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Caregivers' Relationship Closeness with the Person with Dementia Predicts Both Positive and Negative Outcomes for Caregivers' Physical Health and Psychological Well-being

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Abstract

Closer relationships between caregivers and care recipients with dementia are associated with positive outcomes for care recipients, but it is unclear if closeness is a risk or protective factor for the health and psychological well-being of caregivers. We examined 234 care dyads from the population-based Cache County Dementia Progression Study. Caregivers included spouses (49%) and adult offspring (51%). Care recipients mostly had dementia of the Alzheimer's type (62%). Linear mixed models tested associations between relationship closeness at baseline, or changes in closeness prior to versus after dementia onset, with baseline levels and changes over time in caregiver affect (Affect Balance Scale; ABS), depression (Beck Depression Inventory; BDI), and mental and physical health (components of the Short-Form Health Survey; SF-12). After controlling for demographic characteristics of the caregiver, number of caregiver health conditions, and characteristics of the care recipient (type of dementia, functional ability, and behavioral disturbances), we found that higher baseline closeness predicted higher baseline SF-12 mental health scores (better mental health), and lower depression. Higher baseline closeness also predicted greater worsening over time in ABS and SF-12 mental health. In addition, caregivers who reported a loss of closeness in their relationship with the care recipient from pre- to postdementia displayed improved scores on ABS and SF-12 mental health, but worse SF-12 physical health over the course of the study. These results suggest that closeness and loss of closeness in the care dyad may be associated with both positive and adverse outcomes for caregivers, both cross-sectionally and over time.

The Stress Process model (Pearlin, Mullan, Semple, & Skaff, 1990) suggests that caregiving is fundamental to many dyadic relationships (marital, parent-child, etc.), but when one member of a dyad develops dementia, the relationship shifts from an equal exchange of assistance, to a greater burden on the caregiver. Closer relationships between caregivers and care recipients with dementia (the care dyad) serve a protective role for care recipients (Burgener & Twigg, 2002; Norton, et al., 2009; Perren, Schmid, Herrmann, & Wettstein, 2007; Whitlatch, Schur, Noelker, Ejaz, & Looman, 2001) but the literature is inconsistent on whether closeness serves a risk or protective role in the health and psychological well-being of caregivers. Addressing the emotional bond between the caregiver and care recipient is an integral part of counseling dementia caregivers (LoboPrabhu, Molinari, & Lomax, 2006), yet it remains unclear whether closer dyadic relationships or emotional detachment is physically and/or psychologically healthier for caregivers. The current study examines how closeness of the care dyad relationship relates to change over time in caregiver physical health and several indicators of psychological well-being. Such data could answer whether promoting closeness or promoting emotional detachment is recommended for care dyads.

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As dementia-related care commences, dyadic relationships take on new roles and meanings, with potentially adverse outcomes. Comparative research demonstrated that Alzheimer's disease (AD) caregivers reported fewer shared activities and less reciprocity in their relationships, compared to individuals in non-caregiving relationships (Gallagher-Thompson, Dal Canto, Jacob, & Thompson, 2001). The Stress Process model proposes that dementia caregivers are exposed to care-related stressors, increasing their risk of adverse psychological and physical health outcomes. One such stressor is "relational deprivation", or the "deprivation of intimate exchange", which includes losing the closeness of the relationship and a confidant as dementia progresses. As described by Pearlin and colleagues (1990), "The sheer dramatic and involuntary transformation of a cherished relationship is itself a major source of stress" (p. 584). Thus, low levels of closeness and poor overall quality in the current relationship, as well as the change in relationship closeness in the dyad since dementia onset (e.g. feelings of loss) may contribute to caregiving stress and adverse caregivier outcomes.

Relationship "closeness" in the care dyad is conceptualized as the quality of the emotional bond between the caregiver and care recipient (Whitlatch, et al., 2001). Related concepts, such as relationship quality (Lawrence, Tennstedt, & Assman, 1998; Quinn, Clare, & Woods, 2009), marital closeness (Tower, Kasl, & Moritz, 1997), affectional ties (Bengtson & Roberts, 1991), intimacy (Blieszner & de Vries, 2001), and others, are used in studies of late life dyadic relationships (including caregiver dyadic relationships). Relationship quality includes "feelings of emotional closeness to the older person, having positive sentiment towards the older person, and similarities in values and beliefs" (Lawrence, et al., 1998, p. 150). Affectional ties relates to quality of the interaction in the relationship, expressed via love, respect, trust, appreciation and recognition, also included in models of intergenerational (e.g. parent/child) relationships. In some cases, closeness is linked to a related term, but does not comprise it wholly. Moss and Schwebel (1993) suggest that intimacy consists of: commitment, affective intimacy, cognitive intimacy, physical intimacy, and mutuality. Because closeness is an essential contributor to the components of affective, cognitive, and physical intimacy, closeness is not characterized as its own component (Blieszner & de Vries, 2001). In sum, there is a high degree of overlap in terminology related to emotional connection in a dyadic relationship. The construct of *closeness* is utilized in the current study, however research on other related concepts is highly relevant.

Relationship Closeness in Care Dyads: Positive Outcomes for Care Recipients and Mixed Findings for Caregivers

Previous studies of closeness in care dyads demonstrate that closer relationships predict *positive* outcomes for the *care recipient*, including increased well-being and problem-solving skills (Burgener & Twigg, 2002), more positive adjustment to institutionalization (Whitlatch, et al., 2001), slower cognitive and functional decline (Norton, et al., 2009), and fewer behavioral symptoms (Perren, et al., 2007).

