Published in final edited form as:

J Am Acad Nurse Pract. 2009 July ; 21(7): 377–383. doi:10.1111/j.1745-7599.2009.00427.x.

Feasibility of a patient-driven approach to recruiting older adults, caregivers, and clinicians for provider–patient communication research

Jennifer H. Lingler, PhD, RN, FNP [(Assistant Professor)], Lynn M. Martire, PhD [(Associate Professor)], Amanda E. Hunsaker, MPH [(Study Coordinator)], Michele G. Greene, DrPH [(Professor)], Mary Amanda Dew, PhD [(Professor)], and Richard Schulz, PhD [(Professor)]
University of Pittsburgh Schools of Nursing and Medicine, Pittsburgh, Pennsylvania, and Brooklyn College School of Public Health, City University of New York, New York

Abstract

Purpose—This report describes the implementation of a novel, patient-driven approach to recruitment for a study of interpersonal communication in a primary care setting involving persons with Alzheimer’s disease (AD), their family caregivers, and their primary care providers (PCPs).

Data sources—Patients and caregivers were centrally recruited from a university-based memory clinic, followed by the recruitment of patient’s individual PCPs. Recruitment tracking, naturalistic observation, and survey methods were used to evaluate recruitment success.

Conclusions—About half of the patients and caregivers ($n = 54$; 51%) and most of the PCPs ($n = 31$; 76%) who we approached agreed to an audiorecording of the patient’s next PCP visit. Characteristics of patient, caregiver, and PCP participants were compared to those of nonparticipants. Patient characteristics did not differ by participation status. Caregivers who volunteered for the study were more likely to be female and married than were those who declined to participate. Compared to nonparticipants, PCPs who agreed to the study were appraised slightly more favorably by patients’ caregivers on a measure of satisfaction with care on the day of the visit. The vast majority of participating PCPs (95%) reported that the study had little or no impact on the flow of routine clinical operations.

Implications for research—Findings support the feasibility of a patient-driven approach to recruitment for studies involving multiple linked participants. Our discussion highlights possible advantages of such an approach, including the potential to empower patient participants while achieving maximum variability within the pool of clinician participants.

Keywords

Research methodology; recruitment; provider-patient communication; Alzheimer’s disease

Introduction

Effective communication among patients, family caregivers, and clinicians is critical to patient care, and studies to better understand these communication dynamics are greatly needed. Yet, across medical and psychiatric research settings, methodological concerns complicate the conduct and interpretation of naturalistic investigations of provider–patient communication

(Cruz & Pincus, 2003; Duggan, 2006; Roter, 2003). In an effort to streamline enrollment, many studies treat commitment from health-care providers as a critical first step in the recruitment of provider–patient participant units (Levinson, Dull, Roter, Chaumeton, & Frankel, 1998). This approach has proved effective for assuring adequate patient samples, but may result in small numbers of provider participants and/or low provider-to-patient sample ratios. A review of 21 descriptive investigations of provider–patient communication published in Medline-indexed journals between January 2000 and December 2005 shows an average provider-to-patient ratio of 1 physician participant to every 13 patient participants (Beach et al., 2004; Bensing, Roter, & Hulsman, 2003; Bernhardt, Haunstetter, Roter, & Geller, 2005; Berry, Wilkie, Thomas, & Fortner, 2003; Clayman, Roter, Wissow, & Bandeen-Roche, 2005; Cooper et al., 2003; Ellington et al., 2005; Gordon, Street, Kelly, Soucek, & Wray, 2005; Graugaard, Holgersen, Eide, & Finset, 2005; Ishikawa et al., 2005; Ishikawa, Takayama, Yamazaki, Seki, & Katsumata, 2002; Johnson, Roter, Powe, & Cooper, 2004; Mann et al., 2001; Paasche-Orlow & Roter, 2003; Rhoades, McFarland, Finch, & Johnson, 2001; Robinson & Jon, 2004; Roter, Larson, Fischer, Arnold, & Tulsy, 2000; Scott et al., 2001; Sleath, Rubin, Campbell, Gwyther, & Clark, 2001; Tobacman et al., 2005; Wissow et al., 2002). Limitations in the pool of provider participants can threaten external validity and make it difficult to tease out provider effects.

