Persons living with dementia and caregivers' communication preferences for receiving a dementia diagnosis

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A B S T R A C T

Objective: As the number of individuals diagnosed with dementia increases, so does the need to understand the preferences of persons living with dementia (PLWD) and caregivers for how clinicians can deliver a dementia diagnosis effectively, which can be a difficult process. This study describes the diagnostic communication preferences of PLWD and caregivers.
Methods: We conducted semi-structured individual phone interviews with two groups: PLWD who were diagnosed in the past two years ($n = 11$) and family caregivers of PLWD ($n = 19$) living in Florida. PLWD and caregivers were not recruited/enrolled as dyads.
Results: The groups' communication preferences were largely similar. Data were analyzed thematically into five themes: *communicate the diagnosis clearly, meet information needs, discuss PLWD/caregiver resources, prepare for continued care,* and *communicate to establish and maintain relationships.*
Conclusion: Participants wanted clear communication, information, and support, but differed in some details (e.g. the language used to describe the diagnosis and the amount/type of desired information). Clinicians can apply general principles but will need to tailor them to individual preferences of PLWD and caregivers.
Innovation: Limited research has elicited PLWD and caregivers' communication preferences for receiving dementia diagnoses, particularly through an individualized data collection method allowing for richer descriptions and deeper understanding.

1. Introduction

As the number of individuals living with dementia due to Alzheimer's disease and Alzheimer's disease-related dementias (AD/ADRDs) increases, so does the need to understand how clinicians can best communicate a diagnosis to persons living with dementia (PLWD) and their caregivers (often family members) [1]. Receiving a timely diagnosis can validate PLWD experiences and family concerns; allows PLWD and families to access pharmacologic and non-pharmacologic interventions to help with symptoms and quality of life, and offers opportunities for advanced care planning [2-6]. Furthermore, *how* the diagnosis is communicated by clinicians is an important factor that impacts patient-and-caregiver-reported outcomes like trust and rapport, satisfaction, and psychological distress following disclosure [7-9].

Barriers to effective communication of a dementia diagnosis include the time-consuming process of evaluating an individual for dementia [3,10-12], challenges relating to accurate antemortem diagnosis (including frequent mixed pathology) [1,13], and lack of clinician knowledge, particularly for non-specialized clinicians [14,15]. Primary care providers frequently make dementia diagnoses due to a shortage of

dementia specialists in the U.S. [15,16] Clinician background can contribute to how dementia diagnoses are made and communicated (e. g., diagnoses of general "dementia" versus specific etiologies like Alzheimer's or Lewy body disease) [1,15].

Barriers at the PLWD/caregiver level include impaired memory and communication in PLWD [10,17]. Clinicians may need to receive information from caregivers, particularly as dementia progresses [9]. Though PLWD, caregivers, and clinicians largely agree that a caregiver should be present during dementia diagnosis disclosure [3,18], this can also create ethical concerns and confusion for clinicians as they may not be sure who is the most accurate source of information [19]. Furthermore, caregivers may be unclear about their role in the interaction [20], and clinicians can find it difficult to balance both patient and caregiver needs and goals while meeting tight clinical schedules [21-23]. Lastly, there are cultural considerations, as ethnic/racial underrepresented groups often report higher amounts of stigma regarding dementia within their families and communities and greater mistrust in the healthcare system [6].

Existing clinician guidelines for disclosing a dementia include incorporating family members and using effective communication [3,24], but it is unclear whether or how these guidelines are implemented or reflect current PLWD and caregiver preferences [11,25]. For instance, some clinical recommendations conflict with nuanced PLWD and caregiver views, such as terminology to use when disclosing a diagnosis (i.e., more general term such as "dementia" or referencing suspected pathologies like Alzheimer's disease) [3,6,18,26-30]. Person-centered communication that accounts for PLWD and caregiver perspectives is needed [12,24], yet research on clinical dementia communication often focuses on clinician perspectives [21,31-34], or uses audio/video recordings of clinical visits to describe what happens as opposed to investigating what PLWD/caregivers prefer [23,35,36]. To better understand disclosure preferences and establish effective communication practices in dementia clinical care settings, further exploration of PLWD and caregivers' perspectives is needed [25,37,38]. Therefore, the current study aimed to investigate PLWD and caregivers' preferences for receiving a dementia diagnosis through individual interviews.

2. Methods

2.1. Ethical statement

Procedures were approved by the University of Florida Institutional Review Board (IRB202000212). All participants reviewed an informed consent document prior to their interview and provided verbal consent.

2.2. Study design and procedures

The semi-structured interview guide was developed by two authors with co-author feedback. The interview included 12 questions regarding participants' diagnosis experience and information/communication preferences (Supplementary Material A). One-time interviews were conducted by telephone by a female doctoral student with training in qualitative methods (ENW) and no prior relationship with participants. During interviews, the interviewer kept field notes. Interviews were audio-recorded and professionally transcribed. Participants received a $25 gift card following their interview.

2.3. Population and recruitment

Eligibility criteria included: (1) PLWD or caregiver of a PLWD with a self-reported clinical diagnosis of dementia (any type) within the past 2 years; (2) fluent in English or Spanish; (3) ability to consent to participate; and (4) Florida residence (due to study funding). A diagnosis in the last 2 years was required to maximize likelihood that PLWD would be able to consent/participate and to limit recall bias regarding the

diagnosis conversation. PLWD and caregivers were not required to enroll as dyads.

Participants were recruited through clinics at three Florida study sites, State of Florida memory disorders clinics, Florida Dementia Care and Cure Initiative task force mailings, the Family Caregiver Alliance newsletter, Facebook advertising designed by the University of Florida's Clinical and Translational Science Institute, ResearchMatch, and the Alzheimer's Association TrialMatch®.

2.4. Qualitative data analysis

We used the constant comparative method to thematically analyze data, which was chosen to compare participants' similarities and differences in their experiences until clear patterns emerged [39,40]. Additionally, we employed an iterative analytical approach to concurrently conduct interviews, adjust the interview guide as needed, note emerging concepts during data collection, and begin preliminary analysis [39,41]. Data were managed using ATLAS.ti version 9.1.3 for Mac.

