Barriers and Best Practices in Disclosing a Dementia Diagnosis: A Clinician Interview Study

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ABSTRACT: The vast majority of individuals with dementia want to receive a diagnosis. Research suggests, however, that only a fraction of individuals with dementia receive a diagnosis and patients and families often feel the information is poorly explained. We thus aimed to assess clinician-reported barriers to dementia disclosure and recommendations for giving a dementia diagnosis. To accomplish this, we performed telephone interviews with 15 clinicians from different specialties using a semi-structured interview guide. Transcripts were analyzed thematically. Clinician-reported barriers fit 3 categories: patient and caregiver-related barriers, clinician-related barriers, and barriers related to the triadic interaction. Patient and caregiver-related barriers included *lack of social support, misunderstanding the diagnosis*, and *denial.* Clinician barriers included *difficulty giving bad news, difficulty communicating uncertainty*, and *lack of time.* Triadic interaction barriers included c*hallenges meeting multiple goals or needs* and *family requests for non-disclosure.* Recommendations for best practice included for clinicians to foster relationships, educate patients and family, and take a family-centered approach. Clinicians described recommendations for fostering relationships such as using *empathic communication* and *developing and maintaining connection.* Educating patients and families included *tailoring communication*, *explaining how the diagnosis was reached*, and *following up*. Family approaches included *meeting with family members prior* to delivering the diagnosis and *involving the caregiver* in the discussion. Findings may inform updated recommendations for best practices when communicating a dementia diagnosis.

KEYWORDS: Dementia [MeSH], diagnosis [MeSH], communication [MeSH], health communication [MeSH], interview [MeSH]

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Introduction

More than 6 million Americans live with Alzheimer's disease and related dementias (ADRDs), representing more than 1 in 9 people ages 65 and older.[1] At age 45, the estimated lifetime risk of dementia is 1 in 5 for women and 1 in 10 for men.[2] There is an increasing consensus that early detection of dementia is beneficial. A diagnosis in the initial stages of the disease permits the individual with dementia to have access to pharmacological and psychosocial interventions[3] and express preferences for future care.[4,5] However, there are several challenges in providing clear diagnostic information to individuals with dementia.[6,7]

Challenges include both the clinicians' ability to diagnose dementia and their communication with patients and families. First, clinicians may not be diagnosing dementia in a timely manner or appropriate rate. For example, some Medicare beneficiaries report symptoms consistent with probable dementia but have no diagnosis code for this (National Plan to Address Alzheimer's Disease[8]). Second, when clinicians do suspect dementia, many patients remain unaware and may not receive a formal diagnosis.[9] Only approximately half of Medicare beneficiaries with a billing code for dementia in their records report having knowledge of this diagnosis.[9] When diagnoses are made and communicated, patients and families often feel they are not explained in a satisfactory manner.[10]

Communicating a dementia diagnosis is important to facilitate patient-centered care. Yet, while clinicians may inform caregivers regarding a patient's dementia diagnosis, only 48% of specialists and 34% of primary care physicians routinely communicate the dementia diagnosis to the individual with dementia.[11] Most individuals with dementia want to receive a diagnosis. A 2014 systematic review found that more than 90% of individuals without cognitive impairment said they would want disclosure of a dementia diagnosis. Among those already receiving memory care, 85% wanted to be informed of a dementia diagnosis.[5] In a subsequent study, more than 90% of individuals with dementia said that they would want disclosure of the diagnosis as soon as possible.[12]

Table 1. Reported barriers to disclosing a dementia diagnosis.

CLINICIAN-LEVEL BARRIERS	PATIENT/FAMILY-LEVEL BARRIERS	SYSTEM-LEVEL BARRIERS
Low confidence in own ability to diagnose dementia	Lack of ability to understand diagnosis	Limited access to specialists and support services
Not wanting to give a diagnosis that isn't definite	Not wanting diagnosis	Insufficient remuneration for providing dementia care
Communicating prognostic information is challenging due to the uncertain illness trajectory	Fear of losing independence	Diagnosing dementia may strain medical systems
Lack of training on how to communicate diagnosis	Misunderstandings or misattributions about the symptoms of dementia	Insufficient training for how to give dementia diagnosis
Perceived lack of benefit of diagnosing dementia (eg, due to lack of treatments)		Concern about making an accurate diagnosis with limited time and information
Concern regarding patient or family response (eg, emotional distress, or feeling that patient does not want diagnosis)		
Concern regarding stigma surrounding dementia		