Strategies for maximizing provider participation have typically included inviting physicians or physician groups to participate as study consultants or coinvestigators, and subsequently recruiting patients from within their practices. Both the “provider as coinvestigator” and “provider as consultant” approaches to the study of provider–patient interactions are problematic inasmuch as the provider may be exposed to hypotheses or may otherwise bias the research. Less frequently, investigators have used professional society mailing lists and managed care group rosters to recruit provider volunteers who are not formal research collaborators. The use of mailing lists and group rosters has yielded response rates of 16% and 52%, respectively (Cooper et al., 2003; Paasche-Orlow & Roter, 2003). From a research ethics perspective, patients who are recruited using the above methods may feel unduly obligated to participate in a research project to which their healthcare provider has already agreed.

Alternative but as yet unexplored approaches to the recruitment of provider–patient units include patient-driven methods which treat the identification of willing patient, not provider, participants as the first step in gaining entrée for observational studies. Under such a paradigm patients, and in some cases their family caregivers, may be recruited from residential settings, disease-specific support groups, or subspecialty clinical settings. Once patients or patient/caregiver dyads agree to the research, their healthcare providers can be invited to participate, allowing for greater variability in the pool of healthcare providers than is possible through provider-driven recruitment. In this study, patients with Alzheimer’s disease (AD) and their family caregivers were recruited from a single subspecialty site and invited to participate in a naturalistic study of their interactions with their individual, community primary care providers. The objectives were to test the effectiveness of a patient-driven approach to recruitment for provider–patient communication research and to ascertain the feasibility of collecting audiotape and interview data that can be used to explore communication dynamics among patients with AD, their family caregivers, and their PCPs. This report describes our recruitment process and examines the demographic, clinical, and visit satisfaction characteristics of participants who consented to the audiorecording of a primary care encounter.

Methods

Design

This study of recruitment feasibility was part of a 12-month preliminary investigation of the role that family caregivers play in mediating communication between patients with AD and their healthcare providers. With Institutional Review Board (IRB) approval, patients meeting

National Institute of Neurological and Communicative Disorders criteria for probable or possible AD (McKhann et al., 1984) were recruited from the University of Pittsburgh Alzheimer Disease Research Center (ADRC) Memory Disorders Clinic. ADRC participants undergo initial and annual multidisciplinary clinical research assessments which have been described elsewhere (Lopez et al., 2000). Those eligible for this study were community-dwelling adults over 65 years of age with mild-to-moderate AD which we defined as a most recent ADRC-administered Mini-Mental Status Exam score of 16 or greater (Folstein, Folstein, & McHugh, 1975), who received their primary care within a 50-mile radius of the University of Pittsburgh, provided written informed consent to the study, and had a spousal or adult child family caregiver who also provided written informed consent to participate.

Procedures

Potential patient and caregiver participants were approached via telephone call or in-person contact during a regularly scheduled ADRC visit. The recruitment process entailed describing the project to both the patient and caregiver; however, in most instances the study was first presented to the caregiver. In all cases, patient-caregiver dyads were encouraged to take their time in deciding whether to participate and were provided with a one-page overview of the project to supplement the information contained in the informed consent document. The recruitment process was halted if either the patient or the caregiver expressed disinterest during discussion of the study, or if the patient expressed an inadequate understanding of the project during the informed consent process.

If the patient and the caregiver both agreed to participate in the study, the date and time of the patient's next regularly scheduled primary care appointment was ascertained and a letter introducing and describing the project was mailed to the patient's PCP. In the letters, we invited the PCPs to participate in the study and informed them of their patient's willingness to enroll. In two instances, patients and caregivers requested that PCP consent be procured in advance of their own consent. The remaining dyads expressed an understanding that the audiorecording of study visits would be contingent upon PCP consent. Patient-caregiver dyads were given the option of completing postvisit satisfaction surveys even if an audiorecording of the visit was precluded by lack of PCP consent.

Approximately 1 week before each scheduled visit, written informed consent was sought from the patient's PCP. We made a concerted effort to accommodate a range of PCP preferences for the informed consent process. In the first 2 months of the project, we attempted to speak with each PCP by phone to discuss the project. Later, we adopted the practice of allowing the PCP to review the study letter and informed consent form, speaking with us only on an as-needed basis. In all instances, we were available by telephone and willing to meet in person at the PCP's office to address any concerns prior to the conduct of the observation. In addition, office managers were consulted to coordinate the audiorecording of the visit. We typically communicated with office managers at least twice before the visit, once to establish a plan for the efficient setup and breakdown of audiorecording equipment in the exam room and a second time to provide a reminder of our plan to accompany the patient to his or her visit.

