When Dementia Caregiving Ends: The Role of Caregivers' Emotional Connection to the Patient in Current and Former Caregivers' Health

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Abstract

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Caring for a person with dementia (PWD) can be associated with considerable declines in health and well-being during active caregiving, although less is known about how former caregivers fare after caregiving has ended (i.e., after the death of the PWD). There is striking variability in the extent to which caregivers experience declines in health, so it is important to identify factors related to their vulnerability and resilience in order to reveal potential intervention targets. Studies have linked the quality of the PWD-caregiver relationship to caregivers' health, but little is known about the specific interpersonal emotional mechanisms that contribute to long-term caregiver health. The present study addresses these gaps by evaluating caregivers' emotional connection to the PWD in two independent samples and examining associations with caregivers' depression, anxiety, and physical health—concurrently (in current caregivers) and longitudinally (in former caregivers, after caregiving has ended). In Study 1 ($N = 82$), caregivers and PWDs engaged in a conflict conversation in the laboratory, after which caregivers viewed video recordings of the conversation and provided second-by-second ratings of their own affective valence and the PWD's affective valence during the conversation using a rating dial. Caregivers' emotional connection to the PWD was operationalized by summing the number of seconds in which they reported experiencing positive or negative affect simultaneously with the PWD (i.e., co-experienced positive or negative affect). In Study 2 ($N = 335$), caregivers were asked to describe a recent time they felt connected to the PWD, and their responses were recorded verbatim. Caregivers' emotional connection to the PWD was operationalized by summing the number of positive and negative words from the transcripts using text analysis software (i.e., positive and negative emotional connection language). Results revealed that greater co-experienced negative affect between caregivers and PWDs (Study 1) and caregivers' lower positive emotional connection language (Study 2) were associated with higher levels of caregiver depression. In addition, caregivers' positive emotional connection language predicted longitudinal decreases in caregiver depression after caregiving had ended (Study 2), which was robust when accounting for relevant covariates (e.g., caregiver demographics, PWD dementia severity). These findings identify caregivers' greater negative and lower positive emotional connection to the PWD as potential risk factors for caregivers' mental health problems. Future research should explore whether interventions that enhance social connection between caregivers and PWDs are effective in reducing depression and increasing quality of life.

When Dementia Caregiving Ends:
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Dementia and other neurogenerative diseases are progressive, debilitating conditions that give rise to cognitive, emotional, and motor impairments. Over 46 million adults worldwide have been diagnosed with dementia, and this number is estimated to nearly triple by 2050 (Prince et al., 2015). With the growing incidence of these illnesses, the number of loved ones serving as caregivers is also increasing dramatically. In the United States in 2022, approximately 11 million informal caregivers (i.e., family and friends) provided 18 billion hours of unpaid care for persons with dementia and other neurodegenerative diseases (PWDs; Alzheimer's Association, 2023; Galvin et al., 2017). Beyond the substantial time and energy demands associated with caregiving, family caregivers often suffer "collateral damage" manifesting as heightened levels of physical and psychiatric morbidity. Although the act of caring for a loved one with dementia can be profoundly meaningful in the context of family life, the demands of caregiving, along with the gradual loss of an important relationship, cause many caregivers (but not all) to experience substantial declines in physical and mental health (Vitaliano et al., 2003), which may persist years after caregiving has ended (Bodnar & Kiecolt-Glaser, 1994; Corey & McCurry, 2018; Robinson-Whelen et al., 2001).

Although there are many positive aspects of dementia caregiving, such as enhanced self-efficacy and personal growth (Carbonneau et al., 2010; Yu et al., 2018), the adverse effects are well-documented. Caregivers of PWDs have an elevated risk for various physical health problems, including greater physical morbidity (Pinquart & Sörensen, 2007; Vitaliano et al., 2003); poorer self-reported health (Baumgarten et al., 1992); increased heath care utilization (Moritz et al., 1992); elevated rates of dementia (Norton et al., 2010); heightened stress-induced heart rate reactivity (Uchino et al., 1992); greater declines in cellular immune function (Kiecolt-Glaser et al., 1991); and reduced longevity (Schulz & Beach, 1999; Schulz et al., 1995). In terms of psychiatric morbidity, caregivers of PWDs evidence elevated rates of mental health problems, including up to four-fold increases in depression rates (Brodaty & Donkin, 2009; Coope et al., 1995), three-fold increases in seeking treatment for anxiety (Cooper et al., 2007; Cuijpers, 2005), and greater suicidal ideation (O'Dwyer et al., 2013), compared to non-caregiving adults of a similar age. Further, those experiencing greater psychological morbidity and caregiving strain are at an even greater risk for poor physical health and mortality (Brodaty & Hadzi-Pavlovic, 1990; Lee et al., 2003).

Given that caring for a PWD is time-limited, it is important to consider the long-term consequences of caregiving. Because of the terminal nature of these diseases, almost all caregivers will outlive the patients in their care; yet their suffering does not necessarily end when caregiving ends. Compared to research on current caregivers, there is a relative paucity of research on how former caregivers fare after the death of the PWD. Existing evidence suggests that some caregivers return to pre-caregiving health (e.g., clinically significant declines in depressive symptoms after the death of the PWD; Haley et al., 2008; Schulz, Mendelsohn, et al., 2003; Schulz et al., 1997) while others exhibit long-lasting impairment (e.g., no changes in depression 3-4 years after the death of the PWD; Bodnar & Kiecolt-Glaser, 1994; Corey & McCurry, 2018; Robinson-Whelen et al., 2001). Indeed, there are individual differences in how caregivers fare after caregiving ends (Crespo et al., 2013; Schulz et al., 2006), and caregiving experiences prior to the death of the PWD (e.g., levels of strain and social support during caregiving) play a role in shaping caregivers' adjustment to bereavement (Schulz et al., 2001; Stahl & Schulz, 2019). Whereas dementias are progressive conditions with no preventive or curative treatments, caregiver illnesses can be viewed as potentially preventable, or at least amenable to interventions that reduce their severity, duration, and associated disability (e.g., Haley et al., 2008; Levenson et al., 2023; Schulz, Burgio, et al., 2003). It is therefore important to identify factors associated with greater vulnerability to the long-term adverse effects of caregiving as well as to those that occur during active caregiving.

Methodological Considerations in Caregiver Research

Self-Report Versus Observational Measures

Research on risk and resilience factors in dementia caregiving typically utilizes self-report measures (e.g., a questionnaire assessing positive and negative affect) rather than observational measures (e.g., behavioral coding of smiling and frowning) of such factors. These measures, although clearly valuable, can be biased (Van de Mortel, 2008). The validity of self-report data may be further compromised in dementia caregivers who are burdened or depressed (Karlawish et al., 2001; Schulz et al., 2013) and in PWDs with reduced insight and semantic knowledge (Bédard et al., 2003). Observational measures offer more objective, fine-grained assessments that are less vulnerable to these issues. Moreover, observational measures of risk and resilience factors are useful when examining associations with self-report outcomes (e.g., depressive symptoms) to avoid inflated correlations due to common method variance (Lindell & Whitney, 2001).

Cross-Sectional Versus Longitudinal Studies

Another prevalent approach in the dementia caregiving literature is the use of cross-sectional study designs, which do not capture the complex temporal dynamics of caregiving experiences (Mittelman et al., 2021). In addition, few studies measure mediators of caregiver outcomes longitudinally (c.f. Saadi et al., 2021). Given the progressive nature of neurodegenerative diseases, caregivers must adjust to the cascade of changes that occur as the dementia progresses and the PWD-caregiver relationship transforms. Longitudinal study designs are needed to identify predictors and mechanisms (and their bidirectional associations) influencing changes in caregivers' health (Connors et al., 2020; Zhu et al., 2015). Although descriptive longitudinal studies cannot establish causality, they provide a strong model for advancing our understanding of risk and resilience factors involved in caregivers' health trajectories.

Factors Associated with Current Caregivers' Health

Contextual Factors

There is considerable variability in the extent to which caregivers experience adverse consequences during active caregiving. Prevailing research largely focuses on identifying contextual or dispositional factors associated with poor outcomes in current caregivers. Factors related to the caregiving environment, such as lower income or financial instability (Schulz & Williamson, 1991), lower levels of social support (Haley et al., 1987), and cohabitating with the PWD (Brodaty & Hadzi-Pavlovic, 1990) are each independently linked to greater strain and psychological morbidity in caregivers (Brodaty & Donkin, 2009; Schulz et al., 1995). Similarly, demographic characteristics of the caregiver (e.g., being the spouse of a PWD, female, or younger) are associated with greater vulnerability to adverse effects of caregiving (Brodaty & Donkin, 2009; Gallicchio et al., 2002; Schulz et al., 1995). Although uncovering contextual risk factors may help facilitate identification of caregivers who are at greater risk for poor health during caregiving, these are typically non-malleable, thus serving as poor intervention targets for improving caregivers' health.

PWD Factors

Another major theme in the literature has been linking specific PWD symptoms to caregiver outcomes (e.g., Matsumoto et al., 2007). A growing consensus from this work indicates that PWDs' behavioral and psychological symptoms (e.g., disinhibition, apathy, agitation) are among the most distressing and burdensome for caregivers, even more so than their cognitive (e.g., memory loss) or functional (e.g., loss of mobility) symptoms (Merrilees et al., 2013; Ornstein & Gaugler, 2012; Schulz et al., 1995).

Laboratory studies (primarily from our research group) have identified a number of impairments in PWDs' emotional functioning, including emotion reactivity (generation of emotional responses), emotion regulation (adjustment of emotional responses), and emotion recognition (identification of emotions in others), that are negatively associated with caregivers' well-being. In a study of PWDs' subjective emotional experience (i.e., emotion reactivity), we found that greater endorsement of negative, "non-target" emotions (i.e., situationally inappropriate emotions that stimuli were not intended to induce) in PWDs is associated with lower emotional well-being in their caregivers (Chen et al., 2017). Regarding emotion regulation, our laboratory has found that lower use of visual avoidance (i.e., a form of emotion regulation that involves reducing visual attention to unpleasant stimuli) to a disgusting film by PWDs is associated with greater psychological distress in caregivers (Otero & Levenson, 2017). In the realm of emotion recognition, our lab has shown that lower empathic accuracy (i.e., the ability to recognize emotions correctly in others) in PWDs is associated with greater depression in caregivers (Brown et al., 2018). We have also used PWD MRI data to uncover areas of neurodegeneration that are associated with caregivers' health. Consistent with these earlier findings, damage to two regions important for emotional reactivity and regulation in PWDs (i.e., the right ventral anterior insula and the superior medial frontal gyrus) is associated with poorer health in caregivers (Hua et al., 2019).

Declines in PWDs' emotional functioning often become most salient in interpersonal contexts, such as their interactions with caregivers (Ascher et al., 2010; Lwi et al., 2019; Sturm et al., 2011). The impact of PWDs' problematic behaviors on caregivers may be further exacerbated in particular types of neurodegenerative diseases, such as frontotemporal dementia (FTD; de Vugt et al., 2006; Merrilees et al., 2013). For example, individuals with FTD often become emotionally blunted and non-empathic (Rascovsky et al., 2011), which may weaken the emotional connection with their caregiver. Studies reveal that spousal caregivers of individuals with FTD report lower marital satisfaction than caregivers of other types of dementia (e.g., Alzheimer's disease) and implicate PWDs' behavioral symptoms in the deterioration of the relational bond (Ascher et al., 2010; de Vugt et al., 2003). Together, these findings suggest that impairments in PWDs' emotional functioning (i.e., inappropriate emotional experiences, reduced use of emotion regulation, and lower ability to recognize emotions in others) may damage the caregiving relationship, and in turn, caregivers' health.

Caregiver Factors

Despite well-established links between PWDs' emotional functioning and caregivers' vulnerability to poor health, caregivers' own emotional functioning has only just begun to receive attention. Instead, research on caregiver-specific risk factors has more thoroughly examined their personality, perception and experience of the caregiving role, and coping strategies. Regarding personality, higher levels of neuroticism (Shaji et al., 2003), greater expressed emotion (Fearon et al., 1998; Nomura et al., 2005; Safavi et al., 2017), and lower self-esteem (Semple, 1992; Zarit et al., 1986) are linked to greater strain and psychological morbidity in caregivers. In terms of the caregiver role, lower feelings of self-efficacy (i.e., confidence in managing caregiving responsibilities) and greater "role captivity" (i.e., feelings of being trapped in the role) are associated with greater burden and depression in caregivers (Campbell et al., 2008; Gallagher et al., 2011). Additionally, greater use of emotion-focused and confrontative coping strategies and less use of problem-focused coping strategies are associated with higher levels of anxiety in caregivers (Cooper et al., 2007). Last, caregiver health status indicators (e.g., low self-rated health, more chronic health conditions, more frequent health service utilization) are highly correlated with caregiver depression (Brodaty & Hadzi-Pavlovic, 1990; Hooker et al., 1992).

As research on the adverse outcomes of caregiving has largely utilized self-report data, few studies have measured caregiver emotional functioning (i.e., emotion reactivity, emotion recognition, and emotion regulation) through observational measures. In such studies, we have found that caregivers with lower ability to downregulate emotional behavior in response to disgusting stimuli, as well as those with greater levels of emotional empathy (i.e., greater reported emotional responses to a film depicting suffering), have poorer mental health (Hua et al., 2021; Wells et al., 2020). It is worth noting that these associations between observational measures of caregiver emotional functioning and caregiver mental health were independent of traditional self-report measures (e.g., an emotion regulation questionnaire) and PWD factors (e.g., dementia severity). Additional work from our team shows that in caregivers with the short/short variant of the serotonin transporter linked polymorphic region (5-HTTLPR), which is thought to confer heightened emotional reactivity (Belsky & Pluess, 2009; Gyurak et al., 2013; Haase et al., 2013; Hariri et al., 2002), lower empathic accuracy in PWDs is associated with lower psychological well-being in caregivers; whereas this association does not exist in caregivers with other 5-HTTLPR genotypes (Wells et al., 2019).

Taken together, these studies advance the literature of individual differences in caregivers' health, which typically emphasizes contextual and PWD-related risk factors, by suggesting that caregivers' own emotional functioning (i.e., lower emotion regulation ability, greater empathic responses to others' suffering, and genetic predisposition to heightened emotional reactivity) is associated with poorer health. Considering that much of caregiving plays out through interpersonal exchanges with the PWD, and that emotions play an important role in these interactions, examining the emotional qualities of the PWD-caregiver relationship in relation to caregivers' health may deepen our understanding of caregiver vulnerability and resilience factors.

