The Psychological Aftermath of Bereavement:

Risk Factors, Mediating Processes, and Intervention

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The Psychological Aftermath of Bereavement:

Risk Factors, Mediating Processes, and Intervention

De psychische nasleep van het overlijden van een dierbare: Risicofactoren, mediërende processen en interventie

(met een samenvatting in het Nederlands)

Proefschrift

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Voor mijn oma's,

Derkje Hendriks – de Vreede en Grietje Maria Henrietta van der Houwen – van Dijk,

die het verschijnen van dit proefschrift niet meer hebben mogen meemaken.

Ik mis jullie.

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Chapter 1

Introduction

BACKGROUND OF THE PROJECT

Bereavement, defined as the situation of having recently lost a significant person through death, ranks among the most stressful life-events (Holmes & Rahe, 1967). It is an inescapable part of human existence and as such can be viewed as a normal experience. Even so, for most individuals bereavement is associated with a period of intense suffering, with excess risk of mortality and with decrements in both physical and mental health (for a review, see Stroebe, Schut, & Stroebe, 2007). Adjustment can take months or even years and is subject to substantial individual variation. Although most people manage to come to terms with their loss over the course of time, for a sizeable minority mental and physical ill-health is extreme and persistent. Not surprisingly then, a lot of effort has been put into designing interventions for the bereaved, and much subsequent research has focused on determining the effectiveness of these interventions and establishing for whom they are useful (for reviews see Currier, Neimeyer, & Berman, 2008; Schut, Stroebe, van den Bout, & Terheggen, 2001). In this project the focus was on one particular type of intervention, namely, the use of writing assignments to help people cope with their loss.

Writing as a Coping Tool in Bereavement

Bereaved people have long used writing to help them come to terms with their loss. On the one hand, this has been undertaken spontaneously by bereaved people, as illustrated in Rosenblatt's (1983) compilation of 19th century diaries, which explores the content of diaries written by people dealing with bereavement or separation. On the other hand, writing has taken place on the instruction of a professional as part of grief therapy (de Keijser, Boelen, & van den Bout, 1998).

Systematic research into the *effectiveness* of writing for the bereaved has only recently begun, and has been greatly influenced by the work of Pennebaker and colleagues. From this influential work two principal lines of research into the efficacy of writing as a bereavement intervention have evolved. One line involves interventions that are open to all bereaved people (i.e. the criterion for participation being simply that one has experienced a loss through death) and that use the traditional Pennebaker paradigm. The second line involves interventions that focus on bereaved people who are experiencing complications in their grief. This latter type of intervention uses structured writing assignments that are heavily influenced by cognitive-behavioural principles. These two lines of research have led to

different conclusions regarding the efficacy of writing as a coping tool for the bereaved. Our project was designed to explain these differences in findings by testing the efficacy of a newly-developed writing intervention specifically for bereaved people. I will now discuss findings from both lines of investigation and our ideas about why they have led to such different results. Against this background, I present the details of our project.

The Pennebaker Paradigm

An effective paradigm for relieving the impact of traumatic or stressful events (among which bereavement can be counted) is the disclosure technique developed by Pennebaker and colleagues. These and other researchers have repeatedly shown that the simple exercise of writing about one's thoughts and feelings concerning a personal and meaningful topic has a positive impact (e.g. on physical health, employment rates, exam success) among samples ranging from prisoners, chronically-ill patients or the unemployed, to new-intake students or those facing exams (e.g. Pennebaker, Colder, & Sharp, 1990; Stanton et al., 2002). A recent meta-analysis that included one hundred forty-six randomized studies of experimental disclosure concluded that the technique is beneficial for one's psychological health, physical health, and overall functioning (Frattaroli, 2006).

The Pennebaker Paradigm in Bereavement

There are reasons to believe that the Pennebaker disclosure technique should be particularly effective for bereaved individuals. Ever since Freud (1917) pioneered the concept of "grief work" in his classic monograph "Mourning and Melancholia", expression of one's emotional reactions to a loss experience has widely been regarded as an important component of adaptive grieving. Moreover, integration of the loss into the survivor's autobiographical memory is considered a crucial process in successful coping with the loss experience (e.g. Boelen, van den Hout, & van den Bout, 2006). Writing can potentially help integrate the loss into a coherent life narrative (Neimeyer, van Dyke, & Pennebaker, 2008).

Surprisingly, however, a precise replication of Pennebaker's technique did not work for a sample of recently bereaved persons (M. Stroebe, Stroebe, Schut, Zech, & van den Bout, 2002). Neither psychological symptoms nor physical health indices were positively influenced by expressive writing. Other empirical studies back up these findings: results of studies that induced disclosure in bereaved individuals and used a randomised control group

design have generally failed to confirm the disclosure effect (Bower, Kemeny, Taylor, & Fahey, 2003; Kovac & Range, 2000; O'Connor, Allen, & Kaszniak, 2005; O'Connor, Nikoletti, Kristjanson, Loh, & Willcock, 2003; Segal, Bogaards, Becker, & Chatman, 1999; M. Stroebe et al., 2002; Range, Kovac, & Marion, 2000; for a review see M. Stroebe et al., 2002).

In a review of several studies using the basic writing paradigm for bereaved individuals, Pennebaker, Zech, and Rimé (2001) proposed that written disclosure may work best under certain conditions, including a sudden death (with the presumed greater need to come to some understanding of the unexpected death) and for particular persons, such as individuals who avoid emotion. Contrary to expectations, however, M. Stroebe et al. (2002) did not find the disclosure manipulation to be effective for those who had experienced sudden bereavement, or had previously revealed little about their loss, or expressed an actual need to disclose more about it. In short then, researchers who have used Pennebaker's original paradigm have found little evidence to support the use of written disclosure for bereaved persons.

Structured Writing Therapy in Bereavement

Other researchers appear to have had more success using writing assignments with bereaved individuals. Lange and colleagues developed and evaluated a treatment for PTSD and complicated grief, in which the central therapeutic procedure also involved writing (Lange, Rietdijk, Hudcovicova, van de Ven, Schrieken, & Emmelkamp, 2003; Lange, van de Ven, Schrieken, & Emmelkamp, 2001). This treatment was conducted online and consisted of psycho-education, ten 45-minute writing sessions, and personalized feedback. The writing assignments were based on established therapies for posttraumatic stress disorder and research into the effectiveness of social sharing, and consisted of three phases: imaginary exposure, cognitive reappraisal, and social sharing.

Findings from two randomized controlled trials showed that participants in the treatment condition improved more than participants in the waiting-list control condition on traumarelated symptoms and general psychopathology (Lange et al., 2001, 2003). However, results for bereaved people were not provided separately: persons with PTSD and complicated grief were included in both trials and results were provided for the entire group and not for the two groups separately. Thus, one cannot be sure that this treatment was effective for bereaved individuals specifically.

Building on the work of Lange et al. (2001, 2003), Wagner and colleagues designed and tested an Internet-based cognitive-behavioural therapy program (that also included writing, personalized feedback and psycho-education) for bereaved people suffering from complicated grief (Wagner, Knaevelsrud, & Maercker, 2006, 2007). The first phase of their intervention was similar to the one used by Lange and colleagues. The cognitive restructuring and social sharing phases, on the other hand, focused on rather different elements that are more suitable to the bereavement situation. Findings from a randomized controlled trial showed that participants receiving the new treatment improved significantly immediately after treatment, relative to participants in the waiting list control condition, on symptoms of intrusion, avoidance, and general psychopathology as well as on post-traumatic growth (Wagner et al., 2006, 2007). Unfortunately, no long-term effects were investigated. Also, Wagner et al. did not use a grief-specific outcome measure, but instead relied on a traumaspecific measure that may not have been appropriate for all types of bereavement. Thus, the impact of this type of intervention on grief remains unknown. Despite these limitations, the research of Wagner et al. suggests that structured writing assignments can help improve bereaved individuals' mental health, at least in the short term.

Toward Explanation of the Differences in Findings

So how is it that the two lines of research described above could lead to such different results? Four major features distinguish them from each other, each of which could have contributed to the difference in findings: (1) the targeted population (unselected bereaved versus bereaved experiencing significant difficulties in coping with their loss); (2) the (non)employment of cognitive-behavioural principles; (3) inclusion of psycho-education and therapeutic feedback; (4) number of essays and duration of writing.

While all four factors could be relevant, in our view there are good reasons initially to focus further empirical evaluation on the first two. With regard to the targeted population, we posit that bereaved people in general do not benefit from the disclosure manipulation, because they can talk about their loss naturally, that is, within the context of their daily interactions. There are a number of reasons for this. Unlike some of the other stressors that Pennebaker investigated, and despite the intensity of the experience, bereavement is not usually an experience that is out of the ordinary, in the sense that it is a normal human experience for people to die and for their survivors to grieve for them (although death through highly traumatic circumstances, or the death of a child, would be typical exceptions

to this). Nor is it something that is shameful, blameworthy, or usually kept secret, as were some of the trauma's in Pennebaker's studies. Rather, it is an experience about which most people have shared with others and talked about over the course of time, among their relatives and friends (some of whom will be similarly-grieving the loss), and perhaps with their professional caregivers (doctors, clergy, etc.). In most cases this will help the bereaved to integrate the loss experience over the course of the first few months into a coherent narrative. In support of this, Walter (1996) has argued that the process of grieving involves coming to a mutual reconstruction of the narrative about the deceased person within the bereaved (family) group. The disclosure manipulation for these bereaved persons would not normally add very much to that which is already being done in everyday life.

Our argument that most bereaved individuals will not benefit from expressive writing (because of the "normality" of the loss experiences in their lives) is in agreement with the general assessment of the efficacy of intervention (counselling and therapy) for bereaved people. Interventions that are open to all bereaved people (i.e. the criterion for participation being simply that one has experienced a loss through death) generally fail to produce better outcomes than would be expected by the passage of time. Only in cases of high risk and complicated grief are beneficial effects of intervention to be found (for reviews, see Currier et al., 2008; Schut et al., 2001). Given these findings we would expect that only a subsample of bereaved individuals will profit from expressive writing: those who are at high risk for developing problems and those who have already developed problems. A similar point was made by Pennebaker et al. (2001) when they argued that disclosure interventions may only be effective for those coping poorly.

With regard to the second factor (i.e. the (non)employment of cognitive-behavioural principles): another important reason why effects were found by Wagner et al. (2006, 2007) could be that more powerful writing instructions, better fitted to the bereavement situation, were used. The instructions were highly specific, clearly indicating what should be the focus of the assignment, whereas the traditional Pennebaker instructions were far less structured, merely indicating a need to write about deepest feelings and thoughts regarding a certain topic. The instructions used by Pennebaker would be more likely to invite ruminative accounts. Nolen-Hoeksema (2001) has consistently found associations between rumination, negative affect and poor adjustment in bereavement, and has identified ruminative coping as detrimental to positive outcomes.

In addition, there are theoretical reasons why an exclusive focus on the loss (as encouraged in the Pennebaker paradigm) might not be beneficial. The Dual-Process Model

(DPM; M. Stroebe & Schut, 1999) postulates two coping orientations, loss and restoration, attention to both of which is needed for favourable psychological adjustment in bereavement. The protocol by Wagner et al. (2006, 2007) is in line with the DPM, in so far that it emphasizes loss-orientated coping in the first phase, and restoration and integration in phases two and three.

Finally, the writing assignments that Wagner et al. (2006, 2007) developed were heavily influenced by cognitive-behavioural principles. A substantial number of randomized controlled trials and several meta-analyses have demonstrated cognitive-behavioural therapy to be efficacious in the treatment of many mental disorders (for a review, see Leichsenring, Hiller, Weissberg, & Leibing, 2006). Recently it has also been shown to have superior effects in the treatment of complicated grief, compared to interpersonal psychotherapy (Shear, Franck, Houck, & Reynolds, 2005) and supportive counselling (Boelen, de Keijser, van den Hout, & van den Bout, 2007).

In summary then, we contend that writing can benefit the bereaved, but only those bereaved who are at risk for developing problems and those who are experiencing complications in their grief, and only when appropriate instructions are used that are tailored to the bereavement situation.

OUTLINE OF THE PROJECT

To test the above-mentioned hypotheses, a major research project was started in September 2004 at Utrecht University, in which we set out to develop and evaluate a writing intervention that drew from both lines of research described earlier. In this section, some attention will first be paid to the intervention we created. Following this, the design of the study, the procedure that was followed during the course of the study (including our method of recruiting participants), the in- and exclusion criteria that were applied, and the measurement instruments that were used, will be discussed. Before embarking on the main study we subjected our research plans to a medical ethics review board, which we felt was a necessary step, given the sensitive nature of our research. This will be described next, to enable the reader to understand the rather novel and unusual process involved in obtaining ethical approval for our type of research. Finally, information about our sample will be provided and data on response and non-response presented.

The Intervention

Development

Similar to research that has used the traditional Pennebaker paradigm, the intervention we designed consisted of a limited number of assignments and no personalized feedback was provided. The content of the assignments, on the other hand, was heavily influenced by the work done by Lange and colleagues (2001, 2003) and by the work of van Emmerik (2005). Five structured confrontational writing assignments and some general guidelines for writing were developed based on this line of research as well as on studies into the effectiveness of the Pennebaker paradigm (e.g. King, 2001), basic cognitive-behavioural principles, and upto-date bereavement research (e.g. Boelen, van den Bout, & van den Hout, 2006) (see Appendix I for all materials relating to the intervention).

The general guidelines for writing included information about what was expected of participants in terms of time investment and deadlines: we asked them to spend at least one session writing for 20 minutes on each assignment and to complete and return each assignment within one week of receiving it. Many studies that have used the Pennebaker paradigm have had participants write for a number of consecutive days. Given the confrontational nature of the assignments and the sensitivity of the subject, we felt that it would be too much of a burden for participants if they would be required to finish all assignments in five consecutive days. Instead, participants were given one week for each assignment.

The general guidelines also contained advice, for example, about when to write (preferably when at home alone, not immediately before bedtime) and urged participants not to worry about grammar, spelling, or writing style.

The five assignments followed the three phases outlined by Lange, Schoutrop, Schrieken, & van de Ven (2002): exposure, cognitive reappraisal, and integration and restoration. In the first two assignments (exposure phase) participants were asked to focus on the most distressing aspects of the loss, in relation to the loss event (in the first assignment) and with regard to their current situation (in the second assignment), and to describe these aspects in as much detail as possible. Below is a sample instruction for the first assignment:

"We would like you to start by thinking back at your loss experience [...] Then decide for yourself which moments or events during this period have been most significant to

you and/or difficult to talk or think about. Try to write down these moments or events in as much detail as possible, including such facts as where you were, what happened, how you felt, what you were thinking, sights and sounds etc."

In the second part of the second assignment participants were asked to describe matters that were going reasonably well given the circumstances. This was done to help counter the negative increase in mood that accompanies describing distressing events. Moreover, evidence has been found that disclosing positive events is as equally beneficial as disclosing negative events (Frattaroli, 2006).

The third and fourth assignments constituted the cognitive reappraisal phase. In the third assignment information was given about the detrimental effects of dysfunctional grief cognitions using examples and a short vignette. Participants were then asked to identify any unhelpful and helpful thoughts they might be having with respect to their loss, to describe how these thoughts made them feel, and to write down helpful thoughts that might replace the unhelpful thoughts. The fourth assignment asked participants to write a letter of advice to a (hypothetical or real) friend who recently suffered a similar loss and now faced the same difficulties. The letter should, among other things, incorporate lessons learned from the previous three assignments, and challenge negative thinking. An example instruction from this assignment is as follows:

"Try to think back to writing tasks 1 through 3. What issues did you write about? Perhaps you could also pay some attention to these issues in your letter. Is your friend likely to be having any unhelpful thoughts with respect to the loss? If so, what alternative, helpful thoughts can you offer to your friend?"

In the last assignment (integration and restoration phase) participants were asked to write a letter to the deceased from a future perspective detailing how they overcame obstacles and succeeded at accomplishing their goals, as in the following sample instruction:

"In this last writing task we would like you to think about your life in the future (about 2 years from now). Imagine it is now 2009 and everything has gone as well as you would have hoped, considering what happened to you. You have struggled, overcome obstacles, and succeeded at accomplishing your goals. Think of this as the

best possible outcome for you. We would like you to write a letter to your [...], describing this realization in some detail."

Participants were also encouraged to address the meaning (if any) of their loss and any lessons they might have learned. It has been reported that writing about one's "best possible self" has health benefits, possibly because it influences self-regulatory processes (e.g. King, 2001; for a review see Frattaroli, 2006). Moreover, a lack of future orientation has been associated with the development and maintenance of complicated grief (Boelen, van den Hout, et al., 2006).

Pre-testing

From November 2005 to January 2006 a small pilot study was conducted in which we asked thirty-seven bereaved individuals to complete our intervention. The aim of this preliminary study was to see whether the assignments were understandable and acceptable (i.e. not too emotionally taxing) to be eaved people and whether they would follow our instructions (both with regard to the content of the assignments and with regard to the timeline in which the assignments were presented).

After completing each assignment, participants were asked to fill out a short evaluation form. This evaluation form asked questions about the amount of time participants had spent writing, their feelings during writing, the degree to which they experienced the assignment as stressful, whether they considered the assignment to be too stressful and whether the writing instructions were clear to them.

From the results of the study it became clear that our assignments were acceptable to bereaved people: even though most participants experienced the assignments as stressful, only in a small minority of cases was an assignment experienced as being too stressful. We did make a few small adjustments in wording to the assignments based on the content of participants' writings and their recommendations regarding our instructions. No changes were made to the timeline in which assignments were presented as this did not appear to be a problem for our participants.

Design

In order to investigate the effects of completing the intervention we chose to employ a randomized controlled trial with two groups (an intervention group and a waiting list control group) and three measurement points. The first time point of measurement (baseline) took place immediately after participants registered for our study, followed by a second (post) at 3 and third (follow-up) at 6 months after the first measurement moment. Long-term comparisons are seldom used in grief interventions, but they are essential for establishing the efficacy of such programs (Schut et al., 2001).

With regard to the interval between the first and the second measurement point: the post-measure would be used to examine the short-term effects of the intervention making the time between baseline and the post-measure primarily dependent on the length of the intervention. In theory, the intervention would last 5 weeks (five assignments, one per week). However, to accommodate for situations in which participants for some reason would need more time to finish the assignments, a safety margin was built in, and the time between the first and second measurement point was set at 3 months.

A large time interval (e.g. one year) between the first and third measurement point would have been ideal to determine any long-term effects of the intervention. However, we were also bound by logistic considerations, more specifically the limited time that was available to us to conduct and report our study. Therefore, the interval between the first and third measurement point was slightly reduced and set at 6 months. We felt that this time frame would still be able to provide us with valuable information.

Participants in the control condition were not given any writing assignments. They were, however, offered the opportunity to participate in the intervention after answering the last set of questionnaires. Studies that use the traditional Pennebaker paradigm often have participants in the control condition write about mundane tasks, such as detailing what they ate for breakfast. We felt that it would be unethical to ask bereaved people to do this. Asking people to write about more significant things in their daily lives, on the other hand, could easily lead them to include aspects to do with the loss. Thus even writing about everyday activities could be construed as an intervention.

Procedure

Recruitment

For reasons that will be described shortly, we decided to use the Internet as our main recruitment medium and target English-speaking bereaved individuals. A recruiting message was placed on English websites and Internet forums and in English e-mail groups that focus on bereaved persons (see Appendix II for the message that was used). This message was only placed with the permission of the appropriate authorities (moderators, web masters). It contained a short, general description of the study to be conducted and a link to a research website - bereavementresearch.com – that was built especially for this study and that contained detailed information about the study as well as a registration form. This website will be described in more detail later on.

There has been a huge expansion in the number and types of Internet resources available to bereaved people. These range from websites providing all sorts of information about bereavement and grief, to mutual support groups (Internet forums, e-mail groups and chat rooms where bereaved people interact with fellow sufferers) and memorial websites, where bereaved persons can honour their loved ones (M. Stroebe, van der Houwen, & Schut, 2008). This development has not gone unnoticed by bereavement researchers and many of them have used these Internet resources to recruit participants for their studies. Clearly, there are a number of advantages to recruitment through the Internet, two of which especially appealed to us. First, it is an efficient way of recruiting people: researchers can obtain sample sizes that are far larger than those obtained with traditional techniques in a shorter amount of time and with less effort. Sample size calculations had shown us that in order to demonstrate a small effect of the intervention (which would already be of considerable theoretical interest), and taking into account relatively high dropout rates (that are not uncommon in bereavement studies) as well as the type of hypotheses we wanted to test (i.e. moderation effects), we would be needing a large group of bereaved people. Given the limited time that was available to us to conduct our study (and thus to recruit participants) recruitment through the Internet presented itself as an excellent option to us. Second, recruiting participants through the Internet can be considered non-invasive (provided permission has been obtained from the right authorities), especially when it is compared to another often-used recruitment method: the gathering of names and addresses of possible participants from obituary notices in newspapers.

Referring to our decision to target English-speaking persons, since our study design did not contain any elements that would require face-to-face contact with participants, we argued that there would be no reason to limit our recruitment efforts to bereaved people living in the Netherlands. On the contrary: our likelihood of obtaining a large sample size would be greatly increased if we were to target English-speaking bereaved persons, simply because they constitute a much larger population.

One issue that is frequently raised in discussions about Internet use in bereavement research and intervention and that should be mentioned here, is that of sampling bias. We think that there are two points that need to be made regarding this subject. First, it is important to keep in mind that selective participation is quite common in bereavement research (M. Stroebe & Stroebe, 1989) and is not unique to Internet research. Second, sampling bias need not necessarily constitute a serious threat to the validity of a study: problems only arise when the variable towards which the sample is skewed moderates the study variable of interest. For example, women are more likely to participate in bereavement research than men. While investigating the effectiveness of a grief intervention, this will not result in a problem unless the effects of the intervention are dependent on gender. Since we did not have any reasons to assume that the effectiveness of our intervention was dependent on any of the variables towards which Internet samples tend to be skewed (young, female, white, highly educated) we felt that the effect of any sampling bias might be small.

Finally, although the Internet appeared to be a promising venue for recruitment, we could, of course, not be entirely sure that we would indeed succeed in recruiting a large number of participants in this manner in the time frame available to us. Therefore, we also approached a number of organizations for bereaved people located in English-speaking countries and asked for their cooperation in recruiting participants. Organizations were approached via email and were urged to refer anyone who was interested in participating to our research website.

Registration

The research website that we designed consisted of five different pages: (1) a *Home* page, containing detailed information about the study, (2) an *About us* page, containing information – including contact details - about the researchers, (3) a *FAQ* page, containing questions that the researchers knew or suspected (based on the pilot study and years of experience doing bereavement research) bereaved people might be having, and providing

answers to these questions, (4) a *Contact* page containing a form people could fill out if they had any questions they would like to ask the researchers, and (5) a *Register* page containing a registration form, that – among other things - provided possible future subjects with all the necessary information to make an informed decision about participating in the study and asked for their consent.

In order to register for the study participants also had to provide us with a valid e-mail address and their data of residence (country, state/county, and town/village). The e-mail address would be used for the sending of questionnaires and assignments (we return to this issue shortly). The residence data were collected for safety purposes. In case someone would have to withdraw from the study, because they themselves or we as researchers considered participation to be too emotionally taxing, we wanted to be able to provide this person with the contact information of a reliable grief counselling organisation operating in their neighbourhood. We did not ask for participants' exact address, because we felt that anonymity may be a very valuable element of this study, as it could encourage self-disclosure and facilitate the process of dropping out for participants who did not feel up to answering the questionnaires and / or completing the assignments.

Immediately after people submitted the registration form, they were randomly assigned to either the intervention or the waiting-list control group. This was automatically accomplished by a computerized randomizer tool. Following this, an email was generated and sent to participants in which they were thanked for registering for the study. This email also contained information about the course of the study, including information about the group they had been assigned to, as well as the text contained in the registration form, to which they had consented.

Electronic Questionnaires

At all three measurement points participants were sent an e-mail containing a link to an online questionnaire. The first e-mail was sent within 24 hours of registering. This and every other email that was sent to participants from then on contained a link at the bottom of the email that they could click if they wanted to end their participation. This link led to a web page on which participants were thanked for their contribution and were asked to indicate why they had decided to end their participation. They were not required to answer this question.

We had a number of reasons for choosing electronic questionnaires over paper-and-pencil questionnaires. First and foremost: sending out paper-and-pencil questionnaires by postal mail would have been very expensive, given the fact that most – if not all – of our participants would be living abroad. Also, participants would no longer have been able to stay anonymous. Electronic questionnaires offer other advantages as well. By using them we were able to personalize the questionnaires. For example, when a mother indicated that she had lost her son, in the remainder of the questionnaire the word "son" was used to refer to the deceased person (e.g. the item "I have felt myself longing and yearning for my [...]" became "I have felt myself longing and yearning for my son") and questions that did not apply to the mother or her loss were skipped. Furthermore, electronic questionnaires are time saving with respect to data analysis, because they dispense with the need for data entry. And since data entry is automatic, no data entry mistakes can be made, which enhances the quality of the data. Finally, electronic questionnaires can prevent skipping of critical questions.

Questionnaires measured background and loss-related variables, aspects of mental and physical health, and personality and coping behaviour (we will describe the instruments of assessment used in the study shortly). Up to two reminder e-mails were sent if participants failed to respond. Participants who did not respond to the reminder e-mails or who only filled in part of the questionnaires at a certain measurement point were not sent an invitation to fill in questionnaires at the next measurement point.

After completing the first two questionnaires, participants were sent an email in which they were thanked for filling out the questionnaire. This also contained the date they would be sent the next questionnaire. After completing the last questionnaire they were sent an email thanking them for their participation in our study.

Assignments

Participants in the intervention group were sent the general guidelines for writing and the first writing assignment within a day of answering the first questionnaire. The sending of assignments was done by email. Our reasons for choosing electronic over postal mail were for the most part similar to the ones we had for using electronic questionnaires: costs and anonymity. Also, the sending of assignments was spaced at one-week intervals and was conditional on the completion of previous assignments: participants were asked to return their completed assignments to us - because we wanted to be sure that they had indeed complied

with our request - within one week of receiving them. Postal mail would have greatly slowed down this process.

Every time an assignment was sent, participants were urged to contact us if the assignment was unclear to them. We also asked them not to discuss or show their writing or any of the assignments to other (potential) participants if they knew such people. Up to two reminder e-mails were sent if participants failed to return their assignments.

In the last questionnaire, participants assigned to the control group were asked whether they were interested in receiving the writing assignments. Those who indicated that they were, were sent the assignments in a similar fashion as described earlier (i.e. one assignment per week provided that the previous assignment had been returned) upon their completion of the last questionnaire.

Participants

Inclusion and Exclusion Criteria

People who had lost a partner or first-degree relative (parent, child or sibling) through death were invited to participate in our study. The reason for this is that we did not want to limit our intervention study to one type of loss (e.g. to parents who have lost a child), since we were interested in learning about the effects of our intervention beyond specific types of bereavement. However, in order to enhance comparability to other bereavement studies not *all* types of loss (e.g. grandparents, friends, pets) were included.

Given the large individual variation in adjustment to bereavement, we preferred not to set any time limits in our study: people who had very recently suffered a loss were allowed to participate as were people who had suffered their loss several decades ago. However, we did require that participants be significantly distressed by their loss at their time of registration, seeing that an intervention that aims to reduce distress cannot be expected to be much help to people who are not experiencing any distress.

Other inclusion criteria followed logically from the decisions that were made regarding the procedure described earlier: participants had to have access to computer and Internet facilities and be in possession of a valid email address. Because participants in the intervention group would be writing about very personal matters and because it is probably easier for people to do so in their native tongue, we also asked that participants be *native*

English speakers. Finally, participants were required to be 18 years or older, since we would be asking for their consent.

Given the confrontational nature of the intervention, we argued that it would be unwise for people with a condition that would make them extra vulnerable to potential adverse effects to be participating in our study. Therefore, anyone who was suffering from schizophrenia, psychotic episodes, feelings of severe depression, or was seriously considering ending their own life was excluded from our study.

Many of the questions we would be asking participants presumed that they had consciously known or interacted with the person who died. Therefore, participants who had suffered their loss at a very early age were excluded from our study as well.

Compensation

We did not have the financial means to compensate participants for their participation in our study. However, from the outset of the study, participants were promised that they would receive a research report, detailing the main findings of our study, in return for their participation. All participants who indicated in the last questionnaire that they were interested in reading this report, were sent a copy by e-mail at the end of the study (see Appendix III for this research report).

Measurement Instruments

The questionnaires included quite a wide range of instruments. However, only a selection of instruments is presented here, excluding those that were not used in the data-analyses for this thesis (e.g. measures related to health behaviours). Psychometric properties of the instruments will be described in the empirical chapters that follow.

Exclusion Indicators

In line with the exclusion criteria listed earlier, the first four questions at baseline asked participants whether they suffered from schizophrenia or psychotic episodes, whether they had considered themselves to be severely depressed over the last four weeks and whether they had seriously considered ending their own life over the last four weeks. Participants who indicated that they had seriously considered ending their own life were

urged to seek help and were provided with the telephone number of a crisis hotline along with the names of some informative websites.

Biographical and Loss-Related Information

At the first measurement point a number of relevant biographical data were collected, such as gender, age, level of education, work situation, and religious affiliation. Information about the deceased person and the circumstances of the loss were also collected at this point.

Personality

<u>Neuroticism</u> was measured at baseline using the 8-item subscale of the Big Five Inventory (BFI; John & Srivastava, 1999).

Attachment style was assessed at all three measurement points using the Experiences in Close Relationships-Revised Questionnaire (ECR-R; Fraley, Waller, & Brennan, 2000). The ECR-R items appear to be written for people in romantic relationships. Following Fraley's suggestions the word "partner" was therefore replaced by the word "others" to make the items relevant to other kinds of relationships (e.g. "My partner only seems to notice me when I'm angry").

Coping

Coping processes were measured at all three points in time.

<u>Rumination</u> was measured with a self-constructed 8-item questionnaire that was based on literature on rumination in general and on rumination in bereavement specifically (e.g. Boelen, van den Bout, et al., 2006; Nolen-Hoeksema, 1991) (see Appendix IV for the items that were used). Items were rated with respect to the past week on a 5-point scale ranging from (almost) never (= 1) to (almost) constantly (= 5).

<u>Grief cognitions</u> were measured using eighteen items of the 38-item Grief Cognitions Questionnaire (GCQ; Boelen & Lensvelt-Mulders, 2005). The GCQ consists of 9 subscales. From each subscale two items with the highest factor loadings were selected for this study.

<u>Deliberate grief avoidance</u> was measured with 13 items that were formulated on the basis of literature on avoidance in grief (e.g. Boelen, van den Bout, et al., 2006; Bonanno, Papa, Lalande, Zhang, & Noll, 2005) (see Appendix IV for the items that were used). Items

were rated with respect to the past week on a 5-point scale ranging from (almost) never (= 1) to (almost) constantly (= 5) or participants could indicate that the item did not apply to them.

Support

Social support was assessed at all three measurement points with a four–item scale of perceived social support, comprising the same two items for family members and for friends and relatives (a) "On the whole, how much do your [family members] / [friends and relatives] make you feel loved and cared for?" and (b) "How much are your [family members] / [friends and relatives] willing to listen when you need to talk about your worries or problems?" (W. Stroebe, Zech, Stroebe, & Abakoumkin, 2005). Response categories range from "a great deal" to "not at all", and "not applicable".

Information regarding <u>online mutual bereavement support</u> was gathered at the second and third measurement point. We asked about participants' involvement in email lists, Internet forums, and chat rooms both in the past and at the time of measurement.

Mental Health Indicators

Mental health indicators were measured at all three time points.

<u>Professional help seeking</u> was measured by asking participants to indicate whether they were currently receiving assistance related to their grief from a professional.

<u>Medication use</u> was assessed by asking participants to indicate whether they were using medication for anxiety, mood and / or sleep problems.

<u>Grief reactions</u> were measured using 9 items that were formulated on the basis of the criteria for complicated grief proposed for DSM-V (Prigerson, Vanderwerker, & Maciejewski, 2008) (see Appendix IV for the items that were used). It has been shown that these 9 items constitute a concise way of measuring complicated grief (H. Prigerson, personal communication, March 10, 2006). Items were rated with respect to the past week on a 5-point scale ranging from never (= 1) to all of the time (= 5).

<u>Depressive symptoms</u> were assessed using the Center for Epidemiological Studies-Depression Scale (CES-D; Radloff, 1977).

<u>Emotional loneliness</u> was measured using the following two items: (1) I feel lonely even if I am with other people, and (2) I often feel lonely (W. Stroebe, Stroebe, Abakoumkin,

& Schut, 1997). Participants indicated their (dis)agreement with these statements on a 7-point scale ranging from totally disagree (=1) to totally agree (=7).

<u>Positive mood</u> was measured using the corresponding 10 items of the Positive Affect Negative Affect Schedule (PANAS; Watson, Clark, & Tellegen, 1988).

Medical Ethics Review

Even though there were no indications of any negative effects in our pilot study, given the nature of the writing assignments (i.e. confrontational) and the target population (i.e. bereaved individuals, a vulnerable group) as well as the location of our participants (i.e. abroad) we felt that it was important to subject our intervention study to a medical ethics review. Getting a committee to review our study, however, turned out to be quite a challenge as we will explain below.

In the Netherlands there are about thirty accredited Medical Research Ethics Committees (MRECs) responsible for reviewing medical research involving human subjects. MRECs conduct their review activities in accordance with the criteria laid down in the Medical Research Involving Human Subjects Act (WMO). However, the WMO only applies to subjects living in the Netherlands. Since we would be recruiting native English speakers of whom probably none would be living in the Netherlands (based on our pilot study and population statistics, we expected most of our participants to be living in the United States), our request for review was turned down by the MREC affiliated with Utrecht University. We subsequently asked this committee whether they would be willing to conduct a review using the World Medical Association's Declaration of Helsinki as a guideline. This was also declined for fear of liability exposure: there have been cases in the United States in which individual members of medical research ethics committees have been sued by research participants.

