

# What doesn't kill you only makes you stronger?

Experience of posttraumatic growth of partners of cancer patients who participated in an online intervention for partners of cancer patients based on self-compassion and Acceptance and Commitment Therapy

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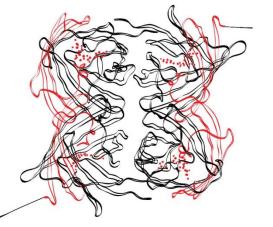
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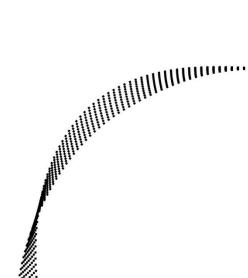
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# **Contents**

Samenvatting
Abstract
Introduction
Problem and General Background5
Posttraumatic Growth (PTG)6
Interventions to support partners of cancer patients
Acceptance and Commitment Therapy (ACT)
Self-compassion
Aim of this study & research question
Methods
The intervention <i>Hold on, for each other</i>
Target group within this study
Demographic data
Instruments
Data analysis
Procedure – development of the coding scheme & answering the research questions 16
Results
In which way do the domains of PTG occur?
Distribution of the domains of PTG across the exercises
Amount of PTG in the different groups of participants after the second measurement point 25
Conclusions and Discussion
Most important results
Strengths, limitations and recommendations
Final remark31
References
Appendix A
Appendix B

#### **Samenvatting**

Doelstelling. Het aantal nieuwe gevallen van kanker neemt steeds meer toe. Gediagnosticeerd worden met kanker heeft grote invloed op de patiënt en de partner en kan tot psychische problemen leiden. Echter kan het ook posttraumatische groei (PTG) teweeg brengen. Er zijn ondersteunende interventies voor partners van kankerpatiënten. Köhle et al. hebben *Houvast, voor elkaar* ontwikkeld dat gebaseerd is op zelfcompassie en Acceptance and Commitment Therapy (ACT). Literatuur toont aan dat zelfcompassie en psychologische flexibiliteit (als gevolg van ACT) ook groei kunnen bevorderen. Deze studie is er daarom op gericht uit te vinden of PTG in de antwoorden van deelnemers van *Houvast, voor elkaar* optreedt. De deelvragen staan stil bij de manier waarop PTG optreedt, in welke oefeningen en of er onderscheid bestaat tussen drie verschillende groepen deelnemers (verbeterd, gelijk gebleven, verslechtert in psychische klachten gemeten door middel van de HADS).

*Methode.* Data in de vorm van .pdf-files met alle antwoorden van 15 deelnemers werd geanalyseerd. Deze deelnemers werden weer in drie groepen onderverdeeld, gebaseerd op hun ontwikkeling op de HADS van het eerste naar het tweede meetmoment. In een iteratief proces werd op zowel de- als inductieve manier een codeerschema ontwikkeld. De deelvragen werden op exploratieve manier beantwoord en er werd beschrijvende statistiek gedaan door tabellen op te stellen met de incident en verdeling van de codes. Alle data werd door een onderzoeker geanalyseerd.

Resultaten. De domeinen waardering voor het leven, persoonlijke kracht en relaties met anderen treden het meest op. Dit resultaat wordt ook weerspiegeld in de soorten oefeningen waarin PTG het meest optreedt. Tenslotte hebben de deelnemers die op de HADS zijn verbeterd ook de meeste PTG lieten zien tijdens de interventie.

Conclusie. Andere studies vonden ook dat partners van kankerpatiënten vooral de bovenvermelde domeinen van PTG laten zien. Daarnaast bleken bepaalde oefeningen meer PTG-gerelateerde inhoud op te leveren en dus meer geschikt te lijken om PTG te bevorderen dan andere. Bij het aanbieden van Houvast, voor elkaar met het oog op het PTG zou daarom overwegen moeten worden alleen de PTG-gerelateerde oefeningen aan te bieden. Dat zou mogelijk sneller tot positieve PTG-gerelateerd uitkomsten kunnen leiden. Een sterk punt van deze studie is het nieuw ontwikkelde codeerschema waarmee alle data gecodeerd kon worden. Aan de ene kant is dat opvallend want de interventie was helemaal niet gericht op PTG. Aan de andere kant is het dat niet omdat deze studie ook kon laten zien dat de constructen – ACT, self-compassie en PTG – elkaar duidelijk overlappen.

#### **Abstract**

Objectives. The number of new cases of cancer steadily increases. Being diagnosed with cancer has a great impact on the patient and the partner and can lead to psychological problems. However, it may also evoke posttraumatic growth (PTG). There are supportive interventions for partners of cancer patients: Köhle et al. developed Hold on, for each other which is based on self-compassion and Acceptance and Commitment Therapy (ACT). Literature shows that self-compassion and psychological flexibility (as a consequence from ACT) may also promote growth. Therefore, this study aims to find out if PTG occurs in the answers of the participants of Hold on, for each other. The subquestions focus on the way in which PTG occurs, in which exercises it occurs and if there is a difference between three groups (improved, remained the same, deteriorated in psychological distress measured by the HADS)..

*Methods.* Data in the form of .pdf-documents with all answered exercises of 15 participants was analysed. These 15 participants were again divided into three groups, based on their development on the HADS from the first to the second measurement point. In an iterative process, a coding scheme was developed in both deductive and inductive way. The subquestions were answered exploratory and there was made use of descriptive statistics. Tables with occurrence and distributions of the codes were compiled. All data was analysed by one researcher.

**Results.** The domains appreciation of life, personal strength, and relating to others occur most often. This result is also reflected in the types of exercises in which most PTG occurs. Lastly, participants who improved on the HADS after the intervention also expressed most PTG during the intervention.

Conclusions. Other studies also found that partners of cancer patients mainly show the aforementioned domains of PTG. Next to it, it turned out that certain exercises yield more PTG-related content and therefore seem to be more helpful in promoting PTG than other exercises do. When offering the intervention with the aim to promote PTG it should be considered to only choose the PTG-related exercises in order to save time and resources of the participant and to eventually enable quicker positive results regarding PTG. One strength of this study is the novel coding scheme with which all data could be coded. On the one hand, this is striking because the intervention was not focused on PTG at all. On the other hand, in the end, it is not because the study also showed that the three constructs – ACT, self-compassion and PTG – clearly overlap each other.

#### Introduction

#### **Problem and General Background**

Every year, the number of new cases of cancer increases. According to a report of the Dutch Cancer Society, the number of new diagnosed cases of cancer for men will increase from 45.110 in the year 2007 up to approximately 66.000 in the year 2020. For women a similar trend is detected: For them the number of diagnosed cases of cancer will increase from 41.690 in the year 2007 up to approximately 57.000 in the year 2020 (Dutch Cancer Society, 2011). However, the Dutch Cancer Society also detects the trend of a declining mortality rate in consequence of cancer. There are still certain forms of cancer that usually end up lethally but meanwhile there is also good treatment for various forms of cancer. By this, the disease does not have to be lethally anymore but becomes chronic or even acute (Dutch Cancer Society, 2011). Due to the rising incidence and the decreasing mortality rates, the overall prevalence of cancer sharply increases (Dutch Cancer Society, 2011).

Being diagnosed with cancer is a life-changing experience and can lead to many psychological problems, such as emotional distress (Manne et al., 2004; Hinnen et al., 2008; Gregurek, Braš, Đorđević, Ratković, Brajković, 2010; Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008; Eton, Lepore, & Helgeson, 2005). This does not only apply to the cancer patient himself but also to close family, for example partners (Köhle et al., 2015; Sklenarova et al., 2014; Northouse, Katapodi, Schafenacker, & Weiss, 2012; Stenberg, Ruland, & Miaskowski, 2010; Kim, Kashy, Spillers, & Evans, 2010; Friðriksdóttir et al., 2011; Pitceathly & Maguire, 2003). According to several authors, partners of cancer patients experience even more distress than the patients themselves (Couper et al., 2010; Janda et al., 2008). In the existing literature, several reasons for the emergence of psychological problems among family caregivers such as partners can be found:

Family caregivers are expected to provide complex care in the home with little preparation or support. When the demands placed on caregivers exceed their resources, caregivers feel overwhelmed and report high stress. (Northouse et al., 2012, p. 237)

Furthermore, informal caregivers have to take over responsibilities and many roles, such as providing support for the patient or attend to financial affairs (Köhle et al, 2015; Eton et al., 2005; Goldzweig, Merims, Ganon, Peretz, & Baider, L., 2012; Stenberg et al., 2010). Besides, uncertainties about the future (Eton et al., 2005) and changing plans regarding the future (Gregurek et al., 2010) may cause psychological problems.

Moreover, some studies state that partners of cancer patients primarily give attention to the needs of their ill partner but do not care that much about their own needs or problems (Sklenarova et al., 2014; Thomas, Morris & Harman, 2002; Pitceathly et al., 2003; Köhle et al. 2015a; Northouse, Katapodi, Song, Zhang & Mood, 2010). Partners of cancer patients may by even much ruder against themselves "than they ever would be to others they cared about [...]." (Neff, 2003, p. 87). Also, if one constantly criticizes oneself, this may also lead to stress and symptoms of depression (Neff, 2011).

