

**The Needs and Wishes of Cancer Patients Regarding a
Smartphone-Supported Self-Help Intervention Based
on Self-Compassion and Mindfulness Exercises:
A Qualitative Study**

Nienke Peeters/studentnr.: s1232282
1st supervisor: Dr. C.H.C. Drossaert
2nd supervisor: Dr. N. Köhle
University of Twente
Health Psychology
Faculty BMS
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Dankwoord

Voor u ligt de scriptie die ik geschreven heb ter afsluiting van mijn Master Gezondheidspsychologie aan de Universiteit Twente. De Universiteit Twente heeft de intentie om met steun van het KWF een online interventie te ontwikkelen voor kankerpatiënten met zelfcompassie en mindfulness als theoretische basis. Om goed aan te kunnen sluiten bij de wensen en behoeften van kankerpatiënten is deze kwalitatieve studie uitgevoerd.

Voorafgaand aan deze master thesis heb ik tijdens mijn stage op de Universiteit Twente een prototype smartphone interventie ontwikkeld, gebaseerd op zelfcompassie en mindfulness oefeningen. Dit prototype is voorgelegd aan de kankerpatiënten in de huidige studie met als doel hun wensen en behoeften omtrent een dergelijke smartphone interventie in kaart te kunnen brengen.

Het ontwikkelen van een psychologische interventie in de vorm van een prototype smartphone app, met de moderne technische mogelijkheden in mijn achterhoofd, heb ik als uitdagend en leerzaam ervaren. Ik hoop dat dit prototype kan bijdragen aan de uiteindelijke ontwikkeling van een werkende smartphone interventie voor kankerpatiënten. Mijn stage binnen de Universiteit Twente, het uitvoeren van een kwalitatieve studie en het schrijven van deze thesis hebben bijgedragen aan mijn professionele ontwikkeling als toekomstig gezondheidspsycholoog.

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Samenvatting

Achtergrond: Kanker en zijn behandeling kunnen een enorme impact hebben op het psychologisch welbevinden en de kwaliteit van leven van de patiënt. Zelfcompassie en mindfulness zijn sterk gerelateerd aan psychologisch welbevinden en zouden van grote waarde kunnen zijn in het omgaan met kanker en zijn behandeling. Smartphone apps spelen een belangrijke rol in het leven van de meeste mensen en zouden gebruikt kunnen worden voor de ontwikkeling van een interventie. Er is echter momenteel geen smartphone interventie beschikbaar voor kankerpatiënten, gebaseerd op zelfcompassie en mindfulness. Deze kwalitatieve studie onderzocht of kankerpatiënten interesse hebben in een smartphone interventie gebaseerd op zelfcompassie en mindfulness oefeningen. Het doel van dit onderzoek was om de wensen en behoeften van kankerpatiënten in kaart te brengen omtrent zo'n interventie.

Methode: Semigestructureerde interviews werden uitgevoerd onder elf kankerpatiënten, die varieerden in leeftijd, geslacht, opleidingsniveau, werksituatie, type en fase van kanker. De patiënten werden gevraagd naar hun achtergrond, hun ervaring/waardering van het boek "Mindfulness bij kanker" en hun ervaring/waardering van de mock-ups van een potentiële app. De verschillende functionaliteiten van de app werden geëvalueerd en hun suggesties en conclusies werden besproken. De interviews werden opgenomen, verbatim getranscribeerd en geanalyseerd door een onderzoeker.

Resultaten: De meeste kankerpatiënten in deze studie gaven aan zelfcompassie als belangrijk te beschouwen. Zelfcompassie zou hun kunnen helpen bij de bewustwording dat ze vriendelijker voor zichzelf dienen te zijn en minder zelfkritisch. Een meerderheid van de respondenten was positief over mindfulness: het zou hen kunnen helpen om te kalmeren tijdens momenten van stress en het zou hen kunnen helpen bij de bewustwording van hun gedachten en gevoelens. Bijna alle respondenten waren positief over de aanbidding van de interventie via een smartphone app: een app is leuk, makkelijk bereikbaar en het biedt variaties en mogelijkheden. De meest populaire functionaliteiten van de app waren personalisatie en tailoring, monitoring, herinneringsberichten en het uploaden van informatie voor onderzoeksdoeleinden. De voorbeeld oefeningen werden door de meeste respondenten als relevant ervaren. Elf van de achttien oefeningen werden zelfs door een grote meerderheid van de respondenten als positief ervaren. Deze elf oefeningen waren evenwichtig verdeeld over de vier gededuceerde categorieën: inzicht gevend, mindfulness/relaxatie, versterken van positieve emoties en relaties met anderen. Bijna alle respondenten zouden de app graag willen ontvangen. Een meerderheid zou eveneens graag de hand-out, met beknopte literatuur over zelfcompassie en mindfulness, willen hebben. Alle respondenten zouden graag willen dat de interventie wordt aangeboden direct na de diagnose kanker.

Conclusie: De kankerpatiënten in deze studie gaven aan dat ze een zelfhulp smartphone interventie, gebaseerd op zelfcompassie en mindfulness oefeningen, zouden waarderen. Deze studie bevat belangrijke informatie over de wensen en behoeften van de patiënten met betrekking tot de inhoud van zo'n type interventie. De genoemde wensen en behoeften kunnen meegenomen worden in de eventuele ontwikkeling hiervan. Een dergelijke zelfhulp smartphone interventie zou het psychologisch welbevinden van kankerpatiënten kunnen verhogen.

Abstract

Background: Cancer and its treatment can have an enormous impact on the quality of life and the psychological well-being of the patient. Self-compassion and mindfulness are strongly associated with psychological well-being and could be of great help for cancer patients to cope with their cancer and its treatment. Smartphone applications play an important role in the daily lives of most people and therefore could be used for the development of an intervention. There is however no smartphone intervention available for cancer patients, based on self-compassion and mindfulness. This qualitative study examined the cancer patient's interest in a smartphone-supported self-help intervention based on self-compassion and mindfulness exercises. The aim of this study was to identify the needs and wishes of cancer patients regarding such an intervention.

Methods: Semi structured interviews were conducted with eleven cancer patients, who varied in terms of age, gender, education, employment, type and stage of disease. Patients were asked about their background, their experience/appreciation of the book “Mindfulness bij kanker” and their experience/appreciation of the mock-ups of a potential app. Furthermore, the features of the app were evaluated and their suggestions and conclusions were discussed. The interviews were audio-recorded, transcribed verbatim and analysed by one coder, using deductive and inductive analysis.

Results: Most of the cancer patients in this study evaluated self-compassion as important. Self-compassion could raise their awareness to be kind towards themselves and could help them to be less critical towards themselves. A majority was positive about mindfulness: it could calm them down in moments of stress and it could raise their awareness of their thoughts and feelings. Almost all respondents were positive about delivering the intervention in the form of a smartphone app: it is fun, easy accessible and offers variation and possibilities. Most popular features of the app were personalization and tailoring, monitoring, push notifications and uploading information for research purposes. Most respondents rated all the example exercises as relevant. Eleven of the eighteen exercises were even positively rated by a great majority of the respondents. These eleven exercises were almost equally divided over the four deduced categories: insight giving, mindfulness/relaxation, enlarging positive emotions and relation with others. Almost all respondents would like to receive the app. A majority of them would also like to receive a hand-out with concise literature about self-compassion and mindfulness. All of the respondents would like to receive this smartphone intervention straight after the diagnosis of having cancer.

Conclusions: The cancer patients in this study indicated to appreciate a smartphone-supported self-help intervention based on self-compassion and mindfulness exercises. This study provides important information about their needs and wishes concerning the content of such an intervention. These needs and wishes could be taken into account when an intervention is developed. Such a smartphone-supported self-help intervention could improve the psychological well-being of cancer patients.

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1. Introduction

Cancer is the leading cause of death around the world according to the World Health Organization. Cancer and its treatment can have an enormous impact on the patient's quality of life and psychological well-being. Most of all, cancer brings uncertainty of the prognosis and the survival odds. Cancer and its treatment can lead to fatigue, pain and/or functional limitations. Furthermore, a large number of cancer patients can develop feelings of anxiety and depression (Pinto-Gouveia, Duarte, Matos & Fráguas, 2014). All these mental health problems are additional contributors to functional impairment in carrying out family, work, and other societal roles (Adler & Page, 2008).

In spite of the aforementioned evidence, there is an inadequate screening for psychological distress in cancer patients, in the everyday practise. The screening that does take place, proves not to be effective in increasing mental health referrals. Therefore, far too few cancer patients receive evidence-based interventions for their mental health symptoms (Leykin et al., 2012). A possible explanation can be a lack of well-trained health professionals in this field of work, who can diagnose depression as comorbidity in cancer patients (Leykin et al., 2012). The physical and psychological symptoms cancer patients perceive are very similar to the symptoms of a depression. It is because of this similarity that depression proves to be underdiagnosed and therefore undertreated in cancer patients (Pinto-Gouveia et al., 2014). It is therefore not surprisingly that patients reported that their emotional needs go unmet (Leykin et al., 2012). Furthermore, patients were not satisfied about the amount and type of information they receive concerning ways to manage their illness and health. They reported that care providers do not consider psychological support as an integral part of their care (Adler & Page, 2008). The care providers are unaware of psychosocial health care resources and they fail to offer referral for depression or other after-effects of stress due to illness in patients and their families (Adler & Page, 2008). This situation may adversely affect the patient's medical and emotional condition, his/her quality of life and ultimate survival (Pinto-Gouveia et al., 2014). Therefore, it is important to explore low-threshold evidence-based treatments which can help cancer patients to cope effectively with their psychological problems.

1.1 Self-compassion

There is a growing scientific literature supporting that self-compassion is strongly associated with mental health (Neff, 2003a). Self-compassion means that an individual is being open to one's own suffering. It is a way of healing themselves with kindness and not avoiding or disconnecting from their own suffering. It involves non-judgmental understanding to one's pain, failures and limitations and the recognition that other people experience this as well. Self-compassion contains three components. The first one is self-kindness, which means that

you have the ability of being warm and understanding to yourself. The second component is called “common humanity”. This component is about recognizing that the human condition is not perfect and that everyone experiences feelings of imperfection, makes mistakes and has to deal with threatening life challenges. By recognizing this, people feel less isolated and alone when they are in pain. The third component is mindfulness, where people turn to their painful thoughts and emotions without suppression or avoidance. These three components can bring some balance in one’s negative experiences, so that these are no longer avoided (Neff, 2003b).

Gilbert (2014) focused on self-compassion as well. He developed the compassion focused therapy (CFT) which uses a three emotion-systems approach. The first one is the threat protection system which provides abilities to detect and respond to the threat. The second one is the drive- and resource seeking system. In here rewards and resources are important. The last one is the soothing and affiliation system, which enables us to sooth and calm ourselves down. Wellbeing and successful adaptation are possible when these three systems are in balance (Gilbert, 2014).

A validated and reliable self-compassion scale (SCS) was designed for research purposes. Research showed that respondents who scored high on self-compassion reported significantly less self-criticism, depression, anxiety, thought suppression and a greater life satisfaction (Neff, 2003a). Self-compassion also leads to a decrease in depression and anxiety within cancer patients and showed to be a promise to contribute to enhance their well-being (Pinto-Gouveia et al., 2014).

Mindfulness is one of the constituent components of self-compassion (Neff & Germer, 2013). Mindfulness contains a moment of present awareness, where people have a non-judgmental, accepting and open attitude (Shennan, Payne & Fenlon, 2011). Mindfulness based interventions (MBI) have well-documented effects on psychological health as well (Baer, Lykins & Peters, 2012). MBI refers to the 8-week programmes of Mindfulness-Based Stress Reduction (MBSR) and its variant Mindfulness-Based Cognitive Therapy (MBCT). Specifically in cancer populations a number of significant benefits have been reliably associated with MBI participation. The cited benefits include reduced symptoms of depression, anxiety, stress, fatigue, fear of recurrence and improved sleep quality, quality of life, energy and physical functioning (L’Estrange, Timulak, Kinsella & D’Alton, 2016). Participation in the MBI leads to an increase of self-compassion and this could be a key mechanism to improve well-being (Neff & Germer, 2013). The mindful self-compassion (MSC) program, contains mindfulness as well as self-compassion and focuses specifically on the development of self-compassion with mindfulness as a secondary component. This program teaches basic mindfulness skills which are crucial to the ability to give oneself compassion (Neff & Germer, 2013). Throughout the program interpersonal exercises were

used to generate an experience of self-compassion with other participants. In this way they can recognize that other participants experience feelings of imperfection, isolation and pain as well. Participants share for example which language they use when they criticize themselves. During the program, they learn to use more kind and supportive language. They also learn practices such as placing their hand on their heart when they feel stressed and they learn some compassionate phrases they can repeat which they can use in daily life. Practices for at home are also assigned, such as writing a compassionate letter to oneself from the perspective of a compassionate friend (Neff & Germer, 2013). A randomized control study, conducted among community adults, showed that the MSC program was effective in increasing self-compassion, mindfulness, compassion for others and other aspects of well-being. The participants showed significantly greater life satisfaction, less anxiety, depression, stress and avoidance, which endured at least one year after completion of the program. This suggests that self-compassion is a teachable skill that can enhance overall quality of life (Neff & Germer, 2013). Besides self-help books, such as ‘Mindfulness bij kanker’ from Linse and Bruining (2015), it seems that there are no other low-threshold interventions available for cancer patients, that are based on enhancing self-compassion and mindfulness. Because of the aforementioned promising results, self-compassion and mindfulness are worthwhile concepts to use in a low-threshold intervention for cancer patients.