At this point we were unsure how to proceed further. We were in touch with the Central Committee on Research involving Human Subjects (CCMO) that oversees all Dutch MRECs as well as a number of people with expertise in the area of Internet research. However, no one was able to provide us with any clear answers. Finally, we contacted the National Institutes of Health (NIH), the largest medical research agency in the United States, for advice. They informed us that our research should be reviewed in the same country where it was funded, even if most of our participants would be residing in the United States. We then sought out another Dutch MREC, one with a lot of experience in reviewing

psychological research, and asked them whether they would be willing to review our study. This committee reasoned that since it could not be ruled out that a native English speaker living in the Netherlands would participate in our study, the WMO did apply, and agreed to evaluate our study. They ruled that it conformed to the criteria set out in the WMO, meaning that we could go ahead with our study as planned.

Sample Data

Response and Attrition

Participants for the study were recruited over a 7-month period, between October 2006 and May 2007. In total, 932 bereaved persons, 556 of whom were assigned to the intervention group, filled out the registration form on our website, indicating their interest in participating in our study (see Table 1 for details on response and attrition rates). The reason that more people were assigned to the intervention group than to the control group has to do with the fact that the random assignment ratio was changed from 1:1 (at the beginning of the study) to 2:1 (during the course of the recruitment period, after 5 months), because the dropout rate turned out to be higher in the intervention than in the control group.

Of the 225 participants who completed the intervention (which we defined as completing 4 or more assignments), 199 finished all five assignments, two participants skipped assignment 3, two participants skipped assignment 4, and 22 did not finish assignment 5. The reason that four participants were allowed to skip an assignment is because they explained to us that they were unable or unwilling to complete a certain assignment, but at the same time expressed a strong desire to continue with the intervention.

A small group of people who did not finish the intervention did complete the second and third questionnaire (27 and 23 respectively) as can be read from Table 1.

Of the original 458 persons in the intervention condition and 294 persons in the control condition who completed the baseline measure, 194 and 219 respectively completed the program (i.e. including intervention and/or post-test and follow-up measures).² This reflects an attrition rate of 45% (54% in the intervention and 26% in the control condition) over the course of the study. A logistic regression analysis was performed in order to check for differences between completers and non-completers with dropout as the dependent variable and relevant background and loss-related variables, mental health indicators, and condition (control or intervention condition) as independent variables. According to the Wald

criterion, age, education level, grief, and condition reliably predicted dropout: completers were older (χ 2 (1, N = 740) = 17.06, p < .001), had higher levels of education (χ 2 (1, N = 740) = 9.45, p < .01), experienced less grief (χ 2 (1, N = 740) = 7.79, p < .01), and were more likely to be part of the control condition (χ 2 (1, N = 740) = 73.59, p < .001) than non-completers.

Table 1
Response and attrition rates

	Intervention group $(n = 556)$	Control group $(n = 376)$
Questionnaire 1		
Started answering questionnaire 1	n = 507	n = 330
Excluded from questionnaire 1	n = 39	n = 28
 Mental health issues 	- n = 16	- n = 17
 Different type of loss 	- n = 12	- n = 9
Very early loss	- n = 10	-n=2
 Not significantly distressed 	- n = 1	
Finished answering questionnaire 1	n = 458	n = 294
Intervention		
Finished assignment 1	n = 345	
Finished assignment 2	n = 298	
Finished assignment 3	n = 257	
Finished assignment 4	n = 223	
Finished assignment 5	n = 204	
Finished intervention (\geq 4 assignments)	n = 225	
Questionnaire 2		
Started answering questionnaire 2	$n = 232 (205)^*$	n = 266
Finished answering questionnaire 2	$n = 231 (204)^*$	n = 256
Questionnaire 3		
Started answering questionnaire 3	$n = 224 (199)^*$	n = 226
Finished answering questionnaire 3	$n = 220 (197)^*$	n = 220

Numbers in brackets refer to the subgroup of participants who finished the intervention.

Dropout was also studied by looking at the reasons participants themselves gave for their withdrawal from the study. Some participants spontaneously gave their reasons for discontinuing their participation. Those who did not were sent an e-mail asking them to indicate in one or two sentences why they had decided to stop. Reasons were classified into two broad categories: those having to do with the study and those being unrelated to the

study. If people gave multiple reasons for discontinuing their participation, their response was categorized as being related to the study if at least one of the reasons they gave could be categorized as such. If it was not entirely clear how the reason that was given should be classified, it was also categorized as being related to the study. Examples of answers categorized as relating to the study are: "Not feeling ready to share feelings. Upsets me too much", "I find that with anything related to my dear son, I have trouble completing", and "I stopped answering the questions, because it was too hard emotionally. I couldn't get through each survey without crying". Examples of answers categorized as unrelated to the study are: "The computer I was using broke down", "I had to undergo a series of back operations over the past year", and "I just didn't have the time".

Of all the people who registered for the study in the intervention group (n = 556), 197 completed the whole study, 39 were excluded, leaving 320 people who dropped out somewhere during the process. 101 of them (32%) gave reasons related to study, 80 (25%) gave reasons unrelated to study and 139 (43%) did not provide an answer for their withdrawal. Of all the people who registered for the study in the control group (n = 376), 220 completed the whole study, 28 were excluded, leaving 128 people who dropped out somewhere during the process. 10 of them (8%) gave reasons related to study, 39 (30%) gave reasons unrelated to study and 79 (62%) did not provide an answer for their withdrawal.

Sample Characteristics

An overview of participants' characteristics as observed in the present study is given in Table 2. The data presented in this table are based on all participants who finished answering the first questionnaire (n = 752) minus a small group of people who suffered multiple simultaneous losses. As it turned out, of all the people who filled out the first questionnaire, seven had suffered multiple simultaneous losses (e.g. one woman had lost three children in a house fire). This constituted a problem for our study, because both the questionnaires and the intervention were designed for persons who had suffered one particular loss. We did not feel comfortable, however, excluding this group from our study. So, especially for this group, extra questionnaires were designed and writing assignments were adjusted (five out of seven persons were assigned to the intervention group) to fit their specific situation. Unfortunately, this group was not large enough to merit separate statistical

Table 2 $Background \ and \ loss \ characteristics \ of \ the \ sample \ (N=745)$

Background characteristics	
Country of residence (N (%))	
USA	495 (66.4%)
UK	146 (19.6%)
Australia / New Zealand	53 (7.1%)
Canada	34 (4.6%)
Other	17 (2.3%)
Sex (N (%))	
Men	49 (6.6%)
Women	696 (93.4%)
Age (in years) (M (SD); minimum - maximum)	43.35 (10.95); 18 - 81
Education (highest level of schooling) (N (%))	
Primary school / elementary school	0 (0%)
Secondary school / high school (not finished)	17 (2.3%)
Secondary school / high school (finished)	104 (14.0%)
Some post-secondary school	179 (24.0%)
College diploma or equivalent	172 (23.1%)
University degree	158 (21.2%)
Postgraduate degree	114 (15.3%)
Unknown	1 (0.1%)
Loss characteristics	
Deceased is (N (%))	
Partner	229 (30.7%)
Child	315 (42.3%)
Parent	123 (16.5%)
Sibling	78 (10.5%)
Cause of death	
Natural causes	490 (65.8%)
Accident / homicide	165 (22.1%)
Suicide	90 (12.1%)
Time since loss (in years) (M (SD))	3.38 (5.27)
< 6 months	179 (24.0%)
>= 6 months and < 12 months	114 (15.3%)
>= 12 months and < 24 months	137 (18.4%)
>= 2 years and < 5 years	161 (21.6%)
>= 5 years or more	154 (20.7%)

analyses. This small subgroup is included in the data presented in Table 1, but is left out of the sample characteristics presented in Table 2.

As expected, most participants were females, living in the USA, who were - on average - relatively young and highly educated. Most of them had either lost a child or their partner.

No differences between the participants in the intervention and control group were found on relevant background and loss-related variables or on mental health indicators, suggesting that randomization was successful.

OUTLINE OF THIS DISSERTATION

The general interest of our project, as will have become evident by now, has to do with the efficacy of bereavement intervention. More specifically, we wanted to test ideas about the conditions under which writing can benefit the bereaved. However, the richness of our dataset enabled us to study other important, related aspects as well. To test one of our central hypotheses - that only bereaved who are at risk for developing problems will benefit from structured writing assignments - information was needed about risk factors in bereavement. Unfortunately, little methodologically-sound research has been done on this subject. We were able to examine a large number of potential risk factors using the longitudinal data from our control group. The same dataset also provided us with the opportunity to investigate *processes* that mediate between the risk factors that we identified and outcome measures. Finally, because we recruited participants both from mutual bereavement support groups and other sources and measured mental health indicators at multiple time points, we could study the characteristics of people who use this type of support, as well as its effects. Below I will discuss the following chapters in more detail.³

As described earlier, the Internet provides all sorts of resources for bereaved people. Although no exact figures are available, there are reasons to suspect that one type of resource, namely online mutual support groups, is becoming increasingly popular with bereaved people. Whereas these groups have received quite a bit of attention over the past few years outside the bereavement area (for example, a number of studies have focused on online breast cancer support groups), surprisingly little research has been devoted to this subject by bereavement researchers. Information is needed about who uses this type of support (among other reasons, because bereavement researchers are recruiting participants for their studies from online support groups) and about its potential to ameliorate bereaved persons' suffering

(certain characteristics of Internet support, such as anonymity and 24/7 availability, may have negative side effects). Therefore, in the following chapter we examined the characteristics of people who use online mutual bereavement support and investigated whether using this type of support predicted changes in mental health over time. For this we used data from the control group only, because of the effect that the intervention may have had on some of the variables that we were interested in.

In order to test our hypothesis that only bereaved persons who are at risk for developing problems will benefit from structured writing, we needed to create a measure for "being at risk". A large body of research has focused on identifying characteristics that are likely to be associated with increased vulnerability (for a review, see M. Stroebe et al., 2007). However, knowledge about risk factors for complications in bereavement remains limited, because many studies suffer from methodological shortcomings. They have focused on only one or on a small set of factors (which increases the chances of reporting spurious results due to the confounding effects of other variables) and have relied on use of a single measure of bereavement outcome. In the *third chapter*, we avoided these pitfalls by simultaneously examining the impact of a large set of potential risk factors (that we derived from the relevant literature on this topic) on multiple outcome measures (grief, depressive symptoms, emotional loneliness, and positive mood). Data from the control group from all three measurement points were included in the analyses (data from the intervention group were excluded from the analyses for reasons explained earlier).

Although the research described in chapter three is clearly valuable, it is also limited in the sense that it does not inform one about pathways through which these predictors become impactful. Knowledge of intermediate mechanisms is essential not only for theoretical reasons, but also because it provides us with targets for intervention (which is important since many risk factors are not amenable to change). Although a considerable amount of research has been devoted to cognitive and behavioural coping processes and how they influence bereavement outcome, few studies have simultaneously examined risk factors, outcomes and the coping processes that might mediate between them. Thus, using the same longitudinal dataset as in chapter three, in the *fourth chapter*, we examined the degree to which three potentially critical processes (rumination, threatening grief interpretations and deliberate grief avoidance) mediated the relationship between the risk factors and outcome measures identified in chapter three.

Finally, in the *fifth chapter* we investigated the efficacy of the intervention we designed on important outcome variables (grief, depressive symptoms, emotional loneliness,

and positive mood). We examined whether its effect was moderated by the degree to which participants (1) were at risk for developing complications (using data from chapter three), (2) had already developed complications in their grieving. We were also interested in exploring processes that might underlie any effects the intervention might have. Given the particular nature of the intervention we designed (i.e. including exposure and cognitive restructuring as its central components), we identified and tested three potential mediating processes, all of which had been linked to detrimental outcomes in bereavement in previous studies (including our own research presented in chapter four): rumination, threatening grief interpretations, and deliberate grief avoidance.

In the final section of this dissertation (*chapter six*) the main results of the empirical chapters will be summarized and critically evaluated. I will address the scientific relevance, as well as the practical implications of our findings, and make some suggestions for future research.

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NOTES

- ¹ Although it remains to be established why this would be more of a problem in bereavement than for other stressful life events.
- ² The number of people in the intervention and control group who completed the entire program (194 and 219 respectively) differs from the number of people who completed the third questionnaire as presented in Table 1 (197 and 220 respectively). The reason for this is that 3 resp. 1 participants for various reasons finished the last questionnaire, but skipped the second questionnaire and as a result did not complete the entire program.
- ³ Chapters 2 to 5 are based on independent journal submissions. Therefore, there will be some redundancy in theoretical introductions and descriptions of the study.

Chapter 2

Online mutual support in bereavement: An empirical examination

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ABSTRACT

Thus far, online mutual bereavement support has not been the subject of rigorous empirical examination, despite the fact that this type of support is rapidly growing. Assessment is needed, not only to establish whether there are desirable effects, but also whether there could be negative side effects. This study was designed to increase our understanding of the people who use online mutual bereavement support and provide a preliminary examination of its potential to ameliorate their suffering. Our findings show that people who are currently using online mutual bereavement support are younger, less likely to be part of a religious community, and more likely to have lost a child than bereaved people who had never used this type of support. The former group also shows worse mental health and reports lower levels of social support than people who had stopped using online mutual bereavement support. There was no indication that people who seek out online mutual bereavement support were more likely to live in remote, rural areas than people who do not use this type of support. Using this type of support did not predict changes in mental health over time. Implications of these findings are discussed.

Mutual self-help approaches for bereaved people were pioneered by Silverman (1972, 1986) some decades ago in her well-known widow-to-widow program. The idea behind this program was that widows would identify with and receive assistance from a role model, namely, another widow who had herself been through the ordeal of bereavement. There have been numerous developments in bereavement support programs since that time, but perhaps the most significant of these has been the emergence of online mutual support groups, which has opened up many new opportunities in the provision of support. In this paper we report an empirical study that sheds light on the characteristics of persons who use online mutual bereavement support, and that examines the impact of this type of support.

Online mutual bereavement support can best be understood in the context of online support in general. Thus, in the following part, we describe features and research findings pertaining to this broader domain. Then we review the available studies that have focused specifically on bereavement. Against this background we present our own empirical work.

The Provision of Online Mutual Support

Online support groups have expanded rapidly in recent years: as of April 2009 Yahoo!Groups (www.yahoo.com) listed over 50.000 electronic support groups in the health and wellness section, more than twice as many as five years ago (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004). Two types of online groups can be distinguished. In synchronous groups, such as chat rooms, individuals can exchange messages in real time. In asynchronous groups, members can read and exchange messages, but are not necessarily simultaneously connected to a network. Examples of the latter include email lists and Internet forums. Registration is typically needed to gain access to chat rooms and email lists, and to post messages on Internet forums (but not to read messages on Internet forums). However, the type and extent of information required to register varies widely between groups, ranging from the provision of a valid e-mail address to extensive demographic and other details.

Online support has a number of potential advantages over traditional face-to-face support. The Internet is not limited by geographical boundaries: it offers access to support to people living in remote areas, where help may not be readily available and to those who cannot easily leave their homes as well as to those who do not have the means (money, transportation) to engage in traditional mutual support. Similarly, it enables people suffering from rare conditions to come into contact with each other, making highly specialized groups possible. Some researchers have suggested that online groups may facilitate disclosure

because its members can remain anonymous (Mo, Malik, & Coulson, 2009). Finally, asynchronous groups offer the possibility to have contact 24 hours a day, seven days a week.

The popularity of online mutual support and its potential to function as an easy accessible, low-cost resource for people experiencing difficulties have captured the interest of researchers. Consequently, many studies have been devoted to virtual health communities. Some have focused on the exchanges that take place within these groups. For example, Mo and Coulson (2008) examined the nature of social support exchanged within an online HIV/AIDS support group by analyzing 1138 messages. Other studies have surveyed members of online support groups in order to gain a better understanding of the characteristics of people using this type of support and their experiences with it. This type of research has provided information about, among others, users of a dental anxiety group (Coulson & Buchanan, 2007), and members of psoriasis (Idriss, Kvedar, &Watson, 2009) and infertility support groups (Malik & Coulson, 2008).

Despite these research efforts, thus far, surprisingly little is known about the efficacy of online mutual support (Eysenbach et al., 2004). An important reason for this is that most studies that have investigated the effects of this type of support suffer from serious methodological shortcomings. Some have relied solely on subjective accounts (i.e. they have asked members of support groups about their satisfaction with this type of support) making it impossible to draw firm conclusions about efficacy (demand characteristics and dropout-biases are well-established limitations of subjective accounts). Others have employed cross-sectional designs (limiting temporal inferences concerning the precise relations between factors investigated) or non-controlled before-after designs (which makes it impossible to attribute improvements of psychological or health outcomes to the intervention as many participants improve naturally over time).

The dearth of sound research on the effects of mutual online support begs the question whether it is really necessary to study this subject. Do these resources even need to actually be helpful (as long as people want to access them and they are not associated with huge burdens to individual or society)? We would argue that there are at least two reasons why it is important to investigate the efficacy of online mutual help groups: (1) to make sure that people are not actually harmed by this type of support, and (2) to assist people in making a decision whether or not to invest their time and energy in this type of support.

Of special interest with regard to the first point are some of the unique features of Internet support mentioned above: anonymity, lack of face-to-face contact, and 24/7 availability. Whereas anonymity may increase disclosure, it can also invite or facilitate

inappropriate responses, perhaps even leading to exploitation or abuse by persons who enter online groups with ulterior motives. Also, the lack of physical cues makes it much more difficult to identify persons who are experiencing serious difficulties and might be in need of professional help. The asynchronous nature of most groups further complicates the possibility to identify such persons in a timely fashion. Finally, 24/7 availability might increase rather than decrease ruminative thinking and distress, and may induce wallowing in one's own problems (Shaw, Han, Hawkins, McTavish, & Gustafson, 2008; Stroebe, van der Houwen, & Schut, 2008). Finally, it could encourage people to withdraw from their normal social world.

Online Mutual Bereavement Support

Bereaved people do not appear to be excluded from the online support trend. On the contrary, mourning and loss support groups make up 10 percent of all electronic support groups in the health and wellness section of Yahoo!Groups alone, making bereavement the third most popular subject after diseases and conditions (43%) and weight issues (13%).

Bereavement researchers' involvement with online support groups so far has mainly been through their employment of these groups to recruit participants for their studies. Only a few studies have made these groups the focus of investigation. Among these, Hollander (2001) examined a large number of e-mails from a number of online support groups for survivors of the suicides of loved ones, while Capitulo (2004) investigated the content of exchanges in one particular email list for mothers who had suffered a perinatal death. Both were qualitative studies that aimed to arrive at a deeper understanding of what exactly happens within these groups, and to identify common themes. They did not provide information about the characteristics of people using this type of support nor about its effectiveness. Insight into who is using online mutual support is important as well.

In a recent cross-sectional survey study Feigelman, Gorman, Chastain Beal, and Jordan (2008) compared members of one of the largest Internet survivor of suicide support groups ("Parents of Suicide") with face-to-face support group affiliates - who had suffered a similar loss - on a large number of variables using univariate analyses. These analyses showed that Internet affiliates were more recent survivors, were more often female, younger, less educated, divorced or separated, and living alone. They also had lower incomes, were more likely to have no religious affiliation, were less likely to participate in any organized religious observances, and experienced less social support and more mental health problems (i.e. grief, depression, suicidal ideation). No differences were found on number of children or

rural-urban residence. However, their results regarding the differences between these two groups should be interpreted with care: spurious results may have been reported both due to the separate analyses of a large number of variables and to the confounding effects of other variables. Feigelman et al. also examined features which support group members value about online participation and concluded that "Our data [...] bear on the question of the helpfulness of Internet support groups in enhancing the adaptation of survivors of child suicide loss" and "Internet users [...] sought and obtained *valuable* help from the Internet support resource" (pp. 239 and 217; italics added). However, there were no sound empirical bases for these claims. The study was cross-sectional in nature and lacked objective measures of gains.

To summarize, we are aware of only one study that has looked at the characteristics of online mutual bereavement support users. However, this investigation suffered from methodological shortcomings and was limited to one specialized support group. No studies to date have examined the efficacy of online mutual bereavement support.

As already explained, it is important that we increase our knowledge of online mutual bereavement support. Therefore, the current study was designed to (1) gain better understanding of the characteristics of online mutual bereavement support users and (2) examine whether using online mutual bereavement support is associated with changes in mental health over time. People currently using online mutual support were compared on a number of potentially discriminating factors to bereaved people who had never used this type of support and to bereaved people who had used this type of support in the past. The selection of these factors was based partly on the results reported by Feigelman et al. (2008) and partly on the literature on bereavement in general. We included demographics (age, gender, education level, rural-urban residence), bereavement-related variables (type of loss, cause of death, time since death, (un)expectedness of the loss), mental health variables (grief, depressive symptoms, and emotional loneliness), and support variables (professional, social support, involvement in a religious community). All factors – except for residence - were examined simultaneously in a multivariate analysis in order to avoid reporting spurious results. This was done in an exploratory manner, given the lack of previous research. Referring to the second interest of the study, a controlled longitudinal design was employed to examine changes over time in relationship to mutual online bereavement support. In addition to the use of multivariate analyses and a longitudinal controlled design mentioned above, further improvements over previous designs are the inclusion of different types of losses and different forms of online support. These increase the generalizability of the results.

METHOD

Participants

This investigation was part of a randomized controlled trial with three measurement points, that looked at the efficacy of an e-mail based writing intervention for bereaved people. Only data from participants who were assigned to the control condition were included in the present study. Because the main variable of interest (i.e. involvement in online mutual bereavement support) was not measured until the second measurement point, a further criterion for inclusion in the current investigation was that complete data were available at the second measurement point. Participants were recruited in two ways: (1) via the Internet, through websites, forums, and e-mail groups that focus on bereaved persons, (2) via organizations and support groups for the bereaved. Due to the worldwide accessibility of the Internet, participants did not come from a specific area or country. To be included in the study, people had to meet the following criteria at the time of registration: (1) at least 18 years of age, (2) native English speaker, (3) having experienced the death of a first-degree relative, (4) being significantly distressed by this loss. People who reported that they were suffering from severe depression, schizophrenia, psychotic episodes and / or were seriously considering ending their life were excluded from the study, as were people who suffered their loss at a very early age (and consequently had never consciously known or interacted with the person who died) and people who suffered multiple simultaneous losses. Participants were randomly assigned to receive or not receive the intervention (i.e. to the intervention or control condition respectively). Participants assigned to the control condition were offered the opportunity to participate in the intervention after answering the last set of questionnaires. The sample consisted of 253 bereaved individuals. Background and loss characteristics are summarised in Table 1.

Procedure

Participants were sent e-mails inviting them to fill in questionnaires online at three points in time: immediately, 3 and 6 months after registering for the study. Questionnaires measured background and loss-related variables, aspects of mental and physical health, and personality and coping behaviour. Up to two reminder e-mails were sent if participants failed to respond.

Table 1 Background and loss characteristics of the sample (N=253)

Background characteristics	
Sex (N (%))	
Men	16 (6.3%)
Women	237 (93.7%)
Age (in years) (M (SD); minimum - maximum)	42.97 (10.98); 19 - 79
Education (highest level of schooling) (N (%))	
Primary school / elementary school	0 (0%)
Secondary school / high school (not finished)	3 (1.2%)
Secondary school / high school (finished)	32 (12.6%)
Some post-secondary school	61 (24.1%)
College diploma or equivalent	63 (24.9%)
University degree	53 (20.9%)
Postgraduate degree	41 (16.2%)
Loss characteristics	
Deceased is (N (%))	
Partner	88 (34.8%)
Child	104 (41.1%)
Parent	41 (16.2%)
Sibling	20 (7.9%)
Cause of death	
Natural causes	175 (69.2%)
Accident / homicide	51 (20.2%)
Suicide	27 (10.7%)
Time since loss (in years) (M (SD))	3.48 (4.71)
< 6 months	30 (11.9%)
>= 6 months and < 12 months	48 (19.0%)
>= 12 months and < 24 months	64 (25.3%)
>= 2 years and < 5 years	56 (22.1%)
>= 5 years or more	55 (21.7%)

Participants who did not respond to the reminder e-mails or who only filled in part of the questionnaires at a certain measurement point were not sent an invitation to fill in questionnaires at the next measurement point. The attrition rate in the group under investigation was 13%. A logistic regression analysis was performed with dropout as the dependent variable in order to check for differences between completers and non-completers. Independent variables included the various predictor and outcome variables (of the regular analyses). According to the Wald criterion, both age and education level reliably predicted dropout: completers were older ($\chi 2$ (1, N = 253) = 5.52, p < .05) and higher educated ($\chi 2$ (1, N = 253) = 7.22, p < .01) than non-completers.

Measurement Instruments

As will be described next, variables were selected from different time points for the purposes of this particular study.

Background and Loss-Related Variables

While registering for the study, participants provided information about their place of residence (country, state/county, and town). At the first measurement point questions were asked about age, gender, education level (measured on a 7-point scale), time since death, formal relationship to the deceased (partner / parent / child / sibling), cause of death (natural causes / accident or homicide / suicide), and level of unexpectedness of the death (measured on a 5-point scale, from *totally expected* to *totally unexpected*).

Support Variables

Social support was assessed with a four—item scale of perceived social support. This scale asked two questions about social support from family members and the same two questions about social support from friends and relatives (a) "On the whole, how much do your [family members] / [friends and relatives] make you feel loved and cared for?" and (b) "How much are your [family members] / [friends and relatives] willing to listen when you need to talk about your worries or problems?" (W. Stroebe, Zech, Stroebe, & Abakoumkin, 2005). Response categories were "a great deal", "quite a bit", "some", "a little", "not at all", and "not applicable". Participants filled out this scale at all three points in time; however in

this article only data from the second measurement point were used. Cronbach's alpha was .91.

<u>Professional help</u> was measured at every time point by asking participants to indicate whether they were currently receiving assistance related to their grief from a professional. Only data from the second measurement point were used in this study.

<u>Involvement in a religious community</u> was assessed at the first measurement point by asking participants whether they were a practicing member of an organized religion.

Online Mutual Bereavement Support

Information was gathered at the second and third measurement point about participants' involvement in three types of online mutual bereavement support: email lists, Internet forums, and chat rooms. For each type of support participants were asked to indicate whether they had ever used this type of support, whether they were currently using this type of support, and, if so, for how many hours on average per week. Only data from the second measurement point were used in this study.

Mental Health Variables

All mental health variables were measured at each time point. Both data from the second and the third measurement moment were used in this study.

Grief reactions were measured using 9 items that were formulated on the basis of the criteria for complicated grief proposed for DSM-V (Prigerson, Vanderwerker, & Maciejewski, 2008). Examples of items are "I have felt that moving on with my life (for example, making new friends, pursuing new interests) is difficult for me" and "I have felt emotionally numb (e.g. detached from others)". It has been shown that these 9 items constitute a concise way of measuring complicated grief (H. Prigerson, personal communication, March 10, 2006). Items were rated with respect to the past week on a 5-point scale ranging from never (= 1) to all of the time (= 5). Cronbach's alpha ranged from .91 to .92, and test-retest reliability was .81.

<u>Depressive symptoms</u> were assessed using the Center for Epidemiological Studies-Depression Scale (CES-D; Radloff, 1977). In this study, Cronbach's alpha ranged from .93 to .95, and test-retest reliability was .74.

Emotional loneliness was measured using the following two items: (1) "I feel lonely even if I am with other people", and (2) "I often feel lonely" (W. Stroebe, Stroebe, Abakoumkin, & Schut, 1997). Participants indicated their (dis)agreement with these statements on a 7-point scale ranging from totally disagree (=1) to totally agree (=7). Cronbach's alpha ranged from .88 to .89, and test-retest reliability was .67.

<u>Positive mood</u> was measured using the corresponding 10 items of the Positive Affect Negative Affect Schedule (PANAS; Watson, Clark, & Tellegen, 1988). In this study, Cronbach's alpha ranged from .95 to .96, and test-retest reliability was .74.

RESULTS

Use of Online Mutual Support

A majority of participants indicated that they were currently involved in online mutual support or had been so in the past (see Table 2). Taking a closer look at the group of participants who were currently using online mutual support (n = 156), Table 2 shows that email lists and Internet forums were being used by 102 and 108 participants respectively (65% resp. 69%), making them equally popular forms of support in this group. Chat rooms were only used by 19 participants (12%). Over two-fifths of participants who were currently involved in online mutual support used more than one form of support.

Table 2

Use of online mutual bereavement support at the second time point (N = 253)

Are currently using online mutual bereavement support	156 (61.7%)	
email list		42 (16.6%)
Internet forum		45 (17.8%)
chat room		3 (1.2%)
email list + Internet forum		50 (19.8%)
email list + chat room		3 (1.2%)
Internet forum + chat room		6 (2.4%)
email list + Internet forum + chat room		7 (2.8%)
Have used online mutual bereavement support in the past	47 (18.6%)	
Have never used online mutual bereavement support	50 (19.8%)	

Participants spent on average 7.4 hours per week (SD = 9.0) using online mutual bereavement support, more than one hour per day on average. People who used two or three

forms of support spent more hours using online support (M = 11.1, SD = 11.0) than people who used only one form of support (M = 4.6, SD = 6.8) (t(154) = -4.42, p < .001). The type of support did not appear to be associated with the number of hours spent online using it: participants who exclusively used email lists (n = 42) spent as much time online as people who exclusively used Internet forums (n = 45), t(85) = -0.20, p = 0.84 (M = 4.0, SD = 5.1 resp. M = 4.2, SD = 4.8).

Predictors of Current and Past Use of Online Mutual Support

Two logistic regression analyses were performed, one in which we checked for differences between people who had never used online mutual bereavement support and those who were currently using it, and one in which we checked for differences between people who had been using this type of support in the past and those who were currently using it. Predictors were demographics (age, gender, education level), bereavement-related factors (time since death, formal relationship to the deceased, cause of death, and expectedness of the death), support variables (social support, professional help, involvement in a religious community) and mental health (grief, depressive symptoms, and emotional loneliness). The results of the analyses can be found in Table 3.

Participants who were currently using online mutual bereavement support differed from participants who had never used this type of support in a number of respects: the first group was younger, more likely to have lost a child (versus a parent or sibling) and less likely to be part of a religious community. Differences were also found between participants who had stopped using online mutual bereavement support and participants who were still using it: the latter group showed worse mental health (i.e. higher levels of grief and emotional loneliness) and reported lower levels of social support.

Additionally, in order to gain more insight into the stable characteristics of online mutual bereavement support users, a new group was created in which we combined people who were currently using online bereavement support with people who had been using this type of support in the past. Using logistic regression analysis, this group was compared to the group of people who had never used this type of support on relevant background (age, gender, education level, involvement in a religious community) and loss-related variables (type of loss, cause of death, (un)expectedness of death, time since death). The results of this analysis were very similar to the one presented earlier in which we compared participants who were currently using online mutual bereavement support with participants who had

never used this type of support: online mutual bereavement support users were younger (p < .10), were more likely to have lost a child (than a parent or a sibling; p < .001 and p < .10 respectively), and were less likely to be part of a religious community (p < .01).³ The analysis also showed that support users were more likely to be female (p < .01).

Table 3

Predictors of current and past use of online mutual bereavement support

	Never used (=0) versus current use (=1)		Used in the past (=0) versus current use (=1)	
	В	SE	В	SE
Demographics				
Age	-0.041*	0.020	-0.007	0.020
Gender $(0 = \text{male}, 1 = \text{female})$	1.185	0.738	-20.839	12459.925
Education level	0.030	0.150	-0.189	0.163
Bereavement-related factors				
Time since death	0.041	0.044	0.110	0.063
Kinship $(0 = \text{child})$				
Partner	-0.347	0.568	-0.413	0.512
Parent	-2.843***	0.657	-1.186	0.633
Sibling	-1.626*	0.741	-0.987	0.802
Cause of death $(0 = natural causes)$				
Accident / homicide	-0.479	0.574	0.678	0.647
Suicide	-0.165	0.668	0.427	0.649
Expectedness of death	-0.018	0.158	-0.113	0.151
Support variables				
Social support	-0.336	0.223	-0.671**	0.217
Professional help $(0 = no help)$	0.470	0.459	0.370	0.429
Involvement in a religious community $(0 = no)$	-1.162**	0.433	0.460	0.426
Mental health				
Grief	0.043	0.042	0.081*	0.041
Depressive symptoms	-0.029	0.030	-0.024	0.030
Emotional loneliness	0.101	0.079	0.179*	0.077

^{*} *p* < .05. ** *p* < .01. *** *p* < .001.

Another variable that has been associated with the use of online mutual support is residence in rural (compared to urban) areas. Because participants in our study came from different countries we were unable to use one system for categorizing participants' place of residence, and therefore could not include this variable in the logistic regression analyses. We

were, however, able to check this hypothesis for a subset of our sample, namely, participants living in the United States (n = 156), by using the 2003 Rural/Urban Continuum Codes from the Economic Research Service (ERS) of the Department of Agriculture. Of all participants living in the United States, 152 (97%) could be classified according to this system. Of this group, 124 persons had used online mutual bereavement support in the past or were still using it. Their residence data were compared to those of the entire population of the United States (see Table 4). Contrary to what is sometimes claimed, people who seek out online mutual bereavement support are not more likely to live in remote, rural areas.

