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## Expectations and Concerns of Older Adults With Cognitive Impairment About Their Relationship With Medical Providers: A Call for Therapeutic Alliances

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### Abstract

We sought to understand the expectations and concerns of older adults with cognitive impairment with regard to their relationship with medical providers. In particular, we observed whether study participants were involved in therapeutic alliances. Medical providers and patients create therapeutic alliances when they agree on the goals of the treatment and share a personal bond. Whereas such alliances have been studied in cancer research, little is known about therapeutic alliances in dementia research. Data were gathered in a qualitative study of 27 older adults with cognitive impairment and analyzed with narrative analysis. We introduce four case studies that illustrate the effects of having or missing a therapeutic alliance. Whereas the participant in the first case benefited from a therapeutic alliance, the other cases are marked by different experiences of abandonment. Findings suggest that interventions should concentrate on ways to enhance the relationship between medical providers and patients with cognitive impairment.

### Keywords

dementia; doctor–patient; nurse–patient communication; trust; geriatrics; access to health care; users’ experiences; memory; memory loss; Alzheimer’s disease; suicide; qualitative; case study; United States

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Almost 50 million people live with cognitive impairment worldwide (the population of a country the size of Spain), and this number is projected to triple by 2050 (Alzheimer’s Disease International, 2018). Estimates indicate that by 2040, 71% of people with cognitive impairment will live in developing countries (The Lancet Neurology, 2008). In the United States alone, it is estimated that in 2019, 5.8 million people of all ages (5.6 million over 65 years of age) are living with cognitive impairment (Alzheimer’s Association, 2019).

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The symptoms of cognitive impairment—memory loss, trouble with thinking, disorientation—can threaten our core identity (Cantor, 2018). Without a cure to reverse the impairment, the irreversibility and gradual worsening of its symptoms can spark despair, sorrow, loss, and dread. Within this context, the time of the diagnosis is an opportunity to discover and attend to the health care and social needs of persons with cognitive impairment. Yet, studies of the delivery of a diagnosis of cognitive impairment, an umbrella term for mild cognitive impairment (MCI), Alzheimer’s disease (AD), and related dementias (Jack et al., 2018), suggest that there is inadequate communication between medical providers (e.g., physicians) and patients (Chong et al., 2016; Savva & Arthur, 2015). A study based in the United States revealed that fewer than half of persons with a diagnosis of dementia (or their caregivers if the person was too impaired) reported being told about the diagnosis (Alzheimer’s Association, 2018; Office of Disease Prevention and Health Promotion, 2016). Factors dissuading physicians from delivering a diagnosis of cognitive impairment include lack of effective treatments to reverse the impairment, skepticism as to the efficacy of available drugs, concern about distressing patients, time required to formulate a diagnosis, and patients’ challenges retaining information (Chithiramohan et al., 2019; Chong et al., 2016; Low et al., 2019). Furthermore, even when the diagnosis is delivered, some medical providers use ambiguous language (Carpenter & Dave, 2004; Clare, 2003; Karnieli-Miller et al., 2007) and perform little follow-up (Campbell et al., 2016; Hill & Walton, 2013). In addition, patients often report feeling distressed (Campbell et al., 2016; De Witt & Ploeg, 2016; Karnieli-Miller et al., 2007; Portacolone, 2018; Portacolone et al., 2018a).

Improving communication regarding cognitive impairment is a national objective of the U.S. federal government under the Healthy People 2020 (soon to become 2030) initiative (Office of Disease Prevention and Health Promotion, 2016). Most recently, the 2018 update of the National Plan to Address AD indicated that to “educate and support people with AD and related dementia and their families upon diagnosis” is a key strategy to enhance the quality of care for people with cognitive impairment (U.S. Department of Health and Human Services, 2018). The World Health Organization (2018), national plans (Alzheimer’s Disease International, 2018; Rosow et al., 2011), and the Alzheimer Association (2019) promote talking about the diagnosis. The rationale behind these efforts is that diagnosed people can plan ahead and be more involved with decisions about their well-being. Within this framework, we have only partial knowledge about the preferences of people with cognitive impairment regarding information about their condition and their relationship with their medical providers (Bamford et al., 2004). For example, ambivalent views emerge about receiving a diagnosis. Whereas most studies emphasize that people with cognitive impairment want to know the information (Alzheimer’s Association, 2015; Dautzenberg et al., 2003; Marzanski, 2000; Pratt & Wilkinson, 2001), some studies observe that participants also resist undergoing assessments for cognitive impairment and do not want more information about their cognitive health (Hoppe, 2019; Marzanski, 2000; Milby et al., 2017; Turnbull et al., 2003). Some hide their impairment from providers (Hansen et al., 2008). These attitudes may stem from the stigma associated with cognitive impairment and to the loss of privileges associated with this diagnosis (e.g., losing a driver’s license). These findings suggest that we need clarity as to how providers can best tailor how they inform and address the needs of people with cognitive impairment.

