



A disease which affects us all: A study evaluating the way in which informal caregivers of cancer patients are self-compassionate and the applicability of the intervention “hold on for each other”.

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Abstract

Background: A growing body of research on the influence of cancer ensures that there is more recognition for the fact that cancer not only affects the patient's life, but also their environment. Informal caregivers often face high challenges, but lack self-compassion, which often makes them do not seek help. Up until now, studies have quantitatively measured the level of self-compassion, but few qualitatively examined the behaviour in which self-compassion (and self-criticism) manifests in informal caregivers. The self-help book "hold on for each other" aims to increase self-compassion. This book is developed for the partners of cancer patients, yet informal caregivers include more than only partners. Therefore, this study will research the suitability of the intervention on a broader group of informal caregivers.

Aim: The objective of this qualitative study is to evaluate in which way informal caregivers of cancer patients are self-compassionate and self-critical. In addition, we examined the suitability of the intervention "hold on for each other" and which changes should be made to adjust the intervention for a broader group of informal caregivers.

Methods: The participants included a sister-in-law, a brother, two daughters, and a friend of cancer patients. The participants were aged 23-53 and mostly female. They were asked to read four chapters of the book and evaluate it using the plus and minus method. Their impressions of the book are discussed in a semi-structured interview. The interviews were transcribed and analyzed using inductive and deductive coding with the help of the program Atlas.ti.

Results: The informal caregivers showed to be self-compassionate as well as self-critical in multiple ways. However, it was noticed there are obstacles to self-compassion. The intervention appealed to four out of five participants, despite some parts that are not fitting their situation yet. In addition, the topics emotions and values were found to be more appealing to this group than resilience and thoughts. Also, were the mindfulness exercises less appealing than the other exercises.

Conclusion: The findings of this research demonstrate the need for future research into how to overcome difficulties being self-compassionate, and which subjects are more suitable for a broader group of informal caregivers. Furthermore, a list of practical changes is provided, which can be used to adjust the intervention to a broader group of informal caregivers.

Keywords: informal caregivers, cancer, self-help intervention, self-compassion, qualitative research.

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1 Introduction

“A disease which affects us all” is how the Dutch Cancer Society (Koningin Wilhelmina Fonds voor de Nederlandse Kankerbestrijding; KWF) describes cancer. This is an accurate description when realizing that before our 75th year of life, one in three men and one in four women get diagnosed with cancer, so it is likely that we, or someone in our surrounding, get diagnosed with this disease (RIVM, 2020). Today, over 100 forms of cancer are known, and due to increased incidence and better treatments, more people are currently living with cancer. This ensures that much research is devoted to supporting patients and their environment in fighting this disease, because it is such a life-altering disease, which does not only affect the patient, but affects us all.

Growing research on this topic ensures there is more recognition for the fact that cancer not only affects the patient’s life, but also the lives of their loved ones. These people are called informal caregivers (Stenberg, Ekstedt, Olsson, & Ruland, 2014). Stenberg, Ruland, & Miaskowski (2010) did a literature review on the burden of informal caregivers of cancer patients and identified more than 200 problems. These problems include psychological problems including anxiety, confusion, depression and feeling guilty, social problems like being isolated, and role strain, besides physical health problems, including physical impairment through pain or sleep, and financial problems because no money can be earned since all time goes to the patient. Due to these extra problems, in addition to the problems they already experience without taking care of a patient, it is understandable that the needs they have increase. Sklenarova et al. (2015) found in their study that caregivers can even have considerably more unmet needs than the patients they care for. Research among 193 patients and caregivers showed 85% of informal caregivers reported unmet needs. These unmet needs can cause multiple forms of psychopathology, like panic disorders in 8% of caregivers,

depression in 4,5%, post-traumatic stress disorder in 4%, and anxiety in 3,5% (Vanderwerker, Laff, Kadan-Lottick, McColl, & Prigerson, 2005).

Despite the high challenges these informal caregivers face and their increased risk for psychopathologies, only few informal caregivers of cancer patients seek help. The reason they do not seek help could be insufficient self-compassion in this group, which is low in this group because often all attention is devoted to the patient, and informal caregivers become self-critical. This is in line with the research of Hlabangana and Heath Hearn (2020), which showed self-compassion is significantly lower in informal caregivers compared to the normal population. Although studies have examined, more quantitatively, the level of self-compassion in informal caregivers, no previous qualitative studies have examined the behaviour in which self-compassion (and self-criticism) manifests in informal caregivers. Yet, such insight can be important to better understand why they do not seek help, and to better tailor the interventions for informal caregivers. Another explanation could be that current interventions do not meet the needs they have as an informal caregiver. The existing interventions focus mostly on (how the informal carer can improve) the wellbeing of the patient, not so much on the well-being of the caregivers themselves. Kedia et al. (2018) performed research into existing interventions for informal caregivers and identified four categories. These categories include communication interventions, coping skills training interventions, multicomponent interventions and stress reduction interventions. The communication-based interventions are focused on the patient and provide the informal caregiver with information, support services, and tools (like a calendar or treatment plan) related to the treatment of the patient. Only one of the interventions based on coping skills (including problem-solving, self-efficacy and emotion regulation) showed significant change in self-efficacy and anxiety (Porter et al., 2011). This intervention included 14 telephone-based sessions of coping skill training and was not based on a theoretical framework. Also, some multi-component interventions are discussed, from which only two

interventions show significant results. Firstly, Badr, Smith, Goldstein, Gomez and Redd (2015) found significant improvements in psychosocial functioning among caregivers who received a psychosocial telephone intervention compared with a usual care control group at 8-week follow-up. Secondly, Sun (2015) reported that caregivers who received an educational intervention to enhance their physical, psychological, social, and spiritual Quality of life (QOL) showed significant improvements in psychological distress, burden, and social QOL at 12-week follow-up. The interventions focused on stress reduction gave positive results, as better social functioning was improved, but no significant impact was found (Kedia et al., 2018). Some interventions show significant improvement, but still, most interventions do not focus on the informal caregiver as an individual, lack support from a theoretical framework and lack easy accessibility.

To support informal caregivers in seeking help, it should be known how self-compassion manifests in this group of people, and fitting frameworks reflecting their needs should be used in an intervention. Fitting theoretical frameworks which could underpin such intervention could be Acceptance and Commitment Therapy (ACT) and self-compassion. ACT is a third-wave behavioural therapy, which core goal is to generate psychological flexibility and facilitate mental wellbeing. This is crucial in maintaining mental health because lower levels of psychological flexibility are related to higher levels of depressive symptoms, anxiety and stress (Han et al., 2020). Self-compassion is also focused on facilitating mental wellbeing. However, this theoretical framework focuses on being warm towards oneself when encountering pain and personal shortcomings, rather than ignoring them or hurting oneself with self-criticism. These two theoretical frameworks can facilitate the well-being of informal caregivers in multiple ways. First, ACT is a fitting theory for informal caregivers, because it focuses on changing an individual's relationship with their thoughts, rather than changing the content of the thoughts, like the fear of the patient not getting better or doubting if they can keep all balls in the air

(Feros, Lane, Ciarrochi, & Blackledge, 2013). Informal caregivers learn to accept challenging thoughts and feelings without being dominated by them. They gain awareness about their values and choose actions that are consistent with what they care about. ACT does not focus on reducing symptoms, but on enabling a person to act effectively towards their distressing symptoms by acceptance strategies, mindfulness techniques, and various behavioural approaches. A recent review of Han, Yuen, Lee, Zhou (2020) examined interventions based on ACT for informal caregivers. It showed that including ACT in a health professional guided intervention for informal caregivers ensured significant effects on the psychological flexibility of the individuals, which ensured this group was better able to maintain mental health in difficult times. And secondly, self-compassion is an important component for this group of individuals, because research shows this group often lacks self-compassion, which can lead to psychopathology. Besides, focusing on self-compassion can help the informal caregiver redirect the attention of the patient to themselves and develop healthier coping behaviour (Hlabangana, & Heath Hearn, 2020; Germer & Neff, 2013). Existing interventions focusing on self-compassion showed that an intervention based on this framework improved healthier behaviour and psychological wellbeing (Hlabangana & Heath Hearn, 2020). However, as mentioned earlier, in current literature, the knowledge of how self-compassionate behaviour manifests in informal caregivers lacks, which could be important in developing a fitting intervention for this group of people. Researching the ways in which informal caregivers are self-compassionate or self-critical could help develop a fitting intervention. This could be a suitable target in supporting informal caregivers, but the interventions focusing on these processes remain scarce.

An intervention that includes these two frameworks and could support the current unmet needs of informal caregivers, is the self-help book “hold-on for each other”. This book is developed by researchers of the University of Twente in cooperation with the VU medical

center. The primary purpose is to provide psychological support for the partners of cancer patients. The partner is guided through eight chapters, which all contain subjects the partner faces in living with someone diagnosed with cancer. These subjects include dealing with emotions, developing resilience, negative thoughts, setting priorities, the importance of positive emotions, communication, picking up life after recovery, and finally how to deal with the last part of life with your partner. ACT and Self-compassion can be traced in the book through psycho-education, exercises, and tips. The partners of cancer patients positively valued this intervention. However, informal caregivers include more than just the partners. It would be valuable to research whether this intervention based on self-compassion and ACT also applies to a broader group of informal caregivers.