Table 4

Residence comparison between US participants who are currently using or have used online mutual bereavement support in the past (n = 124) and US population in general

Code	Description	Sample	United States
1	County in metro area with 1 million population or more	62 (50.0%)	149224067 (53.0%)
2	County in metro area of 250000 to 1 million population	18 (14.5%)	55514159 (19.7%)
3	County in metro area of fewer than 250000 population	19 (15.3%)	27841714 (9.9%)
4	Nonmetro county with urban population of 20000 or more,	8 (6.5%)	14442161 (5.1%)
	adjacent to a metro area		
5	Nonmetro county with urban population of 20000 or more,	1 (0.8%)	5573273 (2.0%)
	not adjacent to a metro area		
6	Nonmetro county with urban population of 2500-19999,	8 (6.5%)	15134357 (5.4%)
	adjacent to a metro area		
7	Nonmetro county with urban population of 2500-19999, not	7 (5.6%)	8463700 (3.0%)
	adjacent to a metro area		
8	Nonmetro county completely rural or less than 2500 urban	1 (0.8%)	2425743 (0.9%)
	population, adj. to metro area		
9	Nonmetro county completely rural or less than 2500 urban	0 (0%)	2802732 (1.0%)
	population, not adj. to metro area		

Changes in Mental Health over Time in Relationship to Online Mutual Bereavement Support

Next, we checked whether making active use of online mutual bereavement support was associated with changes in people's mental health over time (i.e. between the second measurement moment when online activity was measured and the third measurement moment three months later). For each of the mental health variables (grief, depressive symptoms,

emotional loneliness, and positive mood) a model was constructed containing the mental health variable measured at the third measurement moment as a dependent variable and the following predictors: the same mental health variable measured at the second measurement moment, use of online mutual bereavement support at the second measurement moment (yes or never), age, formal relationship to the deceased (dummy coded), involvement in a religious community, and education level. Age, formal relationship to the deceased and involvement in a religious community were added to the model to control for differences between participants who had never used online mutual bereavement support at the second measurement moment and those who were using this type of support at that time. Education level was added, because it predicted dropout between the second and third measurement point (as did age, but this variable was already part of the model). The model was tested using AMOS 7.0, because this program does not assume equal numbers of observations, which means that all cases can remain in the analyses, thereby increasing the precision of the estimates and the power of the statistical tests.

Using online mutual bereavement support did not predict changes in mental health over time. No differences were found on grief (b = 0.819, t = 0.855, p = .39), depressive symptoms (b = 1.833, t = 1.070, p = .29), emotional loneliness (b = -0.724, t = -1.265, p = .21) or positive mood (b = 0.819, t = 0.855, p = .39).

DISCUSSION

Thus far, online mutual bereavement support has not been the subject of rigorous empirical examination. This is unfortunate, because some of the characteristics, which make online support so attractive, may have negative side effects (so we should make sure that people are not actually harmed by this type of support), and because it appears to be an increasingly popular support method (making it important to understand who participates in this type of support). This study was designed first, to increase our understanding of the people who use online mutual bereavement support and second, to provide a preliminary examination of its potential to ameliorate their suffering. With respect to the first interest, our findings showed a number of differences between people who were currently using online support and people who had never used this type of support as well as between the former group and people who had used this type of support in the past. With respect to the second concern, the use of online mutual bereavement support was not associated with changes in

mental health over time. We next review our findings in more detail and address some of the limitations of our study. Finally, we offer some suggestions for further research.

We found that a majority of participants were currently involved in online mutual support or had been so in the past. This is not surprising, given the fact that our sample was partly acquired through email lists and Internet forums for the bereaved. Thus, the likelihood of using online mutual bereavement support in this study is likely to be different from that found among the bereaved in general. Whereas email lists and Internet forums were both popular forms of support, only a small minority reported using chat rooms. Although this may partly be due to the fact that we did not use chat rooms to recruit our participants, it could indeed represent a true preference for asynchronous groups: research shows that 24/7 availability is one of the features of online support that is most appreciated by people (e.g. Feigelman et al., 2008).

Our results showed that a great deal of time was spent interacting on the Internet: more than one hour per day on average. This suggests that online support takes a prominent place in the lives of these bereaved people. This concurs with findings reported by Feigelman et al. (2008), who found that approximately half of all respondents spent six or more hours weekly participating in the Internet support group ("Parents of Suicide") they investigated. Our replication of their data is especially noteworthy, because we included different types of losses and different forms of online support. Furthermore, we extended their findings by showing that a large minority of respondents used more than one form of support and that using more forms of support increased the time spent online.

Our study revealed a number of features of online support users: Participants who were currently using online mutual bereavement support or had done so in the past were more likely to be female, younger, less likely to be part of a religious community, and more likely to have lost a child (than a parent or a sibling) than people who had never used this type of support. Again, this concurs with results reported by Feigelman et al. (2008) who also found that "more women, younger survivors, and those less connected to conventional religious observances were over-represented" (p. 239) in Internet affiliates. The effect of age may well reflect a pattern found among the non-bereaved, showing an overall decline in usage of interactive web services increases age (http://spire.conted.ox.ac.uk/trac_images/spire/SPIRESurvey.pdf). With regard to involvement in a religious community: it is perhaps not surprising that people who are not part of a religious community would seek out another, online, community for sharing thoughts and feelings. However, as with age, this phenomenon need not be bereavement specific.

Our finding that people who have lost a child have a higher chance of being involved in online mutual support could be attributed to the fact that there appear to be more groups available online of parents that suffered the loss of a child: groups that focus on child loss constitute 23% of all mourning and loss support groups in the health and wellness section of Yahoo!Groups (only 12% focus on parent loss). Of course, this does not answer the question why this type of loss is overrepresented online (i.e. people are far more likely to lose their parents or a sibling than a child). One reason for this may be that parents who have lost a child are less likely than people who have lost a parent or a sibling to encounter fellow sufferers in their social network. The Internet facilitates meeting and interacting with such people. It could also reflect the nature of child loss, often claimed to be the worst type of loss that can occur. Parents may feel the need for support over a longer period of time, when others around them may no longer be so forthcoming with their support.

It is interesting to note that the two groups described before (those currently using online mutual support versus those who had never used this type of support) did not differ with respect to professional or social support. This suggests that online mutual bereavement support is not used as a substitute for these forms of support, but rather as an addition to them. This notion is further supported by the fact that people who seek out online mutual bereavement support are not more likely to live in remote, rural areas (where professional help may not be readily available). However, given the cross-sectional nature of this analysis, other explanations may be possible as well. For example, it may be that people start using online support because they are dissatisfied with the help they are getting from family and friends but that their perception of this help subsequently changes. Longitudinal research is needed to further explore these issues.

Differences were also found between people who had stopped using online mutual bereavement support and those who were still using it: the former group showed better mental health (i.e. lower levels of grief and emotional loneliness) and reported higher levels of social support. Although it makes sense that people would stop using online support once they start feeling better, again the cross-sectional nature of the analysis precludes this temporal inference: it could also be the case that people started feeling better after they stopped using online support. In order to better understand this relationship, it is important to look at the changes in mental health over time in relationship to online mutual bereavement support. Fortunately, our longitudinal data set enabled us to do this.

Using online mutual bereavement support was not associated with changes in mental health over time. No differences were found on grief, depressive symptoms, emotional loneliness or positive mood. One reason for this could be that the follow-up period (i.e. 3 months) that we used was too short for changes to become evident. Another possibility might have to do with the fact that we do not know anything about the time people have been using this type of support. Changes in mental health could occur only when people first start, but not over longer durations. However, it could also be the case that the lack of findings is simply in line with research showing that social support does not appear to accelerate the process of recovery from bereavement (W. Stroebe et al., 1997; W. Stroebe et al., 2005).

In discussing our findings, we have already addressed some limitations of our study. A point we have not yet touched upon is the fact that all our participants – including the ones who never used online mutual bereavement support – were Internet savvy: they registered for this study via our website, we were in contact with them via e-mail and they completed questionnaires electronically. One could argue that this has biased our results regarding the differences between those who use and those who have never used online mutual bereavement support. We do not hold this view, rather, we feel that this was a strong point of our study, because it enabled us to attribute any differences we found to a true preference for online mutual bereavement support instead of to a lack of Internet knowledge or access. However, this does not mean that we assume representativeness. Selective participation is, unfortunately, quite common in bereavement research (M. Stroebe & Stroebe, 1989). It remains critically important to acknowledge and to assess the significance of potential biases associated with selection in all investigations.

Our study provides valuable information about users of online mutual bereavement support and it is the first to shed light on mental health changes associated with this type of support. A number of methodological improvements were introduced. Future research should focus on replicating and further exploring our findings. First, longitudinal studies are needed that measure online activity at multiple points in time. This way, one can examine what predicts the commencing and termination of online support use. It also enables one to determine changes over longer periods of time. Second, it is possible that online mutual bereavement support only benefits (or harms) certain groups of people. Research should focus on identifying such moderating variables. Finally, although there appear to be a lot of online mutual support groups available to the bereaved, at this moment nothing is known about the percentage of bereaved that use online mutual bereavement support. Herein lies a major task for future researchers.

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NOTES

- ¹ It is important to keep in mind, though, that this number also includes groups that are very small (i.e. with only a few members) or inactive.
 - ² See Appendix IV.
- ³ Additional analyses clarified that the effect of age was reduced to a trend due to overlapping variances between gender and age.
- ⁴ Of course, we are aware of the fact that our US subgroup is not representative of the North American population in general. However, we have no reason to assume that our group (mostly younger women) would have very different residence patterns from the rest of the population.
- ⁵ We considered adding the number of hours spent on average per week using online mutual bereavement support at the second measurement point as a predictor in the model. However, we decided against this because in a separate analysis no relationship was found between the number of hours spent online and change in mental health.

Chapter 3

Risk factors for bereavement outcome: A multivariate approach

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ABSTRACT

Bereavement increases the risk of ill health, but only a minority of bereaved suffers lasting health impairment. Since only this group is likely to profit from bereavement intervention, early identification is important. Previous research is limited, because of cross sectional designs, small numbers of risk factors and use of a single measure of bereavement outcome. Our longitudinal study avoids these pitfalls by examining the impact of a large set of potential risk factors on grief, depressive symptoms, emotional loneliness and positive mood following recent bereavement (maximum 3 years). Participants provided information 3 times over 6 months. A multivariate approach was chosen to avoid reporting spurious results due to confounding. As expected, risk factors were differentially related to different outcome measures. For example, being high in anxious attachment and having lost a partner were related to more intense feelings of emotional loneliness, while these variables did not predict any of the other outcome variables. By contrast, social support did not influence emotional loneliness, but did predict grief, depressive symptoms and positive mood. Implications of these findings are discussed.

Extensive research has shown that bereavement is associated with excess risk of mortality and with decrements in both physical and mental health (for a review, see M. Stroebe, Schut, & Stroebe, 2007). Although most people are able to adjust to the death of a loved one without long lasting difficulties, a sizeable minority are prone to chronically elevated grief reactions (Bonanno & Mancini, 2008). Much research has been aimed at trying to identify the situational and personal characteristics likely to be associated with increased vulnerability across the spectrum of bereavement outcome variables, in order to understand why bereavement affects people in different ways (M. Stroebe, Folkman, Hansson, & Schut, 2006). This work is important for practical as well as theoretical reasons. Early identification of those who are at risk of suffering lasting health consequences makes it possible to intervene and possibly prevent negative outcomes. Reviews by Schut, Stroebe, van den Bout, and Terheggen (2001) and by Currier, Neimeyer, and Berman (2008) underscore the need to channel professional help to those who need and will benefit from it. Their reviews show that interventions that are open to all bereaved people (i.e. the criterion for participation being simply that one has experienced a loss through death) generally fail to produce better outcomes than would be expected by the passage of time. By studying risk factors (those associated with higher levels of problems) one can also gain insight into the tenability of theories that explain bereavement outcome, because such theories frequently offer different predictions about the factors likely to be associated with this outcome.

Which characteristics are likely to be associated with increased vulnerability? M. Stroebe et al. (2007) recently carried out an extensive review of the literature on risk and protective factors in bereavement. Their study showed that this body of work has resulted in some robust findings, but also in a number of inconsistencies. A shortcoming of most risk factor research which could explain some of the inconsistencies in the literature is its focus on only one or on a small set of factors. This limitation has an important consequence: Spurious results may be reported due to the confounding effects of other variables. For example, it may be the case that the – supposedly - salutary effects of religious beliefs are in fact not due to the nature of these beliefs, but to their relationship with being part of a supportive church community (i.e. people who are part of such a community are more likely to endorse religious beliefs). Only when both variables are included simultaneously in one analysis would this become clear. A study by Wijngaards-de Meij et al. (2005), which looked at predictors of grief and depression in a sample of bereaved parents, illustrates this point. These researchers examined a large number of predictors both separately (i.e. univariately) and simultaneously (i.e. multivariately). This investigation revealed differences between

magnitude and significance of the contribution of several predictors, when the multivariate analyses were compared with the univariate analyses. For example, both the age of the parent and the child were positively related to grief when examined separately, but the age of the parent ceased to be a significant predictor when examined simultaneously with the age of the child (and a number of other variables). This finding has important implications for early intervention, suggesting that the age of the deceased child, but not the age of the parent, should be the focus of attention. Whereas a few researchers have looked at multiple predictors in single investigations (e.g. Kersting et al., 2007; Schulz, Boerner, Shear, Zhang, & Gitlin, 2006; Wijngaards-de Meij et al., 2005), we know of no study that has simultaneously examined a wide variety of predictors.

Another shortcoming in the risk literature concerns the selection of dependent measures. First of all, grief and depressive symptoms have often been used as interchangeable concepts to measure bereavement outcome. However, a number of researchers have convincingly demonstrated that the two can and should be distinguished (e.g. Prigerson et al., 1995; Wijngaards-de Meij et al., 2005). Secondly, some important outcomes have been notably absent from the literature. One of the foremost among these is emotional loneliness, which has been shown to be potentially critical in the context of bereavement: The impact of marital bereavement on health and well-being (including suicidal ideation) was found to be mediated by emotional loneliness (M. Stroebe, & Abakoumkin, 2005; W. Stroebe, Stroebe, Abakoumkin, & Schut, 1997). To our knowledge, only two studies have examined factors that might influence feelings of emotional loneliness. W. Stroebe et al. (1997) showed that – contrary to popular belief – social support does not reduce emotional loneliness. Van Baarsen, van Duijn, Smit, Snijders, and Knipscheer (1997) demonstrated that the presence of favourable conditions, such as good health and high selfesteem, resulted in lower levels of emotional loneliness in a sample of conjugally bereaved older adults. Nevertheless, knowledge about predictors of emotional loneliness remains scarce, which is worrisome, since about a third of the conjugally bereaved show high stable levels of emotional loneliness for years after their loss (van Baarsen et al., 1997).

Another potentially critical variable that has received relatively little attention is positive affect - despite the general influence of the positive psychology movement and its contention that scientists should focus on such variables. A growing body of evidence has shown the beneficial effects of positive affect, including its ability to buffer people against the effects of negative emotions in the aftermath of crises (Fredrickson, Tugade, Waugh, & Larkin, 2003). Several studies have also found positive affect to be a predictor of long-term

bereavement outcome, independent of its concurrent association with depression (Bonanno & Keltner, 1997; Keltner & Bonanno, 1997; Moskowitz, Folkman, & Acree, 2003; Ong, Bergeman, & Bisconti, 2004). For example, in a sample of recently bereaved older adult widows, Ong et al. (2004) reported that the associations between daily stress and depressive symptoms were weakened when positive emotions were also present. The unique predictive power of positive affect evident in the above studies is in line with the dominant bidimensional affect approach, which posits that positive and negative emotions are independent (Reich, Zautra, & Davis, 2003).

Finally, researchers often assume that risk factors do not change during the period of observation in longitudinal studies, probably because they are conceptualized as "independent variables" in the analyses (W. Stroebe & Schut, 2001). However, this assumption may often be unjustified. For example, it is possible that social support fluctuates (e.g. overreliance on support early on may bring about withdrawal of support later on). Factors that can be assumed to change over the course of time should be assessed repeatedly during the observation period.

In summary then, it is important to approach the investigation of risk factors by examining multiple potential variables simultaneously, by including a grief-specific as well as different generic measures of adjustment, and by measuring fluctuating factors repeatedly over the course of bereavement in a longitudinal investigation.

In the current study, several strategies were adopted to carry out these necessary improvements. First, multiple potential risk factors were included simultaneously in a multivariate analysis. Second, factors that were assumed to fluctuate were measured at different time points. Third, data were analyzed in multilevel regression models, which allows inclusion of these so-called time-dependent factors (Hox, 2002). Finally, grief and depression measures were included as well as emotional loneliness and positive affect as dependent variables, to gain more insight into potentially different patterns associated with these diverse phenomena.

METHOD

Participants

This investigation was part of a larger study that looked at the efficacy of an e-mail based writing intervention for bereaved people. Participants were recruited in two ways: (1)

via the Internet, through websites, forums, and e-mail groups that focus on bereaved persons, (2) via organizations and support groups for the bereaved. To be included in the study, people had to meet the following criteria at the time of registration: (1) at least 18 years of age, (2) native English speaker, (3) having experienced the death of a first-degree relative, and (4) being significantly distressed by this death. People who reported that they were suffering from severe depression, schizophrenia, psychotic episodes and / or were seriously considering ending their life were excluded from the study. Participants were randomly assigned to receive or not receive the intervention (i.e. to the experimental or control condition respectively). Only data from participants who were assigned to the control condition were included in the present study. Further criteria for inclusion were that the loved one had died no more than three years previously, and that complete data were available at the first measurement point. The final sample consisted of 195 bereaved individuals. Background and loss characteristics are summarised in Table 1.

Procedure

Participants were sent e-mails inviting them to fill in questionnaires online at three points in time: immediately, 3 and 6 months after registering for the study. Questionnaires measured background and loss-related variables, and aspects of mental and physical health, personality and coping behaviour. Up to two reminder e-mails were sent if participants failed to respond. Participants who did not respond to the reminder e-mails or who only filled in part of the questionnaires at a certain measurement point were not sent an invitation to fill in questionnaires at the next measurement point. The attrition rate was 29.2% over this 6-month period. A logistic regression analysis was performed with dropout as the dependent variable and the predictor and outcome variables (of the regular analyses) as independent variables in order to check for differences between completers and non-completers. According to the Wald criterion, only emotional loneliness reliably predicted dropout: completers experienced less emotional loneliness than non-completers (χ^2 (1, N = 195) = 8.30, p < .01).

Table 1 Background and loss characteristics of the sample at T1 (N=195)

Background characteristics	
Sex (N (%))	
Men	15 (7.7%)
Women	180 (92.3%)
Age (in years) (M (SD); minimum - maximum)	41.50 (10.96); 19-79
Education (highest level of schooling) (N (%))	
Primary school / elementary school	0 (0%)
Secondary school / high school (not finished)	5 (2.6%)
Secondary school / high school (finished)	24 (12.3%)
Some post-secondary school	41 (21.0%)
College diploma or equivalent	48 (24.6%)
University degree	45 (23.1%)
Postgraduate degree	32 (16.4%)
Loss characteristics	
Deceased is (N (%))	
Partner	72 (36.9%)
Child	69 (35.4%)
Parent	40 (20.5%)
Sibling	14 (7.2%)
Cause of death	
Natural causes	130 (66.7%)
Accident / homicide	44 (22.6%)
Suicide	21 (10.8%)
Time from loss (in years) (M (SD))	.91 (.73)
< 3 months	41 (21.0%)
>= 3 months and < 6 months	31 (15.9%)
>= 6 months and < 9 months	24 (12.3%)
>= 9 months and < 12 months	20 (10.3%)
>= 12 months and < 18 months	39 (20.0%)
>= 18 months and < 24 months	23 (11.8%)
>= 2 years and <= 3 years	17 (8.7%)

Measurement Instruments

In selecting the risk factors to be included in our study we decided to leave out all factors that only apply in the case of specific types of bereavement, in order not to limit investigation to certain types of bereavement. Examples of such factors are caregiver characteristics (which would have limited our sample to those persons who had been the caregiver of the person who died) and number of remaining children (which has been identified as a risk factor in bereaved parents and therefore would have limited our sample to this group). The final selection was restricted to those risk factors that have been studied most extensively, to investigate which ones would hold up in a multivariate analysis.

Risk Factors

<u>Bereavement-related predictors</u> were kinship (partner / child / parent / sibling), cause of death (natural causes / accident or homicide / suicide), (un)expectedness (measured on a 5-point scale, from *totally expected* to *totally unexpected*), and time since death.

<u>Intrapersonal predictors</u> were age, gender, education level (measured on a 7- point scale), previous significant losses, religiosity, spirituality, attachment anxiety, attachment avoidance, and neuroticism.

With regard to previous significant losses, a distinction was made between participants who had / had not already lost a first-degree relative to death (i.e. before the death of the person on which this study focused). Religiosity and spirituality were measured separately, each with one item: "How religious / spiritual a person would you describe yourself to be?". Answers were given on a 5-point scale ranging from not at all religious / spiritual (=1) through moderately religious / spiritual (=3) to very religious / spiritual (=5). Attachment was measured using the Experiences in Close Relationships-Revised Questionnaire (ECR-R; Fraley, Waller, & Brennan, 2000). The ECR-R items appear to be written for people in romantic relationships. Following Fraley's suggestions the word "partner" was therefore replaced by the word "others" to make the items relevant to other kinds of relationships (e.g. "My partner only seems to notice me when I'm angry" was changed to "Others only seem to notice me when I'm angry"). Cronbach's alpha for both attachment anxiety and attachment avoidance ranged from .93 to .94, and test-retest reliability was .73 to .84 for attachment anxiety and .76 to .83 for attachment avoidance.

Neuroticism was measured using the 8-item subscale of the Big Five Inventory (BFI; John & Srivastava, 1999). In this study, Cronbach's alpha was .81.

<u>Social predictors</u> were social support, current living arrangements (alone vs. with others), and professional help seeking.

Social support was assessed with a four—item scale of perceived social support. This scale asked two questions about social support from family members and the same two questions about social support from friends and relatives (a) "On the whole, how much do your [family members] / [friends and relatives] make you feel loved and cared for?" and (b) "How much are your [family members] / [friends and relatives] willing to listen when you need to talk about your worries or problems?" (W. Stroebe, Zech, Stroebe, & Abakoumkin, 2005). Response categories were "a great deal", "quite a bit", "some", "a little", "not at all", and "not applicable". Cronbach's alpha ranged from .87 to .92, and test-retest reliability was .60 to .74.

<u>Environmental predictors</u> were being a practicing member of an organized religion, financial deterioration (deterioration vs. no deterioration after the loss), current financial situation (insufficient vs. sufficient means), paid job, medication use (for anxiety, mood or sleep), and significant events around time of death.

It has been suggested that adult attachment style may be susceptible to change over time, especially after major life-events (Davila & Cobb, 2004). Social support is another variable that has been assumed to fluctuate over time (W. Stroebe & Stroebe, 1996). For this reason attachment anxiety, attachment avoidance, and social support were measured repeatedly over the course of our investigation. We also argued that the receipt of professional help and the use of medication might change over time. These variables were therefore also assessed at multiple timepoints. All other predictors were measured once, at the first measurement moment.

Dependent Variables

Grief reactions were measured using 9 items that were formulated on the basis of the criteria for complicated grief proposed for DSM-V (Prigerson, Vanderwerker, & Maciejewski, 2008): (1) I have felt myself longing and yearning for my [...], (2) I have felt bitter over my [...]'s death, (3) I have felt that life is empty or meaningless without my [...], (4) I have felt that moving on with my life (for example, making new friends, pursuing new interests) is difficult for me, (5) I have had difficulty trusting people, (6) I have had difficulty

accepting the death of my [...], (7) I have felt emotionally numb (e.g. detached from others), (8) I have felt that the future holds no meaning or purpose without my [...], and (9) I have felt on edge, jumpy, or easily startled. The blanks were filled in with the appropriate relationship word (e.g., son, partner, sister etc.). It has been shown that these 9 items constitute a concise way of measuring complicated grief (H. Prigerson, personal communication, March 10, 2006). Items were rated with respect to the past week on a 5-point scale ranging from never (= 1) to all of the time (= 5). Cronbach's alpha ranged from .86 to .91, and test-retest reliability was .66 to .80.

<u>Depressive symptoms</u> were assessed using the Center for Epidemiological Studies-Depression Scale (CES-D; Radloff, 1977). In this study, Cronbach's alpha ranged from .90 to .94, and test-retest reliability was .60 to .76.

<u>Positive emotions</u> were measured using the corresponding 10 items of the Positive Affect Negative Affect Schedule (PANAS; Watson, Clark, & Tellegen, 1988). In this study, Cronbach's alpha ranged from .91 to .95, and test-retest reliability was .56 to .71.

Emotional loneliness was measured using the following two items: (1) I feel lonely even if I am with other people, and (2) I often feel lonely (W. Stroebe et al., 1997). Participants indicated their (dis)agreement with these statements on a 7-point scale ranging from totally disagree (=1) to totally agree (=7). Cronbach's alpha ranged from .80 to .87, and test-retest reliability was .50 to .62.

The four dependent variables were measured at all three points in time.

Analyses

A multilevel modelling strategy was adopted for this study. Longitudinal data can be viewed as multilevel data, with repeated measurements nested within individuals. In our study this leads to a two-level model, with the series of repeated measures at the lowest (1st) level, and the participants at the highest (2nd) level. Amongst other advantages, a multilevel approach allows us to add time-varying predictors to our models. Furthermore, it does not assume equal numbers of observations, which means that all cases can remain in the analyses, thereby increasing the precision of the estimates and the power of the statistical tests (Hox, 2002). Finally, with regard to dropout, Little (as cited in Hox, 2002) has shown that when the panel attrition follows a pattern defined as missing-at-random, multilevel analysis leads to unbiased estimates. Multilevel modelling was implemented through MLWiN, Version 2.0.

Continuous predictors were centred on their means and categorical predictors were dummy-coded. For each of the outcome variables a model (Time model) was constructed containing an intercept term, Time (i.e. time since registration for the study (in months)) as a linear predictor and Time x Time as a quadratic predictor. The quadratic predictor was dropped from the model if it turned out to be non-significant. Next, the predictors were added to the model (Predictor model). Due to the large number of predictors, this was done in a two-step fashion. First, the predictors were divided into three groups following the integrative risk factor framework by M. Stroebe et al. (2006): bereavement-related predictors, intrapersonal predictors and social / environmental predictors.² The effects of the variables of each of the three predictor groups were then examined in turn, estimating separate predictor models for each predictor group. In the second step, from each of the separate models run in the first step, only the significant predictors were combined in a final predictor model.

The explained variance (i.e. the part of the variation in the outcome measure that can be explained by the predictors) was calculated following recommendations by Hox (2002). Finally, we checked whether the predictors that were included as time-varying variables in our analyses were indeed subject to change over time. This was done by constructing a model for each of these predictors containing an intercept term, Time (i.e. time since registration for the study) as a linear predictor and Time x Time as a quadratic predictor.³

RESULTS

The results of the multilevel analyses are presented in Tables 2 through 6. As can be seen in these tables, participants' mental health improved over time: grief, depression and emotional loneliness decreased over the study's 6-month period while positive mood increased. Only for grief was prediction improved by adding a quadratic trend for time: data showed that grief decreased more between the first and second measurement moment than between the second and third measurement moment.

Table 2 shows that between 24% and 27% of the variance in the outcome measures was explained by the three predictor groups combined.⁴ Intrapersonal predictors (such as adult attachment style) explained most of the variance in bereavement outcome, whereas bereavement-related predictors (such as expectedness of the death) explained the least variance. Even though the total amount of explained variance was very similar between the outcome measures, there were notable differences in the amount of variance that was explained by each predictor group, especially between positive mood and emotional

loneliness. Bereavement-related predictors did not explain any of the variance in positive mood, whereas they explained 7% of the variance in emotional loneliness. Intrapersonal variables, on the other hand, were far more important in predicting positive mood (26% explained variance) than emotional loneliness (16% explained variance).

Table 2

Explained variance of grief, depressive symptoms, emotional loneliness, and positive mood for predictor groups

	Bereavement-	Intrapersonal	Social /	Total explained
	related predictors	predictors	environmental	variance
			predictors	
Grief	4%	19%	8%	25%
Depressive symptoms	2%	21%	13%	27%
Emotional loneliness	7%	16%	11%	24%
Positive mood	0%	26%	7%	26%

Regarding the specific predictors that significantly contributed to the explanation of variance in mental health, Table 3 shows both a number of similarities as well as disparities between the outcome measures. As discussed in the previous paragraph, bereavement-related predictors contributed to the experience of negative emotions, but did not influence positive mood. Bereaved persons who had lost someone unexpectedly experienced more grief and depressive symptoms (but not emotional loneliness) than those who had expected the death. The type of lost relationship was predictive of the amount of emotional loneliness (but not the experience of grief or depressive symptoms): the loss of a partner caused more emotional loneliness than the loss of a parent or child.

Table 3

Bereavement-related predictors of grief, depressive symptoms, emotional loneliness, and positive mood

	Grief		Depressive symptoms		Emotional Loneliness		Positive mood	
-	В	SE	В	SE	В	SE	В	SE
Time	-0.142***	0.024	-0.214***	.036	-0.024*	0.012	0.087**	0.029
Time x Time	0.005*	0.002	-	-	-	-	-	-
Kinship $(0 = partner)$								
Parent	-1.588	1.463	-0.396	2.133	-1.276*	0.615	0.676	1.594
Child	0.369	1.258	-1.499	1.834	-2.424***	0.529	1.652	1.370
Sibling	-0.463	2.215	-4.006	3.235	-1.092	0.936	1.226	2.418
Cause of death $(0 = natural causes)$								
Suicide	2.669	1.771	3.206	2.581	0.652	0.744	-2.282	1.925
Accident / homicide	1.056	1.416	0.751	2.067	0.033	0.596	-1.427	1.544
(Un)expectedness	0.888*	0.426	1.251*	0.621	0.308	0.179	-0.578	0.464
Time since death	-0.927	0.738	-1.795	1.076	-0.300	0.310	1.458	0.803

^{*} *p* < .05. ** *p* < .01. *** *p* < .001.

Table 4

Intrapersonal predictors of grief, depressive symptoms, emotional loneliness, and positive mood

	Grief		Depressive symptoms		Emotional loneliness		Positive mood	
	В	SE	В	SE	В	SE	В	SE
Time	-0.165***	0.019	-0.258***	0.029	-0.030**	0.010	0.126***	0.023
Time x Time	0.006**	0.002	-	-	-	-	-	-
Gender $(0 = male, 1 = female)$	5.722**	1.770	4.248	2.530	1.015	0.767	-3.829*	1.792
Age	0.017	0.048	0.071	0.069	0.015	0.021	-0.062	0.049
Educational level	-0.403	0.353	-0.337	0.505	0.076	0.154	0.006	0.359
Previous significant losses	1.762	1.006	1.108	1.440	0.796	0.438	-0.288	1.022
Religiosity	0.115	0.474	-0.104	0.677	-0.091	0.206	-0.308	0.480
Spirituality	-0.789	0.479	-0.485	0.686	-0.144	0.209	1.287**	0.487
Attachment anxiety	0.043**	0.017	0.074**	0.025	0.035***	0.008	-0.004	0.019
Attachment avoidance	0.069***	0.017	0.136***	0.026	0.038***	0.008	-0.144***	0.019
Neuroticism	0.174*	0.077	0.360**	0.110	0.046	0.034	-0.292***	0.078

^{*} *p* < .05. ** *p* < .01. *** *p* < .001.

Table 5
Social / environmental predictors of grief, depressive symptoms, emotional loneliness, and positive mood

	Grief		Depressive symptoms		Emotional loneliness		Positive mood	
	В	SE	В	SE	В	SE	В	SE
Time	-0.175***	0.019	-0.273***	0.029	-0.034**	.011	0.133***	0.024
Time x Time	0.006**	0.002	-	-	-	-	-	-
Social support	1.635***	0.345	2.734***	0.517	0.663***	0.174	-2.200***	0.412
Professional help seeking	-0.372	0.640	-0.299	0.981	-0.366	0.339	-0.021	0.784
Medication use	-1.183	0.782	-2.638*	1.169	-0.280	0.392	1.656	0.930
Current living arrangements	-0.180	1.179	-2.418	1.620	-0.434	0.488	0.404	1.260
Being a practicing member of an	0.889	1.050	2.365	1.447	0.666	0.438	-2.073	1.127
organized religion								
Financial situation deterioration	2.380*	1.192	3.157	1.638	1.501**	0.493	-2.468	1.274
Adequacy of financial situation	-0.817	1.245	-4.008*	1.715	-0.707	0.518	-0.225	1.335
Paid job	0.705	1.082	1.312	1.488	0.611	0.449	0.225	1.157
Significant events around time of death	-0.581	1.029	-0.535	1.416	0.180	0.428	0.893	1.102

^{*} *p* < .05. ** *p* < .01. *** *p* < .001.

Table 6
Final model

	Grief		Depressive symptoms		Emotional loneliness		Positive	mood
-	В	SE	В	SE	В	SE	В	SE
Time	-0.175***	0.019	-0.269***	0.029	-0.032**	0.010	0.132***	0.023
Time x Time	0.006*	0.002	-	-	-	-	-	-
Bereavement-related								
Kinship $(0 = partner)$								
Parent	-	-	-	-	-1.219*	0.566	-	-
Child	-	-	-	-	-1.588***	0.464	-	-
Sibling	-	-	-	-	-0.166	0.821	-	-
(Un)expectedness	1.214***	0.324	1.133*	0.464	-	-	-	-
Intrapersonal								
Gender $(0 = male, 1 = female)$	5.878***	1.694	-	-	-	-	-3.656*	1.786
Spirituality	-	-	-	-	-	-	1.033*	0.438
Attachment anxiety	0.025	0.017	0.047	0.025	0.034***	0.008	-	-
Attachment avoidance	0.064***	0.017	0.115***	0.026	0.033***	0.008	-0.124***	0.020
Neuroticism	0.157*	0.072	0.329**	0.103	-	-	-0.266***	0.075
Social / environmental								
Social support	1.134**	0.351	1.785***	0.535	0.237	0.177	-1.230**	0.397
Medication use	-	-	-2.191*	1.112	-	-	-	-
Financial situation deterioration	1.845†	0.947	-	-	1.077*	0.431	-	-
Adequacy of financial situation	-	-	-3.316*	1.416	-	-	-	-

[†] *p* < .10 * *p* < .05. ** *p* < .01. *** *p* < .001

With regard to the intrapersonal predictors, it is interesting to note that attachment avoidance significantly contributed to the prediction of all four outcome measures, with higher levels of attachment avoidance being related to worse mental health. In contrast, attachment anxiety only predicted emotional loneliness, with higher levels of attachment anxiety relating to more emotional loneliness. Neuroticism showed an opposite profile: it did not significantly contribute to the prediction of emotional loneliness, but it was related to all other outcome measures, with higher levels of neuroticism being related to worse mental health. Only positive mood was predicted by spirituality: more spiritual persons experienced more positive emotions.

