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“We need to bring them out from the shadows:” A qualitative study of safety net physician leaders’ perspectives on caregivers

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Abstract

Objective: To explore physician leaders’ perspectives on processes and priorities for engaging with caregivers in their clinical practices as well as within their safety net health systems.

Methods: We conducted in-depth semi-structured interviews with primary care physicians in care management leadership at three California safety net health systems. Interviews explored physicians’ experiences managing medically and socially complex patients with caregivers. Using thematic analysis, two qualitative researchers independently analyzed interview transcripts and established consensus with the broader research team through iterative input to derive major themes.

Results: Fifteen physicians completed interviews. Nine participants were women, 8 were White and 10 reported Spanish language proficiency. Participant interviews generated six major themes: challenges uncovering caregiver identities, recognizing variation in caregivers’ roles, adapting visit

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CRedit authorship contribution statement

Study concept and design: Semere, Lyles; Acquisition of subjects and/or data: Semere, Cembali, Casillas, Lyles; Analysis and interpretation of data: Semere, Cembali, Schillinger, Casillas, Lemberg, Lyles; and Preparation of manuscript: Semere, Cembali, Schillinger, Casillas, Lemberg, Lyles; No other individuals contributed substantially to this research or to the preparation of this manuscript.

Declaration of Competing Interest

The authors have no declaration of competing interests at present or within the 5 years before the submission date of this article. This includes having no interests that present potential influences that may undermine the objectivity, integrity, or perceived conflict of interest of this publication.

Prior presentations

Early findings from this work were presented as a poster at the 2019 Society of General Internal Medicine national meeting in Washington, DC.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.pec.2021.10.019.

communication strategies to include caregivers, engaging caregivers in patient care, and caring for the caregiver.

Conclusions: Engaging caregivers is challenging given the limited recognition of caregiver involvement in patient care by health systems. Adapting visit communication to include caregivers requires bridging language and literacy barriers.

Practice implications: Developing mechanisms to enable the consistent identification of patients' caregivers, facilitate ongoing communication with caregivers, and extend support for them could improve outcomes for vulnerable patients and their families.

1. Introduction

Caregivers serve an essential role by helping those who need assistance due to disability and significant chronic illness remain in community settings. Formal caregivers, including home health nurses and aides, who have received training and are paid for their services, are often most visible to physicians.¹ However, informal caregiving—typically unpaid support provided by family or friends—represents an increasing and less visible source of patient assistance [1]. The need for both formal and informal caregivers is expected to increase significantly over the next few decades, as the aging of the population proceeds and the prevalence of multiple chronic conditions increases. By 2030, nearly 20% of adults living in the U.S. will be over the age of 65, with trends suggesting that more than half will require caregiving at some point [2,3].

Caregivers take on a spectrum of roles that can significantly influence the health and well-being of their care recipients, including assisting with functional limitations, managing medications, providing emotional support and communicating with providers [3,4]. These support roles can be particularly beneficial in safety net health systems, which predominantly serve minorities and patients from lower socioeconomic backgrounds. Such populations frequently have multiple chronic medical conditions, as well as increased risk of early onset disability coupled with social vulnerabilities that lead to complex care needs [5-7]. Caregiving is common among racially/ethnically diverse and low-income groups, with many caregivers facing medical and social complexity. For example, one in five Latinos reports providing unpaid care for an adult with health issues or a disability; 45% of Latino caregivers experience burden related to caregiving, compared to 33% of non-Latino White caregivers [8,9]. Latino and Black caregivers are more likely than White caregivers to report lower household income that creates particular challenges for maintaining their caregiving roles [4].

