intention to make use of a Web-based intervention, which corresponds with the study of Mosher et al. [20] who found that phase of disease was not associated with use of mental health services.

Interestingly, the intention to use a psychological Web-based intervention was not associated with levels of psychological distress. Possible explanations could be that partners experiencing severe distress would prefer a different kind of intervention, such as face-to-face interventions; they have no time or energy to participate in an intervention due to caregiving tasks and other responsibilities; or they already receive sufficient support from their personal network. In fact, some of the partners in our study mentioned these last two explanations as reasons for not being interested in a Web-based intervention, and these findings compare with a study by Clover et al. [30] among cancer patients. In Clover's study, 71% of the patients with high levels of emotional distress declined help because they preferred to manage the distress themselves. On the other hand, it could also be that the intention to use a Web-based intervention is determined by a person's ideas about the usefulness of psychological interventions, in general, and their willingness to reflect on their own behavior, rather than on their actual amount of distress. People with no or mild levels of distress are often not eligible to participate in supportive interventions despite the fact that these interventions could possibly help them cope with their caregiver role, improve their wellbeing, or even prevent development of mental and physical complaints. Low-cost Web-based interventions could be an option for such partners.

Due to the limitations of this study, some caution is needed when interpreting the results. First, we made use of a convenience sample, and information about the response rate is not available. It appeared that the stress level in our sample was somewhat lower than stress levels reported in earlier studies [20, 31-33]. Furthermore, partners of cancer patients with an interest in an intervention might have been more likely to participate in this study than those without any interest, possibly resulting in biased results. In addition, it might have been difficult for partners to decide upon their interest in a non-existent intervention. We did attempt to clarify what an intervention for partners might look like by offering a mock-up version and a short written explanation, and we know from our previous study [19] that this helped partners to elaborate on their wishes. Finally, the intention to make use of an intervention does not necessarily mean that partners will actually take part in it.

We conclude that almost half of the partners of cancer patients were interested in a Web-based intervention, especially those who were younger. Any potential intervention should not be too time consuming, and it should be flexible regarding participation with or without the patient. Furthermore, the intervention should contain information, peer support, and the option of online guidance by a counselor. Web-based delivered and tailored psychological interventions may be a valuable contribution to the healthcare system in order to optimally support partners of cancer patients.

Informed consent and patient details

I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

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Conflict of interest

The authors declare no conflict of interest.

Authorship contributions

All authors made substantial contributions to conception and design of this study. N. Köhle, C.H.C. Drossaert., C.F. van Uden-Kraan, and I.M. Verdonck-de Leeuw contributed to the acquisition of the data. The gathered data was analyzed and interpreted by N. Köhle and C.H.C. Drossaert and these two authors also drafted the manuscript. The other authors participated in revising the manuscript critically for important intellectual content. All authors gave their final approval of the version to be submitted and any revised version.

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4

A web-based self-help intervention for partners of cancer patients based on Acceptance and Commitment Therapy: a protocol of a randomized controlled trial

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ABSTRACT

Background: There is a growing recognition that cancer not only affects the lives of the patients, but also the lives of their partners. Partners of cancer patients are highly involved in the illness trajectory by providing informal care and they often experience distress. However, supporting interventions for this group are scarce and existing interventions bear several limitations. On the basis of the need for theory- and evidence-based supportive interventions for partners of cancer patients, the web-based self-help intervention *Hold on, for each other* has been developed. This intervention is based on Acceptance and Commitment Therapy. The primary objective of the RCT is to investigate the (cost-)effectiveness of the intervention. Additional goals are (1) to examine if psychological flexibility, self-compassion, mastery, supportive behavior, posttraumatic growth and resilience are mediators of the intervention's effects on the partners' mental health; (2) to examine the moderating effects of the socio demographics (age, gender, education, working situation, family situation) and disease-related characteristics of the patients (sort of cancer, stage of disease, duration and treatment of cancer); and (3) to investigate to what extend participants are satisfied with the intervention, which parts of the intervention are mostly used, and how adherent the users are.

Methods/Design: A three-armed randomized controlled trial (RCT) will be conducted to compare two versions of the intervention *Hold on, for each other* with a waiting list control condition. Both intervention conditions contain the same content and differ only with regard to the form of professional support (personal support versus automatic support). Adult partners of cancer patients with mild to moderate depressive and anxiety symptoms, will be recruited through a multi-component strategy. Online measurements by self-assessment will be made on four measurement points (prior to randomization (baseline-measurement) and 3, 6 and 12 months after baseline).

Discussion: When proven effective, *Hold on, for each other* can be an invaluable contribution to the healthcare system and it could be offered to all partners of cancer patients who are in need for additional support.

Trial registration: Dutch Trial Register, trial registration number NTR4035, date of registration: 17 March 2013

KEYWORDS

Cancer; oncology; distress; RCT; partners; self-help; web-based; effectiveness; cost-effectiveness; Acceptance and Commitment Therapy

BACKGROUND

Being partner of a cancer patient is highly demanding. Partners are often involved in the illness trajectory by providing informal care and emotional support, and they regularly have to take on responsibilities of their ill spouse and the household, in addition to their own [1, 2]. In recent years, there is growing recognition that cancer not only affects the lives of the patients, but also the lives of their loved ones. Recent studies have shown that partners and other family caregivers are at risk of experiencing mental and physical health complications. In a systematic review by Stenberg et al [3] 200 problems and burdens have been identified related to caregiving responsibilities among family caregivers. The most frequently reported problems were emotional (e.g. anxiety, depression and fear) and social problems (e.g. financial difficulties, role strain, isolation). Partners even suffered from diminished physical functioning and experienced complaints as pain, sleep problems and fatigue. Partners of cancer patients play an important role in patient recovery and illness management [3]. Therefore, the presence of mental and physical health complaints not only has a paramount impact on the partner's quality of life, but it has also a negative impact on the informal care for the patient [4].

To overcome these problems, supportive interventions are available for partners of cancer patients. A recent meta-analysis [4] and two recent systematic reviews [5, 2] identified a variety of psychosocial interventions for partners. However, most of these interventions were aimed at couples instead of the partner alone, and as a consequence the primary focus was often on the wellbeing of the patients. The needs of the partners have been overlooked and only a few interventions target the partners' self-care as primary aim [4, 5]. Another shortcoming of the existing interventions is that partners of cancer patients seem to make no or only limited use of them [6-8]. This might be a result of poor diffusion strategies or it might indicate that the interventions do not meet the needs and wishes of the target group. Finally, the interventions are often not theory-based and lack thorough evaluation [5, 9]. Therefore, Ussher et al. [5] recommend high quality designs for future studies and better theoretical underpinning of the interventions to gain insight in the processes that might be relevant for partners of cancer patients.

The internet can be of added value in this respect, because it offers opportunities to deliver easy accessible and (cost-)effective interventions [4]. Advantages of web-based interventions for example are a low threshold and flexibility [10, 11]. Participants do not have to make an appointment with a healthcare professional and they can use the web-based intervention at any moment or any location that suits them (24 hours a day, seven days in a week). This flexibility can be of great importance for partners of cancer patients, since they are often very occupied with caring tasks, and as a result have less time for their own health and personal activities [4]. Yet, despite these advantages, the web-based interventions for this population are scarce [9].

To overcome the above mentioned problems with existing interventions and to make use of the advantages the internet offers, we developed an online delivered, theory-based self-help intervention called *Hold on, for each other* to support partners of cancer patients. To make sure that the intervention fits to the needs and wishes of the end users, partners of cancer patients were actively and repeatedly involved during the developmental process. This paper presents the development of the *Hold on, for each other* intervention and the design of a randomized controlled trial to test the (cost-)effectiveness of this intervention.

Theoretical framework

Hold on, for each other is based on Acceptance and Commitment Therapy (ACT). ACT is a form of contextual behavior therapy that focuses on changing a client's relationship with their thoughts instead of changing the content of their thoughts [12]. Clients learn that avoidance, suppression or the attempt to control difficult thoughts can be counterproductive. They also learn to focus on behaviors and actions that are in line with their individual values – the things they care about most. ACT targets to increase psychological flexibility. Psychological flexibility is defined as "the ability to contact the present moment more fully as a conscious human being, and to change or persist in behavior when doing so serves valued ends" [13]. The efficacy of ACT in reducing psychological distress is supported by a growing body of literature (e.g. Hayes et al. [13], including studies among cancer patients [12, 14]. ACT may be useful in partners of cancer patients, because it can help them to deal with the negative emotions caused by cancer (e.g. uncertainty, anxiety, sadness, anger) instead of avoiding these. Avoidance has been identified as one important factor resulting in psychological distress in cancer patients and their partners [15, 16]. ACT may also help partners to cope with dysfunctional thoughts such as "what if the cancer comes back?" or "what if my partner dies?". People are often excessively entangled with their thoughts and they need to learn to defuse from them [17]. This process of so called *cognitive defusion* or *meta- cognitive awareness* has already been proven to be effective in people with general anxiety disorder [18] and recurrent depression [19, 20]. Finally, ACT may help partners of cancer patients to focus on what is really important to them (or in their relationship) and encourage them to act upon these values as much as possible, despite any barriers. This might especially be useful, as existing values, patterns and roles may have been seriously threatened or challenged by the cancer (e.g. Northouse et al. [4]; Applebaum & Breitbart [2]).

Developmental process

To ensure that the intervention actually suits the partners' needs and wishes, we used the method of co-creation, meaning that partners of cancer patients were actively involved during the developmental process and that their input was used to shape the content and the design of the intervention (see Table 1). First, we started with a needs assessment, consisting of an interview- and survey study. We interviewed 16 partners of cancer patients and asked them about their needs and wishes regarding the content and design of a web-based intervention and about the preconditions it should meet. During the interviews we also asked partners how their partner's disease had affected them personally and what has been helpful to them to cope with the situation. We were interested in this information, because we wanted to gather examples of possible problems and solutions to write appealing and recognizable texts and exercises. To validate the results of our interview study, we also conducted a survey-study among 168 partners of cancer patients (results of both studies will be published elsewhere). The most important outcomes of both needs assessment studies were: (1) partners seem to be interested in a web-based intervention; (2) partners could spend about 1 hours a week on an intervention; (3) most prefer that at least some parts of an intervention are addressed to the partner alone; (4) the intervention should contain information and some form of peer support; (5) themes that should be addressed include coping with emotions, communication, sexuality, asking for help and moving on with life after cancer treatment; (6) partners differ in their preferences about the need for having contact with a personal counselor; (7) the intervention should be framed as informal, easy accessible support with a "positive approach" and (8) partners felt that flexibility is one of the most important features.

Based upon theoretical insights, consultations with experts and with the input from the interviews, texts were written and psychological exercises were prepared. At the end of this phase we had developed a first booklet version of the intervention *Hold, on for each other*. Next, we asked three potential users and one expert to evaluate the content. The participants were generally positive about the texts and exercises. They recognized the situations and examples given in the texts and they evaluated the exercises as useful. Yet, the participants also had some recommendations. For example, they suggested to provide more information on topics like sexuality and intimacy, financial and insurance issues and communication issues (e.g. how to communicate with younger children about the disease of their parent).

Based on their feedback, text materials were adjusted and the web-based application was developed. In a usability test, three partners of cancer patients and five immediate family members were observed while walking through the personal homepage of the intervention and the first module of the intervention. After using the intervention, they were asked to evaluate the web-based application. They found that the application was both useful and useable. Furthermore, they liked the conveniently arranged design, the use of fresh colors and the consequent structure of the different modules. The participants also made some suggestions to improve the web application. For example, they said that some instructions of the exercises were unclear or confusing, they were not satisfied with the use of the colors of the “help”- and “home”-button and they disliked the image we had chosen as the header of the application. The participants’ feedback was used to improve the usability of the web-based application (for example a new header was implemented and the color of help-button changed from grey to red). At last, we will study the (cost-) effectiveness of the web-based intervention *Hold, on for each other* in a randomized controlled trial, that is described in this study protocol. Before we move on to the study questions, a short description of the intervention is provided below.

Table 1 Developmental process of *Hold, on for each other*

Step	Aim
1	What are the partners’ needs regarding a web-based intervention? Interview-study Survey-study
2	Development of content material (texts and exercises)
3	Formative study: potential users are asked to evaluate content
4	Development of online application
5	Usability test and adaptation of the application
6	Effect study (RCT)
7	Economic evaluation

Description of the intervention: ‘Hold, on for each other’

Hold on, for each other consists of six modules, which can be worked through in six weeks. In case participants need more time, they have the opportunity to work through the total intervention in maximal 12 weeks. In each module one particular theme is discussed. The first module focuses on the emotional consequences of being a partner of a cancer patient. Participants learn how to recognize, allow and express their emotions. In module 2, participants learn how to manage a period of chronic stress and module 3 focuses on worrying and negative thoughts. Module 4 and 5 are focused on values in life and in the relationship and the commitment to those values. Furthermore, the importance of beloved moments in a relationship are addressed. Module 6 is about the importance of communication. There are also two optional modules (participants can decide which is most relevant to them): one module concentrates on how to move on with life after successful cancer treatment; the other focuses on the terminal phase. If partners decide to do an optional module, they will receive two more extra weeks.

All modules start with a short text that matches the theme of each module (as described above). The texts are enriched with short psychological exercises. Both (texts and exercises) are based on ACT (a detailed overview of the components can be found in Table 2). Next to the ACT-exercises, in each module a meditation exercise (audio- and text-file) based on mindfulness and self-compassion is included. Mindfulness and self-compassion are congruent with ACT, and they can offer interesting insights to partners of cancer patients. Mindfulness can help partners of cancer patients to attend to the present moment in a receptive manner which will, over time, reduce the identification with self-focused thoughts and emotions that can lead to poorer mental health [21]. Besides, mindfulness can help partners of cancer patients to be aware of their painful feelings in a clear and balanced way. This means that they neither ignore nor exaggerate negative experiences [22]. Self-compassion is necessary to recharge batteries and emotional energy needed to care for others. Constantly criticizing oneself, especially for the feeling that one is never doing enough, will eventually lead to stress and symptoms of depression [23].

Next to information and exercises, participants also receive practical information, tips and references to relevant websites and organisations and the modules contain poems or inspiring texts. In order to optimally support the partners of cancer patients with completing the web-based intervention, three persuasive elements according to Kelders [24] were incorporated in the design of *Hold on, for each other*. First of all, the intervention contains a text message service. Participants can choose to receive text messages with short inspiring texts. Second, tunnelling is used in order to guide the participants through the intervention. And third, two types of social support are incorporated in the intervention: peer- to peer support and professional support. To facilitate peer–to-peer contact, participants have the possibility (1) to share their answers on some exercises with other participants (and to read those of others), (2) to add tips and advices and to read tips of others, and (3) to get in contact with other participants in a private e-mail conversation. If participants want to share their answers, or to contact other participants, they have to create a short profile first. This profile consists of: a (nick) name, sex, age, children and form of cancer the ill partner is diagnosed with. This profile provides partners with the opportunity to look for peers who are similar to them.

As mentioned before, the intervention also contains professional support. We want to investigate two different kinds of professional support: personal support (feedback on a weekly basis provided by a counsellor) versus automated support (feedback immediately after completing an exercise). Participants in the “personal support” condition receive weekly feedback from a counsellor through e-mail contact. After the completion of a module, a counsellor sends an e-mail to the participant (at an appointed day of the week) with a reflexion on the progress of the participant and a reaction to possible problems and questions. Participants have the same counsellor during the whole intervention period. Counselling is performed by trained master students Psychology of the University of Twente in the Netherlands who are under supervision of the researcher and a clinical psychologist.

In sum, the role of the counsellor is the guidance and support of the process. Aim of the e-mail contact is predominantly to improve adherence of the intervention. In addition, participants developing serious problems during the enrolment in the intervention can be recognized and advised to find help. Participants in the “automated support” condition will receive short feedback messages directly after completing an exercise. The feedback is developed before the start of the intervention and the messages will appear in a pop-up window.

Present study

This present study has several aims. First, we want to assess the (cost-) effectiveness of the intervention *Hold on, for each other*. Our main hypothesis is that both versions of the intervention lead to a significant reduction of psychological distress compared to a waiting list control condition. In addition, we hypothesize that (positive) mental health, health related quality of life and general health of participants of the experimental conditions will increase and caregiver burden will decrease in comparison to the participants in the waiting list control condition. The second aim of our study is to examine if psychological flexibility, self-compassion, mastery, style of support behavior (overprotection, protective buffering, active engagement), posttraumatic growth and resilience are mediators of the intervention’s effects on the partners’ mental health. Third, we aim to examine the moderating effects of the socio demographics (age, gender, education, working situation, family situation) and disease-related characteristics of the patients (sort of cancer, stage of disease, duration and treatment of cancer). Finally, we want to know to what extend participants are satisfied with the intervention, which parts of the intervention are mostly used, and how compliant the users are.

Table 2 Modules, key components and example exercises of 'Hold on, for each other'

Module	**Key components**	**Example exercise**
Coping with your emotions	Acceptance Self-compassion/ Mindulness	How I put on a brave face?: Description: We ask partners to write down emotional situations they have experienced, how they felt at that moment the situation occurred and how they coped with it. Aim: To help partners to be aware of their own emotions and their coping mechanisms. Are they regularly putting on a brave face and are they suppressing their emotions?
Your resilience-plan – how can you keep going?	Acceptance Self-compassion/ Mindfulness	How much do you demand of yourself?: Description: We ask partners to write down how many hours they work, sleep, and have leisure time each week. Aim: To show partners how much they demand of themselves and if their planning is realistic.
My mind works overtime	Cognitive defusion Self-compassion/ Mindfulness	Worry Box: Description: In this exercise we ask partners to write down their thoughts, worries and fears on a piece of paper and put each paper in a box. After that they have to close the box and put it away. Later they can throw the box away or they can open it once in a month and read the worries again. Aim: To show that worries are often not based on firm grounds. The worry-box can help to put worries in perspective and it can show that ruminating is often useless.
What is now really important?	Values Self-compassion/ Mindfulness	Values in your relationship: Description: We asked partners to write down those things in their relationship that they value the most. Aim: To make them aware of things that are not congruent with their values. Are there things that should be different? Is it worth it to invest in the relationship? What can they do to come closer to their values.
Afraid, tired and moments of joy	Committed action Self-compassion/ Mindfulness	Celebrate your relationship: Description: we asked partners to choose activities (e.g. to write a love letter, to have dinner at their favourite restaurant). Aim: To make them aware of how precious their relationship is and how to live in accordance with their values.
The art of communication	Communicating about what really matters Self-compassion/ Mindfulness	What would you like to talk about?: Description: we ask partners to write down topics they have discussed lately with their partner, if there are topics that haven't been discussed yet, and -if so- why these topics haven't been discussed yet. Aim: To stimulate partners to communicate about the things that really matter.
Moving on with life (optional)	Acceptance, cognitive defusion, values Self-compassion/ Mindfulness	Increase your hope: Description: We ask partners to imagine the situation that their partner is cancer free for almost a year, and that he/she is feeling alright. They -as a partner- have done everything possible to cope with the situation, they have accepted it and they are moving on with life. We ask them to imagine how life could be under these conditions. Aim: To show them that it sometimes can be helpful to create some distance and to have a closer look at their situation from a different point of view.
A good last period (optional)	Acceptance, communicating about what really matters, committed action Self-compassion/ Mindfulness	Beautiful memories: Description: We ask partners to think about (alone or with their spouse) what they can do to produce new memories (e.g. think about things you want to experience together, trips or activities you want to make). Aim: In this exercise a lot of aspects come together. To accept the development of the disease, to talk about what really matters at the moment, and to commit to values and live in accordance to them.

METHODS/DESIGN

Study design

This study is a prospective randomized controlled trial with three parallel groups:

1. Experimental condition 1: Web-based intervention *Hold on, for each other*, with personal support.
2. Experimental condition 2: Web-based intervention *Hold on, for each other*, with automated support.
3. Waiting list control condition: Participants will be on a waiting list for 3 months from entry/intake. They will receive ‘Hold on, for each other’ (with automated feedback) after the first follow-up measurement, three months after the start of the intervention for the experimental condition.

This study has been approved by the Twente Medical Ethics Committee under the file number P13-17 (Dutch trial register: NTR4035). Participation is voluntary and all respondents will provide written informed consent before inclusion.

Population and procedures

The population in this study consists of adult partners of cancer patients. To receive a heterogeneous group of participants, a multi-component recruitment strategy is followed (see Table 3). In all recruitment materials (e.g. advertisements, leaflets) the URL of the website (www.houvastvoorelkaar.nl) is mentioned, where respondents can find more information (including a short promotion video) and where they can apply to participate. On this website, respondents can also read and download the patient information letter. Respondents can also do a self-assessment of eligibility on basis of the in- and exclusion criteria. Inclusion criteria are: (1) age of 18 years and older; (2) being partner of a cancer patient or cancer survivor; (3) having internet access; (4) no problems with the Dutch language; (5) and having mild to moderate symptoms of psychological distress symptoms (> 3 on the Hospital Anxiety and Depression Scale (HADS) [25]. Exclusion criteria are: (1) severe anxiety (score on HADS-A ≥ 15) and severe depression (score on HADS-D ≥ 15); (2) recently started (less than three months ago) with psychological or psychopharmacological treatment; (3) not being able to spend 1-1.5 hours on the intervention every week; (4) partner died because of cancer and (5) diagnosis of partner’s disease is less than 3 months ago. Respondents who are eligible and would like to participate in the study can fill out an online contact form and will then receive an informed consent form by mail (reply envelope included). Respondents are asked to return the signed informed consent within a few days by mail.

After receiving this informed consent, participants are sent an invitation by e-mail to fill out the HADS (14 items). People with severe anxiety and/or depression (cut-off score ≥ 15 on HADS-A and/or ≥ 15 HADS-D) [26] are excluded, because severe distress would require more intensive individual diagnostics and treatment. Participants that are excluded based upon severe psychological distress are contacted by telephone by a psychologist in order to be sure that these people are referred to adequate help. All partners with moderate scores on HADS-A and/or HADS-D (score 11-14 on HADS-A and/or HADS-D) are telephoned to assess the depressive episode module and the anxiety disorder modules of the Mini International Neuropsychiatric Interview (M.I.N.I.) [27]. In people screened as having a depressive disorder and/or an anxiety disorder by the MINI, the Sheehan Disability Scale (SDS) [28, 29] is administered to measure the severity of their symptoms. Participants are asked to rate the extent to which work, social life and family life are impaired by their symptoms on a 10-point scale (0= not at all impaired; 10= extremely impaired). If participants report on at least two areas of their life severe impairment (scores ≥ 7) [28], they will be excluded from the study and will be strictly referred to seek adequate professional help. The telephone assessment of the M.I.N.I will be performed by trained and supervised master students.

Table 3 Recruitment channels and recruitment strategies

Recruitment via…	Recruitment strategy
National newspapers and magazines	Advertisements, newspaper articles
Media	Interviews on radio and television, Twitter, Facebook
Websites and magazines of relevant organizations (e.g. website of Dutch Cancer Society)	Online advertisements, newsletters
Patient organizations and drop-in-centers	Online advertisements, newsletters, leaflets, presentations
Hospitals and psycho-oncological organizations	Online advertisements, newsletters, leaflets, posters, presentations
Other (e.g. psychologists, rehabilitation centers, general practitioners, physiotherapists)	Leaflets, posters

Randomization

Respondents who are eligible, have provided their informed consent, and have completed the baseline (T0) questionnaire, are automatically randomized and divided over the three conditions. Randomization is stratified for gender, so an equal distribution of female and male participants in all conditions is warranted. Additionally, we stratify for the perceived stage of disease, which is measured by the following item: (1) My partner is still in treatment and we have good hope that he/she will recover; (2) The treatment is completed and we are moving on with our lives; (3) My partner is unlikely to be cured. All participants receive an e-mail with the outcome of randomization and a link to start the intervention. Participants are informed about the three different conditions. They know that there is a waiting list control condition and that there are two experimental versions, one with automatic feedback and another with personal feedback. Participants in the experimental conditions will receive immediate access to the web-based intervention *Hold on, for each other*. The intervention is individually administered and the participants can access the intervention at any time, from any place, free of charge. Participants that will be placed on a waiting list have the opportunity to access treatment as usual (TAU) and they will be referred to relevant websites such as the website of Dutch Cancer Society (http://www.kwfkankerbestrijding.nl/ or http://www.kanker.nl) for information. Three months after the baseline measurement, which is directly after the first follow-up measurement at three months, participants on the waiting list receive the opportunity to follow the web-based intervention *Hold on, for each other* with automated feedback. They will also be invited to fill out measurements 6 and 12 months after the baseline measurement (see flowchart, Figure 1).

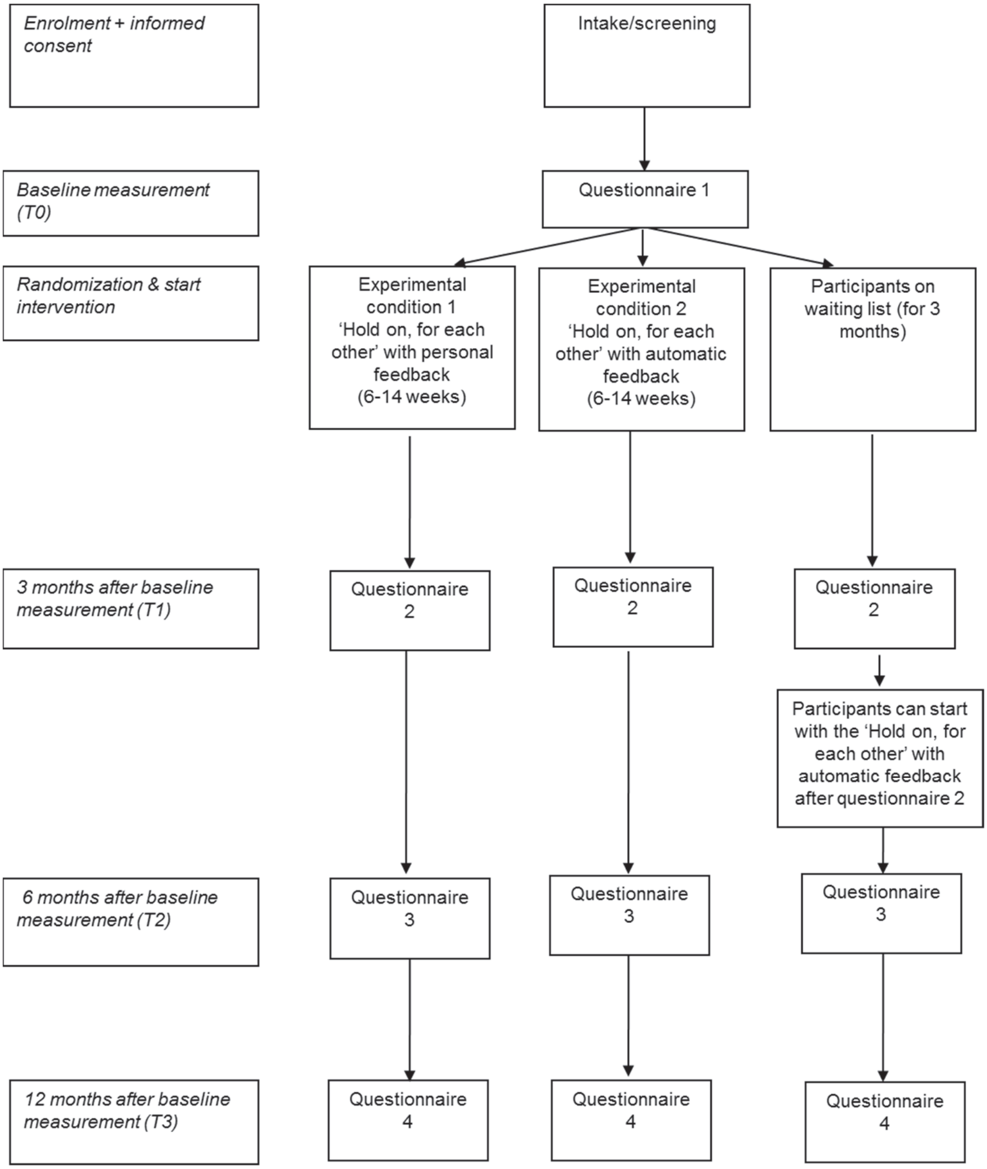

Figure 1 Flowchart of 'Hold on, for each other'

Measurements

Overview

Table 4 gives an overview of all measurements. Participants will be asked to complete online questionnaires at baseline (T0); three months after the baseline measurement (T1); six months after the baseline measurement (T2); and twelve months after the baseline measurement (T3). The intervention as well as the questionnaires can be worked through in the participant's own living environment.