With this discrepancy between the proportion of individuals desiring a diagnosis of dementia when applicable, and the proportion of individuals who actually receive a diagnosis, investigating barriers to disclosing a diagnosis is crucial. Prior research suggests numerous barriers for communicating a dementia diagnosis (Table 1) which includes clinician, patient/family, and system-level factors.[6,8,11,13-19]

Improving the communication of a dementia diagnosis in a timely manner is also recognized as one goal of the U.S. National Plan to Address Alzheimer's Disease.[8] However, consensus-based recommendations for clinicians' disclosure of a dementia diagnosis are now more than 10 years old.[20-22] A 2020 review identified that specific guidelines on how to disclose a dementia diagnosis are lacking.[23] We thus aimed to further investigate more recent clinician-reported barriers and recommendations for how to disclose ADRD diagnoses as part of a larger project to update guidelines for best practices when communicating a diagnosis.

Methods

Study design

This study utilized a descriptive qualitative design[24,25] with data collected through telephone interviews. The current research questions and analysis are part of a larger study investigating patient, caregiver, and clinician experiences in receiving and giving dementia diagnoses and recommendations for optimal disclosure. This study received IRB approval (IRB202000212).

Population and recruitment

We recruited clinicians who disclose dementia diagnoses (rarely or commonly, to obtain a breadth of experiences). Because of state funding for this project, recruitment focused on Florida-based clinicians. We recruited clinicians at the 3 study sites. Additionally, we recruited clinicians through Florida memory disorder clinics, targeted Facebook advertising (designed and disseminated by the University of Florida Clinical and Translational Science Institute), Florida Dementia Care and Cure Initiative task force mailings, and advertising through the Florida Medical Association. Interested clinicians could receive study information via phone or email. All participants received the informed consent document to review prior to the telephone interview and provided verbal consent to participate. Participants received a $25 gift card after completing the interview.

Data collection and analysis

Interviews were conducted by phone in English by a female doctoral student in healthcare communication (ENW) who had no prior relationship with participating clinicians. The semi-structured interview guide was developed by the study team and based on prior literature in healthcare communication (Supplemental Appendix 1). Questions focused on the dementia diagnosis disclosure process, with the possibility of additional questions or probes when appropriate.[26] It also included questions regarding the participants' backgrounds (eg, demographics, training, specialty, years in practice). Interviews were audio-recorded, professionally transcribed, and de-identified prior to analysis.

Reflexivity and responsiveness of the analysis team (ENW, CLB, MJA) included using an iterative process between study design, data collection, and data analysis to ensure methodological rigor.[27] Member checking was not performed as we used Morse's[28] criteria for rigor in qualitative research, in which member checking is not a recommended strategy for increasing validity or reliability of qualitative findings. We used thematic analysis as a method to analyze data,[29,30] which was managed using ATLAS.ti software. This qualitative approach involves several steps, such as developing initial codes, collapsing codes into similar themes or categories, and developing thematic descriptions. Using the steps outlined by Braun and Clarke[29], coders familiarized themselves with data before developing codes for the research questions (barriers, recommendations). Following preliminary development of codes, codes were collapsed into initial themes and refined. We then organized themes into categories based on overarching thematic similarities.[31] The primary coder (ENW) coded each of the 15 transcripts, with regular feedback from additional authors (CLB, MJA). The codebook was refined several times throughout analysis to reflect theme development and descriptions. Themes were considered saturated when no new themes emerged (ie, inductive thematic saturation).[32] The second coder (CLB) close-coded 5 of the transcripts to verify the codebook before additional authors provided final feedback, resulting in a finalized codebook.

