



---

seit 1558

***Grief-Specific Interventions in Cognitive-Behavioral Therapy for  
Dementia Caregivers: Towards Managing Pre-Death Grief, Loss,  
and Change***

Dissertation

zur Erlangung des akademischen Grades

doctor philosophiae (Dr. phil.)

vorgelegt dem Rat der Fakultät für Sozial- und Verhaltenswissenschaften  
der Friedrich-Schiller-Universität Jena

von Dipl.-Psych. Franziska Meichsner

geboren am 24. November 1986 in Schlema

**GutachterInnen:**

1. Prof. Dr. Gabriele Wilz, Friedrich-Schiller-Universität Jena
2. Prof. Dr. Christine Knaevelsrud, Freie Universität Berlin
3. Prof. Richard Schulz, PhD, University of Pittsburgh, USA

**Tag der mündlichen Prüfung:** 13. September 2016

## Table of Contents

<b>ACKNOWLEDGEMENTS .....</b>	<b>5</b>
<b>SUMMARY.....</b>	<b>6</b>
<b>ZUSAMMENFASSUNG.....</b>	<b>8</b>
<b>INTRODUCTION .....</b>	<b>11</b>
<b>1 Theoretical Background.....</b>	<b>13</b>
1.1 The experience of loss, change, and pre-death grief.....	14
1.1.1 The nature of loss and grief during dementia caregiving.....	14
1.1.2 Approaches to the explanation of pre-death grief.....	18
1.1.3 Pre-death grief as a unique experience.....	21
1.1.4 The manifestation of pre-death grief.....	22
1.1.4.1 The influence of length of caregiving and stage of the disease .....	24
1.1.4.2 Differences between subgroups of caregivers.....	24
1.1.5 The impact of pre-death grief during and after caregiving .....	27
1.2 Design and effects of psychosocial and psychotherapeutic interventions .....	28
1.2.1 Interventions for the bereaved.....	28
1.2.2 Interventions for dementia caregivers .....	29
1.2.3 Grief-specific interventions for dementia caregivers .....	30
<b>2 The Present Dissertation .....</b>	<b>35</b>
2.1 Research questions and aims.....	35
2.2 Overview of the setting: Tele.TAnDem & Tele.TAnDem.transfer .....	35
2.2.1 Tele.TAnDem.....	36
2.2.2 Tele.TAnDem.transfer .....	37
2.3 Overview of the three studies.....	41
2.3.1 Study I. Managing Loss and Change: Grief Interventions for Dementia Caregivers in a CBT-based Trial.....	41

2.3.2 Study II. The Caregiver Grief Scale: Development, Exploratory and Confirmatory Factor Analysis, and Validation.....	43
2.3.3 Study III. Dementia Caregivers' Coping with Pre-Death Grief: Effects of a CBT-based Intervention .....	47
<b>3 General Discussion.....</b>	<b>49</b>
3.1 The assessment of pre-death grief.....	49
3.2 Strategies for successful pre-death grief interventions .....	50
3.2.1 Explanations for the treatment effect .....	51
3.3 Further results .....	54
3.4 Methodological strengths of the dissertation .....	55
3.5 Limitations of the dissertation.....	56
3.6 Directions for future research on pre-death grief.....	57
3.7 Implications for clinical practice with dementia caregivers .....	59
3.8 Conclusion .....	60
<b>4 References.....</b>	<b>62</b>
<b>MANUSCRIPTS.....</b>	<b>73</b>
<b>5 Study I</b>	
<b>Managing Loss and Change: Grief Interventions for Dementia Caregivers in a CBT-based Trial.....</b>	<b>74</b>
<b>6 Study II</b>	
<b>The Caregiver Grief Scale: Development, Exploratory and Confirmatory Factor Analysis, and Validation .....</b>	<b>100</b>
<b>7 Study III</b>	
<b>Dementia Caregivers' Coping with Pre-Death Grief: Effects of a CBT-based Intervention.....</b>	<b>127</b>
<b>APPENDIX.....</b>	<b>153</b>

### ACKNOWLEDGEMENTS

Zunächst möchte ich allen Teilnehmerinnen und Teilnehmern der Projekte Tele.TAnDem und Tele.TAnDem.transfer meinen Dank aussprechen. Die Einblicke, die sie in ihre persönlichen Erfahrungen mit der täglichen Betreuung eines an Demenz erkrankten Menschen gewährt haben, und die Zeit, die sie in die kontinuierliche Studienteilnahme investierten, ermöglichten diese Dissertation.

Weiterhin gibt es eine Zahl von Menschen, die mich in dieser Phase meiner akademischen Laufbahn unterstützt haben und denen ich an dieser Stelle danken möchte:

Ein ganz besonderer Dank gilt meiner Betreuerin Frau Prof. Dr. Gabriele Wilz, die mir die Umsetzung meiner Forschungsideen im Rahmen der Tele.TAnDem Projekte ermöglichte. Ihre Rückmeldungen und Hinweise während der Arbeit an jeder einzelnen Studie dieser Dissertation bereicherten und verbesserten diese und förderten mich sowohl in wissenschaftlicher als auch persönlicher Hinsicht.

Ich danke meinen weiteren Gutachterinnen und Gutachtern, Frau Prof. Dr. Christine Knaevelsrud und Herrn Prof. Richard Schulz, PhD, herzlich für ihre Bereitschaft Teil der Promotionskommission zu sein und sich konstruktiv mit dieser Arbeit auseinanderzusetzen.

Besonderer Dank gebührt auch meiner Kollegin Denise Schinköthe, die mich als Erste mit dem Thema dieser Dissertation in Berührung brachte, und mir während der Entstehung der Arbeit auf fachlicher und persönlicher Ebene immer eine wertvolle Unterstützung war.

Weiterhin danke ich meinen Kolleginnen und Kollegen Christina Reiter, Lisette Weise, Dr. Anne-Katrin Risch, Kathi Albrecht, Nils Töpfer und Tanja Kalytta. Danke für eure motivierende Unterstützung und das Schaffen einer Arbeitsatmosphäre, in der wissenschaftliche Ideen gedeihen können und gern umgesetzt werden. Prof. Dr. Renate Soellner und Maren Reder danke ich für den bereichernden methodischen Austausch.

Für das Vertrauen in meine wissenschaftlichen Fähigkeiten und in den Wert meines Promotionsvorhabens geht mein Dank an die Landesgraduierföderung Thüringen, die mich mit einem Stipendium unterstützte.

Mein herzlichster Dank für die wertvolle praktische Unterstützung des Korrekturlesens der Endfassung der Arbeit gilt Carolin Altmann, Judith Hercher und Christina Reiter.

Ein ganz besonderer Dank auch an all die wichtigen Menschen in meinem Leben für die stetigen Ermutigungen und die vielen wertvollen Denkanstöße. Danke für euer Verständnis und die Möglichkeiten des Ausgleichs, vor deren Hintergrund ich diese Arbeit schreiben konnte.

## SUMMARY

Caregivers of a family member with dementia shoulder burdensome tasks that they often fulfil at the expense of their own physical and mental health. Among the most debilitating aspects of caregiving is the experience of pre-death grief, i.e., caregivers' emotional and physical response to losses over the caregiving trajectory. A major loss for the majority of caregivers is the continuous change in the care recipient's personality that results from the cognitive decline over the progression of the disease. Further losses comprise the loss of communication, support, intimacy, shared activities, and plans for the future, as well as changes in the nature of the relationship between caregiver and care recipient. If these losses are perceived as significant, grief is the natural emotional response; yet, caregivers are often either unaware that their physical, affective, cognitive, and psychological symptoms can be attributed to grief or else try to avoid painful reactions.

In the light of results that found pre-death grief to be a barrier in caregiving and related to caregiver burden and depressive symptoms, interventions that facilitate dementia caregivers' coping with pre-death grief are called for. A variety of psychosocial and psychotherapeutic interventions with small but significant effects has been developed, with the most successful of these programs being based on cognitive-behavioral therapy (CBT). There is also a number of studies investigating grief-specific interventions. Despite their promising results, these studies were mostly pilot studies with methodological limitations and no pre-death grief intervention grounded in CBT has been developed to date.

Building upon this research, the objectives of this dissertation were threefold: It was the first objective to provide insights into how intervention strategies rooted in CBT principles can be applied by therapists to specifically target pre-death grief. Based on these results, a grief-specific intervention module was developed and integrated into a comprehensive intervention program. The second objective was to evaluate this intervention's effectiveness regarding caregivers' coping with pre-death grief. As an important prerequisite for the analysis of treatment effects, it was the third objective to develop an instrument for the measurement of pre-death grief, because measures used up until this point were unsatisfactory. These objectives were met in three studies that were conducted within the scope of two randomized-controlled trials evaluating the effectiveness of a cognitive-behavioral intervention for dementia caregivers in Germany (i.e., Tele.TAnDem and Tele.TAnDem.transfer).

Study I, employing qualitative content analysis, analyzed intervention strategies applied by therapists to assist caregivers in managing losses and associated emotions. A category

system with satisfactory intercoder reliability was developed and four main grief intervention strategies were identified: Recognition and Acceptance of Loss and Change, Addressing Future Losses, Normalization of Grief, and Redefinition of the Relationship. Therapists focused on identifying experienced losses, managing associated feelings, and fostering acceptance of these losses.

Study II aimed to introduce a new scale for the measurement of pre-death grief. For the development of the *Caregiver Grief Scale* (CGS), a pool of 21 items was completed by 229 caregivers. The sample was randomly split in half and exploratory factor analysis was conducted on the first data set. The established factor structure was then subjected to confirmatory factor analysis on the second data set. Convincing goodness-of-fit indices emerged for a four-factor model, with factors reflecting different aspects of pre-death grief. The total scale and subscales yielded satisfying internal consistency reliabilities and construct validity coefficients.

The purpose of the final study, Study III, was to examine whether the cognitive-behavioral intervention including the grief-specific intervention module could increase caregivers' coping with pre-death grief, as well as whether these effects could be maintained as of a six-month follow-up assessment. Results revealed a long-term decline in the burden of pre-death grief in the intervention, but not the control group. It can therefore be concluded that the intervention successfully supported caregivers' management of loss and change.

Taken together, the results of the three studies illustrate how grief-specific interventions can be designed to facilitate caregivers' coping with pre-death grief, and support the effectiveness of this approach. The dissertation further adds two instruments to the field of research on pre-death grief: A category system for the qualitative assessment of grief intervention strategies and a scale for quantitative measurement of pre-death grief, the CGS. Future research should look into the relation between grief-specific intervention strategies and strategies targeting other caregiving challenges. It should also focus on the relationship between coping with pre-death grief and other mental health outcomes, and caregivers' adaptation to bereavement. Implications also follow for clinical practice with dementia caregivers. The CGS can be used to screen caregivers for potential problems in their management of pre-death grief. Those caregivers that appear at risk for adverse outcomes should be given access to therapeutic support guided by the CBT-based intervention manual including the grief-specific intervention module.

## ZUSAMMENFASSUNG

Mit der Pflege an Demenz erkrankter Familienmitglieder übernehmen Angehörige eine herausfordernde Aufgabe, die oft zu Lasten ihrer eigenen körperlichen und psychischen Gesundheit geht. Zu den belastendsten Aspekten der Pflege gehört das Erleben von pflegebedingter Trauer, d.h. der emotionalen und physischen Reaktion auf Verluste im Erkrankungsverlauf. Mit dem Fortschreiten der Erkrankung kommt es zu einer kontinuierlichen Veränderung der Persönlichkeit der Erkrankten, die einen maßgeblichen Verlust für viele Angehörige darstellt. Zusätzlich vollzieht sich eine Rollenveränderung zwischen Angehörigen und Erkrankten und es kommt zu weiteren Verlusten, wie denen von Kommunikation, Unterstützung, gemeinsamen Aktivitäten und Zukunftsplänen. Werden diese Verluste von den Angehörigen als bedeutsam eingeschätzt, ist Trauer die natürliche emotionale Reaktion. Jedoch sind sich viele Angehörige nicht bewusst, dass ihre physischen, affektiven und kognitiven Symptome auf Trauer zurückzuführen sind oder vermeiden gezielt das Erleben dieser Reaktionen und die Auseinandersetzung damit.

Trauer kann die Pflege erschweren und steht u.a. mit erhöhter Pflegebelastung und vermehrten depressiven Symptomen in Verbindung. Angesichts dieser Befunde werden Interventionen benötigt, die Angehörige bei der Bewältigung ihrer pflegebedingten Trauer unterstützen. Eine Vielzahl von psychosozialen und psychotherapeutischen Unterstützungsprogrammen für pflegende Angehörige mit kleinen, aber signifikanten positiven Effekten hinsichtlich, u.a., Depressivität und Pflegebelastung wurde bereits entwickelt, wobei die erfolgreichsten dieser Programme auf kognitiv-behavioralen Prinzipien beruhen. Interventionen, die spezifisch auf den Umgang mit pflegebedingter Trauer abzielen, wurden bisher in einer kleinen Zahl von Studien untersucht. Obwohl diese Untersuchungen zu vielversprechenden Ergebnissen führten, waren sie mehrheitlich Pilotstudien und wiesen methodische Einschränkungen auf. Zudem fehlen zum aktuellen Zeitpunkt Interventionen mit Bezug auf pflegebedingte Trauer, die kognitiv-verhaltenstherapeutisch basiert sind.

Vor diesem Hintergrund verfolgte die vorliegende Dissertation drei Ziele: Es sollte zunächst untersucht werden, wie Therapeutinnen und Therapeuten kognitiv-verhaltenstherapeutische Interventionsstrategien anwenden können, wenn Angehörige von pflegebedingter Trauer berichten. Auf Basis dieser Ergebnisse wurde ein trauerspezifisches Modul entwickelt und in ein umfassendes Behandlungsprogramm für pflegende Angehörige integriert. Das zweite Ziel der Dissertation war es die Wirksamkeit dieses Behandlungsprogramms hinsichtlich des Umgangs der Angehörigen mit pflegebedingter



Trauer zu untersuchen. Das dritte Ziel stellte die Entwicklung eines neuen Instruments dar, das es erlaubt pflegebedingte Trauer spezifisch zu erfassen. Dies war eine wichtige Voraussetzung für die Überprüfung des Behandlungserfolgs, da bisher verwendete Instrumente die Besonderheiten pflegebedingter Trauer nur unzureichend abdeckten.

Insgesamt wurden im Rahmen dieser Dissertation drei Untersuchungen (Studien I – III) innerhalb zwei randomisiert-kontrollierter Studien, die die generelle Wirksamkeit des kognitiv-verhaltenstherapeutischen Behandlungsprogramms überprüften (Tele.TAnDem und Tele.TAnDem.transfer), durchgeführt.

Mittels Qualitativer Inhaltsanalyse untersuchte Studie I Interventionsstrategien, die Therapeutinnen und Therapeuten einsetzen, um Angehörige bei der Bewältigung von Verlusten und damit verbundenen Emotionen zu unterstützen. Ein Kategoriensystem mit zufriedenstellender Intercoderreliabilität wurde überwiegend deduktiv entwickelt und vier primäre Interventionsstrategien konnten identifiziert werden: Emotionsfokussierter Umgang mit Verlusterfahrungen und Veränderungen, Normalisieren von Trauer, Rollenredefinition und Thematisieren zukünftiger Verluste. Im Mittelpunkt dieser Strategien standen die Identifikation der erfahrenen Verluste, der Umgang mit den damit verbundenen Emotionen sowie die Akzeptanz von Verlusten, Trauer und Veränderung.

Ziel der zweiten Studie war die Entwicklung und Überprüfung eines neuen Instruments für die Erfassung pflegebedingter Trauer, der *Caregiver Grief Scale* (CGS). 229 pflegende Angehörige beantworteten die 21 ursprünglichen Items der CGS. Die Stichprobe wurde zufällig in zwei Teilstichproben geteilt und eine Explorative Faktorenanalyse wurde anhand des ersten Datensatzes durchgeführt. Die darin gefundene Faktorenstruktur wurde mittels Konfirmatorischer Faktorenanalyse am zweiten Datensatz überprüft. Ein vierfaktorielles Modell wies dabei einen zufriedenstellenden Modellfit auf und die vier Faktoren spiegeln verschiedene Aspekte pflegebedingter Trauer wider. Sowohl die Gesamtskala als auch die Subskalen weisen eine zufriedenstellende interne Konsistenz, Retest-Reliabilität und Konstruktvalidität auf.

Ziel der dritten Studie war es zu überprüfen, ob das kognitiv-verhaltenstherapeutische Behandlungsprogram, welches das trauerspezifische Modul enthält, die Bewältigung pflegebedingter Trauer positiv beeinflussen kann und, ob dieser Effekt auch sechs Monate nach Ende der Intervention noch nachweisbar ist. Es zeigte sich ein langfristiger Abfall in der Belastung durch pflegebedingte Trauer in der Interventions-, jedoch nicht in der Kontrollgruppe. Dies weist darauf hin, dass die Intervention den Umgang der Angehörigen mit Trauer, Verlust und Veränderung positiv beeinflussen kann.

Zusammenfassend zeigen die Ergebnisse der drei Studien wie Interventionen gestaltet sein können, die pflegende Angehörige bei der Bewältigung pflegebedingte Trauer unterstützen, und weisen auf die Effektivität dieses Ansatzes hin. Ergebnis der Dissertation sind zudem zwei Messinstrumente: Ein Kategoriensystem für die Kodierung trauerspezifischer Interventionen und eine Skala für die Erfassung von Verlusten und Arten der Bewältigung pflegebedingter Trauer, die CGS. Zukünftige Forschungsfragen sollten sich dem Zusammenspiel von trauerspezifischen Interventionen und anderen Modulen des Behandlungsprogramms widmen, sowie auch den Zusammenhang zwischen Bewältigung pflegebedingter Trauer und anderen Aspekten psychischer Gesundheit sowie der erfolgreichen Anpassung an die Situation nach dem Tod der Erkrankten untersuchen. In der Praxis kann die CGS eingesetzt werden, um Hinweise auf mögliche Probleme einzelner Angehöriger bei der Bewältigung pflegebedingter Trauer zu erlangen. Diese Angehörigen sollten therapeutische Unterstützung im Sinne des trauerspezifischen Moduls des kognitiv-verhaltenstherapeutischen Behandlungsprogramms erhalten.

## INTRODUCTION

Grief is the psychological response to a personally significant loss (Chan, Livingston, Jones, & Sampson, 2013) and in that it unites all human beings. Over the course of our lives, we all have to face the loss of loved ones. Although this is a painful experience, most people manage to come to terms with the loss after some time, integrate the memory of the deceased loved one, and continue life without that person. For some people, however, grief and loss are constant companions over many years, taking a toll on their health and well-being. This is the case for dementia caregivers.

While medical advances allow us to grow older and lead longer lives, prevalence rates for conditions associated with older age also rise (Robert Koch-Institut, 2015). As of 2015, 46.8 million people worldwide live with Alzheimer's Disease or another form of dementia (Alzheimer's Disease International, 2015) and this number is estimated to almost double every 20 years. The affected persons behind these numbers are not only the patients who receive the diagnosis, but also those close to them: The majority (75%) of persons with dementia is being cared for at home by a family member—mostly a spouse or an adult child—over the longest periods of the disease trajectory (Bundesministerium für Familie, Senioren, Frauen und Jugend, 2015; Schulz & Martire, 2004). Upon embarking on the caregiving career, these family members' lives are dramatically altered. The number of people affected by dementia is therefore much higher; emphasizing that dementia is and will continue to be one of the major challenges of our society.

Among the characteristics of the care situation that significantly affect caregivers' well-being and health are the grief, change, and loss that are experienced continuously over the disease trajectory. Their impact necessitates a clear conceptualization of grief during caregiving and the development of means to support family caregivers of persons with dementia (i.e., dementia caregivers) on their difficult journey. Contributing to research in this field is the focus of the present dissertation.

The dissertation comprises three studies that were conducted within two randomized-controlled trials for dementia caregivers in Germany. The manuscripts, which present the original work and were published in or submitted to peer-reviewed journals, are preceded by an introductory chapter. In this chapter, the joint theoretical background—i.e., the nature and origin of caregivers' grief and interventions that have been studied up until this point—is outlined first. Next, research questions and aims of the present dissertation are derived, the research projects that provided the setting are described, and the three studies are summarized.

Their results are then jointly explained and discussed in the light of current research. An overview of future directions of research with dementia caregivers and the results' implications for clinical practice closes the chapter.

## 1 Theoretical Background

The purpose of this section is to first outline the challenges faced by caregivers and how they affect their physical and mental health. It then moves on to explain the role of grief during caregiving by presenting the nature of losses and the subsequent development and manifestation of grief. A brief review of the current state of research on intervention studies for bereaved individuals and dementia caregivers and a more comprehensive discussion of grief-specific interventions for dementia caregivers follow.

Dementia caregivers are confronted with a difficult situation. Schulz and Martire (2004) described caregiving as a severe, chronic stressor and found that caring for an individual with dementia is more stressful than caring for an older person with physical impairments. Reasons are the “overwhelming number of challenges” (Schulz & Martire, 2004, p. 242) that caregivers face on a daily basis: They provide extensive assistance with activities of daily living, instrumental activities of daily living, negotiate the health care system (Schulz & Martire, 2004), and gradually take over all tasks the care recipient used to be responsible for. Therefore, dementia caregivers provide more assistance than other caregivers, give up more of their personal time, and have less time for work and hobbies and are, as a consequence, more heavily burdened (Schulz & Martire, 2004).

What sets dementia apart from other conditions of older age is the decline in both cognitive and physical abilities. Factors related to this functional decline (i.e., hours of caregiving, impairments in activities of daily living and instrumental activities of daily living) are the most significant predictors of caregiver burden (Kim, Chang, Rose, & Kim, 2012). Also, average disease duration varies between three and twelve years (Kua et al., 2014; Wolfson et al., 2001), with some caregiving duties beginning even before formal diagnosis. The exposure to this prolonged stressful situation places caregivers at risk for both adverse physical and mental health impacts: In their meta-analysis, Pinquart and Sörensen (2003) found that dementia caregivers show higher levels of stress and depression and lower levels of subjective well-being, physical health, and self-efficacy than non-caregivers and caregivers of older persons with a variety of other conditions.

The strongest negative effect was found for clinician-rated depression (Pinquart & Sörensen, 2003), suggesting that caregivers’ emotional well-being is at particular risk. The body of research on depression in dementia caregivers is extensive (Cuijpers, 2005), but another major aspect of the care situation with highly significant impact on caregivers’ emotional well-being has received less scholarly attention: Caregivers’ experience of grief and loss. Behaviors

problems are often named as the most difficult aspect of caregiving (e.g., Schulz & Martire, 2004), possibly because they confront caregivers with changes in care recipient. Schulz and Martire (2004) have further argued that the relationship between caregiver and care recipient changes drastically over the disease trajectory. Losses and changes are therefore a central part of caregiving and can lead to the experience of grief even before the death of the care recipient.

### **1.1 The experience of loss, change, and pre-death grief**

Reference to grief and loss during caregiving has first been made by Mace and Rabins (1981) in their book “The 36-hour day”. Since then, numerous studies have demonstrated that loss and grief are central themes in the caregiving experience (e.g., Madsen & Birkelund, 2013) and studies that included grief-specific instruments demonstrated high prevalence rates (e.g., Adams & Sanders, 2004; Chan et al., 2013; S. Sanders & Adams, 2005). Also in qualitative studies, the majority (59%; Adams & Sanders, 2004; and 68%; S. Sanders & Corley, 2003) of participants agreed to be grieving the loss of their loved one. When asked in retrospect, caregivers confirmed to have also grieved at other times than the actual death of the care recipient (Collins, Liken, King, & Kokinakis, 1993; Diwan, Hougham, & Sachs, 2009).

Although dementia caregivers’ grief was repeatedly addressed over the last two decades, the used terminology was largely inconsistent (Lindauer & Harvath, 2014). To distinguish the specific grief of dementia caregivers from other types of grief, the term *pre-death grief* is used in this dissertation, following the definition by Lindauer and Harvath (2014):

Pre-death grief in the context of dementia family caregiving is the caregiver’s emotional and physical response to the perceived losses in a valued care recipient. Family caregivers experience a variety of emotions (e.g. sorrow, anger, yearning and acceptance) that can wax and wane over the course of a dementing disease, from diagnosis to the end of life. This pre-death grief is due to (a) care recipient psychological death, which is asynchronous with physical death; (b) a lengthy and uncertain disease trajectory; (c) compromised communication between the person with dementia and the family caregiver; and (d) changes in relationship quality, family roles and caregiver freedom. Pre-death grief can contribute to caregiver burden, depression and maladaptive coping. (p. 2203)

The origin of these losses and the resulting grief reaction are described below.

#### **1.1.1 The nature of loss and grief during dementia caregiving**

Pre-death grief emerges within the larger stress process during caregiving (Blandin & Pepin, 2015; Noyes et al., 2010). Yet, as a study by Holley and Mast (2010) highlighted, it is not related to caregiving strain (e.g., hours of care or physical impairments of the care recipient),

but instead to behavior problems of the care recipient. These behavior problems are among aspects of dementia that confront caregivers with changes in the care recipients' personality and daily functioning. This change sets taking care for a person with dementia apart from, for example, taking care of a person with cancer (Johansson, Sundh, Wijk, & Grimby, 2013) or cardiac disease (Ross & Dagley, 2009).

Two kinds of losses can be distinguished (Holley & Mast, 2009; Large & Slinger, 2015; Noyes et al., 2010): Caregiving losses and interpersonal losses. Caregiving losses comprise loss of social, recreational, and work opportunities, loss of personal freedom, and a growing lack of self-care due to increasing caregiving demands (Frank, 2008; Noyes et al., 2010). While some authors also consider these losses as significant for the development of pre-death grief, the focus of this dissertation is on the second type of losses, i.e., interpersonal losses. At the core of interpersonal losses is the change of the care recipients' personality, also termed their *psychosocial death* (Doka, 2004): Over the duration of the disease, patients lose their cognitive abilities, including personal memories, and show a dramatically altered behavior. Therewith, interpersonal losses correspond with the losses mentioned in Lindauer's and Harvath's (2014) definition of pre-death grief (e.g., loss of communication and changes in the relationship). They also support an explanation of pre-death grief that can be found in Bowlby's (1973) theory of attachment: Attachment bonds exist between caregivers and care recipients, regardless of the nature of their relation. These bonds become strained as the disease progresses and the care recipients cease to be their former selves. Consequently, the safety and security the relationship provided are lost and the normative human reaction to this breaking of attachment bonds is grief. The stronger and more important the relationship between caregiver and care recipient was, the more intense is the pre-death grief reaction (S. Sanders, Ott, Kelber, & Noonan, 2008). Caregiving losses, on the other hand, are a direct result of the caregiving process (Noyes et al., 2010). They can result in stress (Noyes et al., 2010) and show some overlap with caregiver burden, i.e., the perceived negative influence of caregiving duties on caregivers' emotional, social, financial, and physical functioning (Zarit, Todd, & Zarit, 1986).

The most significant interpersonal loss seems to be the "receding of the known self" (Blandin & Pepin, 2015, p. 4; Madsen & Birkelund, 2013) and a number of qualitative studies identified a variety of further losses:

The open-ended question "Do you believe that you are grieving the loss of your loved one even though she/he is still alive? Please explain." was included at the end of a larger survey in one such study by S. Sanders and Corley (2003). Thirty-two percent of the 253 participants reported that they were not grieving. These caregivers either focused on what the care recipient

was still able to do in the present, avoided thinking about the future, engaged in religious coping, or stated that the relationship with the care recipient had not been important before. The authors did, however, note that these caregivers still mentioned losses and associated emotions, such as anger or frustration (S. Sanders & Corley, 2003).

As touched upon above, the remaining 68% of the participants in Sanders' and Corley's (2003) study agreed to be grieving. Many of them emphasized the ambiguity between the care recipient's physical appearance and psychological decline that led them to question the relationship. Caregivers also expressed difficulties reacting to the constant changes in the care recipients' mental status over the progression of the disease and the uncertainty they created. Many caregivers had also experienced that the gradual changes lead to role change: Spouses witness the care recipient turn from an equal partner into someone who depends on them completely and they have to take on new tasks that used to be shared in the past as a consequence. Parent-child relationships also change drastically: The parent with dementia becomes more childlike, thus causing a complete role reversal. With the increasing cognitive impairment also comes the loss of hope for a reconciliation of past conflicts.

One of the strongest sources of grief named by participants in this study was having to give up shared activities and the loss of intimacy (S. Sanders & Corley, 2003). As a consequence, caregivers experienced feelings of anger, isolation, and loneliness. Many also expressed a wish for the care recipient to die that, however, led to secondary emotions such as guilt and hopelessness. Some caregivers even reported desperation, loss of control, and suicidal thoughts. S. Sanders and Corley (2003) noted that caregivers recognized emotions that were associated with the experienced losses, but were unsure how to cope with them. They concluded that the ambiguity in the relationship and the dedication to the caregiver role were barriers to addressing pre-death grief.

In a similar study, S. Sanders et al. (2008) identified a number of main themes in the experience of pre-death grief. Among them was the caregivers' yearning for the past, especially for the past relationship with the care recipient and shared dreams. Caregivers also reported to feel isolated; yet, the cause were not the demanding caregiving tasks, but instead that the care recipient was often identified as the primary source of support and socialization before disease onset.

The debilitating effect of pre-death grief was further emphasized in another qualitative study that identified it as the primary barrier while caregiving (Frank, 2008). Study participants scarcely mentioned physical care, but instead lamented challenging behavior problems and loss of personal time, freedom, support, social interaction, and the opportunity to complete



unfinished business with the care recipient. They also described the loss of communication with the care recipient as the disease progressed, the loss of the relationship and, in the end, the loss of the person her- or himself. Statements such as “She is no longer my ‘mum’ but a little lady I’m responsible for” (Frank, 2008, p. 522) illustrated role change. This particular caregiver had detached herself from the role of a daughter and assumed the new role of a caregiver. In summary, the pervasive nature of pre-death grief, which results from constantly witnessing changes and also anticipating future losses, led participants to identify it as the biggest barrier they face as caregivers.

Collectively, these studies highlight the multifaceted nature of caregivers’ losses that also led Meuser, Marwit, and Sanders (2004) to describe pre-death grief as “additive”. An additional aspect unique to the situation of dementia caregivers is the length of the period of time over which losses are experienced. While one loss might be accepted and the caregiver adapts, another one already occurs (Dempsey & Baago, 1998). These compound losses can be overwhelming. Acceptance and adaptation are further complicated because as the disease waxes and wanes, caregivers can never be truly sure which loss has finally occurred and which might just be around the corner. Caregivers try to make sense of the person the care recipient has become and their own new role while, at the same time, they try to maintain a connection with the care recipient. This experience is termed *ambiguous loss*.

Ambiguous loss is often mentioned when dementia caregivers’ pre-death grief is concerned (Large & Slinger, 2015). Boss (2000) defined ambiguous loss as the experience of losses when the person in question is both absent and present. In case of dementia, the care recipient is physically present and often unchanged in appearance, but psychologically she or he becomes more and more absent over the disease trajectory. As a consequence, roles and relationships cannot be readjusted and the ambiguity increases with the progression of the disease (Boss, 2000). Confusion, constant disappointment, uncertainty, and anxiety follow and intensify grief without a possibility of closure (Boss, 2000; Noyes et al., 2010; S. Sanders & Corley, 2003).

Boss (2000) also referred to the caregivers’ situation as “goodbye without leaving” (p.45) and argues that they are denied symbolic rituals, such as funerals, that usually accompany losses. Similarly, McEvoy (2007) and Holley and Mast (2009) stated that the main problem for the families stems from the lack of cultural rituals that allow to grieve losing a person piece by piece while this person remains physically present.

This lack of rituals and norms links to another form of grief: *Disenfranchised grief* (Doka, 1989, 2004). Grief for psychosocial losses—such as for a family member with

dementia—is often disenfranchised because others do not understand why an individual is mourning. As a consequence, they perceive no right to mourn and fail to provide validation and support. Participants in Sanders' and Sharp's (2004) study, for example, reported that their feelings were socially not accepted, or conflicted with religious, family, or cultural values; they were often hurried by others to overcome their grief. These statements illustrate how caregivers lack the opportunity to openly acknowledge and publicly share their negative feelings and may even feel guilty if they do (Doka, 2004). In addition, dementia caregivers often engage in *self-disenfranchisement*: Since the care recipients are still alive and present, many caregivers perceive it as disloyal to grieve for them. Over the long caregiving duration, disenfranchised grief can lead to isolation and hopelessness (Doka, 2004).

### **1.1.2 Approaches to the explanation of pre-death grief**

The findings presented above illustrate both the variety and uniqueness of losses and changes during dementia caregiving. While Bowlby's theory of attachment (1973) offers a basic explanation for pre-death grief, the insights that were gained during the last two decades of research led to the formulation of more specific models.

In an early descriptive model, Dempsey and Baago (1998) proposed that pre-death grief has three dimensions. The first, loss of the person, refers to the care recipient's continuous loss of abilities and the resulting incapability to fulfil past roles in relationships. Second, symbolic loss or psychosocial death covers the loss of hopes, dreams, and expectations. The third dimension, caregivers' loss of personal identity, is a result of the first two dimensions and describes that caregivers are overwhelmed by the need to deal with all losses.

For the more recent *grief-stress model of caregiving* (see Figure 1), Noyes et al. (2010) drew upon studies on the nature of loss and pre-death grief to expand the *stress-process model* (Pearlin, Mullan, Semple, & Skaff, 1990). The authors emphasize that pre-death grief is one of the main stressors in caregiving and propose that the stress it causes is equal to or greater than the stress of post-death grief.

The grief-stress model of caregiving is aimed at the prediction of health outcomes and has three domains: Background and context variables, primary stressors, and outcomes. Background and context variables, such as socioeconomic or demographic factors, influence primary stressors. These primary stressors are then divided into ambiguous loss and role overload. Ambiguous loss emerges through what Noyes et al. (2010) call *relationship losses*. They are caregivers' main sources of pre-death grief, namely the loss of companionship, communication, support, as well as a change in relationship dynamic, and the loss of hope for

improvement of the relationship, i.e., the possibility to address unfinished business. Role overload, on the other hand, is a result of the care provision process and caregiving losses. In line with the attachment theory (Bowlby, 1973), Noyes et al. (2010) included the perception of the significance of the loss. They propose a set of appraisals around the experienced losses regarding both their significance for the caregiver and the caregiver's perceived coping resources. If caregiving losses are more prominent, caregivers feel burdened and stressed by their role. If, however, relationship losses prevail, caregivers experience pre-death grief and show emotions also found in depression and anxiety such as loneliness, regret, hopelessness, confusion, and agitation (Noyes et al., 2010).

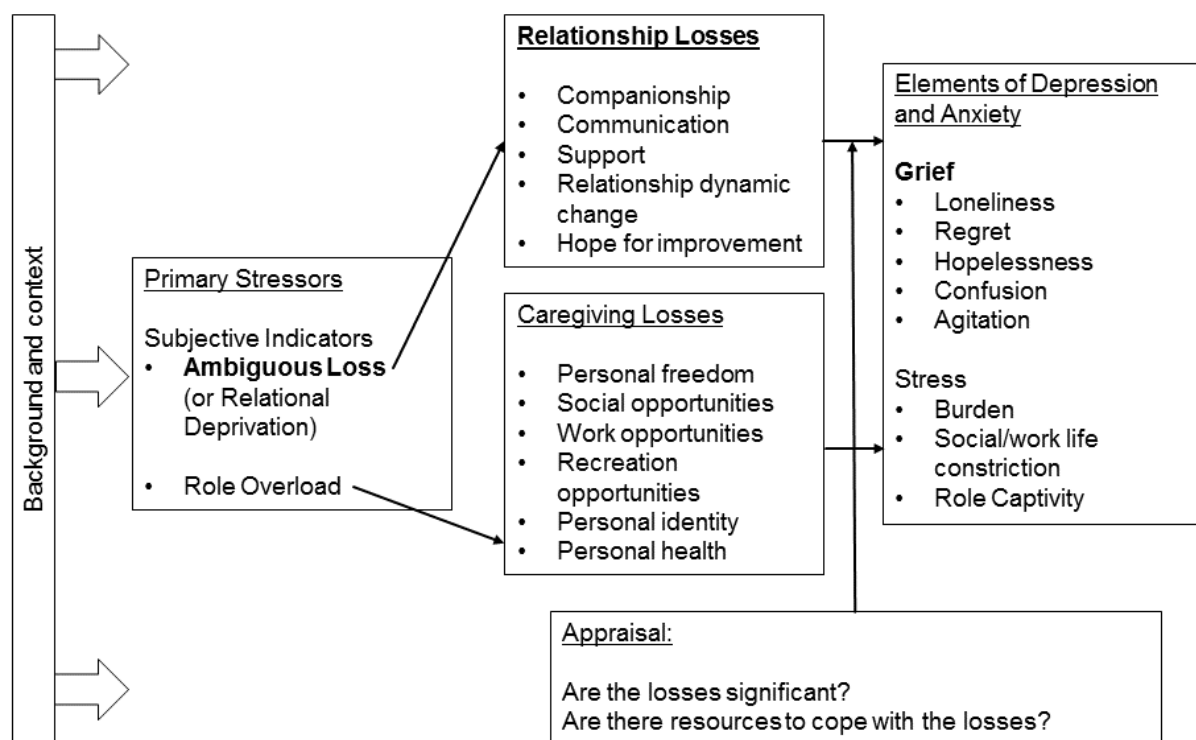


Figure 1. Grief–stress model of caregiving (Noyes et al., 2010, highlighting added for the purpose of this dissertation).

While the grief–stress model of caregiving describes grief as a symptom, Blandin's and Pepin's (2015) *dementia grief model* (see Figure 2) focuses on the overarching grief process over the course of the caregiving duration. The authors propose that pre-death grief cycles through three states: Separation, liminality, and re-emergence. Each state has a dynamic mechanism that is responsible for movement through the process. Each mechanism can fail and the model identifies points that can be targeted by interventions.