Table 4 Measurement overview

		Experimental conditions				Control condition			
Measure	Instrument	T0	T1	T2	T3	T0	T1	T2	T3
Socio-demographics and disease-related characteristics									
Socio-demographics of the partner	Sex, age, education, marital status, cultural background, children, work status	X				X			
Disease-related variables of the patient	Sort of cancer, time of diagnosis, past and current treatment, current situation (prognosis)	X				X			
Outcome measures									
Psychological distress	HADS total	X	X	X	X	X	X	X	X
Mental health	MHC-SF	X	X	X	X	X	X	X	X
Caregiver strain	CSI	X	X	X	X	X	X	X	X
General health	RAND 36	X	X	X	X	X	X	X	X
Health-related quality of life	EuroQol EQ-5D	X	X	X	X	X	X	X	X
Mediators									
Psychological flexibility	AAQ-II	X	X	X	X	X	X	X	X
Self-compassion	SCS-SF	X	X	X	X	X	X	X	X
Posttraumatic growth	PTGI-SF	X	X	X	X	X	X	X	X
Resilience	BRS	X	X	X	X	X	X	X	X
Sense of mastery	Pearlin Mastery Scale	X	X	X	X	X	X	X	X
Support behavior	Active engagement scale	X	X	X	X	X	X	X	X
Evaluation									
Client satisfaction	CSQ-8		X					X	
Evaluation form			X					X	
Economic evaluation									
Healthcare consumption	TiC-P	X			X	X			X
Production loss due to illness and absenteeism	PRODISQ	X			X	X			X
Screening1									
Depression/anxiety (optional screening)	MINI (part: A, B, C, D, E, F, G, H, I, J, P)	X				X			
Severity of symptoms	SDS	X				X			

[1] The MINI and SDS will only be administered in people who have moderate scores on HADS-A and/or HADS-D (score 11 - 14 on HADS-A and/or HADS-D)

Socio-demographics and disease-related characteristics

The following socio-demographics of the partners are assessed: sex, age, education, marital status, cultural background, children, work status. Regarding their partner's disease, participants are asked about type of cancer, time since diagnosis, current treatment and self-reported stage of disease (see description in paragraph 'Randomization').

Outcome measures

Psychological distress—the primary outcome—is measured with the total Hospital Anxiety and Depression Scale (HADS) [25]. The HADS is a 14-item questionnaire that measures the presence and severity of anxiety and depressive symptoms. Answering categories range from 0 to 3 and the items are added to a scale score that can range from 0 – 42. Higher scores mean more symptoms of psychological distress.

Mental health is assessed with the Mental Health Continuum – Short Form (MHC-SF) [30, 31]. The MHC-SF is a 14-item questionnaire that measures three dimension of positive mental health [30]: emotional wellbeing (3 items), psychological wellbeing (6 items), and social wellbeing (5 items). Participants are asked to rate the frequency of feelings they have experienced in the past month. Items are scored on a 6-point scale ranging from 1 to 6. A mean score is computed ranging from 1 to 6 with higher scores indicating higher levels of positive mental health. The Dutch version of the MHC-SF has shown good psychometric properties [31].

Caregiver strain is assessed with the 13-item Caregiver Strain Index (CSI) [32]. The CSI contains at least one item to measure burden in each of the following major domains: employment, financial, physical, social and time. Each item can be answered with 'yes' (1) or 'no' (0). A CSI score is computed by counting the number of 'yes', resulting in a score from 0-13. The CSI has shown good psychometric properties [32].

General health of the partners of cancer patients is assessed with one item of the RAND 36 [33, 34]. This item "How would you rate your own general health?" can be answered on a 5-point scale ranging from 1 - 5, with higher scores indicating better general health.

Health-related quality of life of the participants is measured with the EuroQol EQ-5D [35]. The EQ-5D is a validated instrument for measuring health-related quality of life and it covers five domains of health: mobility, self-care, usual activity, pain/discomfort and depression/anxiety. Each of the five domains has three severity levels; 0 (none), 1 (some), and 2 (severe).

Moderators and mediators

In this study age, gender, stage of disease and compliance (frequency and time spend on the website) are examined as moderators. The following variables are examined as mediators: psychological flexibility, self-compassion, posttraumatic growth, resilience, styles of support behavior and sense of mastery.

Psychological flexibility is measured with the 7-item Acceptance and Action Questionnaire II (AAQ-II) [36, 37]. Answering categories range from 1 to 7 and the items are added to a scale score that can range from 7 to 49, with higher scores indicating more psychological flexibility [36]. The Dutch version of the AAQ-II has shown good psychometric properties [38] also in adults with psychological distress [39].

Self-compassion is measured with the Self-Compassion Scale Short-Form (SCS-SF) [40, 41]. This questionnaire consists of 12 items and is measuring six components of self-compassion: self-kindness, self-judgment, common humanity, isolation, mindfulness and over-identification (2 items for each component). Respondents rate on a 7-point scale ranging from 1 to 7. A mean score is computed with higher scores indicating higher levels of self-compassion. The SCS-SF has adequate psychometric properties [41].

Posttraumatic growth is assessed with the 10-item Posttraumatic Growth Inventory- Short Form (PTGI-SF) [42, 43]. All items are positively formulated and comprising five factors: (1) relation to others (2 items); (2) new possibilities (2 items); (3) personal strength (2 items); (4) spiritual change (2 items); and (5) appreciation of life (2 items). Respondents rate each item on a 6- point scale ranging from 0 to 5 and the items are added to a scale score that can range from 0 - 50, higher scores indicating higher posttraumatic growth. The questionnaire has shown good psychometric properties [43].

Resilience is measured with the 6-item Brief Resilience Scale (BRS) [44]. The BRS assesses the ability to bounce back or recover from stress. Respondents rate on a 5-point scale ranging from 1 to 5. The BRS is scored by averaging the scores on the items (after reversing the negative ones). The score can range from 1 to 5, higher scores indicating higher levels of resilience. The BRS has shown good psychometric properties [44].

The different styles of support behavior are assessed with the 19-item Active engagement scale [45]. Five items constitute the active engagement scale, 8 items measure protective buffering and 6 items measure overprotection. Items can be answered on a 5-point scale ranging from 1 to 5. For each subscale, the items are averaged within subjects into a scale score that ranges from 1 - 5. The Active engagement scale has shown good psychometric properties [46].

Sense of mastery is measured with the 5-item Pearlin Mastery Scale (PMS) [47]. The instrument measures the extent to which one regards one's life chances as being under one's own control in contrast to being fatalistically ruled. Items are scored on a 5-point scale from 1 to 5. The scores on the items are added to a sum score that can vary from 5 to 25. High scores signify that the individual perceives him or herself in control of his or her life.

Evaluation of the intervention

To measure the client satisfaction after the intervention, the 8-item Client Satisfaction Questionnaire (CSQ-8) [48] is used. All items are scored on a 4-point scale ranging from 1 to 4. For each individual a 'satisfaction-score' is computed by averaging their scores on the 8 items. Also a question is included about how the participants evaluated the intervention on a scale from 1 to 10. Furthermore, the participants are asked (1) the number of hours they have on average spend completing the intervention; (2) to what extent they have completed the exercises; (3) if they have used the different components of the web-based intervention; and (4) if they were satisfied with the received feedback. We also asked them to write down three aspects of the intervention they appreciated most and three things they appreciated least. Finally, we asked them if they have suggestions for improvement of the intervention.

Economic evaluation

The economic evaluation will be carried out using the Trimbos questionnaire for Costs associated with psychiatric illness (Tic-P) [49] and the Productivity and Disease Questionnaire (PRODISQ) [50]. Healthcare consumption is measured with two items of the Tic-P. The items are (1) in how far have participants made use of the healthcare facilities in the last four weeks? and (2) to what extent did they receive other help (e.g. from family and friends or homecare) in the last four weeks?. Participants can answer these questions with yes (1) or no (0). In case they made use of a healthcare facility (answer 'yes'), they are asked how often they made use of it. Production losses due to illness and absenteeism will be measured with 6 items of the PRODISQ. Utilities will be derived from the EuroQol (EQ-5D) scores. Mean incremental cost per patient and the incremental cost utility ratio (ICER) will be calculated. The economic evaluation will be assessed from a societal perspective, thus including the intervention costs (such as costs for building the intervention, costs for hosting the website), the costs of formal and informal health care (TIC-P), and the economic costs due to productivity losses in paid and unpaid work in the four weeks preceding the trial (PRODISQ).

Statistical analysis

The data of partners will be coded directly after being collected and will be entered into a statistical database to ensure accuracy and completeness of the data. Before we start with our data analysis, we will check if our data is normally distributed. If it is not, we will choose a non-parametric test. All data will be analyzed using SPSS version 20.

Descriptive statistics

A flow chart of participation during the total study will be drawn. Reasons for drop-out will be summarized. Percentages of missing values and dropout will be displayed. Background variables and summarized scores on questionnaires as mentioned in chapter 6 will be given.

Basic psychometric analyses will be conducted to verify scale structure and internal consistency of the used questionnaires.

Effects

One-way ANOVA’s and χ^2-tests will be performed to see if there are no significant differences at baseline between the two conditions for any of the demographic variables or outcome measures. Non-significant differences will indicate successful randomization. Intention-to-treat analyses will be conducted with use of SPSS missing values analysis to impute all missing data on the continuous measuring multiple imputation methods in SPSS. To examine differences between the conditions on all outcome measures, ANOVA (group x time) will be used. In the case of significant group x time – interactions, Tukey’s post hoc tests will be used.

Effect sizes on the primary outcome variable (HADS total) at post-intervention will be calculated with Cohen’s D using the means and pooled standard deviations of the measurements of the conditions (effect size of above .56 are considered large, .33-.55 are considered moderate, and less than .33 are considered as small [51].

Moderation and mediation analysis

The moderating effect of the socio-demographics (age, gender, education, working situation, family situation) and disease-related characteristics of the patients (type of cancer, stage of disease, duration and treatment of cancer) on the effectiveness of the intervention will be analyzed using regression analyses.

Mediation analysis will be performed as described by Preacher and Hayes [52, 53]. Aim of this analysis is to assess whether psychological flexibility, self-compassion, supportive behavior, posttraumatic growth and resilience are mediators in the effect between the independent variable and the dependent variables.

Sample size calculation

Based upon a previous, similar study [54] we expect effect sizes of at least d=0.5. To demonstrate the presence of an effect of at least d=0.5 as statistically significant in a two-tailed test at alpha = 0.05 and a power of (1-beta) = 0.80, a minimum of 64 participants in each condition will be required at follow-up (power calculation in G*Power). We have extended our sample size with 5 participants per condition in order to take normal distribution of the data as well as possible post hoc tests into account. Anticipating a drop-out rate of 20% between T0-measurement and T3-measurement, at least 87 participants per condition need to be included at T0-measurement. The total study cohort comprises thus 261 participants.

DISCUSSION

Hold on, for each other is the first web-based self-help intervention for partners of cancer patients that is based on both a clear theoretical framework and an iterative and user-centered development. The main purpose of the RCT is to evaluate the (cost-) effectiveness of *Hold on, for each other*, a recently developed web-based intervention for partners of cancer patients. Additional goals are: (1) to examine if psychological flexibility, self-compassion, mastery, supportive behavior, posttraumatic growth and resilience are mediators of the intervention's effects on the partners' mental health; (2) to examine the moderating effects of the socio demographics (age, gender, education, working situation, family situation) and disease-related characteristics of the patients (sort of cancer, stage of disease, duration and treatment of cancer); and (3) to examine to what extend participants are satisfied with the intervention.

Strengths and limitations of the intervention

Hold on, for each other is a unique product. This web-based intervention is based on a clear theoretical framework (ACT) and the needs and wishes of the end-users have been carefully taken into account by the use of co-creation. We think that it is this combination that can make *Hold on, for each other* a successful intervention for partners of cancer patients who are in need of support. Also, this intervention is unique because it is positively framed. Partners who participated in our needs assessments agreed that an intervention for partners of cancer patients should be based on a positive approach. According to them, an intervention should be a source of hope and energy and it should focus on things that still can be done, instead of things that no longer can be done (because of their partner's disease). Therefore, the focus of the intervention is based on the concept of making the best of life in a difficult time.

To the best of our knowledge, *Hold on, for each other* is one of the first web-based interventions for partners of cancer patients. In a literature review only three other web-based interventions for caregivers of cancer patients were found [9]. As we described earlier, the internet and recent technologies offer various possibilities (availability, easy accessible, flexibility) that can be of great value for this target group. Most importantly, partners can do the intervention at any convenient time. Daily exercises are short and can often be done while working, doing the household or giving care.

Another strength of the intervention is that it consists of a variety of components. Partners of cancer patients are offered a package of different features including information, psychological exercises, peer support, practical tips and text messages. Partners can choose freely which of the components they want to use, and in which way they want to use them.

For example, they can decide if they want to have contact with peers, and if so, they can choose if they want to actively write down their own experiences or if they merely want to read experience of other peers. Also, persuasive elements (such as text messages, tunneling and social support) are incorporated in the design of intervention in order to improve adherence to the intervention [24].

If proven effective, *Hold on, for each other* may easily be implemented in the Dutch healthcare system. One part of our implementation plan is to inform the various stakeholders from the beginning of the project: partners and cancer patients via patient societies (e.g. NFK), the Dutch Cancer Society, health care professionals as physicians, nurses, psychologist, social workers and drop-in centers. We have already started informing the stakeholders in the context of recruitment of participants. If the intervention is found to be effective, we expect that hospitals and other organizations with a focus on psycho-oncology (such as drop-in centers, general practitioners, patient organizations) will be interested in referring partners of cancer patients to this easy accessible psychosocial care option. Health care is rapidly changing and incorporating all kinds of e-health applications. In general, there is a growing interest in web-based, automated screening and monitoring of physical and psychological functioning of patients and partners as part of general portals with different functions (information, electronic dossiers, email, et cetera).

Hold on, for each other may also have some limitations. First of all, not every partner may be interested in a web-based self-help intervention. We realize that some partners (for example elderly people) might prefer face-to-face contact with a health care professional instead of a (web-based) self-help intervention. However, we believe that the most important step is that partners of cancer patients are at least offered any kind of help. After that, they can decide for themselves if they need help, and whether they would prefer face-to-face contact with a health care professional or whether they would like to participate in a (web-based) self-help intervention. Besides, we think that it doesn't have to be one or the other. Face-to-face consultation and web-based support can also become more blended, in order to fully utilize the possibilities and advantages of both forms of support. This may also be an appropriate solution for people with severe distress for whom a mere self-help intervention is not sufficient. Highly distressed partners could participate in *Hold on, for each other* under supervision of a health care professional (e.g. a psychologist). The professional could guide them through the intervention and he or she could check on them and constantly monitor on the partners' (mental) health.

Another limitation may be that the intervention is not targeting bereavement. Therefore, *Hold on, for each* other is not applicable for partners who have already lost their ill spouse.

Strengths and limitations of the RCT

Our study will answer questions regarding the (cost-) effectiveness of *Hold on, for each other* and possible determinants of the effects of the intervention on psychological distress in partners of cancer patients. We will also conduct a detailed process evaluation to obtain insight in processes in use of the intervention (e.g. time spent on the website, number of exercises completed, content of the messages exchanges). Additionally, satisfaction with the intervention will be measured. For example, participants will be asked if the intervention met their expectations, if they liked the intervention and what they thought about the content of the feedback. These insights can help us to improve the intervention. Furthermore, long-term effects will be studied and an economic evaluation will be done. These two aspects are also highly relevant for a successful implementation in the Dutch healthcare system.

Our study also has some limitations. First, we have no long-term data for the waiting list control condition. For ethical reasons, the participants in this group receive the intervention after the T1 measurement (three months after the baseline measurement). Second, we expect that it is highly challenging to find enough partners of cancer patients who are willing to participate in this trial. From other studies among informal caregivers of cancer patients it is known that it is difficult to find enough participants to meet the previous calculated power (e.g. [55-57]). In order to anticipate on this challenge, we make use of a variety of recruitment channels and recruitment strategies (see Table 3).

To conclude, this study will yield valuable knowledge about the (cost-) effectiveness of a newly developed web-based self-help intervention for partners of cancer patients. If proven to be effective, *Hold, on for each other* may be offered as standard service for partners of cancer patients in the healthcare system.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

All authors contributed to the design of the study. NK drafted the manuscript and will take care of the recruitment of participants and data collection. CHCD, ETB and IMVDL helped to draft this manuscript. All authors provided comments, read and approved the final manuscript.

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Current status

Recruitment began on February 1, 2014 and will continue approximately through 31.03.2015.

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5

Understanding psychological distress and wellbeing in partners of cancer patients: the role of self-compassion

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Submitted

ABSTRACT

Objective: Self-compassion has been defined as comprising three components: mindfulness, self-kindness and common humanity. Recent studies have shown that self-compassion is an important factor in psychological health. Yet, its role in understanding the mental health of partners of cancer patients has not been studied yet. Therefore, we examined to what extent self-compassion is related to psychological distress and mental wellbeing in this group, and if self-compassion can add to the understanding of levels of distress/wellbeing after controlling for three other psychological resources, that have been related to adaptation to adversity: resilience, psychological flexibility and mastery.

Methods: In this cross-sectional study, 203 partners of cancer patients filled in a questionnaire, including demographics, cancer-related variables, psychological distress (HADS), positive mental wellbeing (MHC-SF) and self-compassion (SCS-SF). In addition, the following psychological resources were assessed: sense of mastery (PMS), resilience (BRS) and psychological flexibility (AAQ-II).

Results: Consistent with previous research, self-compassion was negatively correlated to distress (r=-.38) and positively to wellbeing (r=.35). Self-compassion was not associated with demographics or cancer-related characteristics, and moderately with resilience (r=.31), mastery (r=.35) and psychological flexibility (r=.51). Regression analyses revealed that self-compassion could significantly improve the prediction of distress (P<.001) and wellbeing (P=.05), after controlling for resilience, psychological flexibility and mastery. The positive dimension of the SCS-SF was stronger related to distress and wellbeing than the negative.

Conclusion: Self-compassion appears to be a significant, unique factor in understanding levels of distress and mental wellbeing in partners of cancer patients and could serve as a clue for future supportive interventions.

BACKGROUND

Cancer imposes challenges not only for the individual being diagnosed, but also for their family members. Especially partners of cancer patients are faced with multiple challenges. They often have to provide informal care and emotional and practical support to the patient, next to maintaining their work and/or family life. In addition, partners have to deal with their own emotions, shifts in roles and changes in future perspectives. These challenges may affect their physical, mental and social health [1,2], and studies have shown [e.g. 3] that clinical levels of psychological distress are highly prevalent in partners of cancer patients, and that their distress levels can even be higher than the levels experienced by the patients [1].

The concept of self-compassion may be useful in understanding partner's distress and could be used in interventions to reduce distress and improve wellbeing in partners of cancer patients. In general, self-compassion refers to the ability to be sensitive to the suffering of the self, combined with a commitment to try to alleviate and prevent it. According to Neff [4] self-compassion is composed of three components: self-kindness vs self-judgement, common humanity vs isolation, and mindfulness vs over-identification. Self-kindness refers to the ability of being kind and understanding towards ourselves when we suffer, fail or feel inadequate, instead of flagellating ourselves with harsh self-criticism. The second component, common humanity, refers to the ability of recognizing that the human condition is imperfect; that we all make mistakes and that we are not alone in our suffering. This makes us feel less isolated when we have failed or are in pain. The final component, mindfulness, refers to the ability of turning toward one's painful thoughts and emotions and seeing them as they are, instead of avoiding or supressing them, or over-identifying with them.

In the past decade, the number of studies on self-compassion is growing rapidly. In general, these studies reveal that self-compassion is positively related to wellbeing (including positive affect, life satisfaction and happiness) and negatively to distress (including anxiety, depression, stress, rumination and avoidance) [5-7]. Self-compassion has been associated with an ability to manage adversity and make necessary life changes [8], and has been studied in relation to facing physical conditions such as HIV [9], coping with daily hassles [10] or life stressors such as divorce [11] and exposure to war trauma [12].

Remarkably few studies have looked at self-compassion in the context of informal caregiving [13], and to our knowledge no studies have ever examined self-compassion in partners of cancer patients. Yet, the components of self-compassion can be particularly useful for informal caregivers to better deal with the challenges that are imposed upon them. For example, many spousal caregivers forget or neglect their own needs because their focus lies primarily on the wellbeing of the patient [14,15]. Partners of cancer patients may also ignore or suppress their own negative emotions in an attempt to not upset the partner even more. This so called ‘protective buffering’ can have detrimental effects for the relationship and for the partners’ wellbeing in the long run [16]. Self-compassionate mindfulness may help partners to take a more balanced approach to their negative emotions so that these are no longer avoided and partners feel less isolated [4]. Studies have also shown that partners of cancer patients may feel guilty for not performing well enough in caregiving, for taking time away from caregiving to meet their own needs or for enjoying pleasurable things while their partner is suffering [15,17]. Self-compassion could help these partners to be less hard on themselves and help them to acknowledge and comfort themselves for the difficulties of their caregiving role [8]. The aim of the current study was therefore to explore the role of self-compassion in psychological distress and mental wellbeing in partners of cancer patients.

Although self-compassion has been consistently associated with distress and mental wellbeing, it has not often been studied alongside other, related constructs that have been studied in the context of adaptation to adversity. The ‘psychological resources’ that we were interested in were: sense of mastery, psychological resilience and psychological flexibility. Sense of mastery refers to the extent to which individuals perceive themselves in control of forces that significantly impact their lives. A high sense of mastery has shown to be associated with better adjustment to disease, including cancer [19]. Psychological resilience can be defined as the process of adapting well in the face of adversity or the ability to “bounce back” from difficult experiences and traumatic events [20]. Studies have shown that resilience can protect against emotional distress in cancer patients [21] and their caregivers [22]. Psychological flexibility refers to the willingness to accept difficult thoughts and emotions instead of trying to avoid or control them, in combination with changing or persisting in behaviour that serves self-chosen values. Psychological flexibility has not often been studied in the context of cancer yet, but has been repeatedly associated with increased wellbeing and decreased psychological morbidity [23], for example in patients with chronic pain [24]. Our study aimed to examine the extent to which self-compassion is related to these concepts, and if the concept of self-compassion could significantly add to the explanation of distress and wellbeing in partners of cancer patients after controlling for these variables.

In sum, this study aimed to explore the role of self-compassion in partners of cancer patients. First, we examined to which extent self-compassion is related to distress and mental well-being. Second, we examined if self-compassion would account for unique variance in distress and wellbeing over and above related constructs, including resilience, mastery and psychological flexibility.

METHODS

Design

For this cross-sectional study, we used the baseline data of a three-armed randomized controlled trial (RCT) to evaluate the effects of a web-based supportive intervention for partners of cancer patients (‘Hold on, for each other’) against a waiting list group. Detailed information about the intervention and the RCT is published elsewhere [25]. Ethical approval was obtained from the Twente Medical Ethics Committee under the file number P13-17 (Dutch trial register: NTR4035).

Participants & procedures

Participants were recruited via advertisements in newspapers and on the internet, via relevant patient organisations, ‘drop-in centres’ and hospitals. Inclusion criteria were: (1) being 18 years or older; (2) being partner of a cancer patient; (3) having internet access; (4) willing and able to spend 1-1.5 hours on the intervention every week; and (5) having mild to moderate symptoms of psychological distress symptoms (>3 on the Hospital Anxiety and Depression Scale, HADS). Exclusion criteria were: (1) severe anxiety or depressive symptoms (score ≥ 15 on either HADS_A or HADS_D); (2) recently (<3 months ago) started with psychological or psychopharmacological treatment; (3) problems with the Dutch language; (4) patient already deceased and (5) diagnosis of patient’s cancer was less than 3 months ago. In total 203 partners fulfilled the criteria, gave consent and filled out an online questionnaire before randomization. The data of these 203 partners were used for the current study.

Measures

Personal characteristics, cancer-related characteristics and caregiver strain

Information on participants’ sex, age, educational level and current employment status were assessed. General health of the participants was assessed with one item of the RAND-36 [26,27]: “How would you rate your own general health?” (answering options from 1 – 5; higher scores indicating better health). Regarding their partner’s disease, participants were asked about the type of cancer, the time since diagnosis and the self-reported stage of disease. The latter was measured by asking the respondents which of the following options was most applicable to them: (1) My partner is still in treatment and we have good hope that he/she will recover; (2) The treatment is completed and we are moving on with our lives; or (3) My partner is unlikely to be cured. The burden of caregiving was measured with the Caregiver Strain Index (CSI) [28], consisting of 13 items that measure burden in the following major domains: employment, financial, physical, social and time. Each item could be answered with ‘yes’ (1) or ‘no’ (0). A CSI-score was computed by counting the number of ‘yes’, resulting in a score from 0-13 (Cronbach’s α = 0.66). A CSI-score of > 7 is considered as high caregiver burden [28].

Self-compassion

Self-compassion was measured with the Dutch version of the Self-Compassion Scale Short-Form (SCS-SF) [29,30] that consists of 12 items about the three positive components of self-compassion (self-kindness, common humanity, and mindfulness), and the three negative components (self-judgment, isolation and over-identification): 2 items for each component. Items could be answered on a scale from 1 to 7. A mean scale score was computed, with higher scores indicating higher levels of self-compassion (Cronbach’s α=.86). In line with recent work, from for example [31,32], we also computed scale-scores for the positive (6 items) and negative dimensions (6 items) of self-compassion (Cronbach’s α respectively 0.76 and 0.83).

Psychological distress and mental wellbeing

Psychological distress was measured with the total Hospital Anxiety and Depression Scale (HADS) [33]. The HADS measures the presence and severity of anxiety (7 items) and depressive symptoms (7 items). Answering options range from 0 to 3 and were added into a scale score for anxiety (α = 0.77), depression (α = 0.81) and a total score for psychological distress (α = 0.86). Mental wellbeing was assessed with the Mental Health Continuum – Short Form (MHC-SF) [34,35]. The MHC-SF is a 14-item questionnaire that measures three dimensions of positive mental health: emotional wellbeing (3 items), psychological wellbeing (6 items), and social wellbeing (5 items). Participants are asked to rate the frequency of feelings they have experienced in the past month on a scale from 1 to 6. Higher scores indicate higher levels of positive mental health. For each subscale and for the total scale, a mean scale score was computed (Cronbach’s alpha’s was 0.87 for the total scale, and respectively 0.71, 0.79 and 0.74 for the emotional, psychological and social subscales).

Psychological resources

A number of related psychological variables, called ‘psychological resources’ were assessed, namely: sense of mastery, resilience and psychological flexibility. Sense of mastery was measured with the 5-item Pearlin Mastery Scale (PMS) [36]. This instrument measures the extent to which one regards one’s life chances as being under one’s own control in contrast to being fatalistically ruled. Items are scored on a 5-point scale from 1 to 5 and were averaged into a scale score (Cronbach’s α = 0.80). Higher scores signify that the individual perceives himself more in control of his life. Resilience was measured with the 6-item Brief Resilience Scale (BRS) [20]. Respondents rate on a 5-point scale ranging from 1 to 5. A BRS scale score is computed by averaging the scores on the items (after reversing the negative items). Higher scores indicate higher levels of resilience (Cronbach’s α = 0.81). Psychological flexibility was measured with Dutch version of the 7-item Acceptance and Action Questionnaire II (AAQ-II) [23,37]. The scores on the items range from 1 to 7, and are added into a scale score that can range from 7 to 49, with higher scores indicating more psychological flexibility (Cronbach's α = 0.87).

Statistical analysis

Data were analysed with SPSS version 22. Descriptive analyses were calculated for all variables in the study. To assess relationships between the variables, Pearson correlation coefficients were calculated. To examine the relative contribution of self-compassion in the prediction of distress and wellbeing, a series of hierarchal linear regression (HLR) analyses were conducted, with anxiety (HADS-total) and wellbeing (MHC-total) as dependent variables. In each HLR, demographics were entered in Step 1, cancer-related variables and caregiver strain were entered in Step 2, psychological resources (resilience, mastery and psychological flexibility) were entered in Step 3 and, finally, self-compassion in Step 4. In correlation and regression analyses, self-reported stage of disease was included as two dummy-variables. No evidence for multicollinearity was found in the regression diagnostics.

RESULTS

Description of the study group

Participants in our study were on average 55.7 years of age (range 27-82, SD 10.7) and predominantly females (Table 1). Most were mediate or higher educated and over half had a paid job for more than 20 hours a week. Nearly one in three had children living at home. Their partners suffered from a wide variety of types of cancer. In most cases (56%), the diagnosis was set more than one year ago. The self-reported stage of disease varied, but the majority (58%) stated that their partner would probably not recover. For a considerable number of participants (59%) their partners' cancer lead to high levels of caregiver strain.

