UNIVERSITY OF TWENTE.

Faculty of Behavioral, Management and Social Sciences

Self-critique and self-compassion among cancer patients

A qualitative study

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Dankwoord

Beste lezer,

Voor u ligt mijn afstudeerscriptie die ik heb geschreven ter afronding van mijn Master Gezondheidspsychologie aan de Universiteit Twente. Dit onderzoek is gedaan in opdracht van de Universiteit van Twente, als onderdeel van het promotieonderzoek van J. Austin. In dit verslag wordt beschreven op welke manieren kankerpatiënten zelfkritisch zijn en/of compassie hebben voor zichzelf. Daarnaast worden er enkele (zelf)compassie oefeningen geëvalueerd.

Tijdens mijn afstudeerscriptie voor de Bachelor Psychologie ben ik al in aanraking gekomen met het thema compassie. Een interessant thema dat ertoe heeft geleid dat ik compassie-voller ben gaan leven. Toen ik de omschrijving las van de afstudeeropdracht 'Zelfcompassie in de context van kanker: een kwalitatief onderzoek', werd ik direct enthousiast om mee te werken aan dit onderzoek. Voor mij betekende dit onderzoek de ideale mix om mijn kennis en kunde wat betreft compassie te combineren met het uitvoeren van semigestructureerde interviews onder een uitdagende doelgroep, iets waar ik mij graag verder in wilde ontwikkelen. Uiteindelijk heeft dit geleid tot een leerzaam proces, waarin ik mijzelf in de rol als onderzoeker ontwikkeld heb met deze scriptie als eindresultaat.

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Samenvatting

Achtergrond: Er is behoefte aan psychosociale interventies bij kankerpatiënten die hen vaardigheden bieden om effectief om te gaan met psychosociale uitdagingen, omdat hiervoor nog geen standaardbehandeling wordt aangeboden. Het gebruik van huidige interventies is laag, omdat ze een hoge drempel hebben, niet direct na de diagnose worden aangeboden en zich niet richten op zelfcompassie, op maat gemaakt voor kankerpatiënten. Er zijn steeds meer aanwijzingen dat zelfcompassie sterk wordt geassocieerd met geestelijke gezondheid en onderzoek heeft aangetoond dat zelfcompassie een negatieve correlatie heeft met maten van angst, depressie, piekeren en zelfkritiek. Er is echter weinig bekend over zelfkritiek en zelfcompassie bij kankerpatiënten. Dit onderzoek richt zich op de manier waarop kankerpatiënten zelfkritiek en/of zelfcompassie hebben.

Methode: Voor dit kwalitatieve onderzoek werden zeventien semigestructureerd interviews afgenomen bij kankerpatiënten. Om bekend te worden met het concept zelfcompassie werd hen gevraagd om voorafgaand aan het interview acht reflectieve en meditatieve oefeningen te doen. De interviews werden opgenomen en woordelijk getranscribeerd. Na het selecteren van relevante tekstfragmenten, werden de transcripten geanalyseerd met behulp van deductieve en inductieve analyse.

Resultaten: Met betrekking tot zelfkritiek werden zes categorieën genoemd: sterk moeten blijven, kritische gedachten/gevoelens hebben over zichzelf, boos zijn op zichzelf, zich schuldig voelen, niet zoeken naar connectie/hulp van anderen en hoge eisen stellen. Met betrekking tot zelfcompassie werden acht categorieën genoemd: zelfzorg, positieve gedachten/gevoelens hebben, zoeken naar connectie/hulp van anderen, het toestaan van negatieve emoties/gevoelens, de ziekte en beperkingen accepteren, grenzen stellen, activiteiten doen om gedachten te verzetten en zelfacceptatie. De reflectieve oefeningen werden grotendeels positief gewaardeerd door de respondenten. De meditatieve oefeningen werden minder positief gewaardeerd door de respondenten.

Conclusie: Concluderend kan worden gezegd dat kankerpatiënten over een zekere mate van zelfcompassie beschikken, maar dat zelfkritiek en strengheid voor zichzelf ook veel voorkomt. De concrete informatie over zelfkritiek en zelfcompassie kan gebruikt worden om de reflectieve en meditatieve oefeningen met bijbehorende tekst aan te passen naar de wensen en behoeften van de kankerpatiënten. Binnen de oefeningen dienen keuzemogelijkheden te worden toegevoegd zodat een grotere doelgroep kan worden aangesproken. In aanvullend kwalitatief onderzoek met gestructureerde interviews dienen de aangepaste oefeningen voorgelegd te worden aan de kankerpatiënten om te kijken of dit aansluit bij hun wensen en behoeften. Zo kan de zelfcompassie van kankerpatiënten worden versterkt.

Abstract

Background: There is a need for psychosocial interventions among cancer patients that provide them with skills to effectively cope with psychosocial challenges, because at this moment there is no standard treatment. The uptake of current interventions is low because they have a high threshold, are not offered right after the diagnosis and do not focus on self-compassion, custom-tailored to cancer patients. There is growing evidence that self-compassion is strongly associated with mental health and research has shown that self-compassion negatively correlates with measures of anxiety, depression, rumination and self-critique. However, little is known about self-critique and self-compassion among cancer patients. This research focuses on in which ways cancer patients are self-critical and/or self-compassionate.

Methods: For this qualitative research, seventeen semi-structured interviews were conducted among cancer patients. To become familiar with the concept of self-compassion, cancer patients were asked to do eight reflective and meditative exercises prior to the interview. The interviews were recorded and transcribed verbatim. After selecting relevant text fragments, the transcripts were analyzed applying deductive and inductive analysis.

Results: Regarding self-critique, six categories were mentioned: having to stay strong, having critical thoughts/feelings about themselves, being angry with themselves, feeling guilty, not looking for connection/support from others and setting high demands. Regarding self-compassion, eight categories were mentioned: self-care, having positive thoughts/feelings, looking for connection and support from others, allowing negative emotions/feelings, accepting disease and limitations, setting boundaries, doing activities to clear their head and self-acceptance. The reflective exercises were mainly positively appreciated by the respondents. The meditative exercises were less positive appreciated by the respondents.

Conclusions: In conclusion, it can be said that cancer patients already experience self-compassion to a certain extent, but self-critique and strictness are also common among them. The concrete information about self-critique and self-compassion among cancer patients can be used to tailor the reflective and meditative exercises with accompanying text to the needs and wishes of cancer patients. Options must be added within the exercises so that a larger target group can be addressed. In additional qualitative research with structured interviews, these adjusted exercises must be presented to cancer patients to see whether these fit the needs and wishes of the cancer patients. This way, the self-compassion of cancer patients can be strengthened.

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1. Introduction

1.1 Cancer

Cancer is a common disease in the Netherlands. In 2018 alone 116.500 new cases of cancer were registered, of which 61.000 new cases in men and 55.500 new cases in women (IKNL, 2019). Cancer and its treatment can have an immense impact on the quality of life and the psychological well-being of the patient. Patients report that they experience problems on various levels such as physical, social, and psychological problems.

On a physical level, patients experience side effects of the treatment such as cancer-related fatigue. The patient experiences more fatigue when performing an activity than usual, which interferes with usual functioning. It can be a consequence of active treatment but may also persist into posttreatment periods. Cancer-related fatigue is responsible for a reduced quality of life (Berger et al., 2015). Moreover, patients report having an impaired cognition (Mehnert et al., 2016; Bower, 2014; van den Beuken-van Everdingen et al., 2007; Janelsins, Kesler, Ahles & Morrow, 2014; Bayly & Lloyd-Williams, 2016). Impaired cognition, including concentration, memory, and executive functions, can be caused by chemotherapy which crosses the blood brain barrier, causing brain damage (Cheung et al., 2015; Wang et al., 2015; Vardy, Wefel, Ahles, Tannock & Schagen, 2008; Joly et al., 2015). These cognitive impairments can have tremendous consequences on the patient's quality of life (Castel et al., 2017).

On a social level, patients report social problems at any stage in the disease process (Wright, Selby, Gould & Cull, 2001). For example, prostate cancer patients experience social isolation because of treatment-related side effects such as incontinence (Ettride et al, 2018). Patients in the emerging adulthood (18-25 years of age) also report that they are uncertain about the future and miss guidance for further study or career paths and assistance with getting back to work (Millar, Patterson & Desille, 2010). Patients with social problems are significant more likely to experience mental health problems such as anxiety or depression (Harrison, Maguire, Ibbotson, MacLeod & Hopwood, 1994; Cull, Stewart & Altman, 1995).

On a psychological level, patients report that they experience body-related distress (BID) (Millar, Patterson & Desille, 2010). Chronic distress related to bodily changes can for example be caused by the consequences of breast cancer treatment in women (Fobair et al., 2006). Losing a breast or losing hair can evoke feelings of shame (Hefferon, Grealy, & Mutrie, 2010; Grogan & Mechan, 2017). BID can be associated with significant psychological distress (Kwak et al., 2013a; & Zebrack et al., 2014) and posttraumatic symptoms (Kwak et

al., 2013b). Patients also experience high rates of anxiety and depression (Zabora, BrintzenhofeSzoc, Curbow, Hooker & Piantadosi, 2001).

In conclusion, it can be said that having cancer does not only cause problems with the physical health of a patient, but it can also cause problems on a social- and psychological level.

1.2 Self-critique

The psychosocial problems that cancer patients experience can be associated with self-critique (Gilbert & Irons, 2005). Self-critique consists of two components, namely: *inadequate self* and *hated self*. The first component, *inadequate self*, refers to the feeling of shortcomings and thoughts about imperfection and is related to the need to improve or correct themselves. The second component, *hated self*, refers to the need to harm themselves in case of a failure, wanting to break free from an unwanted part of themselves and feelings of disgust and self-hatred (Gilbert, Clarke, Hempel, Miles & Irons, 2004). People who are self-critical, have hostile thoughts and feelings towards themselves, experience feelings of imperfection and disgust towards themselves and set high demands for themselves (Gilbert et al., 2004). Self-critique can be used as a safety strategy to protect oneself against potential threats from the outside; painful experiences, situations, emotions and memories are regulated with self-critique (Kim, 2005).

Self-criticism is significantly associated with psychological problems (Murphy et al., 2002). Psychological problems such as the distress that is experienced in breast cancer survivors is directly related to a disturbed body image (Scott, Halford & Ward, 2004). Negative thoughts and feelings about their body image can lead to dissatisfaction with one's self (Scott et al., 2004; Stokes & Frederick-Recascino, 2003). Furthermore, cancer patients may experience self-blame regarding the cause of their cancer which can lead to negative self-perceptions and poorer mental health outcomes (Else-Quest, LoConte, Schiller & Hyde, 2009; Phelan et al., 2013). Negative thoughts and feelings about one's body image and self-blame can be seen as examples of self-critique according to the self-critique theory of Gilbert et al. (2004). It is therefore likely that cancer patients experience self-criticism. However, little is known about how cancer patients experience self-critique.

1.3 (Self)-compassion

A way to cope with self-criticism could be compassion. Compassion can be divided into three different flows of compassion, namely: compassion towards others, compassion

from others and self-compassion (Gilbert, 2014). Compassion can be defined as "the desire to alleviate the suffering and its causes in one's self and those around us" (Negi, 2013, p 172 - 180). Gilbert (2009) defines compassion as the ability to be have sympathy, accepting negative emotions, the ability to have empathy and to care. According to Jinpa (2010) compassion consist of four components, namely: 1) being aware of suffering (cognitive component), 2) sympathetically concerned related to being emotionally moved by suffering (affective component), 3) wishing to see the relief of that suffering (intentional component), and 4) responsiveness or readiness to help relieve that suffering (motivational component). Gilbert (2014) states that compassion is related to motivation, emotions and the ability to be supportive, understanding and be helping to others.

This study will focus on the flow of self-compassion because little research is done on self-compassion among cancer patients. Besides that, this study focuses on the flow of self-compassion because it is likely that cancer patients experience a certain level of the antagonist of self-compassion, self-critique. Research has shown that the level of self-critique can be decreased when the level of self-compassion is increased by learning compassion skills to accept negative thoughts and feelings (Feldman & Kuyken, 2011). In addition, developing a kind attitude towards oneself and acceptance play an important role in reducing self-criticism (Neff, 2003a).

Neff and Dahm (2015) define self-compassion as the ability to detect the presence of failures and imperfections with the pain associated, and to perceive this as part of human existence. According to Neff and Germer (2013b) self-compassion consist of three components, namely: mindfulness, self-kindness and common humanity. The first one, mindfulness, refers to a strategy that can help reduce excessive worrying and rumination that leads to anxiety and depressive symptoms (Desrosiers, Vine, Klemanski & Nolen-Hoeksema, 2013). Second, self-kindness refers to a positive and warm attitude and less critical self-judgements regarding changes in physical appearance, psychosocial difficulties, or life limitations (Brion, Leary & Drabkin, 2013; Pinto-Gouveia, Duarte, Mato & Fráguas, 2014; Przezdziecki et al., 2013). The last one, common humanity which refers to a shared experience with others, can provide a sense of social connectedness that can counteract feelings of social isolation (Mattsson, Ringner, Ljungman & von Essen, 2007; Zebrack, 2011).

There is growing evidence that self-compassion is strongly associated with mental health (Neff, 2003a). Research from Neff (2003b) has shown that self-compassion negatively correlates with measures of anxiety, depression, rumination and self-criticism. Moreover, it

has a positive relationship with measures of happiness and optimism. This suggests that self-compassion can have a far-reaching impact on an individual (Neff, 2003a; Neff, Kirkpatrick, & Rude, 2007; Neff, Rude & Kirkpatrick, 2007). Leary, Tate, Adam and Allen (2007) even suggest that self-compassion may help individuals to evaluate themselves and their life experiences after a negative life-event and may act as a psychological buffer.

Self-compassion is particularly important for cancer patients because they are faced with a life-threatening disease, which implies great burdening and suffering (Pinto-Gouveia et al., 2014). Quantitative research of Pinto-Gouveia et al. (2014) shows that in cancer patients, self-compassion is related to decreased psychological symptoms, such as depression and distress, and increased quality of life. Besides, in their sample of cancer patients, self-compassion is significantly linked to psychological and social quality of life dimensions (Pinto-Gouveia et al., 2014). This is an important finding because impaired quality of life and psychological distress is highly prevalent in cancer patients (Honda & Goodwin, 2004; Nordin et al., 2001). Although some quantitative research has been conducted on self-compassion among cancer patients, little qualitative research is conducted on how cancer patients experience self-compassion.