The objective of this study was to qualitatively understand the expectations and concerns of older adults with cognitive impairment with regard to their relationship with medical providers. In particular, we observed whether older adults with cognitive impairment were involved in the theoretical construct of therapeutic alliances. Drawing lessons from other medical specialties, the construct of therapeutic alliance is relevant to supporting providers to work with patients with cognitive impairment because it focuses on methods to tailor providers' communications on patients' needs. Originated in psychoanalysis in the 1950s (Michel, 2011), this theoretical construct is used in oncology (Schnur & Montgomery, 2010), palliative care (McPhee, 2011), suicide prevention (Michel et al., 2011), HIV/AIDS (Fuentes et al., 2016), eating disorders (Zaitsoff et al., 2015), and substance abuse disorders (Ilgen et al., 2006). This study is therefore unique in its contribution because it introduces a new construct in dementia studies.

A medical provider and a patient are involved in a therapeutic alliance (Fuentes et al., 2016) when they agree on the "goals of the treatment [and] the tasks needed to accomplish those goals," and as well, share a "personal bond" (Schnur & Montgomery, 2010, p. 239). Such alliances improve health outcomes because they increase adherence with plans of care, reduce anxiety, and help patients to take better care of themselves (Arnow & Steidtmann, 2014; Ilgen et al., 2006). Providers' empathy is critical in developing such alliances (Apesoa-Varano et al., 2011; Halpern, 2007). Providers who use empathy skillfully during difficult conversations have been shown to decrease patients' anxiety when hearing bad news and increase their adherence to the treatment plan and self-care, most likely through building trust (Derksen et al., 2013).

We assume that therapeutic alliances could be beneficial to persons with cognitive impairment because they could provide relief to the distress of experiencing the symptoms of cognitive impairment, especially in the early stages of the disease (Cipriani et al., 2013; Draper et al., 2010). In this study, the theoretical framework of therapeutic alliance offered a frame of reference in our examination of the expectations and concerns with regard to the relationship of study participants with their medical providers, which added depth to our investigation. The ultimate aim of the study was to understand whether patients with cognitive impairment had a therapeutic alliance with their health care providers. To address this aim, we examined the degree to which older adults with cognitive impairment felt that their health care providers were aware of and partners in addressing their needs.

## Method

The data are part of a multiyear qualitative study on living alone with cognitive impairment funded by the National Institute on Aging and the Alzheimer's Association. This study explores the overall lived experience of an ethnically/racially diverse sample of older adults living alone with cognitive impairment. This article uses a multiple-case study approach. Case study research examines phenomena relying upon multiple sources of information (Yin, 2013). Data were gathered through ethnographic interviews (Spradley, 1979/2016) and participant observation (Atkinson & Hammersley, 1994) of 27 older adults living alone with cognitive impairment who were interviewed multiple times ( $n = 115$ , an average of four interviews per person) between 2014 and 2017, as well as four members of their social circle

interviewed only once. Ethnographic interviews and participant observation were selected because we wanted to understand how study participants assign personal meaning to experiences and events (Rubinstein, 1992) such as their expectations and concerns about their interactions with medical providers. The relationship with medical providers is especially salient to older adults living alone because they often lack caregivers attuned to their priorities and concerns (De Witt & Ploeg, 2016; Portacolone et al., 2018a, Portacolone et al., 2019b; Portacolone, 2018). The sampling method technique in this study was convenience sampling. Administrative staff, physicians, and social workers from medical organizations based in Northern California referred potential participants. Following referral, researchers approached participants over the phone followed by a face-to-face conversation. Eligibility criteria included age  $\geq$  55 years, a medical diagnosis of AD or MCI, living alone, and the ability to provide consent.<sup>1</sup>