Of the various social and environmental predictors that were investigated, those that were related to financial aspects were significantly predictive of negative, but not of positive emotional states: people whose income declined as a result of the loss or who were lacking in financial means experienced more grief and emotional loneliness and more depressive symptoms respectively. Social support predicted all outcome variables (lower levels of perceived social support being related to worse mental health) except for emotional loneliness.

A few predictors that contributed significantly to the explanation of variance in mental health when examined within their own predictor group, ceased to have a significant effect when examined simultaneously with predictors from other predictor groups: attachment anxiety was no longer predictive of grief and depressive symptoms, and social support was no longer predictive of emotional loneliness.

Contrary to expectations, only social support was subject to change over time, increasing over the course of our study. Attachment style remained stable as did the percentage of participants who were receiving professional help and taking medications.

DISCUSSION

This study provided information about predictors of adjustment of persons to the loss of a loved one. It did so while addressing a number of methodological shortcomings identified in the risk literature. First of all, instead of focussing on only one or on a small set of factors, multiple potential risk factors were simultaneously examined. This decreases the chance of reporting spurious results. Secondly, a bereavement-specific (grief), as well as different generic measures of adjustment (depressive symptoms, emotional loneliness, and positive mood) were included. Thirdly, instead of assuming that risk factors are stable during

the period of observation, factors that were assumed to be subject to change were measured repeatedly over the course of our project. We first describe our findings in the context of these shortcomings in previous investigations. Then we discuss the various risk factors that our study identified and address some of the limitations of our study. Finally, we offer some suggestions for further research.

Our results clearly indicate the importance of examining variables from different predictor groups (bereavement-related, intrapersonal, and social / environmental predictors) simultaneously. By looking at the association between symptoms and multiple predictive factors at the same time, we were able to show differences in the magnitude and significance of the contribution of several predictors, indicating their confounding influences. For example, whereas attachment anxiety contributed significantly to the prediction of grief and depressive symptoms when examined within the group of intrapersonal predictors, it failed to reach significance when combined with predictors from the two other predictor groups. We return to this finding later on when discussing our results with regard to adult attachment style.

The inclusion of diverse measures of adjustment allowed us to compare these measures in terms of risk factors. Our results indicate clear variations between outcome measures in this respect, although there are also commonalities. Emotional loneliness shows a distinctive pattern: being high in anxious attachment and having lost a partner is related to more intense feelings of emotional loneliness, while these variables do not predict any of the other outcome variables. Social support, on the other hand, does not influence emotional loneliness, whereas it does predict grief, depressive symptoms and positive mood. Furthermore, our results show that financial aspects are predictive of negative outcome measures, but not of positive mood. Positive mood, in contrast, is predicted by spirituality. The differences that were identified in risk profiles between negative emotions and positive mood are in line with the arguments brought by contemporary researchers, as reported in the introduction. In the same vein, the fact that grief and depressive symptoms are to some extent predicted by different variables - although the difference is not as pronounced as in some studies (e.g. Wijngaards-de Meij et al., 2005) - lends further credence to the notion that "depression" and grief are indeed two different concepts, as discussed earlier.

Whereas it is important in principle to assess fluctuating factors repeatedly over the course of a project, it turns out that most of the predictors that we assumed would be subject to change over time were in fact stable in our study. This is perhaps less surprising in the case of trait-like variables such as attachment styles. But it is puzzling that the receipt of

professional help and the use of medication did not change either. This latter finding does suggest that the stability of most variables in our study might have been due to the fact that we observed people only for 6 months, a relatively short period. Thus, in our view, investigators should continue to take fluctuation into account in future research.

Turning to the various risk factors identified in this study: it is interesting to note that bereavement-related predictors do not play a very important role, except in the case of emotional loneliness, which is predicted by partner loss. This latter finding is in line with Weiss' relational theory of loneliness, which posits that the loneliness of emotional isolation appears in the absence of a close emotional attachment (Weiss, 1975): for most people their romantic partner constitutes their closest emotional attachment. With respect to the other outcome measures, both grief and depressive symptoms are only - and to a small extent predicted by the (un)expectedness of the death. Positive mood bears no relation at all to bereavement-related predictors. Although bereavement-related predictors have traditionally been linked to bereavement outcome, we are not the first to find a lack of significant contribution (e.g. Boelen, van den Bout, & van den Hout, 2003). One explanation for this might be that participants were selected via support groups and organizations for the bereaved. It is possible that people from such groups and organizations are on average more distressed by their bereavement than people who are not a member of such groups or organizations. Furthermore, it was stated explicitly that people had to be significantly distressed in order to participate in our study. Thus, participants may have been "preselected" on the bereavement-related predictors that were measured, thereby decreasing their impact. Such selective participation is, however, quite common in bereavement research (M. Stroebe & Stroebe, 1989). It remains critically important to acknowledge and to assess the significance of potential biases associated with selection in all investigations.

To a certain extent, the findings on adult attachment style and neuroticism are in line with previous research, especially work done by Wijngaards-de Meij et al. (2007a, 2007b). As in these previous studies, we found that when these intrapersonal variables were examined simultaneously, both attachment dimensions explained a unique part over and above neuroticism in grief and depressive symptoms. Our replication of these results is especially noteworthy, because a different (and more reliable) measure of adult attachment style was used. Furthermore, we extended earlier findings by examining the effect of adult attachment style and neuroticism on two new outcome measures - emotional loneliness and positive mood - and with different types of loss. We demonstrated that emotional loneliness is predicted by both attachment dimensions, but not by neuroticism, whereas positive mood is

predicted by attachment avoidance and neuroticism. However, our results also deviate from the abovementioned research, in that the effect of attachment anxiety on grief and depressive symptoms disappeared when it was examined together with social support. Further probing of the relationships between these variables is to be recommended.

It is interesting to note that spirituality predicted positive mood, but none of the other outcome measures. Indeed, this reflects a pattern found among non-bereaved sample. Kim, Seidlitz, Ro, Evinger, and Duberstein (2004) reported that, controlling for religiousness, spirituality was associated with emotional well-being and that it was primarily related to positive but not to negative emotions. However, this does not rule out the possibility that there may also be a bereavement-specific component to this relationship. In so far as being a spiritual person incorporates certain beliefs (e.g. the belief in an afterlife where the deceased one awaits you or a belief that the deceased is still present), it is reasonable to expect that this would add to the experience of positive emotions during bereavement. Most studies that have looked at the effect of religion or spirituality on bereavement outcome have used religious affiliation, religiosity and spirituality as interchangeable concepts (for a review, see Becker, Xander, & Blum, 2007). Given the consensus of opinion that they are not the same, a strong feature of our study was that differentiation between these three aspects was made (although each was measured with a single item). Further research needs to replicate these findings with more reliable measures and further exploration of the general versus bereavement-specific nature of the relationship between spirituality and positive mood is also called for.

We also reported that the amount of (perceived) social support predicts grief, depressive symptoms and positive mood. These results are in line with a number of studies that have shown social support to be related to bereavement outcome, with people who receive more support having more favourable outcomes (e.g. W. Stroebe et al., 2005). Note, however, that social support is a general (not bereavement-specific) risk factor, benefitting the bereaved and non-bereaved alike (W. Stroebe et al., 2005). The fact that social support does not predict emotional loneliness is also in accordance with previous research (W. Stroebe et al., 1997). Again, Weiss' relational theory of loneliness can be called on to explain this finding (Weiss, 1975). In this theory, Weiss draws a fundamental distinction between emotional and social loneliness, and argues that the two types of loneliness cannot compensate for each other. The loneliness of social isolation can only be helped by access to an engaging social network, while emotional isolation can only be remedied by the integration of another emotional attachment or the reintegration of the one who has been lost. In the case of bereavement the latter can be understood as a symbolic reintegration (i.e. continuing bonds).

We found that people who were taking medications for anxiety, mood or sleep problems experienced more depressive symptoms than people who did not take such medications. It seems plausible that feelings of depression lead to medication use, but it is interesting to note that the relationship with medication use held only for depressive symptoms and not for grief. This may indicate that bereaved people and / or their doctors are of the opinion that intense grief symptoms cannot or should not be treated with pharmacological aids. On the other hand, it is also possible that medication was indeed provided, but was not effective in relieving grief symptoms (Hensley, 2006).

Our results show that both *loss* of and *lack* of money were associated with poor bereavement outcome. The *loss* of financial resources was related to grief and emotional loneliness. The relationship with grief makes sense, in that the loss of financial resources can be understood as a secondary loss, that adds to the salience of the first loss. It is unclear why people who experience financial deterioration also experience more loneliness. An explanation in terms of an association between loss of financial resources and loss of a partner (given that both are related to emotional loneliness) cannot apply, because we controlled for this possibility in our analysis, when we examined type of lost relationship and financial deterioration simultaneously. The loss of financial resources is not related to depressive symptoms, but depressive symptoms are determined by *lack* of finances. Both findings are in agreement with research which shows that people easily adapt to changes (either for the better or for the worse) in their financial situation (e.g. Diener, Suh, Lucas, & Smith, 1999), but that economic strain predicts depressive symptoms (e.g. Wadsworth, Raviv, Compas, & Connor-Smith, 2005).

In discussing our findings, we have already addressed a number of shortcomings of our study. At the same time, the present study illustrates the usefulness of a multivariate approach to the investigation of predictors and it provides strong support for the inclusion of bereavement-specific as well as more general outcome measures. We also identified a number of situational and personal characteristics associated with vulnerability. For example, persons who were more avoidant in their style of attachment had poorer bereavement outcomes, regardless of their level of neuroticism. Future research should focus on replicating and further exploring such findings. Two major lines of investigation emerge: First of all, because we did not want to limit ourselves to certain types of bereavement, we focused on predictors that in principle apply to all the bereaved. However, predictors that are only relevant to specific types of bereavement may nevertheless be important in those specific situations. Thus, investigation needs to be extended to such variables, and to examining their

contribution and relative importance compared to the ones already investigated. Second, we did not include any process measures (e.g. rumination or other types of coping) in these analyses. Extension of our research to include such measures is important for two reasons. By examining process measures alongside the predictors which turned out to be important in our study, one could gain further insight into the pathways through which these predictors become impactful. Moreover, knowledge of these mechanisms would provide us with targets for intervention.

Finally, one has to consider the clinical implications of this study. There are two issues addressed by our research. First, as we mentioned in the introduction, early identification of those who are at risk of suffering lasting health consequences may make it possible to intervene and possibly prevent negative outcomes. And even though few of the risk factors that we pinpointed are easily identifiable, it would be possible to develop a screener questionnaire based on these factors. However, additional research would be needed, for example, to establish how these factors should be combined in such a measure, to allow one to predict who benefits most from interventions.

A second point concerns the possibility to target risk factors in intervention. Clearly, interventions can only be aimed at risk factors that easily lend themselves to change. Unfortunately, most of the risk factors that we identified cannot be changed (e.g. gender, (un)expectedness of the death) or might be difficult to change (e.g. neuroticism, attachment style, adequacy of financial situation).

It is clear that additional steps need to be taken to translate our research findings into practice. This remains a challenge for both researchers and clinicians. Nevertheless, we consider our study as providing a fruitful starting point, in that it identifies factors that can be subjected to further investigation. What we also hope to have made clear in this article is how research on risk factors should proceed, and how it should best be conducted, for valid results to be obtained.

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NOTES

- ¹ Participants assigned to the control condition were offered the opportunity to participate in the intervention after answering the last set of questionnaires following the end of their participation in the study.
- ² Social and environmental risk factors were combined into one predictor group to be in line with the risk factor framework developed by M. Stroebe et al. (2006) and because of overlapping variance between the two categories (for example between "being a practicing member of an organized religion" and "social support" and between "current living arrangements" and "current financial situation").
- ³ Time x Time was added as a quadratic predictor to capture any non-linear relationship that might exist between Time and the dependent variables and thereby improve on the model.
- ⁴ The explained variance of the three predictor groups combined (shown in the last column of Table 7) is less than the sum of the explained variance of the three predictor groups separately (shown in the first three columns of Table 7). This is due to dependencies between predictors (i.e. variance that is shared by the predictor groups).
- ⁵ The relationship between grief and financial situation deterioration almost reached significance (p = .051).
- ⁶ In considering the intrapersonal and social and environmental predictors, it is important to keep in mind that this study focused on bereaved persons only and the differences between subgroups among them. Given this focus, we cannot be sure whether the variables that turned out to be important significant predictors of the general (i.e. non-grief specific) outcome measures would also be significant predictors among non-bereaved samples of people. Clearly, this point does not apply to our grief measure.

Chapter 4

Mediating processes in bereavement:

The role of rumination, threatening grief
interpretations, and deliberate grief avoidance

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ABSTRACT

Limited research so far has examined coping processes that mediate between risk factors and bereavement outcome. Knowledge of these pathways is important, since it helps establish why some bereaved persons are more vulnerable than others and suggests possibilities for intervention. In this longitudinal study, conducted internationally, three potentially critical mediators, namely, rumination, threatening grief interpretations and deliberate grief avoidance, were examined in relationship to previously-established risk factors (e.g. expectedness of the death, attachment style) and four major outcome variables (grief, depressive symptoms, emotional loneliness and positive mood). Individuals who were recently bereaved (maximum 3 years) filled in questionnaires at 3 points in time. Results showed that rumination and – to a somewhat lesser extent - threatening grief interpretations played an important role in mediating the effects of various risk factors on outcomes. However, the contribution of these two mediators was dependent on the specific risk factor and outcome measure under consideration. For example, whereas the effect of neuroticism on grief was mediated by both processes (to the extent of 73%), the effect of neuroticism on positive mood was only mediated by rumination, and to a smaller extent (23%). A few risk factors, such as current financial situation and spirituality, were not mediated by either coping strategy. Implications of these findings are discussed.

Bereavement is a highly stressful life-event that is associated with excess risk of mortality and with decrements in both physical and mental health (for a review, see M. Stroebe, Schut, & Stroebe, 2007). While most people are able to adjust to the death of a loved one without long lasting difficulties, a significant minority of the bereaved do not adapt well and continue to experience difficulties (Bonanno & Mancini, 2008). Much research has focused on so-called "risk factors", that is, situational and personal characteristics likely to be associated with increased vulnerability across the spectrum of bereavement outcome variables (M. Stroebe, Folkman, Hansson, & Schut, 2006). An important impetus for this line of work is that early identification of those at risk of suffering lasting health consequences makes it possible to intervene and possibly prevent negative outcomes. It is particularly critical to identify such at-risk persons, because there is no empirical evidence that provision of routine psychological intervention, simply on the grounds that a person has suffered a bereavement, is effective (Currier, Neimeyer, & Berman, 2008).

Although the above line of research is clearly valuable, it is also limited in the sense that it fails to inform one about pathways through which these predictors become impactful. How, for instance, do unexpected deaths become associated with complications in bereavement? Knowledge of intermediate mechanisms is essential, not just for theoretical but also for practical purposes. For example, knowledge of the pathways through which risk factors impact on bereavement outcome should enable us to identify cognitive processes that may be amenable to change in psychotherapy, and provide us with targets for intervention. This is imperative, because many risk factors themselves are either resistant to change (e.g. personality factors, such as neuroticism and attachment style) or cannot be changed at all (e.g. risk factors having to do with the deceased and the bereavement situation).

In a previous study a number of situational and personal characteristics that are associated with increased vulnerability after bereavement were identified (van der Houwen, Stroebe, Stroebe, Schut, van den Bout, & Wijngaards-de Meij, in press; see Table 1 for an overview of these factors). All of these risk factors exerted their impact through main effects. There were no interactions with time of measurement. Thus, even though there was significant improvement in grief, depressive symptoms, emotional loneliness and positive mood during the course of this study, these risk factors appeared to neither accelerate nor slow down this process.

In the current study we build on this previous research to examine mechanisms that mediate the impact of these risk factors, focusing on cognitive and behavioural coping processes (while recognizing that there are other mechanisms that impact on bereavement outcome). Although a considerable amount of research has been devoted to these processes and how they influence bereavement outcome, to our knowledge, few studies have simultaneously examined risk factors, outcomes and the coping processes that might mediate between them. Some of these studies have focused on specific types of bereavement, whereas others have examined more general risk factors. We review these two types of investigation in turn next.

Table 1

Overview of risk factors and their relationship with outcome measures¹

	Grief	Depressive	Emotional	Positive mood
		symptoms ²	loneliness	
Female gender	X			X
High attachment anxiety			X	
High attachment avoidance	X	X	X	X
High neuroticism	X	X		X
High Spirituality				X
Loss of a partner ³			X	
Unexpected death	X	X		
Financial situation deterioration	X		X	
Inadequate financial means		X		
Low social support	X	X		X

¹ Significant relationships between risk factors and outcome measures are signified by 'X'. For example, people high in attachment-related anxiety experience more emotional loneliness.

Field and colleagues investigated mediating factors in adjustment among a sample of conjugally bereaved people (Field, Hart, & Horowitz, 1999; Field & Sundin, 2001). They showed that the effects of anxious attachment (to the deceased spouse) and previous relationship conflict (with the deceased spouse) were mediated by the appraised inability to cope and by blame-related appraisals respectively. Wolchik and colleagues examined the mediational properties of three self-system beliefs (fear of abandonment, coping efficacy, and self-esteem) between post-bereavement stressors (e.g. changes in living situations) and caregiver—child relationship quality, on the one hand, and mental health problems (e.g.

² We also found that taking medications for anxiety, mood or sleep problems was related to depressive symptoms. This factor was not included in the analyses because we felt these variables were directly related (without mediating processes).

³ People who have lost their partner experience more emotional loneliness than people who lost a parent or a child, but not more emotional loneliness than people who have lost a sibling.

internalizing and externalizing problems), on the other hand within a sample of parentally bereaved children (Wolchik, Ma, Tein, Sandler, & Ayers, 2008; Wolchik, Tein, Sandler, & Ayers, 2006). They found – among other things – that fear of abandonment mediated the relations between stressors and both internalizing problems and externalizing problems when examined longitudinally.

Turning now to the investigations that have focused on more general risk factors: Meuser and Marwit (1999) and Robinson and Marwit (2006) investigated whether different forms of coping mediated the relationship between personality and bereavement outcome, and concluded – among other things - that the effect of neuroticism on grief was partly mediated by emotion-oriented coping. Currier, Holland, and Neimeyer (2006) examined sense-making (i.e. the capacity to construct an understanding of the loss experience) as a possible mediator between violent death and complicated grief symptomatology. They reported that sense-making emerged as an explanatory mechanism for the association between violent loss and complications in grieving. Nolen-Hoeksema, Parker, and Larson (1994) hypothesized and confirmed that the effect of four different risk factors (female gender, additional stress, poor social support and initially severe depressive reactions) on depressive reactions was mediated by rumination. In another study the same researchers demonstrated that sense-making and benefit-finding mediated the effects of dispositional optimism-pessimism, religious-spiritual beliefs, and the age at death of the deceased on distress (a composite measure of depressive symptoms, PTSD symptoms, and positive affect, reverse coded) (Davis, Nolen-Hoeksema, & Larson, 1998).

The above research clearly identifies a number of central processes relating to bereavement outcomes. However, knowledge about mediational coping processes remains limited: (1) A number of the risk factors studied are specific to certain types of bereavement, which limits the applicability of the information acquired to these particular kinds of bereavement. (2) Additional, potentially important mediators have not yet been investigated.

How can one identify such mediators? As mentioned earlier, although few studies have simultaneously examined risk factors, outcomes and the coping processes that might mediate between them, further research has indeed investigated a number of coping processes that might account for differences in bereavement outcome. Examples of processes that have received attention over the years are emotional expression (e.g. M. Stroebe, Stroebe, Schut, Zech, & van den Bout, 2002), cognitive appraisals (e.g. Boelen, van den Bout, & van den Hout, 2006), continuing bonds (e.g. Boelen, Stroebe, Schut, & Zijerveld, 2006), meaningmaking (e.g. Davis et al., 1998), rumination (e.g. Nolen-Hoeksema, 2001), and deliberate

grief avoidance (e.g. Shear et al., 2007). While all of these processes may be important, in this study we focus on coping processes that have *consistently* been associated with poor adjustment, either in cross-sectional or longitudinal studies: rumination, threatening grief interpretations (i.e. negative and fearful interpretations of grief reactions that are not necessarily indicative of disturbance) and deliberate grief avoidance. Moreover, some theorists have claimed that negative cognitions and avoidance – among which rumination can be counted (see e.g. Nolen-Hoeksema, Wisco, & Lyubomirsky, 2008) - play a central role in the development and maintenance of complicated grief (Boelen, van den Hout, & van den Bout, 2006; Shear et al., 2007). Thus, it seems particularly important to investigate the mediating role of these three processes in the relationship between risk factors and outcome variables.

In summary then, in this study we examined the mediating properties of rumination, threatening grief interpretations and deliberate grief avoidance between general risk factors (that were identified as important in an earlier study) and outcome in terms of grief, depressive symptoms, emotional loneliness and positive mood.

METHOD

Participants

This investigation was part of a larger study that looked at the efficacy of an e-mail based writing intervention for bereaved people. Only data from participants who were assigned to the control condition were included in the present study. Participants were recruited in two ways: (1) via the Internet, through websites, forums, and e-mail groups that focus on bereaved persons, (2) via organizations and support groups for the bereaved. Due to the worldwide accessibility of the Internet, participants did not come from a specific area or country. To be included in the study, people had to meet the following criteria at the time of registration: (1) at least 18 years of age, (2) native English speaker, (3) having experienced the death of a first-degree relative, (4) being significantly distressed by this loss. People who reported that they were suffering from severe depression, schizophrenia, psychotic episodes and / or were seriously considering ending their life were excluded from the study, as were people who suffered their loss at a very early age (and consequently had never consciously known or interacted with the person who died) and people who suffered multiple simultaneous losses. Participants were randomly assigned to receive or not receive the

intervention (i.e. to the intervention or control condition respectively). Participants assigned to the control condition were offered the opportunity to participate in the intervention after answering the last set of questionnaires. Further criteria for inclusion in the current investigation were that the loved one had died no more than three years previously, and that complete data were available at the first measurement point. The sample consisted of 195 bereaved individuals. Background and loss characteristics are summarised in Table 2.

Procedure

Participants were sent e-mails inviting them to fill in questionnaires online at three points in time: immediately, 3 and 6 months after registering for the study. Questionnaires measured background and loss-related variables, and aspects of mental and physical health, personality and coping behaviour. Up to two reminder e-mails were sent if participants failed to respond. Participants who did not respond to the reminder e-mails or who only filled in part of the questionnaires at a certain measurement point were not sent an invitation to fill in questionnaires at the next measurement point. The attrition rate was 29.2% over this 6-month period. A logistic regression analysis was performed with dropout as the dependent variable in order to check for differences between completers and non-completers. Independent variables included the predictor, mediator and outcome variables (of the regular analyses) as well as other relevant background variables. According to the Wald criterion, only emotional loneliness reliably predicted dropout: completers experienced less emotional loneliness than non-completers (γ^2 (1, N = 195) = 8.46, p < .01).

Measurement Instruments

Background and Loss-Related Variables

At the first measurement point questions were asked about age, gender, education level (measured on a 7-point scale), work status, changes in financial situation due to the loss, current financial situation, living situation, involvement in a religious community, level of religiosity and spirituality, formal relationship to the deceased, cause of death (natural causes / accident or homicide / suicide), level of unexpectedness of the death, significant events around time of death, time since death, previous significant losses, and past professional help

in dealing with the loss. At each measurement point questions were asked about current professional help in dealing with the loss and medication use.

Table 2 $Background\ and\ loss\ characteristics\ of\ the\ sample\ at\ T1\ (N=195)$

Background characteristics	
Sex (N (%))	
Men	15 (7.7%)
Women	180 (92.3%)
Age (in years) (M (SD); minimum - maximum)	41.50 (10.96); 19-79
Education (highest level of schooling) (N (%))	
Primary school / elementary school	0 (0%)
Secondary school / high school (not finished)	5 (2.6%)
Secondary school / high school (finished)	24 (12.3%)
Some post-secondary school	41 (21.0%)
College diploma or equivalent	48 (24.6%)
University degree	45 (23.1%)
Postgraduate degree	32 (16.4%)
Loss characteristics	
Deceased is (N (%))	
Partner	72 (36.9%)
Child	69 (35.4%)
Parent	40 (20.5%)
Sibling	14 (7.2%)
Cause of death	
Natural causes	130 (66.7%)
Accident / homicide	44 (22.6%)
Suicide	21 (10.8%)
Time from loss (in years) (M (SD))	.91 (.73)
< 3 months	41 (21.0%)
>= 3 months and < 6 months	31 (15.9%)
>= 6 months and < 9 months	24 (12.3%)
>= 9 months and < 12 months	20 (10.3%)
>= 12 months and < 18 months	39 (20.0%)
>= 18 months and < 24 months	23 (11.8%)
>= 2 years and <= 3 years	17 (8.7%)

Personality

Attachment organization was measured using the well-validated Experiences in Close Relationships-Revised Questionnaire (ECR-R; Fraley, Waller, & Brennan, 2000; Sibley & Liu, 2004). The ECR-R assesses individual differences with respect to attachment-related anxiety (i.e., the extent to which people are insecure vs. secure about the extent to which others are available and responsive to them) and attachment-related avoidance (i.e., the extent to which people are uncomfortable being close to others vs. secure depending on others). The ECR-R items were originally worded to be relevant to romantic relationships. Following Fraley's suggestions the word "partner" was therefore replaced by the word "others" to make the items relevant to other kinds of relationships (e.g. "My partner only seems to notice me when I'm angry"). Participants filled out the ECR-R at all three points in time. Cronbach's alpha for both attachment anxiety and attachment avoidance ranged from .93 to .94.

<u>Neuroticism</u> was measured at the first measurement point using the 8-item subscale of the Big Five Inventory (BFI; John & Srivastava, 1999). In this study, Cronbach's alpha was .81.

Social Support

Social support was assessed at all three measurement points with a four–item scale of perceived social support, comprising the same two items for family members and for friends and relatives (a) "On the whole, how much do your family members (friends and relatives) make you feel loved and cared for?" and (b) "How much are your family members (friends and relatives) willing to listen when you need to talk about your worries or problems?" (W. Stroebe, Zech, Stroebe, & Abakoumkin, 2005). Response categories range from "a great deal" to "not at all", and "not applicable". Cronbach's alpha ranged from .87 to .92.

Mediator Variables

The three mediator variables were measured at all three points in time.

<u>Rumination</u> was measured with a self-constructed 8-item questionnaire that was based on literature on rumination in general and on rumination in bereavement specifically (e.g. Boelen, van den Bout, et al., 2006; Nolen-Hoeksema, 1991). Examples of items are: "I think

about how bad I feel since my [...] died" and "I think about why my [...] has died". The blanks were filled in with the appropriate relationship word (e.g. son or partner). Items were rated with respect to the past week on a 5-point scale ranging from (almost) never (= 1) to (almost) constantly (= 5). Statistical findings indicated that it was justified to treat the items as forming a single scale at all three measurement points: Cronbach's alpha ranged from .82 to .86, the mean item-total correlation of the 8 items ranged from .55 to .61, and all items had factor loadings of >.46 in a one factor solution. Therefore item ratings were summed to form a single score.

Threatening grief interpretations were measured using the two items with the highest factor loadings from the 4-item subscale "Threatening interpretation of grief" of the Grief Cognitions Questionnaire (GCQ; Boelen & Lensvelt-Mulders, 2005): "If I allow my feelings to run loose, I will lose control" and "If I would fully realise what the death of my […] means, I would go crazy". The blank was filled in with the appropriate relationship word (e.g., son or partner). Agreement with the items was rated on a 6-point scale ranging from strongly disagree (1) to strongly agree (6). Cronbach's alpha ranged from .68 to .74.

Deliberate grief avoidance was measured with 13 items that were formulated on the basis of literature on avoidance in grief (e.g. Boelen, van den Bout, et al., 2006; Bonanno, Papa, Lalande, Zhang, & Noll, 2005). Examples of items are: "I avoid activities I used to do with my [...]" and "I avoid looking at pictures of my [...]". The blanks were filled in with the appropriate relationship word (e.g. son or partner). Items were rated with respect to the past week on a 5-point scale ranging from (almost) never (= 1) to (almost) constantly (= 5) or participants could indicate that the item did not apply to them. Statistical findings indicated that it was justified to treat the items as forming a single scale on all three measurement points: Cronbach's alpha ranged from .86 to .88, the mean item-total correlation of the 13 items ranged from .54 to .57, and all items had factor loadings of >.41 in a one factor solution. Therefore a mean avoidance score was calculated by summing item scores and dividing them by the number of items answered.

Outcome Measures

The four outcome variables were also measured at all three points in time.

<u>Grief reactions</u> were measured using 9 items that were formulated on the basis of the criteria for complicated grief proposed for DSM-V (Prigerson, Vanderwerker, & Maciejewski, 2008). It has been shown that these 9 items constitute a concise way of

measuring complicated grief (H. Prigerson, personal communication, March 10, 2006). Examples of items are "I have felt that moving on with my life (for example, making new friends, pursuing new interests) is difficult for me" and "I have felt emotionally numb (e.g. detached from others)". Items were rated with respect to the past week on a 5-point scale ranging from never (= 1) to all of the time (= 5). Cronbach's alpha ranged from .86 to .91, and test-retest reliability was .66 to .80.

<u>Depressive symptoms</u> were assessed using the Center for Epidemiological Studies-Depression Scale (CES-D; Radloff, 1977). In this study, Cronbach's alpha ranged from .90 to .94, and test-retest reliability was .60 to .76.

<u>Positive mood</u> were measured using the corresponding 10 items of the Positive Affect Negative Affect Schedule (PANAS; Watson, Clark, & Tellegen, 1988). In this study, Cronbach's alpha ranged from .91 to .95, and test-retest reliability was .56 to .71.

Emotional loneliness was measured using the following two items: (1) I feel lonely even if I am with other people, and (2) I often feel lonely (W. Stroebe, Stroebe, Abakoumkin, & Schut, 1997). Participants indicated their (dis)agreement with these statements on a 7-point scale ranging from totally disagree (=1) to totally agree (=7). Cronbach's alpha ranged from .80 to .87, and test-retest reliability was .50 to .62.

Analyses

A multilevel modelling strategy was adopted for this study. Longitudinal data can be viewed as multilevel data, with repeated measurements nested within individuals. In this study this leads to a two-level model, with the series of repeated measures at the lowest (1st) level, and the participants at the highest (2nd) level. Amongst other advantages, a multilevel approach allows us to add time-varying predictors to our models. Furthermore, it does not assume equal numbers of observations, which means that all cases can remain in the analyses, thereby increasing the precision of the estimates and the power of the statistical tests (Hox, 2002). Finally, with regard to dropout, Little (as cited in Hox, 2002) has shown that when the panel attrition follows a pattern defined as missing-at-random, multilevel analysis leads to unbiased estimates. Multilevel modelling was implemented through SPSS Mixed Models Version 16.02.

RESULTS

Developing and Testing the Mediation Model

First, correlations were calculated between the risk factors, mediators and outcome measures. These analyses showed moderate to high correlations between the three mediator variables (the lowest being .24 between rumination and deliberate grief avoidance and the highest being .51 between rumination and threatening grief interpretations). Given the significant overlap between the mediator variables, it was decided to examine all mediators simultaneously. Because the impact of the risk factors that we identified does not change over time, we did not control for measurement (mediators or outcome) at Time 1. Based on the recommendations of MacKinnon (2008) a series of multiple regression analyses was used to test the proposed model in which rumination, deliberate grief avoidance and threatening grief interpretations are hypothesized to mediate between the risk factors on the one hand and grief, depressive symptoms, emotional loneliness and positive mood on the other hand. A set of five multiple regressions was performed for each outcome measure (see Figures 1 and 2 for the corresponding models):

$$Y = i_{1} + c_{1} X_{1} \dots c_{i} X_{i} + e_{i}$$
 (1)

$$M_{1} = i_{2} + a_{1_{1}} X_{1} \dots a_{i_{1}} X_{i} + e_{2}$$
 (2)

$$M_{2} = i_{3} + a_{12} X_{1} \dots a_{i2} X_{i} + e_{3}$$
 (3)

$$M_{3} = i_{4} + a_{1_{3}} X_{1} \dots a_{i_{3}} X_{i} + e_{4}$$
 (4)

$$Y = i_5 + c'_1 X_1 \dots c'_i X_i + b_1 M_1 + b_2 M_2 + b_3 M_3 + e_5$$
 (5)

First, regressions 2 to 4 were conducted to determine whether there were any predictors that were associated with none of the mediators. If so, regressions 2 to 4 were rerun without these predictors and these predictors were left out of regression 1 and 5. For example, while conducting regressions 2 to 4 using the grief predictors, it turned out that financial deterioration was not associated with any of the mediators. Therefore, financial deterioration was left out of all regressions (regressions 2 to 4 were rerun without financial situation deterioration).

