American Journal of Alzheimer's
Disease & Other Dementias®
Volume 21 Number 4
August/September 2006 249-257
© 2006 Sage Publications
10.1177/1533317506290665
http://ajadd.sagepub.com
hosted at
http://online.sagepub.com

Development and Testing of a New Outcome Measure of Relationship Between Patients With Alzheimer's Disease and Their Partners

Margaret C. Reilly, Norman R. Relkin, and Arthur S. Zbrozek

In mild Alzheimer's disease (AD), loss of relationship with the patient is a significant consequence for the partner (relative) and may be amenable to improvement with effective intervention. To evaluate relationship dynamics, the authors developed and tested content and discriminative validity of the self-administered Partner-Patient Questionnaire for Shared Activities among 100 partners of patients with mild to moderate Alzheimer's disease. Principal component analysis confirmed that interference in 17 activities derived from the literature and partner-specified activities comprised a relationship factor; internal

consistency was very high. Time spent caregiving, caregiver esteem, lack of family support, and impact on partner health and activities were significant predictors of the Partner-Patient Questionnaire for Shared Activities, but the patient's cognitive and mood states were not. The Partner-Patient Questionnaire for Shared Activities warrants additional psychometric testing as a measure of Alzheimer's disease outcome.

Keywords: Alzheimer's disease; caregiver burden; caregiver relationship; questionnaire

The onset of Alzheimer's disease (AD) is difficult to detect. It may take years before others notice that a pattern of deficits is emerging since symptoms may be compensated for or hidden. The effects of early or mild disease on the patient's partner (ie, spouse, relative, or nonrelative in close relationship to the patient) have been termed *anticipatory grief*. This arises from, among other things, loss of the relationship, loss of familiar communication with the patient, loss of future plans, and loss of social and recreational interactions. Anticipatory grief has been found to vary by years since disease onset, caregiver type (spouse vs adult child), and dementia severity. Much of the research into anticipatory grief has relied on interviews with small

numbers of caregivers.⁷⁻⁹ The content of the few self-administered questionnaires probing this phenomenon are concerned mostly with distress from caregiver burden, and only a few items address the relationship directly.^{10,11} Despite the limitations of this research, it clearly identifies deterioration and loss of relationship as an early and key outcome in AD.

An instrument that measures interference in the patient-caregiver relationship might provide a more sensitive measure of patient status than typical caregiver burden instruments do. This may be particularly useful in mild AD, when the patient can perform activities of daily living and other activities with minimal assistance. Clinicians do not currently have a brief, reliable measure to gain input from a partner of the patient diagnosed with early or mild Alzheimer's disease to assess the patient's status in the community environment. Likewise, there are no accepted instruments to assess the effect of therapeutic interventions on the patient's relationship to the caregiver. Such an instrument might serve as a model for physicians to structure their discussions with partners to monitor meaningful changes in

Authors' Note: We acknowledge the contributions of Basia Adamiak; Jason Karlawish, MD; Helena Otsa, MBA; and David Strutton, PhD. Wyeth Research funded this study. Ms Reilly received compensation from Wyeth for her participation. Dr Relkin received a grant from Wyeth for this research. Mr Zbrozek is an employee of Wyeth.

Address correspondence to: Margaret C. Reilly, MA, MPH, Reilly Associates, 425 East 51st Street, New York, NY 10022; e-mail: mreilly@reillyassociates.net.

patient status. An instrument that measures routine shared activities may serve as a simplified proxy for measuring the patient's status at home. The purpose of this study was to develop and test a questionnaire to assess the partner-patient shared activities that would be useful in evaluating the effects of interventions in clinical trials of mild AD. Note that the term *partner* is used throughout this report to designate the patient's caregiver or significant other, while the term *spouse* is reserved for those living in union, although not necessarily legally married.

Methods

Measurement Selection Criteria

We deemed the following selection criteria essential: (1) items must assess relationship from the partner's point of view because the patients' responses might not be reliable as AD progressed; (2) items must be important to both spouse and nonspouse partners; (3) items must be sensitive to the improvement or progression of AD, (4) items must be easily administered and completed, and (5) summary scores amenable to statistical analysis must be provided.