Additionally, several studies report that closer dyad relationships predict more *positive* caregiver outcomes. Closer spousal relationships are associated with lower caregiver burden (Spaid & Barush, 1994). In mother-daughter dyads, closer caregiver-reported relationships were associated with more satisfaction with the caregiving role (Walker, Shin, & Bird, 1990). Closer *prior* relationships (before dementia onset) were related to lower levels of caregiver depression (Kramer, 1993; Williamson & Schulz, 1990), lower caregiver burden (Steadman, Tremont, & Davis, 2007; Williamson & Schulz, 1990), lower reactivity to care recipients' behavioral disturbances, and higher levels of effective caregiver communication (Steadman, et al., 2007), quality of life, and satisfaction with caregiving (Kramer, 1993). Netto, Jenny, and Philip (2009) found that some caregivers feel emotionally closer to the

care recipient after dementia onset because caregiving necessitated more frequent interaction in the relationship.

Other studies, however, report that higher relationship closeness predicts *adverse psychological caregiver* outcomes (Cantor, 1983). Among spousal caregivers, husbands who were emotionally closer to their wives with dementia reported higher levels of depression (Tower, et al., 1997). Contrary to the subset of caregivers described above by Netto and colleagues (2009), some caregivers report a significant loss of closeness or relationship quality when comparing pre- vs. postdementia onset (de Vugt, et al., 2003; Morris, Morris, & Britton, 1988), and loss of dyad intimacy is associated with increased caregiver depression (Morris, et al, 1988). Researchers using longitudinal qualitative interviews found that AD was associated with a decline in intimacy in both spousal and parent-adult offspring care dyads, and relationship loss was linked to caregivers' feelings of sadness, frustration, and anger (Blieszner & Shifflett, 1990). Lawrence and colleagues (1998) found that for caregivers in high quality dyadic relationships, greater disability in the care recipient predicted greater feelings of caregiver overload.

Although the effect sizes are smaller than those for outcomes related to global and caregiver-specific psychological well-being, there is evidence that caregivers are more at risk for poorer *physical* health outcomes than non-caregivers, particularly for dementia caregivers (meta-analysis by Pinquart & Sorenson, 2003). A separate meta-analysis supported the same conclusions; caregivers (compared to non-caregivers) were slightly more at risk for 11 health-related outcomes, particularly poorer global health, lower response levels for antibodies, and higher levels of stress hormones (Vitaliano, Zhang, & Scanlan, 2003). There is limited and mixed research on the relationship between care dyad closeness and physical health outcomes for the caregiver. Uchino, Kiecolt-Glaser and Cacioppo (1994) found that higher levels of predementia relationship affection (getting along with/liking each other) predicted better cardiovascular function in caregivers, but higher levels of predementia relationship *cohesion* (e.g. engaging in activities together, exchanging ideas, working together) predicted poorer cardiovascular function in caregivers. Lyons, Sayer, Archbold, Hornbrook, and Stewart (2007), found that decreases in care dyad mutuality were associated with decreases in caregiver physical health, emphasizing the importance of using time-varying variables in understanding these complex relationships.

In sum, having a closer care dyad relationship seems to be consistently associated with beneficial outcomes for the care recipient, but outcomes for caregivers are mixed. While there is evidence of a link between relationship closeness/quality and caregiver psychological well-being and physical health, we can't conclude if closeness serves as a risk or protective factor.

The Current Study

The primary goal of this study is to better understand associations between closeness in the care dyad relationship and caregiver psychological well-being and physical health, both cross-sectionally and longitudinally. If closeness predicts consistently positive outcomes for the care recipient, but mixed outcomes for the caregiver, we need more understanding of the associations to inform basic research and clinical practice, which has thus far considered the emotional bond between the care dyad to be a key element of caregiving counseling and clinical intervention (LoboPrabhu, Molinari, & Lomax, 2006). In addition, past research reports that *decreases* in caregiver and physical health negatively impact caregiver quality of life, as well as non-caregiving roles and relationships (Anderson, Linto, & Stewart-Wynne, 1995), highlighting the importance of predicting level *and change over time* in caregiver physical health and psychological well-being. We also examine the role of kin relationship

(Spruytte, Van Audenhove, Lammertyn, & Storms, 2002), and caregiver gender (Tower, et al., 1997) as moderators, as found in other studies.

The current study examines the effect of baseline care dyad closeness and change in pre- to postdementia closeness on both baseline levels and change over time in caregivers' psychological well-being and physical health (see Figure 1). Sin and Lyubomirsky (2009) describe psychological well-being as a global and complex construct that includes one's affective experience and a cognitive judgment about one's satisfaction (Schimmack, 2008). In this study, we use three separate indicators to assess this construct. A unique feature of this study is that it utilizes participant dyads from a population-based sample of persons with incident dementia (identified within 2–3 years of dementia onset). Studying persons from the community or population avoids selection biases of clinically ascertained samples that may select for more stressed caregivers. Based on the Stress Process model, we hypothesize that both current closeness level and a loss of closeness in the relationship will predict poorer health and psychological well-being for caregivers (cross-sectionally and longitudinally), with stronger associations for indicators of psychological well-being.

Methods

Participants

Participant dyads were enrolled in the Cache County Dementia Progression Study (DPS), a follow-up of individuals diagnosed with dementia from the Cache County Memory Study (CCMS). CCMS was a longitudinal epidemiological study of 5,092 older adults in Cache County, Utah, which identified a total of 942 prevalent (existing at baseline) and incident (onset occurring over the course of study) cases of dementia between 1995 and 2007. In CCMS, an expert review panel (neurologists, geriatric psychiatrists, neuropsychologists) diagnosed dementia according to DSM-III-R criteria (see Breitner, et al., 1999). Utilizing criteria from the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association (NINCSA-ADRDA), a diagnosis of "possible or probable Alzheimer's disease" was assigned (McKhann, et al., 1984). Of the CCMS participants with dementia, 335 individuals identified from the incidence waves (37.6% of dementia sample) and their caregivers were enrolled in DPS between 2002 and 2009, and were reassessed in their place of residence approximately every 6 months (for details on DPS sample selection, see Tschanz, et al., 2011). For the current study, 234 care dyads were included from DPS. Participants were excluded from the analyses because of non-primary caregiver status (n = 65), caregiver relationship status other than spouse or adult offspring (n=19), or missing data on independent, dependent variables, or covariates (n= 17; see Figure 2).

