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## Challenges and Approaches to Involving Family Caregivers in Primary Care

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### Abstract

**Objective:** Older adults are commonly accompanied to routine medical visits. This study identifies challenges and explores approaches to managing patient-family interactions in primary care.

**Methods:** Semi-structured interviews were conducted with primary care clinicians and staff (N=30) as well as older adult patients and family caregivers (N=40). Interviews were analyzed using content analysis.

**Results:** Three major challenges to patient-family interactions were identified: navigating patient autonomy and family motivation to participate; adjudicating patient-family disagreements; and minimizing obtrusive behaviors by caregivers. Three approaches to managing patient-family interactions were identified. *Collaborating* involved non-judgmental listening, consensus-building, and validation of different perspectives. *Dividing* involved separating the patient and family member to elicit confidential information from one member of the dyad. *Focusing* involved re-directing the conversation to either the patient or family member while minimizing input from the other. Approaches varied by patients' cognitive status and overall health condition. In general,

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#### Credit Author Statement

#### Author Contributions

Riffin: study concept and design; data collection and analysis; drafting and preparing the manuscript. Wolff: study supervision; interpretation of data; editing of the manuscript. Butterworth: data analysis and interpretation; editing of manuscript. Adelman: interpretation of data; editing of manuscript. Pillemer: study supervision; interpretation of data; editing of the manuscript. All authors: revision of manuscript for important intellectual content.

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The authors confirm that all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

patients and caregivers expressed the most positive attitudes toward collaborating and patient-directed focusing approaches.

**Conclusion:** Primary care clinicians use varied approaches to managing their interactions with patient-family dyads. Patients and caregivers generally prefer those approaches that involve collaborative rather than individual discussions.

**Practice implications:** Findings suggest the potential for the development of communication-focused interventions to promote positive clinician-patient-family interactions.

## Keywords

Family caregiver; Primary health care; Physician office; Patient-caregiver-provider interactions

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## 1. Introduction

Nearly 40% of older adults are regularly accompanied to primary care visits, typically by adult children and spouses [1]. Compared with unaccompanied patients, individuals who attend appointments with a family member tend to be older, female, less educated, and in worse health [1, 2]. Medical encounters involving caregivers differ from patient-only visits in fundamental ways [3, 4]. Family participation not only increases the duration and complexity of the encounter, but also influences the content and dynamics of the consultation [1, 2, 5]. Patients and their families may enter the appointment with competing agendas and offer conflicting responses to doctors' suggestions [6–8].

Person- and family-centered care approaches to health care delivery have been endorsed internationally [9, 10] with professional societies recommending that clinicians take an active role in facilitating supportive patient-family partnerships [3, 11]. Although most primary care clinicians believe that it is their responsibility to recognize and involve family caregivers in routine medical encounters [8, 12], they report ambiguity about when and how to engage families effectively and efficiently [13, 14]. An evidence base to guide and support clinicians in their interactions with patients and their families could lead to more productive interactions and effective partnerships, as there is currently a lack of specific knowledge about which practices and behaviors are most constructive.

Prior research on clinician-patient-family interactions has largely been conducted in advanced illness or acute care settings [5, 15–19]. Within the setting of oncology, for example, clinicians have identified ethical and legal challenges to family participation in cancer consultations, including family requests for information without the patient's knowledge and requests for non-disclosure of the diagnosis to the patient [16]. With respect to patient and caregiver preferences, prior research in the dementia context suggests that patients and caregivers favor medical visits that involve compassionate dialogue and collective decision-making [20].

The extent to which findings from these contexts translate to primary care is uncertain. With rare exceptions [7], the few studies examining clinician-patient-family interactions in primary care use recordings of office visits and surveys to identify communication patterns [1, 2, 21]. However, these methods do not directly assess clinicians' attitudes and rationales

underlying their behaviors. Further, although prior research has documented varying attitudes and experiences of family caregivers toward medical professionals [22–24], it remains unclear how they and patients perceive and react to specific behaviors and practice styles.

The present study seeks to identify primary care clinicians' challenges with and approaches to managing patient-family interactions and to explore patients' and family caregivers' attitudes and responses to clinicians' approaches. Given our goal of understanding how clinicians, patients, and caregivers think about and interpret their interactions, in-depth interviews were used to allow participants to articulate their reasoning, attitudes, and reactions.