Item Selection

Based on our review of the caregiver burden, anticipatory grief, marital relations, and expressed emotion literatures, and in consultation with an AD clinician, we created a self-administered questionnaire: the Partner-Patient Questionnaire for Shared Activities (PPQSA; appendix). The PPQSA assessed the importance of 17 shared activities, the number of times the activities occurred in the past 24 hours or the past week (indicated with a write-in response), and the extent to which the patient's mood or mental state interfered with the activity. Interference was assessed on a 5-point scale ranging from 0 = not at all to 4 = *extremely*, with higher scores indicating more interference. Partners were also asked to enter up to 3 other important shared activities, answer the frequency and interference questions for these activities, and rank the 5 most important activities.

Study Design

We tested the PPQSA in a convenience sample of partners accompanying patients at medical treatment centers. English-speaking patients ≥50 years of age with an AD diagnosis who signed informed consent and scored between 16 to 27 on the Mini-Mental State Examination (MMSE)¹² were eligible for the study. Partners were eligible if they signed consent, could read and write in English, and lived with or saw the patient at least twice a week. Qualified patients and partners each completed self-administered questionnaires at the site on 1 occasion. The appropriate institutional review boards approved the study.

Questionnaires

Patients completed questions about disease insight and completed the Geriatric Depression Scale (GDS), a 15-item questionnaire that measures symptoms of depression on a scale ranging from 0 to 15, with higher scores indicating greater depression.¹³ A score >5 points is suggestive of depression; a score >10 is almost always indicative of depression.

Partners completed a questionnaire that included the PPQSA, as well as several other instruments. The Work Productivity and Activity Impairment Questionnaire-dyad version (WPAI-DYAD) is a 6-item questionnaire that measures work and daily activity impairment due to a specific health problem in the prior 7 days^{14,15}; in this version, the patient's mood or mental state was specified as the problem. Time Spent Caregiving (TSC) measures the hours spent by partners and others assisting the patient and was adapted from previous research. 16,17 Time assisting with personal care activities, activities around and outside the house, and additional time supervising, guarding, or watching during the past week and yesterday were measured for both the partner and other caregivers by summing individual hours reported (computed) and in separate global questions. The Caregiver Reaction Assessment (CRA) is a 24-item questionnaire that measures the positive and negative aspects of caregiving; items are scored from 1 = strongly disagree to 5 = strongly agree and are grouped into 5 domains: caregiver's esteem, lack of family support, impact on finances, impact on schedule, and impact on health. 18 Additional questions included an assessment of the questionnaire itself.

Statistical Methods

Principal component analyses (PCA) were conducted for the PPQSA items, separately for spouse and nonspouse partners. Varimax rotation was

applied to ensure that the factors were orthogonal; factor loadings were considered if they exceeded a conservative 0.55, to compensate for the recoding of missing data as described in the "Results" section. Internal reliability of PPQSA items was assessed with Cronbach's α , in which a minimum acceptable reliability coefficient of .70 is recommended to support consistency. 19

The PPQSA was scored in 3 ways: (1) as the simple average of activity interference scores, (2) as the average of the interference scores of the 5 most important activities, and (3) as the weighted average of interference scores obtained from 2 regression models. A planned analysis of covariance (ANCOVA) was used to test the relationship between the independent measure of disease severity (ie, MMSE score, 16-21 and 22-27) and the 3 PPQSA scores; post hoc analyses with MMSE as a continuous variable were also performed to confirm results. In subsequent analyses, the simple average of PPQSA interference scores was used as the scoring method. ANCOVA was used to test the relationship between this PPQSA score and TSC for the partner in the past week; GDS, CRA, and WPAI-DYAD scores; and the relationship between MMSE score (independent measure) and other caregiver measures (dependent measures). In all analyses, partner age, gender, and relationship to patient were considered as covariates.

All analyses were conducted using SAS version 8.2. A *P* value less than .05 was required for significance using 2-sided hypothesis tests; no P-value adjustments were made for the analysis of multiple end points.

Results

Study Population

Five medical treatment centers enrolled a convenience sample of 100 qualified dyads during the 1-year period ending October 2004. The demographic and health characteristics of the patient and partner populations are displayed in Table 1. Partners were younger than patients (mean age = 66.4 vs 76.9 years) and less likely to be male (36% vs 51%). Compared to their counterparts in the lower MMSE patient group, partners in the higher MMSE patient group (milder AD) were more likely to be male (39.1% vs 30.6%), married (87.5% vs 69.4%), the spouse of the patient (75.0% vs 87.5%), and have some college education (75.0% vs 45.7%).

