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## “Let him speak:” A descriptive qualitative study of the roles and behaviors of family companions in primary care visits among older adults with cognitive impairment

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### Abstract

**Objective**—Cognitive impairment poses communication challenges in primary care. Although family “companions” commonly attend primary care visits of older adults with cognitive impairment, little is known about how their involvement affects communication. Therefore, we sought to understand how companion involvement affects the quality of primary care visit communication for older adults with cognitive impairment.

**Methods**—Cross-sectional, descriptive qualitative study. Participants were: (1) English-speaking adults age 65 or older with mild, moderate, or severe cognitive impairment, (2) family members or other unpaid companions who accompany older adults to primary care visits, and (3) primary care clinicians. Twenty semi-structured and in-depth qualitative interviews of older adults and their

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**Conflicts of interest:** None declared

companions (N=20 dyads) and two focus groups (N=10 primary care clinicians) were conducted. Interviews and focus groups were transcribed and analyzed thematically.

**Results**—Family companions commonly facilitate communication by advocating for patients, ensuring the accuracy of information exchange and understanding, and preserving rapport. Significant communication challenges were also identified, including patient and companion role ambiguity, competing visit agendas, and primary care clinician confusion regarding the most accurate source of information. Patients, companions, and clinicians each identified strategies to improve communication, chief among them being to identify, differentiate, and respect both patient and companion priorities and perspectives.

**Conclusions**—Family companions actively participate in primary care visits of older adults with cognitive impairment in ways that promote and inhibit effective communication. Findings suggest the need for strategies that more effectively and purposefully involve family in the care of primary care patients with cognitive impairment.

### Keywords

cognitive impairment; family companions; communication; primary care; triadic communication

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## INTRODUCTION

Communication is the fulcrum on which all of healthcare pivots: it is the process by which patients and clinicians establish a therapeutic relationship, exchange health information, and make treatment decisions. As such, the study of communication and the identification of strategies to improve its effectiveness deserve careful attention in efforts to deliver high quality care (Roter and Hall, 1993). While much of the literature about communication in health care focuses on interactions between patients and clinicians, there is increasing recognition that family or friend “companions” often accompany patients to medical visits and that their participation may also affect communication (Eggly et al., 2012; Clayman et al., 2005; Mitnick et al., 2010). Evidence of companions’ influence in medical interactions (Wolff and Roter 2012; Karnieli-Miller et al., 2012; Laidsaar-Powell et al., 2013) suggests that their involvement does not exert a uniform effect on healthcare delivery and medical decision making (Wolff and Roter 2012; Clayman et al., 2005). Understanding the roles and behaviors of companions in medical visits, therefore, could inform interventions to promote patient- and family-centered care by more effectively engaging family companions in communication with primary care physicians.

Cognitive impairment poses specific communication challenges in primary care (Apesoa-Varano et al., 2011; Boise et al., 1999; Harris et al., 2009; Hinton et al., 2007). These challenges include perceived or actual unreliability of information reported by patients (Karnieli-Miller et al., 2012; Hunsaker et al., 2010), limitations of the ability to manage complex care needs due to time, reimbursement, and other system constraints (Hinton et al., 2007), discomfort discussing dementia-related behaviors (Hunsaker et al., 2010), and the inapplicability of the curative paradigm that is often understood as the *sin qua non* of biomedical expertise (Apesoa-Varano et al., 2011). In addition, unique bioethical challenges arise in medical communication and decision-making, as individuals may desire to be

involved in medical decision-making (Hirschman et al., 2005), but their capacity to do so may be constrained by cognitive impairment and the nature of the decisions being made (Serper et al., 2014; Wolf et al., 2012). Balancing patient autonomy with provider need for comprehensive and accurate information from a reliable companion informant may also be a challenge (Gitlin and Hodgson 2016). It has been observed that communication challenges collectively lead to notably poor quality of care, including under-diagnosis of dementia (Bradford et al., 2009; Chodosh et al., 2004), poor management of co-morbid conditions, lack of referral to social services, and missed opportunities to plan for disease progression (Hinton et al., 2007; Boustani et al., 2005). Primary care physicians report that family involvement in clinical visits for patients with dementia can be particularly time-consuming, especially when multiple family companions are present or the patient and family have competing agendas (Hinton et al., 2007).

Despite the importance of communication in the care of persons with cognitive impairment, older adult, family companion, and primary care clinician perspectives in this arena are not well understood. Most studies have examined the linguistic features of diagnosis disclosures in memory clinics (Sakai and Carpenter 2012), verbal activity during visits by various interlocutors (Schmidt et al., 2009), or physician responses to hypothetical scenarios (Werner et al., 2004). To our knowledge, no study has specifically asked patients, families, or clinicians about the role of family companions during primary care visits of older patients with cognitive impairment. Such information could prove useful in the design of strategies to improve communication for primary care patients with cognitive impairment.

## METHODS

In a prior proof-of-concept study, the research team developed and pilot-tested a patient-family agenda-setting checklist for older patients and their companions to complete in the waiting room before a primary care visit (Wolff et al., 2014). The purpose of the checklist was to elicit older adult and companion perspectives regarding patient health issues to discuss with the doctor, and stimulate discussion about the companion's role during the visit (Wolff et al., 2014). As older adults with significant cognitive impairment were excluded from the proof-of-concept study, the current study was undertaken to refine and enhance the checklist to better meet the needs of older adults with cognitive impairment and their companions. We therefore conducted a series of iterative in-depth, semi-structured interviews of older persons with cognitive impairment (N=20) and their family companions (N=21; 20 dyads in total, with one "dyad" comprised of a single patient and two family members) to gain insight regarding their experiences in primary care visits and their perspectives on the checklist. We also conducted two focus groups with primary care clinicians (N=10 clinicians in total) to learn about their experiences in the care of this population. Data collection occurred between April 2015 and January 2016.