1.4 Psychosocial interventions for cancer patients

To treat the disease cancer, many medical protocols are developed. However, no standard treatment is offered yet for the psychosocial problems that occur in cancer patients. Too few cancer patients receive evidence-based interventions for their psychosocial problems because the screening for these problems in cancer patients is inadequate (Leykin et al., 2012). Campo et al. (2017) report that there is a need for interventions that provide cancer patients with skills to effectively cope with the psychosocial challenges that are experienced in cancer patients.

During the past years, various psychosocial interventions have been designed, based on rehabilitation programs such as the fee-for-service cancer rehabilitation (Kirkham et al., 2016) and cognitive behavioral therapy programs such as Cognitive Behavior Therapy for Insomnia (CBT-I) (Johnson et al., 2016). Moreover, interventions based on (self)-compassion have been designed and tested among cancer patients. According to Neff (Neff & Costigan, 2014), self-compassion can be learned through interventions. First, these interventions consist of comprehensive interventions such as the interventions of Campo et al. (2017) and Lathren, Bluth, Campo, Tan and Futch (2018) Their interventions were adapted from two other interventions. First, it consists of the Mindful Self-Compassion (MSC) developed by Neff and

Germer (2013). This program appears to be effective at enhancing self-compassion, mindfulness, and wellbeing (Neff & Germer, 2012). Second, it consists of the Making Friends with Yourself program developed by Bluth, Gaylord, Campo, Mullarkey and Hobbs (2016). This program appears to be promising at increasing psychosocial wellbeing through increasing mindfulness and self-compassion (Bluth et al., 2016). The interventions of Campo et al. (2017) and Lathren et al. (2018) were developed for young adults who survived cancer (Campo et al., 2017; Lathren, 2018). The intervention consists of eight weekly sessions of 90 minutes with didactic instruction, experiential activities, introduction of different meditations and daily tools, and group discussions (Campo et al., 2017; Lathren, 2018). Moreover, Dodds et al. (2015a; 2015b) and Gonzalez-Hernandez (2018) did research on the Cognitvely-Based Compassion Training for women who survived breast cancer. This intervention consists of eight weekly sessions of 120 minutes with didactic instructions, class discussion, and guided meditation practice (Dodds et al., 2015a; 2015b; Gonzalez-Hernandez, 2018). Cognitively-Based Compassion Training in breast cancer patients is a promising and potentially useful intervention to diminish stress. It can enhance self-kindness, common humanity, overall-self-compassion, mindful observation, and acting with awareness skillsets (Gonzalez-Hernandez, 2018). Lastly, Haj Sadeghi, Yazdi-Ravandi and Pirnia (2018) did research on the Compassion-Focused Therapy for women with breast cancer. The intervention contains eight weekly sessions of 90 minutes and the content is based on Gilbert's compassion protocol (Haj Sadeghi et al., 2018). Compassion-Focused Therapy is associated with significant reduction in depression and anxiety in women with breast cancer.

Besides comprehensive interventions, there are also some brief interventions described in the literature. First, there is the Self-Compassionate-Based Writing Intervention used in the studies of Przezdziecki et al. (2016) and Sherman et al. (2018) for women who survived breast cancer. This brief intervention consists of one single session where respondents conduct a writing exercise, guided by self-compassionate prompts, about a distressing event related to their body after breast cancer (Przezdziecki et al., 2016; Sherman et al., 2018). There is preliminary evidence that self-compassionate-focused writing can assist women in managing breast-cancer related body image changes (Przezdziecki et al., 2016). Moreover, Wren et al. (2019) used Lovingkindness meditation in their study for women with breast cancer undergoing surgery. This brief intervention consists of one single session where respondents listen to an MP3 playing the guided meditation during a biopsy procedure, using headphones/earbuds. The meditation focuses on positive emotions towards oneself and others and releasing negative emotions and included silent repetition of phrases. After the biopsy, the

respondents were given a CD of Lovingkindness meditation exercises to practice daily at home for 20 minutes (Wren et al., 2019). There is preliminary evidence that lovingkindness meditation can improve the psychological and physical well-being of breast cancer patients during treatment and survivorship (Wren et al., 2019). These results are promising in the perspective of using psychosocial interventions in the treatment for cancer patients.

However, the uptake in these interventions is generally low as showed in the study of Brebach, Sharpe, Costa, Rhodes and Butow (2016). They found that almost half of the cancer patients do not accept the offer of a psychosocial intervention. But if they do accept a psychosocial intervention, the adherence is high (94%). One factor that is associated with a higher uptake is that a psychosocial intervention should be offered close to the diagnosis. Moreover, telephone interventions are also associated with a higher uptake for various reasons such as that they require less time and travel commitment than face-to-face interventions. (Brebach et al., 2016). Besides, most of these interventions are not tailored to the needs and wishes of cancer patients. Tailoring is a way of personalizing content and transferring information. This behavioral change technique considers for whom the information is intended. The information is adjusted to the cognitive possibilities of the person and the impact of the message is increased through adapted behavioral determinants (Hawkins, Kreuter, Resnicow, Fishbein & Dijkstra, 2008). This ensures that the content is more relevant and adjusted to the needs and wishes of the user (Spittaels, 2007). Moreover, the content is more useful, the information will be read better, it will be better remembered and will be seen as personally relevant in comparison with general information (Napolitano & Marcus, 2002, Spittaels, 2007; Lustria, Cortese, Noar & Glueckauf, 2009; Smeets, Brug & de Vries, 2008).

Considering all the above, it can be said that it is important to design a tailored low-threshold (self)compassion intervention for recently diagnosed cancer patients which can help them to cope effectively with their psychosocial problems. In order to do so, it is important to first clarify in which ways cancer patients are self-critical and/or self-compassionate. This qualitative study will therefore focus on self-critique and/or self-compassion among cancer patients because current research is lacking on this.

1.5 This research

Cancer patients experience problems on a physical, social, and psychological level and self-compassion can help to decrease these problems. However, little is known about in which ways cancer patients are self-critical and/or self-compassionate in the period after they are diagnosed with cancer. It is important to learn more about this because current research is

lacking on how cancer patients experience self-critique and self-compassion. It is relevant to find out how cancer patients experience self-critique and self-compassion so that right kind of help can be provided, tailored to the needs and wishes of cancer patients.

Therefore, this study will explore the ways in which cancer patients are self-critical and/or self-compassionate. In order to do this, a qualitative interview study design is chosen because the experiences of the patients are most important in acquiring new insights. By learning more about self-critique and self-compassion among cancer patients, we can better understand their motives as well as adjust existing interventions or create new interventions to fit the needs and wishes of the cancer patients.

The aim of this study is to gain insight in which ways cancer patients are self-critical and/or self-compassionate after they are diagnosed with cancer.

Based on the findings above, the following main question was formulated:

In which ways are cancer patients self-critical and/or self-compassionate after they are diagnosed with cancer?

2. Design and method of analysis

A qualitative interview study design was chosen to gain insight in which ways cancer patients are self-critical and/or self-compassionate after they are diagnosed with cancer. Semi-structured interviews were conducted to gain insight 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

The respondents were selected with the use of the convenience sampling method (Dörnyei, 2007). The inclusion criteria for this study were: (1) cancer patients or cancer survivors with a diagnosis of cancer no longer than ten years ago; (2) willing to do the (self)compassion exercises two weeks before the interview; (3) willing to participate in the interview; (4) knowledge of the Dutch language, both oral and written. People under 18 years were excluded from the study.

For this study, respondents were recruited in three ways from December 2018 until September 2019. First, potential respondents were recruited via oncologists and oncology nurses of the Medical Spectrum Twente (MST) and University Medical Centre Groningen

(UMCG). Second, potential respondents were recruited from the researcher's own network and by placing posts on Facebook and LinkedIn about the study. Lastly, potential respondents were recruited through the snowball sampling method. The respondents who participated in the study were asked at the end of the interview to assist in identifying other potential respondents from their network to recruit more potential respondents for the study (Etikan, Alkassim & Abubakar, 2015). The potential respondents were directed to the website of the study: https://www.utwente.nl/nl/bms/zelfcompassiebijkanker/. Here, they could find information on the study, the conditions to participate in the study and the registration process.

After the recruitment period, 27 respondents had registered for an interview. The actual uptake of this research was 17 respondents. Reasons for the drop out of respondents were: (1) no response to telephone calls or e-mails (*N*=6), (2) the disease process of the cancer was too much at that moment (*N*=3), (3) other priorities (*N*=1).

2.2. Procedure

After the respondent registered for the study via the website or indicated their interest in the study towards the researcher, the researcher contacted the respondent by telephone to give more information about the study, answer possible questions and make an appointment for an interview. In case that the respondent could not be reached by telephone, an e-mail was sent to follow-up. The appointment for the interview was always planned two weeks or more after the contact, so that the respondent had the time to do the (self)compassion exercises that were necessary for the interview. After the telephone call or e-mail contact, the researcher confirmed the interview via e-mail and sent the respondent the information letter (see appendix 6.1) and the (self)compassion exercises (see appendix 6.3). A few days before the interview, the researcher sent the respondent a reminder for the interview via e-mail.

The guideline was that the interview would last approximately one hour. The interviews took place in three different ways: (1) at the University of Twente in a reserved room in the library, (2) at home with the respondent, (3) by telephone. The informed consent (see appendix 6.2) was filled in at the beginning of the interview by the respondent and the researcher. In case of an interview by telephone, the respondent was asked to fill in the informed consent in advance of the interview and sent it by e-mail to the researcher. In this form, the respondent was informed on the fact that the data and results of the study are processed anonymously. It was also mentioned that audio material will be used and that the data resulting from this, is exclusively used for analysis and/or scientific presentations. The

respondent was also informed on the right to quit participation at any moment without giving a reason.

2.3 Materials

In this qualitative study, seventeen semi-structured interviews were conducted. A semi-structured interview is an interview with a relatively detailed interview guide (see appendix 6.4) with room for improvised follow-up questions, that focuses on the subjective experiences of the respondents on the study phenomenon (Merton & Kendall, 1946; Morse & Field, 1995; Richards & Morse, 2007). Semi-structured interviews are suitable when there is sufficient objective information on the study phenomenon, but lacks subjective information (Merton & Kendall, 1946; Morse & Field, 1995; Richards & Morse, 2007).

2.3.1 The exercises

The basis of the interview guide is based on eight (self)compassion exercises. The exercises were derived from the following books: 'The Mindful Self-Compassion Workbook' from K. Neff and C. Germer (Neff & Germer, 2018), 'Dit is jouw leven' from E. Bohlmeijer and M. Hulsbergen (Bohlmeijer & Hulsbergen, 2013) 'The Compassionate Mind Workbook' from C. Irons and E. Beaumont (Irons & Beaumont, 2017) and 'Compassie als sleutel tot geluk' from M. Hulsbergens and E. Bohlmeijer (Hulsbergen & Bohlmeijer, 2015). Moreover, audio exercises were derived from the website www.bcfmind.nl, a website were mindfulness and compassion exercises/training are offered. The exercises can be divided in two types of exercises: reflective exercises and meditative exercises (See table 1). A more detailed description of the exercises can be found in appendix 6.3.

Table 1. Description of the reflective and meditative exercise used in this study

Exercise	**Type of exercise**	**Content of exercise**
Exercise 1: experiencing self-compassion	Reflective exercise	Gives insight in the difference of self-compassion and compassion towards others
Exercise 2: three emotion system	Reflective exercise	Gives insight in the three emotion systems within themselves
Exercise 3: self-compassion mantra	Meditative exercise	Meditation in the form of a self-compassion mantra
Exercise 4: the flows of compassion	Reflective exercise	Gives insight in the flows of compassion of themselves
Exercise 5: kindness exercise	Meditation exercise	Meditation in the form of a kindness exercise
Exercise 6: compassionate companion	Meditation exercise	Meditation by imagining a compassionate companion
Exercise 7/8: starting and ending the day	Reflective exercise	Starting the day and reflecting on it at the end of the day

2.3.2 The interview scheme

Based on the self-compassion theory of Neff (2003b) and de compassion theory of Gilbert (2014), an interview scheme was prepared. This was done in collaboration with two supervisors and a fellow student. After conducting a few pilot interviews, the interview scheme and the way of interviewing by the researcher were evaluated with help from two supervisors and a fellow master student. The interview scheme was slightly adapted based on the outcomes of this evaluation because it was necessary that more in depth questions were asked. The final interview scheme contained four components. Table 2 shows an overview of the interview scheme. The complete interview scheme can be found in appendix 6.4.

Table 2. Overview interview scheme

Components	**Content**
1. Introduction	- introduction of the researcher, experiences of the respondent with diagnosis
2. General evaluation of the exercises and concept of self-compassion	- general use of the exercises, appreciation, effect, intention, concept self-compassion
3. Evaluating the exercises one by one	- use of each exercise, appreciation, effect, concept self-critique, emotion regulation, flows of compassion
4. Background and closing the interview	- gender, age, marital status, employment, education - receiving results of study, interest in workshops, snowball sampling

During the interviews, the researcher responded to the answers of the respondents and encouraged them to elaborate on their opinions, thoughts and experiences. The first component was about the introduction of the researcher and the experiences of the respondent with the diagnosis and served as an introduction. The respondents were invited to give information about their experiences with their diagnosis, the course of disease and their current well-being. Example questions were: *"What kind of diagnosis do you have? Can you tell me something about that?" "What kind of treatment did you have and how did it go?" "How are you now?"*

The second component of the interview was about the general experiences the respondents had with the exercises. Example questions were: *"Did you do the exercises?" "What did you think of the exercises in general?" "What do you think of the concept self-compassion?"*

The third component of the interview was about the evaluation of each exercise. The respondents were asked questions about their experiences with each exercise separately. Example questions that were the same for each exercise: *"What did you think of this exercise?" "Did you learn something from this exercise?"* Example questions that were specific to the exercises: *"Do you recognize that you are more critical towards yourself than to others?" "Do you recognize the three emotion systems?" "How do the three flows of compassion look like in your situation?"*

The fourth component was about the background of the respondents and closing the interview. The respondents were asked about their social demographics (such as gender, age, employment and education). Also, the respondents were asked if they wanted to receive the results after the study is completed and if they are interested in participating in a workshop about the development of a tool for recently diagnosed cancer patients. Lastly, respondents were asked if they know someone who would be interested to take part in an interview.

2.4 Data-analysis

The recordings of the interviews were converted to transcripts with help of the program Express Scribe Transcription Software, which can play the recording in a delayed manner, facilitating transcribing. The interviews were transcribed verbatim. The data was analyzed with deductive and inductive analysis. First, relevant text fragments were selected and categorized according to one of the themes that were determined prior to analysis, namely self-critique, self-compassion and exercises. After that, equal text fragments were categorized together and were then coded inductively into sub-themes, using Microsoft Excel (2019

3. Results

In this section, the results of the interviews will be discussed. The first paragraph shows a description of the respondents. Then the ways of being self-critical among cancer patients will be discussed. After that, it will be discussed in which ways cancer patients are self-compassionate. Lastly, the opinions of the respondents about the various exercises regarding experiencing self-compassion will be discussed.