Previous studies, in non-safety net systems, suggest that family caregivers report some positive communication experiences when discussing patients' health and treatment with health care providers, but are infrequently asked about their need for help in managing patient care [10]. Less is known about physicians' experiences communicating with caregivers. Limited qualitative work suggests that physicians acknowledge that engaging caregivers is important to patient care [11-13]. A recent national survey conducted by the American Association of Retired Persons (AARP), found that primary care physicians overwhelmingly agreed that family caregivers have an essential role in their patients'

health. However, physicians described challenges communicating with caregivers, including difficulty identifying or reaching caregivers, that are further complicated by competing clinical and administrative demands such as short appointment times and burdensome chart documentation [11]. In safety net health systems, challenges engaging caregivers are likely amplified compared to non-safety health settings, due to patients' and caregivers' limited access to care, competing demands, and the prevalence of communication barriers, including limited English proficiency and low health literacy [5,14]. Prior research has not explored safety net physicians' unique experiences navigating these challenges. Such work could shed light on the importance of caregivers to patients burdened by both medical and social needs, and the ability of providers to identify and effectively engage caregivers in patient care.

Better understanding safety net primary care physicians' perspectives on caregivers is a critical component to engaging caregivers in family-centered care so as to influence outcomes for the most vulnerable patients and their caregivers. In this study, we conducted in-depth, one-on-one interviews with safety net primary care physicians, who had health system leadership roles in care delivery and management. Our objective was to explore physician leaders' perspectives on processes and priorities for engaging with caregivers in their clinical practices as well as within their safety net health systems.

2. Materials and methods

2.1. Study design and setting

This qualitative study was conducted within three large, public safety net health systems in California that care for publicly-insured and uninsured patients: The San Francisco Health Network, Los Angeles County Department of Health Services, and Alameda Health System in Oakland. The San Francisco Health Network includes 14 primary care centers providing services to approximately 60,000 diverse (39% Latino) low-income (over half receive Medical) patients across San Francisco. The Los Angeles County Department of Health Services operates an extensive healthcare network throughout Los Angeles that includes 2 ambulatory care centers and 16 local health clinics serving approximately 800,000 racially/ethnically diverse patients. Alameda Health System is an integrated public health care system that includes 4 primary care medical clinics providing over 300,000 outpatient visits annually, and serves a racially/ethnically diverse group of patients, 39% of whom are African American. All study activities were approved by the University of California, San Francisco and University of California, Los Angeles Institutional Review Boards.

2.2. Recruitment process

Our study team was comprised of health services researchers (WS, AC, CL), practicing safety net primary care physicians (WS, AC), and trained qualitative research assistants (AGC, ML). Together, we identified and recruited primary care physicians practicing within the three targeted safety net health systems. Primary care physicians in health system leadership positions with roles involving care transitions and care management were recruited from April to November 2018, through direct outreach by the study team. Physicians were invited to participate via an email briefly describing the study. Each

participant was offered a \$25 gift card upon completing their interview. Informed consent was waived by the approving study board.

2.3. Interview approach

One to two members of the study team led individual, semi-structured interviews with each participant either in-person at their healthcare setting or remotely using a web-based conferencing tool (Zoom Video Communications; San Jose, CA). Interviews were audio recorded. We developed and iteratively updated an interview guide informed by practical clinical experiences in safety net health settings to help direct conversations (see Supplement). After describing their clinical and administrative roles, participants were asked about their perspectives on engaging with caregivers within the safety net health system. Discussions topics included identifying caregivers in health settings, experiences interacting with caregivers, and communicating with caregivers during medical visits.

2.4. Data analysis

All interviews were transcribed, reviewed for accuracy, and physician information was de-identified prior to analysis. Patient-level protected health information was not included in the interviews. We applied a thematic method to identify, analyze, organize, and describe themes. The thematic method was chosen for flexibility in examining the perspectives of research participants, highlighting similarities and differences, and generating novel insights [15,16]. Using an inductive approach, we analyzed transcripts, moving from specific observations to broader generalizations [17]. WS and AGC independently read and analyzed 6 of the interview transcripts in their entirety. Over multiple meetings, WS and AGC together reviewed their independently identified categories, themes, and illustrative quotes to reach consensus for the codebook. Then WS, AGC, and ML read and analyzed additional transcripts using the codebook which contained thematic definitions and example quotes. Applying a constant comparison open coding approach, the entire research team met regularly to discuss findings and establish consensus regarding the final themes. We reviewed major themes to consider the practice implications and provide recommendations based on these findings.

