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Caregiver Needs Assessment in Primary Care: Views of Clinicians, Staff, Patients, and Caregivers

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Abstract

OBJECTIVES: To understand current practices, challenges, and opportunities for a systematic assessment of family caregivers' needs and risks in primary care.

DESIGN: Qualitative study consisting of in-depth semi-structured interviews.

SETTING: Four primary care practices located in urban and rural settings.

PARTICIPANTS: Primary care clinicians, staff, and administrators (N = 30), as well as older adult patients and family caregivers (N = 40), recruited using purposive and maximum variation sampling.

MEASUREMENTS: Current experiences, challenges, and opportunities for integrating standardized caregiver assessment into primary care delivery. Interviews were audio-recorded and transcribed; transcripts were analyzed using the constant comparative method of data analysis.

RESULTS: Participating clinicians had been in practice for an average of 12.8 years (range = 1–36 y). Patients had a mean age of 84.0 years (standard deviation [SD] = 9.7); caregivers had a mean age of 67.0 years (SD = 9.3). There was wide variability in current practices for identifying caregivers' needs and risks, encompassing direct and indirect approaches, when such issues are considered. Participants posited that integrating standardized caregiver assessment into primary care delivery could help improve patient care, enhance clinician-caregiver communication, and validate caregivers' efforts. Barriers to assessment included insufficient time and reimbursement,

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SUPPORTING INFORMATION
Additional Supporting Information may be found in the online version of this article.

liability concerns, lack of awareness of community resources, and concerns about patient autonomy. To facilitate future uptake of caregiver assessment, participants recommended brief self-administered assessment tools and post-screen discussions with practice staff.

CONCLUSION: Identification of caregivers' needs and risks in primary care is highly variable. Integration of standardized caregiver assessment into practice requires coordinated changes to policy, revision of practice workflows, and an interdisciplinary approach to the development of appropriate assessment tools.

Editor's Note

Geriatrics health professionals are very aware of the importance of caregivers to the health, function, and quality of life of our patients. We pay close attention to the nature and amount of care provided by family and other caregivers, and the challenges they face in doing so. We also understand the potential impact of caregiving on the mental and emotional health of the caregivers themselves. In some cases, our older patients are also caregivers for a spouse, child, other relative, or friend. The authors of this article have an important long-term goal: to develop an assessment of caregivers that can be used in primary care settings. Busy primary care clinicians may not have time to ask relevant questions and make observations that can help them understand the context in which their patients receive care at home. The qualitative data reported should be of value in developing a brief assessment of caregivers that will be feasible and useful in primary care. In the meantime, we should encourage our primary care colleagues and trainees to pay attention to the insights provided by caregivers and their perceived needs. Moreover, using basic behavioral observations during an encounter with an older patient and a caregiver can provide valuable information, as noted in Table 2. Signs of self-neglect, visible distress in the patient or caregiver, and negative interactions between the patient and caregiver should be noted because they may pose a threat to the health and safety of both parties.

—*Joseph G. Ouslander, MD*

Keywords

caregiving; primary care; screening

Nearly 8 million older adults in the United States rely on family caregivers for assistance in meeting their daily needs.[1] These caregivers collectively provide 75% to 80% of the total care to community-dwelling older adults.[2] Although much of the literature on caregiving has examined assistance with daily activities, an understudied aspect of the caregiver role is navigating the healthcare system. In this context, caregivers assume diverse functions. They coordinate care, provide transportation, assist with treatment regimens, and facilitate communication in doctors' visits by preserving rapport, ensuring accurate information exchange, and advocating on the patient's behalf.[3–5] In recognition of caregivers' contributions to healthcare delivery, professional societies have called for more explicit inclusion and support of caregivers in healthcare settings.[6–8] The National Quality Strategy of the US Department of Health and Human Services has specified family engagement as one of its six priorities,[9] and the National Academies of Sciences, Engineering, and Medicine has advocated for systematic "identification, assessment, and support of caregivers throughout the care delivery process."[10]