3.1 Description of the respondents

The characteristics of the 17 respondents are listed in table 3. Among the respondents there were six men (35.3%) and eleven women (64.7%). The average age of the respondents is 47.5 years. The most common diagnosis among the respondents is breast cancer (*N*=7).

Table 3. Characteristics of the respondents (*N*=17)

Respondent	Gender	Age	Cancer
R1	Female	56	Breast cancer
R2	Male	60	Prostate cancer
R3	Female	49	Breast cancer
R4	Male	22	Angiosarcoma in right atrium
R5	Female	54	Breast cancer
R6	Male	49	Plasmablastary lymphoma (rare variant of non-Hodgkin)
R7	Male	68	Bone marrow cancer
R8	Male	23	Testicle cancer
R9	Male	49	Leukemia
R10	Female	23	Lymphoma
R11	Female	55	Breast cancer
R12	Female	32	Leukemia
R13	Female	53	Breast cancer
R14	Female	78	Bowel cancer
R15	Female	30	Breast cancer
R16	Female	53	Breast cancer
R17	Female	55	Bowel cancer

3.2 In which ways are cancer patients self-critical?

Many respondents indicated that they were self-critical at the time of the diagnosis and afterwards. Table 4 provides an overview of six categories concerning in which way the respondents are self-critical, namely: ‘having to stay strong’, ‘having critical thoughts/feelings

about themselves', 'being angry with themselves', 'feeling guilty', 'not looking for connection/support from others', and 'setting high demands'.

Table 4. Ways of being self-critical among cancer patients ($N = 17$)

Code	Total n	Sub code	Subtheme total n	Example quote
Having to stay strong	11	Having to keep carrying on	7	**R4**: Come on, now it's over, carry on. You will get back on your feet.
		Not complaining	6	**R4**: Very quickly I think something like, do not overreact.
		Having to keep taking care of themselves	2	**R1**: Then I think, yes, if you can move, then you have to do it as well.
Having critical thoughts/feelings about themselves	7	Having critical thoughts about their appearance	4	**R4**: I mean when your wake up and you look in the mirror, then you think something like: "Oh yeah, I am on chemo."
		Ignoring/ dismissing own thoughts/feelings	2	**R2**: I am now going to invalidate myself.
		Having a loss of confidence in body	1	**R6**: I fell down a few times because of my numb feet. I put my foot down the wrong way and suddenly I lay down the stairs. So that confidence in your body, that is just lost.
Being angry with themselves	5	Being angry with themselves	5	**R9**: You get angry with yourself because you do not succeed in things.
Feeling guilty	5	Feeling guilty for letting down colleagues/friends	4	**R10**: If someone celebrated their birthday or something, I was invited, and I really wanted to go there. Be a little fun or something. But I did not do that, and I thought that was very stupid or something.
		Feeling guilty to partner	1	**R10**: If I just had something, if I had a fight or something with my boyfriend, then I would feel bad, yes.
		Feeling guilty about lifestyle	1	**R8**: Then you start looking at yourself differently about the thing you have done, if only I had not drunk or smoked.
Not looking for connection/ support from others	4	Must do it themselves	2	**R3**: You have to go though it yourself, nobody else can do that for you.

Table 4. Continued

Code	Total n	Sub code	Subtheme total n	Example quote
		Not contacting health care professional in time	2	**R2**: At that time, I thought, damn, why have I not been to a doctor with these complaints earlier, because I actually had them for quite some time.
		Not wanting to bother others	2	**R2**: But more, you are not going to bother others with that, I really noticed.
Setting high demands	2	Having the urge to proof themselves	2	**R12**: I want things, and I want to perform, and I have to do things and take care of things. On the other hand, because you do not do that well enough. Or you have too much on your plate.

Note. Total n refers to number of respondents who made a statement in this category and subtheme total n refers to number of respondents who made a statement per subtheme in the category.

The first category, ‘having to stay strong’, was mentioned by more than half of the respondents. It mainly consists of ‘having to keep carrying on’ by keeping routine, and doing the things you always do, which is illustrated by the following quote: *“Just do the usual things, hold the routines”* (R3). Moreover, ‘not complaining’ is also seen as a component of ‘having to stay strong’. It is a form of carrying on as appears from the following quote: *“Well come on now, do not complain”* (R9). Lastly, one respondent also mentioned ‘having to keep taking care of themselves’ under this category, for example by having to exercise when you are able to.

Second, the category ‘Being angry with themselves’, consists of ‘being angry at themselves’. Respondents are angry with themselves because they do not succeed in the things they do and they are also angry with themselves although there is no known clear reason for it, illustrated by the following quote: ”*The first couple of days I was angry with myself”* (R8).

The third category, ‘having critical thoughts/feelings’, is primarily focused on the body. The respondents mention that they are ‘having critical thoughts about their appearance’: *“Especially when I am at work, there are many mirrors and I felt like myself but sometimes I walked past such a mirror and I thought: “oh dear”, that made me insecure*” (R11). Also, ‘having a loss of confidence in body’ was mentioned because the body no longer works the same as before the diagnosis. Lastly, a few respondents mentioned that they are ‘ignoring/dismissing their own thoughts/feelings’ by invalidating themselves.

Within the fourth category 'feeling guilty', a distinction can be made between guilt towards others and guilt about personal choices. First, respondents mention that they are 'feeling guilty for letting down colleagues/friends', as the following quote illustrates: *"I have my own company, together with a colleague, and that colleague must now keep things going. I sometimes feel a bit guilty about that"* (R13). Second, one respondent also indicated that she was 'feeling guilty to partner' because of fighting with her partner. Lastly, besides feelings of guilt towards others, a respondent reported guilt about personal choices, namely: 'feeling guilty about lifestyle' and wished that he had not been drinking and smoking.

Fifth, 'not looking for connection/support from others', consists of 'not contacting a healthcare professional in time', as the following quote illustrates: *"You can call day and night and do not let anything obstruct it. And yet, you do not dare, yet you wait too long"* (R7). But it also entails 'not wanting to bother others' and the conviction that you 'must do it yourself' because no one else can go through this course of disease for you.

Lastly, under the category 'setting high demands', one respondent mentioned 'having the urge to proof themselves' by continuing to perform despite the illness.

In conclusion, it can be said that cancer patients are self-critical in various ways. More than half of the respondents mentioned that they have to stay strong. Moreover, respondents often mentioned that they have critical thoughts and feelings about themselves. Furthermore, being angry with themselves, feeling guilty, not looking for connection and support from others and setting high demands are ways that were reported to a lesser extent by the respondents as ways of being self-critical.

3.3 In which ways are cancer patients self-compassionate?

The majority of the respondents indicated that they have become more self-compassionate after they were diagnosed with cancer. Table 5 provides an overview of the different ways in which the respondents are self-compassionate. A distinction could be made between eight categories: 'self-care', 'having positive thoughts/feelings', 'looking for connection/support from others', 'allowing negative emotions/feelings', 'setting boundaries', 'accepting disease and limitations', 'doing activities to clear their head', and 'self-acceptance'.

Table 5. Ways of being self-compassionate among cancer patients ($N = 16$)

Code	Total n	Sub code	Subtheme total n	Example quote
Self-care	15	Taking rest/time for themselves	15	**R3**: Or just take the time for yourself in anyway.
		Taking care of themselves	7	**R13**: That I just take good care of myself at that moment.
		Listening to body	6	**R3**: That I did take the time to listen to my body.
Having positive thoughts/feelings	13	Being kind to themselves	12	**R12**: Being kind to yourself and thinking: "you are doing well this way".
		Being mild for themselves	8	**R1**: For me, self-compassion is a well-developed ability to be mild to yourself.
		Having a positive mindset	4	**R8**: You just have to stay positive, also to yourself.
Looking for connection/support from others	10	Having social contact with others	6	**R2**: Talking about is, is the most important thing.
		Accepting support from others	5	**R3**: Because then you really need others, you cannot do it yourself. If you are just healthy and you do your thing, then you do not think about it. If you really get sick, then you need other people. Then you have to open up.
		Feeling connected with fellow sufferers	3	**R1**: And what I really noticed after the diagnosis is that I find it very easy to feel connected to people who have been diagnosed and, for example, are also going to die or something.
Allowing negative emotions/feelings	7	Allowing to feel sorrow	5	**R6**: It is good that it is there, it is okay that there is sorrow. That you allow that.
		Allowing feeling bad	3	**R9**: Now I have a lot more sense of okay, I can just feel a bit worse.
		Allowing pain	3	**R4**: So indeed, if you are not feeling well, that you can accept that you are in pain.
		Allowing anger	1	**R5**: Sometimes I show that I am angry and that is mainly when I am at home and with a very good friend.
		Allowing feeling tired	1	**R9**: I may also feel very tired at some point.

Table 5. Continued

Code	Total n	Sub code	Subtheme total n	Example quote
Accepting disease and limitations	7	Accepting situation of disease	7	**R3**: I think letting it happen is also very important.
		Surrendering to circumstances of disease	2	**R6**: The disease is just there. You have to accept it and that is a process.
Setting boundaries	7	Knowing and setting boundaries	6	**R13**: But I do notice that if I am really tired, then I can state very clearly that I have to choose for myself now.
		Dividing energy/time	4	**R5**: I have to divide it in portions to keep it manageable.
Doing activities to clear their head	6	Walking	3	**R3**: Or I will go for a walk.
		Doing fun things	2	**R5**: Or do something fun to shift your thoughts a little bit.
		Listening to music	3	**R7**: The past couple of years, I need more music around me. Distraction.
		Writing	2	**R5**: If you are upset about something, write it down and write it out.
		Reading	1	**R5**: I will sit on the couch with […] and a book.
Self-acceptance	5	Being satisfied with themselves	5	**R11**: I am also very satisfied with myself.

Note. Total n refers to number of respondents who made a statement in this category and subtheme total n refers to number of respondents who made a statement per subtheme in the category.

The first category, ´self-care', was mentioned by almost all respondents as a component of self-compassion. According to them 'taking rest/time for themselves' consist of various things such as staying at home, as the following quote illustrates: *"Last week I allowed myself to stay home and be sick, and not to try to do things or work"* (R12). Also, it entails lying in bed/sleeping, sitting on the couch and doing breathing exercises. Moreover, doing mindfulness is also seen a 'taking rest/time for themselves', as one of the respondents stated: *"But what I try to do in difficult situations, especially if I have the idea that those emotions are just waves that are too high, is to look at things from a meta-position"* (R1). Besides 'taking rest/time for themselves', respondents also indicate that it is important to 'take care of themselves' by thinking of themselves as the following quote illustrates: *"So that with any situation, whether it is physical or mental, you think of yourself a little more"* (R4). Furthermore, it entails taking care of themselves in terms of physical health, as the

following quote illustrates: *"Just cook, just eat with the kids even though it is not that tasty. Just drink if you have to drink, suppose it is very disgusting. At a certain point when you have had a lot of chemo's, things like that"* (R3). The last component under the category 'self-care', is 'listening to body' when you are for example in pain or feel tired.

The second category, 'having positive thoughts/feelings' is subdivided in three components. First, 'being kind for themselves' was mentioned by the majority of the respondents and entails loving themselves, having faith in themselves, and encouraging themselves. In addition, 'being mild to themselves' consist of, among others, not judging yourself, as the following quote illustrates: *"Allow yourself to be human and to make mistakes. Do something wrong and be okay with it"* (R12). Also, understanding for themselves, demanding less of themselves, and not being too strict for themselves were mentioned under 'being mild to themselves'. Lastly, 'having a positive mindset' was mentioned by a few respondents. They mention that thinking and feeling positive helps getting them through the day, as the following quote illustrates: *"Getting through the day with a positive thought is also important"* (R3) and *"A positive feeling to have in a day, with a certain rest"* (R3)

Within the third category 'looking for connection/support from others' a distinction can be made between three factors. First, 'having social contact with others' was mentioned by the respondents. This includes talking with others about their disease and visit people in their social environment, as the following quote illustrates: *"But there were always people around, or I would reach out myself. I sometimes do that, call people or I go make visits, as far as my bike allows. I visit people"* (R6). Moreover, 'accepting support from others' is a factor under this category. Respondents described that it is important to know as a cancer patient that you will need help and have to accept help from others to get through this period as one of the respondents said: *"Because then you really need others, you cannot do it yourself. If you are just healthy and you do your thing, then you do not think about it. If you really get sick, then you need other people, then you have to open up"* (R3). Lastly, a few respondents mentioned that 'feeling connected with fellow sufferers' is helpful. This connection stems from sharing thoughts and experiences with fellow sufferers that are not understood by others, which is illustrated by the following quote: *"I also talk about death and about what flowers they want on their coffin and I know a lot about that and that is a strange thing among fellow sufferers. We discuss things in the company canteen that people do not even share with their partner"* (R3).

The fourth category, 'allowing negative emotions/feelings', was mentioned by just over half of the respondents. They mention that it is important not to hide emotions but accept that they are there. 'Allowing to feel sorrow' is the most mentioned negative emotion to allow within this category. Some respondents said that they experience sorrow and emphasize that it is important to name and accept it: *"Okay, name the feelings, allowing, allow sorrow. That may just be there. That's just there"* (R6). Also, 'allowing feeling bad' was mentioned by the respondents and entails that it is okay to feel worse than other days and a day can still be good even when there are bad moments. Furthermore, 'allowing pain' is also part of this category. Respondents indicate that you must accept that it is not going well and that you are in pain. Finally, 'allowing anger' and 'allowing feeling tired' were mentioned by the respondents to a lesser extent.

The fifth category, 'setting boundaries' is about, among other things, 'dividing energy/time'. One of the respondents said: *"Yes you have to conserve your energy, you have to conserve a lot. What you do, when you do something"* (R9). Moreover, it consists of 'knowing and setting boundaries' such as saying no, standing up for yourself, and indicate what you need: *"For example, I think I am starting to stand up for myself. So, when I notice, it is enough now, I cannot handle this for now, I would say that"* (R13).

The sixth category is about 'accepting disease and limitations' and consists of two components. First, 'accepting situation of disease', was mentioned by some respondents and entails that you have to realize and accept that you have cancer. One of the respondents said: *"That you therefore accept that the disease is there. That you have that numbness in your feet, that it is there. That you have to accept that for yourself"* (R6). Besides that, it also consists of 'surrendering to circumstances of disease' which is more about going with the flow of the circumstances of the disease.

Seventh, the category 'doing activities to clear their head' is about 'doing fun things' to shift their thoughts. Activities that were reported are listening to music, walking, writing, and reading.

