

Copyright
by
Kristie Andrea Wood
2020

**The Report Committee for Kristie Andrea Wood
Certifies that this is the approved version of the following Report:**

**Grief and Loss in Adult-Child Relationships with Parents who have
Dementia: A Literature Review and Mixed Methods Study Proposal**

**APPROVED BY
SUPERVISING COMMITTEE:**

Marie-Anne Suizzo, Supervisor

Aaron B. Rochlen

**Grief and Loss in Adult-Child Relationships with Parents who have
Dementia: A Literature Review and Mixed Methods Study Proposal**

by

Kristie Andrea Wood

Report

Presented to the Faculty of the Graduate School of

The University of Texas at Austin

in Partial Fulfillment

of the Requirements

for the Degree of

Master of Arts

The University of Texas at Austin

December 2020

Dedication

This document is dedicated to my grandmother, who taught me about dementia and unconditional love; to my mother, who taught me about grief and loss, and gave me the power to be curious instead of afraid of them both; and to my mentor, Dr. Marie-Anne Suizzo, who gave me the courage, support, and guidance necessary to do these topics justice in scientific inquiry.

Acknowledgements

I want to acknowledge my best friend, Erica T. Jersin for being so interested in and supportive of my work and ideas. I cherish you and our friendship.

Abstract

Grief and Loss in Adult-Child Relationships with Parents who have Dementia: A Literature Review and Mixed Methods Study Proposal

Kristie Andrea Wood, MA

The University of Texas at Austin, 2020

Supervisor: Marie-Anne Suizzo

Adult-children of parents with dementia (ACPD) experience considerable levels of grief and risk for corresponding psychological problems. The effects of grief in ACPD on their identity and self- concept are understudied. In this proposed mixed-methods study, ambiguous loss and self psychology frameworks will be utilized. I will conduct semi-structured interviews to explore how the changing parent adult-child relationship affects adult-child identity and self-concept in 12 adult-children of mothers with dementia. Of particular interest, changes in the relationship that are due to the adult-child's perception of the parent's psychological absence and diminished empathic attunement will be assessed. Data will be analyzed using grounded theory to identify themes. I will collect quantitative data and use descriptive and correlation analyses to confirm and expand on qualitative insights and further identify links between themes from the interviews.

Table of Contents

List of Tables	xi
List of Figures	xii
Introduction	1
The Problem	1
Past Research on the Problem	1
Deficiencies in Past Research	2
Proposed Research	4
Benefit of the Proposed Research	5
Literature Review	6
Grief in Adult Children of Parents with Dementia	6
Grief in Ambiguous Loss	8
Grief and Mental Illness in Family Dementia Caregivers	10
Related Grief Interventions	12
Post Death Grief Interventions	12
Pre Death Grief Interventions	13
Effective Change Mechanisms in Family Caregiver Grief Interventions	14
Inquiry into Specific Aspects of Ambiguous Loss to Inform Intervention ..	14
Identity and Development	15
Identity in Ambiguous loss	16
Identity Definition and Changes in Ambiguous Loss	16
Limited Identity Conceptualization in the Ambiguous Loss Model	17
Empirical Investigation of Identity in Ambiguous Loss	17

Identity and Self-Concept in Prolonged Grief	18
Identity Symptoms in Pathological Grief Diagnostic Criteria	18
Links Between Identity and Grief	18
Implications of Limited Self-Concept Fluency and Self-Concept Clarity for Research Design	19
Identity in Related Contexts: Filial Dementia Caregiving, Parent Mental Illness, Being Forgotten	20
Identity in Filial Dementia Caregiving	20
Identity in Children of Parents with Mental Illness	21
Effects of Being Forgotten on Self-Concept.....	23
Effects of Being Forgotten in Childhood.....	24
Effects of Being Forgotten in Adulthood.....	25
Early Parent Child Relationship Quality	26
Attachment.....	27
Attachment is Central to Models of Grief.....	27
Attachment in Adult-Children of Parents with Dementia.....	28
Parental Bonding.....	29
Deficiencies in Attachment and Early Bonding Research in ACPD	30
Current Proposal Given Research Deficiencies	30
Self Psychology: a Framework for Self-Cohesion, Identity, and Parent Child Relationship Quality	30
The Self and Self-Cohesion in Self Psychology	31
Selfobject Needs	31
Empathic Attunement as a Necessity for Self-Cohesion	32

Empathic Attunement and Selfobject Needs in Adulthood for Cohesive-Self Maintenance	33
Research Questions	34
Qualitative research questions	34
Quantitative research questions	34
Method	35
Definition of Mixed Methods Research.....	35
Type of Design used and its Definition	35
Rationale for Design	36
Addressing Challenges in Using this Design.....	36
Participants.....	37
Recruitment.....	38
Rationale for Recruitment Method	38
Study Procedures	39
Quantitative Data Collection.....	39
Qualitative Data Collection.....	39
Measures	40
Demographics Questionnaire.....	40
Early Parent Child Relationship Quality.....	40
Self-concept and Identity Measure	40
Arble Estimate of Selfobject Pursuits	41
Self-Worth.....	42
Grief	42
Quantitative Data Analysis	43

Qualitative Interview	43
Qualitative Analysis	44
Qualitative Validation	45
Mixed Method Analysis	45
Discussion	46
Summary	46
Limitations	46
Appendices	52
Appendix A - Screening Questions and Background Information	52
Screening Questions and Background Information	52
The QDRS, Quick Dementia Rating System	52
Appendix B - Recruitment Flyer	58
Appendix C - Qualitative Materials	59
Interview Questions	59
Feelings and Sensations List	63
Appendix D - Measures	64
Demographic Information	64
Parental Bonding Instrument	65
Self-Concept and Identity Measure	67
Arble Estimate of Selfobject Pursuits	68
Rosenberg Self Esteem Scale	70
Caregiver Grief Scale	71
References	72

List of Tables

<i>Table 1.</i> Caregiver terms used throughout the literature.....	48
---	----

List of Figures

<i>Figure 1.</i> The current research explores the links between relational change due to psychological absence, early parent child relationship quality, identity, self concept and grief.	49
<i>Figure 2.</i> Typology for classifying a concurrent embedded design. QUAL= qualitative data is prioritized; quan= lower priority given.....	50
<i>Figure 3.</i> Visual diagram of study procedures.....	51

Introduction

The Problem

Adult-children of parents with dementia (ACPD) experience intense pre and post death grief that is complex and understudied. The experiences of ACPD as they witness and cope with their parent's psychosocial deterioration are marked with tragedy and successive interpersonal and intrapsychic losses (Rich, 2008; Silkes & Hall, 2017; Blandin & Pepin, 2017). What's more, these experiences are complicated by whether or not the adult-child is in a caregiver role. Despite variation in caregiving roles—in the literature, most ACPD qualify for the term “informal caregiver,” which generally includes those who provide at least one weekly act of care, e.g. cooking, paying a bill. (Note: because formal/paid caregiving is not discussed in this work, informal caregivers will be referred to simply as caregivers.)

Unfortunately, the number of ACPD is rising and caregivers for dementia sufferers are in increasing demand. Worldwide, 50 million people have dementia, and this is set to triple by 2050 (World Health Organization, 2012). Dementia sufferers' children are among the first in line to step into caregiver roles. This comes at high cost. Filial dementia caregivers (i.e. adult-child caregivers for parents with dementia) suffer increased rates of psychological problems, mental illness (Yıldızhan et al., 2018; Sullivan & Miller et al., 2015; Lindgren et al., 1990; Collins et al., 2019), and physical symptoms (Sörensen & Conwell, 2011; Cucciare et al., 2010). Given that most ACPD qualify as “caregivers” this is startling. Understanding the grief ACPD, caregiver or not, experience, is crucial to provide therapeutic care.

Past Research on the Problem

Dr. Pauline Boss has done extensive theorizing about the unique type of loss experienced by dementia sufferers' loved ones, which she coined “ambiguous loss,” characterized by the physical presence of a person who is psychologically absent (Boss, 2010). In ambiguous loss, loved ones are traumatized and feel “stuck,” as their grief process is halted, coping rituals are

absent, and there is a lack of opportunity for closure (Boss, 2010). As dementia sufferers are perceived as psychologically absent, the capacity for intimacy and shared experience is attenuated. The ambiguous loss model provides therapeutic guidelines for coping with this relational loss.

While it is challenging to find research focusing on changes in the parent adult-child relationship outside the context of caregiver roles, psychological absence appears to be at the core of much relational loss when a parent has dementia. In fact, Boss et al., (1990) found that the more one perceives psychological absence in ambiguous loss, the more likely they are to experience distress. Further, chief complaints reported by ACPD include: difficulty coping with the dementia sufferer's psychological presence/absence-ambiguity (Boss & Kaplan, 2003), psychosocial death, i.e., lost essence of who the individual was once (Furlini, 2001), and deterioration of intimacy and connection (Sanders et al., 2008; Sanders & Corley, 2003).

Linked with psychological absence of the parent (Boss, 2010), the ambiguous loss model has noted that when a parent has dementia, a key compromised area is adult-child identity (Boss & Kaplan, 2003; Cheung et al., 2018; Furlini, 2001; Large & Slinger, 2015; Sikes & Hall, 2017). ACPD may wonder "who am I now that my mother does not remember me?" Identity shifts may also ensue when ACPD take on parenting, or caregiver roles, for example.

Deficiencies in Past Research

A trouble that pervades almost the entire body of related research is inconsistent use of the term caregiver (see Table 1) (Harvey & Burns, 2003). Often, criteria for "caregiver" is left out of Methods sections completely. While the term is so broad it can include many, if not most, ACPD, a comparison of literature where distinction of care involvement is important, is difficult or impossible.

Not only is caregiver criteria unstandardized, a caregiver focus dominates the ACPD literature (Peirce, 2008), which largely explores caregiver role experience and caregiver role burden. This is problematic for two main reasons, firstly, grief due to interpersonal and intrapsychic (e.g. identity) loss may be conflated with distress due to the caregiving role

(Meichsner et al., 2017). As grief may actually hinder caregiver duty (Sanders & Corley, 2003), this construct confusion is not only disturbing, it stymies inquiry into construct directionality. Secondly, a focus on the caregiving role has eclipsed inquiry into how the core parent adult-child relationship is affected in the context of dementia. Studying the root parent adult-child relationship will inform changes in both filial caregiver and non caregiver relationships, and thus inform interventions in both populations. Therefore, symptoms of distress due to caregiving and grief due to change in the parent child relationship must be differentiated.

There are many gaps in the literature regarding grief and changes in the adult-child parent relationship when a parent has dementia. Grief in ACPD is often not distinguished from other types of distress (Meichsner et al., 2017; Blandin & Pepin, 2017). Further, non-caregiver ACPD distress in the parent adult-child relationship is scant in the literature (Barca et al., 2014).

So far, psychological absence has not been opened up as a construct for deeper empirical exploration. Verification of this phenomenon requires replication and phenomenological description. Related to psychological absence, but perhaps more shocking—research on the experience of being forgotten by a loved one with dementia appeared to be completely missing from the literature. Efficacious work with grief allows for disenfranchised grief, e.g. unacknowledged grief (Doka, 1999), to be acknowledged and defined in effort to be metabolized. Ceasing inquiry at such a large “black box”-phenomenon does not easily inform therapeutic grief work.

There is another gap in the literature in regards to identity in ambiguous loss. Boss (2010) described identity as a core feature of ambiguous loss and provided therapeutic guidelines for restructuring identity. However, identity conceptualization in ambiguous loss is mostly limited to family roles. Because identity is much more than the roles one takes on socially, Boss’ theory is insufficient. Even in the limited view proposed by the model, investigation into how ACPD’s identity is affected in ambiguous loss when a parent has dementia is negligible.

Another interesting, but not so obvious deficiency in the literature is a failure to connect early child relationships with identity and grief response in ACPD. Given the interwoven nature of the early parent child relationship quality and the development of child self-concept (Mullis et al., 2003), there is an opportunity to connect these links to grief in ACPD. Some starting blocks do exist from which to build on the relationship between early parent child relationship quality and grief. For example, poor early parent child bonding is associated with increased distress in filial dementia caretaking (Daire, 2002), and attachment is tightly linked with grief response during bereavement (Shear & Shair, 2005). However, a more thorough investigation is proposed here. See Figure 1.

Proposed Research

Utilizing a self psychology lens, empathic attunement is vital for both a child's interpersonal experience (e.g. parent child bonding) and intrapersonal growth (e.g. development of early child identity & formation of the self) (Banai et al., 2005). Therefore, ACPD experience the unraveling of ingredients— empathic attunement, psychological presence, relational security and stability—that were developmentally necessary to form healthy relational bonds (Bowlby, 1973) and a cohesive identity (Kohut, 1978). Therefore, a comprehensive exploration into the impact of parental psychological absence on ACPD's grief includes examination of changes in empathic attunement, early parent child bonding, and adult-child identity and self-concept.

This mixed methods research study will address the relational changes that occur in the parent adult-child relationship when a parent who has dementia is perceived as psychologically absent. An embedded mixed method design will be used, a design in which one data set provides a supportive, secondary role in a study based primarily on the other data set. To address the primary purpose of this study, semi-structured interviews will explore how the adult-child parent relationship changes in the context of a parent's dementia, and its effects on the adult-child's sense of self and identity. A secondary purpose will be to use self-report measures of early parental bonding, identity, self-concept, and grief. The reason for collecting the secondary database is to

address different research questions than the qualitative portion of the study. These quantitative data allow for the assessment of parental bonding, identity and grief. Additionally, self-report measures will offer insight into correlations between early parental bonding, identity, grief.

Benefit of the Proposed Research

There are both theoretical and clinical implications for this research. This work contributes to theoretical understanding of relational changes and psychological absence in a parent adult-child relationship in the context of dementia, expands on filial identity in ambiguous loss, and broadens understanding of the links between early parent child relationship quality, identity, and grief in ambiguous loss. The clinical relevance of this project lies illuminating the experiences ACPD face with regard to identity, grief, and early parent child relationship quality. Because ACPD experience so much grief, it is important to study their losses. Research into these specific aspects of interpersonal and intrapsychic change will enable therapists to better conceptualize, and, thus, offer optimal interventions for ACPD. Further, this work may have treatment implications that extrapolate to other contexts in which adult children cope with ambiguous loss of a primary caretaker, for example, in cases of parental mental illness or comatose.

Literature Review

GRIEF IN ADULT CHILDREN OF PARENTS WITH DEMENTIA

Grief in adult-children of parents with dementia (ACPD) is understudied. Generally, grief is the psychological reaction to a breach in attachment due to loss or death (Bowlby, 1973). Dementia is an umbrella term for cognitive decline severe enough to impede one's independent daily functioning (e.g. Alzheimer's disease, frontotemporal dementia) (Gale et al., 2018). ACPD experience many types of grief and loss, for example, due to changes in the parent child relationship, often while tasked with providing variable amounts of caregiving. ACPD witness their parent's unrecognizable personality changes, cognitive decline, memory loss, uncharacteristic, hurtful behavior, and eventual complete helplessness (Rich, 2008). Research suggests that the grief experienced in dementia has a distinctly tragic quality, unlike that of other terminal illness (Sikes & Hall, 2017). In fact, Blandin and Pepin (2007) coined the term "dementia grief" to encapsulate the blend of ambiguous loss, anticipatory grief, and endurance of continued, small losses pre-death of a loved one with dementia. Of specific interest to here is the adult-child's grief response to changes in the parent child relationship, especially due to the parent's psychological absence. To date, investigation into dementia grief has focused on spouses and children in caregiver roles.