Despite interest in supporting family caregivers in healthcare settings, practical interventions for assessing caregivers' needs and risks are lacking.[10] Such interventions are especially relevant in primary care, typically the initial point of contact in the healthcare system for older adults and their families.[11] In this setting, caregiver assessment meets the US Preventive Services Task Force definition of a secondary prevention strategy.[12] Assessment is a fundamental step in collecting information regarding individual circumstances that is necessary for identifying appropriate referrals and education tailored to specific needs. Further, an assessment can be useful to the primary care clinical team in designing care plans that appropriately account for the caregiver's capabilities and ensure the well-being of the patient.[13,14] Caregiver assessment when connected to appropriate referrals and support that benefit caregiving circumstances may help to address caregivers' unmet need for training[15,16] and confer positive effects for patients, payers, and society by reducing potentially unnecessary hospitalization and institutionalization.[17]

The current knowledge base on caregiver assessment in primary care is surprisingly limited.[18–20] Although a large inventory of psychometrically validated caregiver assessment instruments has been developed for use in intervention research,[21–23] only a few studies, predominantly conducted outside the United States and in settings other than primary care, have examined the potential feasibility and uptake of caregiver assessment in practice.[24–27] Little is known about how primary care clinicians, patients, and caregivers think about caregiver assessment and view the challenges and benefits to its implementation. Understanding these perspectives is crucial to ensuring that future assessment protocols are poised for broader and more systematic use by being responsive to the needs of important end users and congruent with existing practice workflows.

This study was conducted to contribute new insights on this topic by (1) characterizing current approaches to identifying caregivers' needs and risks in primary care, (2) understanding perceived benefits and barriers to implementing standardized caregiver assessment in primary care, and (3) deriving recommendations for the integration of assessment protocols into primary care. Given the lack of empirical data on this topic, qualitative methods were used to assess the experiences and insight of primary care clinicians, administrators, patients, and caregivers. A qualitative approach can help guide future research and intervention studies to achieve higher quality family-centered care delivery. Engaging potential end users early in intervention development processes has important benefits.[28,29] For this reason, the present study elicits participants' reactions to and recommendations for the systematization of caregiver assessment.

METHODS

Study Design and Setting

Semi-structured in-depth interviews lasting approximately 30 minutes were conducted with primary care clinicians, staff, and administrators; older adult patients; and family caregivers. Clinicians, staff, and administrators were affiliated with four primary care practices located in New York City, central New York, and northern Pennsylvania. The practices were selected for their diversity in terms of geography (urban, rural), practice structure (academic affiliate, regional health clinic), specialization (geriatrics, internal medicine), and resources (availability of multidisciplinary staff). Patients and family caregivers were recruited from primary care practices and support groups in the same geographic locations. 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.

Participants

A combination of purposive sampling and maximum variation sampling was used to recruit primary care clinicians, staff, and administrators from diverse disciplines as well as patients and caregivers with varying relationships to one another (eg, spouses).[30,31] Primary care professionals were recruited at weekly staff meetings and were eligible if they had practiced in primary care for at least 1 year beyond training. Patients and caregivers were identified through physician referral (n = 28) and direct outreach by primary care clinic staff (n = 12). Patients were eligible if they were routinely accompanied by a family member to primary care appointments, had sufficient cognitive capacity to provide informed consent, were English speaking, and were older than 65 years. Caregivers were eligible if they routinely accompanied a patient age 65 years or older to primary care appointments, were English speaking, and over the age of 21. Participation of both members of a patient-caregiver dyad was not a requirement for inclusion in this study.

Interview Guides

The interview guides for primary care professionals, patients, and caregivers followed parallel construction and covered identical content (File S1). The guides were pilot-tested with six geriatricians, four internists, two nurses, three patients, and five caregivers to ensure clarity and appropriateness. The first set of questions asked participants to describe how family caregivers are involved in older adults' primary care visits and how their needs and concerns are addressed. The second half of the interview guide was designed to ascertain recommendations for a standardized caregiver assessment, with the goal of deriving actionable knowledge to inform the development of clinically feasible assessment protocols. To elicit this information, the concept of a standardized assessment tool was introduced. Participants were asked for their reactions regarding the use of a standardized assessment tool in primary care practice and to recommend core components of such an assessment.