The study team discontinued participant enrollment once at least three physicians were recruited from each study site and thematic saturation had been reached. We performed all coding using Dedoose, a secure collaborative web-based platform that allows for qualitative data excerpting, coding, and analysis [18]. We referenced the Standards for Reporting Qualitative Research (SRQR) guidelines to improve transparency and clarity in reporting our study findings [19].

3. Results

3.1. Physician characteristics (Table 1)

In total, 15 primary care physicians were approached for study participation and all accepted the invitation to participate. The participants included 3 geriatricians, 2 family medicine physicians, and 10 internal medicine physicians. Nine participants were women, 8 were White and two-thirds (n = 10) of participants reported Spanish language proficiency. The

median number of years in clinical practice was 11 (IQR 10–22). Eleven physicians were directors of medical services or operations for their health system; in these roles, they oversaw and lead the delivery of a spectrum of primary care services. Three physicians had leadership roles within their health system directly related to management of care transitions and patients with complex care needs. Another physician was a health services researcher with a focus on older adults and care delivery (Table 1).

3.2. Major themes with subtheme descriptions (Table 2)

3.2.1. Challenges uncovering caregiver identities—Physicians described a number of *challenges uncovering caregiver identities*. In the first subtheme of this topic, several physicians discussed leveraging the medical visit as an opportunity to meet caregivers (when present) and to learn about their relationship to the patient. Some physicians routinely asked patients about caregiver involvement as a part of history taking: “Who helps you?” or “What kind of support do you have at home?” These lines of inquiry were a gateway to discovering whether or not patients had caregivers and, if so, learning more about their involvement (Table 2).

However, physicians also made multiple statements about the challenges related to *caregivers not showing up*, as a second subtheme. One participant noted, “There are some people who never come with anybody and then I find out they *do* have a caregiver or a family member...so, if I asked from the beginning more specifically then I would have known that.” Another participant felt that caregivers who do not attend visits are often unknown to physicians “unless something is clinically happening with the patient where [physicians] have to identify a caregiver.”

Physicians acknowledged, in another subtheme, the *limitations of the electronic health record (EHR)* in documenting relevant information about the caregiver. At times, physicians might document caregiving information in the social history section or as free text, but they noted these sections of the chart were less frequently accessed by other providers, limiting the value of such documentation. Physicians commented that there was a lack of standardization and inconsistency in documentation about caregivers. Just as identifying caregivers was more common when patients were most ill or in need of caregiving, so too was documentation in the EHR. These included clinical scenarios where patients “...don’t have capacity or have dementia or have things where the role of the caregiver becomes more important.”

3.2.2. Recognizing variation in caregivers’ roles—In considering caregiver involvement on behalf of patients, physicians *recognized variation in caregivers’ roles*, and developed frameworks to understand this variation. In one subtheme, physicians distinguished between the roles of *caregivers inside* vs. *outside of the home*. In-home caregiving responsibilities included helping patients with Activities of Daily Living (ADLs), such as household chores, bathing, transfers, or grooming. Out-of-home caregiving responsibilities included helping patients “negotiate outside of the home,” with Instrumental Activities of Daily Living (IADLs), including shopping or getting to appointments. Physicians also used the in-home vs. out-of-home terminology to describe the caregivers

themselves: a caregiver could be someone in the home, typically a family member, or someone coming from outside of the home coming into the home to help, such as a paid health aide.

In another subtheme, physicians described *informal vs. formal caregivers*. Formal caregivers were paid, trained workers, whereas informal caregivers were unpaid, untrained family members. The distinction between informal vs. formal caregivers had implications for physicians' understanding of caregiver roles on behalf of the patient. As one physician described, "I think if it's an official caregiver, like either In-Home Support Services or a case manager through the county or a licensed clinical social worker, their roles are much more clearly defined as to what they can and cannot do." This physician elaborated with an example that home health aides frequently have particular roles including helping patients with medication management or accompanying patients to medical visits, and that these responsibilities occur within a specified time frame. In contrast, she noted that with informal family caregivers, "I think the lines are a lot less clear, so the family will do anything on this whole spectrum" with respect to caregiving responsibilities, including providing 24-hr care across a number of domains. Physicians acknowledged caregivers frequently assist with ADLs and IADLs, but also described caregiver roles beyond these definitions. A caregiver was part of the "patient's team" or "a person who's involved with helping support another person," including emotionally and socially.