When summarizing the previously stated information, it can be said that informal caregivers have multiple unmet needs when caring for a cancer patient, but often do not seek support for this. This could be due to the low level of self-compassion reported in informal caregivers. However, little is known about how self-compassionate behaviour manifests in this group of people, which could be important in understanding why they do not seek help and developing a fitting intervention. In addition, it could be that the existing interventions do not fit the needs of informal caregivers, and therefore do not seek help. To overcome this gap in the existing literature and interventions, this research investigates two research questions: (1) *“How are informal caregivers of cancer patients self-compassionate and self-critical?”* and (2) *“Is the intervention “Hold on for each other” appealing to informal caregivers other than partners and which parts should be changed to make it better suitable for them?”*

2 Methods

2.1 Design

To answer the research questions, a qualitative study, with semi-structured interviews, was conducted. Using a semi-structured interview scheme makes it easy to precisely get the information and all the same information needed from the respondents. But simultaneously, there was the possibility to ask explanatory questions to clarify the experience the respondents had. While reading the book, participants were instructed to apply the plus and minus method (Jong & Schellens, 2002). This is a frequently used method for text evaluations to track possible difficulties or problems in books, flyers and other forms of written text. For this research, the method includes putting plus signs at the parts they liked and found useful for their situation and putting a minus sign at the parts not fitting for them, unclear, not helpful or uninteresting.

2.2 Participants

The ethical consent committee of the University of Twente first approved the research proposal (requestnr: 210229), after which individuals in the environment of the researcher were asked to participate. The inclusion criteria were: (1) 18 years or older (2) takes care of a cancer patient (3) is not the partner of the cancer patient (4) willing to read (at least) four chapters of the book (5) willing to participate in an interview of approximately one hour and (6) Dutch-speaking. Recruitment was done through convenience sampling and the snowball method, which means existing subjects provided referrals to probable other subjects. This was a fitting method for this study, as the participants needed rare traits. Five persons wanted to participate and fulfilled the inclusion criteria. The relationship with the patient included a brother, a friend, a sister-in-law and two daughters.

2.3 The intervention Hold-on for each other

The participants were instructed to read the first four chapters of the book “Hold on, for each other” which all have a different subject, namely: (1) dealing with emotions, (2) developing resilience, (3) negative thoughts, and (4) setting priorities. The exact content per chapter can be found in Appendix C. These four chapters were chosen due to the limited time available for this research, and because the subsequent chapters are linked. Every chapter includes part psycho-education, followed by exercises, experiences of partners who helped develop the book, and practical tips. Besides, every chapter is summarized at the end, and the reader is asked what he or she wants to take from this particular chapter.

2.4 Procedure

The materials used in this research were an information letter (Appendix A), informed consent (Appendix B) and the book “Hold on, for each other”. The participants received the information letter, which stated the aim of the research and explained what participation in this research included. After receiving the letter, potential participants got a week of decision time, in which they could ask questions when needed. When the person decided to participate in the study, they needed to sign the informed consent, after which they were provided with the book and post-it notes in different colours by the researcher.

The participants used the plus and minus method to evaluate the book. For this study, the method includes sticking green post-its (being pluses) or blue post-its (for minuses). Green post-it should be used at the parts they like and are helpful for their situation, and a blue post-it at the parts that are not fitting for them, and are unclear, not helpful, or uninteresting. Also, they were asked to make suggestions about how the book could be adjusted to fit their situation and write a general comment about each chapter. They were instructed to read the first four chapters

of the book and give a sign to the researcher when they were done reading, so the interview could be planned.

After three weeks of time to read the book, the participants were interviewed for which a structured scheme was used (see Appendix D). The participants had the option to do the interview online or face-to-face. This took approximately one hour and was recorded with the consent of the participants. First, they got information about the interview, they were informed about the five parts of the interview, the way a semi-structured interview works, and they had the opportunity to ask questions. When the questions were answered, consent for recording the interview was asked, for which all participants gave consent

2.5 Interview schedule

The full interview schedule can be found in Appendix D. Background information was gathered, during the interview, including age, relation towards the patient, current state of the patient and respondent, and experienced burden. Secondly, a general impression of the book was discussed, which included questions about how they used the book, which chapter is their favourite, if the book had an impact, and if the participants think this intervention could help other informal caregivers. Thirdly, every chapter was discussed specifically, by asking questions about the use, appreciation and impact of the chapter. In addition, at this point, we went over the pluses and minuses they put on the post-its per chapter. Lastly, information was gathered about self-compassion and self-criticism in informal caregivers, which included questions about whether they were self-critical, and if and how/when they were self-compassionate.

2.6 Data analysis

During the interview, recordings were made which were transcribed verbatim. These transcripts were put in ATLAS.ti, which was used to code the interviews. For the first research question, concerning the self-compassion in informal caregivers, a combination of inductive and deductive coding was used, which means the codebook was partly set before the interviews. Three codes were already set based on the article of Köhle et al. (2017), namely usage, appreciation, and impact. The rest of the codebook was developed inductively, based on the gathered data. This method was used to bundle specific observations into a broader theory.

For the second research question, concerning the suitability of the intervention, an inductive coding method was used. This means the codebook was not set before the interview, the codes were based on the information gathered in the interviews. This method is a bottom-up approach that works from more specific observation (interview fragments) to a more general theory (Thomas, 2006). At this part, the plus and minus signs which the participants placed in the book were also considered.

3 Results

3.1 Description of the research group

Table 1 shows the demographic characteristics of the participants. Four out of five participants were female, and one participant was male. The average age was 42,2 years (SD = 10,48). One out of five participants completed high school and had no further education (HAVO), two out of five completed vocational education (MBO), and two out of five completed higher education (HBO). All participants had a paid job, and their work hours varied from 20 to 60 hours per week. The relationship towards the patients was diverse, namely a sister-in-law, a brother, a friend, and two daughters.

Table 1

Demographic information of the participants and patients.

P	Gender	Age	Highest education	Work situation*	Relationship to patient	Gender patient	Age patient	Length of disease
1	Female	44	HAVO	20 hours	Sister-in-law	F	42	2 years
2	Male	42	MBO	40 hours	Brother	F	44	1 year
3	Female	23	HBO	37 hours	Daughter	F	50	7 years
4	Female	50	MBO	60 hours	Friend	F	48	2 years
5	Female	53	HBO	30 hours	Daughter	F	52	9 months

* Reported in hours per week

3.2 Negative and positive impact of the disease on the caregiver

The participants described both positive and negative impacts of the disease of their loved one on their own quality of life, which could be divided into six categories (Table 2).

Table 2*Impact of illness loved one on participants' Quality of Life*

Burdens	P*	Fragment
Negative impact		
Emotional	5	<i>'But also, the feeling that you're not there for your own family" "Also much ruminating and nightmares. When I visited her, I always wanted to go really much, but if I went back home, I'm always very sad and down.'</i>
Physical	3	<i>'At certain moments when I heard about her, I experienced a "freeze" and I still do sometimes, if I have the idea that something bad will happen I experience bodily sensations'</i>
Social	3	<i>'That we don't undertake as much spontaneous activities with the family as we used to, like with Christmas, Easter and on Sundays we would sit together'</i>
Positive impact		
Appreciation of life	4	<i>'You will appreciate things more, you think more about thing and enjoy the moments you have together more.'</i>
Openness	2	<i>'yes, it sure does something for you. You talk about certain things you would otherwise never have talked about'</i>
Priorities	2	<i>'But also, a bit of laziness. That you think it can be over in a moment, what are you worried about.'</i> <i>Interviewer: where do you see the laxity in it?</i> <i>"Yes, for example, the household is not the most important.'</i>

* Number of participants who reported this burden.

All five patients mentioned experiencing some type of burden. First, all participants experienced emotional burden. This could range from worry and anxiety to self-blame and negative self-image. Besides, three out of five participants experienced physical burdens, like sleeping problems and unpleasant bodily symptoms. For example, one of the participants mentioned experiencing a startle response every time someone unexpectedly mentioned something about the patient. Also, two participants mentioned social burden, like less spontaneously undertaking activities, because the participants felt sorry for the patient that she could not do this anymore, having less time to meet friends or conflict with their partner due to being fractious due to the stress.

On the contrary, four out of five participants also mentioned experiencing positive changes, which can also be divided into three categories. First, four participants experienced more appreciation of life, which ensured they had more joy in life due to this awareness. Secondly, two participants experienced more openness, which is experienced by talking more openly about certain topics that normally would never be talked about. And lastly, two participants experienced better being able to set priorities and make different choices. One person could not mention any positive changes and felt like her parental home was taken from her when her mother got sick, and their family grew apart.

3.3 Research question 1

To answer the first research question, “How are informal caregivers of cancer patients self-compassionate and self-critical?” the interviews were analyzed, which resulted in several forms of self-criticism and self-compassion.

3.3.1 In which ways are informal caregivers self-critical?

When it comes to informal caregivers being self-critical, 48 fragments were selected from the interviews, which can be divided into three categories (see Table 3). Firstly, it was discovered that informal caregivers are harsher towards oneself than another. Which expresses in not allowing themselves to take time for themselves. The informal caregivers often also do not prioritize themselves. Besides, they expect a higher standard from themselves, and they have a hard time allowing their thoughts and emotions to themselves. Secondly, it was identified that informal caregivers do not want to show their weakness to others. They do not show their emotions to others or push them away. In addition, they are reluctant to ask others for help, because this can be perceived as a weakness. And when exhausted, they still rather not show that and continue. Lastly, it was identified that informal

caregivers participating in this study feel guilty or angry. Guilt was in this situation due to the fact that the informal caregiver had less time for her own family and abandoned them, and anger was related to the fact that their loved one got sick. Besides, it could be noticed during the interviews that most participants experienced it as easier to name ways in which they were self-critical and could name more different ways in which they were self-critical.

Table 3

Self- criticism reported in informal caregivers.