Figure 1

Path diagram for the regression model

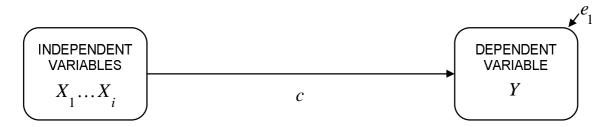
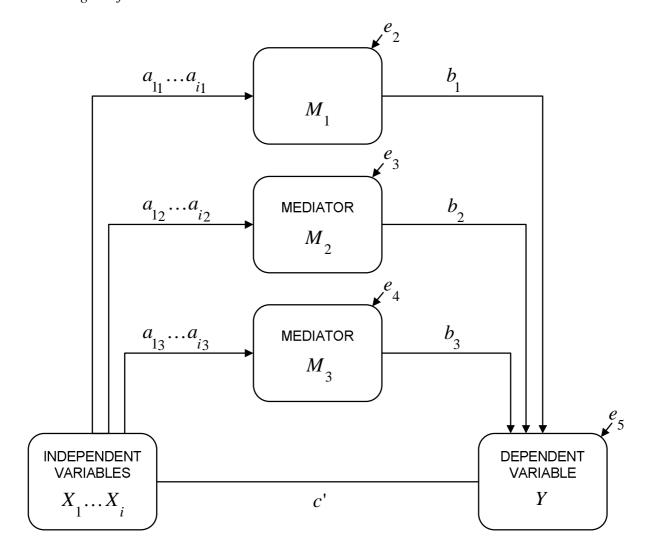


Figure 2

Path diagram for the mediation model



For each combination of predictor variables and mediators, the mediated effect was estimated and then tested for significance using the Sobel test (1982, in MacKinnon, 2008). The proportion of explained mediation was calculated following recommendations by MacKinnon (2008).

The Meditational Properties of Rumination, Threatening Grief Interpretations and Deliberate Grief Avoidance

The outcomes of the regression analyses are presented in Tables 3 through 6. As can be seen in these tables, most of the risk factors were mediated by rumination and many of them also reached their effect via threatening grief interpretations. Interestingly, deliberate grief avoidance did not mediate any of the risk factors.

Our results show that women ruminate more then men, which causes them to have higher levels of grief and lower levels of positive mood. Grief is also increased for women because they assign more threatening interpretations to their grief then men. Unexpected deaths result in more grief and depressive symptoms, because people tend to ruminate more and assign more threatening interpretations to their grief when they have experienced an unexpected versus an expected death. When people experience more support they tend to have lower levels of grief and depressive symptoms and higher levels of positive mood. Our data show that this is partly the case because people who experience more social support ruminate less than people who experience less social support. Personality factors such as attachment style and neuroticism also reach their effect through rumination and threatening grief interpretations. People high in neuroticism and / or with insecure attachments (i.e. high levels of attachment anxiety and / or attachment avoidance) ruminate more and assign more threatening interpretations to their grief, which in turn negatively impacts on their mental health.

Table 3

The mediation model for grief¹

Risk factors			Mediators					
					Threatening grief in	nterpretations	Deliberate grief avoidance	
			(b = 0.376, s.e. = 0.043)		(b = 0.633, s.e. = 0.105)		(b = 0.519, s.e. = 0.364)	
	c (s.e.)	c'(s.e.)	a (s.e.)	explained	a (s.e.)	explained	a (s.e.)	explained
				mediation		mediation		mediation
Gender	5.863 (1.702)	3.474 (1.306)	3.692 (1.506)	24%	1.412 (0.633)	15%	0.226 (0.199)	-
Attachment avoidance	0.073 (0.017)	0.027 (0.015)	0.057 (0.016)	29%	0.043 (0.007)	37%	0.009 (0.002)	-
Neuroticism	0.177 (0.071)	0.041 (0.055)	0.231 (0.063)	49%	0.068 (0.026)	24%	0.005 (0.008)	-
Social support	1.316 (0.342)	0.741 (0.296)	1.046 (0.327)	30%	0.143 (0.136)	-	0.072 (0.036)	-
Expectedness	1.293 (0.324)	0.632 (0.254)	1.096 (0.288)	32%	0.412 (0.121)	20%	-0.004 (0.038)	-

¹ Financial situation deterioration was not mediated by any of the processes that were investigated and was therefore not included in the model.

Table 4

The mediation model for depressive symptoms¹

Risk factors	Mediators							
			Rumination $(b = 0.506, s.e. = 0.068)$		Threatening grie	f interpretations	Deliberate grief avoidance	
					(b = 0.741, s.e. = 0.167)		(b = 0.497, s.e. = 0.580)	
	c (s.e.)	c'(s.e.)	a (s.e.)	explained	a (s.e.)	explained	a (s.e.)	explained
				mediation		mediation		mediation
Attachment avoidance	0.128 (0.025)	0.066 (0.024)	0.057 (0.016)	22%	0.043 (0.007)	25%	0.009 (0.002)	-
Neuroticism	0.392 (0.102)	0.203 (0.087)	0.252 (0.063)	33%	0.076 (0.027)	14%	0.006 (0.008)	-
Social support	2.246 (0.520)	1.583 (0.470)	1.034 (0.329)	23%	0.136 (0.137)	-	0.071 (0.036)	-
Expectedness	1.366 (0.469)	0.504 (0.403)	1.113 (0.292)	41%	0.417 (0.123)	23%	-0.003 (0.038)	-

Adequacy of financial situation was not mediated by any of the processes that were investigated and was therefore not included in the model.

Table 5

The mediation model for emotional loneliness¹

Risk factors	Mediators							
			Rumination		Threatening grief interpretations		Deliberate grief avoidance	
			(b = 0.109, s.e. = 0.024)		(b = 0.151, s.e. = 0.060)		(b = -0.171, s.e. = 0.203)	
	c (s.e.)	c'(s.e.)	a (s.e.)	explained	a (s.e.)	explained	a (s.e.)	explained
				mediation		mediation		mediation
Attachment anxiety	0.038 (0.008)	0.028 (0.008)	0.076 (0.015)	22%	0.023 (0.006)	9%	0.004 (0.002)	-
Attachment avoidance	0.038 (0.008)	0.026 (0.008)	0.065 (0.016)	19%	0.041 (0.007)	16%	0.009 (0.002)	-
Kinship $(0 = partner)$								
Parent	-1.625 (0.549)	-1.499 (0.508)	-0.147 (1.167)	-	-0.644 (0.490)	-	0.061 (0.146)	-
Child	-1.836 (0.463)	-2.269 (0.433)	3.381 (0.987)	suppression	0.315 (0.415)	-	-0.064 (0.124)	-
Sibling	-0.479 (0.826)	-0.938 (0.766)	3.135 (1.748)	-	0.723 (0.735)	-	0.107 (0.218)	-

¹ Financial situation deterioration was not mediated by any of the processes that were investigated and was therefore not included in the model.

Table 6

The mediation model for positive mood¹

Risk factors			Mediators						
		Rumination		Threatening grief interpretations		Deliberate grief avoidance			
			(b = -0.250, s.e. = 0.056)		(b = -0.310, s.e. = 0.137)		(b = -0.750, s.e. = 0.480)		
	c (s.e.)	c'(s.e.)	a (s.e.)	explained	a (s.e.)	explained	a (s.e.)	explained	
				mediation		mediation		mediation	
Gender	-3.589 (1.811)	-2.023 (1.751)	3.822 (1.556)	27%	1.458 (0.653)	-	0.226 (0.199)	-	
Attachment avoidance	-0.133 (0.019)	-0.099 (0.020)	0.054 (0.016)	10%	0.042 (0.007)	10%	0.009 (0.002)	-	
Neuroticism	-0.277 (0.076)	-0.187 (0.074)	0.253 (0.065)	23%	0.076 (0.027)	-	0.005 (0.008)	-	
Social support	-1.228 (0.400)	-0.900 (0.387)	0.977 (0.331)	20%	0.111 (0.138)	-	0.072 (0.036)	-	

¹ Spirituality was not mediated by any of the processes that were investigated and was therefore not included in the model.

A number of risk factors were not mediated by any of the processes that were investigated, namely financial situation deterioration, adequacy of the current financial situation, the relationship to the deceased person, and spirituality.²

Rumination turned out to be a somewhat stronger mediator than threatening grief interpretations: the effects of social support on grief and depressive symptoms, and the effects of gender, neuroticism, and social support on positive mood were mediated by rumination, but not by threatening grief interpretations. Moreover, rumination explained a larger proportion of the mediational path, except in the case of attachment avoidance.

The magnitude of the contribution of rumination and threatening grief interpretations was highly dependent on the risk factor and the outcome measure examined. Together, these processes played a moderate to large role in explaining the relationship between grief and depressive symptoms and their respective risk factors. However, threatening grief interpretations especially, but also rumination, played a lesser part in clarifying the pathways between emotional loneliness and positive mood and their associated risk factors.

DISCUSSION

Research examining how risk factors become associated with complications in bereavement is important for both theoretical and practical reasons. Surprisingly, though, our review of the literature revealed that few investigations had actually provided information on this specific topic. Thus, the aim of the current study was to contribute to scientific understanding of the relationship between risk factors and bereavement outcomes through identification of mediating variables. Data from three measurement points were used to examine whether rumination, threatening grief interpretations and deliberate grief avoidance mediated the general risk factors that had been found to be uniquely associated with grief, depressive symptoms, emotional loneliness and positive mood in a previous study (van der Houwen et al., in press). Findings of the current investigation indicated that both rumination and threatening grief interpretations, but not deliberate grief avoidance, mediated the effect of various risk factors. Rumination appeared to be a somewhat more important mediator than threatening grief interpretations, more often functioning as a mediator and explaining a larger proportion of the mediation. The importance of both processes was dependent on both the risk factor and outcome under examination. Rumination and threatening grief interpretations played a moderate to large role in the prediction of grief and depressive symptoms. However, their contribution (especially that of threatening grief interpretations) to the prediction of emotional loneliness and positive mood was less pronounced. We next review our findings in more detail, describing the results for each of the risk factors examined in turn.

In the current study, the effect of social support on grief, depressive symptoms, and positive mood was shown to be partially mediated by rumination: people with low social support tended to ruminate more, which caused them to have higher levels of grief and depressive symptoms and lower levels of positive mood. Our findings support and extend previous research by Nolen-Hoeksema and colleagues (1994), who demonstrated that rumination mediated the effect of social support on depressive symptoms. In the same study these researchers also showed that female gender reached its effect on depressive symptoms through rumination. Although we did not test this mediational path (because gender had not been found to be uniquely associated with depressive symptoms in our previous study), gender was shown to impact on grief and positive mood partly through rumination: women ruminated more than men, which caused them to have higher levels of grief and lower levels of positive mood.

Gender also had an impact on grief through threatening grief interpretations: women were more likely than men to assign threatening interpretations to their grief, which in turn caused them to have higher levels of grief. However, the same process did not mediate the relationship between gender and positive mood. Indeed, threatening grief interpretations hardly played any role at all in the prediction of positive mood. Also, rumination was implicated to a lesser extent in the prediction of this outcome measure. It would seem that other mediating processes warrant attention in the case of positive mood. We return to this below.

It is interesting to note that the effect of social support on the various outcome measures does not run via threatening grief interpretations. The hallmark of threatening grief interpretations is that people are convinced that they will not be able to handle the very painful emotions that result from the death of their loved one. Social support comprises four types of support, including appraisal (i.e. providing feedback on one's views or behaviour) and emotional support (House, 1981). It could be argued that people who receive more support are more likely to have their beliefs challenged and experience more confidence in confronting their feelings because they do not feel alone in doing so. One would then expect high social support to impact positively on threatening grief interpretations, thus leading to improved mental health. At this point it is unclear why social support has no effect on the degree to which people assign threatening interpretations to their grief reactions.

The effect of the expectedness of the death on grief and depressive symptoms was mediated by both rumination and threatening grief interpretations: people whose loved one had died unexpectedly were more likely to ruminate and assign threatening interpretations to their grief, which caused them to have higher levels of grief and depressive symptoms. Both processes together accounted for 52 to 64 percent of the effect, depending on the outcome measure in question. These numbers are quite high, given the fact that full mediation is very unlikely in social science research (MacKinnon, 2008). It is not surprising though that unexpected deaths give rise to rumination and threatening grief interpretations. Rumination focuses attention, amongst other things, on the causes and consequences of the death. Unexpected deaths would seem more likely to invite this kind of thinking than expected deaths. In a similar vein, it can be argued that unexpected deaths are, on average, more likely than expected deaths to give rise to extreme reactions, which in turn are more likely to be interpreted as threatening.

Turning next to the personality factors investigated in this study: the effects of attachment style and neuroticism were also mediated by both rumination and threatening grief interpretations (except for the relationship between neuroticism and positive mood, which was only mediated by rumination). It is interesting to note that, whereas rumination explained a larger proportion of the mediation for most risk factors, threatening grief interpretations was an equally - and in some instances more - important mediator in the case of attachment avoidance. This makes perfect sense from a theoretical point of view. People who are high in attachment-related avoidance have learned to deal with distress by minimizing attachment-related feelings and behaviour. They would be easily threatened by the strong feelings of separation distress that occur when a loved one dies (Mikulincer & Shaver, 2008).

Contrary to expectations, deliberate grief avoidance did not mediate any of the risk factors when examined simultaneously with rumination and threatening grief interpretations. This is noteworthy, because researchers have claimed that this process plays a central role in the development and maintenance of complicated grief (Boelen, van den Bout, et al., 2006; Shear et al., 2007). Two possible reasons why our findings failed to show this seem plausible: First, most of the persons in this study had low scores on this measure of avoidance, suggesting that they did not consciously avoid reminders of their grief. This is perhaps not surprising, given the way the sample for this study was selected: via online and offline groups that focus on bereaved persons. It seems likely that people who prefer not to be reminded of their bereavement will refrain from joining such groups. The lack of variance in this measure

alone, then, could explain the null findings. Another reason is suggested by Boelen and van den Hout (2008), who found that the detrimental effect of deliberate grief avoidance is particularly pronounced when people have threatening misinterpretations about the consequences of confronting the loss. It is less pronounced when people do not have such misinterpretations.

A few variables were not mediated by any of the processes investigated: financial situation deterioration, inadequate financial means, spirituality, and kinship. With regard to the adequacy of the current financial situation, it seems plausible that a different form of repetitive thinking than rumination may have played a role in mediating its effect on depressive symptoms, namely, worry. Worry typically involves repetitive thinking about future potential threat, imagined catastrophes, uncertainties, and risks (Watkins, 2008). It may very well be the case that people with insufficient financial means worry about their predicament, which in turn increases their level of depressive symptoms. In a similar vein, and following the research by Davis et al. (1998), we would expect spirituality to be related to positive mood via two different processes, also ones that were not investigated in this study: sense making and benefit finding. Whereas other mediating processes than those investigated here are likely to be relevant in the case of current financial situation and spirituality, there may not be any mediating processes involved in the case of financial deterioration and relationship to the deceased. It is possible that the changed financial situation serves as a constant reminder of the absence of the loved person, thereby directly increasing feelings of grief and emotional loneliness. Along the same lines it can be argued that losing one's closest emotional attachment (i.e. one's partner) directly impacts on feelings of emotional loneliness.

In discussing our findings we already mentioned one shortcoming of this study and how it may have affected the results: selecting participants via support groups may have hindered our ability to properly examine the mediating properties of deliberate grief avoidance. Also, one must be cautious in generalizing from these findings to the general population of all bereaved persons, given the fact that participants were (1) self-selected, (2) to a large extent recruited via the Internet, and (3) within the first three years of their bereavement. Selective participation is, however, quite common in bereavement research (M. Stroebe & Stroebe, 1989). It remains critically important to acknowledge and to assess the significance of potential biases associated with selection in all investigations.

Since the impact of the risk factors identified in this study did not change over time, it made no sense to control for measures of outcome and mediating variables at Time 1. Had we

been able to demonstrate (and explain) changes in the outcome measures over time, we could have been more certain about the issue of causality (although it is important to stress that even with longitudinal designs it is impossible to demonstrate true causality, for this experimental studies are necessary). We assume, both on theoretical grounds (e.g. Boelen, van den Bout, et al., 2006; Shear et al., 2007) and previous research - in which Nolen-Hoeksema and colleagues (1994) demonstrated that rumination mediated the effect of social support on *change* in depressive symptoms - that reducing rumination and threatening grief interpretations would reduce grief, depressive symptoms, and emotional loneliness and increase positive mood. However, empirically, we cannot exclude the possibility that we are dealing with parallel processes or even that the coping processes we investigated are a consequence of the outcome measures.

Future research should focus on replicating and further extending our findings. Whereas the processes we investigated played an important role in mediating the effects on grief and depressive symptoms, they had smaller contributions to the prediction of emotional loneliness and positive mood. Moreover, even when both processes accounted for a reasonably high percentage of the effect of the risk factor on the outcome, room remained for other processes. Earlier, we identified a number of promising possibilities: worry, sense making, and benefit finding. Another process that may be of interest is continuing bonds. Longitudinal research into the effects of continuing bonds has thus far been scarce and has led to opposing findings (Field, 2008). Investigation of continuing bonds as mediators can possibly serve two purposes: providing insight in how risk factors become associated with outcome measures while at the same time shedding some light on the discrepant results that have been found.

This study shows that threatening grief interpretations and especially rumination play an important mediating role in bereavement outcome. These findings are in line with current theorizing (see Boelen, van den Hout et al., 2006). They also suggest possibilities for intervention. Boelen and colleagues developed and tested a therapy that focuses, among other things, on changing negative cognitions, such as threatening grief interpretations. Their therapy compared favourable to supportive counselling in a sample of bereaved persons with clinically significant levels of complicated grief (Boelen, de Keijser, van den Hout, & van den Bout, 2007). While we know of no grief therapies that specifically focus on ruminative coping, we do know that techniques exist, such as mindfulness meditation, that can be successfully applied to reduce rumination (Jain et al., 2007) and that could be incorporated in traditional grief therapy.

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NOTES

¹ See Appendix IV.

² With regard to the risk factor "kinship", we found something that has been called inconsistent mediation or suppression. This refers to the situation when the addition of a mediator (in this case rumination) results in a stronger instead of a weaker relationship between the predictor and the outcome measure. An inspection of the correlations between variables involved clarified this. The loss of a partner was associated with less rumination, but with more emotional loneliness than the loss of a child. Rumination and emotional loneliness, on the other hand, were positively correlated. Controlling for rumination would therefore increase the association between partner loss and emotional loneliness.

Chapter 5

The efficacy of a brief Internet intervention for the bereaved

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ABSTRACT

Research so far has shown little evidence that written disclosure facilitates recovery from bereavement. There are good reasons to assume that written disclosure may only benefit those bereaved who are at risk for developing problems or who are experiencing significant psychological problems as a result of their loss, and only when appropriate writing instructions are used. Drawing on previous work in the area of posttraumatic stress, a writing intervention was designed to test these assumptions. Bereaved individuals were randomly assigned to the intervention condition (n=460) or a waiting list control condition (n=297). Both groups filled in questionnaires online at baseline, and 3 and 6 months later. The intervention was administered via e-mail immediately after baseline measurement. Results showed that writing decreased feelings of emotional loneliness and increased positive mood, in part through its effect on rumination. However, writing did not affect grief or depressive symptoms. Contrary to expectations, effects did not depend on participants' risk profile or baseline distress level. Implications of these findings are discussed.

Writing has been used as a coping tool by bereaved people through the centuries. On the one hand, this has been undertaken spontaneously by bereaved people, as illustrated in Rosenblatt's (1983) compilation of 19th century diaries, which explores the content of diaries written by people dealing with bereavement or separation. On the other hand, writing has taken place on the instruction of a professional as part of grief therapy (de Keijser, Boelen, & van den Bout, 1998). Systematic research into the effectiveness of writing for the bereaved has only recently begun, and has been greatly influenced by the work of Pennebaker and colleagues. In this article, we first discuss this influential work, from which two principal lines of research into the efficacy of writing as a bereavement intervention have evolved. The first of these focuses on interventions open to all bereaved, the second on those for persons experiencing complications in their grief. Findings from both lines of research are discussed. Against this background, we present the design for a randomized controlled trial to test the efficacy of a newly developed writing intervention specifically for bereaved people. This integrates elements from both lines of research, and addresses the main weaknesses of previous studies. It also explores processes that are postulated to underlie the effectiveness of this intervention.

The Traditional Pennebaker Paradigm

In 1986 Pennebaker and Beall published a seminal paper reporting an investigation in which they asked individuals to write about their thoughts and feelings concerning a traumatic event for 15 minutes a day over four consecutive days. The results showed improved health over subsequent months when compared with control participants who wrote about superficial topics. This impressive finding led to an expansion of studies using the expressive writing paradigm. These were undertaken with a wide range of participants, using different instructions, settings, outcome measures, and theoretical frameworks (Smyth & Pennebaker, 2008). In a recent meta-analysis bringing together this body of research, Frattaroli (2006) concluded that experimental disclosure is beneficial for one's psychological health, physical health, and overall functioning, but that its average effect size is small.

Use of the Pennebaker Paradigm in Bereavement

Researchers soon recognized the potential of this technique for bereaved people. However, studies that have induced disclosure in bereaved individuals via the traditional Pennebaker paradigm, using a randomised control group design, have generally failed to confirm the disclosure effect (Bower, Kemeny, Taylor, & Fahey, 2003; Kovac & Range, 2000; O'Connor, Allen, & Kaszniak, 2005; O'Connor, Nikoletti, Kristjanson, Loh, & Willcock, 2003; Segal, Bogaards, Becker, & Chatman, 1999; M. Stroebe, Stroebe, Schut, Zech, & van den Bout, 2002; Range, Kovac, Marion, 2000; for a review see M. Stroebe et al., 2002). These investigations have included different samples (e.g. students bereaved by suicide, men and women whose partner had died) and have addressed both psychological and health outcomes. Moreover, all studies have used multiple outcomes, thus increasing the likelihood that a positive result would be obtained. Only in one study was a small improvement in self-reported hopelessness observed (Segal et al., 1999), while in one other (Kovac & Range, 2000), improvement was observed using a measure specific to grief following a suicide (but no effect was found on general grief).

Structured Writing for Treating Complications in Bereavement

Another group of researchers appeared to have more success using writing assignments with bereaved individuals. Lange and colleagues were the first to develop and evaluate a treatment for PTSD and complicated grief, in which the central therapeutic procedure also involved writing assignments (Lange, Rietdijk, Hudcovicova, van de Ven, Schrieken, & Emmelkamp, 2003). This treatment - Interapy - was conducted online and consisted of psycho-education, ten 45-minute writing sessions, and personalized feedback. The writing assignments were based on established therapies for posttraumatic stress disorder and research into the effectiveness of social sharing, and consisted of three phases: imaginary exposure, cognitive reappraisal, and social sharing.

Findings from a randomized controlled trial showed that participants in the treatment condition improved more than participants in the waiting-list control condition on traumarelated symptoms and general psychopathology (Lange et al., 2003). However, both persons with PTSD and complicated grief were included and results were provided for the entire group and not for the two groups separately. Thus, one cannot be sure that Interapy was effective for bereaved individuals per se.

Building on the work of Lange et al. (2003), Wagner and colleagues designed and tested an Internet-based cognitive-behavioural therapy program for bereaved people suffering from complicated grief (Wagner, Knaevelsrud, & Maercker, 2006, 2007). The first phase of their intervention was similar to the one used by Lange et al. (2003). The cognitive

restructuring and social sharing phases, on the other hand, focused on rather different elements that are more suitable to the bereavement situation. Findings from a randomized controlled trial showed that participants receiving the new treatment improved significantly immediately after treatment relative to participants in the waiting list control condition on symptoms of intrusion, avoidance, and general psychopathology as well as on post-traumatic growth (Wagner et al., 2006, 2007). Unfortunately, no long-term effects were investigated. Also, Wagner et al. did not use a grief-specific outcome measure, but instead relied on a trauma-specific measure that may not have been appropriate for all types of bereavement. Thus, the impact of this type of intervention on grief remains unknown. Notwithstanding these limitations, the research of Wagner et al. suggests that structured writing assignments can help improve bereaved individuals' mental health, at least in the short term.

Toward Explanation of the Differences in Findings

So how is it that the two lines of research described above could lead to apparently conflicting conclusions? Four major features distinguish them from each other, each of which could contribute to the discrepancy: (1) the targeted population (unselected bereaved versus bereaved experiencing significant difficulties in coping with their loss); (2) the (non)employment of cognitive-behavioural principles; (3) inclusion of psycho-education and therapeutic feedback; (4) number of essays and duration of writing.

While all four factors could be critical, in our view there are good reasons initially to focus further empirical evaluation on the first two. With regard to the targeted population, we posit that bereaved people in general do not benefit from the disclosure manipulation, because they can talk about their loss naturally, that is, within the context of their daily interactions. Despite the intensity of the emotions it arouses, bereavement is not usually an experience that is out of the ordinary, in the sense that it is a normal human experience for people to die and for their survivors to grieve for them.

The above argument is in agreement with general research on the efficacy of intervention for bereaved people (for a review see Currier, Neimeyer, & Berman, 2008). Interventions that are open to all bereaved people generally fail to produce better outcomes than would be expected by the passage of time. Only in cases of high risk and complicated grief are beneficial effects of intervention to be found. Given these findings, we would expect that only a subsample of bereaved individuals would profit from expressive writing: those who are at high risk for developing problems and those who have already developed

problems. This, then, explains - in part - why Wagner et al. (2006, 2007) who focused on persons suffering from complicated grief, did find effects, whereas studies that used the traditional Pennebaker paradigm and included all bereaved did not.

With regard to the second factor: another important reason why effects were found by Wagner et al. (2006, 2007) could be that more powerful writing instructions, better fitted to the bereavement situation, were used. The instructions were highly specific, clearly indicating what should be the focus of the assignment, whereas the traditional Pennebaker instructions were far less structured, merely indicating a need to write about deepest feelings and thoughts regarding a certain topic. The instructions used by Pennebaker would be more likely to invite ruminative accounts. Nolen-Hoeksema (2001) has consistently found associations between rumination, negative affect and poor adjustment in bereavement, and has identified ruminative coping as detrimental to positive outcomes.

In addition, there are theoretical reasons why an exclusive focus on the loss (as encouraged in the Pennebaker paradigm) might not be beneficial. The Dual-Process Model (DPM; M. Stroebe & Schut, 1999) postulates two coping strategies, loss- and restoration-orientation, attention to both of which is needed for favourable psychological adjustment in bereavement. The protocol by Wagner et al. (2006, 2007) is in line with the DPM, in so far that it emphasizes loss-orientated coping in the first phase, and restoration and integration in phases two and three.

Finally, the writing assignments that Wagner et al. (2006, 2007) developed were heavily influenced by cognitive-behavioural principles. A substantial number of randomized controlled trials and several meta-analyses have demonstrated cognitive-behavioural therapy to be efficacious in the treatment of many mental disorders (for a review, see Leichsenring, Hiller, Weissberg, & Leibing, 2006). Recently it has also been shown to have superior effects in the treatment of complicated grief, compared to interpersonal psychotherapy (Shear, Franck, Houck, & Reynolds, 2005) and supportive counselling (Boelen, de Keijser, van den Hout, & van den Bout, 2007).

Overview of the Current Study

In summary then, we contend that writing can benefit the bereaved, but only those bereaved who are at risk for developing problems and those who are experiencing complications in their grief, and only when appropriate instructions are used that are tailored to the bereavement situation. The aim of this study was to test these assumptions. For this

purpose, we developed and evaluated a writing intervention that draws from both lines of research described earlier. Similar to research that has used the traditional Pennebaker paradigm, this intervention consists of a limited number of assignments and no personalized feedback is provided. The content of the assignments, on the other hand, is heavily influenced by the work done by Lange et al. (2003) and van Emmerik (2005). Should this intervention prove effective, it could offer a cost-effective alternative to the treatment offered by Wagner et al. (2006), because it eliminates the need for trained personnel to provide feedback.

In testing this intervention, a number of methodological improvements were implemented. Grief-specific as well as generic measures of adjustment were included; the immediate as well as the long-term effects of the intervention were investigated; and appropriate analyses to handle attrition were used. Moreover, attention was paid to processes that might mediate the effect of the intervention. Over the years, researchers have attempted to explain the mechanisms underlying the benefits of experimental disclosure (for an overview, see Frattaroli, 2006). However, to our knowledge, no such attempts to establish underlying mechanisms have yet been made in the bereavement area. Given the particular nature of this intervention, which includes exposure and cognitive restructuring as its central components, we identify three potential mediating processes, all of which have been linked to detrimental outcomes in bereavement: deliberate grief avoidance (e.g. Bonanno, Papa, Lalande, Zhang, & Noll, 2005), rumination (e.g. Nolen-Hoeksema, 2001) and threatening grief interpretations (Boelen, van den Bout, & van den Hout, 2006).

We expect the intervention to have a positive effect on the mental health of those bereaved who are at risk for developing problems or who are experiencing significant psychological problems as a result of their loss. Clearly, there may be overlap between these groups (i.e. most people who are at risk will probably be experiencing problems). However, we feel that it is important for conceptual reasons to make this distinction. We also expect the impact of the intervention on mental health to be mediated by its effect on deliberate grief avoidance, rumination, and threatening grief interpretations.

METHOD

Participants

Participants were recruited in two ways: (1) via the Internet, through websites, forums, and e-mail groups that focus on bereaved persons, (2) via organizations and support

groups for the bereaved. Due to the worldwide accessibility of the Internet, participants did not come from a specific area or country. Most of them resided in the USA (66%) or the UK (19%). To be included in the study, people had to meet the following criteria: (1) at least 18 years of age, (2) native English speaker, (3) having experienced the death of a first-degree relative, (4) being significantly distressed by this loss. People who reported that they were suffering from severe depression, schizophrenia, psychotic episodes and / or were seriously considering ending their life were excluded from the study, as were people who suffered their loss at a very early age and people who suffered multiple simultaneous losses. The sample consisted of 757 bereaved individuals, 460 in the intervention and 297 in the control condition. Background and loss characteristics are summarised in Table 1.

No differences between the participants in the control and intervention condition were found on relevant background and loss-related variables or any of the mediator or outcome variables at the first measurement point, suggesting that randomization was successful.

Procedure

The study was IRB-approved. Recruitment took place over a 7-month period, between October 2006 and May 2007. People interested in participating were referred to a website that was created especially for this study, and that provided them with all the necessary information to make an informed decision about participating in the study. People were able to register for the study and give their consent by filling out a form on the website. Upon registering, participants were automatically randomly assigned to the intervention or the control condition. Participants in the control condition were not given any writing assignments, but they were offered the opportunity to participate in the intervention after answering the last set of questionnaires.

Participants were sent e-mails inviting them to fill in questionnaires online at three points in time: immediately, 3 and 6 months after registering for the study. Questionnaires measured background and loss-related variables, and aspects of mental and physical health, personality and coping behaviour. In addition to this, participants assigned to the intervention condition were sent the writing assignments by e-mail after answering the first set of questionnaires. The sending of the assignments was spaced at one-week intervals and was conditional on the completion of previous assignments. Up to two reminder e-mails were sent if participants failed to comply with our requests. See Figure 1 for participant flow and dropout data.

Table 1

Background and Loss Characteristics of the Sample at Baseline (N=757)

Background characteristics	
Gender (N (%))	
Men	49 (6.5%)
Women	708 (93.5%)
Age (in years) (M (SD); minimum - maximum)	43.22 (10.98); 18 - 81
Education (highest level of schooling) (N (%))	
Low	127 (16.8%)
Medium	356 (47.0%)
High	274 (36.2%)
Loss characteristics	
Deceased is (N (%))	
Child	322 (42.5%)
Partner	230 (30.4%)
Parent	126 (16.6%)
Sibling	79 (10.4%)
Cause of death	
Natural causes	498 (65.8%)
Accident / homicide	167 (22.1%)
Suicide	92 (12.2%)
Time from loss (in years) (M (SD))	3.37 (5.24)
< 6 months	180 (23.8%)
>= 6 months and < 12 months	116 (15.3%)
>= 12 months and < 24 months	138 (18.2%)
>= 2 years and < 5 years	168 (22.2%)
>= 5 years or more	155 (20.5%)

As can be seen in Figure 1, of the original 460 persons in the intervention condition and 297 persons in the control condition who completed the baseline measure, 190 and 217 respectively completed the program (i.e. including intervention and/or post-test and follow-up measures). This reflects an attrition rate of 46% (59% in the intervention and 27% in the control condition) over the course of the study, a rate that is even comparable with bereavement studies that have not included an intervention or follow-up over many months (cf. M. Stroebe & Stroebe, 1989). A logistic regression analysis was performed in order to check for differences between completers and non-completers with dropout as the dependent variable and relevant background and loss-related variables, the outcome variables (of the regular analyses), the mediator variables, and condition (control or intervention condition) as

independent variables. According to the Wald criterion, age, education level, grief, and condition reliably predicted dropout: completers were older (χ^2 (1, N=747) = 17.77, p < .001), had higher levels of education (χ^2 (1, N=747) = 10.18, p < .01), experienced less grief (χ^2 (1, N=747) = 8.40, p < .01), and were more likely to be part of the control condition (χ^2 (1, N=747) = 72.11, p < .001) than non-completers.

Measurement Instruments

Background and Loss-Related Variables

At the first measurement point questions were asked about age, gender, education level (measured on a 7-point scale), changes in financial situation due to the loss, current financial situation, level of spirituality, formal relationship to the deceased, cause of death (natural causes / accident or homicide / suicide), level of unexpectedness of the death, and time since death.