A convenience sample was recruited from two sources of patients and family members who had indicated interest in future research studies: 1. Participants in an ongoing dementia behavior study ("Reducing Agitation in People With Dementia: the Customized Activity Trial (TAP);" [clinicaltrials.gov](https://clinicaltrials.gov/ct2/show/study/NCT01892579) identifier NCT01892579), and 2. patients who had received care at a memory clinic at our institution. Inclusion criteria for patients included being age

65 or older, English-speaking, typically attending doctor visits with a family member or other unpaid companion, and being cognitively impaired on the basis of one or more incorrect answers on a 6-item cognitive screen conducted via telephone by a trained research assistant (Boustani et al., 2005; Callahan et al., 2002). Inclusion criteria for companions included accompanying the patient to medical visits without being paid. For eligible and interested patients and companions, oral consent was obtained, and an in-person interview was scheduled at a location convenient for the participants, typically the patient or companion's home. Perspectives on the utility of the checklist and challenges and benefits of companion involvement in medical visits were elicited through semi-structured interviews (Table 1). Following these interviews, demographic information was collected via structured surveys, and participants each received a \$40 gift card.

The clinician focus groups were conducted at two primary care clinics. The medical director at each site invited clinicians to participate and arranged the time and date of each focus group. After oral consent, focus groups elicited clinician perspectives regarding the challenges and benefits of companions' involvement in primary care visits of older adults with cognitive impairment, as well as strategies to improve visit communication. After the focus groups, demographic information was collected via short structured surveys. As we did not collect the names of patients' primary care clinicians or retain the names of patient participants, it is not known if patient participants were under the care of clinician participants.

Interviews and focus groups were transcribed and analyzed thematically, focusing on communication challenges in primary care that were identified in the peer-review literature and in the directed interviews with older adults and companions (Table 1). In our analysis, we also considered statements in the research interview transcripts as a proxy for statements and behaviors that take place during medical visits. We used these statements to understand the roles older adults and companions might assume in primary care visits, even when the content of the statements was not about communication. Specific details about the adaption of the agenda-setting checklist are not presented in this paper, however an early version of checklist is available elsewhere (Wolff et al., 2014). We followed an inductive approach to data analysis in reviewing transcripts to extract initial findings as well as define and name themes (Pope et al. 2011). Findings were iteratively discussed among study authors until consensus on key themes was reached. The study was reviewed and approved by the IRB of the Johns Hopkins University Bloomberg School of Public Health. Data was stored and analyzed using Microsoft Excel files and NVIVO for Mac.

## RESULTS

A total of 59 older adult-family member dyads were contacted, and 20 participated in this study (including one "dyad" with two companions). Older adults (N=20) were on average 83 years of age and predominantly Caucasian (n=14); they varied widely with respect to cognitive function (Mini-Mental State Examination score mean: 17, SD: 8.8, range: 1–30; Table 2). Companions (N=21) were spouses/partners (n=12) and adult children (n=9) who were on average 67 years of age; most were women (n=17) and most (n=19) had a college education or beyond. Patient-companion interviews were on average 73 minutes (SD: 23).

Primary care clinicians (N=10) were physicians (n=8) or nurse practitioners (n=2) who had been in practice for an average of 16 years; most were female (n=8).

Themes that emerged from the interviews and focus groups are organized in three sections, including: 1) What companions do: roles and communicative behaviors, 2) Communication challenges, and 3) Potential strategies to improve communication. Although themes are described separately, aspects of companion roles/communication behaviors, challenges, and solutions are highly interrelated. Table 3 provides illustrative quotes for each identified theme.

### **What Companions Do: Roles and Communicative Behaviors**

Interviews and focus groups revealed important communicative roles played by family companions in advocating for patients; ensuring the accuracy of information exchange and understanding; and preserving rapport, as follows.

**A. Companions advocate**—Family companions endorsed their role as advocates. They implied that the patient might not receive quality care without their advocacy – that information exchange may not be accurate, that symptoms might be overlooked, or that appropriate referrals or services might not be received. Several companions likened their role to the need to advocate for and protect children (for example, A1 and A2). One participant opposed the idea of affording her mother time alone with the primary care clinician as part of the medical visit because she felt she needed to protect her (A3). Companions also described advocating for the continued involvement of the patient in the medical visit when a clinician might default to speaking to the companion (A4). Companions not only identified their advocacy role by name, they also demonstrated advocacy during the interviews. For example, companions coached the older adult to respond to the interviewer’s questions or prompted them to participate in the interview and conversation (C3).

**B. Companions facilitate accurate exchange of information**—Companions and patients described the companion’s role to ensure the accuracy of patient health-related information exchange by reminding the patient to ask questions and translating for the patient (for example, B1 and B2) and they were observed to employ several techniques to facilitate accurate information reporting. Some companions asked older adults leading, declarative questions in such a way that imparted information (B3–B5). For example, when discussing symptoms of dizziness, two adult daughters used questions to prompt their mother to state what they themselves knew to be true, while continuing to promote their mother’s active participation in the conversation (B3). There were also instances in which the companion directly corrected information provided by the patient (B5). Clinicians remarked on the important role that family companions play in ensuring the accuracy of information exchange and they recognized companions’ use of rapport-preserving declarative questions (B6).

**C. Companions preserve rapport**—During the research interviews, companions preserved rapport by apologizing for disruptive behaviors and prompting appropriate

behaviors (C1, C2). For example, when one older adult asked the interviewer an unrelated question, the daughter redirected the conversation to the topic of the interview (C1). During the interviews with research staff, many companions were careful to communicate information in such a way as to respect the older adult's personhood by prompting them to continue in the conversation, even while disagreeing with them (B3). In addition, examples of patient advocacy can also be viewed as examples of preserving rapport between patient and clinician, for example by prompting the clinician to speak with the patient rather than the companion (A4).

### Communication Challenges

Interviews and focus groups also illuminated challenges encountered during primary care visit communication among patients, family companions, and clinicians.