Two coders (ENW, NDP) with advanced training in health communication and qualitative research began by familiarizing themselves with data and assigning initial codes, starting with the caregiver transcripts (the largest participant group). Coders met regularly to discuss emerging patterns and concepts, subsequently collapsing codes and developing themes based on similarities [42]. After initial themes were derived and agreed upon, we parsed out thematic properties. Theme and property descriptions and exemplars were kept in a codebook that was updated throughout analysis.

Coding was overseen by two senior team members, a healthcare communication specialist (CLB) and neurologist (MJA) with qualitative research experience. The analysis team met weekly to discuss themes and properties and revise the codebook as needed. All authors had input before codebook finalization. We used a similar process to code transcripts from PLWD, using the caregiver codebook as an a-priori coding scheme and noting any differences between groups. Data were considered saturated when no new codes or themes emerged (i.e., inductive thematic saturation) [43].

3. Results

3.1. Participants and demographics

Of 12 PLWD contacted, 11 enrolled and participated. Twenty-two caregivers were contacted; three were ineligible due to >2 years since the family member's dementia diagnosis and one was not interested after learning more about the study. Interviews were conducted 6/2020–5/2021. Interviewees received unique participant IDs. ID numbers for PLWD and caregivers are not representative of patient-caregiver dyads. The average interview length was 27 min 22 s for PLWD (12.5 pages) and 31 min 46 s for caregivers (13 pages).

Caregivers were spouses/partners (68.4%) or children (31.6%) of a PLWD. Seventeen caregivers reported living with the PLWD. For PLWD, time since diagnosis ranged from 2 months to 2 years. Participant demographics are summarized in Table 1.

3.2. Themes

We identified five overarching themes for how PLWD and caregivers preferred that clinicians give a dementia diagnosis: 1) communicate the diagnosis clearly; 2) meet information needs; 3) discuss PLWD and caregiver resources; 4) prepare for continued care; and 5) communicate to establish and maintain relationships. Properties of each theme are italicized. To further promote implementation into practice [44], findings are presented as action statements in Table 2.

3.2.1. Communicate the diagnosis clearly

PLWD and caregivers wanted clinicians to *give a clear diagnosis* by

Table 1
Demographics of caregivers and individuals living with dementia.

Age (in years)	Caregivers (*n* = 19)			Individuals Living with Dementia (*n* = 11)		
	Mean	SD	Min-max	Mean	SD	Min-max
	64	11.4	45–91	69.7	8.3	50–80
Gender	%			%		
Women	79%			28%		
Men	21%			72%		
Race/Ethnicity	%			%		
White, not Hispanic/Latino	79%			82%		
White, Hispanic/Latino	16%			9%		
Black, not Hispanic/Latino	–			9%		
Hispanic/Latino (race unspecified)	5%			–		
Diagnosis	*n*			*n*		
Alzheimer disease	6			2		
Dementia with Lewy bodies	4			2		
Parkinson's disease dementia	2			1		
Primary cortical atrophy	1			1		
Mild cognitive impairment	1			2		
Vascular dementia	–			1		
Type unknown/not specified	5			2		
Specialty of diagnosing clinician	*n*			*n*		
Neurology (general/subspecialty unknown)	10			9		
Dementia specialist/memory care	6			2		
Primary care or gerontology	2			–		
Unsure/not specified	1			–		

Table 2
Ecological sentence synthesis of communication preferences.

PLWD and caregivers want clinicians to…	and suggested clinicians do this by…
communicate the diagnosis clearly.	giving a clear diagnosis.
	explaining test results.
	balancing information.
meet information needs	providing education about the diagnosis.
	answering questions.
	discussing next steps.
	preparing PLWD/caregivers for what to expect.
	distributing educational take-home materials.
discuss PLWD and caregiver resources	providing access to a professional support system.
	recommending ongoing support resources.
	discussing care modifications and resources.
prepare for continued care	giving information over several visits.
	scheduling timely follow-up appointments.
	being accessible between appointments.
	engaging in interprofessional communication.
communicate to establish and maintain relationships	taking time.
	communicating empathetically.
	building rapport.
	using appropriate nonverbal communication.

being direct and transparent about their professional opinion: "They should be much more forthcoming. They should make it known what the diagnosis is, not just keep it a secret and prescribe medication" (C12). This included avoiding medical or other types of jargon (e.g., using the word "hypothesis"). However, views differed on whether giving a clear diagnosis meant giving a specific etiologic diagnosis. Not receiving a specific diagnosis sometimes resulted in frustration:

> [The] neurologist does not want to commit [to a specific type of dementia] until he has almost certain proof that it's what he thinks it is. He told, "I have to have a 95% confidence level to diagnose." But why? I mean, is there medical reasons for that? … I think [that is] the frustrating thing for me.
>
> (C04)

Other times, participants were not concerned about the underlying etiology: "[The doctor] did use the word 'cognitive changes atypical for [my age].' So, he wasn't just throwing out the word Alzheimer's, which for many people that would be scary, and maybe not even necessary for early diagnosis" (P04).

When clinicians *explain test results,* it allowed PLWD and caregivers to understand how a clinician arrived at a diagnosis. One PLWD expressed, "I want to see the results of the prior test that were taken, almost sequentially…to kind of review them to see if there is some diagnosis of, you know, mild or not, [and] the progressive deterioration" (P07). Participants often equated thoroughness of the diagnosis to undergoing diagnostic testing: "The neurologist was very good. Explained it all…He said, 'Hey, you had been through every test I can possibly give you'" (P09). Similarly, a caregiver explained:

> I was very satisfied. I think it was three or four visits between the phone interview and going in, and being tested, and having MRI and things. They were very thorough…It was excellent. Whatever they would have said, would have been fine with me because I know that they checked everything.
>
> (C10)

Participants wanted clinicians to *balance information* by offering encouragement or optimism: ("They didn't react like it was an end-all-be-all, that it was a diagnosis that could just stay the way it is," C06) with the reality of the diagnosis and prognosis. For example: "I think that you have to offer some hope and encouragement, but I think you also need to provide a picture of where things might be headed" (C02). Some also acknowledged the challenges that clinicians face when communicating difficult information (i.e., a diagnosis with no cure): "I think she did a good job with what she had to deliver…She didn't make light of it. She was as positive as she could be, but she didn't sugar-coat it, which we wouldn't want" (C05).