Data Collection and Analysis

Data collection occurred between November 2018 and October 2019. Participant characteristics were obtained using a brief self-administered questionnaire. Interviews were conducted by one investigator (C.R., a social scientist). Each interview was audio-recorded and transcribed. Data collection continued until thematic saturation was reached, that is, the point at which no new information was generated from additional interviews.[30] The constant comparative method was used for data analysis whereby transcripts were reviewed continuously and assessed for the emergence of new ideas or themes.[32,33] A preliminary coding structured was developed and iteratively refined and applied to the data. Two trained coders independently coded 40 of the transcripts. Differences in the application of codes were resolved through discussion, and a final coding structure was developed. A single person (C.R.) coded the remaining transcripts according to the final coding structure. NVivo v.9.0 and Dedoose v.8.0.25 were used to assist with data management and analysis.

RESULTS

Participant Characteristics

Table 1 presents study participant characteristics. Thirty primary care professionals were physicians (six geriatricians and ten internists), eight nurses, four practice administrators, a physician assistant, and a social worker (n = 1). A total of 40 patient and family participants included 14 patients and 11 caregivers who were spouses, 11 adult children, or 4 other relatives. Caregivers varied in their roles and degrees of participation in primary care visits (Tables 1 and 2).

Overview of Themes

Themes that emerged from the interviews are organized in three sections, following our research objectives to (1) describe existing practice in identifying caregivers' needs and risks, (2) understand benefits and challenges to implementing a standardized caregiver assessment protocol in primary care, and (3) assemble recommendations for integrating caregiver assessment into primary care. Representative quotations are included in the text and in Tables 2, 3, and 4. Because the responses of the stakeholder groups overlapped to such a large degree, we do not provide a systematic comparison of their responses; instead, we discuss group differences when they occur.

Current Approaches to Identifying Caregivers' Needs and Risks

Direct Approaches.: Direct approaches involved explicit acknowledgment and discussion of caregivers' concerns. Clinicians noted they initiate conversations about caregiver issues by using open-ended questions (Table 2, C): "I try to make it a point to start off to just ask a general question, 'How are you doing?'" Others used their own personal experience with caregiving to validate caregivers' efforts (Table 2, D). In the absence of clinician-initiated approaches, caregivers stated that they would raise specific concerns about their needs (Table 2, E): "[Clinicians] don't ask me. I will tell them" (spouse caregiver).

Indirect Approaches.: Indirect approaches to identifying caregivers' needs and risks involved clinician observation of caregiver and patient behaviors or physical appearance suggestive of stress or inability to provide adequate assistance (Table 2, F–I). Clinicians reported looking for signs of self-neglect of the patient or caregiver (weight loss, inappropriate dress) (Table 2, F), visible distress or body language (crying, agitation) of the caregiver (Table 2, G), or negative interactions between the patient and caregiver (Table 2, H). Other warning signs included poor patient outcomes, such as repeated hospital admissions for the patient or mismanagement of medications (Table 2, I).

Lack of Consideration of Caregiver Issues.: In some cases, caregiver needs and risks were ignored (Table 2, J): "[Clinicians] know I'm there, they just don't ask [about caregivers' concerns]" (spouse caregiver). One internist explained, "I sometimes ask questions to the caregiver when I need to amplify what the patient has said, but most of my conversation is with the patient."

Benefits and Challenges to Implementing Standardized Caregiver Assessment in Primary Care—Existing practice in the identification of caregivers' needs and risks is variable. To determine how this process might be standardized, we introduced the idea of an assessment tool and asked participants to react to this option (see Supplementary File S1).

Benefits.: Participants agreed that a formal assessment tool could help ensure better patient care (Table 3, A). An internist reflected, "As a provider, you have to be cognizant of what [caregivers'] capacity is. The assumption is that the caregiver is taking care of this person perfectly fine and you don't pick up that they may not be, because of their own issues." A formal assessment was discussed as serving for the foundation for productive provider-caregiver communication (Table 3, B): "I do think that it [caregiver assessment] could be helpful… I'm sure that there are things that I'm forgetting sometimes that I don't think to bring up and the [caregiver] doesn't know to bring up or is too embarrassed to bring up" (internist). Participants noted that an assessment helps validate caregivers' efforts by affording an opportunity for them to articulate specific concerns and challenges (Table 3, C): "A caregiver assessment… I think that that's a great thing. There's a lot of stress on the caregiver… and I don't think everybody recognizes" (adult child caregiver).