### Data Collection

Data were collected primarily through ethnographic interviews and participant observation.<sup>2</sup> An in-depth ethnographic interview (Spradley, 1979/2016) involves creating a basic set of entry questions and then tailoring further follow-up questions to respondents' trains of thought, seeking detailed explication of each point of experience that is mentioned. Specifically, participants were asked about their expectations and concerns related to the relationship with medical providers.<sup>3</sup> The interview was adapted for persons with cognitive impairment: Background noise was avoided, and a photo of the researcher was displayed in all correspondence and consent forms (Cridland et al., 2016). The interview outline is available in the Supplemental Material. Data from interviews were supplemented with data from participant observation of participants' daily routines. The researcher had prior extensive experience conducting ethnographic interviews with older adults living alone (Portacolone, 2013) and as socially isolated older adults (Portacolone et al., 2018b). To inform and assure participants of her credentials, she usually showed her university badge (and sometimes driver's license). The study was introduced to potential study participants as an investigation about living alone in old age, without mentioning the cognitive impairment. We made this decision because we did not know if study participants were aware of having a cognitive impairment and because we wanted to observe whether and how narratives about the cognitive impairment spontaneously emerged.<sup>4</sup> The researcher shared her research goals with participants, which is to ultimately enhance the well-being of older adults living alone. She also provided transcripts of interviews when requested. Interviews were audiotaped and lasted approximately 1.5 hours. During interviews, the researcher was alone with the study participant. Home visits lasted approximately 2.5 hours. Participants received a US\$30 gift card at the end of the first interview. In addition, when possible, members of the study participants' social circles were also interviewed and also received a US\$30 gift card at the end of the first and only interview. Audio recordings of interviews and fieldnotes were

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<sup>1</sup>The procedure to obtain consent is detailed in Portacolone (2018).

<sup>2</sup>Author's contributions were the following: Research concept and design: E.P., J.K.J., K.E.C., J.H.; acquisition of data: E.P.; data analysis and interpretation: E.P., J.K.J., K.E.C., J.H.; Manuscript draft: E.P., J.K.J., K.E.C., J.H.; Acquisition of funding: E.P. and K.E.C.; supervision: E.P.

<sup>3</sup>For more details about the study protocol, see Portacolone et al. (2018a) and Portacolone et al. (2019b).

<sup>4</sup>For further details on this decision, see Portacolone et al. (2018a).

professionally transcribed and uploaded in Atlas.ti, a software program for qualitative data analysis. The sample of 27 participants had a mean age of 79.1 years (range = 62–94 years). Eleven had a diagnosis of AD; 16 had a diagnosis of MCI. Sixteen were women. Nineteen were non-Latino White, three non-Latino Black, three Latino, and two Asian. Nine participants had a high school–level education or below and 18 had a Bachelor’s degree or more. The four members of the social circle included two adult children, a partner, and a sibling. With regard to attrition, during the study period, one study participant died, three relocated, four were lost to follow-ups, and one lost interest. The Committee on Human Research at the University of California, San Francisco, approved the study. In this article, participants are identified by a single letter, and potentially identifying features of participants were omitted or slightly changed.

## Data Analysis

Case studies offer “an opportunity to shed empirical light about some theoretical concepts” (Yin, 2013, p. 40) such a therapeutic alliances. In multiple-case design studies, cases serve as multiple experiments with either similar or contrasting results. For this study, we considered data related to each study participant as a whole. For each study participant, we developed a summary of their case with an emphasis on therapeutic alliances. In particular, we examined the story that emerged from participants’ narratives, with attention to characters, settings, actions, and resolutions related to their interactions with health care providers (Nasheeda et al., 2019). The summaries were compared across participants to understand of the cases produced similar of contrasting results. Whereas similar results produce literal replication, contrasting results produce theoretical replications (Yin, 2013). Study participants were deemed possibly experiencing a therapeutic alliance using two broad criteria: (a) they mentioned having a positive relationship with a medical provider, and (b) they mentioned seeing the medical provider regularly. Conversely, study participants were placed in the “abandonment” category if they did not meet both criteria. The research team agreed on the categorization of interviews as either therapeutic alliance or abandonment. In our study, literal replications whereby study participants experienced abandonment instead of a therapeutic alliance were prevalent ( $n = 19$ ). In contrast, only six study participants demonstrated theoretical replication, meaning here that they experienced a therapeutic alliance. Finally, it was difficult to ascertain the presence of a therapeutic alliance in two participants whose adult daughters were highly involved in their medical care. In this article, we selected four cases, one of therapeutic alliance and three of abandonment, that were as much as possible representative of the sample’s overall experiences, as we further explain in the “Results” section. The four cases were selected as representative. In the first case, a man with cognitive impairment seems involved in a therapeutic alliance. In the second case, a man is distressed by the way he is told that he has AD. In the third case, a woman with cognitive impairment takes for granted that her psychiatrist will only give her partial information about her condition. In the final case, a woman with cognitive impairment ultimately commits suicide, a decision interpreted by her son as a way to take care of herself. Her suicide was duly reported to the Committee on Human Research.