3.2.2. Meet information needs

Participants felt clinicians should *provide education about the diagnosis* by "just taking the time and really explaining things" (P04). To enhance understanding, "[clinicians] could use visuals, for example, to explain some of the concepts that I might not be familiar with as a patient" (P08). Some participants described how unmet educational needs cause confusion: "He probably could have elaborated more on really, what is the true definition of Alzheimer's or what's the difference between Alzheimer and dementia. I mean, the average person doesn't know there is a difference" (C18). Others expressed confusion when the etiology was a lesser-known dementia: "It's difficult enough with Alzheimer's, but then you mix it with Lewy body, and everyone is confused" (P11). Not understanding the diagnosis impacted confidence in the diagnosis: "I don't even know if the Alzheimer's diagnosis is accurate.… I just wish someone would talk to us more about [Alzheimer's]" (C08).

Participants also wanted clinicians to *answer questions*. One caregiver described greater satisfaction with a second opinion partly because the clinician answered questions: "I think they're more compassionate. …

They listen, they're caring, they spend time, they answer the questions" (C18). Lack of clinician engagement caused frustration: "I said, 'I have some additional questions' … And he said, 'I'm not willing to go there yet'… I didn't feel like he was trying to help educate me at all" (C04). For some, question-asking may be challenging during initial appointments: "Of course, they're giving you a whole lot of information, but then they ask you, 'do you have any questions?' It's like well, it's difficult to come up with some right on the spot because you don't really know what to ask" (C11).

Participants wanted clinicians to *discuss next steps*, including immediate actions and lifestyle modifications. As one PLWD expressed, "I would've liked to have heard about [how] to slow or reverse the progression. And telling me what has worked so far with people like me with these problems that I could benefit from. That would've [been] helpful" (P08). PLWD expressed frustration with inadequate guidance: "You know what I'm concerned about is how do I correct this? How do I stop it? How do I manage it? And obviously, I'm not getting that kind of advice, because the sense [is], 'Well, it's not that bad'" (P07). Desiring next steps motivated some to seek out dementia specialists: "When it started getting worse is when I sought out the input of a neurologist so that I could get a baseline going forward in terms of memory care. [I wanted to know] if there was something proactive [that] I could do" (P05). Caregivers also reflected this: "I think that course of action needs to be better communicated or a plan or, is there other therapies? Are there other things we can be doing?" (C02).

Some caregivers wanted specific discussions about long-term expectations, such as prognosis and end-of-life issues, to *prepare PLWD and caregivers for what to expect*: "I think that you have to tell what the road looks like ahead. And I think she [doctor] did a very good job of that, but I don't think a lot of providers do" (C02). This education can inform appropriate care arrangements: "I would have liked to know, what is this going to be like over time? Like [if I'm] going to have to have someone in here in the daytime if I'm not here with her, or what is the long-term prognosis" (C11)? Another caregiver said:

> I mean, you get diagnosed with cancer, they have pretty much a roadmap. And all cancers are different. All people are different. But they've got a roadmap. … It's a great approach. I wish we had that for Lewy Body… a checklist of, "Yeah, this is probably Lewy Body, and this and that can happen and that can happen."
>
> (C07)

Participants also wanted clinicians to *distribute educational take-home information* (e.g., websites, pamphlets, information from advocacy organizations): "I think maybe some tentative information, little booklets, things like that could have been provided – maybe more information about the diagnosis on paper" (C06). Caregivers described being overwhelmed by the amount of information they found on their own and preferred clinician-recommended materials: "What would have been helpful for me, because I'm such an information hound, maybe some information, a pamphlet, or some websites…because there's so much [information], when you look at dementia, holy cow" (C05).

3.2.3. Discuss PLWD and caregiver resources

Participants recommended that clinicians *provide access to professional support systems* with the diagnosis: "They took me into a different social worker who went through everything…so, it wasn't like they just said, 'Okay, here's the diagnosis. Go off on your own'" (C07). Having a psychosocial health professional present was a suggestion to help with the emotions of receiving a dementia diagnosis. One PLWD said:

> There needs to be somebody in that setting, whether it's a nurse, whether it's a social worker…even if it's someone who goes into their office once a week when they know they're giving somebody a diagnosis, somebody to kind of smooth over some of the rough spots…I think it's a necessary addition to the role of the neurologist who is really relaying a lot of very medical information.
>
> (P05)

Participants desired clinicians to *recommend ongoing support resources* following a diagnosis, such as support groups or advocacy organization connections. Some caregivers sought professional psychosocial care: "I went out and I got my own therapist so that I could get through this. Because I knew I was in for a long haul here and I felt very isolated and very alone" (C04). Caregivers suggested that PLWD may also need psychosocial resources following a diagnosis: "That might be something that could be helpful for somebody that's diagnosed, too… maybe they need counseling, maybe they need a support group, maybe they need something" (C05). This was echoed by PLWD: "You're only able to absorb so much in an initial visit. It really needs to be ongoing. Not just the medical aspects, but the psychological and sociological aspects as well" (P05).

PLWD and caregivers also wanted to *discuss care modifications and resources* with clinicians, such as patient safety and care coordination resources. "We talked a lot about safety, because we are in a high-rise with an elevator into our condo… he gave us suggestions for that – trying to put a bell on the door or put an alarm system of some sort. He talked to us about a bed rail for the bed. … He gave us those concrete suggestions…practical solutions" (C01). Caregivers needed resources to address lifestyle changes as household responsibilities increased ("I've taken over many, many chores that he used to do" C09) and wanted clinician recommendations: "I was a little bit more hopeful that as being part of a memory center, [the doctor] would explain to me that 'when COVID gets better, we have XYZ program'" (C14).

