“For The Future, For Him, And For Our Life Together”: The Relationship Goals And Well-Being Of Persons Living With Dementia And Their Spousal Care Partners

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“For the future, for him, and for our life together”: The relationship goals and well-being of persons living with dementia and their spousal care partners

Claire Leigh Szapary

A Thesis
Submitted to the Department of Social and Behavioral Sciences
Yale School of Public Health

In Partial Fulfillment of the Requirements for the Degree of Master of Public Health

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Secondary Advisor: Becca Levy, PhD

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ABSTRACT

Background. Identities and dynamics in relationships can change when one spouse develops dementia. This study aimed to understand the various types of goals both spousal care partners and persons living with dementia (PLWD) have for their relationship, and to explore whether approach or avoidance goals were associated with individual wellbeing and relational support – as well as their partners’ wellbeing and support. Methods. A secondary analysis of data from sixty-two spousal dyads where one partner has dementia was conducted. Thematic goal-type categories were determined through a card-sort content analysis methodology using participants’ brief qualitative responses to a question asking about their relationship goals. Responses were also coded according to the approach-avoidance theoretical framework to be used in inferential analyses examining their association to wellbeing outcome measures. All analyses were completed for care partners and PLWD. Results. The types of goals expressed by care partners and PLWD were thematically similar and could be categorized into six meaningfully different perspectives: 1) Opportunities for closeness and reciprocity; 2) Emotion regulation and coping mechanisms; 3) Demonstration of relationship commitment; 4) Maintenance of the status-quo; 5) Demoralization in relationship quality; and 6) Other-Miscellaneous. When the PLWD had an avoidance-type goal, their care partner reported significantly higher positive affect compared to care partners with partners with dementia who had approach-type goals. Moreover, PLWD who reported that their relationship was already positive had significantly higher levels of perceived partner responsiveness compared to those who said they did not have any goals for their relationship. Conclusion. This study sheds light on the different goals, or lack thereof, that both care partners and PLWD have for their relationship. Results also demonstrate the potential positive consequences of having certain relationship goals on wellbeing in the context of dementia. Findings may inform future research and intervention programming to better support spousal dyads through the changes brought on by dementia.
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TABLE OF CONTENTS

Abstract .................................................................................................................................2
Acknowledgements ..............................................................................................................3
Table of Contents ..............................................................................................................4
Introduction ......................................................................................................................5
Methods .............................................................................................................................9
Results ...............................................................................................................................15
Discussion ..........................................................................................................................24
References ..........................................................................................................................30
Tables .................................................................................................................................36
Figure .................................................................................................................................39
Appendix .............................................................................................................................40
INTRODUCTION

Approximately 1 in every 9 Americans that are 65 years and older live with Alzheimer’s Disease (AD).\textsuperscript{1} To date, AD – and other forms of dementia – remain an incurable disorder for which efforts have been mainly directed towards improving the quality of life for persons living with dementia (PLWD) and alleviating functional disability and behavioral problems.\textsuperscript{2,3} As this neurodegenerative disease progresses, PLWD require supervision and assistance to manage their symptoms and monitor their safety – a caregiving responsibility that most often defaults to family members and other close friends.\textsuperscript{4,5} There is substantial research to demonstrate the emotional and physical ramifications that can result from assuming this role. While caregiving can provide meaning and purpose for spouses and be an expression of love and compassion\textsuperscript{6}, commitments to caring for someone with dementia can also lead to a loss of contact with others, reduced engagement in personally fulfilling activities, less paid work time, and significant financial strain.\textsuperscript{7–9}

Spouses who double as caregivers have been found to be particularly at risk for enduring the negative impacts of this demanding role: compared to other informal caregivers (family members or close friends), spousal caregivers (hereafter referred to as care partner or CP) report increased depression rates, worse health outcomes, and a greater perceived burden.\textsuperscript{10,11} They also tend to be less likely to hire a paid caregiver or seek services to distribute the amount of work.\textsuperscript{12} Coping with dementia is a dyadic experience, and preserving the quality of the relationship is essential for the wellbeing of both the PLWD and the care partner. Research suggests that deteriorating relationship quality and depression in care partners is associated with a decline in the cognitive and physical health of the PLWD themselves, and a predictor of nursing home admission.\textsuperscript{13–16}

Much of dementia caregiving research has focused on the “losses” that arise from the disease, emphasizing the sense of burden felt by caregivers and the strategies needed to minimize negative impacts of the changing relationship. The importance of studying factors that contribute to
these challenges is incontrovertible; however, to only examine this through a deficit-based approach is to paint an incomplete picture of the caregiving experience. Caring for someone with dementia is recognized as difficult, but there is a small and growing body of literature dedicated to understanding the positive aspects of caregiving (PAC). There is no consensus on the definition of PAC, and different terms and measurements have been used to describe PAC in dementia; a recent scoping review by Wang et al. (2022) found that across the included quantitative and mixed method studies, 23 distinct types of positive aspects were reported, with positive appraisal, self-efficacy, satisfaction, and wellbeing among the terms most frequently cited. Authors have detailed the extent to which the caregiving experience can be meaningful and rewarding, enrich life, and promote personal growth. Several studies have even identified a protective association between various PAC and caregivers’ own physical and emotional wellbeing. The positive impact of caregiving on the relationship itself is less understood, but emerging evidence suggests that feelings of closeness, commitment, and love can remain intact – or potentially increase.

Research in this field is still limited by the lack of a genuine dyadic approach, with the voices of PLWD often excluded and/or both partners’ outlook on their relationship not equally valued (i.e. measuring PLWD outcomes only through a proxy, not reporting dyadic data). Failure to integrate people with dementia into research creates an imbalance that perpetuates the “caregiver-patient” label – a stereotype that can be especially harmful to those who are already learning to navigate the changes in their marriage. This shift towards a more equitable report of data from both partners has gained increasing attention in research. After all, supporting each individual as well as the couple as a whole is essential to mitigate negative impacts of dementia. Existing reviews have outlined and evaluated the various types of interventions developed to specifically target couples where one partner has dementia; their analyses revealed that the most common study designs incorporated music or other art-forms, exercise, psychoeducation, counselling, cognitive stimulation,
and reminiscence.\textsuperscript{32–35} There were promising findings that these interventions might enhance emotional connection, facilitate closeness, and teach positive coping skills that all ultimately strengthen couples’ relationships.

A two-part series by Bielsten & Hellström in 2017 offered a comprehensive assessment of extant couple-centered interventions in dementia and identified several areas in need of improvement.\textsuperscript{28,29} First, they found that roughly one-third of these interventions drew conclusions based on outcome measures from the care partners’ views alone, neglecting the perspectives of the partner with dementia completely. Second, as a whole, there appeared to be a lack of a true relational understanding of the dynamic and individual needs of the couples, which resulted in sweeping and untailored support. Finally, many of these couple-based interventions were complicated and not easily accessible, jeopardizing sustainability and further isolating hard-to-reach populations. Authors of these reviews have recommended that future research works to become more relationship-centered and harnesses the existing resources and strengths of persons living with dementia and their care partner.

One potential method to highlight the voices of both CPs and PLWD is through identifying dyads’ goals for their relationship – a question that is inclusive by nature and requires respondents to consider the role of themselves and their spouse. Generally, setting and adhering to couple goals is a key indicator of a healthy partnership and a facilitator of high marital satisfaction and quality.\textsuperscript{36–38} However, not all goals are created equal, and psychologists have established distinctions between those that approach a positive outcome and those that avoid the undesired. Approach relationship goals (i.e. goals focused on seeking positive experiences in one's relationship such as enjoyment, intimacy, and development) and avoidance relationship goals (i.e. goals focused on evading negative interpersonal experiences such as conflict, impatience, and disagreement) have been shown to have significant and differential impacts on close relationship satisfaction, communication, perceived
support, and coping. Across various populations, research has suggested that people with strong approach goals typically report better psychological and relational outcomes (e.g. sexual desire, good social life) and fewer problems (e.g. anxiety, negative thoughts) on the daily basis and over time.