## Rigor

To ensure rigor, particular attention was given to data saturation, defined as “the building of rich data within the process of inquiry, by attending to scope and replication, hence building the theoretical aspect of inquiry” (Morse, 2015, p. 587). Specifically, to build *rich* data, we used open-ended questions to understand, in depth, the characteristics of the relationship, if any, between study participants and their medical providers. Richness of data was also ensured by the researcher probing about this relationship over multiple interviews. To attend to the comprehensiveness or *scope* of the data, we included only participants with either diagnosed MCI or AD because we wanted to learn from participants who are expert in this topic. In addition, we placed particular attention to disconfirming evidence (Kuzel & Like, 1992). For example, narratives of abandonment were common from the beginning of data collection. However, because of researchers’ attention to outliers, it gradually became evident that some participants had a positive relationship with their medical providers. As Morse (1995) stated, “It is often the infrequent gem that puts other data into perspective, that becomes the central key to understanding the data and for developing the model” (p. 148). To attend to the *replication* of the data, we recruited 27 participants, even though the replication of cases of abandonment was evident after 20 participants were recruited.

To further ensure rigor and validity in data analysis, the researcher’s reflexivity, that is, her “role, possible bias, and influence on the research and interpretation” (Schoenberg et al., 2011, p. 283), was essential because of her lead role in data collection and analysis. Specifically, the researcher who conducted all the interviews recorded the motivation to pursue this study, her assumptions, as well as her concerns and expectations about the lived experience of older adults with cognitive impairment living alone (Bishop & Shepherd, 2011; Rae & Green, 2016). During data collection, she recorded fieldnotes about the way that her personal characteristics influenced the interactions with study participants. To reduce bias, she regularly sought respondent validation by explaining to participants what she understood from them, which is a technique particularly useful to support the train of thought of cognitively impaired study participants. In addition, during data collection, three strategies were used to decrease power differentials between researcher and study participants (Rae & Green, 2016). First, the researcher often repeated that her goal was to “learn” from study participants. Second, specific efforts were made by the researcher to sit at a lower level than participants and to carefully use silence to allow participants’ processing of thoughts. Third, to reciprocate the information received by study participants, if asked, the researcher self-disclosed details about her personal life (Bishop & Shepherd, 2011). Finally, to ensure rigor, the consolidated criteria for reporting qualitative research informed the study design.

## Results

### “[My physician] knows how to handle me”: Mr. M

Mr. M, 79, defined himself as a “recluse.” A widower, he spent most of time in his apartment either reading or watching political news: “50% of what I do is I sit here and curse the screen.” Whereas his wife was extremely sociable and gregarious, Mr. M preferred to keep some distance from others. For example, when he accompanied his wife at parties,

he preferred to sit and watch others, rather than talking with them. Early on in his first conversation with the researcher, he mentioned his depression. He said, “Certainly I am very depressed, and my biggest problem is getting out of bed in the morning.” The symptoms of cognitive impairment contributed to it: “It’s depressing when you see your mind actually in real time, slowing down.” A diabetic and former scientist, Mr. M was referred to the study by his primary care provider because he had a medical diagnosis of MCI. Yet, when asked about his memory, he denied having received a diagnosis and explained that he was told that his impaired memory is probably linked to his diabetes. Mr. M talked at length about his intensifying impairment. “I can’t remember anything,” adding, “It is very tough to live in that way.” From the beginning of the interview, Mr. M often spontaneously mentioned A, his primary care provider. Mr. M explained that he participated in the research because A “pushes” him “to be more social.” He also explained that A “is just wondering if I have the right kind of help living here in the house. I’ve got assignments that I have to do.” He added, “the assignments that I committed is I’ve got to talk to the person that, the case manager that would help me be able to live by myself in my home.”

Mr. M did hire a case manager to understand whether he could remain in his home, which was his preference. Under the case manager’s recommendation, he also hired a professional who organized his clutter. He was careful about his diet because of his physician’s input regarding his diabetes. Mr. M was fully appreciative of her: “A knows her business, and she is a sharp woman, and she seems to know something about everything.” He added, “I am very impressed with her ... So she is like, ‘What are we doing going forward with you?’ So she knows how to handle me. She knows me like that.”