The last category 'self-acceptance' highlights another side of acceptance. A few respondents indicate 'being satisfied with themselves' because they are fine the way they are and one respondent said that she does not pretend to be different than she is: *"In the sense of what you see is what you get, instead of I want you to see what I want you to see, so to speak"* (R1).

In conclusion, it can be said that cancer patients are self-compassionate in various ways. Almost all the respondents mentioned to use self-care to be self-

compassionate. Moreover, having positive thoughts and looking for connection and support from others, are ways of being self-compassionate mentioned by more than half of the respondents. Other ways of being self-compassionate among cancer patients that are mentioned to a lesser extent are allowing negative emotions and feelings, acceptance of the disease and limitations, setting boundaries, doing activities to clear their head and self-acceptance.

3.4 Experiences of cancer patients with self-compassion exercises

3.4.1 Exercise 1: experiencing self-compassion

Exercise one is about experiencing self-compassion and consists of two components. The first component is about: *"How do I treat a friend?"* The respondent is asked to think of a moment were a friend, or family member had a difficult time. How would the respondent react to this person? The second component is about *"How do I treat myself"?* The respondent is asked to think of a moment were he or she had a difficult time. How would the respondent react to themselves? Thereafter, the respondent is asked to think about the differences in these two components. The respondents were asked to do this exercise once in the first week.

Table 6 Opinions of the respondents with exercise 1: experiencing self-compassion (*N*=17)

Code	Total n	Sub code	Subtheme total n
Positive opinion	12	Makes them aware of how self-critical they are	10
		Clear exercise	3
		A moment for themselves	1
Negative opinion	2	Hard to think of examples	1
		Unclear what to do with newly gained insight	1
Feedback	1	Need for follow-up exercise	1

Note. Total n refers to number of respondents who made a statement in this category and subtheme total n refers to number of respondents who made a statement per subtheme in the category.

Table 6 provides an overview of the opinions of the respondents with exercise one. The majority of the respondents had a 'positive opinion' on this exercise and described the exercise as 'good', 'interesting', and 'valuable'. There are three categories within the positive opinion on this exercise. The first and far most mentioned category is that this exercise 'makes them aware of how self-critical they are'. Respondents indicate that they are much more self-critical to themselves then to others, which is illustrated by the following quote: *"It makes you aware of that I am more kind to others then to myself. So, it does help to look at*

things in a different way" (R12). Some even took this insight with them as a kind of tool that helped them in difficult times: *"And it helps me if I have a hard time, thinking hey… how would I react to [name of friend], that sick friend of mine. That is what is going through my head now and then. What would I say to her? And if you try to imagine that, then you are also friendlier to yourself"* (R5). Second, a few respondents said that the exercise was clearly explained, as the following quote illustrates: *"No, it was just explained very clearly"* (R6). Lastly, one respondent appreciated it that the exercise gave him/her 'a moment for themselves': *"This is just a moment for yourself"* (R3).

Only a few respondents had a 'negative opinion' on the exercise. They indicated that the exercise had little or no value to them. One of them said that it was 'hard to think of examples', which becomes clear in the following quote: *"So you are not so aware of what exactly you are doing when you speak to someone in a kind way. I found that a bit difficult to imagine"* (P13). Besides that, a respondent found it 'unclear what to do with the newly gained insight', illustrated by the following quote: *"I do not know now whether I have I should change what I have seen of myself. That is more a kind of observation of 'oh yes', I notice that I apply this to myself, that I apply this also to others. But I do not necessarily know if I should do something with that or not"* (R4).

One respondent gave the 'feedback' that there is a 'need for follow-up exercise': *"A sort of follow up-up would be useful. To evaluate, how would you do that, what can you do with this conclusion. I have now made a conclusion; okay this is it. But now? I think that's a bit where I ended up"* (R4).

3.4.2 Exercise 2: three emotion systems

Exercise two is about the three emotion systems: the threat system, the soothing system, and the drive system. In this exercise the respondent had to think about their emotions in the past few weeks. How many times were they anxious or worried (the treat protection system)? How many times were they relaxed and calm (the soothing system)? How many times were they energetic and happy or did you feel lust or desire for more (the drive system)? The respondents had to draw three circles, one for each emotion system. The biggest circle should resemble the emotion system the respondent experiences most and the smallest circle should resemble the emotion system that the respondent experiences least. The respondents were asked to do this exercise once in the first week.

Table 7. Experiences of respondents with exercise 2: three emotion systems (*N*=17)

Code	Total n	Sub code	Subtheme total n
Positive opinion	10	Insight in emotions/feelings	9
		Clear and easy exercise	3
		Helps to relax	1
		Knowledge about interaction between emotion systems	1
Negative opinion	3	Hard to imagine	2
		Digital aspect	1
Feedback	2	Need for follow-up exercise	1
		Use more common words	1

Note. Total n refers to number of respondents who made a statement in this category and subtheme total n refers to number of respondents who made a statement per subtheme in the category.

Table 7 provides an overview of the opinions of the respondents with exercise two. More than half of the respondents had a 'positive opinion' on this exercise and described the exercise as 'good', 'interesting', and 'valuable'. Within the positive opinion on this exercise, a distinction can be made between four categories. The first and mentioned most category is that this exercise gives 'insight in emotions/feelings'. More insight is gain in the difference in emotions and feelings before and after the diagnosis, which becomes clear from the following quote: *"Maybe mainly because there is a big difference between the diagnosis and afterwards. You actually know this, but if you have to draw it out, it becomes visual, so it has much more impact"* (R1). In addition, one respondent said: *"Being able to trace where feelings sometimes come from or were reactions sometimes come from. This helps with that"* (R3). Second, this exercise was experiences as a 'clear and easy exercise' by a few respondents. One of the respondents said: *"The advantage is that the figure explains very clearly how you can look at things from those three emotion systems"* (R2). Moreover, one respondent indicated that he appreciated it that the exercise 'helps to relax', which becomes clear in the following quote: "*I notice more peace and relaxation*" (R6). Lastly, one respondent mentioned that he had more ´Knowledge about interaction between emotion systems´, which is illustrated by the following quote: *´That you also see where you stand. That you know that. That also influences your feelings and how you respond to people perhaps"* (R5).

Only a few respondents had a 'negative opinion' on the exercise. They indicated that the exercise had little or no value to them. One of them said it was ´hard to imagine´ in which emotion system you are, as said in the following quote *"And I also found it a bit difficult to really check that with myself, when will I be in this system or that system" (R10).* But it was

also ‘hard to imagine’ because the respondent was diagnosed with cancer a long time ago: *“The last question was whether you had drawn them differently before you were diagnosed, but because it was a long time ago anyway and I was really so different, so much younger or something. I thought it was very difficult to imagine”* (R10). Second, one of the respondents mentioned that she found the ‘digital aspect’ of this exercise worthless. With the digital aspect is meant that something had to be drawn but this was not possible because the respondents received the exercises online via e-mail, which is illustrated in the following quote: *“Well, what I think is worthless, that is very personal though… You must draw it, but the exercise is on the screen. So, I did not do that”* (R13).

Two points of ‘feedback’ were mentioned regarding this exercise. First, a respondent indicated that there is a ‘need for follow-up exercise’, which is illustrated by the following quote: *“I would like to give that back to you as researchers. How do you get that properly balanced? You can get that balanced indeed by doing those exercises? Or by going that follow-up exercise”* (R6)? Second, a respondent said that we should ‘use more common words’ in the exercise to make it more understandable and realistic: *“I would explain it a bit more easily because, as I just said, you have cancer from IQ 140 to IQ … You know what I mean? It must be clear to everyone which way you want to go”* (R9).

3.4.3 Exercise 3: self-compassion mantra

Exercise three, a self-compassion mantra, is an audio exercise. In this exercise the respondent thinks of a difficult time and practices with self-compassion. The respondents were asked to do this exercise every other day in the first week.

Table 8. Experiences of respondents with exercise 3: self-compassion mantra (*N*=17)

Code	Total n	Sub code	Subtheme total n
Negative opinion	10	Exercise is not appealing	6
		Unpleasant voice/way of talking	4
		Subjects in exercise are not recognizable	2
		Not able to choose their own level	2
Positive opinion	4	Helps to relax/slow down	3
		Clear exercise	2
Feedback	1	Need for component where you state your feelings	1

Note. Total n refers to number of respondents who made a statement in this category and subtheme total n refers to number of respondents who made a statement per subtheme in the category.

Table 8 provides an overview of the opinions of the respondents with exercise three. More than half of the respondents had a 'negative opinion' on the exercise. First, they indicated that the exercise had little to no value to them and has a strict connotation. According to them, the 'exercise is not appealing': *"I do not want to say that is has the opposite effect, but it does not come through"* (R4). In addition, another respondent said: *"Yes, it did not catch me"* (R2). Second, some respondents indicated that the woman had a 'unpleasant voice/way of talking' in the exercise. This becomes clear in the following quote*:* *"But the voice actually made me a bit tired"* (R2). Another respondent said: *"I thought the way the lady spoke was too vague for me"* (R3). Third, 'subjects in exercise are not recognizable' was mentioned by some respondents and becomes clear in the following quote: *"I found it all too difficult to think for myself at which moment I could do that. Because in general, I do not have such moments that I am completely lost or something"* (R10). Lastly, a few respondents also mentioned that they were 'not able to choose their own level' in the exercise. One respondent said that this exercise was more for beginners in mindfulness and the other respondent said that the exercise was more for experienced mindfulness practitioners.

Only a few respondents had a 'positive opinion' on the exercise. They described the exercise as 'good', 'interesting', 'valuable', 'relaxing' and 'easy to do'. The exercise 'helps to relax/slow down', as one of the respondents indicates: *"But you will calm down, as soon as you allow that thought"* (R6). A few respondents also thought that it was a 'clear exercise': *"No, it was just very clear. That explanation is just right"* (R6).

One point of 'feedback' was given, namely the 'need for component where you state your feelings' within the exercise or in another exercise. A respondent indicated: *"What I miss a little in this whole is, that it is also good to state your sorrow or pain very well. Otherwise it stays so vague"* (R5).

3.4.4 Exercise 5: kindness exercise

Exercise five, a kindness exercise, is an audio exercise. In this exercise the respondent practices with kindness towards themselves and kindness to a person which they are grateful for. The respondents were asked to do this exercise every other day in the first week.

Table 9. Experiences of respondents with exercise five: kindness exercise (*N*=17)

Code	Total n	Sub code	Subtheme total n
Negative opinion	11	Exercise is not appealing	5
		Long/boring exercise	3
		Unpleasant voice/way of talking	3
		Hard to imagine	2
		Bad sound	1
		Too many instructions	1
Positive opinion	7	Silences are appreciated	3
		Helps being self-kind	2
		Helps to relax/slow down	2
		Changes your mindset	1
		Component of repeating	1
Feedback	1	Less spiritual	1

Note. Total n refers to number of respondents who made a statement in this category and subtheme total n refers to number of respondents who made a statement per subtheme in the category.

Table 9 provides an overview of the opinions of the respondents with exercise five. More than half of the respondents had a ´negative opinion´ on this exercise and described the exercise as 'bad', 'difficult', 'not useful', 'irritating' and 'unnatural'. First, they indicate that the 'exercise is not appealing' as the following quote illustrates: *"I was not touched by it"* (R3). In addition, another respondent said: *"I was quickly done with it, this is not for me"* (R9). Second, a few respondents mentioned that this exercise was a 'long/boring exercise'. One of the said: *"But I thought it was taking too long"* (R2). In addition: *"I find it a bit boring, yes"* (R14). Third, it was mentioned that there was an 'unpleasant voice/way of talking'. Some did not appreciate the voice being female and another thought that the way of talking and the use of words was not right as the following quote illustrates: *"I was not touched by the words she spoke"* (R3). Fourth, one respondent thought it was 'hard to imagine' because he was already cured and did not feel pain or misery as the following quote illustrates: *"The hard part is, if you have not done so much with it, that you suddenly have to put yourself in such a position that you were not involved with yourself. So, I thought that was*

the most difficult part of it." (R4). Fifth, one respondent mentioned that the sound of the audio-file was bad: *"Yes, by the way, I have a remark that it sounds very soft on the site. I put the volume of my laptop on the loudest and then I had to grab my headphones because I could not hear it very well"* (R5). Lastly, one respondent indicated that there were too many instructions and new sentences introduced during the exercise.

Less than half of the respondents had a 'positive opinion' on this exercise and described the exercise as 'good', 'important', 'clear', 'interesting' and 'helpful'. First, the 'silences are appreciated' by the respondents as the following quote illustrates: *"Again, I enjoyed the silences. Because you are wearing headphones and for the rest it was almost completely silent"* (R3). Second, the exercise 'helps being self-kind': *"If you project it on someone else you can suddenly feel very well how that works, then that is a bit easier to get it back again… then it becomes a little easier to give love to yourself"* (R13). Third, one respondent mentioned that the exercise also 'helps to relax/slow down. This is illustrated by the following quote: *"Well the sentences really helped to get, what's that… relaxed. Sort of letting it come and give yourself a moment of calm and quiet. I'm not sure how to say it. Just stay calm. Something like that."* (R10). Fourth, according to one respondent it also 'changes your mindset'. This respondent said: *"Switching, for example, if you wake up with a bad mood. Switching, changing your mind"* (R6). Lastly, the 'component of repeating' was appreciated because it helps to remain practicing this exercise.

One point of 'feedback' was given regarding this exercise. One of the respondents said that the exercise should be 'less spiritual': "*I think you should use more realistic words, not street language, but not so spiritual"* (R9).

3.4.5 Exercise 6: compassionate companion

Exercise six is an audio exercise in which respondents imagine themselves a creature of compassion and love. The respondents were asked to do this exercise every other day in the first week.

Table 10. Experiences of respondents with exercise six: compassionate companion (*N*=17)

Code	Total n	Sub code	Subtheme total n
Positive opinion	7	Clear exercise	5
		Use of own imagination	2
Negative opinion	5	Exercise is not appealing	3
		Hard to imagine	3
		Unpleasant voice/way of talking	2
		Unclear exercise	2
Feedback	3	Less spiritual	1
		Use examples from practice	1

Note. Total n refers to number of respondents who made a statement in this category and subtheme total n refers to number of respondents who made a statement per subtheme in the category.

Table 10 provides an overview of the opinions of the respondents with exercise six. Less than half of the respondents had a 'positive opinion' on this exercise and described the exercise as 'good', 'creative', and 'helpful'. First, the respondents thought that it was a 'clear exercise': *"It is explained very clearly by that woman"* (R6). Second, some respondents indicated that the 'use of own imagination' is easy, interesting, and nice to do. One of the respondents said: *"Because you really had to imagine something. I think that is easier for me than to repeat a thought"* (R10). In addition: *"I thought it was interesting to imagine such a creature and I think I will do this more often"* (R10).

