

Trust Between Physicians and Family Caregivers: Qualitative Insights from Three Family-Centered Academic Medical Centers

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ABSTRACT

Family caregivers increasingly support health care tasks but are not meaningfully integrated into the health care setting in consistent or standard way. Previous literature has established the importance of trust in patient-clinician relationships; yet, little is known about family caregiver-clinician trust, and further, how and when to integrate family caregivers into health care teams so they can better support their relative. This study examined a) how physicians assess and perceive trust with family caregivers, b) the role of culture in trust dynamics, and c) facilitators and barriers to integrating caregivers into health care teams. We conducted twenty qualitative interviews with physicians in geriatrics (n=9) and oncology/hematology (n=11) between January–March 2021. Physicians assess caregivers' competence, reliability/dependability, and fidelity. They assess caregivers' engagement (e.g., asking questions, verbal and non-verbal cues) to determine whether caregivers trust them. Physicians in our study trust other physicians more than caregivers in certain situations (e.g., for objective information, data) while they trust caregivers more than other physicians for information that requires familiarity and time with the patient (e.g., observations in the home environment). When supporting patients from diverse cultural backgrounds, physicians often rely upon caregivers to provide contextual information about relevant cultural norms. Inte-

grating caregivers into the care team early—when the patient-caregiver relationship is strong—can be critical to providing effective patient care. Technology can facilitate the trust-building process to further support caregiver integration. Building trust-driven partnerships between physicians and family caregivers could be critical for effective communication of important information to support patient care. Guidelines and policies related to telehealth, discussions between physicians and caregivers, tools to screen caregivers for skills and caregiver burden, and reimbursements for partnering with caregivers are important priorities for supporting caregivers and patient care.

Keywords: family caregiving, geriatrics, oncology, trust

Confianza entre médicos y cuidadores familiares: conocimientos cualitativos de tres centros médicos académicos centrados en la familia

RESUMEN

Los cuidadores familiares apoyan cada vez más las tareas de atención de la salud, pero no están integrados de manera significativa en el entorno de atención de la salud de manera uniforme o estándar. La literatura previa ha establecido la importancia de la confianza en las relaciones médico-paciente; sin embargo, se sabe poco sobre la confianza entre el cuidador familiar y el médico y, además, sobre cómo y cuándo integrar a los cuidadores familiares en los equipos de atención médica para que puedan apoyar mejor a su familiar. Este estudio examinó a) cómo los médicos evalúan y perciben la confianza con los cuidadores familiares, b) el papel de la cultura en la dinámica de la confianza, y c) los facilitadores y las barreras para integrar a los cuidadores en los equipos de atención médica. Realizamos veinte entrevistas cualitativas con médicos en geriatría (n=9) y oncología/hematología (n=11) entre enero y marzo de 2021. Los médicos evalúan la competencia, confiabilidad/confianza y fidelidad de los cuidadores. Evalúan el compromiso de los cuidadores (p. ej., hacer preguntas, señales verbales y no verbales) para determinar si los cuidadores confían en ellos. Los médicos de nuestro estudio confían más en otros médicos que en los cuidadores en ciertas situaciones (p. ej., para obtener información objetiva, datos), mientras que confían más en los cuidadores que en otros médicos para obtener información que requiera familiaridad

y tiempo con el paciente (p. ej., observaciones en el entorno del hogar). Al apoyar a pacientes de diversos orígenes culturales, los médicos a menudo confían en los cuidadores para que proporcionen información contextual sobre las normas culturales relevantes. La integración temprana de los cuidadores en el equipo de atención, cuando la relación entre el paciente y el cuidador es sólida, puede ser fundamental para brindar una atención eficaz al paciente. La tecnología puede facilitar el proceso de creación de confianza para apoyar aún más la integración del cuidador. La creación de asociaciones impulsadas por la confianza entre médicos y cuidadores familiares podría ser fundamental para la comunicación eficaz de información importante para apoyar la atención del paciente. Las pautas y políticas relacionadas con la telesalud, las discusiones entre médicos y cuidadores, las herramientas para evaluar las habilidades y la carga del cuidador y los reembolsos por asociarse con los cuidadores son prioridades importantes para apoyar a los cuidadores y la atención del paciente.

Palabras clave: cuidado familiar, geriatría, oncología, confianza

医生和家庭护理人员之间的信任：来自三个以家庭为中心的学术医疗中心的定性见解

摘要

家庭护理人员越来越多地支持医疗保健任务，但并未以一致或标准的方式有意义地融入医疗保健环境。以往研究已经确立了信任在医患关系中的重要性；不过，研究不足的是，家庭护理人员与临床医生之间的信任，以及如何与何时将家庭护理人员融入医疗团队，以便其更好地支持他们的亲属。本研究分析了 a) 医生如何评估和感知其与家庭护理人员的信任，b) 文化在信任动态中的作用，以及 c) 将家庭护理人员融入医疗团队一事的促进因素和障碍。我们在2021年1月至3月期间对老年病学（n=9）和肿瘤学/血液学（n=11）的医生进行了 20 次定性访谈。医生评估了家庭护理人员的能力、可靠性和忠诚度。他们评估了护理人员的参与度（例如提问、口头和非口头提示），以确定护理人员是否信任他们。本研究中的医生在某些情况下（例如：客观信息和数据方面）更信任其他医生而不是护理人员，但当其获取需要熟悉病人和花时间与病人接触才能获得的信息时（例如：在家庭环境中的观察），其更信任护理人员而不是其他医生。在为来自不同文化背景的患者提供支持时，医生通常依靠护理人