1.2 Smartphone interventions

As mentioned in the introduction far too few cancer patients receive evidence-based interventions for their mental health symptoms. They reported that their emotional needs go unmet (Leykin et al., 2012). Therefore, it is important to focus on low-threshold interventions which enlarges the possibility that the cancer patients who are in need for this also really have the opportunity to get this treatment. In this case, the cancer patient is less dependent of the referral of a care provider (Leykin et al., 2012). The use of smartphone devices could be an opportunity in this. The use of smartphone interventions c.q. smartphone apps are however in an exploratory stage in healthcare (Wang et al., 2014). They need to be more widely used within psychological research because they are highly accessible, versatile and cost effective (Howells, Ivtzan and Eiroa-Orosa, 2014). Furthermore, they can serve as the therapist’s extended arm into the daily life of the patients (Wang et al., 2014), since they are at arm’s reach and have video and audio capabilities, unrestricted text capabilities, access without internet connection and immediate access to intervention content (Bricker et al., 2014). These characteristics can provide a smartphone app with the following features that could possibly help cancer patients to better cope with their psychological distress: (1) monitoring, (2) push notifications, (3) personalization and tailoring, (4) having contact with fellow sufferers and (5) uploading information.

(1) Monitoring. Participants can monitor their mood, pain and activity which can lead to greater treatment involvement. By monitoring, people are enabled to educate themselves about the relationship of their actions to their psychological well-being (Leykin et al., 2012). For example: when a participant decides to do something nice for himself and he gives his day an 8 out of 10 on the mood meter, he can see that doing something nice is helpful for his well-being.

(2) Use of push notifications. These can be delivered at the user's smartphone at pre-specified times. In this way the user can receive a reminder to fill in his mood meter or he can be triggered to do some other exercises. These push notifications might reduce attrition and eventually produce better outcomes (Leykin et al., 2012).

(3) Personalization and tailoring. Tailoring means that the information delivered is personal and specifically tuned to the participant. In this way it reduces the burden of information that is not relevant to that participant, based on the specific diagnosis or stage of cancer (Leykin et al., 2012). Furthermore, it can give the participant personalized feedback (e.g. 'You gave your day a 7 out of 10! You graded your day higher than yesterday, that is great!'). Some level of customization is of importance because it may help the user feel more understood and they can perceive a greater relevance of the program (Leykin et al., 2012).

(4) Having contact with fellow sufferers. A part of self-compassion is the so-called common humanity according to Neff and Germer (2013). This means that people can recognize that other people suffer as well, make mistakes and that they also have to deal with serious life challenges. This acknowledgement is important, otherwise people can feel isolated from others who are presumably leading normal and happy lives.

(5) Uploading information. In this context, it means that information can be sent to a coach and to a researcher. Uploading information to a coach can be done by interactive progress trackers provided by smartphone apps. This is a mean that enables a coach to have access to the patient's current status and progress, which can encourage their communication. It is also possible, that the coach can get an alert when the participants mood becomes markedly low registered by the mood meter. The coach can respond to this by sending a message in the app to the participant (Leykin et al., 2012). Uploading information to a researcher is an important feature to establish efficacy and effectiveness of the app. Smartphone apps can generate lots of data such as page views and time spent on specific exercises. These data can be used to improve the app or gain insight into participants' behaviour and/or well-being. Information gathered through smartphone apps can be done among large samples of diverse populations. To accomplish this, a smartphone intervention needs to include validated tools and standardized questionnaires to determine whether the intervention is useful (Leykin et al., 2012).

Unfortunately, there is a high dropout rate in eHealth interventions (Eysenbach, 2005).

To explore which features cancer patients find helpful and/or appealing in the smartphone app is important: by closely matching the intervention with the wishes and needs of the intended user, it could increase prolonged usage (Abrás, Maloney-Krichmar & Preece, 2004). By involving the users, the product will be suitable for its intended purpose and the eventual product will be more effective and efficient. Users will feel a sense of ownership of the final design, when their opinions and suggestions are taken into account. This can support the final integration of the product in their daily lives (Abrás et al., 2004).

1.3 Aim of the study

Cancer is the leading cause of death around the world and its treatment can have an enormous impact on the quality of life and the psychological well-being of the cancer patient. Far too few cancer patients receive adequate treatment for their psychological problems. Their emotional needs go unmet. Self-help interventions via a smartphone app, based on self-compassion and mindfulness, could be of great importance for enhancing the psychological well-being of cancer patients and could have the potential to overcome their undertreatment. For now, there is no smartphone intervention available for cancer patients, based on self-compassion and mindfulness. The University of Twente has the intention to develop such a smartphone intervention to improve the psychological well-being of cancer patients. To make this intervention effective and to prevent a high dropout rate, it is important to involve all relevant end-users in the developmental process. Therefore, the wishes and needs of cancer patients, regarding such a smartphone intervention will be examined. This will be done on the basis of a prototype app completed with the book “Mindfulness bij kanker” from Linse and Bruining (2015). Based on the aim of the study, the following main question is formulated: *“What are the needs and wishes of cancer patients regarding a smartphone-supported self-help intervention, which focuses on the enhancement of self-compassion and mindfulness?”* This question can be divided in the following sub-questions:

1. What do cancer patients think of self-compassion and mindfulness as a theoretical basis of a supportive intervention?
2. What do cancer patients think of delivering the intervention via a smartphone app?
3. What do the cancer patients think of the five features presented in the prototype of the app?
4. What are the participants needs and wishes regarding the content of the intervention?
5. When and how can the intervention best be offered according to the participants?

2. Methods

A qualitative research design was chosen to gain insight into the needs, wishes and opinions of cancer patients regarding a smartphone-supported self-help intervention aimed at enhancing their self-compassion and mindfulness. Semi-structured interviews were conducted to gain insights in the aforementioned topics. The Ethics Committee of the University of Twente (Faculty Behavioural, Management and Social Sciences) provided ethical approval for this interview study.

2.1 Participants and procedures

The target group of this study contained a heterogeneous group of cancer patients. The recruitment of the participants took place in two different ways. The first recruitment was based on convenience sampling and snowball sampling. This means that the first participants were recruited based on the network of the researcher and snowball sampling took place because one participant knew other people who were diagnosed with cancer as well. The participants were approached by email. They received an information letter (appendix I) about the purpose of the study. Based on this information, the participants could decide if they wanted to participate or not. If they did, they could fill in an informed consent (appendix II) and send this back to the researcher. There were six respondents who were recruited this way. After receiving the informed consent, the researcher send the participants the mock-ups of a possible smartphone-supported self-help intervention based on self-compassion and mindfulness and the book of Linse and Bruining (2015) named “Mindfulness bij kanker”. In this way the participants could read something about the topic, try some exercises and look at the mock-ups to form an idea about a possible intervention. The participants were asked to especially read chapter eleven from the book because this was specifically about self-compassion. After approximately four weeks, the interviews were planned and took place at the home of the participants.

The second recruitment took place within the ‘Nije Huis’ which is a walk-in consultation service for cancer patients located in Hengelo. The researcher contacted the founder of the Nije Huis and planned a meeting to explain the research content. Based on this meeting, the information letter was sent to the manager of the Nije Huis. She contacted some cancer patients (so-called guests within the Nije Huis) to ask if they wanted to participate. When they agreed to take part in the study, the coordinator sent them the sample pictures (mock-ups) of the app and scheduled the interviews. The founder of the Nije Huis preferred only the mock-ups for the guests because of the intensity of reading the book. Therefore, the second group only received the mock-ups and not the book of Linse and Bruining. Five interviews were conducted with guests of the Nije Huis where the interviews took place.

The inclusion criteria for both the first and second group of the respondents were: (1)

cancer patients or cancer survivors; (2) willing to participate in the interview; (3) both men and women regardless the form and duration of the cancer, treatment prognosis or stage of cancer. People under eighteen years were excluded from this study. Before the start of the interview, respondents were asked permission to audiotape the conversation. The audiotapes were then transcribed verbatim by the researcher. The eleven interviews were conducted by one researcher.

2.2 Mock-ups and interview scheme

2.2.1 Mock-ups

Based upon compassion focused therapy (Gilbert, 2009) and self-compassion theory (Neff, 2003b), eighteen exercises about self-compassion were created into a prototype of a potential intervention via a smartphone app. These eighteen exercises could be divided into four broad categories: (1) insight giving, (2) breathing and relaxation, (3) enlarging positive emotions and (4) relation with others. Table 1 gives an overview of which exercises belong to which categories.

Table 1. Overview categories and exercises

Categories	Exercises
<i>1. Insight giving</i>	<ul style="list-style-type: none"> - Mood meter - Consideration - Make me small - Survival strategies - Change your critical voice - Compassionate figure - Throw it away!
<i>2. Breathing and relaxation</i>	<ul style="list-style-type: none"> - Start of the day - Place a hand on your heart - Fist - Waiting
<i>3. Enlarging positive emotions</i>	<ul style="list-style-type: none"> - Moment for yourself - What am I thankful for? - Upload your music - Time for a photo
<i>4. Relation with others</i>	<ul style="list-style-type: none"> - You and others - Mindful consultation relating to doctors - Partner as fellow sufferer

2.2.2 Interview scheme

Based on literature, an interview scheme was prepared. After conducting two pilot interviews, the interview scheme and the way of interviewing by the researcher were evaluated with help from a senior researcher. The interview scheme was adapted based on the outcomes of this evaluation. Some questions were revised and three questions were added. The final interview scheme contained five components. Table 2 shows an overview of the interview scheme. The complete interview scheme can be found in appendix III.

Table 2. Overview interview

Components	Content
I. Background	- Age, education, employment, children, course of disease, experiences with mindfulness and self-compassion
II. Experience/appreciation book “Mindfulness bij kanker”	- Time spend on reading, general impression of the book, opinion about specific chapters, opinion about chapter eleven concerning self-compassion, what they learned from the book and what they took with them in daily life
III. Experience/appreciation sample pictures	- General impression of the sample pictures, experience of the exercises
IV. Features of an app	- Personalization and tailoring - Push notifications - Contact with fellow sufferers - Monitoring - Uploading information
V. Suggestions and conclusions	- Form of the intervention - Need for an intervention - Timing of the intervention

The first component was about the background of the participants and served as an introduction. The participants were asked about their social-demographics (such as gender, age, education and employment) and they were invited to give information about their diagnosis, the course of their disease and their current well-being. They were also asked about their previous experiences with mindfulness and self-compassion.

The second component of the interview was about participants’ experiences and

appreciation of the book “Mindfulness bij kanker”. The participants were asked about their general impression of the book and if there were specific chapters that did or did not appeal to them. Example questions are: “*What was your general impression of the book?*” “*Are there specific chapters or parts which you found appealing or not?*” “*What did you learn from this book and what are you taking with you in daily life?*” The researcher responded to the participants’ answers and encouraged them to elaborate on these.

The researcher asked specifically about the participant’s opinion of chapter eleven, which content was about self-compassion. Example questions are: “*Did you manage reading chapter eleven and do some of the exercises?*” “*What is your general opinion about this chapter?*” “*What did and did not appeal to you in this chapter?*” “*Do you think it is in line with the situation cancer patients are in?*” Again, the respondents were stimulated to elaborate on their answers.