Aspects	P*	Fragment
Being harsh	5	
- <i>Prioritizing other above self</i>	4	<i>'If someone asks me to do something, I will do that first. I do not have time for myself.'</i>
- <i>Not allowing themselves to take time</i>	3	<i>'Sometimes I am extra tired but then it is just: keep going.'</i>
- <i>Not allowing emotions or feelings</i>	3	<i>'You think more about where your emotions come from and then I still think: stop whining, my sister is going to die and you are whining about this.'</i>
- <i>Set High standard</i>	1	<i>'I often set the bar too high for myself. I am not easily satisfied and have to be able to handle everything from myself.'</i>
Not wanting to show weakness	5	<i>"I always try to keep myself strong and when the time comes, I break."</i>
Feeling guilty or angry	2	
- <i>Guilty for not being able to full fill social roles</i>	1	<i>"But also that you feel like you're abandoning your own family. You can't divide yourself in two, and then I put her on one."</i>
- <i>Angry for the situation they are in</i>	1	<i>'I can get angry about the fact that this is happening to your sister and your parents. Is there no one who thinks I'll skip this family for once?'</i>

** Number of participants that mentioned this impact*

Table 4*Self-compassion reported in informal caregivers.*

Aspects	P*	Fragment
Being mild towards oneself	5	
- <i>Taking perspective</i>	5	<i>"I can think I wish I had done that sooner, but on the other hand I think I can only be in one place at a time"</i>
- <i>Allowing oneself as they are</i>	4	<i>'What I take with me is that in this situation the patient gets all the attention very easily, but that you may be there too.'</i>
- <i>Being aware of your feelings</i>	3	<i>'Yes, as we just said, I try to look more consciously at how I feel and why I feel this way.'</i>
Connecting to others	4	<i>'That you can read in the book that you are not alone.'</i>
Self-care	2	<i>"Yeah, that's just being at home and being busy with things. I get my satisfaction from that, when I've been to the thrift store and I get something nice again. [...]"</i>
Acceptance	1	<i>"That's not something for me, then you start thinking too much. Then you think too much about it again and you can't change it anyway"</i>

3.3.2 *In which ways are informal caregivers self-compassionate?*

When it comes to informal caregivers being self-compassionate, 44 fragments were selected, in which four categories are discovered in this participants sample (table 4). Firstly, informal caregivers showed various ways of being mild towards oneself. For example, by taking perspective in difficult situations, by allowing oneself to be present, by allowing oneself to enjoy things in life, but also by being aware of their emotions and what they need. Thirdly, they connect to others in their tough times, by asking for help, talking to others, and knowing they are not alone in this situation. Fourthly, they engage in self-care by being aware of how they feel and taking time for themselves when needed. Lastly, one of the caregivers accepted the situation as it is. In addition, multiple informal caregivers mentioned more motivation was needed to put themselves first. For them, it was easier to give in and help someone else first.

3.4 Research question 2

In the following section, research question two is discussed; ‘Is the intervention “Hold on for each other” appealing to informal caregivers other than partners, and which parts should be changed to make it better suitable for them?’ Three aspects of the intervention are considered, namely the usage, appreciation and impact. The appreciation will first be discussed in general, after which the appreciation per chapter is considered.

3.4.1 Usage of the intervention

The category usage is divided into two subcategories, namely extent of use and manner of use (Table 5). As can be seen in Table 3, almost all participants read the four chapters. However, most participants did not make the exercises, but only read them and reflected on them. Also, a clear difference can be seen between participants who did and did not do the mindfulness exercises. Three participants tried all the mindfulness exercises, and two participants did not try any. The reason that there is such a clear difference between the participants is that it is an exercise affected by the beliefs they have about mindfulness.

Table 5

Usage of the different chapters.

Participant	Chapter 1	Chapter 2	Chapter 3	Chapter 4
1 Read text?	Yes	Yes	Yes	Yes
Completed Exercises?	Read only	Read only	Read only	Read only
Listened to mindfulness exercises?	No	No	No	No
2 Read text?	Yes	Yes	Yes	Yes
Completed Exercises?	Yes	Read only	Yes	Partly*
Listened to mindfulness exercises?	No	No	No	No
3 Read text?	Yes	Yes	Yes	Yes
Completed Exercises?	Read	Read only	Read only	Read only
Listened to mindfulness exercises?	Yes	Yes	Yes	Yes

* Partly: participants read less than half of the text or made less than half of the exercise.

Table 5 (continued)

4 Read text?	Yes	Yes	Yes	Yes
Completed Exercises?	Yes	Read only	Yes	Partly*
Listened to mindfulness exercises?	Yes	Yes	Yes	Yes
5. Read text?	Yes	Yes	Yes	Partly*
Completed Exercises?	Read	Read	Read	Partly*
Listened to mindfulness exercises?	Yes	Yes	Yes	Yes

How they used the book differed more. Three out of five participants told they divided the text into multiple smaller pieces. One participant explained that he found the text challenging to read and needed a frequent break: ‘interviewer: You told me that you found the text quite challenging to read.’ ‘Yes, I tried to divide it up into smaller pieces, then I would get something to drink or go for a walk and read further after that. Some pieces were also more interesting than others.’

3.4.2 General Appreciation of the intervention

When asked what the participants thought about the intervention. Four of five participants were predominantly positive and thought the intervention was a helpful addition at this time. One participant was less positive about the intervention and stated that because it was hard to read, only a limited number of people would profit from the intervention, and that something more interactive (with videos for instance) would be more appealing. General appreciation of the intervention can be found in Table 6.

Table 6

Positive and negative aspects of the intervention as a whole.

Aspect	P*	Fragment
		<u>Positive aspects</u>
Brings more awareness	4	‘The awareness through the book is good.’

Table 6 (continued)

Usable in daily life	3	<i>"These are tips for everyday life"</i>
Positive approach	3	Interviewer: So, I really notice all those positive things that suit you? <i>"Yeah, because if you are not positive you won't keep it going and you won't make it."</i>
Sequential related exercises.	1	Interviewer: do you also like that the exercises are continued? <i>"Yes, because if you have a short exercise then I think it will help you less. Then it sticks in memory more and goes deeper."</i>
<u>Negative aspects</u>		
Hard to see if it usable for this situation or more on a personal level	3	<i>"It's hard to see if it's really linked to my sister's illness. Is sleeping, for example, linked to that? I do not know. Difficult to separate the disease from the personal."</i>
Lack of sobriety.	3	Interviewer: So a little more acceptance? <i>'Yes, you sometimes miss that sobriety a bit.'</i>
Mindfulness	3	<i>"It's something that doesn't fit me, I'm too sober for that. It's too hovers, actually."</i>
Not appealing/accessible	1	<i>'Making something interactive makes it more accessible. As with movies, a lot of people just hate to read and especially because it's quite hard material.'</i>

* Number of participants who reported this aspect.

According to the participants, the positive aspects of the intervention include that it brings more awareness about the situation they are in and how they stand in it. Also, did the participants appreciate they got practical tips they could use in daily life, and that the book has a positive approach to the situation. And lastly, it was appreciated that the exercises are sequentially related. The negative aspects reported included it was difficult to decide if it was usable for this situation or on a more personal level. Also, was it remarkable that all participants were sober-minded and believed the intervention lacked this sobriety. Besides, the mindfulness exercises were mentioned as negative, the participants did not allow themselves to take time to do this, or they did not feel it was something that fit their personality. Lastly, one person

mentioned the intervention was not appealing, which could be changed by making it more understandable by short videos that would lower the threshold of using the intervention.

To obtain more specific comments on the book, participants were instructed to apply the plus and minus method while reading the chapters (Table 7). The overview of these specific comments gives a general insight into how participants appreciated the intervention.

Table 7

Overview of the plusses and minuses per chapter.

Chapter	Marked as favorite by (P*)	Reason for marking as favorite	Minus (-)	Plus (+)
Chapter 1 (emotions)	2	<i>'In the first chapter you got some more information, I liked that'</i>	10 (25%)	23 (38%)
		<i>'The chapter on emotions was interesting to read, there were many recognizable things in it.'</i>		
Chapter 2 (resilience)	0		12 (29%)	9 (15%)
Chapter 3 (thoughts)	1	<i>'Chapter 3 about thoughts is my favorite chapter, the other chapters are also about thoughts. That's the core of all the chapters a little.'</i>	10 (25%)	11 (19%)
Chapter 4 (values)	2	<i>'Even if your partner isn't sick, it's useful, just to think about what's important in your life. And how do you do it right? [...]'</i> <i>'So, you know you need to enjoy more of what you do have. I'm more aware of what I have, and because of that this really was my favorite part. It gives perspective of all you do have. I got most support out of this.'</i>	9 (21%)	17 (28%)
Total			41 (100%)	60 (100%)

* Number of participants that mentioned this chapter to be their favorite.

The participants were asked why they put a plus or a minus on the post-its. When putting a plus, the participants mentioned the following terms: appealing, agree with the part, recognizable, pleasant to read, important, helpful, and motivating. The following term explained a minus: not helpful, not appealing, not fitting, woolly and too difficult. Two out of four participants mentioned chapter one (about emotions) as their favourite. The reason participants appreciated chapter one positively is they better understand their emotions. One of the participants gave an argument that because she did not live with the patient, she could better distance herself from the situation when at home: 'Because I still have my own place at home and do not live with her, this chapter did not feel as fitting for me as the other chapters'. Three other participants also gave this argument at different parts of the interview. Besides, did two participants mention chapter four (about values) as their favourite chapter because of the positive influence: 'The fact that you should enjoy your family and be thankful for the moment you still got together. The positive influence of this chapter.' Chapter three was mentioned as a favourite chapter (about thoughts) by one participant, because she could use it as guidance for the other chapters, because the other chapters can also be related to thoughts. And lastly, chapter two (about resilience) was not mentioned by any participant and is the only chapter that got more negative comments than positive ones. The reason for this was that most participants mentioned they have their own place to go back to, which ensures that pressure does not become too much.