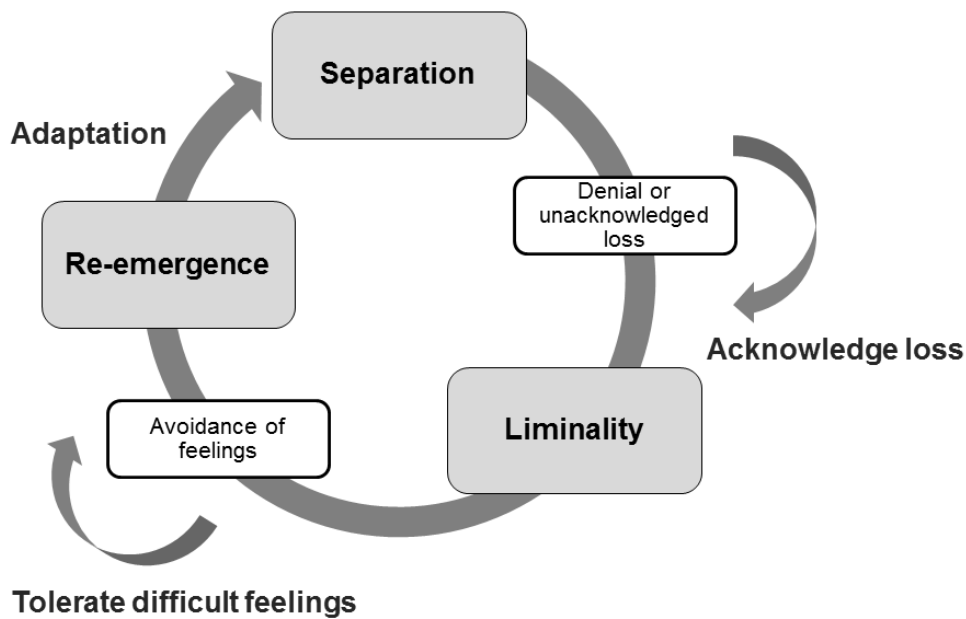


Figure 2. Dementia grief model (Blandin & Pepin, 2015).

The state of separation is characterized by the multiple losses that occur over the disease trajectory; its respective dynamic mechanism is to acknowledge loss. According to Blandin and Pepin (2015), each loss leads to a new state of separation and, therefore, needs to be acknowledged separately. The dynamic mechanism can, however, be inhibited through resistance, a lack of recognition, or denial of the loss.

The liminal state refers to being in-between a previous situation and an emerging new situation (Blandin & Pepin, 2015) and is closely connected to ambiguous loss. Its dynamic mechanism is tolerating difficult emotions that is hindered if caregivers avoid or suppress feelings.

The last state, the state of re-emergence, is characterized by acceptance and the dynamic mechanism is adaptation. This mechanism becomes visible through a caregiver's changed behavior, such as arranging for new circumstances in care or taking on role change. Therewith, it becomes apparent that a new reality that resulted from a loss is incorporated into daily life.

It is of note that the dementia grief model is a cycle. Each new stage of the disease and each new loss can re-start the cycle and caregivers have to fulfill the tasks again. As long as the care situation continues, there is no closure; caregivers have to cycle repeatedly through the process and even before one loss has been accepted another one might occur. This process can lead to the overload that researchers have addressed repeatedly (e.g., Meuser et al., 2004; Walker, Pomeroy, McNeil, & Franklin, 1994).

### 1.1.3 *Pre-death grief as a unique experience*

As pre-death grief is still a relatively new concept, a clear conceptualization of its relation to and distinction from other types of grief is an important prerequisite to continue research in this field.

Pre-death grief shares similarities with post-death grief and some authors (e.g., Meuser et al., 2004) have argued that the two forms of grief are indistinguishable in personal impact and meaning. In addition, comments by caregivers of patients with end stage dementia closely resembled those made by bereaved caregivers in how the caregivers explained to miss characteristics of the care recipient (Adams & Sanders, 2004). This yearning for the past, which is one of the main post-death grief symptoms, has been repeatedly identified in caregivers' narratives (S. Sanders et al., 2008).

There is, however, a number of aspects that set pre-death grief apart from post-death grief. First, a substantial amount of caregivers is not aware that what they are experiencing is grief (e.g., Silverberg, 2007; see also below), and many think it is not right to grieve (i.e., they engage in self-disenfranchisement). Post-death grief, on the other hand, is usually expected and socially accepted. Second, the losses that cause pre-death grief are compounded over the caregiving trajectory, while in post-death grief losses occur concurrently after the loved one has died. Pre-death grief can also be intermittent when lucid moments occur in care recipients what adds to the ambiguity of the situation and can have destabilizing effects on caregivers (Lindauer & Harvath, 2014). These differences directly affect how losses can be incorporated and complicate the grief process for caregivers while most people come to terms with the painful post-death grief after some time (Bonanno et al., 2002). As a result, a different approach to interventions is needed for pre-death grief than for post-death grief.

Early investigations into pre-death grief repeatedly used the term *anticipatory grief* for dementia caregivers' grief. Anticipatory grief—or anticipatory mourning as the concept has been recently renamed—was defined by Rando (2000) as

[...] the phenomenon encompassing seven generic operations (grief and mourning, coping, interaction, psychosocial reorganization, planning, balancing conflicting demands, and facilitating an appropriate death) that, within a context of adaptational demands caused by experiences of loss and trauma, is simulated in response to the awareness of life-threatening or terminal illness in oneself or a significant other and the recognition of associated losses in the past, present, and future. (p. 4)

Even when the term was used for caregivers' grief, the authors then immediately pointed out differences (Lindauer & Harvath, 2014); as an example, Holley and Mast (2009) frame caregivers' grief as a tragic variant of anticipatory grief. The main difference between pre-death grief and anticipatory grief is that anticipatory grief enables a preparation for the death, for example through discussions and attending to unfinished business between the diseased person and the caregiver (Rando, 2000). However, this opportunity does not exist for dementia caregivers because the nature of the disease impairs the possibility of communication (Collins et al., 1993; Dempsey & Baago, 1998). In that, pre-death grief does not meet one of the core criteria of anticipatory grief. It therefore has to be concluded that the two concepts share characteristics but are still sufficiently different. Blandin and Pepin (2015) added that pre-death grief is a specific type of anticipatory grief, because the relationship cannot be maintained until the death of the care recipient but is instead lost from the early stages of the disease onwards.

Last, grieving caregivers often report feelings that might indicate depression, such as hopelessness, sadness, and despair. Yet, pre-death grief still needs to be differentiated from depression (Adams & Sanders, 2004; Walker & Pomeroy, 1996). The difference between the two conditions is that depression is focused on negative interpretations of the self and the world while the focus of pre-death grief is on the loss of the care recipient. Scores on the Beck Depression Inventory were found to be strongly correlated with pre-death grief (Walker & Pomeroy, 1996) and pre-death grief accounted for 48% and 63% of the variance in depression in two separate studies (S. Sanders & Adams, 2005; Walker & Pomeroy, 1996). Also, grief items and depression items loaded on two different factors in a sample of caregivers of care recipients in a nursing home (Kiely, Prigerson, & Mitchell, 2008). These results suggest that what researchers in the past thought to be depression in caregivers might actually be pre-death grief.

#### ***1.1.4 The manifestation of pre-death grief***

As pre-death grief is a unique experience, some particular characteristics need to be considered regarding its manifestation. Dempsey and Baago (1998) described pre-death grief as latent and hidden, because caregivers are often aware of emotions such as anger, guilt, anxiety, and helplessness, but often attribute these responses to the care situation rather than to the losses they experience. Similarly, S. Sanders and Sharp (2004) found that caregivers associated their physical, affective, cognitive, and psychological symptoms with stress and burden rather than grief and Silverberg (2007) argued that caregivers only recognize grief after they are made aware of it.

It is one possible explanation that the energy, resources, and time needed for caregiving make it difficult for caregivers to recognize and process pre-death grief (Large & Slinger, 2015). The time consuming care also leads to a lack of self-care of caregivers, and as a consequence, their emotional needs are not met or ignored. It is also of note that caregivers often feel inhibited to express negative emotions as the care recipient is still alive and often physically unchanged (Doka, 1989). Consequences are unacknowledged or inhibited grief (Large & Slinger, 2015).

Caregivers in Frank's (2008) study reported that it was helpful to acknowledge losses and changes, but also to detach themselves. Understandably, the ambiguity of losses, the resulting grief, and secondary emotions are painful—especially as they are experienced over an extended period. Many caregivers therefore try to withdraw from these feelings, i.e., avoid thinking or talking about it (Frank, 2008; Large & Slinger, 2015). They thus engage in a phenomenon called *experiential avoidance* which means the unwillingness to remain in contact with private experiences (e.g., thoughts and emotions) or to alter their form, their frequency, or the context within which they emerge (Hayes, Strosahl, & Wilson, 1999). Short-term, avoidance can offer respite from emotional pain and help facilitate the processing of painful experiences (Shear, 2010), and thus enable caregivers to continue with caregiving tasks (Large & Slinger, 2015). Experiential avoidance is, however, of concern in the long term because it consumes caregivers' energy and attention (Davis, Deane, & Lyons, 2014) and prevents them from moving through the grief process (Blandin & Pepin, 2015). It also leads to further adverse outcomes since higher avoidance was found to increase mental health impairments (Hayes et al., 2004). Also, Spira et al. (2007) reported specifically for dementia caregivers that high levels of avoidance of negative feelings are associated with increased symptoms of depression. Further, Dupuis (2002) found that caregivers who avoided grief reported more pain and distress than those who acknowledged it.

With regard to detachment, Frank (2008) already advocated for a rethinking of the conceptualization of interventions. In the light of the findings compiled above, health care professionals need to distinguish between a conscious short-term detachment in order to perform caregiving tasks or ongoing experiential avoidance and failure to recognize grief.

The manifestation of pre-death grief has been found to differ depending on a number of characteristics of the caregiver and the care situation that should further be considered. For that reason, the influence of length of caregiving and stage of the disease on pre-death grief are described below, followed by an outline of differences in the intensity and expression of pre-death grief between female and male caregivers, spouses and adult children, as well as caregivers who continue home care compared to those who decide for nursing home placement.

#### *1.1.4.1 The influence of length of caregiving and stage of the disease*

A number of studies investigated the relation between the nature of pre-death grief, length of caregiving, and stage of the disease. Lindgren, Connelly, and Gaspar (1999) reported a constant level of pre-death grief scores over the caregiving duration. On the contrary, Ponder and Pomeroy (1997) found a curvilinear relationship between length of caregiving and intensity of pre-death grief in a cross-sectional study: Caregivers in the early phase of caregiving reported a high intensity of grief that subsequently declined through the second to fourth year of caregiving, only to rise again afterwards.

The influence of stage of the disease on the intensity of pre-death grief was demonstrated repeatedly. In a qualitative study (Adams, 2006), caregivers of care recipients in the early stages did report losses but their grief was often overshadowed by other issues, such as caregiving tasks, concerns about the needs of the care recipient, or feelings of guilt. The highest values of pre-death grief were found for caregivers of late stage dementia patients (Adams & Sanders, 2004; Ott, Sanders, & Kelber, 2007). It has to be noted, though, that some studies (Passoni, Toraldo, Villa, & Bottini, 2015; Warchol-Biedermann et al., 2014) indicate that the perceived, not the objective level of deterioration of the care recipient is a predictor of pre-death grief. Consequently, it is the caregivers' personal perception of loss that causes pre-death grief.

Some of the losses described above are also specific to a certain stage of dementia (Adams & Sanders, 2004): In the early stage, caregivers mainly feel the loss of shared activities, dreams, plans, and goals. During the middle stage, the focus shifts more to losses concerning the personal needs of the caregiver (i.e., caregiving losses). During the final stage, the main loss is often that of the interpersonal relationship between caregiver and care recipient along with both intimacy and emotional closeness (Adams & Sanders, 2004).

#### *1.1.4.2 Differences between subgroups of caregivers*

Expression and intensity of pre-death grief also slightly differ between subgroups of caregivers. First, it is important to consider gender differences. Approximately two-thirds of caregivers are female (Alzheimer's Association, 2015), and study results are therefore derived from largely female samples. S. Sanders, Morano, and Corley (2003), however, conducted a qualitative study on pre-death grief in caregiving husbands and sons. In this exclusively male sample, they replicated their earlier finding that the majority (67%) of caregivers was aware of the changes in both the care recipients and themselves. The husbands and sons described losses and explained to be grieving as a result. What is of concern is that 33% of the participants expressed to be in a state of crisis due to grief: They felt intense pain, despair, and loneliness,



but their grief remained unaddressed because these men felt embarrassed to disclose their feelings. These results are in line with those of another study that found that female caregivers expressed more sadness and anger than male caregivers (Rudd, Viney, & Preston, 1999). In some of the men's comments, it was also evident that they engaged in experiential avoidance as mechanism to cope with the changed relationship (S. Sanders et al., 2003). They feared that if they allowed themselves to recognize and fully acknowledge the changes in the care recipient, they might not be able to fulfill the caregiving tasks anymore. Therefore, the authors (S. Sanders et al., 2003) voiced the concern if avoiding to disclose feelings of pre-death grief might represent the social stigma associated with the open expression of painful emotions that especially applies to men. So, although men often express pre-death grief even less than their female counterparts, the ambiguous situation created by the compounded losses might be even more challenging for them.

The pre-death grief process also differs between spousal caregivers and adult children. In general, S. Sanders et al. (2008) found that when asked about their grief experience, spouses made more statements regarding yearning for the past, isolation, regret, and guilt than adult children. More specifically, Meuser and Marwit (2001) found fundamental differences when they conducted a number of focus groups to investigate differences in grief responses between spouses and adult children. They investigated these differences at each stage of dementia, which also leads to a more detailed understanding of the pre-death grief process across disease stages:

For adult children, the intensity of pre-death grief was almost curvilinear—it was minimal at first, then intense, and moderate at the end (Meuser & Marwit, 2001). When grief was most intense, anger and frustration prevailed and finally, the primary emotion was sadness. During the mild stage of dementia, adult children were mostly task-oriented and focused on the present. Study participants voiced feelings of hopelessness, sadness and anger, but did not directly acknowledge grief. They struggled to contain their grief, denied and avoided to consider what the disease implied for the future. With the moderate stage came a powerful recognition of personal loss; frustration, anger and guilt were openly expressed, and a role reversal was first recognized. Adult children focused on the expected continued grief in the future and voiced to expect relief when the parent dies. When entering the severe stage of the disease, deep sadness, focus on the final and absolute loss, and resignation were predominant in the statements. Adult children defined their grief as additive, and talked about regrets and lost opportunities during the time when the parent was still healthy (Meuser & Marwit, 2001).

For spouses, in comparison, grief was found to increase linearly with sadness as the predominant emotion and shifts to anger and frustration in the end (Meuser & Marwit, 2001).

During the mild stage, spouses were more accepting than adult children. They focused on togetherness and loss of shared aspects of their relationship with the care recipient. They were also more reality-oriented than children; denial and avoidance were not expressed, spouses were instead openly sad and expressed grief. These feelings remained predominant during the middle stage, but spouses also became frustrated. Their statements revealed compassion for the care recipient as well as a strong commitment to caregiving and a focus on current tasks. Similar to adult children, spouses believed that the death of the care recipient would bring relief, but they also focused on being alone after this final loss. Once the severe stage was reached, nursing home placement had occurred for most care recipients. Spouses then expressed a sense of being stuck because their marital relationship had ended or they had realized that a complete role reversal had taken place. Ambiguity, frustration, and anger over this situation were expressed, followed by guilt and regret (Meuser & Marwit, 2001).

Meuser and Marwit (2001) summarized their insights into the differences between spouses and adult children in the experience and expression of pre-death grief in the *stage-sensitive model of grief in dementia caregiving*. The model emphasizes the need to consider the status of the relationship between caregiver and care recipient over the caregiving trajectory. As the loss of the relationship is the driving force behind pre-death grief, it is only reasonable that adult children and spouses differ in their experience because the relationship they lose is entirely different to begin with.

The stage-sensitive model makes reference to how grief manifests itself after nursing home placement (Meuser & Marwit, 2001). The decision for nursing home placement is, in most cases, made at the time when care becomes too demanding to be fulfilled at home or the caregiver lacks the resources for providing the appropriate care. Placement is a milestone with a profound impact on the pre-death grief experience. The physical burden of care is lifted, but caregivers have more time to dwell on losses (Rudd et al., 1999) and might consequently realize their magnitude (Dempsey & Baago, 1998). Also, placement itself constitutes a major loss that is sometimes compared to the care recipient's final death. In contrast to death, placement can be particularly difficult to cope with: Funerals provide ample opportunity for support, sympathy, and remembering to occur while there are no rituals to acknowledge placement (Dempsey & Baago, 1998). It is also because of the finality of the loss, that for many caregivers grief moves from latency into awareness (Dempsey & Baago, 1998) and in one study (Rudd et al., 1999) caregivers of care recipients in a nursing home showed more sadness and guilt than home caregivers.

### **1.1.5 *The impact of pre-death grief during and after caregiving***

Research has demonstrated that post-death grief can sometimes put individuals at risk for the development of physical and mental health problems (Schut & Stroebe, 2005) and the unique constellation of losses during caregiving leads to assume a similar or even heightened risk due to pre-death grief. Doka (1989) even described grief that results from psychosocial losses as unresolvable. A number of studies investigated the consequences of pre-death grief both during and after caregiving:

The intensity of pre-death grief was found to be the best predictor of all negative effects of caregiving, including physical health and distress (Walker & Pomeroy, 1997). It also predicted caregiver burden beyond the effects of demographic variables, behavior problems, and depression (Holley & Mast, 2009). S. Sanders and Adams (2005) identified grief as a significant predictor of depressive symptoms. Pre-death grief can also negatively affect caregiving duties, because caregivers named grief as the biggest barrier in caregiving (Frank, 2008) and it was found to be associated with maladaptive problem solving (Fowler, Hansen, Barnato, & Garand, 2013).

How well caregivers are able to cope with pre-death grief also affects their adaptation to bereavement. In general, dementia caregivers are often in need of additional bereavement services (B. W. Jones, 2009) and more negative outcomes after bereavement were found for caregivers who have problems coping with the care situation (Schulz, Newsom, & Fleissner, 1997). According to the *resource depletion theory* (Chan et al., 2013; Schulz et al., 1997), caregivers' resources can become exhausted because of the prolonged exposure to stressors during caregiving. As a consequence, they lack the resources to adapt to the changed situation. Pre-death grief constitutes one such stressor which explains why it can influence post-bereavement adaptation.

There is a small number of studies that investigated how pre- and post-death grief are related. One study with former caregivers of care recipients who died in a nursing home found no change in intensity of grief from pre- to post bereavement (Kiely et al., 2008). Similarly, Romero, Ott, and Kelber (2014) found that high intensities of pre-death grief also predict high intensities of post-death grief. These studies did, however, not consider how caregivers managed their grief, which seems to play a powerful role in adaptation to bereavement: Acknowledgement of losses was found to be associated with more feelings of relief after bereavement and "readiness to let go" (Collins et al., 1993; P. S. Jones & Martinson, 1992).

The role of preparedness was studied in detail by Hebert, Dang, and Schulz (2006). 222 bereaved caregivers were asked to what extent they were prepared for the care recipient's death.

About one quarter (23%) reported to have not been prepared and these caregivers had more depressive, complicated grief, and anxiety symptoms. No direct association between preparedness and length of illness or length of caregiving was found. It can therefore be hypothesized that preparedness is instead influenced by emotional aspects, i.e., caregivers' management of the losses they experience prior to the care recipient's death.

A similar proposition is made by Hebert, Prigerson, Schulz, and Arnold (2006) in their theoretical model of preparedness. Within the scope of the model, preparedness is defined as a multicomponent concept that has medical, psychosocial, spiritual, and practical components. The authors propose that end-of-life conversations are central for the development of preparedness and name discussing grief and loss as one important focus of these conversations. Therefore, addressing grief and loss should be a part of interventions to facilitate preparedness.

In conclusion, effective coping with pre-death grief is important for two reasons: First, it directly influences caregivers' health and ability to provide care, and second, it can facilitate post-bereavement adaptation. Interventions that foster adaptive coping with pre-death grief and prevent its adverse impacts are therefore needed.

## **1.2 Design and effects of psychosocial and psychotherapeutic interventions**

The previous section has demonstrated that loss, change, and pre-death grief play a significant role during caregiving and are closely connected to caregivers' health. These results demonstrate that while most persons cope well with post-death grief without the need of formalized help (Currier, Neimeyer, & Berman, 2008; Schut & Stroebe, 2005), pre-death grief calls for support. Yet, up until the early 2000s, pre-death grief was not the focus of intervention studies with dementia caregivers (Meuser et al., 2004) and until today studies of high methodological quality are still lacking. The next section briefly touches upon post-death grief interventions and general interventions for caregivers and then moves on to discuss grief-specific interventions for dementia caregivers in more detail.

### **1.2.1 Interventions for the bereaved**

Worden (2009) proposed acceptance of the reality of the loss and management of emotions as the primary goals of post-death grief counseling and therapy. Interventions that aim to facilitate coping with post-death grief have received extensive scholarly attention.

Meta-analyses have shown that interventions are effective when they are designed as indicated interventions, i.e., specifically target persons that are in need of help because they have problems coping with their loss and grief (Currier, Holland, & Neimeyer, 2010; Currier et al., 2008). Interventions based on the principles of cognitive-behavioral therapy (CBT) were

more effective than non-CBT approaches when different types of interventions were compared (Currier et al., 2010). They resulted in greater reductions in, for example, symptoms of grief, depression, and distress immediately after the end of the intervention and after a follow-up period.

### **1.2.2 Interventions for dementia caregivers**

A vast number of interventions for dementia caregivers has been developed and evaluated over the last decades. In general, these interventions proved their effectiveness (Elvish, Lever, Johnstone, Cawley, & Keady, 2013; Gallagher-Thompson & Coon, 2007; Selwood, Johnston, Katona, Lyketsos, & Livingston, 2007). As a result of a meta-analysis of 127 studies, Pinquart and Sörensen (2006) reported small, but positive immediate effects on caregiver burden, depressive symptoms, well-being, knowledge, and caretaking abilities. After a follow-up period, these effects were mostly reduced to small effect sizes, but positive effects on caregiver burden, depressive symptoms, and knowledge were still evident.

Interventions that combine different components, such as education, support, and respite, seem to be most effective (Schulz & Martire, 2004). These multicomponent interventions successfully increased knowledge and skill; yet, they were less effective for emotional aspects, such as caregiver burden and depression. Positive effects on caregiver burden and large effects on depression were found for CBT-based interventions (Pinquart & Sörensen, 2006). Similarly, Gallagher-Thompson and Coon (2007) found the highest effect sizes for CBT-based interventions that specifically targeted depression and anxiety. The effect sizes found in their meta-analysis compare favorably to those of the treatment of affective disorders (Gallagher-Thompson & Coon, 2007). A study by Holland, Currier, and Gallagher-Thompson (2009) further pointed towards CBT as a successful form of support during caregiving that also facilitates caregivers' adaptation to bereavement. Effects on pre-death grief were not addressed in this study, but the results suggest the appropriateness of CBT for pre-death grief.

It has to be noted that most intervention programs aim to support caregivers by providing information or teaching new skills. Yet, the fact remains that many aspects of the disease and the care situation cannot be changed: Losing one's own freedom, sacrificing physical and mental resources, witnessing the care recipient's decline, and negative experiences due to symptoms of dementia are constant companions to caregivers. These difficult experiences result in negative emotions and cognitions. An answer to coping with this demanding situation can lie in *acceptance*. Acceptance describes the active tendency to remain in contact with private

experiences without altering their form, their frequency, or the context that caused them (Hayes et al., 1999). Therewith, it is the opposite of experiential avoidance that has been described above as some caregivers' reaction to pre-death grief. In the light of the findings regarding the detrimental effects of experiential avoidance (Davis et al., 2014; Spira et al., 2007), acceptance of both internal events and dementia offers a path to remaining psychologically flexible, functioning, and healthy despite the many unchangeable aspects of dementia caregiving. Understandably, this is challenging for many caregivers.

An answer to problems that center around experiential avoidance is *Acceptance and Commitment Therapy* (ACT; Hayes et al., 1999), a third-wave approach to CBT. The aim of ACT is to move from evaluating thoughts and emotions as symptoms that have to be avoided, changed, or eradicated towards viewing them as transient psychological events (Davis et al., 2014; Hayes et al., 2004). This changed view will then lead to flexibility and contribute to well-being. The appropriateness of this approach for dementia caregivers was investigated by Losada et al. (2015). They used ACT to promote acceptance of adverse internal events related to caregiving and compared its efficacy to traditional CBT in a study with 135 caregivers. Both ACT and CBT had successfully reduced depressive symptomatology, anxiety, and dysfunctional thoughts after the end of the intervention and had increased leisure activities. Only in CBT could effects for depression be maintained up until the six-month follow-up assessment, but only ACT effectively reduced experiential avoidance.

Despite the large body of intervention studies with dementia caregivers, it is still of concern that not all programs are effective and that most effects remain small and cannot be maintained over a longer period of time. It is a possible explanation that these studies fail to produce more convincing results because they lack a focus on pre-death grief. The literature that has been presented above illustrates the role of pre-death grief over the whole caregiving trajectory and its relation to other indicators of physical and mental health. If grief is therefore not adequately addressed in interventions, caregiver well-being cannot increase. Consequently, interventions that specifically focus on pre-death grief are needed. As CBT-based interventions have been found to positively affect emotional aspects, CBT is the framework of choice. Acceptance-focused interventions are another promising approach since caregivers often avoid pre-death grief.

### ***1.2.3 Grief-specific interventions for dementia caregivers***

The findings discussed above strongly suggest that interventions for dementia caregivers should target pre-death grief. Suggestions as of the goals of grief-specific

interventions have been made throughout the literature. With regard to ambiguous loss, Boss and Kaplan (2003) suggested to focus on helping caregivers to consciously recognize mixed emotions associated with ambiguity to “minimize and manage indecisiveness and immobilization” (p. 222). Other authors (e.g., Dempsey & Baago, 1998; Frank, 2008; Walker et al., 1994) emphasized the importance of normalization and validation of the experienced losses and the feelings of grief. These strategies may stop disenfranchisement and provide the opportunity to complete unfinished business. Silverberg (2007) proposed that grief interventions should focus on three main aspects: Acknowledging pre-death grief and loss, assessing pre-death grief, and assisting in managing it. Thereby, caregivers should be given the opportunity to “let go”.

Although these approaches have been discussed for some time, only four studies that specifically developed, applied, and evaluated grief-specific interventions could be identified. Their content, results, and methodological limitations will be briefly outlined below.

Kasl-Godley (2003) reported a group program for both active and bereaved caregivers. It comprised elements such as supportive discussions to share experiences, psychoeducation to inform about grief and loss and normalize the experience, art therapy to assess and process difficult and painful emotions, cognitive restructuring, and resource dissemination. The 13 study participants met for two hours weekly over a total period of eight weeks. Depressive symptomatology declined for all participants and subjective evaluations were positive. Unfortunately, no results regarding treatment effects on grief were reported, although a measure of grief was included. The study’s results regarding depression are promising, but the lack of a control group, the small sample size, and no significance testing constitute major limitations. Moreover, delivering the same intervention to both active and bereaved caregivers has to be regarded critically because pre- and post-death grief pose different challenges to caregivers. Last, although Kasl-Godley (2003) based her intervention program on the assumption that how well caregivers adapt to role change and cope with losses depends on how pre-death grief is managed, it is not outlined how management of pre-death grief was conceptualized in the study.

In another study, S. Sanders and Sharp (2004) evaluated a psychoeducational grief group. The group was based on a psychoeducational model for post-death grief groups and intervention strategies for addressing grief and loss after bereavement. Its key concept was ambiguous loss. Objectives were to provide education, examine changes that trigger increased grief and loss, explore coping mechanisms that help to manage grief and loss, identify formal and informal means of support, and develop strategies to celebrate the life of the person with dementia before and after disease onset. The group specifically targeted caregivers of care

recipients in the middle and late stages of dementia. Over the five-week intervention duration participants should be enabled to identify their own feelings of grief and loss as well as coping strategies and community resources available to them. Ten caregivers participated and their scores on a measure of pre-death grief were compared with a one-time only measurement of a control group ( $n = 7$ ). Analyses revealed that intervention group scores increased between the baseline and post-intervention assessments. However, because of the small sample size, no significance test was conducted.

The increase in pre-death grief was an unexpected result; participants did, however, state to have found the group extremely helpful. They had not considered the role of grief and loss previously and had therefore attributed their physical and mental health decline to stress and depression (S. Sanders & Sharp, 2004). Participants also stressed that they appreciated that the group provided the opportunity to disclose feelings of grief and loss. Before attending the group, many caregivers had engaged in denial and avoidance of grief and had not been informed that their experience of grief was normal (S. Sanders & Sharp, 2004). These statements indicate that the result might in fact reflect a heightened awareness for pre-death grief. The authors further report that some participants requested follow-up sessions with the group facilitator as their grief intensity had heightened during the intervention duration. A five-week period might therefore be too short to both recognize pre-death grief and develop coping strategies. In conclusion, despite its limitations, the study offers valuable insights into how pre-death grief interventions should be designed and what they can accomplish.

While the two studies described above report group programs, the multicomponent program *Easing the Way* (Ott, Kelber, & Blaylock, 2010) offered individual support. The intervention specifically targeted spouses and was developed based on earlier research on the nature of pre-death grief (Marwit & Meuser, 2002; Meuser et al., 2004; Ott et al., 2007). The primary aim was to decrease pre-death grief by reducing dysfunctional coping mechanisms and strengthening the use of problem-solving and emotion-focused coping strategies. The main focus was on acceptance, normalization, challenging dysfunctional cognitions, reframing, education, identification of respite services, and family meetings. Therapists combined supportive grief counseling, family problem solving, emotional support, and skill building, and referred to community resources. These strategies were chosen and applied according to the caregivers' personal scores on subscales of the *Marwit–Meuser Caregiver Grief Inventory* (MM-CGI; Marwit & Meuser, 2002), leading to a highly individualized intervention. Sessions were conducted per telephone or in a face-to-face setting. Duration of both sessions and the total intervention period was very heterogeneous: Sessions lasted between one and two hours



and the mean intervention duration was 4.8 months, varying between three and eight sessions per caregiver.

The sample size was small ( $N = 20$ ) because the study was conducted as a pilot study. When comparing pre- and post-intervention assessments, a significant moderate effect was found for pre-death grief along with positive effects on depression, anxiety, positive states of mind, and self-efficacy. Among the strengths of the study is the eight-month follow-up assessment. By the time of this assessment, scores for active caregivers had remained stable; however, for caregivers whose care recipients were institutionalized or had died in the meantime grief scores had returned to baseline levels and depression had increased (Ott et al., 2010).

These results indicate that caregivers need further specific support after nursing home placement of the care recipient. One such intervention is the Chronic Grief Management Intervention (Paun et al., 2015) for caregivers of care recipients in long-term care. It was based on the same manual as Easing the Way (Ott et al., 2010), yet adapted to the specific situation of this subgroup of caregivers. Focus is on knowledge and communication, conflict resolution, and grief processing skills to assist caregivers in managing losses and pre-death grief. The intervention was delivered by psychiatric nurses as a multi-component group intervention over a period of 12 weeks with sessions lasting from 60 to 90 minutes. Sessions 7 to 12 were dedicated to pre-death grief and focused on recognizing losses, processing reactions to separation, re-experiencing the relationship, relinquishing old attachments, adjusting to the new situation, and forming new attachments (Paun et al., 2015). The study was conducted as a randomized-controlled trial (RCT) and included a three-month follow-up assessment. Between the baseline and post-intervention assessments, pre-death grief decreased in the intervention group ( $n = 34$ ) while it remained stable in the control group ( $n = 49$ ). The effect could, however, not be maintained up until the time of the follow-up assessment (Paun et al., 2015).

It has to be regarded favorably that insights into the nature of dementia caregivers' pre-death grief have led to the development and evaluation of grief-specific interventions. Although the results of these first intervention studies are promising, they need to be regarded cautiously because of a number of limitations. With the exception of the study by Paun et al. (2015), all studies were declared to be pilot studies and therefore only treated few caregivers and incorporated no real control group; follow-up assessments were only conducted by Paun et al. (2015) and Ott et al. (2010).

The most successful intervention (i.e., Easing the Way; Ott et al., 2010) provided individual support while all other studies used group formats. Group programs offer support to

a larger number of caregivers, but also have considerable disadvantages. They are often difficult to attend for caregivers (Wilz, Schinköthe, & Kalytta, 2015) and do not offer the opportunity to focus on one caregiver's individual situation, emotional reaction, and underlying assumptions. This focus might be especially important when targeting the loss of a significant personal relationship, which constitutes the core of pre-death grief.

Of note, the opposite pattern of results emerged in the studies by S. Sanders and Sharp (2004) and Ott et al. (2010)—grief scores increased in Sander's and Sharp's (2004) study and decreased in the study by Ott et al. (2010)—although pre-death grief was assessed using the exact same instrument. In comparison, S. Sanders and Sharp (2004) provided a group program of a five-week duration while *Easing the Way* (Ott et al., 2010) was an individualized intervention that covered almost five months. Results therefore suggest that caregivers need individual, long-term support to not only recognize their losses but also develop strategies to cope with pre-death grief.

Furthermore, although CBT has proved to be the most successful form of therapy for dementia caregivers, none of the pre-death grief-interventions described above had a CBT background or involved clinical psychologists. It can therefore be concluded that although the origin and nature of pre-death grief are well understood at this point, this knowledge has yet to lead to intervention programs that prove their effectiveness in studies of high methodological quality.

## **2 The Present Dissertation**

### **2.1 Research questions and aims**

It was the aim of the present dissertation to answer this call for the development and subsequent evaluation of a grief-specific intervention for dementia caregivers. Its objectives were threefold: First, to provide insight into how intervention strategies rooted in CBT principles can be applied by therapists to specifically target pre-death grief and meet the caregivers' needs. Based on these results, a grief-specific intervention module was developed and integrated into a comprehensive intervention program, the Tele.TAnDem intervention. It was the second objective to evaluate this intervention's effectiveness regarding caregivers' coping with pre-death grief. As an important prerequisite for this evaluation, the third objective of the dissertation was to develop an instrument for the measurement of pre-death grief. The necessity of this last objective stems from the fact that measures used for evaluation up until this point were unsatisfactory for a number of reasons that are outlined below.

Three separate studies were conducted to meet these objectives. Across these studies, emphasis was placed on the combination of different methodological approaches of high quality. The use of these methods—both quantitative and qualitative—allowed to arrive at a comprehensive understanding of pre-death grief interventions and to overcome methodological limitations of previous studies.

In detail, the first objective was pursued in Study I. Using a qualitative approach, this study examined intervention strategies that were applied by therapists in a CBT-based trial to facilitate caregivers' coping with pre-death grief, loss, and change. The obtained results provided the foundation for the development of the grief-specific intervention module. Study II took on the development and validation of an instrument of sound theoretical and methodological quality that allows to assess pre-death grief. Finally, Study III links the two preceding studies: Using the CGS, it evaluates if the intervention program including the grief-specific intervention module can improve caregivers' coping with pre-death grief.

### **2.2 Overview of the setting: Tele.TAnDem & Tele.TAnDem.transfer**

The three empirical studies all draw on data from two RCTs that evaluated a telephone-based intervention for dementia caregivers in Germany: Tele.TAnDem and Tele.TAnDem.transfer (G. Wilz & R. Soellner, primary investigators). Both trials are briefly described below with regard to their aims, study design, and intervention programs. This outline provides the background for the summary of each of the three studies that is given afterwards.

### 2.2.1 *Tele.TAnDem*

Tele.TAnDem was conducted between the years of 2008 and 2010. The primary aim of this trial was to evaluate the efficacy of an individual, cognitive-behavioral, telephone-based intervention for caregivers of persons with dementia. The sample was recruited all over Germany via advertisements in print media, TV and radio broadcasts, via the Internet, cooperating institutions, or primary care physicians. Caregivers were eligible for the study if they fulfilled the following criteria: Fulltime in-home caregiver of a person with a diagnosis of dementia and a score  $> 3$  on the *Global Deterioration Scale* (Reisberg, Ferris, de Leon, & Crook, 1982), no simultaneous psychotherapy, no cognitive impairment, and no acute mental or physical illness. Participants ( $N = 229$ ) were randomly allocated to either the intervention group, active control group, or untreated control group.

Intervention group participants received seven therapy sessions of 50-minute duration each over a period of three months. The first four sessions took place at weekly intervals and two further sessions followed at fortnightly intervals. The last session was conducted after an interval of another month. All sessions were held via telephone, with the exception of the first session that was sometimes conducted at the study center or in the home of the caregiver. The telephone-based setting was chosen because it was previously demonstrated to be highly suitable for dementia caregivers (Tremont, Davis, Bishop, & Fortinsky, 2008). Interventions delivered via telephone allow caregivers flexible access to support without the problems that they usually encounter in face-to-face or group settings, such as logistic problems, time constraints, or the fact that the care recipient cannot be left alone.

In the first session, one to three individual problem areas were identified and therapy goals were specified (Wilz, Schinköthe, & Soellner, 2011). The remainder of the intervention was dedicated to working towards these goals. Therapists adhered to a manual but were free to individually weigh the modules according to the caregivers' problem areas. The manual described multiple components that focus on managing behavior problems and personality changes of the care recipient, reducing the caregiver's social isolation, increasing utilization of professional and informal support, reducing stress, fostering emotion regulation, reinforcing positive activities, and supporting acceptance of loss and change. Therewith, the manual was rooted in CBT and the techniques (e.g., cognitive restructuring, identifying and scheduling value-oriented positive activities, anger management, problem-solving training, or role-play) were adapted to match dementia caregivers' specific needs. Therapists were six clinical psychologists trained in CBT and with expertise in dementia and caregiving.