员提供有关相关文化规范的背景信息。当患者与护理人员的关系牢固时，及早将护理人员融入护理团队对于提供有效的患者护理而言至关重要。技术能促进信任建立的过程，以进一步支持护理人员的融入。在医生和家庭护理人员之间建立信任驱动的伙伴关系，对于有效传播重要信息以支持患者护理一事至关重要。与远程医疗相关的指南和政策、医生和护理人员之间的讨论、用于筛选护理人员技能和负担的工具、以及与护理人员合作的报销，是支持护理人员 and 患者护理一事的重要优先事项。

关键词：家庭护理，老年病学，肿瘤学，信任

Introduction

Family caregivers (i.e., a spouse/partner, adult child, grandchild) assisting an adult 50 and older supplement formal care from the U.S. healthcare system with 75% of caregivers being responsible for coordinating care and managing medications (AARP & National Alliance for Caregiving, 2020; Wolff et al., 2020). Recent initiatives seek to integrate family caregivers (from hereon, caregivers) into health care teams and the healthcare system broadly (Fortinsky, 2021; Gaugler, 2021; Wolff & Roter, 2011). These initiatives include developing digital health technologies, supportive services for caregivers, funding for care coordinators to liaise with caregivers, clinician-caregiver communication training, and provider incentives (e.g., to physicians for recording caregiver information in the electronic health record, or to healthcare systems for actively involving caregivers) (Friedman & Tong, 2020; National Alliance for Caregiving, 2021; Riffin et

al., 2020; Wittenberg-Lyles et al., 2013; Wolff et al., 2017). Despite these efforts to involve caregivers as members of the “team,” little is known about the relationship between physicians and caregivers. For instance, they may rely on one another for important information for patient care in the health care setting or in the home. Yet the relationship dynamics between caregivers and physicians—and circumstances under which they may partner effectively—have been understudied (Hoff & Collinson, 2017). In particular, while family caregivers’ trust in health professionals has been studied in contexts such as nursing homes, home health, and dementia care (Rogers et al., 2021; Russell et al., 2021; Watkins et al., 2012), examination of physician trust in family caregivers is limited.

One element fundamental to relationships in healthcare is trust, where someone (a trustor) is willing to be vulnerable to another person (a trustee) to perform a specific task (Blendon et al., 2014; Hall et al., 2001, 2002; Mechanic,

1996; Meyer et al., 2007; Rajesh et al., 2003; Stepanikova et al., 2006). Considerable literature has examined trust dynamics in relationships between clinicians and patients and between clinicians and other clinicians (Campos-Castillo & Anthony, 2019; Raj et al., 2018, 2019; Street et al., 2009; Thom et al., 2011). Studies suggest that trust in these relationships is based on multiple dimensions or characteristics such as competence (i.e., skills and training), integrity (i.e., honesty), prior experience, and/or reputation. For instance, a physician might trust a patient to follow clinical recommendations or to be honest about concerns; a patient may trust a clinician to act in the patient's best interest, or to have the skills and competence necessary to provide effective care. Yet little is known about how these dimensions apply to the specific context of clinician trust with caregivers (Fortinsky, 2021). For example, a clinician might trust a caregiver to help their relative follow clinical advice. In turn, a caregiver may trust a physician to make good treatment decisions for their relative. The dynamics of trust between physicians and caregivers could also influence the relationship between physicians and patients. For example, if a caregiver does not trust a physician, they might suggest that their relative enrolls in care with a new physician. If a physician does not trust a caregiver, they may not invite the caregiver to participate in clinical visits. This lack of trust, in turn, may present a barrier to effectively and meaningfully involving and integrating the caregiver into the care team.

Understanding trust dynamics

between clinicians and caregivers is essential for identifying ways to strengthen medical training in order to ensure that clinicians are well-equipped to develop and maintain trusting relationships with patients and their caregivers. It is also critical for creating effective legislation to support integration of caregivers into the care team, as well as for developing policies within organizations to incentivize and encourage caregiver engagement. Understanding facilitators and barriers to caregiver integration could serve as additional opportunities for trust-building between physicians and caregivers. Furthermore, given the impact of cultural distance between patients and physicians on quality of those relationships, it is important to understand the potential role of culture on the trust dynamics between physicians and caregivers, who may serve as navigators or liaisons between patients and physicians (Raj, Zhou, et al., 2021; Somnath, 2006; Sullivan, 2020).

The objectives of the current study were to examine (a) how physicians assess whether they can trust a caregiver and perceive or determine whether a caregiver trusts them, (b) the role of culture in trust-building, particularly in terms of the patient/caregiver's cultural background or racial/ethnic identity; and (c) physicians' perceived barriers and facilitators to caregivers' integration into the health care team.

Methods

Study Design

We conducted semi-structured qualitative interviews with physicians at three

academic medical centers from January–March 2021 to understand how they assess and perceive trust with caregivers, understand the role of culture in trust dynamics, and identify perceived barriers and facilitators to caregivers' integration into the healthcare system. The study was given permission with exemption by the University of Illinois at Urbana-Champaign Institutional Review Board.