PWD-Caregiver Relationship and Current Caregivers' Health

Self-Report Measures

Studies of the PWD-caregiver relationship have predominantly focused on self-reported relationship satisfaction. These studies have consistently demonstrated that poor relationship quality (both during caregiving and before the onset of dementia) is associated with worse outcomes (e.g., greater burden, greater depression) in current caregivers of PWDs (Draper et al., 1996; Fitzpatrick & Vacha-Haase, 2010; Mahoney et al., 2005; Monin et al., 2019; Steadman et al., 2007). Moreover, some caregivers retrospectively report a significant loss of relationship quality and intimacy when comparing their premorbid relationship to their current relationship (de Vugt et al., 2003; Morris et al., 1988); this loss of intimacy is associated with increased caregiver depression (Morris et al., 1988). In one study, poor relationship quality statistically mediated the link between the presence of problem behaviors in older adult care recipients and greater depression in caregivers (Lawrence et al., 1998). Poor relationship quality has also been found to increase risk for PWD nursing home placement (Spruytte et al., 2001), highlighting that declines in PWD-caregiver relationship quality have implications for PWDs and caregivers alike (e.g., Lwi et al., 2017).

Other studies have operationalized the PWD-caregiver relationship through self-report measures of related constructs. For example, insecure attachment style (e.g., a pattern of avoidance and anxiety in relationships; Bowlby, 1969) in PWDs is related to greater burden in caregivers (Magai & Cohen, 1998); and insecure attachment style in caregivers is related to greater caregiver anxiety symptoms (Cooper et al., 2008). Longitudinal, epidemiological studies of caregivers' self-reported closeness to the PWD have also revealed interesting insights. For example, whereas higher PWD-caregiver closeness at baseline predicts better concurrent mental health in caregivers, it also predicts worsening mental health over the course of caregiving (Fauth et al., 2012). Additionally, higher closeness at baseline predicts slower cognitive and functional decline in PWDs over the course of 20 months, and the effect of closeness on functional decline is even stronger in spousal caregiving relationships (Norton et al., 2009). These studies provide a broad framework through which to understand dementia caregiving relationships but are limited by relying solely on self-report measures of relationship constructs.

Observational Measures

Research shows that particular interpersonal emotional behaviors expressed by PWDs and caregivers during a dyadic conflict interaction task in the laboratory are associated with diagnostic differences in PWDs as well as with health in caregivers. For example, individuals with FTD and their spousal caregivers show less mutual gaze (i.e., eye contact; Sturm et al., 2011) and caregivers of individuals with FTD use more negative emotion words during the interaction than caregivers of other PWDs (Ascher et al., 2010). Our team has also started to link interpersonal emotional behaviors to caregivers' health, finding that objectively coded "genuine" smiles (Ekman & Friesen, 1982) expressed by PWDs and greater use of personal pronouns that refer to the couple (e.g., "we," "us") spoken by both PWDs and caregivers during the interaction are associated with better health and well-being in caregivers (Connelly et al., 2020; Lwi et al., 2019). Other studies employing observational measures of PWD-caregiver interactions find that communication quality may be diminished in PWD-caregiver couples (e.g., fewer behaviorally coded expressions of support), compared to non-caregiving couples (Gallagher-Thompson et al., 2001). Together, these studies suggest that the emotional quality of the PWD-caregiver connection may be closely tied to caregivers' health and well-being. However, across studies of the PWD-caregiver relationship (including those that utilize self-report and/or observational measures), longitudinal study designs are quite rare.

Social Connection and Health

The PWD-caregiver relationship represents a key piece of caregivers' overall social connectedness. Social connection is an umbrella term that refers to the quality and quantity of social ties that individuals have with others (Holt-Lunstad et al., 2017). There are three major conceptual components of social connection: *structure* (e.g., number of relationships, frequency of interactions); *function* (e.g., the degree to which others can be relied upon for various needs); and *quality* (e.g., whether relationships and interactions are positive, helpful, or satisfying; Holt-Lunstad, 2018). Each of these components is important for health and may influence health in different ways (Holt-Lunstad, 2022; Holt-Lunstad et al., 2017; Holt-Lunstad et al., 2010). Several meta-analyses have documented the protective effect of social relationships (Holt-Lunstad et al., 2010) and social contact frequency (Shor & Roelfs, 2015) on mortality risk, whereas others demonstrate the risk associated with lacking social connection via loneliness and social isolation (Holt-Lunstad et al., 2015), divorce (Sbarra et al., 2011), and widowhood (Shor et al., 2012). The magnitude of these effects is equivalent to other leading risk factors for mortality such as smoking and obesity (Holt-Lunstad et al., 2015; Holt-Lunstad et al., 2010). Therefore, it is important for researchers to measure specific aspects of social connection, such as emotional quality, to understand these long-term associations with health.

Emotional Qualities of Social Connection

Ample evidence demonstrates that emotions are critical for maintaining social relationships (Levenson, 1999; Sbarra & Coan, 2018) and health (Gallo & Matthews, 2003; Gross & Muñoz, 1995; Mostofsky et al., 2014; Pressman & Cohen, 2005; Richman et al., 2005) in neurotypical or non-caregiving individuals. Positive and negative affective processes (e.g., physiological co-regulation, affective reactivity to stress) are considered primary mechanisms linking close relationships and health-related outcomes (Farrell et al., 2018; Pietromonaco & Collins, 2017; Sbarra & Coan, 2018; Smith & Weihs, 2019). A long line of research has focused on identifying negative emotional behaviors (e.g., hostility, criticism) expressed by individuals in dyadic interactions and their downstream health consequences (Haase et al., 2016; Kiecolt-Giaser et al., 1993; Robles & Kiecolt-Glaser, 2003). Growing evidence also highlights the importance of positive interpersonal processes (e.g., expressing gratitude, sharing good news, emotional disclosure) in building high-quality social relationships and supporting health and well-being (Algoe et al., 2013; Gable et al., 2004; Laurenceau et al., 2005). However, the association between positive affect in close relationships and long-term health has received less attention (e.g., Algoe, 2019; Pietromonaco & Collins, 2017), especially in the dementia caregiving literature.

Positive Affect. The salubrious effects of positive affect are well-documented (e.g., Fredrickson et al., 2008; Kok et al., 2013; Pressman & Cohen, 2005; Sin & Lyubomirsky, 2009). Recent theorizing posits that the benefits of positive affect are amplified when it is shared between and among individuals compared to when it is experienced individually (Fredrickson, 2013, 2016). These added benefits may be because positive affect can become more intense and last longer when socially shared (e.g., Gable et al., 2004; Kraut & Johnston, 1979). Increasing evidence suggests that group-level, linked emotional processes (e.g., shared emotions) are even more instrumental for health and well-being than the emotions of an individual person (Algoe et al., 2013; Brown et al., 2021; Gable et al., 2006). One laboratory study showed that shared experiences of positive affect were associated with stronger feelings of social connection in unfamiliar dyads who watched a television show together (Cheong et al., 2020); and in another laboratory study, social connection mediated the link between positive affect and future health and well-being (Mauss et al., 2011). Positive emotion and social connection have been repeatedly linked in previous research, with evidence suggesting a bidirectional relation (i.e., positive emotion predicts gains in social connection, and social connection reciprocally predicts increases in positive emotion; Fredrickson et al., 2008; Kok & Fredrickson, 2010). As such, the effects of sharing positive emotions within close relationships may accumulate over time, yielding long-lasting health benefits.

Negative Affect. Several studies find that negative affect predicts worse day-to-day health (e.g., hormone and immune functioning; Adam et al., 2006) as well as long-term health outcomes (e.g., cardiovascular disease; Kiecolt-Glaser et al., 2002; Salovey et al., 2000). Negative affect is a core feature of many clinical disorders (e.g., anxiety, depression, eating disorders), which are associated with increased interpersonal problems (e.g., interpersonal sensitivity, fear of evaluation; Fairburn et al., 2003; Steiger et al., 1999). Negative affect may also influence processes that inhibit social connection. For instance, in a laboratory study of married couples, individuals with higher trait negative affect rated their partners' behavior as overly dominant and hostile, compared to ratings of independent coders (Traupman et al., 2011). Another laboratory-based study of couples' interactions found that negative affect reciprocity predicted declines in relationship satisfaction over a 3-year period (Levenson & Gottman, 1985). Nevertheless, negative affect is not universally harmful to social connection. For example, two people who express their mutual dislike of something (e.g., two co-workers who dislike their boss) are more likely to form and maintain a friendship (Rambaran et al., 2015). In addition, there is some evidence that constructive expressions of anger can facilitate improvement in relationship quality (Butler et al., 2018; Gottman & Krokoff, 1989). Thus, careful consideration of the measurement context is needed to understand how positive and negative emotional qualities of social connection are related to individuals' health and well-being.

Caregivers' Emotional Connection to the PWD and Loneliness

Researchers have defined loneliness as the discrepancy between desired and actual relationship quality and quantity (Peplau & Perlman, 1982). Experiences of social isolation and feelings of loneliness are common among caregivers of PWDs (Beeson, 2003; Parsons, 1997; Siriopoulos et al., 1999), with some estimates indicating that up to 80% of caregivers will report feeling socially disconnected due to caregiving responsibilities (Carers UK, 2015). Dementia caregiving can directly affect multiple dimensions of social connection by making it difficult for caregivers to leave the home (Robison et al., 2009), to receive social support (Vasileiou et al., 2017), and to participate in social activities (Clark & Bond, 2000). Further, as previously noted, dementia caregiving can also change the nature of the relationship between the caregiver and the PWD, including reductions in emotional intimacy (Beeson, 2003; Vasileiou et al., 2017).

There is some evidence suggesting that caregivers yearn for the positive emotional qualities of their premorbid relationship with the PWD, including the reciprocity, mutuality, and shared pleasures in their relationship (Blieszner & Shifflett, 1990; Gallagher-Thompson et al., 2001). The declining emotional quality of the connection between the PWD and caregiver may fuel increases in caregivers' loneliness (Beeson et al., 2000), and in turn, fuel reductions in their health and well-being. This process may be particularly true for older and spousal caregivers, as the incidence of loneliness is known to increase with age (Dykstra et al., 2005), when social networks are known to shrink (Carstensen et al., 1999; Wrzus et al., 2013). In light of the powerful influence of close relationships on health in later adulthood (Rook & Charles, 2017), the emotional quality of the PWD-caregiver relationship could affect caregivers' long-term health, including after the death of the PWD (i.e., after caregiving has ended).

How Former Caregivers Fare After Caregiving Has Ended

Although researchers have studied the correlates and consequences of active caregiving for the past several decades, they have only recently questioned what happens to caregivers after the death of their loved one. Do caregivers improve in health to pre-caregiving levels, or do they remain plagued by their caregiving experiences and the slow, difficult loss of their loved one?

Early studies characterizing the health trajectories of former caregivers (following the death of the PWD) have found variability in long-term health changes. For example, a four-year longitudinal study of current caregivers, former caregivers, and non-caregiving adults found that former and current caregivers did not differ on measures of depression, and that both caregiver groups were significantly more depressed than non-caregiving adults (Bodnar & Kiecolt-Glaser, 1994). A similar longitudinal study revealed that former caregivers experienced decreases in stress and negative affect following the death of the PWD; but their levels of depression, loneliness, and positive affect did not improve to levels comparable to non-caregivers, and remained similar to those of current caregivers, up to three years after caregiving had ended (Robinson-Whelen et al., 2001). Another four-year longitudinal study of former non-PWD caregivers (categorized as those who reported no strain versus strained caregivers) and non-caregiving, bereaved spouses found that, following the death of one's partner, depression scores increased for both non-strained former caregivers and non-caregivers, but did not change among caregivers who were already strained (Schulz et al., 2001). Altogether, these findings highlight variability in the long-term health trajectories of former caregivers and suggest that these trajectories may vary as a function of caregiving experiences prior to the death of the PWD.

Research on the sources of variability in former caregivers' health has concentrated on factors related to the context (e.g., social support; Robinson-Whelen et al., 2001), the PWD (e.g., cognitive impairment; Schulz et al., 2006), and the caregiver (e.g., burden; Almberg et al., 2000). Even among the risk factors that have been identified in the literature, the evidence is mixed regarding their associations with health in former caregivers after caregiving has ended. For example, one study found that caregivers who reported more positive appraisals during caregiving described feeling relieved after the death of the PWD (Almberg et al., 2000), whereas another study found the opposite – caregivers who reported more positive aspects of caregiving experienced greater grief and depression after the death of the PWD (Boerner et al., 2004). At the same time, factors that appear to be reliably associated with former caregivers' health include greater preparedness for the death of the PWD (e.g., through anticipatory grief), which may support health and well-being in former caregivers by increasing feelings of relief after the death of the PWD (Hebert et al., 2006; Hovland, 2018; Stahl & Schulz, 2019).

Interestingly, despite the highly interpersonal nature of caregiving (Monin & Schulz, 2009), and well-established links between social relationships and health (Holt-Lunstad et al., 2010; Smith & Weihs, 2019), very little is known about how the nature of the PWD-caregiver relationship affects caregivers' adjustment to the loss of the PWD. Across studies of individual differences in former caregivers' health, the only aspect of the PWD-caregiver relationship that has been mentioned consistently is the relationship type (e.g., spouse, adult children), with spouses being at greater risk for poor health outcomes, such as complicated grief (Boerner et al., 2004; Chan et al., 2013; Crespo et al., 2013).

The literature on spousal bereavement indicates that emotional factors (e.g., laughter, smiling) play a key role in long-term health trajectories after the loss of an important relationship (Bonanno & Keltner, 1997). Further, a prospective study of spousal bereavement revealed that changes in positive emotion accounted for the impact of bereavement on HPA-axis dysregulation in older adults (Ong et al., 2011). Considering the reciprocal influences of positive emotion and social connection on long-term health (Fredrickson et al., 2008; Kok & Fredrickson, 2010), along with the enduring impact of social relationships on health (Farrell et al., 2018; Smith & Weihs, 2019), the positive emotional qualities of the PWD-caregiver relationship may play a role in shaping the health trajectories of former caregivers, after caregiving has ended.

Prior research examining the role of caregivers' emotional connection to the PWD in their long-term health is essentially non-existent. Moreover, studies of former caregivers often utilize retrospective, self-report data (Hovland, 2018; Johansson et al., 2014), without assessments of the PWD-caregiver relationship during caregiving. Thus, observational, longitudinal studies of the emotional qualities of the PWD-caregiver connection represent an important gap in this literature.

The Present Study

The present study evaluates the positive and negative emotional qualities of the connection between PWDs and caregivers, in two independent samples. Study 1 was a cross-sectional, laboratory-based assessment of emotional functioning in PWD-caregiver dyads conducted at the University of California, Berkeley (UCB). Study 2 was a telephone-based supportive care intervention (called *Care Ecosystem*) for PWDs and their caregivers conducted at the University of California, San Francisco (UCSF), in which self-report measures were collected approximately every six to twelve months for up to five years. Both studies included follow-up data collections to measure changes in self-reported mental and physical health, as well as other relevant factors, in now-former caregivers (i.e., after caregiving has ended). Here, I examine the associations between caregivers' emotional connection to the PWD and caregivers' mental and physical health – both concurrently and longitudinally.