Challenges.: Among clinicians and staff, time was a primary concern (Table 3, D): "One of the huge barriers will always remain time… doing the screen and then talking to the caregivers and then like figuring out what is the actual plan for each of the different things that we identify." Patients and caregivers were also cognizant of clinicians' time restrictions: "I'm not really going to vent that much with [clinicians] because they got the next person to see and… other people to deal with" (adult child caregiver). Although the challenge of reimbursement was important to clinicians and staff (Table 3, E), this issue was not raised by patients or caregivers. Clinicians also discussed apprehensions about personal liability and inability to act on or address caregiver issues that were identified through an assessment (Table 3, F): "If you were to give a screener to let's say a caregiver who is not your patient and they write like 'I'm highly depressed and want to kill myself,' now that's a huge liability" (internist). They further specified their lack of knowledge about community resources as a key barrier to caregiver assessment (Table 3, G). Both clinicians and caregivers were concerned about patient autonomy (Table 3, H). They felt that a caregiver assessment might over-shadow the focus on the patient. Patients, however, believe that such conversations "would not interfere with [the] visit," and they affirmed that "it's important for the doctor to be able to assess the input of the caregiver."

Recommendations for Integrating Standardized Caregiver Assessment into Primary Care Delivery

Characteristics of the Assessment Tool.: Participants specified that a caregiver assessment tool should be brief (Table 4, A). Several clinicians suggested that the tool be modeled after instruments that are currently administered in primary care: "Something that wasn't too long you could actually give to the caregiver… Like the PHQ-9 [a depression screener] that is done in the initial visit for everybody and then the mental health team reviews it" (nurse). Participants from all groups agreed that the items on the tool should be tied to patient outcomes and identify concrete actions for follow-up (Table 4, B). They endorsed three primary content domains to be assessed: (1) *help available to the caregiver* so clinicians could recommend respite or suggest that the caregiver ask others to share the caregiving responsibilities, (2) *caregiver's understanding of and ability to assist with health management activities* so that clinicians could offer anticipatory guidance or training in specific tasks, and (3) *caregiver's finances or patient's insurance status* to help clinicians direct the caregiver to appropriate resources. In reconciling the recommendation for brevity with the suggestion for inclusion of several content domains, one participant summarized, "Have as simple as three 'yes' or 'no' questions… like hands-on care, emotional support, financial" (nurse). Caregivers were adamant that the wording be free from judgment about the caregiver's performance and limit assumptions that all caregivers need or want help (Table 4, C). Participants from all groups agreed the tool should be self-administered by caregivers to ensure the accuracy of information provided (Table 4, D).

Need for and Suggestions Regarding Post-Screen Discussions.: Participants proposed that completion of an assessment tool should be followed by an in-person discussion about the needs identified (Table 4, E). To facilitate productive post-screen conversations, clinicians advocated for communication scripts (Table 4, F): "A script for some of these challenging conversations… would help me but would also help me teach [medical] residents how to have those conversations" (geriatrician). Patients and caregivers agreed that "doctors need to be trained in communication" (patient). Participants believed that post-screen conversations should take place without the patient present to afford the most effective discussions (Table 4, G): "I think it should be the caregiver alone… there might be things the caregiver may not reveal in front of the patient" (internist). Patients concurred that "it's okay for [clinicians] to talk to [the caregiver] separately." As a means of preserving patients' autonomy while meeting caregivers' needs for separate consultation, several clinicians asked caregivers to remain in the waiting room during the visit, inviting them in afterward to express their concerns (Table 4, G). Overall, participants recommended a team-based approach to post-screen discussions, emphasizing the value of physician-nurse collaborations and the importance of social work in offering referrals and support (Table 4, H).

