The disappearance of a significant other

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General introduction

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"Even after seven and a half years, whenever I see a Toyota Camry the same colours as Dad's, I check the number plate…When this sort of thing happens, your world changes in an instant: one minute that person is there: the next they're not. From then on your life isn't the same. And the real challenge with this kind of event is that it's uncommon, so the police and the community don't generally know how to respond. It can be very isolating."

(In 2008, Jason's father was last seen driving in his car on a road just outside his hometown (Missing Persons Advocacy Network, 2017))

"You still want to know. Even though we are almost 100% sure that we will not find her, not alive anyway. It is difficult, you know, because when there is an article in the newspaper saying "a body was found somewhere" or we hear in on the TV or the radio or whatever, then you are immediately on edge. And then you follow that news very intensively at such a time, so that sense of uncertainty remains a sensitive issue."

(About 30 years earlier Angie's teenaged sister disappeared on a night home alone leaving only traces of a crime behind)

"It is just as surreal and mind numbing as the first day because there are no answers. I try to exist day to day but the cold fact remains. I cannot give my husband a dignified burial. I cannot find his remains. I wake with Warren constantly in my thoughts. I go to bed the same. It keeps me awake at night. I cannot close this out. I cannot grieve effectively."

(Warren started a hiking trip about 8 years ago and never returned (Missing Persons Advocacy Network, 2017))

These phrases illustrate the psychological impact of the long-term disappearance of a significant other. Exploring consequences of, and care after the long-term disappearance of a significant other is the overarching aim of this dissertation. A missing person is defined as: "Anyone whose whereabouts is unknown whatever the circumstances of disappearance. They will be considered missing until located and their well-being or otherwise established" (Association of Chief Police Officers, 2010, p. 15). In the following, we summarize rates and types of missing persons, followed by a description of (the impact of) confrontation with the disappearance of a significant one, also termed "ambiguous loss" (Boss, 1999). Secondly, an overview is given of bereavement research that served as fundament of this dissertation. Lastly, an outline of the dissertation is presented.

1. THE DISAPPEARANCE OF A SIGNIFICANT OTHER

1.1 Rates of missing persons

In 2014, at least 80 persons[1] were daily reported as missing to the Dutch police. Fortunately, the majority of the missing persons was reconnected with their families within 48 hours (Schouten, van den Eshof, Schijf, & Schippers, 2016). In the Netherlands, yearly the whereabouts of about 100 missing persons remain unknown for more than one year (van Leiden & Hardemen, 2015). These rates of reports of missing persons and the occurrence of long-term missing persons are comparable to countries with similar political climates, for instance Germany and Australia (Schouten et al., 2016).

The long-term disappearance of a loved one can be considered an unnatural loss, and, as such, is a relatively rare phenomenon in the Netherlands compared with other types of unnatural losses. To illustrate this, in 2015 suicidal death, fatal traffic accident, and homicide occurred 1871, 621, and 120 times, respectively (Centraal Bureau voor de Statistiek, 2017a, 2017b, 2017c). Worldwide, disappearances of persons in armed conflict or due to disasters are more common. For example, 1,717 persons were unaccounted for one year after the 9/11 World Trade Center attacks in 2001 (Boss, 2004) and 2,668 persons were still reported as missing two years after the Tsunami in Japan 2011 (see Matsubara et al., 2014). The death of over 14,000 persons during the war in Bosnia Herzegovina in 1992-1995 was still unconfirmed after 10 years (ICRC, 2007). And it has been estimated that 27,000 enforced disappearances took place in Mexico since the beginning of the "war on drugs" initiated in 2006 (Amnesty International, 2016). In the Syrian refugee crisis, millions of people were separated from family and friends (Amnesty International, 2014).

1. Based on at least 30.000 reports to the Dutch police of missing persons in 2014.

1.2 Types of missing persons

In the Netherlands, about 2.9% of all the registered long-term missing persons cases is presumably caused by disasters or accidents, 3.3% caused by war, and 10.6% disappeared while traveling abroad (van Leiden & Hardemen, 2015). These types of disappearances are categorised as *unintentional absence* on a missing continuum (see Figure 1; Biehal, Mitchell, & Wade, 2003). In 10.5% of the Dutch missing person cases, the missing person is presumably killed or kidnapped (i.e., *forced* on the missing continuum). In 23.9% of the cases, the disappearance concerns an asylum seeker who has been separated from others and lost contact with significant others (i.e., *drifted* on the missing continuum). In 6.1% of the cases, the missing person presumably left voluntarily (i.e., *decided* on the missing continuum).