This study was designed to meet key methodological goals: (a) Utilizing observational methods derived from basic affective science (i.e., continuous ratings of subjective affective experience, text analysis of emotional language, direct observation of emotional functioning in an interpersonal context). Although much of the burden of caregiving plays out in the interactions between PWDs and caregivers, few studies have assessed these interactions to identify behavioral markers of their social connection; and (b) Evaluating factors related to caregiver health both concurrently and longitudinally. The longitudinal design enables the investigation of health trajectories by adjusting for initial levels of health during active caregiving. Crucially, this dissertation incorporate data from two independent samples. Study 1 offers comprehensive measurement of a PWD-caregiver interaction under well-controlled laboratory conditions; Study 2 enables longitudinal exploration of temporal and mechanistic influences during caregiving. In sum, the present study uses a multi-method, longitudinal approach to evaluate the role of caregivers' emotional connection to the PWD in their long-term health.

Method

The present study utilized two archival datasets to measure caregivers' emotional connection to the PWD during active caregiving using basic affective science methodologies: (a) continuous ratings of subjective affective experience (Study 1); and (b) text analysis of emotional language from verbatim transcripts (Study 2). Study 1 was a laboratory study of emotional functioning in patients with neurodegenerative diseases and in their familial or close caregivers conducted at UCB. Laboratory visits (including an initial survey of caregiver health) were conducted between 2013-2019, and I served as a facilitator for some of these research visits between 2016-2019. Study 2 was a randomized, controlled trial of a telephone-based supportive care intervention for dementia caregivers conducted at UCSF (Possin et al., 2017; Possin et al., 2019). Longitudinal self-report health data were collected between 2015-2019; I was not directly involved with data collection for this study.

Both studies involved an additional follow-up survey with caregivers who had previously participated in either of these studies. These surveys aimed to measure changes in caregivers' mental and physical health, assessed with the same measures of health as in the original studies during active caregiving. The follow-up surveys also recorded the amount of time that had elapsed since the death of the PWD (if the PWD had passed away). Given this study design, the amount of time between the death of the PWD and the follow-up survey was not uniform across participants and is included as a covariate in longitudinal analyses.

All analyses are conducted separately for Study 1 and Study 2. In the sections below, I describe how these data were obtained, reduced, and analyzed.

Study 1 Method

Participants

Participants were 82 PWD-caregiver dyads who participated in our laboratory-based assessment of emotional functioning at UCB. Participants were initially recruited at the Memory and Aging Center (MAC) at UCSF, where PWDs underwent a full diagnostic evaluation, including neurological, neuropsychological, and neuroimaging assessment. Caregivers of PWDs being evaluated at UCSF were contacted if they opted into a study at UCB. All participants, or the legal guardians as appropriate, consented to participate in a day-long assessment of emotional functioning in our laboratory at UCB. Caregivers' age ranged from 42-79, with a mean age of 64 years. Caregivers were majority female (61%) and White or European American (88%).

Of the 82 active caregivers who participated in the initial laboratory study of emotional functioning, 19 caregivers participated in the follow-up data collection. Out of these 19 caregivers, only 2 were former caregivers (i.e., the person in their care had passed away) and 17 were still active caregivers. Due to the small sample size, analyses were conducted with all 19 caregivers who participated in the "follow-up" survey to explore longitudinal changes in caregivers' health. Their ages (at the time of the initial laboratory visit) ranged from 52-79, with a mean age of 67 years; they were majority female (74%) and White or European American (95%). See **Table 1** for additional demographic details for both the active caregiving sample *(N* = 82) and the follow-up sample (*N* = 19).

Procedure

Within four months of the initial evaluation at the MAC, PWD-caregiver dyads visited the Berkeley Psychophysiology Lab for a comprehensive assessment of emotional functioning, including task designed to measure emotional reactivity, emotional regulation, and emotional recognition in both PWDs and caregivers (Levenson et al., 2008). The present study focuses on data from a dyadic interaction task, in which PWDs and caregivers engaged in a ten-minute conversation about a topic of disagreement. Upon arrival at the Berkeley Psychophysiology Laboratory, all participants (PWDs and caregivers) reviewed the procedures for the day and completed consent forms with the assistance of a graduate student experimenter. Following the completion of the laboratory session, PWDs and caregivers reviewed the video consent forms, which indicated how their videotape records could be used (ranging from no use, to research use, to use in future talks and publications to a research audience, to showing to the general public). Caregivers also completed self-report instruments measuring their physical health, mental health, and additional, contextual factors. Each PWD-caregiver dyad was paid $120 for participation. The UC Berkeley Committee for the Protection of Human Subjects approved all procedures.

For the dyadic interaction task, PWD-caregiver dyads sat facing each other in comfortable chairs 1 meter apart in a well-lit, 3x6 meter laboratory room set up for recording video and physiology from the dyad. Following standard procedures for studying couple interactions (Levenson & Gottman, 1983), PWD-caregiver dyads were briefly interviewed by a graduate student experimenter to identify an area of conflict in their relationship. After the experimenter left the room, the dyad sat quietly for five minutes (serving as a baseline), and then engaged in a 10-minute unrehearsed conversation about the agreed upon topic of conflict. Facial behavior was recorded using partially hidden cameras. This task provides samples of naturalistic interpersonal behavior; it is widely used to study emotional functioning in close relationships (Bradbury et al., 2000). Immediately after the interaction task, caregivers watched the video recording and used a rating dial device to provide continuous ratings of how they felt and how the PWD felt during the interaction (a well-validated procedure for obtaining continuous self-reported affect; Gottman & Levenson, 1985).

In 2019-2020, all caregivers who previously participated in the study were invited to participate in a follow-up data collection, consisting of a one-time survey of their physical health, mental health, and other relevant factors (e.g., active caregiving status, time since the death of the PWD). The same measures of caregivers' health (i.e., depression, anxiety, physical functioning, loneliness) were collected at the initial survey and at the follow-up survey. Caregivers were paid $50 for completing the follow-up survey.

Apparatus

Audiovisual. Remote-controlled high-resolution color video cameras placed behind darkened glass in bookshelves recorded participants' facial behavior and upper body movement. These images were combined into a single split-screen image using a video special effects generator. Lavaliere microphones recorded their voices. Recordings were stored in digital form on our laboratory video file server for subsequent behavioral coding.

Rating Dial. After the dyadic interaction task, a rating dial was placed near the dominant hand of the caregiver following previously established methods (Ruef & Levenson, 2007). The rating dial consists of a small metal box with a rotating knob and attached pointer that rotated across a 180° semi-circle. The semi-circle is divided into 9 equal divisions labelled with descriptors of "very bad" (1; shown with a schematic frowning face) at the far left, "neutral" (5;

shown with a schematic neutral face) in the middle, and “very good” (9; shown with a schematic smiling face) at the far right. The rating dial mirrors the affective circumplex model of valence, in which positive and negative affect fall along a unidimensional scale (Posner et al., 2005).

Continuous Ratings of Subjective Affective Experience

Immediately after the dyadic interaction task, caregivers watched the video recording of their conversation while providing continuous ratings of how they felt during the interaction. Caregivers manipulated the rating dial across a 180° path, with the dial pointer moving over a 9-point scale anchored by the legends “very bad” (1) and “very good” (9), with a line labeled “neutral” in the middle (5). Caregivers were instructed to change the position of the dial as often as necessary so that it always represented how they felt during the interaction (Ruef & Levenson, 2007). Using the voltage generated by the dial, which is proportional to the dial position, the average dial position was computed every second. This resulted in a second-by-second time-series reflecting caregivers’ affective valence during the 10-minute conversation.

Immediately after providing ratings of their own affective experience during the dyadic interaction task, caregivers watched the video recording of their conversation again. During this second viewing of the conversation, caregivers provided continuous ratings of how they perceived the PWD felt during the interaction (using the same procedure as described above). The average dial position was computed every second, resulting in a second-by-second time-series reflecting PWDs’ perceived affective valence during the 10-minute conversation.

Caregivers were excluded from analyses if they were missing more than 15% of rating dial data for their affect or that of the PWD (this occurred for 8 caregivers due to technical issues). In addition, for caregivers with 85-99% of rating dial data (N = 16), each rating dial variable (positive and negative co-experienced and individually experienced affect, described below) was divided by the total number of observations and multiplied by 600 (i.e., the total number of seconds in a 10-minute conversation).

Caregivers’ Emotional Connection to the PWD (Co-Experienced Affect)

Caregivers’ emotional connection to the PWD was operationalized from the number of seconds (cumulative) in which the caregivers rated both themselves and the PWD as simultaneously experiencing the same affective valence (i.e., positive or negative) during the dyadic interaction task. ***Co-experienced positive affect*** was calculated by summing the number of seconds in which both the caregiver and PWD were rated as experiencing positive affect (> 5 on the rating dial at the same time). ***Co-experienced negative affect*** was calculated using the inverse criteria, by summing the number of seconds in which both the caregiver and PWD were rated as experiencing negative affect (< 5 on the rating dial at the same time). None of the rating dial observations were exactly 5 (i.e., the midpoint).

Caregivers’ Individual-Level Affect (Individually Experienced Affect)

Caregivers’ individual-level positive and negative affect was operationalized from their ratings of how they felt during the dyadic interaction task. Caregivers’ individually experienced positive affect was calculated by summing the number of seconds in which caregivers indicated they were feeling positive (> 5 on the rating dial) and the PWD was feeling negative (< 5 on the rating dial). Caregivers’ individually experienced negative affect was calculated using the inverse criteria, by summing the number of seconds in which they indicated they were feeling negative (< 5 on the rating dial) and the PWD was feeling positive (> 5 on the rating dial). None of the rating dial observations were exactly 5 (i.e., the midpoint).

Behavioral Indicators of Positivity Resonance

Video recordings from the interaction were rated for Behavioral Indices of Positivity Resonance (BIPR; Otero et al., 2019). Trained coders rated BIPR in 30-second time intervals on a 0-2 scale, and codes were summed across the entire conversation to calculate one score for each dyad. All coders were blind to diagnosis. To assess reliability, 36% of the conversations were coded by at least two raters. The original study of BIPR in non-caregiving, long-term married couples (Otero et al., 2019) indicated high reliability (intraclass correlation coefficient = .80) and validity (significant associations with positive affect and marital satisfaction). In the present study, reliability was excellent (intraclass correlation coefficient = .95)

Caregiver Self-Report Measures

Caregiver Depression. Caregivers' depressive symptoms for the past week were assessed using the Center for Epidemiological Studies Scale (CES-D; Radloff, 1977). For each of 20 items (e.g., "I felt sad") caregivers rated themselves on a four-point scale from 0 ("rarely or none of the time") to 3 ("most or all of the time"). Four items are reverse scored, then all items are summed. Higher scores indicate greater depression. The CES-D has been validated for measuring depression in older adults (Beekman et al., 1997; Haringsma et al., 2004). Three caregivers did not complete one item on the CES-D in the initial survey; their scores were imputed by taking the average of the 19 completed items and multiplying that value by 20.

Caregiver Anxiety. Caregivers' anxiety symptoms for the past month were assessed using the Beck Anxiety Inventory (BAI; Steer & Beck, 1997). For each of 21-items (e.g., "Unable to relax") caregivers rated themselves on a scale from 0 ("not at all") to 3 ("a lot"). Scores are summed, with higher scores indicating greater anxiety. The BAI has demonstrated reasonable test-retest reliability and validity when used with individuals with anxiety disorders (Beck et al., 1988; Fydrich et al., 1992). Six caregivers did not complete one or two items on the BAI in the initial survey; their scores were imputed by taking the average of the completed items and multiplying that value by 21.

Caregiver Physical Functioning. Caregivers' physical health was measured with the Medical Outcomes Study 36-Item Short-Form (SF-36; Ware & Sherbourne, 1992). The SF-36 evaluates 8 areas of mental and physical health in the past month: (1) physical functioning, (2) role limitation due to physical health problems, (3) role limitations due to emotional problems, (4) energy and fatigue, (5) emotional well-being, (6) social functioning, (7) pain, and (8) general health. The SF-36 has been widely used and has excellent psychometrics (McHorney et al., 1993; Ware & Gandek, 1994). Due to a data collection error in the initial survey, some items of the SF-36 were omitted. However, all 10 items of the physical functioning subscale were administered using a 3-point Likert scale ("Does your health now limit you in these activities?"; e.g., vigorous activities, moderate activities). These items are summed, with higher scores reflecting better physical functioning. All analyses of physical health focus on this scale to maximize validity of complete data. Seven caregivers did not complete one item on the physical functioning subscale in the initial survey; their scores were imputed by taking the average of the 9 completed items and multiplying that value by 10.

Caregiver Loneliness. Caregivers' loneliness was measured with the UCLA Loneliness Scale (Version 3; Russell, 1996). For each of the 20 items (e.g., "How often do you feel left out?”), caregivers rated themselves on a four-point scale from 1 (“never”) to 4 (“always”). Nine items are reverse scored, then all items are summed. Higher scores indicate greater levels of loneliness. This version of the UCLA Loneliness Scale demonstrates excellent psychometric properties, and has been validated for measuring loneliness in older adults (Russell & Cutrona, 1991). Six caregivers did not complete one or two items in the initial survey; their scores were imputed by taking the average of the completed items and multiplying that value by 20.

Caregiver Marital Satisfaction. Caregivers’ marital satisfaction was measured with the Locke-Wallace Marital Adjustment Test (Locke & Wallace, 1959). The Locke-Wallace is a 15-item self-report measure of marital satisfaction, which seeks to differentiate adjusted couples from distressed couples. The questionnaire contains items such as “When disagreements arise, they generally result in… (a) husband giving in, (b) wife giving in, (c) agreement by mutual give and take.” The overall marital satisfaction score was computed based on established protocols, with higher scores representing greater marital satisfaction. Twenty caregivers missed at least one item on the questionnaire in the initial survey and were excluded from analyses of marital satisfaction, given differences in weighting across items.

PWD Measures

PWD Diagnosis. At UCSF, PWDs underwent extensive evaluations and were diagnosed by a multidisciplinary team of neurologists, neuropsychologists, and nurses according to consensus research criteria. There was heterogeneity in PWD diagnoses, including 21 with Alzheimer’s disease (AD; McKhann et al., 2011); 17 with behavioral variant frontotemporal dementia (bvFTD); 14 with clinical syndromes that affect language functioning (e.g., primary progressive aphasia; Gorno-Tempini et al., 2011; Rascovsky et al., 2011); 27 with other neurodegenerative diseases (e.g., corticobasal syndrome, progressive supranuclear palsy, Parkinson's disease; Armstrong et al., 2013; Litvan et al., 1996; Wijesekera & Leigh, 2009); and 3 individuals diagnosed with mild cognitive impairment (MCI).