#### **Posttraumatic Growth (PTG)**

Next to the negative consequences a cancer diagnosis brings along, cancer patients and their partners can also experience positive effects in consequence of the diagnosis and coping with the disease (e.g. Manne et al., 2004; Thornton & Perez, 2006; Jansman, 2014). All these effects can be resumed as *posttraumatic growth* (from now on abbreviated with PTG). Tedeschi and Calhoun are most associated with this term. PTG comprises positive changes due to fighting with life crises, such as bereavement of a loved person, illnesses such as cancer, sexual assault or abuse and many more (Tedeschi and Calhoun, 2004). PTG can find expression in many ways, "including an increased appreciation of life in general, more meaningful interpersonal relationships, an increased sense of personal strength, changed priorities, and a richer existential and spiritual life." (Tedeschi & Calhoun, 2004, p. 1). Overall, the major domains of posttraumatic growth are: (1) personal strength, (2) new possibilities, (3) relating to others, (4) appreciation of life, and (5) spiritual change (Calhoun & Tedeschi, 2006). In the following, these domains will be explained in more detail.

First, the domain *personal strength* entails an increased awareness of one's own strength. People who experience growth in this domain are able to "handle things better" (Tedeschi & Calhoun, 2004, p.6) and are aware that "bad things can and do happen" (Tedeschi & Calhoun, 2004, p.6). Moreover, awareness of one's own strength is often also accompanied by the somewhat paradoxically sense of being vulnerable (Tedeschi & Calhoun, 2004). People, who experience growth in the second domain (*new possibilities*), see new possibilities for their life or for taking new or different paths in their life (Tedeschi & Calhoun, 2004). They may also develop new interests and activities (Calhoun & Tedeschi, 2006). Growth in the third domain is characterized by "more intimate, and more meaningful relationships with other people" (Tedeschi & Calhoun, 2004). People may also experience a growing sense of connection to and compassion for other people who share the same fortune because they also have experiences with loss and tragedy (Calhoun & Tedeschi, 2006). This may make that people get more aware of that they are not the only ones who suffer (Calhoun

& Tedeschi, 2006). However, this domain has a paradoxical element, too. Next to more close and meaningful relationships it may happen that one loses other relationships. This is especially because people find out who their real friends are (Tedeschi & Calhoun, 2004). People who experience growth in the fourth domain have a greater "appreciation for life in general, and many smaller aspects of it" (Tedeschi & Calhoun, 2004, p.6). More precisely, this can entail a "changed sense of what is important" (Tedeschi & Calhoun, 2004, p.6) and a "changed sense of priorities" (Tedeschi & Calhoun, 2004, p.6). Characteristic for this domain are regarding certain things more important than before or realizing "that life is precious" (Calhoun & Tedeschi, 2006, p. 6). The last domain is about spirituality. More precisely, people who experience growth in this domain, see a greater purpose and meaning in life, are more satisfied, and may establish "clarity with the answers given to the fundamental existential questions" (Calhoun & Tedeschi, 2006, p.6). Even people who are not a priori religious can experience growth in this domain (Tedeschi & Calhoun, 2004).

Based on the work of Tedeschi and Calhoun, Bohlmeijer & Bannink (2013) summarize the process of PTG as follows: It starts with a traumatic event. This traumatic event is so shocking that it causes the individual's understanding of the world to totter or even to be destroyed. It is also important to mention that PTG is not the direct consequence to the trauma itself but to the intense struggle with the trauma and the effort to build new schemas about the world and frame new goals. It is the first task to cope with the negative emotions that are accompanied by the traumatic event. Anxiety, despair, anger or grief can be classed among these emotions. Over time, the involved person becomes aware of the reality of the event. Allowing and expressing negative emotions finally makes that the intensity of the feelings and the rumination on the event decreases. Then, the person may be in state to find new values, to solve problems and to imagine new future visions. The traumatic event is integrated in a new life story and constitutes a turning-point in one's life. Finally, the idea occurs that one has grown through the confrontation with the traumatic event (Bohlmeijer & Bannink, 2013).

If partners of cancer patients are nonetheless overpowered by psychological problems that occur in the course of the caregiving process, a psychological intervention may be helpful for them.

#### **Interventions to support partners of cancer patients**

There are a number of supportive interventions that aim to support partners of cancer patients during the caregiving process and with eventually psychological problems due to their partner's cancer. A meta-analysis by Northouse et al. (2010) investigated the existing

interventions: The majority of the evaluated interventions focuses on the well-being of the patient but only few interventions were designed to focus on caregiver's self-care. Also, they are often not theory-based (Ussher, Perz, Hawkins, & Brack 2009). To overcome this problem, Köhle et al. (2015) developed a new intervention called *Hold on, for each other* [Dutch original title: *Houvast, voor elkaar*] that aims to support partners of cancer patients. In the following there will be an outline about the theoretical framework of this intervention and why it is supposed to support the well-being of partners of cancer patients..

#### **Acceptance and Commitment Therapy (ACT)**

The intervention is based on Acceptance and Commitment Therapy (from now on abbreviated with ACT; pronounced as one word). The term already contains its core: ACT is about accepting what is out of one's own personal control and committing to take "action that enriches your life." (Harris, 2009, p. 2). According to Harris (2009), the aim of ACT is to build up a meaningful life and concurrently accepting the pain that is related to everyone's life. The main point of therapy is not to reduce symptoms but to change the relationship with these symptoms. A reduction in symptoms still often appears as a positive side effect.

ACT contains a number of core processes which overlap and are interrelated with each other: (1) contacting the present moment, (2) defusion, (3) acceptance, (4) self-as-context, (5) values, and (6) committed actions. These processes are about consciously experiencing what is happening in this moment and not going along with one's thoughts and losing touch with the environment; about regarding thoughts as "nothing more or less than words or pictures" (Harris, 2009, p.9). Further the processes include accepting negative or dreadful feelings and giving place to these emotions; and being "aware of whatever we're thinking, feeling, sensing, or doing at any moment." (Harris, 2009, p. 11). Lastly, there are two processes about values and about the encouragement to develop larger patterns of actions that are linked to these values. All these processes are not apart from each other. Rather, they can be seen as facets of one whole which again can be called psychological flexibility (Harris, 2009).

Constantly more studies report the efficacy of ACT in reducing symptoms of psychological distress (e.g. Hayes et. al, 2006; Fledderus, Bohlmeijer, Pieterse, & Schreurs, 2012; etc.) and more specific, also for cancer patients (Feros, Lane, Ciarrochi, & Blackledge, 2013; Hulbert-Williams, Storey, & Wilson, 2015). According to Köhle et al. (2015a), ACT may help partners of cancer patients because they learn to "deal with the negative emotions caused by cancer [...] instead of avoiding these." (p. 2). Furthermore, partners of cancer patients could benefit from ACT because it teaches them to handle dysfunctional thoughts or persuasions (Köhle et al, 2015b). Lastly, Köhle et al. (2015b) assume that ACT could help

partners of cancer patients "to focus on what is really important to them" (p. 2) and to act according to these values.

ACT is also related to self-compassion which is another theoretical foundation of *Hold on, for each other*. In more detail, this relationship comes forth from the fourth core process of ACT, *Self-as-context*. According to Harris (2009), there are two different components when talking about the "mind": The thinking and the observing self. The thinking self includes producing thoughts, beliefs, plans etc. Most of the people are very familiar with this self. The observing self is about being "aware of whatever we're thinking, feeling, sensing, or doing at any moment." (Harris, 2009, p. 11). Many people are not aware of this part of the mind. According to Neff & Tirch (2013), the observing self, or the *self-as-context*, offers a "non-attached and disidentified relationship to our experiences" (p. 96) and enables to view own suffering as one would view other people's suffering and to "be touched by the pain in that experience". This is what is also called self-compassion. According to Hayes, the roots and emergence of self-compassion may be found in the core processes of ACT (Neff & Tirch, 2013).

#### **Self-compassion**

For a start, self-compassion is connected to the more general term *compassion*. According to van den Brink and Koster (2013), compassion is the ability to feel affected by pain and suffering. Additionally, compassion contains the wish and motivation to relieve these pain and suffering. Self-compassion includes the understanding that pain and failures are a common thing and that every human may experience it someday. A self-compassionate person is able to forgive himself for these failures and is able to respect himself "as a fully human—and therefore limited and imperfect—being." (Neff, 2003, p. 87).

According to Neff (2003), self-compassion includes three domains: (1) self-kindness, (2) common humanity, and (3) mindfulness. Self-kindness entails the friendly treatment of our negative emotions and vulnerability. Common humanity grounds on the given that we are not the only one with pain and suffering and that these are parts of every human. Mindfulness entails open attention to our emotional pain and makes people not overidentifying with these negative feelings.

Neff (2003) states that "there is good reason to believe that having compassion for oneself promotes mental well-being" (p. 92). She assumes that a self-compassionate attitude towards oneself should lead to a large number of favourable psychological outcomes, as for instance decreased depressive symptoms, decreased anxiety, or more life satisfaction. Meanwhile, there has been empirical research on this: Self-compassion can indeed have a

health-promoting contribution (van den Brink & Koster, 2013). Increased self-compassion is associated with decreased depression, anxiety, ruminating or self-criticism (van den Brink & Koster, 2013). Self-compassion also seems to be protective against throwbacks and is associated with a healthier form of dealing with traumatic events (van den Brink & Koster, 2013).