Participants of the active control group learned a relaxation technique (i.e., progressive muscle relaxation; Jacobson, 1990) and received all instructions via telephone. Sessions were parallel in duration and frequency to those received by the intervention group. Participants of the untreated control group received written educational material about dementia and caregiving as well as a financial compensation.

Assessments of demographic variables and primary and secondary outcome measures (i.e., problem-solving skills, caregiver burden, body complaints, emotional well-being, depressive symptoms, and quality of life) were conducted at baseline before randomization, directly after the intervention ended, at six-month follow-up, and at two-year follow-up. At the time of the post-intervention assessment, intervention group participants showed improved emotional well-being in comparison to both the active and the untreated control group (Wilz & Soellner, 2015). There was also a positive treatment effect regarding body complaints at the time of the post-intervention assessment and regarding subjective health status at the time of the six-month follow-up assessment. Also at the time of the six-month follow-up assessment, intervention group participants showed fewer depressive symptoms compared to the active control group (Wilz & Soellner, 2015). Two years after the end of the intervention, a positive treatment effect on emotional well-being was still evident (Wilz, Meichsner, & Soellner, in press). Participants' subjective evaluations of the intervention, specifically its content and the telephone-based setting, were also positive (Wilz et al., 2011). The trial therefore successfully demonstrated the feasibility, acceptability, and efficacy of the Tele.TAnDem intervention.

### **2.2.2 *Tele.TAnDem.transfer***

Tele.TAnDem.transfer (Soellner, Reder, Machmer, Holle, & Wilz, 2015) was a subsequent trial conducted between the years of 2012 and 2015. The intervention program was refined according to the comments made by the participants of the first trial and study therapists. Most important, the intervention duration was extended to cover a six-month period with 12 sessions. The intervention program was implemented in care provision structures, and it was the aim of the trial to assess the intervention's effectiveness and further compare it with the effectiveness of the same intervention delivered in a face-to-face setting (Soellner et al., 2015).

Tele.TAnDem.transfer was carried out as a non-blinded, two-armed parallel randomized controlled trial with a third non-randomized group (Soellner et al., 2015). Again, participants were recruited nationwide via newspapers, TV and radio broadcasts, cooperating institutions, a project homepage, mailing lists, and primary care physicians. To be eligible for study participation, caregivers had to be the primary in-home caregiver of a person diagnosed with

dementia, have no acute physical illness or mental disorder, and receive no ongoing psychotherapeutic treatment. Those participants who lived in the area of one of the three study centers and who were able to participate in face-to-face sessions were assigned to the face-to-face intervention group ( $n = 49$ ); all other participants were randomly allocated to either the telephone-based intervention or the control group ( $n = 273$ ).

Data was collected at three times (i.e., at baseline, post-intervention, and six-month follow-up) and primary and secondary outcome measures were, for example, emotional well-being and depressive symptoms, coping with pre-death grief and loss, coping with stress and realization of resources, body complaints, aggressive behavior towards the care recipient, and utilization of professional support. Comprehensive analyses of treatment effects are currently ongoing; the analysis of the treatment effect regarding coping with pre-death was one of the objectives of the present dissertation.

As mentioned above, intervention group participants received 12 therapy sessions of 50-minute duration each over a period of six months. The first four sessions were conducted at weekly intervals, the following six sessions at fortnightly intervals, and the two last sessions followed at monthly intervals. Study therapists were 15 clinical psychologists trained in CBT who received pre-intervention training in delivering the Tele.TAnDem intervention and regular supervision.

Therapists followed an intervention manual (Wilz et al., 2015) that comprises ten modules: Basic Elements of Caregiver Interventions; Skills to Structure Sessions and Handle Crises; Changing Dysfunctional Cognitions; Managing Behavior Problems; Stress Management and Regulation of Emotions; Creating Value-oriented Positive Activities; Coping with Change, Loss, and Grief; Increasing the Use of Social and Professional Support in Home-based Care; Recognizing the Limits of In-home Care and Preparation for Nursing Home Placement; and Evaluation (i.e., summary of achieved goals and changes).

The module Coping with Change, Loss, and Grief is most important for the present dissertation. It describes intervention strategies that target recognition of pre-death grief, identification of dysfunctional cognitions concerning pre-death grief, and avoidance of painful emotions. It should be noted that the intervention did not aim at a reduction of pre-death grief per se, as grieving was understood as a normal and appropriate reaction to the caregivers' experiences over the disease trajectory. Further, the intervention did not promote detachment from the care recipient. As numerous authors (e.g., Blandin & Pepin, 2015; Silverberg, 2007; Spira et al., 2007) have stressed the importance of accepting negative emotions and cognitions, the primary aim of the module was instead to help caregivers recognize losses and changes, and

accept the disease, the terminal outcome, and the unchangeable situation as a new reality. At the core of that, caregivers learned to cope through *management of painful emotions*. That means that therapists conveyed how caregivers can recognize and accept emotions such as grief, sadness, loneliness, desperation, and anger, while at the same time they maintain their daily functioning as a caregiver. The key points of the module are briefly outlined below.

The first main point is to help caregivers to *identify and express painful thoughts and emotions*, which is often hindered by disenfranchisement and the ambiguity of losses. First, therapists ask caregivers to describe the changes the disease has caused. This exploration can initiate a cognitive and emotional processing of changes and losses. The therapeutic focus is then primarily on validation and normalization of pre-death grief. Besides, guilt is among other addressed painful emotions, because many caregivers feel guilty due to beliefs how they should do more for the care recipient or their wish for the care recipient to die. Emphasis is also placed on anxiety regarding future losses, future decisions (e.g., for or against nursing home placement), and the situation after the care recipient's death. It is important to address these concerns because anxiety can lead to feelings of helplessness. Therapists therefore initiate caregivers' planning for the future to subsequently strengthen self-efficacy and help to develop coping strategies and realistic expectations.

The next main point is *managing the painful emotions* associated with losses and change. Through the therapists' use of psychoeducation and normalization, caregivers learn how acceptance can positively affect their well-being while avoidance can have negative consequences. As a goal, caregivers should be able to recognize and verbalize their avoided or suppressed emotions. To promote that, therapists repeatedly address emotions and identify associated emotions when discussing losses.

*Acceptance of thoughts and emotions*, the following main point, directly targets caregivers' difficulties in accepting the disease and its progressive nature as well as the painful emotions associated with pre-death grief. Therapists help caregivers to learn to differentiate between their emotions and also recognize consequences of different coping strategies (i.e., avoidance vs. acceptance). Mindfulness exercises that can be incorporated into therapy sessions are outlined because they can facilitate the conscious experience of painful emotions and their acceptance.

Apart from the focus on emotions, the module also includes strategies for the *identification and change of dysfunctional cognitions*. Many caregivers have unhelpful assumptions regarding, for example, the appropriateness of their emotions (e.g., "I must not grieve since my family member is still alive.") or the consequences of their reaction to losses

(e.g., “To accept changes and losses means to give up”). Targeting these cognitions is essential because they can hinder identification, expression, and acceptance of painful emotions. Therapists can help caregivers to identify these cognitions and develop more helpful alternatives with a combination of psychoeducation and techniques of cognitive restructuring (e.g., Socratic dialogue).

The module further addresses the *redefinition of the relationship*. Goals are to explore changes in the relationship between caregiver and care recipient, which have already occurred and that have to be expected in the future, and then to define a new role for the caregiver. Therapists address changes that are associated with the new role, including its pros and cons, and support caregivers to develop self-efficacy and trust in their capability to meet the challenges of the new role.

Besides the focus on painful experiences, emphasis is also placed on *(re)activation of resources*, which facilitates management and acceptance of emotions, and *(re)activation of positive emotions*. Caregivers are given the opportunity to experience their own positive characteristics and abilities in order to better recognize their needs and develop self-efficacy regarding problem management. Therapists can prompt this experience by asking caregivers which coping strategies they have found helpful in the past or what helped them during past times of grief. In addition, focus is on past and current positive experiences with the care recipient.

Last, strategies for facilitating *adaptation to bereavement* and preparation for the time after the care recipient’s death are outlined. Among these strategies is psychoeducation on post-death grief and on mechanisms for coping with the acute grief reaction. Another important component is to inform caregivers how pre-death grief can influence post-death grief, especially that it can result in a lower intensity of post-death grief. This information is important to prevent unhelpful beliefs (e.g., not grieving “enough”) and subsequent feeling of guilt. Planning for the time after the care recipient’s death and identifying alternatives to care related tasks can also be part of the intervention to facilitate adaptation to bereavement.

Taken together, the main aspects of caregivers’ losses and pre-death grief are outlined in the module Coping with Grief, Loss and Change that is part of the Tele.TAnDem intervention. Corresponding therapeutic strategies are described with regard to specific difficulties and challenges, and each strategy is illustrated by case examples.



## 2.3 Overview of the three studies

The following section provides an overview of the three studies that were conducted within the dissertation. It outlines aims, methodology, and key findings of each study and briefly touches upon implications. A general discussion of the results, implications, and limitations is given in Section 3.

### 2.3.1 *Study I. Managing Loss and Change: Grief Interventions for Dementia Caregivers in a CBT-based Trial*

The first study built upon research on grief interventions that has been presented in detail above. The rationale behind the study was that interventions that can successfully enable caregivers to cope with pre-death grief require a sound theoretical and evidence-based foundation. Because of the multifaceted and complex nature of pre-death grief (e.g., Noyes et al., 2010; S. Sanders & Corley, 2003; S. Sanders et al., 2008), interventions should further comprise strategies that allow to address every aspect of pre-death grief.

Study I was aimed at identifying these strategies within the therapy sessions of the Tele.TAnDem trial, which already offered an individualized intervention rooted in CBT principles. As pre-death grief and loss play a major role in dementia caregiving, they were expressed by study participants and a first module that provided therapists with guidelines on how to respond was already included in the manual. Not much was, however, known about the actual application of intervention strategies when caregivers disclosed their grief. It was therefore the objective of the study to provide comprehensive insights into how therapists realized CBT-based interventions with regard to pre-death grief and loss within the Tele.TAnDem trial.

To meet this objective, *qualitative content analysis* (Mayring, 2010), a systematic theory- and rule-based analysis of communication, was applied. This method was chosen because it permits to structure and differentiate between intervention strategies and was therefore well suited to pursue the study's aims. Qualitative content analysis further emphasizes a satisfactory intercoder reliability, which ensures objectivity of the analysis (Mayring, 2010).

Qualitative content analysis requires written material and transcripts of therapy sessions were prepared for the present study. As the first step in the analysis, sessions with caregivers of the intervention group within which grief and loss were addressed were identified via a two-tiered process. The grief-specific sequences were then transcribed verbatim according to previously established rules. Measures were taken to ensure the procedure was valid (e.g., use of two independent raters, cross-check of unselected sessions). As a result, transcripts of

sequences with a grief-specific focus from 61 therapy sessions were obtained. These sessions were part of the therapies with 33 caregivers, i.e., 26.2% of the intervention group of the Tele.TAnDem sample. It is among the strengths of the first study that all sessions with a focus on pre-death grief were included, thus allowing a complete analysis of therapist responses to expressions of grief in the Tele.TAnDem trial.

After the material was identified, the research process turned to the core of qualitative content analysis: The development of a category system. To meet the study's objective, this category system was required to allow the coding of grief-specific interventions. It was developed in a mostly deductive approach and the computation of the intercoder reliability ensured objectivity and adherence to high methodological standards for qualitative research (Flick, 2012). Early versions of the category system were applied to 10% of the material by two independent raters; disagreements were discussed and category definitions and coding rules were subsequently revised until an intercoder reliability that allowed confident interpretation of the coded data was reached (Krippendorff's  $\alpha = .80$ ). The final category system *Grief Intervention Strategies* comprises four categories that represent the overarching intervention strategies to target pre-death grief: Recognition and Acceptance of Loss and Change, Normalization of Grief, Redefinition of the Relationship, and Addressing Future Losses. All transcripts were coded with the developed category system.

Of the four strategies in the category system, Recognition and Acceptance of Loss and Change was used most frequently, followed by Addressing Future Losses, Normalization of Grief, and Redefinition of the Relationship. Analysis of the coded data revealed themes and problems therapists addressed with these strategies (e.g., changes as part of dementia, identification of resources for coping with anticipated losses, adverse effects of avoidance, role change), and the cognitive-behavioral techniques they applied (e.g., psychoeducation, normalization, validation, cognitive restructuring).

In summary, the first study illustrated that therapists focused on identifying, understanding, and managing the painful emotions associated with experienced and anticipated losses; normalized and validated pre-death grief as part of the care situation; and helped caregivers to redefine their changed relationships with the care recipients. The four main strategies are rooted in CBT and successfully cover the multiple facets of pre-death grief, thus ensuring that what is most distressing for caregivers can be addressed. The variety of identified techniques further illustrated that therapists who are trained in CBT have a large spectrum of intervention strategies at hand that can, in combination, support caregivers to accept loss and change and overcome avoidance of associated painful emotions.

The obtained results supported the development of the grief-specific module that was included in the intervention manual for the subsequent trial Tele.TAnDem.transfer. Being grounded in the reality of therapy with grieving caregivers is a major strength of this module and advances the field of pre-death grief interventions. With the developed category system the first study also introduced a new instrument for the qualitative assessment of intervention strategies to the field of grief interventions.

### **2.3.2 Study II. The Caregiver Grief Scale: Development, Exploratory and Confirmatory Factor Analysis, and Validation**

Study II was concerned with methodological aspects of the assessment of pre-death grief, because treatment effects are only meaningful when the construct of interest is operationalized precisely. In the case of pre-death grief, an instrument that covers its multiple aspects is needed. Existing instruments only partially met this requirement and, therefore, the second study took on the development of a new instrument for the assessment of pre-death grief.

Past studies have taken what can be summarized as three different approaches to the assessment of pre-death grief. First, a small number of studies evaluated an intervention's effectiveness on some outcome other than grief, such as depression (Kasl-Godley, 2003). This information is of interest from a clinical perspective because pre-death grief has been shown to increase depressive symptoms (Holley & Mast, 2009; S. Sanders & Adams, 2005). Yet as demonstrated above, pre-death grief and depression are sufficiently different. The effects of a grief-specific intervention on symptoms of depression are therefore of secondary interest while the evaluation of treatment effects on a measure of grief should be the primary concern.

Second, other studies did include one such measure, but none that was specific to pre-death grief. Also in Kasl-Godley's (2003) study, the *Texas Revised Inventory of Grief* (TRIG; Faschingbauer, Zisook, & DeVaul, 1987), an instrument developed for the assessment of post-death grief, was used. How pre- and post-death differ has been explained in detail above. Some studies (e.g., Ponder & Pomeroy, 1997) used subscales from the *Grief Experience Inventory* (GEI; C. M. Sanders, Mauger, & Strong, 1985). Although a non-death version of this instrument is available, it still has to be regarded as inadequate because it does not address the unique aspects of pre-death grief. Some more recent studies (e.g., Kiely et al., 2008; Passoni et al., 2015) have chosen the *Prolonged Grief Disorder-12* (PG-12; Prigerson, Vanderwerker, & Maciejewski, 2008). A pre-loss version of this instrument is available, but its focus is on the assessment of symptoms for a diagnosis of *prolonged grief disorder* (PGD). PGD describes a

persistent and disabling form of grief that is characterized by intense distressing symptoms (e.g., yearning for the deceased, intrusive thoughts, numbness, and a sense of meaninglessness) over more than six months following post-loss (Prigerson et al., 2009). Diagnosing dementia caregivers with PGD has to be regarded critically, because from our perspective pre-death grief constitutes an adequate reaction to the caregivers' experience of loss and change over the disease trajectory that does not warrant a diagnosis of a mental disorder. An instrument with a specific focus on the caregiving experience is the *Anticipatory Grief Scale* (AGS; used by, for example, Johansson et al., 2013; developed by Theut, Jordan, Ross, & Deutsch, 1991). It was, however, validated only with a small, homogeneous sample (i.e., 27 wives of veterans), and its items focus more on coping with dementia than on grief. None of these instruments is well suited for the assessment of pre-death grief: Due to their lack of specificity to pre-death grief, significant aspects, such as ambiguity of losses or avoidance or acceptance of painful emotions, would be missed when applying them.

Third, the majority of studies reviewed above used the MM-CGI (Marwit & Meuser, 2002) that has been developed specifically for the assessment of pre-death grief. The authors conducted an exploratory factor analysis (EFA) of 184 original items based on statements made by spouses and adult children during focus group discussions. The final inventory consists of 50 items that represent three distinct factors. The first factor, Personal Sacrifice and Burden, measures what caregivers had to give up and the extent to which they experience personal losses. Heartfelt Sadness and Longing, the second factor, represents the emotional reaction to the loss of the relationship with the care recipient. It measures emotions like sadness and is the closest to traditional grief. The third factor, Worry and Felt Isolation, addresses caregivers' worries about the future and how they perceive losing personal connections with others due to caregiving responsibilities.

The origin of the items and the intensive research endeavors into the development and validation of both a long and short form (Marwit & Meuser, 2002; Marwit & Meuser, 2005) of the MM-CGI are clear advantages of this instrument. It is, however, of concern that the authors have observed that only one factor—Heartfelt Sadness and Longing—relates to true grief, but still regard the others “to be grief-related factors” (Marwit & Meuser, 2002, p. 759). With items such as “I carry a lot of stress as a caregiver” or “I lay awake most nights worrying about what’s happening and how I’ll manage tomorrow”, the other two factors appear to be more closely associated with caregiver burden and depression, respectively. This overlap has to be regarded critically for a number of reasons.

First, this overlap makes the inventory not grief-specific. Pre-death grief is different from depression, and also burden that relates to the extent that caregiving duties have a perceived negative influence on the caregivers' emotional, social, financial, and physical functioning (Zarit et al., 1986). Grief also necessitates a different therapeutic approach, and, since the MM-CGI does not exclusively assess grief, administering it may not provide therapists with the necessary or expected information. Second, the overlap makes the MM-CGI unsuitable for use in research studies on the differential effects of interventions on, for example, grief versus depression. Third, the MM-CGI's lack of parsimoniousness can also pose a problem in research studies, as many aspects of this instrument, such as "loss of sleep" or lack of "support from others" (Marwit & Meuser, 2002, p. 759) are similarly assessed by measures specific to depression and burden. These measures are usually administered in intervention studies with caregivers and are better suited for the assessment of these constructs. As a consequence, assessments become more time consuming, which could lead to higher drop-out rates among study participants. In some studies (e.g., DeCaporale, Mensie, & Steffen, 2013), researchers have tried to overcome this problem by only using the Heartfelt Sadness and Longing subscale, but one final worrying limitation of the MM-CGI still remains: No items relating to the avoidance of grief and its expression are included. Study I has illustrated how important this aspect and corresponding interventions are. The detection of avoidance, false assumptions, and associated behaviors should therefore be a key component of any instrument used to assess pre-death grief.

The final concern with existing instruments is a methodological one: Most existing measures of grief in general and of caregivers' grief, specifically, were developed using EFA. EFA results can be difficult to replicate, since they are often based on chance correlations. In the past, replication seemed especially difficult with caregiver samples (e.g., Cheng, Kwok, & Lam, 2014) and factor solutions should therefore always be verified using confirmatory factor analysis (CFA).

For these reasons, the objectives of Study II were to overcome the theoretical and methodological limitations outlined above and to develop and inspect psychometric properties and construct validity of a new instrument for the measurement of pre-death grief. The instrument was named the *Caregiver Grief Scale* (CGS). For its development, an initial pool of 21 items was created. Appropriate items were selected from two different kinds of sources, the MM-CGI factor Heartfelt Sadness and Longing (Marwit & Meuser, 2002) and established post-death instruments; i.e., the German version of the TRIG (Faschingbauer et al., 1987; Znoj, 2008), the *Würzburg Grief Inventory* (WüTI; Wittkowski, 2013), and the German version of

the *Inventory of Complicated Grief–Revised–Short Form* (ICG–R; Prigerson & Jacobs, 2001; Znoj, 2004). If necessary, items were adapted to better reflect pre-death grief. In addition, seven new items were developed based on statements made by caregivers in the first Tele.TAnDem trial; these items predominantly refer to the avoidance of grief that was not covered comprehensively by existing instruments. Items are rated on a 5-point Likert scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*).

Data from all participants of Tele.TAnDem.transfer who still provided in-home care at the time of the post-intervention assessment were used. This subsample ( $n = 229$ ) was randomly split in half and EFA was conducted on the first data set. The established factor structure was then subjected to CFA on the second data set. Construct validity was determined by inspecting latent correlations between the CGS and measures of quality of life, body complaints, anxiety, and symptoms of depression.

Convincing goodness-of-fit indices emerged for a four-factor model. The total scale and subscales yielded satisfying internal consistency reliabilities (Cronbach's  $\alpha = .67-.89$ ), retest reliability ( $r = .99$ ), and construct validity coefficients. The first factor, named Emotional Pain, reflects painful emotions that are associated with the loss of the care recipient. Factor 2, Relational Loss, represents the loss of the relationship and what used to be shared between caregiver and care recipient. The third factor, Absolute Loss, focuses on the final inevitable loss of the care recipient and the anticipation of a future without that person. This factor also represents a loss of meaning in life, and the resulting desperation. Factor 4, Acceptance of Loss, reflects the acceptance of dementia as well as the open expression and acceptance of pre-death grief. Therewith, the CGS covers the burden caregivers experience because of pre-death grief and how they cope with it.

Factors 1 to 3 are measured by three items each and Factor 4 is measured by two items. Taken together, the CGS comprises 11 items. Results also supported the existence of a second order general pre-death grief factor. Therefore, both the subscores and the CGS total score can be interpreted confidently. A number of demographic variables were further identified as predictors of a higher intensity of pre-death grief, demonstrating that the CGS allows for the differentiation between subgroups of caregivers.

Study II resulted in an instrument that was developed and validated according to current methodological standards and that covers the multifaceted nature of pre-death grief, yet remains brief enough to be easily used in research and clinical practice. Implications are twofold: First, the CGS can be a valuable tool in clinical practice. For therapists, it allows convenient planning of an intervention; and for caregivers, reading through the items may prompt a first recognition

and identification of losses (see also Section 3.7). Second, and most important for the third study that was conducted as part of this dissertation, the CGS allows a precise evaluation of the effectiveness of grief-specific interventions.

### ***2.3.3 Study III. Dementia Caregivers' Coping with Pre-Death Grief: Effects of a CBT-based Intervention***

Building on the previous two studies, Study III specifically set out to answer the call for pre-death grief intervention studies of high methodological quality. Its objective was to examine whether the Tele.TAnDem intervention that includes the refined grief-specific intervention module can increase caregivers' coping with pre-death grief and whether these effects can be maintained up until a six-month follow-up assessment. Differences in the experience of pre-death grief between subgroups of caregivers were considered by including the variables gender, relationship to care recipient, and changes in the care situation (i.e., remaining a home caregiver vs. nursing home placement) in the analysis. Therewith, Study III also investigated whether treatment effects differed between subgroups of caregivers.

Data from the two randomized groups (i.e., telephone-based intervention [ $n = 139$ ] and control [ $n = 134$ ]) of the Tele.TAnDem.transfer trial were used. The intensity of the experienced burden due to pre-death grief was measured with the CGS. Statistical analyses were conducted using structural equation modeling: A latent change model was developed to test for changes in pre-death grief from baseline to post-intervention assessment and to six-month follow-up (see Steyer, Eid, & Schwenkmezger, 1997, for methodological details). To test for a treatment effect, study group was included as a predictor of change. The sociodemographic variables were included as further predictors in two subsequent models.

A significant treatment effect (i.e., a greater reduction in pre-death grief scores in the intervention, but not the control group; Cohen's  $d = -0.361$ ) was found six months after the intervention ended. When controlling for changes in the care situation and sociodemographic variables, the treatment effect was also found in the assessment completed post-intervention (Cohen's  $d = -0.248$ ). This means that the Tele.TAnDem intervention led to a successful long-term reduction in the burden caregivers experience due to pre-death grief.

The pattern of results can be understood in the light of the nature of pre-death grief and key factors of psychotherapy. Caregivers are often unaware that their psychological and physical symptoms are, in fact, indicators of pre-death grief (Dempsey & Baago, 1998; Silverberg, 2007). When therapists then focused on the identification of losses and changes, and worked towards management and acceptance of the associated painful emotions, they used

*problem confrontation* or *actualization* (Grawe, 2004). In detail, therapists in the study guided caregivers to face and deal with the painful experience of pre-death grief. As one of the common factors of psychotherapy (Grawe, 2004), problem actualization is crucial for long-term improvement. Recognizing and accepting a situation that is both painful—one of the most significant personal relationships in life is lost—and complex—losses are compounded as the disease waxes and wanes—takes time, though. It is therefore likely that after the intervention ended, caregivers were still working through the grief process. Thus, no difference was found between the control and intervention group; yet between the end of the intervention and the six-month follow-up assessment, caregivers in the intervention group appear to have been able to come to terms with their grief better than control group participants.

The analyses also revealed two other effects. First, caregivers still caring at home showed a stronger decline in pre-death grief between the baseline and post-intervention assessments than caregivers who had ceased to be in-home caregivers by that time. Second, spouses reported more intense pre-death grief at baseline than adult children. Change in pre-death grief between the baseline and post-intervention assessments and the baseline and six-month follow-up assessments did not differ between these two groups.

In conclusion, Study III successfully demonstrated that a CBT-based intervention including a grief-specific module can foster caregivers' coping with pre-death grief. Results support the therapeutic approach of assisting caregivers to recognize and then accept losses, change, and painful emotions associated with pre-death grief. Besides, the study overcomes previous methodological limitations because it was conducted within a randomized-controlled design, used a large sample, and examined long-term effects with an instrument specific to pre-death grief.



### **3 General Discussion**

Against the backdrop of the high and continuously rising prevalence rates of dementia, it is of utmost importance for health care professionals to be able to provide support for family members taking care of people with dementia at home. This support must not only cover the fulfilment of caregiving tasks, but also target the caregivers' emotional coping with their challenging situation.

Pre-death grief is among the most painful experiences during caregiving (e.g., Frank, 2008; S. Sanders & Corley, 2003) and if not managed well, it can have further adverse impacts on caregivers' health (Holley & Mast, 2009; S. Sanders & Adams, 2005). Over the last decade, researchers have therefore tried to meet the need for interventions that support caregivers' coping with pre-death grief, loss, and change. The studies that were conducted in this dissertation aimed to expand the knowledge on the design and effectiveness of these interventions.

The first objective of the dissertation was to provide insights into how grief-specific interventions can be delivered as part of CBT and identify intervention strategies that are suitable for grieving caregivers. The obtained results contributed to the refinement of a grief-specific intervention module and the subsequent second objective was to evaluate the effectiveness of an intervention that included this module. As a prerequisite to arrive at meaningful conclusions regarding treatment effects, the development of a new instrument for the measurement of pre-death grief was the third objective of the dissertation.

The three studies that were presented separately in the preceding section are now integrated and jointly discussed. The methodological aspect of the assessment of pre-death grief is considered first, followed by what was learned about the design of pre-death grief interventions and their effectiveness. The section then turns to summarize methodological aspects of the three studies that are new to research on pre-death grief and that allow the dissertation to contribute to the advancement of the field. Limitations are discussed next and an outline of future directions for research and implications for clinical practice concludes the section.

#### **3.1 The assessment of pre-death grief**

After Study I had identified the goals therapists pursued during therapy sessions with a focus on pre-death grief, it was of interest if this particular therapeutic approach can successfully foster caregivers' coping with grief. An essential prerequisite was the development of a new instrument for the assessment of pre-death grief—the CGS. Across past studies, there

used to be inconsistencies and vagueness regarding the conceptualization of pre-death grief (Lindauer & Harvath, 2014) that was also apparent in the choice of assessment tools. These studies relied on the TRIG, AGS, GEI, PG-12, or the MM-CGI; i.e., instruments that are not specific or limited to pre-death grief. This lack of specificity is problematic because meaningful conclusions can only be drawn from study results when the used instruments have proved their validity (Moosbrugger & Kelava, 2012). With the CGS, this dissertation introduced an instrument that does justice to the 13 years of research on pre-death grief that advanced the field since the development of the MM-CGI. Measuring pre-death grief without overlap with other constructs is now possible, thus allowing specific insights into treatment effects.

In the same way as Study I illustrated different key areas of grief interventions, the CGS covers the main aspects of pre-death grief. Statistical analyses revealed the four distinct factors Emotional Pain, Relational Loss, Absolute Loss, and Acceptance of Loss. Therewith, the CGS offers the possibility to quantify aspects that were repeatedly identified in qualitative studies. It further corresponds well with the definition of pre-death grief (Lindauer & Harvath, 2014): The CGS covers perceived losses, central changes in the relationship, and emotions such as sorrow, yearning, and acceptance. It further covers emotions and cognitions associated with the anticipation of the inevitable death of the care recipient. Last, the CGS measures if caregivers manage their pre-death grief through acceptance and disclosure versus avoidance; a difference that is directly linked to mental health and well-being (Hayes et al., 2004; Spira et al., 2007).

Apart from allowing these specific insights, the CGS also provides a total score of pre-death grief. The existence of this general factor was confirmed by the statistical analysis and supports our understanding of pre-death grief: Although caregivers experience a variety of losses and associated emotions, the overarching concept is pre-death grief. Therewith, this dissertation also contributes to arriving at a more specific conceptualization of pre-death grief that was often lacking in past studies (Lindauer & Harvath, 2014).

### **3.2 Strategies for successful pre-death grief interventions**

Currier et al. (2008) have argued that investigations into grief interventions need to identify which approaches work well with certain subgroups. The present dissertation meets this demand by focusing on the subgroup of dementia caregivers: It analyzed what happened during therapy sessions when losses experienced by caregivers and the resulting pre-death grief were addressed and subsequently illustrated the application of a set of grief-specific intervention strategies. These strategies were Recognition and Acceptance of Loss and Change, Normalization of Grief, Redefinition of the Relationship, and Addressing Future Losses and

they supported the development of the successful grief-specific intervention module for the Tele.TAnDem intervention.

Many of the themes and characteristics that were previously identified in the pre-death grief literature, such as avoidance of grief or self-disenfranchisement, emerged as topics within the therapy sessions. Using transcripts from therapy sessions as opposed to interviews or written responses to survey questions, the study was able to go one step further and identify dysfunctional cognitions at the core of these reactions. It also illustrated intervention strategies that can be applied to challenge these dysfunctional cognitions and develop more helpful ones. Besides, emotion-focused strategies were identified that illustrate how acceptance of unchangeable situations during caregiving can be reached. Taken together, the results provide insights into how caregivers can be supported to overcome unhelpful reactions to pre-death grief.

The identified intervention strategies also correspond well with what has been suggested as the focus of grief-specific interventions by, for example, Dempsey and Baago (1998), Doka (2004), Noyes et al. (2010), S. Sanders et al. (2008), and Silverberg (2007). The presentation of examples of all strategies from real therapy sessions corroborates these suggestions for the first time. In addition, the results illustrate how strategies rooted in CBT can be applied to target pre-death grief. This contribution is valuable to both caregiver interventions and CBT: It further expands evidence for CBT as an effective form of psychotherapy for a variety of conditions and adds to the repertoire of effective interventions for dementia caregivers. Possible explanations for the effectiveness of the Tele.TAnDem intervention on the reduction in the burden of pre-death grief are considered below.

### ***3.2.1 Explanations for the treatment effect***

Study III has demonstrated the effectiveness of a CBT-based intervention that included the grief-specific module—the Tele.TAnDem intervention (Wilz et al., 2015)—on successful coping with pre-death grief. The treatment effect was maintained up until six months after the intervention ended. It is encouraging that this long-term effect was found for all caregivers of the intervention group whereas treatment effects could only be maintained for subgroups in previous studies (e.g., Ott et al., 2010).

The effectiveness of the intervention shows that a therapeutic focus on acceptance is beneficial. Accepting and acknowledging losses and painful emotions is the opposite reaction to many caregivers' initial coping strategy. Understandably, they seek to minimize their painful internal experiences in response to the disease and care situation and engage in experiential

avoidance. However, as losses cannot be reversed and the situation cannot be changed, ultimately only their acceptance can maintain caregivers' health.

Possible further explanations for the treatment effect lie in the correspondence between the process and development of pre-death grief on the one hand, and the content and focus of the grief-specific intervention strategies on the other hand. As outlined above, pre-death grief is best explained by two recent models, the grief–stress model of caregiving (Noyes et al., 2010) and the dementia grief model (Blandin & Pepin, 2015). How the grief-specific intervention strategies of the Tele.TAnDem intervention target aspects that are emphasized in these models is explained in the remainder of this section.

The grief–stress model of caregiving (Noyes et al., 2010) emphasizes the role of caregivers' resources in coping with experienced losses. Activating or recovering personal and social resources is one explicit focus of the Tele.TAnDem intervention. When therapists identified what has helped caregivers to deal with losses and changes in the past, they thus enabled them to cope with the challenges posed by the current care situation. What is more, one of the main goals of the grief-specific module—the management of painful emotions—constitutes a resource itself (Wilz et al., 2015). To reach this goal, therapists emphasized the recognition and verbalization of painful emotions and worked towards their acceptance. If learned once, management of painful emotions is helpful throughout the whole disease trajectory, because each loss can result in a new painful emotional reaction. The maintenance of the treatment effect up until the six-month follow-up assessment indicates that caregivers learned to cope with this continuous experience.

Further foci of pre-death grief interventions are presented in the dementia grief model (Blandin & Pepin, 2015). It suggests three central dynamic mechanisms for the management of pre-death grief that are all targeted by the Tele.TAnDem intervention. The first mechanism is to acknowledge loss and it was among the central foci of the intervention. This is evidenced by the finding that strategies pertaining to Recognition of Loss and Change were the most often used grief intervention strategies in Study I. Acknowledging losses also became one of the therapy goals of the module, because caregivers often fail to recognize losses as what they are, for example, when they attribute behavior problems to some negligence on their part rather than as a loss of the care recipient's personhood. With problem actualization (Grawe, 2004), therapists guided caregivers to confront what has been lost because of the disease; a necessary prerequisite to acknowledgment.

The second dynamic mechanism, tolerate difficult feelings, was also targeted by the Tele.TAnDem intervention. Fostering adaptive emotional processing of losses and changes is

at the core of the grief-specific module and therapists guided caregivers to recognize and verbalize avoided emotions and move towards their acceptance. Results of Study I also revealed how important it is to normalize caregivers' emotional reaction to loss. Among those caregivers who recognized their negative emotions as pertaining to pre-death grief were some who did not allow themselves to fully experience these emotions. These caregivers detached themselves from their emotions out of a fear to burden the care recipient, to react inappropriately, or not to be able to provide care in case the sad feelings never ended. Psychoeducation on the nature of emotions in general and on pre-death grief specifically was a valuable intervention strategy to help caregivers to tolerate negative emotions and dedicate time to feeling them.

Adaptation is the third dynamic mechanism and constitutes the desired outcome of another of the intervention's goals, i.e., to support caregivers to accept the changed situation as the new reality. Blandin and Pepin (2015) proposed that adaptation is evidenced by a caregiver's changed behavior. For participants in the Tele.TAnDem and Tele.TAnDem.transfer trials, changed behavior became visible in an accepting attitude towards changes and painful emotions. It further became evident when the therapists' intervention targeted role change and therapists directly identified tasks that caregivers take on as a result. Other modules of the Tele.TAnDem intervention (e.g., accepting outside help or reacting to behavior problems) also pursued behavior changes due to increasing caregiving demands.

In summary, the Tele.TAnDem intervention supports the natural and individual processing of pre-death to bring about caregivers' best possible coping with the situation. The therapeutic approach is grounded in the understanding that pre-death grief is a normal and healthy reaction to the losses and changes that caregivers experience. Therapists therefore constantly validated and normalized pre-death grief what constitutes the opposite reaction to the disenfranchisement caregivers often experienced before. Many caregivers thus became aware of losses and painful emotions for the first time, but this problem actualization led to a change in the caregivers' behavior, such as accepting changes and painful emotions rather than avoiding them. Consequently, the burden of pre-death grief was reduced, as evidenced by the results.

Application of grief-specific intervention strategies was also closely interconnected with strategies from other modules of the Tele.TAnDem manual because therapists weighed the modules according to the caregivers' individual needs. As an example, one module is dedicated to the management of behavior problems. As behavior problems have been shown to predict pre-death grief (Holley & Mast, 2010), it can be assumed that a focus on their adequate management also contributed to the reduction in the burden of pre-death grief. Further research

is needed to better understand the interplay between interventions directed at pre-death grief and those targeting other challenges of the care situation.

### **3.3 Further results**

As predictors of pre-death grief were included in the analyses of Studies II and III, a number of secondary results were obtained. These insights shed more light on differences in the intensity of pre-death grief between subgroups of caregivers. Regarding the relationship to the care recipient, higher pre-death grief scores were found for spouses. This result supports previous findings that spouses express more sadness compared to adult children (Meuser & Marwit, 2001; Rudd et al., 1999).

Pre-death grief was also higher in caregivers who decided for nursing home placement compared to those who continued in-home care. The result might reflect caregivers' natural moving through the grieving process while nursing home placement suddenly leaves caregivers with more time to recognize the full impact of all losses. It seems plausible that this major change in the care situation can cause a more intense pre-death grief reaction, as previously suggested by Rudd et al. (1999) and Dempsey and Baago (1998).

A higher intensity of pre-death grief was also found in Study II for caregivers who lived with the care recipient at the time of the baseline assessment, compared to caregivers who cared for a family member still living in their own home. This effect was independent of the severity of dementia, which was found to be unrelated to the intensity of pre-death grief. There are several possible explanations for this effect: It can be assumed that, when living together, caregivers spend more time around the care recipient which can lead to a constant witnessing of losses, also including more subtle ones. Naturally, this can intensify pre-death grief. It is another possible explanation that the result is an effect of closeness: Living together could indicate a closer relationship between caregiver and care recipient. Closeness of the relationship is the driving force behind pre-death grief; the closer the relationship, the stronger the attachment bonds, and the stronger the attachments bonds that become loosened over the disease trajectory, the higher the intensity of grief. Living with the care recipient also overlaps with the relationship between caregiver and care recipient. Spousal caregivers normally live with the care recipient at onset of the disease while for adult children this might be a transition as the disease progresses. Relationship to care recipient was, however, controlled for in the analysis. More research is therefore needed to better understand the effect.