Figure 1. Missing continuum (Biehal et al., 2003).

These rates should, however, be interpreted with caution, because in most of the registered cases (i.e., 42.7%) the presumed reason/cause of disappearance was not registered. The registrations of missing persons were also based on different databases; saliently, most data originated from a database of a Dutch television show about missing persons and a database of the Dutch police. It is highly likely that the rates of disappearances are biased, due to a lack of a systematic national registration system of missing persons. Furthermore, the rates of disappearances by war and voluntarily missing person cases are most likely higher, because these types of disappearances are under-registered in Dutch databases (Leiden & Hardemen, 2015).

1.3 Ambiguous loss

The disappearance of a loved one is also termed “an ambiguous loss” (Boss, 1999). Boss defines two types of ambiguous loss: 1) psychological absence, but physical presence of a significant other (e.g., parent with dementia) and 2) physical absence, but psychological presence of a significant other (e.g., the disappearance of a spouse). Boss (2006, p. 7) presumes that ambiguous loss is “the most stressful kind of loss due to ambiguity”. Others have described that relatives of missing persons live “in a constant state of anxiety and restlessness” (Hollander, 2016, p. 299) and that an ambiguous loss is “cruel in its unending torment” (Betz & Thorngren, 2006, p. 359). However, these statements are all based on clinical experience, rather than empirical evidence.

Although it is not sufficiently empirically tested, there are several reasons to assume that the grief process following the long-term disappearance of a loved one differs from the grief process after the death of a loved one. Firstly, not knowing whether the loss is temporary or permanent, may lead to preoccupations with the (circumstances of the) disappearance, which in turn may complicate recovery from loss (Boss, 2006). Secondly, holding on to hope for the return of the (remains of the) missing loved one, while at the same time dealing with the absence of the person may prevent people to move on in life, reinforcing prolonged grief (PG) reactions (Heeke, Stammel, & Knaevelsrud, 2015). Furthermore, leaving those left behind without a burial ceremony or site to visit may also contribute to a disturbed grief process (Castle & Phillips, 2003). Fourthly, the absence of specific legislation that enables families of missing persons to obtain the legal right to manage the missing person's affairs[2], may result in considerable financial consequences. For instance, the loss of a missing person's income while continuation of a missing person's mortgage, taxes, and insurances, likely also burdens those left behind. In addition, relatives of missing persons may struggle to find their way through complex legal and ownership issues, with limited professional support available (Blaauw & Lähteenmäki, 2002; Holmes, 2008). Lastly, social marginalization, stigmatization, and lack of social support may be additional stressors that contribute to elevated psychopathology levels post-disappearance (Hollander, 2016; Quirk & Casco, 1994; Robins, 2010).

In sum, the long-term disappearance of a significant other outside the context of armed conflict or disaster appears to be a relatively rare phenomenon. It is conceivable that maladjustment to the loss is more common among relatives of missing persons than relatives of deceased persons because of disappearance-related stressors that may complicate the grief process. Below we present an overview of bereavement research, which is fundamental to this dissertation.

2. BEREAVEMENT RESEARCH

2.1 Grief work and beyond

After a century of research, a debate on which manifestations of grief (if any) should be considered pathological is still ongoing (see for instance Maciejewski & Prigerson, 2017; Stroebe, Schut, & Stroebe, 2007, Stroebe, Stroebe, Schut, & Boerner, 2017a; Zisook, Pies, & Corruble, 2012). The origin of the debate seems to date back to what Stroebe and Schut (1999) called the 'grief work hypothesis'. Freud (1917) is, according to Stroebe, Schut, and Boerner (2017b), the first who described mourning as 'inner labour'. Freud's idea was that mourners need to accept the reality of the loss and detach themselves from the deceased, which is accompanied with inner pain. Those who failed to do their grief work, most likely because of an ambivalent relationship with

2. With the exception of the declaration of presumed death that can be requested in the Netherlands after five years (Ministry of justice and security, 2017).

the deceased, may present pathological grief reactions. These reactions resemble melancholia, including painful dejection, social withdrawal, and decrease in activity. The importance of grief work has also been emphasized in multiple theories that have dominated the literature in the 20th century (see for an overview Stroebe et al., 2017a). For instance, Kübler-Ross' (1969) prescriptive grief stages (i.e., denial, anger, bargaining, depression, and acceptance) and the more descriptive task model of Worden (1991, 2008; i.e., accept the reality of the loss, process the pain of grief, adjust to a world without the deceased, and retain connection to the deceased) are examples of widespread models of grief processes.