There were also some respondents with a 'negative opinion' on the exercise. First, they indicated that the 'exercise is not appealing' because it is too spiritual: *"Because it is just a bit too spiritual for me"* (R4). Also, the respondents indicated that they thought that the exercise was too long-winded and did not fit them. Second, some respondents thought that it was 'hard to imagine' in general but also to imagine just one compassionate companion: *"Yes, because it is not just one person, there are many people who touch you in a different way and who you need in a certain way. So, I could not just find one person that blinks out. So, I could not really imagine that."* (P3). In addition, one respondent said that she thought it was more difficult to have compassion when she imagined a person instead of something else as the following quote illustrates: *"Well what I noticed while I was doing this is that when I have to*

visualize such a companion, I have less connection with it. I imagine compassion as a kind of sun somewhere in my stomach or a flowing river." (R1). Third, a few respondents mentioned that the woman in the exercise had a 'unpleasant voice/way of talking'. The choice of a female voice, the way of talking and the tone in which the narrator spoke were not appreciated. Lastly, a few respondents thought that exercise five was a 'unclear exercise' because it was difficult to follow and because it was not clear whether the compassionate companion should be an existing person or someone imaginary as the following quote illustrates: *"It was unclear whether it had to be a fantasy figure or someone real. That was difficult."* (R3).

Two points of 'feedback' were given, namely the exercise should be 'less spiritual' and in the exercise 'use of examples from practice' should be incorporated.

3.4.6 Exercise 7/8: starting and ending the day

Exercise seven/eight is about starting and ending the day with awareness and care. To get a good idea of what self-compassion is and how it is experienced, it can help to reflect on self-compassion in your daily life every day. The first part of the exercise (exercise seven) can been done immediately when you wake up. The respondent is asked to consider the following: what good things do I wish for myself and others today? Let this intention go through your mind a few times before you get up. The second part of the exercise (exercise eight) is about reflecting on the end of the day on how the day went. Respondents can ask themselves questions about the day such as: What am I grateful for?; In what way was I kind for myself?; What have I done that makes me happy?; How have others contributed to my well-being?; How have I contributed to the well-being of others? The respondents were asked to do this exercise every day, at the beginning and end of the day in the second week.

Table 11. Experiences of respondents with exercise 7/8: starting and ending the day (*N*=17)

Code	Total n	Sub code	Subtheme total n
Positive opinion	9	Reflection on the day creates awareness	8
		Positive start of the day	3
		Small time investment	2
Negative opinion	2	Difficult to do at a specific moment	1
		Difficult to imagine	1

Note. Total n refers to number of respondents who made a statement in this category and subtheme total n refers to number of respondents who made a statement per subtheme in the category.

Table 11 provides an overview of the opinions of the respondents with exercise seven/eight. More than half of the respondents had a 'positive opinion' on this exercise and described the exercise as 'good', 'useful' 'clear' and 'interesting'. First, they indicated that 'reflection on the day creates awareness'. It creates awareness on the goals that were set in the morning as the following quote illustrates: *"You can set goals for yourself every day and at the end of the day you can see to what extent you have achieved those goals and whether it actually contributes to yourself"* (R8). It also creates awareness about what gives you energy or not: *"And in the evening a reflection: What did not go well? What did go well? What did I feel comfortable with? Where did I get energy from?"* (R9). Second, some respondents mentioned that this exercise was a 'positive start of the day' as the following quote illustrates: *"That is changes your mindset, especially at the start of the day. That you just say to yourself: if you do not like it, put something else positive against it"* (R6). Lastly, the exercise is a 'small time investment' according the respondents: *"If you do it every day, it actually takes no time at all"* (R9).

Only a few respondents had a 'negative opinion' on the exercise. One respondent thought that the exercise was 'difficult to do at a specific moment' as the following quote illustrates: *"I think it is difficult to be grateful specific in the morning or in the evening because I think about this during the day also"* (R11). Another respondent thought that is was 'difficult to imagine' because he was already cured from cancer: "*I am no longer concerned with the disease anymore because the treatment is done, and everything is fine now. So, imagining how I feel and what good I wish myself today was quite difficult."* (R4).

4. Discussion

This study aimed to explore in which ways cancer patients are self-critical and/or self-compassionate. Besides that, it aimed to study how reflective and meditative self-compassion exercises are experienced by cancer patients. The current study has shown that, in general, the respondents already experience self-compassion to a certain extent. Besides that, they also experience a significant degree of self-critique. Regarding the exercises that were done, it appeared that the reflective exercises were appreciated more than the meditative exercises.

4.1 Self-critique

Most of the respondents indicated that they are self-critical in one way or another, namely: 'having to stay strong', 'having critical thoughts/feelings about themselves', 'being

angry with themselves', 'feeling guilty', 'not looking for connection/support from others', and 'setting high demands'. Especially 'having to stay strong' was mentioned by almost all of the respondents. Foxwell and Scott (2011) explain in their research that staying strong is a strategy used by head and neck cancer patients to resist succumbing. By not allowing themselves to become downhearted, they keep fighting. In this case, staying strong sounds like something positive and a way not to fall into a downward spiral. However, in the current study having to stay strong has a strict connotation; the respondents have to keep carrying on of themselves, are not allowed to complain and have to keep taking care of themselves. For future research it could be interesting to explore the nuances and differences between staying strong from strictness (self-critique) and staying strong to take good care of your body (self-compassion). Clarification on this can help to define behaviors regarding staying strong that can help to strengthen the self-compassion of cancer patients.

Another important outcome of this study was that many respondents are 'having critical thoughts/feelings about themselves'. Some of the respondents mentioned that they are not satisfied with their physical appearance anymore. This is in line with several studies among cancer patients, were it was found that cancer patients have a disturbed body image (Snoj, Licina & Pregelj, 2008; Yazdi-Ravandi et al., 2013). This kind of self-critique is part of the hated self, described by Gilbert et al. (2004) as having feelings of disgust and self-hatred. The study of Przezdziecki et al. (2013) among breast cancer survivors suggests that self-compassion has a mediating role between a decreased body image and psychological distress and that there is a potential protective effect of higher level of self-compassion for patients with a decreased body image. Therefore, it is important to consider integrating self-compassion in a psychosocial intervention for cancer patients so that it can help to increase the body image and decrease the psychological distress that is experienced with this.

Another interesting result is that some of the respondents mention: not looking for connection/support from others'. In some cases, a health-care specialist was not contacted on time. Unsurprisingly, it is important that a health-care specialist is contacted on time because it can improve the outcomes on survival, earlier stage at diagnosis, improved quality of life and improved patient experience (Mendonca, Abel, Saunders, Wardle & Lyratzopoulos, 2016; Neal et al., 2015). Research of Hamilton (2009) has explored factors associated with the decision to seek help for a potential symptom of cancer (Hamilton, 2009). Factors that are associated with help-seeking for cancer symptoms are that lower cancer awareness and higher perceived barriers are associated with longer anticipated delay (Robb et al., 2009; Quaife et al., 2014). Also, women are more likely to consult than men and the characteristics of the

symptom itself have an influence on help-seeking (Elliott et al., 2011; 2012). For future research it can be interesting to explore how self-critique is linked to the blockades that arise with asking for help. Insight in this can give guidance in developing psychosocial interventions.

4.2 Self-compassion

Most of the respondents indicated that they are self-compassionate in one way or another, namely: 'self-care', 'having positive thoughts/feelings', 'looking for connection/support from others', 'allowing negative emotions/feelings', 'setting boundaries', 'accepting of disease and limitations', 'doing activities to clear their head' and 'self-acceptance'. Especially 'self-care' was mentioned by almost all of the respondents. For example, it was mentioned that the respondents take care of themselves in terms of physical health. This in line with research of Yin et al. (2018), where it is mentioned that self-care strategies of survivors in the process of restoration after low anterior resection of rectal cancer entail for example adhering to a healthy and balanced diet and exercise frequently (Yin et al., 2018). For future research it could be interesting to explore what the relation is between self-compassion and self-care strategies.

A lot of respondents also mentioned 'having positive thoughts/feelings'. They mentioned that they are kind and mild for themselves and have a positive mindset. This corresponds with the definition of self-kindness, an important component of the self-compassion theory from Neff and Germer (2013b): a positive and warm attitude towards yourself and less critical self-judgements regarding changes in physical appearance, psychosocial difficulties, or life limitations (Neff & Germer, 2013b). However, it sometimes did not become clear from the results what the respondents mean exactly with being kind and mild for themselves and having a positive mindset, in the context of cancer. Clarification on these behaviors can give guidance in developing a psychosocial intervention, tailored to the needs and wishes of cancer patients.

It is remarkable that only a few respondents mentioned: 'looking for connection/support from others'. Previous research described this concept as common humanity, which refers to a shared experience with others. It can provide a sense of social connectedness that can counteract feelings of isolation (Mattsson, Ringner, Ljungman & von Essen, 2007; Zebrack, 2011). Common humanity is also one of the components of the self-compassion theory and considered of importance in increasing self-compassion (Neff & Germer, 2013b). Not only a connection with fellow sufferers was mentioned by the

respondents, but also social contact with others, and accepting support from others seemed of importance to them. For future research it could be interesting to explore in which way self-compassion plays a role in looking for social contact and accepting support from others.

Other important outcomes of this study are that the respondents mentioned: 'allowing negative emotions/feelings, 'accepting the disease and limitations' and 'self-acceptance'. Previous research describes this as a mindful state of mind in which one is open and acceptive to experiences in the present moment without being judgmental about it or avoiding or repressing them (Bishop et al., 2004). According to Neff and Dahm (2015), mindfulness is prerequisite to be self-compassionate; one must be willing to experience painful emotions, thoughts and feelings in order to embrace themselves with compassion (Neff & Dahm, 2015). Mindfulness strategies can help to reduce worrying and rumination that can lead to anxiety and depressive symptoms (Desrosiers, Vine, Klemanski & Nolen-Hoeksema, 2013). It is therefore important that cancer patients use mindfulness strategies because it can enhance their quality of life, as research of Van Dam, Sheppard, Forsyth and Earleywine (2011) has shown. It is also recommended to involve mindfulness in future research in developing a psychosocial intervention for cancer patients.

4.3 Exercises

4.3.1 Reflective exercises

The results have shown that many respondents appreciated the reflective exercises and mentioned various positive aspects regarding these exercises, namely: insight/awareness in themselves through reflection, (e.g. in self-critique, emotions/feelings, and in several aspects of their lives), a relaxing moment for themselves, and a positive start of the day. Especially insight and awareness in self-critique made them realize how self-critical they are and helped them to be more kind towards themselves. According to Neff (2003b), self-kindness is an important part of the self-compassion theory and means to be kind and caring to oneself instead of being critical to oneself, when confronted with a painful life experience (Neff, 2003b). Since cancer patients are confronted with a life-threatening disease, self-compassion is particularly important (Pinto-Gouveia et al., 2014). Moreover, the exercises gave them more insight in where their emotions and feelings come from and give them insight into why they respond in a certain way. This is in line with research of Irons and Beaumont (2017) were they say that it can help to understand the three emotion systems so that we can better position difficult emotions (and also beautiful qualities) and learn how to deal with them better. Also, starting the day positively was mentioned by the respondents as a positive aspect

of the reflective exercises. It helped them to change their mindset. Hulsbergen and Bohlmeijer (2015) state that when you propose a desired situation on a daily basis at the beginning of the day, it increases the chance that the desired direction will be started. When you are aware of the intention to do something, the changes are higher that you will act like this. This change will become even more higher when you propose this behavior. Furthermore, the respondents also indicated reflecting on their day creates more awareness on several aspects of their lives. It helped them to get more insight in the positive things of the day. Reflecting on the day at the end of the day can help to develop more self-compassion and decrease feelings of stress and self-critique (Hulsbergen & Bohlmeijer, 2015). All in all, it is clear that creating insight and awareness on the aforementioned topics, can strengthen the self-compassion of cancer patients. Therefore, reflective exercise should be considered in developing a psychosocial intervention for cancer patients.

Besides the aforementioned positive aspects of the reflective exercises, there were also some critical remarks mentioned by the respondents, namely: hard to think of examples, hard to imagine, unclear what to do with the newly gained insight, digital aspect, and difficult to do at a specific moment. What is of importance, is that the respondents mentioned that is was sometimes hard to think of examples or imagine a situation, for example: some respondents thought it was difficult to imagine what the balance of their emotion systems was at the time of the diagnosis because this was already a long time ago for them. This can be explained in terms of memory decay, which makes people forget what happened in the past (Karmarkar & Roles, 2016). This emphasizes the importance of offering a psychosocial intervention to cancer patients who are recently diagnosed.

Respondents mentioned useful recommendations for improving the reflective exercises. First, some respondents mentioned that a follow-up exercise needed that gives guidance on what to do with the newly gained insight which will help them to answers the questions that arose while doing the reflective exercises. We strongly support this recommendation and think that this is important to consider this in developing interventions. Moreover, it was mentioned that more common words should be used to make the exercises understandable and realistic because cancer is present in every social class. This is in line with the research on the principle of tailoring. When the information is tailored to the user, the information will be seen as more useful, the information will be better read, better remembered and will be seen as personally relevant in comparison with general information (Napolitano & Marcus, 2002, Spittaels, 2007; Lustria et al., 2009; Smeets et al., 2008). Adding an option for word choice can result in a larger target group that can be addressed.

Therefore, we recommend to tailor the reflective exercises to the needs and wishes of the cancer patients to make to exercises more appealing for a larger target group.

4.3.2 Meditative exercises

The results have shown that the majority of the respondents did not appreciate the meditative exercises positively. They mentioned various negative aspects regarding these exercises, namely: the exercises were not appealing, unpleasant voice and way of talking, not able to choose your own level, too many instructions, long/boring exercise, hard to imagine, bad sound, and subjects in the exercises are not recognizable. Especially the fact that the exercises were not appealing and that the subjects were sometimes not recognizable are important findings in this study. The respondents were not touched by the exercises and thought that they did not fit their needs and wishes. Moreover, the respondents mentioned also that the voice used in the exercise was unpleasant, just like the way of talking. Also, they were not able to choose their own level, there were too many instructions and some of the exercises were too long/boring. Given this information, the exercises do not seem to fit to the needs and wishes of the respondents in this study. It is important that the content of the exercises is relevant for the user according to the principle of tailoring because the information will then be seen as more useful, the information will be better read, better remembered and will be seen as personally relevant in comparison with general information (Napolitano & Marcus, 2002, Spittaels, 2007; Lustria et al., 2009; Smeets et al., 2008). When developing an intervention for this target group, it is important to consider offering options within an exercise. This includes for example, choosing a female or male voice, choose a level, and choosing the length of the exercise. By offering these options within the exercises, the exercises can be adapted more to the individual and therefore fit the needs and wishes of the user better.