Mr. M’s case is not isolated. Other two white men, both socially isolated, spontaneously and fondly spoke of their physicians and how involved the physician was in their lives. One observed, “D. is a many-layered person. I should have included him in my list of friends [because] you achieve a closeness at some point.” He added,

I’ll never forget the day that [my physician] put his arm around me and he said, “I can refer you to as many departments as you want, but none of them is going to make you feel like you’re 25 again.” And I said, this guy is my doctor.

Another study participant recalled with appreciation a home visit from his physician. He noted, “I’m getting fatter and fatter. I’m going to tell Dr. Z next time I see her, she’s pregnant now, that I have a sympathetic pregnancy.” On a related vein, the fourth participant who reported a therapeutic alliance, a Latina woman, reported appreciating the home visits from her physician, a much younger Latino man concerned about her well-being. Finally, when prompted, the fifth and sixth participants, a White man and a Black woman, spoke with appreciation about their physician’s ability to help them cope with multiple serious chronic conditions.

#### **“It’s not the doctor, it’s not the personality. It’s the situation”: Mr. C**

Mr. C, 65, a freelancer, noticed that something was off with his memory. After a 6-month long wait to get an appointment, he finally saw a neurologist. He recalled, “I’m called into a room with a neurologist and with a social worker. I think there was one other person, maybe, I don’t know. And I’m there. They start telling me about what’s happening and everything.”

Mr. C's distress about hearing the diagnosis of AD was exacerbated by the rapid referral to the social worker as the person to talk to. Mr. C explained, "[Patients] don't want to be shuffled off anywhere else. They want the doctor to console them." He added,

A doctor needs to take you in first by himself, or herself, and say, "Sit down here. Let me tell you what you have." You don't need a social worker there right away ... The doctor needs to have a bedside manner. The doc needs to talk to you for at least 15 minutes, also know *how* to talk to you for like 15 minutes.

Mr. C blamed the "system," rather than the person: "It's because the way they're trained. It's not the doctor, it's not the personality. It's the situation." To prove his point, he compared AD and cancer diagnoses: "If you had severe cancer, do [doctors] just go, 'Okay, here's a social worker?'" He explained, "The doctor is just not a technician ... The doctor is your friend and also someone who tells you the bad news, and also will take ideas from you." We selected this case because it exemplifies poor providers' manners in breaking the news of the diagnosis of cognitive impairment, which is a marker of a missing therapeutic alliance. The distress that originates from an inappropriate delivery of the diagnosis of cognitive impairment has been common across the sample.<sup>5</sup> In addition, this particular distress tends to be exacerbated with the limited involvement of health care providers in supporting the diagnosed patient's coping abilities around living with an untreatable and progressively debilitating chronic condition. For example, following the neurologist's diagnosis, Mr. C's primary care provider visited only sporadically and did not appear involved in supporting his adjustment.

#### **"Doctors don't like to talk about diagnosis with a patient": Ms. S**

Ms. S, 81, lived by herself in a building for seniors. Divorced, she often felt lonely and longed for a romantic partner. Since the death of her only son two decades before, Ms. S's main relationship was with her grandson who visited her at least once a week. During the first visit of the researcher, her moods changed quickly, ranging from being jittery to nonchalant. Although Ms. S had a diagnosis of AD in her medical record, she seemed unaware of it. About her forgetfulness she said, "I don't have Alzheimer's. I don't think I'm going to have it. But I forget things all the time. Names, everything. I forget." She then explained that her psychiatrist gave her medicines for her "memory loss." Ms. S added, "That's the common word for dementia." She then explained that the diagnosis of dementia was her own interpretation because the psychiatrist did not use this term. Asked if she was interested in asking the psychiatrist whether her interpretation was correct, Ms. S replied,

I don't really care. She might evade the question. Because they don't like to put technical words to things sometimes I've noticed ... And I think I know what she would answer. Kind of a low-grade dementia. I don't know where she draws the line. So I'd just rather not ask ... I think I read enough myself that I know the answer to the question. It's just something I've noticed that doctors don't like to talk about diagnosis with a patient.

<sup>5</sup>For further illustrations, see Portacolone (2018) and Portacolone et al. (2018a).



Six months later, Ms. S shared that the directors of her adult day center asked her to stop coming. In her words,

I'm in real pain right now. Because I don't have a place to go during the day. If they don't let me come back. What will I do? I mean really, what would I do? What am I going to do?

She then explained that the director deemed her "too unstable ... Because I talk about not wanting to live. There I said it." Reflecting about her options, she noted, "sometimes I feel like calling 911. But they'll just come out and take me away to a psychiatric place."