However, the adaptive role of grief work has not been empirically supported (Bonanno, 1998; Bonnano & Kaltman, 1999). One of the first examples of a grief model that moves beyond describing tasks, stages, or phases of grief is the dual process model (Stroebe & Schut, 1999, 2010). According to this model, grief is a process of oscillation between confrontation and avoidance of loss-oriented stressors (i.e., aspects of the loss itself) and restoration-oriented stressors (i.e., secondary stressors resulting from bereavement). The dual process model of coping with bereavement describes processes that may occur in general bereavement (Maccallum & Bryant, 2013), in an attempt to explain what adaptive coping with bereavement means (Stroebe & Schut, 2001a). Since the mid 1990's, also another line of research arose that was not focused on normative reactions to the death of a significant other, but rather on debilitating non-normative grief reactions, labelled as "prolonged grief (PG)". Together with the development of the 19-item Inventory of Complicated Grief (ICG) in 1995 by Prigerson et al. research into disturbed grief reactions was initiated and new theoretical ideas were generated. Before we will describe these, we will elaboarte on PG a bit more.

2.2 Prevalence, consequences, and comorbidity of prolonged grief

Different labelling, for instance complicated or traumatic grief, has been used across studies to refer to debilitating non-normative grief reactions that may merit clinical attention. Since the introduction of the term prolonged grief disorder (PGD), this term has found strong consensus among some leading researchers in the field (Prigerson et al., 2009). Because there is no empirical evidence indicating that persistent grief reactions qualitatively differ from acute normative grief reactions (Bryant, 2014), the term PGD is most frequently used in this dissertation to refer to debilitating non-normative grief reactions. Before going into detail about the theory and treatment of PGD, the prevalence, consequences, and comorbidity of PGD are discussed.

2.2.1 Prevalence of prolonged grief

Examples of normative grief reactions are yearning for the deceased, experiencing difficulty accepting the loss, and difficulty engaging in activities following the loss (Prigerson et al., 2009).

When these acute grief reactions persist at least 6 months following the death and cause significant distress and impairments in daily life it may be defined as PGD (Prigerson et al., 2009). PGD will likely be included in the forthcoming 11th edition of the International Classification of Diseases (ICD-11; Maercker et al., 2013), albeit with symptom criteria that are likely to differ from the description put forth by Prigerson et al. (2009). The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) included Persistent Complex Bereavement Disorder as condition for further study (APA, 2013). PGD and PCBD seem to cover the same diagnostic entity, based on resemblance in prevalence, sensitivity, and specificity rates, and predictive validity (Maciejewski, Maercker, Boelen, & Prigerson, 2016). They differ from each other with respect to the time criterion (6 months post-loss for PGD vs. 12 months post-loss for PCBD), number of symptoms (7 for PGD vs. 16 for PCBD), and possible symptom profile heterogeneity (48 ways to meet PGD criteria vs. 37,650 ways to meet PCBD criteria; Lenferink & Eisma, 2018).

The results of a meta-analysis suggest that 9.8% of people confronted with the non-violent loss (e.g., illness) of a significant other at least 6 months earlier is at risk for developing PGD (Lundorff, Holmgren, Zachariae, Farver-Vestergaard, & O'Connor, 2017). Experiencing the death of someone significant that happens unexpectedly and/or has a violent cause heightens the risk of elevated grief-related distress (Boelen, de Keijser, & Smid, 2015; Currier, Holland, & Neimeyer, 2006; Goldsmith et al., 2008; Kaltman & Bonanno, 2003). For instance, prevalence rates of PGD among people confronted with a disaster-related loss vary from 14% to 76% (see for an overview Kristensen, Weisæth, & Heir, 2012) and from 25% to 78% for people bereaved by suicide (see for an overview Linde, Treml, Steinig, Nagl, & Kersting, 2017). The disappearance of a significant other also seems to be a risk factor for poor adjustment (Kristensen et al., 2012). For instance, a study among Colombian people confronted with disappearances due to political repression 7 years earlier, showed prevalence rates of 23% for PGD, 69% for depression, and 67% for posttraumatic stress disorder (PTSD). These rates did not significantly differ from Colombian people exposed to the death of a significant other in the same violent context (Heeke et al., 2015). A comparative study, in the context of war, showed that Bosnian women confronted with the disappearance of their spouse reported significantly higher so-called "traumatic" grief and depression levels than Bosnian women confronted with the death of their spouse (Powell, Butollo, & Hagl, 2010). Another study showed higher depression levels among Bosnian adolescents whose fathers disappeared in war than Bosnian adolescents whose fathers were killed (Zvizdic & Butollo, 2001).