DISCUSSION

This study of primary care clinicians, administrators, patients, and caregivers identifies current practices and promising directions for systematically identifying caregiver needs and risks in primary care. With a user-centered approach to understanding varied perspectives, the present research provides new data on the feasibility, benefits, and challenges to integrating caregiver assessment into primary care. Despite long-standing calls for integration of caregiver assessment in care delivery and the pressing need to move research into practice,[6,10,34] surveys of family caregivers indicate such processes are notably absent.[35,36] Our study goes beyond reports from the caregiver perspective that healthcare providers rarely ask about their needs and concerns.

To our knowledge, this study is the first to describe the spectrum of approaches to caregiver risk identification, ranging from direct acknowledgment, to observation of caregivers' behavioral and physical cues, to complete lack of consideration. There is a high degree of variability in approaches used to identify caregivers' needs and risks. Given consensus regarding the need for explicit inclusion of caregivers in healthcare processes,[6–8,10] there may be merit in developing educational curricula and practice guidelines to better prepare primary care clinicians for effective engagement of family caregivers and improve capacity for caregiver needs assessment.

A number of structural factors impede the integration of caregiver assessment in healthcare settings.[10,37–39] Consistent with findings from prior research on dementia care,[37,39] clinicians in this study identified inadequate reimbursement and insufficient time to meet with caregivers as particularly salient obstacles. To support clinicians in delivering high-quality care, payment reforms must incorporate reimbursement mechanisms for the time spent with caregivers. Although current payment models are typically designed to serve individual beneficiaries rather than the family unit, a new Centers for Medicare & Medicaid Services dementia care planning code includes caregiver assessment as a required element.[40] This mechanism could serve as a model for other diseases and broader diffusion of incentives for conducting caregiver assessments.

This study raises important questions for the future of primary care in an aging society. Clinicians and caregivers emphasized the importance of upholding patient autonomy and obtaining permissions while also articulating the value of separate post-assessment consultations for the caregiver. This situation reflects currents tensions between the dominant biomedical emphasis on individual autonomy and trends toward family-centered care where caregivers are essential partners in the care process.[41,42] Such issues are likely to become increasingly important in an aging population.[10] As growing numbers of older adults with chronic and disabling conditions rely on family caregivers at medical visits,[43] primary care must develop strategies to engage caregivers while preserving patient rights. New models, such as accountable care organizations and patient-centered medical homes, are recognized as holding promise for assessment and support of family caregivers, but best practices do not yet exist.[10] The RAISE (Recognize, Assist, Include, Support, Engage) Family Caregiving Advisory Council may help to stimulate progress in this area by recommending effective models to support caregivers in health and long-term care settings.

Our study offers practical strategies for integrating standardized caregiver assessment into practice. Participants advocated for caregiver assessment tools that include actionable content linked directly to the patient's care plan. They also stipulated that assessment tools be brief, both to ensure the primary focus of the visit remains on the patient and to minimize time demands on caregivers and clinicians. Existing caregiver assessment tools are time consuming and typically evaluate a single construct, such as caregiver stress or depression.[18,19] For some participants in this study, assessment of these domains (eg, stress, depression) in individuals who are not under their medical care raises concerns about personal liability and concerns about treatment. Following existing medical-legal partnership models designed to identify and address social determinants of health,[44] legal counsel will need to be engaged in developing assessment protocols that are feasible to implement. New tools will need to include a brief array of items to be most effective in directing appropriate referrals and identifying risks that can impact the patient's care plan. To this end, findings from this study will be used to inform the development and pilot testing of a caregiver assessment tool in practice, ultimately laying the groundwork for future pragmatic trials.

The development and implementation of brief actionable caregiver assessments in primary care has potential to improve quality of care. In pediatrics, for example, screening for maternal depression at well child visits was shown to facilitate appropriate mental health referrals,[45] and primary care-based interventions that encompass both screening and follow-up have demonstrated positive effects on both maternal and child mental health.[46–48] Implementation of caregiver assessment in state Medicaid programs has been linked with delayed utilization of long-term care services among caregivers.[49] These findings point to the utility of caregiver assessment and the benefits that may be derived from broader deployment in primary care.