Table 1. Description of the participants in the study: demographics and cancer-related characteristics (N=203)

Participants' characteristics		n	%
Gender (n=203)	Female	143	70.4
	Male	60	29.6
Country of birth (n=203)	Netherlands	193	95.1
	Other	10	4.9
Children living at home (n=203)	No	131	66.5
	Yes	72	35.5
Education level (n=197)	low	9	4.6
	middle	81	41.1
	high	107	54.3
Employment (n=203)	employed >20 hours a week	117	57.6
	unemployed/ retired	86	42.4
Age (n=203; range 27-82)	Mean. (SD)	55.7	(10.7)
General Health (n=203; range 1-5	Mean (SD)	3.0	0.7
Cancer-related characteristics			
Type of partner's cancer (n=199)	Bowel cancer	26	12.8
	Prostate cancer	24	11.8
	Lung cancer	22	10.8
	Breast cancer	18	8.9
	Lymph node	17	8.3
	Other*	96	47.3
Time since diagnosis (n-203)	Between 3 and 6 months ago	43	21.2
	Between 6 and 12 months ago	47	23.3
	1 to 5 years ago	81	39.9
	5 to 10 years ago	19	9.4
	More than 10 years ago	13	6.4
Stage of disease (n=203)	Under treatment; good hoop of recovery	52	25.6
	Treatment is finished; partner is recovered	33	16.3
	Patient will not get better anymore	118	58.1
Caregiver strain (n=203; range 0-13)	mean (SD)	7.2	(2.5)
	High strain, CSI-score>7	121	59.6

*in total 40 different types of cancer

Psychological distress, mental wellbeing and self-compassion

In Table 2 the descriptive statistics and intercorrelations of the psychological variables in our study are displayed. As expected, the mean scores on the HADS-total of the participants in our study were somewhat higher than those from the general population. Of the respondents in our sample 72 (36%) had HADS scores of > 15, which is indicative for possible cases (data not shown). Notable are the relatively weak correlations (-.25 thru -.42) between the measures of psychological distress (HADS) and the measures of mental wellbeing (MHC_SF), indicating that the respondents may well experience feelings of mental wellbeing despite their feelings of distress.

As expected, self-compassion was significantly negatively correlated to distress (r=-.38), and positively to mental wellbeing (r=.35). Self-compassion was strongly related to psychological flexibility (r=.51), and moderately to resilience (r=.31) and mastery (r=.35). When looking at the separate dimensions of self-compassion, it appeared that the positive dimension was slightly stronger associated with psychological distress and positive mental wellbeing than the negative dimension. Yet, the negative dimension of self-compassion was stronger associated with the other 'psychological resources' than the positive dimension.

Self-compassion was not significantly associated with any of the demographics or the cancer-related characteristics (data not in table), but was associated with caregiver strain (r=.19, P=.007).

Table 2 Descriptive statistics and bivariate intercorrelations (Pearson's r) of included psychological measures (n = 203)

	mean	(sd)	HADS-T 1	HADS-A 2	HADS-D 3	MHC-total 4	MHC-emo 5	MHC-psy 6	MHC-soc 7	AAQ-II 8	Resilience 9	Mastery 10	SCS-SF 11	SC-posit 12	SC_negat 13
1. HADS total[1]	12.5	(5.6)	-												
2. HADS Anxiety[2]	7.4	(3.1)	.90	-											
3. HADS Depression[2]	5.1	(3.2)	.90	.61	-										
4. MHC-SF total[3]	4.2	(0.8)	-.25	-.13	-.31	-									
5. MHC_emotional[3]	4.4	(0.9)	-.38	-.25	-.42	.71	-								
6. MHC_psychological[3]	4.3	(0.8)	-.25	-.12	-.32	.92	.60	-							
7. MHC social[3]	3.8	(0.9)	-.07	-.02	-.11	.85	.38	.65	-						
8. Psy flexib (AAQ-II)[4]	36.7	(7.4)	-.41	-.32	-.41	.38	.38	.46	.16	-					
9. Resilience (BRS) [5]	3.2	(0.7)	-.26	-.21	-.25	.42	.27	.46	.30	.44	-				
10. Mastery (PMS) [5]	3.2	(0.8)	-.31	-.23	-.32	.28	.28	.30	.14	.60	.31	-			
11. SCS-SF total [3]	4.6	(0.9)	-.38	-.37	-.32	.35	.34	.36	.20	.51	.31	.35	-		
12. SCS- positive[3]	4.6	(1.0)	-.34	-.32	-.29	.31	.27	.31	.22	.30	.19	.19	.74	-	
13. SCS- negative[3]	3.4	(1.2)	.28	.28	.22	-.25	-.28	-.27	-.11	-.50	-.30	-.35	-.84	-.26	-

[1] range 0-42, [2] range 0-21, [3] range 1-6, [4] range 7-49, [5] range 1-5

All displayed correlations are significant with p<.05

Predicting psychological distress

To examine the relative contribution of self-compassion in the explanation of variance in psychological distress we conducted a hierarchical linear regression analysis, with HADS-total score as dependent variable. The personal characteristics, entered in the first model, could not significantly explain the variance in psychological distress (see Table 3). Adding disease related variables and caregiver strain significantly improved the prediction of distress (to 22% explained variance). In the third block, we entered psychological resources (resilience, mastery and psychological flexibility), which further improved the prediction of distress (to 32%). Finally, in the fourth block, we entered self-compassion (total scale-score). The results revealed that self-compassion could significantly add to the explanation of distress, and increased the total amount of explained variance from 32% to 36%. Significant predictors in the final equation were: prognosis- partner recovered vs other (ß= -.17), caregiver strain (ß=.29), psychological flexibility (ß=-.22) and self-compassion (ß=-.23).

Table 3: Hierarchical Multiple Linear Regression analyses to predict Psychological Distress and Mental Wellbeing (N=203)

	Psychological distress (HADS)			**Mental Wellbeing (MHC_SF)**		
	Sign predictors	ß		Sign predictors	ß	
MODEL 1: Personal Characteristics	General health	.18	*	Children at home	.18	*
	R^2=.04, R^2 change=.04 *Fchange (6,190) = 1.3, p=0.28*			*R^2=.05, R^2 change=.05* *Fchange (6,190) = 1.6, p=0.150*		
MODEL 2: + Illness characteristics	General health	.13	*	Caregiver strain	-.20	**
	Caregiver strain	.39	**			
	R^2=.22, R^2 change=.18, *Fchange (4,186) = 10.5, p<0.001*			*R^2=.11, R^2 change=.06,* *Fchange (4,186) = 3.2, p=0.014*		
MODEL 3 : + Psychological resources	Prognosis cured	-.17	*	Prognosis palliative	.15	*
	Caregiver strain	.30	***	Resilience	.29	***
	Psych flexibility	-.32	***	Psych flexibility	.22	*
	R^2=.32, R^2 change=.11, *Fchange (3,183) = 9.6, p<0.001*			*R^2=.29, R^2 change=.18,* *Fchange (3,183) = 15.6, p<0.001*		
MODEL 4 : + Self-Compassion	Prognosis cured	-.17	*	Resilience	.27	***
	Caregiver strain	.29	***	Self-compassion	.15	*
	Psych flexibility	-.22	*			
	Self-Compassion	-.23	***			
	R^2=.36, R^2 change=.04, Fchange *(1,182)* = 10.5, p<0.001			R^2=.31, R^2 change=.02, Fchange *(1,182)* = 4.0, p=0.047		

Model 1: entered sex, age, education level, employed, general health (RAND-36)
Model 2: entered all the above, plus time since diagnosis, prognosis will not get better (vs other), prognosis cured (vs other), CSI
Model 3 entered all the above plus resilience (BRS), psychological flexibility (AAQ-II), Mastery (PMS)
Model 4 entered all the above plus self-compassion (SCS-SF)

We conducted a similar regression analysis in which we entered the two separate measures of self-compassion (SCS-pos and SCS-neg) instead of the total score in the final block. Results revealed similar results: by entering the two measures of self-compassion measures in the final block, the total amount of explained variance of psychological distress was significantly increased from (32% to 37%). Only the positive dimension of self-compassion (SC-pos) revealed to be a significant predictor of distress (ß=-.22) in the final equation next to prognosis- partner recovered vs other (ß= -.16), caregiver strain (ß=.30), psychological flexibility (ß=-.23) (data not shown in table).

Predicting mental wellbeing

In a similar way, we examined to what extent mental wellbeing could be predicted by the variables in our study (table 3). Results revealed that in the final model, the total score on mental wellbeing could be predicted for 31% with the variables in our study. Again, self-compassion could add significantly to the explanation of variance of mental wellbeing, after controlling for demographics, cancer-related variables, and psychological resources. Resilience (ß= .27) and self-compassion (ß= .15) were the only significant predictors of wellbeing in the final equation.

We repeated the analyses with including the separate measures of self-compassion instead of the total score, but this did not yield into any significantly different results: by entering the two measures of self-compassion measures in the final block, the total amount of explained variance of psychological distress was significantly increased from (29% to 31%). Resilience (ß= .28) and the positive dimension of self-compassion (ß= .16) were significant predictors in the final equation (data not shown in table).

CONCLUSIONS

To our knowledge, this is the first study to examine self-compassion in a sample of partners of cancer patients. As expected, self-compassion was positively related to mental wellbeing and negatively to perceived psychological distress (as measured by the HADS). These findings are in line with previous studies [5-7] and confirm that self-compassion is an important component of psychological distress and mental wellbeing.

One of the strengths of our study was that we examined the influence of self-compassion alongside a number of other psychological constructs that have been related to adaptation to adversity, namely psychological flexibility, resilience and sense of mastery. Our findings revealed that self-compassion was only moderately correlated to resilience (r=.31), mastery (r=.35) and psychological flexibility (r=.51). Moreover, our data revealed that self-compassion could significantly add to the total amount of explained variance of both psychological distress (alongside prognosis, caregiver strain, and psychological flexibility) and mental wellbeing (alongside psychological resilience). These results indicate that self-compassion is an important and unique factor in understanding psychological distress and mental wellbeing in partners of cancer patients, and should be considered in future research.

Self-compassion may be particularly relevant, since studies have shown that self-compassion is not a static trait, but can indeed be altered by interventions such as self-compassion training [38] or compassion-focussed therapy [39], and even by less intensive self-help (online) interventions [6]. Bolstering self-compassion seems particularly important for partners of cancer patients, as they tend to neglect or supress their own needs [16] and are prone to self-criticism and feelings of guilt [17]. Self-compassion training may teach partners to acknowledge their own suffering instead of avoiding or supressing their negative emotions. Self-compassion training may also help partners to recognize that they find themselves in an extremely demanding situation, for which they are not responsible and therefore they should be less hard on themselves. If partners recognize that the human condition is imperfect, and that we all make mistakes, partners may be more likely to forgive themselves for not being perfect. By being more kind and forgiving to themselves they will become less afraid of making mistakes or to be rejected by others for not performing well enough. This will open the path for communication and will make them feel less isolated. We therefore recommend that in future supportive interventions for partners of cancer patients attention is paid to improvement of self-compassion.

An interesting finding from our study is the relatively weak correlation (r=-.25) between psychological distress (HADS_total) and positive mental wellbeing (MHC_SF) and the fact that the partners in our study scored relatively high on the MHC_SF. The mean score on the MHC_SF of the partners in our study (M=4.2) is even slightly higher than that found in a Dutch population sample (M=4.0) [35]. Closer inspection of the scores on the subscales of the MHC_SF revealed that the differences with the norm scores occurred predominantly at the social dimension (scores for emotional, psychological and social subscales of wellbeing amounted respectively 4.4, 4.3 and 3.8 in the present study, and 4.7, 4.2 and 3.3 in the population study by Lamers et al [35]). This indicates that the experience of caring for a cancer patient, can be distressing and -at the same time- lead to increased feelings of social wellbeing: a sense of belonging, acceptance and social coherence. These findings are in line with studies showing that caregiving for a partner with cancer can also have positive consequences [2,40] and they support the two-continua model of wellbeing, which states that distress and wellbeing are two related but distinct dimensions [34,35].

Whereas the Self-Compassion Scale is originally composed of 6 subscales (3 positive, 3 negative), recently researchers [31,32] have expressed their doubts about the six subscales, and suggest a two-factor structure: one containing the positive items (self-kindness, common humanity and mindfulness) and one containing the negatively formulated items (self-criticism, isolation and over-identification). In recent meta-analysis Muris and Petrocchi [31] analyzed 18 studies that have examined the relative contribution of the positive and negative dimensions of the SCS and SCS_SF on psychological morbidity. Their results revealed that, overall, the negative dimension was stronger associated with indicators of psychological morbidity than the positive dimension. Muris & Petrocchi [31] argue, however, that the negative items of the SCS seem to measure characteristics that are already known to be associated with (and incorporated in) psychopathology. Therefore, they suggest that the positive dimension may be a better instrument for measuring the true protective nature of self-compassion than the SCS-total score. In our study, we found that rather the positive dimension of self-compassion was stronger related to both distress and mental wellbeing. This even emphasizes the potential of (positive) self-compassion in this particular group. Future studies are needed to better understand the relative contribution of the two dimensions of self-compassion understanding distress and wellbeing in various subgroups and circumstances.

Our results should be interpreted with caution because of some limitations. First, the generalizability of or data is limited because the participants in our study were self-selected applicants for a supportive online intervention, and were mostly female and relatively highly educated. Second, because of the cross-sectional design, no causal relationships can be determined. Therefore, we recommend longitudinal and experimental studies to further examine if self-compassion can be altered in this group, and subsequently, whether an increase in self-compassion can actually lower psychological distress and increase mental wellbeing in this group.

In conclusion, the results of our study suggest that self-compassion appears to be a significant, unique factor in understanding levels of distress and mental wellbeing in partners of cancer patients and could serve as a clue for future supportive interventions.

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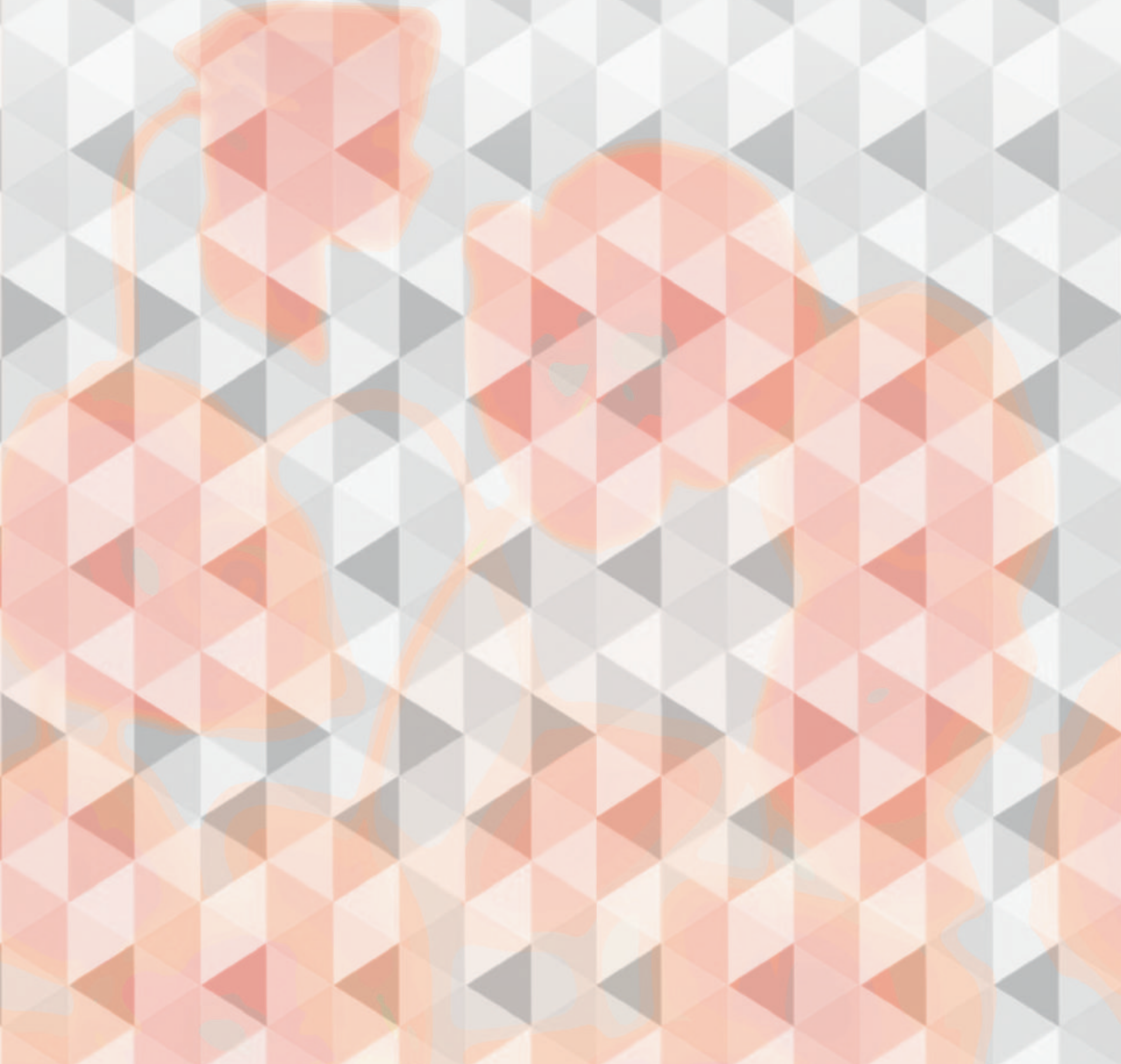
INTERMEZZO



INTERMEZZO

Target group:	Partners of cancer patients (no focus on specific types of cancer or stage of disease)
Aim of the intervention:	To provide information and support, and it helps partners to make the most of the difficult times they are in
Duration of the intervention:	6-12 weeks

Website of Hold on, for each other
The intervention is individually administered and the participants can access the intervention at any time, from any place.

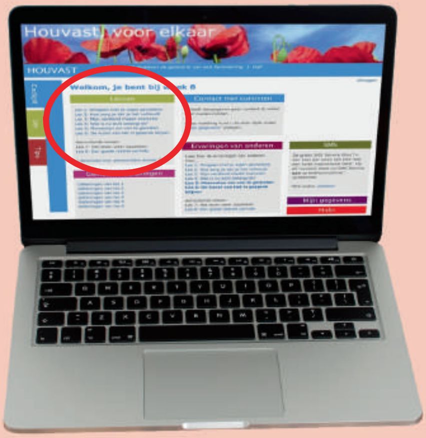
Participants always have to log in in order to enter their personal cockpit (personal homepage)

This is the **personal cockpit** – the first screen when participants have logged in. Here they can find all components of the intervention.

Topics of the modules

	Focus	Key components
Basis modules		
1 – Coping with your emotions	Focus on emotional consequences of being a partner of a cancer patient. Partners learn how to recognize, allow and express their emotions	Acceptance Self-compassion/ Mindulness
2 – Your resilience plan – how can you keep going	Focus on resilience. Partners learn how to manage a period of chronic stress and to improve their resilience	Acceptance Self-compassion/ Mindfulness
3 – My mind works overtime	Focus on worrying and negative thoughts. Partners learn how to cope with dysfunctional thoughts	Cognitive defusion Self-compassion/ Mindfulness
4 – What is now really important?	Focus on values in life and relationship. Partners learn about their personal values and how to live in accordance with those values	Values Self-compassion/ Mindfulness
5 – Afraid, tired and moments of joy	Focus on positive things in life and relationship. Partners learn about how important moments of joy and positive emotions are in this difficult period in their lives	Committed action Self-compassion/ Mindfulness
6 – The art of communication	Focus on communication. Partners learn how to improve their communication skills	Communicating about what really matters Self-compassion/ Mindfulness
Optional modules		
7 – Moving on with life	Focus on challenges that can occur after a successful cancer treatment. Partners learn how to cope with these upcoming challenges	Acceptance, cognitive defusion values Self-compassion/ Mindfulness
8 – A good last period	Focus on topics related to the terminal phase of the patient. Partners learn what they can do in order to have a good last period with their ill partner.	Acceptance, communicating about what really matters, committed action Self-compassion/ Mindfulness

MODULES



Modules – Texts

Structure

- Short **text** that matches theme of each module
- Short **psychological exercises** + **meditation exercise**
- Practical **information**, **tips** and **references** to relevant websites
- Possibility to have contact with **peers**; sharing experiences and tips

Inhoud

1. Inleiding
2. Negatieve en positieve emoties
3. Groot houden
4. Emoties onderdrukken of uit de weg gaan
5. Kernboodschap
6. Weekoefening: Hoe houd ik me groot?
7. Oefening: Hoe houd ik me klein?
8. Oefening: Compassie met jezelf
9. Mindfulness: Thuiskomen bij het nu
10. Oefening Mindfulness: Thuiskomen bij het nu
11. Praktische informatie, tips en verwijzingen

Table of contents

Each module starts with an overview of all components of the particular module and participants can always see their personal progress in the intervention.

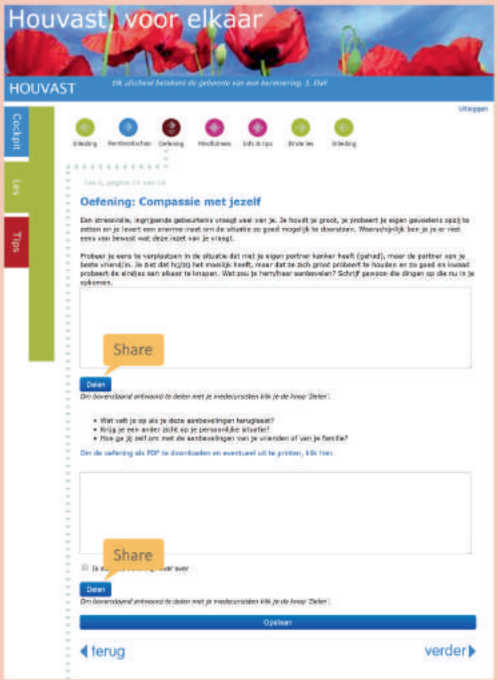
Kernboodschap

Negatieve emoties die niet worden geuit, stapelen zich op. En ze ontstaat een vicieuze cirkel. Het kost steeds meer moeite om ze te onderdrukken. Je hebt steeds meer alcohol, slaapmiddelen of vermijding nodig. Dit leidt tot andere negatieve emoties zoals schuldgevoelens, ontevredenheid of eenzaamheid die ook onderdrukt worden als ze niet ervaren mogen worden.

De gevolgen van de psychische aardbeving kunnen hieraan bijdragen. Ook als partner van een mens met kanker heb je 'recht' op negatieve emoties en steun. Dat begint met het erkennen, toestaan en uiten van deze emoties. Soms is het goed om je klein te houden en je kwetsbaarheid te laten zien. Dat schept een band en mobiliseert steun.

Core message

At the end of the text, all provided information is summarized to one core massage.



Oefening: Compassie met jezelf

Psychological exercises

These are based on ACT and self-compassion.

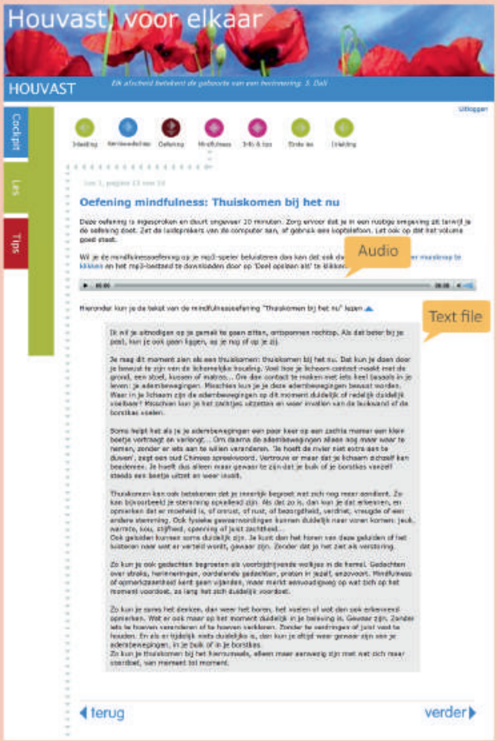
On the left, you can see one the exercises. In this exercise called 'Compassion with yourself' we ask participants to imagine the following situation:

Imagine that not you are partner of a cancer patient, but your best friend is. You see that he or she is struggling with the situation, but he/she still keeps trying to put a brave face on. What would you advise him or her?

We integrated this exercise, because we wanted to show the participants that caregivers often give comfort, support and compassion to the people they care for. But they often neglect their own wellbeing and do not offer that same level of compassion and care to themselves.

Participants can share their answers with other participants, which will be described later in more detail.

Modules – Meditation exercises



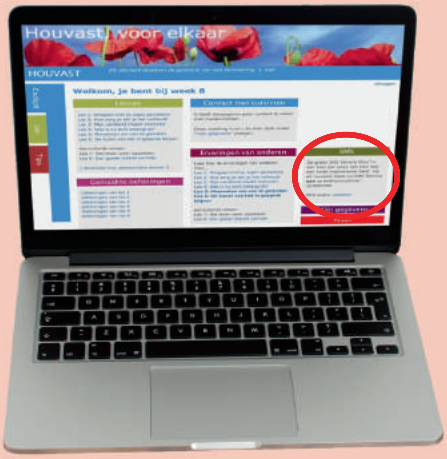
Each module also contains a meditation exercise offered as an audio and text file. These exercises are based on mindfulness and self-compassion, both theories are congruent with ACT.

Modules – Practical information, tips and references

As shown in prior research, it is important that persuasive design elements are incorporated in a web-based intervention in order to optimally support participants with completing the intervention.

Therefore, next to information and exercises, participants also receive practical information, tips and references to relevant websites and organisations and the modules contain poems or inspiring texts.

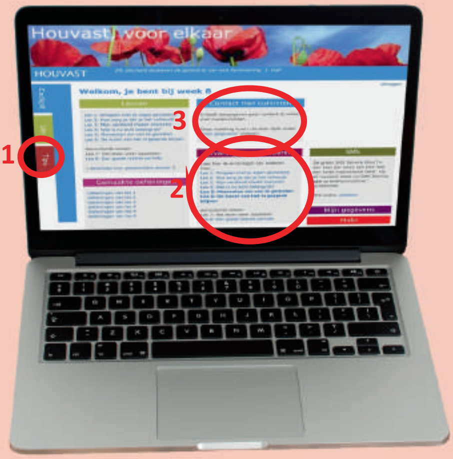
TEXT MESSAGE SERVICE



Geef mij de kracht om te veranderen wat ik kan veranderen, de moed om te verdragen wat ik niet kan veranderen, de wijsheid om het verschil te zien. T. van Avila

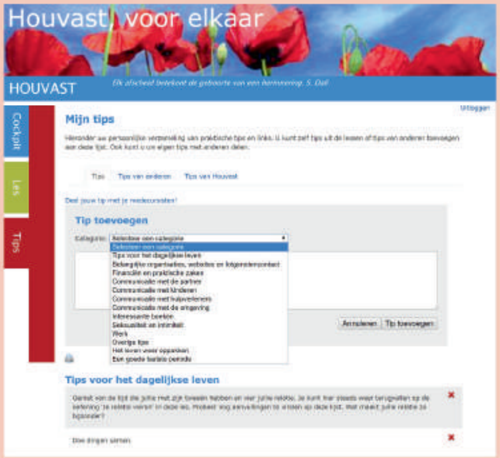
Another persuasive element is the **text message service**. Participants can choose to receive text messages with short inspiring texts once per week.

PEER SUPPORT



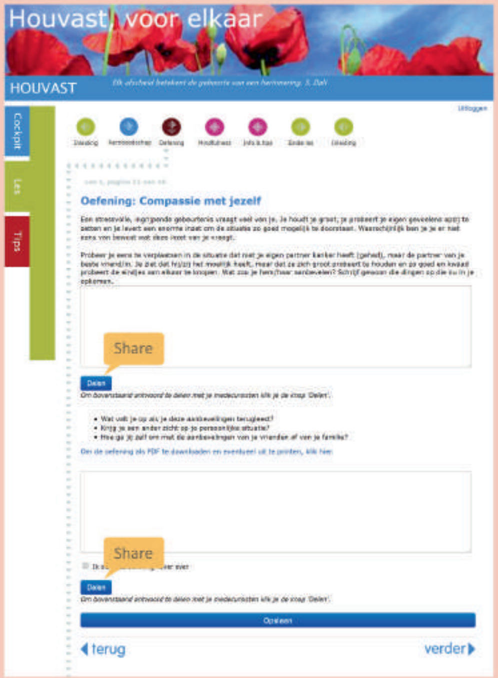
Another persuasive element is **peer support**. To facilitate peer–to-peer contact, participants have the possibility (1) to share their answers on some exercises with other participants (and to read those of others), (2) to add tips and advices and to read tips of others, and (3) to get in contact with other participants in a private e-mail conversation.