2.2.2 Consequences and comorbidity of prolonged grief

PG levels are associated with a host of detrimental health outcomes in bereaved people, including sleep disturbances (Germain, Caroff, Buysse, & Shear, 2005; McDermott et al., 1997), hypertension, cardiac problems (Prigerson et al., 1997), an increased risk for suicidal ideation and behaviour

(Maciejewski et al., 2016; Prigerson et al., 1997), an increased risk for mortality (Stroebe & Schut, 2001b), reduced quality of life (Boelen & Prigerson, 2007; Maciejewski et al., 2016; Silverman et al., 2000), impairments in work and social functioning (Bui et al., 2015; Kristensen, Weisæth, Hussain, & Heir, 2015; Maciejewski et al., 2016; Prigerson et al., 1997), and an increased risk of comorbid mood and anxiety symptoms (Newson, Boelen, Hek, Hofman, & Tiemeier, 2011; Shah & Meeks, 2012).

Factor analytic studies have shown that PG shows overlap with, yet is distinguishable from depression, anxiety, and posttraumatic stress (PTS) in bereaved people (Boelen & Prigerson, 2007; Boelen & van den Bout, 2005; Boelen, van den Bout, & de Keijser, 2003a; Chen et al., 1999; O'Connor, Lasgaard, Shevlin, & Guldin, 2010; Ogrodniczuk et al., 2003; Prigerson et al., 1996). In addition, studies, using latent class analysis have shown that people who are primarily suffering from elevated PG levels following the death or disappearance of a relative are distinguishable from people with elevated PG plus comorbid depression and/or PTS symptoms (Boelen, Reijntjes, Djelantik, & Smid, 2016; Boelen, Spuij, & Reijntjens, 2017; Djelantik, Smid, Kleber, & Boelen, 2017; Heeke, Stammel, Heinrich, & Knaevelsrud, 2017; Lenferink, de Keijser, Smid, Djelantik, & Boelen, 2017; Nickerson et al., 2014).

PG symptomatology shares some commonalities with PTS (including re-experiencing and avoidance symptoms; Heeke et al., 2017; Maercker & Znoj, 2010; Nickerson et al., 2014; O'Connor et al., 2010) and depression symptoms (e.g., sad mood, sense of emptiness, fatigue, and suicidal ideation/behaviour; Boelen et al., 2003a, 2016; Djelantik et al., 2017; MacCallum, Malgaroli, & Bonanno, 2017; Shear et al., 2011). It has been argued that re-experiencing symptoms in PGD differ from those in PTSD with respect to the emotional valence of the memories (Maercker & Znoj, 2010): for PGD re-experiencing of both positive and negative memories, often simultaneously, whereas for PTSD re-experiencing of negative memories is key. Furthermore, avoidance in PGD is aimed at averting painful thoughts and feelings related to the loss, whereas avoidance in PTSD is used to prevent thoughts and memories related to the traumatic event and the recurrence of threat or danger. Depression coincides with inactivity, whereas yearning in PGD seems to be associated with passivity as well as activity (Stroebe & Schut, 1999). In addition, a sad mood in depression is related to low self-esteem, whereas a sad mood in PGD is related to longing for the deceased (Shear et al., 2011).

In sum, since the mid 1990's research on bereavement has focused on PGD. One out of ten people confronted with a non-violent death of a significant other is at risk to develop PGD. Experiencing the disappearance of a significant other heightens the risk of elevated grief-related distress. PGD symptoms resemble normative grief reactions, but differ from these reactions regarding the intensity and duration. A diagnosis of PGD may apply to people experiencing grief reactions that cause significant distress and impairments in daily life following the death of a

significant other 6 months earlier. Elevated PG levels are associated with a host of detrimental physical and mental health outcomes. PG symptoms overlap with, yet are distinguishable, from PTS and depression symptoms.

3. THEORY OF DISTRESS POST-LOSS

Literature on PGD, PTSD, and depression in relatives of missing persons is scarce. To illustrate this, based on a literature review seven quantitative studies have previously examined the psychological consequences for people exposed to the disappearance of a significant other in the context of armed conflict (Heeke & Knaevelsrud, 2015). None of these studies examined correlates of distress post-disappearance that are amendable to change in treatment. Gaining insights into such correlates is relevant for developing psychological treatment for relatives of missing persons in need of support. Previous studies have primarily focused on the associations between sociodemographic and armed conflict-related stressors on the one hand and psychopathology levels on the other hand (Heeke & Knaevelsrud, 2015). To our knowledge, literature on severity and correlates of PGD, PTSD, and/or depression in people exposed to the disappearance of a significant other *outside* the context of armed conflict was absent. In this dissertation, we therefore relied on theories about variables associated with psychopathology in bereaved people that are amendable to therapeutic change.