Feasibility of Using the PPOSA

The missing data rate for the PPSQA was 3.3%. The missing data rates were higher among partners with no college education (4.1%) than those with some college education (2.9%) and higher among those 65 years or older (4.5%) than among younger partners (1.7%). An item analysis of the missing data indicated that the individual questions were not in themselves difficult but that the 3-part formatting of the questions was a problem for some partners.

Content Validity

Content validity was analyzed separately by the relationship of the partner to the patient, that is, for spouses (n = 71) and nonspouses (n = 29). The frequency, importance, and interference in shared activities due to the patient's mood or mental state for spouses are displayed by the patient's MMSE score in Table 2. The most frequent daily activity for both groups of spouses was laughing together; the most frequent weekly activity was doing chores around the house together. The least frequent shared activities were handling family finances, playing cards, and having sex. The percentage of spouses rating the specified activities as important ranged from 21.7% and 29.8% (handling family finances) to 95.5% and 89.4% (laughing) for the low and high MMSE groups, respectively. When spouses were asked to rank the 5 most important activities, spouses in both MMSE groups included having a stimulating exchange of ideas, laughing, spending time with other family, and demonstrating affection as their most important activities. Spouses in the higher MMSE group included spending time with friends, while spouses in the lower group included doing household chores together.

Interference with activities for the low MMSE spouse group ranged from 8.7% (participate in religious services and work on a project) to 39.1% (have a stimulating exchange of ideas); for the high MMSE spouse group, interference ranged from 14.6% (participate in religious services) to 39.6% (confide in each other; Table 2). Although degree of interference was skewed toward the low end for each of the activities, the full range of the response set was used for each activity.

The analysis of nonspouse partners by patient's MMSE score was limited by the sample size and is not displayed. Excluding having sexual relations, the frequency of shared activities was comparable for spouses and nonspouses for 10 activities and higher

Demographic and Health Characteristics of the Patient and Partner Populations by the Patient's Mini-Mental State Examination (MMSE) Score

	Patient MMSE Score			
	16-21 (n = 36)	22-27 (n = 64)	Total $(N = 100)$	
Patient characteristic				
Mean age, y	79.1	75.7	76.9	
Gender, % male	50.0	51.6	51.0	
Time since diagnosis of Alzheimer's disease, mean y	2.6	1.8	2.1	
Physical health, %				
Excellent	20.0	43.8	35.4	
Very good	31.4	25.0	27.3	
Good	20.0	18.8	19.2	
Fair	28.6	10.9	17.2	
Poor	0.0	1.6	1.0	
Geriatric Depression Scale score, %				
0 to ≤5	77.8	82.8	81.0	
>5 to ≤10	19.4	14.1	16.0	
>10	2.8	3.1	3.0	
Insight				
Problems with memory. %	52.8	63.5	59.6	
Memory will worsen				
n	17	37	54	
%	41.2	51.4	48.1	
Partner characteristic				
Mean age, y	67.1	65.9	66.4	
Gender, % male	30.6	39.1	36.0	
Marital status, % married	69.4	87.5	81.0	
Education, %				
Some college or more	45.7	75.0	64.7	
Relationship to patient, % spouse	63.9	75.0	71.0	
Employment status, % employed outside home	19.4	26.6	24.0	
Overall health, %				
Excellent	16.7	18.8	18.0	
Very good	27.8	34.4	32.0	
Good	25.0	21.9	23.0	
Fair	27.8	20.3	23.0	
Poor	2.8	4.7	4.0	

for spouses for 5 activities (laugh, talk, demonstrate affection, spend time with friends, go to a movie). Handling finances was the only activity that had a higher frequency and importance for nonspouses than for spouses. At least 25% of the spouse and nonspouse groups considered each activity important. Although the order of the rankings of important activities varied, the nonspouses identified the same most important activities as spouses did, except for confide in each other, which was ranked by the nonspouses but not by the spouses. With few exceptions, nonspouses were more likely to report interference in shared activities than spouses were, and the full range of interference responses (0-4) was used for each item.