#### Aim of this study & research question

Neff (2003) refers to Maslow and Rogers, who argue that among other things, accepting own pain and failings and being more self-acceptant can lead to growth and change (Neff, 2003). Furthermore, as mentioned earlier, self-compassion is associated with a healthier form of dealing with traumatic events (van den Brink & Koster, 2013). As selfcompassion is linked to growth and self-compassion and ACT are linked to each other in some way as mentioned earlier, it could be assumed that ACT and PTG may also be linked to each other. Actually, there seem to be parallels between these two constructs: In its essentials, ACT is about accepting what is out of one's own personal control and committing to take actions that enriche one's life. Posttraumatic growth is often consequence of events people cannot control such as bereavement of a loved person or illnesses such as cancer and entails increased appreciation of life, more meaningful relationships, an increased sense of personal strength, changed priorities, and a richer existential and spiritual life. Besides, Kashdan and Kane (2010) hypothesized in one of their studies that psychological flexibility, which is the consequence of all core processes of ACT "would be associated with greater reports of posttraumatic growth and meaning in life" (Kashdan & Kane, 2010, p. 85). Based on the study results they were indeed able to approve this hypothesis. However, further literature about a link between ACT and posttraumatic is difficult to find. Based on the preceding argumentations about links between PTG and self-compassion respectively ACT and on the fact that but yet there is not much literature about a possible link between ACT and PTG, it would be interesting to investigate if partners of cancer patients were also able to experience PTG through their participation in *Hold on, for each other*. If they were able to experience posttraumatic growth while the intervention was based on ACT this could be an indication of a link between ACT and PTG.

The assumption can be suggested that partners of cancer patients who get in the context of *Hold on, for each other* the possibility to improve their self-compassion and psychological flexibility may also be able to experience PTG.

This leads to the following research question and corresponding subgestions.

<u>Do partners of cancer patients who participate in the intervention "Hold on, for each other"</u> based on self-compassion and ACT, report PTG?

To investigate this question, the following subquestions are formulated:

- i. In which way do the domains of PTG occur?
- ii. In which exercises of the intervention do the elements of PTG occur more and in which do they occur less?
- iii. Are there differences with respect to PTG between people who scored lower, higher or remained the same on psychological distress (HADS) after the second measurement compared to the first measurement?

The research question and its subquestions will be answered after coding the data. For the coding of the data, a new coding scheme will be developed. Development of this coding scheme will be extensively explained in the methods section.

#### Methods

### The intervention Hold on, for each other

Hold on, for each other is a theory-based online intervention for partners of cancer patients. There are several reasons for providing psychological interventions via the internet. It increases the access to care and makes it available for everyone in any time or place. Furthermore, people using online-interventions can stay anonymous. This may lower the threshold for people who would otherwise fear stigmatization. People who have little time or live in remote areas may also benefit from online interventions (Ossebaard & van Gemert-Pijnen, 2013).

The intervention is based on Acceptance and Commitment Therapy and contains exercises based on self-compassion. It contains six modules which are meant to be worked through within six weeks. If a participant needs more time, he or she can work through the intervention in at the longest 12 weeks. In every module, another topic comes up. The topics range from learning recognizing, allowing and expressing emotions over managing a period of chronic stress or focusing on negative thoughts or on values in life to the importance of communication. There are also two additional modules from which participants can choose the one which is important to them. The first one focuses on life after a successful cancer treatment; the other one focuses on the final stage of cancer.

Every module opens with a brief text about the topic of the module. To these texts, psychological exercises based on ACT are added. Beside this, each module contains a meditation task which is based on mindfulness and self-compassion. Hereinafter a table with an overview over which parts of which theory appear in the lessons.

Table 1. Modules, components of theories and examples of Hold on, for each other (according to Köhle et al., 2015b)

Title of module	Component of theories	Example of an exercise
1 – Dealing with	Acceptance	How do I put on a brave face?
your Emotions	Self-compassion/mindfulness	Participants are asked to pay attention to their emotions during the upcoming week. It is the intention that they write down emotional situations, describe how they felt at that moment and how they dealt with it. <i>Aim</i> : Help participants to become aware of their emotions and their
<b>a</b>		coping strategies.
2 – The resilience	Acceptance	How much do I demand of myself?

plan – How can you ensure that you keep	Self-compassion/mindfulness	Participants are asked to "write down how many hours they work, sleep,
going?		and have leisure time each week." (Köhle et al., 2015b, p. 4). The
		exercise is meant to show participants "how much they demand
		of themselves and if their planning is realistic." (Köhle et al., 2015b, p. 4)
3 – My mind works	Cognitive defusion	The Worries-Box. Participants are
overtime	Self-compassion/mindfulness	asked to write their thoughts, sorrows and fears on a piece of paper. These
		pieces of paper are meant to be put in
		a box. After a while, participants can throw the box away or open it and
		read again what they have written
		down back then. The purpose of this exercise is to show participants "that
		worries are often not based on firm
		grounds." The worries-box can help
		participants to see their thoughts in a new perspective.
4 – What is now	Values	Values in your relationship.
really important?	Self-compassion/mindfulness	Participants were asked to put down those things they consider most
		important within their relationship.
		The aim is to make participants aware of what may not be congruent
		with their values
5 – Very afraid, enormous tired, and		Celebrating your relationship.  Participants were asked to choose
moment to enjoy	Sen compussion inneremess	activities like writing a letter of
		having dinner together. This exercise was meant to show participants the
		preciousness of their relationship and
		how they could live "in accordance with their values." (Köhle et al.,
		2015b, p. 4)
6 – The art of		What would you like to talk about?
staying in conversation with	really matters Self-compassion/mindfulness	Participants were asked to put down topics they have discussed with their
someone	-	partner recently. The aim of this
		exercise is the stimulation of the participants to talk about the things
		they consider important.

7 – Continuing life	Acceptance, cognitive	Strengthen your hope. Participants
(optional lesson)	defusion, values	were asked to "imagine the situation
	Self-compassion/mindfulness	that their partner is cancer free for
		almost a year, and that he/she is
		feeling alright" (Köhle et al., 2015b,
		p. 4). They should imagine a life
		under these conditions. The exercise
		is meant to show participants that it
		can be helpful to look at a situation
		from another point of view.
8 – A good last	Acceptance, communication	Beautiful memories. Participants
period (optional	about what really matters,	were asked to think about
lesson)	committed action	possibilities to create new memories
	Self-compassion/mindfulness	

Participants can also decide to receive text-messages with inspiring texts. Furthermore, two kinds of social support are integrated into the intervention. The first one is peer-to-peer contact. In this context, participants can share their answers to some exercises and can have a look at those of other participants. They can further write advices for their peers and can read those written by other participants. Lastly, they can also make contact with peers and communicate with them via email. The second kind of social support within this intervention is professional support. For that matter, there are two versions of the intervention. In the first one, participants get personal professional support. With personal support, participants weekly get email-feedback from a counsellor on their progress in the intervention. In the second version, participants get automated professional support. With automated support, participants get short feedback immediately after they have completed an exercise. This feedback opens in a separate pop-up window (Köhle et al., 2015b).

#### Target group within this study

In order to investigate the research question and its subquestions, the filled in exercises of *Hold on, for each other* of three different groups of intervention participants were explored. These groups were formed based on the participants' development on the HADS, the Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983). By this, the following groups of participants were formed: (1) improved on the HADS, (2) remained the same on the HADS, or (3) deteriorated on the HADS. The HADS and the precise criteria for assigning participants to one the three groups will be further described in the paragraphs "instruments" and "data analysis".

#### Demographic data

The demographic information age, gender and educational level have been ascertained for all participants, for the selected participants in this study and for the participants in each subgroup and are displayed below.

Table 2. Mean age of all participants in the total group, in the selected group and in the three subgroups in this study

	Minimum age	Maximum age	Mean	Std.Deviation
Total group (N=203)	27	82	55,89	10,72
Selected group (N=15)	34	74	54,60	11,16
Subgroup 1 (remained	42	74	59,8	12,34
the same on HADS)				
Subgroup 2 (improved	34	58	50,2	9,86
on HADS)				
Subgroup 3 (deteriorated	36	63	53,8	11,30
on HADS)				

Table 3. Distribution of gender in the total group, in the selected group and in the three subgroups

	Gender	Frequency	Percent
Total group (N=203)	female	143	70,4
	male	60	29,6
Selected group (N=15)	female	12	80
	male	3	20
Subgroup 1 (remained the same on HADS, N=5)	female	5	100
	male	0	0
Subgroup 2 (improved on HADS, N=5)	female	1	80
	male	4	20
Subgroup 3 (deteriorated on HADS, N=5)	female	3	60
	male	2	40

#### **Instruments**

Within the scope of the randomized controlled trial by Köhle et al. (2015b), participants in the experimental condition filled in the Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983) at the beginning and at the end of the intervention. The

HADS is a self-assessment scale that aims to detect presence and severity of depression and anxiety. It has two subscales, the depression subscale and the anxiety subscale with each seven items. All items are four-point Likert items and their categories range from "very often" to "not at all". Anyway, the verbalisation of these categories is slightly different for each item. For example, the item "I still enjoy the things that I used to enjoy" which comes within the depression subscale has the following answer options: "definitely as much", "not quite so much", "only a little" and "hardly at all". At the end, all points in each subscale are summed up. The scale is also useful for assessing changes "in a patient's emotional state" (Zigmond & Snaith, 1983, 366-367).