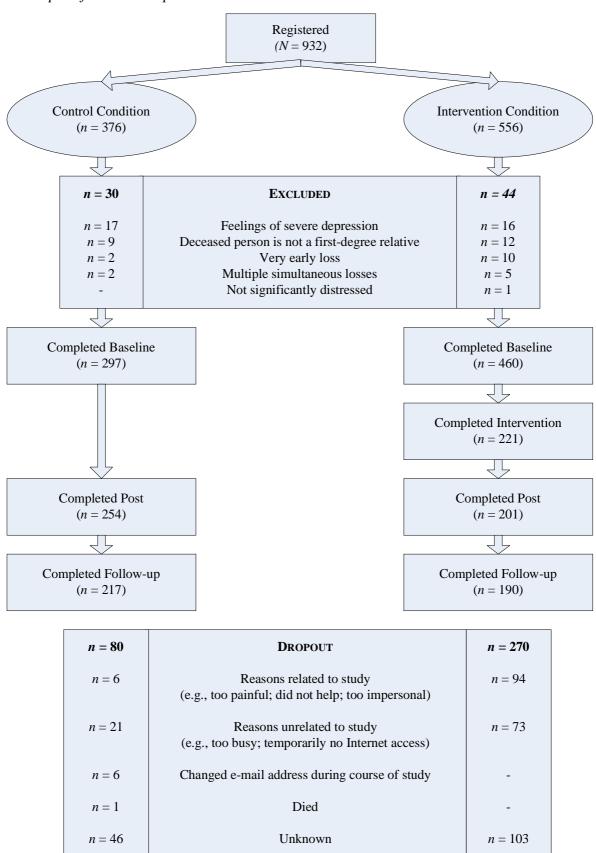
Personality

Attachment organization was measured using the well-validated Experiences in Close Relationships-Revised Questionnaire (ECR-R; Fraley, Waller, & Brennan, 2000). The ECR-R assesses individual differences with respect to attachment-related anxiety and attachment-related avoidance. The ECR-R items were originally worded to be relevant to romantic relationships. Following Fraley's suggestions the word "partner" was therefore replaced by the word "others" to make the items relevant to other kinds of relationships. Participants filled out the ECR-R at all three points in time; however in this article only data from the first measurement point were used. Cronbach's alpha was .93 for both attachment-related anxiety and attachment-related avoidance.

<u>Neuroticism</u> was measured at the first measurement point using the 8-item subscale of the Big Five Inventory (BFI; John & Srivastava, 1999). In this study, Cronbach's alpha was .83.

Figure 1

Participant flow and dropout



Social Support

Social support was assessed at all three measurement points with a four–item scale of perceived social support, comprising the same two items for family members and for friends and relatives (a) "On the whole, how much do your family members (friends and relatives) make you feel loved and cared for?" and (b) "How much are your family members (friends and relatives) willing to listen when you need to talk about your worries or problems?" (W. Stroebe, Zech, Stroebe, & Abakoumkin, 2005). Response categories range from "a great deal" to "not at all", and "not applicable". In this paper only data from the first measurement point were used. Cronbach's alpha was .88.

Mediator Variables

The three mediator variables were measured at all three points in time.

Rumination was measured with a self-constructed 8-item questionnaire that was based on literature on rumination in general (e.g. Nolen-Hoeksema, 1991) and on rumination in bereavement specifically (e.g. Boelen, van den Bout, et al., 2006). An example of an item is: "I think about how bad I feel since my [...] died". The blank was filled in with the appropriate relationship word (e.g. partner). Items were rated with respect to the past week on a 5-point scale ranging from (almost) never (= 1) to (almost) constantly (= 5). Statistical findings indicated that it was justified to treat the items as forming a single scale at all three measurement points: Cronbach's alpha ranged from .86 to .89, the mean item-total correlation of the 8 items ranged from .61 to .67, and all items had factor loadings of >.55 in a one factor solution. Therefore item ratings were summed to form a single score.

Threatening grief interpretations were measured using the two items with the highest factor loadings from the 4-item subscale "Threatening interpretation of grief" of the Grief Cognitions Questionnaire (GCQ; Boelen & Lensvelt-Mulders, 2005): "If I allow my feelings to run loose, I will lose control" and "If I would fully realise what the death of my […] means, I would go crazy". Agreement with the items was rated on a 6-point scale ranging from strongly disagree (1) to strongly agree (6). Cronbach's alpha ranged from .70 to .78.

<u>Deliberate grief avoidance</u> was measured with 13 items that were formulated on the basis of literature on avoidance in grief (e.g. Bonanno et al., 2005). An example of an item is: "I avoid activities I used to do with my [...]". Items were rated with respect to the past week on a 5-point scale ranging from (almost) never (= 1) to (almost) constantly (= 5) or

participants could indicate that the item did not apply to them. Statistical findings indicated that it was justified to treat the items as forming a single scale on all three measurement points: Cronbach's alpha ranged from .86 to .89, the mean item-total correlation of the 13 items ranged from .54 to .60, and all items had factor loadings of >.44 in a one factor solution. Therefore a mean avoidance score was calculated by summing item scores and dividing them by the number of items answered.

Outcome Measures

The four outcome variables were also measured at all three points in time.

<u>Grief reactions</u> were measured using 9 items that were formulated on the basis of the criteria for complicated grief proposed for DSM-V (Prigerson, Vanderwerker, & Maciejewski, 2008). An example of an item is: "I have felt that moving on with my life (for example, making new friends, pursuing new interests) is difficult for me".² It has been shown that these 9 items constitute a concise way of measuring complicated grief (H. Prigerson, personal communication, March 10, 2006). Items were rated with respect to the past week on a 5-point scale ranging from never (= 1) to all of the time (= 5). Cronbach's alpha ranged from .88 to .92.

<u>Depressive symptoms</u> were assessed using the Center for Epidemiological Studies-Depression Scale (CES-D; Radloff, 1977). In this study, Cronbach's alpha ranged from .92 to .94.

<u>Positive mood</u> was measured using the corresponding 10 items of the Positive Affect Negative Affect Schedule (PANAS; Watson, Clark, & Tellegen, 1988). In this study, Cronbach's alpha ranged from .93 to .95.

Emotional loneliness was measured using the following two items: (1) I feel lonely even if I am with other people, and (2) I often feel lonely (W. Stroebe, Stroebe, Abakoumkin, & Schut, 1997). Participants indicated their (dis)agreement with these statements on a 7-point scale ranging from totally disagree (=1) to totally agree (=7). Cronbach's alpha ranged from .80 to .86.

The Intervention

Five structured confrontational writing assignments and some general guidelines for writing were developed based on (1) research into the effectiveness of the Pennebaker

paradigm (e.g. King, 2001), (2) research into the effectiveness of structured confrontational writing (e.g. van Emmerik, 2005), (3) basic cognitive-behavioural principles, and (4) up-to-date bereavement research (e.g. Boelen, van den Bout, et al., 2006). The general guidelines for writing included information about what was expected of participants in terms of time investment and deadlines, but also contained advice, for example about when to write and urged them not to worry about grammar, spelling, or writing style.

The five assignments followed the three phases outlined by Lange et al. (2003): exposure, cognitive reappraisal, and integration and restoration. In the first two assignments (exposure phase) participants were asked to focus on the most distressing aspects of the loss, in relation to the loss event (in the first assignment) and with regard to their current situation (in the second assignment), and to describe these aspects in as much detail as possible. In the second part of the second assignment participants were asked to describe matters that were going reasonably well given the circumstances. This was done to help counter the negative increase in mood that accompanies describing distressing events. Moreover, evidence has been found that disclosing positive events is as equally beneficial as disclosing negative events (Frattaroli, 2006). The third and fourth assignments constituted the cognitive reappraisal phase. In the third assignment information was given about the detrimental effects of dysfunctional grief cognitions using examples and a short vignette. Participants were then asked to identify any unhelpful and helpful thoughts they might be having with respect to their loss, to describe how these thoughts made them feel, and to write down helpful thoughts that might replace the unhelpful thoughts. The fourth assignment asked participants to write a letter of advice to a (hypothetical or real) friend who recently suffered a similar loss and now faces the same difficulties. The letter should, among other things, incorporate lessons learned from the previous three assignments, and challenge negative thinking. In the last assignment (integration and restoration phase) participants were asked to write a letter to the deceased from a future perspective detailing how they overcame obstacles and succeeded at accomplishing their goals. Participants were also encouraged to address the meaning (if any) of their loss and any lessons they might have learned. It has been reported that writing about one's "best possible self" has health benefits, possibly because it influences self-regulatory processes (e.g. King, 2001; for a review see Frattaroli, 2006). Moreover, a lack of future orientation has been associated with the development and maintenance of complicated grief (Boelen, van den Hout, & van den Bout, 2006).

Analyses

A multilevel modelling strategy was adopted for this study. Longitudinal data can be viewed as multilevel data, with repeated measurements nested within individuals. In this study this leads to a two-level model, with the series of repeated measures at the lowest (1st) level, and the participants at the highest (2nd) level. Important advantages of this approach are, first, that it does not assume equal numbers of observations, which means that all cases can remain in the analyses, thereby increasing the precision of the estimates and the power of the statistical tests (Hox, 2002). Second, with regard to dropout, Little (as cited in Hox, 2002) has shown that when the panel attrition follows a pattern defined as missing-at-random, multilevel analysis leads to unbiased estimates. Multilevel modelling was implemented through MLWiN, Version 2.0.

RESULTS

The Effectiveness of the Intervention

To test the effectiveness of the intervention, a model was constructed for each of the outcome measures containing an intercept term, time (i.e. time since registration for the study (in months)) as a linear predictor and time x time as a quadratic predictor. The quadratic predictor was dropped from the model if it turned out to be non-significant. Next, the following predictors were added to the model: age and education level (to control for the effects of dropout), gap (i.e. number of weeks between the completion of the intervention and the second measurement point), dummy-gap⁴, and condition (control or intervention condition). Gap and dummy-gap were dropped from the model if gap turned out to be non-significant. The fit of the resulting model was then compared to the fit of the same model with the time factor made random at the participant level to check whether the regression coefficient for time differed between participants. If entering time as a random effect improved the model, the effectiveness of the intervention was determined by adding condition x time as a predictor to the final model (Intervention model).

Table 2 gives means and standard deviations for the outcome measures. The results of the multilevel analyses investigating the effectiveness of the intervention are presented in Table 3. As can be seen in this table, participants' mental health improved over time: grief, depression and emotional loneliness decreased over the study's 6-month period while

positive mood increased. For grief, depressive symptoms, and positive mood fit was improved by adding a quadratic trend for time: data showed that grief and depressive symptoms decreased more whereas positive mood increased more between the first and second measurement point than between the second and third measurement point. The decrease in grief and depressive symptoms was not dependent on condition (b = -.017, t = -.753, p = .45 resp. b = -.033, t = -.891, p = .37). On the other hand, emotional loneliness and positive mood were influenced by the intervention in a positive way: participants in the intervention condition experienced a stronger decrease in emotional loneliness (b = -.028, t = -2.393, p < .05) and a stronger increase in positive mood (b = .071, t = 2.379, p < .05) than participants in the control condition.

We calculated Cohen's d effect sizes following recommendations by Morris (2008). Short- and long-term effect sizes were 19 and .25 for emotional loneliness and .30 and .23 for positive mood respectively.

Table 2

Mean scores of the outcome measures (SD in parentheses) for the intervention and control condition

	Inte	ervention condit	ion	Control condition			
	Baseline	Post	Follow-up	Baseline	Post	Follow-up	
Grief	26.3 (8.0)	21.5 (8.3)	20.9 (8.9)	26.3 (8.1)	23.5 (8.7)	21.8 (8.7)	
Depressive	25.5 (12.0)	19.7 (12.0)	18.6 (13.1)	25.6 (12.1)	21.8 (12.8)	19.8 (13.4)	
symptoms	23.3 (12.0)	17.7 (12.0)	10.0 (13.1)	23.0 (12.1)	21.0 (12.0)	17.0 (13.1)	
Emotional	9.3 (3.5)	8.3 (3.9)	7.6 (4.0)	9.2 (3.8)	8.9 (3.9)	8.1 (4.0)	
loneliness	9.3 (3.3)	0.5 (5.9)	7.0 (4.0)	9.2 (3.6)	0.9 (3.9)	0.1 (4.0)	
Positive mood	25.8 (8.7)	30.4 (9.4)	30.4 (9.4)	26.2 (8.9)	27.8 (9.9)	29.1 (10.0)	

Risk as Moderator

To test our hypothesis that expressive writing may only benefit those bereaved who are at risk for developing problems, a measure for "being at risk" was created. For this, data were used from a different study that included multivariate analyses to establish which factors uniquely and significantly contributed to the explanation of variance in the outcome measures (for more information, see van der Houwen, Stroebe, Stroebe, Schut, van den Bout, & Wijngaards-de Meij, in press). A regression analysis was conducted for each of the outcome measures with the risk factors that uniquely predicted it as the independent

variables.⁵ The predicted values of the regression analyses were then saved and used as risk scores (resulting in four different risk scores per participant, one for each outcome measure). Finally, a model was constructed for each of the outcome measures by adding the following predictors to the Intervention model: risk (i.e. the appropriate risk score), risk x time, risk x condition, and risk x time x condition.

Contrary to expectations, risk did not moderate the effectiveness of the intervention for grief (b = .013, t = .606, p = .54), depressive symptoms (b = .029, t = .795, p = .43), emotional loneliness (b = .000, t = .002, p = 1.00) or positive mood (b = -.006, t = -.199, p = .84).

Baseline Distress as Moderator

To test our hypothesis that expressive writing may only benefit those bereaved who are experiencing significant psychological problems as a result of their loss, participants were divided into two groups: those who reported significant psychological problems versus those who did not. This was done using two different measures of psychological distress: grief and depressive symptoms. Using a tertile split procedure, two dummy variables were created: one that divided participants in those with high (highest tertile) versus low (lowest tertile) levels of grief at baseline, and one that divided participants in those with high (highest tertile) versus low (lowest tertile) levels of depressive symptoms at baseline.

A model was then constructed for each of the outcome measures by adding the following predictors to the Intervention model: dummy (i.e. low versus high grief or low versus high depressive symptoms), dummy x time, dummy x condition, and dummy x time x condition. Contrary to expectations, baseline grief levels did not moderate the effectiveness of the intervention for grief (b = .021, t = .408, p = .68), depressive symptoms (b = .060, t = .704, p = .48), emotional loneliness (b = .002, t = .061, p = .95) or positive mood (b = .036, t = .512, p = .61). In a similar vein, baseline depressive symptoms levels did not moderate the effectiveness of the intervention for grief (b = .056, t = 1.081, p = .28), depressive symptoms (b = .041, t = -.575, p = .57), emotional loneliness (b = .026, t = .971, t = .33) or positive mood (t = .007, t = .119, t = .91).

Table 3
Intervention Model

	Grie	Grief		Depressive symptoms		Emotional Loneliness		Positive mood	
	В	SE	В	SE	В	SE	В	SE	
Intercept	24.011***	.473	22.651***	.700	8.938***	.197	27.792***	.514	
Time	171***	.016	219***	.027	033***	.008	.119***	.022	
Time x time	.005***	.001	.006**	.002	-	-	005**	.002	
Age	065*	.026	063	.038	009	.012	.024	.028	
Education	791***	.208	599	.307	132	.093	.631**	.225	
Condition	389	.594	671	.870	368	.2611	.815	.634	
Time * condition	017	.022	033	.037	028*	.012	.071*	.030	

Note. Gap (i.e. number of weeks between the completion of the intervention and the second measurement point) was not significantly related to any of the outcome measures and was therefore dropped (together with dummy-gap) from the analyses. Entering time x time as a random effect did not improve the model for grief, depressive symptoms or positive mood. Therefore, time x time x condition was not added as a predictor to the final model.

^{*} *p* < .05. ** *p* < .01. *** *p* < .001.

The mediating Effect of Rumination, Threatening Grief Interpretations, and Deliberate Grief Avoidance

Both Baron and Kenny's approach to mediation (1986) and Sobel's t-test (Sobel, 1982) were used to examine whether the effect of expressive writing on emotional loneliness and positive mood was mediated by rumination, threatening grief interpretations and deliberate grief avoidance. First, we tested whether the intervention impacted the three mediators. These analyses showed that participants in the intervention condition experienced a stronger decrease in rumination than participants in the control condition (b = -.049, t = -2.250, p < .05). We then repeated the analyses that were used to test the effect of the intervention on emotional loneliness and positive mood with rumination included as an extra predictor. Rumination was significantly associated with both emotional loneliness (b = .180, t= 14.818, p < .001) and positive mood (b = -.462, t = -15.718, p < .001) while controlling for the effect of the intervention. Furthermore, adding rumination to the equation resulted in the intervention no longer having a significant effect on emotional loneliness (b = -.019, t = -1.655, p = .10) or positive mood (b = .050, t = 1.734, p = .08). The statistical significance of the mediation effect was confirmed using Sobel's t-test, both for emotional loneliness (t = -2.225, p < .05) and positive mood (t = 2.227, p < .05). Following recommendations by MacKinnon (2008) we calculated that 31% of the effect of the intervention on emotional loneliness and 32% of the effect of the intervention on positive mood was mediated by rumination.

DISCUSSION

Although writing has been used as a coping tool by bereaved persons for a long time (Rosenblatt, 1983), research into its effectiveness has only recently started and has resulted in different findings. In this study, we tested the hypothesis that written disclosure may only benefit those bereaved who are at risk for developing problems or who are experiencing significant psychological problems as a result of their loss, and only when appropriate writing instructions are used. Our findings showed that writing decreased feelings of emotional loneliness and increased positive mood, in part through its effect on rumination. However, writing did not affect grief or depressive symptoms. The effects that we found did not depend on participants' risk profile or baseline distress level.

The fact that we found overall effects of writing on positive mood and emotional loneliness is particularly noteworthy. Effects on positive mood have not been found with the traditional Pennebaker paradigm (O'Connor et al., 2005), which suggests that a more structured intervention, such as the one we designed, is necessary in order to change positive mood. However, since we know of no study that has used the traditional Pennebaker paradigm in bereavement and that has included emotional loneliness as a dependent measure, we cannot be entirely sure that an intervention such as ours would be needed to positively impact on this variable. A similar effect might have been reached with the traditional Pennebaker paradigm.

The effects that we found on emotional loneliness and positive mood though small (.19 to .30), were considerably larger than the average psychological health effect sizes found in studies of intervention disclosure that followed participants for at least a month (i.e. 0.07) (Frattaroli, 2006). Moreover, and importantly, effects were still present at follow-up, which was on average 5 months after participants completed the intervention. This is rare in grief interventions (Currier et al., 2008).

As noted above, whereas we found effects on positive mood and emotional loneliness, our intervention did not lower the level of grief and depressive symptoms. A potential reason for this could be the failure of our intervention to influence avoidance processes: given the nature of the assignments, which we based on cognitive-behavioural principles, we reasoned that the intervention would reach its effect by changing such processes (i.e. deliberate grief avoidance and rumination) and by cognitive restructuring of negative grief interpretations. Even though our intervention had an effect on rumination, deliberate grief avoidance and threatening grief interpretations did not change. It is somewhat surprising that the decrease in rumination did not lead to improvement in grief or depressive symptoms, since our research on mediating processes in bereavement has indicated that rumination plays a role in the prediction of grief and depressive symptoms (van der Houwen, Stroebe, Schut, Stroebe, & van den Bout, 2009). We can only speculate that the impact of the intervention on rumination was too small for an effect to become evident.

We expected writing to be effective for those bereaved who were at risk for developing problems or who were experiencing significant psychological problems as a result of their loss. However, contrary to our expectations, there was no evidence that writing had any effects on grief or depressive symptoms for at-risk or highly distressed participants, or that the effects that were found on emotional loneliness and positive mood for the entire sample were higher for these two groups. Of course, it is possible that our assumptions were

incorrect. However, we feel that this is unlikely given the large amount of evidence that shows that beneficial effects of intervention are only found in cases of high risk and complicated grief (for a review see Currier et al., 2008). Another possible explanation might be related to the fact that the people who entered our study were on average quite distressed. At the beginning of the study participants had an average depression score of 26 on the CES-D that uses a cut-off score of 16 to indicate mild depression and a cut-off score of 27 to indicate major depression (Zich, Attkisson, & Greenfield, 1990). This may have left insufficient room for moderation effects.

Mediation analyses showed that the effects of writing on emotional loneliness and positive mood were partly reached through rumination. Other processes are likely to have played a role as well. It is possible that sharing thoughts, feelings and news with the deceased in the last assignment increased feelings of connectedness to this person thereby reducing feelings of emotional loneliness. With its focus on a best possible future and ways of getting there, assignment five may also have increased feelings of mastery and control, and induced a sense of optimism, resulting in the experience of positive emotions.

A few limitations of this study deserve attention. First, 52% of our participants did not complete all writing assignments. While this is a high percentage it is important to keep in mind that we included data from all participants in our analyses and controlled for variables that predicted dropout, thereby decreasing any bias that may have resulted from it. A number of possible reasons could have contributed to the relatively high dropout. The assignments themselves were emotionally exacting and time consuming, and the fact that participants were comparatively anonymous might mean that they felt fewer obligations to follow through. As a lack of response automatically resulted in their withdrawal, dropping out did not require any action. We do feel, however, that anonymity and ease of withdrawal were very valuable elements of this study, because they did not put any added pressure on persons already going through a difficult time. Also, by design, hardly any psycho-education and no feedback were provided, both of which could have improved motivation and commitment and decreased dropout.

One also has to be cautious in generalizing from these findings to the general population of all bereaved persons, given the fact that participants were self-selected and to a large extent recruited via the Internet. Selective participation is, however, common in bereavement research (M. Stroebe & Stroebe, 1989). It remains critically important to acknowledge and to assess the significance of potential biases associated with selection in all investigations.

In our view this study has contributed to the literature in a number of ways. We followed both intervention and control groups over longer periods of time than has been done in past research. This enabled us to establish whether the intervention had a lasting effect. We broadened the scope by including important outcome variables that have not typically been assessed in grief intervention studies before. We examined processes through which the intervention reached its impact.

Nevertheless, further research is clearly necessary. We feel that a focal line of investigation should explore the provision of feedback on writing, given the fact that studies using writing assignments and including feedback on these *did* find positive effects on trauma-related symptoms and general psychopathology. It would also be informative to further investigate the pathways through which writing impacts on emotional loneliness and positive mood. Earlier we made reference to what might be additional pertinent processes. Insight into these could enable us to improve the assignments, resulting in larger effect sizes.

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NOTES

¹ At the beginning of the study a 1:1 random assignment ratio was used. Because the drop-out rate turned out to be higher in the intervention than in the control condition, this ratio was changed to 2:1 during the course of the recruitment period (after 5 months) so that twice as many participants were assigned to the intervention as to the control condition.

⁴ For participants in the intervention condition who did not complete the intervention and participants in the control condition, data regarding the time between the completion of the intervention and the second measurement point would be missing. Following Cohen and Cohen (1983), and using the missing data dichotomy, a dummy variable was created on which all participants who had missing data on the variable *gap* received a score of 0, while those participants whose data were not missing on this variable were given a score of 1. For the missing scores on *gap*, means from participants who had scores on this variable were substituted.

⁵ Grief was uniquely predicted by (un)expectedness of the death, gender, neuroticism, attachment avoidance, social support, and financial situation deterioration (yes or no); depressive symptoms were uniquely predicted by (un)expectedness of the death, neuroticism, attachment avoidance, social support, medication use (yes or no), and adequacy of financial situation (adequate versus not adequate); emotional loneliness was uniquely predicted by attachment anxiety, attachment avoidance, financial situation deterioration, and kinship; positive mood was uniquely predicted by gender, neuroticism, attachment avoidance, social support, and spirituality.

² See Appendix IV.

³ See Appendix I.

Chapter 6

Discussion

The general aim of our research project was to test ideas about the conditions under which writing, which has been used as a coping tool by bereaved people through the centuries (Rosenblatt, 1983), can help improve bereaved individuals' mental health. To this end a structured writing intervention was developed and subsequently evaluated online among a large sample of bereaved individuals. The resulting dataset not only enabled us to establish the efficacy of the intervention we designed, but also allowed us to investigate a number of important, related aspects: factors that put people at risk for developing complications after bereavement, and processes that mediate between these factors and important outcome measures. Furthermore, because we recruited participants both from mutual bereavement support groups and other sources and measured mental health indicators at multiple time points, we could study the characteristics of people who use this type of support, as well as its effects.

In Box 1 the main results of Chapter 2 to 5 are summarized. In the next section, attention will first be paid to the scientific implications of the results of our research, after which the practical implications will be addressed. This chapter ends with a discussion of the limitations of our study and recommendations for future research.

SCIENTIFIC IMPLICATIONS

Different kinds of scientific implications can be drawn from the research reported in this dissertation. First, the findings have implications for the efficacy of writing as a coping tool in bereavement. They are also of relevance to diverse theoretical perspectives: attachment theory, Weiss' relational theory of loneliness, and Boelen's cognitive-behavioral conceptualization of complicated grief. Finally, there are implications for the measurement of bereavement outcome. I consider each of these in turn in the following parts of this section.

Writing as a Coping Tool in Bereavement

We argued that written disclosure may only benefit those bereaved who are at risk for developing problems or who are experiencing significant psychological problems as a result of their loss, and only when appropriate writing instructions are used (see Chapter 1). Our findings showed that writing decreased feelings of emotional loneliness and increased positive mood for participants in general, partly through decreasing ruminative thinking, but that the size of the effects did not depend on participants' risk or baseline distress level.

Box 1
Summary of the results of Chapter 2 to 5

In Chapter 2 the central questions were (1) who uses online mutual bereavement support, and (2) what is the impact of this type of support on its users? Our findings showed that people who use online mutual bereavement support are younger, more likely to be female and to have lost a child, and less likely to be part of a religious community than bereaved people who have never used this type of support. Using online mutual bereavement support did not predict changes in mental health over time.

In Chapter 3 the impact of a large set of potential risk factors on grief, depressive symptoms, emotional loneliness and positive mood were examined. As expected, risk factors were differentially related to different outcome measures. Grief was uniquely predicted by (un)expectedness of the death, gender, attachment avoidance, neuroticism, social support, and financial situation deterioration; depressive symptoms were uniquely predicted by (un)expectedness of the death, attachment avoidance, neuroticism, social support, medication use, and adequacy of financial situation; emotional loneliness was uniquely predicted by attachment anxiety, attachment avoidance, financial situation deterioration, and type of loss; positive mood was uniquely predicted by gender, attachment avoidance, neuroticism, social support, and spirituality.

In Chapter 4 the aim was to investigate to what extent three potentially critical processes (i.e. rumination, threatening grief interpretations and deliberate grief avoidance) mediated the relationship between the risk factors and outcome measures identified in chapter three. Results showed that both rumination and threatening grief interpretations (but not deliberate grief avoidance) played an important role, but that their contribution was dependent on the specific risk factor and outcome measure under consideration.

In Chapter 5 the efficacy of the intervention we designed was tested. Writing decreased feelings of emotional loneliness and increased positive mood, in part through its effect on rumination. However, writing did not affect grief or depressive symptoms. Our hypotheses - that written disclosure may only benefit those bereaved who are at risk for developing problems or who are experiencing significant psychological problems as a result of their loss – were not confirmed.

One reason for this may be that our sample was quite distressed on average (I will support this claim with some arguments later on, when discussing the limitations of our study), leaving no room for moderation effects.

Effects on positive mood have not been found with the traditional Pennebaker paradigm (O'Connor, Allen, & Kaszniak, 2005), which suggests that a more structured intervention, such as the one we designed, is indeed necessary in order to change positive mood. By contrast, emotional loneliness has not been examined as an outcome measure in studies that have used the traditional Pennebaker paradigm in bereavement, so one cannot be entirely sure that a structured writing intervention such as ours would be needed to positively impact on this variable.

The effects that we found on emotional loneliness and positive mood, though small (.19 to .30), were considerably larger than the average psychological health effect sizes found in studies of intervention disclosure that followed participants for at least a month (i.e. 0.07) (Frattaroli, 2006). Moreover, and importantly, effects were still present at follow-up, which was on average 5 months after participants completed the intervention. This is rare in grief interventions (Currier, Neimeyer, & Berman, 2008).

Contrary to our expectations, no effects of writing were found on grief or depressive symptoms, not even for at-risk or highly distressed participants. We had argued that bereaved people in general would not benefit from the disclosure manipulation, because they can talk about their loss naturally, that is, within the context of their daily interactions. Those who are unable to do so may benefit from writing, we reasoned, but only when assignments are structured, forcing people to face rather than avoid the reality of the death of their loved one. It is possible that in order to really get people to confront painful aspects of their loss, more encouragement and perhaps even tailored feedback is needed than what was offered in our intervention. The following comment, made by one of our participants at the end of the first writing assignment, may illustrate this point: "I'm sorry - I thought that I would write of more than one difficult moment in that horrible time. But I have to stop now [...] I can't bear to think of any more right now". Had we carefully encouraged this and other participants to face these painful facts, grief and depressive symptoms might have been positively affected. One of the reasons that Wagner, Knaevelsrud, and Maercker (2006) did find positive effects on trauma-related symptoms and general psychopathology, may be because such feedback was included in their intervention. The fact that our intervention did not change threatening grief cognitions or deliberate grief avoidance, and only had a small effect on ruminative thinking, also suggests that confrontation did not take place sufficiently.

The question whether our intervention should be offered to bereaved individuals in future will be addressed in the section on practical implications.

Implications for Theoretical Perspectives

Attachment Theory

The results of our research partly confirm - but also challenge - some important assumptions from attachment theory. The association that was found between attachment anxiety and emotional loneliness in Chapter 3 and the fact that this association was partly mediated by ruminative thinking and threatening grief interpretations (as was shown in Chapter 4) is in line with current theorizing in the attachment area. Anxious individuals tend to engage in strategies such as exaggerated appraisals of threats, and rumination about previous threatening experiences that activate the attachment system and lead to proximity-seeking efforts (Mikulincer & Shaver, 2007). In the case of bereavement, proximity cannot be established, which in turn increases the salience of the absence of the deceased person, leading to feelings of emotional loneliness. Surprisingly, though, and in contrast to both attachment theory and previous research (e.g. Wayment & Vierthaler, 2002), attachment anxiety was not associated with grief or depressive symptoms. At this point it is unclear why we failed to find these relationships.

Attachment avoidance turned out to be a strong predictor of grief, depressive symptoms, emotional loneliness, and positive mood. Our results with regard to grief and depressive symptoms contradict most previous studies, that have not found a relationship between attachment avoidance and measures of distress (e.g. Field & Sundin, 2001; Fraley & Bonanno, 2004; Wayment & Vierthaler, 2002). They also challenge a basic assumption of attachment theory, namely that avoidant individuals will not demonstrate increased distress after the death of a loved one. Our findings are, however, in line with recent work done by Wijngaards-de Meij and colleagues among bereaved parents (2007a, 2007b). These researchers explained their findings by referring to the so-called "rebound" effect. This effect occurs when the defences employed by avoidant individuals, that are normally effective in suppressing memories and thoughts concerning separation and loss, break down under highly stressful conditions (Mikulincer & Shaver, 2008). Wijngaards-de Meij et al. argued that this pattern might have occurred in their research, because losing a child can be considered an extremely stressful experience, one which is persistent and very exhausting over time. It

could be argued that in our research as well, we were dealing with a highly distressed sample for whom the effectiveness of avoidant defences was significantly impaired.

Weiss' Relational Theory of Loneliness

Several of our findings lend support to Weiss' relational theory of loneliness (1975). In this theory Weiss draws a fundamental distinction between emotional and social loneliness. Whereas social loneliness results from a lack of social contacts, the loneliness of emotional isolation appears in the absence of a close emotional attachment. Moreover, the two types of loneliness cannot compensate for each other: the loneliness of social isolation can only be helped by access to an engaging social network, while emotional isolation can only be remedied by the integration of another emotional attachment or the reintegration of the one who has been lost. The significant relationship between partner loss and emotional loneliness, that was found in Chapter 3, fits well within this framework (seeing that for most people their romantic partner constitutes their closest emotional attachment), as does the fact that social support does not predict emotional loneliness.

Boelen's Cognitive-Behavioral Conceptualization of Complicated Grief

According to Boelen's model, three processes play a crucial part in the development and maintenance of complicated grief: (1) insufficient integration of the loss into the autobiographical knowledge base, (2) negative global beliefs and misinterpretations of grief reactions, and (3) anxious and depressive avoidance strategies. The model recognizes that background variables influence complicated grief, but posits that this influence is mediated by the model's three core processes (Boelen, van den Hout, & van den Bout, 2006). In Chapter 4 we tested whether, and if so, to what extent threatening grief interpretations (similar to Boelen's misinterpretations of grief), rumination and deliberate grief avoidance (both of which can be considered anxious avoidance strategies) mediated the relationship between the risk factors and outcome measures that had been identified in Chapter 3.

As predicted by the model, both rumination and threatening grief interpretations played an important role in mediating the effects of various risk factors on outcomes. However, no effects were shown for deliberate grief avoidance. One reason for this may be that participants had low scores on deliberate grief avoidance. The resulting lack of variance may have left insufficient room for effects to become evident. Another reason has been

suggested by Boelen and van den Hout (2008), who found that the detrimental effect of deliberate grief avoidance was particularly pronounced when people have threatening misinterpretations about the consequences of confronting the loss. It is less pronounced when people do not have such misinterpretations.

Boelen's theory states that risk factors can only influence complicated grief via the previously mentioned core processes. We did, however, find that financial situation deterioration after the loss (a factor that was shown to be negatively associated with grief in Chapter 3) was not mediated by any of the processes we investigated. It could be that one of the other processes that was postulated by Boelen, such as depressive avoidance, is responsible for this effect. According to Boelen "Depressive avoidance occurs when mourners engage in behavioral patterns of inactivity and withdrawal, and refrain from social, occupational, and recreational activities that could provide positive reinforcement and were important prior to the loss." (Boelen et al., 2006, p. 116). It is possible that a loss of financial resources forces people to withdraw from important and pleasurable activities, which in turn compounds their grief.