The third part of the interview was regarding the respondent's opinion about the use of an app and their experiences and appreciation of the mock-ups of a possible smartphone-supported self-help intervention containing self-compassion and mindfulness exercises. Questions that were asked: “*What is your general impression of the sample pictures?*” “*Are there exercises you have tried and what is your opinion about those?*” The results of these answers could be taken into account if the app is going to be developed.

Part four contained questions about the five features an application could have. These were chosen based on consulted literature. The five features were: (1) personalization and tailoring; (2) push notifications; (3) contact with fellow sufferers; (4) monitoring and (5) uploading information. The content of the features was explained by the researcher and they were also illustrated by mock-ups (appendix IV). Some example questions are: “*What would you think of such a feature?*” “*Which criteria does it need to comply?*” The respondent’s opinion of the five features will be incorporated in the eventual intervention.

The last component of the interview was about possible suggestions and conclusions. The participants were asked in which form the intervention needs to be presented: (1) application and the book, (2) the book alone, (3) the application alone or (4) the application with a hand-out of some concise literature about self-compassion and mindfulness. The participants were also asked if they feel the need for such an intervention. Finally, the timing of the delivery of the intervention was discussed.

During the interviews, participants were encouraged to elaborate on their opinions, thoughts and experiences. The interviews took between the fifty minutes and two and a half hours with an average duration of ninety minutes.

2.3 Data analysis

After the interviews took place, the audio-records were transcribed verbatim by the researcher. To secure the anonymity of the respondents, their names and the names mentioned in the interviews were deleted. The researcher was the only coder in this study. The coder read and reread all transcripts to get familiar with the content. The transcripts were coded by the use of the programme ATLAS.TI. Relevant fragments were selected and coded into one of the five main themes: (1) participant's opinion about self-compassion and mindfulness, (2) participant's opinion about a supportive smartphone intervention for cancer patients, (3) participant's opinion about the five features of the app, (4) participant's needs and wishes regarding the content of the intervention and (5) participant's opinion about when and how the intervention can best be offered. Subsequently, all fragments within each main theme were further categorized into sub themes using inductive analysis. Inductive analysis means that patterns, themes and categories are discovered throughout the transcripts instead of using predefined categories (Brod, Tesler & Christensen, 2009). Two supervisors were involved in the process of obtaining the themes and subthemes. This process endured until consensus was met.

3. Results

In this chapter, the results of the interviews will be discussed. The first paragraph shows a description of the participants. Then the opinion of the respondents concerning the following subjects will be discussed: (1) self-compassion and mindfulness, (2) delivering the intervention via a smartphone app, (3) the features of the app, (4) the needs and wishes regarding the content of the intervention and (5) when and how the intervention can best be offered. In this study, there was one respondent who was not interested in an app, therefore the subjects three and four were not discussed with her.

3.1 Description of the participants

The characteristics of the eleven participants are listed in table 3. Participants were heterogeneous regarding gender, age, education and employment. Nine of the participants were women, diagnosed with breast cancer. The respondents varied in their prognosis, five of the respondents were receiving treatment in the form of medication and all of the respondents were still under surveillance when the interviews took place.

Table 3. Characteristics of the participants (N=11)

Characteristics		N
Gender	Male	2
	Female	9
Age	Mean	54.5
	Range in years	31-73
Children	No	1
	Yes	10
Education	Low	4
	Medium	2
	High	5
Employment	Full-or part-time work	7
	Retired	2
	Disabled	1
	Unemployed/not specified	1
Type of cancer	Breast cancer	9
	Skin cancer (melanoma)	1
	Prostate cancer	1
Undergoing treatment	Yes	5
	No	6
Prognosis (self-reported)	Good	4
	Poor	1
	Uncertain	6

3.2 What do cancer patients think of self-compassion and mindfulness as theoretical basis of a supportive intervention?

Table 4 gives an overview of the themes mentioned by the respondents concerning their opinion about an intervention based on self-compassion and mindfulness.

Table 4. Respondents' appreciation of self-compassion and mindfulness as theoretical basis of a supportive intervention

Concepts	Themes	Theme total n	Example quote
Self-compassion	Raises awareness to be kind towards themselves	8	R4: When I got that invitation about self-compassion I thought wonderful! Self-compassion, that it may exist, that is something I'm really happy about.
	Being less critical towards themselves	7	R6: Cancer made me very hard on myself. I found it difficult to be kind to myself. I don't want to complain. I just want to keep on going. You have the tendency to think: "Why did I not go sooner? How can I do this to my child?" It facilitates feelings of guilt. So yes, look back and say to yourself: "You did not chose this, be happy that you were on time." Self-compassion can definitely be meaningful in this, with a bit of support.
	Increased kindness in how they treated themselves	4	R4: Since I have cancer I stand up early in the morning so I can treat myself. I salve myself with some body crème for example. That is something I can influence, feeding myself with loving energy.
	May help to accept their changed body	3	R4: When you have cancer you are confronted with your body. You can find your body ugly or unreliable and then it is important to be kind to yourself. That you can be mild and kind for your own creation. It is still there, it looks a bit different, but you may be there. You may wear a nice piece of clothing, you may wear a bathing suit and take a swim. That kind of things. Since I have cancer I feel more unprotected. I have a damaged body.
	A more compassionate/ understanding attitude towards their partner	2	R2: I had a lot of discussions with my partner about this subject. Now I have a better understanding of his point of view and is it easier for me to talk with him about my disease.

Table 4. Continued

Concepts	Themes	Theme total n	Example quote
Mindfulness	Calms you down	5	R6: I'm a chaotic person and things can be quickly too much for me. At these moments I take a seat, close my eyes, I'm aware of my breathing, I calm myself down and after that I'm ready to undertake things again. Everything falls into place after I use such an exercise.
	Makes aware that nothing is forever	3	R5: I liked the statement that nothing is forever. When you are feeling sad for example, you can realize that this is a feeling that goes away eventually. This is also the case when you experience something nice. That will also not be forever, so enjoy now you can. Take the moment. I really liked that one.
	Makes aware of fatigue	2	R5: In the book they write about the cycle of fatigue and it made me think. The way I deal with fatigue is often not that functional. You are tired for example, well than you take your rest, that is okay. However, something I recognize in myself is when you feel fit again, you do a lot of work because you want to make up for the time that you rested. In this way you are asking too much of yourself and you get extremely tired again. You stay in a vicious circle. I think the lesson of this was that you need to dose your energy, even when you feel fit and healthy at the moment. I thought that was nicely explained.
	Enhances the beauty of life	1	R4: Openness is something that is enhanced by mindfulness and that is something I like very much. I believe that it can work and that it can enhance the beauty of life.

Self-compassion appeared to be of importance for nine respondents. The first theme, mentioned by eight respondents, was that self-compassion had raised their awareness to be kind towards themselves and not only to others, as one respondent mentioned in the following quote: *“How warm and kind are you towards yourself? I have a lot of compassion for other*

people but I'm pretty hard on myself. Be mild to yourself that was like 'toingtoingtoing' a big lamp.'"

Self-compassion made seven respondents aware to be less critical towards themselves. They mentioned that they had been pretty hard and critical towards themselves since their diagnosis. One respondent said: "*Self-compassion is a very important concept. Since my cancer, I can be excessively critical to myself, especially because I went too late to the doctor. Now I'm aware that it is also important to be kind and mild to yourself.*"

The story of the wolf was explicitly helpful to be less critical towards themselves, for four of these seven respondents. The story is about a good and a bad wolf who lives in a person. The good wolf is kind, understanding and lives in harmony. The bad wolf is resentful and often very angry. They constantly fight with each other to see who is the strongest. The one you feed the most will finally win. The respondents mentioned that this awareness was very important for them. They realized that giving more attention to the good wolf facilitated their self-compassion instead of being excessively critical: "*A nice story within self-compassion is about which wolf you are feeding the most. You need to feed the kind wolf more to facilitate feelings of kindness and understanding for yourself instead of being excessively critical.*"

Four respondents mentioned that they treated themselves with more kindness during their sickness. It seems that for these respondents their sickness already activated some form of self-compassion. One respondent literally treated her body with kindness by salving herself with body crème, as the example in table 4 already illustrated. Two other respondents treated themselves with more kindness by undertaking pleasurable activities.

Self-compassion could facilitate the process of accepting the patients changed body. Three respondents mentioned the difficulty of accepting their changed body as a consequence of the operations, chemotherapy and the medicines they have to take. Self-compassion raised their awareness that they are still alive, which they are grateful for. This helped them in the process of accepting their body the way it is now:

I gained a lot of weight during my chemotherapy. In that case I needed a lot of self-compassion to feel okay with that. At first I was really hard on myself, I tried all crazy stuff because I wanted to be normal again. Real compassion for me would be that I could look in the mirror, could think okay a little less of me would be nice, but be kind to yourself. I'm still alive and I should be thankful of that. I had a two-sided amputation and a reconstruction was no option. In the winter it is okay with sweaters on and some scarfs. In the summer, when everyone is wearing nice tops or blouses, I found it difficult and it demands a lot of self-compassion to think that it is okay. That is something chapter eleven of the book about self-compassion helped me with.

A more compassionate/understanding attitude towards their partner was mentioned by

two respondents. In the process of their cancer they experienced sometimes that it was difficult to keep in contact with each other. After arguing about this, the awareness came that both are suffering in a different way. This led to a better understanding of each other, an improved mutual support and it made them feel less alone. For example:

The partner as fellow sufferer is also a very important thing to take into account. When you have cancer you feel like you are all alone, you think that other people don't know what you are going through, but that is not the case. Your partner and the people around you are struggling as well. At one point my boyfriend had an outburst and he said: "I'm hurting too you know? Everyone asks how you are doing but no one is asking about me." This incident made clear how important it is to say what you feel and that you can share your fears and sorrow.

Whereas most respondents felt quite appealed by the concept of self-compassion, two did not. They did not feel the need for self-compassion, as illustrated by the following quote: *"To feel compassion for myself, I don't know... I don't feel sorry for myself and I don't feel compassion. I think I don't have the need."* In addition, four respondents were unfamiliar with the concept of self-compassion. Two of them were part of the group who did not receive the book. One of them mentioned: *"Self-compassion, what does that mean? I looked that up first. I found it a difficult word."* Another respondent, who was familiar with the concept of self-compassion, suggested to clarify the term: *"I think you may clarify the term self-compassion for some people."*

Mindfulness was considered as meaningful by six respondents. One respondent said: *"Since I have cancer I really feel the need for mindfulness. I want to stay attentive to life and be mild to myself. Can I keep existing the way I am, now I have cancer?"*

Mindfulness exercises could help to calm down and clear the mind, which was mentioned by five respondents, as one respondent argued:

The exercises post-it on your breath and a healing walk, mentioned in the book "Mindfulness bij kanker", were a real eye-opener: being sick and behave sick. The latter is something I do often. When things are getting too much for me, I go for a walk. When I'm walking, I'm very aware of every step I make. That is really strange because you get out of balance, you feel like a kid who is learning to walk again but because of that your mind is empty.

Three respondents argued that mindfulness made them realize that nothing is forever. All kinds of feelings and thoughts are in a constant process of change. For one respondent, this knowledge helped him to endure feelings and thoughts, which he experienced as difficult. He argued that it could also encourage someone to fully benefit from positive experiences.

Mindfulness could also help unravel the problem of fatigue. Two respondents

mentioned this. For one of them the fatigue was a consequence of a vicious circle. He learned that by better dosing your energy, when you feel fit and healthy, you could break this circle of tiredness. The other respondent argued that tiredness is often one-sided attributed to the cancer and its treatment. Mindfulness made her aware that mental issues could be very important as well:

To unravel your fatigue is also a good one in the mindfulness. Feelings of tiredness are often ascribed to cancer or the chemo's while it can also be something else. Something I see and hear from the people around me is that they have a lot of fear and stress. They also have to deal with the reactions from other people or the fact that they do not receive any reaction from certain loved ones. Mental fatigue can also have an impact on your body. So it is important to look at yourself and your fatigue and ask yourself where is it coming from? Is it a direct consequence of the disease or a consequence of other consequences? When you know where it is coming from you can deal with it. That was something I really liked.

One respondent mentioned that staying attentive to the present moment, looking at your life the way it is now and to be mild could enhance the beauty of your life.

Five respondents however argued that mindfulness is not something for them. Two respondents argued that they are too down to earth, as illustrated by the following comment: *"I thought about mindfulness and if it will be something for me, but I think I'm too practical and down to earth."* Another respondent added the following:

In the beginning I thought that it worked, it calmed me down but later on it was always the same. Then you were supposed to drink your coffee and really think about that and be aware of sipping your coffee. That is not something for me.