A total of 34 partners added 42 activities to the PPQSA in response to open-ended questions; of these, 2% were subsequently identified as 1 of the 5 most important activities. Since all activities contributed by partners were conceptually included in the specified activities and could be explicitly included by wording modifications, these other activities were recoded to one of the specified activities; the final PPOSA items are displayed in the appendix. The frequency and importance of the specified activities were rescored to reflect the inclusion of the new activities. Missing responses to the interference questions were recoded to 0 if the frequency of the activity was 0 and the activity was not important or in cases in which the importance response was also missing.

PCA and Internal Consistency

Results of PCA were striking and consistent. The first factor in both the spouse and nonspouse analysis consisted of only the relationship interference questions. Neither of the other 2 sets of questions (ie, frequency and importance of each activity) performed as well: these questions were spread across multiple factors, accounted for considerably less of the variance among respondents, and are not included in the subsequent analyses reported here. For spouses, there were 9 factors in total, accounting for 31.4% of the variance among respondents; for nonspouses, there were 6 factors in total, accounting for 30.9% of the variance among respondents.

For factor 1, relationship interference, participating in religious services was the only item that did not load for spouses, and confiding in each other was the only item that did not load for nonspouses. The concentrated clustering of factor loadings in factor 1 (0.69-0.87 for spouses, 0.64-0.84 for nonspouses) indicated that a simple summation of all items (including the nonloading items) would be an appropriate preliminary scoring method. The overall standardized α for PPQSA interference scores was .95 for spouses and .96 for nonspouses; individual items exceeded .94 in both groups.

Regression analyses were performed to find the most efficient scoring algorithm for the PPQSA interference score. The 5 interference in activity scores identified for the spouse were sexual relations, confide in each other, laugh and have fun together, spend time together with family members, and shared activities in the community. The 6 scores identified for the nonspouse were special, nonroutine projects; demonstrate affection for each other; shop, do errands; take car ride or public transportation; quiet times together; and participate in religious services together. The resulting scoring algorithms explained a total of 98% of the variance in PPQSA interference scores.

Discriminant Validity

Results of the validity testing are displayed in Table 3. The 3 PPQSA interference scores were first tested relative to the categorical and continuous MMSE scores, and since neither MMSE score was found to be a significant predictor of the PPQSA scores, only the average PPQSA score was retained for additional testing since it was the most inclusive activity interference measure. The GDS score was not a significant predictor of this PPQSA score, but TSC was (P = .0005). CRA domain scores were also significant predictors of the PPQSA score (P values \leq .02), except for impact on finances. For the 30 employed partners, work measures were not significant predictors of the PPQSA score, but percentage daily activity impairment, which applied to the entire population, was (P < .0001). Neither of the MMSE measures was found to be a significant predictor of CRA, TSC, or WPAI-DYAD activity impairment scores (not displayed).

Table 4 displays the mean of the caregiver burden scores by PPQSA categorical scores. All measures demonstrated a general trend toward greater caregiving burden as the PPQSA interference score increased (worsened). For example, the amount of time the partner spent caregiving in the prior week increased directly with the increases in the PPQSA score, from 9.8 hours to 15.8 hours to 34.7 hours. WPAI-DYAD activity impairment increased from 20.7% to 34.0% to 50.5%.

Discussion

The PPOSA was constructed to measure the extent to which the AD patient's mood and mental state interfered with the patient-partner relationship. We hypothesized that this measure might prove useful to clinicians as a metric for assessing the effect of therapeutic interventions on the patient's health status in clinical trials.

The conceptual content of the PPQSA was confirmed, and 17 interference questions were found to comprise a consistent and strong factor for both spouse and nonspouse partners, with high internal reliability. The included activities were found both to be important enough and to occur frequently enough to be potentially useful measures of the patient's status. Three methods of scoring the PPQSA were tested, but none was significantly related to the patient's MMSE score. Thus, while the 5 to 6 items in the derived weighted average and the 5 most important activities were theoretically efficient ways of collecting and scoring the PPQSA information, the simple average of the 17 items was retained as the preferred scoring method until other methods could be confirmed in a larger and more representative sample.