Findings

Data collection and participant demographics

Interviews occurred between June 2020 and February 2021. Twenty-two clinicians expressed an interest in the study and 15 participated in the telephone interviews. The median participant age was 53 years (range 34-82 years). About half of the participants identified as female (7, 47%) and most participants reported their race and ethnicity as white non-Hispanic (11, 73%). Two participants identified as white Hispanic (13%), 1 as black/African American (7%), and 1 as Asian (7%). Years in practice ranged from 2 to 50 years (median 23 years). Specialties included neurology (5, 33%), neuropsychology (3, 20%), family medicine/geriatrics (5, 33%), psychiatry (1, 7%), and social work (1, 7%). Two of the participating neurologists specialized in dementia. One of the individuals with a primary focus in family medicine/geriatrics was a nurse practitioner. Most participants (10, 73%) were associated with an academic medical center.

Barriers to disclosing a dementia diagnosis

Clinicians discussed several types of barriers that make effectively disclosing a dementia diagnosis more difficult. We identified 3 overarching categories: patient and caregiver related barriers, clinician related barriers, and triadic interaction related barriers.

Patient and caregiver barriers

Patient and caregiver barriers described by clinicians included: *lack of social support, misunderstanding the diagnosis*, and *denial.* These barriers were often described by clinicians as making the understanding of the initial diagnosis more difficult for patients and caregivers.

Lack of social support. Clinicians described *lack of social support* as a barrier, both in terms of patients who lacked a consistent caregiver and patient-caregiver dyads who had insufficient support for daily tasks and caregiver respite: "Lack of social support around the patient and caregiver [are significant barriers]. Basically, a consistent caregiver for them" (01). This theme also pertained to lack of social support for individuals in the caregiving role and caregiver fatigue: "More importantly, [I discuss] the support from the family and how to tackle little things, everyday things in the family. . . . Especially because if there is only one caregiver involved, there's going to be a lot of fatigue for that caregiver. And I talk about that a lot, and then I try to rally other people that can be part of the support system for that patient" (08).

Misunderstanding of the diagnosis. Clinicians described *misunderstanding the diagnosis* as a barrier for patients and caregivers: "Sometimes, people don't understand the insight into [the diagnosis] as far as patients go. So that makes it a bit more difficult to say, 'you have these difficulties,' but they can't see them" (01). This theme also included confusion about the different types of dementia, such as conflating all dementia with AD. 'They come into the clinic and our patients are confused, because they're like, 'Well, I have dementia.' And that's when I have to give the education that dementia is an umbrella term. Alzheimer is the form of dementia" (07). Furthermore, certain assumptions or stigmas regarding ADRD can cause misunderstanding: "The difficult one is trying to see how people understand the different types of dementia. . . Folks come with their own experiences and beliefs about what dementia is, and what they can and can't do about it" (09).

Denial. Denial was described as patients or caregivers rejecting or disagreeing with the dementia diagnosis. "I think the patient is often in denial, or they have low insight into their condition, and the family obviously sees otherwise" (10). Other times, caregivers were described as the individuals who were in denial about the patients' symptoms and diagnosis:

> Sometimes care partners have poor insight into the illness, where there's a level of denial [when] their loved one is elderly or over 65. And they think that the [patient's] symptoms, it's just part of normal aging, right? So, it's very difficult for them to understand . . . they often want to explain it away. They rationalize [symptoms] (03).

Some clinicians described tensions that arose when patients and caregivers disagreed about the diagnosis: "Very often, the person who is receiving the diagnosis is not opposed to getting it, but sometimes relatives or other people don't want to hear it" (04).

Clinician barriers

Barriers relating to clinicians and clinical settings included *difficulty giving bad news, difficulty communicating uncertainty*, and *lack of time.*

Difficulty giving bad news. Clinicians identified *difficulty giving bad news* as one barrier to effectively communicate a dementia diagnosis. "For most people, it's really uncomfortable giving other people bad news. And I think it takes a lot of practice and experience to gain comfort with it" (12). However, difficulty giving bad news was also often described as particularly challenging due to ADRDs. One clinician explained, "[Clinicians] will say to me, 'I'm afraid to give this diagnosis even to the care partner, because it's such a horrible diagnosis'" (02). Another clinician said, "Nobody wants to be the one that delivers the bad news and news that is so determinant. You're delivering something that we know has no cure when you deliver a diagnosis of Alzheimer's disease, right? So it's hard to do" (13).