Differences in the intensity of pre-death grief between male and female caregivers could not be replicated. Studies that reported gender differences (Rudd et al., 1999) focused on the

emotions that were expressed by caregivers whereas the CGS does not solely focus on emotions, but also covers losses, beliefs about the final loss, and the tendency to avoid or accept both the disease and pre-death grief. Judging by the obtained results, it seems likely that men and women do not differ in this regard.

### **3.4 Methodological strengths of the dissertation**

With the results discussed above, the present dissertation adds favorably to research with dementia caregivers and on their pre-death grief. As some of the characteristics of the chosen setting and methods of the three studies constitute new approaches to this specific field, they are outlined in more detail below.

The majority of existing research on dementia caregivers' pre-death grief was conducted in North America. The present studies are among the few European ones (along with, for example, Johansson et al., 2013; and Warchol-Biedermann et al., 2014) and, to the best of my knowledge, the only studies conducted with a German sample. They therefore contribute to an understanding of pre-death grief across Western cultures and specifically inform health care professionals in Germany.

Next, Currier et al. (2008) found in their meta-analysis that grief interventions with self- and clinically referred samples have generally led to better treatment effects. Against this backdrop, it has to be regarded favorably that research within this dissertation was conducted with samples that were recruited using a combination of different strategies (see also Section 2.2). Of further note, once caregivers had contacted the study center, outreaching strategies (e.g., telephone calls to schedule upcoming assessments, inquiries by telephone or mail when appointments were missed) were used to ensure a low attrition rate. This procedure resulted in relatively few caregivers dropping out of both trials and the insights into interventions that facilitate coping with pre-death grief are not limited to a subgroup that actively seeks help.

The combination of both qualitative and quantitative methods led to a comprehensive understanding of pre-death grief. With its qualitative approach and drawing on data from a larger trial, the first study provided insights into an explicitly CBT-based intervention that was delivered by highly trained therapists who worked under regular supervision. It is among the benefits of qualitative research methods that they closely reflect participants' reality because they rely on their own words and accounts. This is particularly relevant when new phenomena need to be understood and theoretical principles need to be established (Mayring, 2010). With the first intervention study published only a little more than a decade ago (Kasl-Godley, 2003), pre-death grief interventions can still be regarded as one such new area of research.

Although a substantial number of qualitative studies have been conducted previously to gain insight into the nature of pre-death grief, none of these studies focused on how health care professionals can respond to the losses and changes caregivers lament. In addition, there are only few studies that analyzed transcripts of therapy sessions and none of them was conducted with dementia caregivers. Therefore, qualitative insights into CBT are scarce; one possible reason being the time consuming nature of this path of research. With its qualitative analysis of therapy sessions, Study I contributes to closing this gap.

The methods used for the quantitative analyses in Studies II and III constitute the methods of choice for the present research objectives. The combination of EFA and CFA ensured that the established factor structure was not based on chance correlations; and structural equation models allowed to estimate participants' true scores on latent grief variables rather than using scores that cannot be separated from measurement error. The present studies are the first in the field of pre-death grief that used these methods. Their application was made possible by the large samples of both the Tele.TAnDem and Tele.TAnDem.transfer trial, while other studies on pre-death grief were usually conducted with much smaller samples. It is of further note that research was conducted within two RCTs and used data from follow-up assessments.

### **3.5 Limitations of the dissertation**

Although the dissertation has numerous strengths and overcomes shortcomings of earlier research, some limitations still need to be considered. First, by using the CGS to evaluate the effects of the Tele.TAnDem intervention on pre-death grief, it is not possible to compare the treatment effect with the results of other intervention studies that relied on the MM-CGI. The CGS remains one of the contributions of this dissertation to research with dementia caregivers, but it is of interest for future studies how the MM-CGI and the CGS relate to one another.

Second, the CGS puts most emphasis on sadness, yearning, or hopelessness where emotional reactions to loss and change are concerned. These are the predominant emotional aspects of pre-death grief, yet some caregivers also react with emotions such as anger, guilt, and frustration. Adding these emotions to the CGS constitutes a possible future advancement of the instrument.

Third, while this dissertation is one of the few European research endeavors into pre-death grief, it was still conducted with ethnically homogenous Western samples (99.9% of the participants of the Tele.TAnDem trial and 98.9% of the participants of the Tele.TAnDem.transfer trial were of German origin). Generalizability of the results is thus



limited, because cultural and social values are one driving force behind reasons for and the nature of caregiving. Differences may subsequently influence how well caregivers cope with caregiving duties as well as loss and change (Küçük, 2008; Navab, Negarandeh, & Peyrovi, 2012). For example, in one Iranian study (Navab et al., 2012) caregivers expressed to view caregiving as a punishment for past sins which led to intense feelings of sorrow. On the contrary, Liew (2015) investigated pre-death grief with the MM-CGI in an Asian sample and found results comparable to the initial North American study (Marwit & Meuser, 2002). However, differences were found on one subscale, indicating that worries about the future and isolation play a bigger role for Asian caregivers.

Being sensitive to differences in pre-death grief depending on a caregiver's background is also of importance for health care professionals in Germany. Older people that were born in some country other than Germany constitute the most rapidly growing population group in Germany (Mogar & von Kutzleben, 2015). Consequently, the percentage of family caregivers with a different ethnic background will rise. Since these caregivers' experience of pre-death grief may differ from that of caregivers with a German background, they might need grief interventions that are sensitive to cultural differences.

In more detail, people with a Turkish background constitute the largest group of immigrants and many of them are now entering the age where the prevalence of dementia rises (Statistisches Bundesamt, 2015). Persons with dementia with a Turkish background are being cared for at home even more often than their German counterparts (Mogar & von Kutzleben, 2015). Of concern, dementia often constitutes a taboo in Turkish families and is associated with feelings of shame (Küçük, 2008; Mogar & von Kutzleben, 2015). Interviews with Turkish caregivers also revealed an unconditional commitment to caregiving while at the same time having only little knowledge about the disease (Mogar & von Kutzleben, 2015). It can therefore be assumed that these caregivers have even more difficulties recognizing and acknowledging losses and experience more disenfranchised grief. Which support is appropriate for them needs to be the focus of future studies.

### **3.6 Directions for future research on pre-death grief**

The dissertation provides new insights into the assessment of pre-death grief as well as the design and effectiveness of pre-death grief interventions; yet, a number of research questions still remain unanswered. Several suggestions for future paths of research are made below, in addition to those already touched upon above.

Now that evidence for the intervention's effectiveness was found in the reduction of CGS scores, it is of interest to learn about caregivers' personal experiences with the intervention. In more detail, future studies could again apply qualitative methods and investigate which change in their pre-death grief experience caregivers witness themselves and which aspects of the intervention they find most helpful. The therapists' perspective also warrants further attention. Study therapists and supervisors were involved in the development of the category system of Study I and did develop the Tele.TAnDem manual. Building on that, it is now of interest how therapists experienced the application of the grief-specific module within the Tele.TAnDem.transfer trial. Focus group discussions with therapists could provide these insights.

The category system Grief Intervention Strategies that was developed within the first study is now also available for future research endeavors. The availability of this instrument for the coding of intervention strategies will hopefully stimulate more qualitative studies of the processes within therapy sessions.

It was further outlined above how pre-death grief can negatively impact caregiver burden and symptoms of depression. As the positive effect of the intervention on coping with pre-death grief has now been established, it needs to be evaluated if a reduction in the burden of pre-death grief can lead to a subsequent long-term reduction in physical and mental health problems. Outcome measures that need to be included in future analyses are the primary and secondary endpoints of Tele.TAnDem.transfer, such as depressive symptoms or quality of life. A three-year follow-up assessment of the Tele.TAnDem.transfer trial that is currently in preparation will further allow insight into how participants' coping with pre-death grief develops from six months after the intervention ended onwards.

Another possible future direction of research concerns the care recipient's stage of the disease. As the intensity and nature of pre-death grief varies over the disease trajectory (e.g., Adams & Sanders, 2004; Ott et al., 2007; Ponder & Pomeroy, 1997), a particular focus on the optimal timing of different intervention strategies could be beneficial. Therapists in both the Tele.TAnDem and Tele.TAnDem.transfer trial did tailor their interventions to the individual situation of a caregiver. However, as stage of the disease was not of primary importance for the research objectives of both trials, the distribution of care recipients across the disease stages is uneven (i.e., most caregivers cared for care recipients in the moderate or severe stages while only few cared for care recipients suffering from mild or very severe dementia, see also sample descriptions in Studies I and III). A subsequent intervention study for dementia caregivers could balance the number of participants across disease stages. Such a design would allow to draw

conclusions about the best possible fit between intervention strategies and stages of dementia. Based on the current state of research and the results of this dissertation, the following suggestions can be made and would need to be closely examined:

During the early stage, emphasis on acceptance of the disease and the occurring changes, management of emotions, and normalization of pre-death grief including psychoeducation, appears appropriate. This focus would enable caregivers to manage their grief early on during caregiving, thus providing them with an important resource to cope with future losses. When the disease progresses and the care recipient becomes more dependent on the caregiver, interventions could turn predominantly to the recognition of role change and the redefinition of roles. The inevitable final loss including expectations and anxiety of the future seem to be important key points during the final stage of the disease. Intensity of pre-death grief has also been found to be highest towards the end of caregiving. It therefore seems reasonable to suggest favoring grief-specific interventions over those targeting other aspects when working with caregivers of care recipients in the final stages of the disease. As losses are experienced continuously, recognition of losses would be important regardless of the stage of disease.

The death of the care recipient is an inevitable experience for all caregivers and past research has already focused on caregivers' adaptation to bereavement. A number of caregivers seem to develop PGD after the care recipient's death, although the reported prevalence rates vary between 6% (Romero et al., 2014) and 20% (Schulz, Boerner, Shear, Zhang, & Gitlin, 2006). As outlined above, caregivers' management of pre-death grief and their preparedness for the death of the care recipient can influence coping with post-death grief. It therefore needs to be determined if the positive effect of the Tele.TAnDem intervention on the management of pre-death grief extends to a heightened preparedness, positive adaptation to bereavement, and prevention of PGD.

Finally, the high intensity of pre-death grief after nursing home placement calls for an adaptation of the grief-specific module to the needs of the subgroup of caregivers who opted for placement. It remains to be determined which support caregivers need once they have more time to dwell on losses and possibly experience additional painful emotions, such as guilt or increased yearning for the care recipient.

### **3.7 Implications for clinical practice with dementia caregivers**

Besides pointing towards new directions of research, the present dissertation also has several implications for the work of health care professionals. The insights obtained from Study I and the grief-specific intervention module of the Tele.TAnDem manual provide guidance for

cognitive-behavioral therapists; they describe which therapy goals should be pursued when working with grieving dementia caregivers and how they can be reached. More caregivers can thus receive adequate support regarding their management of pre-death grief, especially because efforts are currently underway to make the Tele.TAnDem intervention available to caregivers in Germany outside of research projects.

In addition, the inclusion of the grief-specific module in the Tele.TAnDem manual ensures that therapists become aware of the significance of pre-death grief during caregiving. This is important because many unhelpful assumptions regarding grief and engagement in avoidance are repeatedly overlooked clinically (Shear, 2010) and caregivers themselves are often unaware that it is pre-death grief what they are experiencing (Silverberg, 2007). With the help of the module, therapists can confidently introduce pre-death grief and explore if coping is challenging for a caregiver. Without the module, problems can possibly remain undetected.

Further, therapists should also be alert to a heightened intensity of pre-death grief after caregivers opted for nursing home placement of the care recipient. This emotional reaction to placement must not be regarded as dysfunctional per se but rather as an appropriate reaction to the newly changed situation. However, due to a lack of accompanying rituals caregivers might again feel that their grief is not adequate and try to avoid or suppress it. Therapists should therefore not assume that once the burden of caregiving duties is lifted, caregivers are no longer in need of therapeutic support. On the contrary, assisting them with the emotional processing of the changed situation might prevent further adverse outcomes.

Finally, therapists can also make use of the CGS. Its application can serve two functions: First, it can introduce the topic of pre-death grief. By reading through the items, caregivers may recognize their own experiences and start to identify losses. Therewith, one goal of grief-specific interventions is already addressed. Second, therapists can evaluate the CGS total score and compare scores on the four subscales. Examination of subscores can assist therapists to instantly recognize risks—such as avoidance of painful emotions or a state of crisis due to desperation over the anticipated final loss—and suggest a suitable focus of their intervention. Having the caregiver then complete the CGS at multiple times during therapy can also facilitate the monitoring of treatment outcomes. These possibilities make the CGS a valuable tool for clinical practice.

### **3.8 Conclusion**

Appropriate intervention strategies enable therapists to support caregivers in the maintenance of their physical and mental health over the often long and uncertain disease

trajectory. Among these much-needed strategies are those targeting pre-death grief, loss, and change, as these experiences are major aspects of dementia caregiving.

The present dissertation had the overall aim to contribute to the development and evaluation of such grief-specific interventions grounded in the principles of CBT. It provided detailed insights into how intervention strategies were applied towards pre-death grief and identified four main strategies: Recognition and Acceptance of Loss and Change, Normalization of Grief, Redefinition of the Relationship, and Addressing Future Losses. It further demonstrated that a CBT-based intervention program that included a module based on these strategies led to long-term decline in the burden of pre-death grief. The dissertation also introduced two new instruments: One category system for the qualitative assessment of grief intervention strategies and the CGS, a scale for the quantitative measurement of caregivers' pre-death grief on the four distinct factors Emotional Pain, Relational Loss, Absolute Loss, and Acceptance of Loss.

Within the sociodemographic change, dementia and pre-death grief are pressing challenges. Rituals that allow an appropriate and socially and culturally accepted goodbye from a beloved person over the course of their disease have yet to emerge. In light of the results of this dissertation, CBT offers the possibility to ameliorate the emotional, behavioral, and cognitive processing of continuous loss and change, and thus lift the burden of pre-death grief.

## 4 References

- Adams, K. B. (2006). The transition to caregiving: The experience of family members embarking on the dementia caregiving career. *Journal of Gerontological Social Work, 47*(3–4), 3–29. doi: 10.1300/J083v47n03\_02
- Adams, K. B., & Sanders, S. (2004). Alzheimer's caregiver differences in experience of loss, grief reactions and depressive symptoms across stage of disease: A mixed-method analysis. *Dementia, 3*(1), 195–210. doi: 10.1177/1471301204042337
- Alzheimer's Association. (2015). 2015 Alzheimer's disease facts and figures. *Alzheimer's and Dementia: The Journal of the Alzheimer's Association, 11*(3), 332–384 doi: 10.1016/j.jalz.2015.02.003
- Alzheimer's Disease International. (2015). Dementia statistics. Retrieved from <http://www.alz.co.uk/research/statistics>
- Blandin, K., & Pepin, R. (2015). Dementia grief: A theoretical model of a unique grief experience. *Dementia*. doi: 10.1177/1471301215581081
- Bonanno, G. A., Wortman, C. B., Lehman, D. R., Tweed, R. G., Haring, M., Sonnega, J., . . . Nesse, R. M. (2002). Resilience to loss and chronic grief: A prospective study from preloss to 18-months postloss. *Journal of Personality and Social Psychology, 83*(5), 1150–1164. doi: 10.1037/0022-3514.83.5.1150
- Boss, P. (2000). *Ambiguous loss: Learning to live with unresolved grief*. Cambridge, MA: Harvard University Press.
- Boss, P., & Kaplan, L. (2003). Ambiguous loss and ambivalence when a parent has dementia. In K. Pillemer & K. Lüscher (Eds.), *Intergenerational ambivalences: New perspectives on parent–child relations in later life (Contemporary perspectives in family research)* (Vol. 4, pp. 207–224). Oxford, UK: Elsevier.
- Bowlby, J. (1973). *Attachment and loss: Volument II Separation, anxiety and anger*. New York, NY: Basic Books.
- Bundesministerium für Familie, Senioren, Frauen und Jugend. (2015, October 21). Demenz: Lebensqualität verbessern und Pflegende unterstützen [Dementia: Improving quality of life and supporting caregivers]. Retrieved from <http://www.bmfsfj.de/BMFSFJ/Aeltere-Menschen/demenz.html>
- Chan, D., Livingston, G., Jones, L., & Sampson, E. L. (2013). Grief reactions in dementia carers: A systematic review. *International Journal of Geriatric Psychiatry, 28*(1), 1–17. doi: 10.1002/gps.3795

- Cheng, S.-T., Kwok, T., & Lam, L. C. W. (2014). Dimensionality of burden in Alzheimer caregivers: Confirmatory factor analysis and correlates of the Zarit Burden Interview. *International Psychogeriatrics, 26*(9), 1455–1463. doi: 10.1017/S104161021400101X
- Collins, C., Liken, M., King, S., & Kokinakis, C. (1993). Loss and grief among family caregivers of relatives with dementia. *Qualitative Health Research, 3*(2), 236–253. doi: 10.1177/104973239300300206
- Cuijpers, P. (2005). Depressive disorders in caregivers of dementia patients: A systematic review. *Aging and Mental Health, 9*(4), 325–330. doi: 10.1080/13607860500090078
- Currier, J. M., Holland, J. M., & Neimeyer, R. A. (2010). Do CBT-based interventions alleviate distress following bereavement? A review of the current evidence. *International Journal of Cognitive Therapy, 3*(1), 77–93. doi: 10.1521/ijct.2010.3.1.77
- Currier, J. M., Neimeyer, R. A., & Berman, J. S. (2008). The effectiveness of psychotherapeutic interventions for bereaved persons: A comprehensive quantitative review. *Psychological Bulletin, 134*(5), 648–661. doi: 10.1037/0033-2909.134.5.648
- Davis, E. L., Deane, F. P., & Lyons, G. C. B. (2014). Acceptance and valued living as critical appraisal and coping strengths for caregivers dealing with terminal illness and bereavement. *Palliative and Supportive Care, 13*(2), 359–368. doi: 10.1017/s1478951514000431
- DeCaporale, L., Mensie, L., & Steffen, A. (2013). Respite utilization and responses to loss among family caregivers: Relationship matters. *Death Studies, 37*(5), 483–492. doi: 10.1080/07481187.2012.654593
- Dempsey, M., & Baago, S. (1998). Latent grief: The unique and hidden grief of carers of loved ones with dementia. *American Journal of Alzheimer's Disease and Other Dementias, 13*(2), 84–91. doi: 10.1177/153331759801300206
- Diwan, S., Hougham, G., & Sachs, G. (2009). Chronological patterns and issues precipitating grieving over the course of caregiving among family caregivers of persons with dementia. *Clinical Gerontologist, 32*, 358–370. doi: 10.1080/07317110903110179
- Doka, K. J. (1989). *Disenfranchised grief: Recognizing hidden sorrow*. Lexington, MA: Lexington Books.
- Doka, K. J. (2004). Grief and dementia. In K. J. Doka (Ed.), *Alzheimer's disease: Living with grief* (pp. 139–155). Washington, DC: Hospice Foundation of America.
- Dupuis, S. L. (2002). Understanding ambiguous loss in the context of dementia care: Adult children's perspectives. *Journal of Gerontological Social Work, 37*(2), 93–115. doi: 10.1300/J083v37n02\_08

- Elvish, R., Lever, S.-J., Johnstone, J., Cawley, R., & Keady, J. (2013). Psychological interventions for carers of people with dementia: A systematic review of quantitative and qualitative evidence. *Counselling and Psychotherapy Research, 13*(2), 106–125. doi: 10.1080/14733145.2012.739632
- Faschingbauer, T. R., Zisook, S., & DeVaul, R. (1987). The Texas Revised Inventory of Grief. In S. Zisook (Ed.), *Biopsychosocial aspects of bereavement* (pp. 109–124). Washington, DC: American Psychiatric Press.
- Flick, U. (2012). *Qualitative Forschung: Ein Handbuch [Qualitative research: A handbook]*. Reinbek bei Hamburg, Germany: Rowohlt.
- Fowler, N. R., Hansen, A. S., Barnato, A. E., & Garand, L. (2013). Association between anticipatory grief and problem solving among family caregivers of persons with cognitive impairment. *Journal of Aging and Health, 25*(3), 493–509. doi: 10.1177/0898264313477133
- Frank, J. B. (2008). Evidence for grief as the major barrier faced by Alzheimer caregivers: A qualitative analysis. *American Journal of Alzheimer's Disease and Other Dementias, 22*(6), 516–527. doi: 10.1177/1533317507307787
- Gallagher-Thompson, D., & Coon, D. W. (2007). Evidence-based psychological treatments for distress in family caregivers of older adults. *Psychology and Aging, 22*(1), 37–51. doi: 10.1037/0882-7974.22.1.37
- Grawe, K. (2004). *Psychological therapy*. Seattle, WA: Hogrefe and Huber.
- Hayes, S. C., Strosahl, K., Wilson, K. G., Bissett, R. C., Pistorello, J., Toarmino, D., . . . McCurry, S. M. (2004). Measuring experiential avoidance: A preliminary test of a working model. *The Psychological Record, 54*(4), 553–578.
- Hayes, S. C., Strosahl, K. D., & Wilson, K. G. (1999). *Acceptance and Commitment Therapy: An experiential approach to behavior change*. New York, NY: Guilford Press.
- Hebert, R. S., Dang, Q., & Schulz, R. (2006). Preparedness for the death of a loved one and mental health in bereaved caregivers of patients with dementia: Findings from the REACH study. *Journal of Palliative Medicine, 9*(3), 683–693. doi: 10.1089/jpm.2006.9.683
- Hebert, R. S., Prigerson, H. G., Schulz, R., & Arnold, R. M. (2006). Preparing caregivers for the death of a loved one: A theoretical framework and suggestions for future research. *Journal of Palliative Medicine, 9*(5), 1164–1171. doi: 10.1089/jpm.2006.9.1164



- Holland, J. M., Currier, J. M., & Gallagher-Thompson, D. (2009). Outcomes from the Resources for Enhancing Alzheimer's Caregiver Health (REACH) program for bereaved caregivers. *Psychology and Aging, 24*(1), 190–202. doi: 10.1037/a0014303
- Holley, C. K., & Mast, B. T. (2009). The impact of anticipatory grief on caregiver burden in dementia caregivers. *The Gerontologist, 49*(3), 388–396. doi: 10.1093/geront/gnp061
- Holley, C. K., & Mast, B. T. (2010). Predictors of anticipatory grief in dementia caregivers. *Clinical Gerontologist, 33*(3), 223–236. doi: 10.1080/07317111003793443
- Jacobson, E. (1990). *Entspannung als Therapie. Progressive Relaxation in Theorie und Praxis [Relaxation as therapy. Progressive relaxation in theory and practice]*. Munich, Germany: Pfeiffer.
- Johansson, Å. K., Sundh, V., Wijk, H., & Grimby, A. (2013). Anticipatory grief among close relatives of persons with dementia in comparison with close relatives of patients with cancer. *American Journal of Hospice and Palliative Medicine, 30*(1), 29–34. doi: 10.1177/1049909112439744
- Jones, B. W. (2009). Hospice disease types which indicate a greater need for bereavement counseling. *American Journal of Hospice and Palliative Medicine, 27*(3), 187–190. doi: 10.1177/1049909109349248
- Jones, P. S., & Martinson, I. M. (1992). The experience of bereavement in caregivers of family members with Alzheimer's disease. *IMAGE: Journal of Nursing Scholarship, 24*(3), 172–176. doi: 10.1111/j.1547-5069.1992.tb00714.x
- Kasl-Godley, J. (2003). Anticipatory grief and loss: Implications for intervention. In D. W. Coon, D. Gallagher-Thompson, & L. W. Thompson (Eds.), *Innovative interventions to reduce dementia caregiver distress* (pp. 210–219). New York, NY: Springer.
- Kiely, D. K., Prigerson, H., & Mitchell, S. L. (2008). Health care proxy grief symptoms before the death of nursing home residents with advanced dementia. *American Journal of Geriatric Psychiatry, 16*(8), 664–673. doi: 10.1097/JGP.0b013e3181784143
- Kim, H., Chang, M., Rose, K., & Kim, S. (2012). Predictors of caregiver burden in caregivers of individuals with dementia. *Journal of Advanced Nursing, 68*(4), 846–855. doi: 10.1111/j.1365-2648.2011.05787.x
- Kua, E. H., Ho, E., Tan, H. H., Tsoi, C., Thng, C., & Mahendran, R. (2014). The natural history of dementia. *Psychogeriatrics, 14*(3), 196–201. doi: 10.1111/psyg.12053
- Küçük, F. (2008). Belastungserleben und Bewältigungsstrategien bei pflegenden Angehörigen von demenziell erkrankten türkischen Migranten/-innen [Subjective distress and coping strategies of the caretaker relatives of Turkish migrants suffering from

- dementia]. *The Journal of Gerontopsychology and Geriatric Psychiatry*, 21, 105–116. doi: 10.1024/1011-6877.21.2.105
- Large, S., & Slinger, R. (2015). Grief in caregivers of persons with Alzheimer's disease and related dementia: A qualitative synthesis. *Dementia: The International Journal of Social Research and Practice*, 14(2), 164–183. doi: 10.1177/1471301213494511
- Liew, T. M. (2015). Applicability of the pre-death grief concept to dementia family caregivers in Asia. *International Journal of Geriatric Psychiatry*. doi: 10.1002/gps.4387
- Lindauer, A., & Harvath, T. A. (2014). Pre-death grief in the context of dementia caregiving: A concept analysis. *Journal of Advanced Nursing*, 70(10), 2196–2207. doi: 10.1111/jan.12411
- Lindgren, C. L., Connelly, C. T., & Gaspar, H. L. (1999). Grief in spouse and children caregivers of dementia patients. *Western Journal of Nursing Research*, 21(4), 521–537. doi: 10.1177/01939459922044018
- Losada, A., Márquez-González, M., Romero-Moreno, R., Mausbach, B. T., López, J., Fernández-Fernández, V., & Nogales-González, C. (2015). Cognitive-behavioral Therapy (CBT) versus Acceptance and Commitment Therapy (ACT) for dementia family caregivers with significant depressive symptoms: Results of a randomized clinical trial. *Journal of Consulting and Clinical Psychology*, 83(4), 760–772. doi: 10.1037/ccp0000028
- Mace, N. I., & Rabins, P. V. (1981). *The 36-hour day*. Baltimore, MD: The Johns Hopkins University Press.
- Madsen, R., & Birkelund, R. (2013). 'The path through the unknown': The experience of being a relative of a dementia-suffering spouse or parent. *Journal of Clinical Nursing*, 22(21–22), 3024–3031. doi: 10.1111/jocn.12131
- Marwit, S. J., & Meuser, M. T. (2002). Development and initial validation of an inventory to assess grief in caregivers of persons with Alzheimer's disease. *The Gerontologist*, 42(6), 751–765. doi: 10.1093/geront/42.6.751
- Marwit, S. J., & Meuser, T. M. (2005). Development of a short form inventory to assess grief in caregivers of dementia patients. *Death Studies*, 29(3), 191–205. doi: 10.1080/07481180590916335
- Mayring, P. (2010). *Qualitative Inhaltsanalyse: Grundlagen und Techniken [Qualitative content analysis: Basic principles and techniques]*. Weinheim, Germany: Beltz.
- McEvoy, A. (2007). Dying in pieces. *American Journal of Alzheimer's Disease and Other Dementias*, 22, 11–13. doi: 10.1177/1533317506297340

- Meuser, M. T., & Marwit, S. J. (2001). A comprehensive, stage-sensitive model of grief in dementia caregiving. *The Gerontologist, 41*(5), 658–670. doi: 10.1093/geront/41.5.658
- Meuser, M. T., Marwit, S. J., & Sanders, S. (2004). Assessing grief in family caregivers. In K. J. Doka (Ed.), *Alzheimer's disease: Living with grief* (pp. 169–195). Washington, DC: Hospice Foundation of America.
- Mogar, M., & von Kutzleben, M. (2015). Demenz in Familien mit türkischem Migrationshintergrund. Organisation und Merkmale häuslicher Versorgungsarrangements [Dementia in families with a Turkish migration background. Organization and characteristics of domestic care arrangements]. *Zeitschrift für Gerontologie und Geriatrie, 48*(5), 465–472. doi: 10.1007/s00391-014-0802-y
- Moosbrugger, H., & Kelava, A. (2012). Qualitätsanforderungen an einen psychologischen Test (Testgütekriterien) [Quality criteria für psychological tests]. In H. Moosbrugger & A. Kelava (Eds.), *Testtheorien und Fragebogenkonstruktion [Test theory and scale construction]* (pp. 7–26). Berlin, Germany: Springer.
- Navab, E., Negarandeh, R., & Peyrovi, H. (2012). Lived experiences of Iranian family member caregivers of persons with Alzheimer's disease: Caring as captured in the 'whirlpool of time'. *Journal of Clinical Nursing, 21*(7–8), 1078–1086. doi: 10.1111/j.1365-2702.2011.03960.x
- Noyes, B. B., Hill, R. D., Hicken, B. L., Luptak, M., Rupper, R., Dailey, N. K., & Bair, B. D. (2010). Review: The role of grief in dementia caregiving. *American Journal of Alzheimer's Disease and Other Dementias, 25*(1), 9–17. doi: 10.1177/1533317509333902
- Ott, C. H., Kelber, S. T., & Blaylock, M. (2010). "Easing the way" for spouse caregivers of individuals with dementia: A pilot feasibility study of a grief intervention. *Research in Gerontological Nursing, 3*(2), 89–99. doi: 10.3928/19404921-20100302-01
- Ott, C. H., Sanders, S., & Kelber, S. T. (2007). Grief and personal growth experience of spouses and adult-child caregivers of individuals with Alzheimer's disease and related dementias. *The Gerontologist, 47*(6), 798–809. doi: 10.1093/geront/47.6.798
- Passoni, S., Toraldo, A., Villa, B., & Bottini, G. (2015). Prolonged grief in caregivers of community-dwelling dementia patients. *American Journal of Alzheimer's Disease and Other Dementias, 30*(2), 192–200. doi: 10.1177/1533317514542643

- Paun, O., Farran, C. J., Fogg, L., Loukissa, D., Thomas, P. E., & Hoyem, R. (2015). A chronic grief intervention for dementia family caregivers in long-term care. *Western Journal of Nursing Research, 37*(1), 6–27. doi: 10.1177/0193945914521040
- Pearlin, L., Mullan, J., Semple, S., & Skaff, M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*(5), 583–594. doi: 10.1093/geront/30.5.583
- Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging, 18*(2), 250–267. doi: 10.1037/0882-7974.18.2.250
- Pinquart, M., & Sörensen, S. (2006). Helping caregivers of persons with dementia: Which interventions work and how large are their effects? *International Psychogeriatrics, 18*(4), 577–595. doi: 10.1017/s1041610506003462
- Ponder, R. J., & Pomeroy, E. C. (1997). The grief of caregivers: How pervasive is it? *Journal of Gerontological Social Work, 27*(1–2), 3–21. doi: 10.1300/J083v27n01\_02
- Prigerson, H. G., Horowitz, M. J., Jacobs, S. C., Parkes, C. M., Aslan, M., Goodkin, K., . . . Maciejewski, P. K. (2009). Prolonged grief disorder: Psychometric validation of criteria proposed for DSM-V and ICD-11. *PLoS Medicine, 6*(1–12), e1000121. doi: 10.1371/journal.pmed.1000121
- Prigerson, H. G., & Jacobs, S. C. (2001). Traumatic grief as a distinct disorder: A rationale, consensus criteria, and a preliminary empirical test. In M. S. Stroebe, R. O. Hansson, W. Stroebe, & H. Schut (Eds.), *Handbook of bereavement research: Consequences, coping, and care* (pp. 613–645). Washington, DC: American Psychological Association.
- Prigerson, H. G., Vanderwerker, L., & Maciejewski, P. (2008). A case for inclusion of Prolonged Grief Disorder in DSM-V. In M. S. Stroebe, R. O. Hansson, H. Schut, & W. Stroebe (Eds.), *Handbook of bereavement research and practice: Advances in theory and intervention* (pp. 165–186). Washington, DC: American Psychological Association.
- Rando, T. A. (2000). *Clinical dimensions of anticipatory mourning*. Champaign, IL: Research Press.
- Reisberg, B., Ferris, S. H., de Leon, M. J., & Crook, T. (1982). The Global Deterioration Scale for assessment of primary degenerative dementia. *American Journal of Psychiatry, 139*, 1136–1139. doi: 10.1176/ajp.139.9.1136

- Robert Koch-Institut. (2015). *Gesundheit in Deutschland. Gesundheitsberichterstattung des Bundes. Gemeinsam getragen von RKI und Destatis [Health in Germany. Federal health report]*. Berlin, Germany: Author.
- Romero, M. M., Ott, C. H., & Kelber, S. T. (2014). Predictors of grief in bereaved family caregivers of persons with Alzheimer's disease: A prospective study. *Death Studies*, 38(6), 395–403. doi: 10.1080/07481187.2013.809031
- Ross, A., & Dagley, J. C. (2009). An assessment of anticipatory grief as experienced by family caregivers of individuals with dementia. *Alzheimer's Care Today*, 10(1), 8–21.
- Rudd, M. G., Viney, L. L., & Preston, C. A. (1999). The grief experienced by spousal caregivers of dementia patients: The role of place of care of patient and gender of caregiver. *The International Journal of Aging & Human Development*, 48(3), 217–240. doi: 10.2190/mgmp-31rq-9n8m-2ar3
- Sanders, C. M., Mauger, P. A., & Strong, P. N. (1985). *A manual for the Grief Experience Inventory*. Charlotte, NC: The Center for the Study of Separation.
- Sanders, S., & Adams, K. B. (2005). Grief reactions and depression in caregivers of individuals with Alzheimer's disease: Results from a pilot study in an urban setting. *Health & Social Work*, 30(4), 287–295. doi: 10.1093/hsw/30.4.287
- Sanders, S., & Corley, C. S. (2003). Are they grieving? A qualitative analysis examining grief in caregivers of individuals with Alzheimer's disease. *Social Work in Health Care*, 37(3), 35–53. doi: 10.1300/J010v37n03\_03
- Sanders, S., Morano, C., & Corley, C. S. (2003). The expressions of loss and grief among male caregivers of individuals with Alzheimer's Disease. *Journal of Gerontological Social Work*, 39(4), 3–18. doi: 10.1300/J083v39n04\_02
- Sanders, S., Ott, C., Kelber, S., & Noonan, P. (2008). The experience of high levels of grief in caregivers of persons with Alzheimer's disease and related dementia. *Death Studies*, 32(6), 495–523. doi: 10.1080/07481180802138845
- Sanders, S., & Sharp, A. (2004). The utilization of a psychoeducational group approach for addressing issues of grief and loss in caregivers of individuals with Alzheimer's disease. *Journal of Social Work in Long-Term Care*, 3(2), 71–89. doi: 10.1300/J181v03n02\_06
- Schulz, R., Boerner, K., Shear, K., Zhang, S., & Gitlin, L. N. (2006). Predictors of complicated grief among dementia caregivers: A prospective study of bereavement. *The American Journal of Geriatric Psychiatry*, 14(8), 650–658. doi: 10.1097/01.JGP.0000203178.44894.db

- Schulz, R., & Martire, L. M. (2004). Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *American Journal of Geriatric Psychiatry, 12*(3), 240–249. doi: 10.1176/appi.ajgp.12.3.240
- Schulz, R., Newsom, J. T., & Fleissner, K. (1997). The effects of bereavement after family caregiving. *Aging and Mental Health, 1*(3), 269–282. doi: 10.1080/13607869757173
- Schut, H., & Stroebe, M. S. (2005). Interventions to enhance adaptation to bereavement. *Journal of Palliative Medicine, 8*, S140–S147. doi: 10.1089/jpm.2005.8.s-140
- Selwood, A., Johnston, K., Katona, C., Lyketsos, C., & Livingston, G. (2007). Systematic review of the effect of psychological interventions on family caregivers of people with dementia. *Journal of Affective Disorders, 101*(1–3), 75–89. doi: 10.1016/j.jad.2006.10.025
- Shear, M. K. (2010). Exploring the role of experiential avoidance from the perspective of attachment theory and the Dual Process Model. *OMEGA: The Journal of Death and Dying, 61*(4), 357–369. doi: 10.2190/OM.61.4.f
- Silverberg, E. (2007). Introducing the 3-A grief intervention model for dementia caregivers: Acknowledge, Assess and Assist. *OMEGA: The Journal of Death and Dying, 54*(3), 215–235. doi: 10.2190/D1R5-0473-1922-4N70
- Soellner, R., Reder, M., Machmer, A., Holle, R., & Wilz, G. (2015). The Tele.TAnDem intervention: Study protocol for a psychotherapeutic intervention for family caregivers of people with dementia. *BMC Nursing, 14*(1), 1–6. doi: 10.1186/s12912-015-0059-9
- Spira, A., Beaudreau, S., Jimenez, D., Kierod, K., Cusing, M., Gray, H., & Gallagher-Thompson, D. (2007). Experiential avoidance, acceptance, and depression in dementia family caregivers. *Clinical Gerontologist, 30*(4), 55–64. doi: 10.1300/J018v30n04\_04
- Statistisches Bundesamt. (2015). *Bevölkerung und Erwerbstätigkeit. Bevölkerung mit Migrationshintergrund. Ergebnisse des Mikrozensus 2014 [Population and employment. Persons with migrant background. Results from the micro census 2014]*. Wiesbaden, Germany: Author.
- Steyer, R., Eid, M., & Schwenkmezger, P. (1997). Modeling true intraindividual change: True change as a latent variable. *Methods of Psychological Research Online, 2*, 21–33.
- Theut, S. K., Jordan, L., Ross, L. A., & Deutsch, S. I. (1991). Caregiver's anticipatory grief in dementia: A pilot study. *The International Journal of Aging & Human Development, 33*(2), 113–118.