3.4.3 General suggestions.

During the interview, participants came up with suggestions to improve the intervention as a whole. In total, 17 suggestions were given, which were divided into two categories, namely general aspects of the intervention and aspects related to the difference between partners and the broader group of informal caregivers (Table 8).

Table 8*Suggestions for improvement according to respondents*

Suggestion	P*	Fragment	General
Alternative exercises	3	<i>'Maybe some other exercises in addition to the listening exercises. Exercises where you don't have to turn inward like that.'</i>	
Extra support in exercises	3	<i>'No, I'm not very good at digging into myself, you have to dig those exercises every time. It would be nice if they helped you on your way.'</i>	
More depth	2	<i>'This chapter is all pretty obvious, I already knew most of it, it should have gone a little more into depth. For example, I know how to relax.'</i>	
More statements	1	<i>'As on p. 94 that statement appealed to me. That is encouraging, because it makes you more aware. I would like to see more of that throughout the book.'</i>	
More sobriety	1	Interviewer: So a little more acceptance? <i>'Yes, you sometimes miss that sobriety.'</i>	
More Interactive	1	<i>'It doesn't seem very accessible to me, a whole category of people can't figure it out. I'd rather do something interactive, in a spoken way, like the headspace app. It must really be your thing to pick up a book and start working on it.'</i>	
<u>Difference between partner and other informal caregivers</u>			
Fitting exercises	4	Interviewer: If you adapted this exercise to the relationship with your sister, maybe it would have helped you? <i>"Yes, I think so. Is a good exercise"</i>	
Fitting text	2	<i>'And the word relationship is often too quickly linked to a love relationship. Maybe they should word "relationship" differently.'</i>	

* Number of participants that mentioned this suggestion

Firstly, because some exercises were not experienced as fitting, the participants requested alternative exercises. Secondly, three participants stated they would like more support in formulating or recognizing their thoughts, because they found it difficult to articulate what they are thinking and had difficulties with some exercises because of that. Thirdly, there were suggestions about the depth of the information given in the book, which was found to be shallow. The last three suggestions were all mentioned by only one participant, which included wanting more statements from other informal caregivers, a more sober approach in the book, and the last suggestion is to make the intervention more interactive with videos so the intervention is more accessible. In addition, two suggestions were made to make the

intervention more suitable to the situation of the broader group of informal caregivers. Suggestions included adjusting the exercises and the text to make them more fitting for their situation, since these informal caregivers are not the partners of the patient.

3.4.4 Appreciation per chapter

At this point, the appreciation per chapter will be discussed. This is done by first providing a brief description of the content discussed in the chapter. After this, the positively and negatively valued aspects are discussed, and the suggestions are discussed if the participants named them.

3.4.4.1 Chapter 1 - Dealing with your emotions. Feeling small and standing tall.

Text and exercises to help the reader gain insight into their emotions and how to deal with them. After some information about positive and negative emotions, follow exercises about how the reader deals with emotions, and a listening exercise. The reader learns to recognize, accept, and express emotions. The exercises in this chapter include the following: (a) Which emotions do you recognize in yourself? (b) How do I stand tall? (c) Allowed to be small again, (d) Giving and receiving compassion, and (e) Mindfulness: returning in the present.

The first chapter is appreciated very well. 23 positive fragments were selected and 10 negative ones. The positively and negatively appreciated aspects of this chapter can be seen in Table 9.

Table 9

Positive Aspects of Chapter 1

Aspects	P*	Fragment
Exercise A <i>Which emotions do you recognize in yourself?</i> This exercise includes a list in which emotions can be marked that are recognized by oneself.	3	<u>Positively valued</u> <i>'The list of emotions does make you think and it is nice that they ask you afterwards whether you have ticked positive or negative emotions, that gives it more awareness. If they left this out, you could never imagine so many emotions.'</i>

* *Number of participants that mentioned this aspect*

Table 9 (continued)

Exercise B <i>How do I stand tall?</i> This exercise is about recognizing emotions in oneself and connecting those to situations and behaviour	3	<i>'[...] those with the situations too, then you can write it off your mind.'</i>
Exercise C <i>Allowed to be small again.</i> This exercise lets the reader think about how they dealt with emotions when they were young.	1	<i>' May it be small again. I used to be very angry, then I cried, but I don't do this anymore. Then I was comforted with hugs and feeling safe and secure. That's something to think about next time and ask for this.'</i>
Information	3	<i>'The explanation is less flexible, that keeping you up in the short term can help, but in the long run it will cost you more than it will yield you.'</i>
Statements of other informal caregivers	2	<i>'Because you think about where you stand in life and you think yes, what is written here is actually true again. You think: hey damn it, that was true. While you pushed that away at the time, it was true.'</i>
Subject of the chapter (emotions)	2	<i>'I found the chapter helpful, it was very much about emotions and how you can deal with certain things. I think it's good that attention is devoted to this, because not everyone just knows about it. So it is important that you know a bit more about that before you can change anything about it.'</i>
Recognition	2	<i>'Page 24 that physical component they name. At certain moments when I heard it I had a kind of freeze and I still have that sometimes, when I have an idea that something bad is going to happen then I have a physical sensation. '</i>
Being able to do it alone	1	<i>'Yes, also good to think about, especially because you can do something alone, you can just work on it for a while.'</i>
<u>Negatively valued</u>		
Exercise C <i>Allowed to be small again.</i> This exercise lets the reader think about how they dealt with emotions when they were young.	3	<i>'This one on page 34 appealed to me less, being able to feel small. That's just not really for me. The exercises are very personal.'</i>
Exercise E <i>Mindfulness: returning in the present.</i> This exercise invites the reader to be mindful about the present moment without doing something with this.	1	<i>'I didn't like that, then you might get too close to making yourself small again. That's why I'll skip this. You don't want to think about yourself, then you become vulnerable, and you don't want to be. Making myself vulnerable doesn't suit me, I always have to be there for someone else. I don't know why I think that, but that's something that suits me.'</i>

Firstly, three exercises were appreciated in this chapter, namely exercises A, exercise B, exercise C. However, only one participant appreciated exercise C as positive, because it gave her new insight, whereas it was appreciated negatively by three participants who argued they did not like it because of personal preference and because it made them feel weak. Also, some other positively values aspect were named, which include obtaining new

information applicable to the situation (which helps understand themselves better), the statements of other informal caregivers given in the chapter, the subject of this chapter. Also, some comments were made about the recognition of aspects discussed, and the fact that the participants could work on it alone. Besides exercise C, there was one more negative aspect named by one participant, namely listening exercise E.

3.4.4.2 Chapter 2 - The resilience plan. How do you keep up?

The question 'How do I hold up?' is discussed. Using text and exercises the reader will develop their resilience plan. This will help them stay vital in difficult circumstances. Four important points are discussed: (1) don't demand too much of yourself, (2) use of resources, (3) don't let your thoughts drive you crazy, and (4) make time for moments of relaxation. Subjects included are stress and its consequences, resilience, the importance of relaxation and thoughts. The exercises in this chapter include the following: (a) How much do I ask of myself? (b) Ensuring relaxation, and (c) Mindfulness: It's hard to be human.

This chapter is the only chapter that got more negative appreciations than positive ones. 12 negative fragments were selected, and nine positive ones. Both positive and negative aspects can be seen in Table 10.

Table 10

Positive Aspects of Chapter 2

Aspects	P*	Fragment
<u>Positive aspects</u>		
Exercise B <i>Ensuring relaxation</i> This exercise provides the readers with a list of relaxing activities.	4	<i>'I thought the list of enjoyable activities was good, that's very nice that you can see for yourself what you've done this week and that you can experience what you enjoy and whether you can make more time for that.'</i>
Exercise C <i>Mindfulness: It's hard to be human.</i> This exercise helps the readers to become aware of the emotions they experience at this moment.	1	<i>'I didn't know about mindfulness yet and I thought it was a nice new way to try it out.'</i>

* *Number of participants that mentioned this aspect*

Table 10 (continued)

Usable in daily life	2	<i>'They are tips for everyday life.'</i>
Information	1	<i>'The part of guard your boundaries. Because you read that, you can still feel a boost to tell it at work, for example. And the website is also a good addition.'</i>
Statements of other informal caregivers	1	<i>'Because you read about it, you can still feel a boost to tell it at work, for example.'</i>
Subject of the chapter (resilience)	1	<i>'The subject is also very appealing, because it's all so close, you just come across it at this time.'</i>
Self-compassion	1	<i>'It is the self-compassion story that if you take care of yourself, it will benefit someone else.'</i>
<u>Negative aspects</u>		
Exercise A <i>How much do I ask of myself?</i> This exercise provides the reader with awareness about their hours spent on certain tasks such as work, sleep, and self-care.	4	<i>'Page 46 this did not appeal to me, how much I demand of myself, this does not match my personal situation, it could provide insight to others, but I still have a grip on it at the moment.'</i>
Exercise C <i>Mindfulness: It's hard to be human.</i> This exercise helps the readers to become aware of the emotions they experience at this moment.	3	<i>'So the listening exercise is the same again. That's not what, then you start thinking too much. Then you think too much about it again and you can't change it anyway.'</i>
The subject of the chapter (resilience)	3	<i>'Because I can also live my own life, this chapter was less appropriate in my situation.'</i>
Text about resources	2	<i>'The part about the resources here, that didn't work for me because I didn't have to do any shopping. It was more the mental support.'</i>

The positive aspects include exercises B and listening exercise C. Especially, the exercise B was named often and was positively valued by four participants. The participants liked the positive perspective and awareness of positive aspects of life. Other positive aspects which were mentioned less often are the usability of this chapter in daily life, the information provided in the text, the statements of other informal caregivers in the chapter about their experience with this topic, the subject of this chapter (resilience) and self-compassion. The negative aspect mostly named includes exercise A, was named because it was less applicable, as informal caregivers do not live with the patient, and that the tasks often are divided between several people in the environment of the patient. Other negative aspects named

include the subject of this chapter, the text about resources, and listening exercise C. As can be seen, the subject of this chapter is named positive by only one participant, whereas three participants named it a negative aspect, which indicates this is a less fitting topic for this group of informal caregivers. No suggestions were made.