3.2.3. Adapting visit communication strategies to include caregivers—

Physicians described *adapting visit communication strategies to include caregivers*. In one subtheme, many physicians noted that *prioritizing patient autonomy* was important during visits and they strove to maintain primary communication with the patient. One participant noted, "I always try to engage the patient primarily because it's the patient's health that I'm responsible for, but I will also try to engage the caregiver in a sort of secondary way...at the end of the visit when we do the wrap-up." Because the caregiver can be a source of additional information, when possible, physicians attempted to reserve additional visit time for patients with caregivers. However, they often felt this was not a feasible option in the context of a busy clinical environment.

In another subtheme, physicians described that *navigating barriers in language and health literacy*, commonly encountered in the safety net, further complicated communication with caregivers. Lack of English proficiency could limit both patient's and caregiver's communication with physicians. Physicians felt that some caregivers could facilitate more effective communication on behalf of patients, but also described the pitfalls of incorrectly assuming caregivers have proficient language skills or adequate health literacy. One participant noted, "We treat [caregivers] less like a patient, when a lot of them are very similar to our patients in health literacy issues or language." Participants cautioned that caregivers can become over-whelmed when physicians burden them with information without considering potential communications barriers. Additionally, caregivers may not appreciate the value they could bring to the clinical encounter. As one physician described, "I think it's possible that lower health literacy [caregivers] don't recognize the value of the information that they have about the patient and its importance in helping keep track of the patient's health."

3.2.4. Engaging caregivers in patient care—For the most part, *engaging caregivers in patient care* was easiest in the context of the medical visit. Between-visit communication primarily occurred through telephone calls to caregivers and occasionally through secure message exchanges using the online patient portal. Still, many physicians felt the time constraints of busy clinical practice made it challenging to communicate with caregivers who did not accompany patients to appointments. As one physician noted, “I try, but I don’t always, send communication to them about the visit. That’s probably happened just less than half the time because I’m so busy.” As with *adapting visit communication strategies to include caregivers*, several physicians raised the issue of patient autonomy and pointed out that it was important to verify with patients their degree of comfort with their physician sharing health information with caregivers. In some instances, physicians routinely asked caregivers to leave the room for portions of the patient visit. However, caregiver absence at visits was described as challenging, particularly when patients had cognitive impairments or poor understanding of their care plan that would benefit from caregiver involvement.

Physicians felt that caregivers could benefit from education related to their caregiving duties. One participant commented, “[Caregiving] is not framed as a job and it’s framed as a role sometimes. But it’s really a job. It is something that requires skill and something that requires support like any other type of job.” However, as one physician noted, caregiving training and educational resources are difficult to access in the safety net system: “I don’t think caregivers necessarily are provided educational information on how to care for an older adult...there’s several well-published evidence-based caregiving teaching programs, but a lot of my patients don’t have access to that.” Participants cited a number of important resources that could support caregivers, including caregiver education and strategies for supporting patient care (“medication lists, toolboxes, appointment management, and communication with the doctor”)

3.2.5. Caring for the caregiver—Physicians described finding ways of *caring for the caregiver*. They viewed patient and caregiver health as related, such that the better a caregiver was doing, the more able he or she would be to effectively care for the patient. As one physician explained, “If we care for our patients’ caregivers, that’s an indirect way of taking care of our patients.” Another physician commented, “We know that the more empowered a caregiver is, the better the person gets, so it *is* a part of patient care.” Physicians recognized that caregivers in safety net health systems face particularly difficult obstacles given the life stressors of the patient population they care for. They frequently cited the need for behavioral health support and access to respite care to address caregiver fatigue and burnout. While some physicians routinely asked caregivers about their own well-being or support needs, others described inquiring only when they noticed that a caregiver seemed particularly stressed. Barriers to *caring for the caregiver* included time and resources. One participant stated, “The thing is it definitely requires more handholding than we can do.” Physicians also noted that they are not directly responsible for the caregiver’s care: “We don’t directly address [caregivers], and there are barriers, like we’re not supposed to really treat [caregivers].”