In the last and fourth visit of the researcher Ms. S was more upbeat. Her visits to the adult day health center had resumed, and she was very appreciative of her new public home care aide. We selected this case because it illustrates key features of not having a therapeutic alliance with health care providers. In this case, the participant faced a major crisis related to the provision of care on her own and reported not knowing what do, which was a main theme in our study.<sup>6</sup>

#### **"No one has given a name to what I have": Ms. A**

Ms. A, 72, had been concerned about her increasing forgetfulness, especially after she witnessed the progression of AD in her father who died when she was 65. A divorcee with two adult children, an intimate partner, and a large and close-knit circle of friends, Ms. A was gregarious, wealthy, and lived by herself. Despite her friends' suggestions not to worry about her forgetfulness, Ms. A visited a neurologist to better understand her condition. The neurologist's diagnosis of "mild memory loss" did not match her experience, especially as she felt increasingly forgetful. During the next three encounters with the researcher over the following 5 months, Ms. A reiterated her need to have precise information about her condition: "The most important thing for me is to have kind of what I would call a real assessment of where I am in this process of memory loss. No one has given a name to what I have." She added,

So if I have Alzheimer's I really would like to have somebody say that that is what the situation is right now ... and then anything that would be helpful ... And I'm thinking of my time and I don't want to wait a long time if there was something that would be helpful to me to be doing.

During her last visit, she felt ignored because the neurologist spoke mostly to her son, "No one said much to me and that was okay. I mean nobody asked me anything."

Ms. A also shared her frustration and fatigue about managing her everyday activities with less memory than in the past. "'Where did I put it?' is the bane of my existence," she said. She explained that she obsessively checked her calendar and watch to make sure to remember appointments. She mentioned being very distressed about missing a medical appointment because of her forgetfulness. She also talked about the toll of taking careful notes which she then misplaced or forgot the purpose of. In her words, "It's exhausting and

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<sup>6</sup>For further detail on this theme, see Portacolone et al. (2019b).

then you start to think to yourself, ‘What is the quality of my life anymore? ... Is this worth it?’”

In the last encounter, Ms. A looked pale and disheveled. She said that lately she experienced panic and anxiety. Her friends’ suggestions to “breathe deeply” were not enough. An acupuncturist’s visit did not help, and the psychologist she had been seeing to cope with her forgetfulness was not sensitive enough. She recalled,

He says to me, you’ve got to have a different string on your violin. You’ve been playing this same one that says, “I’m losing my memory, I’m losing my memory, I’m losing my memory, I’m losing my memory. Stop it! That is not helpful. Something more could be so much more productive. So work on the other. Find these other things that are going on that are perfectly great and useful and helpful and are positive.” ... And I told him, “You know, that is going to be so difficult for me. I don’t know how to go about doing that. Because I have spent years with somebody who was losing their memory. It’s a fact that I am losing my memory.”

Five months after saying these words, Ms. A placed her head in a plastic bag, which she then filled with helium, ending her life. Afterward, in an interview with the researcher, Ms. A’ son, M, explained that his mother frequently shared with him her plan to end to her life. He said: “My mom has always, in a sense has always prepared us in many aspects of our lives. Not just with respect to her passing away, but I think in terms of being independent.” He added, “It wasn’t just for her. She sees it, I think she would’ve seen it, ... as a selfless act. Not for her, it’s for us.”

M also described her last visit to the neurologist with her boyfriend and him. During the visit, M asked the neurologist to describe the symptoms of AD, and realized that his mother had most of them. According to M, the neurologist withheld the diagnosis of AD because the doctor had decided that his mother had a strong support system and she did not need any “medical labels.” We selected this case because it illustrates the extreme measures that older adults may resort to to cope with the cognitive impairment. Her case suggests that the lack of a therapeutic alliance might have contributed to the participants’ decision to end her life. Whereas hers was the only case of suicide, other three participants from the study experienced a lack of therapeutic alliance and a shared a desire to end their life.<sup>7</sup>

## Discussion

The influence of interactions with medical providers in the lived experience of patients with cognitive impairment emerges in this multiple-case study. The contrast between the first case of Mr. M and the other three cases suggests that people with cognitive impairment seldom have a therapeutic alliance with the health care providers most involved in their care. Whereas Mr. M benefited from being involved in a therapeutic alliance with his physician, which included knowing that she kept him on her mind, the other cases are each marked by different experiences of abandonment. In the second case, the delivery of a diagnosis of AD did not become an opportunity to create a therapeutic alliance. Instead, Mr. C felt alienated

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<sup>7</sup>For a detailed case of a study participants planning to pursue euthanasia in Switzerland, see Portacolone et al. (2019a).

by the limited “bedside manners” of his neurologist. In the third case, the absence of a therapeutic alliance between Ms. S and her psychiatrist became apparent when Ms. S faced a crisis in the provision of health care on her own. The absence of a therapeutic alliance emerges in the fourth case as well. Ms. A’s distress over the mismatch between a diagnosis of mild memory loss and her profound forgetfulness and the problems she had managing it intensified her anxiety. Notably, Ms. A had a strong support system, yet no one other than her physician was in the position of giving her a diagnosis and, lacking that, no one else directly addressed how frightened she was of a future decline with AD given what she had witnessed with her father.