Because of the limitations of the grief-work hypothesis, theories were generated regarding processes involved in the onset and maintenance of distress after bereavement (Boelen, van den Hout, & van den Bout, 2006a; Bonanno & Kaltman, 1999; Maccallum & Bryant, 2013; Shear & Shair, 2005). One of these theories is Boelen et al.'s (2006a) cognitive behavioural theory of PG. This theory is used as fundament in this dissertation because it attempts to enhance knowledge about underlying processes of PG, rather than normative grief, and specifies how these processes could be assessed and targeted in treatment.

Because the disappearance of a significant other is inherently linked to uncertainties (e.g., not knowing whether the person is alive or dead) that are uncontrollable (Boss, 2006), more than natural losses (e.g., caused by illness), ambiguous losses may give rise to repetitive thinking. This can be understood from the goal-discrepancy theory stating that repetitive thinking focused on goals that have not (yet) been attained (e.g., one feels sad when one wants to feel happy; one misses a loved one that one wants to be close to). What follows is that people with more extreme or unattainable goals may be more inclined to get entangled in repetitive thinking (Ehring & Watkins, 2008; Martin & Tesser, 1989). In this dissertation, we therefore also zoom in on several intrapersonal thinking processes that are expected to relate to disappearance-related distress and could be targeted in treatment.

3.1 Cognitive behavioural theory of prolonged grief

Inspired by cognitive-behavioural models of PTSD (Ehlers & Clark, 2000) and psychopathology (Beck, 1976), a cognitive-behavioural model of PG was developed (Boelen et al., 2006a). This model identifies three underlying but changeable processes that are assumed to play an important role in the onset and maintenance of PG: (a) insufficient integration of the loss into autobiographical knowledge, (b) negative cognitions, and (c) avoidance behaviour.

The first process, insufficient integration of the loss, reflects incongruence between factual knowledge that the loss has happened and experiencing a subjective sense of uncertainty about the permanence of the separation. This sense of uncertainty about the irreversibility of the loss is also coined 'a sense of unrealness' and is often expressed in phrases such as "I know that s/he is dead, but it feels as if it did not happen" (Boelen, 2010, 2017). Following the death of a loved one, most bereaved people naturally adapt to the factual knowledge that the separation is irreversible. The information about the deceased, the relationship with the deceased, and the related thoughts, memories, and feelings are processed and integrated with existing autobiographical knowledge. During this process meaning making takes place, resulting in "a coherent story about the relationship with the deceased with a beginning and an end" (Boelen et al., 2006a). It has been argued that some people have difficulties integrating the loss into autobiographical knowledge. This may result in intrusive memories, ruminative thoughts, feelings of shock, and yearning once the bereaved person is confronted with loss-related stimuli. This could be a variety of loss-related stimuli; all that was once related to the presence of the deceased is now related to his/her absence (Boelen et al., 2006a). Elevated levels of unrealness have been associated with elevated post-loss psychopathology levels (Boelen, 2010, 2017).

The second process includes negative cognitions about the loss and/or its sequelae. These negative cognitions include catastrophic misinterpretations of one's own grief reactions (e.g., "If I let go of my emotions, I will go crazy"), negative beliefs about the self (e.g., "I am ashamed of myself, since s/he died"), life (e.g., "Life has got nothing to offer me anymore"), and future (e.g., "I don't have confidence in the future"). Cross-sectional and longitudinal studies provided support for the associations of negative cognition with PG, PTS, and depression levels on the other hand (Boelen, van Denderen, de Keijser, 2016; Boelen, van den Bout, & van den Hout, 2003b, 2003c, 2006b; Horsch, Jacobs, & McKenzie-McHarg, 2015).

According to the cognitive-behavioural model of PG, the use of avoidance strategies is the third process involved in the onset and maintenance of PG (Boelen et al., 2006a). Avoidance strategies include anxious avoidance and depressive avoidance. Anxious avoidance represents avoidance of situations, places, or people that are associated with the deceased out of the belief that confrontation with reminders of the loss is unbearable. Depressive avoidance represents withdrawal from previous meaningful activities because of the belief that these activities are not

meaningful anymore since the loss. Avoidance behaviours have been linked, concurrently and longitudinally, to elevated psychopathology levels following loss (Boelen & Eisma, 2015; Boelen & van den Bout, 2010).