**D. Disagreement or confusion about the role of the patient and companion—**Patients and their companions often disagreed about the role of the companion. In one case, the patient expressed a desire to speak to his doctor without his wife. The wife did not agree (D1). Some companions expressed dissatisfaction for not being included in the patient's care as much as they would have liked. Family companions expressed frustration at their perception that healthcare professionals undervalued their viewpoints (D2–D4), indicating that this compounded the distress of having an ill family member (D3). Other companions expressed dissatisfaction for the opposite reason: they perceived that healthcare professionals over-attended to them and insufficiently attended to the patient (D5, A4). In a similar vein, clinicians expressed uncertainty about how to interact with patients with severe cognitive impairment, given (often unexpressed) differences in expectations on the part of patients and companions (D6).

**E. Disagreement or confusion about patient health issues—**Patients, companions, and physicians discussed and expressed disagreement regarding patient health issues, prioritized concerns, and agendas for medical visits. For example, two daughters and their mother disagreed about whether their mother had a fear of falling, and they explicitly stated that they disagreed (E1). Primary care clinicians commented on how disagreement between patients and families impedes comprehensive discussion of important patient health issues. Clinicians expressed concern that they may not recognize conflicting opinions or competing agendas, consequently missing the possibility of discussing important and actionable concerns (E2, E3). One physician talked about a patient who presented with a chief complaint of rapid, unintended weight loss but whose daughter was mainly concerned with the patient's cognitive decline. The physician was more worried about the patient's weight loss and what prognosis that symptom might portend (E2).

**F. Establishing an actionable visit agenda—**In focus groups, clinicians discussed the challenge of eliciting the right amount of psychosocial information. They described pitfalls of obtaining too little relevant information (e.g. not knowing that the patient could not pay for their prescriptions) or too much irrelevant information (e.g. problems with transportation not related to healthcare). One clinician suggested that it would be helpful to routinely ask about patient and family companions' financial concerns and a conversation ensued about



how much clinicians would actually want to know regarding this issue. Clinicians indicated that they only wanted to know information which they could act upon (F1–F3). Although clinicians expressed these concerns with regards to all their older adult patients and not just those with cognitive impairment, obtaining the ‘just right’ amount of medically-relevant social information was identified as more challenging within the context of dementia given the particularly important role of socially oriented concerns and the greater level of companion involvement in care.

### Potential strategies to improve communication

**G. Independent companion-clinician communication**—Companions expressed their perceived need to communicate with the clinician independently of the patient, either because they wanted the doctor to know their viewpoint on a particular issue or because they wanted to guide the physician in the best way to communicate with the patient. They described various ways in which they independently communicate with the patient’s clinician, by giving them notes (G1), speaking with them by phone (G2), or using the patient portal to communicate using secure electronic messaging. Clinicians also acknowledged the useful information imparted by family outside of medical visits (G3), specifically remarking on the convenience of electronic communication (G4).

**H. Differentiating patient and family perspectives**—Clinicians endorsed the helpfulness of family perspectives, especially with regards to obtaining information about the patient’s cognitive impairment. For example, one clinician commented about an item on the Medical Wellness Visit checklist (a checklist completed yearly by patients with Medicare Part B) for this reason (H1). Other physicians described routinely making time to speak to each patient and companion separately (H2–H4). Although patients and companions also raised the potential benefit of this strategy (H6, D1), some companions were not receptive to leaving the patient alone during a medical visit (A2).

## DISCUSSION

Results from this study provide insight into the influential and complex roles that family companions assume during primary care visits of older patients with cognitive impairment. We found that family companions advocate on behalf of older adults, ensure the accuracy and comprehensiveness of information exchange, and preserve patient-clinician rapport. Numerous challenges related to family companion involvement were also identified, primarily involving role ambiguity and competing agendas of patients and companions, and conflicting perspectives that collectively contribute to clinician confusion regarding *who* to rely on -- the patient or companion -- as the most accurate source of information. Companions and clinicians discussed strategies to mitigate communication challenges for older primary care patients with cognitive impairment through specifically eliciting companion perspectives and better differentiating patient and companion views and priorities.

The contributions of family companions in facilitating relationship rapport, information exchange, and medical decision-making during face-to-face medical visits of older adults without cognitive impairment (Laidsaar-Powell et al., 2013; Wolff & Roter 2011), as well as

varied behaviors of these companions that may alternatively help *or harm* effective communication, have been identified in prior work (Wolff & Roter 2011; Clayman et al., 2005; Wolff & Roter 2012). Results from our study and others (Hunsaker et al., 2010; K. Schmidt et al., 2009) underscore the particularly influential roles assumed by family companions during primary care visits of older adults with cognitive impairment and significant challenges relating to older adult and family companion perceived “co-ownership” of patient health information in conjunction with the prevailing health system orientation to patient privacy and confidentiality (Petronio et al., 2004; Bute et al., 2016). This issue is even more complex when multiple family members are involved, a glimpse of which was seen in our study when two daughters participated in the interview with their mother. Indeed, the data on multiple family companions are sparse and the effects of multiple companions on care would be a fruitful area for further study.

Prior efforts to improve the quality of primary care communication for older adults with cognitive impairment have predominantly been clinician-oriented (Laidsaar-Powell et al., 2013; Hunsaker et al., 2010). Other work to improve patient-companion communication has been conducted in the realm of oncology (Hoerger et al. 2013; Kornblith et al. 2005) and is not well-developed. A systematic review of communication quality improvement interventions for patients with advanced and serious illness, for example, included no interventional studies that targeted the patient-companion partnership (Fawole et al. 2012). The growing appreciation of the feasibility and benefit of more effective engagement of family caregivers in medical decision-making and communication (Wolff et al., 2014; Garvelink et al., 2016; Pennbrant 2013; Callahan et al., 2014; Carman, K., Dardess, P., Maurer 2013), lack of evidence-based strategies, and communication challenges – especially in the context of cognitive impairment – suggest that strategies to clarify and align patient and family perspectives merit consideration in future research. Agenda-setting strategies, for example, have been established as a powerful and pragmatic approach for motivating patient involvement in face-to-face visits (Harrington et al., 2004; Haywood et al., 2006; Kinnersley et al., 2007).