## 2. Methods

### 2.2. Study Design, Setting, and Participants

The methods for this study have been described in detail elsewhere [14]. In brief, the research involved a qualitative study in which semi-structured, one-on-one interviews lasting 30 minutes were conducted with primary care clinicians, staff, and administrators; older adult patients; and family caregivers. We purposefully sampled four primary care practices from academic and community settings in New York City, central New York, and northern Pennsylvania. The goal of this sampling method was to ensure the inclusion of clinicians who were practicing under different care systems with a diverse set of constraints and resources informing their approach to interacting with older persons and their families (e.g. availability of multidisciplinary staff, geriatrics-specific vs. internal medicine). We sought to recruit patients and caregivers who had varying relationships to one another (e.g. spouses).

Primary care professionals (clinicians, staff, and administrators) were recruited at weekly staff meetings. Professionals from any discipline (medicine, nursing, social work, administration) were eligible if they were over the age of 21 and had practiced in primary care for at least one year beyond training. Patients and family caregivers were recruited through physician referral (n=28) and outreach by primary care clinic staff (n=12). Patients were eligible if they were over the age of 65, routinely accompanied by a family member to primary care appointments, had sufficient cognitive capacity to provide informed consent, and were English-speaking. Family caregivers were eligible if they were over the age of 21, routinely accompanied a patient age 65 years or older to primary care appointments, and were English-speaking. Caregivers were not required to be assisting a participating patient, and participating patients were not required to be under the care of a participating clinician. The project was approved by the Weill Cornell Medicine and Guthrie Clinic Institutional Review Boards. All participants provided informed consent; they received no financial compensation.

### 2.2. Interview Guide

Interview guides were developed and iteratively revised during pretesting (eAppendix). The guides for primary care professionals, patients, and caregivers covered identical content. The first half of the interview guide asked participants to discuss how family caregivers are

involved in older adults' primary care visits. Probes queried about communication processes and interpersonal dynamics in three-way discussions and separate consultations (telephone or email correspondence) with the patient or caregiver. The second half of the interview guide asked participants to offer recommendations for integrating standardized caregiver assessment into primary care. The results presented in this manuscript were derived from analyses performed on the first half of the interview guide. Findings specific to the second half of the interview guide have been published previously [14].

### 2.3. Data Collection and Analysis

All interviews were conducted by one investigator, a social scientist with expertise in family caregiving and training in qualitative methods. Participant characteristics were obtained using a brief, self-administered questionnaire. Data collection continued until additional interviews yielded no new information, signaling that thematic saturation was reached [25]. To reduce the potential for personal bias and subjectivity in interviewing, the investigator used memo writing throughout data collection to identify and reflect on her own assumptions, ideas, and experiences that may influence the research. All interviews were audio-recorded, and subsequently transcribed, de-identified, and entered into NVivo 9.0 and Dedoose 8.0.25, textual data analysis software.

The interview transcripts were analyzed using qualitative content analysis whereby small portions of text were tagged with unique codes representing distinct concepts [26, 27]. Two investigators with clinical and research expertise in family-centered care reviewed initial interpretations of the data, identifying potential biases, unclear and redundant codes, and discrepancies. Reliability in the initial coding phase was achieved through multiple discussions until consensus was reached between coders. Deviant case analysis was also implemented to examine alternative interpretations and reduce biases. A final code structure was developed and all transcripts were (re)coded accordingly.

Several techniques were employed to ensure trustworthiness in data collection and analysis, following the principles of credibility, confirmability, dependability, and transferability [28]. Credibility was strengthened by triangulation of data sources (transcripts and memos) and systematic content analysis by the research team. Confirmability was enhanced by consistent documentation (i.e. audit trail) of analytic decision and interpretations by the first author [29]. Dependability and transferability of the study findings to other contexts was enhanced by review and discussion with health care providers (geriatricians; internists) who were not part of the study team or participant pool.

## 3. Results

### 3.1. Participant Characteristics

Table 1 summarizes participant characteristics. Thirty primary care professionals participated in the study, including 16 physicians, 8 nurses, 4 practice administrators, a physician assistant, and a social worker. Forty patients and family caregivers participated, of which 14 were patients, 11 were spouses, 11 were adult children, and 4 were other relatives.