Measures

Assessments were conducted by a trained research nurse and neuropsychological technician, and written informed consent was obtained for each assessment (see Tschanz et al., 2011). Study procedures were approved by the Institutional Review Boards of Utah State University, and the Johns Hopkins University.

Dependent Variables—The Affect Balance Scale (ABS; Bradburn, 1969; Coleman, Philip, & Mulle, 1995) is a 10-item self-report assessment of whether 5 negative emotions and 5 positive emotions were experienced in the past week (*1=yes; 0=no*). In the ABS index, a higher score indicates a greater proportion of positive psychological well-being. Its validity and reliability are well established (Bradburn, 1969; Diener, 1984; McDowell & Newell, 1987) with test-retest reliability of 0.76, and internal consistency of Positive Affect items ranging between 0.55–0.73, and of Negative Affect items ranging from 0.61–0.73

(Schiaffino, 2003); in the current sample Cronbach α of the whole index = 0.639. We estimated models using the single index described above, as well as the positive and negative scores separately. Results did not differ in models using items individually or combined into the single index, so the single index score is reported for all final models.

Caregiver depressive symptoms were measured via the 21-item self-report Beck Depression Inventory II (BDI; Beck, Rush, Shaw, & Emery, 1979). Each item uses a 4-point (0 to 3) Likert scale to assess the presence of symptoms over the past 2 weeks. Higher values on summed score indicate worse depressive symptoms such as guilt, sadness, crying, and social withdrawal. The scale has demonstrated appropriate reliability and validity in mixed-age samples (see Hunsley & Mash, 2008), and specifically in older adult samples (Gallagher, Nies, & Thompson, 1982). Internal consistency in the current sample was high (Cronbach $\alpha = 0.869$).

Caregiver physical and mental health over the previous four weeks was assessed using the Short-Form Health Survey, SF-12 (a short version of the SF-36; Ware, Kosinski, & Keller, 1996). The SF-12 includes a Physical Component, SF-12 PC, and Mental Component, SF-12 MC, assessing the extent to which normal roles are impacted by physical or emotional capabilities, respectively. Sample items from the SF-12 PC include "How much does your health limit you in the following activities: Climbing several flights of stairs" (not limited at all, limited a little, limited a lot); "In general would you say your health is" (excellent, very good, good, fair, poor). Sample items from the SF-12 MC include "How much of the time in the past 4 weeks did you feel calm and peaceful" (all of the time, most of the time, good bit of the time, some of the time, a little of the time, none of the time); "During the past 4 weeks have you accomplished less than you would like with your work or other regular daily activities as a result of any emotional problems, such as feeling depressed or anxious" (ves. no). SF-12 items are recoded according to scale instructions, and combined into the SF-PC and SF-MC. Subscales range from 0–100, where 50 represents an average, or normed score, and higher scores indicate better health. The SF-MC and SF-PC have been used widely in a variety of clinical and research settings, demonstrating strong psychometric properties (Lee, Browne, & Villanueva, 2008; Ware, et al., 1996).

Independent Variable—Relationship Closeness was assessed at baseline via the Relationship Closeness Scale, a six-item instrument developed by Noelker (1996) and Whitlach, et al. (2001). The measure assesses caregiver agreement with six statements about their current relationship with the care recipient, with responses coded using a 4-point Likert scale. Items in the scale are (a) "My relative always understands what I value in life," (b) "My relationship with my relative has always been close," (c) "My relative always makes me feel that whatever I do for him/her is not enough (reverse coded)," (d) "My relative always makes me feel like a special person," (e) "My relative is often critical of me (reverse coded)", and (f) "My relative and I can always discuss things together". The scale has a reported alpha reliability of 0.90 (Whitlatch, et al., 2001), and in the current sample Cronbach $\alpha = 0.859$. Responses are summed such that higher scores indicate closer dyad relationships. Caregivers are also asked about their relationship with the care recipient prior to the onset of dementia using the same items. Our *Closeness Change* score was created by subtracting predementia closeness scores from current closeness scores, both assessed at baseline, such that negative scores indicate a greater loss of closeness prior to the onset of dementia.

Covariates—Demographic characteristics included in the analyses were: caregivers' age, years of education, gender, and kin relationship to care recipient, as well as care recipients' age and gender. Caregiver gender and kin relationship combinations were defined as: female spouse, male spouse, female adult offspring, and male adult offspring. Models were run

including 19 individuals reporting "other" kin relationships, however findings were robust, so these were excluded in final models to allow more parsimonious interpretation of kin relationship variables. Caregiver comorbidity was captured as the number of endorsed health conditions out of 11. Dementia type was dichotomized into Possible/Probable AD vs. all other dementias.

Duration of dementia was measured as years from diagnosis to initial assessment in DPS baseline. The frequency*severity products were summed across 10 behavioral domains from the *Neuropsychiatric Inventory* (NPI; Cummings, et al., 1994) to assess total neuropsychiatric symptoms (delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, elation/euphoria, apathy/Indifference, disinhibition, irritability/lability, and aberrant motor behavior). Higher scores indicate more severe behavioral symptoms. The functional status of care recipients was assessed by summing nurse ratings on memory, orientation, problem solving, community involvement, and abilities in home and personal affairs producing the "sum of boxes" score on the *Clinical Dementia Rating scale* (CDR; Hughes, et al., 1982).