A small but growing body of evidence suggests that engaging family through health information technology may hold promise for respecting patient preferences for involving family in care delivery (Aikens et al., 2015; Piette et al., 2015; J. L. Wolff et al., 2016). Clinician participants in our study commented on the utility of electronic communication in the care of patients with cognitive impairment, and noted that family companions typically use the patient’s username and password. Some electronic health record vendors grant patients the ability to share access to their account so that companions have their own identity credentials. Such a strategy clarifies and respects patient preferences while affording family members access to patients’ health information and a mechanism to communicate directly with clinicians. Available evidence suggests that shared access is an underused strategy that may hold promise for more explicit and appropriate engagement of families (Wolff, Darer, et al., 2016; J. Wolff, Berger, et al., 2016; Crotty et al., 2015; Urmimala et al., 2014).

Strengths of our study include the inclusion of diverse perspectives of older adults, companions, and clinicians. In addition, the study protocol involved patients and



companions completing a task (the checklist), so we could observe their interactions under circumstances that simulate a formal medical setting. However, several limitations merit comment. Importantly, we examined what companions say they do rather than observing what they do during medical encounters. Although we described patient and companion behaviors during research interviews as a proxy for behaviors during medical visits, what was observed during in-home interviews may not be the same as what occurs during primary care visits. Older adult-family interactions varied widely, and we are unable to specifically comment how our findings might differ by degree of cognitive impairment.. Finally, this study relies on a small convenience sample and findings may not generalize to the broader population of older adults and companions who attend primary care visits together.

In summary, our study suggests that the behaviors and roles of companions affect the comprehensiveness and quality of primary care communication for older adults with cognitive impairment in both positive and negative ways. Study findings underscore the potential benefit of strategies that more effectively engage family companions. Future studies should evaluate the feasibility and benefit of creative solutions to more effectively and purposefully involve families in the care of older patients with cognitive impairment.

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## References

- Aikens JE, Trivedi R, Heapy A, Pfeiffer PN, Piette JDJ. Potential Impact of Incorporating a Patient-Selected Support Person into mHealth for Depression. *J Gen Intern Med.* 2015; 30(6):797–803. [PubMed: 25666218]
- Apesoa-Varano EC, Barker JC, Hinton L. Curing and caring: the work of primary care physicians with dementia patients. *Qual Health Res.* 2011; 21(11):1469–83. [PubMed: 21685311]
- Boise L, Camicioli R, Morgan DL, Rose JH, Congleton L. Diagnosing dementia: perspectives of primary care physicians. *Gerontologist.* 1999; 39(4):457–464. [PubMed: 10495584]
- Boustani M, Callahan CM, Unverzagt FW, Austrom MG, Perkins AJ, Fultz BA, Hui SL, Hendrie HC. Implementing a screening and diagnosis program for dementia in primary care. *J Gen Intern Med.* 2005; 20(7):572–577. [PubMed: 16050849]
- Bradford A, Kunik ME, Schulz P, Williams SP, Singh H. Missed and Delayed Diagnosis of Dementia in Primary Care: Prevalence and Contributing Factors. *Alzheimer Dis Assoc Disord.* 2009; 23(4): 306–314. [PubMed: 19568149]
- Bute JJ, Petronio S, Torke AM. Surrogate Decision Makers and Proxy Ownership: Challenges of Privacy Management in Health Care Decision Making. *Health Comm.* 2016; 116(8):1477–1490.
- Callahan CM, Sachs GA, Lamantia MA, Unroe KT, Arling G, Boustani MA. Redesigning systems of care for older adults with Alzheimer’s disease. *Health Aff (Millwood).* 2014; 33(4):626–632. [PubMed: 24711324]
- Callahan CM, Unverzagt FW, Hui SL, Perkins AJ, Hendrie HC. Six-item screener to identify cognitive impairment among potential subjects for clinical research. *Med Care.* 2002; 40(9):771–781. [PubMed: 12218768]
- Carman KL, Dardess P, Maurer M, Sofaer S, Adams K, Bechtel C, Sweeney J. Patient and Family Engagement. *Health Aff (Millwood).* 2013; 32(2):223–231. [PubMed: 23381514]