### 3.2. Overview of Themes

Themes that emerged from the interviews are organized into two sections: 1) challenges to patient-family interactions and 2) approaches to managing patient-family interactions. Specific findings are described below and illustrated using representative quotations (Tables 2 and 3).

### 3.3. Challenges to Patient-Family Interactions

Three challenges were identified: 1) navigating patient autonomy and family motivation for participation, 2) adjudicating patient-family disagreements, and 3) minimizing obtrusive behaviors by family members.

**3.3.1. Patient Autonomy and Family Motivation.**—Clinicians described struggling to match their practice styles to patients' preferences for family participation (Table 2A). They highlighted a “controversy about how best to interact with people with significant memory problems” (geriatrician), expressing uncertainty about striking the right balance between patient autonomy and family engagement (Table 2B): “I don't have a formula... We don't know how, when, how long, or how fast... at some point we are going to need the caregiver's involvement, so you want to engage them, but you also want to balance autonomy” (social worker). When discussing the need to support patient autonomy, clinicians articulated apprehensions about some family members' motives to participate in the patient's medical visits (Table 2C–D). One internist explained, “Sometimes it feels tricky to have a caregiver who wants to discuss things without the patient, what their motives are.”

Caregivers also expressed the importance of upholding patients' dignity: “I'm careful with the words that I use so it doesn't make [patient] feel less than and that's very important with my aunt who has been so independent” (niece). They also described their motivation to initiate separate consultations with medical providers, pointing to a tension between supporting patient autonomy and ensuring that their own needs for information were met: “[Patient] didn't like me to ask a lot of questions... so I was somewhat constricted by that. So I would have to make those opportunities for myself” (spouse).

**3.3.2. Patient-Family Disagreements.**—Clinicians noted the challenge of adjudicating divergent perspectives of patients and their families (Table 2E): It is “a mental negotiation I'm having [with] myself in each appointment,” especially when “there is conflict in which both parties could be believed” (geriatrician). Common conflicts involved patient-family disagreement about the patients' symptoms (e.g. fatigue), abilities (e.g. driving), and health care needs (e.g. mobility assistance) (Table 2F–K). Clinicians cited patients' cognitive status and caregivers' concerns about the patient's ability to remain independent as contributors to these disagreements (Table 2F–H). One geriatrician remarked, “I think that cognitive impairment is an important part... the story may be very different between what the patient perceives and what the caregiver perceives.”

Patients and caregivers offered differing explanations for their disagreements. Patients reported that family members tended to exaggerate the patient's condition or health requirements (Table 2I). Some caregivers conceded that their own apprehensions and “over-

protectiveness” played a role in their disagreements (Table 2J); whereas others asserted that patients’ inability (due to cognitive impairment; Table 2K) or unwillingness to communicate their symptoms or conditions contributed to conflicting reports with the dyad: “My mom’s very combative with me and she downplays a lot of things” (adult child).

**3.3.3. Obtrusive Behaviors by Families.**—The most commonly-reported obtrusive behaviors were caregivers monopolizing the conversation or interjecting irrelevant information (Table 2L–N). Clinicians discussed how such interruptions impacted the visit dynamics: “You start asking questions and then sometimes the caregiver will butt in and then you see frustration on the part of the patient” (internist). In some circumstances, obtrusive behaviors were viewed as detrimental to patient care: “The caregiver actually pushed the patient to come here and walked in sort of cussing, demanding care, and we tried to explain based on the symptoms your mother has this and that... that is one plain example of how caregivers can resist medical advice and sort of impede the care for the patient” (nurse).

Caregivers viewed their interjections as necessary to facilitate their own understanding (Table 2O) and ensure timely treatment for the patient: “I’m aggressive so that stuff gets done” (spouse). They surmised that “some doctors... may not think that I know... what I’m talking about, but I see [patient] more than they do” (adult child). They also recognized that their contributions were not always positively perceived: “I’ll bring everything up and then you know, [patient] will get annoyed at me” (spouse).