3.3 What do cancer patients think of delivering the intervention via a smartphone app?

In table 6 an overview of the respondent's opinion about the delivering of an intervention via a smartphone app is given.

Table 6. Respondents' opinion about delivering an intervention via the use of a smartphone app

Themes	Total n	Subthemes	Subtheme total n	Example quote
Arguments pro	9	Fun	7	R3: The app is a good one! My first thought was: "Yes an app that is fun and handy".
		Easy accessible	5	R7: People use their phones and apps a lot, it is easy accessible. A lot of people take their phone with them.
		Offers variation and possibilities	4	R5: I like that you can browse through the exercises and that you can choose the exercises that appeal to you.
		Offers a first step in seeking help	3	R7: The app can provide a first step in seeking help. For some people it can be difficult to seek help, which is face to face right away.
		Usable	2	R1: I think it is clear and that it will be usable when this is presented on a smartphone.
		Easy to registrate and monitor	2	R1: I appreciate the part of the app, which asked me to write down three things where I was thankful for, very much.
		Offers reminders	2	R7: The app could give some push notifications, which are useful when you experience a lot of stress. The app could remind you of the things that you could do to calm yourself down.
Arguments con	2	No/little use of smartphone	2	R9: My smartphone is switched off most of the time.
		Too busy	1	R2: We are so busy with answering our emails. Last week we had eight e-mails, it made me crazy.
		Prefer face-to-face contact	1	R9: I'm not someone who would really use the app, I think. When I'm down I would prefer to go to a friend, to talk about my experiences and drink a beer. That would work for me.

The far majority (9 of 11) was positive about the use of an app. Arguments for the app were: it is fun (n = 7), it is easy accessible (n = 5), it offers variation and possibilities (n = 4), it offers a first step in seeking help (n = 3), it is usable (n = 2), it is easy to register and monitor with the app (n = 2) and it offers reminders (n = 2). Arguments against the app were: no/little use of the smartphone (n = 2), too busy (n = 1) and prefer face-to-face contact (n = 1).

Using an app is fun and pleasant, according to seven respondents. One respondent said: *“I would want the app. I think that it will be very pleasant for me. Wonderful.”* Five respondents argued that the app is easy accessible because of the frequent use of the mobile phone in daily life, as illustrated in the following quote: *“People use their phones a lot and they always take it with them nowadays.”* The app offered different kind of exercises and possibilities which is emphasized by four respondents. They liked that they could navigate through the app and choose the exercises that appealed to them. One respondent suggested to make the app more ‘universal’. She said: *“You can make it an universal app for everyone who is confronted with cancer. Not only the patient but also the partner and the children of the patients can benefit from the use of the app.”* The app could offer a first step in seeking help, which was mentioned by three respondents, as one of them said: *“I appreciate the low-threshold of the app. It offers you the possibility to speak about the things that occupy your mind. To make an appointment with your therapist could be an obstacle for a number of people.”* Two respondents argued that the app, as presented in the prototype, was usable. One said: *“It is so easy. It would be usable for me.”* Furthermore, two respondents liked the possibility to register and monitor their mood, experiences that make them happy and things that they are grateful for. They appreciated that they could fill in these data and they could look at it whenever they want to. One respondent said:

You can easily monitor your day, bring some routine in it and ask yourself how your day was. For me it could bring some support. I would download the app. Normally I’m very critical towards such things, but in this case I found it fascinating. I like to receive some instructions and exercises based on monitoring and registration. I appreciate that the app invites you to think about helpful thoughts and kind words you received from loved ones. You can easily collect some compassionate figures or some quotes. This is something you can do every week in your app.

That the app could offer reminders, was mentioned as positive by two respondents. They specified that the app could give some push notifications to remind them to fill in or try out some exercises, which could increase prolonged use of the app. One of them said: *“It is good that the app gives some push notifications to remind you to fill in some exercises, otherwise I could forget it and that would be a pity.”*

One of the eleven respondents made clear that she would not use the app. She argued that she did not have a smartphone and was busy enough with replying to all the emails that

she received. Another respondent preferred face-to-face contact with a friend when he was feeling down. He emphasized the little use of his smartphone and that it is switched off most of the time, however when the app is available in the future he would want to give it a try.

3.4 What do the cancer patients think of the five features presented in the prototype of the app?

The respondent's opinion about the five features of the app, that were addressed in this study, are discussed in this paragraph. These five features are: personalization and tailoring, monitoring, push notifications, uploading information and contact with fellow sufferers. Uploading information is divided into two subthemes: uploading information for research purposes and uploading information to a coach. Table 7 shows an overview of the pro's, con's, preconditions and tips mentioned by the respondents.

Table 7. Respondents' opinion about the five features of the app

Features	Pro	Con	Precondition	Tips
Personalization and tailoring	<ul style="list-style-type: none"> - App is a framework of personal things - Inspirational quotes 	-	-	<ul style="list-style-type: none"> - Choose background, type fonts and colours - Specific sound for notifications - Personal agenda - Scroll through text - Enlarge text - Text can be read out loud
Monitoring	<ul style="list-style-type: none"> - Gives insight 	-	<ul style="list-style-type: none"> - Clear guidelines about frequency and moment of monitoring - Only on a good day 	<ul style="list-style-type: none"> - Choose your own fixed point in time - Use of emoticons
Push notifications	<ul style="list-style-type: none"> - Offers a reminder - Increases awareness - Calms you down 	- Too much	<ul style="list-style-type: none"> - Switch off and on - Choice of push notification 	<ul style="list-style-type: none"> - Set your own time - Push notifications of random pictures
Uploading information (Research)	<ul style="list-style-type: none"> - Handy, makes information more specific 	-	<ul style="list-style-type: none"> - Report in advance - Staying anonymous - No personal things/content of the app 	<ul style="list-style-type: none"> - Specific questions to answer

Table 7. Continued

Features	Pro	Con	Precondition	Tips
Uploading information (Coach)	<ul style="list-style-type: none"> - Important - Useful - Easy accessible - Wishes guidance 	<ul style="list-style-type: none"> - No nonverbal contact and no physical contact 	<ul style="list-style-type: none"> - Useful for others - Understanding that coach is not always available - Contact through e-mails on laptop - Use of walk-in consultation service for cancer patients 	<ul style="list-style-type: none"> -
Contact with fellow sufferers	<ul style="list-style-type: none"> - Meaningful - Sharing information - Need for it 	<ul style="list-style-type: none"> - Too much stimulus - Risk of being deceived - No moderator 	<ul style="list-style-type: none"> - Useful for other people - Use of own name - No negativity - Resemblance 	<ul style="list-style-type: none"> - Interactivity with walk-in consultation service

Personalization and tailoring

This feature was evaluated as positive by ten respondents. Two of them mentioned that the app is a framework of all kind of personal things, as illustrated by the following quote: *“The app is a framework of personal things with your own music, pictures and quotes. I like it!”* Ten respondents were positive about the possibility of adding ‘inspirational quotes’ in the app. This part of the app could give them the opportunity to upload personal quotes and to look at already existing ones. One of them commented: *“Yes, great! A quote I like very much is the following: ‘Try to change what you can change, try to accept what you can’t change and have the wisdom to make a distinction between these two.’”* Personalizing the design of the app was also an important suggestion which was specified as follows: the possibility to choose their own background, their favourite sound for a specific notification, their preferred type fonts and the possibility to add some colours. One respondent argued that it would be nice if you have the possibility to enlarge the text, scroll through the text and to have the option that the text could be read out loud. The last suggestion, in relation to personalization and tailoring, was a personal agenda which could support the user to block some space for personal time, as illustrated by the following quote:

It would be nice if you can upload the activities that you like. This can be matched to a personal agenda in the app where you can block some ‘me-time’ to undertake such an activity or that you just block some time in your agenda and let it open so you can decide later on what you want to do. This could be a real personal touch.

Monitoring

This feature appealed to ten respondents. They liked to register how they were feeling and the specific circumstances they were in, because it could give them insight in the possible reasons why they felt that way: *“It is very good to do this exercise. It can explain why you had such a bad day. It makes you more aware of the influence of the circumstances on your mood.”* Two respondents wished to have more guidelines concerning the moment and frequency of measuring: *“When do you measure this? You need to measure it every day at a specified moment. Maybe offer the possibility that you can choose this for yourself.”* One respondent would only like to monitor on a good day: *“It is nice to evaluate only on a good day. When I have a bad day, I don’t want to think about that too much.”* The use of emoticons was preferred by one respondent. He said: *“I would prefer the use of emoticons. You can easily click on them and it shows how your day was.”*

Push notifications

Nine respondents liked this feature. They mentioned that it could serve as a reminder of all kind of things. Within the intervention, it could remind you of filling in or execute some exercises and you might be surprised by some quotes or pictures. Outside the intervention, it could inform you of some activities in your neighbourhood. One respondent mentioned for example:

That is nice! It can remind you of activities you like to do and the things that make you happy. You can also connect this with some walk-in consultation service for cancer patients. These services offer also some activities and the app can give a push notification when such an activity takes place.

An important precondition however, argued by six respondents, was to get the choice which notification you would like to receive and which one not. One of them said:

Push notifications is something I need to get used to. It is good that it is there as a functionality. I think however that it is important that you can choose for yourself if you want a push notification or not and that you can make a distinction between the things that you want to be notified of.

One respondent did not want this feature. For her it leads to over-stimulation.

Uploading information for research purposes

The possibility to send information for research purposes was well received by ten respondents. One respondent specified that it could be handy, so information could be adapted: *“Yes that could be handy. In that way, you could make the book and the information on the internet more specific.”* Various preconditions linked to this feature were mentioned by seven respondents: they need to be informed about the data collection and about the purpose

of the research in advance, anonymity needs to be guaranteed and they would only like to answer specific questions instead of sending private content of their app. The first precondition can be illustrated by the following quote: *“I would not have a problem with it, but I would like it if they make clear what it is about.”* The second precondition is illustrated by the following quote: *“It must be anonymous or it must give you the option to stay anonymous.”* The last precondition concerned filling in specific questions about the app. Two respondents did not agree that all the information they registered in the app is automatically uploaded to the researcher. They wanted to prevent that very personal information is sent which they could regret later on. One of them said: *“I would never agree that they use my content of the app. People do not see the big deal of it in the beginning, but can regret it later on when they realize there was a lot of personal stuff in it.”*

Uploading information to a coach

Seven respondents were positive about uploading information to a coach. Summarizing their information, one could conclude that some respondents felt the need for help and guidance and would appreciate the low threshold for reaching a coach, as illustrated by the following two quotes: *“Yes this is very nice, a sort of life coach. He could help me with my monitoring, give me tips, motivate me to use the mood meter and keep an overview of things”* and *“I think that this could work. Sometimes you have little things you want to ask but then you must make an appointment with your doctor first. That could be an obstacle for some people.”*

Two respondents argued that they did not feel the need for a coach right now but they thought that it could be useful for others. One respondent did not like the idea of a coach online. She strongly recommended the use of a walk-in consultation service for cancer patients: *“They have a coach who is educated. I think the physiology and the way someone speaks is very important in this case. There are some things you should not want to do online, I guess.”*

Contact with fellow sufferers

This feature was well received by six respondents. Two of them mentioned that it would be nice if you could share some information with fellow sufferers and that you could help each other by asking questions and giving tips, as illustrated in the following quote: *“It could be helpful to share experiences. For example, you could ask if other patients recognize specific symptoms and you could ask for some advice.”* One respondent emphasized her need for fellow sufferers: *“I really feel the need for contact with fellow sufferers.”* The following preconditions were mentioned among these six respondents: someone that they could relate to, the use of their own names and no negativity in the chatroom. The respondent who wanted to find someone who she could relate to, mentioned: *“They must be of the same age, same*

diagnose, have children, that kind of stuff. Maybe that you can fill in some personal information and that you can find someone who relates to that.” Three respondents added that they find it a precondition that everybody uses his own name, as one of them said: *“For me it is a precondition that people use their own names. It needs to be personal and no use of fake names.”* The last precondition, mentioned by three respondents, was that they did not want negativity in the chatroom. One of them argued that if you want to ensure this you would need a moderator who keeps an eye on the content of the chat room. She suggested therefore a combination with the app and a walk-in consultation service for cancer patients:

I find it difficult the way it is presented now. It could be an idea to make it more interactive. You could put in the app a sort of map for every region where people can find each other. No use of addresses but only zip codes for example. In that map, you can see which consultation service is nearby and you can see the people who use the app. In this way, they can get in contact with each other and meet at such a consultation service to drink some coffee, for example.