3.2 Emotion regulation strategies

According to the response styles theory (Nolen-Hoeksema, 1991), responses to affective states are of more importance for maintaining mood disorders than the affective state itself. The way bereaved people respond to a depressed mood, including depressive rumination, was first examined in the 1990s by Nolen-Hoeksema and colleagues (Nolen-Hoeksema, McBride, & Larson, 1997; Nolen-Hoeksema, Parker, & Larson, 1994). Depressive rumination is defined as "repetitively and passively focusing on symptoms of distress and on the possible causes and consequences of these symptoms" (Nolen-Hoeksema, Wisco, & Lyubomirsky, 2008, p. 400). Ironically, in an attempt to understand and solve problems, people start to ruminate; however, by fixating on the problems, rumination impedes active problem solving (Nolen-Hoeksema et al., 2008). Several studies indicated that people who were more inclined to depressive rumination (e.g., "When I feel down, sad, or depressed I think 'Why do I react this way?'") reported higher levels of depression concurrently and longitudinally following the loss of a significant other (Nolen-Hoeksema et al., 1994, 1997).

Similar to depression research (Feldman, Joormann, & Johnson, 2008), in bereavement research studies on affect regulation strategies are mainly focused on the maladaptive role of rumination (Eisma et al., 2015; Morina, 2011; Nolen-Hoeksema et al., 1994, 1997). Knowledge about the effect of positive affect regulation strategies on psychopathology levels is largely lacking, despite previous studies indicating that experiencing/expressing positive mood fosters recovery from loss (Bonnano & Keltner, 1997; Bonanno, Mihalecz, & LeJeune, 1999; Keltner & Bonanno, 1997; Tweed & Tweed, 2011). The Response to Positive Affect (RPA) questionnaire was developed by Feldman et al. (2008) to provoke more research into positive affect regulation strategies, including dampening and enhancing of positive affect. More dampening has been related to increased depression levels (Raes, Smets, Nelis, & Schoofs, 2012); more enhancing has been related to lower depression levels (Nelis, Holmes, & Raes, 2015). The RPA parallels the Ruminative Response Scale, which is often used to assess depressive rumination (Eisma & Stroebe, 2017; Treynor, Gonzales, & Nolen-Hoeksema, 2003). Raes and colleagues found that positive affect regulation strategies, assessed with the RPA, are concurrently and longitudinally linked to depression scores over and above depressive rumination (Raes, Daems, Feldman, Johnson, & Van Gucht, 2009; Raes et al., 2012, 2014).

As more recently argued (Eisma et al., 2015; Eisma & Stroebe, 2017), rumination about the causes and consequences of the loss may be of more relevance to bereaved people than rumination

about the causes and consequences of a depressed mood. Similar to depressive rumination, grief rumination (e.g., "How frequently in the past month did you ask yourself why you deserved this loss?") has also been linked concurrently and longitudinally to elevated psychopathology levels post-loss (Eisma et al., 2015). In the rumination-as-avoidance hypothesis it has been argued that rumination might be a cognitive avoidance style. For instance, by repeatedly thinking about how the loss could have been prevented, the bereaved person avoids thinking about the irreversibility of the loss, which may interfere with acceptance of the loss (Boelen, 2006; Eisma et al., 2013; Eisma & Stroebe, 2017; Stroebe et al., 2007).

Accepting and embracing one's own suffering, coined 'self-compassion', has been identified as a factor preventing people to get entangled in ruminative thinking. A self-compassionate attitude is linked to engagement with, rather than avoidance, of distressing thoughts, memories, and feelings (Leary et al., 2007; Thompson & Waltz, 2008). Based on a finding that self-compassion was significantly and negatively associated with the avoidance PTSD cluster, but not with other PTSD clusters, Thompson and Waltz (2008) concluded that self-compassion might be "a natural process of exposure to trauma-related stimuli" (Thompson & Waltz, 208, pp. 558). Cross-sectional studies have shown that people with higher levels of self-compassion are less inclined to ruminate (Neff, 2003; Svendsen, Kvernenes, Wiker, & Dundas, 2016). The findings of two other cross-sectional studies suggested that depressive rumination might mediate the associations between self-compassion and depression and anxiety levels (Krieger, Altenstein, Baettig, Doerig, & Holtforth, 2013; Raes, 2010). However, the adaptive role of self-compassion in bereaved people remains to be studied.