#### 3.4. Approaches to Managing Patient-Family Dynamics

Clinicians discussed varying approaches to managing patient-family dynamics. These approaches fell into three broad categories: 1) collaborating, 2) dividing, and 3) focusing.

**3.4.1. Collaborating.**—A collaborating approach is characterized by non-judgmental listening, consensus-building, and collective decision-making (Table 3, A1–2). One geriatrician explained, “I play the role of peacemaker... I try to listen to what the patient has to say... then I shift kind of to the caregiver... then I kind of tie, basically kind of merge the two stories.” A hallmark of this strategy is validation of the patient’s and caregiver’s unique perspectives: “Whenever there is disagreement... I try to validate both of those perspectives” (geriatrician). Clinicians who used this approach encouraged three-way discussions, particularly in cases concerning the patient’s independence: “When there’s a question of should this person still be driving... then it’s helpful to come to collective decisions” (internist).

Overall, patients and caregivers felt supported by the collaborating approach (Table 3, A3–5). Patients expressed a strong preference to be “included... in the discussions,” with one patient commenting that validation by the clinician helped to provide “reassur[ance] about the way I was feeling.” Patients and family caregivers felt that this approach helped all parties to “come to a consensus” (patient). They cited non-judgmental listening by the clinician as a key factor in assuaging tensions within the dyad: “[The doctor] is a great listener... so [patient] doesn’t, you know, tend to escalate too much when he starts to get agitated” (spouse).



**3.4.2. Dividing.**—Some clinicians reported dividing their attention by independently meeting with either the patient or caregiver. This dividing approach is distinct for its emphasis on confidentiality and accuracy of information exchange. For some clinicians, it was routine practice to “meet with the patient and then the caregiver alone” (Table 3, B1). For others, patient-oriented division was reserved for specific circumstances as a means of maximizing patient autonomy: to elicit information directly from patients with adequate cognitive capacity and language skills (Table 3, B2) or to minimize obtrusive behaviors by family members: “If I know that this is going to... turn into a visit about the spouse rather than the patient, I will ask [caregiver] to... return in 15 [minutes]” (nurse).

Clinicians typically reserved family-oriented division for cases in which the patient had cognitive impairment (Table 3, B3): “Because [patient] has no insight it is very difficult to talk about... safety at home or is he actually taking his medication... I have to separate some of that conversation because I can’t speak frankly with the caregiver with the patient there” (geriatrician). As noted above, caregivers also played a role in prompting individual consultations, often to convey concerns about the patient’s safety and independence (Table 3, B4): “I have sort of muttered side conversations with the doctor about suggesting that just driving locally is a good idea. [Patient] will head down the hallway with the nurse... the doctor will chat with me while the nurse is chatting with my dad” (adult child).

Patients’ and caregivers’ attitudes toward the dividing approach were variable (Table 3, B4–5). Some contended that “when someone doesn’t feel included they feel out of the loop” (patient), whereas others felt that a patient-directed approach encouraged patient autonomy: “I invite [caregiver] in, but she doesn’t like it... she feels I should have privacy with the doctor” (patient). Others commented that dividing was appropriate for routine visits when the patient was generally healthy, but not in the face of an acute health concern or cognitive impairment, where the family’s input was deemed to be more relevant (Table 3, B5): “When [patient] was very ill, I did a lot of the communicating with the doctor because at one point he had heart failure... But now, he’s much better... so, I don’t have to do that” (spouse).

**3.4.3. Focusing.**—Some clinicians selectively communicated with one member of the patient-caregiver dyad. In contrast with “dividing,” this focusing strategy is used when both the patient and family member are present in the visit. Clinicians described tailoring their focus to the patient’s level of cognition (Table 3, C1), using a patient-focused approach with patients who are cognitively intact (Table 3, C2): “It’s always the patient first. If they are in the room and they seem competent enough, you know we follow the patient not the caregiver” (internist). In general, family caregivers and patients were amenable to the patient-directed strategy (Table 3, C3). As one wife remarked, “it’s not about me. It’s about my husband.”

A family-focused approach involved directing the conversation to the family member. This approach was used as a means of expediting the visit when the patient lacked cognitive capacity (Table 3, C4): “I think I’m deficient at times in maximizing patient autonomy by utilizing their caregiver to get things done. I just find it more practical” (internist). A geriatrician commented, “If you look at the record and you see totally advanced dementia then you know you are going to say ‘hi’ to the patient and ask them a couple of vague

questions, but you are going to get all of your information from whomever the caregiver is” (geriatrician).