People who work at these services could moderate the negativity according to this respondent. Three other respondents were neutral about this feature. They thought that it might be a good feature but they would not use it themselves. One respondent mentioned: *“For me it is not necessary, but others could benefit from it I think.”* Two respondents did not like contact with fellow sufferers. One of them argued that she did not want to be involved with other cancer patients. This would be too tiring for her. The other respondent argued the risk of being deceived: *“You are not sure if someone is who he says he is. I would not like that. I like the walk-in consultation service special for cancer patients where I often go to.”*

3.5 What are the participants needs and wishes regarding the content of the intervention?

3.5.1 Insight giving exercises

The insight giving exercises can be divided in the following seven different exercises: (1) mood meter, (2) taking a distance from your thoughts/feelings, (3) change your critical voice, (4) make me small, (5) survival strategies, (6) compassionate figure and (7) throw it away. Table 8 gives an overview of participants’ ideas about the pro’s, con’s and preconditions/tips of these exercises. In the reflections below, the respondent’s opinion of the different insight giving exercises are discussed.

Table 8. Respondents' opinion about the insight giving exercises

Exercises	Pro	Con	Precondition/Tips
Mood meter	<ul style="list-style-type: none"> - Raises awareness - Offers insight - Pleasant 	<ul style="list-style-type: none"> - Need for clear guidelines about frequency and moment 	<ul style="list-style-type: none"> - Not wanting to use it on a bad day
Taking a distance from your thoughts/feelings	<ul style="list-style-type: none"> - Raises awareness - Important to write your feelings down - Gives insight in your fatigue/emotions 	<ul style="list-style-type: none"> - Too tired to think about it at that moment 	<ul style="list-style-type: none"> - Support of a coach - Connection with mood meter
Change your critical voice	<ul style="list-style-type: none"> - Raises awareness - Helpful 	<ul style="list-style-type: none"> - Unneeded because no feelings of guilt 	<ul style="list-style-type: none"> - Support of a coach - Tone of someone's voice is important
Make me small	<ul style="list-style-type: none"> - Stimulates to show emotions - Offers comfort and support - Back to the basics - Helpful - Nice metaphor 	<ul style="list-style-type: none"> - Difficult 	<ul style="list-style-type: none"> - Exercise in combination with coach - Emotions from when they were little is often too long ago to remember
Survival strategies	<ul style="list-style-type: none"> - Goes to your core - Valuable 	<ul style="list-style-type: none"> - Exercise not clear 	<ul style="list-style-type: none"> - Confronting and difficult, asks for some support/coach - Link with examples/ideas of survival strategies
Compassionate figure	<ul style="list-style-type: none"> - Good exercise 	<ul style="list-style-type: none"> - Exercise not clear - Difficult 	<ul style="list-style-type: none"> - Rather use of emoticons and pictures instead of drawing - Change the word 'compassionate' - Give examples of figures
Throw it away!	<ul style="list-style-type: none"> - Good exercise - Helpful 	<ul style="list-style-type: none"> - Oppressive - Need of distraction instead of giving attention to it 	<ul style="list-style-type: none"> - Possibility to hold on to their thoughts/ record their thoughts - Write the thought down and literally throw it away or destroy it

Exercise: Mood meter

The mood meter empowers the user to monitor his daily feelings and thoughts by rating these. By also offering the possibility to elaborate on the circumstances, monitoring can give the user insight in his well-being.

Ten respondents were positive about the mood meter. Eight of them mentioned that the mood meter could give a clear view of how they were feeling and it could make them more aware of the influence of their daily activities on their feelings. They said that the graph in the exercise could give them insight in their process. Respondents mentioned the following examples they wanted to monitor: their mood, fatigue, pain, moments for themselves, moments of energy and moments of joy/gratefulness. One respondent illustrated this by the following quote: *“I would want such a monitor of the day, so I can registrate the things that I do, such as moments of self-compassion or moments of things that give me energy.”* One respondent preferred to use the mood meter only when she has a good day. She argued that on a bad day it could be an extra burden to write that down. Another respondent would appreciate more clarity about the use of the mood meter. He argued that it was unclear when to use this mood meter and how often.

Exercise: Taking a distance from your thoughts/feelings

This exercise is about the fatigue a person can experience. He is questioned about his thoughts and feelings concerning his fatigue. He is challenged to take a distance from his feelings and thoughts by imagining as if it concerns another person. The purpose of the exercise is to be just as mild to yourself as you would be to another person.

Six respondents appreciated this exercise. They emphasized that they find it important to write down their thoughts and feelings. Some of them mentioned that it could give them insight in their fatigue and emotions. One respondent argued that it raised her awareness that she wants to be milder to herself concerning her fatigue, as illustrated by the next quote:

I find it very difficult to take a pause. I'm a person who is always busy and who is crossing my own boundaries. Then I'm very critical towards myself and by writing down these critical thoughts it makes me more aware of it. I can question myself if it is necessary to be so hard on myself. This raises the awareness that I want to be milder towards myself.

One respondent however, said that when she is tired she does not have the energy to fill in such an exercise. She added that the support of a coach could be helpful then.

Exercise: Change your critical voice

This is a listening exercise. Users listen to a fragment which stimulates them to think about the moments that they are self-critical and it tries to ease this critical voice by offering alternatives.

Seven respondents felt critical towards themselves. They argued that this exercise could help them to reduce and change their critical voice. One respondent said:

Often, I ask myself: Why did I not go earlier to a doctor? How could I do this to my child? I feel guilty that I can't smile while my child is cheerful. This exercise shows me how destructive I am and it could help me to change this.

Three respondents mentioned that they did not feel the need for this exercise. They did not feel critical towards themselves because they did not experience any feelings of guilt towards their cancer. One of them, however, could imagine that this is a good exercise when you do feel critical towards yourself.

Exercise: Make me small

In this exercise, people are asked how they wanted to be comforted when they were young. It emphasizes that children easily seek for comfort while adults found this difficult. The purpose of this exercise is to stimulate the adults to be small again and show their emotions to get some comfort.

Seven respondents were positive about this exercise, although a few found it hard to remember how they liked to be comforted when they were young. They mentioned that the exercise could be helpful and they liked the metaphor. They thought that it could stimulate them to show their emotions and that it could offer them comfort and support, as illustrated in this quote:

Make me small, I found it a good one. I wanted to be strong and give comfort to the people around me but I felt lonely afterwards. People said to me that I did not give them the opportunity to comfort me. Now I realize that showing my emotions and give others the opportunity to comfort me is not a weakness.

Three respondents found it a very difficult exercise. One of them found it very hard to be vulnerable and she admitted that she would skip this exercise. Two respondents suggested that a coach could be helpful in this exercise.

Exercise: Survival strategies

Users are asked about their survival strategies activated in their childhood and in which way they are still helpful or not. In case these strategies are no longer helpful but still used, they are questioned what makes them afraid to let these strategies go. The exercise encourages the user to acknowledge this fear and it stimulates to be observant concerning these strategies.

Eight respondents emphasized that the exercise is difficult and confronting, nevertheless they felt that it could be an important exercise. Five of them would appreciate the help of a coach as mentioned in the following two quotes: *"I find this exercise really difficult. I understand the meaning but to execute this exercise the help of another person is needed"*

and “*It is a difficult exercise where a kind of self-analysis is needed. A sort of a guide who could ask helpful questions would be welcome.*” Another respondent suggested a link in the app, which shows a list of existing survival strategies so users could gain some ideas.

Exercise: Compassionate figure

This exercise is about creating a compassionate figure, which contains some qualities such as wisdom, strength, warmth and it needs to be non-judgemental.

The idea of a compassionate figure appealed to eight respondents. Some of them liked the idea of drawing: “*This exercise of the compassionate figure I liked very much. I have drawn the sun and the sea, where the sun gives warmth, energy, comfort and hope, the sea offers serenity.*” Others preferred seeking pictures on the internet and one preferred the use of an emoticon to make clear how he feels. One respondent suggested to give some examples of figures the user could draw or seek. Another respondent appreciated the exercise very much, but she did not like the word ‘compassionate’ in it. She suggested a change of the title. Two respondents did not like this exercise. One of them emphasized that she did not feel the need for a compassionate figure.

Exercise: Throw it away

In this exercise, users are invited to write down their emotions and thoughts, which they perceive as bothering. It stimulates them to throw these away.

Eight respondents liked the aspect of the exercise to get rid of their thoughts that bothered them. Five of these respondents however preferred the option to focus on their thoughts first before they throw them away. One of them suggested to record your thoughts and one suggested to write them down without throwing them away immediately. This could give them insight in their motives and therefore it could give them the opportunity to make a selection what they want to keep and what they really want to throw away. Two respondents did not like the exercise. One of them experienced throwing away your thoughts as too oppressive. The other respondent preferred to distract herself from bothering thoughts.

Overall conclusion insight giving exercises

A great majority of the respondents emphasized that these exercises could increase their insight in their thoughts and feelings, which could be helpful in changing their behaviour.

3.5.2 Mindfulness/relaxation exercises

Table 9 shows an overview of the respondent's opinion about mindfulness/relaxation exercises, containing: (1) start of the day, (2) place a hand on your heart, (3) fist and (4) waiting. Reflections based on these exercises are presented in this paragraph.

Table 9. Respondents' opinion about mindfulness/relaxation exercises

Exercises	Pro	Con	Precondition/Tips
Start of the day	<ul style="list-style-type: none"> - Pleasant to take the time - Feel the safety of your bed - Calms you down 	<ul style="list-style-type: none"> - Start the day right away, otherwise risk of getting tired again 	<ul style="list-style-type: none"> - Prefer exercise in the evening - Not every cancer patient has their smartphone near their bed because of fear of radiation.
Place a hand on your heart	<ul style="list-style-type: none"> - Calms you down - Relaxation - Needs little time 	<ul style="list-style-type: none"> - Confronting when placing the hand on their prosthesis in case of breast cancer 	<ul style="list-style-type: none"> - Prefer hands on their stomach
Fist	<ul style="list-style-type: none"> - Experience the purpose of it - Pleasant - Useful - Simple 	<ul style="list-style-type: none"> - Not pleasant/unable to execute exercise because of cramps and rheumatism - Did not experience the use of it 	<ul style="list-style-type: none"> - More of these little exercises - Less text in the exercise - Recommend use of a stress ball
Waiting	<ul style="list-style-type: none"> - Good exercise - Useful - Pleasant 	<ul style="list-style-type: none"> - Prefers chatting with others 	<ul style="list-style-type: none"> - Emphasize breathing from the stomach

Exercise: Start of the day

Start of the day is an exercise people can listen to when they wake up in the morning. It stimulates them to be aware of the safety and the warmth of their bed which can make them relax and it can offer them an easy start of the day.

Eight respondents were positive about this exercise. Six of them thought that it was a good exercise for in the morning so they could have an easy start of the day, feel the safety of their bed and it could calm them down, as one respondent mentioned: *“I think it would be pleasant to take some time to wake up relaxed instead of immediately jumping out of bed when the alarm clock goes off.”* Three respondents however emphasized that they need to get out of bed right away. For that reason, two of them preferred the exercise in the evening. The third respondent said that this exercise did not appeal to her because otherwise she would fall

asleep again.

Exercise: Place a hand on your heart

This breathing exercise aims to calm people down in moments of stress.

The exercise appealed to a great majority of the respondents. Six of them stated explicitly that the exercise could calm them down and make them feel more relaxed, as illustrated by the following quote: *“I really like this. Putting your hand somewhere and to caress yourself, that is relaxing.”* A practical argument was that it was easy to do between other things in a day. Four respondents preferred to lay their hand on their stomach instead of on their heart. For two persons placing their hand on their heart was too confronting because of their breast cancer. One respondent argued that placing the hand on the stomach stimulates to breathe low to prevent hyperventilation.

Exercise: Fist

In this exercise, the user is invited to make a fist and to explore if he holds his breath. When this is the case, he is encouraged to breathe relaxed and explore if the feeling in his fist is changed. The purpose of this exercise is to facilitate the acceptance of the cherished things he lost.

Seven respondents appreciated this exercise. They experienced the exercise as easy to execute, pleasant and useful and for these reasons some of them added that they would like more of those exercises in the app: *“It would be nice to have some more of these easy to execute and helpful little exercises.”* Two respondents could not execute the exercise because of physical handicaps: one was suffering of rheumatism and the other one was afraid to get cramps. One respondent recommended the use of a stress ball in this exercise. This could make the execution of the exercise less difficult for people whose fingers are affected by chemo or in any other way. One respondent did not find this exercise helpful.

