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## Verbal Communication among Alzheimer’s Disease Patients, their Caregivers, and Primary Care Physicians during Primary Care Office Visits

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### Abstract

**Objective**—Primary care visits of patients with Alzheimer’s disease (AD) often involve communication among patients, family caregivers, and primary care physicians (PCPs). The objective of this study was to understand the nature of each individual’s verbal participation in these triadic interactions.

**Methods**—To define the verbal communication dynamics of AD care triads, we compared verbal participation (percent of total visit speech) by each participant in patient/caregiver/PCP triads. Twenty three triads were audio taped during a routine primary care visit. Rates of verbal participation were described and effects of patient cognitive status (MMSE score, verbal fluency) on verbal participation were assessed.

**Results**—PCP verbal participation was highest at 53% of total visit speech, followed by caregivers (31%) and patients (16%). Patient cognitive measures were related to patient and caregiver verbal participation, but not to PCP participation. Caregiver satisfaction with interpersonal treatment by PCP was positively related to caregiver’s own verbal participation.

**Conclusion**—Caregivers of AD patients and PCPs maintain active, coordinated verbal participation in primary care visits while patients participate less.

**Practice Implications**—Encouraging verbal participation by AD patients and their caregivers may increase the AD patient’s active role and caregiver satisfaction with primary care visits.

### Keywords

cognitive impairment; speech; communication; primary care; dementia

## 1. Introduction

Family members play a crucial role as caregivers in coordinating the healthcare of loved ones experiencing dementia. One important aspect of such care coordination is facilitating communication between patients with dementia and their healthcare providers. Symptoms like memory impairment and word finding difficulty make it challenging for some patients to

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reliably exchange information with clinicians [1,2]. Such symptoms of Alzheimer's disease (AD) are likely to compound the well-documented effects that communication breakdown has on care outcomes. Poor communication between doctor and patient leads to a variety of negative outcomes including lower overall health status [3,4]. In the context of geriatric care, this may place subsequent increasing demands on family caregivers. For patients with dementia, family caregivers may play an especially important part in preventing communication breakdowns and their adverse consequences.

Balanced against the advantages of relying on information from family and other caregivers as input, is the desirability of including AD patient perspectives on medical care decisions. Recent work has shown that the vast majority of patients with mild to moderate AD and their family caregivers voice preferences for shared decision-making models in which mild to moderately impaired patients maintain involvement in treatment decisions [5]. Yet the extent to which AD patients actually participate in routine discussions of their own healthcare is unclear. In order to include the AD patient perspective it is important to describe and understand the nature of these triadic interactions and the extent to which patients participate. Given the interrelatedness of participation of family caregivers with that of patients with AD in primary care visits, we sought to address the overall level of participation in the flow of verbal communication among the AD patient, caregiver, and primary care physician (PCP).

Effective physician-patient communication involves multiple aspects of the primary care visit and encompasses both verbal and nonverbal communication in the context of routine care delivery [2,6]. In the current study, we focused specifically on verbal participation which is likely affected by marked verbal capacity changes accompanying increasing cognitive impairment with AD. We conducted the study with a sample of mildly to moderately impaired individuals with AD, because of the potential for active verbal participation in primary healthcare visits in this population. In particular, we were interested in describing and comparing levels of verbal participation in primary care visits including the presence of the family caregiver as an active participant. We also explored the effects of limitations imposed on verbal participation by global cognitive impairment and impaired verbal fluency of AD patients.

## 2. Method

### 2.1 Participants

With Institutional Review Board approval, patients meeting National Institute of Neurological and Communicative Disorders criteria for "probable" or "possible" AD [7] were recruited from the University of Pittsburgh Alzheimer Disease Research Center (ADRC) Memory Disorders Clinic via telephone call or in-person contact during a regularly scheduled ADRC research assessment. Eligible patient participants were community dwelling adults over the age of 65 years who had mild to moderate AD (defined as a most recent ADRC-administered Mini-Mental Status Exam (MMSE) score of 16 or greater), and a family caregiver (spouse or adult child) who was also willing to participate [8]. Recruitment efforts targeted patients whose dementia was being managed in primary care [9]. Per ADRC protocol, reports of each participant's annual neurological, psychiatric, and neuropsychological research assessments are routinely provided to their managing primary care providers in a HIPAA-compliant manner. The current study excluded patients whose dementia care was managed by a geropsychiatrist or behavioral neurologist.