PWD Dementia Severity. At UCSF, the Clinical Dementia Rating Scale (CDR; Morris, 1993) was completed using a semi-structured interview with PWDs and their caregivers. The CDR assesses functional performance in six domains: (1) memory, (2) orientation, (3) judgement and problem-solving, (4) community affairs, (5) home and hobbies, and (6) personal care. For each domain, a score is given ranging from 0 (none) to 3 (severe) based on a description of functioning. Scores in each domain are summed to create a composite score, ranging from 0 to 18, with higher scores indicating greater dementia severity. This measure has been a useful staging measure for patients with dementia (Morris, 1997; Williams, Storandt, Roe, & Morris, 2013), has been validated against neuropathology data (Berg, McKeel, Miller, Baty, & Morris, 1993), and demonstrates good reliability (Burke et al., 1988).

PWD Cognitive Impairment. At UCSF, PWDs were administered the Mini-Mental State Examination (MMSE) to assess the severity and progression of cognitive impairment (Folstein, Folstein, & McHugh, 1975). This exam evaluates several domains of cognitive functioning: (1) orientation, (2) registration, (3) attention and calculation, (4) recall, and (5) language. A total score is calculated from summing correctly performed items. Scores range from 0-30, with lower scores indicating greater cognitive impairment. This measure has been useful in detecting dementia and staging disease course (O’Bryant, Humphreys, et al., 2008; O’Bryant, Waring, et al., 2008) and has good reliability and validity for grading cognitive impairment (Tombaugh & McIntyre, 1992).

Study 2 Method

Participants

The present study included 335 PWD-caregiver dyads who participated in the Care Ecosystem study and completed the month 6 telephone survey[1]. Participants were recruited from UCSF and the University of Nebraska Medical Center (UNMC), and screened with the following eligibility criteria: (a) diagnosed with dementia; (b) older than 45 years; (c) eligible for enrollment in Medicare or Medicaid; (d) residing in California, Nebraska, or Iowa (not in a nursing home at the time of screening); (e) fluent in English, Spanish, or Cantonese; and (f) had a caregiver who agreed to co-enroll. At the time of screening, caregivers' age ranged from 47-88, with a mean age of 66 years. Caregivers were majority female (72%) and White or European American (79%). The study used imbalanced randomization, with a 2:1 ratio between Care Ecosystem and usual care (in the present sample, *n* treatment = 218; *n* control = 117). Participants received a $25 gift card for every completed follow-up survey. All study procedures were approved by the UCSF and UNMC Institutional Review Boards.

Of the 335 active caregivers who participated in the initial Care Ecosystem Study, 93 (now-former) caregivers participated in the follow-up ("post-mortem") data collection. Former caregivers' age (at the time of screening) ranged from 49-87, with a mean age of 65 years. Former caregivers were majority female (81%) and White or European American (84%). See **Table 2** for additional demographic details for both active caregivers (*N* = 335) and former caregivers (*N* = 93) from Study 2.

Procedure

The Care Ecosystem is a telephone-based supportive care intervention for dementia delivered by care team navigators (CTNs) and dementia expert providers (advanced practice nurse, social worker, and pharmacist; Possin et al., 2017; Possin et al., 2019). CTNs telephoned dyads in the intervention group monthly for 12 months, responding to problems and providing personalized support and standardized education. One of the goals that CTNs achieved was building self-efficacy (i.e., one's perceived capacity to manage responsibilities and tasks successfully and confidently; Bandura, 2006) in the caregivers (Merrilees et al., 2020). Participants randomized to usual care were offered contact information for support networks and resources. A recent review of caregiver interventions that included over 600 unique studies concluded that Care Ecosystem was one of only seven or eight interventions that were supported by at least "low-strength" empirical evidence (Butler et al., 2020).

Caregivers in both groups completed telephone surveys with research coordinators (who were blinded to treatment group assignment) at baseline, 6 months, and 12 months after randomization. A subset of caregivers who reported high levels of burden at the baseline survey (12-item Zarit Burden Interview > 17; Bédard et al., 2001) were invited to complete additional follow-up surveys approximately every 6 months for 5 years (in the present sample, *N* = 119; *n* treatment group = 74; *n* control group = 45). During each telephone survey, research coordinators administered questionnaires measuring caregivers' physical health and mental health, as well as a number of related factors (e.g., caregiver self-efficacy, PWD dementia severity). Some measures (e.g., caregiver subjective health, caregiver loneliness) were added to the study protocol after data collection had already begun, resulting in fewer observations for these variables. Additionally, at the end of the month 6 and month 12 follow-up surveys,

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[1] The Care Ecosystem enrolled a total of 780 PWD-caregiver dyads (see Possin et al., 2019 for more details).

research coordinators asked caregivers open-ended questions (described below). Research coordinators documented caregivers' verbatim responses to the open-ended questions.[2]

If a PWD passed away during the study, a member of the study team would reach out to invite former caregivers to complete a final post-mortem survey. At the end of the study, all caregivers who provided consent to being recontacted were invited to complete a post-mortem survey, if appliable. As a result, the amount of time between the death of the PWD and the administration of the post-mortem survey varied across caregivers, ranging from 12 days to around 18 months (*M* = 146.72 days, or about 5 months; SD = 116.55 days, or about 4 months). The same measures of caregivers' health (i.e., depression, subjective health, loneliness) were collected at the post-mortem survey as in the original Care Ecosystem study.

Open-Ended Questions

Connection Question. At the end of the 6-month survey, caregivers were asked, "*tell me about a time you felt most connected to [the PWD] in the last few months*."

Coping Question. At the end of the 12-month survey, caregivers were asked, "*tell me about something you have done to cope when caregiving has challenged you.*"

Text Analysis of Caregivers' Emotional Language

Transcripts of caregivers' responses to the open-ended questions in the telephone surveys was processed with text analysis software written by Dr. Robert Levenson (Oedipus Text; Levenson, 1992; Seider et al., 2009) that compares each word against pre-determined dictionaries to provide frequency counts of words in particular emotion families (e.g., positive, negative) and specific emotions (e.g., anger, sadness). Because the meaning of a word can be markedly altered by its context, additional context coding was conducted. Oedipus Text displayed each word detected from a given dictionary (e.g., "close" in the love dictionary) in the context it was used (i.e., the sentence in which it occurred and the preceding and following sentences). Trained coders determined whether the given word was correctly identified by the program (and should be retained for analyses) or if it should be omitted, given the context (e.g., non-emotional homonyms, "*close* the door").

Transcripts of caregivers' responses to the open-ended questions (i.e., the connection question and coping question) in the telephone surveys were processed through Oedipus Text in order to count the number of positive emotion words (e.g., love, amusement) and negative emotion words (e.g., anger, sadness) caregivers used. To assess reliability, 58% of responses were coded by at least two raters. Previous studies have shown high reliability for this kind of contextual coding (Connelly et al., 2020; Seider et al., 2009). Fleiss' kappa, an extension of Cohen's kappa, which controls for chance agreement and provides a single reliability index for the whole coding system, indicated good reliability (kappa = .88) for the present study.

Caregivers' Emotional Connection to the PWD (Emotional Connection Language)

Caregivers' positive emotional connection language was operationalized by summing the number of positive emotion words caregivers used in response to the open-ended connection question. Similarly, ***caregivers' negative emotional connection language*** was determined by summing the number of negative emotion words caregivers used in response to the connection question. These values were then divided by the total number of words caregivers used in response to this question.

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[2] A portion of the responses were not documented verbatim and were excluded from analyses.

Caregivers' Individual-Level Emotion (Emotional Coping Language)

Caregivers' positive and negative emotional coping language (i.e., individual-level emotion, or emotion that is unrelated to their connection with the PWD) were operationalized, separately, by summing the number of positive and negative emotion words caregivers used in response to the open-ended coping question. These values were then divided by the total number of words caregivers used in response to this question.

Caregiver Self-Report Measures

Caregiver Depression. Caregivers' depressive symptoms for the last two weeks were measured at each survey with the Patient Health Questionnaire (PHQ-9; Kroenke et al., 2001). The PHQ-9 is a brief depression severity measure in which all nine diagnostic criteria for depression from the DSM-IV are rated on a scale of 0 ("not at all") to 3 ("nearly every day"). The PHQ-9 has been validated for measuring depression in the general population (Martin et al., 2006). Scores are summed, ranging from 0-36, with higher scores indicating higher levels of depression.

Caregiver Subjective Health. Caregivers' subjective health was measured at each survey with a 1-item measure developed specifically for the study. The item asks caregivers to rate their health on a four-point scale ranging from 1 ("poor") to 4 ("very good"). Higher scores indicate better health.

Caregiver Loneliness. Caregivers' loneliness was measured at the month 6, month 30, month 42, and post-mortem surveys with a 3-item version of the UCLA Loneliness Scale (Russell, 1996), an abbreviated version of the 20-item Revised UCLA Loneliness Scale (Russell et al., 1980). The 3-item version of the UCLA Loneliness Scale has been shown to have satisfactory reliability and validity in a large U.S. population sample (Hughes et al., 2004). The scale asks caregivers to rate how often they feel they lack companionship, feel left out, and feel isolated from others on a scale of 1 ("hardly ever") to 3 ("often"). Scores are summed, ranging from 3-9, with higher scores indicating greater loneliness.

Caregiver Self-Efficacy. Caregivers' self-efficacy was measured at each survey with the Care Ecosystem Caregiver Self-Efficacy Scale (Merrilees et al., 2018), a questionnaire developed specifically for this study to evaluate family caregivers' knowledge and preparedness in managing the challenges of care. The Care Ecosystem Caregiver Self-Efficacy Scale measures 4 items (e.g., "I know where to get the services I need") on a 5-point scale ranging from 1 ("strongly disagree") to 5 ("strongly agree"). Scores are summed, with higher scores indicating greater self-efficacy.

PWD Dementia Severity

At each telephone survey, caregivers completed the Quick Dementia Rating System (QDRS; Galvin, 2015), which is a rapid dementia staging tool. The QDRS asks caregivers to evaluate changes from PWDs' premorbid functioning across 10 domains: (1) memory and recall; (2) orientation; (3) decision-making and problem-solving abilities; (4) activities outside the home; (5) function at home and hobby activities; (6) toileting and personal hygiene; (7) behavior and personality changes; (8) language and communication abilities; (9) mood; and (10) attention and concentration. Each domain has five possible answers, increasing in severity of symptoms. Scores in each domain are summed to create a composite score, ranging from 0 to 30, with higher scores indicating greater dementia severity. The QDRS has been validated against the

CDR, neuropsychological testing, and gold standard measures of function, mood, and behavior (Galvin, 2015).

Aims and Hypotheses

To simplify descriptions of analyses below, I will refer to all measures of caregiver mental and physical health under the broader term of "caregiver health."

Aim 1: To evaluate the role of caregivers' emotional connection to the PWD in current and former caregivers' health.

Hypothesis 1a (H1a). Caregivers with lower positive and greater negative emotional connection to the PWD will have poorer health both concurrently and longitudinally. Further, caregivers' positive emotional connection to the PWD will be associated with caregivers' health, independent of caregivers' negative emotional connection to the PWD.

Rationale. Lower PWD-caregiver relationship quality is related to poor health in current caregivers (Fauth et al., 2012; Fitzpatrick & Vacha-Haase, 2010; Magai & Cohen, 1998; Monin et al., 2019). I expect to extend these findings with (1) observational measures of caregivers' emotional connection to the PWD and (2) longitudinal health in former caregivers, given the long-lasting impact of relationships on health (Kiecolt-Glaser & Wilson, 2017).

Second, I anticipate that both positive and negative emotional connection will be related to caregivers' health. However, I also expect that caregivers' positive emotional connection to the PWD will be associated with caregivers' health, independent of their negative emotional connection, in line with positivity resonance theory (Fredrickson, 2013, 2016). Recent studies suggest that shared positive affect predicts social connection and relationship quality more than shared negative affect (Brown et al., 2021; Cheong et al., 2020). Additionally, evidence suggests that supportive social relationships buffer against the health consequences of stressors across time (Slatcher, 2010) by enhancing perceived social resources and support (Uchino, 2004). Given the stressful nature of the caregiving environment, I expect that caregivers' positive emotional connection to the PWD may be especially potent in mitigating against the adverse health consequences associated with caregiving.

Hypothesis 1b (H1b). The within-person associations between caregivers' emotional connection to the PWD and their health will be stronger longitudinally (in former caregivers) than concurrently (in current caregivers).

Rationale. I expect the influence of caregivers' emotional connection to the PWD on caregiver health to be even more prominent after caregiving has ended because the effects of relationships on health often take years to emerge (e.g., Haase et al., 2016), particularly as individuals age and their social networks shrink (Rook & Charles, 2017).

Aim 2: To determine the predictive validity of caregivers' emotional connection to the PWD on (current and former) caregivers' health by identifying longitudinal mechanisms, ruling out alternative hypotheses, and probing robustness of associations.

Hypothesis 2a (H2a). Longitudinal associations between caregivers' emotional connection to the PWD and caregivers' health will be mediated by increases in caregivers' loneliness.

Rationale. It is well-documented that loneliness contributes to poor health (Luo et al., 2012) and the incidence of loneliness is known to increase with age (Dykstra et al., 2005), when social networks are known to shrink (Carstensen et al., 1999; Wrzus et al., 2013). Research also shows that chronic loneliness impairs health in an accelerated manner across the lifespan (Hawkley & Capitanio, 2015) and that loneliness is related to poor relationship quality in PWD caregivers (Beeson et al., 2000). Therefore, loneliness represents a plausible behavioral mechanism through which poorer emotional connection to the PWD erodes caregiver health.

Hypothesis 2b (H2b). Caregivers' emotional connection to the PWD will predict caregivers' health, independent of individual-level emotion.

Rationale. In order to demonstrate the "value added" of caregivers' emotional connection to the PWD, it is important to rule out alternative hypotheses that may also be associated with caregivers' health, such as individual-level emotion. First, although an individual's emotions are known to predict their health (Gallo & Matthews, 2003; Gross & Muñoz, 1995; Mostofsky et al., 2014; Pressman & Cohen, 2005; Richman et al., 2005), additional work indicates that the effects of emotions are amplified when socially shared (Boothby et al., 2014; Brown et al., 2021; Kurtz & Algoe, 2015), possibly because shared emotion grows more intense and lasts longer (e.g., Gable et al., 2004; Kraut & Johnston, 1979). Therefore, measures of caregivers' emotional connection to the PWD may be more predictive of caregivers' health than measures of caregivers' individual-level emotion.