Analyses—To examine associations between predictor variables and baseline level and longitudinal change in the four caregiver outcomes, we conducted linear mixed models. This method accounts for correlations between repeated measures made on each participant, while allowing for imbalance in the number of available measurement visits per participant. Linear and quadratic time effects were initially tested, with time² term removed in models reported herein, as it was non-significant. The first unadjusted model (no covariates) for each outcome variable included time, baseline closeness, and their interaction. The second base model included time, closeness change, and their interaction. Models with significant interaction terms were re-run with covariates included. Terms were retained in the model if the individual term had an associated Wald statistic with p<0.05 or if the likelihood ratio (LR) chi-square test of models with and without the new terms yielded a p<0.05. Analyses were conducted using SAS Version 9.2.

Results

Table 1 displays sample characteristics for dyads at baseline. Three quarters of the caregivers were female and the most common caregiver type (42%) was adult daughter. Caregivers were observed between 0.8 – 14.8 years after dementia onset. Nearly two-thirds of care recipients had a diagnosis of AD (62%), 52% were female, with average age of 82 years (SD=6.22).

For each outcome, unadjusted models tested for significant change over time as a function of baseline closeness or Closeness Change (Table 2). Results from the models testing psychological well-being outcomes found that higher baseline closeness predicted higher baseline Affect Balance (ABS), as well as significant decreases in ABS over time. Loss of closeness (negative scores in Closeness Change) predicted lower baseline ABS, and increases in ABS over time. Caregivers reporting higher baseline closeness reported significantly lower baseline BDI, but closeness was not related to change in BDI over time, and Closeness Change was not related to baseline level or rate of change in depressive symptoms. Higher baseline closeness predicted higher baseline SF-12 MC scores but significant decreases in SF-12 MC over time. For results from the model of physical health, baseline closeness was not significantly associated with baseline level or rate of change in SF-12 PC, however loss of closeness predicted decreases in SF-12 PC over time (although it was not associated with baseline SF-12 PC). Because change over time in caregiver outcomes was of primary interest in the current analyses, all models with a significant

Baseline Closeness* time or Closeness Change*time interaction term were carried forward into additional models with covariates included.

Baseline Closeness and Closeness Change Predict Change in Caregiver Affect over Time

For the final models predicting caregiver affect (ABS; Table 3), model 1 suggests that having fewer caregiver health conditions, and having AD diagnoses and lower NPI scores in the care recipients predicted higher baseline ABS. There was a significant interaction with closeness for male adult offspring; male offspring with closer relationships had higher baseline ABS than male spouse caregivers with high closeness. Having a greater number of baseline caregiver health conditions also predicted increases in ABS over time. For the main associations of interest, higher baseline closeness was not associated with higher baseline ABS after controlling for covariates, but baseline closeness significantly predicted decreases in ABS over time.

Model two supported similar outcomes for covariates as Model 1, however the closeness by male adult offspring interaction was not significant in model 2, and a significant time X NPI interaction emerged, suggesting that in model 2, greater behavioral symptoms predicted decreases in ABS over time. For the main associations of interest, Closeness Change was not associated with baseline ABS after controlling for covariates, but a loss of closeness before dementia onset to postdementia predicted increases in ABS over time.

Figure 3 graphically represents A) the average change over time for low levels of baseline closeness (estimated for individuals with a baseline closeness score of 17 – the 25^{th} percentile score) and high closeness (score of 22 – the 75^{th} percentile score), and B) the average change over time for caregivers reporting negative Closeness Change (score of -2 in Closeness Change – the 25^{th} percentile score) and no Closeness Change (score of 0 – the 75^{th} percentile score).

Baseline Closeness and Closeness Change Predict Change in SF-12 Mental Health Component over Time

Table 4 displays the final models for SF-12 MC. Model 1 suggests that female adult offspring had lower baseline SF-12 MC scores than male spouses, and fewer caregiver health conditions predicted higher baseline SF-12 MC. Longitudinal declines in SF-12 MC were predicted by higher NPI, but longitudinal increases in SF-12 MC were predicted by a greater number of caregiver health conditions at baseline. For the main outcomes of interest, a closer care dyad relationship at baseline predicted higher baseline SF-12 MC, but significant decreases in SF-12 MC scores over time (Figure 4). In model 2, the same covariate relationships emerged as in model 1, and for the outcomes of interest, Closeness Change was not associated with baseline SF-12 MC, but loss of closeness predicted increases in SF-12 MC over time (see Figure 4).

Closeness Change Predicts Change in SF-12 Physical Health Component over Time

Covariate results from the final model suggest that female adult offspring had significantly better SF-12 PC scores at baseline compared to male spouse caregivers, and having a higher number of health conditions at baseline predicted lower baseline SF-12 PC (Table 5). Closeness Change was not associated with baseline SF-12 PC, but greater losses in closeness predicted poorer SF-12 PC over time (Figure 5).

Discussion

In this population-based sample of caregivers and care recipients with dementia, the association between care dyad relationship closeness and caregiver outcomes differed

between cross-sectional and longitudinal analyses, and between psychological well-being and physical health outcomes. After controlling for covariates, cross-sectional results suggest that higher levels of baseline closeness were significantly associated with less depression (BDI) and better mental health ratings (SF-12 MC) but not with caregiver affect (ABS) or with caregivers' physical health scores (SF-12 PC). In contrast, longitudinal findings suggest that higher baseline closeness is associated with worse outcomes; higher closeness predicts declines over time in caregiver ABS and SF-12 MC. To add to the complexity, after controlling for covariates, Closeness Change was not associated with baseline levels of any of caregiver measures included in this study, yet loss of closeness was associated with increases in psychological wellbeing (ABS, SF-12 MC), and declines in physical health (SF-12 PC). Although these mixed outcomes do not allow us to conclude that closer dyadic relationships serve as *consistent* risk or protective factors for caregivers, our findings reflect prior conclusions that closeness predicts both beneficial (Spaid & Barush, 1994; Walker, Shin, & Bird, 1990; Williamson & Schulz, 1990) and adverse (Cantor, 1983; Tower, et al., 1997; Blieszner & Shifflett, 1990) caregiver outcomes.