Many physicians shared how being a caregiver themselves, often for aging relatives, provided them with insight into the challenges of caregiving and the potential burden that

caregivers face. This understanding at times changed physicians' approaches with caregivers in significant ways. One physician recalled "I'll never forget when the providers told me, looked me straight in the face, 'Well, you know [your father] should have 24-hour supervision.' And I thought to myself, I wonder how many times I've told families that." As a caregiver, this physician could see how complex such a decision was when factoring in his father's desire for independence. The physician went on to describe how this caregiving experience made him appreciate the need to balance his patient care agenda with the need to consider the patient's and family's priorities.

4. Discussion and conclusion

4.1. Discussion

Physicians recognized the importance of caregiver involvement on behalf of patients, but experienced challenges consistently identifying caregivers and limitations engaging them in patient care. Physicians also described the need to balance patient autonomy with drawing valuable information from caregivers. Caregiver well-being was viewed as intimately related to patient well-being.

Studies suggest that nearly 4 in 10 older adults regularly attend physician visits with an unpaid companion, such as a spouse or adult child [20,21]. Rates of visit attendance by caregivers in safety net systems are not well described. However, given the overall high rates of older adults' companionship at visits, it is not surprising that physicians in our study reported that they often relied upon identifying their patients' caregivers during medical encounters. In doing so, they acknowledged that involved caregivers who do not attend medical visits are harder to track. Limited and inconsistent electronic medical record documentation, further complicated physicians' ability to identify caregivers and capture caregiving relevant information. The Caregiver Advise, Record, Enable (CARE) Act, so far implemented across 40 states, requires hospitals notify identified caregivers when patients are discharged or transferred to another facility and offer caregivers discharge planning consultation [22-25]. There is, however, strong recognition that the CARE Act does not adequately address multicultural family caregiving needs nor provide enough consideration for non-English speakers [26,27]. The CARE Act does not include standardization for documenting detailed caregiver information in the medical record and capturing this data outside of hospitalization. By standardizing the capture of caregiving information in the medical record, physicians can begin to consistently document and share with other involved providers on the patient team key caregiver information (name, contact information, relationship to the patient, and caregiving roles) that can support longitudinal patient care.

Even when physicians are aware of patients' caregivers, they experience challenges effectively engaging caregivers in patient care. This was true for the physicians we interviewed, who had leadership experience in areas including complex care management and might be well-positioned to navigate these challenges. Complex care management is designed to assist medically complex patients and their caregivers in managing patients' medical and psychosocial conditions. Triadic encounters involving patients, caregivers, and physicians can introduce complexities that require skilled navigation. These challenges have been explored in the context of cancer care where family caregiver involvement,

although beneficial, can bring about difficult dynamics that may reduce patient autonomy and compromise effective clinical care [28-31]. While evidence-based guidelines have been developed to guide family caregiver inclusive communication in cancer care, similar guidelines do not exist for primary care or working with racial/ethnic diverse populations such as those encountered in safety net settings [32]. Participants described challenges unique to the safety net setting that including communicating with patients and family caregivers with language and literacy barriers. Developing strategies to compensate providers for the additional time required to communicate with caregivers either through longer visit times or reimbursements for between-visit encounters may help to address physician barriers to engaging caregivers.

Physicians noted caregiving could be burdensome, especially true in safety net settings where racially/ethnically diverse patients and caregivers face a number of life stressors. Prior caregiver surveys confirm this view, finding that Black and Latino caregivers when compared to White caregivers are more often in high intensity caregiving situations based on providing a greater number of hours of care as well as more support with ADLs and IADLs; not surprisingly, this translates to higher rates of burden [4]. While physicians acknowledged the stress that caregivers face, they did not routinely screen for caregiver burden or provide support for caregiver needs. Prior studies have found that physicians overwhelmingly recognize that caregivers would benefit from support and that primary care is an ideal context for reaching caregivers, but find that mechanisms to provide such support remain elusive [13]. Physicians may experience barriers to supporting caregivers that include lack of time, lack of compensation, and lack of training [33-36]. Ethical reviews of physician-caregiver engagement have emphasized patient-focused care but state that physicians have an ethical responsibility to caregivers [37]. Mitigating barriers to physicians' engagement with caregivers may prove beneficial for supporting improved caregiver and patient outcomes.