Within the RCT of Köhle et al. (2015b), the cronbach's  $\alpha$  of the HADS was as follows: For the whole HADS, cronbach's  $\alpha$  was .861 at the first measurement point respectively at the baseline measurement and .888 at the second measurement point. For the depression subscale, cronbach's  $\alpha$  was .807 at the baseline measurement and .836 at the second measurement. For the anxiety subscale, cronbach's  $\alpha$  was .773 at the baseline measurement and .810 at the second measurement.

#### Data analysis

This study explored whether partners of cancer patients show PTG while participating in the online intervention *Hold on, for each other*. This was done by means of a content analysis: There was a pdf.-dossier of every participant. This dossier contained all exercises of the intervention and the corresponding answers the participant typed in. The first supervisor of this study randomly selected ten dossiers from each group of participants from which again five dossiers were randomly selected for the content analysis. Prior to the analyses, it was decided to analyse additional dossiers if no saturation would be reached after the first 15 dossiers. In this context, saturation means that as many dossiers are coded until no new codes can be generated anymore. However, in the end, analysis of additional dossiers was not necessary because saturation was reached after analysis of 15 dossiers.

## Procedure - development of the coding scheme & answering the research questions

The content analysis was conducted with the aid of ATLAS.ti, a programme for qualitative data analysis. In total, 15 dossiers have been analysed. Data analysis was an iterative process and both deductive and inductive: The deductive part of the data analysis proceeded as follows: Initially, based on the literature of Tedeschi and Calhoun (Calhoun & Tedeschi, 2006; Tedeschi & Calhoun, 2004), a provisional code book with the domains of PTG was prepared. This provisional code book contained the five overall domains of PTG as well as aspects of these domains as they can be found in the literature. Deductively, the

dossiers have been coded with this code book. The inductive part of the analysis especially refers to the constant revision of the code book while coding the data. For example, when segments of data could not be coded with an already existing code, literature was consulted again to search for additional aspects of PTG. In this manner, the code book was steadily extended. Constant comparison also refers to withdrawing certain aspects of PTG from the provisional code book if these aspects almost never occurred.

The size of the units of analysis within the content analysis varied. The units were not grammatically but substantially based. For the majority of the data, the units mostly comprised one sentence of parts of a sentence. Occasionally, whole exercises could be coded as one unit because they could be covered by one single code. If suitable, one unit could also be coded with more than one code.

To demonstrate what each code contains, a definition based on the literature and an example quotation was given. Originally, the example quotations were in Dutch as the intervention was developed in the Netherlands and the participants were also Dutch. For the readability of this study, the quotations were translated into English.

Based on the coded data, the research questions could be answered. For this purpose, descriptive statistics of the occurrence and the distribution of the codes were applied. More specific, for each subquestion, a table was compiled. For the first subquestion, this was a frequency table with the total frequencies of all codes and the number of participants who showed a code. For the second subquestion, a table was compiled that shows the distribution and the frequency of the codes within the individual exercises of the intervention. For the third subquestion, at first, the three groups had to be compiled. Participants were assigned to one of these groups, depending on the difference score on the HADS between the baseline measurement at the beginning of the intervention and the measurement three months after baseline measurement. Depending on the magnitude and the value of the difference score, a participant was either assigned to the group of participants who improved on the HADS; to the group who remained the same on the HADS or to the group who deteriorated on the HADS. A participant "improved on the HADS" when he or she showed a difference score between baseline and second measurement of  $\Delta \leq -3$ . A participant "remained the same on the HADS" when he or she showed a difference score between baseline and second measurement of  $-3 < \Delta < 3$ . A participant deteriorated on the HADS when he or she showed a difference score between baseline and second measurement of  $\Delta \geq 3$ . For the third subquestion, the

quantity of codes per participant and on average was determined. Furthermore, it was investigated how many exercises participants completed on average.

#### **Results**

In the following, the final coding scheme as it resulted from the data analysis will be described and explained. For this purpose, a detailed description of each code and an example quotation for each code will be given.

All code terms and code descriptions in the coding scheme are based on and can be retrieved in the literature of Tedeschi and Calhoun (2004) & Calhoun and Tedeschi (2006), be it as direct quotations particularly marked as such, as paraphrases or as reformulation based on statements of the authors. The latter however only applies to the code "Paradoxical element: happiness despite grief". This term as such cannot be found in the literature but is an own creation based on the authors' deliberations (Tedeschi & Calhoun, 2004).

The final coding scheme entails the five domains of posttraumatic growth as worked out by Tedeschi and Calhoun (2004, 2006): (1) *Personal Strength*, (2) *New Possibilities*, (3) *Relating to others*, (4) *Appreciation of Life*, (5) *Spiritual Change*. Each domain again entails different numbers of single codes.

For the domain *Personal Strength* there are the following codes: "Can handle things better", "Increased sense of personal strength", "Knowledge that bad things can and do happen" and "Paradoxical element: sense of own vulnerability". "Can handle things better" means that the partner of the cancer patient has the idea that he or she is better able to cope with things/events/situations: "Things that used to be big deals aren't big deals anymore." (Tedeschi & Calhoun, 2004, p.6). This code can be applied when there are quotations such as: "Hopefully, I can say: Time will tell. Often, I experience that things that I am faced with or afraid of turn out better than expected afterwards. I already see now that I got used to many things that I was faced with, e.g. the tube feeding and ground food, afterwards. Don't worry about tomorrow." "Increased personal strength" is the most characteristic code of this domain. The partner of the cancer patient recognizes that he or she possesses personal strength in consequence of coping with the traumatic event: "This is a strength of mine I don't want to miss." The code "Knowledge that bad things can and do happen" means that the partner of the cancer patient is aware of the fact that bad things can and do happen. This code finds expression in quotations such as: "What if the therapy is going to be stopped? Then we have to await how long he will still live." Next to these codes, there is also one paradoxical code in this domain: "Paradoxical element: sense of own vulnerability". Simultaneously with

recognizing one's own strengths the partner may also become aware of the fact that he or she is also vulnerable. This code can be found in quotations such as: "Often I feel as if I have to do everything on my own, as if everything comes down on me."

For the domain *New Possibilities* there are the following codes: "New activities", "New possibilities for taking a new and/or different path in life". "New activities" entails that in consequence of the trauma of the cancer diagnosis and coping with it, the partner becomes interested and engages in new activities, be it in the context of work or in the context of recreation etc. This code can find expression in the following way: "We arranged to go out one day every week. I continue doing mindfulness and yoga. Furthermore I thought about playing tennis more often." The term of the second code in this domain, "New possibilities for taking a new and/or different path in life" already entails its core. Taking another path in life can manifest in e.g. accepting a completely new job or exactly quitting one's job, or anything else not related to work: "In the end of june, I voluntarily quit my job. I already arranged this before Harry got sick. That was lucky under the circumstances, through which I have more time now."

For the domain *Relating to others*, there are the following codes: "Relating to others in general", "Greater connection to people", "More intimate and meaningful relationships", "Increased sense of compassion for others", "Increased sense that they are 'part of the main who suffer" and "Paradoxical element: changing relationships due to losing other relationships". "Relating to others in general" means that the partner appreciates relationships and friendships more and engages more in maintaining them than before the diagnosis: "I am proud of being able to say that I have many friends, most of them already more than 30 years. I consider it important and I also invest in that. I notice that I experience much support from that in this difficult time." The code "Greater connection to people" is given when the partner experiences deeper relationships respectively friendships since the diagnosis. This may find expression as follows: "Family ties became deeper, too." The next code, "More intimate and meaningful relationships" seems to be similar to the previous code but is somewhat more specific and targets the intimacy more than the previous code does. "More intimate and meaningful relationships" means that in consequence of coping with the trauma, the partner experiences relationships to become more intimate and meaningful. A typical example of this code may be: "I am going to invest more consciously in social contacts with people which I experienced as precious during "the cancer"." The code "Increased sense of compassion of others" is about empathising with other people who suffer – that follows on own coping with the diagnosis and the cancer itself. This increased sense of compassion may be expressed in

general and especially with those who also have to fight against cancer or have a partner who has to. "Letting him to cry out close next to me and telling him that he can get everything off his chest at my place and that it is good that he comes to me to show his feelings." The next code, "Increased sense that they are 'part of the main who suffer" may consequently follow on the increased sense of compassion for other people: the partner recognizes that he or she is not the only one bears this fate, but that there are indeed many people who suffer the same fate: "Television programme Imagine Having it...a girl that lost many organs, colostomy, no uterus, finally a CT scan and then it turned out that she had metastasis again after all. Disappointment, compassion, melancholy." The last code in this domain, "Paradoxical element: changing relationships due to losing other relationships" entails that the partner finds out who his or her real friends are and consequently loses some friends or relationships: "Furthermore it is also very confronting to see that our world has become very small. That we have few social contacts although we have a large circle of friends. My husband's fatigue and that he changed in a subtle way through the brain surgery makes that we can only make short appointments, it is searching for how we can find our way with the changing friendships."