The current study offers two important suggestions for better understanding these complex associations. First, our study supports that both current closeness (after dementia onset) and changes in closeness from the predementia relationship are important to assess when predicting caregiver outcomes. Second, our findings suggest that taking a purely crosssectional view of these associations is misleading since closeness is related to better caregiver outcomes cross-sectionally, but worse outcomes longitudinally. Our results are only partially consistent with the Stress Process model, which describes relational deprivation with a loved one as having negative consequences for caregiver stress and wellbeing (Pearlin, et al.,1990). Our finding that higher levels of current closeness predicted declines in affect and mental health for the caregiver, and that a greater loss in the relationship (from pre- to postdementia) predicted poorer physical health over time together support that poorer relationship quality and loss in the relationship may serve as sources of stress for caregivers, negatively impacting their physical health and psychological wellbeing. However, greater loss in closeness from pre- to postdementia predicted improvements in affect and mental well-being over time, which does not support the view that relationship loss is a stressor. These findings suggest that perhaps a withdrawal from the emotional bonds in a relationship (detachment) may protect the caregiver from deteriorating psychological well-being. This suggestion needs to be explored further, but it is supported by caregiving research which proposes that there is a loss of intimacy over the course of caregiving where the caregivers learn to "become strangers" with the care recipient as an adaptive mechanism (Wuest, Ericson, & Stern, 1994). Chesla and colleagues (1994) reported that for some caregivers, increasing closeness is too emotionally difficult, and even in dyads where dementia causes the relationship to become discontinuous and detached, caregivers still focused on providing high quality care, suggesting that if closeness is lost, the caregiver may be protected emotionally but the care recipient does not necessarily face a poorer care environment. Future studies may wish to test whether loss of closeness is related to greater withdrawal, and whether this coping strategy is predictive of better or worse outcomes for caregivers and care recipients.

One question that arises from the current analysis is why changes over time in ABS and SF-12 MC were associated with closeness, but change in BDI was not. We suspect there may be two possible explanations for this finding. First, because this is a population-based study, caregivers had relatively low levels of depressive symptoms at baseline (mean BDI = 8.07). Second, a measure of Affect Balance may be more sensitive to change in non-depressed samples – that is, it may be easier to detect "less positive mood" than "more depressive symptoms."

Research on the role of relationship quality characteristics and physical health outcomes for caregivers is scarce, however our findings fit with some of the available research in this area (Uchino, et al., 1994; Lyons, et al., 2007). The finding that Closeness Change was a significant predictor of SF-12 PC (and baseline closeness was not predictive) suggests that low levels of prior closeness may be driving this association. The presence of a positive Closeness Change score in an individual suggests that his or her report of *prior closeness* might be particularly low, whereas negative Closeness Change scores may be driven by high levels of predementia closeness. The study reporting that relationship affection was positively associated with physical health outcomes (Uchino, et al., 1994) utilized prior closeness as their independent variable. Similarly, Lyons and colleagues (2007) reported positive associations between *changes* in relationship mutuality and *changes* in caregivers' physical health. Therefore the associations between closeness and physical health outcomes may be somewhat dependent on utilizing measures of closeness *prior to dementia* onset, and or the extent to which that relationship closeness changes over time.

Study Strengths and Limitations

Caregiver research is frequently based on convenience or clinical samples, and less often utilizes population-based samples (see Castro, et al., 2007; Cochrane, Goering, & Rogers, 1997). A strength of the current study is that care dyads were selected from a populationbased sample of individuals with incident dementia and their caregivers, assessed at frequent intervals (every 6 months). Participation rates were high, with small rates of drop-out due to refusal. Despite these strengths, a limitation is that the sample consisted of mostly White participants from northern Utah, and results may not generalize to more ethnically diverse populations. A review by Dillworth-Anderson and Gibson (2002) discussed differences across various ethnic groups in regards to emotional and relational aspects of caregiving. Cultural expectations vary regarding family relationships, filial piety, and relationship reciprocity, suggesting that dyadic closeness may serve different, more important, or less important roles in different cultures. For example, in cultures where caregivers and care recipients have lived in extended households for all of adulthood, closer emotional bonds may have existed prior to dementia onset and feelings of emotional loss after dementia onset may portend adverse emotional outcomes for caregivers. Studies of care dyad closeness using cross-cultural caregiving samples are needed.

An additional strength of the study is the measurement of closeness at baseline and closeness change over time. Ablitt, Jones, and Muer (2009) reviewed relationship factors in dementia and found support for the idea that care dyad relationships evolved as the illness progressed. Hellström, Nolan, and Lundh (2007) suggest that change in care dyad relationships may be more iterative than linear in nature. While assessing change in our study is an improvement over past studies of closeness, a limitation of our Closeness Change measure is that predementia closeness reports are retrospective. While this is a common way to assess relationship closeness prior to dementia onset, there might be less bias with actual measurements obtained prior to the onset of dementia. Second, one of the items in the scale is "My relationship with my relative has always been close". We recognize that this language creates some measurement "noise" when comparing current closeness and prior closeness, as the current closeness measure will be influenced by historical reference of whether or not the relationship has "always been close". The use of this item in a current closeness measure implies an inherent stability in the relationship closeness construct such that always being close contributes to current closeness. Alternatively we recognize that relationships are not stagnant, and while under normal circumstances dyadic relations can be considered dynamic, dementia progression may make care dyad relationships even more susceptible to change. Using a scale of closeness that doesn't include past relationship status in current relationship assessment should be further explored. Likewise we need to

recognize that studies using one assessment of "current closeness" may not adequately capture the more complex and dynamic dyadic relationship.