Hypothesis 2c (H2c). Caregivers' emotional connection to the PWD will robustly predict caregivers' health, independent of theoretically related constructs (e.g., marital satisfaction, self-efficacy) and covariates (e.g., demographic and PWD factors) identified from the literature.

Rationale. Marital satisfaction and self-efficacy are related to the emotional quality of the PWD-caregiver relationship and play a role in caregivers' health and well-being (Carbonneau et al., 2010; Fitzpatrick & Vacha-Haase, 2010; Monin et al., 2019). However, self-report measures can be subject to bias (Van de Mortel, 2008), particularly in caregivers who are in poor psychological health (Schulz et al., 2013). Observational measures may provide additional information about the emotional qualities of the PWD-caregiver relationship and reveal powerful associations with caregivers' health.

Although contextual, PWD, and caregiver characteristics influence caregiver health (Brodaty & Donkin, 2009; Ornstein & Gaugler, 2012; Schulz et al., 1995), the quality of the emotional connection is also important (Fauth et al., 2012; Monin et al., 2019), and may provide a more malleable target for mechanism-based interventions (e.g., couples' communication is easier to change than income or PWD diagnosis).

Analytic Approach

All analyses for Study 1 and Study 2 were conducted separately (see **Table 3** and **Table 4** for descriptive statistics and intercorrelations among key study variables). Analyses that were conducted in a structural equation modeling (SEM) framework utilized the *lavaan* package in R (R Core Development Team, 2019; Rosseel, 2012). All models were fit to the entire sample using Full Information Maximum Likelihood (FIML) estimation, maximizing the use of our sample. To evaluate model fit in SEM, the χ^2 test of model fit was inspected as an absolute fit index, and the comparative fit index (CFI) and root mean square error of approximation (RMSEA) were inspected as relative fit indices, following established guidelines (Hu & Bentler, 1999). Nonsignificant χ^2 values (*p*s > 0.05); CFI values greater than 0.95 and RMSEA values less than .08 were used to indicate satisfactory model fit.

To address **Aim 1**, I tested associations between caregivers' positive and negative emotional connection to the PWD (i.e., co-experienced affect or emotional connection language) and caregivers' health (i.e., depression, anxiety, physical health), examining concurrent associations and longitudinal associations separately (**H1a**). Then, I compared the relative strength of significant concurrent versus longitudinal associations (**H1b**).

To address **Aim 2**, I tested associations between caregivers' positive and negative emotional connection to the PWD and caregivers' loneliness (**H2a**); first, examining concurrent associations and longitudinal associations separately; then, exploring changes in loneliness (modeled as a latent variable) as a mediator (Study 2 only). Next, I probed the robustness of significant, concurrent associations by accounting for theoretically related constructs (**H2b**) and a set of *a priori* covariates (**H2c**) used in previous studies (Brown et al., 2020; Chen et al., 2017; Hua et al., 2019; Wells et al., 2019; Wells et al., 2020), including caregiver age (in years), sex (0 = male, 1 = female), and race (0 = person of color, 1 = White); PWD diagnosis (2 variables coded: AD [0 = no, 1 = yes] and bvFTD [0 = no, 1 = yes]; Study 1 only), PWD dementia severity (CDR [Study 1] or QDRS [Study 2]; Galvin, 2015; Morris, 1993), PWD cognitive impairment (MMSE [Study 1 only]; Folstein et al., 1975); and Care Ecosystem intervention group assignment (Study 2 only; 0 = usual care, 1 = intervention). Finally, I conducted multiple regression analyses with caregivers' emotional connection to the PWD predicting changes in caregivers' health, adjusting for significant covariates from the cross-sectional analyses as well as the amount of time since the death of the PWD (given that the timing of a loss is associated with elevations in distress in some individuals; e.g., Bonanno et al., 2002).

Study 1 Results

Preliminary Analyses to Establish Validity of Co-Experienced Affect Measures

Zero-order Pearson's correlations were conducted to examine the associations between BIPR and the four rating dial measures (co-experienced positive affect, co-experienced negative affect, individually experienced positive affect, individually experienced negative affect). As expected, BIPR coding of shared positive affect was significantly positively correlated with co-experienced positive affect ($r(80) = .53$, $p < .001$) and negatively correlated with co-experienced negative affect ($r(80) = -.32$, $p = .003$). In addition, BIPR was not significantly correlated with individual-level positive affect ($r(80) = -.08$, $p = .49$) nor individual-level negative affect ($r(80) = -.15$, $p = .19$).

Associations Between Co-Experienced Affect and Caregivers' Health

Concurrent Associations

Three multiple regression analyses were conducted with both co-experienced positive affect and co-experienced negative affect (measured by the rating dial) as predictor variables and caregivers' concurrent (1) depression, (2) anxiety, or (3) physical functioning as the criterion measure.

First, co-experienced positive affect was not associated with caregivers' depression ($\beta = .15$, $t(79) = 1.04$, $p = .30$); whereas co-experienced negative affect was significantly associated with caregivers' depression ($\beta = .33$, $t(79) = 2.23$, $p = .029$), such that greater co-experienced negative affect was associated with greater levels of depression. Second, neither co-experienced positive affect ($\beta = -.03$, $t(77) = -0.17$, $p = .87$) nor co-experienced negative affect ($\beta = .18$, $t(77) = 1.67$, $p = .25$) were significantly associated with caregivers' anxiety. Third, again, neither co-experienced positive affect ($\beta = -.09$, $t(70) = -0.58$, $p = .57$) nor co-experienced negative affect ($\beta = -.19$, $t(70) = -1.18$, $p = .24$) were significantly associated with caregivers' physical functioning.

Longitudinal Associations

Three multiple regression analyses were conducted to examine whether co-experienced positive affect and co-experienced negative affect (measured by the rating dial) were associated with *changes* in caregivers' (1) depression, (2) anxiety, and (3) physical functioning. In each of these analyses, caregivers' baseline levels of the respective criterion measure are always included as a covariate.

First, in a multiple regression with caregivers' depression (measured at the follow-up survey) as the criterion measure and co-experienced positive affect, co-experienced negative affect, and caregivers' initial levels of depression as predictors, neither co-experienced positive affect ($\beta = .39$, $t(15) = 2.13$, $p = .051$) nor co-experienced negative affect ($\beta = .24$, $t(15) = 1.33$, $p = .20$) were significantly associated with changes in caregivers' depression.

Second, in a multiple regression with caregivers' anxiety (measured at the follow-up survey) as the criterion measure and co-experienced positive affect, co-experienced negative affect, caregivers' initial levels of anxiety as predictors, neither co-experienced positive affect ($\beta = .06$, $t(15) = 0.33$, $p = .74$) nor co-experienced negative affect ($\beta = .13$, $t(15) = 0.77$, $p = .45$) were associated with changes in caregivers' anxiety.

Third, in a multiple regression with caregivers' physical functioning (measured at the follow-up survey) as the criterion measure and co-experienced positive affect, co-experienced negative affect, caregivers' initial levels of physical functioning as predictors, neither co-experienced positive affect ($\beta = .01$, $t(14) = 0.64$, $p = .53$) nor co-experienced negative affect ($\beta = -.01$, $t(14) = -0.58$, $p = .57$) were associated with changes in caregivers' physical functioning.

Comparing the Strength of Concurrent Versus Longitudinal Associations

No significant longitudinal associations between co-experienced affect (positive or negative) and caregivers' health (depression, anxiety, physical functioning) were found for Study 1. Therefore, the strength of concurrent versus longitudinal associations between co-experienced affect (measured by the rating dial) and caregivers' health was not tested.

Associations Between Co-Experienced Affect and Caregivers' Loneliness

Concurrent Associations

In a multiple regression with caregivers' concurrent loneliness as the criterion measure and both co-experienced positive affect and co-experienced negative affect (measured by the rating dial) as predictors, neither co-experienced positive affect ($\beta = -.07$, $t(78) = -0.51$, $p = .62$) nor co-experienced negative affect ($\beta = .21$, $t(78) = 1.36$, $p = .18$) were significantly associated with caregivers' loneliness.

Longitudinal Associations

In a multiple regression with caregivers' loneliness (measured at the follow-up survey) as the criterion measure and both co-experienced positive affect and co-experienced negative affect (measured by the rating dial) and caregivers' initial levels of loneliness as predictors, co-experienced positive affect was not associated with changes in caregivers' loneliness ($\beta = .01$, $t(15) = 1.74$, $p = .10$). There was a modest, albeit statistically significant, association between co-experienced negative affect and changes in caregivers' loneliness ($\beta = .01$, $t(15) = 2.16$, $p = .048$), such that greater levels of co-experienced negative affect predicted increases in caregivers' loneliness over time.

Robustness of Concurrent Association Between Co-Experienced Negative Affect and Caregivers' Depression

To examine the robustness of the association between co-experienced negative affect (measured by the rating dial) and caregivers' concurrent depression, additional analyses were conducted to rule out alternative hypotheses and account for the potential confounding influence of relevant covariates identified from the literature. Because no significant longitudinal associations were found between co-experienced affect and caregivers' depression, anxiety, or physical functioning, robustness analyses focused only on cross-sectional associations.

Accounting for Theoretically Related Constructs

Individual-Level Negative Affect. Multiple regression analyses were conducted with both co-experienced negative affect and caregivers' individually experienced negative affect (measured by the rating dial) as predictors and caregivers' concurrent depression as the criterion measure. There was no association between individually experienced negative affect and caregivers' depression ($\beta = -.06$, $t(79) = -0.55$, $p = .58$), and the association between co-experienced negative affect and caregivers' depression was no longer statistically significant ($\beta = .22$, $t(79) = 1.96$, $p = .054$).

Marital Satisfaction. In a multiple regression with co-experienced negative affect (measured by the rating dial) and caregivers' self-reported marital satisfaction as predictors and caregivers' concurrent depression as the criterion measure, the association between co-experienced negative affect and depression was not significant ($\beta = -.08$, $t(51)= -0.71$, $p = .48$). However, there was a significant, inverse association between caregivers' marital satisfaction and depression ($\beta = -.54$, $t(51)= -4.67$, $p < .001$) such that greater marital satisfaction was associated with lower levels of depression.

Accounting for Caregiver Demographics and PWD Factors

Multiple regression analyses were conducted with co-experienced negative affect; caregivers' age, sex, and race; and PWDs' diagnosis, cognitive impairment, and dementia severity as predictors, and caregivers' concurrent depression as the criterion measure. The association between greater co-experienced negative affect and greater depression remained significant ($\beta = .21$, $t(69) = 2.05$, $p = .044$). Of the covariates, only PWD dementia severity was associated with caregivers' depression ($\beta = .44$, $t(69) = 3.57$, $p < .001$), such that greater dementia severity was associated with higher levels of caregiver depression. The overall model was statistically significant (Adjusted $R^2 = .26$, $F(8, 69) = 4.36$, $p < .001$).

Study 1 Results Summary

In summary, greater co-experienced negative affect (measured by the rating dial) was associated with higher levels of caregivers' concurrent depression, but not caregivers' concurrent anxiety or physical functioning. The association between co-experienced negative affect and caregivers’ concurrent depression was robust when accounting for caregivers’ age, sex, and race and PWDs’ diagnosis, cognitive impairment, and dementia severity. However, this association was not robust when accounting for caregivers’ individual-level negative affect or self-reported marital satisfaction. In addition, co-experienced negative affect was not associated with longitudinal changes in caregivers’ depression, anxiety, or physical functioning. Although co-experienced negative affect was not associated with caregivers’ concurrent loneliness, there was a significant association with changes in loneliness, such that greater co-experienced negative affect predicted increases in caregivers’ loneliness over time. Finally, there were no significant cross-sectional or longitudinal associations between co-experienced positive affect and caregivers’ depression, anxiety, physical functioning, or loneliness.

Study 2 Results

Associations Between Emotional Connection Language and Caregivers’ Health

Concurrent Associations

Two multiple regression analyses were conducted with both positive and negative emotional connection language as predictors and either caregivers’ concurrent (1) depression or (2) subjective health as the criterion measure. First, positive emotional connection language was significantly associated with caregivers’ depression (β = -.11, $t(332)$= -2.02, p = .045), such that greater positive emotional connection language was associated with lower levels of depression; and negative emotional connection language was not significantly associated with caregivers’ depression (β = -.05, $t(332)$= -.88, p = .38). Second, neither positive emotional connection language (β = -.06, $t(332)$= -.54, p = .60) nor negative emotional connection language (β = .12, $t(332)$= .79, p = .43) were significantly associated with caregivers’ subjective health.

Longitudinal Associations

Two univariate, two-wave latent change score (2W-LCS) models were constructed in an SEM framework, with both caregivers’ positive and negative emotional connection language predicting within-person changes in either their (1) depression or (2) subjective health (Castro-Schilo & Grimm, 2018; Henk & Castro-Schilo, 2016; Kievit et al., 2018). The means and variances of caregivers’ health (i.e., depression or subjective health) at Time 1 (measured at the baseline survey) were fixed to 0 and 1, respectively; and the means and variances at Time 2 (measured at the post-mortem survey) were fixed to 0. The latent change factor for caregivers’ health was regressed onto caregivers’ positive and negative emotional connection language as well as the latent factor representing caregivers’ Time 1 health. Correlations were modeled between caregivers’ positive and negative emotional connection language and the latent factor representing caregivers’ Time 1 health. All models were fit using robust (Huber-White) standard errors due to non-normal distributions of the emotional language variables. Because these models are just-identified (i.e., have zero degrees of freedom), there are no model fit indices to report (Lei & Wu, 2007).

First, a 2W-LCS model was constructed with a latent factor representing changes in caregivers’ depression as the criterion measures and positive emotional connection language, negative emotional connection language, and a latent factor representing caregivers’ initial levels of depression as predictors. Caregivers’ positive emotional connection language was associated with changes in their depression (ß = -.36, SE(ß) = 0.08, p < .001), such that greater positive emotional connection language predicted decreases in depression after caregiving had ended. In addition, greater baseline depression predicted decreases in depression over time (ß = -.49, SE(ß) = 0.10, $p < .001$). Caregivers' negative emotional connection language was not significantly associated with changes in their depression (ß = -.05, SE(ß) = 0.10, $p = .61$).