3.4.4.3 Chapter 3 - My mind is working overtime.

This chapter continues with the exercises of the last chapter about relaxation and proceeds with going deeper into thoughts and especially negative ones. This chapter will help to reduce ruminating and negative thinking. This will be done by explaining that thinking is a logical way of coping with difficult circumstances, however, this can turn around in excessively ruminating and negative thinking, which can ensure extra stress. Using exercises, the reader will learn to name thoughts, taking distance from thoughts and approaching everything step by step. Also, mindfulness is introduced to deal with thoughts. The exercises in this chapter include the following: (a) Ensuring relaxation, (b) Naming thoughts, (c) Carrying thoughts and feelings with you, (d) The worriesbox, and (e) Mindfulness: A break from the thoughtsfactory.

This chapter got ambivalent comments from the participants, 10 negative and 11 positive fragments were selected. Both positive and negative aspects can be seen in table 11.

Table 11

Positive aspects of chapter 3

Aspects	P*	Fragment <u>Positively valued</u>
Exercise E <i>Mindfulness: It's hard to be human.</i> This exercise the reader is motivated to adopt another way of thinking by only noticing the thoughts and not paying attention to the content.	3	<i>'Those listening exercises. I liked that and can offer you something, but it really personal, I would like that.'</i>
Exercise B <i>Naming thoughts.</i> This exercises the reader must write their thoughts in thinking clouds like a strip figure	2	<i>'The exercise on page 66, I think it's good that you write things off yourself sometimes and you're encouraged to do that in this chapter. By writing it down you can look at it differently and more consciously.'</i>
Exercise D <i>The worriesbox</i> This exercise includes writing your thoughts on paper and putting them in a box.	1	<i>'That worry box, I sometimes do that myself when I'm with people. Then I say give me all my worries and when I'm in the car I'll throw them all out the window and they blow away.'</i>

* Number of participants that mentioned this aspect

Table 11 (continued)

Statements of other informal caregivers	2	<i>'[...] there was another experience of someone. The experiences of others that are written after the exercises are really motivating.'</i>
Recognition	2	<i>'Page 64 is positive, I do indeed often think about the future, then I lie in bed at night and I start thinking. How are we supposed to go on and I wonder what if she dies.'</i>
Learns how to deal thoughts	1	<i>'Not everything suited me, but this chapter does offer some tips on how to get rid of certain thoughts or how to deal with them.'</i>
Usable in daily life	1	<i>'Movement helps anyway and is something that can be used in daily life, the whole book is that.'</i>
<u>Negatively valued</u>		
Exercise D <i>The worriesbox</i> This exercise includes writing your thoughts on paper and putting them in a box.	3	<i>'Page 68, that worry box, that appealed to me less. That's something that doesn't suit me, I'm too sober for that. Actually too floaty.'</i>
Exercise B <i>Naming thoughts.</i> This exercises the reader must write their thoughts in thinking clouds like a strip figure	2	<i>'Naming thoughts is difficult with that exercise. When I talk about it like now, I find it even easier than if I read or have to write it down in the book.'</i>
Information	2	<i>'I didn't always agree with the chapter. The negative spiral is different because you go back to your own safe world. The fear of being left alone is somewhat less than if it is your partner.'</i>
<u>Suggestions for improvement</u>		
Alternative exercises	1	<i>'Yes, for example, with that worry box, you either like that or you don't like that and then that exercise falls away again and then the chapter is even shorter. An alternative exercise might be appropriate.'</i>
Wanting more support in making the exercises	1	Interviewer: Would you like to see that in this exercise, that they help you on your way. <i>'Yes that would really help.'</i>

The positive aspects included three exercises, first, the listening exercise E, exercise B, and exercise D. However, exercise D was only appreciated positive by one person who already applied a similar exercise in her life before reading about it in the book, whereas it was appreciated negative by three participants who mentioned they did not want to consider it because it seemed like something that does benefit them. Exercise B was also mentioned on both sides, in which writing about thoughts was experienced positively, while formulating those thoughts was difficult for two participants. In addition to these exercises, some other aspects

were also appreciated positively, namely the statements of other informal caregivers given in the chapter, recognition in the chapter, the aspect of learning how to deal with thoughts, and the usability of the chapter in daily life. The negative aspects mentioned in this chapter include, as mentioned earlier, exercise D and B, but also the information provided in the chapter. The participants suggested some changes for this chapter, namely, they would like to be supported more in formulating their thoughts, for example at exercise D, and would like more depth in the information about the thoughts.

3.4.4.4 Chapter 4 - What's really important at this moment?

This chapter emphasizes the fact that cancer is an intensive, life-threatening disease. Because of it, you realize how precious life is, which makes it important to know what is important for you in this time. Using text and exercises insight is gained into values that will help to get more out of life, the relationship with the patient or to make better choices. When living up to values that are important for an individual, obstacles can be recognized beforehand and analyzed. This will help see that some obstacles are sometimes only thoughts and can help to deal with them. Also, is explained how a friendly attitude towards yourself can help to stay balanced. The exercises in this chapter include the following: (a) Carrying thoughts and feelings with you, (b) values in your relationship, (c) values in your life, and (d) Mindfulness: Being kind towards yourself.

With nine negative fragments and 17 positive ones, chapter four is appreciated well. Both positive and negative aspects can be seen in table 12.

The positive aspects included two exercises, namely exercise C and the listening exercise D. In addition, some other aspects were appreciated positively, namely, all participants named the awareness gained through this chapter, the clear information in the chapter, the fact it is usable in daily life, recognition in the chapter and the statement of other informal caregivers. The negative aspects mentioned in this chapter include four exercises. First, exercise B was mentioned because the values did not fit their relationship with the patient, which of course differs from being the partner of the patient. Secondly, exercise A and listening exercise D.

Table 12*Positive aspects of chapter 4*

Aspects	P*	Fragment
<u>Positively valued</u>		
Exercise C values in your life. This exercise the reader becomes aware of the values they find important in life and if they live up to them.	1	'That you consider the obstacles of actions. I think it is very good that you write this down, because you become more aware of it and you know this is what I want to achieve and in your head you can often think of it very nicely but if it is on paper and you If you look at it, you do a lot more with it.'
Exercise D <i>Mindfulness: Being kind towards yourself</i> . This exercise the reader learns to develop self-compassion by means of mildness meditation. They learn to first be friendly towards oneself and only later on towards others.	1	'The meditation was nice again, the moment you take time for it, you also take time for yourself.'
Awareness	5	'Especially that they really go into what you find important in a relationship and consider if you show that and if you do that enough? Or does that need more. You really become aware of that, which is why the exercises are good.'
Clear information	1	'And the text too, very clear explanation.'
Usable in daily life	1	'Page 86: tips for the exercise values in your relationship, that appealed to me, they really help me.'
Recognition	1	'Some recognition. Sometimes you think the world is so dark and everyone only thinks of themselves, but that is not the case.'
Statements of other informal caregivers.	1	' like those examples of others are always good, that you have the goal and the action as with this exercise.'
<u>Negatively valued</u>		
Exercise B <i>values in your relationship</i> . This exercise the reader becomes aware of the relationship they have with the patient.	3	'As on page 81 are the values that are important in a relationship, those values should be changed.'
Exercise A <i>Carrying thoughts and feelings with you</i> . This exercise follows on the exercise in chapter three and provides an evaluation moment to reflect on what the exercise meant for them.	1	'Carrying thoughts and feelings with you. That's what I was talking about with those notes. If I write that down and put it in my pocket, I take it out in the evening and do nothing with it anymore.'

* *Number of participants that mentioned this aspect*

Table 12 (continued)

Exercise D <i>Mindfulness: Being kind towards yourself.</i> This exercise the reader learns to develop self-compassion by means of mildness meditation. They learn to first be friendly towards oneself and only later on towards others.	1	'Listening exercise, kindness to yourself, has a really unpleasant voice and the intervals too, I was almost waiting for him to talk again, I almost thought I had my sound turned off.'
<u>Suggestions for improvement</u>		
Adjusting the values named.	1	'I feel like it's more for the partner and I also had less to think about. If they would adjust the exercises, you would look at it differently.'
More Statements	1	'And then on page 94 a statement that appealed to me. That is encouraging, because it makes you more aware. I'd like to see more of that.'
Change voice listening exercise	1	'If you could change that, it would be better. I would prefer it if it was a female voice. Because then it comes across as more pleasant.'

The positive aspects included two exercises, namely exercise C and the listening exercise D.

In addition, some other aspects were appreciated positively, namely, all participants named the awareness gained through this chapter, the clear information in the chapter, the fact it is usable in daily life, recognition in the chapter and the statement of other informal caregivers.

The negative aspects mentioned in this chapter include four exercises. First, exercise B was mentioned because the values did not fit their relationship with the patient, which of course differs from being the partner of the patient. Secondly, exercise A and listening exercise D.

This chapter got the most suggestions, which included changing the values named in this chapter to more fitting ones for different situations. Also, one participant would like to see more experiences from others because these are motivating. And, lastly, the voice of the meditation exercise should be changed according to one participant, because it was unpleasant to listen to and the breaks were too long. This could be adjusted, for instance, by using a female voice.

3.4.4.5 Impact

All participants experienced a positive impact. Four out of five participants profited so much from the book that they would recommend others to read it. In addition, four participants reported they will read the book again when they are struggling. The other two rather thought that the book will end up in a drawer and will not be used again. To determine which impact the book had on the participants, fragments were selected, which showed whether they experienced a positive impact, no impact at all, or negative impact. These fragments are schematically presented in Table 13 and 14.