Indeed, parent adult-child relationships in the context of dementia are complicated by whether or not the adult-child is in a caregiver role. Filial caregivers are distinct from employed caregivers in many ways, including that the parent child relationship underlies the caregiver role. Relational issues, especially associated with the dementia sufferer's psychological absence in the parent adult-child relationship, are largely neglected in the literature (Barca et al., 2014). Research on ACPD largely explores caregiver role burden. The focus on caregiving has eclipsed inquiry into how the core parent adult-child relationship has been affected. Consequently, health care professionals fail to assess family dynamics, and adult-children do not often feel comfortable discussing relational concerns with healthcare professionals (Wells & Kartozi, 2018). Further, grief

and loss in the parent child relationship may be conflated with distress due to the caregiving role (Meichsner et al., 2017). Symptoms of caregiver stress and grief due to change in the parent child relationship must be differentiated.

Reviewing the literature, I found only two research studies that explore grief in non-caregiving ACPD, neither of which were conducted in the USA. Kjällman-Alm et al. (2013) conducted qualitative study to understand the meaning of being an adult-child of a parent with dementia. Researchers conducted interviews with 9 participants aged 35-65, recruited from a municipal center dementia care support group in Sweden. Participants were asked about their experiences before and after the parent was diagnosed with dementia. The researchers hypothesized that personality changes would pose the greatest challenge to adult-children as it is important for adult-children's development to see their parents as role models. Using a phenomenological hermeneutical approach, researchers concluded that being an adult-child of a parent with dementia meant: 1) frustration, with subthemes of powerlessness, anger, and bitterness at the parent and how they were changing and doing 'crazy things', desire to disconnect when things got 'crazy', striving for control, and feeling resigned; 2) loss, with subthemes of feeling abandoned, missing connection, sorrow and loneliness; and 3) being burdened, with subthemes of feeling worn out, being worried, wishing well, being the parent, and having a bad conscience. Further, the researchers suggested that being an adult-child of a parent with dementia meant being threatened by the possibility of inheriting the disease and by enduring a psychic crisis, in which shifts in reality jeopardize identity and sense of safety. The researchers state that ACPD require support as they adapt to losing a parent who is still alive, and psychoeducation regarding dementia and their parent's behavior and needs.

In the second study, Barca et al. (2014) interviewed 14 Norwegian participants aged 20-37 about their experiences with a parent suffering from young onset dementia (diagnosed <65 years old). The researchers found that participants felt grief due to the child parent role reversal, felt neglected by parents, family, and health services, and that they longed to be seen as individuals

and have their feelings, personal needs, and experiences acknowledged during their parents' dementia. Barca and colleagues recommended that children of parents with dementia receive person-centered care and family oriented support.

Both of these studies in non caregiver ACPD overlap in findings of the adult-child's sense of abandonment, parental neglect of their inner world, and profound loss of connection in the relationship. These aspects of relating require psychological and emotional availability. Unfortunately, psychological absence is par for the course when one has dementia. A parent's ability to provide psychological support and reciprocation in the parent child relationship is attenuated due to progressive neurological deterioration specific to dementia. While there are many changes to explore in the parent adult-child relationship in the context of dementia, the effect of the parent's psychological absence on the relationship and the adult-child's identity and sense of self is the focus of the proposed work.

GRIEF IN AMBIGUOUS LOSS

The psychological absence of a loved one despite their physical presence is commonly referred to as an "ambiguous loss," coined by Dr. Pauline Boss. Ambiguous loss describes a situation in which closure is impossible and ambiguities within a family system ensue (Boss, 2007, 2010; Boss & Couden, 2002; Boss & Kaplan, 2003; Boss & Yeats, 2014). Two situations of ambiguous loss exist (Boss, 2007). In one situation, someone is physically absent but mentally remains in the family, for example during deployment or kidnap. In the second situation, a person is psychologically and emotionally unavailable, yet physically present. The latter occurs in dementia. In ambiguous loss, the parent with dementia is neither all here, nor all gone; their status is "ambiguous," stymying closure.

Grief is markedly high in dementia grief (Blandin & Pepin, 2017; Doka, 2010) as ACPD perpetually grieve the "parent lost" (Furlini, 2001). This continued sense of loss is due, in part, to the incongruity between the psychological absence of the person with dementia and their physical presence. An adult-child's perception of the parent may oscillate between "here" and "gone,"

which effectively creates waves of grief. Lack of clarity on a parent's psychological presence additionally creates "boundary ambiguity," in which loved ones cannot decide if the dementia sufferer is "in" or "out" of the family (Boss et al. 1988). Boss posits that boundary ambiguity, and the resultant ambivalence within relationships, is more distressing than the dementia itself; it is perhaps the greatest stressor for loved ones (Furlini, 2001). Scholars have even indicated that ambiguous loss and grief pose a greater barrier to caretaking than hands-on care issues (Frank, 2008; Shuter et al, 2014).

The ambiguous loss model provides a strengths-based therapeutic framework to aid in increasing coping and resilience in 6 areas: restructuring identity, finding meaning, gaining mastery, increasing capacity for ambivalence, reframing attachments, and gaining hope (Boss, 2006). However, empirical research that utilizes this framework in family members of dementia sufferers is scant. Further, there is limited research on the qualitative experiences that occur in each of these defined areas.

Of particular interest is the lack of empirical research on ambiguous loss when a loved one has dementia outside the context of caregiving. Studies focus on providing dementia care (Peirce, 2008; Globerman, 1994). An interplay between caregiver behavior, care recipient behavior, and caregiver distress has been established by Boss and colleagues (1999), while there remains a gap in the literature about the relationship between parents with dementia and non-caregiving children. Still, as many adult- children are not caregivers, many are, depending on the definition of caregiver.

The term caregiving is broad and unstandardized, ranging to include individuals who provide assistance once per week, to those who provide complete care (Cuijpers, 2005; Harvey & Burns, 2003). Curiously, caregiver definitions are often not even included in the methods research sections. Definitions are reported within this document where available. As the term caregiver is so broad, there are some instances where caregiver research offers insight into the parent adult-child relationship without getting overshadowed by exploration into the burden of providing care.

The work of Dupuis (2002) offers an example of research with an unclear caregiver definition that provides valuable insight into the parent adult-child relationship in the context of dementia. With the goal of understanding ambiguous loss in the context of dementia care, Dupuis interviewed filial dementia caregivers. Caregiver criterion was that the adult-children had to be listed as the primary emergency contact for parents living in long term care facilities. Participants were deemed to have “institution-based caregiving careers” despite lack of criteria for time or activity commitment.

Dupuis (2002) provided findings of emotional turmoil in ambiguous loss in 61 filial caregivers. Participants reported experiencing phases of grief in which ambiguities changed, instead of a stable loss. The first phase was described as anticipatory loss, characterized by dreaded future uncertainty. Progressive loss followed, corresponding with the parent’s cognitive and motor decline. In this phase, adult-children reported a sense of helplessness as the disease progressed and they noted loss of psychological “thereness” from their parents. Finally, acknowledged loss marked the adult-children’s acceptance of the certainty of their parent as “gone,” even while physically present. Acknowledged loss can come with family crisis, psychosocial death, in which the dementia patient’s personal essence vanishes despite their physical body remaining, and acknowledgement that the parent is not who they used to be (Dupuis, 2002). In sum, ACPD are continually mourning ambiguous losses, which shift in different phases of grief marked by their parent’s disease.

GRIEF AND MENTAL ILLNESS IN FAMILY DEMENTIA CAREGIVERS

The vast grief and loss faced by ACPD put them at considerable risk for mental illness. Clinical levels of grief, depression, and anxiety have been cited in dementia carers up until, and sometimes extending into, post-death bereavement (Blandin & Pepin, 2017; Cuijpers, 2005; Pinquart & Sörensen, 2003a; Shuter et al., 2014). Although estimates of grief diagnoses and clinical depression specific to children of parents with dementia could not be found, related estimates for dementia family caregivers will be reported. In dementia family caregiving, a strong

link has been made between pre death grief and post death complicated grief (Blandin & Pepin, 2017). It is estimated that significant levels of grief and loss in dementia family caregivers pre-mortem is between 47% and 71%, and, postmortem, approximately 20% of family caregivers have persistent complicated grief, also referred to as prolonged grief disorder (Chan et al., 2013). These estimates for pathological grief are likely underestimated, as grief may be misconstrued as depression or symptoms of caregiver burden (MacCourt et al., 2017).

Therefore, grief may be comorbid or mislabeled as different pathology. Depression and anxiety are also more prevalent in family caregivers than in general populations. In recent systematic reviews, researchers found that the pooled prevalence of anxiety and depression in dementia family caregivers is 31% (Kishita et al., 2020). Further, anxiety is significantly higher in dementia family caregivers than in family caregivers of loved ones with other terminal illness (Kishita et al., 2020). A less recent meta analysis concluded that the risk for depressive disorder while caregiving was approximately 3-40% (Cuijpers, 2005). And, one year post-mortem, approximately 30% of dementia family caregivers are at risk for clinical levels of depression (Schulz et al., 2006).

As the consistent predictors of poor mental health in family caregivers are variables that also occur in family non caregivers, psychological distress rates in family non caregivers may be similar. For example, depressive mood in caregivers is significantly linked to the dementia sufferer's behavior problems (Pinquart & Sörensen, 2003b). Additionally, the perceived ambiguity of the dementia patient's psychological presence is associated with more distress for a family caregiver than their caregiving involvement (Boss et al., 1990). There are mixed findings on whether or not caregiving hours are associated with caregiver mental health problems as another study found that hours spent caregiving predicted depression but not anxiety (Kishita et al., 2020). This study also concluded that mental health problems in family caregivers were most significantly predicted by psychological inflexibility of the caregiver (Kishita et al., 2020). Regardless, a care recipient's behavior problems, uncertainty of the dementia sufferer's psychological presence, and

psychological inflexibility are all likely to be experienced by both family caregivers and non caregivers, and could thus lead to psychological problems in both populations.

Overall, the prevalence and risk of poor mental health outcomes for ACPD is alarming. More data to inform effective therapeutic interventions is needed (Collins & Kishita, 2019). As continual pre death grieving underlies the experience of loved ones with dementia (Blandin & Pepin, 2017), and grief is often mistaken for depression and caregiver burden (MacCourt et al., 2017), it is important to create knowledge that informs effective grief interventions.

Although depression and grief can be highly entangled, differentiation is important because they require different clinical conceptualization and treatment. Depression is a mood disorder and treatment depends on clinical conceptualization. Grief symptoms may overlap with depressive symptoms, such as emotional pain, but conceptualization of grief centers around loss. “Treating” grief often entails making space to mourn loss, and providing interventions to understand and process one’s experience. However, existing grief interventions related to grieving parents with dementia are insufficient.

RELATED GRIEF INTERVENTIONS

Post Death Grief Interventions

There do not appear to be post death grief interventions for ambiguous loss. I presume that this is because once the dementia patient is gone, the loss is no longer ambiguous. However, dementia carers often spend years in a state of emotional turmoil and perpetual grieving (Dupuis, 2002; Blandin & Pepin, 2017). Therefore, post mortem grief interventions for this population must take this into account. Additionally, general post death grief interventions do not show promise for coping with the loss of a loved one with dementia. A recent meta analysis found that grief interventions for bereaved adults are moderately statistically effective in reducing grief in bereaved adults, had pooled effect sizes too small to be considered clinically relevant (Johannsen et al., 2019).

Pre Death Grief Interventions

Therapeutic interventions that specifically target pre-death grief in family caregivers are few (Meichsner et al., 2019). Even though the ambiguous loss model provides a strengths-based therapeutic framework to aid in increasing coping and resilience, no dementia caregiver intervention research that utilized this framework was found. The single ambiguous loss intervention study that I did find, concentrated on grief coping mechanisms in a psychoeducation group (Sanders & Sharp, 2004). Instead of using the ambiguous loss conceptual therapeutic framework, these researchers proposed a novel framework that allowed participants to confront and cope with their grief responses, and did not succeed in attenuating reports of pre-death grief. Another intervention that included grief counseling, emotional support, psychoeducation, skill building, and connections to community resources showed a moderate effect in reducing pre-death grief for dementia caregiver spouses (Ott et al., 2010), but when adapted for other family caregivers, the effects on pre-death grief waned at followup (Paun et al., 2015).

These grief interventions show promise. They aimed to correct a traditional approach to therapeutic dementia caregiver interventions, which tended to heavily focus on the practical demands and burden of caregiving. The scholars noted that, in fact, loss of intimacy, companionship, and ambiguous loss are among the greatest sources of grief in dementia caregiving relationships (Sanders & Corley, 2003; Sanders, Ott, Kelber, & Noonan, 2008).

The importance of addressing emotional injuries was corroborated in a recent therapeutic grief intervention case study conducted by Meichsner and colleagues (2019), which analyzed time spent on different areas of caregiver distress during an intervention. Utilizing cognitive behavioral therapy (CBT), therapists offered individual therapy to one adult-child caregiver and one spouse caregiver, which were then analyzed to identify how therapists successfully help caregivers manage their grief. The researchers found the spouse participant's grief increased linearly throughout therapy, whereas their adult-child participant experienced the most grief when coming to terms with ambiguous loss and psychological deterioration of their parent (i.e. grief peaked then

waned). This suggests that adult-child caregivers report the most grief due to parental psychological absence. Further, spouses and children of those with dementia experience grief differently and require different therapeutic approaches.

Effective Change Mechanisms in Family Caregiver Grief Interventions

To inform effective grief interventions for ADCP, recommendations from effective therapeutic intervention research for family caregivers will be followed. Change mechanisms reported to yield significant reductions in grief and distress in family caregivers include naming and recognizing loss (Blandin & Pepin, 2017; Boss & Yeats, 2014; Johannsen et al., 2019; MacCourt et al., 2017; Meichsner et al., 2019). Often, the client may not have words to describe their experience until a clinician with conceptual understanding equips them with the ability to acknowledge, label, and process their experience. Thus, to inform effective grief interventions for ACPD, clinicians must increase understanding of specific facets of ambiguous loss to facilitate naming and acknowledgment of loss and change.

Inquiry into Specific Aspects of Ambiguous Loss to Inform Intervention

One aspect of ambiguous loss that is ripe for inquiry is perception of psychological absence. Findings reveal that the more an adult-child perceives psychological absence of the parent, the more likely they are to experience distress (Boss et al., 1990). Psychological absence of the parent is painful for the adult-child due to both the psychosocial death of the parent and the incongruity of the parent's psychological absence amidst their physical presence in ambiguous loss. As family members' chief complaints, e.g. difficulty coping with ambiguity (Boss & Kaplan, 2003), psychosocial death (Furlini, 2001), and deterioration of intimacy and connection (Sanders et al., 2008; Sanders & Corley, 2003), emanate from the psychological absence of the dementia sufferer, it is important to further investigate perceived psychological absence of parents with dementia.

Family member identity is also compromised in ambiguous loss (Boss & Kaplan, 2003; Cheung et al., 2018; Furlini, 2001; Large & Slinger, 2015; Sikes & Hall, 2017) and linked with the psychological absence of the person ambiguously lost (Boss, 2010). A delineation between interpersonal effects (e.g. on connection, intimacy) and intrapersonal effects (e.g. on identity, self-concept) may be useful. Identity formation and maintenance are tightly interwoven within the connection and intimacy of close relationships (Aron et al., 1991). Therefore, comprehensive exploration into the impact of a parent's psychological absence on adult-child grief may include examination of early parent child bonding, and adult-child identity and self-concept.