Several limitations warrant comment. As a qualitative study, conclusions cannot be drawn about the prevalence of the experience or attitudes of clinicians, patients, or caregivers. This small purposive sample included participants with diverse roles in primary care from a range of practice settings but may not be representative of primary care more broadly. Given the scope of this article, we did not systematically compare differences between geriatricians and internists or differences across practice sites. Regional variations and disparities in access to primary care may exist. Our study transcripts suggest the need for flexibility in tailoring protocols to the unique considerations of individual caregivers and practices.

As health systems move toward value-based delivery models that emphasize quality and accountability,[50] and the number of individuals relying on family members continues to rise, developing scalable protocols that facilitate systematic assessment of caregivers will be critical. The present study lays the groundwork for future research, policy, and practice in this area. It provides actionable recommendations and identifies the specific changes needed to make caregiver assessment in primary care a reality. To the extent that newly developed caregiver assessment tools can meet the criteria specified by participants in this study and are confirmed in larger samples of health system stakeholders, important benefits are likely to result.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

Participant Characteristics

Primary Care Clinician, Staff, and Administrator Characteristics (N = 30)	
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
Patient and Family Caregiver Characteristics (N = 40)	
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 (1.0)
Relationship to patient, n (%)	
Patient	14 (35.0)
Spouse	11 (27.5)
Adult child	11 (27.5)
Other relative, friend	4 (10.0)
Caregiving context	
Years assisting patient, M ± SD	9.9 ± 10.7
Hours per week spent assisting patient, M ± SD	60.1 ± 61.6
Accompanies patient to every healthcare visit, n (%)	18 (69.2)
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)

Abbreviations: M, mean; NP, nurse practitioner; RN, registered nurse; SD, standard deviation.

Table 2.

Caregiver Roles in Primary Care Visits and Approaches to Identifying Caregiver Needs and Risks

Caregiver roles: Type of involvement and intensity of participation	
A.	**Advocate and historian**
	“It’s depressing to [patient] that he gets things wrong. So, he’s quiet… I’m very aggressive… so that stuff gets done. I mean, I am very hyper-organized and so when we go in [to the visit], I go in with a list. Here are the things that we are seeing some resolution on. Here are the things that are worse.” (spouse caregiver)
B.	**Facilitator of information exchange**
	“I will ask questions, not to be annoying, but just to clarify things for me, or maybe talk about another option that [doctor] had not brought up.” (adult child caregiver)
	“I answer questions with [patient’s] help. I consult with [patient]. Sometimes it’s to explain the question. Sometimes it’s to jog memory in terms of what’s been happening at home.” (adult child caregiver)
Direct approaches: Queries and affirmations	
C.	**Clinician queries using open-ended questions**
	“Sometimes when a patient has a lot going on, they are demented, or they have really bad diabetes or things that require a lot of assistance. when the patient is getting changed I step out—the caregiver will step out and. I’ll just say, you know, ‘how are you doing with all this?’” (internist)
	“They [clinicians] will say, ‘How are you doing?’ You know, ‘Have you had any more luck with getting help in the house?’ You know, those things.” (spouse caregiver)
D.	**Clinician statement of personal experience**
	“It comes up in the interaction. I dare to interject and I say, ‘Yes, I know how this is hard, I went through the same thing with my father when he had Alzheimer’s’ and they open up immediately.” (nurse)
	“I’m the primary caregiver for my two adult boys who are profoundly disabled. because of that, I’ve had to go further into some of the issues that a lot of physicians just do not know about with respect to caregiving. without me saying, ‘I’ve noticed that you look really sad and depressed’. it’s a way of addressing it [caregiver stress] without opening up that can of worms completely.” (internist)
E.	**Caregiver initiation of concerns**
	“I hope they [caregivers] realize the door is open if they feel I can do something for them to mitigate that stress. But, it’s not something that I have directly pursued.” (internist)
	“I absolutely know what I can do and know what I cannot do, and I say what I need to say when I’m with the doctor. I am not shy and very comfortable in my own skin.” (niece caregiver)
Indirect approaches: Use of physical or behavioral cues	
F.	**Signs of self-neglect**
	“Weight loss often triggers conversations about what’s going on in the household. Who does the food shopping? Who does the food preparation? What are you guys eating?. Like do you notice all of a sudden, they used to be a lot more well dressed before or clothes are soiled.” (nurse)
G.	**Visible distress**
	“[Caregivers] that are sort of sad and crying they request some of the nurses ‘Oh can I talk to you for a bit’.and sort of get teary eyed. ‘Oh it’s been hard, it’s been really tough, I’m sick myself.’” (nurse)
H.	**Negative interactions between patient and caregiver**
	“For me, if there is anger going on, without knowing them [patient and caregiver] and they start yelling at each other sometimes or the other one yells at one.” (medical assistant)
I.	**Poor patient outcomes**