Caregivers described needing help coordinating care: "I am putting together a team…but that's the problem. I don't have any coordinated effort that I think would be much more helpful." (C07). However, caregivers reported barriers to accessing resources related to cost, insurance, and lack of guidance:

> It wasn't until I got very sick in the last summer that I said, "Okay, you need some help." They wanted to hospitalize me for pneumonia. I couldn't go to the hospital. I had no backup for him, and he couldn't be left alone. … Long story short, the neurologists that we saw were zero help in helping me, as the caregiver, understand the journey that I was about to embark on.
>
> (C04)

3.2.4. Prepare for continued care

Participants preferred that clinicians *give information over several visits* to limit feeling overwhelmed and allow time for processing: "In the beginning they don't give you so much information…They slowly give you the details so that people have more time to think and to digest" (C09). Another caregiver explained:

> It's all overwhelming in the beginning, but I think if you walk out with all of that information, and then maybe if they followed up with you, that would be good…Because no matter how good a job you do at the diagnosis, there's so much more that's going to happen in the next 30 to 90 days.
>
> (C07)

Participants wanted clinicians to *schedule timely follow-up appointments*: "It would be nice to be getting more follow up from any of the physicians, even our GP" (C11). Additionally, participants preferred more frequent assessments to monitor dementia progression: "[Appointments] every six months – I don't think that's near enough. … This is a degenerative disease, it has ups and downs, ebbs and flows. … You're not going to see that unless you see him more regularly" (C07). Participants expressed related frustrations with scheduling: "The appointments were very far in the future, and I said no…because I couldn't wait any longer. I mean, I had to get tough because if I didn't, no one would see her for – I don't know how long" (C09). Long appointment intervals were perceived to negatively impact quality of care: "It's just

that it's sometimes difficult because you don't see the doctor for six months at a time. … I don't feel like there's good continuity, because I can't call. These doctors are booked months and months in advance" (C14).

Additionally, participants preferred clinicians *be accessible between appointments*. Participants appreciated clinician responsiveness: "I left a voicemail on the doctor's phone that night. And I think he got us in either the very next day or the day afterwards" (C01). Conversely, participants were discouraged by unsuccessful outreach attempts: "After the test, we never went back to see him. My wife called the office maybe a week later and didn't get anywhere with them, never talked to him" (C18). When doctors were unavailable, participants reported benefitting from connecting with other clinical staff: "If I didn't see him, I would see the nurse or the social worker, and they would get all the information, get with him, find out what we needed to do" (C07).

Participants desired that their clinicians *engage in interprofessional communication* by consulting or making referrals and by communicating with the PLWD's other clinicians:

[The doctors] don't talk. That's the problem…There's still a breakdown or a gap with respect to, I guess, historical records and doctors being conscientious enough to really go back and look at a patient's history there, if there is one.

(C16)

Participants appreciated clinicians' encouragement to seek out second opinions:

I said to him, "Do you think it'd be wise if we got a second opinion? And do you have someone to recommend?" … He said to us point blank, "I recommend it. As a matter of fact, I hope to learn from it." So, I really liked that a lot.

(C01)

3.2.5. Communicate to establish and maintain relationships

Participants wanted clinicians to *take time* to establish and maintain relationships by speaking with and listening to them. Participants often cited time as critical for increasing the quality of interactions, yet acknowledged its scarcity: "It's just, there's so much volume that the doctors have and so they are very focused and they're helpful, but it's a very short amount of time that you have" (C14). Participants discussed how time-constrained clinician interactions impacted their understanding of a diagnosis: "He's seen five different neurologists, and not one of them took the time to sit down and say, 'Let's talk about dementia. … Let's talk about what we're kind of looking at here'" (C04). Although some described benefitting from lengthy clinician discussions ("I felt very confident with the neurologist and like I said, she spent two hours talking with us" P04), most expressed appreciation for even slightly prolonged meetings: "And he gave us all the time in the world. I mean, 30 minutes for a doctor is a lot of time" (C01).

Participants suggested clinicians to *communicate empathetically*, expressing understanding and/or concern: "I think you need to be empathetic to each person's situation" (C02). When this was done, participants appreciated it: "I could tell he was empathetic. He was concerned about us…I like that kind of approach, and that's what I needed, and that's what they gave me" (C07). Caregivers who felt clinicians showed little or no empathy expressed surprise and disappointment: "His bedside manner was not great, and he pretty much wrote [patient] off and said, 'you might as well call hospice,' and I'm like, are you freaking kidding me?…I was in shock when I heard that." (C16). Some suggested for other professionals to assist doctors in communicating the diagnosis with empathic delivery: "If a [medical] office knows that their doctor is not warm and fuzzy or able to communicate – because this is a very serious diagnosis, this is your brain – they should have a liaison to cushion the blow" (P05).

According to participants, clinicians can *build rapport* to support

PLWD and caregivers: "He had a very warm approach…very cordial, respectful. He was very engaging and put me at ease, and somebody I would want to see again" (P07). Caregivers were particularly appreciative of clinicians who included patients in rapport-building: "[The doctor] spoke to my husband, which a lot of people just speak to me assuming he does not know anything, and that's not the case. I think when you have that diagnosis, people automatically write you off as totally incapacitated" (C02). Participants were disappointed with minimal communication: "He [the doctor] just listens and doesn't say anything…I wish he were more verbal, he's not. He just keeps everything to himself and doesn't talk to us very much" (C12). PLWD echoed this: "If he'd been more personable…it would certainly help what could be a very emotional experience" (P08). Prolonged time between appointments contributed to difficulty relationship-building: "These doctors are booked months and months in advance, because they're so busy, that you don't feel like you really have any kind of rapport, in my view" (C14).

Finally, participants desired clinicians to *use appropriate nonverbal communication*, including making eye contact, sitting eye level, and physical touch: "She came in and she sat down, and she said, 'Well, I have some bad news and some good news.' And so, we were comfortable with that" (C03); "I think the lady, especially the assistant was very empathetic. She was holding my hand, kind of squeezed it as we were leaving, which was nice" (C11). Negative nonverbal communication signaled a different message: "I come in and I'm asking a lot of questions because I'm trying to educate myself on this and they're looking at their watch going, 'Man, I gotta get to the next patient'" (C04). Another caregiver reported similar experiences: "[The clinician was] watching his watch for how long he had to be with us. And for a diagnosis like dementia, I don't think your watch [matters] so much" (C01).