IDENTITY AND DEVELOPMENT

The link between identity and social relationships has its roots in early development, when parent psychological presence is vital for both a child's interpersonal experience (e.g. parent child bonding) and intrapersonal growth (e.g. development of early child identity & formation of the self) (Banai et al., 2005). Erik H. Erikson (1902-1994) is perhaps the most influential theorist to discuss the link between identity, development, and social systems. In his psychosocial theory of development, identity is the sense of self that is born according to an "epigenetic principle," i.e. genetically defined plan, along with one's unique psychological, cultural, and social experiences (Muus, 1996). Family relations are especially important in forming one's identity (Seligman & Shanock, 1995).

Erikson elucidated the psychosocial mechanisms of identity development. According to his theory, one's consolidated identity is achieved by the end of the transition from adolescence to adulthood (Seligman & Shanock, 1995). However, while one's sense of self (e.g. "ego") may be consistent with relative perceived continuity, Erikson posited that identity continues to update throughout the lifespan. Erikson held that we traversed stages of development at the onset of "identity crises," i.e. critical periods in development that entail psychosocial conflict. Identity crises may also be conceptualized as crucial periods in which inner (personality) and outer tensions (society/social systems) must be resolved (Seligman & Shanock, 1995).

While Erikson's theory of identity development is more firmly rooted in ego-psychology than relational theory, Erikson still stresses the weight of prior relationships in present experiences (Seligman & Shanock, 1995). For example, Erikson posits that early achievements and failures carry over into future critical periods and identity crises (Muus, 1996). In sum, Erikson's theory offers a link between identity development, family and social experiences. Ambiguous loss can be viewed as an identity crisis (Kjalman, 2013; Ormandy, 2019) in which integration of new reality must be embraced in the face of social and intrapsychic conflict to form an updated identity.

IDENTITY IN AMBIGUOUS LOSS

Identity Definition and Changes in Ambiguous Loss

According to the ambiguous loss model, identity is a core area affected when a parent has dementia. The concept of identity is complex and has been defined differently by different scholars. The developmental perspective of Heinz Kohut's self psychology posits that the self and identity evolves from early primary caretaker relationships (Layton, 1990). Kohut describes the self as the locus of personality, motivation, thoughts, feelings, and attitudes towards oneself and the world (1971, 1978). Boss (2010) refers to identity as the totality of who one is, especially the roles one plays in relation to others.

Throughout the course of dementia, a loved one's identity shifts as their roles change (Cheung et al., 2018; Large & Slinger, 2015). For instance, the adult-child of a parent with dementia may experience a role reversal, in which they undertake a parental role and experience their parent in the child role. Additionally, a parent's psychological absence may influence the adult-child's identity as a parent's mental representation of their child is crucial for a child's identity and sense of self (Bach, 2001). For illustration, ambiguous loss inspires identity assessment with questions such as "Who am I now that my mother does not recognize me as her son?" As neurodegeneration in dementia ensues, the parent with dementia may forget who their

child is entirely; thus, impacting the adult-child's sense of self. Once a parent does not know who you are, a pertinent question is: Who am I now? (Boss, 2010).

Limited Identity Conceptualization in the Ambiguous Loss Model

Identity conceptualization in ambiguous loss is mostly limited to family roles. This is because ambiguous loss was originally conceptualized as a relational disorder in the greater framework of family stress theory (Boss & Yeats, 2014). Family stress theory conceptualizes stress as an interaction between provoking stressors, family resources and meaning attached to the event by the family (Price et al., 2020). Consequently, identity in ambiguous loss has primarily been discussed in terms of interpersonal experiences, such as shifting family roles (Boss, 1992; Boss et al., 1990; Caron et al., 1999), rather than in terms of its intrapsychic effects, such as on sense of self and self-worth.

Fittingly, ambiguous loss therapeutic guidelines almost exclusively address changes in identity that are due to shifts in family roles. The model proposes identity restructuring through increasing relational strength, and flexibility in accepting new roles (Boss, 2006). It is stressed that when old identities are no longer adaptive, restructuring identity first requires a willingness to change (Boss & Yeats, 2014). Creating new meaningful social roles that espouse responsibilities that are rewarding intrinsically as well as within one's family unit are encouraged. Further, restructuring identity by defining deliberate roles with boundaries, and establishing shared values and views is thought to combat inherent ambiguity in ambiguous loss. However, because identity is much more than the roles one takes on socially, Boss' theory is insufficient.

Empirical Investigation of Identity in Ambiguous Loss

Empirical investigations on how identity is affected in ACPD experiencing ambiguous loss is scant, even in the limited view proposed by the model. I found only a doctoral dissertation that specifically investigated the effects of a parent's dementia on an adult-child's identity. Utilizing narrative theory and art therapy, Ormandy (2020) investigated the effect of ambiguous loss on

adult- children whose parents have dementia. Ormandy found that accounts of identities were nearly absent or intertwined with family member identities in participant expression, and participants whose parents had already died began to revise their identity based on who they had become after their parents' death.

IDENTITY AND SELF-CONCEPT IN PROLONGED GRIEF

Identity Symptoms in Pathological Grief Diagnostic Criteria

The importance of exploring the impact a parent's dementia has on an adult-child's identity is strengthened by the implication of self-concept in prolonged grief (PG) after a loved one's death. Both persistent complex bereavement disorder (PCBD) in the DSM 5 and prolonged grief disorder (PGD) in the International Classification of Diseases 11, also called "complicated grief" (CG) (Jordan & Litz, 2014), describe psychological disorders characterized by insupportable PG that disturbs daily functioning for an extended period beyond 6 months. PCBD and PGD are considered the same diagnostic entity (Maciejewski et al., 2016) and share much overlapping diagnostic criteria, such as a diminished sense of self/identity that causes significant distress in important areas of life functioning (Jordan & Litz, 2014). Note the subtle distinction between PGD, a grief disorder, and PG, symptoms of PGD and the level of which is assessed by the amount of items endorsed on measures of PGD.

Links Between Identity and Grief

Scholars have theorized about the relationship between identity and prolonged grief. Maccullum and Bryant (2013) draw on the self-memory model for autobiographical memory (Conway & Pleydell- Pearce, 2000). According to this model, autobiographical memories, self-goals and self-knowledge are reciprocally grounded in each other. Therefore, internal conflict arises without congruence between coherent self-identity and life experiences across time.

Applying the self-memory model to prolonged grief, memory and emotional disturbances are thought to ensue following a loved one's death to the extent that one's identity-affirming goals

were thwarted (Maccallum & Bryant, 2013). Maccullum and Bryant (2013) build on this theory in their Cognitive Attachment Model, which integrates attachments, memory, and identity. Here, identity is central to the maintenance of PG. The researchers posit that the more one's identity is fused with the deceased, i.e., "merged self-identity," the more likely one is to experience PG. However, other researchers have found that identity confusion, e.g. feeling as though a part of oneself died with the deceased, and lower self-concept fluency, i.e. language around self-concept, are linked with PG rather than merged self-identity (Bellet et al., 2020). Therefore, both merged-identity and identity confusion with the deceased exists and both have been correlated with the maintenance of PG.

Another aspect of identity, self-concept clarity has also been associated with PG. Self-concept clarity is an individual's perception of their own global, coherent, and persistent traits that define their identity and concept of who they are (Boelen et al., 2012). PG severity after death of a loved one has been correlated with diminished self-concept clarity (Boelen, 2017; Boelen et al., 2012), while reductions in grief have been found to coincide with increased self-concept clarity (Boelen et al., 2012). As identity and self-concept are involved in grief response, increased understanding of the links between ambiguous loss and adult-child's identity when a parent has dementia may inform therapies for reconstruction of identity, new self-narratives, and grief interventions.

Implications of Limited Self-Concept Fluency and Self-Concept Clarity for Research Design

This work along with Ormandy's (2020) findings inform my research methodology. Although ACPD may not be able to produce language that describes their experience, they may be able recognize it. By inviting participants to complete surveys that contain language to describe their experience and then allowing participants to access these surveys during an interview may bypass limited language regarding identity in ambiguous loss. In sum, grieving individuals generally possess limited nuanced language to describe their experience, similarly ACPD have shown limited language to describe their identity within ambiguous loss (Ormandy, 2020).

Therefore, a research design which provides related language may afford deeper inquiry into their distress.

IDENTITY IN RELATED CONTEXTS: FILIAL DEMENTIA CAREGIVING, PARENT MENTAL ILLNESS, BEING FORGOTTEN

Although we don't fully understand how ACPD identity is affected by ambiguous loss, there is some research on how identity is adversely impacted in filial dementia caregiving and related ambiguous loss contexts, including when a parent has mental illness, and when one is forgotten.

Identity in Filial Dementia Caregiving

When interviewing aging and dementia filial caregivers in Singapore, Mehta and Leng (2017) found that forgoing traditional employment to caretake impacted identity. These caregivers tended to work around the clock and reported no differentiation between leisure time at home and caregiving. Their identity in the family was blurred and provision of constant care meant forgoing attention to their own needs.

Tuomola and colleagues (2016) found that two aspects of self-concept: mastery and self-esteem were compromised in Singaporean dementia caregivers. These findings mirror that of earlier work by Skaff and Pearlin (1992) in the USA, which found that enmeshment in caregiving duties and lack of time for oneself can incite a loss of identity and sense of self, especially when social contact is limited outside the caregiving role (i.e. “role engulfment”). Self-loss, e.g. loss of a sense of who one is and loss of important parts of oneself, was also correlated with behavioral problems of the dementia sufferer, resulting in the caregiver’s constant supervision. Furthermore, these researchers provided further evidence for the discriminant validity of self-loss, counter to previous views that self-loss and self-gain are two poles on one spectrum. Self-gain can occur due to meaning and fulfillment from a caregiving role, and is related to mastery and self-esteem, however increasing self-gain does not decrease self-loss.

These findings are particularly interesting for noting cross cultural similarity. While caregiving is typically studied in western countries, the rapid growth of aging and dementia populations in Asia has spurred dementia caregiver research (Tuomola et al., 2016). One might hypothesize that cultural familism would play a role in identity implication in filial caregiving. Familism is a value placed on collective family needs over individual needs, and is strong in Singapore (Tuomola et al., 2016). In the USA, independence, in which the needs of the individual over the collective, tends to be highly valued. Despite these differences in social structure, caregiver identity in Singapore and Western countries appear to be compromised in similar ways (Tuomola et al., 2016).

Furlini (2001) demonstrates that the loss of connection in a filial relationship takes a heavy toll on identity and self-concept. Upon interviewing three caregiving daughters of parents with Alzheimer's, Furlini (2001) found that the psychosocial death of a mother with dementia comes with crucial relational changes, which are minimally explored in the literature. Relational changes impact beliefs, meaning ascribed to the illness, and shifts in life philosophy as a result of integrating the experience of having a parent with dementia into a new world view. Recalling Kohut's definition of the self as the locus of personality, motivation, thoughts, feelings, and attitudes towards oneself and the world (1971, 1978, 1984), such relational changes shake the fabric of the self. Relational changes that occur as a function of a parent's psychological absence has stark implications on ACPD sense of self.

Identity in Children of Parents with Mental Illness

Does parental mental illness during childhood cause a similar impact regarding identity in ACPD? In both parental mental illness and parental dementia, there is an ambiguous loss in which the parent is physically present, and to some degree, psychologically absent and emotionally unavailable. Parental mental illness affects approximately one in four children, and is associated with negative long term effects (Metz & Jungbauer, 2019). Parental mental illness has been found to be more detrimental to adjustment in youth than parental physical illness, such as cancer, or

illness in any other family members (Pakenham & Cox, 2014). One could argue that since development has already occurred by the time an adult-child's parent has dementia, the impact would be different. However, important similarities may exist to be explored.

Murphey et al. (2016) examined adult-children's narratives about growing up with a parent with mental illness and found that the greatest emerging theme was a loss of self. In this study, 13 adults aged 30-78 were asked to generate narratives of childhood, teenager, early adulthood, adulthood, and parenting periods. Adult children reported loss of knowing who they were as people, lack of their own sense of reality, and uncertainty about which emotions they should be feeling.

Overall, adult-children reported feeling a lack of emotional connection with parents and others, and lost about who they were. Additionally, some participants reported deficient emotional literacy, in that they had trouble understanding and interpreting their own emotions. Similar to ACPD and individuals with PG, these participants seem to display low self-concept clarity.

Adults who grew up with parental mental illness may also experience a long term inability to engage in secure attachments, in which both parties in a dyad are consistent and responsive to the needs of the other (Duncan & Browning, 2009; Knutsson-Medin et al., 2007; Mowbray et al., 2006; O'Connell, 2008). Reupert and Maybery (2013) emphasized attachment bond disturbances, arguing that a child may seek "sensitive, responsive nurturing" cues from a parent but may actually receive inconsistent emotional responses as a result of parental mental illness (p. 363). A child's desire for consistency in the face of unpredictable, unclassifiable behavior is echoed by other scholars who have investigated children's experiences of growing up with mentally ill parents (Foster, 2010; Murphy et al., 2016). Making sense of unreliable parental care has been tied to developing an acutely sensitive pulse on the parent's behaviors at the cost of the child's ability to tune into their own internal world. The repercussions of this trade off have been noted by Donald Winnicott, when he writes that poor parental caretaking incites a child's "transfer of consciousness from the [development of their inner world] to [their physical and emotional needs]" (Winnicott,

1989, p. 5) and in John Bowlby's notion of anxious insecure attachment, when the child is preoccupied with maintaining emotional responsiveness from an inconsistent caretaker. Additionally, these findings corroborate Kohut's theory that children develop a cohesive sense of self in a healthy, empathic relationship with the mother.

In addition to effects on identity, children with mentally ill parents reported other adverse effects. In response to their stressful homelife, children report guilt, shame, sadness, fear, anger, and confusion (Metz & Jungbauer, 2019). While some children are praised socially for undertaking domestic and financial care taking activities for their parents and may experience self-esteem boosts and resiliency from social praise (Kallander et al., 2018), caring for and living with a mentally ill parent is often performed in secret, and, thus, could, instead, lead to shame and despair (Dam & Hall 2016; Murphy et al. 2016). Similarity is worth noting between children of mentally ill parents and previously mentioned findings that adult-children caregivers report self-gain but this is independent of their reported experiences of self-loss (Skaff & Pearlin, 1992).

EFFECTS OF BEING FORGOTTEN ON SELF-CONCEPT

Another context related to the ambiguous loss experienced when a parent has dementia is being forgotten, or not held in mind. If psychological availability were a spectrum between psychological presence and psychological absence, forgetting loved ones would characterize a behavior at the extreme end of psychological absence. Unfortunately, as neurodegeneration in dementia ensues, mental representations of loved ones are often a casualty.

Being forgotten by a parent with dementia may threaten one's sense of self. Kohut posits that our ability to form a cohesive self is afforded by a primary caretaker who validates our existence (Banai et al., 2005; Kohut, 1978). Self-concept is greatly impacted by one's social relationships, therefore, identity may be harmed by threats to important social relationships (Wirth & Wesselmann, 2018), such as in the case of having a parent with dementia. The impact of being forgotten by a mother with dementia has not yet been explored in scientific literature. However, the impact of being forgotten in other contexts may provide insight.