A few respondents also mentioned some positive aspects regarding the exercises. They thought that the exercises helped them to relax and to slow down, the silences are appreciated, the exercises helped them to be self-kind, it changes their mindset, the component of repeating was appreciated, and the use of their own imagination was also positively experienced. Especially the fact that the exercises helped them to relax and slow down is an important finding. Mindfulness, which is a component of the self-compassion theory (Neff & Germer, 2013b), can help someone to relax and reduce excessive worrying and rumination (Desrosiers et al., 2013). The study of Bluth et al. (2016) also showed this among young adults who survived cancer. There program showed promising results in increasing

psychosocial wellbeing trough increasing mindfulness and self-compassion (Bluth et al., 2016). It was also mentioned that the exercises can change one's mindset, for example: from waking up with a bad mood to a more positive mindset. According to Neff (2003b), self-compassion has a positive relationship with measures of happiness and optimism. With the development of an intervention, it is important to keep in mind that mindfulness can be a helpful way to increase the self-compassion of cancer patients. Moreover, it was mentioned that the exercises helped them to be more self-kind. Self-kindness is also a component of the self-compassion theory (Neff & Germer, 2013b) and refers to a positive and warm attitude and less critical self-judgements regarding changes in physical appearance, psychosocial difficulties, or life limitations (Brion et al., 2013; Pinto-Gouveia et al., 2014; Przezdziecki et al., 2013). The study of Scott et al. (2004) showed that breast cancer survivors experience distress that is directly related to a disturbed body image. Self-kindness could therefore be of importance in developing a more positive and warmer attitude towards oneself in cancer patients and should be considered in developing a psychosocial intervention for cancer patients.

4.4 Strengths and limitations

4.4.1 Strengths

A strong point of this study is the qualitative interview study design that was chosen. This research method is flexible because the study could be conducted at any quiet place or via the telephone. This way, a larger group of respondents could be reached. With the relatively detailed interview guide, more subjective knowledge about the concepts of self-critique (e.g. self-critique on their body) and self-compassion (e.g. seeking help) among cancer patients was obtained. This study is relatively new in the study of self-critique and self-compassion among cancer patients and is a relevant basis for new findings in this field. It can therefore be the start of new studies and insights for the treatment of psychological problems in cancer patients. The new insights can be an addition to the existing literature on self-critique and self-compassion among cancer patients. The new insights can be used to alter existing interventions or develop new interventions that are tailored to the needs and wishes of the cancer patients.

4.4.2 Limitations

There are also some limitations to this study. Although the study has the intended number of respondents we aimed for, there are still a few weaknesses. First of all, not all

respondents were recently diagnosed with cancer. Therefore, it was sometimes difficult for the respondents to remember what it was like after the diagnosis. Because of that, they could not answer all the questions that were asked during the interview. Moreover, we aimed for a heterogenous group of respondents, but the majority of the respondents is female. Besides, most of the respondents were diagnosed with breast cancer. Therefore, the results may not be generalizable among other cancer patients. To enlarge the possibility of generalization, it is recommended that future research aims at a heterogenous group of respondents in terms of gender and diagnosis.

Another limitation of this study is that data saturation has not been reached regarding the concepts of self-critique and self-compassion among cancer patients. This impacts the quality of the study and hampers content validity (Fusch & Ness, 2015). In retrospect, the interview schedule used in the study was too broad. Also, there was only limited time (1 hour per interview) to conduct an interview with this too broad interview schedule. Because of that, it was difficult to ask in-depth questions. It is therefore possible that not all answer categories were found. To reach data saturation, it is recommended for future research to make the interview schedule more specific on the topics of self-critique and self-compassion.

4.5 Conclusion

In conclusion, it can be said that cancer patients already experience self-compassion to a certain extent, but self-criticism and strictness are also common among them. The concrete information about self-critique and self-compassion among cancer patients can be used to tailor the reflective and meditative exercises with accompanying text to the needs and wishes of cancer patients. Options must be added within the exercises so that a larger target group can be addressed. In additional qualitative research with structured interviews, these adjusted exercises must be presented to cancer patients to see whether these fit the needs and wishes of the cancer patients. This way, the self-compassion of cancer patients can be strengthened.

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6. Appendices

Appendix 6.1 – Information letter

Titel van het onderzoek
Zelfcompassie na de diagnose kanker: gezamenlijke ontwikkeling van een smartphone app

Inleiding
Geachte heer/mevrouw,
U ontvangt deze informatiebrief omdat u minder dan tien jaar geleden de diagnose kanker heeft gekregen en omdat u interesse heeft getoond in het wetenschappelijke onderzoek van de Universiteit van Twente, getiteld: "Zelfcompassie na de diagnose kanker: gezamenlijke ontwikkeling van een smartphone app". Middels deze brief krijgt u meer informatie over het doel en de achtergrond van het onderzoek. Tevens kunt u lezen wat deelnemen aan dit wetenschappelijke onderzoek precies inhoudt en wat er met uw gegevens wordt gedaan. Indien u na het lezen van deze brief besluit dat u wilt deelnemen aan het wetenschappelijke onderzoek, vragen we u om een toestemmingsformulier in te vullen. U kunt zelf kiezen aan welke onderdelen u wil deelnemen. Hebt u na het lezen van de informatie nog vragen? Dan kunt u terecht bij de een van de onderzoekers, die onderaan deze brief vermeld is.

1. Wie zijn de onderzoekers?
De onderzoekers die dit wetenschappelijke onderzoek uitvoeren zijn Judith Austin, Mara Velmans en Michelle Van Vlierberghe. Judith Austin is promovenda aan de Universiteit van Twente. Mara Velmans is Masterstudent Positieve Psychologie en Michelle Van Vlierberghe is Masterstudent Gezondheidspsychologie en Technologie, beide aan de Universiteit van Twente. Samen doen zij wetenschappelijk onderzoek naar compassie na de diagnose kanker. Het wetenschappelijk onderzoek staat onder supervisie van dr. Stans Drossaert en prof. dr. Ernst Bohlmeijer.

2. Wat is het doel van onderzoek?
De diagnose kanker heeft bijna altijd een enorme impact op het leven van mensen. Om mensen in deze moeilijke tijd een steuntje in de rug te geven, willen wij graag een hulpmiddel ontwikkelen dat kan helpen de veerkracht te vergroten. Dit doen we niet alleen: het doel van dit project is om een hulpmiddel te ontwikkelen dat echt past bij degenen die hem gaan gebruiken. Daarom vragen wij patiënten en verpleegkundigen om mee te helpen met de ontwikkeling ervan. Het hulpmiddel bestaat uit een zelfcompassie app voor op de smartphone en zal worden begeleid door verpleegkundigen. De zelfcompassie app wordt een laagdrempelige ondersteuning die vooral in de eerste fase na de diagnose een houvast kan bieden.

3. Hoe wordt het onderzoek uitgevoerd?

Het onderzoek bestaat uit zeven workshops waarin we samen de app gaan ontwikkelen. Daarnaast worden er individuele interviews gehouden. Als u wilt deelnemen, kunt zelf aangeven of u mee wilt doen aan de workshops, de interviews of aan allebei.

Workshops
De workshops duren ongeveer 4 uur en vinden plaats in Enschede op de Universiteit van Twente of in Groningen in het UMCG (afhankelijk van uw regio). De workshops vinden tussen november 2018 en mei 2020 plaats. In de workshops zullen patiënten, verpleegkundigen, onderzoekers en programmeurs aanwezig zijn (ongeveer 12 personen). Tijdens de workshop bespreken we uw
ervaringen en bedenken we met creatieve spellen en brainstorm-methodes hoe de zelfcompassie app eruit gaat zien. Het project is eigenlijk meer een ontwerp-samenwerking dan een typisch onderzoek. Afhankelijk van het aantal aanmeldingen kunt u voor één of meerdere workshops worden uitgenodigd. Het uitgangspunt is om meerdere workshops met dezelfde mensen te doen, zodat we samen steeds kunnen voortbouwen op de vorige workshop.

Interviews
Naast de workshops zijn er ook individuele interviews. Als u meedoet aan een interview, dan wordt u eerst gevraagd om twee weken een aantal zelfcompassie oefeningen thuis uit te proberen. Dit kost ongeveer 10 minuten per dag. Daarna maakt een onderzoeker een afspraak met u voor een interview (afhankelijk van uw voorkeuren bij u thuis, op een neutrale plek of telefonisch). De onderzoeker stelt u vragen over uw ervaringen met de oefeningen en uw ervaringen in het algemeen in de periode na uw diagnose. Het interview duurt ongeveer een uur.

Alle activiteiten van het project staan los van de zorg die u ontvangt (en hebben hier geen invloed op).

4. Wat wordt er van u verwacht?
Er wordt een actieve bijdrage aan de workshops verwacht. U wordt gevraagd een evaluatieformulier in te vullen na de workshops en u geeft toestemming voor het gebruik van uw gegevens voor de doeleinden van dit onderzoek (zie punt 6). Ook kan het zijn dat u gevraagd wordt om tussen de workshops door oefeningen of opdrachten thuis te doen (vrijwillig). Als u meedoet aan een interview, wordt u gevraagd om thuis zelfcompassie oefeningen uit te proberen in de twee weken vooraf aan het interview. Zowel van de workshops als van de interviews worden audio- en/of video-opnames gemaakt, zodat er geen informatie verloren gaat. Uiteraard wordt met deze opnames uiterst zorgvuldig omgegaan, lees meer hierover bij punt 6.

5. Wat gebeurt er als u niet wenst deel te nemen aan dit onderzoek?
U beslist zelf of u meedoet aan het onderzoek. Deelname is vrijwillig. Als u besluit niet mee te doen, hoeft u verder niets te doen. U hoeft niets te tekenen. U hoeft ook niet te zeggen waarom u niet wilt meedoen. U krijgt gewoon de behandeling die u anders ook zou krijgen. Als u wel meedoet, kunt u zich altijd bedenken en toch stoppen. Ook tijdens het onderzoek. U hoeft geen reden te geven waarom u wilt stoppen.

6. Wat gebeurt er met uw gegevens?
Voor dit onderzoek worden uw persoonsgegevens gebruikt en bewaard. Het gaat om gegevens zoals uw naam, adres, geboortedatum en om informatie over uw diagnose. Ook gebruiken we

gegevens van de dingen die u vertelt in de workshops, bijvoorbeeld uw ervaringen, wensen of behoeften en uw suggesties voor de app. Het verzamelen, gebruiken en bewaren van uw gegevens is nodig om de vragen die in dit onderzoek worden gesteld te kunnen beantwoorden en de resultaten te kunnen gebruiken in de masterscripties van Mara Velmans en Michelle Van Vlierberghe en om deze uiteindelijk te publiceren. Wij vragen voor het gebruik van uw gegevens uw toestemming.
Vertrouwelijkheid van uw gegevens Om uw privacy te beschermen krijgen uw gegevens een code. Uw naam en andere gegevens die u direct kunnen identificeren worden daarbij weggelaten. Alleen met de sleutel van de code zijn gegevens tot u te herleiden. De sleutel van de code blijft veilig opgeborgen op de Universiteit van Twente. Ook in rapporten en publicaties over het onderzoek zijn de gegevens niet tot u te herleiden.

Toegang tot uw gegevens voor controle
Sommige personen kunnen op de Universiteit Twente toegang krijgen tot al uw gegevens. Ook tot de gegevens zonder code. Dit is nodig om te kunnen controleren of het onderzoek goed en betrouwbaar
is uitgevoerd. Personen die ter controle inzage krijgen in uw gegevens zijn bevoegde medewerkers van dit onderzoek, de Inspectie voor de Gezondheidszorg en controleurs van de Raad van Bestuur van de Universiteit van Twente, waar het onderzoek wordt uitgevoerd. Zij houden uw gegevens geheim. Wij vragen u voor deze inzage toestemming te geven.

Bewaartermijn gegevens
Uw gegevens moeten 10 jaar worden bewaard op de Universiteit Twente. Hierna worden de gegevens vernietigd.

Intrekken toestemming
U kunt uw toestemming voor gebruik van uw persoonsgegevens altijd weer intrekken. De onderzoeksgegevens die zijn verzameld tot het moment dat u uw toestemming intrekt worden nog wel gebruikt in het onderzoek.

Meer informatie over uw rechten bij verwerking van gegevens
Voor algemene informatie over uw rechten bij verwerking van uw persoonsgegevens kunt u de website van de Autoriteit Persoonsgegevens raadplegen.

Bij vragen over uw rechten kunt u contact opnemen met de verantwoordelijke voor de verwerking van uw persoonsgegevens. Voor dit onderzoek kunt u terecht bij de ethiek commissie van de Universiteit Twente. Zie bijlage A voor contactgegevens en website.

Bij vragen of klachten over de verwerking van uw persoonsgegevens raden we u aan eerst contact op te nemen met de ethiek commissie van de Universiteit Twente.

7. Zijn er extra kosten of krijgt u een vergoeding wanneer u besluit aan dit onderzoek mee te doen? Indien u reiskosten moet maken, worden deze vergoed. U krijgt geen vergoeding voor deelname aan het onderzoek. Deelname aan dit onderzoek staat volledig los van uw ziekenhuisbehandeling en de kosten die u daarvoor maakt.

8. Door wie is dit onderzoek goedgekeurd?
De Raad van Bestuur van het MST heeft goedkeuring gegeven om dit onderzoek uit te voeren. Het onderzoek wordt door KWF gesponsord en een beoordelingscommissie van het KWF heeft het doel en de opzet van het onderzoek positief beoordeeld.

9. Wilt u verder nog iets weten?
Voor het stellen van vragen en het inwinnen van nadere informatie voor, tijdens en na het onderzoek kunt u contact opnemen met Judith Austin (onderzoeker op dit project) op het telefoonnummer 053-4897024 of via het e-mailadres zelfcompassiebijkanker@utwente.nl. Voor het nalezen van informatie over het onderzoek kunt u kijken op de website www.utwente.nl/zelfcompassiebijkanker. Indien u na zorgvuldige overweging besluit deel te nemen aan dit wetenschappelijk onderzoek, dan vragen we u om samen met de onderzoeker het toestemmingsformulier te ondertekenen en van een datum te voorzien.