Before each observation, a master's-prepared research assistant (RA) met the patient and caregiver either at their home or at the PCP office to put them at ease and to review the procedure. When the patient was called to the exam room, the RA accompanied him or her to assemble the recording equipment. All participants were advised of the option of pausing or stopping the recording at any time although, to our knowledge, no one did so. The RA remained in the office waiting area during the medical visit. Upon notification by the office staff or the patient's return to the waiting area, the RA returned to the exam room to remove the recording equipment. Immediately following each visit, the RA gathered postvisit assessment data in a semistructured interview format either on site or in the respondent's home. When interviewing

participants on site, we ensured confidentiality by conducting the interview in an exam room, conference room, or other private location. Patient and caregiver satisfaction with the clinical encounter was measured using the cognitive, affective, and behavioral subscales of the 26-item Medical Interview Satisfaction Scale (MISS; Wolf, Putman, James, & Stiles, 1978). Cronbach's alpha for the subscales in the current sample are as follows: cognitive (.83), affective (.79), and behavioral (.88). The 6-item communication subscale and the 5-item interpersonal treatment and trust subscales of the Primary Care Assessment Survey (PCAS; Safran et al., 1998) were used to evaluate overall satisfaction with primary care provision. Cronbach's alpha for the subscales in the current sample are: communication (.93), interpersonal treatment (.93), and trust (.81).

PCP demographic questionnaires were left with office staff along with postage paid return envelopes. Patient and caregiver respondents each received an honorarium of \$25 each for their time. PCPs received no monetary compensation; however, we provided each practice site with a day-of-visit snack to show our appreciation of their involvement.

Results

Recruitment feasibility

Of 106, 54 patient–caregiver dyads (51%) who were contacted at the ADRC agreed to participate in the study and 46 (43%) declined to participate. In six instances (6%), discussion of the study showed potential participants to be ineligible because of residential status ($n = 3$), severity of patient's cognitive impairment ($n = 1$), a planned change in PCP ($n = 1$), or caregiver ineligibility ($n = 1$; second-degree relatives were excluded). Of the 54 volunteers, 31 had scheduled primary care appointments occurring during the 12-month study period. From these 31, 25 had PCPs who also consented to the study. In all but one instance, caregivers reported it to be their usual practice to accompany the patient to the primary care visit.

Patient and caregiver participants and nonparticipants

Of the 46 eligible dyads who did not participate, 29 agreed to a brief demographic survey and reason for refusal interview. An IRB waiver of written informed consent for the refusal interviews was obtained. Reasons for participant refusal included: caregivers being too busy ($n = 3$), patients being too frail ($n = 2$), patients lacking insight into the AD diagnosis ($n = 2$), and caregivers reporting that the PCP relationship was not conducive to participation ($n = 1$). In seven instances, potential participants declined because of lack of interest, citing no specific reason. Although not an exclusion criterion, involvement in other ongoing research projects ($n = 8$) was the most frequently cited reason that families declined to participate.

Table 1 summarizes the demographic characteristics of (a) patient and caregiver participants and (b) patient and caregiver nonparticipants who were willing to be interviewed. Patient participants and nonparticipants did not significantly differ on these demographic characteristics. However, caregiver participants were more likely to be women ($X^2 = 5.48$, $df = 1$, $p = .019$) and less likely to be married (Fisher's exact test, $p = .043$) as compared to nonparticipants. The relationship of the caregiver with the patient also significantly influenced likelihood of agreement to participate ($X^2 = 8.97$, $df = 2$, $p = .011$). Although 100% of adult sons ($n = 5$) declined to either hear about or enroll in our study, only 51% of the spouses ($n = 20$) and 20% of the adult daughters ($n = 4$) did not participate.

PCP participants

Participating PCPs were from 20 different practices located in a range of urban, suburban, and rural settings. Table 2 summarizes the characteristics of the 23 individual PCPs who consented to the study. In most cases of PCP refusal, we were informed by office staff. If a reason for the

refusal was provided, we recorded it. In only two instances was it possible to administer our brief demographic questionnaire and reason for refusal survey to declining PCPs. Based on those surveys and information provided by office staff, the most frequently cited reason for PCP refusal ($n = 3$) was the potential for disruption of the flow of clinic operations.