To date, literature surrounding goal-setting in the context of dementia is limited, and discussion of spousal relationship goals is entirely absent. A few studies have investigated personalized goal attainment for persons with dementia and their care partner, yet their focus was more broadly on decision-making in medical care, rehabilitation, accessing services, and quality of life. What types of goals both individuals have for their relationship and whether there are positive consequences to having certain goals remain unknown. Learning about spousal dyads’ goals for their relationship might aid in the development of interventions that work with couples to set or maintain positive goals, thereby preserving the quality of their partnership even in the face of dementia. Therefore, the purpose of this study was to gain insight into relationship goals for couples in which one person has dementia and to determine how common some were compared to others.

Moreover, using the approach-avoidance motivational theory framework, we sought to explore whether certain goal-types were associated with individual own wellbeing and perceived relational support – as well as their partners’. These research aims were as follows:

**Aim 1:** To describe the different types of goals care partners and persons living with dementia have for their relationship and to quantify the frequencies of these relationship goal types as well as code them as approach-type and avoidance-type.

**Aim 2a & 2c:** For care partners, examine associations between own goal types and spouse’s goal types (independent variables; with goal types categorized as approach/avoidance/no goals because relationship is already positive/no goals because relationship is already negative) and CP positive affect, negative affect, and perceived partner responsiveness (dependent variables).
**Aim 2b & 2d**: For persons living with dementia, examine associations between own goal types and spouse’s goal types (independent variables; with goal types categorized as approach/avoidance/no goals because relationship is already positive/no goals because relationship is already negative) and PLWD positive affect, negative affect, and perceived partner responsiveness (dependent variables).

All aims were exploratory.

**METHODS**

**Participants and Procedure**

Secondary data analysis was performed using self-report measures and goal descriptions from persons living with dementia (PLWD) and their spousal care partners (CP) who participated together in an original controlled pilot study conducted by Monin and colleagues in 2018-2020. The purpose of the primary study was to assess the feasibility and acceptability of the Wish Outcome Obstacle Plan (WOOP) intervention among spousal dyads in which one person had dementia. WOOP is founded on the techniques of Mental Contrasting with Implementation Intentions and is meant to serve as a brief goal-setting activity to help individuals visualize and accomplish attainable outcomes in their everyday lives. It contains a series of straightforward and self-guided steps, and has demonstrated success in a variety of health contexts such as back pain, stroke, physical activity, and relationship dysfunction.

Recruitment targeted home healthcare and adult daycare services and geriatrician networks, and flyers were placed in local communities. The major eligibility criteria required that 1) couples were married or in a co-inhabiting relationship; 2) one partner was told by a clinician that they have Alzheimer’s or a related dementia disease and met a particular cutoff score on the Mini-Mental State Examination (16 ≤ and ≤ 27); and 3) both were aged 55 years or older and agreed to participate (see Monin et al., 2022 for complete details on the eligibility and enrollment process).
After completing baseline surveys, PLWD and CPs were randomized as a couple to either the WOOP intervention group or the waitlist-control group and followed for 16 days before completing an evaluation at postintervention and at 3 months for follow-up. Dyads in the control group received a brief educational discussion and booklet at baseline as well as 4 general supportive phone calls throughout the 16-day study period. The intervention group received a 1 hour guided WOOP training and were provided with 16 WOOP cards to fill out daily, which consisted of writing out a wish, outcome, obstacle, and if-then plan on a worksheet. This task was primarily directed at the care partners given preliminary feedback that the WOOP components might be too distressing for the persons with dementia. WOOP CPs also received 4 brief phone calls (5-20 minutes) over the 16 days to review their most recent WOOP card. Control dyads received the WOOP training following their final 3-month assessment.

The original published study consisted of 45 older persons living with dementia and their spousal care partners (n = 90 individuals). Almost all intervention sessions and milestone assessments were administered through in-person home visits. The findings showed that WOOP was a feasible and acceptable intervention, and WOOP CPs had increased quality of life and positive affect and decreased perceived stress. WOOP PLWD also had increased quality of life and decreased perceived stress, though these effects were not statistically significant. These results were based on the 45 dyads that were enrolled before in-person gatherings became prohibited due to the worsening COVID-19 pandemic; however, throughout Summer 2020, an additional 18 dyads were recruited and enrolled in the WOOP study virtually by collecting all data through the phone.

Evaluating the potency of the intervention was not of primary interest in the present study and therefore data from both the in-person and phone visits were collapsed, resulting in one dataset of dyad members’ goals and responses to self-report measures Only couples that reported at least
one goal from either partner at any of the study timepoints were included in the sample description and analyses.

**Measures**

**Participant Characteristics.** The following demographic data were collected on all participants at baseline: age, gender, race/ethnicity, education level, employment status, and number of chronic conditions, which was measured through the 24-item Physical Comorbidity Index. Care partners were asked to report their marital length and number of children on behalf of the couple. The Neuropsychiatric Inventory (NPI) was completed by the care partner to assess the various types of dementia-related symptoms of their partner at all three timepoints. Both individuals completed the MMSE at baseline and 3 months to assess cognitive functioning; for participants over the phone, the Telephone Interview for Cognitive Status (TICS) was administered, and the published conversion tool was used to find the equivalent MMSE total scores.

**Relationship Goals.** All participants (both CP and PLWD) were presented with the question: “What goals do you have that pertain to how you act in your relationship?” An open-ended text box was provided so that they could provide up to a few sentences in their response. For the 2 week and 3-month follow-up, only the care partner was asked to respond to this question.

**Outcome Measures.** Outcomes were measured in the CP and PLWD at baseline, 2 weeks, and at 3-month follow-up. Participants were asked to respond using the past week as a reference. Positive and Negative Affect. The 20-item Positive and Negative Affect Schedule (PANAS) is the most widely used scale to measure positive affect (PA) and negative affect (NA) across diverse sample populations. Affect is integral to the human experience and describes the various mental states that are involved in feelings. PA and NA are two dimensions that encompass affective states with a positive or negative valence and have thus been utilized in the PANAS to serve as reliable indicators of affect. The original PANAS was designed by Watson et al. (1998) and includes 10 positive (e.g.,
excited, proud) and 10 negative (e.g., distressed, afraid) markers of affect. Participants rated the extent to which they have felt this way over the past week using response options that spanned from 1 (very slightly or not at all) to 5 (extremely). Scores were assessed separately for positive affect and negative affect, forming two subscales that range from 10 to 50. On both scales, higher scores are indicative of higher positive and negative affect. The Cronbach’s alphas were 0.89 (CP-PA), 0.84 (CP-NA), 0.78 (PLWD-PA), and 0.84 (PLWD-NA) and mean scores were used for all. 

Perceived partner responsiveness. A 10-item measure created by Lemay et al. (2007) was used to assess the degree to which a respondent felt they could count on their spouse for help and comfort when feeling distressed. Participants rated how much they agree or disagree with items such as “My spouse was always there for me whenever I needed him/her” and “My spouse was sensitive to my needs” on a 5-point scale that ranged from 1 (disagree strongly) to 5 (agree strongly). Possible scores ranged from 10 to 50, with higher scores indicative of higher levels of spousal support. The Cronbach’s alphas were 0.89 (CP) and 0.94 (PLWD) and mean scores were used for both.