The domain Appreciation of Life contains the following codes: "Appreciation of life (in general)", "Changed sense of what is important", "Major shift in how one approaches daily life", "Smallest joys in life get a special meaning" and "Paradoxical element: Happiness despite grief". The code "Appreciation of life" is given when it is obvious that the partner of the cancer patient appreciates life more since the diagnosis: "Very surprised that I sufficiently go on doing pleasant things: going for a walk, enjoying with my partner, being outside, delicious food, sociability. In a word, being happy in the situation as it is right now." "Changed sense of what is important" entails that the partner considers other things to be (more) important than before since the diagnosis. A typical quote for this code may be: "More and more, I try to figure out possibilities to create more time for myself." "Major shift in how one approaches daily life" means that, as a result of considering other things to be important, the partner may also change his or her approach of his or her daily life: "When talking about work I would consider dealing with someone who has cancer as work, too." The code "Smallest joys in life" is about valuing more small things such as smiling children, drinking a coffee etc. in consequence of the cancer: "Enjoying doing some gardening work". The last code in this domain, "Paradoxical element: Happiness despite grief" is about still being able to enjoy the pleasant sides and moments in life although the person has a difficult time and has to cope with the diagnosis and the cancer itself: "Genetically, for me the glass is always

half-full. Although there is almost nothing left in the glass now, I can enjoy the last nip that is left. This is always the most delicious one!"

The domain *Spiritual change* only contains one code: "Spiritual change (in general)". The partner experiences a greater sense of meaning in life, satisfaction and may also get answers to the fundamental questions of life. One does not have to be religious in order to experience growth in this domain. A typical example quotation of this code may be: "Inspiration, peace and harmony, giving meaning, ensoulment, silence, deceleration, faith, observing, reflection, meditation, consciousness, integrity, nature"

With the coding scheme, almost all answers to the exercises could be coded. Exceptions were formed by exercises in which participants only had to tick options from a list that apply to them. Furthermore, exercises that could be print out by the participants were not covered by the coding scheme. Lastly, the second exercise from lesson one was not covered by the coding scheme as it referred to the participant's childhood and delivered no content regarding PTG. Negatively coloured answers especially appeared within the scope of the codes "Paradoxical element: sense of own vulnerability" and "knowledge that bad things can and do happen".

In the following, three paragraphs will have a more detailed focus on the answer of each one of the three subquestions.

#### In which way do the domains of PTG occur?

At first, the following table will give an overview over the amounts of all codes in all dossiers. It contains all codes from the coding scheme together with the total amount of each code in all dossiers been analysed and the number of participants who showed a particular code (N).

Table 4. Distribution of the domains and codes over all dossiers and participants

Code	Total amount in all	N
5	dossiers	
Domain appreciation of life (AOL)		
Smallest joys in life get a special meaning	110	9
Changed sense of what is important	58	12
Paradoxical element: happiness despite grief	19	7
Major shift in how one approaches daily life	17	6
Appreciation of life (in general)	15	9
	219	Ø 8,6
Domain personal strength (PS)		
Paradoxical element: sense of own vulnerability	82	13
Knowledge that bad things can and do happen	47	15
Increased sense of personal strength	18	10
Can handle things better	13	9
	160	Ø 11,75
Domain relating to others (RTO)		
Increased sense of compassion for others	40	15
Greater connection to people	28	8
More intimate and meaningful relationships	16	8
Paradoxical element: changing relationships due to losing	10	5
other relationships		
Relating to others in general	8	6
Increased sense that they are "part of the main who suffer"	4	4
	106	Ø 7,67
Domain new possibilities (NP)		
New activities	9	6
New possibilities for taking a new and/or different path in	3	3
life		
	12	Ø 4,5
Domain spiritual change (SC)		
Spiritual change (in general)	2	1
-	2	1
	4	Ø 2

The domain appreciation of life (AOL) occurs most often in the dossiers of the participants of *Hold on, for each other*. Although this is the domain that occurs most often with respect to its codes, it is not the one that occurs in the most dossiers. The domain that occurs in the most dossiers is *personal strength* (PS). With respect to single codes, it can be said that "smallest joys in life get a special meaning" and "paradoxical element: sense of own vulnerability" occur most often in the dossiers (110 times respectively 82 times). The codes

"Knowledge that bad things can and do happen" and "increased sense of compassion for others" are shown by most, namely by all 15 participants.

Furthermore, with respect to its codes, the domain *personal strength* occurs second most commonly and the domain *relating to others* occurs third most commonly.

In terms of number of participants who showed a particular code, the codes "Paradoxical element: sense of own vulnerability", "changed sense of what is important" and "increased sense of personal strength" are shown by second, third and fourth most participants.

The domain *spiritual change* (SC) occurs least of all. Its only code is only shown by one participant and also just two times in total.

#### Distribution of the domains of PTG across the exercises

To answer the second subquestion, at first, another table was compiled. It shows for all exercises within the intervention *which* domains of PTG occured in the answers of the participants and for each exercise *how often* this domain occurred. Furthermore, the total amount of different codes in every single exercise and the average amount of PTG in a concerning exercise is displayed. This value takes the number of codes into account that was shown in a concerning exercise. Additionally, a more detailed version of this table can be found in Appendix A. Next to the domains of PTG, it also contains the individual aspects of the domains respectively the codes.

Table 5. Occurrence of domains of PTG in answered individual exercises of the intervention

domain	Personal strength	New possibil ities	Relating to others	Appreci ation of life	Spiritual change	Total amount of codes	Average amount of PTG <sup>a</sup>
lesson & exercises							
Lesson 1							
Exercise of the week: How do	22	-	15	9	-	11	4,2
I bear up?							
Compassion with yourself	5	-	22	3	-	9	3,3
Lesson 2							
Follow-up exercise of the	16	-	1	3	-	7	2,85
week: How do I bear up?							
Part 1/2							
Follow-up exercise of the	11	-	7	-	-	8	2,25
week: How do I bear up?							
Part 2/2							
How much do I claim from	1	3	-	14	-	6	3
myself?							
Lesson 3							
Follow-up exercise of the	4	-	2	11	-	9	1,8

week: Ensure recreation							
The answers to what-if-	27	-	-	3	-	4	7,5
questions							
Name the thoughts	10	-	-	8	-	8	2,25
The Worries-Box	5	1	-	-	-	3	2
Lesson 4							
Follow-up exercise: Carry	8	-	-	3	-	6	2
your thoughts and emotions							
with you							
Values in your relationship	4	-	8	12	-	9	2,67
Lesson 5							
Three good things	1	1	16	89	1	9	12
Cuddling attentively	1	-	4	2	-	4	1,75
Lesson 6							
Follow-up exercise:	2	1	4	8	-	8	1,88
Celebrating your relationship							
What do you want to talk	7	-	7	10	-	8	3
about?							
Dealing with drastic events	24	-	8	16	-	8	6
The Love Me-method	2	-	2	1	-	3	1,67
Lesson 7							
Strengthen your hope	-	1	6	6	-	8	1,63
Wise counsel part 1/2	2	-	-	9	-	6	1,83
Wise counsel part 2/2	5	-	1	1	-	6	1,17
What do you especially need	-	3	1	8	1	6	2,17
now?							
Lesson 8							
Pretty memories	-	-	-	3	-	3	1

*Note.* For a more detailed table, see Appendix A

In "How do I bear up?" (lesson 1), the greatest amount of different codes occurs (11). This is followed by several exercises in which nine or eight codes occur, for example "Compassion with yourself" (lesson 1), "Name the thoughts (lesson 3)" or "Three good things" (lesson 5). The fewest codes occur in the exercise "Pretty memories" (lesson 8) (3).

With respect to the average amount of PTG, the exercise "Three good things" (lesson 5) is ahead (12). That means that in this exercise most PTG occurs compared to the other exercises. At the same time, this is also the exercise with the largest *total* amount of PTG (108, see extend table in Appendix A). "The answers to what-if-questions" (lesson 3) shows the second largest average amount of PTG (7,5). The second largest total amount of PTG occurs in the exercise "Dealing with drastic events" (lesson 6) (48, see extended table in Appendix A).

Exercises that are mostly unrelated to PTG in terms of that few to no codes or frequencies occur, are: "Worries-box (Zorgen-doos)" (lesson 3), "Cuddling attentively

<sup>&</sup>lt;sup>a</sup>As measured by the amount of codes that occurred in the corresponding exercise

(Knuffelen met aandacht)" (lesson 5), "Love-Me method (Love-Me methode)" (lesson 6), "Wise counsel part 2 (Wijze raad deel 2)" (lesson 7) and "Pretty memories (Mooie herinneringen)" (lesson 8).

Summing up, it can be said that three exercises are clearly related to PTG: "Three good things" (lesson 5), "The answers to what-if-questions" (lesson 3) and "Dealing with drastic events" (lesson 6).

# Amount of PTG in the different groups of participants after the second measurement point

For the third subquestion, a table was compiled that is split with respect to the development of psychological distress from first to second measurement. The rows therefore show the three groups of participants: "Improved on HADS", "remained the same on HADS" and "deteriorated on HADS". The table further contains the number of expressions of PTG per participant and the average number of expressions of PTG per development on the HADS.