Specifically, the contrast between the first case and the other three points to the importance of providers tailoring their care empathically to meet the specific individual needs of patients whose lives are rapidly changing because of cognitive impairment. In the first case, Mr. M’s ongoing feeling that he was held in his physician’s mind was an essential element of the alliance. Studies of the doctor–patient relationship corroborate this finding as they underline the value of providers’ “longitudinal care” which allows the development of trust, shared knowledge, and personal bonds (Ridd et al., 2009). Within this framework, patients with cognitive impairment may benefit from regular contact with providers because they may need additional support and tailored services to retain and process information, as well as to be able to continue living in their homes, which is often their preference.

Whereas the anxiety-reducing benefits of a therapeutic alliance have been studied in people with psychiatric illness (Zugai et al., 2015), suicidal ideations (Michel et al., 2011), and cancer (Schnur & Montgomery, 2010), only a few studies discussed the effects of cultivating the doctor–patient relationship for people with dementia (Bahro, Silber, Box, & Sunderland, 1995; Bahro, Silber, & Sunderland, 1995; Cheston, 1998; Lecouturier et al., 2008; Miller, 1989; Tripathi et al., 2009), and none of these studies specifically discussed therapeutic alliances. In 1995, Marcel Bahro, the author of two studies, underscored the importance of better understanding the psychological needs of patients with cognitive impairment (Bahro, Silber, Box, & Sunderland, 1995; Bahro, Silber, & Sunderland, 1995). He noted that by focusing strictly on measurable behaviors and biological features of AD, studies neglected “the psychodynamic aspect of this dementing illness.” On a related note, Lecouturier et al. (2008) empathized the need to understand the preferences of the person with cognitive impairment at the time of diagnosis. Furthermore, such investigations privileged therapeutic alliances involving physicians instead than nurses and other health care providers.

To address the gap in knowledge on the effects of therapeutic alliances with patients with cognitive impairment, as well as on any barriers or facilitators of such alliances, more studies are clearly needed. The perspective of providers, which is missing in this investigation, is crucial to understand whether such therapeutic alliances may be feasible and whether they may have benefits similar to alliances with patients who may be seriously ill, but cognitively healthy.

Despite this partial understanding, our findings suggest that there are several reasons it might be important for patients with cognitive impairment to have therapeutic alliances with their providers. First, like patients with cancer and other serious diagnoses, people diagnosed

with cognitive impairment are facing substantial existential issues that evoke great distress. As our cases demonstrate, this distress is then compounded because people with these conditions increasingly find themselves unable to function and cope with emotional distress as they might have before their cognitive impairment. Second, these findings suggest that the creation of therapeutic alliances is important for persons with cognitive impairment because they have difficulties holding onto and organizing information about their illnesses, how to get help to meet their daily needs, and what to expect in the future. As a result, they may benefit from having medical providers partner with social services to help them to manage and process this information. However, taking lessons from the case of Mr. C, at the time of the diagnosis, the responsibilities of medical providers *versus* social workers should be clearly explained to patients. Third, older adults, especially with cognitive impairment, rely more on their feeling of trust in a provider—that is, on their intuitive and associative processes—than on the facts the provider conveys (Sinz et al., 2008). Trust in their providers may help them accept needed treatment and social supports; the sense that their provider has them in mind may help reduce their anxiety by making them feel cared for.

We suggest that the delivery of the diagnosis of cognitive impairment should be viewed as an opportunity to create, or strengthen, therapeutic alliances between medical providers and their patients. Rather than focus on a narrow informational goal of delivering a diagnosis, providers could aim to develop an ongoing therapeutic alliance which will help activate patients and caregivers to digest this information. Given that patients with cognitive impairment may forget having received a diagnosis, it is important to schedule regular follow-up visits that include caregivers if available, and recognize that the patient's sense that the provider is a trusted resource is in itself a valuable aspect of treatment.