Second, a 2W-LCS model was constructed with a latent factor representing changes in caregivers' subjective health as the criterion measure and positive emotional connection language, negative emotional connection language, and a latent factor representing caregivers' initial levels of subjective health as predictors. Neither caregivers' positive emotional connection language (ß = .06, SE(ß) = 0.06, $p = .30$) nor negative emotional connection language (ß = -.03, SE(ß) = 0.13, $p = .81$) was significantly associated with changes in their subjective health after caregiving had ended.[3]

Comparing the Strength of Concurrent Versus Longitudinal Associations

To determine whether the association between caregivers' positive emotional connection language and their depression is significantly different concurrently versus longitudinally, I evaluated change in model fit using chi-square likelihood ratio tests. Two SEMs were constructed, each with two regression paths from caregivers' positive emotional connection language predicting: (1) their depression during caregiving (concurrent) and (2) after caregiving has ended (longitudinal; adjusting for initial levels of depression). In the first SEM, these regression paths were freely estimated. In the second SEM, these regression paths were constrained to be equal. Chi-square likelihood ratio tests revealed that there was not a significant difference in model fit $\chi(1, N = 335) = 1.59$, $p = .21$, suggesting that the strength of the associations between caregivers' positive emotional connection language and their depression may be similar concurrently and longitudinally.

Associations Between Emotional Connection Language and Caregivers' Loneliness

Concurrent Associations

In a multiple regression with caregivers' concurrent loneliness as the criterion measure and both positive emotional connection language and negative emotional connection language as predictors, neither positive emotional connection language ($\beta = -.11$, $t(61) = -0.89$, $p = .38$) nor negative emotional connection language ($\beta = .02$, $t(61) = 0.14$, $p = .89$) were significantly associated with caregivers' current levels of loneliness.

Longitudinal Associations

Modeling Changes in Loneliness. A latent growth curve model (LGM; Olsen & Kenny, 2006) was constructed to model caregivers' loneliness trajectories from the month 30, month 42, and post-mortem surveys, which included a latent intercept (loadings of 1, 1, 1) and a latent slope (loadings of 0, 1, 2). The initial LGM of caregivers' loneliness trajectories (without any predictors) had excellent fit, $\chi^2(1) = .88$; $p = .35$; CFI = 1.00; RMSEA = .00. In addition, the

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[3] Longitudinal analyses were repeated in a regression framework, with caregivers' emotional connection language predicting former caregivers' depression or subjective health (respectively), adjusting for caregivers' initial levels of depression or subjective health. These analyses revealed a similar pattern of results. Caregivers' positive emotional connection language predicted decreases in caregivers' depression ($\beta = -.35$, $t(68)= -2.01$, $p = .049$), whereas negative emotional connection language was not significantly associated with changes in their depression ($\beta = -.05$, $t(68)= -0.77$, $p = .45$). There were no significant associations between caregivers' positive emotional connection language or negative emotional connection language and changes in their subjective health (both *p*s > .64).

loneliness slope was negative, albeit not statistically significant (*ß* = -.40, SE(*ß*) = 0.11, *p* = .13), suggesting that caregivers' loneliness may have decreased across the three timepoints (see **Figure 1**).

Predicting Changes in Loneliness. Another LGM was constructed, with the latent slope of caregivers' loneliness regressed onto caregivers' positive emotional connection language, caregivers' negative emotional connection language, and the latent intercept of caregivers' loneliness. Correlations were included between the latent intercept of caregivers' loneliness and caregivers' positive and negative emotional connection language. The model had excellent fit, $\chi^2(3) = 1.26$; *p* = .74; CFI = 1.00; RMSEA = .00. The results suggested an inverse association between positive emotional connection language and changes in loneliness over time, but it was not statistically significant, (*ß* = -.65, SE(*ß*) = .18, *p* = .078). Negative emotional connection language was not significantly associated with changes in loneliness (*ß* = -.03, SE(*ß*) = .07, *p* = .86).

Loneliness as a Mediator. A mediation model was constructed (see **Figure 2**) to examine whether changes in caregivers' loneliness (modeled as a latent slope via LGM) explain the association between increased positive emotional connection language (during caregiving) and lower depression (after caregiving has ended). Bias-corrected bootstrapped confidence intervals were produced from 1000 samples to test the indirect effects. Confidence intervals that exclude 0 are considered statistically significant, although *p* values are reported for reference, which correspond to the z-statistic under a standard normal distribution (Preacher & Hayes, 2008).

The model had excellent fit, $\chi^2(3) = 4.44$; *p* = .22; CFI = .98; RMSEA = .04. In this model, positive emotional connection language did not significantly predict the latent slope of loneliness, adjusting for the latent intercept of loneliness (*b* = 0.32, 95% CI = [-1.00, 0.23], *ß* = -.46, *p* = .37). Similarly, the latent slope of loneliness did not significantly predict depression, adjusting for the latent intercept of loneliness (*b* = 1.83, 95% CI = [-4.89, 12.62], *ß* = .24, *p* = .96). Finally, positive emotional connection language did not significantly predict depression (b = -1.87, 95% CI = [-9.22, 0.41], *ß* = -.35, *p* = .93). The total effect was significant (*b* = -2.46, 95% CI [-6.47, -0.70], *ß* = -.46, *p* = .088), but the indirect effect was not significant (*b* = -.59, 95% CI [-8.45, 1.96], *ß* = -.11, *p* = .98). Therefore, the results from this model indicate that changes in loneliness do not mediate the association between positive emotional connection language and former caregivers' depression.

Longitudinal Changes in Loneliness and Depression. Exploratory analyses were conducted to examine whether changes in caregivers' loneliness are associated with changes in their depression, and whether positive emotional connection language is independently associated with these two change processes. Changes in loneliness and depression were modeled from the month 42 survey to the post-mortem survey using a bivariate 2W-LCS model. As expected, changes in depression were positively associated with changes in loneliness (*ß* = .49, SE(*ß*) = 0.09, *p* = .009). In addition, greater positive emotional connection language predicted decreases in caregivers' depression (*ß* = -.36, SE(*ß*) = 0.16, *p* = .046), but did not predict changes in caregivers' loneliness (*ß* = -.37, SE(*ß*) = 0.31, *p* = .38), when accounting for earlier levels of each construct.

Robustness of Associations Between Positive Emotional Connection Language and Caregivers' Depression

Accounting for Covariates in Concurrent Associations with Depression

To examine the robustness of the association between positive emotional connection language and caregivers' depression, additional analyses were conducted to rule out alternative hypotheses and account for the potential confounding influence of relevant covariates identified from the literature. The results focus first on concurrent associations, then longitudinal associations. The robustness of longitudinal associations was examined by accounting for significant covariates in the cross-sectional analysis. In addition, given data collection procedures, the timing of the administration of the post-mortem survey varied across caregivers, and thus the amount of time since the death of the PWD was included as a covariate in longitudinal analyses.

Positive Emotional Coping Language. A SEM was constructed that included regression paths from both positive emotional connection language (measured at month 6) and positive emotional coping language (measured at month 12) to caregivers' depression. Depression was modeled as a latent factor indicated by the caregivers' total scores on the PHQ-9 at the month 6 and month 12 surveys, with factor loadings constrained to be equal across timepoints. The SEM had excellent fit, $\chi^2(2) = 0.60$; *p* = .74; CFI = 1.00; RMSEA = .00. The association between positive emotional coping language and depression was not significant (*ß* = .01, SE(*ß*) = 7.23, *p* = .94), and the association between positive emotional connection language and depression was no longer statistically significant (*ß* = -.12, SE(*ß*) = .61, *p* = .083).

Caregiver Self-Efficacy. In a multiple regression with positive emotional connection language and caregivers' self-reported self-efficacy predicting caregivers' concurrent depression, the association between positive emotional connection language and depression was not statistically significant (*β* = -.09, *t*(332)= -1.87, *p* = .063). However, there was a significant association between caregivers' self-efficacy and depression (*β* = -.35, *t*(332)= -6.86, *p* < .001), such that greater levels of self-efficacy were associated with lower levels of depression.

Caregiver Demographics, Intervention Group, and PWD Factors. Multiple regression analyses were conducted with caregivers' concurrent depression as criterion measure and the following predictors: caregivers' positive emotional connection language; caregivers' age, gender, and race; intervention group assignment; and PWDs' dementia severity. The association between positive emotional connection language and depression was not significant (*β* = -.10, *t*(269) = -1.39, *p* = .17), and there were no significant associations between any of the covariates and caregivers' depression.

Accounting for Significant Covariates in Longitudinal Associations with Depression

Longitudinal analyses were repeated with positive emotional connection language predicting a latent factor representing changes in caregivers' depression, accounting for baseline levels of depression, the amount of time between the death of the PWD to the post-mortem survey, and caregivers' baseline levels of self-efficacy. Correlations were modeled among all covariates. In a 2W-LCS model, greater positive emotional connection language continued to predict decreases in depression (*ß* = -.38, SE(*ß*) = 0.10, *p* < .001), when accounting for baseline levels of depression. Of the covariates, greater baseline depression predicted decreases in depression ($ß = -.44$, SE($ß$) = 0.10, $p < .001$) as did more time since the death of the PWD ($ß = -.19$, SE($ß$) = 0.08, $p = .024$).[4]

Study 2 Results Summary

In summary, greater positive emotional connection language was associated with lower levels of caregivers' concurrent depression, but not caregivers' subjective health. However, the association between positive emotional connection language and depression was not robust when accounting for alternative hypotheses (i.e., positive emotional coping language) or relevant covariates from the literature (caregiver self-efficacy, caregiver demographic factors, intervention group assignment, PWD dementia severity). Still, greater positive emotional connection language was associated with longitudinal decreases in depression after caregiving had ended, and this association was robust when accounting for caregiver self-efficacy and time since the death of the PWD. Positive emotional connection language was not associated with either caregivers' concurrent loneliness nor changes in loneliness over time; but the association between greater positive emotional connection language and decreases in caregivers' depression was independent of their earlier levels of loneliness. Finally, there were no significant cross-sectional or longitudinal associations between negative emotional connection language and caregivers' depression, subjective health, or loneliness.

Discussion

Social connection—the structure, function, and quality of our relationships—is vital for health and well-being. Dementia caregivers often lack social connection in numerous ways, which may contribute to their remarkably elevated rates of mental and physical health problems. The PWD-caregiver relationship is a central feature of the caregiving experience, and interpersonal emotional processes play a major role in shaping the quality of close relationships. The positive and negative emotional qualities of caregivers' connection to the person in their care is an aspect of social connection that may be a source of vulnerability or resilience to caregivers' current and future health outcomes.

The present study evaluated two observational measures of caregivers' emotional connection to the PWD in relation to caregivers' health during caregiving and after caregiving has ended. Regarding study hypotheses, first (**H1a**), greater positive and lower negative PWD-caregiver emotional connection were expected to predict worse health in current and former caregivers. Second (**H1b**), associations between PWD-caregiver emotional connection and caregivers' health were expected to be stronger longitudinally than concurrently. Third (**H2a**), longitudinal associations between PWD-caregiver emotional connection and caregivers' health were expected to be mediated by increases in caregivers' loneliness. Fourth (**H2b**), positive PWD-caregiver emotional connection was expected to predict caregivers' health, independent of negative PWD-caregiver emotional connection and individual-level emotion. Fifth (**H2c**), associations between PWD-caregiver emotional connection and caregivers' health were expected to be independent of relevant covariates identified from the literature. Consistent with the

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[4] Longitudinal analyses were repeated in a regression framework, with caregivers' positive emotional connection language predicting former caregivers' depression, adjusting for the same covariates (caregivers' baseline depression, the amount of time between the death of the PWD to the post-mortem survey, and caregivers' baseline self-efficacy). These analyses revealed similar results. Caregivers' positive emotional connection language predicted decreases in depression after caregiving had ended ($\beta = -.37$, $t(63) = -2.22$, $p = .030$).

primary hypothesis (**H1a**), aspects of PWD-caregiver emotional connection were associated with current and former caregivers' health. Specifically, greater co-experienced negative affect and lower positive emotional connection language were associated with higher levels of depression in caregivers. There was mixed evidence regarding the robustness of these effects, their temporal dynamics (i.e., cross-sectional or longitudinal), and associations with caregivers' loneliness.

Study 1 focused on caregivers' subjective ratings of affect that they co-experienced with the PWD. Results revealed that greater co-experienced negative affect that occurred during a laboratory-based interaction between caregivers and PWDs was associated with higher levels of depressive symptoms and loneliness in current caregivers. No significant associations were found with co-experienced positive affect or with caregiver anxiety and physical functioning. In addition, the fourth hypothesis (**H2b**) predicted that the association between co-experienced *positive* affect and caregivers' health would be independent of co-experienced *negative* affect, but the results pointed to the opposite effect; the association between co-experienced *negative* affect and caregivers' depression was independent of co-experienced *positive* affect. Further, the association between co-experienced negative affect and caregivers' depression was not robust when accounting for individual-level negative affect, marital satisfaction, or other sociodemographic and contextual covariates. There were also no significant longitudinal associations found between co-experienced affect and changes in caregivers' health.

Study 2 focused on caregivers' emotional language when describing a time they felt connected to the PWD. Results revealed that greater positive emotional connection language was associated with lower levels of depressive symptoms in current caregivers and decreases in depressive symptoms in former caregivers. Contrary to the second hypothesis (**H1b**), there were no significant differences in the strength of this association concurrently versus longitudinally. Partial support was found for the fourth hypothesis (**H2b**), in that the association between *positive* emotional connection language and caregivers' depression was independent of *negative* emotional connection language, but not *individual-level* positive emotion (indexed by positive emotional coping language). In addition, partial support was found for the fifth hypothesis (**H2c**): the concurrent association between positive emotional connection language and caregivers' depression was not robust when accounting for covariates, but the longitudinal associations between positive emotional connection language and changes in caregivers' depression were robust when adjusting for caregivers' baseline self-efficacy, age, PWD dementia severity, as well as the time interval between the death of the PWD and the post-mortem survey. Finally, there was weak evidence suggesting that greater positive emotional connection language may be associated with longitudinal decreases in caregivers' loneliness ($ß = -.65$), but this association was not statistically significant ($p = .077$). In addition, changes in loneliness did not mediate the association between positive emotional connection language and former caregivers' depression, contrary to the third hypothesis (**H2a**).

Taken together, these results suggest that caregivers who have more co-experienced negative affect with the PWD (Study 1) and caregivers who use less positive emotional connection language (Study 2) experience have higher levels of depression and loneliness.