Table 6. Differences between participants of the three groups (improved, remained the same, or deteriorated on the HADS after second measurement) regarding the total amount of PTG

	Expressions of PTG per participant	Average amount of expressions of PTG
Improved on HADS		44,2
•	10	
	49	
	23	
	49	
	90	
Remained the same on HADS		32,2
	78	
	14	
	41	
	4	
	24	
Deteriorated on HADS		23,4
	31	
	21	
	5	
	4	
	56	

The group that improved on psychological distress, measured by the HADS, showed the greatest average amount of PTG. Simultaneously, the group of participants who remained the same on psychological distress after the second measurement comes second in terms of

average amount of expressions of PTG. In the group of participants who deteriorated on psychological distress after the second measurement,

In all three groups, there is each one obvious outlier: In the group that improved on psychological distress, there is one participant who expressed PTG 90 times. In the group of participants who remained the same on the HADS after the second measurement, one participant showed just four expressions of PTG in total while another expressed PTG 78 times. In the group of participants who deteriorated on the HADS, one participant expressed far more PTG than the other participants of this group (56).

For this subquestion, it was also controlled how many exercises participants completed. As lesson 7 and 8 were optional, the number of possible exercises varied. The participants could choose one of these lessons but did not have to. If they did, the number of possible exercises again depended on which of the two lessons they chose. The group of participants who improved on the HADS also completed most exercises (15 out of averagely 20,8 exercises).

Participants in the group that deteriorated on the HADS completed slightly more exercises (12,4 out of averagely 20,4 exercises) than participants in the group that remained the same on the HADS (12,4 out of averagely 21,4 exercises). In this field, there are also some outliers: In the group of participants who improved on the HADS, one participant completed only ten exercises out of 19 while other participants in this group completed far more exercises (19 out of 23 exercises). In the group of participants who remained the same on the HADS after the second measurement, one participant completed just five out of 19 exercises. In the group of participants who deteriorated on the HADS, one participant completed far more exercises than the other participants in this group (21 out of 23 exercises) while another one in this group completed only 5 out of 19 exercises<sup>1</sup>.

<sup>&</sup>lt;sup>1</sup> The different total numbers of completed exercises depend on which additional lesson (7 or 8) the participant chose

#### **Conclusions and Discussion**

It was aim of the present study to investigate if partners of cancer patients who participate in the theory based online intervention *Hold on, for each other* are able to experience PTG. Based on the literature, there was reason to presume that partners of cancer patients who participate in *Hold on, for each other* and get the possibility to improve their self-compassion and psychological flexibility, are also able to experience PTG.

#### **Most important results**

Analysis of the data disclosed that participation in *Hold on, for each other* is associated with the occurrence of PTG.

Regarding the first subquestion, especially the domains appreciation of life (AOL), personal strength (PS) and relating to others (RTO) occur most often. More specific, especially the codes "smallest joys in life", "paradoxical element: sense of own vulnerability", "knowledge that bad things can and do happen" and "increased sense of compassion for others" occur most often. Interestingly, other studies which also focused on PTG in partners or other family members of cancer patients, revealed similar results: Manne et al. (2004) found out that partners of cancer patients especially grew in the domains of personal strength, appreciation of life and relationship with others. The same applies for the study of Jansman (2014) and a yet unpublished study by Köhle, Drossaert and Bohlmeijer (2016).

As the analysis in this study disclosed the same domains occurring most often, its results could confirm what other studies found out earlier, namely that partners of cancer patients especially experience PTG in the domains personal strength, appreciation of life, and relation to others. However, the question remains whether PTG in these domains occurred during and due to the intervention or whether it already existed before participants started with the intervention. On the one hand, dealing with the ACT and self-compassion based exercises could have facilitated the emergence of PTG because self-compassion may motivate for growth and change (Neff, 2003). Furthermore, self-compassion may also support healthier dealing with traumatic events (van den Brink & Koster, 2013). Becoming psychologically flexible as it results from ACT is also associated with more posttraumatic growth (Kashad & Kane, 2010). On the other hand, PTG can already occur in consequence of hearing about the diagnosis and purely coping with the disease (Manne et al., 2004; Thornton & Perez, 2006; Jansman, 2014). Thus, people participating in Hold on, for each other may already have experienced PTG before due to coping with the diagnosis and the disease of the partner. In future research, a PTG-related questionnaire, for example the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996) should be given to the participants of Hold on, for each

*other* before they start with the intervention and after the finished it to determine whether they possibly already experienced PTG before the start and whether their levels of PTG could be improved through the intervention.

With respect to the second subquestion, it can be concluded that most PTG occurs in the exercises "Three good things" (lesson 5), "The answers to what-if-questions" (lesson 3) and "Dealing with drastic events" (lesson 6). Furthermore, the results from the first subquestion appear here, too: In the abovementioned exercises, almost entirely the domains appreciation of life and personal strength occur. As mentioned before, these domains rank among those occurring most often in the dossiers of the participants. This is not surprising: "Three good things" is about not focusing too much on negative experiences. It is about standing still with the things that are going well in one's life (Mongrain & Anselmo-Matthews, 2012). In this exercise, the construct self-compassion appears: The exercise is about being kind to oneself and about thinking mindfully about what is positive in one's life. Simultaneously, the domain *personal strength* is about a person's strengths, thus things that are positive, that are going well etc. With the exercise "Three good things", the participant starts to think about positive experiences in his or her daily life. He or she may get another view on what is positive. Simultaneously, the domain appreciation of life is about changing sense of what is important in one's life. This way, it makes sense that in *Three good things*, the domains personal strength and appreciation of life occur. The appearance of PTG in this self-compassion related exercise and the overlap between self-compassion and the occurring codes in this exercise show that these two constructs – self-compassion and PTG – are indeed closely related to each other.

"The answers to what-if-questions" is about that people normally try to avoid such questions because they are about worries and doubts. However, avoiding them results in the opposite, namely that these questions arise again and again. In this exercise, participants are consciously standing still at these questions. By doing this exercise, they get the awareness that some things are out of one's own control. Becoming aware and accepting what is out of one's own personal control is part of the core of ACT (Harris, 2009). Simultaneously, the domain *personal strength* also entails an increased awareness that "bad things can and do happen" (Tedeschi & Calhoun, 2004, p.6) in one's life. "Dealing with drastic events" asks the participant to evaluate how he or she and his or her partner deal with drastic events, primarily with the cancer. By definition, PTG is the realization that one has grown after being confronted with a traumatic event (Bohlmeijer & Bannink, 2013). Thus, this exercise affords the opportunity to think about one's own ways of dealing with traumatic events and

subsequently pave the way for PTG. The appearance of PTG in this exercise shows that these two constructs – ACT and PTG – are indeed closely related to each other. Until now there is little literature about this link, only Kashdan & Kane (2010) could show an association between psychological flexibility and greater reports of PTG.

Overall, certain exercises in *Hold on, for each other* yield more PTG-related content than other exercises do. Obviously, these exercises are more helpful in promoting PTG than those exercises in which less or even no PTG occurred. If the intervention is to be used to promote PTG, it should be considered if participants really have to do all exercises. It may be more time efficient and may faster lead to positive results regarding PTG if participants could directly choose relevant exercises. In further research, it could be investigated which exercises re clearly PTG related and which are less and which consequently should be taken along in a differentiated version of *Hold on, for each other*. As recommended earlier, also a steady measurement of the development of PTG in the form of a PTG-related questionnaire should be done.

With respect to the third subquestion, analysis of the data disclosed that participants in the group that improved in psychological distress measured by the HADS, also showed most PTG compared to the other two groups. Participants in this group also completed most exercises. Participants who deteriorated on psychological distress showed least PTG. A possible explanation for this finding may be the dose-response relationship. Howard, Kopta, Krause & Orlinsky (1986) introduced the term, that initially originates from the biological sciences (Hansen, Lambert, & Forman, 2002), to psychotherapy. In psychotherapy, "dose" means the number of therapy sessions and "effect" or response means the "percentage of patients improved" (Kopta, 2007, p. 727). Generally, it says that following a certain amount of sessions of psychotherapy is required, to improve symptoms. In Hold on, for each other, principally, all exercises are optional. Participants do not have to complete an exercise before they can go on with the following. It should be considered to make completion of exercises mandatory and necessary to go on with the intervention. That would enable a better doseresponse relationship for the participants. However, mandatory completion of the exercises would also entail that participants have to invest more time into the intervention. Oosterik (2014) found out that *Hold on, for each other* is well received by the participants i.a. precisely because it is not too time-consuming. This is reason to believe that making completion of exercises mandatory could consequently increase non-adherence. The developers of the intervention should therefore weigh whether they make completion of the exercises mandatory in order to eventually improve the dose-response relationship or whether they keep

the exercises up as being optional in order to reach as much people as possible. Again, further research could investigate which exercises are clearly related to one the three construct and which are less or even not related. Based on this and based on which construct is aimed to be promoted, a selection of exercises could be made. That would decrease the workload and the time necessary to complete the intervention while it may faster lead to positive results regarding the chosen constructs.