Patients held negative views toward the family-focused approach: “I don’t appreciate that at all... It’s insulting to exclude somebody you’re talking about if they’re in the same room” (patient). Most caregivers agreed that caregiver-directed discussions undermined the patient’s autonomy during the visit (Table 3, C5). However, several family caregivers of persons with cognitive impairment reported using tacit forms of communication, including body language and facial expressions, to communicate their perspective (Table 3, C6). One caregiver explained: “[Patient] gets very agitated and angry if I correct him... I try not to do it in front of him. I make faces in the background, so [doctor] knows that what he is saying is not quite...” (spouse).

## 4. Discussion and Conclusion

### 4.1. Discussion

In this study, participants identified important challenges to family participation in older primary care patients’ visits, including difficulty: (1) navigating patient autonomy and caregivers’ motivation for involvement; (2) adjudicating patient-family disagreements; and (3) minimizing obtrusive behaviors by family caregivers. Clinicians described three main approaches to managing patient-family interactions. *Collaborating* involved three-way discussions. *Dividing* involved individual consultations with the patient or the caregiver. *Focusing* involved selective communication with one member of the patient-caregiver dyad. Clinicians’ approaches shifted from patient-oriented to caregiver-oriented with declines in patients’ cognition. In general, patients and caregivers preferred collaborating and patient-focused strategies relative to dividing approaches.

Study results build on prior literature describing the ways in which family caregivers may promote or inhibit effective interpersonal processes in routine medical visits [2, 30–34]. Quantitative studies of audio-recorded primary care consultations have demonstrated links between autonomy-enhancing behaviors by caregivers (facilitating patient-doctor understanding; clarifying health information) and positive patient outcomes, such as greater verbal participation in decision-making [31, 35]. Qualitative research has identified benefits to family participation, including ensuring accurate information exchange and preserving patient-clinician rapport, as well as challenges, including competing agendas and clinician confusion about the family’s role [7]. Our study corroborates and extends these findings by drawing on insight from in-depth interviews to better understand primary care clinicians’ approaches to managing family participation and patients’ and family caregivers’ receptivity.

This study highlights how clinician-patient-family dynamics are affected by patient cognition. On the whole, clinicians’ approaches to family engagement transitioned from patient-oriented (encompassing *collaborating* and patient-only *dividing*) to family-oriented (encompassing family-focused *directing* and *dividing*) with declines in patient cognitive function. Family members also played a role in shaping the visit dynamics. They endorsed patient-focused discussions when the patient had full capacity, but reported taking a more active stance, using tacit (facial expressions) and overt (interjections; side conversations)



forms of communication to convey their perspectives when the patient had cognitive impairment.

Our findings fit with prior conceptual work describing the roles that caregivers assume (advocate, passive participant, antagonist) [33] and research suggesting a role shift in dementia caregivers from *companion* who attends medical visits as a passive observer to *caregiver* who actively engages in the patient's health care [36]. Longitudinal research is needed to better understand how clinician-patient-family communication patterns change over time and the impact on patient and family outcomes (satisfaction with care; adherence). Such studies will be relevant to the design of practice-based interventions that can help clinicians adapt to evolving interpersonal dynamics and optimize family participation at various points in the dementia trajectory.

Concerns about patient autonomy and confidentiality, caregivers' motives, and the potential for patient-family conflict and additional time led some clinicians to discourage family participation. In contrast, the desire to maximize efficiency, ensure the fulfillment of treatment recommendations, and arrive at collective decisions led to greater family engagement. These observations reflect current debates about the ethics of balancing patient autonomy with family involvement [13, 37–39] and underscore the complexity of optimizing family participation in older adults' medical visits. Strategies to help clinicians streamline their deliberations and respond to patients' varied preferences for caregiver involvement [2, 40] warrant consideration but are not without consequences.