Identification of Participating Institutions

Given our interest in trust-building between physicians and caregivers, we employed a site selection that drew upon exemplar hospitals from the Institute for Patient- and Family-Centered Care (IPFCC) (IPFCC, 2021). The IPFCC, headquartered in McLean, VA, and sponsored by healthcare systems and hospitals across North America, aims to strengthen partnerships between patients, families, and healthcare professionals to improve quality and safety. Specifically, one of the IPFCC's best practices involves changing the concept of families as "visitors" to families as "partners." Accordingly, they have developed a list of fifteen hospitals and/or healthcare systems in the U.S. and Canada that meet at least 15 of 20 criteria regarding (a) hospital leadership's advocacy for family-centered care and family participation; (b) written policies encouraging family input and participation; and (c) materials for patients based on patient and family feedback that reflect family participation policies (IPFCC, 2021).

We selected three large, geographically diverse U.S. academic medical centers from this list as physicians in academic centers may be more likely to have research or training responsibilities that may influence the types of experiences they have with caregivers or want to model for their trainees in clinical care or clinical research in the context of a broader approach towards improving patient outcomes (IPFCC & Vizient, 2021; Washington, 2018; Yaffe, 2008).

Participants

We recruited participants between January and February 2021 through individual emails to physicians listed on institution websites as specializing in geriatric medicine, medical oncology and/or hematology anticipating that these represent specialty care for which patients may be more likely to require support from family caregivers (Bevans & Stenberg, 2012; Kent et al., 2016; Raj, 2020; Wolff & Spillman, 2014). We expected that clinicians in these specialties might be familiar with the challenges associated with trust dynamics with caregivers and might have considered the facilitators and barriers to their integration in health care teams more extensively. We expected that findings from participants in this study could be valuable for developing specific recommendations for other medical institutions.

The individualized email, which included the study goal (i.e., wanting to learn more about how clinicians identify and build trust with family caregivers of adult patients), was sent to 166 physi-

cians across the three institutions over a period of one week. To limit our sample to physicians supporting adult patients, we did not email any physicians who were listed in pediatric hematology/oncology. After one round of emails, we recruited 13 participants who completed the interview. Although we had reached saturation in that no new themes were emerging within or across institutions and we were observing consistency in emergent themes, we continued to recruit participants by sending a second email to non-respondents and recruited seven additional participants in order to ensure further consistency. Among physicians who were not enrolled, other than non-response, the most common reason for not participating was limited availability due to COVID-19 patient care responsibilities followed by duties that involved limited clinical care.

Procedures

One of the authors conducted all interviews via videoconferencing (Zoom) while the other observed. We used an interview guide adapted from previous work on physician trust (Raj et al., 2019). Interviews were 30-40 minutes and followed a semi-structured interview protocol. We asked participants four main questions: (1) How do you assess whether you can trust family caregivers?; (2) How do you determine whether caregivers trust you?; (3) How does culture (of the patient and/or caregiver, in terms of their cultural background) play a role in your trust-building practices with caregivers?; and (4) What are the facilitators

and barriers associated with integrating caregivers into health care teams? Upon hearing the first few participants comparing trust with caregivers with trust with other physicians, we asked all subsequent participants to compare trust dynamics with caregivers with trust dynamics with other physicians (i.e., Who do you trust more: a family caregiver or another physician, and why?).

Analysis

All interviews were audio-recorded and transcribed professionally through human transcription by the audio-to-text transcription service, Rev. Then we conducted a thematic analysis, an approach through which researchers can identify, analyze, and interpret patterns emerging from qualitative data (Boyatzis, 1998; Mays et al., 2005) they are under increasing pressure to adopt a more systematic approach to the utilization of the complex evidence base. Decision-makers must address complicated questions about the nature and significance of the problem to be addressed; the nature of proposed interventions; their differential impact; cost-effectiveness; acceptability and so on. This means that Cochrane-style reviews alone are not sufficient. Rather, they require access to syntheses of high-quality evidence that include research and non-research sources, and both qualitative and quantitative research findings. There is no single, agreed framework for synthesizing such diverse forms of evidence and many of the approaches potentially applicable to such an endeavour were devised for either qualitative or quan-

titative synthesis and/or for analysing primary data. This paper describes the key stages in reviewing and synthesizing qualitative and quantitative evidence for decision-making and looks at various strategies that could offer a way forward. We identify four basic approaches: narrative (including traditional ‘literature reviews’ and more methodologically explicit approaches such as ‘thematic analysis’, ‘narrative synthesis’, ‘realist synthesis’ and ‘meta-narrative mapping’. We developed our initial codebook using a deductive approach based on previous studies on physician trust (Wilk & Platt, 2016; Wu et al., 2022). We identified five dimensions of trust that are observed in dynamics between both physicians and other clinicians and physicians and patients: *competence* (the ability to perform a task successfully or with skill), *reliability/dependability* (carrying out tasks as expected or in a timely manner, exhibiting consistent quality), *confidence* (a judgment that someone will

meet another’s expectations), *integrity* (honesty and professional behavior), and *fidelity* (acting in the best interest of others) (Hall et al., 2001; Moskowitz et al., 2011; Raj et al., 2019; Thom et al., 2011; Wilk & Platt, 2016). Then, we reviewed transcripts and used an inductive approach to generate new preliminary codes to reflect participant interviews. We used the final set of codes as our codebook. Using this codebook, both members of the study team independently coded all transcripts. Since we initially used a deductive approach, any codes from previous work on physician trust that did not emerge from our interviews were removed from the codebook. The study team met every two weeks to discuss codes and resolve any discrepancies through discussion. During this process, we iteratively identified and modified subthemes by combining or separating them as needed (Figure 1). We used Microsoft Word for coding and qualitative analysis.