	Frequency of the Activity, ^a $\tilde{x} \pm \text{SD (Range)}$ MMSE Score		Important Activity, ^b % MMSE Score		Interference Moderately, Quite a Bit, or Extremely, ^c % MMSE Score	
Shared Activity	16-21 (n = 23)	22-27 (n = 48)	16-21 (n = 23)	22-27 (n = 48)	16-21 (n = 23)	22-27 (n = 48)
Have a stimulating exchange of ideas	$2.2 \pm 2.4 \ (0-8)$	$2.5 \pm 3.6 \; (0-20)$	78.3	76.6	39.1	29.2
Laugh	$5.3 \pm 5.3 \; (0-24)$	$3.4 \pm 3.3 \ (0-15)$	95.5	89.4	30.4	27.1
Confide in each other	$2.0 \pm 2.0 \ (0-6)$	$1.9 \pm 2.2 \ (0-10)$	78.3	81.3	30.4	39.6
Talk about a TV show, the news, book, or magazine	$4.1 \pm 4.9 \; (0-20)$	$2.8 \pm 2.4 \ (0-10)$	91.3	87.2	34.8	35.4
Demonstrate affection, such as kissing, hugging	$4.7 \pm 4.3 \; (0-15)$	$2.6 \pm 3.4 \ (0-20)$	95.5	87.2	30.4	37.5
Run errands, such as buy groceries	$3.3 \pm 2.9 \ (0-10)$	$2.3 \pm 2.1 \ (0-9)$	77.3	50.0	26.1	25.0
Work on a project	$0.8 \pm 1.8 \; (0-8)$	$0.9 \pm 1.5 (0-9)$	36.4	41.9	8.7	18.8
Handle family finances	$0.6 \pm 1.6 \; (0-7)$	$0.8 \pm 1.5 (0-7)$	21.7	29.8	17.4	20.8
Participate in religious services	$1.0 \pm 2.9 \; (0-14)$	$0.5 \pm 1.1 (0-6)$	38.1	43.2	8.7	14.6
Spend time with friends	$2.0 \pm 1.7 (0-5)$	$2.1 \pm 1.9 (0-7)$	82.6	87.2	13.0	27.1
Spend time with other family	$2.2 \pm 2.2 \ (0-7)$	$1.8 \pm 1.8 \; (0-7)$	87.0	89.4	17.4	18.8
Do chores around the house	$5.6 \pm 10.8 \; (0-50)$	$3.3 \pm 3.5 (0-15)$	56.5	72.3	21.7	25.0
Make major decisions	$1.5 \pm 3.4 \; (0-15)$	$1.3 \pm 2.2 \ (0-10)$	56.5	68.2	13.0	27.1
Play cards, board games, etc	$0.8 \pm 2.1 \ (0-7)$	$0.3 \pm 0.9 \; (0-4)$	56.5	26.1	17.4	16.7
Go to a movie, restaurant, or community event	$2.4 \pm 2.3 \ (0-8)$	$2.2 \pm 1.9 \; (0-9)$	91.3	85.1	26.1	20.8
Plan a future event, such as a trip, vacation, holiday	$0.9 \pm 1.9 \; (0-8)$	$0.9 \pm 1.1 \ (0-5)$	77.3	84.8	17.4	27.1

 $0.1 \pm 0.4 (0-2)$

Table 2. Frequency, Importance, and Interference of PPQSA Shared Activities by MMSE Scores for Spouse Partners

Note: PPQSA = Partner-Patient Questionnaire for Shared Activities; MMSE = Mini-Mental State Examination.

 $0.3 \pm 0.8 (0-3)$

Have sexual relations

The patient's degree of depression was not significantly related to PPQSA score, but time spent caregiving and other measures of caregiver burden were. Furthermore, MMSE did not predict any of the other caregiver burden measures. Although other researchers have generally found an association between the patient's disease stage or performance level and caregiver burden, the relationship has been found to be mediated by other factors, such as caregiver characteristics, the caregiver's relationship to the patient, and coping mechanisms, 20-25 such that at a given level of objective burden, there is a considerable variation in caregiver distress.²⁶ Some of the positive consequences of caregiving, such as increased self-esteem, may also confound the relationship between disease severity and caregiver burden²⁷⁻³¹ and provide additional support for the concept of burden as multidimensional, not global.⁷

50.0

21.7

33.3

47.6

With dementia patients, the relationship between disease severity and caregiver burden is complex because of the dimensions of disease severity, that is, cognitive impairment, functional impairment, and behavioral disturbance, which may have a differential effect on the caregiver.³² Previous research in AD suggests that behavioral manifestations of dementia may be more predictive of caregiver burden than cognitive or functional impairment.^{7,33} The lack of significant association between patient cognitive level and caregiver burden observed in this study is consistent with these previous reports.