Data Analysis Plan

Content analysis of goals

The relationship goals from the dyads were very brief, often one sentence or less, and could be meaningfully sorted into discrete categories. As such, we identified the card-sort content analysis method as an appropriate approach to addressing our first aim. Both CP and PLWD goals were first defined inductively, which required the employment of an open-criterion single card-sort method. Open-criterion means that the criterion for card-sort categories were not pre-determined, but instead were established through analysis of the relationship goal data. A single-sort method means that all responses were only sorted into one category that was most applicable; no responses were sorted into more than one category.
Four authors (C.S., E.J., S.V., and Y.G.) conducted the card-sort content analysis of the CP and PLWD goals. All authors were young, female-identifying student researchers working towards a graduate degree in the social and behavioral sciences. Some of us had personal experience being involved in the care of a loved one with Alzheimer’s Disease or related dementias (C.S., S.V.) and all have professionally engaged in research and coursework directly related to gerontology and/or close relationships. We strived to avoid any conscious or systematic biases and to remain as neutral as possible in the interpretation and communication of our findings while acknowledging that our positionality has influenced this paper to some extent.

First, the authors read through all CP responses (blinded to intervention group or timepoint) and collaboratively developed a codebook that described a set of categories to reflect all participant goals. Discussions informed by previous literature and through data exploration solidified the different CP goal-type categories. Once the codebook was developed, the team conducted closed-criterion, single card sorting to sort all responses into one of the determined categories, ascribing numeric values to each open-ended goal response based on the category they were sorted into. The coders first trained toward card-sorting reliability by each independently sorting the same random selection of 30 CP responses (in a counterbalanced order) into one of the pre-defined categories. After the initial 30 responses were coded, intercoder reliability was assessed, for which the minimum threshold was 75% agreement across the four coders, and a high intraclass correlation coefficient (ICC). These thresholds were achieved (90.0% at ≥75% agreement, ICC=0.84). The four authors coded the remaining CP responses – each in a randomized order – and reconvened to resolve all discrepancies (80.0% at ≥75% agreement). This methodological approach was then used to analyze the PLWD goals. The team open-coded the PLWD responses and returned for a conversation about potential goal-types. After discussing, we arrived at themes that were similar to those that emerged for CP responses, and thus chose to apply the same goal-type categories as above. Since there was a
smaller number of goals due to collection only at baseline, the authors coded all responses at once (no trial period). The same 75% agreement threshold was enforced and a high ICC was achieved (89.9% at ≥75% agreement, ICC=0.906). The coders again met to resolve inconsistencies. Following this process, every CP participant had three new variables (reflecting the three study timepoints) and every PLWD participant had one new variable (baseline) that corresponded nominally to one of the relationship goal categories.

A narrative was generated for each goal-type to provide consolidated descriptions. The frequencies of each goal-type were calculated at the three timepoints for CPs and at baseline for PLWD. Percentages of goal-types were identified to capture how common they were at each timepoint and to illustrate the overall movement and shift of certain goals across the study period.

**Coding goals for approach and avoidance goal-type categories**

Next, the original responses were then coded according to the aforementioned approach-avoidance theoretical framework common in goal-pursuit research. Since these relationship goal categories were defined deductively, a closed-criterion single card-sort method was performed. Because the data had previously been inspected during the content analysis phase, the authors were aware that some responses would not satisfy the definition of either an approach or avoidance type goal. Therefore, to maximize data inclusion, two goal-type categories similar to those in the first phase of analysis were added (i.e. no goals because the relationship was already positive or no goals because the relationship was already negative) to contribute to a total of four nominal categories. In this phase, two authors (C.S. and E.J.) independently coded a random 25% selection (in a counterbalanced order) of all CP and PLWD responses. They achieved high agreement (91.9% agreement, ICC=0.876), resolved the few discrepancies, and author C.S. sorted the remaining responses. This approach allowed for the quantification of the frequency of a priori goal-types in preparation for the second research aim.
Examining associations between approach/avoidance goals and CP and PLWD affect and perceived partner responsiveness

Normality and homoscedasticity of the data were examined. To determine potential covariates of the approach-avoidance goal-types and outcome measures (positive affect, negative affect, and perceived partner responsiveness), Pearson correlations, t-tests, ANOVA, and chi-square analyses were run. As shown in Supplementary Tables 1 and 2, there were no significant covariates with goal-type and outcome measurements. The lack of empirical evidence of confounding study variables meant that simplified models were sufficient to address the second research aim. Therefore, we conducted independent sample t-tests and one-way ANOVAs with Bonferroni (equal variances assumed) and Games-Howell (unequal variances assumed) post-hoc comparisons. All analyses were two-tailed and interpreted at an alpha level of $\alpha = 0.05$. SPSS version 28 was used. This was completed for baseline data only to avoid any potential influence of the WOOP intervention on participant outcomes.

RESULTS

Participant Characteristics

Sixty-two dyads (n=124 participants) were included in the analysis. Counts at each timepoint may not sum to the total sample size as every participant did not provide a response at every phase of the study. A small number of the sample did not meet original MMSE inclusion criteria but remained in the analysis for therapeutic and compassionate purposes (Two CP had a MMSE below 27, three PLWD had an MMSE score below 16, and eleven PLWD had an MMSE score above 27 with NPI scores of 1, 1, 2, 2, 3, 4, 5, 6, 7, 9, [one missing]). Table 1 provides all participant characteristics. The mean age of care partners was 73.8 (SD=7.0), while the mean age of persons with dementia was 76.3 (SD=7.7). The overall sample population was majority White race (88.4%) and, while there was a roughly even distribution of gender, women were more likely to be a care
partner than have dementia (65.6% vs 39.3%). Many of the participants were well-educated (61.8% holding a bachelor’s degree or higher) and most couples were retired (73.3% of care partners and 85.3% of persons with dementia). The mean duration of marriage was 41.8 years (SD=17.3) and 82.8% of couples had children. On average, care partners and persons with dementia had roughly an equal number of chronic medical conditions (CP: 3.9 (SD=2.2) and PLWD: 3.4 (SD=2.3)).

**Care Partner and Persons Living with Dementia Goals for Their Relationship**

Content analysis of participant responses revealed six prevailing categories elucidating the different types of goals individuals had for their relationships where one partner has dementia. While the goals of care partners and persons living with dementia were reviewed independent of each other, ultimately the same six categories emerged: 1) Opportunities for closeness and reciprocity; 2) Emotion regulation and coping mechanisms; 3) Demonstration of relationship commitment; 4) Maintenance of the status-quo; 5) Demoralization in relationship quality; and 6) Other-Miscellaneous. While categories 1-4 described either explicit goals or responses that indicated maintenance and continuation, category 5 was reserved for responses in which participants stated having no goals for their relationship due to its declining state. Goals that could not be meaningfully sorted were identified as category 6. The goal-types categories are summarized in Table 2 and supporting evidence for each is discussed in turn. Note that the order in which they are described below is solely a nominal presentation, and the analysis of their frequencies and observed patterns appears in the subsequent section.

**Opportunities for closeness and reciprocity**

Many participants spoke about a desire for more regular shared interactions of a positive nature that would foster opportunities for meaningful and enjoyable engagement. This goal seemed to manifest in a variety of different ways – for some, more tangible, others emotional. Care partners and persons living with dementia alike discussed wanting to take part in fun activities together such
as exercising, listening to music, and hanging out in social settings with other friends and family. Scheduling routine date nights or planning trips were often-cited goals of care partners. Participants even wished to undertake seemingly mundane daily affairs together like grocery shopping and cleaning. Increasing moments of intimacy was embedded within many of the care partners’ goals (e.g. “to hug and be hugged in return”; “to hug and kiss more often”). They spoke of wanting to give and receive more love. For many PLWD, this goal-type took the form of communication, both through overt requests like “increase communication” and through more internalized actions such as “to be honest with myself and my spouse about my feelings and emotions.” Within the realm of communication, listening was as important as talking. “I’m learning to listen during conversation because I have memory issues,” wrote one participant with dementia. It appears as though the specifics of the interaction were not of fundamental importance; rather, spouses were yearning for any opportunity that would garner a sense of closeness, intimacy, and mutuality. As one care partner put it, he hoped for “increased ‘moments’ of enjoying life together.”