In conclusion, to enhance our understanding of clinical correlates of psychological symptoms in relatives of missing persons, several theories drawing from research in PG, depression, and PTSD are relevant. First, the cognitive behavioural theory of PG has repeatedly shown to be relevant for our understanding of how negative cognitions and avoidance behaviours are related to post-loss distress and how these variables could be targeted in treatment. Drawing from depression research, ruminating about one's sad mood (i.e., depressive rumination), but also ruminating about the causes and consequences about the loss (i.e., grief rumination) have been identified as risk factors for distress in bereaved people. Lastly, based on depression and PTSD research, indicating the protective role of adaptive regulation of positive affect and self-compassion, it seems worthwhile to explore how these clinical correlates relate to PG, PTS, and depression levels post-loss.

4. TREATMENT OF DISTRESS POST-LOSS

To the best of our knowledge, only one study examined treatment effects for relatives of missing persons. In this quasi-randomised controlled trial (Hagl, Rosner, Butollo, & Powell, 2015), 57 women whose husbands were missing following the war in Bosnia Herzegovina, as well as 62 women whose husbands were killed in war were allocated to one of two conditions. In the first condition people received dialogical exposure group therapy, using an empty-chair method derived from Gestalt therapy to start a direct dialogue with the deceased/missing husband. The second condition consisted of a supportive group in which people talked *about*, instead of *to*, the deceased/missing husband. In addition, elements of CBT including targeting unhelpful thoughts and behavioural elements were added to both conditions. Although the findings of this trial indicate that both conditions seem effective in reducing PTSD and so-called "traumatic grief" levels (i.e., yielding small to moderate effect sizes), the trial was limited in several ways. First, it had some methodological drawbacks, for instance, the use of a quasi-randomization procedure and the measure used to assess grief reactions had psychometric weaknesses. Second, the generalizability of the findings to people confronted with a disappearance not related to the Bosnia-Herzegovina war is limited due to unique features of this study sample (e.g., exposure to other war-related stressors and specific type of disappearance, and low literacy levels).

Based on overviews of treatment effects for bereaved people at least two conclusions can be drawn. Firstly, PG can successfully be treated, but there is limited evidence that PG can be prevented (Boelen & Smid, 2017; Doering & Eima, 2016; Linde et al., 2017; Mancini, Griffin, & Bonanno, 2012; Wittouck, van Autreve, de Jaegere, Portzky, & van Heeringen, 2011). For instance, a meta-analysis reviewed the effectiveness of nine preventive interventions and five PG treatments. Overall, they concluded that PG treatments, but not preventive interventions, yielded significant reductions in PG levels at post-treatment and follow-up compared with pre-treatment (Wittouck et al., 2011). Treatment is therefore most effective when targeted at people experiencing clinically relevant PG levels.

Secondly, cognitive behavioural therapy (CBT) has shown to be most effective in reducing grief-related distress (Boelen & Smid, 2017; Currier, Holland, & Neimeyer, 2010; Doering & Eisma 2016; Mancini et al., 2012). CBT is therefore to date the treatment of choice for bereaved people in need of professional support (see for instance Dutch guidelines for treatment of disturbed grief in Boelen & van den Bout, 2017). CBT includes exposure, cognitive restructuring, and behavioural activation, targeted at the three processes of the cognitive-behavioural model of PG (Boelen et al., 2006a).

Some argue that, unlike treatments for bereaved people, treatment for relatives of missing persons should not focus on "closure" or "coming to terms with the loss", because this may

provoke resistance in relatives of missing persons (Boelen & Smid, 2017; Boss, 2006; Glassock, 2006). Instead, treatment should focus on learning how to manage persistent negative thoughts and feelings related to the disappearance, for instance with mindfulness training (Boss, 2006). These recommendations rely on clinical experiences, rather than empirical evidence.

Mindfulness-based interventions (MBIs) have shown to be promising for bereaved people (O'Connor, Piet, & Hougaard, 2014; Thieleman, Cacciatore, & Hill, 2014). In a controlled pilot study, elderly bereaved people with clinically relevant PGD, PTSD, and/or depression levels received 8 weekly group sessions of mindfulness based cognitive therapy immediately (n = 12) or after about 7 months of waiting (n = 18). Those who started immediately with the intervention showed a significantly larger reduction in depression levels from pre-treatment to 5 months post-treatment (but non-significant differences for PGD and PTSD levels) compared with people in the waiting list control condition (O'Connor et al., 2014). In an uncontrolled trial, mindfulness-based treatment coincided with significant reductions in depression and PTSD levels (grief reactions were not assessed) from pre- to post-treatment in a treatment-seeking bereaved sample (n = 42; Thieleman et al., 2014).