Peer support –Tips (1)



Participants can add tips and advices. If they want to share a tip they can select a category, to which their advice belongs to. And they can also create their personal list of tips and advices by adding (or deleting) tips from both the intervention and other participants.

Peer support – Experiences from others (2)



Participants can share their answers on some exercises with other participants (and to read those of others).

Earlier we showed the exercise 'Compassion with yourself'. We use this exercise here as well in order to show how it looks like when participants share their experiences with others.

And this is how it looks like when you open the experiences of participants.

Peers support – Contact with participants

This is the third option to get in touch with other participants. Participants can have a private e-mail conversation. Like facebook you have your own mailbox.

However, participants have to create a short profile first, if they want to contact other participants or share their answers (see figure below).

Examples

"Do you want to have contact with other participants or share (some) of your answers?"

- (Nick)name
- Sex (is already registered)
- Age (is already registered)
- Children
- Type of cancer patient is diagnosed with

Preview

6

Impact of a web-based self-help intervention for partners of cancer patients based on Acceptance and Commitment Therapy and self-compassion: a qualitative study

Köhle N, Drossaert CHC, Jaran J, Schreurs KMG, Verdonck-de Leeuw IM, Bohlmeijer ET

Submitted

ABSTRACT

Background: Partners of cancer patients are the cornerstone of supportive cancer care. They assume different roles and responsibilities that optimally support the patient. Such support is highly demanding, and many partners report psychological and physical health problems. However, many partners of cancer patients do not use professional supportive care themselves. Offering a Web-based self-help intervention based on Acceptance and Commitment Therapy and self-compassion could be an important resource to support partners of cancer patients. This qualitative study aimed to examine the impact of a Web-based self-help intervention based on ACT and self-compassion among partners of cancer patients.

Methods: Individual in-depth interviews, about partners' appreciation of the intervention and lessons learned, were conducted with 14 partners of cancer patients who used the Web-based self-help intervention. Interviews were audio-recorded, transcribed verbatim and analyzed by three independent coders.

Results: In general, partners appreciated the intervention, however, they also expressed ambivalent feelings towards peer support, the content of the feedback of their personal counselor, and the 'tunneled' structure of the intervention. The majority of the partners reported being more self-compassionate accepting that they experienced negative thoughts and feelings, and they learned to increase the distance between their thoughts and themselves. Furthermore, the partners became more aware of their personal values, and they were better able to commit to those values. They also reported other (non-specific) helpful processes such as insight and acknowledgement, positivity, the possibility to tell their story, time for themselves, and feeling closer and more connected with their partner (the patient).

Conclusions: Partners of cancer patients appreciated the Web-based self-help intervention based on ACT and self-compassion. The intervention helped them to cope with negative emotions, thoughts, and one's suffering; to practice self-kindness; and to clarify values based on difficult recent experiences. In addition, the intervention supported them to obtain insight and acknowledgement, positivity, to tell their story, make time for themselves, and feeling closer and more connected with the patient. We think that a Web-based psychological intervention based on ACT and self-compassion may be a valuable contribution in supporting partners of cancer patients.

KEYWORDS
Acceptance and commitment therapy; self-compassion; cancer; oncology; partner; web-based interventions; user experiences; qualitative; interview

BACKGROUND

Partners of cancer patients have to cope with multiple challenges, including the fear of an unpredictable future and possible death of the patient, feelings of guilt, inadequacy (always wishing to do more), self-doubt and frustration [1]. High levels of distress and caregivers' strain have been demonstrated in many studies (e.g., [1-3]). However, offering support to partners can be challenging as most partners are extremely busy. Web-based interventions could be a solution as they are easily accessible and flexible to use. Therefore, we developed – in close cooperation with partners of cancer patients – the Web-based self-help intervention *Hold on, for each other*. This intervention is based on Acceptance and Commitment Therapy (ACT; [4]) and self-compassion. ACT is a distinct model of behavioral therapy that aims to help people accept what is out of their control (e.g., distressing feelings) and to commit to actions that enrich their lives [5]. The acronym ACT stands for (A) accept your thoughts and feelings, and be mindfully present; (C) choose values that are important in your life (e.g., openness); and (T) take action towards your values (e.g., sharing emotions openly with the partner). ACT has been proven effective for a variety of problems, including chronic pain [6], depression and anxiety [7-9]. However, as far as we know, it has not been applied in interventions for partners of cancer patients despite being potentially useful. Partners of cancer patients are often entangled with unhelpful thoughts (such as "What if the cancer comes back?") and distressing feelings such as guilt, fear and anxiety (e.g., [1]). ACT can help partners to experience these difficulties without resisting them, allowing them to live according to their values, applying them as corresponding actions in their lives and relationships, despite the barriers that can occur due to the cancer.

Self-compassion is defined as the ability to hold one's feelings of suffering with a sense of warmth, connection and concern [10, 11]. Neff [10, 11] proposes three major components of self-compassion: self-kindness versus self-judgment, common humanity versus isolation, and mindfulness versus over-identification. Self-kindness refers to the ability to treat oneself with care in times of distress rather than harsh self-judgment. Common humanity entails recognizing that imperfection is a shared aspect of the human experience rather than feeling isolated by one's failures. Mindfulness in the context of self-compassion is about holding one's painful thoughts and feelings in balanced awareness rather than over-identifying with them. Research has demonstrated that higher levels of self-compassion are related to greater psychological health (in terms of less depression and anxiety) [12], greater happiness, optimism and life satisfaction [13, 14], greater relational wellbeing [15] and appears to be a powerful source of coping and resilience in times of distress (e.g., [16]). Although self-compassion has not been studied in the context of partners of cancer patients, it might particularly be useful for them because they often have unrealistically high expectations of themselves [1, 17, 18] and many also experience feelings of guilt for not doing enough for their ill partner or whenever they engage in personal activities even while their partner is suffering [1, 19]. Self-compassion may help partners of cancer patients renew their physical and emotional energies and enhance their emotional resources, both vital activities when coping with the challenges of being a caregiver [20].

The aim of this qualitative study was to explore the impact of a Web-based self-help intervention *Hold on, for each other* among partners of cancer patients. The following questions were addressed: (1) Which elements of the intervention were appreciated by the participants and what suggestions do they have for improvements? (2) What did participants learn from the intervention? The results of this study will help to interpret the effectiveness of Web-based self-help interventions targeting partners of cancer patients.

METHODS

Study sample and procedures

Partners of cancer patients were recruited from an ongoing randomized controlled trial (RCT) [21]. More detailed information about this RCT is presented in the study protocol [21]. At the moment of data collection for the current study, 52 partners of cancer patients had completed the *Hold on, for each other* intervention as well as the three- and six-months measurements after the baseline measurements. Of this group, 30 partners had indicated that they were willing to participate in the interview, and we randomly selected 20 partners for this study. Partners were contacted by e-mail and invited to participate in a telephone interview about their experiences with *Hold on, for each other*. Attached to the e-mail, they received the interview questions as well as a short summary of every lesson. With partners who were willing to participate, an appointment for a telephone interview was made. In total, 14 interviews were conducted. Five out of the twenty partners could not be reached and one partner withdrew from participation. Once the partners had given their oral informed consent (written informed consent had already been given in the context of the RCT), the interview took place. The interviews were conducted in Dutch by a masters student of Health Psychology (JJ), who had been trained in conducting interviews. During the first three interviews, the student was supervised by a psychologist and the researcher of the RCT (NK). We decided not to include more participants when we found that no new information was found in the last three interviews, indicating that data saturation had been reached after the 14 interviews [22]. All interviews were audio-recorded and transcribed verbatim. Testimonies appearing in this article have been translated from Dutch into English by an outsourced professional translator. Personal characteristics of the partners and cancer-related characteristics of the patients were gathered in the context of the RCT.

Description of hold on, for each other

Hold on, for each other (see Figure 1 and Table 1) is an intervention that aims to help partners to positively persevere during the difficult times they find themselves facing. Built and co-created with partners in order to ensure it complies with their needs and wishes, the intervention consists of six lessons, and in each lesson one particular theme is discussed (see Table 1). The intervention makes use of tunneling, which means that partners were guided through the intervention [23]. First-time users were tunneled through two information pages in order to introduce them to the different components of the intervention. The content of each lesson and the lessons themselves were delivered in a predetermined sequence of steps. A next page or lesson could only be accessed when the previous page or lesson was completed. The aim of this tunneled structure was to enhance the change process of the participants by offering them the most appropriate intervention content at a particular moment in time [24].

Welkom

"Kanker heb je samen", is een bekende uitspraak. Uiteraard gaat er veel zorg en aandacht van u maar ook van familie, vrienden, professionele hulpverleners en dokters naar de patiënt. Maar ook voor partners is het een moeilijke periode, waarin veel verandert en partners te maken krijgen met vragen als: Hoe begeleid ik mijn partner het beste en hoe houd ik het zelf vol? Wat betekent dit voor onze relatie?

De Universiteit Twente en VU medisch centrum hebben, met financiële steun van KWF Kankerbestrijding en Stichting Alpe d'HuZes de cursus 'Houvast, voor elkaar' ontwikkeld, voor partners van mensen die kanker hebben (overleefd). Deze online cursus biedt informatie en steun en helpt u, alleen of samen met uw partner, het beste te halen uit deze moeilijke tijd. De Universiteit Twente wil onderzoeken hoe effectief deze cursus is en is op zoek naar deelnemers. Misschien wilt u meedoen aan dit onderzoek.

In het onderzoek krijgen de deelnemers gratis toegang tot de online cursus, en vragen we hen om een aantal keer een vragenlijst in te vullen. Om te kunnen nagaan hoe effectief de cursus is, krijgen sommige deelnemers meteen toegang tot de cursus, en anderen pas na 3 maanden. Of u meteen toegang krijgt tot de cursus of pas later, wordt door loting bepaald.

We willen u op deze website graag meer informatie geven over de cursus, het onderzoek en uitleggen wat deelname voor u betekent. Daarna kunt u zelf kiezen of u mee wilt doen aan het onderzoek. Lees de informatie rustig door. Bespreek het met uw partner, vrienden en familie. Als u na het lezen van de informatie nog vragen heeft, kunt u terecht bij de onderzoekers. U vindt de contactgegevens via de knop 'Contact' op deze website.

Elk afscheid betekent de geboorte van een herinnering. S. Dali

Welkom, je bent bij week 8

Les 1: Omgaan met je eigen gevoelens
Les 2: Hoe zorg je dat je het volhoudt
Les 3
Les 4
Les 5
Les 6
Aanvullende lessen:
Les 7: Het leven weer oppakken
Les 8: Een goede laatste periode

[download mijn persoonlijke dossier]

U heeft aangegeven geen contact te willen met medecursisten.

Deze instelling kunt u te allen tijde onder "mijn gegevens" wijzigen.

Lees hier de ervaringen van anderen

Les 3: Mijn verstand maakt overuren
Les 4: Wat is nu echt belangrijk?
Les 5: Momenten om van te genieten
Les 6: De kunst van het in gesprek blijven

Aanvullende lessen:
Les 7: Het leven weer
Les 8: Een goede laatste periode

De gratis SMS Service stuurt u één keer per week een sms met een korte inspirerende tekst. Op dit moment staat uw SMS Service **aan** op telefoonnummer: 123456789.

SMS Coach uitzetten

Oefeningen van les 1
Oefeningen van les 2
Oefeningen van les 3
Oefeningen van les 4
Oefeningen van les 5
Oefeningen van les 6

Figure 1: Screenshots of the *Hold on, for each other* website and personal homepage

Table 1: Focus of the lessons, underlying theories and example exercises of *Hold on, for each other*

Lesson	Focus	Underlying theories	Example exercise
Coping with your emotions	Focus on emotional consequences of being a partner of a cancer patient. Partners learn how to recognize, allow and express their emotions.	Acceptance, Self-compassion/ Mindfulness	*How often do I put on a brave face?* Description: We asked partners to write down emotional situations they have experienced, how they felt at that moment when the situation occurred and how they coped with it. Aim: To help partners to become aware of their own emotions and their coping mechanisms. Are they regularly putting on a brave face and suppressing their emotions?
Your resilience-plan – how can you keep going?	Focus on resilience. Partners learn how to manage a period of chronic stress and to improve their resilience.	Acceptance, Self-compassion/ Mindfulness	*How much do you demand of yourself?* Description: We asked partners to write down how many hours they work, sleep, and have leisure time each week. Aim: To show partners how much they demand of themselves and if their planning is realistic.
My mind works overtime	Focus on worrying and negative thoughts. Partners learn how to cope with dysfunctional thoughts.	Cognitive defusion (gain control over thoughts), Self-compassion/ Mindfulness	*Name your thoughts.* Description: We asked partners to write down the five most often occurring thoughts that are associated with the disease of their partner. Afterwards, they are asked to read the thoughts aloud and to pay attention for what he/she experiences. Then they are asked again to read the thoughts aloud but now with the addition "I have the thought/ feeling that…". They are asked again what their experiences are. Aim: To help partners create a greater distance between their thoughts and themselves, and to show them that thoughts are not necessarily a reflection of reality.
What is now really important?	Focus on values in life and relationships. Partners learn about their personal values and how to live in accordance with those values.	Values, Self-compassion/ Mindfulness	*Values in your relationship.* Description: We asked partners to write down those things in their relationship that they value the most. Aim: To make them aware of things that are not congruent with their values. Are there things that should be different? Is it worth investing in their relationship? What can they do to bring their actual life choices closer?
Afraid, tired and moments of joy	Focus on positive things in life and their relationship. Partners learn about how important moments of joy and positive emotions are in this difficult period in their lives.	Committed action, Self-compassion/ Mindfulness	*Celebrate your relationship.* Description: We asked partners to choose activities (e.g., write a love letter, have dinner at their favourite restaurant). Aim: To make them aware of how precious their relationship is and how to live in accordance with their values.
The art of communication	Focus on communication. Partners learn how to improve their communication skills.	Communicating about what really matters, Self-compassion/ Mindfulness	*What would you like to talk about?* Description: We asked partners to write down topics they have discussed lately with their partner, topics that have not yet been discussed, and - if so - why these topics have not yet been addressed. Aim: To stimulate partners to communicate about the things that really matter.

Table 1: continued

Lesson	Focus	Underlying theories	Example exercise
Optional lessons			
Moving on with life	Focus on challenges that can occur after a successful cancer treatment. Partners learn how to cope with these upcoming challenges.	Acceptance, Cognitive defusion (gain control over thoughts), Values, Self-compassion/ Mindfulness	*Increase your hope.* Description: We asked partners to imagine the situation in which their partner is cancer free for almost a year, and that he/she is feeling all right. They - as a partner - have done everything possible to cope with the situation. They have accepted it, and they are moving on with life. We ask them to imagine how life might be under these conditions. Aim: To show them that it sometimes can be helpful to create some distance and to have a closer look at their situation from a different point of view.
A good last period	Focus on topics related to the terminal phase of the patient. Partners learn what they can do in order to have a good last period with their ill partner.	Acceptance, communicating about what really matters, Committed action, Self-compassion/ Mindfulness	*Beautiful memories.* Description: We asked partners to think about (alone or with their partner) what they can do to produce new memories (e.g., things to experience together, trips or activities to make). Aim: To synthesise various aspects previously explored. To accept the development of the disease, talk about what really matters at that particular moment, commit to values and live in accordance with them.

Every lesson starts with a short text about the topic of that lesson. The core messages of ACT and self-compassion are integrated in these texts (see Table 1). The texts are enriched with short psychological exercises that are based on ACT and self-compassion. Each lesson also contains a mindfulness exercise based on self-compassion, that can be read or downloaded as a mp3-file. Partners also receive practical information, tips and references to relevant websites. Users can freely decide if they want to receive text messages (one per lesson) with short inspiring texts. Moreover, partners have different options to come into contact with peers. Previous studies pointed out that people often fear peer contact because they are afraid of being confronted with negative stories [25, 26]. To minimize this risk, *Hold on, for each other* offers three kinds of peer support. First, partners can share their answers on some exercises with other participants (and read the answers given by other participants). Second, they can share (and read) tips and advice, and third, they can contact other partners by sending a private message (message system is integrated in the website of the intervention). All the components are optional, and partners can decide freely to use them or not. Partners also receive support: automated support or personal support (weekly feedback messages from a personal online counselor (a trained masters psychology student of the University of Twente, The Netherlands), explained in more detail in study protocol [21]).

Interview scheme

A semi-structured interview scheme was used. Partners of cancer patients were asked about experiences regarding the: (a) Web-based intervention in general; (b) psycho-education (lessons and psychological exercises); (c) mindfulness exercises; (d) peer support; and (e) practical information, tips and references. For each of these topics, partners were asked about what they appreciated, if they had any suggestions for improvements, and what they had learned. During the interview, partners were encouraged to motivate their answers and experiences.

Data analysis

Two coders (JJ, NK) read the transcripts twice in order to become familiar with the data. Afterwards they independently selected relevant fragments and coded them in one of two predefined categories: appreciation of the intervention and the effects of the intervention. Inductive analysis – meaning that subthemes derived from data, instead of predefined categories – was further used to categorize all fragments into subthemes. After every five interviews, the coders met to discuss their subthemes. When dissimilarities were found, the two coders reached a consensus and the coding scheme was redefined. When the two coders finished their analysis, a third researcher (CHCD) checked the categorization and the three researchers further discussed any disagreements about the categories. Final categories were defined on the basis of consensus between the three researchers.

RESULTS

Study sample

The personal characteristics of the partners and the cancer-related characteristics of the patients are listed in Table 2. The mean age of the partners was 55 years old, and the majority were female, highly educated and employed. The patients were diagnosed with a variety of cancers. In most cases, the diagnosis was 1-5 years ago, and the partners mostly stated that their ill partner was unlikely to be cured.

Table 2: Personal characteristics of the partners and cancer-related characteristics of the patients (N=14)

Characteristics	N	%
Gender (female)	11	79
Age years, mean (S.D.); [range]	55.3 (9.3) [34-68]	
Country of birth (the Netherlands)	14	100
Education		
Low	2	14
Middle	6	43
High	6	43
Employment		
Employed (> 20 hours per week)	8	57
Unemployed/ retired	6	43
Children		
No / or living away from home	10	71
Yes, living at home	4	29
Type of cancer		
Colon cancer	2	14
Kahler's disease	2	14
Lung cancer	2	14
Prostate cancer	2	14
Leukemia	1	7
Bladder cancer	1	7
Lymph node cancer	1	7
Pancreatic cancer	1	7
Head- and neck cancer	1	7
Breast cancer	1	7
Time since diagnosis		
3-6 months	4	29
1-5 years	8	57
5-10 years	1	7
>10 years	1	7
Treatment		
No	5	36
Yes	9	64
Stage of disease		
Patient is still in treatment with curative intent.	4	29
Treatment with curative intent is completed; patient is recovered.	1	7
Patient will (probably) not recover.	9	64

Appreciation

In the next sections, the partners' appreciation of the intervention is described, starting with more general comments and followed by their appreciation on the following components of the intervention: psycho-education (lessons and psychological exercises); mindfulness exercises; peer support; practical information, tips, references and text message service; and personal support (see Table 3). Some partners mentioned arguments for both why they appreciated a specific element or why they did not appreciate it. Therefore, the number of participants not always adds up to 14. In addition to the appreciation, an overview of the partners' suggestions regarding both the improvement of the intervention and a dissemination of such an intervention is provided.

The general comments were divided into six categories: (1) unspecified; (2) structure/design; (3) topics addressed; (4) flexibility; (5) anonymity; (6) (positive) approach. Unspecified comments included quotes such as *"I thought it was a very interesting course."* Seven partners mentioned that they appreciated the structure and design of the intervention: *"I am always amazed how well it is made, and how many great elements it comprises."* However, four partners were less satisfied with the structure and the fact that they were guided through the intervention, because they felt it was unclear or did not fit their needs:

> *I noticed during the course that it was difficult to adapt my life and its rhythm to the rhythm of the course. Of course one does not have exactly those needs in exactly that order… I can imagine it was carefully thought out, but it did sometimes feel like someone was stepping on the brake.*

Five partners particularly appreciated the topics addressed in the intervention, because they fit their personal situation and were highly relevant for partners of cancer patients: *"The words 'Hold on' [in the intervention's name] say it all, since it is something to 'hold on' to. Wherever or whenever, people profit from it. For one person, this element is important, for another person, another element."* Others (n=4) indicated that certain topics were not that relevant for them: *"Some parts made me think, this doesn't mean anything to me."*

Some partners liked the flexibility of the intervention (n=4). They appreciated that no exercise was mandatory, but that you could freely decide what you wanted to use and how you wanted to use it: *"I appreciated being able to follow at my own pace, to be busy with … let's say … formulating my thoughts and feelings."*

Two partners liked that they could stay anonymous, and one partner particularly liked the positive nature of the intervention and the way partners were approached:

> *Also the care with which [the researchers designed and formulated] everything. Yes, I think it deserves a big A. Also how you [designed the intervention to] approach people, in such a pleasant way. In any case, the threshold is low, so one does not get the feeling one is doing things the wrong way.*

Appreciation of psycho-education (lessons and psychological exercises)

While the partners did not cite any particular lesson, they all mentioned reasons why they liked the psycho-education. Some (n=5) reported an appreciation for general aspects such as

"And then I sent it off and waited excitedly for the next session" and *"We participated with a lot of pleasure and greatly profited from it."* Other partners highlighted why they liked a particular topic or exercise. For example, one partner appreciated *"… the first lesson, in particular, especially because it made you express your feelings and put them into words, since we are always so busy with other people."* Another partner said: *"And that lesson [6] arrived just in time for me, which struck me again. Just spit it out and type or write it down, and then you are rid of it…"*

Ten partners also mentioned some particular aspects of the intervention that they appreciated less. Four partners mentioned that (some parts of) the psycho-education were not relevant for them: *"I can't name any examples now, but there were questions that I kind of skipped, though I don't remember what they were. I didn't think they applied to me."* Five partners indicated that they did not like one particular exercise, called "The answers to what-if questions," for numerous reasons. One felt that this exercise was particularly unappealing, for example: *"I always consider what-if questions senseless."* Another felt the exercise was too negative: *"I'm not busy with such what-if questions, but try to think in terms of solutions. So I don't always worry like 'imagine that …' I'd rather think in terms of positive solutions."* Still others felt that such what-if questions were too difficult to think about: *"I really found what-if questions quite complicated."* However, this exercise also helped some partners to cope with difficult thoughts, which we later describe in the section about long-term effects.

Appreciation of the mindfulness exercises

The majority of the partners appreciated the mindfulness exercises because they experienced them as pleasant, fun, interesting and relaxing (n=10): *"Yes, very pleasant. In the beginning, at first, I thought: what I am doing here? But then gradually… it was very pleasant."*

Three partners were more critical, indicating that they had no need for such exercises or that the exercises were not appealing to them: *"I didn't have much use for it. At that moment, I was too busy for it, and anyway, it wasn't really my thing."*

Appreciation of peer support

Two partners appreciated the possibility of having contact with peers because they were interested in sharing their tips and experiences and reading the tips of others: *"They offered tips, and I always read those, which I thought was really great."* However, the majority of the partners did not use the peer support, and some of the partners had multiple reasons for not doing so. Reasons for this included that they did not need peer support (n=6) or they had sufficient support from their private network (n=3): *"I didn't feel the need for it, since I am in such close contact with my friends and family."* Other reasons for not using the peer support were: they were afraid of being confronted with negative stories (n=3); they had no emotional energy for the story of another partner (n=3); they were doubting that peers could help each other (n=2); they wanted to stay anonymous (n=1); peer support via the intervention felt too impersonal (n=2); and they were afraid that their situation was not comparable to that of others (n=2):

> *It was also difficult for me, because I realized that amongst the fellow participants, there were some whose partners were terminally ill. Since that is not my situation, I feel very privileged and would not dare to come forward with my things, which are really not that bad... You could also read about the situation they were in, which, yes, made me feel ashamed of sharing my things.*

Appreciation of practical information, tips and references, and the text message service

Six partners appreciated the practical information because it was pleasant to read and contained useful information: *"I recall those tips… those summaries of all the information. I did appreciate all those practical tips a lot, just reading through them once."* Two partners mentioned that they appreciated the text message service: *"I really liked them and also showed them to [my partner], like: 'Now see what I got!'"*

Some partners (n=3) did not like the practical information, because: they felt that the information provided was not relevant for them (n=1), they were not in need of such information (n=1), or they had no energy to read long texts (n=1): *"I was not in the mood to read long texts, so I just forgot about it."*

Appreciation of personal support

Six of the partners received support from a personal counselor during the intervention. One participant didn't mention if he/she appreciated this component. One participant reported being satisfied with the personal counselling: *"Yes, that was very nice, it was really nice to get personal support."*

Four partners were not entirely satisfied with the support provided by their counselor because they had expected personal feedback instead of feedback that mostly targeted their progress in the intervention. They would have liked to have the possibility to talk to a professional from time to time, for example via telephone, because then they might have the opportunity of discussing matters more deeply. This contact could also function as a motivator to stay engaged with the intervention. One partner felt that the language of the feedback messages was obviously language social workers use:

> *'How good of you' and 'Nice to hear' and 'Oh well, that doesn't matter.' Yeah, I thought, come on, I'm 60. A further disadvantage is that I am a social worker myself, so that is really social worker's language that really doesn't work for me.*

Table 3: Partners' appreciation of specific parts of the intervention

Category	n (%)[1] pro	Pro argument	n (%)[1] against	Against argument
Psycho-education	14 (100)	General comments; unspecified	10 (71.4)	Not personally relevant Particular exercise not appealing
Mindfulness exercises	10 (71.4)	Exercises are pleasant, fun, interesting and relaxing	3 (21.4)	No need for mindfulness exercises Mindfulness exercises are not appealing
Peer support	3 (21.4)	Possibility to exchange tips and experiences with peers	12 (85.7)	No need for peer support Sufficient support from personal network Afraid of being confronted with negative stories No capacity to listen to the story of another partner Doubting that peers could help each other Preference to stay anonymous Web-based support felt too impersonal Afraid that personal situation is not comparable to that of others
Practical information, tips and references; text message service	6 (42.9)	Pleasant to read useful information	3 (21.4)	Information not personally relevant No need for this information No time to read long texts
Personal support	1[2] (20.0)	General argument; not further specified	4[2] (80.0)	Preference for more personal feedback instead of feedback on progress using the intervention Preference to have the opportunity to talk to a professional from time to time Language of feedback messages was not appealing

[1] Participants could give reasons for both why they appreciated a specific component or why they didn't appreciate it. Therefore, the numbers not always add up to 14.

[2] Six of the partners received support from a personal counselor during the intervention. Five of them talked about what they appreciated or didn't appreciate about this element. The percentage is based on this number of partners (n=6) and not on the total number of participants (n=14).

Suggestions for improving and dissemination the intervention

In addition to the suggestions for improvement of the intervention (less rigid structure of lessons and more personal support), one partner also indicated an interest in a book version of the intervention. In addition, three partners mentioned that they would like to see an additional lesson about bereavement: *"From my personal experience, I would perhaps have liked an extra lesson that went more into detail about how things are once your partner has passed away. I mean, like an optional lesson."*

We also asked partners to reflect on how we could improve the dissemination of such an intervention. The majority of the partners (n=12) said that they would have preferred an introduction of the intervention via a healthcare professional (such as an oncologist, nurse or social worker) in the hospital. There were different preferences regarding the optimal moment for introducing the intervention. Based on the answers provided by the partners, it appeared that every partner has his or her own moment in the cancer trajectory when support is needed, indicating that it might be important to offer the partners such an intervention at various times. This need is illustrated by the following testimony:

> *When somebody hears that [the cancer] has spread and there is nothing that can be done about it – I would not say something like, "Well, we offer a course you might like to attend." In any case, I would wait a little while and then, during the next stage [of the disease], offer the course a few times or at least point it out: "This is there for you, but if you don't want to make use of it, that's fine. But this is what we do offer." For indeed, there is so much attention on the patient and really no attention for those nearest [to him].*

Lessons learned from the intervention

In response to the question regarding what the partners learned from the intervention, the majority (n=11) answered in general terms such as: *"I greatly profited from it. Not all parts were successful, not all lessons were effective, but still I greatly profited from it."* Seven partners indicated that the intervention encouraged them to think about their situation. Four partners noted that the intervention was offered at a moment when they particularly needed help, and they liked the fact that they finally had received some attention: *"I was so happy this came onto my path for, as a partner, I was so sad and worried. Of course, all the attention goes to the sick partner and only very few people really ask, 'And how are you doing?'"*

Specific learning experiences could be divided into two categories: (1) the short-term effects or working elements of the intervention that partners had experienced during or directly after the intervention and (2) the long-term effects or effects on their wellbeing and relationship that partners were still experiencing at the time of the interview.