The relatively small sample sizes of spouses (n = 70), nonspouses (n = 30), and the employed (n = 30) are

a. Daily frequency for items 1 to 5 and weekly frequency for items 6 to 17.

b. In response to, "Is activity important for you to do with the patient?"

c. Excludes responses of "not at all" and "a little bit."

Table 3. Summary of Validation Results for the Partner-Patient Questionnaire for Shared Activities (PPOSA)

Validation Criteria	PPQSA Score, P Value ^a (N = 100) ^b
MMSE score (16-21 vs 22-27)	NS
MMSE (continuous)	NS
GDS	NS
TSC: total hours partner spent caregiving in the past week	.0005
CRA: impact on schedule	.0004
Caregiver esteem	.02
Lack of family support	.03
Impact on health	.02
Impact on finances	NS
WPAI-DYAD: daily activity impairment	<.0001
Absenteeism ^c	NS
Work impairment ^c	NS
Overall productivity loss ^c	NS

Note: MMSE = Mini-Mental State Examination; NS = not significant; GDS = Geriatric Depression Scale; TSC = Time Spent Caregiving; CRA = Caregiver Reaction Assessment; WPAI-DYAD = Work Productivity and Activity Impairment Questionnaire-dyad version.

limitations of the study. Although the items selected for inclusion in the PPQSA are the most important shared activities for both spouses and nonspouses and occur with adequate frequency to be measured on a weekly basis, additional testing in large populations is required to confirm this, and responsiveness to clinical change should be assessed.

Our results indicate that as the time spent by the partner in caregiving increases and the usual daily activities of the partner are negatively affected, there will be a corresponding increase in interference with shared activities important to the relationship. Further research should be conducted to determine if the PPQSA interference scores would complement caregiver burden measures or replace them as a primary metric of therapeutic value. Additional research should be considered to determine whether the PPQSA could provide meaningful information in a clinical practice setting by serving as an efficient proxy for the patient's status.

Conclusion

The PPQSA measures the most important shared activities for partners of patients with AD and may be a useful clinical proxy for assessing disease severity.

Caregiver Burden Scores by Partner-Patient Questionnaire Table 4. for Shared Activities (PPQSA) Scores

	PPQSA Score			
Caregiver Burden Score	<1 (n = 56)	1-2 (n = 25)	>2 (n = 19)	$0-4 (N = 100)^a$
CRA				
Impact on schedule	2.8 ± 0.9	3.0 ± 0.7	3.5 ± 0.9	3.0 ± 0.9
Caregiver esteem	3.9 ± 0.6	3.6 ± 0.6	3.6 ± 0.7	3.7 ± 0.7
Lack of family support	2.2 ± 0.9	2.3 ± 0.7	2.8 ± 0.8	2.3 ± 0.9
Impact on health	2.3 ± 0.9	2.5 ± 0.6	2.5 ± 1.0	2.4 ± 0.9
Impact on finances	2.5 ± 1.0	2.6 ± 1.0	2.6 ± 1.3	2.5 ± 1.1
WPAI-DYAD				
Percentage daily activity impairment	20.7 ± 24.5	34.0 ± 24.3	50.5 ± 34.9	29.9 ± 29.4
TSC				
Total hours partner spent caregiving yesterday	3.0 ± 6.4	3.0 ± 3.9	12.6 ± 16.2	4.8 ± 9.4
Total hours others spent caregiving yesterday	0.7 ± 1.8	0.9 ± 2.3	2.3 ± 5.8	1.0 ± 3.1
Hours partner spent caregiving in the past week	9.8 ± 20.6	15.8 ± 25.7	34.7 ± 50.9	16.1 ± 31.0
Hours others spent caregiving past week	6.4 ± 24.4	12.5 ± 24.0	24.1 ± 45.8	11.2 ± 29.6
Computed total hours partner spent caregiving yesterday	3.5 ± 6.6	3.9 ± 4.3	14.8 ± 19.8	5.8 ± 11.0
Computed total hours partner and others spent caregiving past week	16.7 ± 34.5	29.4 ± 46.3	56.2 ± 57.8	26.7 ± 44.2