Our study has important limitations. We had a relatively small sample of 15 physicians. However, we reached thematic saturation and our study focus was narrow lending itself to a small sample [38]. Additionally, our participants were physician leaders with key experience and insights in care management in safety net health systems. Given the lack of qualitative work exploring physician experiences with caregivers, particularly in the safety net setting, our findings are an important contribution. We focused our study in California, which may limit the generalizability of our findings. We did, however, include three safety net health systems to consider variation across clinic settings. We recognize the benefit of including patient and caregiver input, but focused on physician perspectives given the paucity of literature in this area. In future work, it may be beneficial to simultaneously explore physician, patient, and caregiver perspectives on their triadic communication.

4.2. Conclusion

To our knowledge, this is the first study to qualitatively explore primary care physician leaders' perspectives on engaging caregivers in safety net settings. This is a critical topic given the overall prevalence of caregiving in our society, yet a lack of evidence for practical workflows in clinical practice to effectively engage caregivers in patient care. We need

explicit attention to supporting caregivers in safety net health systems, where both patients and caregivers face medical and social complexities that contribute to challenges in care. Our findings highlight the opportunity for better policies to document caregiver involvement and strategies to support caregivers in order to promote improved outcomes for patients and their families.

4.3. Practice implications

The emerging themes informed our development of practice implications and recommendations that are relevant to healthcare systems in general and specifically safety net settings (Box 1). For the themes, *challenges uncovering caregiver identities* and *recognizing variation in caregivers' roles*, we note that physicians inconsistently document caregiver involvement in the medical record and have differing approaches to describing caregiver roles. We recommend specific coding within the medical chart that includes caregiver identifiers, documentation of presence at medical visits, and perceived roles on behalf of the patient. The themes *adapting visit communication strategies to include caregivers* and *engaging caregivers in patient care*, suggest the challenges of time constraints and communication barriers physicians experience in the safety net system when trying to involve caregivers in patient care. We recommend health system support and compensation for providers' longer visit times with complex patients and telehealth encounters with caregivers when discussing patient matters. For *caring for the caregiver*, physicians appear to recognize the importance of considering caregiver well-being, and we recommend targeting resources to enhance their ability to elicit and support caregiver needs.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Box 1

Practice implications and policy recommendations.

Major theme	Practice implications	Policy recommendations
<i>Challenges uncovering caregiver identities</i>	<ul style="list-style-type: none"> Physicians can be unaware of patients' involved caregivers. Caregiver involvement on behalf of patients is frequently absent from or inconsistently documented in the health record. 	<ul style="list-style-type: none"> Train physicians to consistently inquire, in history taking, about patients' involved caregivers. Create coding for physician documentation, within the patient medical record, reporting caregiver involvement and details of caregiving.
<i>Recognizing variation in caregivers' roles</i>	<ul style="list-style-type: none"> Physicians use varying terms and categories to describe caregiver roles. 	<ul style="list-style-type: none"> Emphasize clear physician language that describes caregiver's relationship to the patient and roles on behalf of the patient.
<i>Adapting visit communication strategies to include caregivers</i>	<ul style="list-style-type: none"> Effectively communicating with caregivers during medical visits is time consuming. Navigating caregiver language and literacy barriers is challenging. 	<ul style="list-style-type: none"> Implement longer medical visits for patients with caregivers, especially when these patients and/or caregivers have communication barriers.
<i>Engaging caregivers in patient care</i>	<ul style="list-style-type: none"> Physicians spend significant time engaging in between-visit communication with caregivers. 	<ul style="list-style-type: none"> Develop reimbursement metrics for physicians' between-visit telehealth encounters with caregivers.
<i>Caring for the Caregiver</i>	<ul style="list-style-type: none"> Physicians recognize that caregiver well-being is important but do not feel well-equipped to support caregiver needs in the safety net setting. 	<ul style="list-style-type: none"> Develop targeted strategies and resources (respite referrals, access to social and behavioral assistants, caregiver educational material) to assist physicians and the broader healthcare team when responding to caregivers' needs.