- Tremont, G., Davis, J. D., Bishop, D. S., & Fortinsky, R. H. (2008). Telephone-delivered psychosocial intervention reduces burden in dementia caregivers. *Dementia*, 7(4), 503–520. doi: 10.1177/1471301208096632
- Walker, R. J., & Pomeroy, E. C. (1996). Depression or grief?: The experience of caregivers of people with dementia. *Health & Social Work*, 21(4), 247–254. doi: 10.1093/hsw/21.4.247
- Walker, R. J., & Pomeroy, E. C. (1997). The impact of anticipatory grief on caregivers of persons with Alzheimer's disease. *Home Health Care Services Quarterly*, 16(1–2), 55–76. doi: 10.1300/J027v16n01\_05
- Walker, R. J., Pomeroy, E. C., McNeil, J. S., & Franklin, C. (1994). Anticipatory grief and Alzheimer's disease: Strategies for intervention. *Journal of Gerontological Social Work*, 22(3–4), 21–39. doi: 10.1300/J083V22N03\_03
- Warchol-Biedermann, K., Mojs, E., Gregersen, R., Maibom, K., Millan-Calenti, J. C., & Maseda, A. (2014). What causes grief in dementia caregivers? *Archives of Gerontology and Geriatrics*, 59(2), 462–467. doi: 10.1016/j.archger.2014.05.013
- Wilz, G., Meichsner, F., & Soellner, R. (in press). Are psychotherapeutic effects on family caregivers of people with dementia sustainable? Two-year long-term effects of a telephone-based cognitive behavioral intervention. *Aging and Mental Health*. doi: 10.1080/13607863.2016.1156646
- Wilz, G., Schinköthe, D., & Kalytta, T. (2015). *Therapeutische Unterstützung für pflegende Angehörige für Menschen mit Demenz. Das Tele.TAnDem Behandlungskonzept [Therapist support for dementia caregivers: The Tele.TAnDem Intervention Program]*. Göttingen, Germany: Hogrefe.
- Wilz, G., Schinköthe, D., & Soellner, R. (2011). Goal attainment and treatment compliance in a cognitive-behavioral telephone intervention for family caregivers of persons with dementia. *The Journal of Gerontopsychology and Geriatric Psychiatry*, 24(3), 115–125. doi: 10.1024/1662-9647/a000043
- Wilz, G., & Soellner, R. (2015). Evaluation of a short-term telephone-based cognitive behavioral intervention for dementia family caregivers. *Clinical Gerontologist*. doi: 10.1080/07317115.2015.1101631
- Wittkowski, J. (2013). *Würzburger Trauerinventar [Würzburg Grief Inventory]*. Göttingen, Germany: Hogrefe.
- Wolfson, C., Wolfson, D. B., Asgharian, M., M'Lan, C. E., Ostbye, T., Rockwood, K., & Hogan, D. B. (2001). A reevaluation of the duration of survival after the onset of

- dementia. *New England Journal of Medicine*, 344(15), 1111–1116. doi: 10.1056/nejm200104123441501
- Worden, J. W. (2009). *Grief counseling and grief therapy: A handbook for the mental health practitioner*. New York, NY: Springer.
- Zarit, S. H., Todd, P. A., & Zarit, J. M. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. *The Gerontologist*, 26(3), 260–266. doi: 10.1093/geront/26.3.260
- Znoj, H. (2004). *Komplizierte Trauer [Complicated Grief]*. Göttingen, Germany: Hogrefe
- Znoj, H. (2008). Texas-Revised Inventory of Grief: Validierung der deutschen Version TRIG-D [Texas-Revised Inventory of Grief: Validation of the German version TRIG-D]. *Psychosomatik und Konsiliarpsychiatrie*, 2(4), 236–239. doi: 10.1007/s11800-008-0131-3



## **MANUSCRIPTS**

Study I:

Managing Loss and Change: Grief Interventions for Dementia Caregivers in a  
CBT-based Trial

This manuscript has been published as:

Meichsner, F., Schinköthe, D., & Wilz, G. (2015). Managing loss and change: CBT-based grief interventions for dementia caregivers. *American Journal of Alzheimer's Disease and Other Dementias*, 31(3), 231–240. doi: 10.1177/1533317515602085

### Abstract

Dementia caregivers often experience loss and grief related to general caregiver burden, physical and mental health problems. Through qualitative content analysis, this study analyzed intervention strategies applied by therapists in a randomized-controlled trial in Germany to assist caregivers in managing losses and associated emotions. Sequences from 61 therapy sessions that included interventions targeting grief, loss, and change were transcribed and analyzed. A category system was developed deductively and the intercoder reliability was satisfactory. The identified grief intervention strategies were: Recognition and Acceptance of Loss and Change, Addressing Future Losses, Normalization of Grief, and Redefinition of the Relationship. Therapists focused on identifying experienced losses, managing associated feelings, and fostering acceptance of these losses. A variety of CBT-based techniques was applied with each strategy. The findings contribute to understanding how dementia caregivers can be supported in their experience of grief and facilitate the development of a manualized grief intervention.

*Keywords:* Alzheimer's disease, grief, cognitive-behavioral therapy, telephone, caregiver support, qualitative content analysis

## 1 Introduction

An estimated 44.4 million people worldwide are currently diagnosed with Alzheimer's disease or another form of dementia and this number is expected to increase to 75.6 million by 2030 (Alzheimer's Disease International, 2014). It is, however, not only those with dementia who should be of concern, but also their caregivers. In addition to physical care, caregivers are confronted with changes in the behavior and personality of their family members (Perren, Schmid, & Wettstein, 2006). Witnessing these changes can lead to experiences of loss and grief on a daily basis, with which many caregivers are unable to cope. In this article, we report the results of a qualitative content analysis examining how clinical psychologists in a telephone-based cognitive-behavioral intervention study responded to support caregivers in accepting and dealing with these changes.

### 1.1 Grief and Loss in Dementia Caregivers

Dementia caregivers are often heavily burdened. They show higher levels of stress and depression as well as lower levels of subjective well-being, physical health, and self-efficacy than non-caregivers and caregivers of patients with other diseases (Pinquart & Sörensen, 2003). These differences are due to unique aspects of the dementia caregiving situation (Pinquart & Sörensen, 2003), as well as to the loss of the relationship with the care recipient. As attachment bonds are threatened and broken over the course of the disease, caregivers are confronted with a constantly changing situation. According to Bowlby's (1973) theory of attachment, breaking of attachment bonds can cause grief in the case of a meaningful relationship. This was demonstrated through an open-ended question included at the end of a quantitative study (Sanders & Corley, 2003): 253 caregivers, the majority of whom taking care for a family member in the moderate or severe stages of the disease at home, were asked if they were grieving the loss of their loved one. Sixty-eight percent reported that they are currently grieving and caregivers who did not report grief verbalized associated feelings.

The grief caregivers experience is similar to the grief after the death of a loved one (Meuser, Marwit, & Sanders, 2004) and has a multifaceted nature (Noyes et al., 2010; Sanders & Corley, 2003; Sanders, Ott, Kelber, & Noonan, 2008). In contrast to the grief after bereavement, caregiver grief is prolonged and has no clear starting or ending point (Sanders & Corley, 2003) as, in most cases, the disease progresses over eight to ten years (Alzheimer's Association, 2012). Along with cognitive decline and loss of memory, the care recipients' personality may change drastically; they remain physically present, but become psychologically absent, a phenomenon termed *ambiguous loss* (Boss, 2000). Another critical

component of the caregiver grief experience is *anticipatory grief* (Rando, 1986), which includes grief over past, present, and future losses. Since the family member is still alive, caregivers often feel that their losses cannot be openly acknowledged and publicly mourned, because these losses are not socially recognized, or conflict with religious, family, or cultural values (Sanders & Sharp, 2004). The resulting feelings of helplessness and isolation from the broader community have been described as *disenfranchised grief* (Doka, 2004). Noyes et al. (2010) integrated the above findings into the *grief–stress model of caregiving*. They propose that ambiguous loss is associated with the loss of companionship, communication, support, hope for improvement, and relationship dynamic change.

Caregivers are, however, often not aware of the grief inherent in dementia caregiving, and confuse symptoms with symptoms of stress (Silverberg, 2007). This phenomenon is referred to as *masked grief* (Dempsey & Baago, 1998) and because that grief is so often overlooked, it is one of the major risk factors for physical and mental health problems in dementia caregivers. Grief has been associated with caregiving burden (Holley & Mast, 2009), the development of physical problems (Stroebe, Schut, & Stroebe, 2007), and depressive symptoms (Sanders & Adams, 2005), and can be a barrier to the fulfilment of caregiving tasks (Frank, 2008).

## **1.2 Grief and Loss Interventions**

While grief is a normal experience and psychotherapeutic interventions are not necessarily needed (Worden, 2009), dementia caregivers constitute a high-risk group for the development of physical and mental health problems. Therefore, they can benefit from specialized interventions. Interventions can increase dementia caregivers' ability to cope with the losses they have already experienced and prepare for the death of their care recipient (Kasl-Godley, 2003). To date, some recommendations have been made regarding grief interventions for dementia caregivers (Dempsey & Baago, 1998; Doka, 2004; Holley & Mast, 2009; Noyes et al., 2010; Sanders et al., 2008; Silverberg, 2007). Studies on existing interventions (Kasl-Godley, 2003; Sanders & Sharp, 2004) mostly used group settings and focused on identifying and managing grief reactions. Kasl-Godley (2003) reported a decline in depressive symptoms, and while participants in the study by Sanders and Sharp (2004) showed an increase in grief from pre- to post-intervention, they reported that the group was helpful, because they learned about how grief influences health and well-being. An individualized approach was taken by the multicomponent grief intervention *Easing the Way* (Ott, Kelber, & Blaylock, 2010) that

yielded a significant reduction in grief symptoms. However, these studies were pilot studies with small numbers of participants and did not incorporate control groups.

Acceptance of the reality of the loss and management of emotions were proposed as goals for grief counseling and therapy (Worden, 2009). Studies that investigated interventions for problematic adaptations to loss have also found cognitive-behavioral therapy (CBT) to be effective, especially when dysfunctional thought patterns occurred (Boelen, de Keijser, van den Hout, & van den Bout, 2007). Holland, Currier, and Gallagher-Thompson (2009) investigated the effects a CBT-based intervention during caregiving had after bereavement and found improvement in normal and complicated grief symptoms. Emotional support, conveying information, and teaching cognitive skills were most effective for normal grief, while cognitive and behavioral strategies had the biggest impact on complicated grief (Holland et al., 2009).

Another focus for the design of interventions is that dementia caregivers are facing a difficult situation that cannot be changed per se. With emphasis on acceptance, mindfulness, and overcoming avoidance of experience, *Acceptance and Commitment Therapy* (S. C. Hayes, Strosahl, & Wilson, 1999), a third-wave approach to CBT, also offers an appropriate framework.

### **1.3 Study Objectives**

It was the objective of the present study to examine intervention strategies applied in a CBT-based trial to support grieving caregivers. Grief and loss have conclusively been shown to be part of the caregiving process, putting caregivers at risk of the development of physical and psychological problems both before and after the death of the care recipient. Consequently, dementia caregivers can benefit from psychotherapeutic interventions directly aimed at coping with losses and the resulting grief. There is, however, a need for studies that develop and subsequently evaluate such interventions; preferably with a cognitive-behavioral background. The present study aims to provide an understanding of the problems therapists explore and the intervention strategies they choose when grief and loss are expressed by caregivers in individual, CBT-based therapy.

## **2 Method**

The study was conducted within a randomized-controlled trial (RCT; Wilz, Schinköthe, & Soellner, 2011). Using transcripts from therapy sessions, the present study qualitatively analyzed the therapeutic approach to grief, while the main RCT evaluated the effectiveness of a telephone-based, cognitive-behavioral intervention for dementia caregivers in Germany. The

individual telephone-based setting seemed highly appropriate (Tremont, Davis, Bishop, & Fortinsky, 2008) because it allows caregivers flexible access to support without the problems they usually encounter in face-to-face or group settings (e.g., logistic problems, time constraints, care recipient cannot be left alone). Participants were recruited via mainly newspapers, cooperating institutions, and primary care physicians, and were eligible for the study if they fulfilled the following criteria: fulltime in-home caregiver of a person with a diagnosis of dementia and a score greater than “3” on the *Global Deterioration Scale* (Reisberg, Ferris, de Leon, & Crook, 1982), no simultaneous psychotherapy, no cognitive impairment, and no acute mental or physical illness. Participants were allocated to one of three study groups: Intervention group, treated control group, or untreated control group. Caregivers in the intervention group received seven manualized 50-minute therapy sessions over a period of three months. Six clinical psychologists trained in counseling and CBT delivered the intervention and received both pre-intervention training in application of the manual and regular supervision. While no therapist had a specific background in grief counseling, interventions for grieving caregivers were part of the training.

The manual was CBT-based and also included exercises on mindfulness and acceptance. It consisted of the modules Improving Problem Solving and Coping with Challenging Behavior, Increasing Pleasant Activities, Coping with Stress and Acute Burden, Identifying and Modifying Dysfunctional Thoughts and Core Beliefs Using Cognitive Techniques, Psychoeducation, and, most important for the present study, Accepting the Disease and Coping with Change, Loss, and Grief. Therapists were free to differentially weigh modules according to the caregiver’s individual needs. All therapy sessions were audiotaped.

Qualitative content analysis (Mayring, 2004), a systematic theory- and rule-based analysis of communication, was chosen as the methodological framework for the present analysis. It permits to structure and differentiate between intervention strategies, which meets the study’s aims, since therapists’ responses to grief were expected to vary. Qualitative content analysis also relies on intercoder reliability, which ensures objectivity of the analysis.

## **2.1 Identification of the Material for Qualitative Data Analysis**

The study sample consisted of 229 caregivers. For the present analysis, only sessions with caregivers in the intervention group ( $n = 129$ ) were considered. Therapy sessions during which grief and loss were addressed were identified via a two-tiered process: First, therapists’ session protocols and ratings on a newly developed adherence scale (Schinköthe & Wilz, 2014), which included the application of interventions targeted at loss and change, and an

adapted German version of the *Cognitive Therapy Scale*, which assesses therapeutic competences and the application of cognitive-behavioral techniques, were searched for interventions regarding grief, loss, and change. Second, two independent raters (the first and second authors) listened to all identified therapy sessions and selected sessions for analysis if their content reflected relationship losses (i.e., relationship dynamic change, loss of companionship, communication, and support; Noyes et al., 2010) and associated emotions. The agreement of the two raters was 95.6%, which was deemed satisfactory. Disagreements were discussed until consensus was reached. The sequences from the selected sessions that contained the grief intervention were transcribed verbatim.

To determine that the identification procedure was valid and no relevant sessions were missed, the intervention group was divided into three subgroups: *no focus on grief* (caregivers with 0 sessions identified according to the procedure described above), *minor focus on grief* (1 or 2 sessions identified), *major focus on grief* (3 or more sessions identified). Two caregivers were randomly selected from each group and the audiotapes of all their therapy sessions that had not previously been identified as relevant for the study were screened for interventions regarding grief, loss, and change. Since the *major focus on grief* group only consisted of four caregivers, all of these caregivers were selected.

This screening did not yield any new grief intervention or counseling techniques, indicating that the identification procedure can be regarded as valid. Although grief was addressed in one session, this was in the context of a review of the previous session's content; as grief interventions had previously taken place, grief and loss were also mentioned. This was, however, a repetition, and was therefore not classified as a new intervention. In three other sessions, losses were briefly mentioned, but therapists instead focused on other therapy goals. This identification procedure therefore ensured that all material pertaining to grief interventions was analyzed.

## 2.2 Sample

Thirty-three caregivers (26.19% of the intervention group) received grief interventions and were included in the analysis. They were almost entirely female (90.9%,  $n = 30$ ) and the sample included spouses (69.7%,  $n = 23$ ) and adult children (30.3%,  $n = 10$ ). The average age was 62.97 years ( $SD = 10.46$ ) with a range of 45 to 87 years. On average, participants had been providing caregiving duties for 4.6 years ( $SD = 3.09$ ). Most care recipients were in the moderately severe (18.2%), severe (51.5%), or very severe (18.02%) stages of dementia.



### 2.3 Development of the Category System and Coding Procedure

Qualitative content analysis is defined by a set of previously established steps (Mayring, 2004; see Figure 1). A category system that allows coding of grief intervention strategies was developed using a mostly deductive approach: Literature on grief interventions (e.g., Worden, 2009) and dementia caregiver grief (Doka, 2004) was reviewed and intervention strategies recommended within this literature were defined as categories. Additional strategies were added from the transcripts using an inductive approach. Coding rules and anchor items (i.e., good examples of the application of a strategy) were added to the category system.

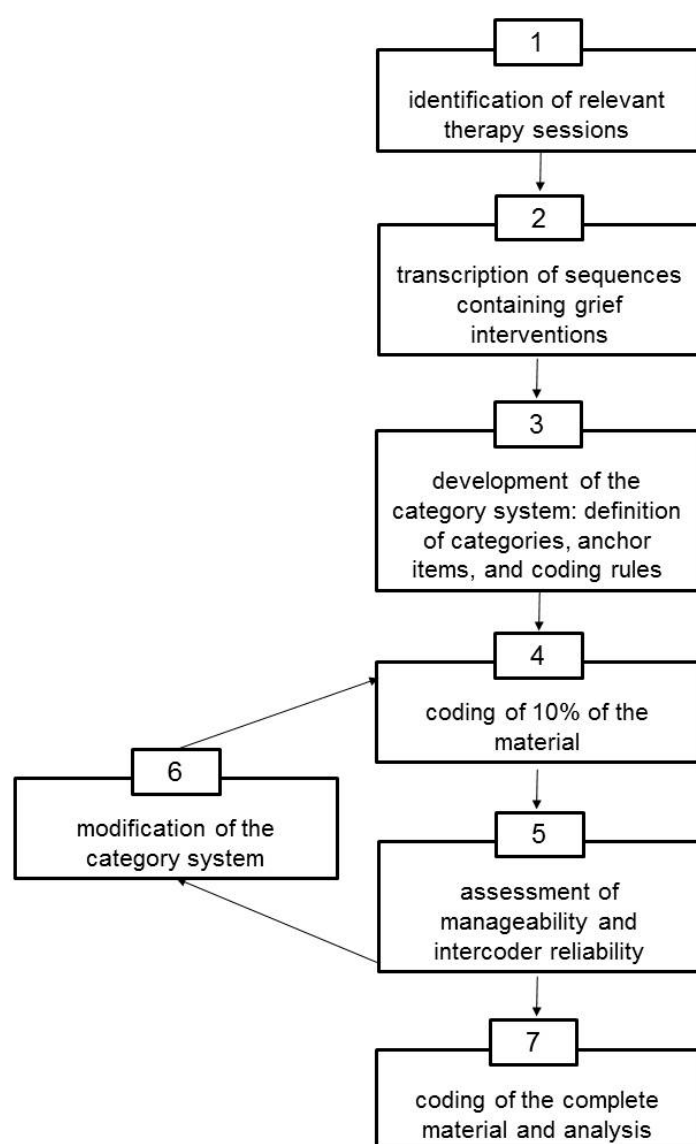


Figure 1. Flow model of the study.

Intercoder reliability was computed as a statistical measure of agreement between two independent coders. Krippendorff's alpha ( $\alpha$ ; A. F. Hayes & Krippendorff, 2007) was chosen because of its statistical superiority over other coefficients. Values over  $\alpha = .80$  indicate a reliable category system, which allows for confident data interpretation, values between  $\alpha = .68$  and  $.80$  allow only tentative conclusions, and values lower than  $\alpha = .68$  require a revision of the category system. As recommended (Mayring, 2004), ten percent of the material was randomly chosen for the first coding cycle and coded by two independent coders (the first and second authors) with experience in CBT for dementia caregivers, to assess both the intercoder reliability and the manageability of the category system. The intercoder reliability (Krippendorff's  $\alpha = .74$ ) was deemed too low. To improve reliability, all disagreements were discussed and revisions were made: Two categories that overlapped were merged to create a new category and the coding rules of all categories were improved to give more precise guidelines. In the second coding cycle, ten percent of the material was again randomly selected and coded independently. In this second cycle, the intercoder reliability was found to be satisfactory (Krippendorff's  $\alpha = .80$ ) for interpretation of the coded data.

The final category system consists of four categories that represent main grief intervention strategies and refer to different aspects of the grief experience: Recognition and Acceptance of Loss and Change, Normalization of Grief, Redefinition of the Relationship, and Addressing Future Losses (see Table 1). In the coding process, the categories were assigned to the sequences of the therapy sessions that included grief interventions. Longer sequences were broken up into thematic units that were coded separately. Coding and analysis were conducted using ATLAS.ti software (ATLAS.ti Scientific Software Development GmbH, 2012).

Table 1

*Category System of Grief Intervention Strategies*

Name of the Category	Definition	Anchor Item	Coding Rule
I: Recognition and Acceptance of Loss and Change	<p>The therapist supports the caregiver in accepting losses associated with the disease and in accepting the new reality. The focus is also on the verbalization and disclosure of painful emotions associated with these losses (e.g., Worden, 2009).</p>	<p>“Because of this disease, he has changed so much; he is not the man you married, the man he used to be, anymore. In reality, you have already had to say goodbye to your husband, even though he is still alive.”</p>	<p>The therapist concretizes and explores what has changed due to the disease and which losses (primary or secondary) the caregiver has experienced. The therapist asks the caregiver to name and describe associated emotions from specific situations.</p> <p>Also focuses on feelings of guilt.</p>
II: Normalization of Grief	<p>Some caregivers assume that it is not right to grieve and therefore avoid it. Many also fear that grieving could lead to depression. The therapist communicates that it is normal and healthy to grieve and explains the difference between normal grief and depression.</p>	<p>“I think it is normal to be sad once in a while. I think it is quite important.”</p> <p>“Well, because...you worry you could become depressed if you allow yourself to grieve, be sad...”</p>	<p>The therapist explains that grief is a normal reaction to a family member’s dementia, that caregivers should allow themselves to grieve, and that grief does not cause mental health problems.</p> <p>Can also be directed at grief or expressions of grief (e.g., crying) experienced during the therapy session.</p>

As the disease progresses, the cognitive abilities and personality of the care recipient change (Noyes et al., 2010). This has strong implications for the relationship between caregiver and care recipient. The intervention is aimed at the recognition of these changes and the redefinition of the spousal or child identity.

“You are not husband and wife anymore. Maybe you are mother and child, but more likely caregiver and care recipient, right?”

### III: Redefinition of the Relationship

The therapist explores the changes in the relationship between caregiver and care recipient or helps the caregiver to redefine the relationship with the care recipient. Also includes the adoption of roles and tasks the care recipient used to be responsible for.

Dementia is a terminal disease. As the disease progresses, the caregiver anticipates further losses (Rando, 1986) and is confronted with decisions that could increase grief.

“You said, you hope you don’t have to go as far as putting your husband in a nursing home [...]. How do you cope with the fact that your husband is suffering from a terminal disease?”

### IV: Addressing Future Losses

The therapist focuses on anticipatory grief, painful future decisions associated with grief, and plans for the future, which can include the time after the care recipient has died.

---

*Note.* This is a shortened version of the category system, intended to give an overview. All examples were translated from German.

### 3 Results

The qualitative analysis was based on the selection of all therapist responses to grief. Sequences from 61 therapy sessions (i.e., 9 hours and 44 minutes) were transcribed and sequences had a mean duration of six minutes (range = 30 seconds to 27 minutes). Grief interventions generally occurred early on in therapy, with over half occurring in the first (27.87%), second (16.39%), or fourth (18.03%) sessions of the therapy process. In most cases, either one (47.54%) or two (32.79%) sequences per session included grief interventions.

The analysis showed that therapists targeted recognizing and naming experienced losses, expressing associated feelings, and fostering acceptance of these losses. To achieve this, therapists most frequently used intervention strategies coded as Recognition and Acceptance of Loss and Change, followed by Addressing Future Losses, Normalization of Grief, and Redefinition of the Relationship. Only in very rare cases (six out of the 61 sessions; 6.45%) did therapists apply strategies that could not be coded with the existing categories. These interventions generally pertained to caregiving losses (i.e., personal freedom, social opportunities) rather than relationship losses (Noyes et al., 2010). Over the course of a session, therapists almost always used either one (62%; 38 sessions) or two (33%; 20 sessions) strategies; three strategies were used in only five percent of the sessions (3 sessions), and all four strategies were never used in a single session.

#### 3.1 Recognition and Acceptance of Loss and Change

Recognition and Acceptance of Loss and Change was used the most frequently: it made up 47.31% of grief interventions (in relation to the total of all applied intervention strategies) and was used in 44 of the 61 sessions (see Table 2 for examples). Within this category, therapists addressed the loss of spousal communication, intimacy, and rituals, as well as the recognition that plans made for the time after retirement could no longer be fulfilled.

With psychoeducation therapists then linked the care recipient's behavior to the disease, thus framing the experienced losses as part of the disease. If caregivers held on to unrealistic hopes of finding some kind of treatment or discovering a reversible factor that had caused the symptoms (e.g., weather conditions, see Table 2) therapists addressed and restructured these dysfunctional thoughts.

Caregivers experienced many painful emotions associated with these losses and changes, which they often had problems recognizing or understanding. Therapists guided caregivers to identify painful emotions, such as grief, anger, guilt, and linked these emotions to

previously identified losses. To validate the existence of negative emotions, therapists also emphasized what is special about caring for someone with dementia.

### **3.2 Addressing Future Losses**

Therapists addressed future losses in 22.58% of their interventions and in 21 of the 61 sessions (see Table 3). When caregivers were confronted with the knowledge that the disease was terminal or that the final stage has been reached, thoughts of the care recipient's death became inevitable and caregivers anticipated future losses. Therapists addressed the associated feelings and thoughts with a focus on reaching acceptance of the inevitable loss. Many caregivers avoided thinking about the future because it caused severe anxiety. Therapists then encouraged caregivers to prepare themselves and assisted in identifying resources that could help them cope in the future.

### **3.3 Normalization of Grief**

Therapists focused on the Normalization of Grief in 13.98% of all grief interventions, addressing it in 13 of the 61 sessions (see Table 4). This intervention strategy was used when caregivers reported being sad or crying but forbidding themselves to admit to experiencing grief and sadness. Therapists first explained how they accept painful emotions and encouraged their expression during therapy sessions. They also used psychoeducation to clarify that grief is a normal reaction to the caregivers' situation, and validated the emotion and its expression. The therapists explained that it can be beneficial to acknowledge one's grief, as avoiding it can have adverse effects on caregivers' physical and mental health.

Some caregivers were afraid that being sad or crying would have negative consequences for their health that would, in the end, prevent them from taking care of their loved one; they were also afraid that the sad feelings would never end. Therapists again used psychoeducation and cognitive restructuring to correct such assumptions. As a balance to the expression of negative emotions, therapists also encouraged caregivers to engage in positive activities to take care of themselves when they were feeling sad.

### **3.4 Redefinition of the Relationship**

Therapists focused on Redefinition of the Relationship in 9.68% of grief interventions and in nine of the 61 sessions (see Table 5). It was clear from the caregivers' statements during the therapy sessions that they were often not aware how their roles were changing over the course of caregiving. Role change centered on caregivers having to give up their roles as spouses or children and to instead identify as caregivers. Therapists explored how the roles have changed between a caregiver and care recipient and then focused on redefining this relationship.

Table 2

*Examples for the Category Recognition and Acceptance of Loss and Change*

Exploration of losses	Classification of changes as part of dementia	Addressing unrealistic hopes and cognitive restructuring	Identification of painful emotions	Psychoeducation on loss as a unique aspect of dementia caregiving
<p>T: <i>And now you are confronted with [the dementia] so much; he has changed directly, right? [...] With your husband changing, the isolation, and that your own life is not how you imagined it, right?</i></p> <p>C: <i>Yes ... we had this wonderful apartment by the beach in Mallorca and we had all these plans. [...] They will never come true now, right?</i></p>	<p>T: <i>Because of this disease, he has changed so much; he is not the man you married, the man he used to be, anymore. In reality, you have already had to say goodbye to your husband, even though he is still alive. [...]</i></p> <p>C: <i>Exactly! Now you've said the right thing. And I have not said goodbye to many things and it will go on, this goodbye.</i></p>	<p>T: <i>Is it possible that behind the thought "The weather could have caused the forgetfulness," there is hope that he might get better again?</i></p> <p>C: <i>Yes! Don't you think so? [...]</i></p> <p>T: <i>I can understand this hope and, in fact, many spouses find it very difficult to accept the progressive nature of the disease. That's something you don't want and you always hope that it doesn't progress further. And I can imagine that behind your thought that the weather could have caused his decline, there</i></p>	<p>T: <i>How do you feel when you realize there is something you always used to do [together] and all of a sudden it is not possible anymore?</i></p> <p>C: <i>Well, I feel the loss and that makes me sad.</i></p>	<p>T: <i>There is a difference between someone who has a partner, but that partner is not capable of being a real partner anymore, and someone who does not have a partner at all and who can get used to the situation. You are married, you have a partner. But still he cannot offer you what a healthy man could offer.</i></p> <p>C: <i>Yes.</i></p> <p>T: <i>And that is sad, that is what is sad about dementia. Sometimes it is easier to accept it when somebody dies, but this disease is so difficult to bear because the person</i></p>

---

*is hope that he'll get better when the weather changes?*

*C: Yes. It's so hot at the moment and he doesn't remember so many things. He hardly recognizes his son, he asks me ten times a day "Who is that?". You don't think that's already....?*

*T: It is possible. Maybe it's the natural cause of the disease. [...]*

*C: I'm glad you told me. I really hoped, if the weather got cooler, he would get better...*

*is still here but also gone.*

---

*Note. T = therapist, C = caregiver.*



Table 3

*Examples for the Category Addressing Future Losses*

Addressing feelings and thoughts associated with losses	Identification of resources for coping with anticipated losses
<p>T: <i>You are witnessing that his health is deteriorating and you lose him a little more each day.</i></p> <p>C: <i>Yes, that exactly is my problem.</i></p> <p>T: <i>How does that make you feel?</i></p> <p>C: <i>Not so good, it makes me very sad. [...] I know it means I will be alone again.</i></p>	<p>T: <i>Saying goodbye is a difficult topic that we don't like to think about. But it could also be helpful to think about it before it is imminent, although you don't know exactly what is coming, to think about what you would need for it to be a good goodbye. Something you would like to have done together or what you would like to have said. Just as a preparation to feel—I don't know if you could call it that—"ready." I think it is helpful to prepare for these difficult moments by thinking them through.</i></p>

Note. T = therapist, C = caregiver.

Table 4

*Examples for the Category Normalization of Grief*

Expression of acceptance of negative emotions	Framing grief as a normal reaction, validation of its expression	Explanation of adverse effects of avoidance	Restructuring of unhelpful assumptions
<p>T: It is okay to be sad one evening, to cry, and to say to yourself "I will function again tomorrow, but today I allow myself some moments of sadness." That is, I think, absolutely okay.</p>	<p>T: This sadness you are feeling is absolutely normal and it is important to allow yourself to grieve. These negative emotions are absolutely normal; they are a kind of signal [...]—they mean that you had a wonderful time with your husband and it is very important to give them space and to admit them for a moment, okay?</p> <p>C: Yes, I am admitting them.</p>	<p>T: It is very important that you give this sadness some space in your life. And I'd like to encourage you that it is absolutely okay to cry from time to time. It is healthy to allow ourselves to grieve rather than trying to avoid it. What do you think could happen if we tried avoiding it?</p> <p>C: I can imagine that we would explode one day.</p> <p>T: Yes, or we could become physically ill, or wouldn't sleep well. We could also become depressed.</p>	<p>T: I think that was an important session today.</p> <p>C: Definitely, yes, definitely. Now that you've said that I can admit grief and not instantly become depressed, I think that I should admit it more. It doesn't mean that I have to cry for hours, but just to say "It is not bad, it is what it is," right?</p> <p>T: Exactly. And it actually is a normal reaction. I think—even if you cried for a few hours—it would be normal and it does not mean that you would become depressed. It is a normal, healthy reaction to the goodbye you are living through, right? It is difficult and you have a right to be sad. That's not bad.</p>

*Note.* T = therapist, C = caregiver.

Table 5

*Examples for the Category Redefinition of the Relationship*

Exploration of role change	Redefinition
<p>T: How would you define your current role? Does it still feel like a mother–daughter relationship?</p> <p>C: No, it's not like that anymore, it's the other way around. It's more like me being the mother and my mother is like a child. The roles have changed.</p> <p>T: And what does that mean for your relationship?</p> <p>C: I can't expect things from her anymore, I'm responsible now. I can't rely on her advice anymore.</p>	<p>T: Anyway, your relationship has changed, it is not like it used to be. That is painful; you are not husband and wife anymore. Maybe you are caregiver and care recipient now, aren't you? [...]</p> <p>C: Well, you know what I think sometimes? It would be better if I could define us as caregiver and patient.</p>

Note. T = therapist, C = caregiver.

## 4 Discussion

To our knowledge, the present study is the first to use a qualitative approach to analyze therapy sessions with dementia caregivers. Its results are based on the complete analysis of all sequences from therapy sessions drawn from a larger intervention study that were identified as relevant to the research question. Qualitative content analysis was a suitable method and, as indicated by the satisfactory intercoder reliability, the developed category system proved to be a reliable instrument for the qualitative assessment of therapists' responses to grief.

The results illustrate which intervention strategies therapists could apply to respond to grief and contribute to our understanding of how dementia caregivers can be supported in their experience of loss to prevent further adverse impacts. The overarching intervention concept of the trial was CBT-based and therapists frequently used CBT-techniques such as psychoeducation, restructuring of dysfunctional thoughts regarding grief, or engagement in positive activities to balance negative emotions. With each category representing a different aspect of the grief experience, the results support the conceptualization of dementia caregiver grief being multifaceted (Noyes et al., 2010; Sanders & Corley, 2003; Sanders et al., 2008).

Within the category of Recognition and Acceptance of Loss and Change, therapists addressed the loss of companionship between caregivers and care recipients, their current life situations and shared plans for the future, and associated emotions. This category includes a variety of different intervention strategies that cannot be separated from each other and it is their combination that enables therapists to guide caregivers towards an understanding and acceptance of the experienced losses. It became evident in many therapy sessions that caregivers had recognized these losses, but still found it difficult to see them as part of the disease, or to understand their own emotional reactions. Silverberg (2007) has argued that many caregivers only recognize their grief after they are explicitly told that this is what is happening to them. Therapists in our study therefore either introduced grief themselves or guided caregivers to understand that this was the actual emotion they were experiencing. They addressed the emotions that caregivers felt in specific situations, or towards the caregiving situation in general. These are important points to address in therapy; Doka (2004) has pointed out that although the caregiver situation is a tremendous source of negative feelings, caregivers are often unable or unwilling to admit this, out of a desire not to burden the care recipient, a fear of social sanctions, or a simple lack of opportunities to disclose such emotions. To facilitate disclosure, the therapists educated caregivers about the nature of emotions to help them to understand why they felt certain ways. Although many of the study participants had been caregivers for years and had received information about dementia, many still had incorrect

assumptions about what can cause changes in the care recipient's behavior. It was therefore also part of the Recognition and Acceptance of Loss and Change to educate caregivers about the natural course of the disease. This information can be helpful for caregivers to let go of false hopes and to accept the changes as irreversible.

Addressing Future Losses focused on losses over the disease trajectory, including the death of the care recipient. Unlike the loss of shared plans between caregivers and care recipients, which was addressed under the category of Recognition and Acceptance of Loss and Change, intervention strategies in this category focused on losses that had not already occurred but that had to be expected because of the disease's progressive nature. Many caregivers were reluctant to discuss the future, but therapists emphasized how important it was for them to prepare themselves for the death of their care recipients, rather than to avoid thinking about it. The importance of this preparation was clearly illustrated in a study by Hebert, Dang, and Schulz (2006), which assessed the extent to which 222 bereaved dementia caregivers had been prepared for the death of their care recipients. Results showed that unprepared caregivers experienced more complicated grief, depression, and anxiety.

When therapists focused on Normalization of Grief, caregivers learned that grief is a normal aspect of caregiving and that acknowledging it does not have negative consequences, but might even prevent further physical and mental health problems. Dementia caregivers are often afraid of being overwhelmed by painful emotions, are unsure of how to manage these emotions (Sanders & Corley, 2003), or experience disenfranchised grief (Doka, 2004). For caregivers in our sample it was more often the case that they themselves did not seem to allow and or accept their grief, indicating feelings of *self-disenfranchisement* (Dempsey & Baago, 1998; Sanders & Sharp, 2004). Many believed that admitting their grief would be wrong or unfair to care recipients, or were afraid of negative consequences for their mental health if they were to admit their grief. In this case, therapists again restructured such thoughts and provided information about the nature of grief, which helped caregivers to accept the existence of negative emotions. As Spira et al. (2007) found caregiver avoidance of negative feelings to be associated with increased depressive feelings, helping caregivers to accept the existence of negative emotions was a key strategy.

When focusing on Redefinition of the Relationship, the therapists supported the caregivers in understanding that their spousal or parent-child relationships were lost. Most caregivers had already perceived changes in their roles, as their loved ones had gradually changed from equal spouses or parents into more child-like persons. Addressing this experience during therapy was still painful but the therapists encouraged the caregivers to define their new

roles, which were mostly those of caregivers or parents. In our extensive experience with CBT for dementia caregivers, these types of roles help to fulfill daily caregiving tasks and accept outside help. Therapists did, however, not aim at emotionally disengaging the caregiver from the care recipient. On the contrary, we believe that supporting caregivers to abandon emotional avoidance and accept the occurring role change leads to a more empathic and adequate behavior towards the care recipient. The design of the study did not allow testing this hypothesis, but changes in caregiver behavior and the intervention's impact on the care recipients need to be evaluated in the future.