Difficulty communicating uncertainty. Difficulty communicating uncertainty was identified as another clinician barrier. ADRD diagnoses are often associated with varying degrees of certainty regarding the underlying etiology of the dementia symptoms. Addressing uncertainty was seen as an important part of communicating the diagnosis: "Explaining the logic of that diagnosis to patient and family. . . enables me to explain to a patient and family members why I drew the conclusions I did. I can also explain to them points of uncertainty" (14). Sometimes, access to clinical resources was described as aiding in communicating uncertainty. For example, a clinician stated that "having [access to diagnostic] tools is helpful, 'cause then, you can give them a little bit more certain [diagnosis].. . . and you can give them a little bit better idea about what to expect" (10).

Lack of time. Another barrier identified by clinicians was *lack of time*, primarily related to clinic schedules and appointment length. "Time is probably the main barrier. . . it's really hard to get through all of the history and physical exam and counseling" (12). In addition to the medical evaluation, a diagnosis of ADRD requires discussions about the patient's future that are difficult to complete during a single appointment. There is limited opportunity to discuss prognosis, advanced directives, and wills or estate planning, especially during the appointment where the diagnosis is being made: "I think those are the aspects of care that I feel that I'm leaving the most out or attending to in less detail when I should be, because there just isn't time" (14). Finally, clinicians mentioned that lack of time also creates challenges associated with communicating uncertainty or educating patients who misunderstand the diagnosis. As 1 clinician said, "When we have more time, it's more time to sit with the patients, the families . . . the more time we have to facilitate the conversation, the better" (15).

Triadic interaction barriers

The term "triadic interaction" is used in clinical communication research to describe the occurrence of having a doctor, patient, and caregiver together at the clinical consultation. Triadic interaction barriers were described as those that make the appointment more difficult to facilitate and meet the needs of everyone involved. This was often described in terms of conflict within the triad due to competing interests or wishes, such as c*hallenges meeting multiple goals or needs* and *requests for non-disclosure.*

Challenges meeting multiple goals or needs. Challenges meeting multiple goals or needs refers to the difficulties in creating a balance between meeting the patient and caregiver needs, particularly if these needs conflict with each other. Some challenges could arise due to competing preferences:

> Interviewer: You said that sometimes it's not necessarily the patient that doesn't want to hear [the diagnosis], but it's their caregivers [who don't]?
>
> Interviewee: Right. Sometimes they [patients] don't want to hear it and sometimes they do want to hear it. So it becomes very challenging – you need to address the expectations that people are having (04).

Similarly, another clinician emphasized the challenge of meeting multiple needs: "[A dementia diagnosis] is much more nuanced. . . how do you deliver a diagnosis and how do you do it in an honest and a sensitive way? And how do you meet the needs of everybody involved while being scientifically honest" (02)?

Requests for non-disclosure. Clinicians also identified *requests for non-disclosure* as a triadic interaction barrier. This involved family members not wanting the clinician to disclose the diagnosis to the patient: "We always get these family members that call up and say they don't want you to mention Alzheimer's. I don't see any value of not mentioning it, so I always mention it" (15). Another clinician had similar experiences: "When we talk about the diagnosis, [the family] will say to me, 'please don't tell my loved one they have Alzheimer's disease.' And at that point, I will have a conversation with that care partner. . . because I can't – I have to tell [the patient] the truth" (03). These types of conversations make it difficult for clinicians to meet the needs of both the caregivers and the patients: "The biggest issues come when family members say, 'You can't tell them the diagnosis, it will just devastate them. And then the patient will be going, 'I want a diagnosis. I want to know what's wrong'"(02).

Clinician recommendations for best practices

In addition to querying barriers, we asked clinicians about best practices for effectively delivering a dementia diagnosis. Recommendations included the following categories: foster relationships, educate patients and family, and take a family-centered approach. Themes in each category are presented in italics.

Foster relationships

One type of recommendation for delivering a dementia diagnosis was to foster relationships with patients and caregivers. Clinicians *build rapport*, *use empathic communication*, and *develop and maintain connections* to foster relationships.