“In terms of evaluating how well [caregivers] are doing, part of that has to do with evaluating how well the patient is doing. If the medications are being well managed, I know that something about this partnership is working. It’s more inferences based on what I’m seeing in the office.” (geriatrician)

Absence of an approach

J. **Lack of consideration of caregiver issues**

“I always focus on the individual, in terms of the person who’s my patient. I explain that I generally do not see adult patients with another individual in the room. [I] have them sit in the waiting room.” (internist)

“That’s where the gap is. It’s almost like the assumption is that I’m the caregiver and I’m going to take care of all these things, whether I want to or whether I can.” (adult child caregiver)

Table 3.

Benefits and Barriers to Standardized Caregiver Assessment

Potential benefits of standardized caregiver assessment

A. **Better patient care**

“The caregiver’s health is important. Particularly as the person gets more sick it’s so important that [the caregiver] get their health taken care of, not just their physical health but their mental health.” (internist)

“The most important thing that they [clinicians] need to know is that I have a very large responsibility where he [patient] is concerned and [his] healthcare. Ultimately that will affect his [patient’s] care because if anything happens to me, then he is no longer able to stay at home.” (spouse caregiver)

“The doctors should make an attempt to find out how the [caregiving] situation involves the patient’s health. the physician involved should be aware of their [the patient’s] surroundings.” (patient)

B. **Improved caregiver-provider communication**

“They [caregivers] can answer whatever they want in a survey. and based on that feedback you can rearrange your approach so that you can be more effective.” (nurse)

“There are two varieties [of caregivers]. There are the ones [caregivers] that do not complain. and there’s others that complain bitterly because of the resentment of the situation and watching their person disintegrate. So, I think, getting people to talk in a productive way.” (spouse caregiver)

“It’s important for the doctor to be able to assess the input of the caregiver. to understand whom she’s speaking with and what the caregiver is capable of communicating to the doctor.” (patient)

C. **Validation of caregivers’ efforts**

“If they feel like they [caregivers] are being validated and somebody is acknowledging the burden they are facing. Some of them will feel better because they have gotten things off their chest.” (geriatrician)

“I wish when my mom was caring for my dad that their shared doctor had asked how she was doing. It would have been comforting for her to hear that people appreciate. or ask if she needed help.” (patient)

Challenges and barriers to standardized caregiver assessment

D. **Insufficient time**

“It’s a time constraint. It’s another thing to do that’s not part of the visit that you still have to document all the other stuff. So, if the patient does not have much going on and you have a lot of time to talk about [caregiver issues], if the patient has a lot of new symptoms you really do not have time.” (geriatrician)

E. **Inadequate reimbursement**

“[When] the family member comes into talk it’s hard to bill it as a visit because there is no physical exam, there is no patient. There may be billing codes for goals of care, maybe you could do that.” (geriatrician)

“I cannot devote as much time to the caregiver as I can to the patient. I just spent 20 minutes on the phone with a family caregiver and I had like a 30-minute visit with them yesterday and I cannot, I am not billing for a 15-minute visit.” (geriatrician)

F. **Apprehensions about personal liability and inability to act on identified concerns**

“The one thing that I could not do if the person were not my patient is to refer to our social worker. I do try if they feel you know really stressed and everything to try to give them resources or idea.” (nurse)

“Doctors tend to be insecure about stirring up feelings that are below the surface.A tendency with doctors to want to not rock the boat and deal with the fear of not being equipped to do counseling.” (patient)

G. **Lack of awareness of community resources**

“I do not feel like I’m an expert at any of them [community resources] because each organization might have its own thing that they can do or not do.” (geriatrician)

H. Concerns about patient autonomy

“It all depends on the capacity of the individual and what permission I have. So, I will not have those conversations unless I have direction from the patient and often indirection from them.” (internist)

“I do not want to get into a whole story about me. It’s not really about me. It’s about just taking care of my mother and what’s the best situation for her.” (spouse caregiver)

“I invite [caregiver] in, but she does not like to. She feels I should have privacy with the doctor.” (patient)

Table 4.