#### **4.1 Implications for Caregiver Interventions**

According to the caregivers' self-report within the process evaluation (Wilz et al., 2011) conducted to gain insight into the treatment implementation, grief interventions helped them to accept losses, and facilitated emotional processing. The final aim of interventions in all categories was acceptance of loss and change and overcoming avoidance of associated painful emotions. As this is in line with the goals of ACT, it can be concluded that third-wave approaches to CBT are suitable for grieving caregivers. By focusing on acceptance of the new reality, the therapists also chose an approach that is among the main aspects of grief counseling and therapy after bereavement (Worden, 2009). The categories were partly based on strategies recommended by Doka (2004) and Worden (2009) and then adapted to account for the special situation of grieving caregivers. The good reflection of the material by the category system both highlights that the established grief intervention strategies are suitable for dementia caregivers, but also brings to our attention what special aspects therapists need to focus on when working with this group.

Based on these results, we developed a grief intervention module that has been included in a CBT manual for dementia caregivers (Wilz, Schinköthe, & Kalytta, 2015). The module is being applied by therapists in an ongoing RCT with dementia caregivers, and analyses of its applicability and effectiveness are currently conducted.

In accordance with previous research in this area (Dempsey & Baago, 1998; Silverberg, 2007), the present study highlights how difficult it is for dementia caregivers to recognize and talk about their grief. It is important for therapists who work with dementia caregivers to keep this difficulty in mind and to ask about experiences of grief and loss openly; however, therapists must of course make decisions regarding the appropriate interventions on a case-by-case basis: for example, while some caregivers can benefit from overcoming their avoidance of grief, avoidance can also serve a protective function that helps caregivers to cope with their daily

tasks. More research is needed to better understand how therapists can recognize grief, as well as when and if the expression of grief should be encouraged during the therapy process.

## **4.2 Limitations**

Although the present analysis provides valuable insights into grief interventions, it has several notable limitations. The first is that only the sequences that included intervention strategies explicitly directed at grief and loss were transcribed; other techniques that therapists used that may have been indirectly connected to grief were not included. To address this limitation, transcriptions of the complete therapy sessions are provided in an ongoing qualitative study.

Second, sessions from only 26.19% of the sample were included in the analysis, leaving information regarding how other participants coped with their experienced losses unknown. We know from other studies (e.g., Sanders & Corley, 2003) that most caregivers suffer from grief, which is often not addressed directly, but is instead expressed indirectly through vague negative emotions or physical symptoms. Caregivers within the larger sample may not have received the grief interventions under study because they avoided bringing up losses in their sessions. Conversely, it is also possible that these caregivers had already found ways to cope with their grief, or that they did not experience their losses as significant or as causing grief; in either case, these caregivers would not need therapist support. However, more research is needed to understand these individual caregiver experiences, and to better differentiate between when caregivers are avoiding grief and when they are genuinely not experiencing it.

Due to the telephone-based setting, it is also possible that certain nuances pointing to indirect or masked grief were not noticed. Caregivers, however, expressed a high satisfaction with the telephone-based setting (Wilz et al., 2011) and in an ongoing study, the satisfaction of participants in a face-to-face setting was equally high to that in the telephone-based condition.

Despite these limitations, this study answers the call for grief intervention guidelines specifically tailored to the unique needs of dementia caregivers. The resulting set of intervention strategies was derived directly from therapy sessions and we anticipate that these strategies can therefore be successfully integrated into other therapy settings.

## 5 References

- Alzheimer's Association. (2012). 2012 Alzheimer's disease facts and figures. *Alzheimer's and Dementia: The Journal of the Alzheimer's Association*, 8, 131–168.
- Alzheimer's Disease International. (2014). Dementia statistics. Retrieved from <http://www.alz.co.uk/research/statistics>
- ATLAS.ti Scientific Software Development GmbH. (2012). ATLAS.ti (Version 6.2). Berlin, Germany: ATLAS.ti Scientific Software Development GmbH.
- Boelen, P. A., de Keijser, J., van den Hout, M. A., & van den Bout, J. (2007). Treatment of complicated grief: A comparison between cognitive-behavioral therapy and supportive counseling. *Journal of Consulting and Clinical Psychology*, 75(2), 277–284. doi: 10.1037/0022-006X.75.2.277
- Boss, P. (2000). *Ambiguous loss: Learning to live with unresolved grief*. Cambridge, MA: Harvard University Press.
- Bowlby, J. (1973). *Attachment and loss: Volument II Separation, anxiety and anger*. New York, NY: Basic Books.
- Dempsey, M., & Baago, S. (1998). Latent grief: The unique and hidden grief of carers of loved ones with dementia. *American Journal of Alzheimer's Disease and Other Dementias*, 13(2), 84–91. doi: 10.1177/153331759801300206
- Doka, K. J. (2004). Grief and dementia. In K. J. Doka (Ed.), *Alzheimer's disease: Living with grief* (pp. 139–155). Washington, DC: Hospice Foundation of America.
- Frank, J. B. (2008). Evidence for grief as the major barrier faced by Alzheimer caregivers: A qualitative analysis. *American Journal of Alzheimer's Disease and Other Dementias*, 22(6), 516–527. doi: 10.1177/1533317507307787
- Hayes, A. F., & Krippendorff, K. (2007). Answering the call for a standard reliability measure for coding data. *Communication Methods and Measures*, 1(1), 77–89. doi: 10.1080/19312450709336664
- Hayes, S. C., Strosahl, K. D., & Wilson, K. G. (1999). *Acceptance and Commitment Therapy: An experiential approach to behavior change*. New York, NY: Guilford Press.
- Hebert, R. S., Dang, Q., & Schulz, R. (2006). Preparedness for the death of a loved one and mental health in bereaved caregivers of patients with dementia: Findings from the REACH study. *Journal of Palliative Medicine*, 9(3), 683–693. doi: 10.1089/jpm.2006.9.683



- Holland, J. M., Currier, J. M., & Gallagher-Thompson, D. (2009). Outcomes from the Resources for Enhancing Alzheimer's Caregiver Health (REACH) program for bereaved caregivers. *Psychology and Aging, 24*(1), 190–202. doi: 10.1037/a0014303
- Holley, C. K., & Mast, B. T. (2009). The impact of anticipatory grief on caregiver burden in dementia caregivers. *The Gerontologist, 49*(3), 388–396. doi: 10.1093/geront/gnp061
- Kasl-Godley, J. (2003). Anticipatory grief and loss: Implications for intervention. In D. W. Coon, D. Gallagher-Thompson, & L. W. Thompson (Eds.), *Innovative interventions to reduce dementia caregiver distress* (pp. 210–219). New York, NY: Springer.
- Mayring, P. (2004). Qualitative content analysis. In U. Flick, E. von Kardorf, & I. Steinke (Eds.), *A companion to qualitative research* (pp. 266–269). London, Great Britain: Sage.
- Meuser, M. T., Marwit, S. J., & Sanders, S. (2004). Assessing grief in family caregivers. In K. J. Doka (Ed.), *Alzheimer's disease: Living with grief* (pp. 169–195). Washington, DC: Hospice Foundation of America.
- Noyes, B. B., Hill, R. D., Hicken, B. L., Luptak, M., Rupper, R., Dailey, N. K., & Bair, B. D. (2010). Review: The role of grief in dementia caregiving. *American Journal of Alzheimer's Disease and Other Dementias, 25*(1), 9–17. doi: 10.1177/1533317509333902
- Ott, C. H., Kelber, S. T., & Blaylock, M. (2010). "Easing the way" for spouse caregivers of individuals with dementia: A pilot feasibility study of a grief intervention. *Research in Gerontological Nursing, 3*(2), 89–99. doi: 10.3928/19404921-20100302-01
- Perren, S., Schmid, R., & Wettstein, A. (2006). Caregivers' adaptation to change: The impact of increasing impairment of persons suffering from dementia on their caregivers' subjective well-being. *Aging & Mental Health, 10*(5), 539–548. doi: 10.1080/13607860600637844
- Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging, 18*(2), 250–267. doi: 10.1037/0882-7974.18.2.250
- Rando, T. A. (Ed.). (1986). *Loss and anticipatory grief*. Lexington, MA: Lexington Books.
- Reisberg, B., Ferris, S. H., de Leon, M. J., & Crook, T. (1982). The Global Deterioration Scale for assessment of primary degenerative dementia. *American Journal of Psychiatry, 139*, 1136–1139. doi: 10.1176/ajp.139.9.1136

- Sanders, S., & Adams, K. B. (2005). Grief reactions and depression in caregivers of individuals with Alzheimer's disease: Results from a pilot study in an urban setting. *Health & Social Work, 30*(4), 287–295. doi: 10.1093/hsw/30.4.287
- Sanders, S., & Corley, C. S. (2003). Are they grieving? A qualitative analysis examining grief in caregivers of individuals with Alzheimer's disease. *Social Work in Health Care, 37*(3), 35–53. doi: 10.1300/J010v37n03\_03
- Sanders, S., Ott, C., Kelber, S., & Noonan, P. (2008). The experience of high levels of grief in caregivers of persons with Alzheimer's disease and related dementia. *Death Studies, 32*(6), 495–523. doi: 10.1080/07481180802138845
- Sanders, S., & Sharp, A. (2004). The utilization of a psychoeducational group approach for addressing issues of grief and loss in caregivers of individuals with Alzheimer's disease. *Journal of Social Work in Long-Term Care, 3*(2), 71–89. doi: 10.1300/J181v03n02\_06
- Schinköthe, D., & Wilz, G. (2014). The assessment of treatment integrity in a cognitive behavioral telephone intervention study with dementia caregivers. *Clinical Gerontologist, 37*(3), 211–234. doi: 10.1080/07317115.2014.886653
- Silverberg, E. (2007). Introducing the 3-A grief intervention model for dementia caregivers: Acknowledge, Assess and Assist. *OMEGA: The Journal of Death and Dying, 54*(3), 215–235. doi: 10.2190/D1R5-0473-1922-4N70
- Spira, A., Beaudreau, S., Jimenez, D., Kierod, K., Cusing, M., Gray, H., & Gallagher-Thompson, D. (2007). Experiential avoidance, acceptance, and depression in dementia family caregivers. *Clinical Gerontologist, 30*(4), 55–64. doi: 10.1300/J018v30n04\_04
- Stroebe, M., Schut, H., & Stroebe, W. (2007). Health outcomes of bereavement. *The Lancet, 370*(9603), 1960–1973. doi: 10.1016/s0140-6736(07)61816-9
- Tremont, G., Davis, J. D., Bishop, D. S., & Fortinsky, R. H. (2008). Telephone-delivered psychosocial intervention reduces burden in dementia caregivers. *Dementia, 7*(4), 503–520. doi: 10.1177/1471301208096632
- Wilz, G., Schinköthe, D., & Kalytta, T. (2015). *Therapeutische Unterstützung für pflegende Angehörige für Menschen mit Demenz. Das Tele.TAnDem Behandlungskonzept [Therapist support for dementia caregivers: The Tele.TAnDem Intervention Program]*. Göttingen, Germany: Hogrefe.
- Wilz, G., Schinköthe, D., & Soellner, R. (2011). Goal attainment and treatment compliance in a cognitive-behavioral telephone intervention for family caregivers of persons with

dementia. *The Journal of Gerontopsychology and Geriatric Psychiatry*, 24(3), 115–125. doi: 10.1024/1662-9647/a000043

Worden, J. W. (2009). *Grief counseling and grief therapy: A handbook for the mental health practitioner*. New York, NY: Springer.

## Study II:

### The Caregiver Grief Scale: Development, Exploratory and Confirmatory Factor Analysis, and Validation

This manuscript has been published as:

Meichsner, F., Schinköthe, D., & Wilz, G. (2015). The Caregiver Grief Scale: Development, exploratory and confirmatory factor analysis, and validation. *Clinical Gerontologist*, 39(4), 342–361. doi: 10.1080/07317115.2015.1121947

### Abstract

*Objective.* Pre-death grief is among the most debilitating aspects of dementia caregiving and can have adverse impacts on caregivers' physical and mental health. The specific assessment of grief is therefore an important prerequisite for both clinical and research settings. The present study aimed to build upon previous research and develop a scale for the measurement of grief in dementia caregivers.

*Methods.* An initial pool of 21 items was created through both the selection of appropriate items from existing instruments and the development of new items. 229 caregivers ( $M_{\text{age}} = 63.8 \text{ years} \pm 10.5$ ) completed the scale along with measures of construct validity. The sample was randomly split in half and exploratory factor analysis was conducted on the first data set. The established factor structure was then subjected to confirmatory factor analysis on the second data set.

*Results.* Convincing goodness-of-fit indices emerged for a four-factor model, with factors reflecting different aspects of caregiver grief (i.e., Emotional Pain, Relational Loss, Absolute Loss, and Acceptance of Loss). The total scale and subscales yielded high internal consistency reliabilities (Cronbach's  $\alpha = .67-.89$ ) and construct validity coefficients.

*Conclusions.* The Caregiver Grief Scale is now available for use in clinical and research settings to aid therapists and researchers in assessing the burden caregivers experience due to grief and evaluating the effects of grief-specific interventions.

*Keywords:* psychological assessment, caregiver health, dementia, grief, factor analysis, validity and reliability

## 1 Introduction

Dementia caregivers' experience of grief and loss has received growing scholarly recognition over the last 20 years. Lindauer and Harvath (2014) define caregivers' pre-death grief as the "emotional and physical response to the perceived losses in a valued care recipient" (p. 2203). In caring for persons with dementia a continuous breaking of attachment bonds takes place over the caregiving trajectory: Although the care recipients are still physically present, their personalities change and they lose memories and abilities, thus becoming psychologically absent. This leads to the loss of companionship, communication, and the care recipient's support, as well as the experience of role change on a daily basis (Noyes et al., 2010). If significant, these losses cause grief, which can manifest through a variety of emotions such as sorrow, anger, confusion, and hopelessness (Lindauer & Harvath, 2014; Noyes et al., 2010).

Caregivers' pre-death grief shares similarities with Rando's (2000) concept of *anticipatory grief* which includes the awareness of the absolute loss and the recognition of associated losses in the past, present, and future. Anticipatory grief can serve an important psychological function: If coped with adequately, it can facilitate adaption to bereavement (Rando, 2000). However, it has also been noted (Holley & Mast, 2009) that dementia caregivers' experience of anticipatory grief is more severe and studies have conclusively shown that caregiver grief is also associated with poorer physical and mental health (Holley & Mast, 2009; Sanders & Adams, 2005). Therefore, specific interventions that help caregivers to cope with their grief are needed. In that, caregivers' pre-death grief is different from post-death grief that most individuals manage without psychological help (Schut & Stroebe, 2005).

A necessary precondition for the development and evaluation of grief interventions is the ability to quantify the extent to which caregivers experience grief. In the past, studies that investigated caregiver grief have relied either on measures related to grief (e.g., depression) or on measures developed for post-death grief, such as the *Texas Revised Inventory of Grief* (TRIG; Faschingbauer, Zisook, & DeVaul, 1987). The *Anticipatory Grief Scale* (Theut, Jordan, Ross, & Deutsch, 1991) does focus on the caregiving experience, but it was validated only with a small, homogeneous sample (i.e., 27 wives of veterans), and its items focus more on coping with dementia than on grief. This use of non-specific instruments makes it more likely that specific aspects of the caregivers' situation and grief reaction, such as continuous losses or the tendency to avoid grief (Meichsner, Schinköthe, & Wilz, 2015), will be missed, making these instruments poorly suited for the assessment of caregiver grief.

To date, only the *Marwit–Meuser Caregiver Grief Inventory* (MM-CGI; Marwit & Meuser, 2002) has been developed specifically for the assessment of caregiver grief. The

authors conducted an exploratory factor analysis (EFA) of 184 original items based on statements made by caregivers and the final inventory consists of 50 items that represent three distinct factors with high internal consistencies. The first factor, Personal Sacrifice and Burden, measures what caregivers had to give up and the extent to which they experience personal losses. Heartfelt Sadness and Longing, the second factor, represents the emotional reaction to the loss of the relationship with the care recipient. It measures emotions like sadness, and is the closest to traditional grief. The third factor, Worry and Felt Isolation, addresses how caregivers perceive losing personal connections with others due to caregiving responsibilities and their worries about the future. The authors of the MM-CGI have observed that the factor Heartfelt Sadness and Longing relates to true grief, but still regard the others “to be grief-related factors” (Marwit & Meuser, 2002, p. 759).

With the present study, we aimed to build upon this previous important work by more specifically targeting caregiver grief alone and by adding items relating to the avoidance of grief and its expression. This seems important, because we found in a previous study (Meichsner et al., 2015) that some caregivers avoid openly expressing grief (e.g., crying or talking about it), either out of a desire not to burden the care recipient, or out of fear that expression of these feelings could lead to depression. However, Spira et al. (2007) reported specifically for dementia caregivers that high levels of avoidance of negative feelings (i.e., a phenomenon referred to as *experiential avoidance* in *Acceptance and Commitment Therapy*; Hayes, Strosahl, & Wilson, 1999) are associated with increased symptoms of depression. Caregivers who avoid grieving experienced losses also miss the opportunity to prepare themselves for the final loss of the care recipient and this lack of preparedness has been associated with more complicated grief, depression, and anxiety after bereavement (Hebert, Dang, & Schulz, 2006). The detection of false assumptions and associated behaviors should therefore be a key component of any instrument used to assess caregiver grief.

Finally, most existing measures of grief in general and of caregiver grief in particular were developed using EFA. EFA results can be difficult to replicate, since they are often based on chance correlations, and in the past replication seemed especially difficult with caregiver samples (e.g., Cheng, Kwok, & Lam, 2014). Factor solutions should therefore always be verified using confirmatory factor analysis (CFA).

All of the reasons outlined in this section indicate the need for an instrument specific to the assessment of caregiver grief. The instrument should cover the different aspects of caregiver grief, most importantly experienced losses and caregivers' emotional reaction to them, as well as the tendency to avoid or accept losses and grief. Furthermore, the instrument should allow

grief to be differentiated from depression, anxiety, and other care-related distress (Chan, Livingston, Jones, & Sampson, 2013) and should be brief enough to be used in both research and clinical settings. It was therefore the aim of the present study to develop and validate a brief scale that specifically measures the multifaceted nature of caregiver grief, confirm this scale's factor structure through CFA, and gather data on construct validity.

## 2 Method

### 2.1 Sample

Participants (229 home-caregivers of a family member with dementia) were German residents who were taking part in a larger ongoing intervention study with three study groups (telephone-based intervention, face-to-face intervention, untreated control group; see Soellner, Reder, Machmer, Holle, & Wilz, 2015, for study details).

Table 1

*Sample Characteristics (N = 229)*

Caregivers	
Age in years, <i>M (SD)</i>	63.8 (10.5)
Age range	35–87
Gender (Female), <i>n (%)</i>	181 (79.0)
Relationship to care recipient, <i>n (%)</i>	
Spouse	134 (58.5)
Adult child	91 (39.8)
Other	4 (1.7)
Education, <i>n (%)</i>	
Primary or other	10 (4.4)
Secondary: Level 2	123 (53.7)
Secondary: Levels 3 & 4	13 (5.7)
Tertiary: Levels 5 & 6	83 (36.2)
Monthly household net income in EUR, <i>n (%)</i>	
< 499	2 (0.9)
500 – 999	16 (7.0)
1,000 – 1,499	28 (12.3)



1,500 – 1,999	36 (15.9)
2,000 – 2,499	49 (21.6)
2,500 – 2,999	37 (16.3)
3,000 – 3,999	35 (15.4)
> 4,000	24 (10.6)
Living with care recipient, <i>n</i> (%)	182 (79.5)
Care duration in years, <i>M</i> ( <i>SD</i> )	4.9 (3.6)
Range	0–19
<hr/>	
Care recipients	
<hr/>	
Age in years, <i>M</i> ( <i>SD</i> )	78.5 (9.4)
Age range	55–104
Gender (Female), <i>n</i> (%)	120 (52.4)
Type of dementia, <i>n</i> (%)	
Alzheimer's Disease	101 (44.2)
Vascular dementia	23 (10.0)
Frontotemporal dementia	13 (5.7)
Other/unknown	92 (40.1)
<hr/>	

The full version of the developed scale was included from the post-intervention assessment forward. A series of one-way analyses of variance and  $\chi^2$ -tests carried out to test for group differences revealed no differences between study groups for either demographic variables or for any of the grief items (all  $p > .05$ ). We therefore combined the data from all caregivers from all study groups who were still providing full-time at-home care at the time of assessment to arrive at a sample size large enough to yield trustworthy parameter estimates. Caregivers were on average 63.9 years old ( $SD = 10.5$ ) and the majority of the sample was female (79.0%,  $n = 181$ ). Most caregivers were either taking care of a spouse (58.5%,  $n = 134$ ) or parent (39.8%,  $n = 91$ ) with dementia. Further demographic information is summarized in Table 1. To evaluate the scale's test-retest reliability, data from the subsample of caregivers who were still providing care at the time of our six-month follow up assessment ( $n = 184$ ) were used.

## 2.2 Procedure

### 2.2.1 Development of the Caregiver Grief Scale (CGS)

An initial pool of 21 German-language items (see Table 2) was generated. Seven new items were developed, eight items were drawn from Factor 2 of the MM-CGI, and six items were drawn from established and widely used instruments of post-death grief: Two items from the German version of the TRIG (Faschingbauer et al., 1987; Znoj, 2008), one item from the *Würzburg Grief Inventory* (WüTI; Wittkowski, 2013), and three items from the German version of the *Inventory of Complicated Grief–Revised–Short Form* (ICG–R; Prigerson & Jacobs, 2001; Znoj, 2004). All items were rated on a five-point Likert scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*).

The seven new items were generated based on statements made by caregivers in a prior study by some of the authors of the present paper (Wilz & Soellner, 2015), with the goal of including important aspects that have not been included in previous instruments (e.g., avoidance of grief, see Table 2 for all newly developed items). Items from existing instruments were selected only if they were suitable for dementia caregivers. Selection was discussed by all three authors until consent was reached. Two items from the MM-CGI (Items 3 and 6) were slightly modified to ensure their appropriateness for all caregivers. For example, “It hurts to put her/him to bed at night and realize she/he is gone” assumes that caregivers put the care recipient to bed at night, which is not true for all participants. Item formulation was therefore changed to “It hurts to realize that she/he is gone” (see also Table 2). Formulation of the TRIG, WüTI, and ICG–R items was also adapted to refer to caregiver grief instead of post-death grief when necessary. Items from the MM-CGI were translated into German by two researchers whose first language is German and who were experts in the field of caregiver grief. The items were back-translated into English by a native speaker and versions were checked for their congruence. Item formulation was discussed and improvements were made to the German translation when necessary.

### 2.2.2 Assessment

A questionnaire was mailed to all participants and further information and instructions were provided in a scheduled telephone-based interview. The university’s ethics committee approved the study and all participants provided consent prior to participation. Participants completed a demographic questionnaire and the following four instruments were used for analysis of convergent and divergent validity based on previous research (e.g., Marwit & Meuser, 2002, also see above):

*General Depression Scale (German Version of the Center for Epidemiologic Studies Depression Scale; CES-D)*

The CES-D (Hautzinger, Bailer, Hofmeister, & Keller, 2012) is used to assess the existence and duration of general depressive symptoms. Test-takers are asked to respond to 20 items using a four-point Likert-type scale ranging from 1 (less than one day) to 4 (*five to seven days*). The scale was demonstrated to have high internal consistency (Cronbach's  $\alpha = .89$  to  $.92$ ; see Table 3 for internal consistencies in the present sample) and convergent validity was established through high positive correlations with, for example, the *Beck Depression Inventory* (Hautzinger et al., 2012).

*Hospital Anxiety and Depression Scale–German Version (HADS-D)*

The anxiety subscale from the German version of the HADS (Herrmann-Lingen, Buss, & Snaith, 2011) was used to assess symptoms of anxiety. This subscale is used to measure to what extent seven symptoms of anxiety were experienced during the preceding week on a four-point Likert-type scale ranging from 0 (*never*) to 3 (*all the time*). Satisfactory internal consistency was reported for this subscale (Cronbach's  $\alpha = .80$ ). Validity was, for example, demonstrated through high positive correlations between the anxiety subscale of the HADS and *Spielberger's State-Trait Anxiety Inventory* and the *Beck Depression Inventory* (Bjelland, Dahl, Haug, & Neckelmann, 2002).

*WHO Quality of Life-BREF–German Version (WHOQoL-BREF)*

This 26-item short version of the WHOQoL (Angermeyer, Kilian, & Matschinger, 2000) measures the perceived quality of life for the domains of Physical Health, Psychological Health, Social Relationships, and Environment on a five-point Likert-type scale ranging from 1 (*very dissatisfied*) to 5 (*very satisfied*). Internal consistencies for the various domains ranged from Cronbach's  $\alpha = .57$  to  $.88$ . The WHOQoL-BREF was found to discriminate well between both healthy persons and persons with health problems as well as between persons with physical and mental health problems (Angermeyer et al., 2000).

*Gießen Body Complaint List (GBB-24)*

The GBB-24 (Brähler, Hinz, & Scheer, 2008) is designed to measure body complaints by asking participants how much they are burdened by 24 physical symptoms. Participants respond using a five-point Likert-type scale, ranging from 0 (*not at all*) to 4 (*strongly*). The GBB-24 comprises the subscales Fatigue, Gastric Disorders, Rheumatic Pains, and Heart Trouble, for a total score of Overall Burden. This instrument was demonstrated to have satisfying to high internal consistencies for all subscales, with the original Cronbach's  $\alpha$  ranging

from .75 to .94 for the various subscales. Convergent validity was demonstrated through high positive correlations with, for example, the somatization subscale of the *Symptom Checklist-90-R* (Schlagenhauf, 2003).

It was hypothesized that the CES-D, the HADS-D, and the Psychological Health domain of the WHOQoL-BREF constitute convergent measures, while the remaining WHOQoL-BREF domains and the GBB-24 serve as divergent measures.

Differences between subgroups of caregivers for a number of demographic variables were explored. The selected variables were all drawn from previous studies' findings (e.g., Chan et al., 2013; Marwit & Meuser, 2002): Gender, relationship to care recipient, living with care recipient, duration of caregiving, time since diagnosis, and severity of dementia as measured by the *Global Deterioration Scale* (Reisberg, Ferris, de Leon, & Crook, 1982).

### **2.3 Statistical Analysis**

In the present study, the sample was randomly split into two data sets of equal size (Set 1,  $n = 115$ ; Set 2,  $n = 114$ ) using the random sample function in IBM SPSS Statistics 21. All other statistical analyses were performed with MPlus Version 7 (Muthén & Muthén, 2012) using Maximum Likelihood Estimation.

The amount of missing data was moderate and data were missing at random. Across all variables used in the analysis, missing data proportions ranged between 0.4 and 4.3 percent. Full Information Maximum Likelihood was used for the estimation of missing data.

EFA was performed on the first data set. The potential number of factors was determined according to the Eigenvalues  $> 1.0$  rule, screeplot, model interpretability, and model fit. Items with loadings  $\geq .40$  were regarded as belonging to a specific factor and were considered for the final solution. Since we assumed that different aspects of grief are intercorrelated, oblique rotations using the OBLIMIN method were chosen to aid factor interpretation. CFA was then performed on the second data set to confirm the identified model.

In addition to the  $\chi^2$  statistic, which is sensitive to sample size, model fit was evaluated using the Comparative Fit Index (CFI), Tucker Lewis Index (TLI), Root Mean Square Error of Approximation (RMSEA), and Standardized Root Mean Square Residual (SRMR) for both the EFA and CFA models. A well-fitting model should yield  $CFI/TLI \geq 0.950$ , and  $RMSEA/SRMR \leq 0.050$  (Marsh, Hau, & Grayson, 2005).  $RMSEA/SRMR$  values of  $\leq 0.080$  indicate moderate fit. Models were compared using Akaike's Information Criterion (AIC), whereby smaller values indicate superior models.

Using the whole sample, Cronbach's  $\alpha$  was calculated for the final set of items and for each factor, to determine internal consistency. The latent Pearson product-moment correlation between the CGS total scores at the post-intervention and six-month follow up assessment was inspected to assess retest reliability. For the determination of the scale's construct validity, latent Pearson product-moment correlations between the CGS total score and factor scores and the other instruments were computed. Statistical comparisons were done following the procedure outlined by Meng, Rosenthal, and Rubin (1992); the goal of these comparisons was to determine whether correlations with the convergent measures were significantly larger than correlations with discriminant measures.

To assess differences in the CGS total score regarding demographic variables, multivariate and univariate latent regressions were implemented. The CGS total score was included as the latent dependent variable, and gender, relationship to care recipient, living with care recipient, duration of caregiving, time since diagnosis, and severity of dementia were entered as predictors. Dummy coding was used for gender (0 = male, 1 = female), relationship to care recipient (0 = adult child, 1 = spouse), and living with care recipient (0 = no, 1 = yes). Regression of indicators onto all demographic variables was fixed to zero to control for differential item functioning.

### **3 Results**

Each individual item was first tested for skewness and kurtosis. Skewness ranged between  $-1.12$  ( $SE = 0.16$ ; Item 4) and  $3.00$  ( $SE = 0.16$ ; Item 13) with only three items reaching values greater than  $\pm 1.00$ . Kurtosis ranged between  $9.78$  ( $SE = 0.32$ ; Item 13) and  $-1.28$  ( $SE = 0.32$ ; Item 9) with six items reaching values greater than  $\pm 1.00$  and only one item exceeding the  $\pm 2.00$  rule (see Table 2 for results for all items).

#### **3.1 Exploratory Factor Analysis**

EFA was performed on the first data set. Results supported as many as four possible factors based on the Eigenvalue  $> 1.0$  rule and screeplot. Three to six factors were extracted and items with small ( $< .40$ ) loadings, ambiguous loadings, and negative residuals were excluded; factors with only one remaining item were excluded. Three factors with five, three, and four items, respectively, were retained for the final solution, yielding a model with very good fit ( $\chi^2[33] = 35.204$ , n.s., CFI = 0.997, TLI = 0.995, RMSEA = 0.024, SRMR = 0.023).

#### **3.2 Confirmatory Factor Analysis**

To confirm the factor structure, the three-factor-model was tested using CFA on the second data set. The model did not fit the data well, with most fit indices being outside the

acceptable range ( $\chi^2[51] = 113.793$ ,  $p < .001$ , CFI = 0.913, TLI = 0.887, RMSEA = 0.104, SRMR = 0.079, AIC = 3776.695). Inspection of modification indices, standardized residuals, and the content of each factor and its respective items suggested that Factor 1 should be split into two factors: One relating to emotions (Items 1–3) and another relating to acceptance (Items 5 and 6). Item 19 was excluded because of its large residual variance and large standardized residuals with other items across factors. It also had a low loading on its factor.

The resulting four-factor model—the model discussed in the preceding paragraph, but with Factor 1 split into two factors—yielded acceptable goodness of fit. Although the model was still significant, the  $\chi^2$ -to-df ratio was in the acceptable range and all other fit indices were satisfactory ( $\chi^2[38] = 68.941$ ,  $p = .002$ , CFI = 0.953, TLI = 0.932, RMSEA = 0.085, SRMR = 0.053, AIC = 3436.165). The reduction of the AIC by 340.530 points also clearly indicates that the four-factor model is superior to the three-factor model. The factor structure did not differ between study groups ( $\chi^2[142] = 197.962$ ,  $p = .001$ , CFI = 0.961, TLI = 0.955, RMSEA = 0.072, SRMR = 0.096).

Table 2

*Overview and Descriptive Statistics for Items*

Nr.	Item	Source	Mean ( <i>SD</i> )	Skewness ( <i>SE</i> )	Kurtosis ( <i>SE</i> )
1	I feel terrific sadness.	MM-CGI, Factor 2	2.10 (1.20)	-0.01 (.16)	-0.77* (.32)
2	This situation is totally unacceptable in my heart.	MM-CGI, Factor 2	3.50 (1.06)	-0.32* (.16)	-0.48 (.32)
3	It hurts to realize that she/he is gone.	MM-CGI, Factor 2, modified <sup>a</sup>	3.79 (1.18)	-0.91* (.16)	0.07 (.32)
4	<i>I feel very sad about what this disease has done.</i>	MM-CGI, Factor 2		-1.12* (.16)	0.67* (.32)
5	It is hard for me to allow myself to grieve and show my sadness.	newly developed	2.84 (1.07)	0.07 (.16)	-0.44 (.32)

6	I'm having a hard time accepting that she/he is suffering from this disease.	MM-CGI, Factor 2, modified <sup>b</sup>	3.08 (1.31)	-0.17 (.16)	-1.16* (.32)
7	I miss so many of the activities we used to share.	MM-CGI, Factor 2	3.78 (1.30)	-0.74* (.16)	-0.66* (.32)
8	I long for what was, what we had and shared in the past.	MM-CGI, Factor 2	3.77 (1.25)	-0.69* (.16)	-0.65* (.32)
9	<i>I'm angry at the disease for robbing me of so much.</i>	MM-CGI, Factor 2		0.08 (.16)	-1.28* (.32)
10	<i>I hide my tears when I think about how she/he will never be the same.</i>	TRIG		0.19 (.16)	-1.25* (.32)
11	<i>I regret to have missed so many opportunities during the time we shared.</i>	WüTI		0.66* (.16)	-0.38 (.32)
12	<i>There are so many unsaid things that I cannot tell her/him now.</i>	newly developed		0.48* (.16)	-0.88* (.32)
13	<i>I blame myself for this disease.</i>	newly developed		2.97* (.16)	9.78* (.32)
14	<i>I am afraid of becoming depressed when I allow myself to grieve.</i>	newly developed		0.77* (.16)	-0.41 (.32)
15	It burdens me not to be able to talk to her/him anymore.	newly developed	3.63 (1.33)	-0.54* (.16)	-0.96* (.32)
16	<i>I feel it's unfair that I will lose her/him because of this disease.</i>	TRIG		0.30 (.16)	-1.21* (.32)
17	I feel like the future holds no meaning or purpose without her/him.	ICG-R	1.98 (1.06)	1.12* (.16)	0.78* (.32)
18	I feel that life is empty without her/him.	ICG-R	2.38 (1.18)	0.62* (.16)	-0.36 (.32)

19	<i>I feel bitter over losing her/him because of this disease.</i>	ICG-R		0.65* (.16)	-0.62 (.32)
20	<i>It is hard for me to talk to someone about how sad all this makes me.</i>	newly developed		0.53* (.16)	-0.80* (.32)
21	I try to avoid thinking about the fact that I will lose her/him.	newly developed	2.64 (1.33)	0.27 (.16)	-1.11* (.32)

*Note.* Items in italics were not retained in the final solution. All items were rated on a five-point Likert scale ranging from 1 (“strongly disagree”) to 5 (“strongly agree”). MM-CGI, Factor 2 = Marwit–Meuser Caregiver Grief Inventory, Heartfelt Sadness and Longing factor (Marwit & Meuser, 2002); TRIG = Texas Revised Inventory of Grief (Faschingbauer et al., 1987); WüTI = Würzburg Grief Inventory (Wittkowski, 2013); ICG–R = Inventory of Complicated Grief–Revised–Short Form (ICG–R ; Prigerson & Jacobs, 2001). Items from the MM-CGI, TRIG, and ICG–R are shown in their original English versions with modifications to Items 3 and 6 made for clarity. Item 11 was translated into English by the first author of the present paper. New items were developed based on statements made by caregivers in a prior study by some of the authors of the present paper. F1 = Factor 1, F2 = Factor 2, F3 = Factor 3, F4 = Factor 4 of the CGS.

<sup>a</sup>Original item formulation: “It hurts to put her/him to bed at night and realize she/he is gone.”

<sup>b</sup>Original item formulation: “I’ve had a hard time accepting what is happening.”

\* $p < .05$

### 3.3 Final Model and Reliability

Factor 1 was named Emotional Pain and is measured by Items 1, 2, and 3 (see Figure 1 for items pertaining to each factor and Table 2 for descriptive statistics); Factor 2, Relational Loss, is measured by Items 7, 8, and 15; Factor 3, Absolute Loss, is measured by Items 17, 18, and 21; and Factor 4, Acceptance of Loss, is measured by Items 5 and 6. A high internal consistency reliability was found for the total scale (Cronbach’s  $\alpha = .89$ ), as well as for Factors 1 (Cronbach’s  $\alpha = .81$ ), 2 (Cronbach’s  $\alpha = .89$ ), and 3 (Cronbach’s  $\alpha = .82$ ). The internal consistency for Factor 4 was moderate (Cronbach’s  $\alpha = .67$ ). The correlation between the CGS total scores six months apart was .998 ( $p < .001$ ), indicating high retest reliability.