Table 13

The positive impact of the intervention.

Impact	P*	Fragment
I gained insight in:	5	<i>'You read that and then you start looking at things in a different way, such as your relationship with your sister. Everything just goes on in life, but if you read this you will think about it anyway'</i>
- <i>That compassion is needed</i>	4	<i>'For me personally also, that I am a bit more aware that sometimes I can also ask someone else to go with her to the hospital if it doesn't suit me'</i>
- <i>Values</i>	2	<i>'So you can see what things are important to you and what your relationship with your sister is like.'</i>
- <i>Emotions</i>	1	<i>'You really do think about it. That you notice that you are worrying and become aware that you only live once. Just make the best out of it.'</i>
I became more aware of:	5	
- <i>Emotions</i>	3	<i>'Recognizing those emotions in yourself, it's nice that you think about it. The awareness.'</i>
- <i>Positive aspects of their life</i>	3	<i>'Yes, that you are aware of the moment. Maybe your house or your car is not beautiful but look at what you do have: the space, 2 great kids, happily running through the garden. You have to cherish those moments.'</i>

** Number of participants that mentioned this impact*

Table 13 (continued)

- Behaviour	3	<i>'That you consider the obstacles of actions. I think it is very good that you write that down, because you write that down you first of all become more aware of it and you know this is what I want to achieve and in your head, you can often think of it very nicely but if it is on paper and you if you look at it, you do much more with it'</i>
I became more aware of:	5	
- Emotions	3	<i>'Recognizing those emotions in yourself, it's nice that you think about it. The awareness.'</i>
- Positive aspects of their life	3	<i>'Yes, that you are aware of the moment. Maybe your house or your car is not beautiful but look at what you do have: the space, 2 great kids, happily running through the garden. You have to cherish those moments.'</i>
- Behaviour	3	<i>'That you consider the obstacles of actions. I think it is very good that you write that down, because you write that down you first of all become more aware of it and you know this is what I want to achieve and in your head, you can often think of it very nicely but if it is on paper and you if you look at it, you do much more with it'</i>
I was able to distance myself from the situation	3	<i>'yes that is something that really brought me something, writing it down really helps to distance myself from the situation'</i>
I Felt supported	3	<i>'Actually, it's an extra pillar of support. It gives you something to hold on to, as the title says.'</i>
I gained knowledge about emotions	2	<i>'[...] that you might be able to distinguish between emotions a bit more. You think more about where your emotions come from.'</i>
I can deal with thoughts	2	<i>'That your thoughts don't confiscate you, but that you can control it''</i>
Others	1	
- I gained knowledge about self		<i>'That you get a little more knowledge about what is happening, that they get a better grip on it. Everything happens to you and you have no idea that there is a structure to it.'</i>

The arguments most often mentioned are 'I gained insight' and 'I became more aware'. These two aspects were mentioned by all five participants and have some overlap. However, the difference between these two aspects is that gaining insight is about learning something new

about yourself or your situation and becoming aware is paying more attention to something you already knew, but which went to the background. The participants gained insight into three aspects, all related to the different topics of the chapters. Awareness was gained about emotions. The participants, for instance, mentioned they noticed emotions more than before and could argue why they felt this certain emotion. But also, about the positive things in life, the participants reported that in this difficult situation, they often forget about the positive things. And lastly, they became aware of their behaviour and the consequences of certain behaviour, which often regarded the way they handle situations.

Besides, most fragments named connected to the theoretical frameworks underpinning the intervention. The impact factors connected to ACT are being able to distance oneself from the situation and dealing with thoughts. The impact factors related to self-compassion are becoming more aware, feeling supported, knowledge about emotions and knowledge about themselves. The only impact factor that cannot be related to any of the frameworks is I gained insight.

Table 14

No impact of the intervention

Impact	P*	Argument
Difference between knowing and doing	3	'Knowing things and feeling things is simply a big difference.'
Long term impact	1	'It's hard for me to say whether it's been of any use to me. I'd say it's something that could have more impact in the long run.'
Preferred talking	2	'I think it's better to talk to you about it that way than to just read this book myself. Or talk about it with a good friend. That gives me more relief than reading such a book.'
Personal preference	2	'[...] such moments of relaxation are really important. But practicing doesn't suit me.'

* *Number of participants that mentioned this impact*

Aside from the positive impact on the participants, there were also named arguments why the intervention had no impact (Table 14). The participants reported four arguments to support why the intervention had no impact. First, three participants reported they experienced a difference between knowing and doing. They understood what was written in the book and realized the importance of applying this information. However, applying this knowledge was challenging. This could indicate participants should be motivated more to take action based on their newly gained knowledge. In addition, one participant reported no impact at the moment, but believes it has an impact on the long term. And next to this, multiple people reported rather to talk about the burdens they experience or did not profit from the intervention due to personal preferences against several methods used. Lastly, three participants reported the same negative effect of using this intervention, namely that reading the book ensured too much thinking about the situation: ‘*[...] I was thinking too much about it and you can't change it anyways.*’

3.5 Summary of the findings

A brief overview of the results will be presented. All participants mostly reported negative impact due to being an informal caregiver, like emotional, physical, and social burden.

However, four out of five participants were also able to name the positive impact of being an informal caregiver, which includes the appreciation of life, openness, and priorities.

Regarding the first research question, several forms of self-compassion and self-criticism were reported. There was noticed that informal caregivers could better name when and how they were self-critical, compared to self-compassion. Regarding the second research question, it appeared that overall, four out of five participants positively valued the intervention. The informal caregivers found the combination of text and exercises helpful, but multiple participants were not keen about the concept of mindfulness, and therefore did not try these

exercises. In addition, it appeared two chapters were more appealing, namely chapter one about emotions and chapter four about values. A frequently named reason for the other chapters to be less appealing included they were less fitting or needed because the situation differs from that of a partner. Namely, this group of informal caregivers have their own place to go back to. Furthermore, participants reported it was difficult to apply the obtained knowledge, in which informal caregivers found it hard to, for instance, apply self-compassion even when knowing it is important for their mental health. Lastly, as this study yielded an extensive list of improvements, Appendix E provides an overview of the concrete changes that should be made.

4 Discussion

This study aimed to answer two questions: “*How are informal caregivers of cancer patients self-compassionate and self-critical?*” and “*Is the intervention “Hold on for each other” appealing to informal caregivers other than partners and which parts should be changed to make it better suitable for them?*” To answer these questions, five informal caregivers, other than partners of the patient, were interviewed about their level of self-compassion and opinion of the book “hold on for each other”.

Regarding the first research question, this study showed that self-compassion, as well as self-criticism, are present in the studied group of informal caregivers. Self-criticism came forward in informal caregivers as being harsh towards oneself, not wanting to show weakness and feelings guilty or angry. And self-compassion came forward as being mild towards oneself, connecting to others, self-care, and acceptance. While both aspects were present in the sample, participants found it more difficult to recognize self-compassion than self-criticism. This could indicate that informal caregivers need to be supported to become more aware of ways to be self-compassionate. Yet, the participants also mentioned that acting self-compassionate, even when they know how, is an obstacle. An example of this is that one participant noticed he was stressed at work and wanted to spend his time after work to relax, but then a friend called if he could help him at his house that evening. He did not want to show that he was tired, so he did help that friend. This could indicate this group of informal caregivers should be supported more in their behaviour and how to act according to self-compassionate thoughts. This also coincides with the impact of the intervention the informal caregivers reported, namely that no impact was noticed because there is a difference between “knowing and doing”. A possible explanation for this is the fear for compassion, which is the fear of others perceiving self-compassion as weak. Kirby, Day and Sagar (2019) namely found that people can fear to be self-compassion because they expect it to be perceived as

weakness or self-indulgent, or that compassionate efforts will be perceived as incompetent, unhelpful, or rejected.

Despite the difficulty applying self-compassion, the participants showed forms in which they were self-compassionate, namely being mild towards oneself, connecting to others, self-care, and acceptance. This could be because they became aware of it through the book, but it could also be because some might also experience the room and energy to engage in self-compassionate acts next to caring for the cancer patient. Four out of five participants namely mentioned they had their own place to go back to, and the tasks are divided over multiple people, which ensures the pressure does not become too high. From this could be drawn that the time spent caring also influences the way informal caregivers are self-compassionate. Hlabangana and Heath Hearn (2020) already showed that time spent caring is related to depression. Low levels of self-compassion increase the chance for depression, which could indicate that the time spent caring also influences self-compassion. Future research could be devoted to research whether the time spent caring is also related to self-compassion. One participant did not mention she had her place to go back to. She also reported only negative burden and found it more difficult to name ways in which she was self-compassionate. This is in line with the previous findings of Lloyd, Muers, Patterson, and Marczak (2019), who found lower levels of self-compassion are related to more caregiver burden and dysfunctional coping styles. When considering the result that informal caregivers have difficulty being aware of how they are self-compassionate and of behaving self-compassionate, it can be concluded that more interventions should be based on increasing self-compassion and should focus on decreasing the ways in which informal caregivers reported to be self-critical: being harsh towards oneself, not wanting to show weakness, and feeling guilty or angry. Future research could be devoted to how to overcome the difficulties

informal caregivers experience in being self-compassionate, which could contribute to developing an even more effective intervention.

Regarding the second research question, this research showed that the intervention “Hold on for each other” is an appealing intervention for informal caregivers when adjusted to the situation of this broader group of informal caregivers. The research of Köhle (2016) showed the intervention is appealing for partners of cancer patients. The current study extends these findings by stressing the importance of an intervention for a broader group of informal caregivers. However, not all topics appealed to this group of informal caregivers, namely, the topics emotions and values appealed more than the topics thoughts and resilience.