### 2.2 Procedures

Upon consent of patient/caregiver pairs to the study, the date and time of the patient's next regularly scheduled primary care appointment was ascertained and a letter describing the

project was mailed to the patient's PCP. PCPs were advised that the major goal of the study was to describe AD caregiver participation in primary care visits. Approximately one week before the scheduled visit, written informed consent was sought from the patient's PCP. Audio recording of study visits was contingent upon PCP consent and PCP office managers were consulted in advance to coordinate the audio recording. Research personnel were available to personally address all participants' concerns prior to the observation.

Before each observation, a research assistant (RA) met the patient and caregiver either at home or on site to put them at ease and review the study procedure. The RA remained in the office waiting area during the medical visit. Audio recording equipment was collected by the RA at the conclusion of each primary care visit.

**2.2.1 Questionnaire data following study primary care visit**—Immediately following the visit, the RA conducted a post-visit assessment in structured interview format. Global cognitive status of the patient was assessed using the Mini Mental Status Exam [8]. Previously obtained demographic data were confirmed and measures of patient and caregiver satisfaction with the primary care physician and visit were obtained from the Primary Care Assessment Survey (PCAS) [10]. Patient and caregiver were interviewed separately. Communication and Interpersonal Treatment subscales of the PCAS were used to evaluate patient and caregiver satisfaction with interpersonal aspects of primary care provision. The communication satisfaction subscale included items such as: "The doctor gave me a chance to say what was really on my mind". The interpersonal treatment subscale included items such as: "I felt this doctor accepted me as a person" [10]. Additional data on patient cognitive status, including verbal category fluency scores [11], were collected from the most recent visit of the patient to the ADRC.

Primary care visits occurred within twelve months of the participant's most recent ADRC visit. This time frame was viewed as reasonable given the slow rate and insidious nature of decline in cognition among patients with AD. Patient and caregiver respondents each received a small honorarium of \$25 for their time. PCPs received no monetary compensation.

**2.2.2. Audio taped interview coding for verbal participation**—Interview tapes were played back and coded by research assistants for patient, caregiver (CG), and PCP speech. In the event that an individual was speaking, he or she was coded as speaking for any full second that speech began or ended (to the nearest second). Brief pauses of less than one second between utterances were coded as continuous speech. Overlapping utterances with one person finishing and the other starting were coded so that each participant finished his or her turn, and the first full second of speech by the following speaker began the next coded utterance. In the event that an individual's utterance overlapped another person's speech for greater than one second, or overlapped in the middle of the other speaker's turn, both individuals were coded as speaking during the overlapping seconds. The number of seconds of speaking for each individual was summed and divided by the total number of seconds of speech coded for each triad, resulting in a measure of verbal participation as a proportion of total visit speech.

### 2.3 Analysis

Key questions addressed in our analyses were the levels of verbal participation by CG, PT, and PCP, effects of PT global cognitive impairment on verbal participation, and association between verbal participation levels and reported satisfaction with the primary care visit. We described and compared verbal participation across participant groups (PCP, CG, PT), using ANOVA to test for differences in the proportion of total speaking time across groups. The relation between verbal participation of different triad members was investigated using correlation (Pearson's  $r$ ).

Given the exploratory nature of the study, we described a number of associations among PT verbal fluency, PT global cognitive status, and triad members' verbal participation. Association of verbal participation and satisfaction with the primary care visit was also explored by comparing patient, caregiver, and PCP levels of verbal participation with patient and caregiver reported satisfaction on the PCAS communication and interpersonal treatment sub scales [7]. Descriptive analyses of verbal participation by gender, caregiver/patient relationship, and education were also performed for patients and caregivers.