4. Discussion and conclusion

We investigated PLWD and caregiver communication preferences for receiving a dementia diagnosis through semi-structured interviews and thematic analysis, resulting in five overarching themes. Although themes represent distinct categories, findings should be contextualized together to better understand the relationship between preferences [40].

4.1. Discussion

Although participants agreed it is important for clinicians to communicate the diagnosis clearly, PLWD/caregivers views differed on the amount or type of detail needed for clarity, including whether a specific etiology (i.e., "Alzheimer's disease") is needed for the diagnosis to be considered clear or helpful [6,18]. Some PLWD and caregivers may view the term "Alzheimer's disease" as stigmatizing as opposed to helpful [18,26-30], though clinician guidelines recommend giving a specific etiology during diagnosis [3]. This underscores the need to incorporate PLWD views when developing guidelines. Benefits to disclosing suspected pathologies include understanding disease-specific symptoms (e.g., hallucinations in Lewy body diseases), connections to specific advocacy organizations, obtaining appropriate treatments, and improved family patience and planning [4,23,45]. Research has found that caregivers often want to know a specific diagnosis though PLWD's views are more nuanced, creating challenges for clinicians [25].

Terminology preferences may also be impacted by educational gaps surrounding AD/ADRDs and dementia. Current participants sometimes experienced confusion about this and wanted education about differences between 'dementia' and pathologies like AD. Meeting information needs may be best accomplished over multiple visits, which is sometimes preferred by PLWD/caregivers to provide time for processing [18,24,46]. Furthermore, follow up visits can re-orient PLWD/caregivers to information, as it is likely they will not remember all information during disclosure [18,24,25]. However, systems-level barriers like clinical schedules/short visits and follow up appointment

availability can make this challenging [47]. One way to supplement clinician education is to provide materials to increase knowledge about dementia [48], support decision-making, and improve satisfaction and medication compliance (e.g., question prompt lists, decision aids) [48,49].

Participants preferred clinicians to balance information by offering encouraging information along with the 'bad' news. Similar studies have highlighted the desire for clinicians to offer hope [3,18,37,50], though this needs to be balanced with the reality of the progressive nature of dementia [13,37], which can be challenging for clinicians [37].

The desire for an actionable plan is also described in other studies [3,20]. Discussing short- and long-term steps (e.g., home/lifestyle modifications) can help families make plans and cope with the diagnosis together [24,51]. Caregivers' sense of preparedness and self-efficacy are associated with less distress [52] and decreased burden [53-55]. Care modifications and resources for PLWD can also offer caregivers respite and ease burden and depression [56]. However, clinicians may not be aware of available support resources [14,15].

Stated desires for post-disclosure team follow up are consistent with prior studies [10], though sometimes clinicians feel this lies outside their role [14]. Interprofessional care teams, which some participants desired, often include clinical psychologists or social workers that can help provide resources and support, and may decrease burden on physicians/advanced practice providers and nurses [57]. Interprofessional communication was also valued for care continuity. Collaborative care models can improve health outcomes and quality of care for PLWD [58], particularly as many PLWD see multiple specialists for various health issues. This can fragment care and make managing disease-specific outcomes more difficult [59].

Lastly, participants valued when clinicians took time, communicated empathetically, built rapport, and used nonverbal communication. Although generally recommended as good communication skills in most healthcare settings [60], clinicians should contextualize these to meet PLWD and caregivers needs [25]. Clinician rapport-building is associated with lower reported depression and anxiety for PLWD post-disclosure [9].

Although most participants' communication preferences overlapped, there were mixed views regarding preferred terminology and type or amount of information received. Clinicians can account for different preferences by assessing PLWDs' and caregivers' priorities and goals of care through pre-appointment questionnaires or checklists [25,61,62], pre-diagnostic counseling [25], or simply asking at appointments [3]. Education-based interventions targeting PLWD and caregivers can provide knowledge about dementia as well as skills for communicating with clinical teams and other family members [63]. Some clinicians may benefit from education on delivering difficult diagnoses, e.g. by using adapted frameworks such as SPIKES-D [64]. Clinician interventions to develop patient-centered communication skills can increase the likelihood that PLWD and caregivers understand the diagnosis [3], and should extend beyond the diagnosing clinician. Research suggests that clinicians who may not diagnose dementia but provide care to PLWD (e. g., primary care clinicians) need similar communication competencies [3,25].

4.2. Limitations

This study occurred in Florida, which may affect generalizability. However, identified themes are consistent with what is previously reported. Participants with a diagnosis >2 years prior were excluded to limit recall bias, but this excludes different perspectives. We did not collect information on the type of clinician giving the dementia diagnosis. Saturation of themes was achieved within the whole study population, but subgroups (e.g., by diagnosis, race/ethnicity) were too small for saturation. Participants may have provided socially desirable answers despite speaking to an unaffiliated interviewer. Expressed participant preferences do not necessarily imply that these strategies improve diagnosis disclosure. A limitation on integrating results into current practice is that some findings would likely require system-level changes (e.g., to address appointment length, intervals between appointments). Finally, the majority of our participants were whites/non-Hispanic/Latinos and therefore it is unclear if our results generalize to culturally/ethnically underrepresented groups.

4.3. Innovation

Research on disclosing and receiving dementia diagnoses within the past 10 years has overwhelmingly captured clinician or caregiver perspectives or utilized audio/video recordings of patient-caregiver-clinician clinical visits [25]. Qualitative studies that typically allow for richer description often include PLWD in a group setting (e.g., focus groups) or interview patient-caregiver dyads together [9,19,65,66], which may impact participants' responses [67]. This study identified communication preferences from the perspective of PLWD through individual interviews, generally finding PLWD preferences to overlap with caregiver preferences. Though preferences do not necessarily imply that these strategies improve diagnosis disclosure, they help inform patient-centered clinician approaches.