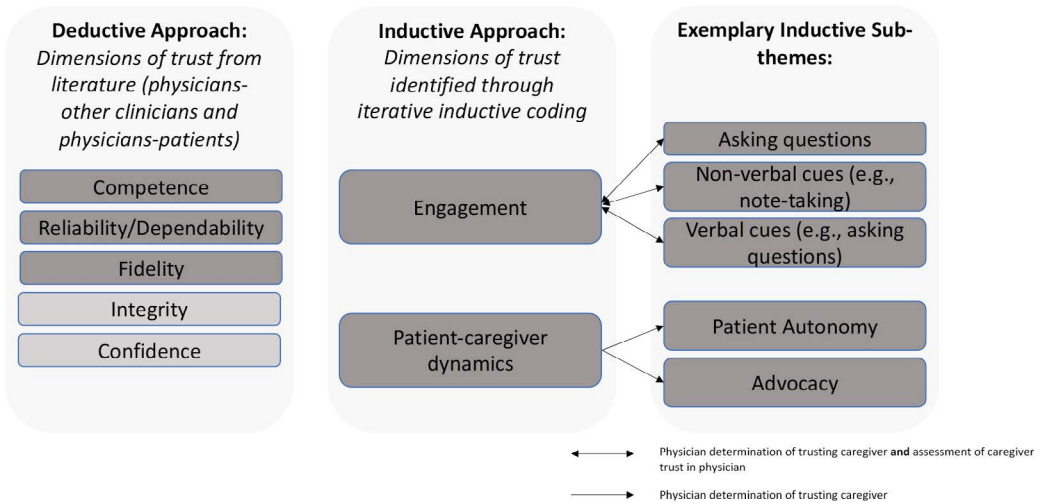


Figure 1. Deductive and inductive coding approach (n=20)

Results

Twenty physicians from three U.S. academic medical institutions participated in the interview. At Institution 1 (Midwest), three geriatricians and four oncologists participated.

In Institution 2 (West coast), four geriatricians and three oncologists participated; and in Institution 3 (South), two geriatricians and four oncologists participated (Table 1).

Table 1. Characteristics of Study Sample

	Institution 1	Institution 2	Institution 3
Total participants	7	7	6
Female	4	3	2
Region	Midwest	West	South
Average years since graduating medical school	23.1	30.3	16.5

Participants discussed how they assess whether they can trust caregivers, how they perceive or determine whether caregivers trust them, and the role of culture in trust-building with caregivers. In addition, they described facilitators and challenges to integrating caregivers within care teams.

Assessing trust in family caregivers

Participants discussed multiple dimensions of trust that have been identified in the literature including the caregiver's: a) competence; b) fidelity; and c) reliability/dependability.

Participants assessed caregivers' *competence*, or their skill and ability to carry out a particular task (Raj et al., 2019), including their insight and responsiveness to their care recipient's needs. This included decisions made during the visit as well as outside of the health care setting. For instance, one participant explained:

You're starting to get a sense in the first couple of weeks ... Are you really going to be able to have this caregiver control meds, for example, because if patients have a lot of nausea meds, are they going to get confused, is it going to be a real issue? – P20

In addition, they assess caregivers' *fidelity*, meaning whether they are acting in the best interest of the patient (i.e., the care recipient) (Wilk & Platt, 2016). Participants discussed that in some circumstances caregivers might demonstrate fidelity by advocating for the patient or making decisions that align with the patients' preferences. However, in other cases, caregivers might demonstrate fidelity by urging the patient to consider the physician's advice if it is in the patient's best interest, even if the patient has a different preference that could lead to an adverse outcome. Participants also reported being attuned

to the caregiver's kindness towards the patient, the patient's autonomy in decision-making in the presence of the caregiver, the patient's verbal and non-verbal cues, and the extent to which the caregiver respected the patient's preferences and opinions:

If the decision that the caregiver is expressing is in alignment with what either the patient has previously expressed as their preference, or is in alignment with what the physician is saying is in the best interest of the patient, then I think ... that to me is evidence that the caregiver has the patient's best interest at heart. Yeah, I think it does speak to trust in that person. – P6

Another illustrated:

Some of that is nonverbal. They [the patient] looks at their caregiver, they have body language that suggests that their caregiver is an important part of that conversation. They sometimes explicitly tell you, 'I want my husband to be here.' But if you have a sense of people, you can see when you actually should be screening for domestic abuse, for example, and those are situations in which I'm very conscious of limiting my information to those people so that the patient remains in power to be able to guide how much information they want. – P12

Participants discussed that they assess whether a caregiver is *reliable/de-*

pendable in doing certain tasks for their relative in order to assess whether they can trust them (Raj et al., 2018). For instance, they evaluate whether a caregiver will follow through with a particular task (e.g., changing their care recipient's diet) or is engaged in their relative's care (e.g., accompanying the patient to the visit, taking notes, eye contact, body language). One participant explained:

Are they punctual? And are they coming to an appointment? That is certainly a very strong clue if they don't come. Or do they call in and let you know, "I will be late?" All those little things, I think, you can compose into an overall assessment. – P11