### 3. Results

#### 3.1 Verbal participation of AD patients, caregivers, and primary care physicians

Primary care visits ranged from 11.7 to 55.7 minutes in length ( $M = 24.0$  min,  $SD = 9.6$  min). At least one individual was speaking for much of the time; total combined speaking time occupied 5 – 49 minutes ( $M = 19.4$  min,  $SD = 8.9$  min) of visits. Periods of non-speaking were accounted for by breaks in dialogue resulting from interruptions by office staff and PCP pauses for chart review or prescription writing. PCP verbal participation was highest at 53% of total visit speech, followed by caregivers (31%) and patients (16%). Comparing all three triad members, we found that average verbal participation of caregivers was significantly lower than PCPs. Verbal participation for AD patients was lower than either CG or PCP, with patients occupying only 16% of total speaking time on average. ( $M = .16$ ,  $SD = .10$ ;  $M = .31$ ,  $SD = .16$ ;  $M = .53$ ,  $SD = .14$ , for AD patient, caregiver, and PCP, respectively;  $F(2,66) = 42.20$ ,  $p < .001$ ).

Caregiver verbal participation played a pivotal role in the triadic interaction, as it was correlated with both patient and PCP speech. Caregiver and PCP verbal participation were strongly negatively related ( $r = -.76$ ,  $p < .001$ ; see Table 2). Caregiver and AD patient verbal participation were also negatively correlated ( $r = -.52$ ,  $p = .011$ ). PCP verbal participation, however, was not related to AD patient verbal participation ( $r = -.16$ ,  $p = .459$ ).

AD patients in general participated at a lower rate than either caregivers or PCPs and AD patients with greater cognitive impairment and lower verbal fluency tended to participate at lower rates than those that were less impaired (Table 2). PCPs, however, did not appear to adjust verbal participation to AD patients; PCP verbal participation was not related to any AD patient cognitive characteristics. Mean global cognitive status of AD patients in the study was in the mildly impaired range ( $M = 21.41$ ,  $SD = 4.16$ ). Mean verbal category fluency for patients was 10.10 ( $SD = 4.10$ ).

#### 3.2 Verbal participation and satisfaction with primary care

Satisfaction with interpersonal treatment by PCP was positively related to a caregiver's own level of verbal participation ( $r = .455$ ,  $p = .034$ ; for CG verbal participation and interpersonal treatment). In general, though, caregiver and AD patient satisfaction with the visit was unrelated to verbal participation patterns observed; patient reported satisfaction on the PCAS interpersonal treatment and communication sub scales [10] was not related to verbal participation by any of the triad members.

#### 3.3 Demographic factors and verbal participation

Exploratory analyses showed that verbal participation was not significantly different among caregivers of different gender, education level, or relationship to patient. Basic demographic data describing gender, age, ethnicity, education level, and caregiver/patient relationship are in Table 1.

Although caregiver gender was not associated with CGs' own verbal participation levels, nor with participation by PCP, caregiver gender was related to AD patients' verbal participation ( $t(21) = -2.3, p = .033$ ). Patients with male caregivers had higher levels of verbal participation ( $M = .25, SD = .11$ ) than patients with female caregivers ( $M = .14, SD = .09$ ).

Higher caregiver education levels were associated with lower PCP verbal participation ( $F(1,21) = 5.26, p = .032$ ). PCPs had lower verbal participation ( $M = .45, SD = .15$ ) in primary care visits with caregivers with a college education (4 year degree) or higher ( $n = 14$ ) than they did in visits with caregivers that had some college, or a high school degree ( $n=9$ ) only ( $M = .58, SD = .10$ ). Because CG education and CG satisfaction with interpersonal treatment were both related to their verbal participation, we performed a partial correlation to test whether controlling the effects of caregiver education would eliminate the association between verbal participation and satisfaction. The relation between CG verbal participation and satisfaction with interpersonal treatment by the PCP remained even when effects of CG education level were controlled ( $r = .426, p = .027$ ).