Note: CRA = Caregiver Reaction Assessment; WPAI-DYAD = Work Productivity and Activity Impairment Questionnaire-dyad version; TSC = Time Spent Caregiving.

a. P values were derived from analyses of covariance, with partner age, gender, and relationship to patient as covariates. Higher caregiver burden was associated with greater interference in shared activities.

b. Sample size may vary due to missing information.

c. n = 30.

a. Sample size may vary due to missing information

Appendix Items in the Original and Final Partner-Patient Questionnaire for Shared Activities (PPOSA)

Original PPOSA ^a	Final PPOSA

Have a stimulating exchange of ideas Laugh

Confide in each other

Talk about a TV show, the news, book, or magazine

Demonstrate affection, such as kissing, hugging

Run errands, such as buy groceries

Work on a project

Handle family finances

Participate in religious services Spend time with friends Spend time with other family

Do chores around the house

Make major decisions Play cards, board games, etc Go to a movie, restaurant, or community event

Plan a future event, such as a trip, vacation, holiday

Have sexual relations

Have a stimulating exchange of ideas together

Laugh and have fun together

Confide in each other

Quiet times together, for example, watching TV, reading, listening to music, or talking

Demonstrate affection toward each other, such as kissing and hugging

Shop, do errands, or take a car ride or public transportation together

Special, nonroutine projects you did together, for example, packing for a trip, cleaning out the garage, preparing for a holiday or party

Handle joint finances together, such as pay bills, file taxes, and manage money

Participate in religious services together

Spend time together with friends

Ability to spend time with family members, such as siblings, in-laws, children, or grandchildren

Shared activities around the house, such as cooking and eating together, cleaning, and yard work

Make major decisions together

Play cards, board or word games, etc, together

Shared activities in the community, such as going to a doctor's appointment, movie, sporting event or restaurant, taking a walk, or playing a sport

Ability to plan a future event, such as a trip, vacation, or holiday together

Having sexual relations

a. In the original, the general question elicited activities shared together with the patient. In the final version, together was added to each item.

References

- i. Kuhn DR, Ortigara A, Farran CJ. A continuum of care in Alzheimer's disease. Adv Pract Nurs Q. 1997;2(4):15-21.
- 2. Walker RJ, Pomeroy EC. Depression or grief? The experience of caregivers of people with dementia. Health Soc Work. 1996;21:247-254.
- 3. Farran CJ, Keane-Hagerty E, Salloway S, Kupferer S, Wilken CS. Finding meaning: an alternative paradigm for Alzheimer's disease family caregivers. Gerontologist. 1991;31:483-489.
- 4. Loos C, Bowd A. Caregivers of persons with Alzheimer's disease: some neglected implications of the experience of personal loss and grief. Death Stud. 1997;21:501-514.
- 5. Ponder RJ, Pomerov EC. The grief of caregivers: how pervasive is it? J Gerontol Social Work. 1996;27:3-21.
- 6. Meuser TM, Marwit SJ. A comprehensive, stage-sensitive model of grief in dementia caregiving. Gerontologist. 2001; 41:658-670.

- 7. Furlini L. The parent they knew and the "new" parent: daughters' perceptions of dementia of the Alzheimer's type. Home Health Care Serv Q. 2001;20(1):21-38.
- 8. Perry J. Wives giving care to husbands with Alzheimer's disease: a process of interpretive caring. Res Nurs Health. 2002;25:307-316.
- 9. Moyle W, Edwards H, Clinton M. Living with loss: dementia and the family caregiver. Aust J Adv Nurs. 2002;19(3):25-31.
- 10. Theut SK, Jordan L, Ross LA, Deutsch SI. Caregiver's anticipatory grief in dementia: a pilot study. Int J Aging Hum Dev. 1991;33:113-118.
- 11. Marwit SJ, Meuser TM. Development and initial validation of an inventory to assess grief in caregivers of persons with Alzheimer's disease. Gerontologist. 2002;42(6):751-65.
- 12. Folstein MF, Folstein SE, McHugh PR. "Mini-Mental State": a practical method for grading the cognitive state of patients for the clinician. J Psychiatr Res. 1975;12:189-198.