Effects of Being Forgotten in Childhood

Dr. Sheldon Bach (2001), psychoanalyst and faculty at New York University, advances the metaphor that a child's experiences are like beads, and the filament on which to string them is made available only by their continual representation in a mother's mind:

... A person's specific memories and experiences are like individual beads that can achieve continuity and gestalt form only when they are strung together to become a necklace. The string on which they are assembled is the child's continuous existence in the mind of the parent, which provides the continuity on which the beads of experiences are strung together and become the necklace of a connected life (p. 748).

Children know they are represented in the mother's mind when they are recognized, remembered, responded to, and given empathy. Bach reiterates that self-object constancy (e.g. knowing we exist outside of other people) is afforded by being maintained in a mother's memory.

Bach extends the idea by writing that our "aliveness" is validated by existing in the memory of others, beginning with our first primary caretaker. When a mother fails to hold her child in mind, the child's sense of self is challenged (Winnicott, 1952). The mother's ability to maintain a rich, unified, reliable memory of her child is necessary groundwork for the child's formation of self memory, from which to draw upon useful self-images in stressful times (Bach, 2001). Being forgotten is the ultimate unresponsiveness to one's being.

Dr. Edward Tronick's "still-face" paradigm illustrates the effects of being forgotten by mothers in infancy in a semblance of ambiguous loss. In the still-face experiments, mothers were instructed to "look depressed" or emotionless while holding the gaze of their infants, thus offering their children no emotional reciprocity, responsiveness, or physical mirroring (Tronick et al., 1978). The researchers found that the children responded to the emotional withdrawal of their mothers by entering into despair, fighting to regain her attention, and some children, eventually, reciprocated the emotional withdrawal. Even moments-long instances of insufficient emotional reciprocity and responsiveness led to a breakdown in the infant's emotional regulation. The still-

face paradigm offers a stark example of the implications for primary caretaker psychological absence. When a mother with dementia looks at her adult-child as if she doesn't know them, or does not change her expression when her adult-child talks to her, that situation closely resembles the still-face paradigm. When a parent with dementia fails to maintain the unspoken contract to mutually hold her child in mind, the adult-child may not only wonder, "where did mother go?" but also "where did *I* go?"

Effects of Being Forgotten in Adulthood

Being forgotten is associated with decreased mood, self-esteem, and life meaning in adulthood (King & Geise, 2011). In a pair of studies by two social psychology researchers, King and Geise (2011) explored the effects of being forgotten. In one study, 96 women who had completed 2 lab sessions 2 days apart, were randomly assigned to be remembered, forgotten, complimented, or to a control group on their second session. Researchers looked for group differences in state self-esteem, mood, and life meaning. Meaning in life was significantly less in the forgotten group, but not in any other groups.

Remembering others can indicate that their existence is meaningful, while being forgotten appears to imply that one is not meaningful enough to remember, which reduces one's sense that their life is meaningful (King & Geise, 2011). In the second study, 47 women who had completed an online group reading exercise class received feedback two days later that either no one remembered them, that everyone remembered them, or that no one wanted to work with them again. Results indicated that those who were forgotten endorsed significantly lower levels of life meaning than those who were remembered, although those who were forgotten did not statistically differ in life meaning than those who were told no one wanted to work with them. The researchers concluded that being forgotten even by transient acquaintances affects one's sense of mattering in the world. Interestingly, they also noted that since the effects on the global measure of life meaning were seen and not state mood or self-esteem, that one may more likely see significant impacts of being forgotten on global measures of self-esteem. However, Skaff and Pearlin (1992) point out

that global measures of self-concept (including self-esteem and mastery) may serve as resources that buffer against negative outcomes due to situational threats to self-concept.

King and Geise (2011) recommend future research that examines one's place in the mental life of another through examining real, rather than lab, experiences, which will be done in the proposed study. I was only able to find two empirical studies on the effects of being forgotten. This is a shocking gap in the literature as forgetting someone is the greatest form of psychological absence in dementia sufferers,

Although ACPD may garner responsiveness in other social ties, being forgotten by a mother with dementia may have poor repercussions on adult-children's identity and sense of self due to the crucial role a mother's responsiveness plays in development. For example, parent unresponsiveness during development is a risk factor for child pathology and insecure attachment (Duncan & Browning, 2009; Knutsson-Medin et al., 2007; Mowbray et al., 2006; O'Connell, 2008). The unresponsiveness and lack of empathic attunement imposed by dementia mimics the injury of insecure attachment and may transform even previously healthy relationships in ways that have yet to be enumerated. The effect of diminishing parent psychological absence and the subsequent receding of both memory and responsiveness on an adult-child's identity and sense of self have yet to be empirically explored in ACPD.

EARLY PARENT CHILD RELATIONSHIP QUALITY

Given the interwoven nature of the early parent child relationship quality and the development of child self-concept (Mullis et al., 2003), there is opportunity for these links to be connected to ACPD grief. There have been some starting blocks from which to build on the relationship between early parent child relationship quality (e.g. early parent child bonding is associated with distress in dementia caretaking) and grief (e.g. attachment is a cornerstone of bereavement and PG research).

Attachment

One's earliest experiences of connecting with others occurs in infancy when attachment bonds with caregivers are formed (Reite, 2012). John Bowlby's attachment theory suggests children come into the world biologically predisposed to form symbiotic, proximal bonds with attachment figures (e.g. a mother) and that these attachments are evolutionarily rooted to foster closeness and protection for the child (Cassidy & Shaver, 2016). Attachment theory advances three basic human drives: the child's desire for care and protection; child's desire to explore his environment; and the attachment figure's need to provide care and protection. These propensities work systematically. When a child perceives danger in his environment, solace from an attachment figure is pursued, and the attachment system is said to be activated. While the attachment system is activated, exploration attenuates. When the child feels secure and that their attachment figure is a reliable source of safety, the attachment system can deactivate and exploration arises once again (Cassidy & Shaver, 2016).

Healthy attachment bonds are marked by a child's security in exploring their world, and in the process, discovering and creating their identity as well as surroundings. These bonds go on to help shape identity, and self-worth, and how one relates to others in close relationships (Bowlby, 1973; Morris et al., 2018). Therefore, strong attachment relationships allow one to embrace their identity with adequate self-worth during development (Pittman et al., 2011). Research has provided evidence that childhood attachment styles carry into adulthood (Lee et al., 2018). Adult attachment has been assessed in the following work.

Attachment is Central to Models of Grief

Attachment is central to several models of grief. Both the biobehavioral attachment based model of prolonged grief (Shear & Shair, 2005) and the cognitive behavioral model of prolonged grief (Boelen et al., 2006) posit that PG is maintained when the mental representation of the loved one is not updated upon their death. The incongruity between cognition and reality causes emotional dysregulation, distress, and grief until updating inline with reality ensues. The dual

process model of bereavement (Stroebe et al., 2010) advances that coping arises from oscillating between avoidance and integration of the loss to rebuild a life without the deceased loved one. Here, attachment style accounts for one factor in aiding bereaved individuals process loss to rebuild life. The ambiguous loss framework (Boss, 2010) states that attachment bonds become ambiguous in ambiguous loss, and require revision to embrace the ambiguity of the loss and celebrate what is left of the person and mourn what is gone.

Attachment in Adult-Children of Parents with Dementia

Crispi and colleagues (1997) investigated filial dementia caregiver and parent attachment bonds with institutionalized parents to examine the relationship between attachment and caregiver burden. In a study of 108 ACPD, they investigated the relationship between state attachment: attachment style (anxious, avoidant, secure), and trait attachment: attachment preoccupation (e.g. a desire for more connection from the relationship and compulsive thoughts about the relationship), on two dimensions of caregiver burden: psychological symptomatology and caregiving difficulty. The researchers found that attachment style predicted caregiving difficulty and psychological symptomatology, while attachment preoccupation predicted psychological symptomatology, independent of caregiving difficulty (Crispi et al, 1997). Attachment style predicted both aspects of caregiver burden: caregiving difficulty and psychological symptomatology in a multiple regression analysis. Secure attachment style was associated with less caregiver burden. Later findings corroborate these claims that caregivers with secure attachment suffer less caregiver burden than do those with insecure attachment (Magai & Cohen, 1998).

Chen and Bailey (2016) conducted a study that introduced a novel way to use attachment theory when interpreting the meaning ascribed to relational and behavior change in filial dementia caregiving. The researchers proposed a two-part memory system underlying attachment: episodic memory, which consists of conscious memories of events and stories; and procedural memory, which consists of unconscious behavioral memories, e.g. how to ride a bike. The researchers posit

that episodic memory allows for the conscious meaning ascribed to behaviors and roles within the caregiving relationship. For example, how an adult-child caregiver interprets anger from their parent with dementia based on prior experiences. If a parent was mostly compassionate and tolerant, anger from a parent will be more easily seen as a feature of the illness. On the other hand, if a parent was aggressive and intolerant, a dementia sufferer's anger may be viewed as manipulative, conscious, and intentionally hostile. Behaviors, such as conflict within the parent adult-child relationship, was associated with unconscious procedural knowledge of a secure base script (a secure parent child attachment bond schema). Participants with more secure base script knowledge reported less conflict and preoccupation with the parent with dementia. While more caregiver involvement has typically been associated with secure attachment (Markiewicz et al., 1997), secure base script knowledge may provide firmer caregiver boundaries. While patterns emerged, ACPD with adjustment difficulty due to attachment style may operate in unpredictable ways in ambiguous loss (Chen & Bailey, 2016).

Parental Bonding

A parent child bond is a reciprocal connection of love, empathy and nurturance. Parental bonding has been used to conceptualize the genesis of one's personality, quality of relationships formed throughout a lifespan. Generally, more favorable parent-child bonds yield better later life outcomes (e.g. mental health) (Manassis et al., 1999).

Daire (2002) investigated the relationship between early parent child bonding and distress in caregiving sons. Findings revealed that sons who received more care, such as empathy and closeness, reported significantly less emotional distress during caretaking than those who reported less care from their demented parent during ages 0-16. Since grief was not assessed, it is possible that grief was masked as caregiver distress as MacCourt (2017) points out.

Deficiencies in Attachment and Early Bonding Research in ACPD

Attachment is a complex system, and its effects, studied quantitatively in terms of styles, offer only part of a picture. Insecure attachment styles are consistently associated with poor outcomes (Ein- Dor et al., 2010), as is poor early parental bonding. In therapeutic grief work, insecure attachment styles and weak bonds must be identified by operationalizing the attachment relationship and analyzing its constituent parts (e.g. consistency, care provision, responsiveness, safety) to enable processing of disenfranchised grief.

Current Proposal Given Research Deficiencies

Taken together, there is reason to explore the links between parent child relational changes due to perceived psychological absence, identity, and early parent-child bonding in ACPD. Because identity is significantly formed in one's early relationship with a primary caretaker, early child-mother relationships may best illustrate the relationship between identity and ambiguous loss experienced by ACPD. Further, due to findings that low self-concept clarity and fluency is common in grief, utilizing a framework that appears to unify the experiences of ACPD will be used to guide the research.

SELF PSYCHOLOGY: A FRAMEWORK FOR SELF-COHESION, IDENTITY, AND PARENT CHILD RELATIONSHIP QUALITY

The theoretical school of self psychology introduced by Heinz Kohut, MD (1913-1981) was the first major psychoanalytic movement in the USA to recognize the critical role of empathy for human development and therapeutic change. Core to the theory is the self: a mental system that organizes and processes subjective experience in relation to developmental [selfobject] needs (Banai et al., 2005). Selfobject needs are involved in sustaining the self and are usually met by others (Kohut, 1971). A detailed overview of the primary selfobject needs appear in a later section.

The Self and Self-Cohesion in Self Psychology

For Kohut (1971, 1978, 1984), the self is the locus of personality, motivation, thoughts, feelings, and attitudes towards oneself and the world. Kohut believed we are tasked with gaining self-cohesion in healthy narcissistic development. During this time, parents meet their child's required "selfobject functions," which describe roles that are necessary to form and sustain one's sense of self and self-cohesion. In healthy narcissistic development, these roles are performed by others, and are to be, eventually, internalized by the child, aiding the formation of a cohesive self-structure. A cohesive self-structure enables identity, values, meaning, self-actualization, and healthy self-esteem (Banai et al., 2005). Strong self-structure also enables the child to withstand hardship and distress. When "empathic failure" outweighs empathic attunement and selfobject needs are not met, children lack the ability to self-regulate, maintain healthy interpersonal relations, and ultimately feel a sense of self-fragmentation (Kohut, 1978; Arble & Barnet, 2015).

Selfobject Needs

Kohut (1978, 1984) theorized that caregivers promote a child's self-development by providing three core selfobject needs: mirroring, idealizing, and twinship. These selfobject needs address Kohut's tripartite model of the self: the pole of ambitions, the pole of ideals, and the intermediate area of talents and skills, respectively (Kohut, 1984, p. 192-193). Kohut (1984) described selfobject needs that promote development along these three poles of the self:

(a) *Mirroring* - need to be recognized as grandiose, powerful, adored; existence and accomplishments need to be validated and admired in the mother's eyes; pride must be mirrored in the parent's eyes. With sufficient mirroring, the child introjects self-acceptance, self-worth, vigor, and furnishes self-efficacy to meet ambitious and goals in adult life. This is associated with adult commitment to meaningful work and accomplishments (Kohut, 1978).

(b) *Idealizing* - need for someone more powerful who is idealized, makes the child feel safe, and proves the child's power by their connection. Role model's self-state is drawn on for

calmness, inspiration, and soothing. This leads to adult ability to create and live by goals, values, and principles.

(c) *Twinship* - need for sharing important characteristics with primary others, embracing personal similarity in intimate relationships. This manifests itself in developing a sense of belonging and ability to develop validating, accepting relationships.

In theory, early empathic attunement—demonstrating understanding of the thoughts, feelings, and motives of another from their unique perspective— allows a parent to meet these needs, so that the child may form a cohesive-self, thwarting psychopathology (Barker & Barker, 1987).

Empathic Attunement as a Necessity for Self-Cohesion

According to Kohut, a parent's provision empathic attunement lay at the core of a child's healthy psychological development and formation of a cohesive-self (Baker & Baker, 1987). Kohut's model is a fitting framework to investigate the parent child relationship, impact of psychological absence (e.g. lack of empathic attunement) on the adult-child's self-concept, and unmet emotional and identity-affirming needs within the relationship.

Kohut stressed that when parents provide empathic attunement, their children are more capable of withstanding hardship (Arble & Barnett, 2017). Conversely, more instances of failed empathic attunement and neglect to fulfill selfobject needs for a child during development, put the child at risk for inability to cope with distressing times, and "fragmentation" (Kohut, 1977). In a state of fragmentation, individuals may report "falling apart" in times of distress (Arble & Barnett, 2017). This is particularly relevant, because a parent's capacity to offer empathic attunement diminishes due to dementia. This informs two research questions of the current study: how do ACPD experience diminished empathic attunement, and what effect does it have on their self-concept?

Empathic Attunement and Selfobject Needs in Adulthood for Cohesive-Self Maintenance

Some scholars argue that identity is constantly updated and renegotiated (Karen Tracy & Jessica Robles, 2013; Muus, 1996), suggesting that empathic attunement and provision of selfobject function in adult life continues to be important for self-cohesion. According to self psychology, the child's social network expands with age and the mother becomes less of a primary source of empathic attunement and selfobject needs (Barker & Barker, 1987). Thus, adults will be less externally hungry for selfobject needs, and more capable of drawing on introjected resources for strength in times of distress, but this ability may depend on the early parent child relationship.