**Emotion regulation and coping mechanisms**

When participants were asked to share their goals for their relationship, a majority mentioned having patience and understanding as well as learning how to accept and adapt. Doing so often required changing their attitudes and behaviors. Care partners wrote about wanting to engage in more self-modulating and self-soothing techniques when faced with dementia-related challenges, such as counting, breathing, and drawing on humor. Gaining control was frequently discussed in the context of frustration and other negatively valanced emotions (e.g. “To have better self-control in reacting to his certain behaviors toward and with me”). Many care partners hoped to handle situations with less anger and more compassion (e.g. “Become less frustrated, better able to recognize his symptoms & deal with them in a caring and competent way”) and to try to separate their partner from the disease (e.g. “To be less critical, knowing that he can’t control it”; “Accepting that [spouse] cannot control what she sometimes cannot
understand. It's not her fault”; “Trying to understand how [spouse] must feel”). For some, emotion regulation goals entailed taking care of themselves in order to take better care of their spouse. Lastly, several care partners stated that remembering and referencing the past was a helpful strategy they hoped to draw on more going forward:

“Being patient. Also looking back on our 46 years of marriage & pulling out good vibes from our past.

Even though we can't beat this bump, we will continue to work on it. Cause bottom line is love can help us get [through] it. Some good, some not so good, but together.”

It is important to note that a desire for patience and understanding was a mutual feeling. Persons living with dementia were similarly frustrated by the challenges presented by this illness and were also looking to manage and redirect their emotions for the sake of themselves and their relationship.

“My goal is to not become upset with my partner when expressing or voicing concerns and forgetting the word to be used in a sentence. To not get angry if I forget where things are placed and blame my partner for not helping me "remember" or find the lost objects.”

Just as many care partners expressed a need for extreme patience, PLWD were often yearning for the same thing. For example, one participant wrote that he hoped to “be patient, kind, responsible, to do [his] share of things that need to be done as much as possible.” For other participants, their goals revolved around relieving the caregiving burden off of their spouse by mitigating some of the stress – or at the very least trying not to increase it. A desire for better mood-regulation was stated by nearly everyone at some point throughout the study period. There were a wide array of techniques and strategies to accomplish this goal as participants approached it from various angles.

**Demonstration of relationship commitment**

Across the responses, a common goal emerged regarding the notion of demonstrating love and commitment to the spouse and the relationship. Care partners wrote about wanting to be
explicit in this affirmation by either verbalizing these feelings or relaying it through their actions. One participant stated that she hoped to “continue the process of returning the expression of affection, humor and gentleness into our relationship.” Reiterating this respect and high-regard to their spouse with dementia seemed to be important to several care partners (e.g. “to give my spouse a sense that he retains my love and has a dignity/self-worth”; “to communicate my high regard for him”). Spouses love and admiration for their partner were not declining in the face of this disease – a message that was reflected in many of their goals. For others, this sentiment of a personal responsibility to demonstrate their relationship commitment surfaced through goals that referenced the caregiving role. “To be a good caregiver-keeping safe and at home as long as possible,” wrote one care partner; “To stay strong and together and I pray I don’t die first,” said another. Persons living with dementia were also concerned with making sure they exhibited their devotion to their partner. In their goals, they often discussed wanting to be “the best spouse possible,” contributing as “a good team member,” and helping their partner remain “happy and feel secure.”

Maintenance of the status quo

Some participants used this study question as an opportunity to discuss an already thriving, positive, or stable relationship, effectively stating that their goals were to just continue or maintain what they already had. For example, care partners wrote that they wished “to be able to maintain a happy, forgiving and loving relationship,” or that they had no goals because “we seem to be doing fairly well.” A few participants drew upon their length of marriage as support for their goal of maintenance and continuation (e.g. “maintain the love and affection that we have shared for 58+ years and still make the right health care decisions for and with my wife.”). This was a popular goal among persons living with dementia. To many, their marriage was “perfect,” and “already excellent,” and therefore they felt that there was not anything else to add. Below is one response by a participant with dementia:
"I can't find a fault nowhere. Some men have to worry and worry. Not with me and my wife. I want us to live right for God. There's nothing more to worry about other than my family getting along well. And they are. Some people have nothing compared to us."

It appears that some interpreted this prompt as a potential invitation to reveal the negative aspects of the relationship; after all, having a goal might imply that there is room for improvement. In turn, many people with dementia responded that they could not make their relationship “any better” and declared that they were already satisfied and fulfilled with the status quo.

**Demoralization of relationship quality**

For others, this question served as an outlet to explicitly state that they had no goals for their relationship – often as a result of dementia-related obstacles and frustrations. Through their words, it was evident that some care partners felt disheartened or worn-down and could not provide a goal when asked. “I don’t think I have since I strongly feel my relationship is cracking up. It’s all over the place,” wrote one participant; “None- spouse getting harder to cope with; she doesn’t seem to understand much of what I say regarding instructions,” admitted another. Some people living with dementia shared this demoralization. A handful of participants recognized the struggles felt by their care partner and used that as corroborating evidence for their lack of a goal (e.g. “Not really. Sometimes I think he's not happy with my memory”).

**Other-Miscellaneous**

This final goal-type was reserved for any response that did not fall into any of the other categories, or because the content was so limited that its goal-type could not be determined. In these few instances, responses were one-word, illegible, or simply failed to meet the inclusion requirements for the definitions of the remaining categories (e.g. “The above awareness moderates my transgressions.”).

**Goal-Type Frequency and Distribution Patterns**
The card-sort analysis allowed for the frequencies of each goal-type to be determined at the three study points for CPs and at baseline for PLWD. Beginning at baseline, the distribution of goal-types was considerably more even among persons living with dementia compared to the care partner participants (See Table 2). Nevertheless, the most common goal-type for both was “emotion regulation and coping mechanisms.” Just under two-thirds of care partners (61.7%) and approximately one-third of PLWD (31.7%) had a goal deemed to be of this type. The second most frequent goal differed between the two: for care partners, it was “demonstration of relationship commitment” (18.3%) while for persons living with dementia, “maintenance of the status quo” (28.3%). Following this, participants seemed to endorse the remaining goal-types in fairly equal amounts. However, it is important to note that, at baseline, no care partners expressed goals within the “demoralization of relationship quality” category and no PLWD had goals that fell into “other-miscellaneous.” There were no significant differences in the profile characteristics of individuals who had certain goals and further details of this analysis can be requested from the author.

Figure 1 illustrates the change in goal-type distribution across the study period. There is a shift in frequency at the 2 week point, which marked the end of the official WOOP homework cards to be collected. The proportion of care partners who had an “emotion regulation and coping mechanisms” goal-type nearly halved from baseline, as more participants reported having goals that met other category criteria. A greater percentage expressed a desire for opportunities of closeness and reciprocity (17.3%), surpassing the once second-most-common goal-type, “demonstration of relationship commitment.” Increases in the frequency of “demoralization of relationship quality” and “other-miscellaneous” goal-types were observed albeit rather still low. Additionally, there were now more care partner partners who stated that they were hoping to maintain the status quo (13.5%). At 3-months follow-up, goals were assessed for a final time. The percentage of the “emotion regulation and coping mechanisms” goal-type climbed once again, now claiming just about half of all
goals (48.9%). There remained a steady rise in those looking to increase opportunities for closeness, and a decline in all other remaining goal-types (see Figure 1).