Implications for the Measurement of Bereavement Outcome

Grief and depressive symptoms have often been used as interchangeable concepts to measure bereavement outcome. However, a number of researchers have convincingly demonstrated that the two can and should be distinguished (e.g. Prigerson et al., 1995; Wijngaards-de Meij et al., 2005). Furthermore, some important outcomes have been notably absent from the literature: emotional loneliness (which research has shown to be potentially critical in the context of bereavement; e.g. M. Stroebe, Stroebe, & Abakoumkin, 2005; W. Stroebe, Stroebe, Abakoumkin, & Schut, 1997) and positive mood (which has been identified as a predictor of long-term bereavement outcome, independent of its concurrent association with depression; e.g. Ong, Bergeman, & Bisconti, 2004). Therefore, all four outcome measures were included in our research.

Results from Chapter 3 supported the notion that "depression" and grief are indeed two different concepts by showing that they are to some extent predicted by different variables (although the differences we found were not as pronounced as in some studies; e.g. Wijngaards-de Meij et al., 2005). Moreover, clear variations were shown between outcome measures in terms of risk factors. For example, being high in anxious attachment and having lost a partner was shown to be related to more intense feelings of emotional loneliness, while

these variables did not predict any of the other outcome variables. Findings from Chapter 4 also showed that the contribution of specific mediating processes was dependent on the outcome measure under consideration. Furthermore, as reported in Chapter 5, the intervention we designed had an impact on some, but not on all outcome measures. By including multiple outcome measures we were able to arrive at a more complete picture of the variables involved in adjustment to be reavement. Clearly, then, to understand the phenomena and manifestations associated with be reavement, we would advocate for continued inclusion of multiple outcome measures.

PRACTICAL IMPLICATIONS

Several recommendations can be made for health professionals from the research described in the empirical chapters. First, I will suggest how our findings can be used for early detection of people at risk for developing complications after bereavement. Then, the consequences of our research for bereavement intervention will be discussed. Our study is also relevant to bereavement researchers who are (planning on) conducting their investigations via the Internet. I will, therefore, end this section with some advice for this group.

Recommendations for Health Professionals

Detection of At-Risk Individuals

In Chapter 3 and 4 a number of characteristics and processes were shown to be associated with increased vulnerability. There are several ways in which these findings can be translated into instruments for detection. One possibility would be to work toward development of a screening questionnaire, based on the risk factors and processes that were identified. Such a tool could then, for instance, be used by counsellors to determine which bereaved individuals would be in need of extra attention. This suggestion fits nicely with an approach currently being explored by Cruse Bereavement Care Scotland (CBCS), the leading charity in Scotland specialising in bereavement. Moving away from offering counselling as a default service, CBCS is now piloting a process of assessing their prospective clients and subsequently matching their services to the needs of each client. It is important to stress that additional research would be necessary before a screening questionnaire that would be based

on our results, can be usefully implemented. Cut-off scores would have to be established, as well as data gathered about how information concerning different factors can best be combined into one single assessment.

Intervention

The main aim of our research project was to test ideas about the conditions under which writing can benefit the bereaved. Although the structured writing assignments that we created were primarily developed and examined (in Chapter 5) with this goal in mind, we, of course, also hoped that they would constitute an effective intervention. I will now first discuss to what extent we succeeded in achieving this secondary goal and what conclusions should be drawn from this for the implementation of our intervention. The research described in Chapter 2 to 4 also offers some leads for intervention. These will be summarized next.

The intervention we designed increased participants' positive mood and lowered their feelings of emotional loneliness, partly through decreasing ruminative thinking. Furthermore, effects lasted up to 5 months after participants completed the intervention. However, as noted above, no effects were found on grief and depressive symptoms, and the effects that were found on positive mood and emotional loneliness were small. It has been argued that the practical importance of an effect depends entirely on its relative costs and benefits (see Frattaroli, 2006), meaning that our intervention could be considered worthwhile as long as the costs involved are low. An important question then becomes what the costs were for the participants in our study. First and foremost, no negative effects were found on any of the variables that were investigated, therefore writing did not in any way have a negative influence (in terms of outcome measures) on participants in general (which means that there were no costs in this regard). Nevertheless, participants did spend quite a bit of time writing, so there were obviously costs in terms of time investment. More important still, both the relatively high attrition rate, the explanations that participants who were assigned to the intervention condition gave for dropping out, as well as the comments they made in their questionnaires and e-mails, suggested to us that the costs in terms of emotional distress may have been quite substantial: many participants told us that they had had a hard time finishing the assignments.² Although this was neither unexpected nor – given the subject and nature of the assignments – avoidable, it is uncertain whether the small effects on positive mood and emotional loneliness outweigh the emotional distress that often seems to have accompanied completing our assignments.

Turning now to another potential intervention: the use of online mutual bereavement support. It has been claimed that this type of support is helpful to bereaved individuals (cf. Feigelman, Gorman, Chastain Beal, & Jordan, 2008) and there is anecdotal evidence that its use is being promoted by some grief counselors. Although our results regarding the impact of online mutual bereavement support should be considered preliminary (as we explained in Chapter 2), at this point there appears to be no reason to encourage bereaved people to start using it – positive effects were not evident. On the other hand, as long as people themselves want to access these groups, there is also no evidence that this is harmful or that it should be discouraged.

A different aspect relating to intervention also needs consideration at this point: earlier I described how the risk factors that were identified in Chapter 3 could be used to screen bereaved individuals. Risk factors may also provide targets for intervention. Clearly, interventions can only be aimed at risk factors that easily lend themselves to change. Unfortunately, most of the risk factors that we identified cannot be changed (e.g. gender, type of loss) or might be difficult to change (e.g. neuroticism, attachment style). This does not apply to the mediating processes, rumination and threatening grief interpretations, that were identified in Chapter 4. Both offer good possibilities for intervention, and our findings suggest that changing them should result in improved mental health. I know of at least one therapy study that has focused on changing negative cognitions, such as threatening grief interpretations, in bereaved individuals with favourable results (Boelen, de Keijser, van den Hout, and van den Bout, 2007). Furthermore, techniques exist, such as mindfulness meditation, that can be successfully applied to reduce rumination (Jain et al., 2007) and that could be incorporated in traditional grief therapy.

Recommendations for Bereavement Researchers

Using Online Mutual Support Groups for Recruiting Bereaved Individuals

Online mutual bereavement support groups are often used by bereavement researchers to recruit participants for their studies. This is understandable: recruitment through these groups is easy, cost-effective, and non-invasive (permission must, of course, been obtained from the right authorities). However, people who engage in online mutual bereavement support may be different from their bereaved counterparts who do not seek out this type of help. Although sampling bias need not necessarily constitute a serious threat to the validity of

a study (as explained in Chapter 1), it is important to gain knowledge about who participates in online mutual bereavement support. Because we recruited participants both from online groups and other sources, we were able to compare these groups in terms of background and other characteristics. It turned out that the first group was younger, more likely to be female, to have lost a child, and not be part of a religious community. This means that it would be unwise to recruit participants from online support groups when the study variable of interest is moderated by age, gender, loss of a child or involvement in a religious community, since this would be likely to lead to biased estimates. Also, if one were interested in studying sex differences in bereavement or investigating how men cope with their loss, or how people in general deal with the death of a parent or sibling, it would be best to use another medium of recruitment: women are strongly overrepresented in online support groups, whereas people who have lost a parent or sibling are underrepresented.

The Use of Electronic Questionnaires

As described in Chapter 1, electronic questionnaires were chosen over paper-and-pencil questionnaires for a number of reasons, most of which were of a practical nature: we argued that using online questionnaires would save us time and money, and would allow participants to stay anonymous. The fact that we would be able to personalize the questionnaires - through text inserts and routing - was an added bonus for us. As it turned out, our research may have benefitted considerably from personalizing the questionnaires. First, participants really appreciated the personalized items (i.e. that, for example, the item "I have felt myself longing and yearning for my [...]" read "I have felt myself longing and yearning for my sister" for participants who had lost their sister), many of them told us so. Second, the fact that questionnaires were programmed to only show the relevant questions to each participant made them very simple to navigate: we received a lot of compliments about how easy to understand and well laid out our questionnaires were. Both aspects may very well have contributed to the fact that very few participants dropped out halfway through a questionnaire, even though questionnaires were much longer than is common in online research.³

LIMITATIONS

Absence of Pre-Loss Measures and Non-Bereaved Controls

Very few studies in the bereavement area have gathered information about participants prior to their loss, and our study was no exception. In what ways could this have affected our findings and the conclusions that were drawn from them? First, it is possible that a number of the relationships that were identified in chapter 3 are not unique to be reavement (of course, this point does not apply to associations that include bereavement-specific risk factors and / or grief). We know for a fact that this is the case for relationships involving social support, that has been shown to be a general risk factor, benefitting the bereaved and non-bereaved alike (W. Stroebe, Zech, Stroebe, & Abakoumkin, 2005). However, this point may also apply, for example, to the relationship between spirituality and positive mood or that between attachment style and emotional loneliness. Had pre-loss information on these variables been available, we could have checked whether the relationships that were found post-loss were already present before the loss. Alternatively, more could have been learned about the general vs. bereavement-specific nature of some of the relationships by including a group of non-bereaved controls (it would, though, have extended the study to unmanageable proportions in the time available for this research project). This would have allowed us to examine the same relationships in bereaved and non-bereaved persons. Although this information would have constituted a valuable addition to our data, it is important to remember that the absence of pre-loss measures or control groups does not in any way invalidate our findings.

Second, factors that are assumed to be stable, such as neuroticism, may nevertheless have been influenced by the death of the loved person. This means that relationships that were shown to exist post-loss, may not have been found had pre-loss information about these supposedly stable factors been used. For example, the association between neuroticism and grief may only exist for neuroticism when measured post-loss and not for neuroticism, when assessed before the loss. This should be kept in mind when a screening questionnaire (such as the one that was discussed in the previous section) were to be used with people *prior* to their bereavement, for instance when assessing the risk level of caregivers of terminally-ill patients.

Selection

Participants in our study were self-selected. Many of them were recruited via the Internet, mostly via online mutual bereavement support groups, whereas others came from organizations and support groups for the bereaved. Moreover, all participants had to be significantly distressed by their loss and have Internet access. As a result, our sample was skewed with respect to a number of characteristics (a subject that was already touched upon in Chapter 1). In some cases this may have influenced our findings. I will discuss this in more detail below.

It is highly likely that our participants were suffering from worse mental health than their bereaved counterparts who did not volunteer to participate. Research shows that women (a group that was strongly overrepresented in our study) who are more depressed are more likely to participate in bereavement research (M. Stroebe & Stroebe, 1989). Recruiting participants via (online) support groups and requiring that they be significantly distressed by their loss may have further contributed to this selection. Baseline depression scores, that were fairly high, confirm our view that participants were quite distressed on average. As explained before in the corresponding chapters, it is possible that the impact of some of the predictors that were investigated in Chapter 3 was lessened as a result of this. Participants' high distress level may also have left insufficient room for the moderation effects that we expected to find in Chapter 5.

People who entered our study chose to do so freely. They knew that their participation would require them to think and respond to questions about their loss. This may be the reason that participants had low scores on deliberate grief avoidance, one of the mediators that was investigated in Chapter 4 and 5. After all, people who want to refrain from thinking about their loss (i.e. those who would presumably have high scores on deliberate grief avoidance), will not participate in bereavement research. The resulting lack of variance in this measure may be the reason that no effects were found with regard to deliberate grief avoidance.

Using the Internet and (online) support groups to recruit our participants resulted in a sample that was mostly female, young and highly educated. Neither age nor education level have been shown to be moderators of the experimental disclosure effect (Frattaroli, 2006). So we can be reasonably confident that the effectiveness of the intervention would not have been different for older, less educated bereaved individuals. Effect sizes do tend to be larger when studies have more male participants (Frattaroli, 2006). It has been suggested that men may benefit more from experimental disclosure, because they tend to be less likely than women to

naturally disclose information, as a result of traditional sex roles. However, our intervention did not simply ask participants to write about "their deepest thoughts and feelings". Quite the contrary, the writing assignments we designed were heavily structured and relied on cognitive-behavioural principles. It seems doubtful that men would profit more from this type of structured writing than women. Still, this is an empirical question that deserves study.

Attrition

Of the original 458 persons in the intervention condition and 294 persons in the control condition who completed the baseline measure, 194 and 219 respectively took part in all phases of the study. This reflects a drop-out rate of 45% (54% in the intervention and 26% in the control condition) over a 6-month period, which is substantial, but certainly not uncommon in bereavement research (cf. M. Stroebe & Stroebe, 1989). In order to decrease any bias that may have resulted from attrition, we used full information estimation procedures, including all available data from each participant in our analyses. Furthermore, we examined and subsequently controlled for variables that predicted dropout. However, our approach to handle attrition rests on the assumption that the drop-out in our study did not depend on unobserved data after controlling for measured variables. Although it cannot be categorically stated that this assumption is correct, at this point we have no reason to assume otherwise.

FUTURE DIRECTIONS

Throughout this dissertation recommendations have been made for future studies. Below I will elaborate on those that deserve some extra attention and also offer a few new suggestions. First, I will argue in what directions research on structured writing in bereavement should proceed. Then, some ideas for research on risk factors and mediating processes in bereavement will be presented.

Research on Structured Writing in Bereavement

The structured writing assignments that we developed and evaluated had a positivealbeit small - impact on feelings of emotional loneliness and positive mood, but did not influence the experience of grief or depressive symptoms. As noted earlier, one possibility why no effects on these latter variables were found may be that people really need to be strongly encouraged to confront the reality of their loss, and that our intervention lacked in this respect. Therefore, a focal line of investigation should explore the provision of feedback on writing as well as the form this feedback should take.

Our findings showed that ruminative thinking mediated approximately one-third of the effect of writing on emotional loneliness and positive mood, leaving room for other processes. Insight into these pathways might make it possible to improve the assignments, resulting in larger effect sizes. This is important, because at this point the benefits of our intervention may not outweigh its costs. In Chapter 5 we made reference to what might be pertinent processes: sharing thoughts, feelings and news with the deceased in the last assignment may increase feelings of connectedness to this person, thereby reducing emotional loneliness. With its focus on a best possible future and ways of getting there, assignment five may also increase feelings of mastery and control, and induce a sense of optimism, resulting in the experience of positive emotions. Future research should further explore these and other processes.

As I pointed out earlier in this chapter, men have been shown to benefit more from experimental disclosure than women (Frattaroli, 2006). Although it is doubtful whether this effect of gender also applies to the structured writing assignments that we designed, this question also deserves further study.

Research on Risk Factors and Mediating Processes

Clearly, additional longitudinal studies are necessary to replicate and extend the results that were found in Chapter 3 and 4. Replication is especially important with regard to our finding that attachment anxiety did not significantly predict grief or depressive symptoms, which contradicts both attachment theory and previous research in this area.

The risk factors that were investigated in Chapter 3 explained approximately one-quarter of the variation in the outcome measures, leaving the majority of the variance still unaccounted for. Therefore, investigation needs to be extended to new variables. Thus far, only predictors that in principle apply to all the bereaved were examined, because we did not want to limit ourselves to certain types of bereavement. However, predictors that are only relevant to specific types of bereavement may nevertheless be important (i.e. explain additional variance) in those specific situations. So, future research should include bereavement-specific variables in addition to general predictors.

In Chapter 4 rumination as well as threatening grief interpretations were shown to play an important role in mediating the effects of the risk factors - identified in Chapter 3 - on bereavement outcome. Their contribution, however, was dependent on the specific risk factor and outcome measure under consideration. Moreover, a number of risk factors were not mediated by any of the processes investigated. Both in Chapter 4 and the current chapter suggestions were made for other processes that might (also) play a role in mediating the effects of these and other risk factors: worry, sense making, benefit finding, continuing bonds and depressive avoidance. Investigation into these processes could provide valuable insights as well as new targets for intervention.

Research on risk factors and mediating processes is not just important for theoretical, but for practical reasons as well. Early identification of those who are at risk of suffering lasting health consequences makes it possible to intervene and possibly prevent negative outcomes. However, as I pointed out earlier in this chapter, additional information is needed before screening instruments, that enable identification, can be usefully implemented. In clinical practice, risk profile scores, such as the ones we created and used to test our hypotheses in Chapter 5, are unworkable. Instead, cut-off points are necessary. Family doctors and counsellors have to make "yes or no" decisions: should this bereaved person receive (extra) help or not. Establishing such cut-off points should be of primary concern to bereavement researchers. More important still, the significance of screening rests entirely on the assumption that it is possible to prevent negative outcomes. More research is needed to ascertain that interventions aimed at at-risk persons do indeed show positive results.

Looking back over the scope of this dissertation, it becomes clear that almost all of the major facets associated with bereavement, from risk factors through mediating processes to intervention, have been the subject of detailed investigation. As I have explained in this last chapter, some of the results can be directly translated for the purpose of clinical practice. On the other hand, it has also become evident that, in many cases, the results lead the way toward further research. Hopefully, both of these types of endeavour will ultimately lead to improvements in the lives of bereaved persons.

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NOTES

- ¹ It is important to acknowledge that I adopt an individual perspective when discussing the pros and cons of our intervention. One could argue that a thorough cost-utility analysis should also include the costs and benefits to society at large (for an example of such an approach, see Onrust, Smit, Willemse, van den Bout, & Cuijpers, 2008). Unfortunately, such an analysis is beyond the scope of this dissertation.
- ² It is important to note that many participants also told us how much the writing assignments had made them think about important things and how much they were helped by them.
- ³ The first questionnaire took approximately 45 minutes to complete, the second and third questionnaire about 30 minutes.

Samenvatting

(Summary in Dutch)

Het overlijden van een dierbare is een zeer ingrijpende gebeurtenis, die verstrekkende gevolgen kan hebben voor de fysieke en psychische gesteldheid van de nabestaanden. Hoewel de meeste nabestaanden uiteindelijk in staat zijn om zich aan te passen aan hun veranderde leven, is er ook een niet te verwaarlozen groep die blijvende gezondheidsproblemen ondervindt. Het wekt dan ook geen verbazing dat veel onderzoek zich heeft gericht op het ontwikkelen van rouwinterventies en het bepalen van de effectiviteit daarvan. In dit proefschrift lag de nadruk op een bepaald type interventie, namelijk het gebruik van gestructureerde schrijfopdrachten om nabestaanden te helpen bij het verwerken van hun verlies.

Rouwende mensen maken al heel lang spontaan gebruik van de mogelijkheid om hun gevoelens over hun verlies op papier te zetten. Ook therapeuten maken regelmatig gebruik van schrijfopdrachten als onderdeel van rouwtherapie. Onderzoek naar de *effectiviteit* van schrijven bij rouw is echter relatief nieuw en heeft tot verschillende conclusies geleid.

Sommige onderzoekers hebben nabestaanden gevraagd gedurende een aantal dagen hun diepste gedachten en gevoelens met betrekking tot hun verlies op papier te zetten. Het gedurende enige tijd schrijven over je diepste gedachten en gevoelens met betrekking tot een bepaald onderwerp (het zogenaamde Pennebaker paradigma) leidt bij veel groepen mensen tot positieve resultaten, maar blijkt nauwelijks effect te sorteren bij rouwende mensen.

Andere onderzoekers hebben zich specifiek gericht op nabestaanden die problemen ondervonden bij het verwerken van hun verlies (in tegenstelling tot de onderzoekers genoemd in de vorige paragraaf wiens enige selectiecriterium voor deelname aan onderzoek was dat een familielid of bekende van de deelnemer overleden was). Deze onderzoekers maakten gebruik van gestructureerde schrijfopdrachten, die sterk beïnvloed waren door cognitieve gedragsprincipes en waarin duidelijk werd aangegeven waar over geschreven moest worden. Ook kregen deelnemers in deze onderzoeken niet alleen opdracht de verschillende schrijfopdrachten uit te voeren, maar leverden getrainde therapeuten commentaar op het geschrevene en werd er informatie aan de deelnemers gegeven over hun aandoening. Minimaal een onderzoek heeft overtuigend laten zien dat de mentale gezondheid van de nabestaanden direct na afloop van een dergelijke interventie sterk verbeterd was.

Meerdere factoren kunnen verantwoordelijk zijn geweest voor de verschillende effecten van schrijven die tot nu toe gevonden zijn. Wij veronderstelden dat twee daarvan speciale aandacht verdienen: (1) de populatie waarop het onderzoek zich richt en (2) de aard van de schrijfopdrachten. Meer specifiek veronderstelden we dat nabestaanden kunnen profiteren van schrijven, maar alleen die nabestaanden die wellicht in de toekomst of nu reeds

problemen ondervinden bij het verwerken van hun verlies, en alleen als gedetailleerde schrijfinstructies worden gebruikt die zijn toegesneden op de situatie van rouwende mensen.

In september 2004 werd daarom een grootschalig onderzoeksproject gestart aan de Universiteit Utrecht dat als doel had om bovenstaande hypothesen te toetsen door middel van het evalueren van een nieuw te creëren schrijfinterventie. De interventie die wij ontworpen, werd sterk beïnvloed door eerder werk op het gebied van schrijftherapie en bestond uit vijf verschillende opdrachten. In de eerste opdracht werd aan de deelnemers gevraagd de meest ingrijpende momenten rond het verlies in detail te beschrijven. In de tweede opdracht lag de nadruk op het beschrijven van lastige zaken die zich op dat moment voordeden. Daarnaast werd aan de deelnemers gevraagd om aan te geven wat zij naar hun eigen idee bereikt hadden sinds het overlijden van hun dierbare. De derde opdracht gaf deelnemers eerst informatie over wat verstaan wordt onder functionele en disfunctionele gedachten met betrekking tot verlies en de effecten van zulke gedachten op de emoties die we ervaren. Vervolgens werd hen gevraagd beide typen gedachten en de emoties die deze oproepen bij zichzelf te identificeren en aan te geven hoe disfunctionele gedachten omgezet zouden kunnen worden in functionele gedachten. In de vierde opdracht werd aan de deelnemers gevraagd een adviesbrief te schrijven aan een al dan niet hypothetische vriend of vriendin die een vergelijkbaar verlies had meegemaakt. In de laatste opdracht schreven deelnemers een brief aan de overledene vanuit een toekomstig perspectief (twee jaar later dan de werkelijke datum). In deze brief beschreven zij onder andere hoe het nu met hen ging en ook hoe ze waren omgegaan met problemen die ze in de afgelopen twee jaren waren tegen gekomen.

Alvorens met het onderzoek te beginnen, werd de schrijfinterventie eerst getest bij een kleine groep nabestaanden om na te gaan in hoeverre de verschillende opdrachten begrijpelijk en acceptabel waren voor deze groep. Daarna werd het onderzoek ter goedkeuring voorgelegd aan een medisch-ethische commissie.

Deelnemers voor het onderzoek werden geworven van oktober 2006 tot en met mei 2007 (1) via het Internet, door berichten te plaatsen op websites en forums en in e-mailgroepen die zich specifiek op nabestaanden richten en (2) via organisaties en zelfhulpgroepen voor nabestaanden. Om mee te mogen doen aan het onderzoek moest men minimaal 18 jaar oud zijn, Engels als moedertaal hebben en rouwen om het overlijden van een eerstegraads familielid of partner. Mensen die naar eigen zeggen ernstig depressief of suïcidaal waren of leden aan schizofrenie of psychotische episoden konden niet aan het onderzoek deelnemen. Ook mensen die hun dierbare op zeer jonge leeftijd verloren hadden (en de overledene dus nooit bewust hadden gekend) en mensen die meerdere verliezen

tegelijkertijd geleden hadden, werden uitgesloten van deelname. In totaal gaven 932 nabestaanden aan geïnteresseerd te zijn in deelname aan het onderzoek, waarvan er 556 willekeurig werden toegewezen aan de schrijfgroep en 376 aan de wachtlijstgroep.¹

Onmiddellijk na aanmelding voor het onderzoek en 3 en 6 maanden daarna vulden alle deelnemers een elektronische vragenlijst in, die hen per e-mail werd toegestuurd. In de vragenlijst werd geïnformeerd naar achtergrondkenmerken van de nabestaande (zoals leeftijd en geslacht), kenmerken van het verlies (zoals informatie over wie er overleden was en wanneer en wat de doodsoorzaak was geweest) en werd met behulp van een groot aantal vragen nagegaan hoe het gesteld was met de psychische en fysieke gezondheid van de nabestaande en ook op welke wijze de nabestaande met het verlies omging.

Na het invullen van de eerste vragenlijst kregen deelnemers die waren ingedeeld in de schrijfgroep vijf weken lang elke week per e-mail een schrijfopdracht toegestuurd. Zij werden geacht de opdracht diezelfde week nog uit te voeren en terug te sturen. Deelnemers die waren ingedeeld in de wachtlijstgroep kregen gedurende deze periode geen schrijfopdrachten toegestuurd. Hen werd wel de mogelijkheid geboden om aan het einde van het onderzoek, na het invullen van de derde vragenlijst, de schrijfopdrachten te ontvangen.

Niet alle personen die zich aanmeldden voor deelname aan het onderzoek begonnen uiteindelijk met het invullen van de eerste vragenlijst en van sommige personen bleek tijdens het invullen van de vragenlijst dat zij niet voldeden aan de criteria die wij voor deelname hadden gesteld. Uiteindelijk waren er van 745 nabestaanden gegevens beschikbaar op het eerste meetmoment. Die groep bleek grotendeels uit vrouwen te bestaan (93%) en de gemiddelde leeftijd lag rond de 43 jaar. Men was voor het merendeel woonachtig in de Verenigde Staten (66%) en het Verenigd Koninkrijk (20%). Veel nabestaanden hadden een kind (42%) of partner (31%) verloren, sommigen een ouder (17%) of broer of zus (10%). In de meeste gevallen was er sprake van een natuurlijke doodsoorzaak (66%), soms van een ongeluk of moord (22%) of van zelfdoding (12%). Het verlies had gemiddeld ruim drie jaar geleden plaatsgevonden, bij ruim een derde van de nabestaanden had het verlies het afgelopen jaar plaatsgehad.

Ook tijdens het onderzoek vielen er op verschillende momenten deelnemers uit. Van de 453 nabestaanden in de schrijfgroep, waarvan gegevens beschikbaar waren op het eerste meetmoment, waren er 191 die het gehele project doorliepen (i.e. die de schrijfopdrachten voltooiden en de tweede en derde vragenlijst invulden). In de wachtlijstgroep vielen in totaal 75 personen uit. Uit nadere inspectie van de data bleek dat leeftijd, opleidingsniveau en de mate van rouw bepalend waren voor uitval. Vooral jongere mensen, die lager opgeleid waren

en meer rouwden, verlieten tussentijds het onderzoek. Ook de groep waaraan men was toegewezen bleek van invloed: uitval was aanzienlijk groter in de schrijfgroep dan in de wachtlijstgroep.

Hoewel we primair geïnteresseerd waren in het toetsen van onze hypothesen door middel van het onderzoeken van de effectiviteit van de interventie die wij ontworpen hadden, bood de uitgebreide hoeveelheid gegevens die wij verzameld hadden ook de mogelijkheid om andere belangrijke gerelateerde fenomenen te onderzoeken.

Om te beginnen hebben we in hoofdstuk twee gekeken naar lotgenotenhulp voor nabestaanden via Internet. Hieronder vallen e-mailgroepen, forums en chatrooms, waar nabestaanden elkaar advies en steun geven. Er zijn aanwijzingen dat deze vorm van hulp groeiende is, maar er is nog veel onduidelijkheid over wie er precies gebruik van maken. Het is belangrijk om hier meer over te weten te komen, onder meer omdat rouwonderzoekers deelnemers voor hun studies werven via dit type lotgenotengroepen. Het is evenmin bekend of lotgenotenhulp via Internet nabestaanden daadwerkelijk helpt bij het verwerken van hun verlies: bepaalde karakteristieken van hulp via Internet, zoals de voortdurende beschikbaarheid en anonimiteit, zouden negatieve bijwerkingen kunnen hebben. De twee vragen die daarom centraal stonden in hoofdstuk twee waren (1) wie maken er gebruik van lotgenotenhulp via Internet en (2) met welk resultaat? Bij het beantwoorden van deze vragen maakten we alleen gebruik van de gegevens van de wachtlijstgroep, omdat we niet zeker konden zijn van de invloed die de schrijfinterventie mogelijk had gehad op de gegevens van de schrijfgroep. Vrouwen, jongere mensen, mensen die een kind verloren hadden en zij die geen deel uitmaakten van een religieuze gemeenschap bleken meer geneigd hulp te zoeken bij lotgenoten via Internet. In tegenstelling tot wat soms wel wordt gedacht of beweerd, was deze groep niet vaker woonachtig in afgelegen gebieden (waar andersoortige hulp wellicht minder voorhanden is). Nabestaanden die aangaven gebruik te maken van lotgenotenhulp via Internet bleken zich drie maanden later niet beter of slechter te voelen dan nabestaanden die geen gebruik van dit soort hulp maakten.

Om onze hypothese te kunnen toetsen dat alleen kwetsbare personen (i.e. die nabestaanden die mogelijk problemen zullen ondervinden bij het verwerken van hun verlies) zullen profiteren van gestructureerd schrijven, was informatie nodig om deze groep te kunnen identificeren. Hoewel veel onderzoek erop gericht is geweest risicofactoren in kaart te brengen, heeft geen enkele studie tot nu toe een groot aantal verschillende factoren tegelijk onderzocht. Een andere tekortkoming in eerder onderzoek betreft de selectie van uitkomstmaten. Vaak zijn depressieve symptomen gebruikt als indicator voor

rouwsymptomatologie, terwijl ondertussen bekend is dat depressie en rouw van elkaar te onderscheiden syndromen zijn. Andere belangrijke uitkomstmaten, zoals emotionele eenzaamheid en positieve stemming, zijn nauwelijks onderzocht. In hoofdstuk drie is daarom bekeken welke factoren een unieke bijdrage leveren aan de voorspelling van rouw, depressieve symptomen, emotionele eenzaamheid en positieve stemming. Wederom werd in dit hoofdstuk alleen gebruik gemaakt van gegevens uit de wachtlijstgroep. De volgende factoren bleken geassocieerd met het psychisch niveau van functioneren van de nabestaanden: sekse, gehechtheidsstijl, neuroticisme, spiritualiteit, de relatie tot de overledene, de mate waarin het verlies verwacht was, de financiële teruggang na het verlies, het beschikken over voldoende financiële middelen en sociale steun. Zoals verwacht waren sommige risicofactoren gerelateerd aan bepaalde uitkomstmaten, maar niet aan andere. Zo werd emotionele eenzaamheid, bijvoorbeeld, niet beïnvloed door sociale steun, terwijl deze factor wel bepalend was voor het niveau van rouw, depressieve symptomen en positieve stemming. Aan de andere kant werden de laatstgenoemde uitkomstmaten niet beïnvloed door de relatie tot de overledene, terwijl deze factor wel van invloed was op de ervaring van emotionele eenzaamheid: nabestaanden die hun partner verloren hadden, voelden zich eenzamer dan nabestaanden die een ouder, kind, broer of zus verloren hadden.

De resultaten uit hoofdstuk drie zijn waardevol, omdat ze ons inzicht bieden in factoren die geassocieerd zijn met het niveau van psychisch functioneren van nabestaanden. Ze vertellen ons echter weinig over hoe deze relaties tot stand komen. Waarom leidt een onverwacht overlijden tot meer rouw en depressieve klachten? Welke processen spelen hier een rol bij? Antwoord op dergelijke vragen zijn niet alleen interessant vanuit theoretisch oogpunt, maar kunnen ook aanknopingspunten bieden voor interventie. Voortbouwend op de resultaten uit hoofdstuk drie hebben we in hoofdstuk vier daarom gekeken in hoeverre drie potentieel kritieke processen, rumineren, catastrofale misinterpretaties van de eigen rouwreacties en het vermijden van stimuli die geassocieerd zijn met het verlies, mediëren tussen risicofactoren enerzijds en uitkomstmaten anderzijds. Zowel rumineren als misinterpretaties speelden een belangrijke rol in het mediëren van de effecten van de risicofactoren op de uitkomstmaten. Hun bijdrage bleek echter sterk afhankelijk van de risicofactor en uitkomstmaat in kwestie. Samen verklaarden deze twee processen, bijvoorbeeld, 73% van het effect van neuroticisme op rouw, terwijl het effect van neuroticisme op positieve stemming alleen - en in mindere mate - gemedieerd werd door rumineren. Bij sommige risicofactoren bleek geen van de drie onderzochte processen een rol te spelen.

In hoofdstuk vijf hebben we de effecten van onze schrijfinterventie onderzocht. Zoals al eerder beschreven op pagina 173 en 174 was de uitval van deelnemers, met name in de schrijfgroep, betrekkelijk groot. Om zo optimaal mogelijk met de beschikbare gegevens om te gaan, hebben in we in onze analyses gebruik gemaakt van een techniek die het mogelijk maakt gegevens van alle personen, ook zij die slechts een of twee vragenlijsten hebben ingevuld, op te nemen. Het voordeel hiervan is dat we in staat waren nauwkeuriger uitspraken te doen over het effect van onze interventie, dan anders mogelijk was geweest. Uit deze analyses bleek dat onze interventie een effect had op twee van de vier uitkomstmaten. Deelnemers in de schrijfgroep ervoeren zowel vlak na als enige tijd na het afronden van de interventie meer positieve emoties en minder emotionele eenzaamheid dan deelnemers in de wachtlijstgroep. Deze effecten waren echter niet heel sterk. Additionele analyses wezen uit dat het effect van de schrijfinterventie op positieve stemming en emotionele eenzaamheid deels tot stand kwam doordat schrijven rumineren verminderde wat vervolgens een positief effect had op de ervaring van positieve emoties en emotionele eenzaamheid. Schrijven bleek niet van invloed op het ervaren van gevoelens van rouw of depressie. In tegenstelling tot wat we verwacht hadden, bleek het voor het effect van de interventie niet uit te maken of we te maken hadden met een kwetsbare groep nabestaanden of zelfs met nabestaanden die op dat moment al problemen ondervonden met het verwerken van hun verlies.