Met vriendelijke groet,
Het onderzoeksteam

Bijlage
A: Contactgegevens
B: Toestemmingsformulier

Bijlage A: Contactgegevens

Voor vragen over (de inhoud van en deelname aan) het onderzoek en andere vragen kunt u contact opnemen met:
Mevr. Judith Austin (onderzoeker op dit project, Universiteit Twente)
Telefoonnummer: 053 - 489 7024
E-mail adres: zelfcompassiebijkanker@utwente.nl
Website onderzoek: www.utwente.nl/zelfcompassiebijkanker

Bij klachten over het onderzoek kunt u contact opnemen met een onafhankelijk persoon van de Universiteit Twente:
Marion Sommers – Spijkerman (onderzoeker)
Telefoonnummer: 053 – 489 6545
E-mail adres: m.p.j.spijkerman@utwente.nl

Voor meer informatie over uw rechten als deelnemer aan onderzoek:
Ethiek Commissie van de afdeling BMS van de Universiteit Twente
E-mail adres: ethicscommittee-bms@utwente.nl
Website: https://www.utwente.nl/en/bms/research/ethics/

Appendix 6.2 – Informed consent

Bijlage B: Toestemmingformulier

Titel onderzoek: Zelfcompassie na de diagnose kanker: gezamenlijke ontwikkeling van smartphone app
Verantwoordelijke onderzoekers: M.K. Van Vlierberghe

In te vullen door de deelnemer

Ik verklaar op een voor mij duidelijke wijze te zijn ingelicht over de aard, methode en doel van het onderzoek. Ik kon aanvullende vragen stellen. Mijn vragen zijn genoeg beantwoord. Ik had genoeg tijd om te beslissen of ik meedoe.

Ik weet dat sommige mensen mijn gegevens kunnen inzien. Die mensen staan vermeld in de informatiebrief.

Ik geef toestemming om mijn gegevens te gebruiken, voor de doelen die in de informatiebrief staan.

Ik geef toestemming om mijn onderzoeksgegevens 10 jaar na afloop van dit onderzoek te bewaren.

Ik begrijp dat audiomateriaal en/of videomateriaal of bewerking daarvan uitsluitend voor analyse en/of wetenschappelijke doeleinden zal worden gebruikt.

Ik stem geheel vrijwillig in met deelname aan dit onderzoek. Ik behoud me daarbij het recht voor om op elk moment zonder opgaaf van redenen mijn deelname aan dit onderzoek te beëindigen.

Naam deelnemer: …….
Datum: …… Handtekening deelnemer: ……

In te vullen door de uitvoerende onderzoeker

Ik heb een mondelinge en schriftelijke toelichting gegeven op het onderzoek. Ik zal resterende vragen over het onderzoek naar vermogen beantwoorden. De deelnemer zal van een eventuele voortijdige beëindiging van deelname aan dit onderzoek geen nadelige gevolgen ondervinden.

Naam onderzoeker: ……
Datum: …… Handtekening onderzoeker: ……..

Appendix 6.3 – (Self)compassion exercises

(Zelf)compassie

Introductie zelfcompassie

Het leven is soms moeilijk. We krijgen te maken met tegenslagen, bijvoorbeeld in onze familie of met onze gezondheid. Ook gebeurt er van alles om ons heen in de wereld wat moeilijk te bevatten is. Het liefst staan we hier niet al te lang bij stil. Dit voelt niet prettig, en als we dit te lang doen verliezen we de mooie dingen van het leven uit het oog. Toch kan het nuttig zijn om ook bij de moeilijke dingen die we tegenkomen stil te staan - in plaats van ze proberen weg te stoppen of te vermijden - zodat we de ruimte hebben om onze ervaringen te verwerken.

"Zelfcompassie gaat over een milde, vriendelijke en warme houding tegenover onszelf in tijden van tegenslag." Zelfcompassie betekent niet dat je altijd maar toegeeft aan waar je zin in hebt of dat je 'soft' voor jezelf bent: er is juist moed en wijsheid voor nodig om onder ogen te zien dat een moeilijke situatie er is, en wat ervoor nodig is om binnen de omstandigheden vooruit te komen.

Twee weken oefeningen doen

Uit onderzoek blijkt dat het oefenen van (zelf)compassie mensen kan helpen om hun welzijn te verhogen en stress en angst te verminderen. (Zelf)compassie oefeningen kunnen handvaten zijn om je compassie te versterken. Op de volgende pagina's staan verschillende reflectie- en luisteroefeningen om uit te proberen. Dit kost 10 minuten per dag, waarbij je in week 1 andere oefeningen doet dan in week 2. In het interview bespreken we vervolgens je ervaringen. Als een oefening niet lukt of je niet aanspreekt geeft dat niet: dat is jouw ervaring die voor ons waardevol is om te horen. Wel is het goed om de luisteroefeningen (3, 5 & 6) meerdere keren te proberen op verschillende momenten, omdat het vaak tijd kost om aan iets nieuws te wennen. Eventueel kun je voor jezelf een notitieboekje bijhouden met je ervaringen.

Overzicht: hoe vaak doe ik de verschillende oefeningen?

Week 1:
- Oefeningen 1, 2 en 4: eenmalig
- Luisteroefeningen 3, 5 en 6: afwisselend dagelijks (één oefening per dag)

Week 2:
- Oefeningen 7 en 8: beiden dagelijks

Zelfcompassie ervaren

De onderstaande oefening kan helpen om zelf een beeld te krijgen van wat zelfcompassie is.

Oefening 1. "Hoe behandel ik een vriend?"

5 min. (eenmalig)

Gebaseerd op een oefening uit 'The Mindful Self-Compassion Workbook' - K. Neff & C. Germer

Voor de oefening is het prettig om comfortabel te gaan zitten op een plek waar je niet gestoord wordt. Er worden je drie vragen voorgelegd om op te reflecteren. Je kunt na het lezen van elke vraag de ogen even sluiten of op één punt richten en jezelf de tijd geven om te ervaren wat er in je opkomt.

1. Denk eens terug aan momenten waarop een vriend(in), familielid of kennis het moeilijk had - het zat niet mee, hij/zij voelde zich te kort schieten of had iets vervelends meegemaakt - en jij voelde je oké. Wat zou typisch jouw manier zijn om op die persoon te reageren? *Welke woorden gebruik je? Welke toon heeft je stem? Hoe zijn je lichaamshouding, je non-verbale gebaren?*

Neem +- 2 minuten de tijd en ga dan naar het volgende deel van de oefening.

Vervolg van oefening 1.

2. Denk nu eens terug aan momenten waarop je het zelf moeilijk had - het zat je niet mee, je voelde je tekort schieten of je had iets vervelends meegemaakt. Wat zou dan typisch jouw manier zijn om op jezelf te reageren? *Welke woorden gebruik je? Welke toon heeft je stem? Hoe is je lichaamshouding, je non-verbale gebaren?*

Neem +- 2 minuten de tijd.

3. Wat merk je op? Is er verschil?

Veel mensen valt het op dat zij streng op zichzelf reageren, vaak strenger dan ze op een vriend(in), familielid of kennis zouden reageren. Als dat voor jou ook zo is dan kun je zelfcompassie ook zien als:

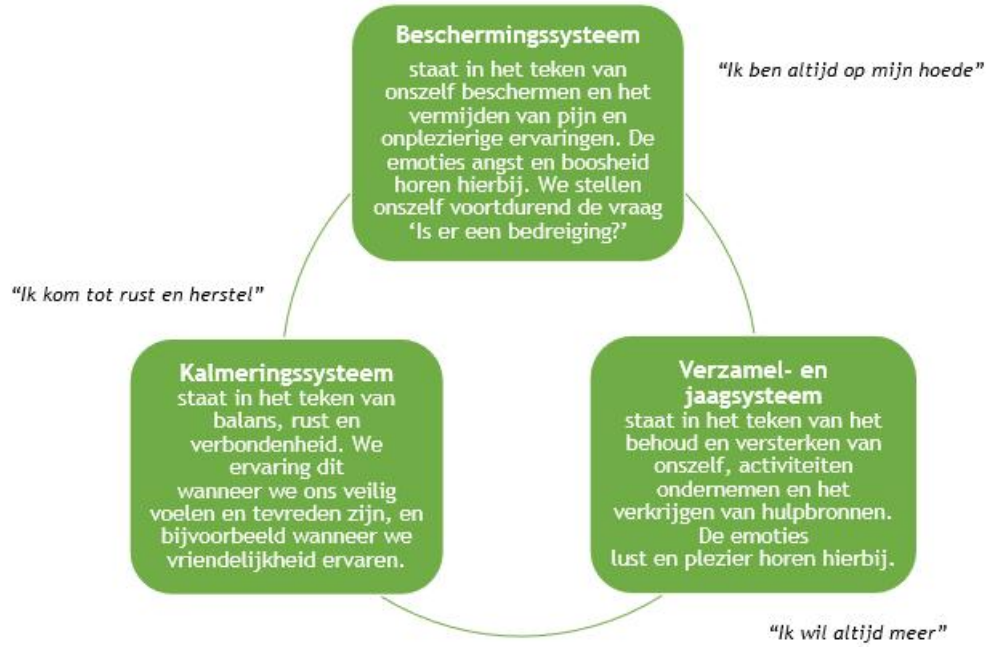
"Onszelf behandelen met dezelfde vriendelijkheid als we bij een vriend (of kennis, familielid) zouden doen wanneer we het moeilijk hebben."

Onze evolutionaire bagage

Bij de vorige oefening merken veel mensen dat ze erg kritisch op zichzelf zijn. Het is goed om te bedenken dat het niet onze schuld is dat we zoveel zelfkritiek en vaak ook stress, schaamte, angst en boosheid ervaren. We hebben hier allemaal last van, ieder op zijn eigen manier. Dit heeft te maken met hoe onze hersenen functioneren. Onze hersenen zijn gevormd door vele miljoenen jaren van evolutie. Door onze hersenen zijn we in staat tot hele mooie dingen (denk bijvoorbeeld aan kunst, technologie of medicijnen die door mensen gemaakt zijn) maar ook hele vervelende dingen (piekeren, overmatige zelfkritiek).

De structuur van onze hersenen zijn ontstaan in een tijd waarin mensen in de natuur leefden en een staat van alertheid nodig was om te overleven. Vanuit deze leefstijl zijn er grofweg drie basissystemen in onze hersenen ontstaan om met onze emoties om te gaan. Het kan helpen om inzicht te hebben in deze systemen, zodat we onze moeilijke emoties (en ook onze mooie eigenschappen) beter kunnen plaatsen en er beter mee om kunnen leren gaan.

De drie emotiesystemen



Gebaseerd op het werk van psycholoog Paul Gilbert & op het boek 'Dit is jouw Leven' - E. Bohlmeijer & M. Hulsbergen

Uit balans

Al deze emotiesystemen zijn in de basis gezond: we hebben ze allemaal nodig. Soms raken de drie systemen echter uit balans. We zijn dan bijvoorbeeld constant alert (overactief beschermingssysteem) of hebben altijd een drang naar méér (overactief verzamel- en jaagsysteem). Het kan ook zijn dat we juist helemaal geen doelen meer stellen of geen dingen meer ondernemen (inactief verzamel- en jaagsysteem). Voor veel mensen brengt de diagnose van kanker de drie emotiesystemen uit balans. We komen dan in een soort overlevingsstand terecht, waarin we alert en vaak angstig zijn. De rust en verbondenheid die nodig zijn voor emotioneel herstel en een gevoel van tevredenheid en veiligheid kunnen achterblijven (inactief kalmeringssysteem).

Oefening 2. Drie emotiesystemen

<5 min. (eenmalig)

Gebaseerd op een oefening uit 'The Compassionate Mind Workbook' - C. Irons & E. Beaumont

Sta eens stil bij je emoties in de afgelopen weken. Hoe vaak was je angstig of maakte je je zorgen (beschermingssysteem)? Hoe vaak was je ontspannen en kalm (kalmeringssysteem)? Hoe vaak was je energiek en blij of voelde je lust of drang naar méér (verzamel- en jaagsysteem)? Teken hieronder drie cirkels, één cirkel voor elk emotiesysteem, waarbij de grootte van de cirkel aangeeft welk emotiesysteem je het meest ervaart.

Wat valt je op? Had je deze cirkels anders getekend voordat je de diagnose kanker kreeg?

Compassie voor jezelf

Zelfcompassie oefeningen kunnen helpen om het kalmeringssysteem meer in balans te brengen, door tot rust te komen en vriendelijk te zijn voor jezelf. In de onderstaande oefening sta je stil bij een moeilijk moment en oefen je met compassie voor jezelf.

Oefening 3. Zelfcompassiemantra — 3 min.

Voor deze luisteroefening van BFC Mindfulness & Compassie is het prettig om comfortabel te gaan zitten op een plek waar je niet gestoord wordt. Als je de oefening een keer gedaan hebt kun je hem op elk moment van de dag toepassen als het even wat moeilijker gaat (evt. ook zonder audio). Ga naar de website www.bfcmind.nl/index.php/zelfcompassiebijkanker en speel het audiobestand 'Zelfcompassiemantra' af.

De drie stromen van compassie

Naast compassie voor onszelf kunnen we ook compassie geven en ontvangen van anderen. We noemen dit ook wel de drie stromen van compassie. In onderstaande reflectieoefening sta je stil bij jouw ervaring hiermee.

Oefening 4. De stromen van compassie — <5 min. (eenmalig)

Sta eens stil bij de afgelopen weken. Op welke manier was je vriendelijk en behulpzaam voor jezelf? Op welke manier was je vriendelijk en behulpzaam voor anderen? Op welke manier waren anderen vriendelijk en behulpzaam voor jou, stond je daarvoor open? Maak hieronder de drie pijlen dikker met een pen, waarbij de dikte van de pijl aangeeft welke stroom van compassie je het meest ervaart.

Wat valt op? Had je de pijlen anders getekend voordat je de diagnose kanker kreeg? Of tijdens de behandeling?

Compassie geven en ontvangen

We kunnen ons voorstellingsvermogen gebruiken om ons in te beelden dat we compassie geven en ontvangen, aan onszelf en anderen. Dit kan helpen om ons kalmeringssysteem te versterken. In oefening 5 en 6 probeer je dit uit.

NB. Je hoeft de oefeningen niet achter elkaar te doen: het is voldoende om één luisteroefening (oefening 3, 5 of 6) per dag te doen.

Oefening 5. Vriendelijkheidsoefening (metta) — 11 min.

Voor deze oefening van BFC Mindfulness & Compassie is het prettig om comfortabel te gaan zitten op een plek waar je niet gestoord wordt. Ga naar de website www.bfcmind.nl/index.php/zelfcompassiebijkanker en speel het audiobestand 'Metta 1' af.

Oefening 6. Compassionele metgezel — 8 min.

Voor deze oefening van BFC Mindfulness & Compassie is het prettig om comfortabel te gaan zitten op een plek waar je niet gestoord wordt. Ga naar de website www.bfcmind.nl/index.php/zelfcompassiebijkanker en speel het audiobestand 'Compassionele metgezel' af.