This study had several limitations. We are unable to draw conclusions about the prevalence of participants' attitudes or approaches to clinician-patient-family interactions, given the qualitative nature of this study. It is possible that individuals agreeing to participate in interviews about family caregiving may not be representative of the broader primary care population. Although this paper provides insight into the challenges of managing patient-family dynamics, it did not examine the positive aspects of caregiver participation, which have been described elsewhere [14, 31, 35, 41, 42].

#### 4.2. Conclusion

This study contributes to a small but growing body of literature on family involvement in older adults' medical appointments. It identifies major challenges to family participation in primary care, including the potential for diminished patient autonomy, within-family disagreements, and obtrusive behaviors by family caregivers. It also highlights patients' and caregivers' preferences for medical visits that involve collaborative rather than individual discussions. Despite excluding patients with severe cognitive impairment from this study, cognitive impairment was nevertheless found to be a salient factor in shaping clinician-patient-caregiver interactions. This observation suggests the potential utility of communication-focused programs for clinicians that are tailored to the dementia context and offer training in skills such as setting ground rules (based on patients' preferences), establishing boundaries (to reduce or eliminate obtrusive behaviors by caregivers), and understanding evolving roles (in the context of cognitive impairment)."

### 4.3. Practice Implications

Family involvement in primary care introduces unique challenges that require careful management by clinicians. Although practical guidance for supporting clinician-patient-family partnerships has been articulated at the organizational level [43], synergistic efforts to improve the capacity of primary care clinicians to engage meaningfully with patients and their families are needed.

Study results illustrate patients' varied preferences for caregiver involvement and the heterogeneity of caregivers' contributions within primary care consultations. These findings set the stage for quantitative research to evaluate practice-based strategies for clarifying and aligning patients' expectations with family caregivers' roles in the medical encounter [44, 45]. Studies of online patient portals, for example, may examine the impact of incorporating designated fields that ascertain patients' preferred mode of communication and preferences for caregiver involvement on visit outcomes (e.g. duration; caregiver behaviors; patient satisfaction). Established mechanisms for clarifying patient preferences for family participation, such as patient-caregiver agenda-setting tools [46], could also be embedded into the portal and completed in advance of the visit. To complement these structured approaches, collaborative care initiatives that combine expertise from biomedical and psychosocial disciplines should be considered, as prior literature suggests the benefits of team-based care on interpersonal communication and supporting patients' preferences [47, 48].

Finally, despite the longstanding family medicine residency training requirement in behavioral health, caregiver communication and engagement has received little attention in medical education [49, 50]. Curricula designed to support patient-family-clinician partnerships should integrate principles from psychology and psychotherapy [48, 51] that are consistent with the collaborating approach favored by study participants, including non-judgmental listening, rapport building, and collective decision-making. Embedding such concepts into geriatric training has the potential to enhance patient and caregiver satisfaction with communication and alleviate the discomfort clinicians report in addressing challenging caregiver situations [8, 52].

### Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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### Highlights

- Managing patient-family interactions can be challenging for primary care clinicians.
- Patient autonomy, family disagreements, and obtrusive behaviors are key concerns.
- Clinicians use varied approaches to manage patient-family interactions.
- Patients and caregivers prefer collaborating and patient-focused approaches.
- Patient cognition is a salient factor in shaping clinician-patient-family dynamics.



**Table 1.****Participant Characteristics**

<i>Primary Care Clinician, Staff, and Administrator Characteristics (N=30)</i>	
Female, n(%)	21 (70.0)
Race/ethnicity, n(%)	
White, non-Hispanic	13 (43.3)
African American	2 (6.7)
Asian	7 (23.3)
Hispanic	5 (16.7)
Other	3 (10.0)
Role in practice, n(%)	
Physician	16 (53.3)
Geriatrician	6 (20.0)
Internist	10 (33.3)
Nurse: NP/RN	8 (26.7)
Physician assistant, social worker	2 (6.0)
Practice administrator, medical assistant	4 (13.3)
Years practicing, M ± SD	12.8 (10.8)
Hours per week spent seeing outpatients, M ± SD	24.1 (11.9)
Self-reported % of older adults in patient panel, M ± SD	67.3 (31.1)
<i>Patient and Family Caregiver Characteristics (N=40)</i>	
Patient age, M ± SD	84.0 (9.7)
Caregiver age, M ± SD	67.0 (9.3)
Female, n(%)	32 (80.0)
Race/ethnicity, n(%)	
White, non-Hispanic	32 (80.0)
African American	3 (7.5)
Asian	0 (0.0)
Hispanic	4 (10.0)
Unknown	1 (10)
Relationship to patient, n(%)	
Patient	14 (35.0)
Spouse	11 (27.5)
Adult child	11 (27.5)
Other relative, friend	4 (10.0)
Patient health conditions, reported by the patient (if self) or caregiver, n(%)	
Cancer	7 (17.5)
Lung disease	4 (10.0)
Heart attack	12 (30.0)
Musculoskeletal pain	9 (22.5)
Dementia	11 (27.5)