Short-term effects (working elements of the intervention)

Short-term effects could be divided into five categories: (1) insight and acknowledgement, (2) ACT- and self-compassion-related, (3) guidance and solutions, (4) positivity, and (5) attention as the caregiving partner (see Table 4).

Insight and acknowledgement: The majority of the partners reported that the intervention helped them to better understand their situation (n=10) and that they found confirmation of their ability to cope with the difficult situation (n=4).

Eight partners indicated that it was pleasant to be acknowledged as a partner and to realize that their feelings and emotions are "normal" and not uncommon in their situation:

> *The realization that one understands what is happening inside, by asking 'Why do I behave in this way now?' and 'Can I behave in a different way?' worked as a self-reflection. It was self-reflection, but also helped others [other people in this partner's life] to understand that it [this partner's behavior] is not unusual …*

ACT- and self-compassion-related: Half of the partners reported having a positive experience with the mindfulness exercises. These exercises gave them rest, peace, time to reflect, and time to be fully aware of themselves and their surroundings, as illustrated in the following quote: *"Indeed a short moment for oneself. Just for a moment, let me call it a conscious moment, or how shall I call it? A moment of recollection, one in which you really get quiet."*

Seven partners indicated that they learned to be more (self-)compassionate. The intervention taught them to be more kind and caring towards themselves, to ask for help and to share their experiences with others. One partner said: *"I told myself: 'That's not proper. You shouldn't enjoy yourself, because you've been through something very unpleasant.' And then I heard during the lesson: 'On the contrary, you really should enjoy yourself.' And that helped me a lot."*

Five partners reported that the intervention helped them to create more distance from their own thoughts, as illustrated in the following quote:

> *Looking at oneself and, in some way, taking distance from oneself. If I may speak about Lesson 7, at a certain moment it says: 'If you were ten years older now, and you were still the same person with the same experiences, how would you look at yourself and which tips would you give yourself?' That was such a powerful way to take some distance from oneself: now I am ten years older and I am going to give myself some tips, which you can only*

> *formulate if you can take a distance. That is such a freeing experience, such a … I can't explain it, but it's so incredibly good!*

Guidance and solutions: Most of the partners mentioned that the intervention provided guidance and useful solutions. In particular, the guidance to improve their communication with the patient was mentioned (n=8). The texts and exercises stimulated conversations and provided an effective method to talk about sensitive topics like negative emotions and positive experiences, such as recollecting memories of special events like holidays or weddings. To illustrate this sub-category, one participant reported:

> *We talked about things we had not mentioned for a long time. It's like you protect each other. You don't tell each other certain things, because the situation is so difficult and you're just surviving. Things that are really important, things that were important before – you don't think of them any longer. The lesson pointed this out to us, so we started talking about it all and that was so incredibly good.*

Three partners mentioned that the intervention also provided helpful solutions for problems they had. Two indicated that the intervention provided useful tips on how to ask for help from the social network or how to decline it. Another partner indicated that the intervention provided some guidelines on how to become more self-reflective and that this self-reflection could help adjust one's behavior.

Positivity: Six partners indicated that the intervention helped them to think and act more positively. One partner mentioned that it was fun to do the intervention because it brought new insights and was enjoyable. Another partner mentioned that the intervention brought positivity, but did not specify further. Three partners liked the fact that through the intervention they felt more connected with their partner. They were more aware of the positive aspects in their relationship and they valued these even more. Another partner reported having become more aware of the little things in life that can make a difference:

> *I followed that lesson during a particularly difficult time, and it greatly helped me to carefully think about the whole situation. Also about the rays of light, for it all seems so hard. And when I thought about those rays of light, I told myself: "Oh yes, remember? There still are so many nice things!*

Attention for me as the caregiving partner: Some of the partners (n=3) reported that the intervention gave them the opportunity to have some time for themselves, and they valued the possibility to tell their story (n=3): "*There just happened to be elements in the course that simply were of great importance to me, especially the opportunity to tell my story.*" One partner felt that the intervention offered some structure during what felt like a chaotic and difficult time.

Table 4: Short-term effects (working elements of the intervention)

Short-term effects	Total n (%)	Subthemes	Subtheme Total n (%)	Example quote
Insight and acknowledgement	13 (92.9)	Better understanding of the situation (psycho-education)	10 (71.4)	“There were many emotions that I recognized, as you know, but reading about them made me think, ‘Yes, that’s how it is.’ Like the expression ‘emotional roller coaster,’ which suddenly appeared to be true also for me. One is familiar with the phrase, but then suddenly it becomes part of one’s life.”
		Experiencing acknowledgement and recognition.	8 (57.1)	“I also felt confirmed in my feelings. So I am not crazy, this is normal, this is a phase in my life and a process to go through and that all people in my situation have to face.”
		Confirmation of their ability to cope with a difficult situation	4 (28.6)	“I felt like I had done really well. By following the course, I discovered that this feeling of mine had been quite right, for things did indeed go well.”
ACT- and self-compassion-related	11 (78.6)	Be more (self-) compassionate	7 (50.0)	“So indeed, if I remember what was said, you know like ‘Do not demand too much from yourself,’ ‘Take time to relax,’ and the other sources of help, then I think: ‘Yes, that is right.’ It really helped me a lot.”
		Be more mindful	7 (50.0)	“It was really good to sometimes be really quiet, just to listen for a moment and feel my feelings and be quietly present to myself for some time.”
		Creating distance from your own thoughts	5 (35.7)	“It was like letting your thought-factory go on a holiday, so to say. I put [the mindfulness exercise] on my mp3 player and sometimes took it with me to bed. So when I could not sleep, I would play it.”
Guidance and solutions	9 (64.3)	Guidance to improve communication	8 (57.1)	“They were very difficult subjects about which we first explored independently from one another. We then talked with each other about our answers.”
		Helpful solutions	3 (21.4)	“Those exercises helped me to experience my meetings with friends as relaxing. And indeed, why wouldn’t you share your worries?”
Positivity	6 (42.9)	Positivity	6 (42.9)	“Well, we consciously looked at what we had done together, also at the positive things, even though it was not all that positive. Still, we said: ‘We haven’t done so badly, you know?’ Small things, they don’t need to be so big.”
Attention for me as a partner	5 (35.7)	Moments for myself	3 (21.4)	“Those are the moments you hold on to, you know? When you think: ‘Yes, how wonderful! I feel so relaxed now.’ Those are the moments, during the short time one has, that you try to make your own.”
		Telling my story	3 (21.4)	“The course really helped, because I was able to talk and write about it and thus gain distance from it all. In daily life one meets so very few people with whom you can share your story. And in this case, I was able to share it.”
		Structure	1 (7.1)	“It provides one with so many handles. And also with some structure in all the chaos, so to say.”

Long- term effects (effects on wellbeing and relationship)

Long-term effects are the effects that the partners were still experiencing at the time of the interview. These can be divided into four categories (listed from the most to least mentioned): (1) ACT- and self- compassion-related skills, (2) positivity, (3) connectedness, and (4) personal growth. The categories and their subcategories are listed in Table 5.

ACT- and self-compassion-related skills: The majority of the partners (n=11) felt more self-compassionate after the intervention. They realized that it is important to also focus on oneself, to be kind and caring not only towards the patient, but also towards oneself:

> *I have also become a lot kinder to myself, also thanks to these lessons. Because I had to write down things and answer questions, I came to realize that I was also judging myself. And well, that is something I have done already for a long time. But now I naturally enter into a different phase of my life, and then it is so important to be very kind to myself, to allow myself some time to just do nothing for a little while. Or just to really take care of myself and pamper myself a little.*

Eight partners reported being more aware of their surroundings, and they felt more calm and relaxed after the mindfulness exercises: *"Also afterwards, the mindfulness exercise helped me to stay much calmer in everyday life… It helped me to be more conscious and calmer."*

Eight partners reported that the intervention helped them to gain control over their thoughts, allowing them to not simply accept their thoughts as literally true:

> *One of the tips one receives is to think with every thought: 'That is a thought' or something like that, for instance 'I have thoughts that say…' That is really good because it shows that a thought is not the truth. You think it and it is just an image. And that gives one some kind of strength. I feel stronger by those thoughts, by formulating them in this way.*

In addition, the intervention helped half of the partners to live in accordance with their personal values (n=7). Five partners indicated that they had learned to accept their needs, such as spending more time with their ill partner. Two partners indicated being stricter about protecting their personal boundaries:

> *I learned that is always easy to drop everything and be there for everyone else while forgetting oneself. It is not right that everyone else runs your life. You should be able to say: "Wait there for a moment and don't come any further."*

Almost half of the partners (n=6) reported feeling more acceptance towards their own emotions – like fear or worries, for example:

> *I learned something from the what-if questions. At the time, I was very busy with these kinds of questions. During that lesson, I came to understand that one has to learn how to deal with them. What if this, what if that – you have to learn to give such questions their place. That doesn't mean finding an answer to what-if, but rather that it is normal to have what-if questions and to know how to deal with them. That doesn't mean they direct your life, but that you give them their place, like: "This is the question to which I, for the moment, do not have an answer and that's that."*

Four partners felt that they could better communicate about what really matters. The lessons stimulated conversations between partners and patients, and they felt that they remained more open towards each other, as is illustrated in the following quote:

> *Yes, afterwards we were more open towards each other about topics we would not have talked about so easily before. After the conversation, we carried on in a different way, so it absolutely brought us something.*

Some of the partners (n=4) reported that the intervention helped them to be more aware of their personal values in life and their relationship:

> *I came to understand that the most important thing is my family. That is what it is all about. I realized my values … I realized more clearly which are the most important values in my relationship and in my family situation.*

Positivity: More than half of the partners (n=9) mentioned that they were more positive about their lives since they had completed the intervention. They were more aware of the small positive things in life that make life worth living. One partner said: "*And now I do see [those rays of light], yes! Perhaps I did so before without realizing it, it happens so spontaneously. And now I think: … Those rays of light make it all more pleasant."*

Connectedness: Almost half of the partners (n=6) mentioned that they became closer and felt more connected to their partner: *"It gave us a sense of belonging, like: Hey, we are actually quite happy together."*

Personal growth: Three partners reported that they became stronger and more resilient as a result of the intervention, as is illustrated in the following quote: *"Yes, during that time I really was … sad. It was all so difficult, but thanks to the lessons, I came to see that I am much stronger than I thought I was."*

Table 5: Long- term effects (effects on wellbeing and relationship)

Long-term effects	Total n (%)	Subtheme	Subtheme Total n (%)	Example quote
ACT- and self-compassion-related	14 (100)	More (self-) compassionate.	11 (78.6)	"What is it all about? At the side of a sick partner, it is also about oneself. Yes, I see this also as a parent, you know. It is a combination of things, also in your role as an employee. As a partner too, but all of that can only happen if you stay in it also for yourself."
		More aware of the here and now/more relaxed.	8 (57.1)	"Just looking at things, not specifically, but with more awareness, so to say."
		Control of thoughts (cognitive defusion).	8 (57.1)	"Yes, some relaxation. At night you lie awake, and you try to remember the course and then bring some quiet to your thoughts and feelings."
		Living in accordance with personal values.	7 (50.0)	"Yes, just say: 'I don't feel like it' or 'I don't have time for that' or 'I won't make time for that.' "
		More acceptance of emotions.	6 (42.9)	"Through the lessons I somewhat learned to think: Yes, it is indeed very difficult and it is alright if I feel sad sometimes."
		Better communication about what really matters.	4 (28.6)	"It is also good to talk about it with my husband. He doesn't talk very easily, but thanks to the topics that were included, we also learned to really talk to each other."
		Awareness of values in life and relationship.	4 (28.6)	"Especially 'what is really important.' One tends to easily to just continue in the same old way."
Positivity	9 (64.3)	Positivity (enjoy the little things).		"It is still a source of inspiration for me, just to think about positive things and really dwell on them, like enjoying the sunshine while taking a walk and those kinds of things. Simply with real awareness."
Connectedness	6 (42.9)	Spouses got closer (more connected).		"In any case it brought us together for a conversation. From both sides, so to say, with the right instruments to better understand each other and to help each other during the whole process."
Personal growth	3 (21.4)	Stronger and more resilient.		"Through the course, you move forward a bit and you grow. And the essence – you know it and you keep it alive."

DISCUSSION

This study aimed to investigate the impact of a Web-based self-help intervention based on ACT and self-compassion. We found that, in general, the intervention was positively appreciated and partners' learned lessons appeared to be helpful in supporting them to cope with the challenging situations they faced. Our findings can partly be explained by processes related to ACT- and self-compassion that were the basis of the intervention.

Most partners reported short- and long-term learning effects related to these theories. Partners, for example, mentioned that the intervention made them aware of the importance of not only focusing on (the needs of) the patient and being kind and caring towards him or her, but to also treat themselves with the same amount of compassion. Some partners also mentioned that the intervention helped them to be more mindfully present and to accept their (negative) emotions instead of over-identifying or avoiding them, which refers to the A(cceptance) part of the ACT-model. The acceptance of negative emotions and sensations has often been found to be related to better mental health (e.g., [27]). In addition, the intervention helped partners to improve their ability to have more control over difficult thoughts, by creating a greater distance between their thoughts and themselves. This process, called cognitive defusion, is one of the core processes of the ACT model and it seems to be particularly important for partners of cancer patients because they often over-identify with unhelpful thoughts and feelings [1]. This result is in line with previous studies among other populations [28, 29]. Bacon et al. [28] examined the active processes of ACT in people experiencing psychotic disorders, and Mathias et al. [29] focused on the ACT processes in chronic pain patients. Both studies found that cognitive defusion is an ACT process that facilitated change in their participants. Partners also mentioned that our intervention helped them to become more aware of their personal values, more effective in communicating their values with the patient, and better able to commit to these values. These findings refer to the "C(hoose)" and "T(ake action)" of the ACT model and show that values and committed action may help partners of cancer patients. It seems that these processes can help them reorganize and rediscover their personal values and to live in accordance with them, despite the barriers caused by the cancer. Previous research has identified these ACT processes as contributing to positive change in other study populations, such as people with psychotic disorders [28] and patients with chronic pain [29].

Besides the processes related to ACT and self-compassion, our intervention seems to have also helped partners via a number of other processes such as insight and acknowledgement, positivity, possibility to tell their story, time for themselves, and feeling closer and more connected with the patient. Although these factors are not specifically related to ACT and self-compassion, they may be an important consequence of acceptance and self-compassion. In this respect, the impact of positivity is perhaps the most interesting. Nearly two-thirds of the partners reported that the intervention helped them to become more positive in life: allowing them to become aware of the little things in their lives and relationships that make life worth living (e.g., enjoying the weather; going for a walk; quality time with the family; a good conversation). Gaining acceptance towards one's emotions, becoming kinder towards oneself and acquiring awareness of one's values may result in an overall broader awareness, an improved experience of positive emotions, and an increase in enjoyment and appreciation of the positive things that remain in one's life. According to Fredrickson's broaden-and-build theory [30, 31], recurrent experiences of positive emotions (e.g., gratitude, love, feelings of joy) can increase a variety of personal resources such purpose in life, self-acceptance, mindfulness and positive relationships with others [32]. These resources can consequently lead to an increased life satisfaction and decreased levels of depressive symptoms. This aspect seems particularly crucial for partners of cancer patients because they are often confronted with many negative emotions, uncertain future perspectives and a high burden of responsibilities [1].

Another interesting factor that our findings revealed is the possibility of telling one's personal story. This factor seemed important for the partners because, by telling their story, they felt acknowledged. They also valued finally receiving some attention. During the patient's illness trajectory as well as within the social network of the partnership, the main focus often lies on the patient. As a consequence, the needs and concerns of the partners are often overlooked, and they have a minimal opportunity to tell their story. (Web-based) interventions aimed at this group can offer the attention and comfort they are vitally missing.

Besides offering clues about processes of (positive) change, our study also provided valuable information about the partners' appreciation of the intervention in general as well as specific elements. This information might be of interest for developers of future Web-based interventions for identical or similar groups. First, partners did not appreciate peer support as much as the other elements of the intervention. For example, they mentioned that they were not in need of peer contact or they were afraid of being confronted with negative stories. This result is in line with the outcomes of previous studies, which pointed out that people often fear peer support because they are afraid of hearing negative stories [25, 26]. While we tried to minimize this risk by offering different options of peer support, according to the users' experience, it seems that this approach was not sufficient to reassure the partners. Second, whereas previous research showed that personal feedback about a participant's progress is a valuable addition to an intervention [7, 33], the partners in our study mentioned that they would have liked the feedback to be more personal and to discuss some matters more deeply. For this specific group, more personal feedback could be important because, within the patient's care environment, often little or no room exists for the partners to tell their story or to express their concerns and questions. A more blended approach of the intervention (a combination of Web-based and face-to-face components) could be a possible solution to this problem [34]. Third, whereas some partners particularly appreciated the ‘tunneled’ structure of the current intervention, others preferred a less strict structure. As described earlier, we chose to deliver the content in a step-by-step format with a predefined order because we thought that this particular sequence of modules would be most beneficial for the partners, as it would give the partners sufficient time to process all the information. Furthermore, we chose that the next module could only be accessed when the previous one was completed and when partners had been active in the module for a minimum of one week. We expected that without this structure, partners would log in one or two times, scan all modules at once and would not return to the intervention.

Finally, regarding the dissemination of this intervention, partners suggested that healthcare professionals in hospitals (e.g., oncologists, nurses or social workers) should introduce the intervention not just once, but several times during the patient’s cancer trajectory. Partners seem to have different needs regarding when they might want to obtain support. Some partners would like to receive a psychological intervention immediately after the diagnosis, whereas others want to participate when they think it is necessary. We have to consider that partners often do not ask for help. Often they are not aware of their own health problems or they even neglect them because the patient’s wellbeing is their utmost priority (e.g., [35-37]). We expect that by offering an intervention (at various stages) to the partners, they may be more aware of the fact that they are at risk of developing physical or psychological health problems and that receiving help is not unusual. This multiple introduction of the intervention may help to lower partners’ threshold of asking for help for themselves.

Although ACT and self-compassion are increasingly being used as a theoretical framework for supportive (Web-based) interventions for a number of conditions (e.g., [6-9, 38]), most studies have been quantitative. Qualitative research is essential because it can reveal recommendations for improvement of interventions and valuable information about reasons for success and failure of an intervention [39]. Qualitative results can also provide insights into what the active ingredients of an intervention are [40] and if the underlying theory is appropriate [39].

The results from our qualitative study suggest that the training of ACT-related processes and self-compassion can indeed help partners of cancer patients to cope with the challenging situation they are facing. The outcomes of this study need to be interpreted with caution. First, it could be possible that the partners who were willing to participate in this study were initially more positive about the intervention than partners who did not want to participate. Second, because this study was retrospective, indicating that the results relied on participants' memories of the intervention. In anticipation of this possible limitation, before interviewing the participants, we provided them with a short summary of every lesson of the intervention. Yet, some partners still had difficulties remembering specific elements of the intervention. Quantitative effect studies are, of course, necessary to evaluate the effects of the intervention on psychological distress, caregiver burden, mental wellbeing and other outcome measures. Therefore, we are currently conducting a randomized controlled trial.

Conclusions

The Web-based self-help intervention, based on ACT and self-compassion, was appreciated by partners of cancer patients and helped them to cope with negative emotions, thoughts, and their own suffering; to practice self-kindness; and to clarify values based on their difficult recent experiences. In addition, the intervention supported them to obtain insight and acknowledgement, positivity, to tell their story, make time for themselves, and feel closer and more connected with the patient.

Declarations

Ethics approval and consent to participants

The Twente Medical Ethical Committee (Enschede, The Netherlands) approved this study in the context of a larger RCT (file number P13-17; Dutch trial register: NTR4035). All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Participants had given their oral informed consent before the interview took place. Written informed consent had already been given in the context of the RCT.

Consent for publication

Not applicable.

Availability of data and materials

The datasets generated during and/or analyzed during the current study are not publicly available due to the qualitative character of the data and in order to protect the anonymity of the participants. Datasets are available from the corresponding author on reasonable request.

Conflict of interest

The authors declare that they have no competing interests.

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Authors' contributions

All authors made substantial contributions to conception and design of this study. NK, CHCD and JJ contributed to the acquisition of the data. The gathered data was analyzed and interpreted by NK, CHCD and JJ and these three authors also drafted the manuscript. The other authors participated in revising the manuscript critically for important intellectual content. All authors gave their final approval of the version to be submitted and any revised version.

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7

Web-based self-help intervention for partners of cancer patients based on Acceptance and Commitment Therapy and self-compassion training: A randomized controlled trial with automated versus personal feedback

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Submitted

ABSTRACT

Objective: To evaluate the effectiveness of two versions (personal feedback versus automated feedback) of a psychological Web-based self-help intervention for reducing psychological distress among partners of cancer patients. The intervention was based on Acceptance and Commitment Therapy (ACT) and self-compassion training. Participants' adherence and satisfaction were also studied.

Methods: A total of 203 partners of cancer patients with mild to moderate distress were randomized to the personal feedback (PF) condition (n=67), the automated feedback (AF) condition (n=70) or to a waiting list (WL) condition (n=66). Participants completed measures before and after the intervention to assess psychological distress (primary outcome) and mental health, caregiver strain, general health, posttraumatic growth, resilience, self-compassion, psychological flexibility, mastery, and support style. Participants in the two experimental conditions also completed these measures at a 6-month follow-up.

Results: Results revealed that in the short term: (1) the AF-condition was effective in reducing distress when compared to a WL-condition and (2) there were no differences between the PF and WL conditions. In the long-term, the PF condition seemed more effective than the AF condition for reducing distress. Participants positively appreciated the intervention and 68.6% of the participants were adherent.

Conclusions: A Web-based self-help intervention based on ACT and self-compassion training does have the potential to reduce psychological distress in partners of cancer patients. The AF condition seems to speed up recovery in the short term. In the long term, the PF condition seems to be more beneficial. However, future research is essential to investigate the most appropriate form and content of the intervention's feedback.

KEYWORDS

Cancer; Oncology; Distress; RCT; Partners; Self-help; Web-based; Acceptance and Commitment Therapy; ACT; Self-compassion

INTRODUCTION

It is widely acknowledged that cancer and its treatment not only affects the lives of the patients but also that of their family caregivers. The situation can be particularly difficult for partners or spouses since they are often the primary informal caregivers [1, 2]. For many such caregivers it is difficult to disengage themselves from their caregiving situation, as they long to help the patient to feel better or feel a sense of duty to support the patient in every possible way [3, 4]. Partners of cancer patients must also manage and cope with the patient's multidimensional needs, such as treatment monitoring, managing symptoms and possible treatment side effects, coordinating appointments, accompanying the patient to the appointments, providing emotional, financial and spiritual support, and assisting with personal care (e.g., [3, 5]). Beyond these highly demanding responsibilities, partners also have to maintain their regular activities such as household tasks, child care and work responsibilities [3]. This challenging situation can result in high levels of psychological distress, caregiver burden, deteriorated physical health and diminished social functioning (e.g., [3, 6-9]).

In order to help partners maintain their own physical and mental health and, in turn, provide the best possible care for the patient, evidence-based and easily accessible interventions for partners of cancer patients are needed. Although some of these interventions have become available during the last decade, most partners do not use these professional supportive interventions because they are not aware of their own (mental) health problems, they have no time to oversee their own health or they are reluctant to seek help [4, 10, 11]. Web-based interventions have the potential to surmount these barriers, as they would inherently allow partners to receive help at home at any convenient time and, if they prefer, to remain anonymous [12-15]. Previous studies have shown that the majority of caregivers have Internet and e-mail access [13]; they frequently use the Internet to receive information and support regarding the patient's disease and care [16]; and they are receptive to Web-based tools that might help with their caregiving tasks and reduce their caregiver burden [4, 13]. Research has also demonstrated that, in addition to information, tips and support, some partners feel a need for Web-based interventions because they are looking for acknowledgement and someone they can talk to [4]. Perhaps as a result of such desired contact, some partners of cancer patients currently participate in Web-based discussion forums and/or blogs (e.g., [13]). However, up until now, the Internet has rarely been used to deliver interventions to partners of cancer patients [12, 14]. Therefore, we developed the Web- and theory-based self-help intervention called *Hold on, for each other* for partners of cancer patients. In order to ensure that the intervention actually complied with partners' needs and wishes, we actively involved them in the development process of this new intervention [17, 18].

The intervention *Hold on, for each other* is based on Acceptance and Commitment Therapy (ACT; [19]) and elements of self-compassion training. ACT is a form of cognitive behavior therapy that aims to help people to accept the unavoidable aspects in life, be mindfully present, choose important values in life and live in accordance to those values [19]. ACT has been successfully applied in a Web-based intervention for people with mild to moderate depressive and anxiety symptoms [20]. Self-compassion is the ability to act with kindness and understanding towards yourself (instead of harshly judging or criticizing yourself) whenever you are having a difficult time or when you fail at something [21]. The ACT processes and the elements of self-compassion (self-kindness, common humanity and mindfulness) are interconnected. According to Tirch, Schoendorff and Silberstein [22] both ACT and self-compassion aim to improve mindfulness and willingness, help people disentangle themselves from difficult thoughts, and stimulate them to take action in accordance with their valued aims. However, self-compassion has the more explicit aspiration to develop "the capacity for awareness of suffering and the motivation and ability to alleviate or prevent [the] suffering we encounter" [22]. This aspiration may be particularly relevant to partners of cancer patients since they usually have high expectations of themselves; partners would often do anything to help the patient feel better, regardless of the cost or personal toll it might require. While engaged in this highly demanding act, most partners frequently neglect their own health problems, overlook their personal needs, and even feel guilty when they do eventually meet their own needs or enjoy pleasurable things when their ill partner (the patient) is suffering [23].

In this study two different versions of feedback were explored (personal versus automated feedback). In general, the aim of the feedback was primarily to improve adherence [24]. We chose to examine these two versions of feedback because previous research had found that an automated feedback web-based intervention for treatment of people with mild to medium depressive symptoms can be as effective and reach the same adherence as the same intervention with personal feedback [25].

The aim of this study was to evaluate the effectiveness of these two versions of the Web-based self-help intervention *Hold on, for each other* on partners' psychological distress (primary outcome) as well as on their positive mental health, general health, caregiver burden, psychological flexibility, self-compassion, sense of mastery, supportive behavior, posttraumatic growth and resilience. A second aim was to explore the participants' satisfaction with and adherence to the intervention.

METHODS

Design

The design of the current study is described in detail by Köhle, Drossaert, Schreurs, Hagedoorn, Verdonck-de Leeuw and Bohlmeijer [26]. We carried out a prospective randomized controlled trial in which participants were randomly assigned to either one of the two versions of the Web-based intervention *Hold on, for each other*: 1) personal feedback condition (PF condition) versus 2) an automated feedback condition (AF condition) as well as 3) a waiting list control condition (WL condition). Participants were not blinded to the condition. This study was approved by the Twente Medical Ethics Committee under the file number P13-17 (Dutch trial register: NTR4035).

Intervention and control condition

The Web-based intervention *Hold on, for each other* consists of six modules (plus two optional modules), which could be worked through in 6 to 12 weeks (participants were asked for a minimum time-investment of 1 to 1.5 hours per week). Each module includes psycho-educational texts, short psychological exercises (based on ACT and self-compassion training), and meditation exercises (based on self-compassion). For a more detailed overview of the intervention, please refer to the study protocol [26]. In addition, we offered practical information, tips and references to relevant websites, inspiring texts/poems, and an (optional) weekly text message service with short inspiring texts. The program also contained opportunities for peer support, for which we tried to embed low-threshold options. We based this decision on the knowledge that some people experience peer support as confronting, as they fear the possibility of hearing negative stories [27, 28]. Participants' first option was to share answers on some of the exercises with other participants (and read other partners' answers). For their second option, they could add tips and advice and read similar input from their peers. Thirdly, they could contact other participants in order to exchange private e-mail conversations.