**Approach-Avoidance Goals: Associations with Well-being**

The frequencies of all recoded responses according to the approach-avoidance goal-type paradigm can be found in Supplementary Table 3. For care partners, at baseline, all eligible goals were sorted into either approach or avoidance goal-type categories and the majority of their goals were avoidant (63.2%). As the study period progressed, this distribution between approach and avoidance-type goals leveled out, and more responses were sorted into the two “no goals” categories either because they were feeling already positive or their relationship was deteriorating. The largest percentage of persons living with dementia had approach-type goals (38.6%) at baseline, though many reported having a lack of goals as well. The following section reviews the findings from the statistical analyses investigating whether there were significant associations between these various goal-types and two measures of wellbeing at baseline.

**Aim 2a: Were care partners’ relationship goals (approach/avoidance) related to care partners’ positive affect, negative affect, and perceived partner responsiveness?**

There were no significant associations between the type of relationship goal care partners reported and their mean positive affect \(t(55)=1.057, p=0.295\), negative affect \(t(55)=1.123, p=0.266\), or perceived partner responsiveness \(t(55)=-0.750, p=0.456\).

**Aim 2b: Were persons with dementias’ relationship goals (approach/avoidance/no goals because relationship already positive/no goals because relationship already negative) related to persons with dementias’ positive affect, negative affect, and perceived partner responsiveness?**
Persons living with dementia who reported that their relationship was already positive had significantly higher levels of perceived partner responsiveness compared to those who said they did not have any goals for their already deteriorating relationship [omnibus: F(3,55)=3.113, p=0.034; post-hoc: mean difference=0.67, p=0.020]. A marginally significant association also existed between these two goal-types in terms of positive affect [omnibus: F(3,50)=2.662, p=0.061; post-hoc: mean difference=0.75, p=0.145]. There were no significant associations between the type of relationship goal PLWD reported and their mean negative affect [omnibus: F(3,50)=0.658, p=0.582].

**Aim 2c: Were care partners’ relationship goals related to their partner with dementias’ positive affect, negative affect, and perceived partner responsiveness?**

There were no significant associations between the type of relationship goal care partners reported and their partner with dementias’ mean positive affect (t(48)=−0.741, p=0.463), negative affect (t(48)=1.654, p=0.105), or perceived partner responsiveness (t(54)=−0.375, p=0.709).

**Aim 2d: Were persons with dementias’ relationship goals related to their care partners’ positive affect, negative affect, and perceived partner responsiveness?**

When the person living with dementia had an avoidance-type goal, their care partner reported significantly higher positive affect compared to care partners with partners with dementia who had approach-type goals [omnibus: F(3,55)=3.183, p=0.031; post-hoc: mean difference=0.69, p=0.038]. There were no significant associations between the type of relationship goal persons with dementia reported and their care partners’ mean negative affect [omnibus: F(3,55)=0.463, p=0.709] or perceived partner responsiveness [omnibus: F(3,55)=2.074, p=0.114].
DISCUSSION

Changing identities within couplehood may be likely when one partner develops dementia. Goal-setting is a strategy that has demonstrated success in cultivating healthy relationships, yet to date has never formally been researched in the context of spousal dyads in which one person has dementia. This study gave a voice to both care partners and persons living with dementia by highlighting the various goals each dyad member had for their relationship. Three novel findings arose from the content and inferential analyses. First, there appeared to be a consensus on the types of goals care partners and PLWD expressed. Second, nuances in the characterization of these goals were detected, which produced six distinct perspectives: 1) Opportunities for closeness and reciprocity; 2) Emotion regulation and coping mechanisms; 3) Demonstration of relationship commitment; 4) Maintenance of the status-quo; 5) Demoralization in relationship quality; and 6) Other-Miscellaneous. Lastly, approach-avoidance coding revealed significant associations between the goals of PLWD and their perceived spousal responsiveness as well as their partners’ positive affect.

Results indicated that, in this sample of spousal dyads, similar themes emerged from the goal responses of care partners and persons living with dementia, eradicating misconceptions that PLWD are not capable of having the same desires as their healthy counterpart. Many PLWD have reported themselves that they feel excluded, dismissed, and treated differently for a disease that is beyond their control. Communication is often addressed to their caregiver rather than themselves, perpetuating the idea that they are to be viewed as a “third party” rather than someone directly involved. Findings from this study instead demonstrated that PLWD wanted patience, closeness, and love just as much as their partner did. In fact, at baseline, 85% of PLWD’s goals met the criteria for goal-types 1 through 4; this is highly comparable to the observed 95% of care partner goals that were also of these types. This is supported by a core assumption of the social exchange theory,
which posits that each partner brings something to the relationship to maintain an equilibrium of “give-and-take.”\textsuperscript{68} The contributions of each partner should be valued commensurately and PLWD should not be presumed to have different goals for their relationship due to the state of their health.

The various types of goals expressed by participants aligned with what previous literature has suggested are major sources of change in spousal dyads where one partner has dementia. After all, it makes sense that individuals’ goals revolved around striving to improve upon the very things that have jeopardized their relationship quality and wellbeing. Existing research has thoroughly described the shifts in couplehood after the onset of dementia, providing substantial evidence for adjustments in roles, a loss of shared activities, and heightened emotions such as frustration and grief.\textsuperscript{69–71} This study was unique in that it translated these experiences into desires for the future by directly asking participants to delineate the goals they have that pertain to how they act in their relationship.

It is not unexpected that many participants were yearning for more opportunities for meaningful engagement. Generally, people facilitate social closeness with each other through partaking in shared activities\textsuperscript{72}, and data within the specific field of dementia have shown that perceived relationship closeness can increase through these interactions.\textsuperscript{73,74} Many of the existing interventions for spousal dyads were designed to promote just this, improving relationship quality and satisfaction through physical activity, creative-arts, and other enjoyable programs.\textsuperscript{34,75} Participants’ consistent report of a desire for more of these types of interactions should confirm the need for greater development and wider dissemination of these dyadic interventions. Moreover, intimacy remained a longing for twelve care partners, which counteracts the aging sexual stigma that paints older adults as less interested or deserving of relational romance; however, notably, there was only one explicit mention of intimacy from PLWD. Whether this incongruity in goal-type has any appreciable effects on the dyad requires further attention.
Regarding a care partner as needing strategies to emotionally regulate is not a new discovery but finding that PLWD expressed goals for more patience and acceptance in the context of their relationship is. How to practice patience when caring for someone living with dementia is the predominant focus in media and research, alike. On the other hand, understanding the coping strategies used by PLWD to manage the relational struggles they experience has received limited recognition. By asking participants about their goals for their relationship, this study gave PLWD the platform to be in an active position rather than passive. They, too, voiced concerns of agitation and frustration with their partner, and hoped for better emotional regulation. Future research and interventions must work to establish patience in both partners and acknowledge that PLWD are learning to navigate the changes in their relationship as well.

This study confirmed the body of literature that points to the abundance of love that persists in couples where one partner has dementia. The notion of sustaining couplehood through relationship maintenance and demonstration of commitment has been previously well-described and was also a prominent theme in this sample. Care partners wanted to provide their spouse with dementia a sense of security and validate that their love was not diminishing despite dementia, which can be a concern for PLWD. Moreover, having a marriage that was previously or presently strong seemed to influence the types of goals mentioned. Many participants who referenced their marriage stated in their goals that they either wanted to reiterate this commitment to their partner or maintain what they currently had. Just as high relationship quality prior to dementia onset predicts positive aspects of caregiving, it appears that it might also be associated with goal-type. Importantly, reporting high levels of love and affection was not the case for everyone. Preserving a sense of togetherness is a challenge, and changes in the relationship can be a source of pain for both partners. The holistic focus of this study is a strength, illuminating that it is not always possible to have goals for a relationship, and they can be negatively charged for those that do.
While the characterizations of each goal-type stand on their own, their respective frequencies and movement through time also became evident. It was interesting that almost every care partner who responded to this study question shared some goal at baseline. That is, no care partner stated that their relationship was deteriorating, and only a small percentage said that they wanted to maintain what they already had – leaving the remaining care partners each with a goal of some type. On the contrary, PLWD tended to discuss their relationship in a more positive light, with just under one third claiming that their goal was to continue with their already “excellent” marriage. This is in line with previous research that has shown that PLWD often rate their relationship more positively than care partners, who interpret the quality of their relationship as relatively lower. Stress related to caregiving has been identified as a main predictor of this discrepancy in self-reports, and possibly explains why a greater proportion of care partners expressed having some goal to work towards during the baseline visit of this study. It is also possible that this intervention self-selected for participants who were eager to make a change in their relationship or that as time went on they felt more comfortable disclosing the negative aspects of their relationship.