The proposed research rests the notion that a powerful mechanism of change in therapeutic interventions is the client's ability to name their experience, as increased cognitive awareness eases clients into coping and mobilizes the grieving process (Boss & Couden, 2002). I will use a self psychology framework to inform semi-structured interview questions, which has not yet been used with this population in the literature.

Research Questions

The following research questions refer to relationships with mothers with dementia.

Qualitative research questions

Research Question 1: What relationship changes do adult-children of parents with dementia experience?

b) Which relationship changes are the most distressing and why?

Research Question 2: Do adult-children of parents with dementia experience psychological absence; if so, what is their experience of it?

Research Question 3: Is an adult-child's self-concept and identity changed by a parent's perceived psychological absence; if so, how?

Research Question 4: Do adult-children of parents with dementia experience diminished empathic attunement; if so, what is their experience of it?

Research Question 5: Is an adult-child's self-concept and identity changed by a parent's diminished empathic attunement; if so, how?

Research Question 6: What is the greatest source of grief for an adult-child of a parent with dementia?

Quantitative research questions

Research Question 7: Is early parent child relationship quality related to 1) grief severity, 2) self-worth, 3) identity function, 4) desire for certain selfobject needs fulfilled by their mother?

Method

Definition of Mixed Methods Research

Mixed Methods research design involves collecting both qualitative and quantitative data. Creswell et al. (2003) offer the following definition “the collection or analysis of both quantitative and qualitative data in a single study in which the data are collected concurrently or sequentially, are given a priority, and involve the integration of the data at one or more stages in the process of research” (p. 213). This methodology rests on the assumption that integrating both types of data will provide a better understanding of research questions than one data type alone (Creswell & Plano Clark, 2007).

Type of Design used and its Definition

To address these research questions, the proposed study utilizes a concurrent embedded design (also known as concurrent nested design). In this design, one data set provides a supportive, secondary role in a study based primarily on the other data type (Creswell et al., 2003). Embedded designs are utilized when one data set is not sufficient by itself and different questions require different types of data (Hanson et al., 2005). This design is also useful when there is limited time to address all research questions within an overarching qualitative study. Data types can be embedded at the design level and collected concurrently, then merged during analysis (Creswell & Plano Clark, 2007).

In this proposed study, I will use a concurrent embedded design, which nests a supportive quantitative component within a largely qualitative design, represented by notation QUAL(quant). Concurrent data collection will occur such that quantitative surveys are nested within a primary qualitative study. See Figure 3 for typology. Therefore, qualitative and quantitative methods will be mixed at the design level and connected at the level of interpretation. See Figure 4.

Rationale for Design

Overall, this approach was chosen for the ability to embed supporting quantitative measures within a larger qualitative study. One advantage of this design is that the less prioritized data type may be included to help answer different questions or sets of questions (Hanson et al., 2005). Interviews are time consuming; collecting measures for identity function, selfobject needs, and grief allows for all research questions to be addressed within one research visit. Since this population may have limited vocabulary for their experiences (Ormandy, 2019), exposure to quantitative surveys that label experiences they may experience may allow them to recognize their experiences that they could not spontaneously articulate. Therefore, the use of quantitative measures is strategic. Additionally, concurrent embedded nested designs have been used by other researchers in counseling psychology, such as Aspenson et al. (1993), Guernina (1998), and Blustein et al. (1997).

Addressing Challenges in Using this Design

Challenges exist in using an embedded design. Creswell and Plano Clark (2007) warn that it can be difficult to merge results from two methodologies, which are used to answer different research questions. They recommend keeping two sets of separate results. Such is the plan here.

Other challenges arise in data collection. The same participants for both qualitative and quantitative data collection will be selected to enable easier merging and comparison of data types. This is because the quantitative data collected will have little meaning independent of the qualitative data.

Sample size is another point of consideration. Since quantitative data requires more cases for validation and significance than qualitative data, quantitative samples are often larger than the qualitative sample. However, since embedded data will address different questions (e.g. what grief is the adult-child experiencing?) than the primary data (e.g. does being forgotten by a mother with dementia influence one's sense of self?), there is a challenge of comparing different sized data sets in a meaningful way (Creswell & Plano Clark, 2007). Sacrificing interview length in order to

conduct more interviews so there is less of a chasm between the number of quantitative and qualitative samples is one option. However, since inquiry is scant regarding this topic, in depth interviews are not to be compromised. Therefore, a suitable sample size for a qualitative study was chosen (Creswell & Plano Clark, 2007).

Another possible challenge is introducing bias through data collection. When collected concurrently, one form of data could influence the other. While scholars stress that this is particularly important in intervention studies, there is a fine line between introducing bias in this study and introducing concepts to aid participant ability to recognize and label their experience using language they could not generate spontaneously. To minimize this bias, participants will be told that there are no right or wrong answers, and that some of the surveys may be helpful or unhelpful for describing their unique experience.

A final issue to consider is the occurrence of contradictory results. If and when this is the case, I will present findings and explicitly state that more research is necessary to understand conflicting results (Creswell & Plano Clark, 2007). In sum, challenges have been identified and addressed where possible.

PARTICIPANTS

Participants will be 12 adult-children of mothers with dementia. Mothers are chosen to best illustrate the relationship between constructs of interest according to self psychology. Eligible participants will meet the following criteria: 1) over the age of 18, 2) their mother had to be their primary caretaker during infancy through age 16, 3) must not consider themselves the primary caretaker for their mother, as caretaker stress may burden individuals beyond the scope of this project, 4) experienced at least one encounter in which their mother did not recognize them, 5) mother must be alive or no more than 1 year post mortem prior to interview, and 6) while participants' mothers are not required to have a formal dementia diagnosis, severity of dementia will be determined during screening. Participants will be asked to provide responses to the Quick Dementia Rating System

(QDRS) (Galvin, 2015). Eligible participants will report a QDRS total of 6 or more and a QDRS cognitive score of at least 3.5 for their mother. These numbers provide cut offs for at least mild dementia. Participants will have the option to complete screening questions on Qualtrics or a phone call. See screening and background information questions in Appendix A.

RECRUITMENT

Due to the global Covid-19 pandemic, much recruitment effort will be put into online recruitment through convenience sampling. I will post announcements in social media communities related to dementia, aging, and caregiving, for example, on Facebook and Alzheimer's Association web message boards. Community centers, assisted living centers, and memory care centers in major cities in the USA will be contacted by phone and asked if they are able to send digital recruitment fliers to possible participants and/or their listserv (see Appendix B for flier). Fliers list a Google Voice phone number and email address for contact. Finally, I will also use the "snowball" method of recruitment, asking participants if they would ask their friends or acquaintances who meet the inclusion criteria to contact us for a phone screen. When a prospective participant inquires about the study, I will explain the study to them and ask if they have questions. If they meet inclusion criteria and are interested, an appointment will be scheduled.

Rationale for Recruitment Method

Convenience sampling was chosen because it is the fastest, most inexpensive way to recruit. Traditionally, convenience sampling may threaten generalizability, but given a small sample size and qualitative-weighted study, generalizability is not the aim. I have offered group therapy in assisted living centers and conducted research at memory care clinics, and individuals have already expressed interest, making recruitment goals seem more feasible with this approach than with impersonal recruitment methods.

STUDY PROCEDURES

The study will consist of one wave of data collection. Due to the global Covid-19 pandemic, all sessions will be conducted online via Zoom video conferencing software. During the research visit, I will explain the study goals, procedures and informed consent form.

Quantitative Data Collection

After signing the consent form, participants will be sent self-report questionnaires to complete via Qualtrics. Participants will be given the option to complete the measures solo or by having them read by me and answering orally. Participants will be given instructions that there are no right or wrong answers, and to pick the answer that describes their unique authentic experience. Following survey completion, participants will be given a 10-20 minute break.

Qualitative Data Collection

Participants will be invited to engage in a 60-120 minute audio and/or video-recorded interview about their relationship with their mother. Participants will be given the option to access the previous measures to reflect on their experience during the interview. In addition, participants will be given two handouts to aid them: a chart of psycho-emotional availability behaviors, and a list of feelings and sensations to reference to enhance their emotional vocabulary if they report that they cannot describe their experience or express difficulty naming emotions (see Appendix C).

In effort to minimize any bias introduced by participants first completing the quantitative measures, participants will be encouraged to only report what reflects their authentic experience. Participants will be told that there are no right or wrong answers, and if any of the language on the surveys was useful to help them to describe their experiences, they will be able to access and reflect on the measures during the interview. Because the interview may be emotionally dysregulating for participants, the interview will conclude with questions designed to facilitate reflections of hope and gratitude for their parent. I will be available to answer any questions or read items to participants who need assistance. Following the interview, participants will be thanked and asked

if they can be contacted in the future to identify whether or not findings are an accurate portrayal of their experience.

MEASURES

Demographics Questionnaire

A demographics questionnaire will assess participants' age, gender, race/ethnicity, education, marital status, type of parent dementia, approximate time since parent dementia symptom onset, number of hours spent weekly with the parent, and time past since death, if relevant.

Early Parent Child Relationship Quality

The Parental Bonding Instrument (PBI) (Parker et al., 1979) was developed to measure one's subjective recollection of being parented through 16 years of age. It is the most widely used measure for this purpose (Wilhelm et al., 2005). The PBI measures two scales: care and overprotection/control. Participants are instructed to answer each item dependent on how they remember their parents during their first 16 years of age, completed for both mothers and fathers separately (Parker et al., 1979). Each form contains 25 items: 12 "care" items ($\alpha = .93$; Arrindell et al., 1998) and 13 "control" items ($\alpha = .93$; Arrindell et al., 1998). For example, the item "Frequently smiled at me" reflects parental care for a child, while the item "Let me dress in any way I pleased" reflects control. This measure was chosen for its wide use to assess adolescent parent bonding and favorable psychometric properties.

Self-concept and Identity Measure

The Self-Concept and Identity Measure (SCIM) is a self-report measure designed to assess identity consolidation and disturbance (Kaufman et al., 2015). The SCIM consists of 27 items to measure both healthy and pathological identity functioning in the following core areas: self-concept and role continuity across environments and among different persons, b) consistencies in

values and interests, c) self-worth, d) self/other-differentiation, and e) cohesion (i.e., feeling whole or complete). Participants are asked to indicate how much they agree or disagree with responses ranging from 1=strongly disagree to 7=strongly agree. Higher scores are associated with higher identity disturbance. Three subscale scores are given for 1) Distributed Identity– discontinuity in a person’s values, opinions and beliefs, and overdependence on others for defining one’s identity, e.g. “I am only complete when I am with other people.” 2) Consolidated Identity– sense of knowing who one is, identity commitment, consistency in beliefs and values, and positive self-worth, e.g. “I know what I believe or value.” And 3) Lack of Identity– feelings of emptiness, being lost, broken, and simply not knowing who one is, e.g., “I feel like a puzzle and the pieces don’t fit together.” Internal consistency of the SCIM is excellent (Cronbach’s $\alpha = 0.88$; Kaufman et al., 2015). The three subscales additionally showed strong internal consistency: Disturbed identity; Cronbach’s $\alpha=0.86$, Consolidated Identity;

$\alpha=0.76$, and Lack of Identity $\alpha=0.87$, respectively). Despite the use of the SCIM for its use in assessing identity functioning in personality disorders, this measure was chosen because it is the first identity functioning measure to assess both healthy and pathological identity functioning in non-treatment seeking samples. Additionally, the Lack of Identity subscale is of particular interest, as this construct is scant in empirical literature yet central to Kohut’s theory of self-cohesion.

Arble Estimate of Selfobject Pursuits

The Arble Estimate of Selfobject Pursuits (AESOP) was developed to assess primary selfobject needs identified by Kohut (Arble & Barnett, 2017). The AESOP is a 31-item self-report measure with statements rated on a 7-point scale ranging from 1=not at all true of me to 7=very true of me. With permission from Arble, first author of the instrument, I have adapted the measure to address selfobject needs that are desired from the mother with dementia, instead of assessing general selfobject needs. The measure has displayed good internal consistency on all three scales reported from Arble and Barnett (2017): Idealizing, e.g. “I feel better when I’m in the presence of

wise people” (Cronbach’s $\alpha = .93$). Adapted to: “One of the hardest things about my mother’s dementia is that I can no longer count on her to be my hero;” Mirroring, e.g. “When I am doing well at something, I need people to realize that I’m doing a good job” (Cronbach’s $\alpha = .79$). Adapted to: “One of the hardest things about my mother’s dementia is that when I am doing well at something, I need my mother to realize that I’m doing a good job;” and Twinship; e.g. “I like knowing that my feelings are shared by others” (Cronbach’s $\alpha = .80$). Adapted to: “One of the hardest things about my mother’s dementia is feeling lonely during shared moments because she is not on the same wavelength as I am.” This measure was chosen because it has the best psychometric properties of the two extant measures that assess Kohut’s selfobject needs.

Self-Worth

The Rosenberg Self Esteem Inventory (SEI) (Rosenberg, 1965) is a 10-item scale measuring global self-worth by measuring both positive and negative feelings about the self (internal consistency=0.77, minimum Coefficient of Reproducibility= >0.90; Rosenberg, 1965). All items, e.g. “On the whole, I am satisfied with myself”; “All in all, I am inclined to think that I am a failure,” are answered using a 4 point scale format ranging from 1=strongly agree to 4=strongly disagree. This measure was chosen because it is the gold standard measure of trait self-worth, is a core aspect of one’s self-concept.

Grief

The Caregiver Grief Scale (CGS) was designed to measure caregiver grief (Meichsner et al., 2016). However, the questions are relevant for non caretaking loved ones of those with dementia. This measure was chosen because it is the only tool available that focuses on different aspects of grief, including avoidance of grief, without additionally measuring other constructs, such as depression. The CGS consists of 11 questions, which are answered on a 5-point Likert scale from 1=strongly disagree to 5=strongly agree. Four subscales of grief are assessed including Emotional Pain, e.g. “I feel terrific sadness”, Relational Loss, e.g. “I long for what was, and what

we had shared in the past,” Absolute Loss, e.g. “I feel that life is empty without him/her,” and Acceptance of Loss, e.g. “It is hard for me to allow myself to grieve and show my sadness.” Psychometric properties for the CGS are favorable, with high internal consistency reliabilities for 3 factors and a moderate level for one factor: Emotional Pain (Cronbach’s $\alpha = .81$), Relational loss (Cronbach’s $\alpha = .89$), Absolute Loss (Cronbach’s $\alpha = .82$), Acceptance of Loss (Cronbach’s $\alpha = .67$), CGS total score (Cronbach’s $\alpha = .89$) (Meichsner et al., 2016).

Quantitative Data Analysis

Raw data will be prepared for analysis by collecting survey scores in Qualtrics and outputting the data into a spreadsheet. Data will be explored with visual inspection for any missing or outlier values and with descriptive statistics. To address research question 7: is early parent child relationship quality related to 1) grief severity, 2) self-worth, 3) identity function, 4) desire for selfobject needs fulfilled by their mother? Linear regressions will be run in SPSS to assess predictive ability of the PBI on the other measures (independent variable: PBI; dependent variables, tested separately: SCIM global and subscale totals, AESOP global and subscale totals, SEI total, GCS global and subscale totals). Further, Pearson correlations will be used to create a correlation matrix between survey data. Correlations and regressions will be purely exploratory, as the sample will be limited to 12 participants.