As mentioned before, in all groups there are obvious individual outliers regarding the total amount of PTG and the number of completed exercises. Apparently, the individual differences are larger than the differences between the groups. Based on this, a personalization of the intervention for each participant should be considered. Within persuasive system design, personalization entails offering personal content to the user. Personalized content should be presented on a first site (Oinas-Kukkonen & Harjumaa, 2009). Kelders, Pots, Oskam, Bohlmeijer and van Gemert-Pijnen (2013) for example studied different versions of a particular online invention, one of which included the possibility of personalizing one's own homepage within the intervention. A personalized homepage could contain a diary, testimonials or overviews of completed exercises and feedback (Kelders et al., 2013).

#### **Strengths, limitations and recommendations**

Analysis of the data resulted in the generation of a novel coding scheme that can now be used to code any interview or completed exercises in an online intervention related to PTG or where PTG is presumed. In the concerning data of this study, the domain *spiritual change* hardly ever occurred. Therefore, for use in other contexts than *Hold on, for each other* firstly a revision of the coding scheme should be considered to guarantee that no PTG relevant content, especially those with respect to *spiritual change*, is overlooked during the coding process. For further use in the context of *Hold on, for each other* it can be supposed that the coding scheme is complete because except of the single code in the scheme, the domain *spiritual change* hardly ever occurred in any of the analysed dossiers. Thus, it can be assumed that it will neither in any other dossier of any participant of *Hold on, for each other*.

The fact that nearly all data could be coded with the coding scheme based on PTG while the intervention was primarily based on ACT and self-compassion raises the question whether these three constructs – PTG, ACT and self-compassion may lie so close together. It can be recommended to study these constructs in a comparative way in future research. For example, it would be worth to investigate whether participants of a potential online

intervention primarily based on PTG, are also able to experience self-compassion or psychological flexibility which is the consequence of ACT.

The explorative style of the study can be considered both as strength and limitation. For one, it was an efficient manner to investigate whether participants experienced PTG. Furthermore, it provided a completely new coding scheme that can be used to code qualitative data with respect to PTG. However, it was not more than that. The tables compiled to answer the research questions are only able to sketch a first impression. No statistical measures were used to e.g. calculate means or difference scores. Further research should examine the research questions in a quantitative way to eventually support the present findings.

Two further limitations have to be kept in mind: Firstly, the seventh and eighth lessons were optional. Participants could choose one of these two but often they did not choose any but only did the first six lessons. That may be the reason why in the exercise "pretty memories" the fewest codes in total occur as it is part of the eighth lesson. As a consequence, this result has to be interpreted with caution: One cannot know whether this exercise would be more associated to PTG if the exercise was mandatory. Secondly, for some exercise, the participants could choose whether they would do them online or whether they would print them out. In some cases, it was thus not possible to track whether a participant indeed did not complete an exercise or whether he or she just printed it out and did it on paper. Further research should take into account this pitfall of not knowing whether participants indeed did not fill an exercise or whether they just did the printed version. Thus, in order to ensure that the data are complete, at first the depiction of the data in the dossiers should be reconsidered.

#### Final remark

The present study was able to disclose that participants of an intervention that is actually predominantly based on ACT and self-compassion are also able to experience PTG, particularly in the domains *Appreciation of life, Personal Strength* and *Relating to others*. The constructs ACT, self-compassion and PTG all turned out to be related among each other. Especially for the link between ACT and PTG there was little literature until now.

This study also resulted in a new coding scheme that makes it possible to code data of an online intervention on PTG. The coding scheme suits very well in this context; for use in contexts others than the intervention *Hold on, for each other* it should be applied with caution and at first be revised if necessary.

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**Appendix A**Tabel A1. Part one extended version of the table "Occurrence of domains of PTG in answered individual exercises of Hold on, for each other"

domain	Total	Total	Average	Personal	Code	s in th	is dom	ain:	New	Code	es in	Relati	Code	es in th	is don	ain: (	1) rela	ting
	amount	amount	amount	strength	(1) co	an han	dle thi	ngs	possibi	this		ng to	to ot	hers in	gener	al, (2)	greate	r
	of codes	of PTG	of PTG <sup>a</sup>		bette	r, $(2)$ $i$	ncreas	ed	lities	dome	ain: (1)	others	conn	ection	to peo	ple, (3	) more	,
						of per				new	, ,			ate an				
						gth, (3				activ	ities						sed ser	ise of
						rledge i		ıd		(2) n				assioi				ise of
						s can d				' /	bilities						y are '	'nart
					_	en, (4)				-	iking a			e main				part
						doxica		ant.		new/	-						, (o) hangin	or.
					-	oxica of ow		eni.		differ			-				ing oth	-
lesson & exercises						rabilit					in life			ionshi		io iosi	ing oin	e i
lesson & exercises						(2)	(3)	(4)		(1)	(2)			(2)	(3)	(4)	(5)	(6)
Lesson 1					(1)	(2)	(3)	(4)		(1)	(2)		(1)	(2)	(3)	(4)	(3)	(0)
	11	46	4.2	22		2	2	10				15		3	1	0	1	1
Exercise of the week: How do	11	40	4,2	22	-	2	2	18	-	-	-	13	-	3	1	9	1	1
I bear up?		20	2.2	_	1	1		2				22	1	1		20		
Compassion with yourself	9	30	3,3	5	1	1	-	3	-	-	-	22	1	1	-	20	-	-
Lesson 2		20	2.05	1.5		2												
Follow-up exercise of the	7	20	2,85	16	1	3	I	11	-	-	-	1	-	I	-	-	-	-
week: How do I bear up? Part																		
1/2	_					_												_
Follow-up exercise of the	8	18	2,25	11	1	2	2	6	-	-	-	7	-	1	-	2	1	3
week: How do I bear up? Part																		
2/2																		
How much do I claim from	6	18	3	1	-	-	-	1	3	2	1	-	-	-	-	-	-	-
myself?																		
Lesson 3																		
Follow-up exercise of the	9	17	1,9	4	-	3	-	1	-	-	-	2	-	1	-	-	-	1
week: Ensure recreation																		
The answers to what-if-	4	30	7,5	27	-	-	21	6	-	-	-	-	-	-	-	-	-	-
questions																		

#### Frauke Pelters, 1186957

Name the thoughts	8	18	2,25	10	2	1	4	3	-	-	-	-	-	-	-	-	-	-
The Worries-Box	3	6	2	5	-	-	2	3	1	1	-	-	-	-	-	-	-	-
Lesson 4																		
Follow-up exercise: Carry	6	12	2	8	5	1	3	-	-	-	-	-	-	-	-	-	-	-
your thoughts and emotions																		
with you																		
Values in your relationship	9	24	2,67	4	-	2	1	1	-	-	-	8	1	1	5	1	-	-
Lesson 5																		
Three good things	9	108	12	1	-	1	-	-	1	1	-	16	1	12	2	-	1	-
Cuddling attentively	4	7	1,75	1	-	-	1	-	-	-	-	4	2	-	2	-	-	-
Lesson 6																		
Follow-up exercise:	8	15	1,88	2	-	-	1	1	1	-	1	4	-	-	4	-	-	-
Celebrating your relationship																		
What do you want to talk	8	24	3	7	-	-	3	4	-	-	-	7	-	3	1	3	-	-
about?																		
Dealing with drastic events	8	48	6	24	-	1	3	20	-	-	-	8	-	3	1	4	-	-
The Love Me-method	3	5	1,67	2	-	-	-	2	-	-	-	2	-	-	-	2	-	-
Lesson 7																		
Strengthen your hope	8	13	1,63	-	-	-	-	-	1	1	-	6	1	1	-	-	-	4
Wise counsel part 1/2	6	11	1,83	2	1	-	1	-	-	-	-	-	-	-	-	-	-	-
Wise counsel part 2/2	6	7	1,17	5	1	1	1	2	-	-	-	1	1	-	-	-	-	-
What do you especially need	6	13	2,17	-	-	-	-	-	3	3	-	1	1	-	-	-	-	-
now?																		
Lesson 8																		
Pretty memories	3	3	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-

Table A2. Part two extended version of the table "Occurrence of domains of PTG in answered individual exercises of Hold on, for each other"

	1 .	~ .				• .		~
domain	Appreci			nis don	,	1)	Spiritual	Codes in
	ation of			on of li	change	this		
	life			) chan		domain:		
				ortani				(1)
				w one				spiritual
		daily	v life, (	4) sma		change in		
		life g	get a sp	pecial i	meanii	ıg,		general
		(5) p	arado.	xical e	lement			
lesson & exercises		happ	oiness (	despite	grief			
		(1)	(2)	(3)	(4)	(5)		(1)
Lesson 1								
Exercise of the week: How do	9	1	-	-	4	4	-	-
I bear up?								
Compassion with yourself	3	1	1	1	-	-	-	-
Lesson 2								
Follow-up exercise of the	3	-	1	1	1	2	-	-
week: How do I bear up? Part								
1/2								
Follow-up exercise of the	-	-	-	-	-	-	-	-
week: How do I bear up? Part								
2/2								
How much do I claim from	14	-	6	7	1	-	-	-
myself?								
Lesson 3								
Follow-up exercise of the	11	2	1	1	5	2	-	-
week: Ensure recreation								
The answers to what-if-	3	-	1	-	-	2	-	-
questions								
Name the thoughts	8	2	2	1	-	3	-	-
The Worries-Box	_	-	-	-	-	-	-	-
Lesson 4								
Follow-up exercise: Carry	3	1	1	-	-	1	-	-
your thoughts and emotions								
with you								
•	•						•	