Recommendations for Future Research

Future investigations will expand upon the present study to examine how relationship closeness changes during the course of dementia, and how this relates to caregiver outcomes. We also wish to explore specific aspects of relationship closeness that impact caregiver outcomes. For example, Norton and colleagues (2009) reported that one item (the extent to which caregivers felt appreciated) appeared to drive the association between closer relationships and slower decline in the care recipient. It is possible that feelings of reciprocity in the dyadic relationship may be a particularly important element of closeness in associations between closeness and caregiver outcomes. Exchange theory suggests that lack of reciprocity from the care recipient would predict poorer outcomes for caregivers, yet exchange theory is not consistently supported in studies of late-life caregiving (Dwyer, Lee, Jankowski, 1994). Dwyer and colleagues advise that researchers may need to distinguish between short term reciprocity where caregivers currently receive less than they give to the relationship, vs. reciprocity over the lifetime where caregivers perceive that what they give to the relationship balances with what the care recipient gave to them at prior points in time. Finally, we propose that future studies examine the *dynamics* of closeness and psychological well-being and physical health to observe whether closeness has differential outcomes that fluctuate over time. It is our hope that research can maximize longitudinal studies involving the caregiver and care recipient to identify an optimal balance of relationship closeness, or certain behaviors associated with closer relationships that lead to maximizing positive outcomes for both members of the dyad.

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Emotional Closeness of the Care Dyad Relationship

Relationship Closeness after Dementia Onset (Baseline Closeness)

Change in Closeness of Relationship from Prior to Dementia (Closeness Change)

Level and Change in Caregiver Psychological Well-being

Ratio of Positive to Negative Affect (Affect Balance Scale)

Depressive Symptoms (Beck Depression Inventory)

Self-reported Mental Health (Mental Health Component of the SF-12)

Level and Change in Caregiver Physical Health

Self-reported Physical Health (Physical Health Component of the SF-12)

Figure 1. Constructs, Indicators, and Measures included in the Study

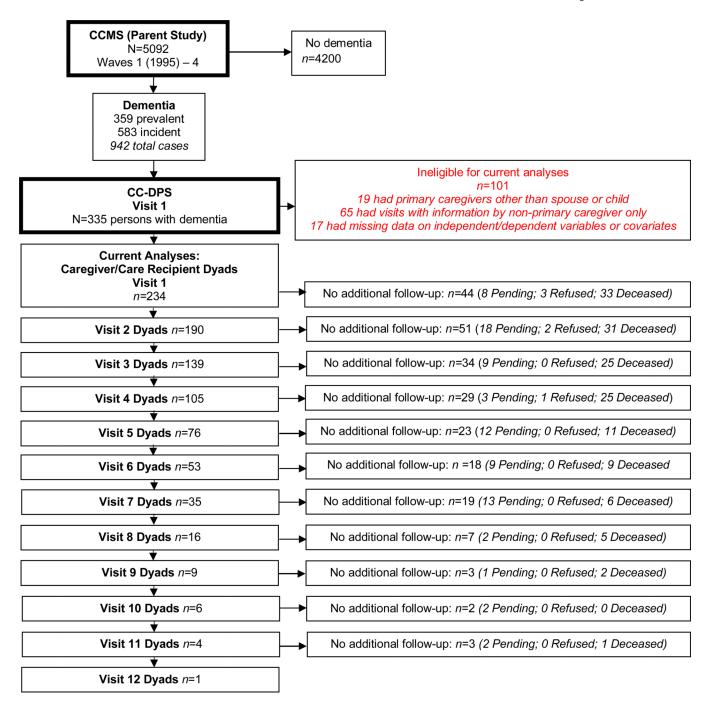


Figure 2.Sample Reduction from Cache County Study on Memory in Aging (CCSMA) to Current CC-DPS Sample at each Visit

Note: "Pending" status means that participants would be eligible for follow-up assessment but have not been re-visited because DPS data collection ended before the subsequent visit.

A: Baseline Closeness effects on Affect Balance B: Closeness Change effects on Affect Balance

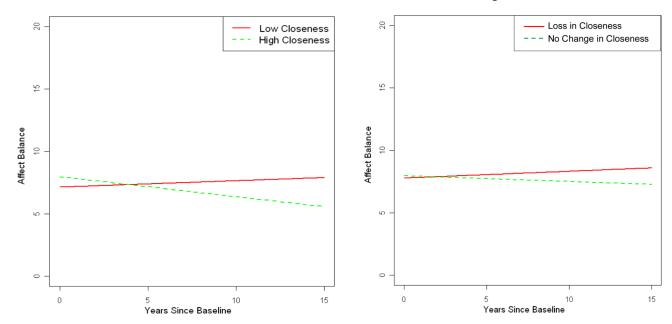


Figure 3.

Affect Balance: A) Closer caregivers compared to less close caregivers; and B) Caregivers reporting loss in closeness compared to those reporting no change in closeness

Note: Lines represent change for prototypical levels (25th and 75th percentiles) of A) baseline closeness and B) change in closeness from predementia to baseline (postdementia) closeness. Loss in Closeness (25th percentile) indicates care dyads decreased in closeness from predementia to postdementia; No Change in Closeness (75th percentile) indicates that there was no reported change in closeness scores from predementia to postdementia

A: Baseline Closeness effects on Mental Health B: Closeness Change effects on Mental Health