**Table 2.****Challenges to Family Caregiver Participation in Primary Care**

<b>Patient Autonomy and Caregiver Motivation</b>	
<b>A.</b>	"I have patients who, although they need the help, would not want a family member involved... I've gotten a few times a little bit of a negative feedback coming from the patient saying 'I am the patient, I'm the one who makes the decisions. [Caregiver] is just here with me to keep me company or to help me get here.'" (geriatrician)
<b>B.</b>	"The worst case is when a caregiver calls ahead of time and says the patient... is doing this or that and they are concerned about it, and then how to bring that up in a visit if [the patient is] not with the caretaker at that time... Sometimes the caretaker will want to speak with me outside the room which is always problematic too... They don't want me to bring it up that they told me this information like it's some kind of secret... You have to kind of tread lightly." (nurse)
<b>C.</b>	"I think, in our training and in our experiences, we become ironically, a little bit uncomfortable in the outpatient setting not having all of these [family members] be there... I'm not sure why. You can't always assume a caregiver is... 100 percent there for the right reasons." (nurse)
<b>D.</b>	"The [patient's] daughters had actually led the prior physician to believe that there was cognitive impairment with paranoia... cases where it is actually elder abuse or financial mistreatment, we should have our antennas up." (internist)
<b>Patient-Caregiver Disagreements</b>	
<i>Clinician Perspectives</i>	
<b>E.</b>	"[Patient and caregiver] will have very different views; it's really very hard to adjudicate." (internist)
<b>F.</b>	"It's usually something that the patient is going to... disagree with, like memory loss or they're not drinking enough fluid or they're not taking their medicines. It's usually when it's something they don't want to do... The caregiver will say something like, 'My mom's not really taking her meds the way she should be,' and then the patient will say 'No, I disagree with that.'" (geriatrician)
<b>G.</b>	"You see tension between the patient and the caregiver or you know the patient wants to be much more independent." (geriatrician)
<b>H.</b>	"In terms of other geriatric syndromes or other aspects of how independent patients are... Patients and caregivers will disagree [about] how often they fall or how much they need help with their mobility and how much they are able to be independent." (geriatrician)
<i>Patient and Caregiver Perspectives</i>	
<b>I.</b>	"I contradict [caregiver] because I think she is a little severe with me. She will make a comment about something I find is slightly exaggerated... I would say I have no condition and she said to me 'No, you had that years ago. You complained of the same problem.' ...For example, I am complaining about fatigue and she said to me, 'You always have been' and I don't quite agree with that... I don't feel that's very true." (patient)
<b>J.</b>	"[Patient] would fall a lot, so I would have to prepare his food and carry it out to him on a tray and that sort of thing... He sees [his condition] in a different way than I do and I was also being very over-protective." (spouse)
<b>K.</b>	"[Patient] will disagree with me about how her memory works... because obviously she doesn't feel like she forgets that much." (adult child)
<b>Obtrusive Behaviors by Caregivers</b>	
<b>L.</b>	"Oftentimes the visit with the geriatric patient will then turn into a counseling session for the caregiver... They start talking about like, you know, how she's getting, as an example, 'Mom's getting up in the middle of the night. She is more confused. I haven't slept in God knows how long. I've missed work. I can't do this anymore.'" (nurse)
<b>M.</b>	"Sometimes the caregiver actually interrupts when he or she hears the patient saying things that they feel is not correct." (internist)
<b>N.</b>	"There are a couple [caregivers] who are just, I would say in a sense are disrespectful to the person (patient) and it's very upsetting because it's like you can't do anything about it." (nurse)
<b>O.</b>	"I will ask questions, not to be annoying, but just to clarify things for me, or maybe talk about another option that they hadn't brought up... [Medical professionals] may not like it. Some of them probably don't want the extra questions, but I think the patient is entitled to that." (adult child)