4.4. Conclusion

PLWD and caregivers desired clear communication, information, and support, but differed in some details (e.g. the language used to describe the diagnosis and the amount/type of desired information). These preferences can inform best practices for person-centered communication when disclosing a dementia diagnosis, educational and behavioral interventions, communication skills trainings, and system-level programs to improve the dementia diagnosis experience.

CRediT authorship contribution statement

Easton N. Wollney: Formal analysis, Investigation, Writing – original draft, Writing – review & editing. **Carma L. Bylund:** Conceptualization, Formal analysis, Funding acquisition, Investigation, Writing – original draft, Writing – review & editing, Supervision. **Noheli Bedenfield:** Project administration, Writing – original draft. **Naomi D. Parker:** Formal analysis, Validation, Writing – original draft, Writing – review & editing. **Mónica Rosselli:** Writing – review & editing. **Rosie E. Curiel Cid:** Writing – review & editing. **Marcela Kitaigorodsky:** Writing – review & editing. **Melissa J. Armstrong:** Conceptualization, Formal analysis, Funding acquisition, Investigation, Supervision, Writing – original draft, Writing – review & editing.

Declaration of competing interest

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.pecinn.2024.100253.

References

[1] Association As. Alzheimer's disease facts and figures. 2022.

[2] Association As. Policy brief: Early detection and diagnosis of Alzheimer's dementia. https://www.alz.org/media/documents/policy-brief-early-detection-diagnosis-alzheimers.pdf; 2017.

[3] Lecouturier J, Bamford C, Hughes JC, et al. Appropriate disclosure of a diagnosis of dementia: identifying the key behaviours of 'best practice'. BMC Health Serv Res May 1 2008;8:95. https://doi.org/10.1186/1472-6963-8-95.

[4] Van Den Dungen P, Van Kuijk L, Van Marwijk H, et al. Preferences regarding disclosure of a diagnosis of dementia: a systematic review. Int Psychogeriatr 2014; 26(10):1603–18. https://doi.org/10.1017/s1041610214000969.

[5] Connolly A, Gaehl E, Martin H, Morris J, Purandare N. Underdiagnosis of dementia in primary care: variations in the observed prevalence and comparisons to the expected prevalence. Aging Ment Health 2011;15(8):978–84. https://doi.org/10.1080/13607863.2011.596805.

[6] Blinka MD, Gundavarpu S, Baker D, et al. "At least we finally found out what it was": dementia diagnosis in minoritized populations. J Am Geriatr Soc 2023;71(6): 1952–62. https://doi.org/10.1111/jgs.18329.

[7] Jiang S. Pathways linking patient-centered communication to health improvement: a longitudinal study in China. J Health Commun 2019;24(2):156–64. https://doi.org/10.1080/10810730.2019.1587110.

[8] Street RL, Makoul G, Arora NK, Epstein RM. How does communication heal? Pathways linking clinician–patient communication to health outcomes. Patient Educ Couns 2009;74(3):295–301. https://doi.org/10.1016/j.pec.2008.11.015. /03/01/2009.

[9] Wynn MJ, Carpenter BD. Discourse features among providers, patients, and companions and their effect on outcomes of dementia diagnosis disclosure. J Gerontol B Psychol Sci Soc Sci Jun 14 2019;74(5):756–63. https://doi.org/10.1093/geronb/gbx154.

[10] Derksen E, Vernooij-Dassen M, Scheltens P, Olde-Rikkert M. A model for disclosure of the diagnosis of dementia. Dementia. 2006;5(3):462–8. https://doi.org/10.1177/147130120600500313.

[11] Werner P, Karnieli-Miller O, Eidelman S. Current knowledge and future directions about the disclosure of dementia: a systematic review of the first decade of the 21st century. Alzheimers Dement Mar 2013;9(2):e74–88. https://doi.org/10.1016/j.jalz.2012.02.006.

[12] Stubbe DE. The health care triad: optimizing communication in dementia care. FOCUS. 2017;15(1):65–7. https://doi.org/10.1176/appi.focus.20160033.

[13] Fox C, Lafortune L, Boustani M, Brayne C. The pros and cons of early diagnosis in dementia. Br J Gen Pract 2013;63(612):e510–2. https://doi.org/10.3399/bjgp13x669374.

[14] Foley T, Boyle S, Jennings A, Smithson WH. "We're certainly not in our comfort zone": a qualitative study of GPs' dementia-care educational needs. BMC Fam Pract 2017;18(1). https://doi.org/10.1186/s12875-017-0639-8.

[15] Association As. Special report. On the front lines: Primary Care Physicians and Alzheimer's Care in America. 2020 Alzheimer's Disease Facts and Figures, Vol. 16; 2020. p. 63–71.

[16] Drabo EF, Barthold D, Joyce G, Ferido P, Chang Chui H, Zissimopoulos J. Longitudinal analysis of dementia diagnosis and specialty care among racially diverse Medicare beneficiaries. Alzheimers Dement Nov 2019;15(11):1402–11. https://doi.org/10.1016/j.jalz.2019.07.005.

[17] NIA. Alzheimer's caregiving: Changes in communication skills. National Institute on Aging; May 17, 2017. Updated. Accessed Nov. 8, 2023, https://www.nia.nih.gov/health/alzheimers-changes-behavior-and-communication/alzheimers-caregiving-changes-communication.

[18] Byszewski AM, Molnar FJ, Aminzadeh F, Eisner M, Gardezi F, Bassett R. Dementia diagnosis disclosure: a study of patient and caregiver perspectives. Alzheimer Dis Assoc Disord Apr-Jun 2007;21(2):107–14. https://doi.org/10.1097/WAD.0b013e318065c481.

[19] Vick JB, Amjad H, Smith KC, et al. "Let him speak:" a descriptive qualitative study of the roles and behaviors of family companions in primary care visits among older adults with cognitive impairment. Int J Geriatr Psychiatry Jan 2018;33(1): e103–12. https://doi.org/10.1002/gps.4732.

[20] Karnieli-Miller O, Werner P, Aharon-Peretz J, Sinoff G, Eidelman S. Expectations, experiences, and tensions in the memory clinic: the process of diagnosis disclosure of dementia within a triad. Int Psychogeriatr Nov 2012;24(11):1756–70. https://doi.org/10.1017/s1041610212000841.