Participants were also attuned to caregivers' engagement as a signal of their reliability/dependability. They explained that caregivers' attention and participation in the conversation could signal whether they could be counted on to follow through with instructions or recommendations, and to ask questions during instances of uncertainty:

I ask them, "Do you have any questions, now that we talked to the patient?" Most supportive [caregivers], are actually the ones who come up with questions and take the stress off the patient's hands ... But if they're disinterested ... if they just have not said a single word during the encounter, doesn't tell me that they're a particularly significant part of the patient's circle of dependence. – P14

Assessing Caregiver Trust in Physicians

Participants recognized that they could not be certain whether a caregiver trusts them but used signals to try to determine caregivers' trust in them. These signals included the patient and caregiver returning for subsequent visits and verbal (e.g., expressing gratitude) and non-verbal cues (e.g., body language). Another signal included whether caregivers ask questions and the manner in which they ask questions. For instance, a caregiver asking many questions about a treatment or recommendation in a manner that indicated their wanting to know more, signaled to participants that the caregiver trusted them:

I have another patient who he's very anti-vaccine, very anti-mask for COVID, and they wear masks in the clinic, but they think it's a joke ... But they really want to know my opinion, and they engage with me and like, "Well, what do you think?" And then they sit, and they listen. And they're like, "Okay, okay." And so, even as frustrating as those conversations are, if they didn't trust me, or they thought I was going to chastise them or something, they probably wouldn't bring it up in the first place ... Those are the patients I know that trust me.
– P5

In contrast, however, participants also illustrated instances where they felt a lack of trust based on how caregivers asked questions and then would per-

sist in opposing the response or recommendation provided by the physician:

If they do not trust me as a physician, they ask questions, which are contrary to what I offer them. So if I'm suggesting option A, then they would be focused on option B and, not to have a discussion, but to have an antagonizing wheel. – P10

Though participants identified ways that they assess whether they can trust caregivers and perceived whether they are trusted by caregivers based on specific signals, culture emerged across interviews as an important theme in trust dynamics between physicians and caregivers.

Role of Culture

Participants explained several strategies for building trust with caregivers including considerations for trust-building with culturally diverse patients and their caregivers. First, participants emphasized that trust likely means the same thing across cultures, and yet the process for building and establishing trust may be different. Participants in two institutions (west coast and Midwest) discussed the cultural aspect of trust-building primarily in terms of navigating language and ethnic differences while participants in the southern institution primarily discussed racial, religious and socioeconomic diversity and its impact on trust-building. Participants, accordingly, had varied approaches to building trust with caregivers and navigating the cultural con-

text of their patients and caregivers. For some, building trust with a caregiver involved learning about cultures of predominant patient communities in their own time or by asking colleagues or social workers for support.

Participants also learn about their patient's culture directly from patients and caregiver(s). This included norms around the health care visit, for instance, in cultures where caregivers are expected to relay important health information to the patient on behalf of the physician, or in other cultures where medical decisions are made at the family level rather than by the patient independently:

I think you have to understand those cultural differences and you have to make sure that they know that you care about those cultural elements ... In some cultures, when you talk to someone, you have to look at them in the eyes. In some other tribes, they take it as an insult. So, you have to ask explicitly, 'Is there any particular elements that I need to know about?' – P9

Another explained:

My view is first of all, to really listen to where they come from ... not geographically necessarily, but where is their cultural home and what are their spiritual needs? And what is the structure within a family? Is it a strongly patriarchal structure, or is it a more balanced, or is the mother or grandmother still the person

... one has to listen and sort of really feel your way into it. – P11

Participants discussed that building trust with caregivers requires recognizing cultural differences and identifying ways to align practices with patients' and caregivers' norms and preferences. These actions were seen as fundamental to developing a strong and sustainable relationship with caregivers and maintaining their engagement in their relative's health care.

Integrating Caregivers into the Care Team

Participants discussed multiple facilitators and barriers associated with integrating caregivers into the health care team as a way towards maintaining relationships that could promote effective patient care. They explained that early conversations with patients about caregivers could facilitate effective integration. These conversations would ideally occur in the first visit, and would involve setting expectations about caregivers' involvement, evaluating caregivers' competence, reliability, and fidelity, assessing family dynamics, and becoming familiar with the family and home context. For instance, one participant illustrated that conversations with patients about who they consider a "caregiver" is relatively common among physicians who frequently work with caregivers:

I think that's probably the one thing that is relatively standardized with practices and groups of doctors that often work with

caregivers, that you start off with the patient about what they're willing to and who they would like to include within that circle of caregivers or family members that are involved within their care. – P16

Participants were also optimistic about the possibility of digital health technology, and specifically, telehealth (i.e., the delivery of health care and information via telecommunications such as videoconferencing and electronic transmission) facilitating the integration of caregivers (NEJM Catalyst, 2018). Telehealth emerged as a particularly promising way for participants to connect with caregivers during COVID-19 that they believed would continue to be useful beyond the pandemic. Participants described that assessing whether they can trust a caregiver may be slightly more difficult via telehealth because it is more difficult to observe signals such as engagement or patient-caregiver dynamics; however, they viewed caregivers' presence on telehealth visits as an indication of their engagement and dependability.