Exercise: Waiting

This listening exercise focuses on the breath with the aim of releasing some tense to help people who are stressed and tense while waiting for an appointment with their doctor.

Nine of the respondents evaluated this exercise as useful and pleasant: *“Such a breathing exercise is perfect while waiting.”* There was one respondent who preferred chatting with other people while he was waiting.

Overall conclusion mindfulness/relaxation exercises

Especially the physical component of these exercises, which could lead to relaxation, appealed to a great majority of the respondents. They also appreciated that these exercises were short and simple and suggested to include more of these exercises in the app.

3.5.3 Exercises to enlarge positive emotions

An overview of the respondent's opinion about the four exercises to enlarge positive emotions is shown in table 10. These four exercises are: (1) upload your music, (2) moment for yourself, (3) time for a photo and (4) what am I thankful for? This section will reflect on these different exercises.

Table 10. Respondents' opinion about the exercises to enlarge positive emotions

Exercises	Pro	Con	Precondition/Tips
Upload your music	<ul style="list-style-type: none"> - Comforting - Gives energy - Facilitates emotions 	<ul style="list-style-type: none"> - Already have a playlist - Too much work 	<ul style="list-style-type: none"> - Useful for people who do not have specific playlists - Uploading music could depend on age - Give some musical suggestions - Categorization could be based on moods
Moment for yourself	<ul style="list-style-type: none"> - Reduces stress - Could give an overview - Stimulating 	<ul style="list-style-type: none"> - 	<ul style="list-style-type: none"> - A little column with some negative energy - Make it interactive (use of push notifications)
Time for a photo	<ul style="list-style-type: none"> - Gives overview of precious moments 	<ul style="list-style-type: none"> - No need, already have that for their own - Reminder of sickness 	<ul style="list-style-type: none"> - Pleasant for other people
What am I thankful for?	<ul style="list-style-type: none"> - Tangible - Good one - Pleasant - Gives insight 	<ul style="list-style-type: none"> - 	<ul style="list-style-type: none"> - Option to read it back later on - Use of the word happy instead of thankful - Also write negative things down and show the distribution in a graph.

Exercise: Upload your music

This exercise allows people to upload their music which gives them comfort and can help them to relax.

Six respondents liked to upload their music. Themes that arose were that music could be comforting, could give energy and could facilitate emotions. Some of them added that they could easily categorize their music based on moods. One respondent liked the suggestion of songs so she could try these out. Two respondents had already a lot of music on their mobile phone so for them this feature was not necessary in the app. Two respondents did not like the idea of uploading music to their app. It would take too much time, according to them.

Exercise: Moment for yourself

This exercise is about taking good care for yourself by writing down what you did for yourself during the day. This could stimulate you to do something pleasant or relaxing every day.

Nine respondents mentioned that this exercise could reduce stress and that it could give them an overview of the things that they like to do for themselves. They argued that this could be helpful in times of stress. Some respondents added that push notifications could be used as a stimulation to fill in the exercise.

Exercise: Time for a photo

In this exercise it is possible to upload photos, which could facilitate feelings of joy. In moments of fear or stress these pictures could serve as a comfort.

Six respondents liked the idea of taking and uploading pictures in the app because it could give them an overview of some precious moments where they could go back to if they feel sad or if they want to relax and think back at positive moments. Three respondents did not see the benefit of uploading photos in the app. Two of them mentioned that they already have pictures on their phones or in albums. One respondent said that he has photos on his wall, which is enough for him. Another respondent argued that she did not like the exercise because the pictures could remind her of a period of sickness.

Exercise: What am I thankful for?

Thankfulness is a strong emotion, which could ease feelings of fear and worry. This exercise asks about the three things someone is grateful for.

Ten respondents were positive about this exercise. They found it tangible, pleasant and it could give them insight in the things they are still thankful for, which was really important according to them. In this way, they could remind themselves of positive things when they are in a sad mood. One respondent specified:

I appreciated the part of the app, which asked me to write down three things where I was thankful for. I would like it if the app could produce a list of this. This gives me the opportunity to have an overview after a period of time for all the things where I was grateful for.

Another respondent added the suggestion to offer the opportunity to write some negative things down as well. She argued that in this way you could get an insight in all your feelings and the app could show a distribution of these data in a graph.

Overall conclusion exercises to enlarge positive emotions

Almost all of the respondents argued that these exercises could comfort them in moments of

stress and sadness and that these exercises could give them insight in the things they still appreciate in life.

3.5.4 Exercises about relation with others

Table 11 shows an overview of the opinions of the respondents concerning the three exercises about relation with others. These three exercises are: (1) you and others, (2) mindful consultation relating to doctors and (3) partner as fellow sufferer. This paragraph reflects on these different exercises.

Table 11. Respondents' opinion concerning the exercises about relation with others

Exercises	Pro	Con	Precondition/Tips
You and others	<ul style="list-style-type: none"> - Recognition - Support - Helpful 	<ul style="list-style-type: none"> - Not applicable - Other people's cancer not that important - Comparison 	<ul style="list-style-type: none"> - No negative information - Possibility to upload your own situations - Offering tips how you could react to others
Mindful consultation relating to doctors	<ul style="list-style-type: none"> - Helps you remember the important things - Important to set your boundaries 	<ul style="list-style-type: none"> - Pitiful intro, appointment with doctor could be fun as well 	<ul style="list-style-type: none"> - The word mindful is confusing. Change the title. - Add the tip to record your consult and to bring someone with you - Add space where you could draft your own list
Partner as fellow sufferer	<ul style="list-style-type: none"> - Helpful - Important - Partner suffers as well 	<ul style="list-style-type: none"> - No added value if you do not have a partner 	<ul style="list-style-type: none"> - Tips for the partner how to keep in contact with the patient - Possibility for the partner to upload his feelings and thoughts in the app - Add some explorative questions to ask the partner and children

Exercise: You and others

This exercise shows awkward situations and experiences from other cancer patients, so the user can recognize that he is not alone in this.

Eight respondents liked this aspect of the app. It offered them especially recognition that also other cancer patients are confronted with awkward questions and useless recommendations. One respondent mentioned that she would benefit from tips in the app about how to respond to such comments. Furthermore, she suggested that she would appreciate it if you could upload your own awkward situations as well. She said:

It is nice if you can upload your own situations and the app can give you some tips about how to respond to people. During my sickness, I had so many visitors and it made me

crazy. I found it hard to say that they were not welcome at that time. The app could be a support in this, by giving some tips.

Two other respondents added that this feature also could be used to upload positive experiences. Two respondents did not feel the need for this exercise. One mentioned that sharing this kind of experiences with other cancer patients is not desirable for her. The other one mentioned that he did not recognize this kind of situations so this exercise was not applicable for him.

Exercise: Mindful consultation relating to doctors

This part of the app offers tips so the user can go ‘mindful’ and prepared to the appointment with their doctor.

Nine respondents mentioned that mindful consultation relating to doctors could help them remember the important things they would like to ask and it could stimulate them to set their boundaries. They suggested to add two other tips in the app: bring someone with you to the appointment and the possibility of recording the conversation. They argued that it is common to forget the things the doctor has said. Furthermore, they would appreciate if the app offers some space for creating their own list of questions for the medical consult. A critical remark however, mentioned by three respondents, was about the term ‘mindful’ in the exercise. They found it a confusing term. One of them suggested the change of the title.

Exercise: Partner as fellow sufferer

This exercise gives some communication tips between the patient and their partner. It stimulates the patient to have compassion for himself as well as for his partner.

Nine respondents found the tips in relation to their partner as fellow sufferer helpful and important. They emphasized the importance of realizing that the partner suffers as well. A suggestion from three respondents was to include the loved ones of the patients in this exercise because the partner could also find it difficult to speak up to the patient. They would like that the app offers some tips for the partner as well about how to keep in contact with the patient. Two respondents added that their disease had a great impact on their children and that this was very emotional for them. They both desired some guidance in the app how to deal with this issue. One of these respondents suggested explorative questions in the exercise, which could give her support in the communication with her child and her partner. She gave the following examples: *“What are you thinking about the situation that we are in? What are you thinking/feeling in relation to my cancer: are you afraid that I’m dying?”*

There was one respondent who did not have a partner. For him this exercise had no added value.

Overall conclusion exercises about relation with others

Almost all of the respondents mentioned that these exercises could raise their awareness that they are not the only ones who suffer from difficult situations. Furthermore, the tips that were given in some of these exercises were evaluated as helpful.

3.6 When and how can the intervention best be offered according to the participants?

In this section, the timing and the form of an intervention is discussed. At the end of the interview the following question was asked: *“In which stage of the illness should we offer this intervention?”* All respondents would like to receive the intervention immediately after their diagnosis, which is illustrated by the following quotes: *“Right away. When you get your diagnosis, you need some tools. I read some things now and I thought: That were things I really could have used while I was in the beginning of my disease.”* *“When you are just getting diagnosed or when you receive the treatment, I think this can be really helpful”* and *“I lost my fulfilment of the day. I did not know where to go to with my feelings. This intervention would have been very nice at the beginning of my disease.”*

Table 12 shows an overview of the different forms an intervention can be presented in. The respondents could choose between the four following options: (1) app with hand-out, (2) only the app, (3) only the book and (4) app and the book. During the interviews two respondents added two extra options: (5) only the hand-out and (6) the combination of an app and a walk-in consultation service for cancer patients.

Table 12. Respondents’ opinion about the form of the intervention

Form of intervention	Total n	Example quote
App with hand-out	6	R3: I would choose the app with a bit of basic literature. Something about self-compassion and the basics of mindfulness and how that works.
Only the app	3	R8: I would choose the app.
Only hand-out	1	R2: It depends on your age, when you are 20 years old you would like the app perhaps but I would prefer a short, practical version of some literature (73 years old).
Combination of app and walk-in service centre for cancer patients	1	R11: I would say the app in combination with a walk-in service centre for cancer patients.
Only the book	0	-
App and the book	0	-

Almost all respondents were positive about having the app. Nine of the eleven respondents said that they really would like to have the app. One respondent had some doubt about the usefulness of the app but he mentioned that he would try it. Six respondents would also like a hand-out with concise literature about self-compassion and mindfulness. Some of them argued that reading a whole book is too much when you had chemotherapy, as one respondent said: *“I did not have the concentration to read and I heard that often from the people around me. So, a book, that is just too much. Maybe a magazine or some articles that is possible, but definitely in combination with the app.”* Two respondents added the suggestion of a reading list containing book tips. Three respondents would only prefer the app. One respondent mentioned: *“Only the app in my case. You can put all your personal stuff in it and you have it always with you, because of your smartphone or iPad.”* There was one respondent who did not like the app. She would only prefer the hand-out. Another respondent suggested the combination of the app with a promotion of a walk-in service centre for cancer patients:

Even reading a magazine is hard when you are getting chemo. The book is difficult and there are a lot of repetitions in it. That is also the strength of the book but the strength of the app is that you can swipe and can choose what you want. I would omit the book and choose for the app and the promotion of a walk-in service centre.

4. Discussion

This study aimed to investigate the needs and wishes of cancer patients regarding a smartphone-supported self-help intervention based on the enhancement of self-compassion and mindfulness. We found that, in general, such an intervention was appreciated by most of the cancer patients in this study, especially in the beginning of their disease.

Most of the cancer patients appreciated the concept of self-compassion. They felt that self-compassion could be helpful in different ways: it raised their awareness to be kind towards themselves, it made them less critical towards themselves, it increased kindness in how they treated themselves, they felt that it may help them in the acceptance of their changed body and they experienced a more compassionate/understanding attitude towards their partner. Especially the raised awareness to be kind towards themselves and to be less critical towards themselves were mentioned by almost all of the cancer patients in our study. This self-kindness is an important part of the self-compassion theory: it is the tendency to be kind and caring to oneself, instead of being harshly critical when confronted with painful life circumstances (Neff, 2003b). Some participants mentioned that this attitude of self-kindness and caring to oneself helped them in the process of accepting their changed body. These findings are in line with the study of Przedziecki et al. (2013), which provided preliminary evidence for a mediating role of self-compassion between body image disturbance and psychological distress. The results of the study by Przedziecki et al. (2013) suggested a potential protective effect of higher level of self-compassion for patients at risk of experiencing body image disturbance.