The topic thought was less appealing, not because it was less fitting to their situation, but because the participants had difficulty formulating their thoughts. In addition, the topic resilience was less appealing because the participants did not experience the stress as excessive. Especially, the topic resilience appeared to differ between partners and other informal caregivers of cancer patients. As mentioned earlier, they do not experience the pressure becoming too much because they have their own place to return to and divide the tasks with others. This is in line with the findings of Walsh and Murphy (2020), who stated that the type of care informal caregivers provide influences the caregiver burden experienced, namely, when having fewer tasks, less caregiver burden is experienced. However, it can be envisioned that only having fewer tasks as an informal caregiver does not solve all unmet needs 85% of the informal caregivers reported (Sklenarova et al., 2015). They still have to deal with all the other aspects of being an informal caregiver, like anxiety of the patient not getting better or feeling guilty that their life goes on when they go home, and the patient’s life does not. When adjusting this intervention to a broader group of informal caregivers, other examples could be given in which ways resilience is needed, so it is more applicable. Also, in supporting this group to continue living their own life and seek help, ACT is a fitting

theoretical framework. Especially because ACT will help the informal caregiver accept the situation they are in and motivate them to explore which values are important to them as an individual. Future research could be devoted to which subjects are more suitable for a broader group of informal caregivers.

Notably, while the participants rated the mindfulness exercises (meditation) less appealing, they also mentioned experiencing positive effects related to mindfulness (as the concept of being in the present). The participants were not keen about the concept of meditation, which could indicate that another form of mindfulness could be more appropriate for this group. The impact of mindfulness that appealed to the participants included being aware and gaining insight. The literature supports the positive impact of mindfulness.

Kinnunen et al. 2020 showed it can facilitate acceptance, attention, awareness and subjective psychological wellbeing in general. However, it is known that motivation is correlated with performance, which means that people who are not motivated to participate in mindfulness also have decreased performance and could influence the benefit gained from it (Berinato, 2018). The meditation exercises, which the participants were dubious about, aim to facilitate being in the here and now, which reduces symptoms of depression and increases well-being (Carmody & Baer, 2007). This could be beneficial for this group of people because depression develops due to unmet needs. However helpful, the present study shows that in practice, this group of informal caregivers were not motivated to try meditation.

This could be linked to the fact that participants experienced taking time for themselves and being self-compassionate as challenging. For the meditation, the reader should consciously take time to find a quiet spot and take time for him-/herself. Possibly this form of being mindful is too complicated for informal caregivers who are not self-compassionate yet, nevertheless, could it be fitting at a later stadium when self-compassion has increased in informal caregivers.

This research adds to existing literature by illustrating the pitfalls of developing an intervention for informal caregivers, like the difficulty behaving self-compassionate and the motivation to try interventions. But also shows the different needs in an intervention for a broader group of informal caregivers, like different topics. Besides, it fills the information gap of qualitative research about self-compassion in informal caregivers, which could be used to adjust the intervention for this group.

4.1 Strengths and Limitations

This study has strong and weak points which should be discussed. The strong point of this research is that it gives an in-depth view of how self-compassion manifests in informal caregivers, which to our knowledge has not been researched before. This can be considered when developing a new intervention for informal caregivers. However, more research is needed, as the current study only included five participants. Additionally, this research provides a practical list of changes that should be made to adjust this intervention to a broader group of people. This can be used by the authors of “Hold on for each other” when they decide to adjust this intervention.

A limitation of this study is the lack of time for this research. Due to time restrictions, the participants were asked to read four chapters instead of the initially planned six. Having time to read more chapters of the book could have influenced the outcome of this research. The participants could, for example, find the other topics in the book less appealing than the first four, which influences the view of the intervention. This also ensured the researcher did not have much time, which led to only a limited number of participants being included in this study, because of which could be questioned whether a full image of all participants was acquired. In addition, it should be mentioned the extent to which self-compassion can be evaluated is questionable. The intervention “hold on for each other” aims to increase the self-

compassion of the reader. This could ensure the participants in this study appear more self-compassionate than before reading the book. Besides, another potential problem is that one researcher did the coding process, while normally two researchers carry out this process.

There was attempted to compensate for this by checking the chosen codes by the supervisor guiding this research. Despite these limitations, this research gives vulnerable insights into the way self-compassion manifests in informal caregivers and shows that there is a need for an intervention based on this.

5 Conclusion

This study investigated two research questions: (1) *“How are informal caregivers of cancer patients self-compassionate and self-critical?”* and (2) *“Is the intervention “Hold on for each other” appealing to informal caregivers other than partners and which parts should be changed to make it better suitable for them?”*. Regarding the first research question, it was discovered how self-compassion and self-criticism behaviorally manifests in informal caregivers. Besides, it was discovered that being self-compassionate has some obstacles. Regarding the second research question, it was discovered that an intervention like ‘hold on for each other’ appeals to a broader group of informal caregivers. Yet, not all subjects are fitting to the different situation these informal caregivers are in. Future research should focus on how to overcome difficulties being self-compassionate, and which subjects are more suitable for a broader group of informal caregivers.

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7 Appendix A
Information letter

Onderzoek “Hou vast, voor elkaar”

“Een ziekte die ons allemaal raakt”, zo beschrijft het KWF de ziekte kanker. Dit is een passende omschrijving als je bedenkt dat voor ons 75e levensjaar 1 op de 3 mannen en 1 op de 4 vrouwen de diagnose krijgt. Dit maakt het heel erg waarschijnlijk dat wij of een dierbaar iemand in onze omgeving met deze ziekte te maken krijgt, wat natuurlijk een verschrikkelijk idee is. Het krijgen van de diagnose kanker is een ingrijpende gebeurtenis voor degene die het overkomt, maar ook voor hun dierbaren. Uit onderzoek blijkt namelijk dat informele zorggevers ook vaak worstelen met klachten zoals angst, somberheid, vermoeidheid en stress. Het is niet niks om je leven aan te passen om zo voor iemand te kunnen zorgen. Hierdoor is er gebleken dat deze mensen behoefte hebben aan hulp voor het omgaan met angsten, het omgaan met emoties en informatievoorziening. Hiervoor zijn al een aantal interventies ontwikkeld, maar deze zijn vooral gericht op de partners van de patiënten en niet voor andere mogelijk zorgverleners (zoals (volwassen) kinderen, ouders of broers/zussen).

Momenteel is er een onderzoek gaande aan de Universiteit Twente naar een hulpprogramma voor andere doelgroepen, te weten partners van kankerpatiënten. Van de partners van kankerpatiënten is bekend dat zij met dezelfde soort problemen kampen als andere mensen in de omgeving van de kankerpatiënt, maar voor deze laatste groep zijn minder gepaste hulpprogramma's beschikbaar. De hulpinterventie is het boek “Hou vast, voor elkaar” en is ontworpen met behulp van de partners van kankerpatiënten.

Doel van dit onderzoek

Aangezien informele zorggevers meer omvatten dan alleen partners van de patiënten en dat deze mensen met dezelfde klachten kampen, wordt onderzocht in hoeverre het boek “Hou vast, voor elkaar” aansluit bij de behoefte en wensen van de informele zorggevers. Daarnaast zal worden gekeken welke aanpassingen gedaan zouden moeten worden om de interventie passend te maken.

Wat houdt deelname in?

Als u deelneemt zult u een zelfhulpboek mee naar huis krijgen. U wordt gevraagd de eerste 6 hoofdstukken van dit boek thuis goed te bestuderen. Tijdens het lezen,

kunt u met post-its passages markeren die u goed of juist minder goed vindt. Na ongeveer 3 weken zal er een (online) interview plaatsvinden, waarin u gevraagd wordt naar uw bevindingen. Vragen die u kunt verwachten zijn: wat vond u goed aan dit hoofdstuk? Wat hebt u gemist? Welke onderdelen zouden moeten worden aangepast? Heeft het boek u geholpen en in welk opzicht?

Wanneer u besluit mee te doen zal de verdere procedure worden toegelicht. Als u na het lezen van deze informatie nog vragen heeft twijfel dan niet en neem gerust contact op. Graag voor 19 Maart laten weten of u besluit mee te doen.

Nikki Binnenmars, 06-37603290 of n.binnenmars@student.utwente.nl

8 Appendix B

Informed consent

Toestemmingsformulier

Geachte heer, mevrouw,

U wordt verzocht onderstaande informatie door te lezen. Als u het met de informatie eens bent en besluit mee te werken aan het onderzoek, dient u de gegevens in te vullen onderaan dit formulier. Dit formulier zal alleen gezien worden door de onderzoeker en haar 2 begeleiders, namelijk C. Drossaert en S. de Vos.

- Ik heb de informatiebrief over dit onderzoek gelezen. Ik heb de informatie begrepen, de mogelijkheid gehad om vragen te stellen en deze zijn naar mijn tevredenheid beantwoord.
- Ik ben ervan bewust dat de deelname aan dit onderzoek vrijwillig is en dat ik op ieder moment zonder verantwoording kan stoppen.
- Ik geef toestemming aan de onderzoeker om de gegevens uit het interview te gebruiken voor het onderzoek en snap dat de informatie niet met derden buiten dit onderzoek gedeeld zal worden.
- Ik ben bereid om deel te nemen aan het onderzoek en dus de opgegeven hoofdstukken te lezen en mij hierna te laten interviewen door de onderzoeker.

Naam deelnemer: _____

Handtekening deelnemer: _____ Datum: _____

Handtekening onderzoeker: _____

9 Appendix C

Content of the chapters

Content of the first 4 chapters of the intervention “hold on, for each other”, Köhle et al., 2013.