Postvisit satisfaction ratings were completed by family caregivers. PCPs who participated were appraised more positively on the cognitive subscale (e.g., “the doctor told me [and my family member] what the medicines he [or she] prescribed would do for my family member”) and affective subscale (e.g., “I really felt understood by the doctor”) of the MISS than those who did not agree to an audiorecording. Caregivers’ ratings of satisfaction on the behavioral subscale (e.g., “the doctor seemed to rush me during this examination”) of the MISS did not differ by PCP participation status. MISS total scores were marginally higher for PCPs who participated in the study versus those who did not ($t = 2.16$, $df = 27$, $p = .058$). There were no between-group differences in ratings of overall satisfaction with care as measured by the PCAS.

Discussion

Our data provide strong support for the feasibility of a patient-driven approach to recruitment for observational studies of triadic communication in the clinical care of older adults with cognitive impairment. Overall, 76% of the PCPs who we contacted agreed to participate in the study, a rate which exceeds that achieved in many published reports of conventional, provider-driven recruitment. The vast majority (95%) of those who participated reported the study to have little or no impact on the flow of operations.

Importantly, no participating providers expressed concern regarding payment for their involvement, or cited lack of monetary compensation as a reason for declining to participate. The willingness of providers to participate in our study suggests a genuine respect for, and eagerness to accommodate, patient and caregiver decisions regarding research participation.

The importance of striving for representative provider samples is underscored by our finding that participating PCPs were rated more favorably on the MISS than those who did not consent to the audiorecordings. This finding offers preliminary support for previous speculation that clinicians who consent to this type of research are likely to be exceptionally good communicators (van den Brink-Muinen et al., 2003). A number of other factors may have contributed to the high rates of participation among providers. First, willingness to participate may vary with the type of patient. Providers may be especially sympathetic to the wishes of those living with the burden of AD. Second, the fact that we had prior approval from both family member and patient may have created strong demands for provider participation. Finally, we made a concerted effort to minimize the burden of research involvement among provider participants. The PCPs in our sample were not asked to approach their patients about study participation, nor were they asked to devote any resources to identifying potential patient participants.

The high rate of provider participation in this study should be considered in light of the fact that nearly half of the potentially eligible patient and caregiver dyads opted not to hear about, or declined to participate in, this research. This modest agreement rate indicates that families felt comfortable about declining to enroll in the study. This is an important consideration given the intrusiveness of audiotape in the clinical setting and the potential for older adults, particularly those disempowered by dementia, to feel unduly obliged to participate in research.

Comparison of basic demographic and clinical characteristics showed no differences between participating and nonparticipating patients, but did raise concerns about the representativeness of the resulting caregiver sample. For example, caregiving daughters were more likely than sons to volunteer for the study. The extent to which daughters may perceive communication

research as especially valuable, or sons may perceive a need to protect their cognitively impaired parents from the burden of research involvement, are unknown and may reflect the presence of a yet-to-be determined set of factors influencing research participation decisions among AD care dyads.

Given that provider factors and caregiver preferences will likely influence sample characteristics under both conventional and patient-focused approaches to recruitment for communication studies, researchers who are evaluating options for the recruitment of multiple linked research participants need to be mindful of the range of sources of sample bias. If the goal of an investigation is to get representative provider behavior, then patient-driven recruitment may be a particularly good strategy. If the goal is to have a more homogeneous provider sample, then traditional approaches to recruiting from within healthcare provider practices may be reasonable. In some instances, a mix of provider-driven and patient-driven recruitment methods may be desirable. Tradeoffs should be weighed in light of specific research questions and the type of bias that is most important to minimize within the targeted sample.

Implications

Family caregivers play a pivotal, yet understudied, role in communication between healthcare providers and geriatric patients, particularly those with cognitive impairment (Fortinsky, 2001). Given the complexity of patient–professional relationships, the presence of a family member carries potential for both positive and negative effects on communication dynamics during clinical encounters. In the AD context, the participation of a family member who is involved in the patient’s daily care may improve the reliability of the medical history and assist the patient with future recall of information exchanged during the visit (Adams, McIlvain, Geske, & Porter, 2005). Yet, there may be drawbacks to such three-way interaction as caregivers may face practical challenges when conveying sensitive information in the company of their loved one. For example, both patients and caregivers may experience significant distress when caregivers are called upon to provide a clinical history about driving safety or behavioral symptoms while the patient is present in the exam room. The study presented here lays the groundwork for the conduct of future research to better understand and ultimately test interventions to improve these complicated communication dynamics.