Table 1

Physician characteristics (n = 15).

Characteristics	n (%)
Women	9 (60.0)
Race ^a	8 (61.5)
White	2 (15.3)
Chinese	2 (13.3)
Indian	1 (6.7)
Iranian	
Ethnicity ^a	2 (15.3)
Latino, Chicano	
Foreign language proficiency ^a	
Spanish	10 (76.9)
Mandarin, Cantonese	2 (15.4)
Hindi, Gujarati	1 (7.7)
Farsi	1 (7.7)
Post-graduate years in clinical practice, median [IQR]	11 [10–22]
Clinical specialty	3 (20.0)
Geriatrics	
Internal Medicine	10 (66.7)
Family Medicine	2 (13.3)
Health system role	
Director, Medical Services or Health System Operations	11 (53.3)
Lead, Complex Care or Care Transitions	3 (20.0)
Health services research	1 (7.7)

All percents calculated for non-missing values.

^a n = 13; two participants chose not to answer.

Table 2

Themes and subthemes with illustrative quotations.

Themes and subthemes	Illustrative quotations
<i>Challenges uncovering caregiver identities</i>	
When caregivers don't show up	<ul style="list-style-type: none"> 'We don't routinely engage with [caregivers], so sort of if they show up, we know about it and if they don't—or unless something is clinically happening with the patient where we have to identify a caregiver—I don't think we do a great job of knowing who's out there.' 'I have a handful of people who never come with anybody else. But then there are some people who never come with anybody and then I find out they do have a caregiver or a family member...so, if I asked from the beginning more specifically then I would have known that.'
Limitations of the electronic health record (EHR)	<ul style="list-style-type: none"> 'for patients who don't have capacity, or have dementia, or have things where the role of the caregiver becomes more important, it's usually charted ...but I think there's a lot of people whose medical issues haven't gotten that serious who do have those people and then it's very inconsistently charted.' 'I don't think we have a formal box for a caregiver in our EHR [electronic health record], but we should. So, I write it in the section about social history...it's actually really buried in the EHR so it's kind of bad for us to do it, but that's been my practice.' 'if the patient has a caregiver I'll try to make it clear in my notes so that I can refer back to it later, or that other people can refer back to it but I wouldn't say we sort of have it in a uniform way across providers that are documenting that.'
<i>Recognizing variation in caregivers' roles</i>	
Caregivers inside and outside of the home	<ul style="list-style-type: none"> 'So there's one category of caregiver that I think is much more home-oriented and then I think of sort of with the folks that I work with caregivers of being also a broader group of people who help clients negotiate outside of their home...make it to the bank appointments.'
Informal vs. formal caregivers	<ul style="list-style-type: none"> 'I typically, in primary care, I use the term "caregiver" to talk about people, either in the home, or who are coming from outside of the home into the home to take care of a patient. So, whether that's a family member or like an in-home supportive services person from the outside. Somebody going in and providing assistance to a patient.' 'I think, obviously, they're paid professional caregivers, but the majority of caregivers are doing it for friends and family, I don't know, informally. And most don't think of themselves as caregivers.' 'I think some of it just depends on who [the caregiver] is. Like the family, I think the lines are a lot less clear so the family will do anything on this whole spectrum. I think if it's an official caregiver, like either In-Home Support Services or a case manager through the county or a licensed clinical social worker, their roles are much more clearly defined as to what they can and cannot do.'
	<ul style="list-style-type: none"> 'I've probably seen every spectrum of caregiving. There's your classic formal caregiver, which would be somebody that would be paid formally and you have a contract with the patient to help take care of the patient and do a lot of the hands-on Activities of Daily Living or Independent Activities of Daily Living care for the patient but in my definition of caregiver, I include conservators that are helping manage the patient's assets, family – family in town, family from far away, informal caregivers like next-door neighbors that oftentimes can either accompany the patient or help assist the patient when they're transitioning between places. So, I think the definition of caregiver is pretty expansive.'