- 13. Alden D, Austin C, Sturgeon R. A correlation between the GDS long and short forms. *J Gerontol*. 1989;44:124-125.
- Reilly MC, Zbrozek AS, Dukes EM. The validity and reproducibility of a work productivity and activity impairment instrument. *Pharmacoeconomics*. 1993;4:353-365.
- Reilly Associates. WPAI references. Available at: http:// www.reillyassociates.net/WPAI_References.html.
- 16. Clipp EC, Moore MJ. Caregiver time use: an outcome measure in clinical trial research on Alzheimer's disease. *Clin Pharmacol Ther.* 1995;58:228-236.
- 17. Marin DB, Dugue M, Schmeidler J, et al. The Caregiver Activity Survey (CAS): longitudinal validation of an instrument that measures time spent caregiving for individuals with Alzheimer's disease. *Int J Geriatr Psychiatry*. 2000; 15:680-686.
- 18. Given CW, Given B, Stommel M, Collins C, King S, Franklin S. The Caregiver Reaction Assessment (CRA) caregivers to persons with chronic physical and mental impairments. *Res Nurs Health*. 1992;15:271-283.
- 19. Cronbach LJ. Coefficient alpha and the internal structure of tests. *Psychometrika*. 1951;16:297-334.
- Pearlin L, Mullen J, Semple S, Skaff M. Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist*. 1990;30:583-594.
- 21. Weitzner MA, McMillan SC, Jacobson PB. Family caregiver quality of life: differences between curative and palliative cancer treatment settings. *J Pain Symptom Manage*. 1999;17:418-428.
- Annerstedt L, Elmstahl S, Ingvad B, Samuelsson S. Family caregiving in dementia: an analysis of the caregiver's burden and the "breaking point" when home care becomes inadequate. Scand J Public Health. 2000;28:23-31.
- 23. Williamson GM, Shaffer DR, Schulz R. Activity restriction and prior relationship history as contributors to

- mental health outcomes among middle-aged and older spousal caregivers. *Health Psychol.* 1998;17:152-162.
- 24. Joyce J, Leese M, Szmukler G. The Experience of Caregiving Inventory: further evidence. *Soc Psychiatry Psychiatr Epidemiol*. 2000;35:185-189.
- 25. Noelker LS, Townsend AL. Perceived caregiving effectiveness: the impact of parental impairment, community resources, and caregiver characteristics. In: Brubaker TH, ed. Aging, Health and Family: Long-term Care. Newbury Park, Calif: Sage; 1987:58-79.
- Platt S. Measuring the burden of psychiatric illness on the family: an evaluation of some rating scales. *Psychol Med.* 1985;15:383-393.
- 27. Lawton M, Kleban M, Moss M, Rovine M, Glickman A. Measuring caregiving appraisal. *J Gerontol Psychol Sci.* 1989;44: 61-71.
- 28. Pasacreta JV, McCorkle R. Cancer care: impact of interventions on caregiver outcomes. *Annu Rev Nurs Res.* 2000;18:127-148.
- 29. Butcher H, Holkup P, Buckwalter WJ. The experience of caring for a family member with Alzheimer's disease. *Nurs Res.* 2001;23(1):33-55.
- 30. Picot SJ, Youngblut J, Zeller R. Development and testing of a measure of perceived caregiver rewards in adults. *J Nurs Meas.* 1997;5(1):33-52.
- Berg-Weger M, Rubio DM, Tebb SS. The Caregiver Well-Being Scale revisited. *Health Soc Work*. 2000;25:255-263.
- 32. Baumgarten M. Health of persons giving care to the demented elderly: a critical review of the literature. *J Clin Epidemiol*. 1989;42:1137-1148.
- Harvey RJ. Young Onset Dementia: Epidemiology, Clinical Symptoms, Family Burden, Support and Outcome. London, UK: Dementia Research Group, Imperial College School of Medicine; 1998.