The opinion about the concept of mindfulness was divided among the participants. A small majority mentioned the following positive aspects of mindfulness: it could calm them down, it could make them aware that nothing is forever, it could help them to better cope with their fatigue and it could enhance the beauty of life. Neff and Germer (2013) showed in their study that the participants of the mindful self-compassion program (MSC) experienced significantly greater life satisfaction. One respondent in our study mentioned that staying attentive to the present moment, looking at your life the way it is now and to be mild could enhance the beauty of life. This illustrates that mindfulness is a component of self-compassion and that a certain degree of mindfulness is a precondition to be self-compassionate (Neff, 2003b). However, nearly half of the participants doubted if mindfulness is suitable for them. A few of them explicated that they may feel too down to earth to practice mindfulness. In contrast to this scepticism, the evaluation of the four mindfulness/relaxation exercises were however surprisingly positive. This could be possibly explained because of the relaxation component of these exercises, which appealed to a great majority of the respondents. It is possible that they did not associate this relaxation component with the concept of

mindfulness.

Another important outcome of this study was that almost all of the participants were positive about the presentation of the intervention in the form of a smartphone app. There was only one respondent who argued that she was not interested in such an intervention. The other respondents mentioned that they take their smartphone with them every day and use apps on a daily basis. They mentioned various advantages of the app: it is usable, fun, easy accessible and it offers variation and possibilities. A study by Khalaf (2013) confirmed that smartphone devices are checked several times a day. He argued that users, when checking their smartphone devices, choose to engage with applications most of the time. This emphasizes the usefulness of smartphone applications when offering online interventions.

The most popular features of the app, that were addressed in this study, were monitoring, push notifications, personalization and tailoring, and uploading information for research purposes. The participants in our study mentioned that monitoring gave them insight in the background of their specific feelings. This result is in line with a study by Hermansen-Kobulnicky (2009), where cancer patients reported symptom self-monitoring as useful. The respondents in our study also mentioned that the push notifications could serve as a reminder to execute the exercises in the app. An important precondition however, mentioned by several respondents in our study, is to have the possibility to choose which push notifications they want to receive and which ones they want to switch off. This to avoid that they receive too much messages. Leykin et al. (2012) emphasized the importance of the use of push notifications because it can reduce attrition and eventually produce better outcomes. All of the respondents were positive about the feature personalization and had ideas about how they would like to personalize their app. Leykin et al. (2012) mentioned that some level of customization is of importance because it may help the user feel more understood and they could perceive a greater relevance of the program. Uploading information to a researcher was also well received by the participants. Arguments for sending information was that they would like to be of help to others. The cooperativity of the respondents to participate in scientific research is an important feature to establish efficacy and effectiveness of the app. To determine this, a smartphone intervention needs to include validated tools and standardized questionnaires (Leykin et al., 2012). Several respondents however, do not want that their personal content from the app will be sent. The use of questionnaires could overcome this. Guarantee of anonymity was also an important precondition mentioned by the respondents. These preconditions for this specific feature are important to take into account when such a smartphone intervention is developed.

Uploading information to a coach was another feature that was positively rated by a great majority of the respondents. They appreciated the low-threshold for reaching a coach.

Some respondents mentioned that they would appreciate support from a coach by some exercises which were perceived as difficult and confronting. One respondent explicitly mentioned that there is little psychological guidance for emotional problems cancer patients could experience. This is supported by Leykin et al. (2012) who argued that cancer patients reported that their emotional needs go unmet. This feature, uploading information to a coach, might facilitate cancer patients by seeking more help and guidance for their perceived psychological symptoms.

Contact with fellow sufferers was the least popular feature of the app. Arguments against this feature were the negativity that could arise in the chat room and the possibility to be deceived. Sharing experiential information could have negative effects and therefore deserves more attention in future research. With the growing availability of information, from fellow sufferers outside the formal treatment environment, the effect is difficult to determine and control (Rini et al., 2007). This could explain that nearly half of the respondents did not want this feature in the app despite their appreciation of contact with fellow sufferers. They preferred face-to-face contact. A small majority of the respondents however, wanted this opportunity in the app. Arguments for this feature were that it could be helpful to share experiences and ask for advice. This is in correspondence with results from previous research among cancer patients by Rini et al. (2007). They found that experiential information could affect cancer patients in a variety of positive ways: it reduces fear and uncertainty, gives them hope and forges common bonds. Neff and Germer (2013) also emphasized the importance of the recognition that other people suffer as well, make mistakes and have to deal with threatening life challenges. This so called common humanity is part of the self-compassion theory.

Most respondents rated all the exercises in the prototype app as relevant. Eleven of the eighteen exercises were positively rated by a great majority of the respondents. These eleven exercises were almost equally divided over the four broad categories which were deduced: insight giving, mindfulness/relaxation, enlarging positive emotions and relation with others. The two most popular exercises were the mood meter and what I'm thankful for. In the mood meter, almost all of the respondents appreciated that they could monitor their feelings and thoughts. It could give them a clear view of how they were feeling and it could make them more aware of the influence of their daily activities on their feelings. Leykin et al. (2012) argued that mood monitoring enables patients to educate themselves about the relationship of their actions to their psychological well-being. This could also improve treatment involvement (Leykin et al., 2012). The exercise 'What I'm thankful for' appealed again to almost all of the respondents. They argued that it could give them an overview of positive things which could serve as a relieve to them when they are in a sad mood. Thankfulness is a

strong emotion which can ease feelings of fear and worry (Stichting Trimbos-instituut, 2013). Positive emotions could facilitate happiness which could result in feeling more connected to the environment and it could offer more resilience when dealing with threatening life challenges (Germer, 2009). Two less popular exercises were ‘Uploading music’ and ‘Time for a photo’. However, a small majority were still positive about these exercises. The other respondents mentioned that they already have a lot of music and photos on their smartphone.

Respondents mentioned useful recommendations for improvement of the app. First of all, some respondents emphasized the importance of the involvement of their partner and loved ones in the app. Respondents mentioned that they felt isolated and lonesome because they assumed that they were the only ones who were suffering. As a consequence of our study they recognized however that their partner and loved ones were suffering as well. They suggested that the exercise ‘The partner as fellow sufferer’ could be extended. The partner could also find it difficult to speak up to the patient. Therefore, they would appreciate that this exercise offers also specific tips for the partner how to keep in contact with the patient. Previous research reported as well that the diagnosis of cancer could be as distressing for the partner and children as for the patient (Adams, Boulton & Watson, 2009). Therefore, we strongly support the recommendation of the participants in our study to offer the possibility to involve their partners and loved ones in a future intervention. A second recommendation is the possibility of a personal agenda in the app, which could support the user to block some space for personal time. This could encourage the respondent to undertake activities they like and it could help them to reserve time for moments for themselves. Almost all respondents argued that ‘Moment for yourself’ is a very important exercise. A third recommendation was about a link in the app which provides information of the program of the nearest walk-in consultation service for cancer patients and other interesting activities in their neighbourhood. This could also be helpful for respondents who prefer face-to-face contact with fellow sufferers. The fourth recommendation was the use of an open lesson plan flow in the app because of its flexibility. This could enable participants to view any lesson in any order and to choose the exercises that they found appealing and possibly helpful. This could be beneficial for participants who would prefer to choose their own specific topic, what could improve the effectivity and efficiency of the app and therefore it could decrease the dropout rate (Leykin et al., 2012). The last recommendation of the respondents was that the app could provide tips to keep you moving, because of the importance of physical exercise for cancer patients. A study of Blanchard, Courneya and Stein (2008) showed that cancer survivors reported higher quality of life when they met the physical activity guidelines published by the American Cancer Society. This recommendation contained 150 minutes of moderate-to-strenuous or 60 minutes of strenuous physical activity per week.

A last recommendation from all of the participants in our sample was to offer the smartphone-supported self-help intervention immediately after the diagnosis of cancer. They emphasized the need for support how to deal with the possible consequences of cancer and its treatment. The diagnosis of cancer and its treatment can have an enormous impact on the patient's quality of life and psychological well-being (Pinto-Gouveia et al., 2014). The National institute for Health and Care excellence (NICE) also suggested that psychological interventions should play an integral part of support offered to cancer patients (Shennan, Payne and Fenlon, 2011). A majority of the respondents argued as well that the app could be useful after their treatment. This finding is supported by Stanton et al. (2005) who mentioned that it is a myth that the patient no longer should need support after treatment. Cancer patients often perceived that the active support decreased once their treatment was finished. This could contribute to a sense of isolation, where the safety net and support could diminish quickly (Stanton et al., 2005). Therefore, we recommend the implementation of the intervention straight after the patient's diagnosis of cancer and offer it as long as the patient feels the need for it.

Strong points and limitations

The immediate involvement of the target group is a strong point of this study. By involving the respondents, their sense of ownership of the final design is increased. This is important for the final integration of the product in their daily lives (Abrás et al., 2004). For this reason, a recommendation will be to continue the involvement of the participants in the further development of the app.

There are however some limitations to this study. First of all, this qualitative study contained a rather small number of respondents. We aimed for a heterogeneous group of respondents, to explore their wishes and needs concerning a smartphone-supported self-help intervention based on self-compassion and mindfulness exercises. In our sample, there were more women than men and most of the participants were diagnosed with breast cancer. Therefore, the results may not be generalizable among other cancer patients. We obtained nevertheless a lot of valuable information based on the use of a prototype app in combination with the self-compassion and mindfulness components. We think that these valuable results can be taken into account for the development of a smartphone-supported self-help intervention. A recommendation for future research would be to develop the intervention and examine its effects in a mixed methods study. The effects of the intervention can then be evaluated based on self-compassion, psychological distress, mental well-being and other outcome measures. These measures can be specified in future research and a randomized controlled trial can be conducted. It would be worthwhile if this research aims at a greater population who are especially divided in terms of gender and type of cancer, to enlarge the

possibility of generalization.

Second, during the interviews it appeared that some of the respondents found it difficult to fully understand the term self-compassion. This was particularly the case for the respondents who did not read the book “Mindfulness bij kanker”, where chapter eleven was especially about self-compassion. Nevertheless, during the interviews it appeared that all of the respondents did not feel the need to receive a whole book. The current information letter however could not prevent that some people did not understand the meaning of self-compassion thoroughly. This flaw was overcome in this study by a verbal explanation during the interview. However, a lack of understanding of the concept of self-compassion during the recruitment, could have as a consequence that potential respondents detain from the study. Therefore, we recommend a short hand-out about self-compassion and a list of some useful books. It is important that this hand-out is given together with the information letter at the beginning of the recruitment to ensure that all potential respondents are sufficient informed about the concept of self-compassion and the aim of the study.

A third limitation of this research is that some questions were not asked systematically to the respondents in the pilot interviews. Some topics appeared to be important during these pilot interviews, therefore questions were added to the interview scheme later on in the research process. We do not perceive this as a real problem because these respondents commented on these topics spontaneously.

A last limitation is that it might have been difficult for respondents to decide if they were interested in a smartphone-supported self-help intervention that did not exist yet. We think however, that we have overcome this problem by presenting mock-ups during the interviews. By using mock-ups in our study, participants were enabled to imagine such a smartphone-supported self-help intervention and it stimulated them to think about their wishes, needs and ideas concerning such an intervention. The participants responded positively to these mock-ups and were convinced that the app as presented was usable. During the interviews the participants had a lot of input, which could be taken into account in the development of the smartphone intervention later on. Bailey, Biehl, Cook and Metcalf (2008) argued that paper prototyping is a widely used and validated technique for exploring and evaluating early interface designs. In their study, major design issues were identified by the use of paper prototyping. They were able to uncover usability issues before they started with a high-fidelity prototype. Therefore, we recommend the use of a low-fidelity prototype, designed by mock-ups, to other researchers that are at the beginning of the development of a smartphone-supported self-help intervention.

Conclusions

Our study shows that a smartphone-supported self-help intervention, based on self-compassion and mindfulness exercises could be a useful aid in helping newly diagnosed cancer patients to cope with their psychological distress.

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Appendix I: Information letter

Leven met kanker...

Het krijgen van kanker is een ingrijpende gebeurtenis. Zelfs na succesvolle behandeling hebben veel kankerpatiënten te maken met negatieve gevoelens als somberheid, angst, schaamte of zelfverwijt. Sommige mensen kunnen wel wat hulp gebruiken om de draad weer op te pakken.