[21] Bailey C, Dooley J, McCabe R. How do they want to know?' Doctors' perspectives on making and communicating a diagnosis of dementia. Dementia (London) Oct-Nov 2019;18(7–8):3004–22. https://doi.org/10.1177/1471301218763904.

[22] Bennett CE, De Boos D, Moghaddam NG. Developing a tool to support diagnostic delivery of dementia. Dementia. 2019;18(7–8):2505–25. https://doi.org/10.1177/1471301217750936.

[23] Karnieli-Miller O, Werner P, Neufeld-Kroszynski G, Eidelman S. Are you talking to me?! An exploration of the triadic physician-patient-companion communication within memory clinics encounters. Patient Educ Couns Sep 2012;88(3):381–90. https://doi.org/10.1016/j.pec.2012.06.014.

[24] Fisk JD, Beattie BL, Donnelly M, Byszewski A, Molnar FJ. Disclosure of the diagnosis of dementia. Alzheimers Dement 2007;3(4):404–10. https://doi.org/10.1016/j.jalz.2007.07.008.

[25] Yates J, Stanyon M, Samra R, Clare L. Challenges in disclosing and receiving a diagnosis of dementia: a systematic review of practice from the perspectives of people with dementia, carers, and healthcare professionals. Int Psychogeriatr 2021; 33(11):1161–92. https://doi.org/10.1017/s1041610221000119.

[26] Aminzadeh F, Molnar FJ, Dalziel WB, Ayotte D. A review of barriers and enablers to diagnosis and management of persons with dementia in primary care. Can Geriatr J 2012;15(3):85–94. https://doi.org/10.5770/cgj.15.42.

[27] Blay SL, Toledo Pisa Peluso E. Public stigma: the community's tolerance of Alzheimer disease. Am J Geriatr Psychiatry Feb 2010;18(2):163–71. https://doi.org/10.1097/JGP.0b013e3181bea900.

[28] Werner P, Goldstein D, Buchbinder E. Subjective experience of family stigma as reported by children of Alzheimer's disease patients. Qual Health Res 2010;20(2): 159–69. https://doi.org/10.1177/1049732309358330.

[29] Lopez RP, Rose KM, Kenney L, Sanborn V, Davis JD. Managing shame: a grounded theory of how stigma manifests in families living with dementia. J Am Psychiatr Nurses Assoc 2020;26(2):181–8. https://doi.org/10.1177/1078390319832965.

[30] Wollney EN, Bylund CL, Bedenfield N, et al. Clinician approaches to communicating a dementia diagnosis: an interview study. PloS One 2022;17(4): e0267161. https://doi.org/10.1371/journal.pone.0267161.

[31] Van Rickstal R, De Vleminck A, Engelborghs S, Van den Block L. Experiences with and perspectives on advance care planning in young- and late- onset dementia: a focus group study with physicians from various disciplines. Front Aging Neurosci 2023;15:1130642. https://doi.org/10.3389/fnagi.2023.1130642.

[32] Griffin JM, Riffin C, Bangerter LR, Schaepe K, Havyer RD. Provider perspectives on integrating family caregivers into patient care encounters. Health Serv Res 2022;57 (4):892–904. https://doi.org/10.1111/1475-6773.13932.

[33] Abe M, Tsunawaki S, Dejonckheere M, et al. Practices and perspectives of primary care physicians in Japan and the United States about diagnosing dementia: a qualitative study. BMC Geriatr 2021;21(1):540. https://doi.org/10.1186/s12877-021-02457-7.

[34] Saunders S, Ritchie CW, Russ TC, Muniz-Terrera G, Milne R. Assessing and disclosing test results for 'mild cognitive impairment': the perspective of old age psychiatrists in Scotland. BMC Geriatr 2022;22(1). https://doi.org/10.1186/s12877-021-02693-x.

[35] Aufill J, Amjad H, Roter DL, Wolff JL. Discussion of memory during primary care visits of older adults with cognitive impairment and accompanying family. Int J Geriatr Psychiatry 2019;34(11):1605–12. https://doi.org/10.1002/gps.5172.

[36] Dooley J, Bass N, McCabe R. How do doctors deliver a diagnosis of dementia in memory clinics? Br J Psychiatry Apr 2018;212(4):239–45. https://doi.org/10.1192/bjp.2017.64.

[37] Poyser CA, Tickle A. Exploring the experience of the disclosure of a dementia diagnosis from a clinician, patient and carer perspective: a systematic review and meta-ethnographic synthesis. Aging Ment Health 2019;23(12):1605–15. https://doi.org/10.1080/13607863.2018.1506747.

[38] Visser LNC, Kunneman M, Murugesu L, et al. Clinician-patient communication during the diagnostic workup: the ABIDE project. Alzheimers Dement (Amst) 2019; 11:520–6. https://doi.org/10.1016/j.dadm.2019.06.001.

[39] Glaser BG, Strauss AL. The discovery of grounded theory: Strategies for qualitative research. Aldine de Gruyter; 1967.

[40] Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006; 3:77–101. https://doi.org/10.1191/1478088706qp063oa. 01/01.

[41] Morse JM. Critical analysis of strategies for determining rigor in qualitative inquiry. Qual Health Res 2015;25(9):1212–22. https://doi.org/10.1177/1049732315588501.

[42] Braun V, Clarke V, Rance N. How to use thematic analysis with interview data. In: Moller AVN, editor. The counselling and psychotherapy research handbook. SAGE Publications Ltd; 2015. chap 13, https://sk.sagepub.com/books/the-counselling-and-psychotherapy-research-handbook.

[43] Saunders B, Sim J, Kingstone T, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. Qual Quant 2018;52(4):1893–907. https://doi.org/10.1007/s11135-017-0574-8.

[44] Sandelowski M, Leeman J. Writing usable qualitative health research findings. Qual Health Res 2012;22(10):1404–13. https://doi.org/10.1177/1049732312450368. -10-01 2012.

[45] Riva M, Caratozzolo S, Cerea E, et al. Diagnosis disclosure and advance care planning in Alzheimer disease: opinions of a sample of Italian citizens. Aging Clin Exp Res 2014;26(4):427–34. https://doi.org/10.1007/s40520-014-0195-1.