Conclusion

We found that patients with AD, their caregivers, and primary care providers are generally receptive to a patient-focused strategy for identifying volunteers for participation in naturalistic studies of provider–patient communication. Our report shows the feasibility of implementing such a recruitment approach in a timely manner, at little cost, and with minimal burden to participants. An additional advantage is that cognitively impaired patient participants may be less threatened by approaches that position them as the gatekeeper to studying the provider–patient relationship. Future investigations incorporating the methods developed in this study may yield better provider-to-patient sample ratios and more varied provider samples, resulting in more generalizable findings. By virtue of such increased external validity, these studies may inform the care of geriatric patients in primary care settings to a greater extent than has previously been possible.

Acknowledgments

This work was supported by a seed money award from the University of Pittsburgh Institute for Doctor–Patient Communication and by National Institutes of Health grants T32 MH19986, P50 AG05133, and P30 MH71944. Dr. Lingler is supported by a Brookdale Foundation Leadership in Aging Fellowship. The authors thank Drs Steven T. DeKosky, Bruce Ling, and Robert Arnold for their support and feedback during the conduct of this research.

References

- Adams WL, McIlvain HE, Geske JA, Porter JL. Physicians' perspectives on caring for cognitively impaired elders. *The Gerontologist* 2005;45:231–239. [PubMed: 15799988]
- Beach MC, Roter D, Larson S, Levinson W, Ford DE, Frankel R. What do physicians tell patients about themselves? A qualitative analysis of physician self-disclosure. *Journal of General Internal Medicine* 2004;19(9):911–916. [PubMed: 15333054]
- Bensing JM, Roter DL, Hulsman RL. Communication patterns of primary care physicians in the United States and the Netherlands. *Journal of General Internal Medicine* 2003;18(5):335–342. [PubMed: 12795731]
- Bernhardt BA, Haunstetter CM, Roter D, Geller G. How do obstetric providers discuss referrals for prenatal genetic counseling? *Journal of Genetic Counseling* 2005;14(2):109–117. [PubMed: 15959642]
- Berry DL, Wilkie DJ, Thomas CR Jr, Fortner P. Clinicians communicating with patients experiencing cancer pain. *Cancer Investigation* 2003;21(3):374–381. [PubMed: 12901283]
- Clayman ML, Roter D, Wissow LS, Bandeen-Roche K. Autonomy-related behaviors of patient companions and their effect on decision-making activity in geriatric primary care visits. *Social Science & Medicine* 2005;60(7):1583–1591. [PubMed: 15652689]
- Cooper LA, Roter DL, Johnson RL, Ford DE, Steinwachs DM, Powe NR. Patient-centered communication, ratings of care, and concordance of patient and physician race. *Annals of Internal Medicine* 2003;139(11):907–915. [PubMed: 14644893]
- Cruz M, Pincus HA. Research on the influence that communication in psychiatric encounters has on treatment. *Psychiatric Services* 2002;53:1253–1266. [PubMed: 12364673]
- Duggan A. Understanding interpersonal communication processes across health contexts: advances in the last decade and challenges for the next decade. *Journal of Health Communication* 2006;11(1):93–108. [PubMed: 16546921]
- Ellington L, Dudley WN, Baty BJ, Upchurch R, Larson S, Roter D, et al. Communication analysis of BRCA1 genetic counseling. *Journal of Genetic Counseling* 2005;14(5):377–388. [PubMed: 16195944]
- Folstein MF, Folstein SE, McHugh PR. "Mini-mental state." A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research* 1975;12(3):189–198. [PubMed: 1202204]
- Fortinsky RH. Health care triads and dementia care: integrative framework and future directions. *Aging and Mental Health* 2001;5:S35–S48. [PubMed: 11513496]
- Gordon HS, Street RL, Kelly PA, Soucek J, Wray NP. Physician patient communication following invasive procedures: an analysis of post-angiogram consultations. *Social Science & Medicine* 2005;61(5):1015–1025. [PubMed: 15955403]
- Graugaard PK, Holgersen K, Eide H, Finset A. Changes in physician patient communication from initial to return visits: a prospective study in a haematology outpatient clinic. *Patient Education & Counseling* 2005;57(1):22–29. [PubMed: 15797149]
- Ishikawa H, Hashimoto H, Roter DL, Yamazaki Y, Takayama T, Yano E. Patient contribution to the medical dialogue and perceived patient-centeredness. An observational study in Japanese geriatric consultations. *Journal of General Internal Medicine* 2005;20(10):906–910. [PubMed: 16191136]
- Ishikawa H, Takayama T, Yamazaki Y, Seki Y, Katsumata N. Physician-patient communication and patient satisfaction in Japanese cancer consultations. *Social Science & Medicine* 2002;55(2):301–311. [PubMed: 12144143]
- Johnson RL, Roter D, Powe NR, Cooper LA. Patient race/ethnicity and quality of patient-physician communication during medical visits. *American Journal of Public Health* 2004;94(12):2084–2090. [PubMed: 15569958]
- Levinson W, Dull VT, Roter DL, Chaumeton N, Frankel RM. Recruiting physicians for office-based research. *Medical Care* 1998;36(6):934–937. [PubMed: 9630134]
- Lopez OL, Becker JT, Klunk WE, Saxton J, Hamilton RL, Kaufer DI, et al. Research evaluation and diagnosis of probable Alzheimer's disease over the last two decades. *Neurology* 2000;55:1854–1862. [PubMed: 11134385]