**Table 3.**

**Approaches to Optimizing Interactions with Patient-Caregiver Dyads**

Approach	Clinician Perspectives	Patient and Caregiver Attitudes and Responses
Collaborating	<p>A1. "I will try and... make it as much of a three-way conversation as possible. I will explicitly say 'Since we have the benefit of having so-and-so here I'm going to ask' because the family often has a different perspective." (geriatrician)</p> <p>A2. "[Something that can help is just trying to calm the situation down and explaining [that] I'm trying to get as much information as I can from both people... It's not a judgement, it's just information." (geriatrician)</p>	<p>A3. "[The doctor helped facilitate] open discussion and [was] responsive to my personal need and respectful... We talked about [my speech impairment] in real depth... the doctor and my wife put in their points of view and it was really collegial." (patient)</p> <p>A4. "She's a very responsive doctor. We feel very comfortable with her... Whatever I think is important she is willing to hear, and she checks with my mother as well." (adult child)</p>
Dividing	<p>B1. "My practice style is one in that I always talk to [and] examine, individuals, adults by themselves... I will invite [caregivers] back after the visit to express any concerns and you know, I'll explain anything to [caregiver] that [they] want to know. It's the right of the patient saying that it's okay." (internist)</p> <p>B2. "I've discouraged caregivers from coming in... when the patient themselves can give me the story, they have full cognition, they speak English, there's nothing that is impeding our communication." (nurse)</p> <p>B3. "If it's someone with cognitive impairment they're not going to be terribly accurate about a lot of things, like what happened at the doctor's visit or what the meds are. Depending on how impaired they are, my time alone with them will be fairly short" (nurse).</p>	<p>B4. "I find it problematic and just kind of weird... [Doctor] doesn't ever want anybody who is with the patient to go back into the exam room with them... I think that's a situation that shouldn't happen if the patient is comfortable with somebody else being with them." (adult child)</p> <p>B5. "I just like for my mom to have more you know, independent appointment. Most of the time I just sit in the waiting room and let her talk to the doctors. Now that has changed a little bit since she had her stent put in and the aortic valve replacement because I want to make sure I go in and talk to them." (adult child)</p> <p>B6. "I couldn't... ask honestly if [the doctors] thought [the treatment] was going to really work, because [patient] was there... I'd have to run back or if [patient] was going to the bathroom I'd ask that question by myself, because I wouldn't want my husband to hear that." (spouse caregiver)</p>
Focusing	<p>C1. "Sometimes you have family members that pick up the ownership of the care, of especially people who are more frail or who are demented... so you talk with them. Sometimes it's on the opposite spectrum where the caregiver comes in but the patient is still very functional and cognitively intact... I try to focus on the patient... I think you tailor, or at least I tailor kind of the interaction." (geriatrician)</p> <p>C2. Patient-focused: "[Sometimes] the patient gets pushed out of the way... [I] try to get the caregiver to stop talking for a minute and put the patient first and just say 'I'd really like to just talk to Mr. So and So for a minute. Can you tell me more about what's been going on?' And then, have some sort of redirecting phrase." (geriatrician)</p> <p>C3. Family-focused: "If a patient is cognitively impaired and... they are not giving coherent responses. I'll look to the caregiver much more than I would if the patient is able to be an accurate historian." (internist)</p>	<p>C4. Patient-focused: "I want the focus to be on [patient's] medicine and what she has to do. I feel like the doctor's job is to give her the information that she needs, and my job is to make sure that she follows through with it." (adult child)</p> <p>C5. Family-focused: "[Patient] would cancel the appointment if they began talking to me as opposed talking to him... He would say, 'Hey, I'm the patient here. You, doctor, are wasting my time.'" (spouse)</p> <p>C6. Family-focused: "I usually disagree and at that point [patient] usually disagrees with me and he will say something like... 'I'm doing okay'... Typically, [the doctor] gives me a knowing look and we don't talk about it any further than that." (spouse)</p>