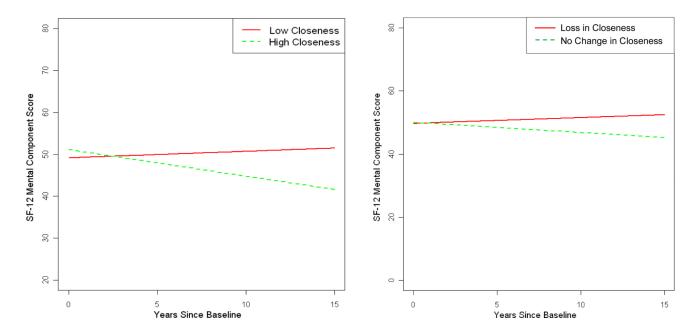
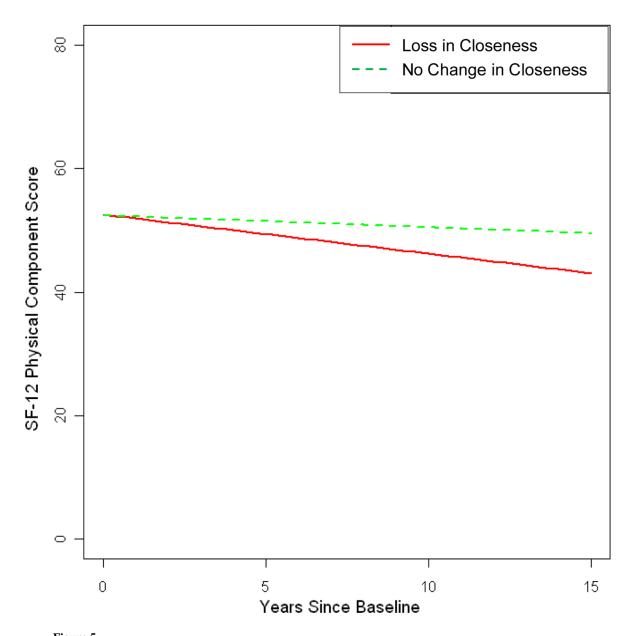


Figure 4.SF-12 Mental Health Component: A) Closer caregivers compared to less close caregivers; and B) Caregivers reporting loss in closeness compared to those reporting no change in closeness

Note: Lines represent change for prototypical levels (25th and 75th percentiles) of A) baseline closeness and B) change in closeness from predementia to baseline (postdementia) closeness. *Loss in Closeness* (25th percentile) indicates care dyads decreased in closeness from predementia to postdementia; *No Change in Closeness* (75th percentile) indicates that there was no reported change in closeness scores from predementia to postdementia

Closeness Change effects on Physical Health



SF-12 Physical Health Component: Caregivers reporting loss in closeness compared to those reporting no change in closeness

Note: Lines represent change for prototypical levels (25th and 75th percentiles) of change in closeness from predementia to baseline (postdementia) closeness. *Loss in Closeness* (25th percentile) indicates care dyads decreased in closeness from predementia to postdementia; *No Change in Closeness* (75th percentile) indicates that there was no reported change in closeness scores from predementia to postdementia

 Table 1

 Descriptive Characteristics of Care Dyad Participants at Baseline

Caregiver	
Kin relationship and Gender:	
Female adult offspring N (%)	98 (41.88)
Female spouse N (%)	80 (34.19)
Male adult offspring N (%)	22 (9.40)
Male spouse N (%)	34 (14.53)
Age M (SD)	69.47 (14.0)
Education in years M (SD)	14.2 (2.37)
Number of medical conditions M (SD)	1.91 (1.45)
Number of follow-up visits	
All participants M (SD)	2.35 (2.31)
Participants with more than one visit	3.13 (2.16)
Relationship Closeness at Baseline M (SD)	18.9 (4.04)
Closeness Change M (SD)	-0.60 (3.02)
Affect Balance M (SD)	7.59 (1.97)
Beck Depression Inventory M (SD)	8.07 (9.03)
SF-12 Mental Health Component M (SD)	50.50 (9.18)
SF-12 Physical Health Component M (SD)	49.89 (10.72)
Care recipient	
Male N (%)	112 (48)
Female N (%)	122 (52)
Age M (SD)	82.0 (6.22)
Possible/Probable Alzheimer's disease diagnosis N (%)	144 (61.54)
Dementia duration in years M (SD)	3.29 (1.80)

Note: Caregivers were observed between 0.8-14.8 years after dementia onset. Negative scores in Closeness Change indicate a greater loss of closeness from predementia levels to postdementia levels

 Table 2

 Base Mixed Models for Caregiver Outcomes without Covariates

	Estimate	SE	T-statistic	p-value
Model 1: Affect Balance				
Intercept	4.40	0.60	7.35	<0.01 *
Time	0.84	0.27	3.10	<0.01 *
Baseline Closeness	0.16	0.03	5.25	<0.01 *
Baseline Closeness*Time	-0.05	0.01	-3.34	<0.01 *
Model 2: Affect Balance				
Intercept	7.55	0.13	57.76	<0.01 *
Time	-0.10	0.06	-1.79	0.08
Closeness Change	0.09	0.04	2.33	0.02 *
Change in Closeness* Time	-0.05	0.02	-2.65	<0.01 *
Model 3: Beck Depression Inventory				
Intercept	15.04	2.81	5.35	<0.01 *
Time	-1.67	1.31	-1.27	0.20
Baseline Closeness	-0.35	0.15	-2.4	0.02 *
Baseline Closeness*Time	0.07	0.07	1.04	0.30
Model 4: Beck Depression Inventory	•			
Intercept	8.49	0.63	13.51	<0.01 *
Time	-0.35	0.30	-1.17	0.24
Closeness Change	0.05	0.20	0.27	0.79
Closeness Change * Time	-0.03	0.10	-0.28	0.78
Model 5: SF-12: Mental Health Com	ponent			
Intercept	38.00	2.59	14.67	<0.01 *
Time	3.16	1.40	2.24	0.02 *
Baseline Closeness	0.68	0.13	5.10	<0.01 *
Baseline Closeness*Time	-0.18	0.07	-2.51	0.01 *
Model 6: SF-12: Mental Health Com	ponent			
Intercept	51.07	0.58	87.74	<0.01 *
Time	-0.53	0.30	-1.79	0.08
Closeness Change	0.29	0.19	1.57	0.11
Closeness Change * Time	-0.30	0.11	-2.80	<0.01 *
Model 7: SF-12: Physical Health Cor	mponent			
Intercept	48.13	3.32	14.49	<0.01 *
Time	-2.03	1.28	-1.59	0.11
Baseline Closeness	0.03	0.17	0.19	0.85
Baseline Closeness*Time	0.09	0.07	1.42	0.16
Model 8: SF-12: Physical Health Con	mponent			

Model 8: SF-12: Physical Health Component

	Estimate	SE	T-statistic	p-value
Intercept	49.00	0.71	68.55	<0.01 *
Time	-0.11	0.25	-0.44	0.66
Closeness Change	0.06	0.23	0.26	0.79
Closeness Change * Time	0.22	0.10	2.18	0.03 *

Note: Negative scores in Closeness Change indicate a greater loss of closeness from predementia levels to postdementia levels.