## 4. Discussion and Conclusions

### 4.1 Discussion

**4.1.1 Verbal participation patterns across patient caregiver PCP triads**—During routine primary care visits, PCPs and caregivers appear to be competing for time in the verbal participation of the visit, judging from the negative relation between PCP and CG verbal participation. At the same time, AD patients do make use of some of the total speaking time, depending in part on their global cognitive status. AD patient participation, however, was not significantly related to participation by the PCP, as might be expected in a primary care visit focused on the patient. Instead, the results reported here support a more dominant verbal role for the caregiver. Caregiver participation was central to the interaction and was influenced both by degree of global cognitive impairment in the patient and by verbal participation of the AD patient and the PCP. Caregivers appeared sensitive to patients' global cognitive status, increasing their participation when patient cognitive status was lower. Caregivers also participated at a higher rate if they had four years or more of college education, perhaps because they were more articulate and knowledgeable about the disease. Also, female caregivers participated more than males. Since females are generally more intensively involved in care provision of their AD patient relative, this gender difference may be due to their desire for more information about the issues and concerns that they had about the AD patient.

The caregivers' verbal participation in triadic interaction is also related to their reports of satisfaction with the primary care visit, specifically their satisfaction with interpersonal treatment of the AD patient by the PCP. The less caregivers participated, the less satisfied they were with interpersonal treatment of the patient by the PCP. This finding builds upon prior research linking the involvement of visit companions (usually caregivers) to older patients' self-reports of satisfaction with care [12]. To our knowledge, the current study is the first to describe specific aspects of the triadic interaction that correlate with caregiver satisfaction within a well-defined clinical population (patients with mild to moderate AD).

One implication of this is that it is important for PCPs to allow caregivers to talk and for them to listen during typical primary care visits. Secondly, our finding further supports previous calls for interventions to enhance AD caregivers' communicative effectiveness in triadic medical encounters [9].

In contrast to caregivers, PCP verbal participation was not related to AD patient communication (verbal participation) or to patient cognitive characteristics. To find these effects in a sample of patients without profound impairment, suggests that PCP communicative behavior is the

result of uniform treatment of patients as AD patients, and a general recognition of the caregiver's special communicative role in these triadic interactions. Alternatively, it could be argued that patients are not particularly responsive to the verbal participation patterns of the PCP. For AD patients, verbal participation measured as total proportion of visit speech is unrelated to the effects of gender, education, or their relationship with their caregiver. Although patient verbal participation was low, this appears not to affect their satisfaction with the primary care visit, as satisfaction scores were unrelated to patients' verbal participation rate. This finding is surprising in light of the large literature linking patient-directed visit participation interventions to satisfaction with care [13,14].

Verbal participation patterns observed and association with patient cognitive status and caregiver satisfaction must be interpreted with caution, due to the limitations of the current study. The preliminary nature of the current study and small sample size precluded more elaborate statistical testing of associations among cognitive, demographic, and verbal participation measures. Future studies using larger, more representative samples are needed to confirm and further elucidate centrality of caregiver verbal participation in primary care visits. Although patterns observed suggest limited verbal participation of AD patients in primary care visits, further research is necessary to determine the relation between quantity of verbal participation and quality of verbal interaction among AD patients, their caregivers, and primary care physicians.