- Chodosh J, Petitti DB, Elliott M, Hays RD, Crooks VC, Reuben DB. Physician recognition of cognitive impairment: Evaluating the need for improvement. *J Am Geriatr Soc.* 2004; 52(7):1051–1059. [PubMed: 15209641]
- Clayman ML, Roter DR, Wissow LS, Bandeen-Roche K. Autonomy-related behaviors of patient companions and their effect on decision-making activity in geriatric primary care visits. *Soc Sci Med.* 2005; 60:1583–1591. [PubMed: 15652689]
- Crotty BH, Walker J, Dierks M, Lipsitz L, O'Brien J, Fischer S, Slack WV, Safran C. Information Sharing Preferences of Older Patients and Their Families. *JAMA Intern Med.* 2015; 175(9):1492–7. [PubMed: 26147401]
- Eggy S, Penner LA, Hagiwara N, Gonzalez R, Harper FWK, Heath EI, Albrecht TL. Patient, companion, and oncologist agreement regarding information discussed during triadic oncology clinical interactions. *Psycho-Oncology.* 2012; 22(3):637–645. [PubMed: 22337320]
- Fawole OA, Dy SM, Wilson RF, Lau BD, Martinez KA, Apostol CC, Vollenweider D, Bass EB, Aslakson RA. A Systematic Review of Communication Quality Improvement Interventions for Patients with Advanced and Serious Illness. *J Gen Intern Med.* 2012; 28(4):570–577. [PubMed: 23099799]
- Garvelink MM, Ngangue PAG, Adekpedjou R, Diouf NT, Goh L, Blair L, Légaré F. A Synthesis of Knowledge About Caregiver Decision Making Finds Gaps in Support for Those Who Care for Aging Loved Ones. *Health Aff (Millwood).* 2016; 35(4):619–626. [PubMed: 27044961]
- Gitlin LN, Hodgson N. Who should assess the needs of and care for a dementia patient's caregiver? *AMA J Ethics.* 2016; 18(12):1171–1181. [PubMed: 28009243]
- Harrington J, Noble LM, Newman SP. Improving patients' communication with doctors: A systematic review of intervention studies. *Patient Educ Couns.* 2004; 52(1):7–16. [PubMed: 14729285]
- Harris DP, Chodosh J, Vassar SD, Vickrey BG, Shapiro MF. Primary care providers' views of challenges and rewards of dementia care relative to other conditions. *J Am Geriatr Soc.* 2009; 57(12):2209–16. [PubMed: 19943831]
- Haywood K, Marshall S, Fitzpatrick R. Patient participation in the consultation process: A structured review of intervention strategies. *Patient Educ Couns.* 2006; 63(1–2):12–23. [PubMed: 16406464]
- Hinton L, Franz CE, Reddy G, Flores Y, Kravitz RL, Barker JC. Practice constraints, behavioral problems, and dementia care: Primary care physicians' perspectives. *J Gen Intern Med.* 2007; 22(11):1487–1492. [PubMed: 17823840]
- Hirschman KB, Joyce CM, James BD, Xie SX, Karlawish JHT. Do Alzheimer's disease patients want to participate in a treatment decision, and would their caregivers let them? *Gerontologist.* 2005; 45(3):381–388. [PubMed: 15933278]
- Hoerger M, Epstein RM, Winters PC, Fiscella K, Duberstein PR, Gramling R, Butow PN, Mohile SG, Kaesberg PRK, Tang W, Plumb S, Walczak A, Back AL, Tancredi D, Venuti A, Cipri C, Escalera G, Ferro C, Gaudion D, Hoh B, Leatherwood B, Lewis L, Robinson M, Sullivan P, Kravitz R. Values and options in cancer care (VOICE): study design and rationale for a patient-centered communication and decision-making intervention for physicians, patients with advanced cancer, and their caregivers. *BMC Cancer.* 2013; 13(188)
- Hunsaker AE, Schmidt K, Lingler JH. Discussing Dementia-Related Behaviors During Medical Visits for People with Alzheimer's Disease. *Am J Alzheimers Dis Other Demen.* 2010; 25(3):248–254. [PubMed: 20147601]
- Karnieli-Miller O, Werner P, Neufeld-Kroszynsk G, Eidelman S. Are you talking to me?! An exploration of the triadic physician–patient–companion communication within memory clinics encounters. *Patient Educ Couns.* 2012; 88(3):381–390. [PubMed: 22789148]
- Kinnersley P, Edward A, Hood K, Cadbury N, Ryan R, Prout H, Owen D, MacBeth F, Butow P, Butler C. Interventions before consultations for helping patients address their information needs. *Cochrane Database Syst Rev.* 2007; ONLINE FIRST:1–10.
- Kornblith AB, Regan M, Kim Y, Greer G, Parker B, Bennett S, Winer E. Cancer-related communication between female patients and male partners scale: a pilot study. *Psychooncology.* 2005; 15:780–794.
- Laidsaar-Powell RC, Butow PN, Bu S, Charles C, Gafni A, Lam WWT, Jansen J, McCaffery KJ, Shepherd HL, Tattersall MHN, Juraskova I. Physician–patient–companion communication and

- decision-making: A systematic review of triadic medical consultations. *Patient Educ Couns.* 2013; 91(1):3–13. [PubMed: 23332193]
- Mitnick S, Leffler C, Hood VL. Family Caregivers, Patients and Physicians: Ethical Guidance to Optimize Relationships. *J Gen Intern Med.* 2010; 25(3):255–260. [PubMed: 20063128]
- Pennbrant S. A trustful relationship-the importance for relatives to actively participate in the meeting with the physician. *Int J Qual Stud Health Well-being.* 2013; 8(1):1–12.
- Petronio S, Sargent J, Andea L, Reganis P, Cichocki D. Family and friends as healthcare advocates: Dilemmas of confidentiality and privacy. *J Soc Pers Relat.* 2004; 21(1):33–52.
- Piette JD, Striplin D, Marinec N, Chen J, Trivedi RB, Aron DC, Fisher L, Aikens JE. A Mobile Health Intervention Supporting Heart Failure Patients and Their Informal Caregivers: A Randomized Comparative Effectiveness Trial. *J Med Internet Res.* 2015; 17(6):e142. [PubMed: 26063161]
- Pope C, Ziebland S, Mays N. Analysing qualitative data. *BMJ.* 2011; 320(7227):114–116.
- Roter, D., Hall, J. *Doctors Talking with Patients, Patients Talking With Doctors.* Auburn House; Westport, CT: 1993.
- Sakai EY, Carpenter BD. Linguistic Features of Power Dynamics in Triadic Dementia Diagnostic Conversations. *Patient Educ Couns.* 2012; 85(2):295–298.
- Schmidt K, Lingler J, Schulz R. Verbal Communication among Alzheimer's Disease Patients, their Caregivers, and Primary Care Physicians during Primary Care Office Visits. *Patient Educ Couns.* 2009; 77(2):197–201. [PubMed: 19395224]
- Serper M, Patzer RE, Curtis LM, Smith SG, O'Connor R, Baker DW. Health literacy, cognitive ability, and functional health status among older adults. *Health Serv Res.* 2014; 49(4):1249–1267. [PubMed: 24476068]
- Urmimala S, Bates DW. Care Partners and Online Patient Portals. *JAMA.* 2014; 1364:E29–30.
- Werner P, Gafni A, Kitai E. Examining physician-patient-caregiver encounters: the case of Alzheimer's disease patients and family physicians in Israel. *Aging Ment Health.* 2004; 8(6):498–504. [PubMed: 15724831]
- Wolf S, Curtis LM, Wilson EAH, Revelle W, Waite KR, Smith SG, Weintraub S, Borosh B, Rapp DN, Park DC, Deary IC, Baker DW. Literacy, cognitive function, and health: Results of the LitCog study. *J Gen Intern Med.* 2012; 27(10):1300–1307. [PubMed: 22566171]
- Wolff JW, Berger A, Clark D. Patients, care partners, and shared access to the patient portal: online practices at an integrated health system. *J Am Med Inform Assoc.* 2016; 23(6):1150–1158. [PubMed: 27026614]
- Wolff JW, Darer J, Larsen K. Family Caregivers and Consumer Health Information Technology. *J Gen Intern Med.* 2016; 31(1):117–121. [PubMed: 26311198]
- Wolff JL, Roter DR, Barron J, Boyd CM, Leff B, Finucane TW, Gallo JJ, Rabins PV, Roth DL, Gitlin LN. A tool to strengthen the older patient-companion partnership in primary care: Results from a pilot study. *J Am Geriatr Soc.* 2014; 62(2):312–319. [PubMed: 24417565]
- Wolff JL, et al. Inviting patients and care partners to read doctors' notes: OpenNotes and shared access to electronic medical records. *J Am Med Inform Assoc.* 2016; 24(e1):e166–e172.
- Wolff JL, Darer JD, Berger A, Clarke D, Green JA, Stamatz RA, Delbanco T, Jan W. Family presence in routine medical visits: A meta-analytical review. *Soc Sci Med.* 72(6):823–831.
- Wolff JL, Roter DL. Older adults' mental health function and patient-centered care: Does the presence of a family companion help or hinder communication? *J Gen Intern Med.* 2012; 27(6):661–668. [PubMed: 22180197]