 $[\]ensuremath{^{*}}$ indicates statistical significance at a level of p < 0.05.

 Table 3

 Effect of Baseline Closeness and Closeness Change on Trajectory of Affect Balance: Results of the Final Model

Model Term	Estimate	SE	T-statistic	p-value
Model 1: Effect of Baseline Closeness				
Intercept	7.27	1.65	4.40	<0.01*
Time	0.56	0.27	2.11	0.04*
Baseline Closeness	0.02	0.08	0.24	0.81
Time*Baseline Closeness	-0.04	0.01	-3.16	<0.01*
Alzheimer's Diagnosis	0.43	0.21	2.05	0.04*
Female Adult offspring Caregiver	-2.06	1.74	-1.18	0.24
Female Spouse Caregiver	0.28	1.87	0.15	0.88
Male Adult offspring Caregiver	-5.56	2.89	-1.92	0.06
Male Spouse Caregiver	0.00			
Baseline Closeness*Female Adult offspring Caregiver	0.15	0.09	1.67	0.10
Baseline Closeness*Female Spouse Caregiver	0.02	0.09	0.21	0.84
Baseline Closeness*Male Adult offspring Caregiver	0.30	0.14	2.12	0.04*
Baseline Closeness*Male spouse Caregiver	0.00			
Number of Health Conditions	-0.39	0.07	-5.78	<0.01*
Time* Number of Health Conditions	0.10	0.04	2.83	0.01*
Behavioral Symptoms of Care Recipient (NPI)	-0.03	0.01	-3.67	<0.01*
Model 2: Effect of Closeness Change				
Intercept	8.02	0.22	36.92	<0.01*
Time	-0.04	0.06	-0.77	0.44
Closeness Change	0.00	0.06	-0.03	0.98
Time * Closeness Change	-0.05	0.02	-2.47	0.01*
Alzheimer's Diagnosis	0.57	0.21	2.69	0.01*
Number of Health Conditions	-0.28	0.06	-4.97	<0.01*
Time* Number of Health Conditions	0.07	0.02	3.07	<0.01*
Behavioral Symptoms of Care Recipient (NPI)	-0.04	0.01	-4.70	<0.01*
Time* Behavioral Symptoms of Care Recipient (NPI)	-0.01	0.00	-2.93	<0.01*

Note: Male Spouse is the reference group for the categorical kin relationship variable.

 $^{^*}$ indicates statistical significance at a level of p < 0.05.

Table 4

Effect of Baseline Closeness and Closeness Change on Trajectory of SF-12 Mental Health Component:
Results of the Final Model

Model Term	Estimate	SE	T-Statistic	p-value
Model 1: Effect of Baseline Closeness				
Intercept	50.20	2.98	16.83	<0.01*
Time	1.53	1.32	1.16	0.25
Baseline Closeness	0.42	0.13	3.24	<0.01*
Time*Baseline Closeness	-0.16	0.07	-2.40	0.02*
Female Adult offspring	-3.80	1.39	-2.73	0.01*
Female Spouse	-0.97	1.40	-0.69	0.49
Male Adult offspring	-3.56	1.93	-1.84	0.07
Male Spouse	0.00			-
Number of Health Conditions	-1.90	0.31	-6.10	<0.01*
Time* Number of Health Conditions	0.67	0.18	3.76	<0.01*
Time* Behavioral Symptoms of Care Recipient (NPI)	-0.16	0.03	-4.59	<0.01*
Model 2: Effect of Closeness Change				
Intercept	58.86	1.39	42.45	<0.01*
Time	-1.68	0.46	-3.67	<0.01*
Closeness Change	0.18	0.17	1.05	0.29
Time * Closeness Change	-0.25	0.10	-2.50	0.01*
Female Adult offspring	-4.17	1.42	-2.95	<0.01*
Female Spouse	-1.33	1.42	-0.94	0.35
Male Adult offspring	-3.56	1.97	-1.80	0.07
Male Spouse	0.00		•	•
Number of Health Conditions	-2.01	0.32	-6.30	<0.01*
Time* Number of Health Conditions	0.69	0.19	3.74	<0.01*
Time* Behavioral Symptoms of Care Recipient (NPI)	-0.18	0.03	-5.21	<0.01*

 $[\]ensuremath{^{*}}$ indicates statistical significance at a level of p < 0.05.

 Table 5

 Effect of Closeness Change on Trajectory of SF-12 Physical Component: Results of the Final Model

Model Term	Estimate	SE	T-Statistic	p-value
Intercept	49.38	1.64	30.07	0.00*
Time	-0.19	0.26	-0.74	0.46
Closeness Change	-0.06	0.20	-0.29	0.77
Time * Closeness Change	0.22	0.10	2.19	0.03*
Female Adult offspring	6.26	1.77	3.54	0.00*
Female Spouse	0.19	1.80	0.10	0.92
Male Adult offspring	3.46	2.47	1.40	0.16
Male Spouse	0.00			
Number of Health Conditions	-1.81	0.30	-6.12	0.00*

indicates statistical significance at a level of p < 0.05.