Ontwikkeling van een nieuwe interventie

Momenteel overweegt Universiteit Twente om een laagdrempelige zelfhulp interventie te ontwikkelen, gebaseerd op het begrip “zelfcompassie”. Bij zelfcompassie gaat het om het vermogen om met warme gevoelens, zorg en begrip te reageren op eigen gevoelens van lijden. Bij de ontwikkeling van deze interventie willen we graag enkele patiënten betrekken. Daarom vragen wij u om ons hierbij te helpen.

Doel van dit onderzoek

Het doel van dit onderzoek is om te onderzoeken of zelfcompassie en zelfcompassie oefeningen kunnen helpen om het welbevinden van (ex-)kankerpatiënten te bevorderen. Daarnaast is het van belang om te onderzoeken hoe zelfcompassie oefeningen bruikbaar gemaakt kunnen worden voor (ex-)kankerpatiënten. Dit zou bijvoorbeeld kunnen via een boek, via kleine oefeningen op de smartphone en/of via emailbegeleiding.

Wat houdt deelname in?

Als u deelneemt zult u het boek: “Mindfulness bij kanker” van Linse & Bruining (2015) opgestuurd krijgen samen met een aantal voorbeeldplaatjes van een smartphone app. U wordt gevraagd het boek thuis te lezen en de voorbeeldplaatjes te bekijken. U zult hier gedurende vier weken ongeveer vier uur per week mee bezig zijn. Na ongeveer vier weken zal er een interview plaatsvinden van een uur, waarin we u vragen zullen stellen zoals: Wat spreekt u wel of niet aan? Zijn er oefeningen die u zou aanraden? Welke tips heeft u voor de ontwikkeling van de interventie? Wat vindt u van het gebruik van een smartphone app? Etc.

Het interview kan naar uw voorkeur plaatsvinden bij u thuis, of op de Universiteit Twente. Alles wat u ons vertelt, zal uiteraard strikt vertrouwelijk behandeld worden. Als dank voor u deelname mag u het boek houden. Voor meer informatie kunt u contact opnemen met: Nienke Peeters - 0623359991. Als u wilt deelnemen aan het onderzoek, dan mag u het bijgevoegde toestemmingsformulier invullen en opsturen naar het emailadres: n.j.peeters@student.utwente.nl

Appendix II: Informed consent

Toestemmingsformulier

Geachte heer/mevrouw,

U wordt verzocht onderstaande tekst door te lezen. Wanneer u medewerking wilt verlenen aan het onderzoek, kunt u onderaan uw gegevens invullen en opsturen naar het volgende emailadres: n.j.peeters@student.utwente.nl.

1. Ik heb de informatiebrief over het onderzoek gelezen. Ik kreeg de mogelijkheid vragen te stellen over het onderzoek en mijn vragen zijn voldoende beantwoord.
2. Ik ben ervan op de hoogte dat deelname vrijwillig is. Ik weet dat ik op ieder moment kan besluiten mijn deelname te onderbreken en dat ik daarvoor geen reden hoeft te geven.
3. Ik geef toestemming om de gegevens uit het interview te gebruiken voor doeleinden die in de informatiebrief zijn beschreven.
4. Ik ben bereid deel te nemen en me te laten interviewen door Nienke Peeters en geef toestemming voor een geluidsopname van het interview.

Naam:

Adres:

Postcode en woonplaats:

Telefoonnummer:

Emailadres:

Handtekening:

Datum:

Appendix III: Interview scheme

Het interviewschema

Nummer respondent	
Datum interview	
Tijdstip aanvang interview	
Tijdstip einde interview	

Welkom

Mijn naam is Nienke Peeters en ik volg de masteropleiding Gezondheidspsychologie aan de Universiteit Twente. In het kader van mijn stage ben ik bezig met dit onderzoek. Ik voer dit onderzoek uit onder begeleiding van Dr. Stans Drossaert.

Dank en uitleg procedure interview

Allereerst wil ik u bedanken voor uw bereidheid om deel te nemen aan dit onderzoek. Ik weet dat u een moeilijke periode doormaakt en des te meer stel ik het op prijs dat u deel wilt nemen aan dit onderzoek.

Toestemming opname interview

Ik zou graag een geluidsopname willen maken van het interview, zodat de gegevens naderhand, anoniem, gebruikt kunnen worden. De geluidsopname zal anoniem worden uitgeschreven. In het eindverslag zullen de gegevens zodanig worden gepresenteerd dat ze niet herleidbaar zijn tot persoon. Gaat u akkoord met het opnemen?

Indien 'ja':

Dan wil ik u nu een korte uitleg geven over de opbouw van het interview.

Indien 'nee':

Zou u kunnen vertellen wat hier de reden van is?

Uitleg opbouw interview

Het interview bestaat uit vijf onderdelen. Allereerst zal ik u een paar achtergrondvragen stellen. Vervolgens zal ik een aantal vragen stellen over uw ervaring/waardering van het boek. In het derde deel wil ik uw waardering van de voorbeeld-app en de daarin beschreven oefeningen bespreken. Het vierde gedeelte zal gaan over de mogelijkheden die een app te bieden heeft en wat u daarin belangrijk vindt. Het laatste gedeelte is voor uw eventuele vragen en suggesties. Hiermee kunnen we het interview afsluiten.

Heeft u tot dusver nog vragen?

Deel 1: Achtergrond

1. Zou u me kunnen vertellen hoe oud u bent?
2. Wat is uw hoogst voltooide opleiding?
3. Wat is uw huidige arbeidssituatie?
4. Heeft u kinderen?
 - Nee
 - Ja, thuiswonende kinderen
 - Ja, uitwonende kinderen
5. Wanneer is uw diagnose gesteld?
 - Kunt u heel kort iets vertellen over het verloop van de ziekte?
 - Hoe gaat het nu met u?
 - Ondervindt u nog steeds hindernissen door kanker?
6. Had u voor het lezen van dit boek al ervaring met zelfcompassie/mindfulness?

Deel 2: Uw ervaring/waardering van het boek

7. Kunt u zeggen hoeveel tijd u ongeveer heeft besteed aan het lezen van het boek en het maken van de oefeningen?
8. Wat is uw algemene indruk van het boek en de oefeningen daarin?
9. Zijn er in het bijzonder hoofdstukken of oefeningen geweest die u wel aanspraken of die u juist niet aanspraken?
10. Wat heeft u van dit hoofdstuk geleerd? Past u dit geleerde toe in uw dagelijks leven?
11. Is het u gelukt om hoofdstuk 11 te lezen?
12. Wat is uw algemene indruk van dit hoofdstuk? Wat spreekt u aan in dit hoofdstuk en wat niet?
13. Wat heeft u van dit hoofdstuk geleerd? Past u dit geleerde toe in uw dagelijks leven?

Deel 3: Uw ervaring/waardering over de voorbeeldplaatjes van de app

14. Wat is uw algemene indruk van de voorbeeldplaatjes?
15. Zijn er oefeningen die u heeft geprobeerd? Hoe is dit gegaan?
16. Welke oefeningen spraken u in het bijzonder aan?
17. Welke oefeningen spraken u minder of niet aan?

18. Zijn er oefeningen die u met regelmaat zou willen toepassen?

Deel 4: Mogelijkheden die een app te bieden heeft

Persoonlijke invulling

In de app kunt u uw account een persoonlijke invulling geven. Hierbij kunt u denken aan eigen foto's, muziek, uitspraken of het toevoegen van uw eigen compassievolle figuur. U kunt bijvoorbeeld een afspeellijst samenstellen op basis van muziek die u kan helpen bij het ontspannen in tijden van stress.

19. Wat zou u ervan vinden als u zelf deze dingen zou kunnen verzamelen in de app?

20. Heeft u nog andere suggesties?

Herinneringsberichten (ook wel push-berichten genoemd)

Een app kan berichten verzenden naar uw mobiele telefoon. Deze pushberichten kunnen ingezet worden als herinnering wanneer u een opdracht zou kunnen uitvoeren maar het zou ook een pushbericht kunnen zijn die een inspirerende uitspraak of tip laat zien.

21. Wat zou u ervan vinden als er op willekeurige momenten bovengenoemde berichten worden gestuurd? Of zou u dat zelf willen instellen (hierbij kunt u denken aan tijdstippen of helemaal geen meldingen)?

22. Heeft u nog andere suggesties?

Lotgenoten contact

Een app kan tevens gebruikt worden voor lotgenoten contact. Hierbij kunt u denken aan een chat functie, waarin je bijvoorbeeld onderlinge ervaringen kunt delen.

23. Wat zou u ervan vinden als er een chat functie met lotgenoten was in de app?

24. Aan welke voorwaarden dient dit volgens u te voldoen?

25. Heeft u nog andere suggesties?

Monitoring

Bij monitoring kan gedacht worden aan een korte test om te kijken hoe het met u gaat (denk hierbij aan uw mate van welbevinden, mate van eventuele pijn, mate van spanning, etc). Uw uitslagen kunt u vervolgens terugvinden in de grafiek. Op deze manier kunt u, uw eigen voortgang monitoren.

26. Wat zou u hiervan vinden?

27. Welke onderwerpen zou voor u nog meer zinvol zijn om bij te houden in een app?

Zelf toevoegen (Ook wel uploads genoemd)

Bij uploads kan gedacht worden aan informatie die doorgestuurd wordt van de app naar de onderzoeker of naar een coach. Dit zou van toepassing kunnen zijn voor onderzoeksdoeleinden. De stemmingsmeter zou hier een voorbeeld van kunnen zijn maar ook antwoorden op bepaalde vragen in de oefeningen. Daarnaast zou een counselor feedback kunnen geven op de door jou ingevulde opdrachten.

28. Wat zou u hiervan vinden?

29. Aan welke voorwaarden dient dit volgens u te voldoen?

Deel 5: Suggesties & Afsluiting

Alle onderdelen van het onderzoek zijn nu besproken.

30. U hebt nu een heel pakket van ons aangeboden gekregen, een boek en een voorbeeld-app, wat denkt u dat uw lotgenoten zullen verkiezen in de toekomst:

- App en boek
- Boek alleen
- App alleen
- Alternatief: App en een verkorte schriftelijke versie van meest toepasselijke literatuur (max. 30 pagina's).

Heeft u in het algemeen nog suggesties voor verbetering?

31. Heeft u nog bepaalde dingen gemist?

Uitleg vervolg en dank

Het interview zal geanalyseerd worden. Het verslag en dat van andere deelnemers zal mij helpen bij het beoordelen van het boek en de oefeningen. Wellicht zal er aan de hand van dit onderzoek een passende eHealth interventie ontwikkeld worden.

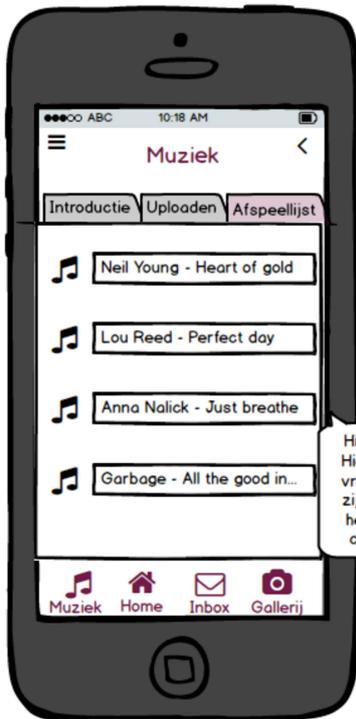
Indien u geïnteresseerd bent in de uitkomsten van dit onderzoek, zou ik u kunnen mailen. Zou ik in dat geval uw e-mailadres mogen noteren?

E-mail:

Dan zijn we nu aan het eind gekomen van het interview. Ik wil u hartelijk danken voor uw medewerking.

Appendix IV: Mock-ups five features

1. Personalization



Hier kunt u uw eigen muziek uploaden. Hierbij kunt u denken aan muziek wat u vrolijk maakt, maar het kan ook muziek zijn die u ondersteunt als u het moeilijk heeft. Op deze manier kunt u zelf een compassievolle afspeellijst creëren.



Hier kunt u bijvoorbeeld een eigen gekozen afbeelding, foto of tekening toevoegen. Ter ondersteuning kunt u er kenmerken bij schrijven.



Hier kunt u zelf inspirerende uitspraken toevoegen of een aantal doorlezen die beschikbaar worden gesteld door de app. Daarnaast kan de app deze uitspraken op een willekeurig moment naar u verzenden, mocht u dat prettig vinden. Inspirerende uitspraken kunnen ondersteunend zijn in een moeilijke periode.

2. Push notifications



3. Contact with fellow sufferers



4. Monitoring



5. Uploading information (coach/research)