#### Frauke Pelters, 1186957

Values in your relationship	12	-	11	-	1	-	_	-
Lesson 5								
Three good things	89	-	-	-	88	1	1	1
Cuddling attentively	2	-	-	-	-	2	-	-
Lesson 6								
Follow-up exercise:	8	-	1	1	4	2	-	-
Celebrating your relationship								
What do you want to talk	10	1	7	-	2	-	-	-
about?								
Dealing with drastic events	16	-	14	2	-	-	-	-
The Love Me-method	1	-	1	-	-	-	-	-
Lesson 7								-
Strengthen your hope	6	1	2	2	1	-	-	-
Wise counsel part 1/2	9	3	3	1	2	-	-	-
Wise counsel part 2/2	1	-	1	-	-	-	-	-
What do you especially need	8	2	5	-	1	-	1	1
now?								
Lesson 8								
Pretty memories	3	1	-	1	1	-	-	

# Appendix B

Table B1. Overview of all exercises within the intervention "Hold on, for each other"

Week in the	Name of the	Description of the exercise as it occurs	annotation
course of the	exercise	to the participants	amotation
intervention	CACICISC	to the participants	
1			
	Exercise of the week: How do I bear up?	Table for seven days and with the following columns: "situation", "emotion/feeling", and "behaviour"  For seven days, participants have to describe a situation in which they bear up and how they feel and behave during	
	How do I show vulnerability?	Adults often do bear up. In this exercise the opposite is up for discussion, namely how people show vulnerability. Participants are asked to think about how they showed their emotions when they were young. They are asked how they wanted to be soothed and how they felt with that	This exercise was not taken into account within this study as it referred to the participant's childhood and had no content regarding PTG
	Compassion with yourself	It starts with the statement that stressful and drastic events are very claiming. One bears up and makes many efforts to sustain the situation. Probably one is not aware of what this behaviour demands from someone. It is the purpose of this exercise to put oneself in the situation in which not the own partner is diagnosed with cancer but the partner of a close friend. One should imagine that the other one has a rough ride but tries to bear up. The participant is asked what he or she would advise his or her best friend and to write these things down. After that, the participant is further asked what is catching his or her eyes when rereading his or her advices. Besides, he or she is asked if this gives him/her another view on his/her own	

situation. The last question is about how the participant him/herself deals with advices from family or friends.

2

Follow-up exercise of the week: How do I bear up? Part The participant is asked which emotion occurs most often with him/her and how he/she bears up

1/2 Follow-up

exercise of the week: How do I bear up? Part 2/2

The participant is asked to think about the extent to which bearing up has helped him/her. The participant is further asked to think about what exactly has helped; if he/she lost something due to bearing up and if yes, what exactly.

How much do I claim from myself?

The participant is asked to estimate the number of hours he/she spends to work. In this case, under work job, household, taking care of the partner and children, doing the shopping, cooking, ... may come. Besides, the participant is asked to estimate how many hours he/she spends to sleeping and to recreation. After that, the participant is asked to think about what is catching his/her eyes and what he/she thinks about the ratio between sleeping, working and recreation

Exercise of the week: Ensure recreation

It begins with the statement that it is difficult find recreation to and you enjoyment when experience chronic stress and that you may not even know anymore through which way you can relax. The participant then gets a list with things, activities, etc people can get pleasure from. The participant is asked to look at the list every evening and to tick the things he/she experienced through the day. The participant is point to that if he/she does that some time that he/she will then get a new eye for things he/she can get

This exercise was not taken into account within this study as it was one where participants just had to *tick* those things that apply

pleasure from, despite the difficulties the cancer of the partner brings along.

3

Follow-up exercise of the week: Ensure recreation
The answers to what-if-questions

The participant is asked to write down what it meant to him/her to look at the list and tick relevant things/activities every day

What-if-questions are often expressions of worries and doubts. If such a question occurs we quickly don't want to think about it anymore. But exactly by trying to avoid such questions and thoughts, they come back again and again. It is a solution to even stick at the frightening thoughts. The participant is asked to write down his/her most important what-if-question. After that, he/she should answer this question. This answer may evoke another what-if-question which again has to be answered. The participant should go as long as no new questions arise.

Name the thoughts

Thoughts are quick. Often they are already gone before we recognize them. I comic strips, thoughts are placed in speech balloons. The participant is asked to draw a puppet with a thought balloon and to write down the five most often occurring thoughts associated with the disease of the partner. Afterwards, the participant is asked to read the thoughts aloud and to for what attention he/she pay experiences. Then, he/she is asked again to read the thoughts aloud but now with the addition "I have the thought/ feeling that ...". Finally, the participant is asked to write down what he experiences when reading the thoughts aloud.

The Worries-Box

Another way to deal with worries, and negative thoughts is to make a worries-box. The participant is asked to write down all his/her current thoughts,

worries and fears on a piece of paper and to put it into the box. After that, the box is closed and put to a place that does not immediately attract the attention. Later, one can throw the papers away or read them again. The participant is asked what he/she feels when rereading the worries and if they still exist and they were justified.

4

Follow-up exercise: Carry your thoughts and emotions with you The participant is asked to write down what he/she experienced when carrying the papers with the thoughts.

Values in your relationship (short version)

At first, the participant gives the things a moment's thought that make his/her relationship valuable. The participant can do this exercise with his/her partner but it is not essential. The participant should write down what he/she currently considers very valuably in his/her relationship. Furthermore, the participant is asked who he/she wants to be in the relationship. Following questions are: Which conclusions do you make?/ Do you want it to be different at the moment?/ Is it worth the effort to invest in the relationship now, too?

Values in your relationship (long version)

This version is more detailed and entails 5 steps:

(1) Which value regarding your relationship is most important to you?, (2) In how far do live according to these values?, (3) conclusion, (4) One step closer to your actions – determining actions, (5) identifying obstacles

exercise This was not taken into account within this study participants could print it out and as it was not filled in of the any dossiers

Values in your life

Similar to the previous exercise, except that it is now about values in *life*. This

This exercise was not taken

exercise aims to help the participant to become more aware of what he/she considers important in life and aims to challenge the participant to live more and more according to these values

into account within this study as participants could print it out and as it was not filled in of any the dossiers

5

Follow-up exercise: Values in your life

At first, the participant is asked to look back at the exercise "values in your life" from the previous lesson. The participant should give a conclusion whether he/she lived more according to

his/her values the last week

Celebrating your relationship

This exercise is an impetus to think about how one can celebrate the relationship more intensively. Participants get a list from which they can choose one or more activities and are asked to do them in the following week.

This exercise was not taken into account within this study as it was one where participants just had to tick those things that apply

Exercise of the week: Three good things

In a difficult period of time it is extra important to pay attention to joyful emotions. This boosts one's resilience and can improve one's mood. The participant is asked to take 5 minutes at the end of each day to give three good or positive things a moment's thought. The participant is further asked to think about why those things were positive.

Cuddling attentively

This is a mindfulness exercise for the participant and his/her partner. They are asked to position themselves face to face and then to cuddle attentively for five minutes. Afterwards they should talk about their experiences and write

them down

6

Follow-up exercise: Celebrating your relationship

The participant is asked to tell about whether he/she succeeded in celebrating his/her relationship, and, if yes, how he/she experienced that, and, if not, why.

What do you want to talk about?

The participant is asked about the topic most discussed with the partner. Then, the participant is asked if there are topics that were not discussed but he/she gladly wants to talk about. In the following, the participant is asked whether there are reasons for not talking about certain topics. This exercise can be done together with the partner. Then questions they answer the themselves and talk about it afterwards. Is there new information? Is that confronting or comforting?

**Dealing** with drastic events

This exercise is about how participant and his/her partner deal with drastic events. For this purpose, there are several questions that have to be answered.

There is always communication The participant gets a list with rules that do not really help in an effective communication. If he/she recognizes rules that apply to his/her communication, then he/she should tick them. He/she can also fill in the list with own rules

This exercise was not taken into account within this study as it was one where participants just had to tick those things that apply

method

The Love-Me A method if communication does not function very well and to bring up a problem for discussion

7

This lesson was optional. **Participants** could choose this or the following one

or none

# Strengthen your hope

The participant is asked to imagine that one year has passed. The symptoms did not come back and the partner feels quite vigorous again. You did everything in your power to cope with the difficult situation. You commenced life again. The participant is asked to imagine how his/her life looks like this one year later. He/she is further asked who he/she interacts with people in his/her environment: Are there new friendships?/ Did existing relationship intensify?

Wise counsel part 1/2

The participant is asked to imagine being 10 years older and that the disease of the partner is 10 years ago. Now he/she looks back to this period. The participant should imagine that the 10 years older-self gives advice to the actual self and write down what this advice looks like.

Wise counsel part 2/2

The participant is asked what catches his/her eyes when he/she rereads the advices from the previous exercise

What do you especially need now?

People have needs on different levels, e.g. self-care, recreation, autonomy, connection to other people, ... The participant is given an overview with needs on different domains and has to tick which are most important for him/her at the moment

8

This lesson was optional.

Participants could choose this or the previous one or none

Pretty memories In this exercise, the focus is on generating new, beautiful memories