Build rapport. Clinicians described their ability to *build rapport* with patients and caregivers as important for effectively communicating ADRD diagnoses. Clinicians sometimes did this by trying to connect on a personal level with patients or caregivers (eg, "When I talk to patients and their families, I always make some connections regarding their lives in some way." 06). For some clinicians, this included their own familial experiences with dementia: "I tell them how I understand 'cause of my experience with patients over the years, and as well as my parents" (06). Building rapport also involved specific communication strategies: "In my opinion, if you are focused on building rapport and you use a lot of emotional communication techniques, you can build a rapport even substantially in the first visit" (12).

Use empathic communication. Empathic communication was described as being sensitive to the needs and feelings of patients and caregivers and was described as particularly important due to the nature of dementia: "It's a pretty emotional moment for people, so a great deal of empathy is called for" (14). Empathic communication was important for delivering the diagnosis and the treatment of patients: "empathy is a main thing. When patients come back to me with the diagnosis of dementia, they feel overwhelmed. They don't know what to expect in the future, how to rethink their life at home" (08). Lack of empathic communication was referenced as a motivating factor for patients to seek a second medical opinion. As 1 clinician said, "I do a lot of second opinions. A lot of patients who had other doctors and feel they don't have the best bedside manner. You know, they want to hear from someone who cares" (15).

Develop and maintain connections. Clinicians' ability to develop and maintain connections was described as important for effectively delivering a dementia diagnosis, including how the diagnosis is received by patients and caregivers. "I think that if. . . you have successfully developed a good [relationship]. . . or you're building a good relationship. . . The same diagnosis is going to be received very differently" (05). Another clinician reported similar experiences: "If [patients and caregivers] think that they're on your side, they get less anti-diagnosis. . .. they have to feel that you're supporting them" (15). Connections are important not only for delivering the diagnosis, but for following up and delivering additional information long-term: "It depends on how you say it and how the relationship has evolved for you – to then sit at that third visit and deliver the new sort of findings. It makes a huge difference" (05). Maintaining connections helps clinicians as well as patients and caregivers: "It definitely gets easier over time as you developed a relationship with someone, I think, to have a deeper conversation and have it go smoothly" (12).

Educate patients and family

The second type of recommendation focused on educating patients and family members about their diagnosis, such as what their diagnosis means, how their lives may change, and differentiating underlying causes of dementia. Clinicians described the following strategies to educate patients and family members: *tailor communication, explain how the diagnosis was reached, educate patients and caregivers about the diagnosis*, and *follow up to ensure understanding.*

Tailor communication. Clinicians recommended to *tailor communication* based on several factors, such as culture, language, education, and patient/caregiver understanding of dementia. "I do my best to translate the science into terms that patients and their families can readily understand. What that means differs from patient to patient" (14). Clinicians also reported tailoring their communication depending on the acceptance or denial of the diagnosis:

> It's also important to understand where the patient and the care partners are at.. . . You can have a care partner who highly suspects that this is going on, and that's an easier way to talk to them about it than somebody who really doesn't think it's this at all. And maybe is in denial or rationalizing. So, you're going to be a little more gentle (03).

Clinicians discussed tailoring education to pre-existing knowledge of the disease ("I think it's important to ask the family and the patient . . . what do they know about the condition?" (08)). Clinicians also highlighted the importance of explaining the diagnosis to patients and caregivers, regardless of their background or familiarity with dementia: "Even if they knew nothing [about the diagnosis], you can kind of explain it to them and kind of answer the questions to their understanding level" (01).

Explain how the diagnosis was reached. A second recommendation was to *explain how the diagnosis was reached*—"I think [clinicians] have to . . . not just to come out and say, 'you have Alzheimer's disease,' but explain the data" (03). Explaining how the diagnosis was reached may aid in reducing uncertainty or building trust, which can be important for fostering relationships. Similarly, it may help patients and caregivers better understand and accept the diagnosis. "The first step is making the diagnosis and conveying it to patients and family in a way that they understand the logic of it. They understand that there were specific data that I obtained during that clinic visit that point to one specific kind of dementia" (09).