An implication of this study is that it is time that interventions to enhance the well-being of patients with cognitive impairment in clinical settings concentrate on ways to enhancing the relationship between health care providers and patients. Establishing and sustaining a trust-based relationship with cognitively impaired patients is central to providing ethically acceptable health care for two reasons. First, respect for persons, including scaffolding whatever autonomy remains for people with progressive cognitive impairment, includes helping patients know what is happening to them and what to do about it. By sharing their knowledge, health care providers respect their patients' autonomy and respect any form of capacity that the patient still has to plan and make important life decisions. Second, by not pursuing or failing to give patients the option to pursue conversations about their diagnosis, need for support, and possible future outcomes, providers may leave patients' most difficult fears about the future unaddressed and contribute to their feelings of distress (Macrae, 2010; Morgan & Zhao, 1993). Thus, by negligence, they are failing to protect patients from foreseeable harms.

Practices concerning treatment of patients change over time. Nowadays, it would be unthinkable to avoid providing medical care to patients subjected to domestic violence or with substance dependence because clinicians did not ask, and patients did not tell. It should be just as inconceivable to present-day providers to fail to address questions about progressive cognitive impairment. As with other stigmatized populations in medicine,

providers need guidance to take the first step toward inquiring into and naming the problem, so that they can openly accompany patients facing a difficult journey ahead.

One additional point. While we have written of a doctor–patient therapeutic alliance, this alliance is perhaps better understood as between the patient and core members of a health care team. The complex needs and comorbidities of people with cognitive impairment (Carpentier & Grenier, 2012; Macrae, 2010; Van Steenwinkel et al., 2014) suggest that they would especially benefit from a trust-based relationship with an interdisciplinary team of providers, led by a “captain of the ship,” in the words of a study participant. In addition, health care providers and their team could benefit from protocols developed in palliative care (Dean & Willis, 2016) or in oncology (Baile et al., 2000). These protocols provide insights on creating and sustaining therapeutic alliances through empathic listening and adjusting the amount of information delivered to patients’ willingness to learn about their condition at specific points in time.

Finally, one policy implication of these findings is that health system organizations have the responsibility to support physicians, as well as teams of providers, to take the time to establish therapeutic alliances with patients with cognitive impairment. For example, billing systems should account for the time and effort spent to develop, over time, these alliances. Specifically, billing systems should account for the time that the providers’ team spends in the clinic as well as in patients’ homes. The presence of providers in patients’ homes is beneficial because living at home with cognitive impairment requires support with everyday tasks (e.g., paying bills, buying groceries); thus, providers can ensure that patients feel properly supported within the household, which strengthens the therapeutic alliance.

## Limitations

This study has four limitations. First, whereas the use of case studies allows depth, the generalizability of the findings is limited by the small sample. In particular, the results are too limited to reach the conclusion that a better doctor–patient relationship would alleviate patients’ distress. In addition, the sample was too small to assess, in depth, the differences between participants with MCI and AD. Considering that all six of the participants categorized as having a therapeutic alliance have a diagnosis of MCI, the results are too limited to reach the conclusion that older adults with MCI are more likely than those with AD to have a therapeutic alliance. The sample is also too small to conclude that those with the cognitive capacity to participate more fully in their care might be able to engage in a therapeutic relationship, while more cognitively impaired older adults cannot. Second, study participants’ cognitive impairment likely hampered recollections of their interactions with medical providers. Nonetheless, participants’ narratives reveal their own recollections and thoughts about such interactions, which was the purpose of the study. Third, because participants of the four cases lived by themselves, the perspective of people with cognitive impairment living with others is missing. Finally, because participants were predominantly non-Latino White, the perspective of people with cognitive impairment from other racial/ethnic backgrounds is also missing.

## Conclusion

People with cognitive impairment, whether it is diagnosed or not, usually sense that something is amiss. The responsibility of health care providers and overall society is to make them feel supported over time by sharing knowledge and resources. Within this paradigm, a better understanding of therapeutic alliances in dementia research is an essential step in this direction. To address these gaps in understanding, we call for further investigations aimed at better understanding of the feasibility, opportunities, barriers, and facilitators of therapeutic alliances across different races and ethnicities. A focus on cross racial-ethnic differences in this area is critical, considering concerning findings suggesting that racial/ethnic minorities with cognitive impairment and their families experience distress that stems from specific issues such as language barriers, discrimination, and limited culturally relevant service (Babulal et al., 2019). Investigations should also assess whether and how the diagnosis of cognitive impairment represents an opportunity to create or strengthen such alliances.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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