De resultaten van het onderzoek beschreven in hoofdstuk twee tot en met vijf hebben verscheidene implicaties. Er is anekdotisch bewijs dat lotgenotenhulp voor nabestaanden via Internet door hulpverleners wordt aangeprezen. Op grond van het onderzoek beschreven in hoofdstuk twee zijn er geen redenen om nabestaanden aan te moedigen gebruik te maken van dit type hulp. Aan de andere kant: als nabestaanden hier tijd en energie in willen stoppen zijn er ook geen aanwijzingen dat dit ontmoedigd moet worden. Rouwonderzoekers kunnen ook lering trekken uit de resultaten gepresenteerd in dit hoofdstuk. Nabestaanden die gebruik maken van lotgenotenhulp via Internet wijken op verschillende punten af van nabestaanden die dit niet doen. Het werven van respondenten voor rouwonderzoek via online lotgenotengroepen kan zo aanleiding geven tot selectieproblemen.

In hoofdstuk drie en vier bleek een aantal karakteristieken en processen geassocieerd te zijn met kwetsbaarheid. Deze kennis zou gebruikt kunnen worden om een detectie-instrument (bijvoorbeeld in de vorm van een vragenlijst) te ontwikkelen dat vervolgens ingezet zou kunnen worden om kwetsbare personen te identificeren. Hoewel de risicofactoren uit hoofdstuk drie zich over het algemeen niet goed lenen voor interventie, geldt dit niet voor de processen die we identificeerden in hoofdstuk vier. Minimaal een therapie heeft zich tot nu

toe succesvol gericht op het veranderen van negatieve cognities, waaronder catastrofale misinterpretaties van rouwreacties, bij nabestaanden. Ook bestaan er technieken die zich richten op het verminderen van rumineren.

De schrijfinterventie die wij construeerden had relatief langdurige en positieve, maar kleine effecten op emotionele eenzaamheid en positieve stemming. Rouw en depressieve symptomen werden niet door onze interventie beïnvloed. Met ongestructureerde schrijfopdrachten zijn niet eerder effecten op positieve stemming gevonden (het effect op emotionele eenzaamheid is niet eerder onderzocht) wat suggereert dat een gestructureerde interventie zoals die wij ontwierpen noodzakelijk is om positieve stemming bij nabestaanden te verbeteren. Ook waren de effecten die wij vonden, hoewel klein, nog altijd groter en langduriger dan de effecten die doorgaans met ongestructureerde schrijfopdrachten gevonden worden.² Opvallend was dat de effecten die wij vonden niet sterker waren bij kwetsbare personen of nabestaanden die al problemen ondervonden bij het verwerken van hun verlies. Een mogelijke verklaring hiervoor is dat de nabestaanden die aan ons onderzoek meedededen al relatief veel psychische klachten hadden, waardoor een goede vergelijking tussen personen met relatief weinig en relatief veel klachten niet meer mogelijk was.

Het is de vraag of het verstandig is om de interventie die wij ontwierpen op dit moment op grote schaal te implementeren. Hoewel er langdurige effecten op een aantal maten werden gevonden, waren deze effecten klein. Bovendien konden er geen effecten aangetoond worden op belangrijke andere maten. Daarnaast bleek uit het commentaar van de deelnemers dat zij het schrijven vaak zwaar hadden gevonden.

Het lijkt belangrijk om nu eerst na te gaan hoe de door ons ontworpen schrijfinterventie zo aangepast kan worden dat rouw en depressieve symptomen in positieve zin beïnvloed worden en dat de effecten op emotionele eenzaamheid en positieve stemming vergroot worden.

VOETNOTEN

¹ Bij aanvang van het onderzoek was de kans om in de schrijfgroep terecht te komen gelijk aan de kans om in de wachtlijstgroep terecht te komen. De uitval in de schrijfgroep bleek echter groter dan de uitval in de wachtlijstgroep. Om die reden werd in de loop van de wervingsperiode (na 5 maanden) de kans om in de schrijfgroep terecht te komen met een factor 2 vergroot.

2 Het gaat dan om psychische effecten van ongestructureerd schrijven die gevonden zijn bij allerhande groepen, niet bij nabestaanden.

Dankwoord

(Acknowledgements)

First and foremost I would like to thank the many participants who were willing to share their personal details and stories with me. The research reported in this thesis would not have been possible without you and I am immensely grateful for your cooperation. I also would like to give thanks to all the people who have helped me recruit participants for my study. Your contribution to my work has been invaluable.

Maggie, Jan, Wolfgang en Henk: dank voor jullie inzet en betrokkenheid. Afspraken met jullie konden altijd snel ingepland worden, mijn stukken werden vlot gelezen en van zinnig commentaar voorzien en op mijn mails werd meestal binnen 24 uur, maar vaker nog, binnen enkele minuten, gereageerd. Kom daar maar eens om bij de meeste begeleiders! Zonder iemand te kort te willen doen, wil ik mijn speciale waardering uitspreken voor de rol die Maggie de afgelopen jaren heeft gespeeld. Maggie, jouw deur stond altijd open en hoe druk je ook was, als ik binnen kwam lopen, maakte je tijd voor me vrij. Je was niet alleen geïnteresseerd in alles wat met mijn (ons) werk te maken had, maar leefde ook intens mee met alle leuke, maar ook verdrietige dingen die zich de afgelopen jaren in mijn persoonlijke leven afspeelden. Soms kun je als aio wel wat extra steun gebruiken, zeker als je te maken hebt met vier begeleiders die allemaal verschillende (en soms volstrekt tegengestelde) ideeën hebben over hoe een inleiding het beste opgebouwd kan worden of hoe de resultaten in een artikel gepresenteerd zouden moeten worden. Op dat soort momenten gingen we samen achter jouw computer zitten en hielp je mij te komen tot een voor iedereen aanvaardbaar compromis. Ik denk niet dat je weet hoezeer je mij daarmee geholpen hebt.

Veruit het grootste deel van mijn aio-tijd heb ik alleen in een kamer achter de computer doorgebracht. Dat voelde soms best wel eenzaam. Ik prijs mezelf dan ook gelukkig met een groot aantal collega's bij wie ik altijd terecht kon voor een kletspraatje, een kop thee en een luisterend oor. Buitengewoon veel dank ben ik verschuldigd aan Denise, Jaap, Joanne, Leoniek, Melanie en Patricia, die telkens weer bereid waren te luisteren naar alles dat mij dwars zat - ook als het om iets ging dat ze al minstens honderd keer hadden gehoord - en die mij altijd weer wisten op te beuren en te motiveren.

Dear Carol, it was really great getting to know you and having you as my roommate during my last few months at work. I am grateful for all the hard work you put into our project and I am sorry for the fact that the results turned out the way they did. I also would like to thank you for your help on the research report for participants. Your extensive experience with bereaved people really helped me translate the scientific findings into a readable piece of text. The many compliments we received after sending out the report attest to this.

Gedurende mijn promotietraject kreeg ik, zoals zoveel promovendi, met een aantal tegenslagen te maken. Zonder de hulp van Jan Morenc bij alle perikelen rondom de medischethische toetsing van mijn onderzoek en de aansprakelijkheidsverklaring van de Universiteit Utrecht, weet ik niet of het project ooit van start zou zijn gegaan. Tegenwoordig is het binnen het Departement Psychologie beleid om geen verlenging meer aan promovendi te verlenen, zelfs niet in die gevallen waar er aanzienlijke vertraging ontstaan is geheel buiten de schuld van de promovendus om. Ik ben mijn promotor Jan van den Bout daarom zeer erkentelijk voor de inspanningen die hij ongetwijfeld heeft moeten verrichten om mijn contract met een half jaar verlengd te krijgen.

Evelien en Sophia, wat fijn om twee zulke lieve en slimme vriendinnen te hebben! Ik kon en kan altijd bij jullie terecht en ik hoop van harte dat we elkaar blijven zien, spreken en mailen mochten Erik en ik besluiten naar het zuiden des lands te verhuizen. Enne...bedankt voor jullie perfecte timing! Eigenlijk had ik nog wel wat willen afvallen, maar tussen twee hoogzwangere paranimfen vallen die paar extra kilo's van mij echt niet op ©

Oeds en Nine, lieve ouders, met een vader die VVD en een moeder die PSP stemde was er nooit gebrek aan gespreksstof thuis. Ik herinner me de felle discussies tijdens onze uitgebreide zondagochtendontbijten. Even was het stil als we daarna gedrieën Het Capitool (zoals Buitenhof toen nog heette) keken onder het genot van een gebakje, waarna de woordenstrijd weer losbarstte, gevoed door de zojuist besproken onderwerpen op TV. Ik denk niet alleen met veel plezier en genegenheid terug aan die tijd, ik weet ook zeker dat veel van de academische vaardigheden die mij tijdens mijn loopbaan als promovenda zo van pas zijn gekomen hun basis vinden in die zondagen thuis.

Tot slot, Erik, mijn allerliefste, het zijn tropenjaren geweest, voor mij en voor ons. Ik kijk met verlangen uit naar de eerste zaterdag waarop ik zonder promotiekopzorgen samen met jou door Utrecht kan struinen, eindigend in Kafé België met een Chouffe voor onze neus.

Toen ik op 1 september 2004 aan mijn werk als promovenda aan de Universiteit Utrecht begon, leefden mijn beide oma's nog. Oma Detta begreep niet zo goed wat mijn werkzaamheden nu precies inhielden en oma Greet vond het eigenlijk maar raar dat iemand onderzoek naar rouw zou doen, maar beiden waren – ieder op hun eigen wijze - geïnteresseerd en leefden met me mee. Ik vind het ontzettend jammer dat zij dit boekje, met daarin de neerslag van het onderzoek waar we zo vaak over gesproken hebben, nooit zullen zien en lezen en dat zij er op 4 november niet bij zullen zijn. Ik draag dit proefschrift aan hen op.

Curriculum Vitae

Karolijne van der Houwen werd op 30 juli 1972 geboren in Utrecht. Na het behalen van haar diploma aan het Stedelijk Gymnasium te Utrecht, ging zij in 1990 farmacie studeren aan de Universiteit Utrecht. In 1997 begon zij aan een tweede studie, psychologie, aan de Universiteit van Amsterdam. Begin 2001 studeerde zij cum laude af in de sociale psychologie. Vanaf mei 2001 was Karolijne als wetenschappelijk medewerker werkzaam bij Traffic Test, een onderzoeks- en adviesbureau op het gebied van verkeer en vervoer. Van september 2004 tot maart 2009 was zij als assistent in opleiding verbonden aan de afdeling Klinische en Gezondheidspsychologie aan de Universiteit Utrecht. Op dit moment werkt Karolijne als statistisch onderzoeker bij het Centraal Bureau voor de Statistiek in Heerlen.

Appendix I

The intervention

General guidelines for writing

- 1. Please read the writing instructions carefully so you have a clear idea of what is expected of you and why.
- 2. After you have finished reading the writing instructions, we would like you to take some time to reflect on the writing task. You're free to take as much time as you like provided you return the completed writing task on time.
- 3. It is best if you don't write immediately before bedtime.
- 4. When doing the writing task, try to avoid distraction as much as you can. If at all possible, try to write when you're at home alone.
- 5. You are free to write as often and for as long as you like on the writing task, provided you spend at least one session writing for 20 minutes.
- 6. We do not care about grammar, spelling, or writing style and please do not worry about these either. We are interested in your personal story, in what you have to say, not in how you say it.
- 7. More is not necessarily better. As long as you follow the general guidelines any result long or short is fine with us.
- 8. Please return your completed writing task within a week by replying to this email. You can either attach your completed writing task to the e-mail (as a Word document for instance) or simply send the completed writing task as the text of your email.

Assignment 1

We would like you to start by **thinking** back at your loss experience. By this we mean the period between the time you first became aware your [...] might die [or had died] up until and including your [...]'s funeral. Then decide for yourself which **moments or events during this period have been most significant to you and/or difficult to talk or think about.** Try to **write down** these moments or events in as much detail as possible, including such facts as where you were, what happened, how you felt, what you were thinking, sights and sounds etc. **Please note, we do not expect you to write down the whole sequence of events that took place during this period. Try to focus on the most significant moments or events.**

Assignment 2

In the first assignment you were asked to describe difficult moments or events that happened some time ago. This time we would like you to describe your present situation and how things are going for you right now. There are two things we would like you to write about.

First, we would like you to focus on matters you find particularly difficult to deal with or which you even try to avoid. These can be as diverse as, for example, subjects you have a hard time talking or thinking about, objects, places, situations or people you try to avoid, and thoughts, feelings, or memories you try to keep away from. It's important that you not only describe exactly the things that are difficult for you, but also how these things make you feel.

Secondly, we would like you to focus on matters that are going reasonably well given the circumstances, things - big or small - that you feel you have accomplished since your [...] died, any progress you feel you have made since then. Try to name as many of these things as possible.

Assignment 3

In this third writing task we would like you to describe helpful and unhelpful thoughts you might be having with respect to the loss of your [...]. By helpful thoughts we mean thoughts that make it easier for you to deal with your grief. By unhelpful thoughts we mean negative thoughts that make it harder for you to come to terms with your sorrow. Helpful and unhelpful thoughts very often concern the way you think about yourself, your grief, your life, and the future. Below we will provide you with some examples of helpful and unhelpful thoughts by way of illustration.

helpful thought concerning **yourself**: I still have a lot to offer to other people. **unhelpful** thought concerning **yourself**: Since my [...] died, I am no good to anyone.

helpful thought concerning your **grief**: I can handle my grief even though it hurts very much. **unhelpful** thought concerning your **grief**: If I let my emotions go, I will go crazy.

helpful thought concerning your **life**: My life has purpose, even though my [...] has died. **unhelpful** thought concerning your **life**: Since my [...] died, my life is meaningless.

helpful thought concerning the **future**: It might take some time, but I am convinced things will get better.

unhelpful thought concerning the future: In the future I will never be really happy again.

Helpful and unhelpful thoughts pop in and out of our heads automatically and for the most part we are unaware of them. They nevertheless have a big influence on the way we feel and behave, as the following example shows.

Jenny lost her husband Theo five months ago. Jenny thinks she's no good to anyone since Theo died. Therefore, she stays at home, doesn't answer the phone or doorbell, and doesn't respond to invitations. As time goes by most people stop showing an interest in her. As a result Jenny becomes more and more lonely, which only increases her longing for Theo. One day, Jenny gets a call from an old friend, Emma, and they have a long talk. During this talk Emma manages to convince Jenny that even though Theo has died, she still has a lot to offer to other people. The next day Jenny decides to get a job. Through this work she meets new people whom she can talk to and whose company she enjoys. Even though she still misses Theo very much, she is starting to feel satisfied with her new life.

Because unhelpful thoughts can have such a negative impact it's important to become aware of them and try to replace them with more helpful thoughts.

We would like to ask you to try to identify helpful as well as unhelpful thoughts you might be having with respect to the loss of your [...]. Please describe these thoughts, as well as the way these thoughts make you feel. When describing unhelpful thoughts try to think of and describe helpful thoughts they can be replaced with.

Assignment 4

Please imagine that a good friend of yours has recently suffered a similar loss to the one you have. In this fourth writing task we would like you to write a letter of advice to this friend. Try to use the following points in writing this letter.

- 1. What moments were especially difficult for you during and since your loss? Maybe you can offer your friend the same advice that you would like to have had during those difficult moments.
- 2. Try to think back to writing tasks 1 through 3. What issues did you write about? Perhaps you could also pay some attention to these issues in your letter.
- 3. Suppose your friend has the same attitude toward important things (such as life, the future) as you yourself had following the death of your [...]. Would you try to change your friend's attitude? Why or why not?
- 4. Is your friend likely to be having any unhelpful thoughts with respect to the loss? If so, what alternative, helpful thoughts can you offer to your friend?
- 5. Is there something to be learned in time from what your friend has been through? If so, what can be learned from it?

Assignment 5

In this last writing task we would like you to think about your life in the future (about 2 years from now). Imagine it is now 2009 and everything has gone as well as you would have hoped, considering what happened to you. You have struggled, overcome obstacles, and succeeded at accomplishing your goals. Think of this as the best possible outcome for you. We would like you to write a letter to your [...], describing this realization in some detail. Please, be sure to include the following topics in your letter:

- 1. A description of what has happened to you these last two years (between 2007 and 2009) including a description of how you overcame major obstacles or challenges.
- 2. The meaning of your loss, both then (in 2007) and now (in 2009).
- 3. Lessons, if any, you have learned from what you have been through.

Appendix II

Recruiting message

The Centre for Bereavement Research and Intervention at Utrecht University, The Netherlands is currently recruiting participants for a study into the efficacy of a new grief intervention. This intervention consists of five different homework assignments that are sent to participants by e-mail. Assignments will take on average 30 minutes to complete.

You are cordially invited to participate in this study if you meet the following inclusion criteria:

- age 18 years or older
- native English speaker
- having experienced the death of a partner, parent, child or sibling and being significantly distressed by this
- access to computer and Internet facilities
- in possession of a valid e-mail address

Please visit our website (http://www.bereavementresearch.com) for more information and to register for this study.

Thank you for taking the time to read this message.

The research team,

Jan van den Bout, Professor of Psychology

Wolfgang Stroebe, Professor of Psychology

Margaret Stroebe-Harrold, Associate Professor of Psychology

Henk Schut, Assistant Professor of Psychology

Karolijne van der Houwen, PhD candidate

Appendix III

Research report for participants

Efficacy of a brief Internet-based writing intervention for the bereaved

Research report

The research discussed in this report was conducted at Utrecht University, The Netherlands. The following researchers took part in the project: Karolijne van der Houwen (PhD student), Margaret Stroebe (Professor of Clinical Psychology), Henk Schut (Associate Professor of Clinical Psychology), and Jan van den Bout (Professor of Clinical Psychology), all working at the Department of Clinical and Health Psychology, and Wolfgang Stroebe (Professor of Social Psychology), working at the Department of Social and Organizational Psychology.



1. Introduction

A research study into the efficacy of a brief writing intervention for bereaved persons was started at Utrecht University, The Netherlands, in September 2004. The intervention consisted of five different writing assignments. The assignments were tailored to suit the unique situation of bereaved persons. We were interested in learning whether completing the writing assignments would have a beneficial effect on people's well-being and functioning. The main findings of our study are presented below. We will:

- explain the design of the study, i.e. the way that the writing assignments were formulated and tested, and how we carried out our study;
- give some details about the bereaved people who participated in our study, e.g. their
 age, the type of loss they suffered, how long they had been bereaved, and their
 reasons for participating;
- look at whether completing the writing assignments had an effect on participants' well-being;
- discuss how participants experienced their involvement in our study;
- end this report with a summary of our findings and some conclusions.

Where possible and appropriate we will illustrate our findings with comments made by participants.

2. The design of this study

At the beginning of the study, we developed five different writing assignments. We based these on the successful work previously done by other researchers in the area of post-traumatic stress disorder and bereavement. We then conducted a small preliminary study in which we gave these assignments to thirty-seven bereaved persons to examine how the tasks came across. The main purpose of this was to make sure that the assignments were acceptable to bereaved people, and that they were not too emotionally demanding.

We invited people to participate in our study through two different channels: (1) via the Internet, through websites, forums, and e-mail groups that focus on bereaved persons, (2) via organizations and support groups for the bereaved. To be eligible for the study, participants had to have lost a close relative: a partner, parent, child or sibling. Also, people had to be significantly distressed by their loss at the time of signing up. We thought it important not to include persons who had already come to terms with their grief, since these persons could not

be expected to benefit from writing about their loss experience. People interested in participating were referred to a website that was created especially for this study. This website provided all the necessary information to make an informed decision about participating in the study. People were able to register for the study and give their consent by filling out a form on the website. We were careful to ensure that there was no pressure on anyone to participate, and that everyone was free to stop at any point during the study.

Upon registering, participants were automatically assigned to one of two groups, either the Immediate Writing Group or the Delayed Writing Group. The Delayed Writing Group would be given the opportunity to do the writing after completing all questionnaires in the same timeframe as the Immediate Writing Group. Their feedback showed us how people would progress if they did not do the assignments, giving us something to compare the Immediate Writing Group to.

First, both groups were asked to fill out a questionnaire. This questionnaire asked about background and loss-related aspects, such as participants' age, sex, education level, and their relationship to the person who died. It also inquired about participants' well-being, and how they were coping with their loss. After filling out the questionnaire the Immediate Writing Group was asked to complete the five assignments. A new assignment was sent every week, provided that the previous assignment had been completed and returned by e-mail. The Delayed Writing Group was not asked to do anything. At three months after completing the first questionnaire both groups filled out a second questionnaire, and at six months they filled out a third questionnaire. After completing the third questionnaire, participants in the Delayed Writing Group were offered the opportunity to complete the five writing assignments.

It was decided to conduct the entire study online, since this makes it easier for participants to stay anonymous. We felt that anonymity was important, because we would be asking people to write and answer questions about personal and sensitive matters. We thought that participants would feel more free in their writing if their identity was not known to us.

3. The participants in this study

 932 bereaved persons filled out the form on our website, indicating their interest in participating in our study.

- 837 bereaved persons started answering the first questionnaire. Of this group 73 bereaved persons were not included in our study, either because they were suffering from severe feelings of depression or because they did not meet our criteria for inclusion (e.g. some people had suffered the loss of a loved one that was not a close relative, such as a friend, which was outside the limits of our study).
- This left us with 764 bereaved persons who could be included in our study. This number far exceeded our expectations, and we are very grateful for the fact that so many bereaved persons joined our study.

3.1 General characteristics

Due to the worldwide accessibility of the Internet, participants did not come from a specific area or country. Most of the participants lived either in the USA (67 percent) or the UK (19 percent), some lived in Australia or New Zealand (7 percent) or Canada (5 percent), while a few others (2 percent) lived elsewhere. The vast majority of our participants were female (93 percent). It is very common for bereavement studies to consist mainly of female participants, especially when recruitment for the study has taken place via the Internet. The age of the participants varied from 18 to 81 years old, with an average age of 43 years. Fifty-nine percent of the participants had at least a college degree or equivalent. Most participants had suffered the loss of a child (42 percent) or their partner (30 percent), some had lost a parent (16 percent) or a sibling (10 percent). Seven participants had unfortunately suffered multiple simultaneous losses. Most deaths were due to natural causes (66 percent), some were the result of an accident or homicide (22 percent), others resulted from suicide (12 percent). Participants had on average been bereaved for 3 years. However, the time since bereavement differed widely between participants, varying from 2 days to 46 years. Half of the participants had been bereaved within the last 18 months.

3.2 The impact of bereavement

Participants were quite distressed on average, with moderate to high levels of grief and depressive symptoms. Comments made by participants at the end of the questionnaires made it ever more clear to us, the researchers, how life-shattering the loss of a loved one can be. A mother who had lost her son told us: "The death of a child is a life changing event, it effects your past, your present and your future. It is against the natural way of things and others do not know how to cope. Many people avoid me now for fear of what they might say and an even bigger fear of what I might say. Many times when either me or my partner have

mentioned our son's name, people have changed the subject or walked away". A woman who had lost her partner said: "One aspect of grief that I have encountered is that before the death of my partner I was one person and now I am another. I think totally differently and have different expectations".

3.3 The timeframe of grief

The comments participants made reinforced our idea that you cannot put a timeline on grief, or as one person put it: "Although my sister left my side over 6 years ago, I know I am still in denial. I have gotten used to not being with her or hearing her voice each day, but I talk to her, either in my mind or outwardly each and every day... and I lean on her sensibility to guide me on my daily journey". A bereaved mother told us: "My son died 8 years ago next month. I think about him all the time, there isn't much of the day that he doesn't surface in my mind. Not having him here seems so wrong and I feel so sad that he lost his life".

3.4 Reasons for participation

Most participants indicated that they decided to register for our study because they were hoping that their participation in our study would result in better care for bereaved persons in the future, and would add to understanding of bereaved persons. This is of course an ultimate goal that we, the researchers, share with our participants. Another important reason for signing up was that participants felt that the study offered them the possibility to share their experience with others.

4. The effects of writing

The aim of our study was to see whether completing the writing assignments had a beneficial effect on people's well-being and functioning. We examined this by comparing the questionnaire responses given by the participants in the Delayed Writing Group to the responses given by the participants in the Immediate Writing Group. We examined four different indicators of well-being:

- 1. Grief
- 2. Depressive Symptoms
- 3. Emotional loneliness
- 4. Positive Mood.

Our findings showed that writing had a positive effect on well-being, but only on Emotional Loneliness, and Positive Mood. This means that participants who completed all five assignments experienced less emotional loneliness and more positive emotions in the months after they completed the assignments than participants in the Delayed Writing Group, who had not written yet. This result, while real, was quite small: people who wrote felt just a little less lonely and a bit more positive than people who did not write. Writing did not have an effect on the experience of Grief or Depressive Symptoms. We examined the effects of writing approximately one and four months after participants completed the last assignment. From this it became clear that even though effects (on Emotional Loneliness and Positive Mood) were small, they did last up to four months after writing.

We were not only interested in finding out whether our writing intervention was effective. We also wanted to know *how* writing reached its effect. Our results showed that writing had a beneficial impact on Emotional Loneliness and Positive Mood through its influence on "rumination". Rumination can be defined as a repetitive focus on – constantly thinking about or going over - different aspects of the loss (for example, why the person died, and what could have prevented the death), and/or on one's own response to the loss (for example, on feelings of sadness or distress). A lot of research, including this study, shows that negative feelings, such as Grief and Depression, are increased by rumination, and that positive feelings are decreased by rumination. Writing helped lessen rumination: people who wrote ruminated less than people who did not write. This, in turn, lessened feelings of emotional loneliness and increased the experience of positive emotions.

5. The experience of participants in the Immediate Writing Group

As mentioned earlier, participants in the Immediate Writing Group filled out three questionnaires, similar to the participants in the Delayed Writing Group. In addition to this, participants in the Immediate Writing Group were sent five writing assignments after they had completed the first questionnaire.

Assignment One:

Participants were asked to describe the moment or moments during their loss event that they considered to be the most stressful in as much detail as possible.

Assignment Two:

Participants were asked to describe things that were most distressing to them at the current time and also to describe any progress they felt they had made since their loss.

Assignment Three:

Participants were asked to describe any unhelpful and helpful thoughts they might be having with regard to their loss. They were also asked to try and write down helpful thoughts that might replace the unhelpful thoughts.

Assignment Four:

Participants were asked to write a letter of advice to a (hypothetical) friend that had experienced a similar loss.

Assignment Five:

Participants were asked to write a letter to their deceased loved one from a future perspective, detailing how they overcame particular obstacles.

Questionnaire Completion rates:

Questionnaire One: 458 participants
Questionnaire Two: 231 participants
Questionnaire Three: 220 participants

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Assignment completion rates:

Assignment One: 345 participants
Assignment Two: 298 participants
Assignment Three: 257 participants
Assignment Four: 223 participants
Assignment Five: 204 participants

Looking at these numbers it is clear that quite a lot of participants in the writing group decided to stop their participation in our study. This is not unusual in this type of study, and it was not unexpected. Many participants told us that they just could not find the time to spend on the assignments every week: "I stopped because I was always running out of time", "My life became very busy, new home, new job, etc". Others said that they found the assignments too emotionally burdensome: "I found I'm just not ready to do this much writing about my grief yet", "I am struggling to write down my feelings, it is bringing everything back", "I have tried but have found myself unable to deal with all the emotions this brings up. I still find it very painful to deal with and cannot think or write about this without falling to pieces". A few persons stopped because they did not feel comfortable with the anonymity of

the process: "It has become too painful and personal to do on-line. For me, it requires an inperson experience with someone I know and trust. It is beyond my boundaries for on-line communication".

Participants who did complete all assignments indicated to us that the essays that they wrote were highly personal, that they revealed a lot of their emotions in the assignments and that they found completing the assignments to be quite emotional at times. Prior to starting on the assignments, most participants had – at least to a certain extent - talked and thought about the topics we asked them to write about. However, most participants had not yet written about these topics. The majority of participants in the Immediate Writing Group felt that they had benefited from writing, that the writing experience had been valuable to them and that they had gained new insights from completing the assignments. One bereaved mother wrote: "This has been a very helpful study for me, especially when I did the essays in the first part." When looking back over the things I wrote about, I was surprised to find that some things rose to the surface that I thought I had forgotten, or had suppressed. I was surprised to find out that I still harbored some resentments and this enabled me to seek ways of trying to resolve the conflicts that I found were still in my emotions and thoughts. I felt this study helped me to "peel away" some of the layers of my grief that I had not explored before. Although it was painful for me to do so, it helped me to understand myself and my emotions better and helped me in my grief journey". A total of 57 percent of participants who finished all assignments told us that they would definitely recommend the writing assignments to others in similar situations, and a further 32 percent said that they would probably recommend the assignments to others. However, a few participants indicated that they felt that completing the assignments may have had a negative effect on their well-being and functioning, and that they would not recommend these assignments to other bereaved people.

We, as researchers, were moved (often to the point of tears) by the accounts that participants wrote. Many participants trusted us with very personal and sensitive information, things that they sometimes shared for the first time. We are extremely grateful for the fact that so many people were willing to spend their valuable time completing our assignments, especially because this often involved confronting painful memories.

6. The experience of participants in the Delayed Writing Group

As described before, participants who were assigned to the Delayed Writing Group were asked to fill out questionnaires at three points during the course of the study: at the beginning of the study, and three and six months after they filled out the first questionnaire.

Questionnaire Completion rates:

Questionnaire One: 294 participants

Questionnaire Two: 256 participants

Questionnaire Three: 220 participants

These numbers indicate that the majority of participants in the delayed writing group filled out all three questionnaires.

Although the questionnaires were mainly used to compare respondents in the Immediate Writing versus Delayed Writing groups, it turned out that most of the participants in the latter group felt that filling out the questionnaires was useful to them. Participants had very different reasons for finding this helpful, but a number of reasons were often mentioned. Quite a lot of participants told us that the questions made them think and realize things: "It has again reminded me how far I have come in my grief", "I have recognized strengths by answering questions", "It has been helpful to reflect on where I am in the progress of my grief path", "'It made me think of things I have been avoiding since my dad died". Participants also told us that the questionnaires enabled them to monitor their own progress: "I feel I have made progress and the timing of the questionnaires has supported this, some of the questions are the same and I know I've been able to give more positive answers throughout the study", "I have noticed a change in my answers from the first questionnaire to the last one. It shows me that I am progressing". Another reason that was often mentioned by participants was that the questionnaires made them realize that their feelings and thoughts were normal: "The wording of the questions made me realize that some of the stuff I have been feeling is natural and not unique", "It helped me understand that grief is normal".

Although most participants in the Delayed Writing Group filled out all three questionnaires, a significant minority only filled in one or two questionnaires. A few participants told us that they stopped being part of our study, because filling out questionnaires was somehow

distressing to them: "I did not finish participating in the study, because I felt like the best way for me to get over my grief was to stop focusing on it so much. I was letting my grief consume my life", "When I started working through the questionnaire I found it too hard to contemplate". However, the majority of participants in this group withdrew from our study because of reasons that were not related to the content of the questionnaires, such as technical difficulties ("I could not access the last part of the questionnaire"), and time constraints ("I just didn't have the time").

7. Summary and conclusions

The writing assignments that we developed helped people feel a little less lonely, and a bit more positive, but they did not help lessen people's feelings of grief and depression. While these effects were small, they did last up to four months after writing. Writing was partly effective because it helped decrease rumination (repetitively focusing on different aspects of the loss and on one's own response to the loss).

Some researchers have claimed that interventions can possibly harm bereaved people. There were no indications that this happened in our study. We think that an advantage of the anonymous character of our study is that participants did not feel pressured to stay in our study, so they could leave if they did not feel up to it. This may have prevented negative effects from occurring.

We would like to take this opportunity to thank all bereaved persons who have made a contribution to our study. We are utterly grateful for your support and trust in us.

Appendix IV

Questionnaires used in the study

Items used to measure rumination:

- 1. I think about how bad I feel since my [...] died.
- 2. I think about why my [...] has died.
- 3. I think about the things that I would like to have done differently in my relationship with my [...].
- 4. I think about the consequences if I keep on feeling sad.
- 5. I think about things that happened when my [...] died.
- 6. I think about how my [...]'s death could have been prevented.
- 7. I think about who is responsible for my [...]'s death.
- 8. I think about the way I react to my [...]'s death.

Items used to measure deliberate grief avoidance:

- 1. I try to keep thoughts or memories about my [...]'s death that arouse painful emotions from becoming conscious.
- 2. I avoid people who remind me of my [...] or [...] death.
- 3. If I see something on television about death, I switch to another channel or turn off the television.
- 4. I avoid places that remind me of my [...] or [...] death.
- 5. I suppress memories of emotional events that occurred when my [...] died.
- 6. I avoid talking about my [...] or [...] death.
- 7. I try to suppress thoughts about my [...] or put them out of my head.
- 8. I avoid looking at pictures of my [...].
- 9. I try to occupy myself with things like work or hobbies in order not to think about my loss.
- 10. I avoid activities I used to do with my [...].
- 11. If I feel thoughts or emotions about my [...]'s death emerging, I try to seek distraction by engaging in hobbies or other activities.
- 12. I avoid situations that remind me of my [...] or [...] death.
- 13. If people start talking about my [...] or [...] death, I quickly change the subject.

Items used to measure grief:

- 1. I have felt myself longing and yearning for my [...].
- 2. I have felt bitter over my [...]'s death.
- 3. I have felt that life is empty or meaningless without my [...].

- 4. I have felt that moving on with my life (for example, making new friends, pursuing new interests) is difficult for me.
- 5. I have had difficulty trusting people.
- 6. I have had difficulty accepting the death of my [...].
- 7. I have felt emotionally numb (e.g. detached from others).
- 8. I have felt that the future holds no meaning or purpose without my [...].
- 9. I have felt on edge, jumpy, or easily startled.

The blanks were filled in with the appropriate relationship word (e.g. son or partner) and possessive pronoun (his or her).