And yet, participants also recognized barriers to caregivers' integration in the health care team. The most commonly reported barrier was risky dynamics between the patient and caregiver, for instance in an abusive relationship or in a relationship with power asymmetries:

I think the drawback is when the caregivers try to take over the meeting ... or if they have some other agenda [like] they want the

person to go to a nursing home or turn over their finances to someone ... So that's where we do the divided appointments.”
– P7

In other cases, patients may not want caregiver involvement, for instance, if patients want to remain independent and having a caregiver present reinforces their perception of “being a burden” or “being dependent.”

Despite these barriers, participants in our study expressed that their specialties often warranted integrating caregivers and sometimes involved finding creative solutions (such as using FaceTime) to engage caregivers, especially when caregivers cannot always be physically present during an appointment.

Comparing Trust-Building with Caregivers Versus with Other Physicians

When asked who they were more likely to trust, participants were often visibly surprised by our question, but were also very thoughtful and candid in their responses. Some participants expressed more trust in caregivers, given their familiarity with the patient:

It's better to hear from the patient and their family member. Because what my colleague or my doctor would tell me, I don't think that it's going to be any different than how I'm going to approach it. But if I talk to the caregiver, I get a different perspective. For example, nausea,

symptom burden, or fatigue, the referring physician will tell me, ‘He doesn’t have a lot of fatigue, he’s doing fine.’ But then when you talk to the caregiver, they tell us that ‘He’s doing very bad, he’s not able to walk.’ So, I would trust the family member more in that situation. – P10

Others discussed that certain situations or types of information warrant greater trust in caregivers versus other physicians:

As far as objective information, data are concerned, I think I would definitely lean towards the physician. But when it comes to assessing sort of the whole environment, all the other contributing factors to a patient’s condition, it is, I think, definitely a family member who is in a better position and generally, able to provide more detail that may be helpful that the physician, even though he or she may have seen the patient a couple of times, may not even be aware of. – P11

Discussion

In this study, we conducted qualitative interviews with twenty physicians across three institutions to understand how they assess trust with caregivers, the role of culture in trust-building processes, and to examine the facilitators and barriers to formally integrating caregivers into health care teams. To our knowledge, this is the first study to examine trust dynam-

ics between physicians and caregivers, who are often responsible for communicating with care providers and accompanying patients, but are rarely integrated into health care teams in a formal or standardized way (Iott et al., 2020; Wolff et al., 2012). Here, we focused on physicians from geriatrics and oncology, anticipating that the duration and intensity of the physician-patient relationship could yield insights into trust-building in a context where it may be especially valuable.

We found that, consistent with prior literature, physicians identify a caregiver as being trustworthy when they demonstrate reliability/dependability, competence, and fidelity (Corazzini, 1977; Moskowitz et al., 2011; Raj et al., 2019; Thom et al., 2011; Wilk & Platt, 2016). These traits indicate to physicians that the caregiver’s involvement will be beneficial to the overall care of their patient. In addition, physicians also observe dynamics between the patient and their caregiver to evaluate the quality of support provided in the relationship. Physicians perceive or determine whether a caregiver trusts them by evaluating the level and nature of their engagement during health care visits—a pattern that is easier to detect in-person but can be enabled through technology. Although we explicitly asked participants to reflect on these trust dynamics with caregivers for the purpose of the interview, responses indicated that in many instances, they deliberately assess these signals of trust with caregivers (e.g., verbal cues, engagement) either during the visit or after, and particularly in circumstances

where caregiver engagement could be problematic for the patient's wellbeing.

We also found that culture plays an important role in trust-building and maintenance between physicians and caregivers. Trust building varies across cultures due to different social norms and distinctions between personal and professional relationships (Doney et al., 1998). Often, physicians spend time learning about cultural nuances from their patients and their families, and on their own time (e.g., through reading articles). They discussed that this enables them to effectively build and maintain trustful relationships with patients and their caregivers. They also perceived that demonstrating an interest and commitment to culturally sensitive care also facilitated caregivers' meaningful involvement in their relative's care. In fact, participants in our study were enthusiastic about integrating caregivers into care teams in the geriatrics and oncology contexts. They considered caregiver involvement to typically be beneficial, especially when initiated early on in the relationship and in circumstances of positive patient-caregiver dynamics; and trust may facilitate this integration of caregivers. It is notable that participants in our study expressed that they may trust physicians more for some types of information or tasks while trusting caregivers more for other information or tasks. This suggests that caregivers may, indeed, be a critical component of the health care team and that their integration—when built on trusting relationships with physicians—can contribute greatly to patient care. As suggested in

previous literature, technology offers particular utility in facilitating caregiver integration but is largely dependent on caregivers' access to and comfort with the technology, and patients' preferences for their caregivers' involvement (Wolff et al., 2016, 2017; Wolff et al., 2016).

Implications for Policy and Practice

Findings from our study suggest a critical role of trust—and the role of physicians and the care team—to integrate caregivers into health care teams so they can support their relative(s) in and out of the health care setting. This may involve a formal discussion to assess caregiver competency, reliability/dependability, fidelity, and dynamics with the patient. For instance, during an initial consultation or at a time in the process that seems most appropriate based on the caregiver's readiness, physicians or social workers could assess caregivers' understanding of their relative's health conditions and care needs, along with their plans for following recommendations in the home. This would provide an additional opportunity for physicians and caregivers to build trust with one another and an opportunity to screen for threatening (e.g., abusive) patient-caregiver dynamics. There could be opportunities for developing formal procedures by which designated caregivers could indicate their understanding of medical tasks and responsibilities (e.g., medication management) in the home (e.g., skills training videos followed by discussions or certifications).