Negative Co-Experienced Affect and Depression

The results suggest that greater co-experienced negative affect is a risk factor for greater depression in active caregivers of PWDs. Given the cross-sectional nature of this finding, the direction of this association is unclear. It may be that caregivers who are experiencing higher levels of depressive symptoms are more likely to perceive and possibly evoke moments of shared negative affect in social interactions with the PWD. In line with this view, prospective studies of emotion contagion find that individuals experiencing depression tend to induce more negative affect and depressive symptoms in others (Joiner & Katz, 1999). On the other hand, it could be that experiencing more moments of shared negative affect with the PWD contributes to caregivers feelings of greater depression. Ample evidence demonstrates that high levels of negative affect and negative affect reciprocity are associated with marital dissatisfaction, which is robustly linked with greater depression (Beach, 2014; Levenson et al., 1994; Levenson & Gottman, 1985). In the current study, the association between co-experienced negative affect and caregivers' depression was not independent of caregivers' self-reported marital satisfaction, which could be expected given that marital satisfaction and depression shared common method variance (i.e., self-report questionnaire). However, decreased marital satisfaction could also be a mechanism that explains the association between co-experienced negative affect and caregivers' depression. Moreover, the association between co-experienced negative affect and depression is likely bidirectional.

There are additional considerations regarding the specificity of this finding. First, the results indicate that co-experienced negative affect, and not individually experienced negative affect, is associated with caregivers' depression. Although emotions typically occur in the context of social interactions or relationships (Butler, 2011; Levenson, 2013), few studies examine dyad-level or group-level interpersonal emotional processes (cf. Kang & Wheatley, 2017; Timmons et al., 2015). The present results suggest that measuring dyad-level, shared emotion may elevate our understanding of individual differences in health. Relationship partners may form a dyadic emotional system, influencing each other across emotional channels (e.g., experience, behavior, physiology), which contributes to emotional and physiological stability for both individuals in a close relationship (Butler & Randall, 2013). For instance, evidence suggests that holding a romantic partner's hand can reduce neural activation in response to an impending threat (Coan et al., 2006). At the same time, interpersonal regulatory processes can also go awry, leading to undesirable consequences. For example, when two individuals co-ruminate by repeatedly discussing their worries, they both tend to experience increased anxiety (Parkinson & Simons, 2012). Additional work is needed to clarify the specific mechanisms through which interpersonal emotional processes are linked with health (e.g., interpersonal emotion regulation, synchrony; Butler, 2015).

Next, significant associations were not found between co-experienced positive affect and caregivers' health. This finding contrasts with my own prior research in middle aged and older adult couples (non-caregivers) showing that co-experienced positive affect predicts long-term health and longevity (Wells et al., 2022) along with numerous studies demonstrating links between positive affect and health (e.g., Folkman & Moskowitz, 2000; Fredrickson et al., 2008; Pressman & Cohen, 2005). Dementia caregiving relationships have unique characteristics and consequences, and stressful experiences are an intrinsic aspect of dementia caregiving (Pearlin et al., 1990). Caregivers' subjective ratings of affect were drawn from a conflict conversation, which often induces stress (Levenson & Gottman, 1983), and caregivers may be especially vulnerable to moments of shared negative affect in this context. Perhaps associations between co-experienced positive affect and caregivers' health would emerge in an interaction context where positive affect is more prevalent (e.g., lower co-experienced positive affect may be more diagnostic of interpersonal problems in this context). In addition, there may be contexts in which co-experienced negative affect is associated with more favorable outcomes, such as when one individual is providing social support to another individual who is in distress.

Finally, no significant concurrent associations were found between co-experienced affect and caregivers' anxiety or physical functioning, and no longitudinal associations were found with any measure of health. Regarding anxiety, these findings add to the traditional nosology classifying anxiety and depression as overlapping, but somewhat distinct, constructs (e.g., Clark & Watson, 1991; Kotov et al., 2017). Additionally, caregivers' subjective ratings of affect were measured using a dimensional approach (i.e., positive to negative) rather than a specific-emotions approach. It may be that caregivers' and PWDs' shared experiences of specific emotions, such as sadness and guilt, are associated with higher levels of depression, whereas shared experiences of specific emotions such as fear are associated with higher levels of anxiety. Regarding physical functioning, the effects of relationships on health often become stronger over time, as individuals age and their social networks shrink (Rook & Charles, 2017), and therefore these effects might not be observed cross-sectionally. Still, there were no longitudinal associations between co-experienced affect and health found in this study. One reason may have been the substantially reduced sample size at the follow-up survey, which reduced statistical power for detecting longitudinal associations with health. In addition, co-experienced affect might confer both risk and resilience to long-term changes in caregivers' health. Although co-experienced negative affect was associated with elevated risk for caregiver depression concurrently, the absence of co-experienced negative affect following the death of the PWD may lead caregivers to feel relieved, and consequently, less depressed (i.e., more resilient) after caregiving has ended.

Positive Emotional Connection Language and Depression

These findings indicate that lower positive emotional connection language is associated with greater depression in current of caregivers of PWDs and greater increases in depression in former caregivers of PWDs. It is compelling to posit that positive emotional connection language is a resilience-related factor that protects against the development of depressive symptomatology, but it is not possible to determine causality with these observational, cross-sectional data. Of course, depression can also influence the spoken language of individuals (Rude et al., 2004), and caregivers who are more depressed may use less positive emotional language when describing their connection to the PWD. Regardless of the direction of these effects, the present results deepen our understanding of emotional language and depression in caregivers of PWDs, and they highlight positive emotional connection language as a potential resilience factor against the development of depressive symptomatology.

The associations with caregivers' depression were specific to positive (but not negative) emotional language, and to positive connection (but not positive coping) language. Caregivers who use more positive language to describe their connection to the PWD may be more satisfied with their relationship, which could lead to lower levels of depression. In addition, these caregivers may experience more positive emotion during interactions with the PWD, which are a fundamental component of the caregiving experience. Sharing positive affect with others may be even more consequential for health and well-being than individual experiences of positive affect (Fredrickson, 2016). Therefore, caregivers may derive more benefits, such as lower depression, from positive affect that is experienced in a social context (i.e., connecting with the PWD) compared to a less social context (i.e., coping with challenges). Nevertheless, the association between positive emotional connection language and depression was not completely independent of positive emotional coping language. Although there was no significant association between positive emotional coping language, the inclusion of this variable in the model attenuated the association between positive emotional connection language and caregivers' depression such that it was no longer statistically significant (*p* = .083). This may be because in general, positive emotional language tends to reflect an optimistic disposition (Gasper et al., 2020), and optimism is associated with lower vulnerability to depression (Achat et al., 2000; Scheier et al., 2001).

Caregivers' Emotional Connection to the PWD and Loneliness

The two studies showed disparate patterns of findings in terms of the associations between caregivers' emotional connection to the PWD and caregivers' loneliness. In Study 1, greater negative co-experienced affect was associated with greater loneliness in current caregivers, but there were no significant longitudinal associations with loneliness. By contrast, in Study 2, emotional language was not significantly associated with caregivers' concurrent levels of loneliness, but greater positive emotional connection language modestly predicted decreases in loneliness over time (although this association only approached significance, *p* = .077). Decreased loneliness was hypothesized to be a mechanism through which greater positive emotional connection contributes to decreases in depression. However, support was not found for this proposed mediation effect, and positive emotional connection language predicted only decreases in depression, but not loneliness, when modeling these two change processes simultaneously.

The bidirectional association between loneliness and depression is well-documented, especially in older adults (Cacioppo et al., 2006; Cohen-Mansfield et al., 2016; Domènech-Abella et al., 2017). There is strong evidence from prospective, longitudinal studies that loneliness predicts subsequent increases in depressive symptoms (Cacioppo et al., 2010) and that depressive symptoms predict subsequent increases in loneliness (Dahlberg et al., 2015). Additionally, the literature has identified numerous correlates of loneliness, such as perceived emotional support, perceived instrumental support, and large, diverse social networks (Santini et al., 2015). Discrepancies across findings (e.g., whether loneliness predicts depression, or vice versa) may be related to different conceptualizations of loneliness. Weiss proposed that there are two types of loneliness: social loneliness, which refers to a deficit in the amount or quality of relationships; and emotional loneliness, which refers to a deficit in relationship closeness and intimacy (Weiss, 1973). Many dementia caregivers are likely to experience both forms of loneliness, including social isolation from the increasing demands of caregiving as well as declines in relationship quality with the PWD as the disease progresses (Victor et al., 2021).

It is interesting to note that across the sample in Study 2, caregivers' average levels of loneliness decreased between the month 42 survey and the post-mortem survey. Although some caregivers continue to experience high levels of loneliness during the end-stage of dementia (Shanley et al., 2011) and after caregiving has ended (Robinson-Whelen et al., 2001), it appears that some caregivers may feel less lonely in the later stages of caregiving and after caregiving ends. The reason for the observed "bounce back" effect in loneliness is unknown. As caregivers adapt to the caregiving role, they might become more comfortable reaching out to their social networks for support, leading to decreases in social loneliness. In addition, caregivers may accept the inevitable loss of their relationship with the PWD (e.g., anticipatory grief) and feel less emotional loneliness over time. These explanations fit with the literature pointing to the protective impact of social support during active caregiving and during bereavement (Almberg et al., 2000). The possible longitudinal association between greater positive emotional connection language and decreases in caregivers' loneliness highlights a potential resilience factor. Caregivers who use more positive emotional language to describe their connection with the

PWD may also have more positive emotional connections in general (i.e., with others in their social network), which could help them feel less lonely as they transition from active caregiving.

Measurement of Emotional Connection

Two approaches from affective science were used to characterize the emotional quality of the connection between dementia caregivers and the person in their care. In the first approach, caregivers engaged in a naturalistic interaction with the PWD and provided continuous ratings of their affective valence and of the PWD's affective valence, which were analyzed together to quantify co-experienced positive and negative affect. In the second approach, caregivers responded to an open-ended question about a time they felt connected to the PWD, and the transcripts of their responses were analyzed to quantify positive and negative emotional language. Both approaches, while observational in nature, are drawn from the perspective of the caregiver, and thus the results should be interpreted through that lens. For instance, in Study 1, caregivers evaluated the PWD's affective valence, rather than PWDs rating their own affect, which may have yielded different results. In Study 2, the caregivers' emotional language was interpreted to reflect the emotional quality of the PWD-caregiver relationship, but the PWDs may have different perceptions of the relationship and use different language to describe it.

This study focused on subjective emotional experience and emotional language, which represent distinct, yet related, aspects of emotional functioning. The subjective experience, or "*feelings*", comprises the phenomenological state of an individual (Nummenmaa et al., 2018). On the other hand, language is a behavior that functions to communicate information and express emotion, which can reveal insights into one's priorities, intentions, and thoughts (Tausczik & Pennebaker, 2010). Whereas the subjective experience is a consciously accessible feeling, emotional language may reflect unconscious states, such as when errors in speech betray a person's deeper motives or fears (Freud, 1901; Pennebaker et al., 2003). Caregivers' use of positive emotional language could indicate a positive subjective state, but it could also reflect more durable attitudes, beliefs, or traits (e.g., optimism) that have long-lasting benefits for health (e.g., Danner et al., 2001). It is useful to measure both language and experience (along with other emotion modalities, such as facial behavior and physiology) in order to obtain comprehensive assessments of emotional functioning.

These results suggest that both positive and negative emotion are important for different aspects of the caregivers' emotional connection to the PWD, and accordingly, their health. Specifically, negative affective experience and positive emotional language were both associated with caregivers' depression. This pattern of findings fits with the literature highlighting that positive and negative affect are independent constructs (Diener et al., 1995). That is, the absence of negative affect does not imply the presence of positive affect (and vice versa). Therefore, it is important to consider both negative and positive dimensions of affect when evaluating emotional connection. Although not addressed in the current study, mixed emotional states (i.e., both positive and negative) can also occur, and are likely common in the caregiving context (e.g., feeling both affection and sadness). Future research should evaluate mixed emotions regarding the caregivers' emotional connection to the PWD and associations with caregivers' health.

Clinical Implications

Caregivers of PWDs have heightened risk for poor mental and physical health and reduced quality of life (Schulz et al., 1995). Experiences of loneliness and social disconnection are common among dementia caregivers (Beeson, 2003; Kovaleva et al., 2018), and may persist for years after caregiving has ended (Robinson-Whelen et al., 2001). Apart from a recent pilot study (Van Orden et al., 2023), there are currently no evidence-based interventions that promote social connection in dementia caregivers (Van Orden & Heffner, 2022). In general, interventions targeting the PWD-caregiver dyad are rare (but cf. Whitlatch et al., 2006; Zarit et al., 2004), and have focused on communication, care planning, and mutual understanding. One study proposed that teaching caregivers supportive skills could enhance the quality of the PWD-caregiver relationship, but the intervention was not found to be effective (Martin-Cook et al., 2005). The present study adds to a growing literature highlighting caregivers' social connection as a promising intervention target to improve dementia caregivers' health and well-being (Van Orden & Heffner, 2022)

In particular, interventions that enhance caregivers' emotional connection to the PWD may help reduce caregivers' depressive symptoms and loneliness. Based on the findings from Study 1, it could be useful to explore interventions that reduce moments of co-experienced negative affect among PWD-caregiver dyads. Additional work is needed to clarify the nature of these emotional moments. For instance, if caregivers are sharing the negative affect and distress of PWDs, leading to increases in their own distress, then interventions that increase emotional distance between oneself and another's distress could be useful (Hua et al., 2021). In addition, the results from Study 2 suggest that increasing caregivers' positive emotions about connecting with the PWD may be a potential avenue for intervention. Interventions that create opportunities for shared, meaningful, and pleasurable activities among the caregiver-PWD dyad (e.g., listening to music together; Baker et al., 2012) might reduce caregivers' depression by increasing the quality of their emotional connection to the PWD (Gallagher-Thompson et al., 2001; Roland & Chappell, 2015).

It is important to acknowledge that it may not be possible for the caregiver-PWD dyad to engage in these activities, especially as the disease progresses. Therefore, it could be useful to explore whether strengthening caregivers' social connection (i.e., the quantity and quality of social ties) with others may improve their health and well-being (Holt-Lunstad et al., 2017). A handful of studies have found that behavioral activation interventions can reduce loneliness in non-caregiving older adults (Bruce et al., 2021; Choi et al., 2020; Pepin et al., 2021), however many promising interventions are too time-consuming to be feasible for already busy and overburdened dementia caregivers. Low-cost, scalable interventions that enhance social connection in dementia caregivers are needed, such as those that leverage technology and enhance social support (Czaja et al., 2013; Czaja & Rubert, 2002). Future research should also investigate treatment targets for caregiver anxiety, given that no significant associations were found in this study and interventions vary in their effectiveness for particular problems for caregivers (Sun et al., 2022).

Strengths and Limitations

Strengths of this study include examining two independent samples of dementia caregivers; collecting follow-up data to understand the longitudinal trajectories of caregivers' health, including after caregiving has ended; measuring loneliness longitudinally to assess mechanisms and changes over time; recruiting a heterogeneous sample in terms of neurodegenerative disease diagnoses; and utilizing observational measures of caregivers' emotional connection to the PWD rather than traditional self-report questionnaires.