Participants in the PF condition received weekly feedback in the form of e-mail messages from a personal counselor. After completing a module, these participants were encouraged to email their personal counselor about their experiences with the module, questions about the content of the intervention, and (technical) problems that occurred. Subsequently, the counselor replied to partner's e-mail with a reflection on the participant's progress in the module and a reaction to the questions and problems. Counselors were five trained masters psychology students of the University of Twente, The Netherlands. During their training, they received information on the following topics: (1) challenges partners of cancer patients are confronted with, (2) development process of the intervention, (3) theoretical background and (4) study design and aims. They were also trained to write e-mails to the participants in the following structured way: (1) compliment/reinforce the participant, (2) provide a short review of the past module and lessons learned, (3) answer the participant's questions/reactions and problems and further explain any unclear aspects of the intervention, (4) preview the upcoming topic(s) and (5) positively reinforce the participant in order to motivate him or her. Communication between the participants and counselors was provided within the enclosed and encrypted web-based system of the intervention. In contrast, participants in the AF condition received short, pre-programmed feedback messages immediately after completing an exercise. Participants assigned to the WL condition received the intervention with automated feedback after the post-intervention measurement (T1), three months after the baseline measurement.

Participants

Participants were recruited from February 2014 to June 2015 through a multi-component recruitment approach (e.g., via national newspapers, patient organizations, hospitals and psycho-oncological centers) throughout The Netherlands. Applicants were referred to a website (www.houvastvoorelkaar.nl) where they could find information about the study and the intervention and where they could apply to become a participant. Inclusion criteria were: 18 years or older, being a partner of a cancer patient/survivor, having Internet access, mastery of Dutch, and having mild to moderate symptoms of psychological distress, i.e., > 3 on the Hospital Anxiety and Depression Scale (HADS; [29]). Exclusion criteria were: anxiety and/or depressive symptoms (self-reported during the application process or a score ≥ 15 on HADS anxiety and/or depression), having recently (< 3 months ago) started with psychopharmacological treatment, currently receiving psychological treatment, not being able to spend 1 to 1.5 hours on the intervention, the cancer diagnosis of the patient was < 3 months ago, and the patient died.

Power analysis

A sample of 64 participants per condition at post-intervention and 6-months follow-up was needed to detect an effect size of .50 (Cohen's *d*) for the primary outcome with a power of (1-beta) = .80 in a two-tailed test (p <. 05). The sample size was extended by another five participants per condition to take into account normal distribution and possible post hoc analyses. Anticipating a drop-out rate of 20% between baseline (T0) and long-term follow-up (T3; not included in this study), our goal was to include 87 participants in each condition at baseline.

Randomization

Randomization was stratified for gender and the self-reported stage of the disease, and was conducted *a priori* by an independent researcher not included in the study who used a computer-generated random sequence of numbers, made with randomizer.org. All participants received the outcome of the randomization via e-mail, and the two experimental conditions additionally received a link to start the intervention. Participants were aware of the different conditions, and they started the intervention at an individual time point (directly after the randomization).

Measures

All participants completed Web-based questionnaires at baseline (T0) and post-intervention (T1; 3 months after T0). Participants in the two experimental conditions also completed these measures at a 6-month follow-up (T2). Due to ethical considerations, we chose to offer participants in the WL condition access to the intervention with automatic feedback after they completed the T1-measurement. As a consequence, we have no long-term comparison data for this group.

Partners' personal characteristics and patients' cancer-related characteristics.

The following socio-demographics of the partners and cancer-related characteristics of the patients were assessed: sex, age, education, marital status, cultural background, children, work status, type of cancer, time since diagnosis, current treatment and self-reported stage of the disease. The self-reported stage of the disease was measured with the question "How would you describe the situation of your partner?" Partners could answer with the following: (1) My partner is still in treatment, and we have good hope that he/she will recover. (2) The treatment is completed, and we are moving on with our lives. (3) My partner will (probably) not recover.

Satisfaction and adherence

Participants' overall satisfaction with the intervention at post-treatment was measured with the Client Satisfaction Questionnaire (CSQ-8; Larsen, Attkisson, Hargreaves, Nguyen [30]). Higher scores are an indication of more satisfaction, ranging from 1 (very negative) to 4 (very positive). A mean score across all items was calculated as well as a mean score for every item. Participants were also asked to rate the intervention on a scale from 1 (extremely poor) to 10 (excellent). In addition, participants were asked how much time they had spent on the intervention on average every week. Adherence to the Web-based intervention was measured objectively by log files. Participants who reached module 6 were classified as adherent.

Outcome measures

The primary outcome measure of this study was psychological distress which was assessed with the Hospital Anxiety and Depression Scale (HADS; 14 items, range 0-42 [29]). Higher scores on this scale indicate more psychological distress. Secondary outcome measures were positive mental health, caregiver strain and general health. Positive mental health was measured with the Mental Health Continuum Short-Form (MHC-SF; 14 items; range 1-6 [31, 32]). Higher mean scores indicate higher levels of mental health. Caregiver strain was measured with the Caregiver Strain Index (CSI; 13 items; range 0-13 [33]). Higher scores on this scale indicate that caregivers experience more strain due to their caregiving tasks. General health was measured with one item of the RAND 36 (range 1-5; higher scores indicating better general health [34, 35]).

The following variables were examined as process measures: psychological flexibility, self-compassion, posttraumatic growth, resilience, different styles of support behavior, and sense of mastery. The Acceptance and Action Questionnaire II (AAQ-II; 7 items, range 7-49 [36, 37]) was used to measure the psychological flexibility. Higher scores indicate higher levels of psychological flexibility. Self-compassion was assessed with the Self-compassion Scale Short-Form (SCS-SF; 12 items; range 1-7 [38, 39]). Higher mean scores on the SCS-SF indicate that individuals are more self-compassionate. The Posttraumatic Growth Inventory Short-Form was used to measure the level of posttraumatic growth (PTGI-SF; 10 items; range 0-50 [40, 41]) with higher scores indicating more posttraumatic growth. Resilience was measured with the Brief Resilience Scale (BRS; 6-items [42]). The mean score can range from 1-5, with higher scores indicating that individuals are more resilient. The different styles of support behavior were assessed with the Active Engagement Scale [43, 44]. This scale measures active engagement (5 items), protective buffering (8 items), and overprotection (6 items). For each subscale, a mean score was calculated, with higher scores indicating higher levels of active engagement, protective buffering and overprotection (range 1-5). The Pearlin Mastery Scale (PMS; 5 items; range 5-25 [45]) was used to measure a sense of mastery, with higher scores signifying that the individual perceives him or herself in control of his or her life. A more detailed description of the questionnaires can be found in Köhle et al. [26].

Statistical analysis

All statistical analyses were performed using SPSS 20.0 (IBM SPSS Statistics). All tests were two-tailed. One-way analysis of variance (ANOVA) and χ^2 tests were conducted in order to examine if there were significant differences at baseline between randomized conditions, for any of the socio-demographics, cancer-related characteristics and outcome measures. An intention-to-treat analysis (ITT) was conducted to impute missing values on all outcome measures with an expectation-maximization method [46]. Little's MCAR test indicated that missing data were completely at random (χ^2 (530) = 385.47, p = 1.000).

First, two 2 (condition) x 2 (time) ANOVAs were conducted to examine whether one of the two different versions of the intervention (personal feedback versus automated feedback) was more effective than the WL control condition on all outcome measures at T1. Paired sample *t*-tests were conducted in order to test whether the changes in the outcome measures from baseline (T0) to post-intervention (T1) within each condition were significant, and whether the effects of the experimental conditions could be maintained from post-intervention (T1) to follow-up (T2). Two 2 (condition) x 2 (time) ANOVAs (PF versus AF) were used to examine differences between PF and AF on the change in all outcome measures from baseline (T0) to post-intervention (T1) and from post-intervention (T1) to follow-up (T2). Effect sizes (Cohen's *d*) between the conditions at post-intervention (T0-T1) and at follow-up (T1-T2) were calculated using means and pooled standard deviations. Effect sizes of 0.56-1.2 were considered large, 0.33-0.55 as moderate, and less than 0.33 as small [47].

We evaluated participants' adherence, satisfaction and drop-out with the use of descriptive statistics, χ^2 tests and one-way analyses of variance (ANOVA).

RESULTS

Study population

Figure 1 shows a flowchart of the participants in this study. A total of 371 partners of cancer patients expressed an interest to participate in the intervention. Based on the study's criteria, 114 applicants were excluded before the randomization and 54 declined to participate. Some participants were excluded because of a combination of different criteria. The most occurring reasons for exclusion were that: the cancer diagnosis was less than 3 months ago (n=48), applicants were not the partner of a cancer patient (either they were related to the patient in another way or the patient was deceased) (n=29), they reported that they were experiencing severe distress (n=26), or they were currently receiving psychological treatment (n=26). The remaining 203 participants were randomized to the PF condition (n=67), the AF condition (n=70) or the WL condition (n=66) after receiving their informed consent and completing the baseline questionnaire (T0).

Table 1 shows an overview of the participants' characteristics and the cancer-related characteristics of the patients. Participants had a mean age of 56 years (SD = 10.72, range 27-82). The majority was female (70.4 %), and of Dutch origin (95.1 %). Most of the participants had a medium to high level of education (84 %) and a paid job (59.6 %). Patients were diagnosed with a variety of cancers (in total 27 different types). In most cases, the diagnosis was 1-5 years ago, 38.8% were currently not under treatment, and 58.1 % of the participants indicated that the patient would (probably) not recover. One-way analysis of variance (ANOVA) and χ^2 tests showed that there were no significant differences at baseline between randomized conditions for any of the socio-demographics, cancer-related characteristics and outcome measures, indicating a successful randomization.

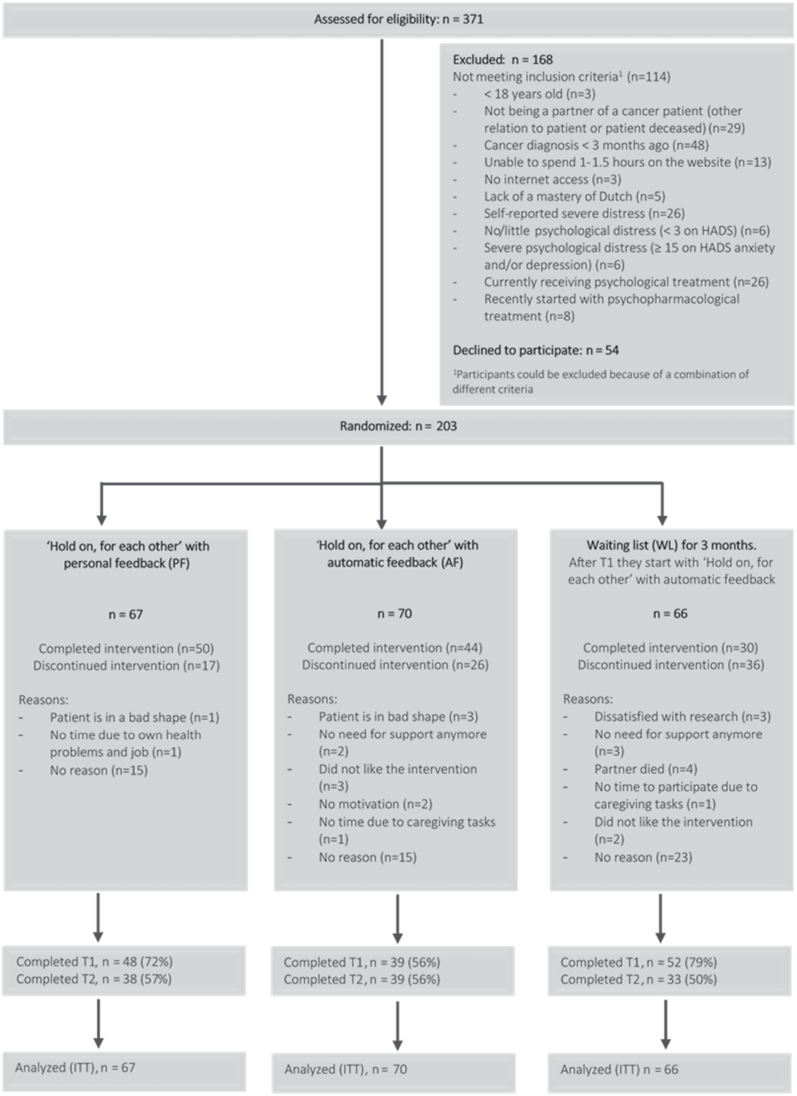

Figure 1. Flowchart of participants. T1, post-intervention (3 months after baseline); T2, follow-up (6 months after baseline)

Table 1: Partners' personal characteristics and patients' cancer-related characteristics

	Total (n=203)		PF (n=67)		AF (n=70)		WL (n=66)		*P*[2]
	n	%	n	%	n	%	n	%	
Partners' personal characteristics									
Gender (n=203)									.974
Female	143	70.4	47	70.1	50	71.4	46	69.7	
Male	60	29.6	20	29.9	20	28.6	20	30.3	
Age, mean (S.D.), years [range] (n=203)	55.89 (10.72) [27-82]		56.97 (9.88) [29-82]		56.40 (11.15) [30-79]		54.24 (11.03) [27-79]		.251
Country of birth (n=203)									.177
The Netherlands	193	95.1	61	91.0	68	97.1	64	97.0	
Other	10	4.9	6	9.0	2	2.9	2	3.0	
Children (n=203)									.240
No/or living away from home	131	64.5	43	64.2	50	71.4	38	57.6	
Yes, living at home	72	35.5	24	35.8	20	28.6	28	42.4	
Education (n=197)									.065
Low	32	16.2	6	9.0	14	20.0	12	18.2	
Middle	58	29.4	19	28.4	25	35.7	14	21.2	
High	107	54.3	41	61.2	28	40.0	38	57.6	
Employment (n=203)									.184
Paid job	121	59.6	41	61.2	36	51.4	44	66.7	
No job	82	40.4	26	38.8	34	48.6	22	33.3	
Cancer-related characteristics of the patient									
Sort of cancer (n=199)									.254
Colon cancer	28	14.1	8	11.9	7	10	13	19.7	
Prostate cancer	24	12.1	5	7.5	12	17.1	7	10.6	
Lung cancer	23	11.6	5	7.5	9	12.9	9	13.6	
Breast cancer	18	9.0	8	11.9	8	11.4	2	3.0	
Lymph node cancer	17	8.5	9	13.4	5	7.1	3	4.5	
Head-and neck cancer	11	5.5	5	7.5	3	4.3	3	4.5	
Leukemia	11	5.5	6	9.0	1	1.4	4	6.1	
Bone marrow cancer	11	5.5	4	6.0	3	4.3	4	6.1	
Brain tumor	8	4.0	1	1.5	4	5.7	3	4.5	
Kidney cancer	8	4.0	1	1.5	4	5.7	3	4.5	
Other[1]	40	20.1	15	22.4	13	18.6	12	18.2	
Time since diagnosis (n=203)									.600
Between 3-6 months ago	43	21.2	13	19.4	12	17.1	18	27.3	
Between 6-12 months ago	47	23.2	15	22.4	18	25.7	14	21.2	
1-5 years ago	81	39.9	28	41.8	27	38.6	26	39.4	
5-10 years ago	19	9.4	6	9.0	10	14.3	3	4.5	
>10 years ago	13	6.4	5	7.5	3	4.3	5	7.6	
Current treatment (n=201)									.982
No	78	38.8	26	38.8	27	38.6	25	37.9	
Yes	123	61.2							
Stage of disease (n=203)									.995
Patient is still in treatment with curative intent	52	25.6	17	25.4	18	25.7	17	25.8	
Treatment with curative intent is completed; patient is recovered	33	16.3	12	17.9	11	27.5	10	15.2	
Patient will (probably) not recover	118	58.1	38	56.7	41	58.6	39	59.1	

PF, personal feedback; AF, automatic feedback; WL, waiting list

[1] 17 different sorts of cancer

[2] One-way ANOVA for age, chi-square tests for the remaining variables

Treatment adherence and drop-out

According to the log data, within the AF and PF conditions, 94 (68.6%) participants completed the intervention by reaching the last module (module 6) and 43 (31.4%) participants of the experimental conditions did not fully adhere in the intervention (furthest module reached: module 1: n=11; module 2: n=8; module 3: n=7; module 4: n=14; module 5: n=3). The percentage of adherers in the experimental groups was highest in the PF condition (74.6%) versus 62.9% in the AF condition. However, the difference between the two experimental conditions was not significant [$\chi^2 = 2.2$, $p = .138$]. As shown in Figure 1, reasons for non-adherence in all conditions were: the deteriorating health or death of the patient (n=8), the intervention was not appealing (n=5), no need for support anymore (n=5), no time to participate because of one's own health problems, job or caregiving tasks (n=3), dissatisfaction with research (n=3), and lack of motivation (n=2). However, the majority of the participants (n=53) provided no reason(s) for non-adherence. There were no significant differences between adherers and non-adherers with regard to person- and cancer-related characteristics and outcome measures at baseline. On average participants reported to have spent 1 hour 51 minutes per week on the website (n=120): participants in the PF condition (n=48) reported spending on average 2.0 h per week on the website and participants in the AF condition (n=39) 1 h 32 min ($F = 2.28$; $p = .135$).

At post-intervention, data were available for 139 participants (drop-out rate 32 %), and at follow-up for 110 participants (drop-out rate 46 %; see Figure 1). There were no significant differences at baseline on all outcome measures between participants who completed all questionnaires (T0, T1, and T2) and those who did not. There were also no significant differences on all outcome measures between participants who did or did not complete T1 and T2.

Changes from baseline (t0) to post-intervention (t1)

The means and standard deviations for all outcome measures, the results of the repeated measures ANOVA, and the effect sizes between conditions are presented in Table 2. In Table 3, the results of the paired sample t-tests for the differences within conditions between T0 to T1 and T1 to T2 are shown. A significant interaction effect was found for the AF condition on the primary outcome variable, HADS-T and HADS-A. For HADS-A, partners' distress in the AF condition decreased significantly from T0 to T1, whereas the distress from partners in the WL condition significantly increased (HADS-A and HADS-T). For the PF condition, no significant interaction effects were observed from T0 to T1 for psychological distress. Regarding the remaining outcome variables, similar patterns were found. For the AF condition, significant interaction effects from T0 to T1 were found for caregiver strain, resilience, self-compassion, psychological flexibility, protective buffering and overprotection.

The scores on these variables improved for participants in the AF condition (significant improvement in resilience, protective buffering and overprotection), whereas they remained the same or significantly deteriorated for those in the WL condition. For the PF condition, no significant interaction effects were found on any of the secondary outcome variables except for overprotection. This score remained stable in the PF condition, whereas it significantly deteriorated in the WL condition. The PF and AF condition differed in the short term regarding HADS-A, protective buffering and overprotection. Distress (HADS-A), protective buffering and overprotection in the AF condition significantly decreased from T0 to T1, whereas they stayed the same or slightly improved in the PF condition.

Changes from post-intervention (t1) to follow-up (t2)

Due to participants in the WL condition starting the intervention with automated feedback after they completed the T1-measurement, we did not have their comparison data for the follow-up (T2) measure. However, we examined changes from post-intervention to follow-up in the experimental conditions. Repeated measures ANOVA revealed significant differences between PF and AF on the change in outcome measures from post-intervention (T1) to follow-up (T2). A significant interaction effect was found on the primary outcome variable. Partners' distress (HADS-T, HADS-D and HADS-A) in the AF condition significantly increased from T1 to T2, whereas the partners' distress (HADS-T and HADS-A) in the PF condition significantly decreased from T1 to T2. We found significant interaction effects for all secondary outcome measures except for general health and posttraumatic growth. In general, the scores within the PF condition remained the same or significantly improved from T1 to T2, whereas the scores within the AF condition remained the same or significantly deteriorated. The only exception was active engagement. This score significantly deteriorated in the PF condition, whereas it slightly (but not significantly) improved in the AF condition. These findings suggest that the intervention with AF seems to speed up recovery in the short term, however the PF condition seems to be more beneficial in the long term.

Satisfaction

Participants were generally satisfied with the intervention, with an average score of 3.0 on the CSQ-8. The majority of the participants rated the quality of the intervention as good. Most (84%) would recommend it to other people in need of similar help, and most (81%) indicated that they received the kind of support they wanted. On a scale from 1-10, the intervention was evaluated with a 7.4 [SD = 1.3, n = 87]. There were no significant differences in the scoring by the participants in the PF versus the AF condition.

Table 2. Means and standard deviations for outcome measures and results of repeated measures ANOVA for intervention effects, and effect sizes (Cohen's *d*) between conditions

		Condition						ANOVA: *F*						ANOVA: *F*	
								Time x condition (T1-T0)			Cohen's *d* (T1)			Time x condition (T2-T1)	Cohen's *d* (T2)
Outcome	Score	PF (n=67)		AF (n=70)		WL (n=66)		PF v. WL	AF v. WL	PF v. AF	PF v. WL	AF v. WL	PF v. AF	PF v. AF	PF v. AF
		M	SD	M	SD	M	SD								
HADS-T	T0	12.5	5.8	12.4	5.5	12.7	5.6	0.74	7.48**	3.77	–	0.6	–	32.90***	0.6
	T1	13.2	5.1	11.2	5.0	14.3	6.0								
	T2	11.8	4.6	15.0	5.7	–	–								
HADS-D	T0	4.9	3.4	5.1	3.1	5.5	3.2	0.21	3.09	1.53	–	–	–	15.00***	0.5
	T1	5.5	2.8	5.0	2.8	6.4	3.2								
	T2	5.1	2.3	6.4	3.1	–	–								
HADS-A	T0	7.6	3.1	7.4	3.0	7.2	3.0	1.20	9.76**	5.13*	–	0.6	-0.6	39.30***	0.7
	T1	7.7	2.7	6.2	2.7	8.0	3.4								
	T2	6.7	2.8	8.6	3.0	–	–								
MHC-T	T0	4.2	0.8	4.2	0.7	4.1	0.8	1.70	0.02	1.49	–	–	–	14.25***	0.9
	T1	4.1	0.7	4.0	0.8	3.9	0.7								
	T2	4.2	0.6	3.6	0.7	–	–								
CSI	T0	7.5	2.6	6.9	2.7	7.3	2.3	1.48	4.47*	0.52	–	0.6	–	14.54***	0.3
	T1	7.3	2.4	6.4	2.0	7.7	2.6								
	T2	7.0	2.2	7.8	2.8	–	–								
RAND 36	T0	3.0	0.6	3.0	0.7	3.0	0.8	0.22	0.01	0.32	–	–	–	0.33	–
	T1	3.0	0.5	3.1	0.6	3.1	0.7								
	T2	2.9	0.5	3.1	0.5	–	–								
PTGI-T	T0	16.3	8.2	15.0	8.9	15.3	7.8	0.43	0.26	1.13	–	–	–	0.68	–
	T1	23.4	8.8	20.7	8.8	21.7	7.4								
	T2	24.9	7.7	21.0	7.3	–	–								
BRS	T0	3.1	0.7	3.2	0.6	3.2	0.6	2.16	6.24*	0.69	–	0.3	–	12.01***	–
	T1	3.2	0.6	3.4	0.6	3.2	0.6								
	T2	3.2	0.4	3.1	0.5	–	–								
SCS-T	T0	4.5	0.9	4.7	0.9	4.6	0.8	2.92	5.95*	0.61	–	0.7	–	22.71***	0.3
	T1	4.5	0.9	4.9	0.8	4.4	0.7								
	T2	4.6	0.7	4.4	0.9	–	–								

PF, personal feedback; AF, automatic feedback; WL, waiting list; HADS-T= Hospital Anxiety and Depression Scale Total; HADS-D= Hospital Anxiety and Depression Scale Depression subscale; HADS-A= Hospital Anxiety and Depression Scale Anxiety subscale; MHC-T= Mental Health Continuum Short Form Total; CSI= Caregiver Strain Index; PTGI-T= Posttraumatic Growth Inventory Total; BRS= Brief Resilience Scale; SCS-T= Self-Compassion Scale Short Form Total; AAQ-II= Acceptance and Action Questionnaire; PMS=Pearlin Mastery Scale; ABO_AE=Active Engagement Scale; ABO_PB=Protective Buffering; ABO_OP=Overprotection.*p < .05; **p < .01; ***p < .001 (two-tailed).

Table 3: Results of paired sample t-tests to examine changes in the conditions from T0-T1 and T1-T2

	T1-T0			T2-T1	
Outcome	PF	AF	WL	PF	AF
	t	*t*	*t*	*t*	*t*
HADS-T	1.01	-1.75	2.10*	-2.23*	5.87***
HADS-D	1.43	-0.26	2.18*	-1.26	4.22***
HADS-A	0.32	-2.85***	1.67	-2.63*	6.24***
MHC-T	-0.36	-2.24*	-2.27*	0.82	-4.33***
CSI	-0.51	-1.67	1.32	-1.15	4.10***
RAND 36	-0.16	0.65	.049	-0.96	-0.20
PTGI-T	7.97***	6.05***	8.39***	1.42	0.32
BRS	1.10	2.54*	-0.97	-0.34	-5.87***
SCS-T	0.46	1.50	-1.98	1.44	-4.95***
AAQ-II	-0.25	1.95	-2.05*	1.72	-6.66***
PMS	1.61	2.41*	0.71	2.22*	-7.29***
ABO_AE	-2.80***	-2.59*	-3.12***	-2.20*	1.67
ABO_PB	-1.37	-4.20***	1.28	-2.13*	6.68***
ABO_OP	-0.96	-4.72***	2.08*	-1.68	5.26***

PF, personal feedback; AF, automatic feedback; WL, waiting list; HADS-T= Hospital Anxiety and Depression Scale Total; HADS-D= Hospital Anxiety and Depression Scale Depression subscale; HADS-A= Hospital Anxiety and Depression Scale Anxiety subscale; MHC-T= Mental Health Continuum Short Form Total; CSI= Caregiver Strain Index; PTGI-T= Posttraumatic Growth Inventory Total; BRS= Brief Resilience Scale; SCS-T= Self-Compassion Scale Short Form Total; AAQ-II= Acceptance and Action Questionnaire; PMS=Paerlin Mastery Scale; ABO_AE=Active Engagement Scale; ABO_PB=Protective Buffering; ABO_OP=Overprotection. *$p < .05$; **$p < .01$; ***$p < .001$ (two-tailed)

DISCUSSION

This study showed that a Web-based intervention based on ACT and self-compassion training was positively appreciated and that it does have the potential to support partners of cancer patients and to reduce their psychological distress. In particular, two different versions of this intervention with regard to personal versus automated feedback were studied. While the AF condition seems to speed up recovery in the short term, the PF condition seems to be more beneficial in the long term. It is puzzling why there was no improvement or even a slight deterioration in the short-term for participants in the PF condition and why the effects of the AF condition could not be maintained in the long term. One possible explanation could be that participants had different expectations regarding the form of personal feedback. From our qualitative evaluation study (submitted elsewhere), we know that not all participants were entirely satisfied with the support provided by their counselor because they had expected more personal feedback instead of feedback that mostly targeted their progress in the intervention. However, the weekly communication with the counselor may have been motivating, resulting in more commitment to the intervention and more motivation to complete it. Participants in the PF condition spent more (albeit not significantly more) time on the website every week (2 hours v. 1 hour 32 min) and more participants completed the intervention (74.6 % v. 62.9 %). Also the fact that participants in the PF condition had to wait for their feedback (until a prescheduled time of the week), whereas participants in the AF condition received feedback directly after they completed an exercise, might have caused participants to elaborate and reflect more on texts and exercises. In addition, participants in the PF condition could actively share their emotions and experiences with their personal counselor. This reflective process could have been confronting, with the consequence that symptoms remained the same or even slightly increased before they could decrease. However, sharing emotions and experiences, and thinking about and actively reflecting on the core messages and exercises of the intervention might have been a key process in helping participants to better cope with their situation and internalize lessons learned which the partners could then apply in their daily life.

Our findings seem to contradict previous research by Kelders et al. [25] who found that a Web-based intervention with automated feedback for people with depression and anxiety was as effective as a Web-based intervention with personal feedback. However, this apparent contradiction can be explained by the different forms of feedback and also by the different population. To the best of our knowledge, Kelders et al. [25] are the first to compare a Web-based intervention with two different versions of feedback. Evidently, more research is essential to obtain insights into the best possible form and content of feedback for Web-based healthcare interventions.

This study also examined partners' satisfaction with the intervention. They were highly satisfied with *Hold on, for each other.* These results are in line with the results of our qualitative evaluation study, in which participants expressed their appreciation of the intervention and its different components (submitted elsewhere). The positive evaluation is likely to be the result of our developmental process for *Hold on, for each other*, in which we actively involved the partners in all phases. First, we conducted a needs assessment, followed by formative evaluations of the content and usability testing of a prototype of the intervention [26]. In addition to implementing end-users' input, we also involved experts in the development of the intervention in order to ensure that we did not overlook any relevant information. The relatively high adherence rate also indicate that the intervention appeals to the target-group. On average, adherence rates of Web-based interventions are usually lower (about 50%) [48]. In our study, 68.6% of the participants adhered to the program, which is especially high, considering the unpredictable situation partners of cancer patients face every day and the many challenges that confront them. These results confirm the importance of actively involving end-users and other stakeholders in the developmental process of a Web-based healthcare intervention [49-51].