Using an established goal-type theoretical framework, we found a significant association between the goals of PLWD and their spouse’s wellbeing, such that when the PLWD expressed an avoidance-type goal, their care partner reported significantly higher positive affect compared to care partners with spouses with dementia who had approach-type goals. In other words, care partners whose spouse’s goals mainly revolved around mitigating stress and practicing patience so as to prevent negative interactions had higher positive affect than care partners with spouses whose goals focused on achieving some outcome. Plausible mechanisms to explain this finding can only be speculative, as approach-avoidance goals have not yet been empirically explored in the spousal caregiving context. While prior research has suggested that, in general, people with approach goals have greater subjective wellbeing and self-reported relationship quality, there is also an argument in
favor of viewing these dichotomous goals as more fluid and dynamic rather than fixed and opposing. Elliot (2008) proposed that the implications of having one goal-type over the other for wellbeing likely vary as a function of individual differences. For couples in which one person has dementia, the care partner might benefit from having a spouse with avoidance-goals rather than approach. Perhaps in dementia caregiving – oftentimes a period of adjustment and acceptance – it is more advantageous to have a partner with goals that aim to alleviate stress than those that are overly optimistic. The same statistical relationship did not hold true when assessing the impact of care partners’ goals on the spouse with dementia, nor was there an association between care partners’ goals and their own wellbeing. A significant association did exist, however, between the goals of PLWD and their perception of their partners’ responsiveness. It is unsurprising that, compared to those who said their relationship was declining, the PLWD who endorsed an already positive relationship reported feeling relatively more comforted and understood by their partner: high marital satisfaction is closely related to perceived spousal support. In the caregiver population, it is possible that this goal-type framework is not appropriate or nuanced enough to detect discernable differences. Whether the pursuit of avoidance goals (vs approach) is optimal in its promotion of wellbeing in the face of dementia requires further evaluation.

Limitations and Recommendations for Future Directions

This study is not without its limitations. The causal nature and directionality of effects between goal-types and wellbeing cannot be determined as a result of the correlational analyses. Whether certain goals influence wellbeing – or if wellbeing shapes goals – remains uncertain, though it likely follows a cyclical pattern. Along the same lines, the goals offered at study timepoints reflected only snapshots in time and it is possible that they were not representative of what participants believed and practiced throughout their everyday lives. After all, goals can be transient, allowing individuals to change their minds and seek out a combination of goal-types (i.e. both
approach and avoidance). The study sample was largely homogenous, as most dyads were White and heterosexual. Testing study aims in a diverse population might produce results that are more generalizable. Moreover, there was a wide range of dementia severity in PLWD; utilizing the MMSE to assess cognitive function had the advantage of applying standardized well-known thresholds but the disadvantage of potentially excluding or including someone by mistake due to cutoffs that are built from age-based normative data. A one-way ANOVA of PLWD MMSE scores and PLWD goal-types (1-6) revealed that PLWD with emotion regulation goals had a higher mean MMSE than PLWD with maintenance goals (mean difference=3.8, $p=0.033$). This suggests that level of cognition might impact certain goal-types of PLWD, particularly between those who want more self-modulating strategies and those who only wish to continue with their relationship as is. The effects of goal-setting on the early, middle, and late stages of dementia requires further evaluation. Finally, these findings must be interpreted in the context of the WOOP intervention. Participation in this kind of research might select for certain types of people (e.g. a caregiver interested in gaining coping skills to deal with the changes in the relationship). The six goal categories that emerged from this study are likely not exhaustive, and we may have missed other couples with unique perspectives. Exploring the effect of the WOOP intervention on goal-types was not a study objective; while we did not include a longitudinal component in our inferential analyses for this reason, we cannot be certain that the thematic descriptions of these goals are void of any interventional influence.

The results from this study are intended to be hypothesis-generating and to be used in future research and intervention design. While findings might suggest the utility of goal-setting activities in spouses where one partner has dementia, they also serve as potential ideas from which interventions can draw, centering their programming around the various goal-types. For example, after learning that many dyadic members expressed desires for better emotion regulation strategies, an activity might incorporate mindfulness techniques to instill patience, acceptance, and gratitude in the couple.
Williams and colleagues highlighted the importance of couples being able to engage in emotional communication to sustain high relationship satisfaction. In the present study, participants wrote down their goals or told it to the interventionist who then recorded it. Future research should examine whether there is any added benefit to having couples interact and communicate these goals to each other face-to-face. Lastly, robust analytical methods such as Actor-Partner Interdependence Modelling could explore the influence of both partners’ goal-types on both partners’ wellbeing, which can be assessed through outcomes other than positive affect and perceived partner responsiveness.

**Conclusion**

Many spouses feel as though they have lost some part of their relationship when one partner becomes diagnosed with dementia. Although this change can provoke feelings of stress, sadness, and anger, it can also be an experience growth, purpose, and love. Setting goals for one’s relationship can serve as a healthy outlet for wedded individuals, but how this manifests in spousal dyads where one partner has dementia remains unknown. As such, the present study investigated the various types of goals both care partners and persons living with dementia have for their relationship. Additionally, we overlaid the approach-avoidance theoretical framework to understand if certain goal-types were significantly associated with positive affect and perceived partner responsiveness. The results from this study might provide insight into an additional factor that can promote a positive dimension of care partners’ wellbeing, which has established associations to the mental and physical health outcomes of persons living with dementia. Even though relationships change with the onset and progression of dementia, it is never too late to set goals. It is important that programs guide couples to focus on the strengths of their relationship and what is still left to be done rather than the past and what has been lost.
REFERENCES:


56. Bakker TJEM, Duivenvoorden HJ, van der Lee J, Olde Rikkert MGM, Beekman ATF, Ribbe MW. Integrative Psychotherapeutic Nursing Home Program to Reduce Multiple Psychiatric Symptoms of