- Mann S, Sripathy K, Siegler EL, Davidow A, Lipkin M, Roter DL. The medical interview: differences between adult and geriatric outpatients. *Journal of the American Geriatrics Society* 2001;49(1):65–71. [PubMed: 11207844]
- McKhann G, Drachman D, Folstein M, Katzman R, Price D, Stadlan E. Clinical diagnosis of Alzheimer's disease: report of the NINCDS-ADRDA Work Group under the auspices of Department of Health and Human Services Task Force on Alzheimer's disease. *Neurology* 1984;34:939–944. [PubMed: 6610841]
- Paasche-Orlow M, Roter D. The communication patterns of internal medicine and family practice physicians. *Journal of the American Board of Family Practice* 2003;16(6):485–493. [PubMed: 14963075]
- Rhoades DR, McFarland KF, Finch WH, Johnson AO. Speaking and interruptions during primary care office visits. *Family Medicine* 2001;33(7):528–532. [PubMed: 11456245]
- Robinson JD, Jon FN. Grounding research and medical education about religion in actual physician-patient interaction: church attendance, social support, and older adults. *Health Communication* 2004;16(1):63–85. [PubMed: 14979852]
- Roter DL, Larson S, Fischer GS, Arnold RM, Tulskey JA. Experts practice what they preach: a descriptive study of best and normative practices in end-of-life discussions. *Archives of Internal Medicine* 2000;160(22):3477–3485. [PubMed: 11112242]
- Roter DL. Observations on methodological and measurement challenges in the assessment of communication during medical exchanges. *Patient Education & Counseling* 2003;50(1):17–21. [PubMed: 12767579]
- Safran DG, Kosinski M, Tarlov AR, Rogers WH, Tair DA, Lieberman N, et al. The primary care assessment survey: tests of data quality and measurement performance. *Medical Care* 1998;36(5):728–739. [PubMed: 9596063]
- Scott JG, Cohen D, DiCicco-Bloom B, Orzano AJ, Jaen CR, Crabtree BF. Antibiotic use in acute respiratory infections and the ways patients pressure physicians for a prescription. *Journal of Family Practice* 2001;50(10):853–858. [PubMed: 11674887]
- Sleath B, Rubin RH, Campbell W, Gwyther L, Clark T. Physician-patient communication about over-the-counter medications. *Social Science & Medicine* 2001;53(3):357–369. [PubMed: 11439819]
- Tobacman JK, Kissinger P, Wells M, Prokuski J, Hoyer M, McPherson P, et al. Implementation of personal health records by case managers in a VAMC general medicine clinic. *Patient Education & Counseling* 2004;54(1):27–33. [PubMed: 15210257]
- van den Brink-Muinen A, Verhaak PFM, Bensing JM, Bahrs O, Deveugele M, Gask L, et al. Communication in general practice: differences between European countries. *Family Practice* 2003;20:478–485. [PubMed: 12876125]
- Wissow LS, Roter D, Larson SM, Wang MC, Hwang WT, Johnson R, et al. Mechanisms behind the failure of residents' longitudinal primary care to promote disclosure and discussion of psychosocial issues. *Archives of Pediatrics & Adolescent Medicine* 2002;156(7):685–692. [PubMed: 12090836]
- Wolf MH, Putman SM, James SA, Stiles WB. The medical interview satisfaction scale: development of a scale to measure patient perceptions of physician behavior. *Journal of Behavioral Medicine* 1978;1(4):391–401. [PubMed: 755868]