Nevertheless, it should be noted that we did have difficulties with enrolment for this study (our requirement of power analysis was not met), despite: (1) the low-threshold character of our web-based intervention, (2) the use of a multi-component recruitment strategy and (3) a long (18 months) recruitment period. This result is in line with previous research (e.g., [52]).

Remarkably, 31% of the applicants were excluded from our study, mainly because the patient's cancer diagnosis was less than three months ago, applicants were not the actual partner of the cancer patient, or the patient was deceased, the applicant reported suffering from severe distress or they were currently receiving psychological treatment. Many applicants were quite disappointed that they were excluded. The fact that so many applicants were interested in engaging with our intervention clearly indicates that there is an unmet need among this group. Future studies are needed to examine if the current intervention can be adapted to the excluded applicants, or if other interventions could be offered to them. In addition, the difficulties with recruitment underline the need for better and more structured implementation of (Web-based) interventions for cancer caregivers at various points in the cancer trajectory.

This study has three main limitations. First, partners' distress in our study sample was relatively low when compared to the results of previous studies [53-55], leaving less room for improvement in the primary outcome [17]. Relatively low partner distress also indicates that we might not have succeeded in reaching the people who are most in need of an intervention. On the other hand, based on both our qualitative evaluation study as well as the results from the Client Satisfaction Questionnaire (CSQ-8), it appears that partners judged the intervention to be helpful and would recommend it to other partners. Second, we could not test whether the improvements of the PF condition from T1 to T2 were significant compared with the WL condition. Due to ethical considerations, we chose to offer participants in the WL condition access to the intervention with automatic feedback after they completed the T1-measurement. As a consequence, we have no long-term comparison data. Third, our study population mainly consisted of higher-educated females, and, therefore, our results may not be generalizable to a wider population. But this limitation is not particular to our study alone; it also occurs, in general, for other research into Web-based interventions (e.g., [56]).

Conclusion

This study demonstrates that a Web-based intervention based on ACT and self-compassion training has the potential to support partners of cancer patients and to reduce their psychological distress. Participants positively appreciated the intervention and the adherence rates were higher than in Web-based interventions targeting other populations. More research is needed to further investigate the long term effects of this Web-based intervention and the most appropriate form and content of feedback it might provide for this target group.

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8

SUMMARY AND GENERAL DISCUSSION

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Introduction

Partners of cancer patients are an essential pillar in the cancer trajectory. Cynthia's personal testimony, with which we started this thesis, clearly demonstrates that the patient's cancer can have an enormous impact on the partner's life and (mental) health. To support partners such as Cynthia during this difficult time, psychological interventions are needed. However, partners are often extremely busy and supporting them can be challenging. Web-based interventions offer a possible solution to aiding partners since such interventions circumvent caregivers' time restraints and daily, unpredictable demands by being easily accessible and flexible to use. In order to fulfil partners' needs and meet their challenges, the main aim of this research project was to develop and evaluate a psychological Web-based self-help intervention for partners of cancer patients that would be based on approaches from positive psychology (Acceptance and Commitment Therapy and self-compassion). The research questions of this thesis were as follows:

1. Is a Web-based intervention a useful and effective alternative for partners of cancer patients?
2. Are the processes of ACT and self-compassion applicable and beneficial for this target group?
3. Is co-creation useful in the development of a Web-based intervention for partners of cancer patients? And what are our recommendations for future intervention developers?

In this final chapter, a summary of the main findings presented in each chapter is given, the three research questions are answered and future directions are addressed.

Summary and main findings per chapter

As already mentioned in the Chapter 1 of this thesis, Web-based interventions have a great potential to be implemented in the healthcare system [1, 2]. Yet, they often have to deal with usability problems [3-5] and high attrition rates [6-8]. To tackle these problems, various authors have emphasized the need for a systematic and iterative development process, involving relevant end-users at various points in time [9, 10]. The studies described in the first part of this thesis (Chapters 2, 3, 4, 5) relate to this user-centered development.

In **Chapter 2** we described an interview study that was conducted as a needs-assessment. In this study, we interviewed 16 partners of cancer patients in order to examine their interest in a Web-based intervention and identify their needs and wishes for such an intervention.

We found that the need for a Web-based intervention varied, but that a substantial number of the partners were indeed interested in a Web-based intervention. Reasons for their interest were: a need for acknowledgement, looking for someone they could talk to, and being interested in information, tips and some form of support. Partners indicated that they preferred an intervention that would not be too time consuming, would have an informal character and would be based on a positive approach. Although some partners would appreciate an intervention that their ill partner and themselves could follow together, many partners preferred an intervention targeted at them alone, or that would contain at least some parts addressed exclusively to them.

In addition, desired functionalities were a provision of information and opportunities for peer support. However, whereas the majority of partners (n = 10) were interested in some kind of peer support, some partners (n=4) were not sure about their need for peer support or were not interested at all (n = 2). Arguments against peer support were, for example: having no time to support others, being unsure whether the experiences of others could help them personally, and the fear of being confronted with negative stories. Due to the varying opinions about this functionality, we came to the conclusion that peer support should be optional and offered in a way that facilitates sharing of positive tips and experiences and reduces the chances of unwanted confrontation with negative stories. We also explored partners' preferences for incorporating (professional) psychological counseling into the intervention. Results showed that their need for such counseling varied. Most of the partners (n=9) liked the idea that a professional would support them during their participation in an intervention. However, there was also a group that doubted the necessity of such support.

This qualitative study described in Chapter 2 provided us with valuable information regarding the content and requirements for the intervention. However, to gain more insight into the wishes of a broader group of partners, a quantitative study was conducted as described in **Chapter 3**. For the second part of the needs assessment, we conducted a quantitative survey study among 168 partners of cancer patients. The aim of this study was to more systematically examine partners' needs and wishes regarding the content, design and preconditions of a Web-based intervention, and see if the results corresponded to our initial qualitative study. In addition, we aimed to examine partners' intention to use such an intervention and the extent to which this intention could be predicted with partners' socio-demographics, patients' cancer-related variables, and partners' psychological functioning.

Our study confirmed the results from our qualitative study. We found that 35% of the partners would maybe be interested and 13% were definitively interested in an intervention that would be available to them. In line with the results from the qualitative study, partners indicated that they would prefer the intervention to not be too time consuming and contain information as well as peer support. Half of the partners indicated that they would like to receive Web-based support from a personal counselor, and again, the majority indicated that they preferred an intervention that would at least contain some parts addressed exclusively to them. Regarding the second aim, we concluded that it was difficult to predict interest. Of all the included demographics and cancer-related variables, only a younger age was significantly related to the intention to use a Web-based intervention.

Based upon the results of these two needs assessment studies and our literature review, a first (paper) version of the intervention was developed, and offered to partners of cancer patients for their feedback. Their comments were subsequently translated into a new, Web-based version of the intervention, which was again offered to partners for feedback. This process of development is described in **Chapter 4**. Besides the empirical and theoretical basis for our intervention, we described a summary of the development process and a protocol for a randomized controlled trial (RCT) to examine the effect of the intervention. In this chapter, we provided information about why it is important to offer theory- and evidence-based interventions, and what Web-based interventions could offer to partners of cancer patients. Subsequently, we described the theoretical background (Acceptance and Commitment Therapy and self-compassion) and development process (co-creation with end-users and experts via, for example, needs assessment and formative evaluations) for our intervention which we called *Hold on, for each other.* Furthermore, a detailed description of the content (texts, exercises, and additional information) and functionalities (e.g., peer support) of the intervention was provided and the protocol of the effect-study was discussed. We used a three-armed RCT to compare two versions of the intervention with a waiting list control condition. The intervention conditions were the same regarding the content of the intervention, but they differed in the form of support: one condition received weekly feedback messages by a personal online counselor, the other condition received automated feedback messages (programmed beforehand) directly after the partner had completed an exercise module. The waiting list control condition was on a waiting list for three months, after which time partners could start with the intervention with automated feedback. Participants were asked to fill out Web-based questionnaires before the intervention and 3, 6 and 12 months after the baseline measurement. The primary outcome measure was psychological distress. Additional outcome measures were mental health, caregiver strain, general health, health-related quality of life (secondary outcome measures), and psychological flexibility, self-compassion, posttraumatic growth, resilience, support behavior styles and sense of mastery (process outcome measures).

In the study described in **Chapter 5**, the specific role of self-compassion in relationship to partners' psychological distress and mental wellbeing was examined. A growing number of studies have demonstrated a relationship between self-compassion and distress and wellbeing (e.g., [11-13]), but, as yet, this had not been studied among partners of cancer patients. For this study, the baseline measurement of our RCT (n = 203 partners of cancer patients) was used. Although this study was not conducted directly within the context of the development of our intervention, we think that it provided interesting information for the usefulness and applicability of self-compassion in interventions for partners of cancer patients. The main findings of this study were that self-compassion is negatively related to psychological distress and positively related to mental wellbeing. In addition, self-compassion could significantly improve the prediction of distress and mental wellbeing after controlling for some other relevant psychological concepts that have been studied in relationship to coping with adversity: resilience, psychological flexibility and mastery. These results are an indication that self-compassion can be relevant for interventions among partners of cancer patients.

An overview of the content and some screenshots of the final intervention *Hold on, for each other* (http://www.houvastvoorelkaar.nl) can be found in the **intermezzo** of this thesis. Our intervention aims to provide information and support to partners of cancer patients. It consists of: (1) short texts about topics such as coping with emotions and unhelpful thoughts, communication, and personal values; (2) short psychological exercises based on ACT and self-compassion; (3) practical information, tips and references; and (4) peer support.

The second part of this thesis (Chapters 6 and 7) focused on the evaluation of *Hold on, for each other*, which we felt was essential since research has shown that a thorough evaluation is necessary for an implementation in the healthcare system [14]. Quantitative RCTs are widely used to evaluate the effectiveness of an intervention [14]. However, it has been shown that RCTs are not sufficient to gain full insights into the effects [14, 15]. Additional qualitative studies are necessary because they can provide further explanations into the reasons for success or failure of an intervention [15], reveal what the active ingredients of an intervention are [14], and help to examine the appropriateness of the underlying theory [15]. Therefore, we chose to use both qualitative and quantitative evaluation methods accompanied by a basic evaluation of log data in order to best evaluate the effects of *Hold on, for each other*.

In **Chapter 6**, the impact of *Hold on, for each other* was explored. In this qualitative evaluation study, 14 partners of cancer patients - who used *Hold on, for each other* - were asked about their appreciation of the intervention, if they had any suggestions for improvements, and what they had learned from the intervention. Findings revealed that the intervention had been helpful to the partners. They reported that they had become more mindfully present and had experienced more self-compassion, acceptance towards difficult experiences, awareness of personal values and had gained more of an ability to commit to those values.

In addition, the intervention helped them to obtain insights into and acknowledgment of their situation, to experience more positivity in their lives, to tell their story, to make time for themselves, and to feel closer and more connected with the patient. Our study showed that participants were positively satisfied with the intervention. For instance, they appreciated the fact that the intervention was easily accessible, that they finally received some attention (instead of the attention exclusively being paid to the patient's needs), and they were happy to find some acknowledgement. Besides the aspects of the intervention that were appreciated, some partners also expressed ambivalent feelings towards peer support, the content of the feedback of their personal counselor and the 'tunneled' structure of the intervention. As aforementioned, our qualitative evaluation study also examined partners' suggestions for improvements. Their suggestions were: (1) less rigid structure of lessons; (2) more personal support; (3) adding a book version to the Web-based version; (4) an additional lesson about bereavement; (5) an introduction of the intervention via healthcare professionals in the hospital; (6) the intervention should be offered at various stages in the illness trajectory (for further details, see Chapter 6).

Chapter 7 describes the RCT results used to evaluate the effectiveness of two versions (personal feedback versus automated feedback) of *Hold on, for each other*. The primary goal of the intervention was to reduce psychological distress among partners of cancer patients. A total of 203 partners of cancer patients were randomized to three conditions: the condition with personal feedback (PF condition, n = 67), the condition with automated feedback (AF condition, n = 70), and a waiting list control condition (WL condition, n = 66). The log data of our intervention were used to determine the adherence rates of the participants. Participants reaching the last module (module 6) were classified as adherent. The results showed that *Hold on, for each other* has great potential to reduce psychological distress in partners of cancer patients. The AF condition seems to speed up recovery in the short-term. In the long-term, the PF condition seems to be more beneficial. However, the results are inconclusive and more research is needed to further investigate the long-term effects and the most appropriate form and content of feedback for this target group. Regarding the partners' satisfaction with the intervention, we found that they rated the quality of the intervention as good, they would recommend it to other partners, and they indicated that the intervention helped them to cope more effectively with their situation. With regard to the adherence rates, we found that 68.6% of the partners in our experimental conditions were adherent.

Answers to the research questions

Is a web-based intervention a useful and effective alternative for partners of cancer patients?

We cautiously conclude that a Web-based intervention can be a useful alternative to traditional face-to-face therapy for partners of cancer patients. However, at this stage, we cannot conclude that it is effective. Based on the studies of this thesis, we know that there seems to be a need for such an intervention (Chapters 2, 3, 6 and 7). Second, as aforementioned, most partners positively appreciated the intervention for various reasons, such as the intervention's low threshold, easy accessibility, positive character, and how it provides the partners with attention and acknowledgement (Chapters 6 and 7). Third, a majority of partners said that they learned something from the intervention and that it helped them to cope more effectively with the challenging situation they faced (Chapters 6 and 7). Fourth, results of our quantitative evaluation demonstrated that the intervention has the potential to support partners of cancer patients and to reduce their psychological distress (Chapter 7). However, our results were inconclusive and, therefore, more research is necessary to examine the long-term effects and the most appropriate form and content of feedback for this particular group.

Although results of this thesis are promising, we also have to mention that, despite the great efforts we made to reach our target group by recruiting via various channels, including a close cooperation with hospitals and other cancer-related organizations, study enrolment was lower than expected. Consequently, we were not able to meet the requirements of our power analysis (Chapter 7). We expected that more partners would be interested in participating because of the intervention's easily accessible, informal and positive character. Unfortunately, this was not the case. In contrast, many of the partners that did succeed to find us explicitly mentioned that they were so glad that they finally did locate some support targeted to their particular caregiving needs. They told us we should definitely bring the intervention to the attention of a wider audience, because they had searched via various channels but found it difficult to find appropriate support. Future research should focus on how we can reach partners more efficiently and what possible barriers might be preventing their participation in such a potentially helpful intervention. A particularly interesting observation is that 31% of applicants were excluded from our study because the diagnosis of the patient's cancer was less than 3 months ago, applicants were not the partner of a cancer patient (but another relation to the patient or the patient was deceased), they reported suffering from severe distress or they already were undergoing psychological treatment. Therefore, we would suggest that future research should focus on how to adapt this intervention for the groups that were excluded. One possible adaptation would be to offer a blended-care variant of *Hold on, for each other*. Blended care is a combination of self-help via a website and personal encounters with a healthcare professional. It is increasingly implemented in mental healthcare and promising results have been reported (e.g., [16]).

In this thesis we also wanted to gain insight into the most applicable and effective way to support caregiving partners. From previous research we know that some kind of feedback should be provided in a Web-based intervention in order to improve its effectiveness and adherence rates [8, 17-19]. Based on the results of this thesis, we would recommend some form of *personal* support. The findings suggest that personal feedback from a healthcare professional (e.g., psychologist, social worker) can be of added value for this specific target group. We found that personal support can give partners the possibility to tell their story, help them to feel acknowledged, motivate them to complete the intervention, and/or allow a healthcare worker to check on them (Chapter 2). However, in our qualitative evaluation research about the impact of the intervention (Chapter 6), some of the participants who received personal feedback indicated that they were not fully satisfied with the feedback from their personal counselor. They expected more personal support, instead of support targeted at their process in the intervention. In our needs assessment (Chapter 2 and 3) we also found that the participants were divided about the best form of feedback, and in our quantitative evaluation study (Chapter 7) we also came to the conclusion that future research is essential to investigate the most appropriate form and content of the intervention's feedback.

Are the processes of act and self-compassion applicable and beneficial for partners of cancer patients?

Yes, we think that the processes of ACT and self-compassion are applicable and beneficial for partners of cancer patients. During the interview study (Chapter 2) participants mentioned that they would prefer a positive approach. They indicated that they suffered from all the misery in their lives and that they really missed having something offered to them as a partner of a cancer patient. Our interviews revealed that many partners tend to neglect their own needs as their focus is always directed on the patient's wellbeing. For example, one partner mentioned that he was not aware that he might also need some kind of support. All his attention was focused upon his wife's health. He wanted to be her 'hero' and stated that his own problems were not at all a priority. This finding – that partners neglect their own needs and emotions and/or are extremely harsh and demanding on themselves – has also been found in previous studies [20-22]. The following testimony is from one of the partners we interviewed, and it underpins this harsh personal criticism:

> *"Me and my daughters were grocery shopping in the city. Out of the blue, I became very emotional, and I was so angry at myself that I was in the city doing some grocery shopping*

> *while my husband was lying in bed suffering from cancer. [I] felt completely wrong, and went home immediately."*

During the interviews, partners indicated that an intervention targeted at them should be a source of hope and energy instead of being another burden or an additional source of negativity. Therefore, they hoped to find a focus on positive things in an intervention. When we asked them which topics should be addressed in the intervention they added "dare to enjoy" and "acceptance of the disease" as preferred topics. These wishes are very much in line with the principles of ACT and self-compassion. Chapter 5 of this thesis underlines the applicability of self-compassion for partners of cancer patients, for we found that self-compassion is negatively related to psychological distress, positively to mental health of the partners, and can significantly add to the prediction of distress and wellbeing after controlling for related psychological variables such as resilience, psychological flexibility and mastery. This is an indication that self-compassion is an important and unique factor in understanding partners' distress and should be targeted in an intervention.

In our qualitative evaluation study (Chapter 6) we found that the short- and long-term effects that partners reported were, to a large extent, indeed related to the processes of ACT and self-compassion. Partners, for example, reported to be more self-compassionate (e.g., they realized that it was also important to be kind and caring towards oneself), and mindful (living in the here and now) as a result of the intervention. We also found other processes that seemed to have helped the partners: insight and acknowledgement, positivity, possibility to tell their story, time for themselves and feeling closer and more connected in their relationships. These processes are not particularly related to the processes of ACT and self-compassion, yet they may be an important consequence of them.

In our quantitative evaluation study (Chapter 7) we found some indications that *Hold on, for each other* can improve self-compassion and psychological flexibility among partners of cancer patients. When compared to the WL condition, the AF condition was effective in increasing self-compassion and psychological flexibility in the short-term. However, the effects of the AF condition could not be maintained over six months. There were no differences between the PF condition and WL condition on the short-term regarding these two outcome variables. In the long-term, however, self-compassion and psychological flexibility in partners of cancer patients in the PF condition increased slightly, but not significantly.

Is co-creation useful in the development of a web-based intervention for partners of cancer patients? And what are our recommendations for future intervention developers?

We conclude that the systematic and iterative process of co-creation helped us to develop an acceptable intervention that meets the end-users' needs. Through the various steps of our development, we received valuable information about the partners' needs regarding the content and design of *Hold on, for each other*. In this section, we wish to first provide some examples that underline the usefulness of co-creation and then offer some recommendations for intervention developers based on our experiences regarding this approach.

First, by talking to the partners, we obtained insights into how the patient's disease had affected their personal life and how they coped with the daily challenges. This information was particularly useful for developing texts that might be appealing and recognizable. Partners who participated in our studies also indicated that they actually preferred an intervention that might be offered exclusively to them, or that they could at least do some parts of it without the patient (Chapters 2, 3 and 6). This was essential and novel information considering the fact that most available interventions for cancer caregivers are targeted at the patients and caregivers together [23]. Based on the results of our interview study (Chapter 2) and the formative evaluations of the intervention (as briefly described in Chapter 4, and described in more detail in [24, 25]), we learned that bright colors such as light blue or bright red should be used in an Web-based intervention for partners of cancer patients. Participants repeatedly mentioned that an intervention should be a source of hope and energy, indicating that an inappropriate use of colors or pictures might result in higher attrition rates. In our needs assessment, we also learned that a convenient and consistent structure is essential so that the intervention is applicable for all partners.

Second, during our needs assessment, we learned that many people have had no previous experience with Web-based interventions. Therefore, it is difficult for them to decide if they want to participate or not. Clear information about what they can expect from a Web-based intervention and what the intervention looks like and does should, therefore, be offered to them. In our case, we provided this information in two ways: applicants could find a description of the intervention on its website, and we also developed a 4-minute information video about the content and the preconditions of the intervention (see www.houvastvoorelkaar.nl). Partners and other people mentioned that they particularly like the video, because it showed them what they might expect from the intervention.

The above mentioned findings confirm how vital it is to actively involve the end-users in the development process (e.g., [26, 27]) of a Web-based intervention. The fact that partners of cancer patients appreciated the intervention (Chapters 4, 6 and 7), and that our adherence rates were higher than that of other Web-based interventions, despite the unpredictable and challenging situation of that partners of cancer patients face in their daily lives [28] (68.6 % v. 50 %, Chapter 7). These two findings indicate that we succeeded in developing an appealing and fitting intervention for this particular group.

Although we think that co-creation was indispensable in the development of our intervention, we would like to offer some recommendations to future intervention developers. First of all, intervention developers should consider that this development process is time consuming. The different studies that we undertook needed to be planned and carefully conducted. Developers should definitively take the time factor into account when they begin to plan their development process. Furthermore, we would recommend using a structural approach such as intervention mapping [29] or the CeHRes-roadmap [30]. These frameworks offer great support during the entire development process. In addition, in order to be transparent to stakeholders and other researchers, we recommend that developers publish their intervention development and the study protocol (Chapter 4).

In our needs assessment, it was difficult for some partners to decide upon their interest in and their needs regarding a Web-based intervention that had yet to exist. In addition, the majority of our partners had no experience with Web-based interventions. To give them an idea about how a Web-based intervention for partners might look like, we used short descriptions and mock-ups of a possible Web-based intervention (Chapters 2 and 3). We also used a set of prompt cards to help partners decide which topics the intervention should include (Chapter 2), and we developed a prototype of the intervention so that partners could evaluate its usability (Chapter 4). As previously mentioned, we also provided an information video on the website of our intervention. Partners of cancer patients in our studies responded well to these methods and we think that these ultimately helped them to elaborate on their wishes. Therefore, we recommend future developers to use these described methods, especially when developing a new intervention or informational product for a target group who might not yet be familiar with their own needs or desired outcomes or the potentialities and limitations of such an intervention.

In line with this aspect, developers should also consider the fact that if you ask people an open question such as what functionalities an intervention should offer, they will probably answer that it should contain everything! We think that when you are not familiar with a specific kind of tool or intervention, it is difficult to decide what you actually want and need and, consequently, it becomes easier to just want everything in the first place. For example in our studies, we found inconsistent results regarding the needs and preferences regarding peer support. The findings of our needs assessment (Chapter 2 and 3) indicated that most partners of cancer patients would like to have the possibility to share their experiences with peers, however, some were hesitant because they feared being confronted with negative stories. This result corresponds with previous studies [31, 32]. Because of these findings, we tried to develop easily accessible and flexible peer support options that would enhance sharing positive experiences and would minimize the possibility of (unintentionally) coming into contact with negative stories (see the Intermezzo). However, our qualitative evaluation study revealed, that partners did not appreciate this functionality as much as the other functionalities of the intervention, with the consequence that they hardly used it (Chapter 6 and 7). This limited use of peer support was also found in previous studies among other target groups. For example, a study among patients that were treated for arthritis, breast cancer and fibromyalgia found that only a small percentage of patients engaged in face-to-face and Web-based peer support groups [33]. Partners in our studies indicated that they did not use peer support because they were afraid of coming into contact with confronting stories. This indicates that we did not succeed in developing peer support options that take away their doubts and fears about peer support. In conclusion, developers of future Web-based interventions should consider that although end-users may indicate a need for a particular functionality, practice may show that the functionality does not fit the end-user (or vice versa) after all. this not necessarily means that they actually use it when it is offered to them.

Future directions

Based on the results of this thesis, we can recommend several areas to explore in future research. First, during the entire project, we kept a close eye on the context. Partners of cancer patients and other stakeholders, such as psychologists with experience in psycho-oncology, were actively involved in the development and evaluation of *Hold on, for each other*. We think that the structured development of the intervention, the theoretical background, and the positive approach equipped *Hold on, for each other* to be a unique product with great potential. While we focused on partners of cancer patients, we think that the intervention might also be applicable for other groups. Therefore, future research should examine if the intervention is also applicable for other caregivers of cancer patients, such as adult children, siblings or friends. Moreover, it would be interesting to study if *Hold on, for each other* is applicable for partners/caregivers of patients suffering from other chronic diseases, for example stroke, dementia or amyotrophic lateral sclerosis (ALS). One of our masters students in the Department of Health Psychology, University of Twente, The Netherlands, asked a sample of partners of patients who suffered from a stroke (n=9) and social workers (n=3) to explore how they experienced the content of *Hold on, for each other* [34]. The results of this study are promising. The majority of the partners were enthusiastic about the intervention and indicated that they benefited from it. The social workers were equally enthusiastic, stating that the content of the intervention could teach caregiving partners that the patient not only suffers, but that the patient's health condition can also have a great impact on their lives and that such a result is normal and experienced by many others in similar circumstances.

In this thesis we combined various research methods in order to thoroughly evaluate the impact of the intervention [14, 15]. We used qualitative and quantitative evaluation techniques as well as log data. Log data analysis can give insights into the 'real-time' use statistics that record every step a user has undertaken in an intervention [35], helping us to understand which parts of an intervention are more explored and beneficial [35-37]. In this thesis, we only used log data for identifying the adherence rates in our randomized controlled trial (Chapter 7), however, log data can be used more intensively. One of our masters students in the Department of Health Psychology started to analyze a part of the log data [38], and has since discovered that most participants (82.8%) used the mindfulness exercises at least once during the intervention, but that participants hardly used the different elements of peer support. We think that an in-depth analysis of log data can be of great value in optimizing the intervention and in studying adherence patterns and dose-response relationships. However, during this project, we also experienced that it was highly challenging to manage the enormous amount of data and to analyze and understand the output. Therefore, we would recommend that future research should focus on a more structured and systemic approach with regard to how log data should be collected, and we suggest the development of a log data protocol. Such a protocol could be used for a broad selection of Web-based interventions. Similar to how the CONSORT guidelines help researchers report their randomized controlled trials, a log data protocol could help researchers decide which information should be logged, how this should be conducted, and how the results of this analysis should be reported. This structured way of gathering log data could improve the quality of results and stimulate the comparison of results across different studies.

Currently, we are also occupied with analyzing the content of the e-mail correspondence between the participants in the personal feedback condition and their personal counselors. We expect that this will provide important insights into the impact that particular behaviors of the counselor (and participant) can have on the effect of the intervention. Although previous studies have demonstrated the importance of personal guidance (e.g., [17]), only a few studies have examined how such counseling should look like or what elements it should contain. To our knowledge, only two studies have examined what exactly is being exchanged in e-mail counseling [39, 40]. Holländare et al. [39], for example, found that therapists in internet-based cognitive behavior therapy for people suffering from depression most frequently encouraged, affirmed and guided their patients. However, both studies [39, 40] came to the conclusion that more research is needed to examine therapist behavior in Web-based interventions. Our content analysis of the exchanged e-mail correspondence between counselors and participants of *Hold on, for each other* can provide additional information about this matter.

In this thesis we gained some interesting insights into how to further implement our intervention. Partners indicated that they would like to hear about the existence of the intervention via health professionals in the hospitals, for example via oncologists, nurses and social workers. Also they mentioned that the intervention should be offered to them during the various stages of the illness-trajectory, because they concluded that every partner has different needs at different times throughout the cancer patient's illness. We think that the implementation of the intervention should focus on three aspects: 1) creating awareness (e.g., using awareness campaigns) for the challenging situation of partners (and also other caregivers) of cancer patients, 2) informing all important stakeholders (including patients, partners, healthcare professionals, patient organizations, health insurance companies and other relevant organizations) about the availability and possibilities of *Hold on, for each other,* and 3) exploring together with these stakeholders, how the intervention can be incorporated in standard care. Regarding the first aspect, we think that creating awareness is necessary in order to show partners that they are at risk of developing physical and mental health problems due to the caregiving situation they are in. Such an awareness campaign could also show cancer caregivers and their social environments that it is okay to not always put on a brave face, but that it is normal, for example, to feel overwhelmed by the situation and to seek help. Regarding the second aspect, we think that it is important to inform relevant stakeholders about the intervention and the outcomes of the evaluation studies described in this thesis. During the planning of this project and also during the recruitment phase of our effect study, we made contacts with a large number of important stakeholders such as Dutch Cancer society, patient organizations, psycho-oncological centers and hospitals. We gave presentations and demonstrations about *Hold on, for each other* and we tried to be visible in the media. For further implementation it is important to maintain and expand these contacts and to involve these stakeholders in further implementation initiatives [10]. Together with them, it should be examined how the intervention can best be incorporated in daily clinical practice or in existing structures. For example, it should be discussed who can give any personal support and who will maintain the website. During the project we already started to develop manuals for giving feedback and for managing the program (the intervention itself). These manuals could be adapted and used to train future counselors.