[46] Innes A, Szymczynska P, Stark C. Dementia diagnosis and post-diagnostic support in Scottish rural communities: experiences of people with dementia and their families. Dementia. 2014;13(2):233–47. https://doi.org/10.1177/1471301212460608.

[47] Wollney EN, Armstrong MJ, Bedenfield N, et al. Barriers and best practices in disclosing a dementia diagnosis: a clinician interview study. Health Serv Insights 2022;15. https://doi.org/10.1177/11786329221141829.

[48] Sustersic M, Gauchet A, Foote A, Bosson J-L. How best to use and evaluate Patient Information Leaflets given during a consultation: a systematic review of literature reviews. Health Expect 2017;20(4):531–42. https://doi.org/10.1111/hex.12487.

[49] Grime J, Blenkinsopp A, Raynor DK, Pollock K, Knapp P. The role and value of written information for patients about individual medicines: a systematic review. Health Expect 2007;10(3):286–98. https://doi.org/10.1111/j.1369-7625.2007.00454.x.

[50] Grossberg GT, Christensen DD, Griffith PA, Kerwin DR, Hunt G, Hall EJ. The art of sharing the diagnosis and management of Alzheimer's disease with patients and caregivers: recommendations of an expert consensus panel. Prim Care Companion J Clin Psychiatry 2010;12(1). https://doi.org/10.4088/PCC.09cs00833oli. PCC.09cs00833.

[51] Robinson L, Clare L, Evans K. Making sense of dementia and adjusting to loss: psychological reactions to a diagnosis of dementia in couples. Aging Ment Health 2005;9(4):337–47. https://doi.org/10.1080/13607860500114555. 07/01 2005.

[52] Wawrziczny E, Berna G, Ducharme F, Kergoat MJ, Pasquier F, Antoine P. Modeling the distress of spousal caregivers of people with dementia. J Alzheimers Dis 2017; 55(2):703–16. https://doi.org/10.3233/jad-160558.

[53] Merrilees JJ, Bernstein A, Dulaney S, et al. The Care Ecosystem: promoting self-efficacy among dementia family caregivers. Dementia. 2020;19(6):1955–73. https://doi.org/10.1177/1471301218814121.

[54] Fortinsky RH, Kercher K, Burant CJ. Measurement and correlates of family caregiver self-efficacy for managing dementia. Aging Ment Health May 2002;6(2): 153–60. https://doi.org/10.1080/13607860220126763.

[55] Ducharme FC, Levesque LL, Lachance LM, et al. "learning to become a family caregiver" efficacy of an intervention program for caregivers following diagnosis of dementia in a relative. Gerontologist 2011;51(4):484–94. https://doi.org/10.1093/geront/gnr014.

[56] Sörensen S, Conwell Y. Issues in dementia caregiving: effects on mental and physical health, intervention strategies, and research needs. Am J Geriatr Psychiatry 2011;19(6):491–6. https://doi.org/10.1097/jgp.0b013e31821c0e6e.

[57] Lee L, Molnar F, Hillier LM, Patel T, Slonim K. Multispecialty interprofessional team memory clinics: enhancing collaborative practice and health care providers' experience of dementia care. Can J Aging 2022;41(1):96–109. https://doi.org/10.1017/S0714980821000052.

[58] Galvin JE, Valois L, Zweig Y. Collaborative transdisciplinary team approach for dementia care. Neurodegener Dis Manag 2014;4(6):455–69. https://doi.org/10.2217/nmt.14.47.

[59] Blaum CS, Rosen J, Naik AD, et al. Feasibility of implementing patient priorities care for older adults with multiple chronic conditions. J Am Geriatr Soc 2018;66 (10):2009–16. https://doi.org/10.1111/jgs.15465.

[60] King A, Hoppe RB. "best practice" for patient-centered communication: a narrative review. J Grad Med Educ Sep 2013;5(3):385–93. https://doi.org/10.4300/jgme-d-13-00072.1.

[61] Tinetti M, Dindo L, Smith CD, et al. Challenges and strategies in patients' health priorities-aligned decision-making for older adults with multiple chronic conditions. PloS One 2019;14(6):e0218249. https://doi.org/10.1371/journal.pone.0218249.

[62] Vu T, Mroz EL, Hernandez-Bigos K, et al. Persons living with dementia and multiple chronic conditions identifying health priorities with care partners. J Am Geriatr Soc Jun 2023;71(6):2005–8. https://doi.org/10.1111/jgs.18257.

[63] Bylund CL, Wollney EN, Campbell-Salome G, et al. Improving clinical and family communication for adult child caregivers of a parent with a blood cancer: single-arm pre-post pilot intervention. JMIR Cancer 2022;8(3). https://doi.org/10.2196/38722. e38722. /7/5 2022.

[64] Peixoto VGDMNP, Diniz RVZ, Godeiro Junior CDO. SPIKES-D: a proposal to adapt the SPIKES protocol to deliver the diagnosis of dementia. Dement Neuropsychol 2020;14(4):333–9. https://doi.org/10.1590/1980-57642020dn14-040001.

[65] Griffin JM, Riffin C, Havyer RD, et al. Integrating family caregivers of people with Alzheimer's disease and dementias into clinical appointments: identifying potential best practices. J Appl Gerontol 2020;39(11):1184–94. https://doi.org/10.1177/0733464819880449.

[66] Gruters AAA, Christie HL, Ramakers IHGB, Verhey FRJ, Kessels RPC, De Vugt ME. Neuropsychological assessment and diagnostic disclosure at a memory clinic: a qualitative study of the experiences of patients and their family members. Clin Neuropsychol 2021;35(8):1398–414. https://doi.org/10.1080/13854046.2020.1749936.

[67] Schuster RC, Brewis A, Wutich A, et al. Individual interviews versus focus groups for evaluations of international development programs: systematic testing of method performance to elicit sensitive information in a justice study in Haiti. Eval Program Plann 2023;97. https://doi.org/10.1016/j.evalprogplan.2022.102208. 102208. /04/01/ 2023.