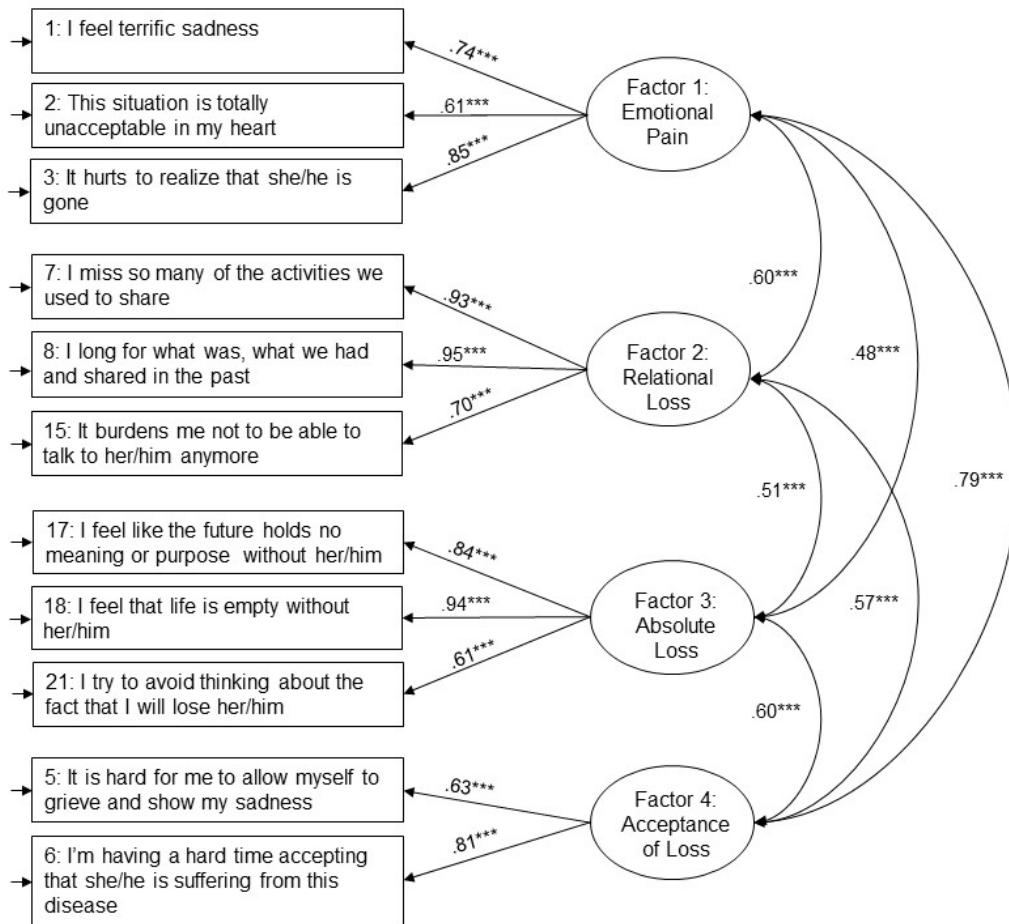


Figure 1. Four-factor model with standardized items loadings and factor intercorrelations.  $**p < .01$ .  $***p < .001$ . Estimations are based on the whole sample ( $N = 229$ ).

Figure 1 shows the final four-factor model with standardized loadings and factor intercorrelations. Standardized loadings were all greater than .60, with most being greater than .80. All four factors exhibited similar mean loadings: Factor 4 showed the weakest mean loadings (.72) and Factor 2 the highest mean loadings (.86); mean loadings for Factors 1 and 3 were .76 and .80, respectively.

Correlations between all four factors were moderate to high. In response to this promising pattern, the model was tested as a second-order model, i.e., a general factor model, with CFA and found to fit well ( $\chi^2[43] = 75.282, p = .002, CFI = 0.976, TLI = 0.970, RMSEA = 0.057, SRMR = 0.063$  for the combined sample).

### 3.4 Validity

All instruments included for the determination of construct validity were subjected to CFA. The following measures or subscales yielded model fits that allowed for the confident interpretation of latent correlations: CES-D ( $\chi^2[170] = 409.10, p < .001, CFI = 0.818, TLI =$

0.796, RMSEA = 0.078, SRMR = 0.063), HADS ( $\chi^2[14] = 33.265, p = .003, CFI = 0.960, TLI = 0.941, RMSEA = 0.077, SRMR = 0.039$ ), WHOQoL-BREF domains of Psychological Health ( $\chi^2[9] = 17.229, n.s., CFI = 0.986, TLI = 0.977, RMSEA = 0.050, SRMR = 0.029$ ) and Social Relationships ( $\chi^2[0] = 0.000, n.s., CFI = 1.000, TLI = 1.000, RMSEA = 0.000, SRMR = 0.000$ ), and GBB-24 subscale Heart Trouble ( $\chi^2[9] = 12.904, n.s., CFI = 0.986, TLI = 0.976, RMSEA = 0.043, SRMR = 0.030$ ).

The CGS showed good construct validity (see Table 3). The total score had moderate correlations with depression, anxiety, and psychological health. Moderate correlations indicate that grief is related to these constructs, but still sufficiently different. Closer inspection of the correlations for the individual factor scores revealed higher correlations for Factors 1 and 4. Correlations between the total score and body complaints and social relationships were in the low range with, again, higher correlations for Factors 1 and 4, though the differences were not as pronounced as for depression, anxiety, and psychological health.

Statistical comparisons revealed that correlations with convergent measures were significantly larger than correlations with discriminant measures for the CGS total score, as well as for Factors 1 and 4 (all  $p < .001$ ). However, not all correlations differed significantly for Factors 2 and 3: For Factor 2, the only significant differences were between the correlations with depression and social relationships (Fisher's  $z = 3.344, p < .001$ ), anxiety and social relationships (Fisher's  $z = 3.767, p < .001$ ), and psychological health and body complaints (Fisher's  $z = -3.198, p < .001$ ); for Factor 3, the above mentioned differences and the difference in the correlation with anxiety and body complaints (Fisher's  $z = 3.262, p < .001$ ) reached significance.

Model fit was satisfactory for all regression models in the analysis of subgroup differences. The multivariate model for all demographic variables revealed two significant predictors, and univariate latent regression models confirmed these results: Relationship to care recipient ( $\beta = .597, p < .001$ ) and living with the care recipient ( $\beta = .174, p = .017$ ) were found to be significant predictors of the intensity of grief, with being a spouse and living with the care recipient indicating higher values on the CGS. The regression coefficients for gender ( $\beta = .041, p = .581$ ), duration of caregiving ( $\beta = -.041, p = .598$ ), time since diagnosis ( $\beta = .050, p = .504$ ), and severity of dementia ( $\beta = -.078, p = .300$ ) did not reach significance.

Table 3

*Validity Determination: Internal Consistencies for the Present Sample (N = 229) and Latent Correlations*

	CES-D	HADS	WHOQoL -BREF: Psycho- logical Health	GBB-24: Heart Trouble	WHOQoL -BREF: Social Relation- ships
Internal Consistency (Cronbach's $\alpha$ )	.88	.82	.81	.73	.60
Latent Correlations					
CGS total score	.48	.55	-.47	.31	-.25
F1: Emotional Pain	.54	.58	-.55	.35	-.29
F2: Relational Loss	.21	.25	-.16	.19	-.17
F3: Absolute Loss	.30	.39	-.16	.19	-.13
F4: Acceptance of Loss	.40	.45	-.46	.21	-.17

*Note.* CES-D = Center for Epidemiologic Studies Depression Scale; HADS = Hospital Anxiety and Depression Scale; WHOQoL-BREF = WHO Quality of Life-BREF; GBB-24 = Gießen Body Complaint List. CGS = Caregiver Grief Scale; F1 = Factor 1, F2 = Factor 2, F3 = Factor 3, F4 = Factor 4. Latent correlations were estimated using MPlus software.  $p < .001$  for all correlations

## 4 Discussion

The purpose of the present study was to develop a brief scale for the measurement of caregiver grief, to examine and confirm its factor structure, and to determine construct validity. To date, the only instrument developed directly for the measurement of caregiver grief is the MM-CGI (Marwit & Meuser, 2002). This inventory includes factors that also resemble depression and burden while not covering avoidance of grief that has only recently been shown to play an important role in caregivers' coping with grief (Meichsner et al., 2015; Spira et al., 2007).

Items from established grief instruments were chosen and adjusted and new items were developed from statements made by caregivers themselves. This procedure of combining existing items and caregiver-sourced items grounded the CGS in established research while

focusing directly on the identified gaps. The final CGS comprises eleven items, assessing four significant aspects of caregiver grief through four distinct factors: Emotional Pain, Relational Loss, Absolute Loss, and Acceptance of Loss. The CGS is therefore the first instrument to effectively capture the well-documented multifaceted nature of caregiver grief (Noyes et al., 2010; Sanders & Corley, 2003). Furthermore, the existence of a latent second-order grief variable unites the measured aspects of caregiver grief into one specific overarching construct.

All items exhibited moderate to high loadings on their respective factors, meaning that all items contribute equally and homogeneously to the latent variables. The composite CGS and all factors also demonstrated high internal consistency reliabilities, with only Factor 4 showing reliability in the moderate range. High retest reliability indicates robustness of the scale. These results allow for the confident use and interpretation of the CGS total score and scores on all factors in both research and clinical practice (see below).

Factor 1, Emotional Pain, reflects the experience of grief and other painful emotions that are associated with the loss of a beloved family member. This factor had the highest correlations with psychological health and symptoms of depression and anxiety. These high correlations are unsurprising, given that this factor's items measure emotional states that are assessed by the CES-D, HADS, and the Psychological Health domain in similar ways. Factor 2, Relational Loss, represents losses related to the relationship and what was shared with the care recipients when they were still healthy, such as communication and daily activities. These are losses central to caregiver grief (Noyes et al., 2010). Factor 3, Absolute Loss, focuses on the absolute loss of the care recipient and the anticipation of a future without that person. This factor represents a loss of meaning in life, and the resulting desperation. This urgent distress has been documented in studies such as one by Sanders, Morano, and Corley (2003), which found that, for some caregivers, the grief reaction can become so intense as to resemble a state of crisis. It is therefore crucial for therapists in clinical settings to examine a caregiver's score on this factor, with high scores indicating a pressing need for interventions to regulate emotions and prevent further adverse impacts. Factor 4, Acceptance of Loss, reflects both the acceptance of dementia and of the grief reaction. This acceptance includes the open expression of grief because caregivers often avoid expressing or even feeling grief while the care recipient is still alive; a phenomenon also known as *disenfranchised grief* (Doka, 2004). Since higher levels of experiential avoidance were found to be associated with elevated symptoms of depression in dementia caregivers (Spira et al., 2007), this factor is a valuable part of the CGS, particularly for clinical practice. Caregivers who score high on this scale would benefit from having their therapist address underlying assumptions regarding the appropriateness of grieving and also

focus on the management of negative emotions and experiences to reduce experiential avoidance.

In terms of factor intercorrelations, Factors 1 and 4 had the strongest relationship with each other while Factors 1 and 3 shared the lowest correlation. All other correlations were in the moderate range. The high intercorrelation between Factors 1 and 4 was not surprising, first, because EFA indicated that items from Factors 1 and 4 represented a single factor, and second, because the distress caused by the emotional reaction to losses (i.e., Factor 1) and the acceptance of these losses (i.e., Factor 4) can be expected to be associated. Nonetheless, the experienced pain caused by losses and caregivers' acceptance thereof are still distinct enough to justify two separate factors. Also, providing a score for both emotional pain and acceptance can be considered one of the advantages of the CGS since both scores are of high importance for clinical practice as they call for different therapeutic interventions. The low correlation between Factors 1 and 3 can be explained by the fact that these two factors represent the painful experience of loss, but at different points in time: Factor 1 relates to emotions that are experienced at the present while Factor 3 is related to the final loss of the care recipient in the future.

Construct validity was determined through correlations with established instruments. The CGS had low correlations with body complaints and social relationships. This pattern is consistent with the findings reported in other studies and was, for example, also found for the MM-CGI (Marwit & Meuser, 2002). Moderate correlations were found between the CGS and psychological health and symptoms of depression and anxiety, although Factors 2 and 3 of the CGS showed lower correlations with measures of these symptoms—an unsurprising result, as Factors 2 and 3 focus on experienced and anticipated losses, respectively, rather than on emotional states. The moderate correlations indicate that there is a relationship between grief and psychological health, depression, and anxiety, but that grief constitutes a unique aspect of the caregiving experience, underlining the need for a separate instrument. It can therefore be concluded that the scale developed in the present study maintains a focus on grief, comparing favorably to the MM-CGI.

Regression analyses showed that the CGS also allows for the differentiation between subgroups of caregivers based on key demographic variables. Being a spouse and living with the care recipient predicted a higher intensity of grief, while caregiver gender, time since diagnosis, duration of caregiving, and severity of dementia were not found to significantly influence the intensity of grief. These results are interesting from both a practical and methodological perspective: They confirm Meuser's and Marwit's (2001) findings that the grief

experience differs between spouses and adult children with sadness being predominant and more openly expressed in spouses. It can further be assumed that caregivers who live with the care recipients showed higher values on the CGS because the constant witnessing of even small losses in daily life increases the experienced grief. The sensitivity to these differences is an advantage of the CGS for clinical practice and it is also a necessary prerequisite for the investigation of differential effects in, for example, further intervention studies.

#### **4.1 Implications and Outlook**

Since the fit indices for the final model were satisfactory, the CGS can be used confidently in both research and clinical settings to efficiently and specifically assess caregiver grief and evaluate grief-specific interventions. The CGS can also be used by health care professionals to quickly assess the magnitude of caregivers' grief reaction by computing the mean CGS total score. Comparing mean scores on the four factors will provide practitioners with a more differentiated insight into a caregiver's grief experience. A ready-to-use version of the CGS is presented in Appendix A and descriptive statistics for all scales are provided in Appendix B as a guideline to evaluate derived scores.

The use of a formal instrument is important in counseling, because caregivers are often either unaware that they are experiencing grief (Silverberg, 2007), or feel guilty about their grief and are therefore reluctant to discuss it. Presenting a scale that asks directly about grief and loss can serve as a signal to caregivers, validating and normalizing their experience. Comparing caregiver scores for the four factors can also guide therapists in selecting appropriate intervention strategies.

Further research is needed to investigate the scale's measurement invariance across time and different groups for the use in intervention studies. Validation against more caregiver-specific measures (e.g., caregiver burden or uplifts) as well as other measures of grief, in particular the MM-CGI, would be another important future focus. We also seek to make the CGS available for international use and the validation of an English version is underway.

#### **4.2 Limitations**

Although the CGS was developed and validated based on a sound theoretical background and statistical procedures, some limitations should be considered.

All of the developed items were only included from the post-intervention assessment on; as a result, the present study's sample comprised participants from different study groups. However, since no significant group differences were found for either grief items or demographic variables, data were used from all participants, instead of from a single study

group. Combining study groups provided us with the larger sample necessary to perform CFA, and thereby meet current standards for scale development. Also, the established factor structure did not differ between groups leading to the conclusion that the intervention did not affect the caregivers' report on the factors which further justifies the combination of study groups. Nonetheless, the use of post-intervention data limits the result's generalizability and investigation of the factor structure in an untreated sample is needed. Furthermore, even though data from three study groups were combined, the number of cases for the CFA was just enough to meet minimum requirements for sample size. Since the accuracy of parameter estimation depends on a large enough sample, replications of the results in larger samples are desirable.

With regard to the EFA, the set of items was small to begin with because data collection was part of a trial that required caregivers to complete multiple assessments and a manageable questionnaire length had to be ensured. While the brevity of the scale is an advantage, the use of only two or three items to assess each factor may diminish reliability. However, despite the small number of items, internal consistency was highly satisfactory for all factors except Factor 4.

The determination of construct validity was limited, as not all of the subscales of the WHOQoL-BREF and the GBB-24 showed satisfactory model fit, model fit being a necessary precondition for the confident interpretation of latent correlations. The subscales selected for the determination of discriminant validity (i.e., the Social Relationships domain of the WHOQoL-BREF and the Heart Trouble subscale of the GBB-24) also showed middle to low reliabilities. Nonetheless, the scales were used for the present study because they constitute established and widely disseminated instruments for the assessment of quality of life and physical symptoms. However, we still recommend validating the CGS against other instruments with higher reliabilities and whose factor structure has been confirmed by CFA.

The model fit for the CES-D was also not entirely satisfactory with the incremental fit indices (i.e., CFI and TLI) being outside the desired range. This limitation calls for a more cautious interpretation of this particular latent correlation, since it slightly limits its trustworthiness. In addition, although differences between correlations between the CGS and convergent and divergent measures reached significance with only few exceptions, differences were small. Last, due to the nature of the trial from which data were obtained, the results are for now limited to community-dwelling German older adults.

### **4.3 Conclusion**

We have developed a brief eleven-item, four-factor scale for the assessment of caregiver grief. This scale reflects the multifaceted nature of caregiver grief, with a factor structure determined through EFA and verified using CFA. The CGS is now available for use in diverse settings. Validation of the English version is underway, so as to make the scale available for international use, and we welcome an international research focus that can contribute to the scale's dissemination.



## 5 References

- Angermeyer, M. C., Kilian, R., & Matschinger, H. (2000). *WHOQOL-100 und WHOQOL-BREF. Handbuch für die deutschsprachigen Versionen der WHO-Instrumente zur internationalen Erfassung von Lebensqualität [WHOQOL-100 and WHOQOL-BREF. Handbook for the German Version of the WHO Instruments for the International Assessment of Quality of Life]*. Göttingen, Germany: Hogrefe.
- Bjelland, I., Dahl, A. A., Haug, T. T., & Neckelmann, D. (2002). The validity of the Hospital Anxiety and Depression Scale: An updated literature review. *Journal of Psychosomatic Research*, *52*, 69–77. doi: 10.1016/S0022-3999(01)00296-3
- Brähler, E., Hinz, E., & Scheer, J. W. (2008). *GBB-24. Der Gießener Beschwerdebogen. Manual [GBB-24. The Gießen Body Complaint List. Manual]*. Berlin, Germany: Hans Huber.
- Chan, D., Livingston, G., Jones, L., & Sampson, E. L. (2013). Grief reactions in dementia carers: A systematic review. *International Journal of Geriatric Psychiatry*, *28*(1), 1–17. doi: 10.1002/gps.3795
- Cheng, S.-T., Kwok, T., & Lam, L. C. W. (2014). Dimensionality of burden in Alzheimer caregivers: Confirmatory factor analysis and correlates of the Zarit Burden Interview. *International Psychogeriatrics*, *26*(9), 1455–1463. doi: 10.1017/S104161021400101X
- Doka, K. J. (2004). Grief and dementia. In K. J. Doka (Ed.), *Alzheimer's disease: Living with grief* (pp. 139–155). Washington, DC: Hospice Foundation of America.
- Faschingbauer, T. R., Zisook, S., & DeVaul, R. (1987). The Texas Revised Inventory of Grief. In S. Zisook (Ed.), *Biopsychosocial aspects of bereavement* (pp. 109–124). Washington, DC: American Psychiatric Press.
- Hautzinger, M., Bailer, M., Hofmeister, D., & Keller, F. (2012). *Allgemeine Depressions Skala. Manual [German Version of the Center for Epidemiologic Studies Depression Scale. Manual]*. Göttingen, Germany: Hogrefe.
- Hayes, S. C., Strosahl, K. D., & Wilson, K. G. (1999). *Acceptance and Commitment Therapy: An experiential approach to behavior change*. New York, NY: Guilford Press.
- Hebert, R. S., Dang, Q., & Schulz, R. (2006). Preparedness for the death of a loved one and mental health in bereaved caregivers of patients with dementia: Findings from the REACH study. *Journal of Palliative Medicine*, *9*(3), 683–693. doi: 10.1089/jpm.2006.9.683
- Herrmann-Lingen, C., Buss, U., & Snaith, R. P. (2011). *Hospital Anxiety and Depression Scale—German Version (HADS-D). Manual*. Bern, Switzerland: Huber.

- Holley, C. K., & Mast, B. T. (2009). The impact of anticipatory grief on caregiver burden in dementia caregivers. *The Gerontologist, 49*(3), 388–396. doi: 10.1093/geront/gnp061
- Lindauer, A., & Harvath, T. A. (2014). Pre-death grief in the context of dementia caregiving: A concept analysis. *Journal of Advanced Nursing, 70*(10), 2196–2207. doi: 10.1111/jan.12411
- Marsh, H. W., Hau, K.-T., & Grayson, D. (2005). Goodness of fit in structural equation models. In A. Maydeu-Olivares & J. J. McArdle (Eds.), *Contemporary psychometrics: A festschrift for Roderick P. McDonald*. (pp. 275–340). Mahwah, NJ: Lawrence Erlbaum.
- Marwit, S. J., & Meuser, M. T. (2002). Development and initial validation of an inventory to assess grief in caregivers of persons with Alzheimer's disease. *The Gerontologist, 42*(6), 751–765. doi: 10.1093/geront/42.6.751
- Meichsner, F., Schinköthe, D., & Wilz, G. (2015). Managing loss and change: CBT-based grief interventions for dementia caregivers. *American Journal of Alzheimer's Disease and Other Dementias*. doi: 10.1177/1533317515602085
- Meng, X.-L., Rosenthal, R., & Rubin, D. B. (1992). Comparing correlated correlation coefficients. *Psychological Bulletin, 111*, 172–175. doi: 10.1037/0033-2909.111.1.172
- Meuser, M. T., & Marwit, S. J. (2001). A comprehensive, stage-sensitive model of grief in dementia caregiving. *The Gerontologist, 41*(5), 658–670. doi: 10.1093/geront/41.5.658
- Muthén, L. K., & Muthén, B. O. (2012). *MPlus user's guide* (7th ed.). Los Angeles, CA: Muthén & Muthén.
- Noyes, B. B., Hill, R. D., Hicken, B. L., Luptak, M., Rupper, R., Dailey, N. K., & Bair, B. D. (2010). Review: The role of grief in dementia caregiving. *American Journal of Alzheimer's Disease and Other Dementias, 25*(1), 9–17. doi: 10.1177/1533317509333902
- Prigerson, H. G., & Jacobs, S. C. (2001). Traumatic grief as a distinct disorder: A rationale, consensus criteria, and a preliminary empirical test. In M. S. Stroebe, R. O. Hansson, W. Stroebe, & H. Schut (Eds.), *Handbook of bereavement research: Consequences, coping, and care* (pp. 613–645). Washington, DC: American Psychological Association.
- Rando, T. A. (2000). *Clinical dimensions of anticipatory mourning*. Champaign, IL: Research Press.

- Reisberg, B., Ferris, S. H., de Leon, M. J., & Crook, T. (1982). The Global Deterioration Scale for assessment of primary degenerative dementia. *American Journal of Psychiatry*, *139*, 1136–1139. doi: 10.1176/ajp.139.9.1136
- Sanders, S., & Adams, K. B. (2005). Grief reactions and depression in caregivers of individuals with Alzheimer's disease: Results from a pilot study in an urban setting. *Health & Social Work*, *30*(4), 287–295. doi: 10.1093/hsw/30.4.287
- Sanders, S., & Corley, C. S. (2003). Are they grieving? A qualitative analysis examining grief in caregivers of individuals with Alzheimer's disease. *Social Work in Health Care*, *37*(3), 35–53. doi: 10.1300/J010v37n03\_03
- Sanders, S., Morano, C., & Corley, C. S. (2003). The expressions of loss and grief among male caregivers of individuals with Alzheimer's Disease. *Journal of Gerontological Social Work*, *39*(4), 3–18. doi: 10.1300/J083v39n04\_02
- Schlagenhauf, F. (2003). *Körperbeschwerden in einer psychosomatischen Ambulanz: Eine Untersuchung mit dem Gießener Beschwerdebogen (GBB-24)* [Body complaints in a psychosomatic outpatient clinic: An assessment using the Gießen Body Complaint List (GBB-24)]. Unpublished Dissertation. Clinic for Psychosomatic Medicine and Psychotherapy, Heinrich-Heine-University Düsseldorf, Germany.
- Schut, H., & Stroebe, M. S. (2005). Interventions to enhance adaptation to bereavement. *Journal of Palliative Medicine*, *8*, S140–S147. doi: 10.1089/jpm.2005.8.s-140
- Silverberg, E. (2007). Introducing the 3-A grief intervention model for dementia caregivers: Acknowledge, Assess and Assist. *OMEGA: The Journal of Death and Dying*, *54*(3), 215–235. doi: 10.2190/D1R5-0473-1922-4N70
- Soellner, R., Reder, M., Machmer, A., Holle, R., & Wilz, G. (2015). The Tele.TAnDem intervention: Study protocol for a psychotherapeutic intervention for family caregivers of people with dementia. *BMC Nursing*, *14*(1), 1–6. doi: 10.1186/s12912-015-0059-9
- Spira, A., Beaudreau, S., Jimenez, D., Kierod, K., Cusing, M., Gray, H., & Gallagher-Thompson, D. (2007). Experiential avoidance, acceptance, and depression in dementia family caregivers. *Clinical Gerontologist*, *30*(4), 55–64. doi: 10.1300/J018v30n04\_04
- Theut, S. K., Jordan, L., Ross, L. A., & Deutsch, S. I. (1991). Caregiver's anticipatory grief in dementia: A pilot study. *The International Journal of Aging & Human Development*, *33*(2), 113–118.
- Wilz, G., & Soellner, R. (2015). Evaluation of a short-term telephone-based cognitive behavioral intervention for dementia family caregivers. *Clinical Gerontologist*. doi: 10.1080/07317115.2015.1101631

Wittkowski, J. (2013). *Würzburger Trauerinventar [Würzburg Grief Inventory]*. Göttingen, Germany: Hogrefe.

Znoj, H. (2004). *Komplizierte Trauer [Complicated Grief]*. Göttingen, Germany: Hogrefe

Znoj, H. (2008). Texas-Revised Inventory of Grief: Validierung der deutschen Version TRIG-D [Texas-Revised Inventory of Grief: Validation of the German version TRIG-D]. *Psychosomatik und Konsiliarpsychiatrie*, 2(4), 236–239. doi: 10.1007/s11800-008-0131-3

## Appendix A

*Caregiver Grief Scale*

		Strongly disagree	Disagree	Somewhat agree	Agree	Strongly agree
1	I feel terrific sadness.	1	2	3	4	5
2	This situation is totally unacceptable in my heart.	1	2	3	4	5
3	It hurts to realize that she/he is gone.	1	2	3	4	5
4	I miss so many of the activities we used to share.	1	2	3	4	5
5	I long for what was, what we had and shared in the past.	1	2	3	4	5
6	It burdens me not to be able to talk to her/him anymore.	1	2	3	4	5
7	I feel like the future holds no meaning or purpose without her/him.	1	2	3	4	5
8	I feel that life is empty without her/him.	1	2	3	4	5
9	I try to avoid thinking about the fact that I will lose her/him.	1	2	3	4	5
10	It is hard for me to allow myself to grieve and show my sadness.	1	2	3	4	5
11	I'm having a hard time accepting that she/he is suffering from this disease.	1	2	3	4	5

*Note.* Instructions for scoring: A total mean score can be computed as well as subscores for four factors: Factor 1, Emotional Pain, is comprised of items 1, 2, and 3; Factor 2, Relational Loss, is comprised of items 4, 5, and 6; Factor 3, Absolute Loss, is comprised of items 7, 8, and 9; and Factor 4, Acceptance of Loss, is comprised of items 10 and 11. See Appendix B for descriptive statistics for the total score and factor scores. Validation of this English version is underway.

## Appendix B

*Descriptive Statistics for the Caregiver Grief Scale Total Score and Factor Scores*

	Internal Consistency (Cronbach's $\alpha$ )	Mean	SD
CGS total score	.89	3.005	0.71
F1: Emotional Pain (Items 1–3)	.81	2.996	0.89
F2: Relational Loss (Items 4–6)	.89	3.777	1.20
F3: Absolute Loss (Items 7–9)	.82	1.982	0.91
F4: Acceptance of Loss (Items 10, 11)	.67	2.846	0.68

*Note.* F1 = Factor 1, F2 = Factor 2, F3 = Factor 3, F4 = Factor 4. All items were rated on a five-point Likert scale ranging from 1 (“strongly disagree”) to 5 (“strongly agree”). Means are unstandardized latent means. Estimations are based on the whole sample ( $N = 229$ ).

Study III:

Dementia Caregivers' Coping with Pre-Death Grief: Effects of a CBT-based  
Intervention

This manuscript is currently under review in a slightly modified version as:

Meichsner, F. & Wilz, G. (under review). Dementia caregivers' coping with pre-death grief: Effects of a CBT-based intervention. Manuscript submitted for publication.

### Abstract

*Purpose of the study.* Pre-death grief plays a significant role in dementia caregiving, yet despite its adverse impacts on caregivers' health, grief intervention studies of high methodological quality are still lacking. It was the purpose of the present study to examine whether a cognitive-behavioral intervention including a grief intervention module could increase caregivers' coping with pre-death grief and whether these effects could be maintained as of a six-month follow-up assessment.

*Design and Methods.* In a randomized-controlled trial examining the effectiveness of a cognitive-behavioral intervention, 273 caregivers were allocated to either an intervention or control group. Intervention group participants received 12 therapy sessions over six months, and all participants completed a measure of pre-death grief. The analysis was conducted using latent change models: In the first model, study group was included as a predictor of change in pre-death grief; subsequent models also included care situation and sociodemographic variables.

*Results.* The burden due to pre-death grief was reduced for intervention but not control group participants at the time of the six-month follow-up assessment (Cohen's  $d = -0.361$ ). When controlling for changes in the care situation and sociodemographic variables, the treatment effect was also found in the assessment completed post intervention (Cohen's  $d = -0.248$ ).

*Implications.* Results indicate that a cognitive-behavioral intervention including grief-specific strategies can successfully foster caregivers' coping with loss and change and reduce burden of pre-death grief. Future research should focus on the relationship between coping with pre-death grief and other mental health outcomes, and caregivers' adaptation to bereavement.

*Keywords:* Alzheimer's disease, structural equation models; caregiving – informal; loss



## 1 Introduction

Being a caregiver of a family member with dementia is becoming a reality for more and more persons worldwide. Globally, 46.8 million people (Alzheimer's Disease International, 2015) are suffering from dementia. While staying at home for as long as possible is a wish of both these patients and their families, caring for a family member with dementia is a challenging task that is often associated with psychological distress, depressive symptoms, and reduced physical health (Pinquart & Sörensen, 2003). Health care professionals have recognized the needs of these family caregivers, developing a variety of interventions that have small but significant effects on problems such as depression, and caregiver burden (Elvish, Lever, Johnstone, Cawley, & Keady, 2013; Pinquart & Sörensen, 2006). The most successful of these programs have been based on cognitive-behavioural therapy (CBT; Gallagher-Thompson & Coon, 2007).

One aspect of the caregiving experience that is missing in even the most comprehensive intervention programs is coping with grief and loss. *Pre-death grief* is experienced by a majority of caregivers (Chan, Livingston, Jones, & Sampson, 2013), and is defined as the “emotional and physical response to the perceived losses in a valued care recipient” (Lindauer & Harvath, 2014, p. 2203). While similar in intensity to post-death grief (Meuser, Marwit, & Sanders, 2004), pre-death grief has some unique characteristics: First, caregivers go through multiple phases of losses over the often long and unpredictable disease trajectory (Lindauer & Harvath, 2014). Second, because care recipients are physically present but become more and more psychologically absent as the disease progresses, caregivers experience ambiguous loss (Boss, 2000). Ambiguous loss leads to the loss of companionship, communication, and support, as well as to major changes in the relationship between caregiver and care recipient (Noyes et al., 2010). If caregivers perceive these losses as significant, grief is experienced (Noyes et al., 2010).

While pre-death grief can have positive effects if it is coped with adequately (such as the facilitation of subsequent adaptation to bereavement), many studies have also demonstrated its adverse impacts. Pre-death grief has been associated with depressive symptoms (Sanders & Adams, 2005) and has been directly related to caregiver burden (Holley & Mast, 2009). These findings emphasize the need for interventions that foster caregivers' coping with pre-death grief. However, despite the growing scholarly attention on pre-death grief that has taken place over the last 20 years, and despite a number of promising pilot studies developing and evaluating grief interventions, there is a lack of high-quality studies investigating specific interventions.

In one pilot study, an eight-week group program (Kasl-Godley, 2003) was offered in which caregivers were guided in managing their grief reactions through, e.g., supportive discussion or psychoeducation. Depressive symptoms declined in all group members, but the sample size was small and no control group was incorporated.

In another such study, Sanders and Sharp (2004) conducted a five-week psychoeducational grief group. This intervention aimed to assist caregivers in recognizing their grief and identifying coping strategies that might help them with feelings of grief and loss, and make use of resources. Grief symptoms were measured before and after the intervention and compared with a one-time measure of a control group. An unexpected increase in grief from pre-intervention to post-intervention assessment was found, but no significance test was conducted due to the small sample size. According to the authors (Sanders & Sharp, 2004), education about grief and its normalization could have caused this apparent increase, and participants still indicated that the group was helpful for them.

Ott, Kelber, and Blaylock (2010) conducted a feasibility study of a multicomponent intervention comprising supportive grief counseling, family problem solving, emotional support, education, skill building, and referral to community resources. Results indicated a moderate effect on grief symptoms.

While these results point towards the effectiveness of grief interventions for dementia caregivers, tentative conclusions can be drawn because they were derived from pilot studies that only investigated small samples, that did not conduct follow-up assessments, and that, in most cases, did not incorporate control groups.

In an intervention study conducted in our group (Wilz & Soellner, 2015), grief and loss were frequently expressed by caregivers during therapy sessions. In response, we developed and refined a grief intervention module (Meichsner, Schinköthe, & Wilz, 2015b) that would enable therapists to provide appropriate support. The primary aim of this grief-specific module is to foster caregivers' acceptance of the disease, the inherent changes and losses, and the associated painful emotions, leading to better coping with pre-death grief.

This module was incorporated into our intervention manual (Wilz, Schinköthe, & Kalytta, 2015) and was applied within a consecutive randomized-controlled trial (RCT; Soellner, Reder, Machmer, Holle, & Wilz, 2015). It is the purpose of the present study to evaluate the intervention's effectiveness on coping with pre-death grief. We expected that this intervention would enable us to facilitate caregivers' acceptance of loss and change, as well as their coping with grief. It was therefore hypothesized that the burden experienced through pre-

death grief—as evidenced by pre-death grief scores—would be successfully reduced after completing the intervention. We further expected this effect to be sustained over the six-month follow-up period.

Of course, the grief experience is not the same for all caregivers, and continued home care or nursing home placement (here, the *care situation*), whether the caregiver is female or male, and whether the caregiver is a spouse or adult child will affect the nature and intensity of pre-death grief (Rudd, Viney, & Preston, 1999; Sanders & Adams, 2005). For this reason, we added the variables of *care situation*, *gender*, and *relationship to care recipient* to the analyses. We wanted to know if these predictors were associated with differences in pre-death grief, as well as whether treatment effects differed for subgroups of caregivers.

With these objectives, this study seeks to build upon and expand earlier work in the area of pre-death grief interventions. Previous methodological limitations are overcome through the recruitment of a large sample, a randomized-controlled design, and the inclusion of a follow-up assessment.

## 2 Design and Methods

The present analyses were conducted within an RCT with in-home family caregivers of persons with dementia in Germany. It was the primary aim of the trial to evaluate the effectiveness of a telephone-based CBT intervention in established care provision structures (see Soellner et al., 2015). Multiple indicators of physical and mental health were assessed and targeted by the manualized intervention, one of them being pre-death grief.

### 2.1 Participants

Participants were recruited from across Germany via e.g. newspapers, cooperating institutions, mailing lists, and primary care physicians. To be eligible for study participation, individuals had to be the primary in-home caregiver of a person diagnosed with dementia, have no acute physical illness or mental disorder, and not receiving ongoing psychotherapeutic treatment. Participants ( $N = 273$ ) were randomly allocated to one of two groups: Control ( $n = 134$ ) and telephone-based intervention ( $n = 139$ ).

Sample characteristics are displayed in Table 1. There were no significant group differences for any of the sociodemographic variables (all  $p > .05$ ). Over the course of the study duration, the caregiving situation changed for a number of participants: 14 caregivers decided to move from home caregiving to a nursing-home placement between the baseline and post-intervention assessments, and another 14 did so before the six-month follow-up assessment; 22 caregivers lost their loved ones between the baseline and post-intervention assessments, and

another 24 between before the six-month follow-up assessment. Attrition was low: Only 36 participants dropped out of the study between the baseline and post-intervention assessment, and another seven dropped out between post-intervention and six-month follow-up.

Table 1

*Sample Characteristics*

	Intervention group ( <i>n</i> = 139)	Control group ( <i>n</i> = 134)
<b>Caregivers</b>		
Age in years, <i>M</i> ( <i>SD</i> )	63.90 (11.47)	64.49 (10.61)
Age range	23–85	38–91
Gender (Female), <i>n</i> (%)	112 (80.60)	108 (80.60)
Relationship to care recipient, <i>n</i> (%)		
Spouse	83 (59.80)	82 (61.20)
Adult child	54 (38.90)	50 (37.30)
Other	2 (1.30)	2 (1.50)
Education <sup>a</sup> , <i>n</i> (%)		
Primary or other	7 (5.04)	6 (4.48)
Secondary: Level 2	78 (56.12)	73 (54.48)
Secondary: Levels 3 & 4	12 (8.63)	13 (9.70)
Tertiary: Levels 5 & 6	42 (30.22)	42 (31.34)
Living with care recipient, <i>n</i> (%)	111 (81.60)	107 (79.90)
Care duration in years, <i>M</i> ( <i>SD</i> )	4.79 (3.62)	5.00 (3.74)
Range	< 1–19	< 1–18
<b>Care recipients</b>		
Age in years, <i>M</i> ( <i>SD</i> )	78.55 (9.31)	78.98 (9.42)
Age range	55–99	44–104
Gender (Female), <i>n</i> (%)	71 (51.10)	68 (50.70)
Type of dementia, <i>n</i> (%)		
Alzheimer's Disease	67 (48.60)	56 (41.90)
Vascular dementia	17 (12.30)	13 (9.70)
Frontotemporal dementia	4 (2.90)	10 (7.50)

Other/unknown	50 (36.20)	55 (41.10)
Severity of dementia <sup>b</sup> , <i>n</i> (%)		
Light	1 (0.70)	–
Mild	4 (2.90)	5 (3.70)
Moderate	53 (38.40)	52 (38.80)
Severe	47 (34.10)	54 (40.30)
Very severe	33 (23.90)	23 (17.20)

*Note.* <sup>a</sup>Education levels as defined by the International Standard Classification of Education.

<sup>b</sup>Severity of dementia was measured using the *Global Deterioration Scale* (Reisberg, Ferris, de Leon, & Crook, 1982).

## 2.2 Intervention

Participants in the intervention group received twelve 50-minute individual therapy sessions over a duration of six months; control group participants received treatment as usual and were financially compensated for their participation in the assessments. The intervention was delivered by clinical psychologists who were trained in CBT and who were knowledgeable about dementia and dementia caregiving. All sessions were conducted via telephone, because this allows flexible access to support without the logistical problems of traveling somewhere (and arranging care for the care recipient) posed by in-person interventions.