**Key points**

- Family companions of older adults with cognitive impairment commonly facilitate communication by advocating for patients, ensuring the accuracy of information exchange and understanding, and preserving rapport.
- Significant communication challenges posed by family companion presence in primary care visits include patient and companion role ambiguity, competing visit agendas, and clinician confusion regarding the most accurate source of information.
- Strategies to improve communication include identifying, differentiating, and respecting both patient and companion priorities and perspectives.

**Table 1**

## Interview Guide

*Part 1: Feedback about checklist*

What are your reactions to the checklist? Was anything confusing? Did you understand the instructions? Was anything difficult?

Do you have any suggestions about how to make the checklist simpler or less confusing?

Did you understand what was being asked about each of the health concerns? Do you think any of the concerns could be dropped? Is anything missing? What about the response categories? Are the response categories straightforward? Too complicated? Better as yes or no?

What do you think about the second activity? Did you understand the instructions? Is this activity helpful? Do you think it would be better to ask patients to identify the most important support role?

Let's look at the checklist again. What changes could we make to address your ideas?

*Part 2: Medication concerns.*

How well do you understand the medications that you have been prescribed?

How well do the two of you communicate about medications? Do you talk to each other about questions and concerns that you may have about medications? Are there times that you do NOT talk with each other about your medication-related concerns? Tell me about that.

Do the two of you ever disagree about medications? Tell me about that. (Do you disagree all the time or only under certain circumstances or about certain drugs – do you have more disagreement about taking the medications or making decisions about what to take?)

Do you talk to the doctor about your questions or concerns about medications? How well does that usually go? What do you think might improve these discussions? What could we change about the checklist to better address these medication concerns? Thinking more broadly about your primary care practice, is there anything the practice could do to help with these concerns or challenges?

What is the most difficult part of arranging for, giving, and monitoring effects of medications? Have you ever had a medication emergency? Do you think it could have been avoided? Tell me about it.

**Table 2**

## Study Participant Characteristics

	Patients (n=20)	Companions (n=21)
Age; mean (range)	83 (65–100)	67 (50–85)
Female; n (%)	10 (50%)	17 (81%)
Race		
Caucasian; n (%)	14 (70%)	14 (67%)
African American; n (%)	6 (30%)	7 (33%)
College or beyond education; n (%)	14 (70%)	19 (90%)
Low health literacy <sup>1</sup>	15 (75%)	1 (10%)
Mini-Mental State Examination; <sup>2</sup> mean (range)	17 (1–30)	--
Average number of medications	<5: 6 patients 5–10: 11 patients >10: 3 patients	--
Relationship of Family Companion		
Spouse/partner; n (%)	--	12 (57%)
Adult Child; n (%)	--	9 (43%)
<b>Clinicians (n=10)</b>		
Age; mean (range)	48 (38–66)	
Female; n (%)	8 (80%)	
Physician; n (%)	8 (80%)	
Nurse practitioner or registered nurse; n (%)	2 (20%)	
Years in practice; mean (range)	16 (6–33)	

<sup>1</sup>Wallace LS, Rogers ES, Roskos SE, Holiday DB, Weiss BD. 2006. BRIEF REPORT: Screening Items to Identify Patients with Limited Health Literacy Skills. *J Gen Int Med*, 21(8); 874–877.

<sup>2</sup>Folstein MF, Folstein SE. 1975. Mini-mental state: A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res*, 12: 189–198.