De dag bewust en zorgzaam beginnen en afsluiten (week 2)

Om een goed beeld te krijgen van wat (zelf)compassie is en hoe jij dit ervaart, kan het helpen om elke dag even stil te staan bij (zelf)compassie in je dagelijks leven. Zo wordt het meer een onderdeel van de dag. Naast de luisteroefeningen van week 1 vind je hier daarom twee korte oefeningen om in week 2 dagelijks de dag mee te beginnen en af te sluiten. Hoewel de oefeningen niet lang duren is het fijn om even rustig de tijd te nemen.

Oefening 7. De dag beginnen — <5 min.

Gebaseerd op een oefening uit 'Compassie als sleutel tot geluk' - M. Hulsbergen & E. Bohlmeijer

Deze oefening kun je doen direct bij het wakker worden. Sta als je wakker wordt even bewust stil bij je lichaam, je liggende houding, voel hoe je lichaam contact maakt met het matras. Volg het ritme van je ademhaling tijdens een paar in- en uitademingen. Je hoeft je adem niet te sturen. Voel hoe je lichaam in en uit ademt. Bedenk voor jezelf: *Wat voor goeds wens ik mezelf en anderen vandaag toe?* Laat deze intentie een paar keer door je gedachten gaan voordat je opstaat.

Oefening 8. Reflecteren op de dag — 5 min.

In deze oefening neemt je aan het einde van de dag de tijd om stil te staan bij hoe de dag verlopen is. Het kan fijn zijn om hier een rustige plek voor te zoeken en eventueel je antwoorden op te schrijven. Je kunt je de volgende vragen stellen over de dag: *Waar ben ik dankbaar voor?; Op welke manier was ik vriendelijk voor mezelf?; Wat heb ik gedaan waar ik blij mee ben?; Hoe hebben anderen bijgedragen aan mijn welzijn; Hoe heb ik bijgedragen aan het welzijn van anderen?*

Wij hopen dat de ervaring van het uitproberen van (zelf)compassie oefeningen waardevol voor je is. Mocht je tussendoor vragen hebben, neem dan contact op met je interviewer of stuur een mailtje naar zelfcompassiebijkanker@utwente.nl.

Appendix 6.4 – Interview guide

Interviewschema
Introductie
Hartelijk dank dat je wilt meewerken aan het wetenschappelijke onderzoek naar zelfcompassie na de diagnose kanker door middel van dit interview.
[Evt.: vragen of je 'je' mag zeggen, afstemmen op persoon/leeftijd]

Scenario 1
Wij zullen ons kort even voorstellen. Mijn naam is Mara Velmans. Ik ben masterstudent Positieve Psychologie aan de Universiteit van Twente. Mijn naam is Michelle Van Vlierberghe. Ik ben masterstudent Gezondheidspsychologie en Technologie. Beide doen wij wetenschappelijk onderzoek in het kader van onze afstudeerscriptie naar zelfcompassie na de diagnose kanker.

Scenario 2
Ik zal mij kort even voorstellen. Mijn naam is Mara Velmans. Ik ben masterstudent Positieve Psychologie aan de Universiteit van Twente. Samen met Michelle Van Vlierberghe doe ik wetenschappelijk onderzoek in het kader van mijn afstudeerscriptie naar zelfcompassie na de diagnose kanker.

Scenario 3
Ik zal mij kort even voorstellen. Mijn naam is Michelle Van Vlierberghe. Ik ben masterstudent Gezondheidspsychologie en Technologie. Samen met Mara Velmans doe ik wetenschappelijk onderzoek ik het kader van mijn afstudeerscriptie naar zelfcompassie na de diagnose kanker.

De diagnose kanker heeft bijna altijd een grote impact op het leven van mensen. Om mensen in deze moeilijke tijd een steuntje in de rug te geven, willen wij graag een hulpmiddel ontwikkelen dat kan helpen de veerkracht te vergroten. Dit doen we niet alleen: het doel van dit project is om een hulpmiddel te ontwikkelen dat echt past bij degenen die hem gaan gebruiken. Daarom vragen wij patiënten en verpleegkundigen om mee te helpen met de ontwikkeling ervan. Het hulpmiddel bestaat uit een zelfcompassie app voor op de smartphone en zal worden begeleid door verpleegkundigen. De zelfcompassie app wordt een laagdrempelige ondersteuning die vooral in de eerste fase na de diagnose een houvast kan bieden.

Door middel van het afnemen van individuele interviews, hopen we waardevolle informatie te verkrijgen van jou als ervaringsdeskundige met betrekking tot zelfcompassie na de diagnose kanker. Deze informatie zal vervolgens gebruikt worden bij het ontwikkelen van het hulpmiddel. Het interview zal ongeveer 1 uur duren.

Je persoonsgegevens zullen strikt vertrouwelijk behandeld worden en de gegevens die je tijdens het interview verstrekt, worden anoniem verwerkt en zullen op geen enkele manier naar jou kunnen worden herleid.

In dit interview staat jouw mening centraal, dus neem alsjeblieft alle tijd die je nodig hebt om de vragen te beantwoorden. Ik zal vooral luisteren en proberen niet te onderbreken, tenzij dit nodig is om niet al teveel uit te lopen. Ik zal af en toe aantekeningen maken wanneer ik dit nodig acht.

Heb je nog vragen voorafgaand aan dit interview?

Interview

Uitleg: Ik zal eerst wat algemene vragen stellen over je ervaringen rondom de diagnose. Daarna zal ik een aantal vragen stellen over de oefeningen die je gedaan hebt en over je ervaringen met zelfcompassie en compassie.

Interview deel 1: Diagnose

1. Wat voor diagnose heb je gehad? Kun je mij daar wat over vertellen?
2. Wanneer heb je deze diagnose gekregen?
3. Wat voor behandeling heb je gehad en hoe is dit verlopen?
4. Hoe gaat het nu met je?

Interview deel 2: de oefeningen en (zelf)compassie

Uitleg: Eerst zal ik wat vragen stellen over de oefeningen in het algemeen, daarna gaan we de oefeningen een voor een na. Bij sommige oefeningen zullen we wat langer stil staan bij het onderwerp van de oefening.

5. (gebruik) Heb je de oefeningen gedaan? (welke heb je wel gedaan, welke niet, welke meer dan één keer? hoeveel tijd heb je er in totaal ongeveer aan besteed?)
6. (waardering) Wat vond je in het algemeen van de oefeningen? Wat vond je goed of leuk of belangrijk? Wat vond je minder goed of moeilijk of onduidelijk?
7. (effect) Heb je iets gehad aan de oefeningen? (wat?) Of waren ze op een bepaalde manier helpend voor je? (hoe?)
8. (intentie) Zijn er oefeningen waarvan je in de toekomst nog eens gebruik zou maken? Welke? Waarom wel of niet? Op welke momenten?
9. (concept zelfcompassie) Wat vind je van het concept zelfcompassie? Waarom past zelfcompassie wel of juist niet bij de situatie van mensen met kanker?

Uitleg: Nu gaan we wat meer op de specifieke oefeningen in.
De eerste oefening ging over vriendelijkheid naar een vriend toe en vriendelijkheid naar jezelf toe. Hierbij moest je nadenken over hoe je zou reageren als een vriend ergens mee zat en hoe je reageert op jezelf wanneer je het even moeilijker hebt.

10. (gebruik) Heb je deze oefening gedaan? (evt. hoe vaak? Hoeveel tijd aan besteed)
11. (waardering) Wat vond je van deze oefening? Wat vond je goed of leuk? Wat vond je minder goed, onduidelijk of moeilijk?
12. (effect) Heb je iets geleerd van deze oefening? Of heb je er iets aan gehad op de één of andere manier (licht toe)
13. (concept zelfcompassie) Herken je dat dat je kritischer bent naar jezelf dan naar anderen? Kun je voorbeelden geven van hoe je kritisch bent geweest naar jezelf sinds je de diagnose hebt? Kun je ook voorbeelden geven van momenten waarop je juist compassievol naar jezelf was?

Uitleg: De tweede oefening ging over de drie-emotiesystemen, waarbij je drie cirkels moest tekenen waarbij de grootste cirkel het systeem was wat het meest aanwezig was en de kleinste het systeem wat het minst aanwezig was.

14. (gebruik) Heb je deze oefening gedaan? (evt. Hoe vaak? Hoeveel tijd aan besteed?)
15. (waardering) Wat vond je van deze oefening? Wat vond je goed of leuk? Wat vond je minder goed, onduidelijk of moeilijk?
16. (effect) Heb je iets geleerd van deze oefening? Of heb je er iets aan gehad op de één of andere manier (licht toe)?
17. (concept (zelf)compassie) Herken je deze emotieregulatie systemen? Spreekt je dit aan of juist niet? Kun je uitleggen of de diagnose iets veranderd heeft in de balans tussen de drie systemen?

Uitleg: De derde oefening was een korte audio-oefening waarin je oefent met compassie voor jezelf.

18. (gebruik) Heb je deze oefening gedaan? (evt. Hoe vaak? Hoeveel tijd aan besteed?)
19. (waardering) Wat vond je van deze oefening? Wat vond je goed of leuk? Wat vond je minder goed, onduidelijk of moeilijk?
20. (effect) Heb je iets geleerd van deze oefening? Of heb je er iets aan gehad op de één of andere manier (licht toe)
21. (concept zelfcompassie) Hoe zou je zelfcompassie beschrijven in je eigen woorden? Kun je een voorbeeld geven van wat zelfcompassie voor jou is? Is dit nog anders voor of na de diagnose?
22. (concept zelfcompassie) Denk je dat je op een moeilijk moment eraan zou kunnen denken om compassie voor jezelf te hebben? Lukt het je wel eens om afstand te nemen van een moeilijke situatie, of wordt je eerder overweldigd door gedachten en gevoelens? Hoe was dit in de periode na de diagnose?
23. (concept zelfcompassie) Heeft je diagnose invloed gehad op in hoeverre je je verbonden of afgesloten voelt van andere mensen? Kun je een voorbeeld geven van manieren waarop je je verbonden of juist afgesloten hebt gevoeld?

Uitleg: Oefening 4 ging over de stromen van compassie. Hierbij heb je aangegeven via welke stroom je het meest ervaart, van jezelf naar jezelf, van jezelf naar een ander of van de ander naar jou toe.

24. (gebruik) Heb je deze oefening gedaan? (evt. Hoe vaak? Hoeveel tijd aan besteed?)
25. (waardering) Wat vond je van deze oefening? Wat vond je goed of leuk? Wat vond je minder goed, onduidelijk of moeilijk?
26. (effect) Heb je iets geleerd van deze oefening? Of heb je er iets aan gehad op de één of andere manier (licht toe)?

27. (concept (zelf)compassie) Spreekt het je aan, die stromen van compassie? Kun je iets vertellen over hoe het zit met de drie stromen van compassie bij jou? Welke stroom is het grootste en welke het kleinste? Heeft de diagnose kanker iets veranderd in de stromen? (en zo ja wat?)
28. (concept compassie) Hoe vond je het om compassie van anderen te ervaren tijdens je ziekte proces en heeft je dat iets opgeleverd?
29. (concept compassie) Hoe vind je het om compassie te geven aan anderen?
30. (concept compassie) Zijn er tijden wanneer het makkelijker of moeilijker vindt om compassievol te zijn tegenover anderen of compassie te ontvangen?
31. (concept compassie) In hoeverre is het geven of ontvangen van compassie veranderd na de diagnose?

Uitleg: oefening 5 was een audio-oefening waarin je je voorstellingsvermogen gebruikt om je in te beelden dat je compassie geeft en ontvangt, aan onszelf en aan anderen.

32. (gebruik) Heb je deze oefening gedaan? (evt. Hoe vaak? Hoeveel tijd aan besteed?)
33. (waardering) Wat vond je van deze oefening? Wat vond je goed of leuk? Wat vond je minder goed, onduidelijk of moeilijk?
34. (effect) Heb je iets geleerd van deze oefening? Of heb je er iets aan gehad op de één of andere manier (licht toe)

Uitleg: oefening 6 was een audio-oefening waarin je je een compassionele metgezel voorstelt.

35. (gebruik) Heb je deze oefening gedaan? (evt. Hoe vaak? Hoeveel tijd aan besteed?)
36. (waardering) Wat vond je van deze oefening? Wat vond je goed of leuk? Wat vond je minder goed, onduidelijk of moeilijk?
37. (effect) Heb je iets geleerd van deze oefening? Of heb je er iets aan gehad op de één of andere manier (licht toe)

Uitleg: Oefening 7 en 8 gingen over het beginnen en afsluiten van je dag.

38. (gebruik) Heb je deze oefening gedaan? (evt. Hoe vaak? Hoeveel tijd aan besteed?)
39. (waardering) Wat vond je van deze oefening? Wat vond je goed of leuk? Wat vond je minder goed, onduidelijk of moeilijk?
40. (effect) Heb je iets geleerd van deze oefening? Of heb je er iets aan gehad op de één of andere manier (licht toe)

Interview deel 3: Afsluiting

Uitleg: Dan zijn wij bij het afsluitende deel van dit interview aangekomen

39. Heb je nog vragen of opmerkingen of zijn er nog onderwerpen niet aan bod gekomen die je nog graag zou willen bespreken?
40. Tenslotte heb ik nog wat vragen over uw achtergrond.

- Man/vrouw (noteren)
- Wat is je leeftijd?
- Ben je getrouwd/samenwonend of alleenwonend? (single/ weduwe/ of gescheiden)
- Wat past het best bij jouw situatie, qua werk?
    - (werkend fulltime, of studeert; werkend part time; werkzoekend; zit in ziektewet; arbeidsongeschikt; huisvrouw/man, of met pensioen)
- Wat is je hoogst afgeronde opleiding?

41. Wil je graag de resultaten ontvangen als het onderzoek is afgerond? (Email achterlaten).
42. Werk je mee aan de workshops? Zo nee, heb je daar nog interesse in (doorverwijzen naar website of informatie sturen via de email). Zouden we je in de toekomst eventueel mogen benaderen voor andere interviews of het uitproberen van andere oefeningen?
43. Wij zijn nog opzoek naar mensen die kanker hebben of kort geleden hebben gehad die interesse hebben om mee te doen aan een interview. Ken je misschien nog mensen die interesse zouden kunnen hebben? (vraag naar contact gegevens of door laten verwijzen naar website)

Dan willen wij je vriendelijke bedanken voor je medewerking. Mocht je nog vragen hebben dan kun je contact opnemen met Judith Austin, de contactgegevens kun je vinden in de informatie brief die je hebt ontvangen.