Qualitative Interview

In a semi-structured interview, participants will be asked questions in eight broad categories 1) about their relationship with their mother, 2) their experience of their mother’s psychological absence and 3) empathic attunement, 4) how their mother’s psychological absence and 5) diminished empathic attunement affects their relationship with her, 6) how their mother’s psychological absence and 7) diminished empathic attunement affects their identity and sense of self, and 8) their greatest source of interpersonal and intrapsychic grief. Interview questions can be found in Appendix B.

Qualitative Analysis

Data will first be explored by reading the interviews for a general understanding of the database (Creswell & Plano Clark, 2005). To analyze the qualitative data, I will use grounded theory procedures (Strauss & Corbin, 1998). Using grounded theory one starts with a question, and instead of letting the answer be guided by theory and constrained by a priori hypotheses, the inquiry takes its own shape to inform a theory (Wimpenny & Gass, 2000). Each interview transcript will be read reflectively and analyzed through coding themes. Throughout the coding process, memoing will be done to record evolving thoughts and ideas about emerging themes.

To begin, I will conduct open coding, in which broad categories of information and statements are grouped together (Strauss & Corbin, 1998). While open coding, it's important to be aware of tracking central phenomena that are core to the process being described by the participant. For example, in a pilot study, I had recognized a common factor of ACPD feeling unacknowledged (e.g. "When I walk into a room I am not greeted"). Additionally, I will track other emerging categories (e.g. minimal eye contact), yet the focus would be on the central phenomenon in each question, which other data will be organized around.

The next step is to conduct axial coding (Strauss & Corbin, 1998) which is a more sophisticated categorization and relating of the data to notice categories and connections. Strauss and Corbin (1998) provide an organizing scheme to systematically link categories with subcategories. In axial coding, the reader is to be aware of the process of a phenomenon, for example by awareness of answers to questions like when, why, who, where, what? For example, in a pilot study, a connection between major concepts and lesser concepts emerged, such as visits with mother (ranging from many to few), interpersonal greetings (ranging from being greeted warmly to being ignored).

Selective coding is the next phase. Here, the major categories are integrated and refined to inform a theory. Upon refining a theory, a visual model to portray the process will be created (Morrow & Smith, 1995). If fitting, hypotheses will be proposed based on the data.

Qualitative Validation

Qualitative validation will be established by member checking. In this approach, the researcher presents summaries of findings to key participants, who endorse whether or not the findings are accurate portrayals of their experiences (Creswell & Plano Clark, 2007). Findings that do not reflect participant experiences will then be modified in an iterative process of refining and member checking once more.

Mixed Method Analysis

To merge both data types, the process described by Creswell and Plano Clark (2007) will be followed, in which qualitative and quantitative data will be analyzed separately and connected in the interpretive level of analysis (p. 140). I will furnish quotes or other information about a theme followed by statistical results that confirm or refute the qualitative results. Comparisons between both data types will be considered in a discussion. Further, to mitigate threats to data analysis validity, a matrix with quantitative categorical data and qualitative themes will be developed (Creswell & Plano Clark, 2007).

Discussion

SUMMARY

Overall, the prevalence and risk of poor mental health outcomes for ACPD is alarming. More data to inform effective therapeutic interventions is needed (Collins & Kishita, 2019). Continual grief and loss underlie the experiences of ACPD (Blandin & Pepin, 2017). Dementia grief is disenfranchised, masked and often mistaken for depression and caregiver burden (MacCourt et al., 2017). Therefore, it is of utmost importance to create knowledge that informs effective grief interventions. Exploration into change, grief, and loss in the core parent child relationship is needed. A powerful mechanism of change in therapeutic interventions is the client's ability to name their experience, as increased cognitive awareness eases clients into coping and mobilizes the grieving process (Boss & Couden, 2002). Thus, increasing understanding of ACPD experience will contribute to both theoretical knowledge and inform clinical work with ambiguous loss. Further, this work will inform parent adult-child relationships in related ambiguous loss contexts such as parents suffering mental illness and comatose.

LIMITATIONS

There are several potential limitations to this study. Assessing change based on self-report data collected at one time point introduces subjective bias. I aim to minimize erroneous retrospective reporting by providing interview questions that are very clear and offer definitions of constructs that are easy to understand, and invite the participant to be thoughtful of their experience with these constructs. Another limitation of this study may be in using a self psychology framework that places emphasis on predictive power of early parent child relationships and parenting. However, it is possible to use this framework to investigate relationship history without putting the onus of poor outcomes on insufficient parenting. This brings up a final notable limitation, which is that assessment of construct directionality will not be possible, although

hypotheses for future directionality testing may emerge. Despite these limitations, this work may still provide value for future research and clinical applications.

<u>Term</u>	<u>Definition</u>
Caregiver	Individuals who provide assistance to care recipients once per week or more (can be paid or not)
Dementia caregiver	Individuals who provide assistance to care recipients with dementia once per week or more
Dementia carer	Loved one or caregiver of a dementia sufferer
Family caregiver	Loved ones of people with dementia who provide care once per week or more
Filial caregiver	An adult-child caregiver for a parent
Informal caregiver	Unpaid caregiver (often family)
Primary caregiver	Individuals who are responsible for complete assistance for care recipients

Table 1. Caregiver terms used throughout the literature.

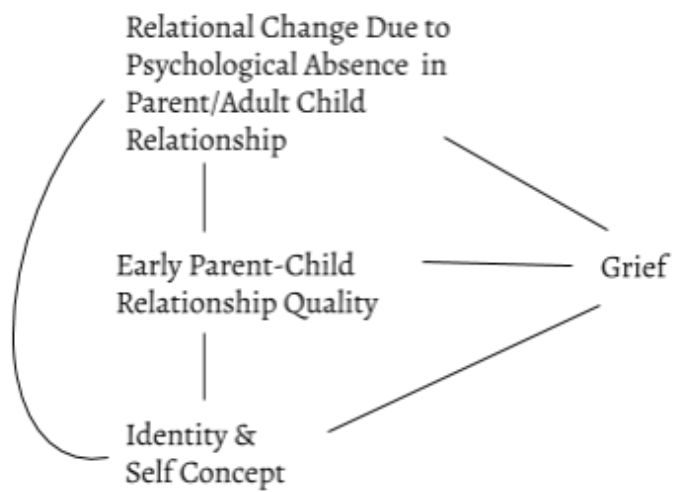


Figure 1. The current research explores the links between relational change due to psychological absence, early parent child relationship quality, identity, self concept and grief.

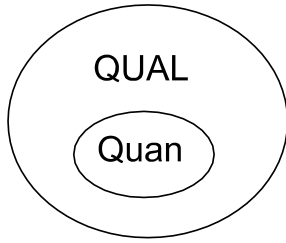


Figure 2. Typology for classifying a concurrent embedded design. QUAL= qualitative data is prioritized; quan= lower priority given.

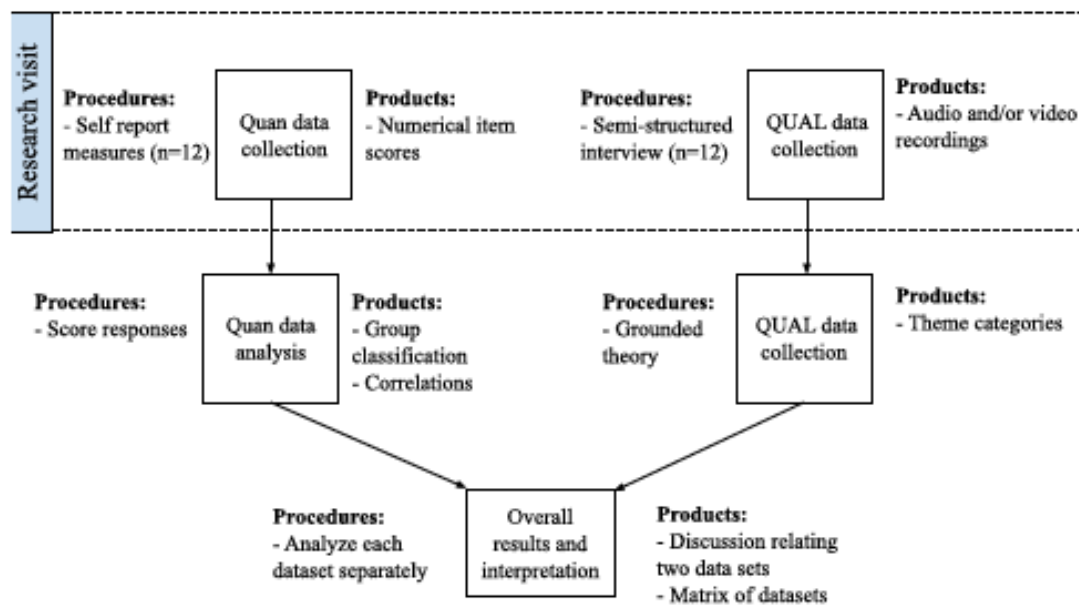


Figure 3. Visual diagram of study procedures.

Appendices

APPENDIX A - SCREENING QUESTIONS AND BACKGROUND INFORMATION

Screening Questions and Background Information

1. Are you over 18?
2. What type of dementia did/does your mother have?
3. How long ago did your mother develop symptoms? If passed, how long did she have symptoms premortem?
4. Is your mother alive or has she been post mortem within 1 year?
5. Was your mother your primary caretaker until you were at least 16 years old?
6. Do you consider yourself your mother's primary caretaker?
7. I am going to ask you to rate some aspects of your mother's dementia symptoms in terms of their severity. Is that okay with you? (Proceed to QDRS.)

The QDRS, Quick Dementia Rating System

1. Memory and recall
- 0 No obvious memory loss or inconsistent forgetfulness that does not interfere with function in everyday activities
- 0.5 Consistent mild forgetfulness or partial recollection of events that may interfere with performing everyday activities; repeats questions/statements, misplaces items, forgets appointments
- 1 Mild to moderate memory loss; more noticeable for recent events; interferes with performing everyday activities

2 Moderate to severe memory loss; only highly learned information remembered; new information rapidly forgotten

3 Severe memory loss, almost impossible to recall new information; long-term memory may be affected

2. Orientation

0 Fully oriented to person, place, and time nearly all the time

0.5 Slight difficulty in keeping track of time; may forget day or date more frequently than in the past

1 Mild to moderate difficulty in keeping track of time and sequence of events; forgets month or year; oriented to familiar places but gets confused outside familiar areas; gets lost or wanders

2 Moderate to severe difficulty, usually disoriented to time and place (familiar and unfamiliar); frequently dwells in past

3 Only oriented to their name, although may recognize family members

3. Decision making and problem-solving abilities

0 Solves everyday problems without difficulty; handles personal business and financial matters well; decision-making abilities consistent with past performance

0.5 Slight impairment or takes longer to solve problems; trouble with abstract concepts; decisions still sound

1 Moderate difficulty with handling problems and making decisions; defers many decisions to others; social judgment and behavior may be slightly impaired; loss of insight

2 Severely impaired in handling problems, making only simple personal decisions; social

judgment and behavior often impaired; lacks insight

3 Unable to make decisions or solve problems; others make nearly all decisions for patient

4. Activities outside the home

0 Independent in function at the usual level of performance in profession, shopping, community and religious activities, volunteering, or social groups

0.5 Slight impairment in these activities compared with previous performance; slight change in driving skills; still able to handle emergency situations

1 Unable to function independently but still may attend and be engaged; appears “normal” to others; notable changes in driving skills; concern about ability to handle emergency situations

2 No pretense of independent function outside the home; appears well enough to be taken to activities outside the family home but generally needs to be accompanied

3 No independent function or activities; appear too ill to be taken to activities outside the home

5. Function at home and hobby activities

0 Chores at home, hobbies and personal interests are well maintained compared with past performance

0.5 Slight impairment or less interest in these activities; trouble operating appliances (particularly new purchases)

1 Mild but definite impairment in home and hobby function; more difficult chores or tasks abandoned; more complicated hobbies and interests given up

2 Only simple chores preserved, very restricted interest in hobbies which are poorly

maintained

3 No meaningful function in household chores or with prior hobbies

6. Toileting and personal hygiene

0 Fully capable of self-care (dressing, grooming, washing, bathing, toileting)

0.5 Slight changes in abilities and attention to these activities

1 Needs prompting to complete these activities but may still complete independently

2 Requires some assistance in dressing, hygiene, keeping of personal items; occasionally

incontinent

3 Requires significant help with personal care and hygiene; frequent incontinence

7. Behavior and personality changes

0 Socially appropriate behavior in public and private; no changes in personality

0.5 Questionable or very mild changes in behavior, personality, emotional control,

appropriateness of choices

1 Mild changes in behavior or personality

2 Moderate behavior or personality changes, affects interactions with others; may be avoided by friends, neighbors, or distant relatives

3 Severe behavior or personality changes; making interactions with others often unpleasant or avoided

8. Language and communication abilities

0 No language difficulty or occasional word searching; reads and writes as in the past

0.5 Consistent mild word finding difficulties, using descriptive terms or takes longer to get

point across, mild problems with comprehension, decreased conversation; may affect reading and writing

1 Moderate word finding difficulty in speech, cannot name objects, marked reduction in work production; reduced comprehension, conversation, writing, and/or reading

2 Moderate to severe impairments in speech production or comprehension; has difficulty in communicating thoughts to others; limited ability to read or write

3 Severe deficits in language and communication; little to no understandable speech is produced

9. Mood

0 No changes in mood, interest, or motivation level

0.5 Occasional sadness, depression, anxiety, nervousness, or loss of interest/motivation

1 Daily mild issues with sadness, depression, anxiety, nervousness, or loss of interest/motivation

2 Moderate issues with sadness, depression, anxiety, nervousness, or loss of interest/motivation

3 Severe issues with sadness, depression, anxiety, nervousness, or loss of interest/motivation

10. Attention and concentration

0 Normal attention, concentration, and interaction with his or her environment and surroundings

0.5 Mild problems with attention, concentration, and interaction with environment and surroundings, may appear drowsy during day

1 Moderate problems with attention and concentration, may have staring spells or spend time with eyes closed, increased daytime sleepiness

2 Significant portion of the day is spend sleeping, not paying attention to environment, when having a conversation may say things that are illogical or not consistent with topic

3 Limited to no ability to pay attention to external environment or surroundings Cognitive subtotal (questions 1, 2, 3, 8)

Behavioral subtotal (questions 4, 5, 6, 7, 9, 10)

Total QDRS score

NOTE. The following descriptions characterize changes in the patient's cognitive and functional abilities. You are asked to compare the patient now to how they used to be—the key feature is change. Choose one answer for each category that best fits the patient—NOTE, not all descriptions need to be present to choose an answer.

Copyright 2013 The Quick Dementia Rating System James E. Galvin and New York University Langone Medical Center.



Does your mother have dementia?

**We, at the University of Texas at Austin,
are conducting research about relationships
with mothers who have dementia.
Participants must be 21+. We are interested
in YOUR experiences!**

Participants will spend 1-2 hours talking and
filling out surveys in person or over the phone.

For more information, call or text: (415)
577-3068, or email: kristiewood@utexas.edu

APPENDIX C - QUALITATIVE MATERIALS

Interview Questions

Relationship

1. How would you describe your relationship with your mother pre-dementia?
2. Can you tell me a story that exemplifies your relationship with your mother in the past?
 - b. Can you tell me about your relationship with her now?
 - c. In a couple sentences, how has your relationship changed?