Trials among people with depressive symptoms have shown that repetitive thinking, including rumination and worry, is one of the most important mechanisms of change in MBIs (see for an overview Gu, Strauss, Bond, & Cavanagh, 2015). Given the assumption that relatives of missing persons are, more than bereaved people, inclined to repetitive negative thinking, adding elements of mindfulness to CBT might be specifically beneficial for relatives of long-term missing persons.

5. OUTLINE OF THE DISSERTATION

Exploration of consequences of, and care after, the disappearance of a significant other was fueled by experiences from relatives of missing persons, researchers, and professionals working with families of missing persons, suggesting that grief following ambiguous loss differs in severity, nature, and treatment from grief following the death of a significant other (Betz & Thorngren, 2006; Boss, 2004, 2006; Giesen, 2003). Yet, empirical evidence related to these claims is limited. We argue that it is important to take further steps in this unexplored field to offer guidelines to professionals supporting relatives of missing persons in order to optimize care for people whose significant other is missing.

In **Chapter 2**, a systematic review is presented in which we summarize empirical studies examining the prevalence and correlates of psychological symptoms in relatives of missing persons. In addition, we explore the empirical evidence related to the claim that the disappearance of a loved one is "the most stressful kind of loss" (Boss, 2006, p. 7) by summarizing the results of studies comparing psychopathology levels between relatives of missing and deceased persons.

Studies comparing psychopathology levels between these groups have so far exclusively focused on losses in the context of war or state terrorism (i.e., armed conflict). In this context, exposure to additional potential traumatic events likely affect psychopathology levels (Johnson & Thompson, 2008). This raises the question to what extent do the results of comparative studies in the context of armed conflict generalize to relatives of missing and deceased persons outside this context? In **Chapter 3**, we address this question by comparing PG and PTS levels between people confronted with the disappearance and homicidal loss of a significant other.

Studies examining correlates of distress post-disappearance that are amendable to change in treatment are lacking. Therefore, we aim to identify correlates of disappearance-related distress that could be target in treatment. We focus on cognitive-behavioural and emotion regulation processes that are assumed to play an important role in the onset and maintenance of distress following the disappearance of a significant other.

The associations between cognitive-behavioural variables and post-loss psychopathology levels have mainly been examined in people confronted with a non-violent (e.g., illness) loss of a loved one. However, a previous study has shown that these cognitive-behavioural variables mediate the effect of violent loss (i.e., accident, homicide, and suicide) on PGD, depression, and PTSD levels (Boelen et al., 2015). In **Chapter 4**, we examine whether cognitive-behavioural variables are also related to distress in relatives of missing persons.

Based on previous findings, indicating that positive affect regulation strategies are linked to depression scores over and above rumination, it has been argued that positive affect regulation strategies are at least as important as ruminating about negative affect in depression (Raes et al., 2009, 2012, 2014). Although the detrimental effect of depressive rumination in bereaved people has repeatedly been shown, the role of positive affect regulation strategies has never been examined. In **Chapter 5**, we explore to what extent positive affect regulation strategies are linked to psychopathology levels following the loss of a loved one, over and above rumination. We examine this in two samples separately: a) a sample of people confronted with the recent death of a significant other, and b) a sample of people confronted with the long-term disappearance of a significant other.

According to the rumination-as-avoidance hypothesis (Stroebe et al., 2007), rumination is viewed as a way of avoiding painful aspects of a loss. Self-compassion, is viewed as a way of being naturally exposed to painful inner experiences (Thompson & Waltz, 2008), and may work as an antidote to rumination. In **Chapter 6**, we test (1) the prediction that greater self-compassion is related to lower PG, PTS, and depression levels in relatives of missing persons and (2) to what extent grief rumination mediates these associations.

Adaptive coping strategies are further explored in an interview-study. During the data-collection phase of the studies included in Chapter 3-6, it was salient that a significant proportion of

relatives of missing persons did not meet criteria for clinically relevant levels of psychopathology. Insights into 1) the course of functioning over time in retrospect, and 2) coping strategies considered helpful by these non-clinical relatives of missing persons are gained in **Chapter 7**.

In **Chapter 8,** it is argued in a study protocol of a pilot randomised controlled trial why CBT with elements of mindfulness may be appropriate for reducing psychological distress among relatives of missing persons in need of support. In **Chapter 9** the feasibility and preliminary effectiveness of this treatment approach is evaluated.

The main findings from the preceding chapters are summarized in **Chapter 10**. The findings are discussed and integrated in relation to bereavement research and beyond. Furthermore limitations, clinical implications, and recommendations for future research are provided.

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