Adapting visit communication strategies to include caregivers

- 'I always try to engage the patient primarily because it's the patient's health that I'm responsible for but I will also try to engage the caregiver in a sort of secondary way...at the end of the visit when we do the wrap-up, I may ask the caregiver, "Oh do you have anything else to add?'"

Illustrative quotations

Themes and subthemes

	<ul style="list-style-type: none"> • 'I try to always talk to the older person directly...I try to intervene indirectly and talk to the caregiver. If I'm going to only talk to the caregiver during an encounter where the patient is still there, I ask permission.' • 'I'll get corroboration from the caregiver and most of the time, it's an organic conversation and they're both kind of answering or depending on the patient's preference, sometimes, and I see this a lot. I think it does depend on cultural factors, but sometimes the patient does prefer for their caregiver, who might be their eldest son or daughter, whomever, to answer the question so I respect that but I always try to have the patient's choice be primary.'
<p>Navigating barriers in language and health literacy</p>	<ul style="list-style-type: none"> • 'it's no different than talking to a patient and I try to keep things in short phrases and simple languages and also use analogies and try to think of something that they're already familiar with and then kind of make parallels and analogies, try not to use medical jargons and big, huge words' • 'What [physicians] do is we'll sort of end the visit by turning to [caregivers] and just rolling a ton of information at them, a ton of stuff to do, assuming that's completely okay on their ends that they have no trouble following through with all that stuff and they understand everything you're saying. So we treat them less like a patient when a lot of them are very similar to our patients in health literacy issues or language.'
<p><i>Engaging Caregivers in Patient Care</i></p>	<ul style="list-style-type: none"> • 'If I'm really worried about something or making big changes, I will try to call whoever their caregiver is and say, "Hey, here's what we talked about today. This appointment's really important. Please make sure they make it." And I think one of the biggest values for any type of caregiver is that they are having more regular contact with the patient outside of the institution' • 'I try and keep the caregiver involved with everything so if they're not in the appointment, then I try but I don't always, send communication to them about the visit...I also do a lot of communication through the portal. I try and get as many of the caregivers signed up on the portal if they can.' • 'I really encourage the caregivers to come to every appointment, just so that we can all be on the same page and talk about the same things. And then that's generally what happens. If the caregiver can't be at the appointment, I will often call the caregiver to let them know what the plan is.'
<p><i>Caring for the caregiver</i></p>	<ul style="list-style-type: none"> • 'I feel like it tends to be more stressful in the safety net...there are more life stressors in this patient population, which makes caregivers more susceptible to stress....So in a way, if we care for our patients' caregivers, that's an indirect way of taking care of our patients.' • 'people ignore [caregivers] and they don't pay enough attention to what they need or want and we need to bring them out from the shadow of the clinic we're in and know the visible place in our visit that they're in. We know that the more empowered a caregiver is, the better the person gets so it is a part of patient care.' • 'sometimes you just – you hear frustration in voices...so you check-in. And I think the people that you don't know about are the people who aren't there who are in the background, who are not showing up to appointments.' • 'I'll never forget when the providers told me, looked me straight in the face, "Well, you know [your father] should have 24-hour supervision." And I thought to myself, 'I wonder how many times I've told families that.' But you know, as a family member, you make some choices based on what are the battles you're willing to have.' • 'I think being a caregiver to my mom, I'm just like the children of so many of my patients helping – you know, trying to do the best thing for our parent, and it's really challenging. But I think it just makes me a little more empathic.' • 'I kind of have a lot of sensitivity towards how difficult it is to be an advocate for the people you're the caregiver for even if you're a little bit further away. It definitely has affected my role as a provider, recognizing how people do have kids and other things, and fulltime jobs, and they're taking care of their parents or advocating for their parents, totally made me way more sensitive to caregiving.'
<p>Caregiver care as part of patient care Relating to caregivers through personal caregiving experience</p>	