Educate patients and caregivers about the diagnosis. Clinicians described the need to *educate patients and caregivers about the* *diagnosis*. This included clearing up confusion regarding types of dementias—"Make sure that you give them a basic description of what it is because so many people have heard of Alzheimer's. You want to make sure that they understand a medical description of what it is" (09). Giving patients and caregivers realistic expectations regarding their diagnosis also was viewed as an important aspect of the diagnosis process as it allows patients and families to plan for the future. This included setting realistic expectations about prognosis: "It's important to be honest with people and to tell them what to expect and tell them the kind of things they could do to mitigate any problems that might arise" (06).

Follow up to ensure understanding. Clinicians recommended that there should be *follow up to ensure understanding* with patients and caregivers. This included following up in person or by phone after the initial diagnosis disclosure appointment. This allows patients and caregivers time to process the information and address any additional questions or needs following the diagnosis:

> At those [initial] appointments, most families are just soaking in this information. So it's really more of a support, answering any initial questions that they may have. And then usually maybe like a week later, I will have a follow phone call with them. And that's when we start to develop, 'Okay, what now, what do you we need to do? Do you have any additional questions' (D07)?

Follow up is also based on patient and caregiver needs: "Generally, we like to bring people back if they're not getting it, or they're very upset, within a week or two for follow-up. But there are certain people who want to wait a month, process it and then get back to us" (02).

Take a family-centered approach

Lastly, clinicians highlighted the need to take a family-centered approach to deliver a dementia diagnosis. Specifically, clinicians recommended to *meet with family members prior to the diagnosis* and *involve the caregiver or family when delivering information*.

Meet with family members prior to the diagnosis. Some clinicians recommended *meeting with family members prior to the diagnosis* to develop a sense of family dynamics and patient/caregiver preferences for types and amount of information. "Before we give a diagnosis, we always have a conversation with the family as to how much they would like to get into it and what information would they like and what information would be useful" (02). Some clinicians recommended using this strategy to get a sense of how the patient may react to the diagnosis: "First, get a sense of how the patient may receive the information and using the family to help them with that. I think it is really helpful to meet with a family member first" (10). Clinicians sometimes recommended doing this while patients were undergoing testing or getting vitals taken. This approach potentially conflicts, however, with the previously mentioned clinician views that the diagnosis should always be discussed with patients directly, regardless of caregiver preferences expressed in advance.

Involve the caregiver or family when delivering information. Clinicians recommended to *involve the caregiver or family when delivering information* as another family-centered approach to delivering a dementia diagnosis: "It's always better if you could have their spouses with them to give [the diagnosis] at the same time" (15). This was recommended regardless of type or severity of ADRD:

> It depends on the condition, like MCI versus advanced dementia. In many cases, for MCI, it's easier, but the information may not be retained long-term. So, this is why you really need the extended family or a caregiver that can help with everything (08).

When delivering the diagnosis to both individuals simultaneously, one clinician recommended that, "you have to say Alzheimer's disease to both the care partner and the patient" (13). This was sometimes seen as a way to avoid confusion between caregivers and patients regarding the diagnosis by increasing transparency.

Discussion

Understanding the barriers and recommendations associated with communicating a dementia diagnosis is necessary to improve the frequency with which dementia diagnoses are given to patients and caregivers and to improve the experience of receiving a dementia diagnosis. This is important not only for the diagnosis interaction but also for setting the tone for productive ongoing clinical relationships and engagement. Most studies on this topic have explored giving or receiving a dementia diagnosis from the patient and caregiver perspective, and clinicians' views are largely missing.[33] In the current study, we identified barriers and recommendations by interviewing clinicians who give dementia diagnoses rarely or frequently.

Themes regarding identified barriers fell into 3 categories: patient and caregiver-, clinician, and triadic interaction barriers. Patient/family barriers and clinician barriers in our study were similar to the existing literature, providing additional validation of these barriers (Table 1). In a departure from prior studies (Table 1), the current study also identified *triadic interaction barriers*. Patient/family and clinician barriers can create a ripple effect, carrying over into and impacting the triadic interaction, which highlights the intersectionality of barrier types identified in the current study.