While some policies (e.g., the Caregiver Advise, Record, Enable Act) requires hospitals to ask patients if they have a caregiver and contact that designated caregiver with discharge information, these policies have not been implemented across all states and evaluating the implementation and effectiveness of the policy has demonstrated challenging (Coleman, 2016; Mason, 2017). One possibility would be to develop standardized language in consent documents for patients in both inpatient and outpatient settings such that patients can designate a caregiver, the extent of information they wish to be shared with the caregiver, and preferred modes of communication between caregivers and clinicians. This would provide the patient with a sense of autonomy over their health information and will equip healthcare providers with a better, more formal understanding of their patient's preferences regarding their caregiving circumstances.

Integrating caregivers into health care teams also requires system-level efforts to invite and recognize caregivers as a key part of care teams—that they are not just visitors, but active partners in patient care (IPFCC, 2021). In fact, physicians in our study distinguished that the types of trust they experience with other physicians are often different from the types of trust they experience with caregivers; and these different aspects of trust complement each other, leading to the communication of different—but equally critical—pieces of information. This may require formalizing a process by which clinicians can designate a caregiver as being involved

in a patient's care, and even the types of support they provide. This process would be distinct from patient consent documents, but would require a standard conversation with patients and their caregivers. Information distinguishing patients who should be consulted individually versus those to be consulted with their caregiver could inform efficient visits that mitigate the risk of engaging caregivers who may not have the patient's best interest at heart. This could be especially important given persisting issues of fragmented care within the health care system, particularly for older adults who may see multiple specialists for distinct health conditions and associated needs. For these patients, standard language in their health record could be conveyed to different clinicians involved in a patient's care such that all clinicians would be attuned to the patient's circumstances and dynamics with their caregiver.

Achieving this level of integration will also require that health care organizations recognize and emphasize the relationship between caregiver integration and quality of care. Identifying the related structure, process, or outcome quality measures will require further study, and policymakers will need to develop procedures for reimbursing high performing clinicians and health care systems (i.e., specifically in terms of their engagement with caregivers) (National Alliance for Caregiving, 2021; Phongtankuel et al., 2020). This will also require institutional encouragement of greater collaboration between physicians and other professionals such as social workers, medical interpret-

ers, patient navigators, and community health workers, all of whom could facilitate important discussions with caregivers and contribute to the building of trust between systems, providers, caregivers, and patients. One promising first step could be for healthcare systems to create a field in the electronic health record to designate a caregiver (National Alliance for Caregiving, 2021).

Technology-Facilitated Caregiver Integration

While participants in our study discussed the value of telehealth in engaging caregivers during visits, they did not discuss a standard protocol for doing so; it is possible that participants in our study were more likely to invite a caregiver to participate in the telehealth visit. However, studies with caregivers suggest that may not be common practice—or at least, consistent—to invite and facilitate caregivers to participate in telehealth (Raj et al., 2020). Further research is needed to understand the potential for developing caregiver-facing portals with patients' consent that could enable better exchange of information between caregivers and physicians. While studies have examined the use of tools within the health care visit itself, trust extends outside of the doctor's office—it is critical to ensure continuity of care not only for patients, but also for their caregivers (Wolff et al., 2017). Such a portal could have limited information as designated and consented to by patients (e.g., medication management instructions) and culturally tailored information (e.g., dietary

information) (Raj, Zhou, et al., 2021). This additional channel of communication could help caregivers become part of important conversations between health care team members (including physicians, nurses, social workers, and other professionals) and contribute meaningful information while also obtaining information necessary to help them support their relative. Policies such as the Health Insurance Portability and Accountability Act (HIPAA) could be modified to account for the growing and critical role of caregivers beyond circumstances where caregivers are considered surrogate decision-makers for patients (Latulipe et al., 2018).

Indeed, additional designations and discussions can take time, and health literacy presents a barrier to caregivers' engagement in the healthcare system that has been especially emphasized in the context of cancer caregiving (Fields et al., 2018; Wittenberg et al., 2017). However, physicians in our study indicated that dedicating time to trust-building supported sustainable relationships and engagement from patients and caregivers. In contrast, they saw time constraints as barriers to trust building with implications for continuity of care and patient follow up. This investment could be especially valuable in relationships with patients and caregivers from diverse cultures who may already experience mistrust in the healthcare system (Nong et al., 2020). Caregivers of these patients may even have an important role in facilitating patient trust in physicians, and in turn, physicians may act as a critical broker of trust with the system (Platt et al., 2019)

store and transfer information across boundaries of health care, public health and research. Health information brokers such as health care providers, public health departments and university researchers function as “access points” to manage relationships between the public and the health system. The relationship between the public and health information brokers is influenced by trust; and this relationship may predict the trust that the public has in the health system as a whole, which has implications for public trust in the system, and consequently, legitimacy of involved institutions, under circumstances of health information data sharing in the future. This paper aims to discuss these issues. Design/methodology/approach In this study, the authors aimed to examine characteristics of trustors (i.e. the public. Future research should examine the nuances of trust-building in relationships between culturally diverse physicians and culturally diverse caregivers. Fostering relationships with caregivers can also facilitate caregivers’ and patients’ comfort with asking questions to clinicians and advocating for their needs. This discomfort might be especially salient for caregivers who are unfamiliar with the U.S. health system or have experienced discrimination or other forms of exclusion within the system (e.g., language barriers) (Shim, 2010).