Finally, we should acknowledge that the studies described in this thesis are subject to certain limitations. First, the participants in our studies were all self-selected. Partners of cancer patients with an interest in a (Web-based) intervention or partners who were more positive about the intervention might have been more likely to participate. Second, the partners of cancer patients that participated in our studies were highly educated and relatively young, and they also reported lower levels of psychological distress compared to participants in other reported research [41-43]. Although this may be caused by the fact that we excluded people with severe anxiety and depressive symptoms in our RCT, it may also be an indication that we did not succeed in reaching partners of cancer patients who are the most in need of support. We also hoped to reach a broad group of partners with the use of a multi-component recruitment strategy, but this approach was not sufficient. Future research should focus on how we can recruit partners of cancer patients in the most appropriate way. Third, in this thesis, we primarily focused on Web-based interventions in form of a website. We did not asked participants about other possible ways of delivery, such as the use of apps or blended-care options (combination of self-help via a website and personal encounters with a healthcare professional (e.g., psychologist or social worker). Future research could anticipate this. Fourth, as yet we have not conducted an economic evaluation of *Hold on, for each other.* This evaluation is highly relevant for a successful implementation in the healthcare system and, therefore, we recommend that future research also include such an analysis.

Concluding thoughts

Overall, the studies in this thesis contribute to the growing awareness of the challenging situation partners of cancer patients are confronted with. This thesis has shown that a Web-based intervention is a good alternative for partners of cancer patients, that processes of ACT and self-compassion are useful and applicable to this target group, and that co-creation is essential to develop an acceptable and user-friendly Web-based intervention. In this thesis we focused on partners of cancer patients. However, we think that the obtained insights are also of great value and potentially helpful for other groups, such as all caregivers of cancer patients and also partners and caregivers of patients suffering from other chronic diseases.

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SAMENVATTING

(Dutch Summary)

SAMENVATTING

Kanker treft niet alleen degene die gediagnosticeerd is met de ziekte. Het treft ook zijn of haar omgeving, en in het bijzonder zijn of haar partner. De kanker van de patiënt kan een enorme impact hebben op het leven van de partner en diens (geestelijke) gezondheid. Om partners te steunen in deze moeilijke tijd, zijn psychologische interventies nodig. Partners zijn echter vaak ontzettend druk en hun aandacht is veelal gericht op het welzijn van de patiënt, in plaats van hun eigen welzijn. Het ondersteunen van partners kan daarom een uitdaging zijn. Online interventies bieden een mogelijke oplossing om partners van kankerpatiënten te helpen. Online interventies zijn makkelijk toegankelijk en flexibel. Dit is van belang omdat partners (die vaak ook de rol van mantelzorger hebben) vaak beperkt tijd hebben en omdat zij te maken hebben met dagelijkse, onvoorspelbare eisen. Met oog op de behoeften van de partners en de uitdagingen waarmee zij geconfronteerd worden, was het doel van dit proefschrift: het ontwikkelen en evalueren van een online zelfhulp interventie voor partners van kankerpatiënten die gebaseerd is op benaderingen vanuit de positieve psychologie (Acceptance and Commitment Therapy (ACT) en zelfcompassie).

Samenvatting en belangrijkste bevindingen per hoofdstuk

Online interventies hebben een groot potentieel om geïmplementeerd te worden in de gezondheidszorg [1, 2]. Echter, deze interventies hebben nog vaak te maken met problemen wat betreft de gebruiksvriendelijkheid [3-5] en met een hoge uitval van gebruikers [6-8]. Om deze problemen aan te pakken, hebben verschillende auteurs de noodzaak van een systematisch en iteratief ontwikkelproces benadrukt, waarbij eindgebruikers op verschillende momenten bij de ontwikkeling betrokken worden [9, 10]. De hoofdstukken die in het eerste deel van dit proefschrift beschreven staan (Hoofdstuk 2 t/m 5), hebben betrekking op deze *user-centered* ontwikkeling.

In **hoofdstuk 2** werd een interviewstudie beschreven die is uitgevoerd als een behoeftenonderzoek. In deze studie zijn 16 partners van kankerpatiënten geïnterviewd om hun interesse in een online interventie te onderzoeken. Hun behoeften en wensen voor een dergelijke interventie werden hierbij geïdentificeerd. De behoefte aan een online interventie bleek te variëren, maar een aanzienlijk aantal van de partners was geïnteresseerd in een online interventie. Redenen voor hun belangstelling waren: behoefte aan erkenning, op zoek zijn naar iemand met wie zij konden praten, en het geïnteresseerd zijn in informatie, tips en ondersteuning. Partners gaven aan dat hun voorkeur uitgaat naar een interventie die niet al te tijdrovend is, die een informeel en positief karakter heeft. Hoewel sommige partners een interventie zouden waarderen die zij samen met hun zieke partner zouden kunnen volgen, is er ook een groep partners die de interventie liever alleen zou willen doen, of deels alleen en deels samen met hun partner.

Gewenste functionaliteiten waren informatie en mogelijkheden om in contact te komen met lotgenoten. Terwijl de meerderheid van de partners geïnteresseerd was in een vorm van lotgenotencontact, was er ook een deel dat het niet wist of niet wilde. Argumenten tegen lotgenotencontact waren bijvoorbeeld: geen tijd hebben om anderen te ondersteunen, onzeker zijn of de ervaringen van anderen hen persoonlijk kunnen helpen, en de angst om geconfronteerd te worden met negatieve verhalen. Vanwege de uiteenlopende meningen over deze functionaliteit, kan geconcludeerd worden dat lotgenotencontact optioneel moet worden aangeboden. Het lotgenotencontact moet bovendien aangeboden worden op een manier die het delen van positieve tips en ervaringen vergemakkelijkt. Op deze manier kan de kans op ongewenste confrontatie met negatieve verhalen verminderd worden. We hebben ook gekeken naar de voorkeuren van de partners wat betreft het aanbieden van (professionele) psychologische begeleiding in de interventie. Resultaten toonden aan dat ook de behoefte aan dergelijke begeleiding varieert. Het merendeel van de partners (n = 9) vond het een goed idee dat een professionele hulpverlener hen tijdens hun deelname aan een interventie zou steunen. Er was echter ook een groep die aan de noodzaak van dergelijke steun twijfelde.

Deze, in hoofdstuk 2 beschreven, kwalitatieve studie leverde ons waardevolle informatie over de inhoud en de voorwaarden voor de interventie. Om meer inzicht te krijgen in de wensen van een bredere groep partners, werd ook nog een kwantitatieve studie uitgevoerd, die is beschreven in **hoofdstuk 3**. In dit onderzoek vulden 168 partners van kankerpatiënten een vragenlijst in. Het doel van deze studie was om op een meer systematische manier te onderzoeken wat de behoeften en wensen van partners zijn met betrekking tot de inhoud, vormgeving en randvoorwaarden van een online interventie. Ook is gekeken of de resultaten overeenkwamen met de resultaten uit ons kwalitatief onderzoek. Daarnaast wilden wij onderzoeken of de intentie om aan een dergelijke interventie mee te doen, voorspeld kon worden aan de hand van demografische gegevens, kanker-gerelateerde variabelen of de mate van psychologische distress van de partners.

De resultaten bevestigden de uitkomsten van ons kwalitatief onderzoek. We vonden dat 35% van de partners misschien geïnteresseerd zou zijn en 13% zeker geïnteresseerd was in een internet-interventie voor partners van kankerpatiënten. In overeenstemming met de resultaten van het kwalitatieve onderzoek, gaven partners aan dat de interventie niet te tijdrovend zou moeten zijn en dat deze interventie informatie en lotgenotencontact zou moeten bevatten. De helft van de partners gaf aan dat zij graag online begeleiding van een persoonlijke counselor zou willen krijgen, en de meerderheid gaf aan dat hun voorkeur uitgaat naar een interventie die uitsluitend - of in ieder geval grotendeels - op hen persoonlijk is gericht (in plaats van op het koppel). Ten aanzien van de tweede doelstelling, kunnen wij concluderen dat het moeilijk was om de interesse in een online interventie te voorspellen.

Van alle opgenomen demografische en kanker-gerelateerde variabelen, was alleen een jongere leeftijd significant gerelateerd aan de intentie om een online interventie te gebruiken.

Op basis van de resultaten van deze twee behoeftenonderzoeken en onze literatuurstudie werd een eerste (papieren) versie van de interventie ontwikkeld en aangeboden aan partners van kankerpatiënten. Wij hebben hen gevraagd om feedback te geven op deze eerste versie. Hun opmerkingen werden vervolgens vertaald in een nieuwe, online versie van de interventie, die vervolgens weer aan partners werd voorgelegd voor hun feedback. Dit ontwikkelproces is beschreven in **hoofdstuk 4**. Daarnaast hebben wij in dit hoofdstuk aangetoond waarom het belangrijk is om theorie- en evidence-based interventies aan te bieden en wat online interventies kunnen bieden aan partners van kankerpatiënten. Vervolgens hebben wij de theoretische achtergrond (Acceptance and Commitment Therapy en zelfcompassie) beschreven, is er een gedetailleerde beschrijving van de inhoud (teksten, oefeningen, en aanvullende informatie) en de functionaliteiten (bijvoorbeeld lotgenotencontact) van de interventie gegeven en werd het protocol van het effect-onderzoek besproken. We hebben een driearmige RCT gebruikt om twee versies van de interventie met een wachtlijst controle conditie te vergelijken. De inhoud van de twee interventie condities waren identiek, maar ze verschilden in de vorm van ondersteuning: partners in één conditie ontvingen wekelijkse feedback berichten van een persoonlijke online counselor, partners in de andere conditie kregen (vooraf geprogrammeerde) geautomatiseerde feedback berichten direct nadat de partner een oefening had voltooid. De wachtlijst controle conditie was op een wachtlijst van drie maanden, waarna partners konden beginnen met de interventie met geautomatiseerde feedback. Deelnemers werden gevraagd om online vragenlijsten in te vullen voor de interventie en 3, 6 en 12 maanden na de nulmeting. De primaire uitkomstmaat was psychologische distress. Aanvullende uitkomstmaten waren de geestelijke gezondheid, belasting door mantelzorg, algemene gezondheid, gezondheids-gerelateerde kwaliteit van leven (secundaire uitkomstmaten), en psychologische flexibiliteit, zelfcompassie, posttraumatische groei, veerkracht, over-protectie, beschermend bufferen, actieve betrokkenheid en zelfeffectiviteit proces uitkomstmaten).

In de studie die beschreven is in **hoofdstuk 5**, is de specifieke rol van zelfcompassie in relatie tot psychologische distress en mentale gezondheid bij partners van kankerpatiënten onderzocht. Een groeiend aantal studies heeft een relatie tussen zelfcompassie, distress en welbevinden aangetoond (bijvoorbeeld [11-13]), maar tot nu toe was dit niet onderzocht bij partners van kankerpatiënten. Voor dit onderzoek werd de nulmeting van onze RCT gebruikt (n = 203 partners van kankerpatiënten). Hoewel deze studie niet rechtstreeks in het kader van de ontwikkeling van onze interventie werd uitgevoerd, denken wij dat het interessante informatie voor de bruikbaarheid en toepasbaarheid van zelfcompassie voor partners van kankerpatiënten op heeft geleverd. De belangrijkste bevindingen van dit onderzoek waren dat, in overeenstemming met eerder onderzoek, zelfcompassie negatief is gerelateerd aan psychische klachten en positief gerelateerd aan geestelijk welbevinden. Daarnaast laat het onderzoek zien van zelfcompassie een aanzienlijke bijdrage kan leveren aan het voorspellen van distress en geestelijk welbevinden van de partners van kankerpatiënten, zelfs nadat gecontroleerd is voor een aantal andere psychologische concepten die gerelateerd zijn aan omgaan met tegenslag: veerkracht, psychologische flexibiliteit en zelfeffectiviteit. Deze resultaten zijn een indicatie dat zelfcompassie van belang is in interventies ter verbetering van het psychologisch welbevinden van partners van patiënten met kanker.

Een overzicht van de inhoud en een aantal screenshots van definitieve versie van de interventie *Houvast, voor elkaar* (http://www.houvastvoorelkaar.nl) zijn te vinden in het **intermezzo** van dit proefschrift. Onze interventie biedt informatie en ondersteuning aan partners van kankerpatiënten. De uiteindelijke interventie bestaat uit: (1) korte teksten over onderwerpen zoals het omgaan met emoties en niet helpende gedachten, communicatie en persoonlijke waarden; (2) korte psychologische oefeningen gebaseerd op ACT en zelfcompassie; (3) praktische informatie, tips en verwijzingen; en (4) lotgenotencontact.

Het tweede deel van dit proefschrift (hoofdstuk 6 en 7) was gericht op de evaluatie van *Houvast, voor elkaar*. Kwantitatieve RCTs worden veel gebruikt om de effectiviteit van een interventie evalueren [14]. Er is echter aangetoond dat RCTs onvoldoende zijn om volledig inzicht te krijgen in de effecten [14, 15]. Extra kwalitatieve studies zijn nodig omdat zij een nadere toelichting op de redenen voor het succes of falen van een interventie geven [15], zij inzicht in de actieve ingrediënten van een interventie geven [14], en zij kunnen helpen om de geschiktheid van de onderliggende theorie te onderzoeken [15]. Daarom hebben wij ervoor gekozen om zowel kwalitatieve als kwantitatieve evaluatiemethoden te gebruiken, aangevuld met log data om de effecten van *Houvast, voor elkaar* zo nauwkeurig mogelijk vanuit verschillende perspectieven te bestuderen.

In **hoofdstuk 6** wordt een kwalitatieve evaluatiestudie beschreven, waarin 14 partners van kankerpatiënten - die *Houvast, voor elkaar* hadden gebruikt – werden gevraagd naar hun waardering van de interventie, of zij suggesties voor verbetering hadden en wat zij van de interventie hadden geleerd. Partners gaven aan dat de interventie zinvol voor hen is geweest. Zij meldden dat zij door de interventie met meer aandacht aanwezig waren, zij ervoeren meer zelfcompassie en acceptatie van moeilijke ervaringen, zij waren zich beter bewust van persoonlijke waarden en zij konden beter naar hun eigen waarden leven. Daarnaast heeft de interventie hen geholpen om beter inzicht en erkenning van hun situatie te verkrijgen, om meer positiviteit in hun leven te ervaren, om hun verhaal te vertellen, om tijd vrij te maken voor zichzelf en om zich meer verbonden met de patiënt te voelen. Onze studie toonde aan dat de deelnemers in het algemeen tevreden waren met de interventie. Zo waardeerden zij het feit dat de interventie makkelijk toegankelijk was, dat er eindelijk wat aandacht voor hen was (in plaats van dat het grootste deel van de aandacht uitgaat naar de behoeften van de patiënt) en ze waren blij om erkenning te vinden. Naast deze positieve waardering, benoemden sommige partners ook ambivalente gevoelens ten opzichte van een aantal onderdelen, namelijk lotgenotencontact, de inhoud van de feedback van hun persoonlijke counselor en de getunnelde structuur van de interventie. Suggesties voor verbetering van de interventie waren, aldus de partners: (1) minder rigide structuur van de lessen; (2) meer persoonlijke ondersteuning; (3) het aanbieden van een boek versie naast de online cursus; (4) een extra les over rouw. Ook hadden zij enkele tis voor verdere implementatie, namelijk: (1) een introductie van de interventie via professionele hulpverleners in de gezondheidszorg (vooral in het ziekenhuis); en (2) de interventie moet aangeboden worden in verschillende stadia van de ziekte traject.

Hoofdstuk 7 beschrijft het onderzoek naar de effectiviteit van de twee versies (persoonlijke feedback versus geautomatiseerde feedback) van *Houvast, voor elkaar*. Het primaire doel van de interventie was om psychologische distress van partners van patiënten met kanker te verminderen. In totaal werden 203 partners van kankerpatiënten gerandomiseerd in een van de drie condities: de conditie met persoonlijke feedback (PF conditie, n = 67), de conditie met geautomatiseerde feedback (AF conditie, n = 70), en een wachtlijst controle conditie (WL conditie, n = 66). Vragenlijsten werden ingevuld op baseline (vóór de interventie) en na 3 en 6 maanden. De loggegevens van de deelnemers interventie zijn gebruikt om de therapietrouw te bepalen. Deelnemers, die de laatste module (module 6) hebben bereikt en voltooid, werden geclassificeerd als adherent.

De resultaten toonden aan dat *Houvast, voor elkaar* potentieel heeft om psychologische distress in partners van kankerpatiënten te verminderen. De AF conditie lijkt het herstel op korte termijn te versnellen. Op lange termijn lijkt de PF conditie gunstiger te zijn. De resultaten zijn echter niet eenduidig en daarom is verder onderzoek nodig om de effecten op lange termijn en de meest geschikte vorm en inhoud van feedback voor deze doelgroep te onderzoeken. Met betrekking tot de tevredenheid van de partners van de interventie vonden we dat de partners de kwaliteit van de interventie als goed hebben beoordeeld, zij zouden de interventie aan andere partners aanbevelen en gaven aan dat de interventie hen heeft geholpen om effectiever om te gaan met hun situatie. Wat de therapietrouw betreft hebben wij gevonden dat 68,6% van de partners in onze experimentele condities adherent was.

Hoofdstuk 8 bevat de algemene discussie van dit proefschrift. De belangrijkste uitkomsten en suggesties voor vervolgonderzoek werden besproken. Dit proefschrift heeft laten zien dat (1) een online interventie een goed alternatief is voor partners van kankerpatiënten, (2) processen van ACT en zelfcompassie nuttig en toepasbaar zijn voor deze doelgroep, en (3) co-creatie belangrijk is om een acceptabele en gebruikersvriendelijke online interventie voor partners van kankerpatiënten te ontwikkelen.

Hoewel dit onderzoek zich heeft gericht op partners van kankerpatiënten, denken wij dat de interventie ook voor andere groepen van toepassing zou zijn. Toekomstig onderzoek zal dan ook moeten aantonen of *Houvast, voor elkaar* ook geschikt is voor andere mantelzorgers van kankerpatiënten (zoals volwassen kinderen, broers, zussen of vrienden) of zelfs voor partners/mantelzorgers van patiënten met andere chronische ziekten zoals beroerte, dementie of Amyotrofe Laterale Sclerose (ALS). Daarnaast is vervolgonderzoek nodig op het gebied van log data. In dit proefschrift hebben wij gebruik gemaakt van verschillende onderzoeksmethodieken om de effecten van de cursus in kaart te brengen. Naast kwalitatieve en kwantitatieve evaluatietechnieken hebben wij ook eenvoudige log data gebruikt. Een meer diepgaande analyse van deze data is echter wenselijk omdat dit van grote waarde is voor het optimaliseren van de interventie en het bestuderen van therapietrouw en dosis-respons relaties. Naast analyse van de log data zijn wij ook bezig om de inhoud van de uitgewisselde e-mailberichten tussen deelnemers en online begeleiders te onderzoeken. De inhoud van deze berichten levert waardevolle inzichten op over de impact die bepaald gedrag van de begeleider (en ook van de deelnemer) op het effect van de interventie kan hebben. Hier is in de literatuur nog weinig over bekend.

Dit proefschrift heeft bijgedragen aan nieuwe bevindingen wat betreft de implementatie van deze online cursus. Partners van kankerpatiënten hebben aangegeven dat zij graag over het bestaan van deze cursus geïnformeerd zouden willen worden via professionele hulpverleners in het ziekenhuis (zoals oncologen, verpleegkundigen, maatschappelijk werkers). Ook gaven zij aan dat de cursus op verschillende momenten tijdens het ziekte traject aangeboden zou moeten worden omdat elke partner verschillende behoeften op verschillende momenten heeft. Onze conclusie was dan ook dat de implementatie van *Houvast, voor elkaar* zich voornamelijk zou moeten richten op drie aspecten: (1) het creëren van aandacht voor de moeilijke situatie waarin de partners (en ook andere mantelzorgers) zich bevinden (bijvoorbeeld door middel van grote campagnes), (2) het informeren van belangrijke stakeholders (inclusief patiënten, partners, professionals in de gezondheidszorg, patiëntenorganisaties, zorgverzekeraars en andere relevante organisaties (zoals KWF Kankerbestrijding)) over de beschikbaarheid en de mogelijkheden van *Houvast, voor elkaar*, en (3) om samen met de stakeholders te verkennen hoe we de cursus het beste kunnen integreren in de standaard zorg in Nederland.

Samenvattend heeft het onderzoek in dit proefschrift een bijdrage geleverd aan bewustwording van het belang van ondersteuning van partners van kankerpatiënten, is een interventie ontwikkeld die door deze zeer kwetsbare doelgroep als prettig wordt ervaren en laat het interessante mogelijkheden voor verdere implementatie en aanvullend onderzoek zien.

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DANKWOORD

DANKSAGUNG

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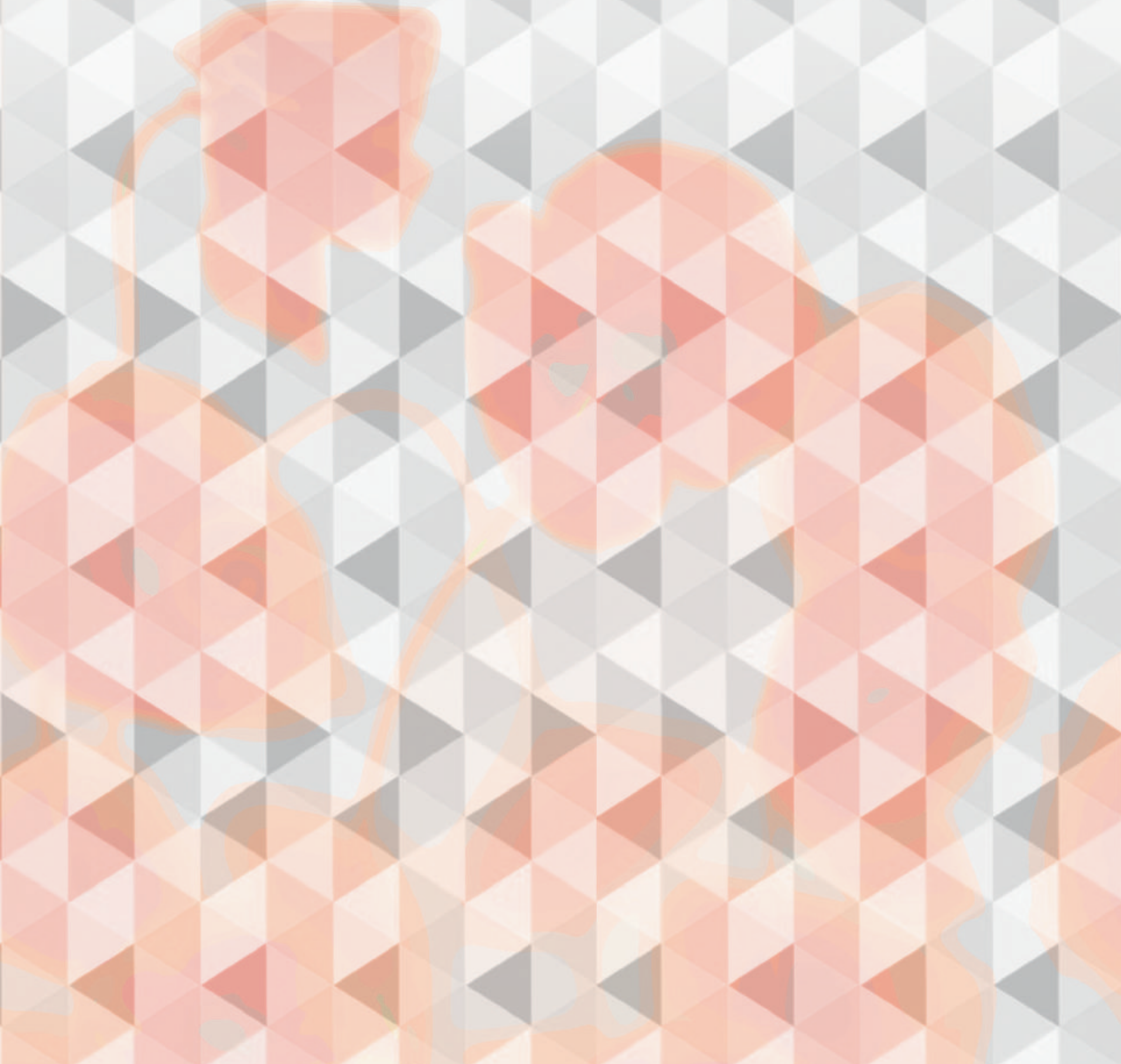

> “ *Du darfst nur deine Lebensfreude durch nichts und niemanden zerstören lassen. Geh du deinen Weg, bis hin ans Ziel, du wirst es sicher schaffen!* “
>
> *– Bianka Köhle, 1997, Zitat aus meinem Poesiealbum*

An dieses Zitat musste ich denken, als ich über mein Danksagung nachgedacht habe. Seinen eigenen Weg und ein klares Ziel vor Augen zu halten ist sicherlich nicht immer einfach. Durch unterschiedliche Einflüsse, zum Beispiel Menschen denen man auf seinem Weg begegnet, neue Erfahrungen die man macht oder durch neue Umgebungen, kann sich ein Weg schnell verändern. Aus einer deutlichen Einbahnstraße wird plötzlich ein holpriger Trampelpfad, eine Schnellstraße oder manchmal auch eine Sackgasse. Hier kann man unterschiedlich drauf reagieren; man kann in Panik geraten und die Orientierung verlieren, sich einfach treiben lassen, oder andere Menschen nach dem Weg fragen. Während meiner Promotion habe ich unterschiedliche Wege eingeschlagen und auch zu diesem Zeitpunkt weiß ich eigentlich nicht so genau, wie ich letztendlich ans Ziel gekommen bin. Ich hatte aber das Glück, dass ich auf meinem Weg vielen Menschen begegnet bin, die mich auf unterschiedlichste Weise begleitet und unterstützt haben.

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Nadine Köhle
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Jullie waren We hebben het
mijn Houvast, voor elkaar

CURRICULUM VITAE

CURRICULUM VITAE

Nadine Köhle was born in Arnsberg (Germany), on June 4th 1987. In 2006 she received her high school diploma from the Franz-Stock-Gymnasium in Arnsberg (Germany). After graduating from the college of commerce in 2007 in Arnsberg (Germany), Nadine commenced a study Psychology at the University of Twente in Enschede (the Netherlands). After receiving her Bachelors degree in 2010, Nadine received her Masters degree after finishing a one-year Master in Health Psychology. After her graduation she worked as a lecturer at the University of Amsterdam. In February 2012, Nadine started her PhD-project at the University of Twente at the department Psychology, Health & Technology. The project was conducted in collaboration between University of Twente, Free University Medical Centre, Free University and University of Groningen. Supervisors in the study were dr. C.H.C Drossaert (daily supervisor), prof. dr. E.T. Bohlmeijer (first promotor) and prof. dr. I.M Verdonck- de Leeuw (second promotor). In September 2016, Nadine started to work as a lecturer at the department of Psychology, Health & Technology at the University of Twente, the Netherlands.

LIST OF PUBLICATIONS

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Published papers

Köhle, N., Drossaert, C.H.C., Oosterik, S., Schreurs, Karlein M.G., Hagedoorn, M., Uden-Kraan, C.F. Van, Verdonck- de Leeuw, I.M. & Bohlmeijer, E.T. (2015). Needs and Preferences of Cancer Patients Regarding a Web-Based Psychological Intervention: a qualitative study. JMIR cancer, 1(2). 10.2196/cancer.4631

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Nadine Köhle is a lecturer at the department of Psychology, Health & Technology at the University of Twente, the Netherlands. Her PhD thesis describes the participatory development and mixed-methods evaluation of a Web-based self-help intervention for partners of cancer patients. Her general research interests include supporting partners of patients and informal caregivers in general, positive psychology (such as Acceptance and Commitment Therapy, mindfulness and self-compassion), eHealth, and participatory design.