64. IBM SPSS Statistics for Windows, Version 28.0. Published online 2021.


Table 1. Participant Characteristics

<table>
<thead>
<tr>
<th>Variable</th>
<th>Care partner ($n = 61$)</th>
<th>Persons living with dementia ($n = 62$)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in years (mean, $SD$)</td>
<td>73.8 (7.0)</td>
<td>76.3 (7.7)</td>
</tr>
<tr>
<td>Range</td>
<td>54–88</td>
<td>55–99</td>
</tr>
<tr>
<td>Gender, $n$ (%)</td>
<td>Female: 40 (65.6)</td>
<td>Female: 24 (39.3)</td>
</tr>
<tr>
<td></td>
<td>Male: 21 (34.4)</td>
<td>Male: 37 (60.7)</td>
</tr>
<tr>
<td>Race, $n$ (%)</td>
<td>White: 55 (90.2)</td>
<td>White: 52 (86.7)</td>
</tr>
<tr>
<td></td>
<td>Black: 3 (4.9)</td>
<td>Black: 4 (6.7)</td>
</tr>
<tr>
<td></td>
<td>AI/AN: 1 (1.6)</td>
<td>No primary: 2 (3.3)</td>
</tr>
<tr>
<td></td>
<td>Other: 2 (3.3)</td>
<td>Other: 2 (3.3)</td>
</tr>
<tr>
<td>Hispanic, $n$</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Same-sex couple, $n$</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Education, $n$ (%)</td>
<td>&lt;High school: 0 (0)</td>
<td>&lt;High school: 2 (3.3)</td>
</tr>
<tr>
<td></td>
<td>High school: 6 (9.8)</td>
<td>High school: 7 (11.5)</td>
</tr>
<tr>
<td></td>
<td>Some college: 14 (23.0)</td>
<td>Some college: 15 (24.6)</td>
</tr>
<tr>
<td></td>
<td>Associate’s: 1 (1.6)</td>
<td>Associate’s: 1 (1.6)</td>
</tr>
<tr>
<td></td>
<td>Bachelor’s: 12 (19.7)</td>
<td>Bachelor’s: 7 (11.5)</td>
</tr>
<tr>
<td></td>
<td>Some grad school: 12 (19.7)</td>
<td>Some grad school: 9 (14.8)</td>
</tr>
<tr>
<td></td>
<td>Professional: 16 (26.2)</td>
<td>Professional: 20 (32.8)</td>
</tr>
<tr>
<td>Employment, $n$ (%)</td>
<td>Full time: 4 (6.7)</td>
<td>Full time: 1 (1.6)</td>
</tr>
<tr>
<td></td>
<td>Part time: 5 (8.3)</td>
<td>Part time: 2 (3.3)</td>
</tr>
<tr>
<td></td>
<td>Homemaker: 3 (5.0)</td>
<td>Retired: 52 (85.3)</td>
</tr>
<tr>
<td></td>
<td>Retired: 44 (73.3)</td>
<td>Not employed: 6 (9.8)</td>
</tr>
<tr>
<td></td>
<td>Not employed: 4 (6.7)</td>
<td></td>
</tr>
<tr>
<td>Number of chronic conditions, mean ($SD$)</td>
<td>3.9 (2.2)</td>
<td>3.4 (2.3)</td>
</tr>
<tr>
<td>MMSE, mean ($SD$)</td>
<td>28.9 (1.2)</td>
<td>22.9 (5.1)</td>
</tr>
<tr>
<td>Variable</td>
<td>Care partner ((n = 61)^a)</td>
<td>Persons living with dementia ((n = 62))</td>
</tr>
<tr>
<td>---------------------------------------------------</td>
<td>-----------------------------</td>
<td>------------------------------------------</td>
</tr>
<tr>
<td>MMSE scores frequencies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>26: 2</td>
<td></td>
<td>&lt;16: 3</td>
</tr>
<tr>
<td>27: 10</td>
<td></td>
<td>16: 1</td>
</tr>
<tr>
<td>28: 5</td>
<td></td>
<td>17: 6</td>
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<td>29: 20</td>
<td></td>
<td>18: 1</td>
</tr>
<tr>
<td>30: 23</td>
<td></td>
<td>19: 2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>20: 4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>21-24: 15</td>
</tr>
<tr>
<td></td>
<td></td>
<td>25-27: 18</td>
</tr>
<tr>
<td></td>
<td></td>
<td>28-30: 11</td>
</tr>
<tr>
<td>CP report of Neuropsychiatric Inventory</td>
<td>n/a</td>
<td>5.3 (3.1)</td>
</tr>
<tr>
<td>Number of symptoms of PLWD, mean ((SD))</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marital length in years, mean ((SD))</td>
<td>41.8 (17.3)</td>
<td>n/a</td>
</tr>
<tr>
<td>Has children, (n (%))</td>
<td>Yes: 48 (82.8)</td>
<td>n/a</td>
</tr>
<tr>
<td></td>
<td>No: 10 (17.2)</td>
<td></td>
</tr>
</tbody>
</table>

Notes: CP = care partner; MMSE = Mini Mental State Exam; n/a = not applicable; PLWD = person with dementia;

\(^a\) One CP did not provide any demographic data
<table>
<thead>
<tr>
<th>Goal-Type</th>
<th>Definition</th>
<th>Partner</th>
<th>Frequency</th>
<th>Exemplars</th>
</tr>
</thead>
<tbody>
<tr>
<td>Opportunities for closeness and</td>
<td>Any goal that states a desire for more regular shared interactions of a</td>
<td>CP</td>
<td>Baseline: 8.3%</td>
<td>● “Staying together, eating healthy and active, i.e. attending programs at library, community/senior center etc.”</td>
</tr>
<tr>
<td>reciprocity</td>
<td>positive nature that allows for opportunities for meaningful and enjoyable</td>
<td></td>
<td>2 weeks: 17.3%</td>
<td>● “Continue to have &quot;date nights&quot; every week. Had a get-away weekend together. Try to keep up with our social events, normal friendships and relationships. Keep &quot;love&quot; foremost in our lives.”</td>
</tr>
<tr>
<td></td>
<td>engagement (e.g. activities, intimacy, communicating).</td>
<td></td>
<td>3 months: 23.4%</td>
<td>● “To try to do activities that include him, don't verbalized “worries,” keep on cooking and baking.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>PLWD</td>
<td>Baseline: 15%</td>
<td>● “Accepting that [partner] cannot control what she sometimes cannot understand. It's not her fault.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>● “To try to do activities that include him, don't verbalized “worries,” keep on cooking and baking.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>● “Always working together for what we like to do.”</td>
</tr>
<tr>
<td>Emotion regulation and</td>
<td>Any goal that focuses on the various ways to cope and respond to the</td>
<td>CP</td>
<td>Baseline: 61.7%</td>
<td>● “Accepting that [partner] cannot control what she sometimes cannot understand. It's not her fault.”</td>
</tr>
<tr>
<td>coping mechanisms</td>
<td>challenges that arise from dementia. This includes both emotion- and</td>
<td></td>
<td>2 weeks: 34.6%</td>
<td>● “Be more patient and understanding. Think before I talk-answer with calming words- speak more rationally. Do not criticize.”</td>
</tr>
<tr>
<td></td>
<td>action-oriented self-modulating strategies such as acceptance, patience,</td>
<td></td>
<td>3 months: 48.9%</td>
<td>● “Become less frustrated, better able to recognize his symptoms &amp; deal with them in a caring and competent way.”</td>
</tr>
<tr>
<td></td>
<td>understanding and adapting.</td>
<td>PLWD</td>
<td>Baseline: 31.7%</td>
<td>● “I try to be patient, kind, responsible, to do my share of things that need to be done as much as possible.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>● “Do not get upset at minor problems - think before speak or react.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>● “Cope. Try to realize he means well. Patience.”</td>
</tr>
<tr>
<td>Demonstration of relationship</td>
<td>Any goal in which the participant alludes to the personal responsibility</td>
<td>CP</td>
<td>Baseline: 18.3%</td>
<td>● “Continued to give my spouse a sense that he retains my love and has a dignity/self-worth.”</td>
</tr>
<tr>
<td>commitment</td>
<td>to express and demonstrate a commitment to their partner and their</td>
<td></td>
<td>2 weeks: 13.5%</td>
<td>● “To be more loving and sympathetic to try NOT to lose sight of the man and husband he once was.”</td>
</tr>
<tr>
<td></td>
<td>relationship (e.g. support, reiteration of love, honoring marriage).</td>
<td></td>
<td>3 months: 10.6%</td>
<td>● “To keep my wife healthy and happy. Be supportive and understanding to her. Remain grateful to her for all her help and love. Be a good team member.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>PLWD</td>
<td>Baseline: 10%</td>
<td>● “Want to be the best spouse possible.”</td>
</tr>
<tr>
<td>Maintenance of the status quo</td>
<td>Any goal that references the maintenance or continuation of an already</td>
<td>CP</td>
<td>Baseline: 6.7%</td>
<td>● “To be able to maintain a happy, forgiving and loving relationship.”</td>
</tr>
<tr>
<td></td>
<td>positive, good, strong, or stable relationship.</td>
<td></td>
<td>2 weeks: 13.5%</td>
<td>● “The goals that I experience and accomplished is that my relationship between my spouse is excellent. Doing 35 years together.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3 months: 8.5%</td>
<td>● “We seem to be doing fairly well.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>PLWD</td>
<td>Baseline: 28.3%</td>
<td>● “The only thing that I would really want is to keep my relationship with my wife the same way that it has always been. It can’t get any better.</td>
</tr>
<tr>
<td>Demoralization of relationship</td>
<td>Any response that explicitly states having no goals for the relationship or</td>
<td>CP</td>
<td>Baseline: 0%</td>
<td>● “To continue the love I get from my wife. To continue the love I have with my wife.”</td>
</tr>
<tr>
<td>quality</td>
<td>that</td>
<td></td>
<td>2 weeks: 7.7%</td>
<td>● I like the way it is &quot;we used to have big arguments.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3 months: 6.4%</td>
<td>● “None- spouse getting harder to cope with; she doesn’t seem to understand much of what I say regarding instructions.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>● “I don’t think I have since I strongly feel my relationship is cracking up. It’s all over the place.”</td>
</tr>
</tbody>
</table>
mentions a decline in relationship quality without mention of anything positive.