Additionally, addressing the physical, mental and employment burdens associated with caregiving remains an issue to be addressed through policy (Adelman et al., 2014; Kim et al., 2012). Participants expressed that caregivers

who are reliable/dependable in coming to appointments and follow recommendations may be assessed as being more trustworthy than caregivers who appear disinterested or disengaged. While our participants emphasized nonverbal cues (e.g., texting during an appointment versus notetaking), caregiver engagement may be limited by the extensive and time-consuming responsibilities that caregivers uphold. For example, caregivers with the dual pressures of employment and caregiving responsibilities may face time and financial constraints in attending health care visits (Feinberg, 2016). Policies enabling the passage of information to trusted and designated caregivers may be particularly valuable in these cases, where having more information about their relative’s health care needs may help caregivers perform various tasks. Professionals such as social workers may be especially relevant to facilitating this process of information provision to caregivers. Further, financial support for caregivers may help alleviate some of the financial burden associated with caregiving, such as through Medicaid waiver programs (Kaye & Teshale, 2020).

Implications for Medical Training

Our study also informs several recommendations for medical training. As we learned from several participants, while physicians are taught to build relationships with physicians, the process of building relationships with caregivers is primarily learned through experience in certain specialty contexts. Given our aging population and the increasing role of caregivers in health care across

specialties (Ortman et al., 2014; Wolff et al., 2012; Wolff et al., 2020), the likelihood of interacting with caregivers will continue to grow. Although participants in our study primarily related the COVID-19 pandemic to the subsequent potential for using technology to facilitate integration with caregivers, the pandemic has also likely increased the likelihood of caregiver involvement across various clinical domains (e.g., due to long COVID) (Olsen, 2021).

Participants in our study were relatively experienced, having an average of 16 to 30 years of experience in the profession. Future research could examine how physicians who are newer to the profession approach family engagement and could also evaluate how medical training has evolved over time to incorporate lessons about family caregiver engagement, particularly to assess whether this form of training has grown alongside the increasing global emphasis on supporting family caregivers. Medical programs may consider incorporating lessons on trust-building with patients and caregivers throughout training. This may require further research to identify the specific roles and responsibilities of caregivers within a health care team and recognizing the value that caregivers can provide in patient care. For instance, as we found in our study, caregivers may be critical to patients enrolling and continuing their care, but they may also be invaluable sources of information about patient behaviors, concerns, preferences, and needs in their place of residence—where they likely spend the majority of their time. Health care and

caregiver organizations along with programs such as Medicaid could expand opportunities for training caregivers in health care tasks ranging from observing patient progress to managing medication side effects (Coleman, 2016; Raj & Singer, 2021; Teshale et al., 2020). Support from these entities could assist clinicians so that they can immediately involve caregivers without taking time from consultations to train caregivers.

Involving caregivers early on could be beneficial, not only in the geriatrics and oncology contexts, but also in other domains such as primary care as well as other specialties such as nephrology and endocrinology. For instance, if a primary care physician is aware of an individual who may serve as a caregiver in the future, their engagement from an early stage could be beneficial both to the caregiver as well as to the patient later on in their life (Raj et al., 2021). The relationship between primary care physicians and patients is distinct in that it could be built over decades, and a patient who did not initially require support may eventually receive support from a caregiver. This may present an interesting scenario where physician-patient trust could be well-established but building physician-caregiver trust may require effort. Future research should seek the perspectives of patients, caregivers and physicians to better understand their preferences for caregiver involvement in health care teams in addition to concerns about training and health literacy and their perspectives on the boundaries of formal and informal health care work across different clinical contexts. Research should also solici-

it the perspectives of family caregivers, and specifically, how they determine trust in physicians and other health care professionals who are caring for their relative(s), as well as how this influences their subsequent involvement and decision-making in health care related responsibilities.

Limitations

Our study has some limitations. Although we conducted all interviews via videoconferencing to build rapport with participants, it is possible that some participants were less forthcoming about their experiences or perspectives than they would have been in person. Our use of the IPFCC list of exemplary hospitals to select participating institutions may not be inclusive of hospitals and systems that use other approaches to engage with caregivers and does not account for biases or limitations in how organizations are selected as exemplars. We also selected larger institutions from which we recruited participants; it is possible that smaller institutions or clin-

ics may build trust with caregivers and integrate them in other informal ways because of long-term and even multi-generational relationships with family members. The perspectives of these types of institutions should be sought in the future as well.

Conclusion

Involving caregivers in health care teams has the potential to improve patient care, facilitate physician decision-making, and support caregivers. Integrating caregivers in a more standardized way requires fostering sustainable relationships between caregivers and physicians. Medical training has an important role in formalizing, standardizing, and even redefining the role that caregivers have in health care teams in order to facilitate their involvement and potentially improve patient care. Building trust-driven relationships with caregivers may represent a promising first step to effectively integrating caregivers.

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Ethical Approval

This study was granted permission with exemption by the University of Illinois at Urbana Champaign Institutional Review Board on January 12, 2021 (protocol #21563).

Disclaimers

None.

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