**Table 3**

Qualitative Findings

<i>1. What Companions Do: Roles and Communicative Behaviors</i>	
A Companions advocate	<p><b>1</b> <i>Wife:</i> "I think my job is to be his advocate... I take that very seriously, just as when I – when my kids were little, I was their advocate" (Dyad 5, MMSE: 10/30).</p> <p><b>2</b> <i>Daughter:</i> "Patients their age really need an advocate...patients their age...they...just get swept...swept under the rug." (Dyad 7, MMSE: 5/30).</p> <p><b>3</b> <i>Daughter:</i> "... even if it was a female personal exam, I would really like to be in there to see what's going on. 'Cause like I said... she doesn't remember her own body problems. So I would need to be there to help tell the doctor, or to see what's going on." (Dyad 20, MMSE: 19/30).</p> <p><b>4</b> <i>Daughter:</i> Some doctors, when a companion is there, they don't talk to the patient. They're asking the patient the question, but they look at the companion...And especially if you're elderly because they—that's a putdown. They feel like the doctors are not respecting [them], and so when I'm there and they do that, I will look at the patient and say, "Well what do you think about what he said?... " I [try] to cue the doctor to ask--talk to the patient. (Dyad 3, MMSE: 13/30)</p>
B Companions facilitate accurate exchange of information	<p><b>1</b> <i>Wife:</i> I tell him...remember that [question] you wanted to ask... <i>Patient:</i> I don't know how else you can...help the patient if you don't do that, ask [the family member] to provide data...it has to be said. Even if it is true, or not true, it has to be said...The doctor should be able to judge what's right or not." (Dyad 16, MMSE: 29/30)</p> <p><b>2</b> <i>Daughter:</i> Sometimes a doctor says something and then I tell you, I translate it, you know I—I try to explain it to you...At this point, I always go with her and I really do kind of translate. (Dyad 6, MMSE: 16/30)</p> <p><b>3</b> <i>Daughter 1:</i> Sometimes do you feel like you have that woozy head or dizziness? <i>Patient:</i> No, 'cause I go and lay down. I lay down when my head – <i>Daughter 2:</i> When we were just in the bathroom, didn't you feel like you had a woozy head? <i>Patient:</i> Where? The bathroom? <i>Daughter 2:</i> Just – yes, just a few minutes ago. <i>Patient:</i> I did. (Dyad 1, MMSE: 11/30)</p> <p><b>4</b> <i>Interviewer:</i> How well do you understand the medications that you've been prescribed? <i>Wife:</i> Listen to what she's asking you...do you know why you take the medications you take? Do you? <i>Patient:</i> Yes. <i>Wife:</i> Do you know why you take the medications that the doctor has prescribed for you? You take them because the doctor prescribed them, and I say, "Here's your medicine." But do you really know why you are taking each one of those pills? <i>Patient:</i> I don't. (Dyad 2, MMSE: 19/30)</p> <p><b>5</b> <i>Patient:</i> I don't take any medicine <i>Daughter:</i> Well, that's not entirely true. Well you take the high blood pressure medicine. You take a pill for the high blood pressure every morning. (Dyad 6, MMSE: 16/30)</p> <p><b>6</b> <i>Primary care clinician:</i> ...a lot of times it's—especially when any Alzheimer's patients, like, they forget about their pain until they go to stand up. And so their caretaker is like, "Oh, you remember when I got you in the car today and you were moaning and groaning?" (Focus Group #1)</p>
C Companions preserve rapport	<p><b>1</b> <i>Daughter:</i> "Ma, ma, you can't do that. You can't ask them about no children...This hasn't got nothing to do with her children." (Dyad 9, MMSE: 2)</p> <p><b>2</b> <i>Wife:</i> He wouldn't let me button his pants today. I'm sorry.... They're on. That's a plus. (Dyad 8, MMSE: 1/30)</p>
<i>2. Communication Challenges</i>	

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<p>D Disagreement or confusion about the role of the patient and companion</p>	<p>1 <i>Patient</i>: “You’re just, you’re just nose. You want to hear everything I have to say to the doctor, and I think that’s not a good idea. I think people, if somebody is nuts, you don’t want to talk to the doctor with the patient and the family there. You want to talk to the doctor by yourself, and you want to talk to the [family] by themselves, and you want to talk to them together, and then he gets a better picture. That’s my opinion.” (Dyad 16, MMSE 29/30).</p> <p>2 <i>Wife</i>: “Now there are some people who criticize their doctor for talking always to the companion and not directly to the...patient, [but with this particular doctor], I felt that...I wasn’t respected sufficiently... (Dyad 10, MMSE 21/30)</p> <p>3 <i>Wife</i>: Clinicians] get angry with me and they’re like, “Let him speak,” as if this is a picnic for me, which it is not...And as a matter of fact, it’s very disturbing to me to know that he can’t remember that he had a stent put in his heart [last month]...The fact of the matter is...he’s not going to remember what to ask, and if I write a note he might not remember to look at it. You can’t pin a note to an intelligent, grown man’s sweater.” (Dyad 15, MMSE 26)</p> <p>4 <i>Wife</i>: “He [the patient] doesn’t always understand the questions and before she was finished in five minutes, she had him as clinically depressed. And it’s in his records now that he’s clinically depressed because she was asking him, “Do you feel sad?” and he was going, “Yeah.” But I’m the person you ask, not him. (Dyad 5, MMSE: 10/30)</p> <p>5 <i>Husband</i>: “I took her [the patient] to the doctor and she would get very, very upset if [the doctor] talked to me —she probably would have walked out by now because enough eye signals and she realizes she’s not in control of the situation.” (Dyad 18, MMSE 23).</p> <p>6 <i>Clinician</i>: “There are some times when if someone is really far gone, we, as providers, will just talk to the caregivers...and maybe at the end of the visit, [someone is thinking] like wow she didn’t even treat the patient like a real patient, and that could be really insulting.” (Focus group #1)</p>
<p>E Disagreement or confusion about patient health issues</p>	<p>1 <i>Daughter 1</i>: Do you feel safe?  <i>Patient</i>: Yeah.  <i>Daughter</i>: Okay. Alright, so she’s saying she does not have a falling or fear of falling, and I disagree.  <i>Daughter 2</i>: Me too.  <i>Daughter</i>: Okay. I think that sometimes we feel there’s a fear of falling. So sometimes you get a little nervous that we’re going to, you know, you’re going to fall sometimes. (Dyad 1 patient participant and two daughters, MMSE: 11/30)</p> <p>2 <i>Primary Care Clinician</i>: “The patient and the caregiver may come in with their own agendas. Like, the caregiver’s like, I don’t like her living situation, and the patient’s like, I’m tired of this person. And they may never tell you that they’ve got chest pain, shortness of breath...” (Focus Group #1)</p> <p>3 <i>Primary Care Clinician</i>: “You’ve got three agendas in the visit. You’ve got yours, the patient’s, and the caregiver’s.” (Focus group #2)</p> <p>4 <i>Primary Care Clinician</i>: “I’m seeing a lady today for the third time in less than seven days. And the reason why she came in was weight loss, but, you know, but the daughter came along and the daughter was concerned about her memory...Guess what I was concerned about? Her weight loss. She scored a 28 out of 30 [on the MMSE], did a good clock draw test. I’m like, you’re freaking 90...your daughter’s worried about memory; it’s not a memory thing. You need to find this cancer.” (Focus group #1)</p>
<p>F Establishing an actionable visit agenda</p>	<p>1 <i>Primary Care Clinician 1</i>: Would you want to know about that, though?  <i>Primary Care Clinician 2</i>: Yeah. We can’t do anything.  <i>Primary Care Clinician 3</i>: They can’t afford their medical? They can’t afford their - -  <i>Primary Care Clinician 4</i>: Well, yeah, in some ways, I mean, I, I’ve redirected people to figuring out that they were going to one pharmacy, and saying, you can go to Walmart and we can do the —I’ll, I’ll only pick meds off of the Walmart brand....  <i>Primary Care Clinician 2</i>: I mean I know [financial concerns] become medication concerns.  <i>Primary Care Clinician 1</i>: We run into people who we don’t know that about, either. I first found out one of my patients was homeless for nine months, while I was seeing him every couple of months and I had no clue.  <i>Primary Care Clinician 3</i>: ...[You] can’t help with everything, but some things, you can. (Focus group #1)</p>