Empathic Attunement/Psychological absence

3. Over the history of your relationship, how would you describe extent to which your mother has been able to understand and been in tune with you and events in your life?
4. Do you feel like she is paying attention to you and is interested in what you are saying?
5. If not, what is it like to not be in tune, or, on the same wavelength, with your mother?
6. Do you feel heard and seen?
 - a. When no -- how is that different than the past?
 - b. What is that like to not be heard and seen now?
 - c. How do you make sense of it?
7. When a parent has dementia, people report that the parent is “there, but not really there.” In other words, the person is physically there, but psychologically absent. Psychological absence can include not paying attention, not being emotionally present, lack of eye contact, and forgetting you altogether. Do you relate to this? If so, what is it like in your own words?
 - a. What is your experience of it?

- b. How has your mother's psychological absence changed your relationship with her?
 - c. How has her psychological absence changed how you feel in the relationship?
 - d. What thoughts and emotions does thinking about these changes this elicit?
8. There are different ways to view psychological absence. How do you make sense of her psychological absence?
- a. Do you ever take it personally and interpret her psychological absence in terms of what it means about you and how it affects you? If so, what thoughts and feelings are associated with taking this way of viewing it?
9. What is the hardest part about your mother's psychological absence?
- a. What do you miss the most about your mother being psychologically and emotionally more available?
10. Has your mother ever forgotten who you are, even for a second?
- a. What was that like? What thoughts and feelings went through your mind?
 - b. What does it mean or what would it mean for your mother to forget you?
11. One of the hardest parts about having a mother with dementia is the sense that the essence of who she once was is now gone. Do you relate to this?
- a. What is it like for you?

Identity and Self Worth

12. This is a big question. In a few sentences, who are you?
13. Who are you to your mother (before she started to forget)?
- a. Does she see you in a way no one else does?

b. Some people feel that losing someone who sees them in a certain way creates a loss within them, what is your experience with that?

14. Our identities are so tightly linked with how our loved ones see us. It's been said that our existence in the mind of a parent is essential for our sense of self. Do you relate to this?

a. What is your experience of this with your mother?

b. Has this changed through her illness?

c. Is a part of you lost if your mother cannot hold your existence in mind? If so, say more.

15. Some people say that the way a mother is in tune with us and has empathy for us has an effect on our self-esteem, self-worth, identity, and how we view ourselves. What is your experience with that?

a. How has your relationship with your mother shaped your self esteem or self worth?

b. How has your sense of self, identity, and self-worth changed due to your mother's psychological absence?

16. Sometimes when we are grieving someone we love, even if they are still physically here, it can cause us to feel broken, fragmented, or lost about who we are. How do you relate to this, if at all?

Grief

17. What causes you the greatest sense of grief and loss when you think about the changes that have occurred in your relationship with your mother?

18. What causes you the greatest sense of grief and loss when you think about the changes that

have occurred to your own sense of self, identity, and self-worth?

Strengths/Security

19. What strength does she give you?
20. How has your relationship with your mom equipped you to handle losing her?
21. What is your support like now? Who/what will be there to support you when she dies?

Feelings and Sensations List



Feelings List

Accepting / Open	Angry / Annoyed	Connected / Loving	Disconnected / Numb	Fragile	Stressed / Tense
Calm	Agitated	Accepting	Aloof	Helpless	Anxious
Centered	Aggravated	Affectionate	Bored	Sensitive	Burned out
Content	Bitter	Caring	Confused	Grateful	Cranky
Fulfilled	Contempt	Compassion	Distant	Appreciative	Depleted
Patient	Cynical	Empathy	Empty	Blessed	Edgy
Peaceful	Disdain	Fulfilled	Indifferent	Delighted	Exhausted
Present	Disgruntled	Present	Isolated	Fortunate	Frazzled
Relaxed	Disturbed	Safe	Lethargic	Grace	Overwhelm
Serene	Edgy	Warm	Listless	Humbled	Rattled
Trusting	Exasperated	Worthy	Removed	Lucky	Rejecting
Aliveness / Joy	Frustrated	Curious	Resistant	Moved	Restless
Amazed	Furious	Engaged	Shut Down	Thankful	Shaken
Awe	Grouchy	Exploring	Uneasy	Touched	Tight
Bliss	Hostile	Fascinated	Withdrawn	Guilt	Wearry
Delighted	Impatient	Interested	Embarrassed / Shame	Regret	Worn out
Eager	Irritated	Intrigued	Ashamed	Remorseful	Unsettled / Doubt
Ecstatic	Irate	Involved	Humiliated	Sorry	Apprehensive
Enchanted	Moody	Stimulated	Inhibited	Hopeful	Concerned
Ennergized	On edge	Despair / Sad	Mortified	Encouraged	Dissatisfied
Engaged	Outraged	Anguish	Self-conscious	Expectant	Disturbed
Enthusiastic	Pissed	Depressed	Useless	Optimistic	Grouchy
Excited	Resentful	Despondent	Weak	Trusting	Hesitant
Free	Upset	Disappointed	Worthless	Powerless	Inhibited
Happy	Vindictive	Discouraged	Fear	Impotent	Perplexed
Inspired	Courageous / Powerful	Forlorn	Afraid	Incapable	Questioning
Invigorated	Adventurous	Gloomy	Anxious	Resigned	Rejecting
Lively	Brave	Grief	Apprehensive	Trapped	Reluctant
Passionate	Capable	Heartbroken	Frightened	Victim	Shocked
Playful	Confident	Hopeless	Hesitant	Tender	Skeptical
Radiant	Daring	Lonely	Nervous	Calm	Suspicious
Refreshed	Determined	Longing	Panic	Caring	Ungrounded
Rejuvenated	Free	Melancholy	Paralyzed	Loving	Unsure
Renewed	Grounded	Sorrow	Scared	Reflective	Worried
Satisfied	Proud	Tearful	Terrified	Self-loving	
Thrilled	Strong	Unhappy	Worried	Serene	
Vibrant	Worthy	Upset		Vulnerable	
	Valiant	Weary		Warm	
		Yearning			

Body Sensations

Achy	Contracted	Gentle	Numb	Shaky	Sweaty
Airy	Dizzy	Hard	Pain	Shivery	Tender
Blocked	Drained	Heavy	Pounding	Slow	Tense
Breathless	Dull	Hollow	Prickly	Smooth	Throbbing
Bruised	Electric	Hot	Pulsing	Soft	Tight
Burning	Empty	Icy	Queasy	Sore	Tingling
Buzzy	Expanded	Itchy	Radiating	Spacey	Trembly
Clammy	Flowing	Jumpy	Relaxed	Spacious	Twitchy
Clenched	Fluid	Knotted	Releasing	Sparkly	Vibrating
Cold	Fluttery	Light	Rigid	Stiff	Warm
Constricted	Frozen	Loose	Sensitive	Still	Wobbly
Contained	Full	Nauseous	Settled	Suffocated	Wooden

©2013 Hoffman Institute Foundation Rev. 03/15

APPENDIX D - MEASURES

Demographic Information

Age _____
Sex _____
Type of parent dementia _____
Visits per week with parent _____
Visits per month with parent _____
Hours spent per week with parent _____
Hours spent per month with parent _____
Time since symptom onset (years and months) _____
Time since death, if relevant (years and months) _____

Ethnicity:

European American or White Hispanic or Latinx _____
Black or African American _____
Native American or American Indian Asian American / Pacific Islander Other _____

Education: *Specify highest degree or level of school you have completed? If currently enrolled, highest degree received.*

No schooling completed Nursery school to 8th grade Some high school, no diploma _____
High school graduate, diploma or the equivalent (for example: GED) _____
Some college credit, no degree _____
Trade/technical/vocational training Associate degree _____
Bachelor's degree _____ Master's degree _____ Professional degree _____ Doctorate degree

Occupation _____

Marital status:

Single, never married _____
Married or domestic partnership _____ Widowed _____
Divorced _____ Separated _____

Children _____ Siblings _____

Parental Bonding Instrument

MOTHER FORM

This questionnaire lists various attitudes and behaviours of parents. As you remember your MOTHER in your first 16 years would you place a tick in the most appropriate box next to each question.

	Very like	Moderately like	Moderately unlike	Very unlike
1. Spoke to me in a warm and friendly voice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Did not help me as much as I needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Let me do those things I liked doing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Seemed emotionally cold to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Appeared to understand my problems and worries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Was affectionate to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Liked me to make my own decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Did not want me to grow up	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Tried to control everything I did	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Invaded my privacy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Enjoyed talking things over with me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Frequently smiled at me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Tended to baby me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Did not seem to understand what I needed or wanted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Let me decide things for myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Made me feel I wasn't wanted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Could make me feel better when I was upset	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Did not talk with me very much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Tried to make me feel dependent on her/him	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Felt I could not look after myself unless she/he was around	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Gave me as much freedom as I wanted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Let me go out as often as I wanted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Was overprotective of me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Did not praise me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. Let me dress in any way I pleased	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

FATHER FORM

This questionnaire lists various attitudes and behaviours of parents. As you remember your FATHER in your first 16 years would you place a tick in the most appropriate box next to each question.

	Very like	Moderately like	Moderately unlike	Very unlike
1. Spoke to me in a warm and friendly voice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Did not help me as much as I needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Let me do those things I liked doing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Seemed emotionally cold to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Appeared to understand my problems and worries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Was affectionate to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Liked me to make my own decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Did not want me to grow up	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Tried to control everything I did	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Invaded my privacy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Enjoyed talking things over with me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Frequently smiled at me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Tended to baby me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Did not seem to understand what I needed or wanted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Let me decide things for myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Made me feel I wasn't wanted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Could make me feel better when I was upset	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Did not talk with me very much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Tried to make me feel dependent of her/him	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Felt I could not look after myself unless she/he was around	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Gave me as much freedom as I wanted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Let me go out as often as I wanted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Was overprotective of me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Did not praise me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. Let me dress in any way I pleased	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Self-Concept and Identity Measure

Self-Concept and Identity Measure (SCIM)
Kaufman, Cundiff, & Crowell (2015)

Please read each statement carefully. Circle the number 1 through 7 that best represents your level of agreement for each statement. If you don't know whether you agree or disagree with a statement, circle the 'I don't know' option.

	Strongly Disagree	Disagree	Somewhat Disagree	Neither Agree Nor Disagree	Somewhat Agree	Agree	Strongly Agree	I don't know
1. I know what I believe or value	1	2	3	4	5	6	7	DK
2. When someone describes me, I know if they are right or wrong	1	2	3	4	5	6	7	DK
3. When I look at my childhood pictures I feel like there is a thread connecting my past to now	1	2	3	4	5	6	7	DK
4. Sometimes I pick another person and try to be just like them, even when I'm alone	1	2	3	4	5	6	7	DK
5. I know who I am	1	2	3	4	5	6	7	DK
6. I change a lot depending on the situation	1	2	3	4	5	6	7	DK
7. I have never really known what I believe or value	1	2	3	4	5	6	7	DK
8. I feel like a puzzle and the pieces don't fit together	1	2	3	4	5	6	7	DK
9. I am good	1	2	3	4	5	6	7	DK
10. I imitate other people instead of being myself	1	2	3	4	5	6	7	DK
11. I have been interested in the same types of things for a long time	1	2	3	4	5	6	7	DK
12. I am so different with different people that I'm not sure which is the "real me"	1	2	3	4	5	6	7	DK
13. I am broken	1	2	3	4	5	6	7	DK
14. When I remember my childhood I feel connected to my younger self	1	2	3	4	5	6	7	DK

Arble Estimate of Selfobject Pursuits

Instructions: These are questions concerning your thoughts and feelings about yourself and your relationship with your mother. Please read each statement carefully and decide how much the statement is generally true of you **over and above** how much you generally miss your mother and wish for her to be healthy. Please rate each question on a scale from: 1 = "Not at all true of me"; to 7 = "Very true of me". Be sure to answer every item and try to be as honest and accurate as possible in your responses.

One of the hardest things about my mother's dementia is that...

1. When she thought like I did and could relate to my experience, it was easier to overcome difficulties or solve problems.

1 2 3 4 5 6 7

Not at all Very true true of me of me

2. I crave her admiration.

1 2 3 4 5 6 7

3. I can't have faith in her as an authority figure. 1 2 3 4 5 6 7

4. I'm devastated when she seems to criticize me or not like my contributions. 1 2 3 4 5 6 7

5. When I am doing well at something, I need her to realize that I'm doing a good job. I need/miss her validation.

1 2 3 4 5 6 7

6. I miss admiring her for who she used to be. 1 2 3 4 5 6 7

7. I feel that she cannot appreciate/see the struggles I've had to face. 1 2 3 4 5 6 7

8. I wish she knew that I need her recognition. 1 2 3 4 5 6 7

9. Without mothers who can give us courage, the world is a scary place. 1 2 3 4 5 6

10. When she doesn't recognize my accomplishments, I feel insecure. 1 2 3 4 5 6 7

11. Whenever I can, I try to spend time with people that I look up to. 1 2 3 4 5 6 7

12. I worry that people don't care about me or my life. 1 2 3 4 5 6 7

13. I feel unappreciated.

1 2 3 4 5 6 7

14. I wish my mother knew my value and understood my contributions better. 1 2 3 4 5 6 7

15. I always wanted a friend who is just like me. My mother can no longer offer this.

1 2 3 4 5 6 7

16. I like talking with people who have opinions similar to mine. Mother's dementia affecting this bothers me.

1 2 3 4 5 6 7

17. I want my friends and mother to share my beliefs. 1 2 3 4 5 6 7

18. I want to be close to people who have some special talent, skill, or wisdom about them. It bothers me that my mother has lost this. 1 2 3 4 5 6 7

19. I feel as though people in my life haven't celebrated my accomplishments. 1 2 3 4 5 6 7
20. When I'm stressed, I seek advice from people who are in the same situation. 1 2 3 4 5 6 7
21. There is at least one person in my life that I look to as a model of how I would like to be.
1 2 3 4 5 6 7
22. It's easier for me to handle stress when I know that other people are going through the same
thing. 1 2 3 4 5 6 7
23. I can no longer count on my mother to be my hero. 1 2 3 4 5 6 7
24. Life would be a lot better if my mother could still appreciate me. 1 2 3 4 5 6 7
25. It helps me to be around people going through the same things that I am going through.
1 2 3 4 5 6 7
26. I dream or fantasize about being recognized for the work that I do. 1 2 3 4 5 6 7
27. I feel my mother does not really listen to me, I crave to feel heard by her. 1 2 3 4 5 6 7
28. It hurts when the people I look up to don't live up to my expectations. 1 2 3 4 5 6 7
29. I like knowing that my feelings are shared by others. 1 2 3 4 5 6 7
30. I try to surround myself with successful people. 1 2 3 4 5 6 7
31. I sometimes dream or fantasize about meeting famous or influential people. 1 2 3 4 5 6 7

Rosenberg Self Esteem Scale

Please record the appropriate answer for each item, depending on whether you Strongly agree, agree, disagree, or strongly disagree with it.

- 1 = Strongly agree
- 2 = Agree
- 3 = Disagree
- 4 = Strongly disagree

1. On the whole, I am satisfied with myself.
2. At times I think I am no good at all.
3. I feel that I have a number of good qualities.
4. I am able to do things as well as most other people.
5. I feel I do not have much to be proud of.
6. I certainly feel useless at times.
7. I feel that I'm a person of worth.
8. I wish I could have more respect for myself.
9. All in all, I am inclined to think that I am a failure.
10. I take a positive attitude toward myself

Caregiver Grief Scale

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.

From Meichsner et al., (2016).