Limitations of this study include lack of racial and ethnic diversity in study samples, which limits the generalizability of the results. Second, relatively modest effects were not robust to the inclusion of some covariates. Third, unstandardized time intervals for the follow-up data collection were an issue. Prospective, longitudinal studies of dementia caregiving are needed to characterize their health and well-being as they transition from the caregiving role. Fourth, low response rates in the follow-up survey, particularly in Study 1, limited the examination of health changes in former caregivers, after caregiving has ended.

In addition, the Study 1 time series analyses classified seconds into discrete categories (i.e., co-experienced positive affect, co-experienced negative affect, individually experienced positive affect, individually experienced negative affect). This method ignores differences in affect intensity and patterns that could emerge from a more dimensional approach. For example, a caregiver who experiences lower intensity negative affect (e.g., closer to the midpoint, 5 out of 9, on the rating dial) while the PWD experiences higher intensity negative affect (e.g., closer to 1 out of 9 on the rating dial) may be more resilient and less vulnerable to depression, compared to caregivers who co-experience higher intensity negative affect together with the PWD. However, in the current discretizing approach, these types of moments would be collapsed into the same category (i.e., co-experienced negative affect). Finite mixture modeling approaches, such as latent class analysis, could help reveal meaningful subcategories of emotional moments that are obscured in the current data reduction method (Oberski, 2016).

Conclusions

The present study examined two different measures of dementia caregivers’ emotional connection to the person in the care and associations with caregivers’ current and future health. These findings indicate that caregivers who experience more shared moments of negative affect with the PWD and caregivers who use fewer positive emotion words to describe their connection to the PWD have higher levels of depression and loneliness. Greater positive emotional connection language also predicted longitudinal decreases in caregivers’ depression after the death of the PWD. Loneliness and social isolation are widespread public health issues in the United States (Office of the Surgeon General, 2023). The number of people providing informal care for a loved one with dementia will grow exponentially in the coming decades (Prince et al., 2015), and these individuals may already be vulnerable to feelings of loneliness given the unprecedented levels of loneliness in our society. Indeed, social relationships are critical for health and well-being, including risk for individual morbidity and mortality (Holt-Lunstad et al., 2010), and the emotional quality of caregiving relationships represents a compelling area for further inquiry.

Interventions that upregulate caregivers’ experiences of positive emotional connection (e.g., savoring positive experiences with the PWD, expressing gratitude to the PWD; Moskowitz et al., 2021) as well as those that downregulate experiences of shared negative affect (e.g., training caregivers to de-escalate conflict by responding to the PWD's negative affect with neutral affect; Gottman et al., 1998) may preserve the quality of the caregiving relationship, and in turn, mitigate caregivers’ loneliness and depression. Tailored interventions are likely to be more effective than “one size fits all” interventions, as they address the specific needs of individual participants and increase engagement (Martire, 2013). Moreover, earlier diagnosis of dementia could also help caregivers better prepare for and cope with the inevitable personal and relational losses as the disease progresses (de Vugt & Verhey, 2013). Additional research is needed to advance our understanding of the emotional factors that affect loneliness, social relationships, and depression in dementia caregivers as well as the general public in order to reduce the societal burden of this increasingly pressing concern.

Table 1. *Study 1 caregiver sociodemographic and PWD disease characteristics. Means and SDs provided unless otherwise noted.*

Variable	*N* = 82 Initial sample	*N* = 19 Follow-up sample
Caregiver age at baseline (years)	64.08 (8.53)	51.70 (8.24)
Caregiver sex = female, *N* (%)	50 (60.98%)	14 (73.68%)
Caregiver race, *N* (%)		
Asian/ Asian American/ South Asian	3 (3.66%)	1 (5.26%)
Latino/ Chicano/ Hispanic	4 (4.88%)	0 (0.00%)
Multi-racial/ Other	3 (3.66%)	0 (0.00%)
White/ Caucasian/ European American	72 (87.80%)	18 (94.74%)
Caregiver education, *N* (%)		
High School/ GED	7 (8.54%)	2 (10.56%)
2-year College	11 (13.42%)	0 (0.00%)
4-year College	29 (35.37%)	8 (42.11%)
Master's degree	20 (24.39%)	7 (36.84%)
Ph.D., M.D., or other professional degree	15 (18.29%)	2 (10.56%)
Caregiver relationship to the PWD = spouse, *N* (%)	75 (91.47%)	18 (94.74%)
PWD cognitive impairment (MMSE)	22.91 (8.63)	24.00 (8.15)
PWD dementia severity (CDR-Box)	4.02 (2.62)	3.95 (2.13)

Note. PWD = person with dementia. MMSE = Mini-Mental Status Exam. CDR-Box = Clinical Dementia Rating Scale (Sum of Boxes)

Table 2. *Study 2 caregiver sociodemographic and PWD disease characteristics. Means and SDs provided unless otherwise noted.*

Variable	*N* = 335 Active caregivers	*N* = 93 Former caregivers
Caregiver age at baseline (years)	66.29 (9.89)	65.20 (9.36)
Caregiver gender = female, *N* (%)	242 (72.24%)	75 (80.65%)
Caregiver race, *N* (%)		
Asian	23 (6.87%)	9 (9.67%)
Black or African American	13 (3.88%)	3 (3.23%)
Native Hawaiian or Pacific Islander	2 (0.60%)	0 (0.00%)
White	264 (78.81%)	78 (83.87%)
Unknown	33 (9.85%)	3 (3.23%)
Caregiver education, *N* (%)		
Less than high school	17 (5.07%)	3 (3.23%)
High school graduate or equivalent	37 (11.04%)	6 (6.45%)
Some college	87 (25.97%)	18 (19.35%)
College degree or higher	194 (57.91%)	66 (70.97%)
Caregiver relationship to the PWD, *N* (%)		
Spouse	179 (53.43%)	50 (53.76%)
Daughter	106 (31.64%)	35 (37.63%)
Son	23 (6.87%)	6 (6.45%)
Sibling	6 (1.79%)	0 (0.00%)
Other	21 (6.27%)	2 (2.15%)
PWD baseline dementia severity (QDRS)	12.33 (6.51)	15.17 (6.47)

Note. PWD = person with dementia. QDRS = Quick Dementia Rating System.

Table 3. *Descriptive statistics and intercorrelations among key study variables (Study 1)*

Variables	1	2	3	4	5	6	7	8	*N*	Mean	SD
1. Co-experienced PA									82	123.15	162.42
2. Co-experienced NA	-0.68***								82	282.05	195.03
3. Caregiver individual PA	-0.12	-0.51***							82	110.69	140.88
4. Caregiver individual NA	-0.16	-0.15	-0.25*						82	84.11	89.78
5. Depression (CES-D)	-0.07	0.23*	-0.17	-0.09					82	12.8	8.77
6. Anxiety (BAI)	-0.15	0.19	0.01	-0.17	0.64***				80	7.04	7.04
7. Physical Functioning (SF-36)	0.04	-0.13	0.2	-0.11	-0.28*	-0.20			73	86.23	86.23
8. Loneliness (UCLA)	-0.22	0.26*	-0.13	0.04	0.63***	0.41***	-0.15		81	40.78	10.24
9. Marital Satisfaction (LW)	0.35**	-0.44***	0.15	0.15	-0.56***	-0.52***	0.42**	-0.43***	54	104.56	27.47

Note. PA = positive affect; NA = negative affect; CES-D = Center for Epidemiological Studies; BAI = Beck Anxiety Inventory; SF-36 = Medical Outcomes Study 36-Item Short-Form; LW = Locke-Wallace Marital Adjustment Test.

* $p < .05$. ** $p < .01$. *** $p < .001$.

Table 4. *Descriptive statistics and intercorrelations among key study variables (Study 2)*

Variables	1	2	3	4	5	6	*N*	Mean	SD
1. Positive emotional connection language							335	0.68	1.13
2. Negative emotional connection language	-0.01						335	0.15	0.50
3. Positive emotional coping language	0.40**	-0.04					56	0.88	1.22
4. Negative emotional coping language	-0.06	0.38**	-0.04				56	0.14	0.44
5. Depression (PHQ-9, month 6)	-0.11*	-0.05	-0.05	-0.08			335	4.14	4.47
6. Health (month 6)	-0.07	0.10	--	--	-0.46***		62	3.35	0.94
7. Loneliness (month 6)	-0.11	0.02	--	--	0.51***	-0.28*	64	5.12	2.19

Note. Reporting raw means and SDs for emotional language variables; variables adjusted to account for total number of words spoken in all analyses. PHQ-9 = Patient Health Questionnaire-9. -- = insufficient observations to estimate. * $p < .05$. ** $p < .01$. *** $p < .001$.

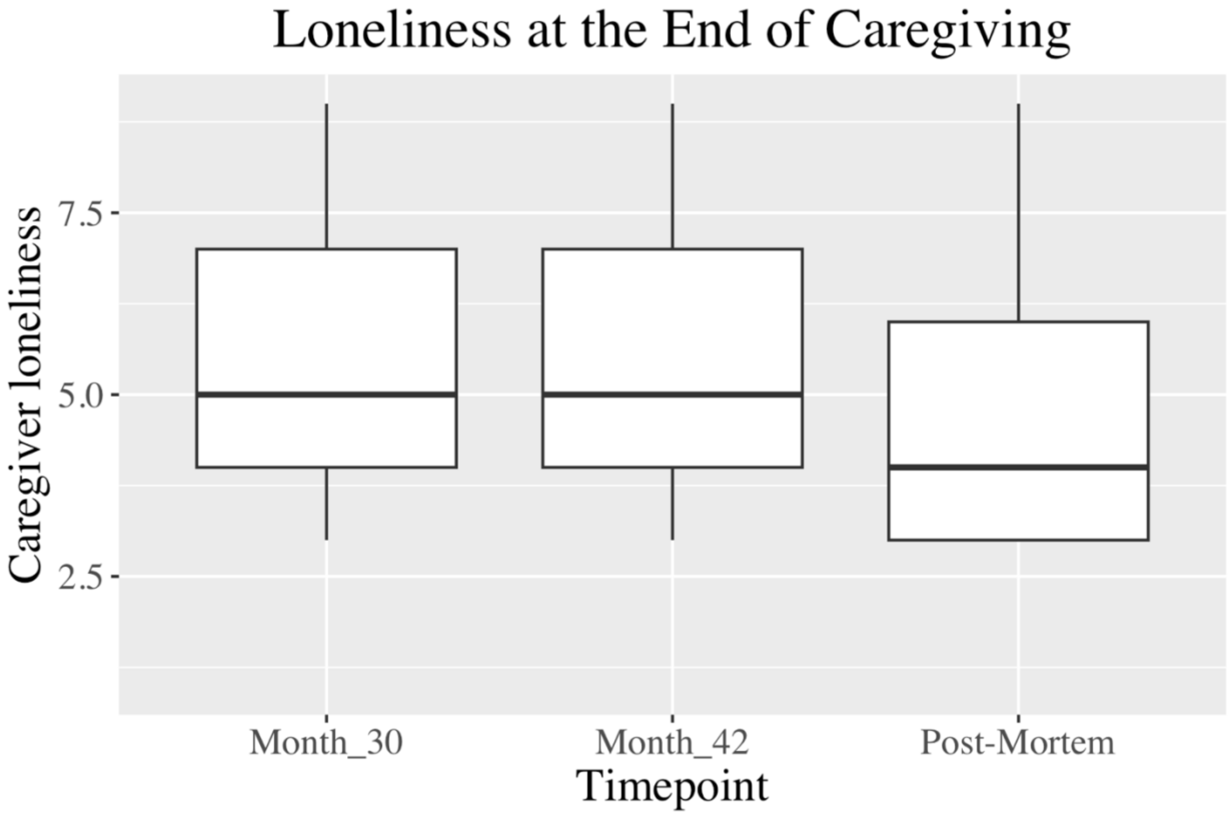

Figure 1. Boxplots of the distribution of caregivers' loneliness at the month 30, month 42, and post-mortem surveys. The boxplot displays the median score, interquartile range (IQR), and range of scores for each timepoint. The median score is represented by the horizontal line inside the box, while the IQR is represented by the vertical lines that extend from the top and bottom of the box. The whiskers of the boxplot extend to the most extreme data points.

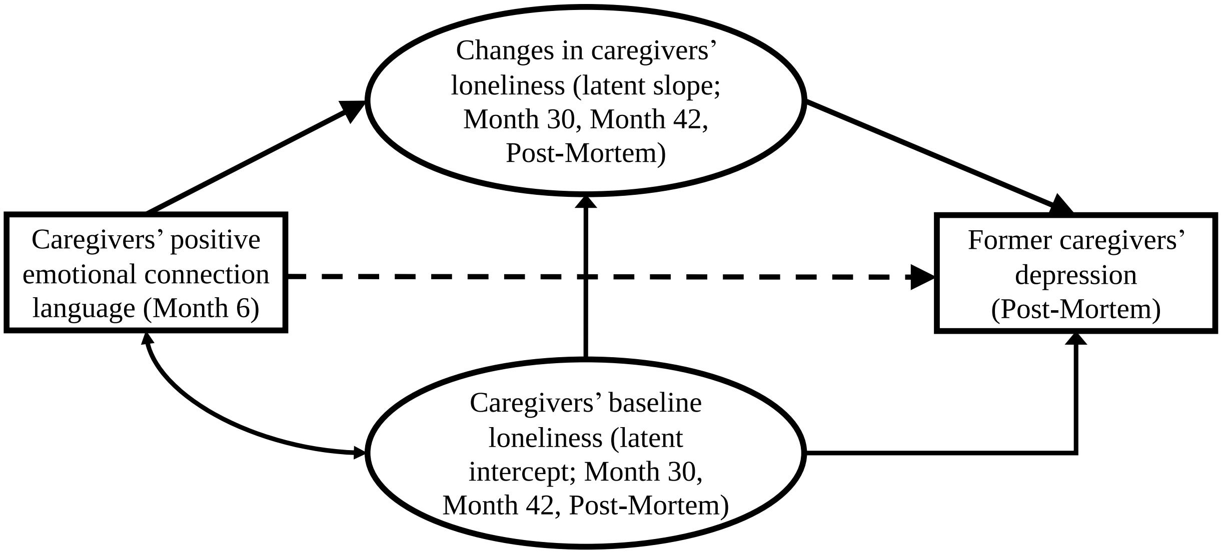

Figure 2. Theoretical mediation model, with changes in caregivers' loneliness (latent slope) mediating the association between caregivers' positive emotional connection language and former caregivers' depression while accounting for caregivers' baseline levels of loneliness (latent intercept). *Note.* Observed variables for modeling caregivers' loneliness latent intercept and slope (i.e., loneliness measured at month 30, month 42, post-mortem surveys) omitted for visual clarity.

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