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	<p>2 <i>Primary Care Clinician 1:</i> But yeah, because it could mean a whole boatload of stuff. I mean, even [if you ask about] transportation concerns—sometimes because they don't drive, but sometimes it's...</p> <p><i>Primary Care Clinician 2:</i> Yeah, my car needs new brakes...</p> <p><i>Primary Care Clinician 1:</i> And you're like, yeah, I don't—I'm not helping you with that. (Focus group #1)</p> <p>3 <i>Primary Care Clinician:</i> "There are times when I could spend a half an hour because of the patient is complaining of pain and shortness of breath, and then at the end of the visit, they're probably saying yeah, they never talked about how are we going to get them hooked up with the social worker for the food—Meals on Wheels. You know, like, that's where sometimes we've completely missed the point of what their agenda was." (Focus group #1)</p>
<p><b>3. Potential Strategies to Improve Communication</b></p>	
<p>G Independent companion-clinician communication</p>	<p>1 <i>Daughter:</i> "And so I wrote a little note and gave it to the receptionist when we signed in, so that [the clinician] would know what my concerns were." (Dyad 3, MMSE: 13/30)</p> <p>2 <i>Wife:</i> "Our family doctor talked to [the patient] about his drinking... which I had asked [the doctor] to do. He [the clinician] didn't do it on his own. And I said, okay, do you want me in the office? He [the clinician] said no. So, if you recall, that day he went alone... I call [the clinician] at different times... that's the only way I would get to talk to him alone." (Dyad 19, MMSE 30/30)</p> <p>3 <i>Primary Care Clinician 1</i> ... a lot of times you think that the [family companion] doesn't want to talk or bring up certain things... in front of the patient.</p> <p>4 <i>Clinician 3</i> Right. In front of the patient. I get a note—patient is really concerned about something. Don't say anything when you're in the room. (Focus group #1)</p> <p>5 <i>Primary Care Clinician:</i> ... since we have MyChart, if you've got someone that's already has already got, like, mild cognitive deficits, or dementia, or whatever, and they sign up for MyChart it's not really the patient that signs up for the MyChart, it's the family member, and I love that. (Focus Group #1)</p>
<p>H Differentiating patient and family perspectives</p>	<p>1 <i>Primary Care Clinician:</i> "I think that the one thing that might be good... with the Medicare Wellness, is that where it says 'Do you or any family members have any concerns about your memory, your concentration or thought process?' I think that's good, because you know, I watch patients who will check yes to that, and it will be that they were told by a family member to come in and to mention this." (Focus group #1)</p> <p>2 <i>Primary Care Clinician:</i> "[I always begin by asking...] How are you guys related? And then... I look at the patient—do you want your husband to be present during this visit? And then they say yes. But then halfway through the interview, again, I'll be like, is there anything that you might want to talk about without them being in here? ... Most of the time I kick family members out ... And I—and I guarantee, every time you do, you find something out. [And] guess what? Patients are appreciative, right? Because they were like, you know, I didn't want to say anything while they were here and I didn't feel like I could say that I could kick them out" (Focus group #1).</p> <p>4 <i>Primary Care Clinician:</i> "I find... it very useful to have the patient spend time with the doctor [alone] but also the opposite is true, too, after the patient leaves, especially if it was a cognitive problem... It's often, and we're talking like maybe three minutes, but just enough so that the family member knows that you're engaged with the idea that this patient has cognitive problems. They can give you certain things. He drinks too much or something like that." (Focus group #2)</p> <p>5 <i>Primary Care Clinician:</i> "...if we're talking about people with cognitive impairment, people that are—I don't know. I'm hearing more and more about elder abuse and that it's much more common than we think. And it's nice to have some time alone with patients to be able to check into that a little bit... And I think also a lot of the caregivers that are coming with people are also their payee and have sometimes another agenda when they're talking to us, so I sort of like that, that you set up that expectation at the beginning that I am going to have some alone time with this patient." (Focus group #2)</p> <p>6 <i>Wife:</i> And there are times then when the doctor does want to talk to me alone and that's fine, you know? (Dyad 5, MMSE: 10/30)</p>