**PLWD**
Baseline: 15%

- “Not really. Sometimes I think he’s not happy with my memory.”
- “I don’t have any goals about that.”

**CP**
Baseline: 5%
- 2 weeks: 13.5%
- 3 months: 2.1%
- “The above awareness moderates my transgressions.”
- “Mi. [partner] is more peaceful.”

**PLWD**
Baseline: 0%
n/a

### Other-Miscellaneous

Any goal that does not meet the inclusion requirements for the definitions of the five other categories.

Any response that has such limited content (i.e. one word) that its goal-type cannot be determined.

**CP**
Baseline: 5%

- 2 weeks: 13.5%
- 3 months: 2.1%
- “The above awareness moderates my transgressions.”
- “Mi. [partner] is more peaceful.”

**PLWD**
Baseline: 0%
n/a

---

**Figure 1. Changes in the Distribution of Care Partner Goal-Types Over Study Period**

![Changes in Care Partner Goal-Type Distribution Over Study Period](image)
**APPENDIX**

**Supplementary Table 1. Associations Among Study Variables for Care Partners at Baseline**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Goal-Type*</th>
<th>POS AFF</th>
<th>NEG AFF</th>
<th>Spouse Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>t = -0.30, p = 0.78</td>
<td>-0.17</td>
<td>0.03</td>
<td>0.01</td>
</tr>
<tr>
<td>Gender</td>
<td>χ² = 3.48, p = 0.18</td>
<td>t = -0.84, p = 0.41</td>
<td>t = 1.35, p = 0.18</td>
<td>t = -2.94, p = 0.005*</td>
</tr>
<tr>
<td>Race</td>
<td>χ² = 12.35, p = 0.05</td>
<td>F = 4.19, p = 0.009**</td>
<td>F = 0.54, p = 0.66</td>
<td>F = 1.46, p = 0.23</td>
</tr>
<tr>
<td>Education</td>
<td>χ² = 4.61, p = 0.92</td>
<td>F = 0.81, p = 0.54</td>
<td>F = 1.56, p = 0.19</td>
<td>F = 1.23, p = 0.31</td>
</tr>
<tr>
<td>Employment</td>
<td>χ² = 9.17, p = 0.33</td>
<td>F = 0.99, p = 0.42</td>
<td>F = 1.52, p = 0.21</td>
<td>F = 2.46, p = 0.06</td>
</tr>
<tr>
<td>Chronic conditions</td>
<td>t = -0.68, p = 0.50</td>
<td>-0.07</td>
<td>0.21</td>
<td>0.10</td>
</tr>
<tr>
<td>MMSE</td>
<td>t = 0.86, p = 0.41</td>
<td>-0.06</td>
<td>-0.10</td>
<td>0.008</td>
</tr>
<tr>
<td>Marital length</td>
<td>t = -0.88, p = 0.38</td>
<td>-0.10</td>
<td>-0.16</td>
<td>-0.10</td>
</tr>
</tbody>
</table>

**Supplementary Table 2. Associations Among Study Variables for Persons Living With Dementia at Baseline**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Goal-Type*</th>
<th>POS AFF</th>
<th>NEG AFF</th>
<th>Spouse Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>F = 2.24, p = 0.09</td>
<td>-0.23</td>
<td>0.07</td>
<td>-0.04</td>
</tr>
<tr>
<td>Gender</td>
<td>χ² = 0.26, p = 0.97</td>
<td>t = -0.19, p = 0.85</td>
<td>t = 0.12, p = 0.90</td>
<td>t = 0.21, p = 0.83</td>
</tr>
<tr>
<td>Race</td>
<td>χ² = 13.1, p = 0.16</td>
<td>F = 0.50, p = 0.61</td>
<td>F = 0.42, p = 0.66</td>
<td>F = 1.35, p = 0.27</td>
</tr>
<tr>
<td>Education</td>
<td>χ² = 21.17, p = 0.27</td>
<td>F = 0.81, p = 0.54</td>
<td>F = 0.51, p = 0.79</td>
<td>F = 1.23, p = 0.31</td>
</tr>
<tr>
<td>Employment</td>
<td>χ² = 8.34, p = 0.50</td>
<td>F = 0.51, p = 0.68</td>
<td>F = 0.14, p = 0.93</td>
<td>F = 1.78, p = 0.16</td>
</tr>
<tr>
<td>Chronic conditions</td>
<td>F = 0.12, p = 0.95</td>
<td>-0.007</td>
<td>0.47†</td>
<td>-0.12</td>
</tr>
<tr>
<td>MMSE</td>
<td>F = 2.15, p = 0.10</td>
<td>0.12</td>
<td>0.19</td>
<td>-0.06</td>
</tr>
</tbody>
</table>

*Two-level variable

**p < .01.

†p < .001

*Four-level variable
<table>
<thead>
<tr>
<th>Goal-Type Frequencies</th>
<th>Baseline*</th>
<th>2 weeks</th>
<th>3 month follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Care partner</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Approach: 36.8%</td>
<td>Approach: 38.5%</td>
<td>Approach: 43.5%</td>
<td></td>
</tr>
<tr>
<td>Avoidant: 63.2%</td>
<td>Avoidant: 40.4%</td>
<td>Avoidant: 41.3%</td>
<td></td>
</tr>
<tr>
<td>No Goals/Already Positive: 0%</td>
<td>No Goals/Already Positive: 5.8%</td>
<td>No Goals/Already Positive: 10.9%</td>
<td></td>
</tr>
<tr>
<td>No Goals/ Deteriorating: 0%</td>
<td>No Goals/ Deteriorating: 15.3%</td>
<td>No Goals/ Deteriorating 4.3%</td>
<td></td>
</tr>
<tr>
<td><strong>Persons Living With Dementia</strong></td>
<td>Approach: 38.6%</td>
<td></td>
<td>Not applicable</td>
</tr>
<tr>
<td>Approach: 38.6%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoidant: 23.2%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No Goals/Already Positive: 23.2%</td>
<td>No Goals/ Already Positive: 15%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No Goals/ Deteriorating 15%</td>
<td>No Goals/ Deteriorating 4.3%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*3 care partner goals at baseline were coded as other-type goals that did not fit into any category and were not included in analyses.