Characteristics of and Suggestions for a Standardized Caregiver Assessment Protocol

Characteristics of the assessment tool

A. **Minimize time demands through brevity and clarity**

“Start off with two questions. If they [caregiver] score a 3 or higher. you know whatever the scoring system is. We can look at that and refer them for some help or recommend whatever after that.” (nurse)

B. **Identify specific issues for follow up by including actionable content domains**

“There needs to be a tangible outcome or they [caregivers] need to feel like they are feeling heard. If all we are saying is that we are identifying the caregiver burden without doing anything, I think that is unsatisfying to the provider, and it is going to be unsatisfying to the caregivers as well.” (geriatrician)

“A paper questionnaire just to see what issues there might be, the right direction based on how many issues. Then from that, they [practice] could contact us and say, ‘We have a support group, meet with the social worker, or work with the doctor’ what the options are.” (adult child caregiver)

Content domains:

i. Help available: “The first things I would want to put [on the tool] is What help is available to you, the caregiver?’ Because that means better care for the person and less stress on the caregiver.” (internist)

ii. Understanding of and assistance with health management: “Questions that would check their. ability and understanding of the person’s illness. If they [caregivers] do not understand why they are doing things, it is not really helpful to the patient managing symptoms, meds, providing personal care.” (nurse)

iii. Finances and insurance: “Does [caregiver] have the resources to pay for a [paid] caregiver or do you need some help, you know, applying for Medicaid or something like that?” (nurse)

C. **Minimize judgment and assumptions about caregivers’ abilities and need for assistance**

“A lot of caregivers. might be afraid to tell the providerthat they are not doing as much as they feel they should be.. If it’s [screen] really clear this is not about judging whether the caregiver is doing a good job, it’s more about trying to provide the right support for the caregiver.” (spouse caregiver)

D. **Ensure accuracy and honesty through self-administration**

“Have them fill it out by themselves. It is probably not something that can be done during a visit itself, both for time constraints and for purposes of making sure the answers are honest.” (geriatrician)

“I do not want anybody walking me through it. It’s too invasive.I think having someone actually walk you through it might feel a little coercive.” (adult child caregiver)

Need for and suggestions regarding post-screen discussions

E. **Incorporate post-screen discussions**

It would be helpful to have a follow-up visit to address something specifically. You know, how is the caregiver being supported? What is that is needed to provide the ongoing support?” (spouse caregiver)

F. **Leverage communication scripts**

“Having specific phrases to learn can be really helpful. and then you can always overtime adjust it. A lot of it is similar to what the fellows learn in other situations, about communication skills and nonjudgmental language and get the full picture before making like big declarations.” (geriatrician)

G. **Involve separate consultations**

“It would be helpful if there was some mechanism for me to voice my perception of what is going on without her [patient]. It would need to be a separate visit. where you could express to someone what your experience, and hear about options, or other ways to handle stuff.” (adult child caregiver)

"It [discussion of caregiver issues] needs to be private. It absolutely, yeah, that needs to be like totally private or else it becomes. it just automatically becomes not about the caregiver." (spouse caregiver)

"I always talk to, individuals, adults by themselves. I try to get through a visit one-on-one. I will invite [caregiver] back after the visit and then [he or she] can express any concern." (internist)

H. Engage interdisciplinary teams

"If you actually had a provider and a nurse, you know working together throughout the day, then you know they could take a look at this [caregiver assessment]." (nurse)

"My role is being able to meet and assess the patient as well as the caregiver. It's helpful I think to really look at that dyad. That helps me also guide caregiver referrals, resources, and information." (social worker)

"If there was 5 or 10 minutes sit down with a social worker where they ask, 'How are you guys handling your medications?'. and 'Do you need to see a psychiatrist, a therapist?'" (adult child caregiver)