Clinician recommendations for communicating a dementia diagnosis included fostering relationships, educating patients and family members, and taking a family-centered approach. Overall, these recommendations align with research on patient-centered communication and care across health contexts,[34] though in our study clinicians discussed how to employ these behaviors in the context of cognitive impairment and triadic encounters. Focusing on dementia disclosure specifically is important because clinicians tend to view diagnosis and management of dementia as more complex than other diagnoses, and giving a dementia diagnosis well may take more time and effort.[13]

Barriers to disclosing a dementia diagnosis

Identified *patient and caregiver barriers* included lack of social support, denial, and misunderstanding the diagnosis. Caregiver presence is generally recommended for disclosing a dementia diagnosis,[22] though some clinicians also expressed the importance of social support for individuals outside of the diagnostic interaction (eg, support for fatigued caregivers). Patient denial was previously identified as a barrier to disclosing a diagnosis.[18,35] Prior research found that clinicians and caregivers were more likely to agree about a diagnosis than clinicians or caregivers and the patient,[36] but about 25% of caregivers can also experience denial.[37] When in denial, caregivers may prefer for clinicians to use language they perceive as less stigmatizing when disclosing the diagnosis to the patient (eg, "memory loss").[37] Although not identified as a primary theme in the current analysis, some of the same clinician participants described concerns regarding the stigma surrounding terms like "Alzheimer's disease" and/or "dementia."[38] However, prior guidance regarding giving dementia diagnoses recommends that clinicians give a specific diagnosis to avoid the risk of patients and families misunderstanding the diagnosis and to better inform treatment and prognostic planning.[22]

Clinician barriers to disclosing a dementia diagnosis included communicating diagnostic uncertainty, discomfort breaking bad news, and lack of time. Similar studies have also found themes regarding uncertainty, such as uncertainty about the patient's preferences for knowing the diagnosis.[39] In the current study, uncertainty pertained to clinicians communicating diagnostic uncertainty. As some clinicians in the current study pointed out, some diagnoses may be more difficult to establish, and it is impossible to have absolute certainty unless an autopsy is performed. Clearly communicating the diagnosis, such as explaining how the diagnosis was reached by clinicians, may lessen the risk of patient and caregiver misunderstanding or uncertainty.[35] One scoping review noted how communication skills training may help clinicians disclose a diagnosis more effectively.[40] The clinician-level barrier regarding lack of time is something identified by both clinicians and patients.[11,16,40] Although not a finding in the current study, research has also emphasized the need for clinicians to balance honesty with hope and optimism.[14]

In the current study, *triadic interaction barriers* included challenges meeting multiple needs and requests for nondisclosure. Studies describing triadic interactions in memory care identified clinicians' concerns about recognizing differing or competing goals between patients and caregivers,[41] indicating that clinicians are aware that there are complex dynamics when a third individual is present. Similarly, caregivers recognize the added layer of complexity resulting from the patients' cognitive impairment.[35] One study highlighting the challenge of meeting multiple needs in dementia care described clinicians as having to "negotiate the balance."[42] Specific behaviors that contribute to triadic barriers, like requests for nondisclosure, were previously reported.[37] Some findings related to triadic interaction barriers may also apply to other healthcare settings (eg, geriatrics, oncology). Similarities include acknowledgment of the added complexity of triadic interactions[43,44] and clinicians' uncertainty about caregiver roles in triads.[45]

The current study did not identify system-level barriers to disclosure of a dementia diagnosis (Table 1) other than time. We included time as a physician-level barrier in the current analysis, but it also represents a system-level barrier given its relationship with health care settings and billing implications. The study interview guide queried barriers to communicating a dementia diagnosis generally, without prompts regarding certain barrier types. The lack of system-level barriers in participant responses may indicate that these are less problematic than other barrier types. However, the preceding interview questions asked clinicians to focus on recent clinical experiences, so participants may have been more focused on clinical encounters than systemic considerations in their responses.