Table 1

Characteristics of caregivers and patients, comparison to nonparticipants

Variable	Family caregivers		Patients	
	Agreed (<i>n</i> = 31)	Refused (<i>n</i> = 29)	Agreed (<i>n</i> = 31)	Refused (<i>n</i> = 29)
Age, years, mean (SD)	66.8 (11.3)	70.5 (10.9)	79.5 (6.4)	79.6 (4.5)
Sex, frequency (%)				
Female	24 (77)	14 (48)	19 (61)	16 (55)
Male	7 (23)*	15 (52)*	12 (39)	13 (45)
Race, frequency (%)				
White people, Caucasian	28 (90)	27 (93)	28 (90)	28 (97)
Black people, African American	3 (10)	2 (7)	3 (10)	1 (3)
Marital status, frequency (%)				
Married, or living as married	22 (71)	27 (93)	19 (61)	20 (69)
Not married	9 (29)*	2 (7)*	12 (39)	9 (31)
Education, years, frequency (%) ^a				
<12	0 (0)	0 (0)	8 (26)	
12–14	16 (52)	20 (69)	17 (55)	
>14	15 (48)	9 (31)	6 (19)	
Caregiver relationship to care recipient, frequency (%)				
Spouse	12 (39)	20 (69)		
Adult child	19 (61)*	9 (31)*		
Caregiver employment status, frequency (%)				
Full-time job	7 (22.6)	5 (17.2)		
Part-time job	2 (6.5)	0 (0)		
Homemaker	5 (16.1)	4 (13.8)		
Retired	17 (54.8)	18 (62.1)		
Unemployed (not retired)	0 (0)	1 (3.4)		
Refused	0 (0)	1 (3.4)		
Caregiver rating of care patient physical health, mean (SD)				
5 = <i>Excellent</i> , 4 = <i>Very good</i>				
3 = <i>Good</i> , 2 = <i>Fair</i> , 1 = <i>Poor</i>	3.4 (0.9)	3.2 (1.0)		
Annual income, frequency (%) ^b				
<\$10,000	3 (9)			
\$10,000–\$50,000	15 (45)			
>\$50,000	13 (40)			
Refused	2 (6)			

Note. SD, standard deviation.

* $p < .05$.

^a Care recipient education data are not available for nonparticipants.

^b Household income data are not available for nonparticipants.

Table 2

Demographic characteristics of participating providers

Variable	Primary care provider (<i>n</i> = 23) ^a
Age, years, mean (range)	49.8 (33–73)
Sex, frequency (%)	
Female	7 (30)
Male	16 (70)
Race, frequency (%)	
White people, Caucasian	20 (87)
Black people, African American	1 (4)
Asian	2 (9)
Medical specialty, frequency (%) ^b	
Geriatrician	5 (22)
Family practitioner	6 (26)
Internist	11 (48)
Nurse practitioner	1 (4)
Years in practice, mean (range)	18.8 (3–42)
Patients with AD currently under care, mean (range)	69.8 (2–270)
Impact of study on operations flow (<i>n</i> = 20), frequency (%)	
No significant impact	
Mildly disruptive or inconvenient	16 (80)
Moderately disruptive or inconvenient	3 (15)
	1 (5)

^aTwo primary care providers (PCPs) consented to recordings for multiple patients; two PCPs did not return the survey, in which cases race and gender data were provided by patients and caregivers.

^bOne PCP identified as a geriatrician, family practitioner and internist and another identified as a geriatrician and internist. Both are counted as a geriatrician above.