The intervention was manualized and based on cognitive-behavioral techniques that had been adapted for use with dementia caregivers (Wilz et al., 2015). The efficacy of this approach had been demonstrated in a previous RCT conducted by our group (Wilz & Soellner, 2015). The intervention manual comprised ten modules that focused on different challenging aspects of the caregiving situation, such as Changing Dysfunctional Cognitions or Coping with Behavioral Problems (Soellner et al., 2015).

The module Coping with Change, Loss, and Grief was the most important one for the treatment effect under study in the present analyses. This module was developed based on our extensive experience in psychotherapy with dementia caregivers and was refined through the results of a qualitative analysis of therapists' intervention strategies addressing grief and loss (Meichsner et al., 2015b). This module's main goal is to foster caregivers' acceptance of the disease and the associated emotions. To pursue this goal, techniques for recognizing and expressing thoughts and emotions, accepting painful thoughts and emotions, identifying and restructuring dysfunctional cognitions regarding grief, redefining the relationship with the care

recipient, activating resources, and preparing caregivers for the death of the care recipient are included.

### 2.3 Assessment: The Caregiver Grief Scale

Assessments were conducted three times: At baseline before randomization, at the end of the six-month intervention (i.e., post-intervention assessment), and at the six-month follow-up. For each assessment, a questionnaire on demographic characteristics and outcome variables was mailed to all participants.

Caregivers' coping with pre-death grief was assessed with the *Caregiver Grief Scale* (CGS; Meichsner, Schinköthe, & Wilz, 2015a). In developing this tool, an initial pool of items was created using both appropriate items from existing pre-death and post-death grief instruments (e.g., Marwit–Meuser Caregiver Grief Inventory, Marwit & Meuser, 2002; Inventory of Complicated Grief–Revised–Short Form, Prigerson & Jacobs, 2001) and new items based on statements made by caregivers in our prior study (Wilz & Soellner, 2015). The final scale comprises 11 items pertaining to four factors that reflect four different aspects of pre-death grief: Emotional Pain, Relational Loss, Absolute Loss, and Acceptance of Loss. Items are rated on a 5-point Likert scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). The total scale and all factors yielded satisfying internal consistency reliabilities (Cronbach's  $\alpha = .67-.89$ ).

For the present analysis, pre-death grief was measured using the eight items pertaining to the factors of Emotional Pain, Relational Loss, and Acceptance of Loss only, as the remaining three items were included from the post-intervention assessment forward (Meichsner et al., 2015a). Emotional Pain (e.g., “This situation is totally unacceptable in my heart.”) reflects the experience of grief and other painful emotions associated with the loss of a family member. Relational Loss refers to losses related to the relationship and what was shared with care recipients in the past (e.g., “It burdens me not to be able to talk to her/him anymore.”). Both the acceptance of dementia and of the grief reaction (e.g., “It is hard for me to allow myself to grieve and show my sadness.”) are represented by the factor Acceptance of Loss. Caregivers who decided on nursing home placement during any phase of the study also completed the CGS, bereaved caregivers at the time of an assessment did not complete this assessment (see the following paragraph for the procedure for missing values).

## 2.4 Statistical Analysis

Descriptive analyses for the sample were carried out using IBM SPSS Statistics 21. All other analyses were conducted with MPlus Version 7 (Muthén & Muthén, 2012) and were intention-to-treat analyses.

The amount of missing data was moderate. Across the eight variables, the missing data proportions ranged from 0.4% at baseline, to 22.7% at post-intervention, to 32.2% at six-month follow-up. Full Information Maximum Likelihood (FIML) was used for missing data. In addition, three variables that were associated with attrition or missing values due to death of the care recipient (i.e., severity of dementia at baseline and post-intervention, caregivers' previous diagnosis of a mental disorder) were included as auxiliary variables (Enders, 2010). We also used three baseline variables that were correlated with pre-death grief (i.e., depression, anxiety, and psychological quality of life; Meichsner et al., 2015a) as auxiliary variables. An inclusive strategy that incorporates auxiliary variables into the missing data handling procedure is recommended to reduce possible bias due to missing data. Such a procedure makes the assumption that data are missing at random more plausible, and improves statistical power (Collins, Schafer, & Kam, 2001).

Model fit was evaluated using the  $\chi^2$  statistic, the  $\chi^2/df$ -ratio, and the following goodness-of-fit indices: Comparative Fit Index (CFI) and Root Mean Square Error of Approximation (RMSEA). A well-fitting model should yield  $CFI \geq 0.900$  and  $RMSEA \leq 0.070$  (Hu & Bentler, 1999).

The intervention's effect was tested with multiple steps: First, a latent state model with indicator-specific factors was tested for measurement invariance across time and study groups, as strong measurement invariance is a necessary prerequisite for longitudinal analyses. Second, based on the latent state model, a latent change model was developed to test for changes in pre-death grief (see Steyer, Eid, & Schwenkmezger, 1997, for methodological details). Third, to test for group differences, study group was included as a predictor of change. Further predictors were included in two subsequent steps, outlined below.

The latent state model consisted of three latent variables representing pre-death grief at baseline, post-intervention, and six-month follow-up, respectively. Indicators for the latent variables were the eight items of the CGS aggregated into three parcels, A, B, and C. Assignment to parcels was based on the identified factors (Little, Rhemtulla, Gibson, & Schoemann, 2013), and, due to the non-normal distribution of the parcels, Maximum Likelihood Robust (MLR) was used as an estimator.

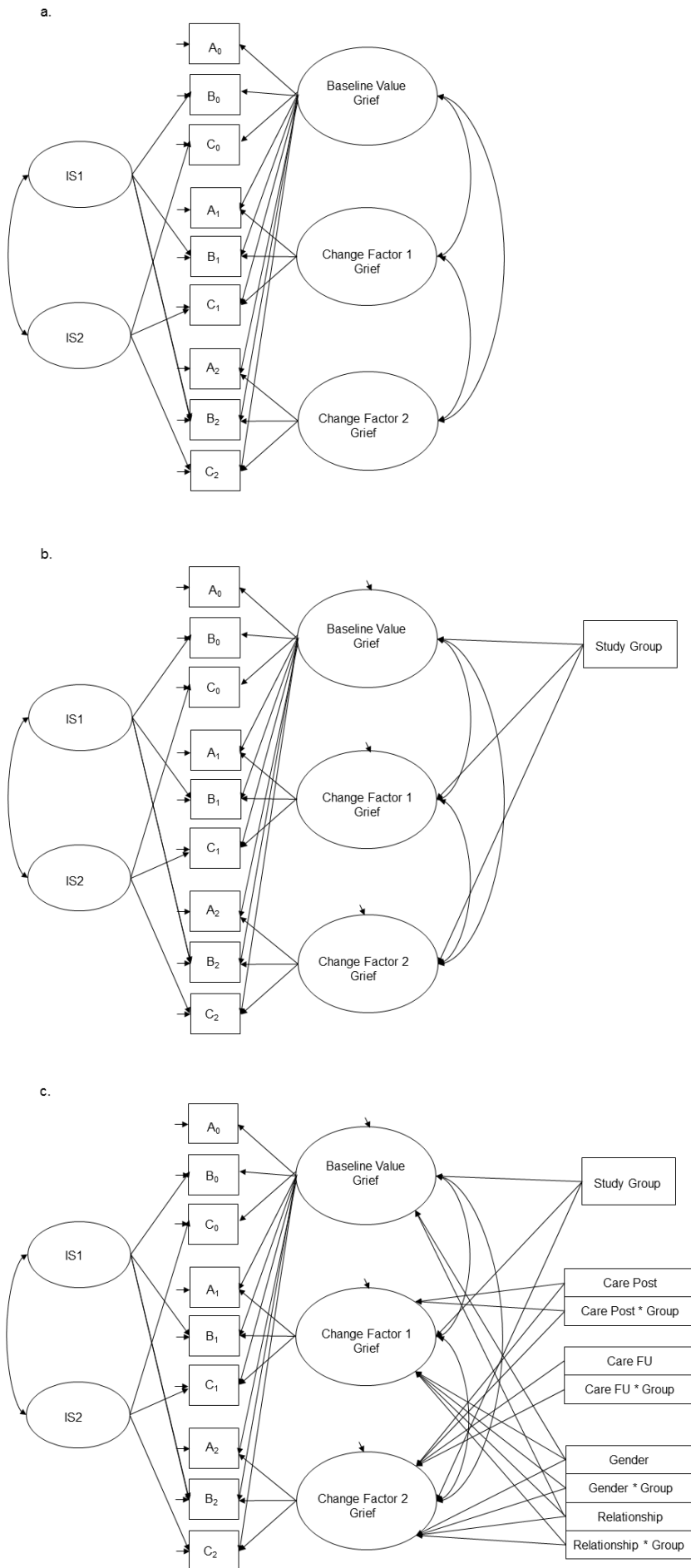
Two indicator-specific factors—IS1 and IS2—were included to account for indicator-specific effects. For the scaling of the latent variables, the first indicator's loading was fixed to one. To test for strong measurement invariance, factor loadings and intercepts were restricted to be equal over time and study groups. In line with recommendations made by Vandenberg and Lance (2000), *partial invariance* (i.e., invariance of the majority of indicators, with the variant parameters being freely estimated) was considered if model fit was not deemed satisfactory.

The latent change model was based on the latent state model (see Figure 1a). The latent variable of the baseline assessment represented the initial pre-death grief value. Two change factors were included, with the first representing the difference between the mean of the baseline and the post-intervention assessment, and the second representing the difference between the mean of the baseline and the follow-up assessment. Factor loadings and intercepts were again restricted to be equal over time and groups.

The effect of the intervention was tested by adding study group as a dummy-coded predictor (0 = control group, 1 = intervention group; see Figure 1b). Care situation (i.e., whether a caregiver was still caring for the person with dementia at home) immediately after the intervention as well as at the six-month follow-up was included as a further predictor of change. The final model (see Figure 1c) also included sociodemographic variables identified in previous studies as predictors of grief (i.e., gender and relationship to care recipient). Dummy coding was also used for care situation (0 = nursing home placement, 1 = still caring at home), gender (0 = male, 1 = female), and relationship to care recipient (0 = adult child, 1 = spouse). Interaction terms between study group and each predictor were computed and included as predictors of change to test for differential effects of the intervention.

Effect sizes were calculated by transforming the  $z$ -statistic of the predictors' regression coefficients into Cohen's  $d$  values. Values greater than 0.1 indicate small effects, values greater than 0.5 indicate moderate effects, and values greater than 0.7 indicate large effects (Cohen, 1988).





*Figure 1.* Latent change models with indicator-specific factors (a) and study group (b), and care situation and sociodemographic variables (c) as predictors.  $A_0-C_0$  = parcels at baseline,  $A_1-C_1$  = parcels at post-intervention,  $A_2-C_2$  = parcels at six-month follow-up; IS1 = indicator-specific factor for Parcel B, IS2 = indicator-specific factor for Parcel C. Factor loadings and intercepts were restricted to be equal over time (except for the intercept of  $C_0$ ). Care = nursing home placement vs. still caring at home, relationship = adult child vs. spousal relationship to care recipient.

### 3 Results

#### 3.1 Latent State Model

Very convincing goodness-of-fit indices emerged for the latent state model with indicator-specific factors ( $\chi^2[21] = 31.458, p = .066, CFI = 0.991, RMSEA = 0.043$ ). The assumption of strong measurement invariance was at first not met, as indicated by the unsatisfactory model fit ( $\chi^2[29] = 107.808, p < .001, CFI = 0.932, RMSEA = 0.100$ ). After inspecting freely estimated parameters, the intercept of Parcel C at baseline was not restricted to be equal across time. This resulted in a model with an excellent fit ( $\chi^2[28] = 40.093, p = .065, CFI = 0.990, RMSEA = 0.040$ ), and the assumption of strong partial measurement invariance was approved. Fit for the model with strong partial invariance across time and study groups was also satisfactory ( $\chi^2[63] = 93.157, p = .008, CFI = 0.973, RMSEA = 0.059$ ).

#### 3.2 Latent Change Model

Fit for the latent change model was equal to the fit for latent state model ( $\chi^2[28] = 40.093, p = .065, CFI = 0.990, RMSEA = 0.040$ ). The estimated mean baseline value of pre-death grief was 3.616 ( $SE = 0.054, p < .001$ ; see Table 2 for means and variances). The mean value of change from baseline to post-intervention was significant ( $M = -0.110, SE = 0.049, p = .025$ ), but the mean value of change between baseline and follow-up did not reach significance ( $M = -0.097, SE = 0.052, p = .064$ ). These results indicate a decrease in pre-death grief in both study groups between baseline and post-intervention assessment, but not between the baseline and six-month follow-up assessments. Variances of the baseline value ( $Var = 0.658, SE = 0.078, p < .001$ ) and both change factors ( $Var = 0.337, SE = 0.086, p < .001$  and  $Var = 0.315, SE = 0.083, p < .001$ , respectively) were significant, indicating interindividual differences in pre-death grief that warrant further inspection.

#### 3.3 Latent Change Model including Study Group as a Predictor of Change

When study group was included as a predictor, model fit remained very good ( $\chi^2[34] = 49.299, p = .044, CFI = 0.987, RMSEA = 0.041$ ). Standardized regression coefficients are displayed in Table 3. The intervention and control group did not differ in their baseline value of pre-death grief ( $\beta = .015, p = .817$ ). The influence of study group on the change in pre-death grief from baseline to post-intervention was not significant ( $\beta = -.130, p = .124$ ), but study group had a significant impact on the change between baseline and follow-up ( $\beta = -.262, p = .003$ ). The change score for the intervention group had a higher negative value, indicating a stronger decline of pre-death grief in the intervention compared to the control group. The Cohen's  $d$  value of  $-0.361$  points towards a small effect.

### 3.4 Latent Change Model including Study Group and Care Situation

Model fit remained satisfactory ( $\chi^2[54] = 86.879$ ,  $p = .003$ , CFI = 0.982, RMSEA = 0.047) when care situation at post-intervention and follow-up, as well as the interaction terms, were added to the model. After controlling for differences in the care situation, study group still had a significant impact on the change between baseline and follow-up ( $\beta = -.918$ ,  $p < .001$ , Cohen's  $d = -0.431$ ).

Care situation at time of the post-intervention assessment also had a significant influence on the change in pre-death grief from baseline to post-intervention ( $\beta = -.181$ ,  $p = .008$ , Cohen's  $d = -0.324$ ), with caregivers still caring at home showing a stronger decline in pre-death grief. The influence of all other predictors was not significant (all  $p > .050$ ).

### 3.5 Latent Change Model including Study Group, Care Situation, and Sociodemographic Variables

Model fit remained satisfactory after gender and relationship to care recipient, as well as the interaction terms between these variables and study group, were included ( $\chi^2[72] = 96.265$ ,  $p = .031$ , CFI = 0.991, RMSEA = 0.035). After controlling for all predictors, the influence of study group on the change in pre-death grief between baseline and follow-up remained significant ( $\beta = -.912$ ,  $p = .004$ , Cohen's  $d = -0.352$ ). Furthermore, influence of study group on the change between baseline and post-intervention now also reached significance ( $\beta = -.696$ ,  $p = .042$ , Cohen's  $d = -0.248$ ). The decrease in pre-death grief was again greater for the intervention group.

Also, the influence of still being a home caregiver at the time of the post-intervention assessment on the reduction of pre-death grief from baseline to post-intervention remained significant ( $\beta = -.203$ ,  $p = .001$ , Cohen's  $d = -0.401$ ) after controlling for all other predictors.

Relationship to care recipient ( $\beta = .211$ ,  $p = .001$ , Cohen's  $d = -0.399$ ), but not gender ( $\beta = .128$ ,  $p = .057$ ), had an influence on the baseline value of pre-death grief, as being a spousal caregiver predicted a higher value of pre-death grief. The influence of all other predictors was not significant (all  $p > .050$ ).

Table 2

*Unstandardized Means and Variances in the Latent Change Models*

	Initial Value			Change Factor 1			Change Factor 2			
	Estimate	SE	p-value	Estimate	SE	p-value	Estimate	SE	p-value	
Model 1	Mean	3.616	0.054	<.001	-0.110	0.049	0.025	-0.097	0.052	.064
	Variance	0.658	0.078	<.001	0.337	0.086	<.001	0.315	0.083	<.001
Model 2	Mean	3.603	0.074	<.001	-0.033	0.074	.661	0.055	0.077	.475
	Variance	0.657	0.077	<.001	0.331	0.084	<.001	0.291	0.078	<.001
Model 3	Mean	3.605	0.075	<.001	0.358	0.149	.016	0.434	0.127	.001
	Variance	0.661	0.078	<.001	0.326	0.081	<.001	0.289	0.082	<.001
Model 4	Mean	3.160	0.160	<.001	0.193	0.208	.351	0.366	0.256	.153
	Variance	0.658	0.080	<.001	0.395	0.088	<.001	0.375	0.096	<.001

*Note.* Model 1 = Latent change model, Model 2 = Latent change model including study group, Model 3 = Latent change model including study group and care situation, Model 4 = Latent change model including study group, care situation, and sociodemographic variables; SE = standard error.



Study group	.026	0.067	.689	-.696	0.343	.042	-.912	0.318	.004
Intervention (control)									
Care situation post									
Home									
caregiver (nursing home)	-	-	-	-.230	0.062	.001	-.098	0.082	.233
Care situation post*group	-	-	-	.497	0.321	.122	.373	0.347	.282
Care situation FU									
Home									
caregiver (nursing home)	-	-	-	-	-	-	-.172	0.105	.101
Care situation FU*group	-	-	-	-	-	-	.288	0.222	.195
Gender									
Female (male)	.128	0.067	.057	.103	0.098	.292	.061	0.114	.593
Gender*group	-	-	-	.014	0.167	.934	.026	0.192	.893
Relationship to care recipient									
Spouse (adult child)	.211	0.065	.001	.183	0.111	.100	.166	0.135	.218
Relationship to care recipient*group	-	-	-	.142	0.142	.320	.098	0.163	.548

Model  
4

*Note.* Post = post-intervention assessment; FU = six-month follow-up assessment; Model 2 = Latent change model including study group, Model 3 = Latent change model including study group and care situation, Model 4 = Latent change model including study group, care situation, and sociodemographic variables; *SE* = standard error.

<sup>a</sup>Reference category in parentheses. <sup>b</sup>Denotes the interaction between the two predictors.



## 4 Discussion

It was the aim of the present study to determine if a telephone-based CBT intervention that included a grief-specific intervention module could successfully foster caregivers' acceptance of loss and change, thereby reducing the burden of pre-death grief. To our knowledge, this is the first study that has investigated the effects of a grief-specific intervention that had a randomized-controlled design, a large sample, and a follow-up assessment, and for which latent change analysis was applied.

We found a significant treatment effect at the time of the six-month follow-up assessment. When controlling for changes in the caregiving situation as well as for gender and relationship to the care recipient, the treatment effect also emerged immediately after the intervention ended. Latent change models provided a highly evolved method to answer the proposed research questions, because they allowed us to examine interindividual differences in true intraindividual change that is free from measurement errors.

When study group was included as the only predictor of change, a treatment effect was found at six-month follow-up, but not directly after the intervention. This pattern of results might be attributable to the underlying psychotherapeutic mechanisms: When therapists addressed losses caused by the disease's progression and associated painful emotions, this may have initially intensified the grieving process for many caregivers. The reason for this reaction is that caregivers are often unaware of the grief inherent in dementia caregiving, and confuse its psychological and physical symptoms with symptoms of stress (Dempsey & Baago, 1998; Silverberg, 2007). During the intervention, therapists used *problem confrontation* or *actualization* (Grawe, 2004), guiding caregivers to face, experience, and deal with the painful experience of pre-death grief. Problem actualization is one of the common factors of psychotherapy (Grawe, 2004) and therefore crucial for long-term improvement. After the six-month intervention ended, caregivers were still working through the grieving process, and although lower pre-death grief scores were found for all participants, no difference was found between the control and intervention groups. However, between the end of the intervention and the six-month follow-up assessment, caregivers in the intervention group appear to have been able to come to terms with their grief better than those in the control group, as evidenced by significantly lower pre-death grief scores for this group compared to the control group.

Dementia is a progressive disease that brings a constant decline in care recipients' abilities; as a result, caregiving demands are always increasing and the caregiving situation changes constantly. In the present study, this disease progression resulted in 28 caregivers opting for nursing home placement, either over the course of the intervention or during the six-

month follow-up period. When controlling for care situation and sociodemographic variables, the treatment effect was even more pronounced: A greater decline in pre-death grief was found for the intervention compared to the control group at post-intervention, and this effect was maintained as of the follow-up assessment.

Those who were still home caregivers at the time of the post-intervention assessment tended to have lower values of pre-death grief. This is in line with prior findings showing that nursing home placement is associated with a strong sense of loss, which can result in a greater experience of pre-death grief, especially sadness, guilt (Rudd et al., 1999), and separation distress (Kiely, Prigerson, & Mitchell, 2008).

A significant influence for baseline pre-death grief values was found for relationship to care recipient, with spouses experiencing more pre-death grief than adult children. This finding corroborates the results from focus group discussions reported by Meuser and Marwit (2001). These authors found that the emotional responses to losses are different for spouses and adult children, with spouses experiencing a more intense sadness.

The effect of gender on pre-death grief that was previously demonstrated (Rudd et al., 1999) could not be replicated in the present study, nor could any interaction between study group, gender, and relationship to care recipient be found. This result was, however, not surprising: Although the intervention was based on a manual, skilled therapists adapted its techniques to each caregiver's needs, creating highly individualized treatment.

All effect sizes were in the small-to-moderate range, and seem reasonable if evaluated under the assumption that caregivers are facing a continuously difficult care situation. It does, however, seem promising that treatment effect sizes at the time of the six-month follow-up assessment were greater than those from the post-intervention assessment. This increasing effect points towards the long-term effect of the intervention on caregivers' ability to cope with pre-death grief.

#### **4.1 Implications and Outlook**

The present study demonstrated the effectiveness of a CBT-based intervention in fostering dementia caregivers' coping with pre-death grief. This result underlines the necessity for health care professionals who work with dementia caregivers to explore whether losses are experienced and perceived as significant, and to intervene accordingly.

Further research is needed on long-term effects, i.e., how pre-death grief develops from the six-month follow-up onwards. It is also not yet known how successfully coping with pre-death grief may be related to other aspects of physical and mental health. We are currently

conducting analyses to learn more about how therapists' use of the grief intervention module relates to the application of the other modules provided in the manual.

More research is also needed to understand whether or not post-death grief is impacted by interventions directed at pre-death grief. Building upon the findings of Hebert, Dang, and Schulz (2006) who have highlighted the importance of preparedness for the death of the care recipient, we plan to investigate whether a decline in pre-death grief is associated with increased perceived preparedness and a subsequent more positive adaptation to bereavement.

#### **4.2 Limitations**

Although the present study has multiple strengths some limitations need to be considered. First, therapists were free to implement the manual's ten modules when and how they felt it best served participants, meaning that the intensity and timing of grief-specific interventions over the six-month intervention duration were not fully uniform across all participants. Although this flexible and individualized approach was the best way to address each individual caregiver's needs, further research is needed to determine the most effective implementation and combination of intervention modules.

Another limitation of the present study was that our grief-specific interventions predominantly focused on the challenges encountered by caregivers who were still caring for the care recipient at home, rather than in a nursing home. Caregiving and the pre-death grief experience both change greatly with nursing home placement. In the future intervention techniques targeting the unique aspects of this changed situation need to be included in the module to support caregivers during decision making and after placement.

#### **4.3 Conclusion**

This has been the first randomized-controlled design study to investigate the effectiveness of a CBT-based intervention for dementia caregivers with a focus on pre-death grief. Our results indicated a greater decline in burden of pre-death grief in the intervention than in the control group, leading to the conclusion that the intervention can successfully foster caregivers' coping with grief and loss.

Given the rising number of people with dementia (Alzheimer's Disease International, 2015), it is of utmost importance for health care professionals to be able to provide support for family members—not only regarding the fulfillment of caregiving tasks, but also how to cope emotionally with this challenging situation. Having intervention strategies at hand that foster acceptance of and coping with grief, loss, and change can ensure caregivers' continued physical

and mental health and permit them to come to terms with the end of one of life's most meaningful personal relationships.

## 5 References

- Alzheimer's Disease International. (2015). Dementia statistics. Retrieved from <http://www.alz.co.uk/research/statistics>
- Boss, P. (2000). *Ambiguous loss: Learning to live with unresolved grief*. Cambridge, MA: Harvard University Press.
- Chan, D., Livingston, G., Jones, L., & Sampson, E. L. (2013). Grief reactions in dementia carers: A systematic review. *International Journal of Geriatric Psychiatry, 28*(1), 1–17. doi: 10.1002/gps.3795
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences*. Hillsdale, NJ: Erlbaum.
- Collins, L. M., Schafer, J. L., & Kam, C.-M. (2001). A comparison of inclusive and restrictive strategies in modern missing data procedures. *Psychological Methods, 6*(4), 330–351. doi: 10.1037/1082-989X.6.4.330
- Elvish, R., Lever, S.-J., Johnstone, J., Cawley, R., & Keady, J. (2013). Psychological interventions for carers of people with dementia: A systematic review of quantitative and qualitative evidence. *Counselling and Psychotherapy Research, 13*(2), 106–125. doi: 10.1080/14733145.2012.739632
- Enders, C. K. (2010). *Applied missing data analysis*. New York, NY: Guilford Press.
- Gallagher-Thompson, D., & Coon, D. W. (2007). Evidence-based psychological treatments for distress in family caregivers of older adults. *Psychology and Aging, 22*(1), 37–51. doi: 10.1037/0882-7974.22.1.37
- Grawe, K. (2004). *Psychological therapy*. Seattle, WA: Hogrefe and Huber.
- Hebert, R. S., Dang, Q., & Schulz, R. (2006). Preparedness for the death of a loved one and mental health in bereaved caregivers of patients with dementia: Findings from the REACH study. *Journal of Palliative Medicine, 9*(3), 683–693. doi: 10.1089/jpm.2006.9.683
- Holley, C. K., & Mast, B. T. (2009). The impact of anticipatory grief on caregiver burden in dementia caregivers. *The Gerontologist, 49*(3), 388–396. doi: 10.1093/geront/gnp061
- Hu, L.-T., & Bentler, P. M. (1999). Cutoff criteria for fit indices in covariance structure analysis: Conventional criteria versus new alternatives. *Structural Equation Modeling, 6*(1), 1–55. doi: 10.1080/10705519909540118
- Kasl-Godley, J. (2003). Anticipatory grief and loss: Implications for intervention. In D. W. Coon, D. Gallagher-Thompson, & L. W. Thompson (Eds.), *Innovative interventions to reduce dementia caregiver distress* (pp. 210–219). New York, NY: Springer.

- Kiely, D. K., Prigerson, H., & Mitchell, S. L. (2008). Health care proxy grief symptoms before the death of nursing home residents with advanced dementia. *American Journal of Geriatric Psychiatry, 16*(8), 664–673. doi: 10.1097/JGP.0b013e3181784143
- Lindauer, A., & Harvath, T. A. (2014). Pre-death grief in the context of dementia caregiving: A concept analysis. *Journal of Advanced Nursing, 70*(10), 2196–2207. doi: 10.1111/jan.12411
- Little, T. D., Rhemtulla, M., Gibson, K., & Schoemann, A. M. (2013). Why the items versus parcels controversy needn't be one. *Psychological Methods, 18*(3), 285–300. doi: 10.1037/a0033266
- Marwit, S. J., & Meuser, M. T. (2002). Development and initial validation of an inventory to assess grief in caregivers of persons with Alzheimer's disease. *The Gerontologist, 42*(6), 751–765. doi: 10.1093/geront/42.6.751
- Meichsner, F., Schinköthe, D., & Wilz, G. (2015a). The Caregiver Grief Scale: Development, exploratory and confirmatory factor analysis, and validation. *Clinical Gerontologist*. doi: 10.1080/07317115.2015.1121947
- Meichsner, F., Schinköthe, D., & Wilz, G. (2015b). Managing loss and change: CBT-based grief interventions for dementia caregivers. *American Journal of Alzheimer's Disease and Other Dementias*. doi: 10.1177/1533317515602085
- Meuser, M. T., & Marwit, S. J. (2001). A comprehensive, stage-sensitive model of grief in dementia caregiving. *The Gerontologist, 41*(5), 658–670. doi: 10.1093/geront/41.5.658
- Meuser, M. T., Marwit, S. J., & Sanders, S. (2004). Assessing grief in family caregivers. In K. J. Doka (Ed.), *Alzheimer's disease: Living with grief* (pp. 169–195). Washington, DC: Hospice Foundation of America.
- Muthén, L. K., & Muthén, B. O. (2012). *MPlus user's guide* (7th ed.). Los Angeles, CA: Muthén & Muthén.
- Noyes, B. B., Hill, R. D., Hicken, B. L., Luptak, M., Rupper, R., Dailey, N. K., & Bair, B. D. (2010). Review: The role of grief in dementia caregiving. *American Journal of Alzheimer's Disease and Other Dementias, 25*(1), 9–17. doi: 10.1177/1533317509333902
- Ott, C. H., Kelber, S. T., & Blaylock, M. (2010). "Easing the way" for spouse caregivers of individuals with dementia: A pilot feasibility study of a grief intervention. *Research in Gerontological Nursing, 3*(2), 89–99. doi: 10.3928/19404921-20100302-01

- Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging, 18*(2), 250–267. doi: 10.1037/0882-7974.18.2.250
- Pinquart, M., & Sörensen, S. (2006). Helping caregivers of persons with dementia: Which interventions work and how large are their effects? *International Psychogeriatrics, 18*(4), 577–595. doi: 10.1017/s1041610506003462
- Prigerson, H. G., & Jacobs, S. C. (2001). Traumatic grief as a distinct disorder: A rationale, consensus criteria, and a preliminary empirical test. In M. S. Stroebe, R. O. Hansson, W. Stroebe, & H. Schut (Eds.), *Handbook of bereavement research: Consequences, coping, and care* (pp. 613–645). Washington, DC: American Psychological Association.
- Reisberg, B., Ferris, S. H., de Leon, M. J., & Crook, T. (1982). The Global Deterioration Scale for assessment of primary degenerative dementia. *American Journal of Psychiatry, 139*, 1136–1139. doi: 10.1176/ajp.139.9.1136
- Rudd, M. G., Viney, L. L., & Preston, C. A. (1999). The grief experienced by spousal caregivers of dementia patients: The role of place of care of patient and gender of caregiver. *The International Journal of Aging & Human Development, 48*(3), 217–240. doi: 10.2190/mgmp-31rq-9n8m-2ar3
- Sanders, S., & Adams, K. B. (2005). Grief reactions and depression in caregivers of individuals with Alzheimer's disease: Results from a pilot study in an urban setting. *Health & Social Work, 30*(4), 287–295. doi: 10.1093/hsw/30.4.287
- Sanders, S., & Sharp, A. (2004). The utilization of a psychoeducational group approach for addressing issues of grief and loss in caregivers of individuals with Alzheimer's disease. *Journal of Social Work in Long-Term Care, 3*(2), 71–89. doi: 10.1300/J181v03n02\_06
- Soellner, R., Reder, M., Machmer, A., Holle, R., & Wilz, G. (2015). The Tele.TAnDem intervention: Study protocol for a psychotherapeutic intervention for family caregivers of people with dementia. *BMC Nursing, 14*(1), 1–6. doi: 10.1186/s12912-015-0059-9
- Steyer, R., Eid, M., & Schwenkmezger, P. (1997). Modeling true intraindividual change: True change as a latent variable. *Methods of Psychological Research Online, 2*, 21–33.
- Vandenberg, R. J., & Lance, C. E. (2000). A review and synthesis of the measurement invariance literature: Suggestions, practices, and recommendations for organizational research. *Organizational Research Methods, 3*, 4–70. doi: 10.1177/109442810031002

Wilz, G., Schinköthe, D., & Kalytta, T. (2015). *Therapeutische Unterstützung für pflegende Angehörige für Menschen mit Demenz. Das Tele.TAnDem Behandlungskonzept [Therapist support for dementia caregivers: The Tele.TAnDem Intervention Program]*. Göttingen, Germany: Hogrefe.

Wilz, G., & Soellner, R. (2015). Evaluation of a short-term telephone-based cognitive behavioral intervention for dementia family caregivers. *Clinical Gerontologist*. doi: 10.1080/07317115.2015.1101631



**APPENDIX**

## Ehrenwörtliche Erklärung

Hiermit versichere ich, Franziska Meichsner, geboren am 24.11.1986 in Schlema, dass mir die geltende Promotionsordnung der Fakultät für Sozial- und Verhaltenswissenschaften der Friedrich-Schiller-Universität Jena bekannt ist; dass ich die Dissertation selbst und ohne unzulässige Hilfe Dritter angefertigt habe, sowie alle benutzten Hilfsmittel und Quellen angegeben habe; dass Frau Prof. Dr. Gabriele Wilz als Betreuerin der Arbeit fungierte und, dass Frau Prof. Dr. Gabriele Wilz und Frau Denise Schinköthe, M.Sc. mich als Koautorinnen bei der Erstellung der präsentierten Manuskripte unentgeltlich unterstützten (siehe Eigenständigkeitserklärung für eine Übersicht über die Arbeitsanteile aller beteiligten Autorinnen); dass Frau Julia McMillan die der Dissertation zugrunde liegenden Manuskripte entgeltlich sprachlich korrigierte und dass Frau Dipl.-Psych. Franziska Schug im Rahmen ihrer Abschlussarbeit an der Transkription des Materials für Studie I beteiligt war; dass darüber hinaus Dritte weder unmittelbar noch mittelbar geldwerte Leistungen von mir für Arbeiten erhalten haben, die im Zusammenhang mit dem Inhalt der vorgelegten Dissertation stehen und ich insbesondere *nicht* die Hilfe einer/s PromotionsberaterIn in Anspruch genommen habe; dass ich die Dissertation weder im Inland noch im Ausland in gleicher oder ähnlicher Form als Prüfungsarbeit für eine staatliche oder wissenschaftliche Prüfung eingereicht habe; dass ich keine gleiche, eine in wesentlichen Teilen ähnliche oder eine andere Abhandlung bei einer anderen Hochschule bzw. anderen Fakultät als Dissertation eingereicht habe.

Ich versichere, dass ich nach bestem Wissen die reine Wahrheit sage und nichts verschwiegen habe.

Jena, den 4. März 2016

.....

## Eigenständigkeitserklärung

Diese kumulative Dissertation beruht auf den nachfolgend aufgeführten drei Studien:

<b>Bezeichnung in der Dissertation (Kapitel)</b>	<b>Publikationsstatus</b>	<b>Vollständige Literaturangabe</b>
Study I: Managing Loss and Change: Grief Interventions for Dementia Caregivers in a CBT-based Trial	Zur Publikation angenommen im <i>American Journal of Alzheimer's Disease and Other Dementias</i> Datum der Bestätigung über die Annahme des Manuskripts: 26.04.2015	Meichsner, F., Schinköthe, D., & Wilz, G. (2015). Managing loss and change: CBT-based grief interventions for dementia caregivers. <i>American Journal of Alzheimer's Disease and Other Dementias</i> , 31(3), 231–240. doi: 10.1177/1533317515602085
Study II: The Caregiver Grief Scale: Development, Exploratory and Confirmatory Factor Analysis, and Validation	Zur Publikation angenommen im <i>Clinical Gerontologist</i> Datum der Bestätigung über die Annahme des Manuskripts: 16.11.2015	Meichsner, F., Schinköthe, D., & Wilz, G. (2015). The Caregiver Grief Scale: Development, exploratory and confirmatory factor analysis, and validation. <i>Clinical Gerontologist</i> , 39(4), 342–361. doi: 10.1080/07317115.2015.1121947
Study III: Dementia Caregivers' Coping with Pre- Death Grief: Effects of a CBT-based Intervention	Zur Begutachtung eingereicht. Datum der Bestätigung über die Einreichung des Manuskripts: 04.03.2016	Meichsner, F. & Wilz, G. (under review). Dementia Caregivers' Coping with Pre-Death Grief: Effects of a CBT-based Intervention.

Alle drei Studien wurden von mir, Franziska Meichsner, als Hauptautorin angefertigt. Entwicklung der Fragestellungen, Konzeption, Literaturrecherche, Datenaufbereitung und –analyse, Ergebnisdiskussion, Erstellung und Revision der Manuskripte oblagen hauptverantwortlich mir.

Frau Prof. Dr. Gabriele Wilz war als Betreuerin der Dissertation eng in jeden der oben genannten Arbeitsschritte eingebunden und gab mir zu mehreren Zeitpunkten des Entstehungsprozesses der Manuskripte ausführliche Rückmeldungen. Sie fungiert auch als Koautorin aller drei Manuskripte.

Die Datenerhebung erfolgte im Rahmen der unter der Leitung von Frau Prof. Dr. Gabriele Wilz und Frau Prof. Dr. Renate Soellner durchgeführten Projekte Tele.TAnDem

(Förderkennzeichen LTDEMENZ-44-092, Bundesministerium für Gesundheit) und Tele.TAnDem.transfer (Förderkennzeichen IIA5-2512FSB555, Bundesministerium für Gesundheit).

Frau Denise Schinköthe, M.Sc. fungiert als Koautorin der Manuskripte I und II und war auch in die Entwicklung der Fragestellungen dieser Studien eingebunden. In Studie I übernahm sie die Ko-Kodierung der ausgewiesenen Anzahl von Transkripten, die die Berechnung der Intercoderreliabilität erlaubte. Zudem fand die Auswahl des Materials und die Erstellung des Kategoriensystems, wie im Rahmen qualitativer Forschung von Bedeutung, in engem Austausch zwischen mir und Frau Schinköthe statt. In Studie II war Frau Schinköthe maßgeblich an der Auswahl, Zusammenstellung und Neuentwicklung der Items der *Caregiver Grief Scale* beteiligt. Zu beiden Manuskripten gab mir Frau Schinköthe Rückmeldung im Entstehungsprozess.