References

- Aron, A., Aron, E. N., Tudor, M., & Nelson, G. (1991). Close relationships as including other in the self. *Journal of Personality and Social Psychology*, 60(2), 241–253.
<https://doi.org/10.1037/0022-3514.60.2.241>
- Bach, S. (2001, October 1). *On Being Forgotten And Forgetting One's Self*. The Psychoanalytic Quarterly. <https://doi.org/10.1002/j.2167-4086.2001.tb00619.x>
- Baker, H. S., & Baker, M. N. (1987). Heinz Kohut's self psychology: An overview. *American Journal of Psychiatry*, 144(1), 1-9.
- Banai, E., Mikulincer, M., & Shaver, P. R. (2005). "Selfobject" Needs in Kohut's Self Psychology: Links With Attachment, Self-Cohesion, Affect Regulation, and Adjustment. *Psychoanalytic Psychology*, 22(2), 224–260. <https://doi.org/10.1037/0736-9735.22.2.224>
- Barca, M. L., Thorsen, K., Engedal, K., Haugen, P. K., & Johannessen, A. (2014). Nobody asked me how I felt: Experiences of adult children of persons with young-onset dementia. *International Psychogeriatrics*, 26(12), 1935–1944.
<https://doi.org/10.1017/S1041610213002639>
- Bellet, B. W., LeBlanc, N. J., Nizzi, M.-C., Carter, M. L., van der Does, F. H. S., Peters, J., Robinaugh, D. J., & McNally, R. J. (2020). Identity confusion in complicated grief: A closer look. *Journal of Abnormal Psychology*, 129(4), 397–407. <https://doi.org/10.1037/abn0000520>
- Blandin, K., & Pepin, R. (2017). Dementia Grief: A Theoretical Model of a Unique Grief Experience. *Dementia (London, England)*, 16(1), 67–78.
<https://doi.org/10.1177/1471301215581081>

- Boelen, P. A. (2017). Self-Identity After Bereavement: Reduced Self-Clarity and Loss-Centrality in Emotional Problems After the Death of a Loved One. *The Journal of Nervous and Mental Disease*, 205(5), 405–408. <https://doi.org/10.1097/NMD.0000000000000660>
- Boelen, P. A., Keijsers, L., & van den Hout, M. A. (2012). The Role of Self-Concept Clarity in Prolonged Grief Disorder. *The Journal of Nervous and Mental Disease*, 200(1), 56–62. <https://doi.org/10.1097/NMD.0b013e31823e577f>
- Boelen, P. A., Stroebe, M. S., Schut, H. A. W., & Zijerveld, A. M. (2006). Continuing Bonds and Grief: A Prospective Analysis. *Death Studies*, 30(8), 767–776. <https://doi.org/10.1080/07481180600852936>
- Boss, P. (1992). Primacy of perception in family stress theory and measurement. *Journal of Family Psychology*, 6(2), 113–119. <https://doi.org/10.1037/0893-3200.6.2.113>
- Boss, P. (2007). Ambiguous Loss Theory: Challenges for Scholars and Practitioners. *Family Relations*, 56(2), 105–110. JSTOR.
- Boss, P. (2010). The Trauma and Complicated Grief of Ambiguous Loss. *Pastoral Psychology*, 59(2), 137–145. <https://doi.org/10.1007/s11089-009-0264-0>
- Boss, P., Caron, W., Horbal, J., & Mortimer, J. (1990). Predictors of Depression in Caregivers of Dementia Patients: Boundary Ambiguity and Mastery. *Family Process*, 29(3), 245–254. <https://doi.org/10.1111/j.1545-5300.1990.00245.x>
- Boss, P., & Couden, B. A. (2002). Ambiguous loss from chronic physical illness: Clinical interventions with individuals, couples, and families. *Journal of Clinical Psychology*, 58(11), 1351–1360. <https://doi.org/10.1002/jclp.10083>

- Boss, P., & Kaplan, L. (2003). 9. *AMBIGUOUS LOSS AND AMBIVALENCE WHEN A PARENT HAS DEMENTIA* / *Emerald Insight*. Intergenerational Ambivalences: New Perspectives on Parent- Child Relations in Later Life.
[http://www.emerald.com/insight/content/doi/10.1016/S1530- 3535\(03\)04009-3/full/html](http://www.emerald.com/insight/content/doi/10.1016/S1530-3535(03)04009-3/full/html)
- Boss, P., & Yeats, J. (2014). Ambiguous loss: A complicated type of grief when loved ones disappear. *Bereavement Care*, 33, 63–69. <https://doi.org/10.1080/02682621.2014.933573>
- Bowlby, J. (1973). Attachment and Loss: Volume II: Separation, Anxiety and Anger. *The International Psycho-Analytical Library*. <https://www.pep-web.org/document.php?id=IPL.095.0001A>
- Caron, W., Boss, P., & Mortimer, J. (1999). Family Boundary Ambiguity Predicts Alzheimer's Outcomes. *Psychiatry*, 62(4), 347–356.
<https://doi.org/10.1080/00332747.1999.11024882>
- 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.
<https://doi.org/10.1002/gps.3795>
- Cheung, D. S. K., Ho, K. H. M., Cheung, T. F., Lam, S. C., & Tse, M. M. Y. (2018). Anticipatory grief of spousal and adult children caregivers of people with dementia. *BMC Palliative Care*, 17(1), 124. <https://doi.org/10.1186/s12904-018-0376-3>
- Collins, B., & Kishita, N. (2019). Prevalence of depression and burden among informal caregivers of people with dementia: A meta-analysis. *Ageing & Society*.

<https://doi.org/10.1017/S0144686X19000527>

- Conway, M. A., & Pleydell-Pearce, C. W. (2000). The construction of autobiographical memories in the self-memory system. *Psychological Review*, 107(2), 261–288.
<https://doi.org/10.1037/0033-295X.107.2.261>
- Cuijpers, P. (2005). Depressive disorders in caregivers of dementia patients: A systematic review. *Aging & Mental Health*, 9(4), 325–330.
<https://doi.org/10.1080/13607860500090078>
- Creswell, J. W., & Clark, V. L. P. (2017). *Designing and conducting mixed methods research*. Sage Publications. In print.
- Creswell, J. W., Plano Clark, V. L., Gutmann, M. L., & Hanson, W. E. (2003). Advanced mixed methods research designs. In A. Tashakkori & C. Teddlie (Eds.), *Handbook of mixed methods in social and behavioral research* (pp. 209–240). Thousand Oaks, CA: Sage
- Ein-Dor, T., Mikulincer, M., Doron, G., & Shaver, P. R. (2010). The Attachment Paradox: How Can So Many of Us (the Insecure Ones) Have No Adaptive Advantages? *Perspectives on Psychological Science*, 5(2), 123–141. <https://doi.org/10.1177/1745691610362349>
- Frank, J. B. (2008). Evidence for Grief as the Major Barrier Faced by Alzheimer Caregivers: A Qualitative Analysis. *American Journal of Alzheimer's Disease & Other Dementias*, 22(6), 516–527. <https://doi.org/10.1177/1533317507307787>
- Furlini, L. (2001). The Parent They Knew and the “New” Parent: Daughters’ Perceptions of Dementia of the Alzheimer’s Type. *Home Health Care Services Quarterly*, 20(1), 21–38. https://doi.org/10.1300/J027v20n01_02

- Gale, S. A., Acar, D., & Daffner, K. R. (2018). Dementia. *The American journal of medicine*, 131(10), 1161–1169. <https://doi.org/10.1016/j.amjmed.2018.01.022>
- Hanson, William E.; Creswell, John W.; Plano Clark, Vicki L.; Petska, Kelly S.; and Creswell, J. David, "Mixed Methods Research Designs in Counseling Psychology" (2005). Faculty Publications, Department of Psychology. 373.
<https://digitalcommons.unl.edu/psychfacpub/373>
- Harvey, K. & Burns, T. (2003). Relatives of patients with severe mental disorders: Unique traits and experiences of primary, nonprimary, and lone caregivers. *American Journal of Orthopsychiatry*, 73(3), p. 324-333.
- Johannsen, M., Damholdt, M. F., Zachariae, R., Lundorff, M., Farver-Vestergaard, I., & O'Connor, M. (2019). Psychological interventions for grief in adults: A systematic review and meta-analysis of randomized controlled trials. *Journal of Affective Disorders*, 253, 69–86. <https://doi.org/10.1016/j.jad.2019.04.065>
- Jordan, A. H., & Litz, B. T. (2014). Prolonged grief disorder: Diagnostic, assessment, and treatment considerations. *Professional Psychology: Research and Practice*, 45(3), 180–187. <https://doi.org/10.1037/a0036836>
- King, L. A., & Geise, A. C. (2011). Being Forgotten: Implications for the Experience of Meaning in Life. *The Journal of Social Psychology*, 151(6), 696–709.
<https://doi.org/10.1080/00224545.2010.522620>
- Kishita, N., Contreras, M. L., West, J., & Mioshi, E. (2020). Exploring the impact of carer stressors and psychological inflexibility on depression and anxiety in family carers of people with dementia. *Journal of Contextual Behavioral Science*, 17, 119–125.

<https://doi.org/10.1016/j.jcbs.2020.07.005>

Kohut, H. (1972). Thoughts on narcissism and narcissistic rage. *The psychoanalytic study of the child*, 27(1), 360-400.

Kohut, H. (1968). The psychoanalytic treatment of narcissistic personality disorders: Outline of a systematic approach. In P. Ornstein (Ed.), *The search for the self* (Vol. 1, pp. 477–509). New York: International Universities Press. (Original work published 1968)

Kohut, H. (1971). *The Analysis of the Self: A Systematic Approach to the Psychoanalytic Treatment of Narcissistic Personality Disorders*. University of Chicago Press.

Kohut, H. (1977). *The restoration of the self*. New York, NY: International University Press.

Kohut, H. (1978). *The Restoration of the Self*. University of Chicago Press.

Kohut, H. (1984). *How does analysis cure?* Chicago, IL: University of Chicago Press.

Large, S., & Slinger, R. (2015). Grief in caregivers of persons with Alzheimer's disease and related dementia: A qualitative synthesis. *Dementia*, 14(2), 164–183.

<https://doi.org/10.1177/1471301213494511>

Layton, L. (1990). A Deconstruction of Kohut's Concept of the Self. *Contemporary Psychoanalysis*, 26(3), 420–429. <https://doi.org/10.1080/00107530.1990.10746670>

Maccallum, F., & Bryant, R. A. (2013). A Cognitive Attachment Model of prolonged grief: Integrating attachments, memory, and identity. *Clinical Psychology Review*, 33(6), 713–727. <https://doi.org/10.1016/j.cpr.2013.05.001>

MacCourt, P., McLennan, M., Somers, S., & Krawczyk, M. (2017). Effectiveness of a Grief Intervention for Caregivers of People With Dementia. *OMEGA - Journal of Death and Dying*, 75(3), 230–247. <https://doi.org/10.1177/0030222816652802>

- Maciejewski, P. K., Maercker, A., Boelen, P. A., & Prigerson, H. G. (2016). “Prolonged grief disorder” and “persistent complex bereavement disorder”, but not “complicated grief”, are one and the same diagnostic entity: An analysis of data from the Yale Bereavement Study. *World Psychiatry*, 15(3), 266–275. <https://doi.org/10.1002/wps.20348>
- Magai, C., & Cohen, C. (1998). Attachment Style and Emotion Regulation in Dementia Patients and their Relation to Caregiver Burden. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, 53, P147-54.
<https://doi.org/10.1093/geronb/53B.3.P147>
- Meichsner, F., Köhler, S., & Wilz, G. (2019). Moving through predeath grief: Psychological support for family caregivers of people with dementia. *Dementia*, 18(7–8), 2474–2493.
<https://doi.org/10.1177/1471301217748504>
- Mullis, R. L., Brailsford, J. C., & Mullis, A. K. (2003). Relations between identity formation and family characteristics among young adults. *Journal of Family Issues*, 24(8), 966-980.
- Muuss, R. E. (1996). Chapter 3: Erik Erikson’s theory of identity development and Chapter 4: Theoretical expansion and empirical support for Erikson’s theory. In R. E. Muss, *Theories of adolescence* (pp. 42-75). New York, N.Y.: McGraw-Hill.
- Ormandy, K. (2020). *Ambiguous Loss of Dementia: Identity Exploration through Narrative Inquiry and Collage* (Doctoral dissertation, Notre Dame de Namur University).
- Ott, C. H., Kelber, S. T., & Blaylock, M. (2010). “Easing the Way” for Spouse Caregivers of Individuals with Dementia. *Research in Gerontological Nursing*.
<https://doi.org/10.3928/19404921-20100302-01>

- Parker, G., Tupling, H., & Brown, L. B. (1979). Parental bonding instrument (PBI). *British journal of medical psychology*, 52(1), 1-10.
- 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. <https://doi.org/10.1177/0193945914521040>
- Peirce, E. L. (2008). *A Qualitative Study of Non-Caregiving Adult Children's Experiences of a Parent's Alzheimer's Disease* (Doctoral dissertation, Virginia Tech).
- Pinquart, M., & Sörensen, S. (2003a). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging*, 18(2), 250– 267. <https://doi.org/10.1037/0882-7974.18.2.250>
- Pinquart, M., & Sörensen, S. (2003b). Associations of Stressors and Uplifts of Caregiving With Caregiver Burden and Depressive Mood: A Meta-Analysis. *The Journals of Gerontology: Series B*, 58(2), P112–P128. <https://doi.org/10.1093/geronb/58.2.P112>
- Price, S. J., Price, C. A., & McKenry, P. C. (2020). Families Coping With Change. *Families & Change: Coping With Stressful Events and Transitions*, 3.
- 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. https://doi.org/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, 495– 523. <https://doi.org/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.
https://doi.org/10.1300/J181v03n02_06
- Shear, K., & Shair, H. (2005). Attachment, loss, and complicated grief. *Developmental Psychobiology*, 47(3), 253–267. <https://doi.org/10.1002/dev.20091>
- Shuter, P., Beattie, E., & Edwards, H. (2014). An Exploratory Study of Grief and Health-Related Quality of Life for Caregivers of People With Dementia. *American Journal of Alzheimer's Disease & Other Dementias*, 29(4), 379–385.
<https://doi.org/10.1177/1533317513517034>
- Sikes, P., & Hall, M. (2017). 'Every time I see him he's the worst he's ever been and the best he'll ever be': Grief and sadness in children and young people who have a parent with dementia. *Mortality*, 22(4), 324–338. <https://doi.org/10.1080/13576275.2016.1274297>
- Stroebe, M., Schut, H., & Boerner, K. (2010). Continuing bonds in adaptation to bereavement: Toward theoretical integration. *Clinical Psychology Review*, 30(2), 259–268.
<https://doi.org/10.1016/j.cpr.2009.11.007>
- Tuomola, J., Soon, J., Fisher, P., & Yap, P. (2016). Lived Experience of Caregivers of Persons with Dementia and the Impact on their Sense of Self: A Qualitative Study in Singapore. *Journal of Cross-Cultural Gerontology*, 31(2), 157–172. <https://doi.org/10.1007/s10823-016-9287-z>
- Wells, M., & Kartoiz, C. (2018). Ask the Right Questions: What Do Non-Caregiving Adult Children Need From Health Care Providers? *Journal of Gerontological Nursing*, 44(5),

26–31. <https://doi.org/10.3928/00989134-20180209-01>

Winnicott, D. W. (1989). *Holding and Interpretation: Fragment of an Analysis*. Grove Press.