## 4.2 Conclusions

Despite the limitations of the current preliminary study, our results show that active verbal participation by caregivers exceeds that of mild to moderately impaired AD patients in primary care visits overall, suggesting an important influence of caregivers on verbal communication during primary care visits [15]. The results for PCP and caregiver suggest competition for speaking time. Caregivers may in fact adjust their verbal participation by reducing speech to listen to PCP or by taking advantage of PCP quieter moments to communicate their thoughts and questions verbally. Patients participate verbally depending on their level of global cognitive impairment, but it is unclear whether their verbal participation level reflects the communication occurring between caregiver and PCP. Earlier studies suggest that some patients with AD are generally displeased with their interactions with healthcare providers [16]. The relatively low level of patient verbal participation we found supports the idea that triadic interactions can limit the verbal participation of AD patients in their own primary care visits. Our findings on patient verbal participation in the presence of caregivers also suggest the need for a conceptual model of triadic interaction that builds on existing frameworks developed to explain communication in dyadic doctor/patient or caregiver/patient relationships.

## 4.3 Practice Implications

The proportion of total visit speech as a measure of verbal participation is our approach to assessing triadic patterns of communication at a very basic level. Results using this measure are essentially open to multiple interpretations and are not necessarily indicative of low quality communication. If caregivers are able to communicate with both PCPs and patients in triadic fashion, their verbal participation levels may indicate a functional role in the delivery of primary care to patients with AD [12]. Given current indicators of the importance of active participation in primary care visits for older adults with dementia, however, our results also suggest that special efforts should be made to include the AD patient in ongoing verbal communication during primary care visits. Patterns of speaking by patients, their caregivers, and primary care providers during primary care visits may have important implications for health care delivery to patients with AD.

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**Table 1**

Demographic characteristics and verbal participation rates of family caregivers, AD patients, and primary care physicians (PCPs)

	Caregivers (n = 23)	Patients (n = 23)	PCPs (n = 20) <sup>I</sup>
Verbal Participation, proportion of total speaking time (SD)	.31 (.16)	.16 (.10)	<b>.53 (.14)</b>
AD patient global cognitive status MMSE score (SD)	-	21.41 (4.16)	-
Age, years, mean (SD)	68.0 (10.6)	79.3 (6.3)	48.4 (9.8)
Gender (proportion)			
Female	18 (.78)	13 (.57)	6 (.30)
Male	5 (.22)	10 (.43)	14 (.70)
Race, frequency (proportion)			
White, Caucasian	20 (.87)	20 (.87)	18 (.90)
Black, African American	3 (.13)	3 (.13)	1 (.05)
Asian	0 (0)	0 (0)	1 (.05)
Marital Status, frequency (proportion)			
Married, or living as married	17 (.74)	15 (.65)	
Not married	6 (.26)	8 (.35)	
years of education, frequency (proportion)			
<12	0 (0)	6 (.26)	
12–14	14 (.61)	9 (.39)	
>14	9 (.39)	8 (.35)	
Caregiver relationship to care recipient, frequency (proportion)			
Spouse	15 (.65)		
Adult child (daughter)	8 (.35)		

<sup>I</sup>One single PCP had visits with two different patient/caregiver pairs in the study. Another PCP had visits with three different patient/caregiver pairs, reducing the total number of PCPs in the study to 20.



**Table 2**

Correlation of verbal participation (VP) in the interview triad (patient, caregiver, PCP)

	Patient VP	Caregiver VP	PCP VP
Patient VP <sup>1</sup>	–	–.52**	–.16
Caregiver VP	–.52**	–	–.76***
PCP VP	–.16	–.76***	–
Patient MMSE score (global cognitive status)	.422*	.389*	<b>.126</b>
Patient verbal fluency	.452*	–.475*	.216
Patient satisfaction (interpersonal treatment) <sup>2</sup>	.148	.195	–.348
Patient satisfaction (communication)	–.218	.393	–.313
Caregiver satisfaction (PCP interpersonal treatment of patient) <sup>2</sup>	–.149	.455*	–.378
Caregiver satisfaction (PCP communication with patient)	–.153	.387	–.384

<sup>1</sup> Verbal participation (VP) defined as proportion of total interview speaking time

<sup>2</sup> Satisfaction defined as patient or caregiver responses to interpersonal treatment and communication scores on PCAS

\* P < .05,

\*\* P < .01,

\*\*\* P < .001