Clinician recommendations for best practices

Clinicians recommended *fostering relationships* by building rapport, using empathic communication, and maintaining connections with patients and caregivers. Recommendations for fostering relationships may have benefits beyond communicating a diagnosis. For example, building rapport, which was previously suggested for communicating a diagnosis,[22] may decrease patient depression and anxiety following a dementia diagnosis disclosure.[46] Empathic communication was also previously identified by patients, caregivers, and clinicians as important when giving or receiving a formal diagnosis.[18] For instance, empathic communication can increase patient understanding of their diagnosis[47] and help them feel better about their diagnosis.[48] Patient preferences can be difficult for clinicians to understand, particularly when meeting for the first time.[14] Given this, providing a diagnosis over several visits may help to overcome this barrier.[14,49] This highlights the importance of establishing and maintaining connections with patients and caregivers.

Clinicians' recommendation to *educate the patient and family* when disclosing a dementia diagnosis is similar to studies which have identified patient or caregiver education-level to be a barrier to disclosure.[35] Clinicians in this study recommended educating patients and family by tailoring communication, explaining how the diagnosis was reached, and providing follow up care. Communication should be tailored to patient background and preferences.[14,22] Clinicians can explain how the diagnosis was reached by explaining testing and results.[49,50] Research recommends scheduled follow-up appointments post-disclosure,[22,49] which may be done by the disclosing clinician or other team members. These visits may include monitoring pharmacological treatments and providing psychosocial resources.[49]

Research indicates that clinicians are generally aware of the complex family dynamics which can create barriers (eg, triadic interaction barriers).[39,51] *Taking a family-centered approach* aligns with research which has found that patients, caregivers, and clinicians agree on the value of caregivers being present during the diagnosis appointment.[21,22,52,53] The level of caregiver involvement may depend on patient competence and need, as caregivers are typically more active in dementia settings than in other contexts.[45] Shared decision-making among the triad may allow clinicians to manage the needs and expectations of patients and family members.[14]

Some clinicians recommended meeting with family members prior to the diagnosis, which has also been recommended by clinicians in similar studies.[41] However, other studies suggest that clinicians should consult with patients first to assess patient preferences for receiving the diagnosis, such as whether the patient wants a family member present when initially receiving the diagnosis or if they would prefer to hear the news privately before bringing in family members.[53] Separate discussions may not be feasible due to time constraints and most clinicians disclose the diagnosis to the patient and family at the same time.[49] The optimal approach is likely determined by the specific situation and the patient's preferences.[22] More research is needed to establish clear guidelines for approaching this.

Strengths and limitations

Study strengths include the recruitment of participants from diverse backgrounds (eg, specialty, years in practice) and demographics, which captured a variety of experiences relating to disclosing a dementia diagnosis. Though the focus of this study was on Florida clinicians, themes were consistent with research performed in other settings. As noted above, interviews did not query specific types of barriers to disclosure of a dementia diagnosis (Table 1), which may have resulted in missing system-level barriers other than time.

Future Directions

This study is part of a larger, ongoing investigation which also included interviewing individuals with dementia and caregivers regarding their experiences of receiving a dementia diagnosis and their recommendations for diagnosis disclosure. The barriers and recommendations identified in this study may help inform guidelines, interventions and clinical practices to mitigate barriers to giving a dementia diagnosis. The ultimate goal is to improve the frequency and quality of dementia disclosures. Results related to the triadic interaction barriers may also help inform research on clinician-patient-companion interactions in dementia and other healthcare settings.

Conclusion

We identified several barriers and recommendations related to communicating a dementia diagnosis that were congruent with previous studies.[22] Our study adds to the literature by addressing the triadic interaction barriers, as well as areas of conflicting clinician recommendations, indicating a need to tailor certain aspects of the diagnostic communication to patient preferences.

Author Contributions

MJA and CLB designed and planned the study and secured funding acquisition as co-principal investigators. MJA and NB oversaw recruitment efforts and coordinated with MR, REC, MK, and XL, who assisted with recruitment from different locations. ENW and NB collected interview data. ENW and CLB primarily analyzed data, which was subsequently reviewed by all authors. ENW and MJA drafted the manuscript, with all authors provided editing and feedback throughout the writing process. All authors read and approved the final manuscript.

Ethic Approval Statement

The University of Florida institutional review board provided study approval (IRB202000212). The study used an IRB-approved waiver of documentation of informed consent. All participants provided verbal informed consent. All information, including quotes, were de-identified.

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Supplemental Material

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