Chapter 1	Dealing with your emotions. Feeling small and standing tall. <ol style="list-style-type: none">1. Negative and positive emotions2. Exercise: Which emotions do you recognize in yourself?3. Suppressing emotions or getting out of the way.4. How to handle this?5. Exercise: How do I stand tall?6. Exercise: Allowed to be small again.7. Exercise: Giving and receiving compassion.8. The value of self-compassion9. Mindfulness: returning in the present.10. Summarized
Chapter 2	The resilience plan. How do you keep up? <ol style="list-style-type: none">1. What are the consequences of stress?2. Resilience.3. Don't ask too much of yourself.4. Exercise: How much do I ask of myself?5. Ensure moments of relaxation6. Exercise: Ensuring relaxation.7. Use your resources.8. Don't let your thoughts drive you crazy.9. Mindfulness: It's hard to be human.10. Summarized
Chapter 3	My mind is working overtime. <ol style="list-style-type: none">1. Exercise continued: Ensuring relaxation2. The thoughts factory.3. Learning to deal with rumination and negative thoughts.4. Exercise: Naming thoughts5. Exercise: Carrying thoughts and feelings with you.6. Exercise: The worriesbox.7. Mindfulness: A break from the thoughtsfactory.8. Summarized
Chapter 4	What's really important at this moment? <ol style="list-style-type: none">1. Exercise continued: Carrying thoughts and feelings with you.2. Values: Chosen life direction.3. Values in your relationship.4. Exercise: values in your life.5. Mindfulness: Being kind towards yourself.6. Summarized.

10 Appendix D
Interview schedule

Naam respondent:

Datum en tijd interview:

Welkom en procedure

Allereerst heel erg bedankt voor het deelnemen aan mijn onderzoek. Ik weet dat dit een emotioneel onderwerp is en stel het daarom heel erg op prijs dat u toch besloten heeft om mee te doen.

Wat gaan we vandaag doen: zoals ik in het begin al kort heb genoemd gaan we vandaag een interview doen van +/- een uur, waarin we het gaan hebben over uw ervaringen met het boek. Ik ga dit doen aan de hand van een semigestructureerd interview, wat inhoudt dat de vragen in principe vastliggen maar ik aan de hand van uw antwoord wel extra vragen kan stellen om uw volledige ervaring in beeld te brengen.

Tijdens het interview bestaat uit 4 onderdelen en zal beginnen met een aantal algemene vragen over u, daarna een aantal algemene vragen over uw indruk van het boek, dan gaan we uw ervaringen per hoofdstuk bespreken en afsluitend zal ik nog een aantal vragen stellen over hoe je terugkijkt op deze ervaring.

Als u de vragen niet begrijpt aarzel dan niet om verdere uitleg te vragen. Tijdens het interview kunt u geen foute antwoorden geven, het gaat mij om uw ervaring en daarom wil ik u ook graag aanmoedigen om zo open mogelijk te zijn over uw ervaringen met het boek. De antwoorden van het onderzoek zullen ook niet gedeeld worden met anderen en zullen na het afronden van het onderzoek verwijderd worden. Mocht u tijdens het interview toch twijfelen over uw deelname dan bent u altijd vrij om het onderzoek af te breken.

Heeft u op het moment nog vragen of opmerkingen?

Start Interview

Om het uitwerken van het interview makkelijker te maken zou ik graag een opname maken van het interview, deze opnames zullen na het uittypen worden verwijderd. Gaat u hiermee akkoord?

DEEL 1: Achtergrond deelnemer. (7 min)

1. Hoe oud bent u en de patiënt?
2. Wat is uw hoogst voltooide opleiding?
3. Wat is uw huidige werksituatie?
4. Wat is uw relatie met de patiënt?
5. Wat voor diagnose heeft de patiënt en hoe lang is hij/zij al ziek? Ernst/Stadium?
6. Hoe gaat het op dit moment met u en de patiënt?
7. Wat betekent de ziekte van je ... voor jou?
8. Welke veranderingen heeft de ziekte te weeg gebracht in jouw leven?
(taken/emoties/gevoelens/zorgen)
 - Positieve veranderingen?
 - Negatieve veranderingen?
9. Welke taken heb je als informele zorggever?
 - Wat doe je allemaal voor de patiënt?
10. Waar loop je tegen aan/ heb je eerder tegenaan gelopen?
11. Heb je hier wel eens hulp voor gezocht?

DEEL 2: Algemene indruk van het boek. (8 min)

1. Heb je alle 4 de hoofdstukken gelezen?
 - Zo nee, kun je ook vertellen waarom?
 - Hoe heb je het lezen aangepakt?
2. Wat is je algemene indruk van het boek?
 - Wat waren je favoriete delen?
 - Was vond je minder goed aansluiten?

- Wat moet er veranderd worden?
3. Heeft het boek je geholpen?
- **Doorvragen:** Hoe? Heeft het op nog meer manieren geholpen?
 - Denkt u dat het andere naasten van kankerpatiënten zou kunnen helpen?

DEEL 3: Ervaring per hoofdstuk. (8 min per hoofdstuk)

We gaan nu uw ervaringen per hoofdstuk bespreken en gaan kijken waar en waarom u een plus of een min heeft geplaatst.

Hoofdstuk 1: Je klein voelen en groothouden: omgaan met je eigen gevoelens

Hoofdstuk 2: Het veerkrachtplan: hoe zorg je dat je het volhoudt

Hoofdstuk 3: Mijn verstand maakt overuren

Hoofdstuk 4: Wat is nu eigenlijk echt belangrijk?

1. Heb je het hoofdstuk gelezen?
 - Wat vond je van dit hoofdstuk? Sprak deze je aan?
 - Heeft dit hoofdstuk je aan het denken gezet?
2. Heb je de oefeningen gemaakt?
 - Wat vond je van de oefeningen? Spraken deze je aan?
 - Hebben de oefeningen je aan het denken gezet?
3. Wat is volgens jou de belangrijkste boodschap van dit hoofdstuk?
4. Wat waren volgens jou de sterke punten van dit hoofdstuk?
 - Waar heb je een +?
5. Wat vond je minder aansprekend of minder goed? En wat kan er nog verbeterd worden om het aan jouw situatie aan te passen?
 - Waar heb je een - ?
6. Heb je op de één of andere manier iets gehad aan (de oefeningen in) dit hoofdstuk?
 - Probeer je de opgedane kennis van dit hoofdstuk ook toe te passen in je leven?

DEEL 4: Self-compassie (10 min) (overal voorbeelden vragen)

1. Ben je vaak kritisch naar jezelf toe?
2. Hoe vaak besteed je bewust aandacht aan hoe jij je voelt?
 - Merk je wanneer het slecht gaat?
 - Welke situaties?
3. In welke situaties zet jij jezelf op de eerste plek?
 - En wanneer niet?
4. Zijn er momenten dat je bewust tijd voor jezelf neemt?
 - Hoe merk je wanneer je tijd nodig bent?
 - Hoe vaak? En hoe doe je dat?

DEEL 5: Afsluitende informatie. (5 min)

1. Heb je nog opmerkingen die we nog niet besproken hebben?
2. Op welke manier zou je baat hebben bij een interventie zoals deze? En op welke manier niet?
 - Heeft u zelf baat gehad bij het boek?
 - Heeft het u nog op een andere manier geholpen?
 - Zijn er nog onderwerpen die ontbreken?
3. Hoe kijk je terug op deze ervaring?
 - Wat is je het meeste bijgebleven?
 - Wat voor advies zou je ons mee willen geven?

11 Appendix E

List of improvements

Part of the book	Page	Adjustments	Suggestion
General		Substitute for the mindfulness exercises, so when the reader does not like these a different exercise can be done. Changing voice of the mindfulness exercises.	provide and additional exercise in which the reader can be mindfull in a different way, by for example letting them focus on the here and now. Add possibility to choose female or male voice.
Chapter 1: Dealing with your emotions. Feeling small and standing tall.	p.34	Exercise C <i>Allowed to be small again</i> was negatively valued by multiple participants, because it did not fit them, and they felt vulnerable.	Different exercise or motivating the client more to try to be vulnerable. The difficulty of presenting oneself vulnerable could be named so they know it is normal that it can be difficult to do this.
Chapter 2: The resilience plan. How do you keep up?	p. 46	Exercise A <i>How much do I ask of myself?</i> The participants experienced difficulties in separating their personal life from being an informal caregiver.	Indicate that it about personal life as well as about being an informal caregiver and maybe make a clear difference in time spent being an informal caregiver and personal life.
	p. 45	The participants could not recognize themselves enough in the examples given.	Change examples which are more fitting to the situation of these informal caregiver. For instance, rush from home to patient to do chore, but leaving own home in a mess.
	p.51	The participants could not recognize themselves in the examples given about resources.	Make the text more fitting to their situation. One participant experienced for example that she wanted to do something but other were already doing it. Could state that it is okay is other people in the environment sometimes do more and consequently you have less to do.
Chapter 3: My mind is working overtime.	p. 66	Exercise B <i>Naming thoughts</i> . The participants had difficulty identifying the thoughts to put in the text balloons.	The participants were already helped by the text of Jelle, maybe examples could be given of what thoughts these informal caregivers have. This could be done in a the form of a list so they can cross what they recognize.
	p.68	Exercise D <i>The worriesbox</i> . The participants did not like the concept of this exercise.	Provide and alternative exercise.
	all	The participants found the chapter rather short.	Provide more in-depth information about thoughts. For example, about how someone is able to be more aware of their thought. On a busy day most do not stand still at way they feel or think, but rather distract oneself by work.
Chapter 4: What's really important at this moment?	p. 79	Exercise B <i>values in your relationship</i> . The values named were not fitting for the situation the participants were in.	Change the values, for different types of relationships e.g. friend, brother/sister, parents.