



Published in final edited form as:

J Alzheimers Dis. 2018 ; 61(4): 1517–1529. doi:10.3233/JAD-170723.

The Effects and Meanings of Receiving a Diagnosis of Mild Cognitive Impairment or Alzheimer's Disease When One Lives Alone

Elena Portacolone^{a,*}, Julene K. Johnson^{a,b}, Kenneth E. Covinsky^c, Jodi Halpern^d, and Robert L. Rubinstein^e

^aInstitute for Health & Aging, University of California San Francisco, San Francisco, CA, USA

^bCenter for Aging in Diverse Communities, University of California San Francisco, San Francisco, CA, USA

^cDivision of Geriatric Medicine, University of California San Francisco, San Francisco, CA, USA

^dSchool of Public Health, University of California Berkeley, Berkeley, CA, USA

^eDepartment of Sociology and Anthropology, University of Maryland Baltimore County, Baltimore, MD, USA

Abstract

Background—One third of older adults with cognitive impairment live alone and are at high risk for poor health outcomes. Little is known about how older adults who live alone experience the process of receiving a diagnosis of mild cognitive impairment (MCI) or Alzheimer's disease (AD).

Objective—The aim of this study was to understand the effects and meanings of receiving a diagnosis of MCI or AD on the lived experience of older adults living alone.

Methods—This is a qualitative study of adults age 65 and over living alone with cognitive impairment. Participants' lived experiences were elicited through ethnographic interviews and participant observation in their homes. Using a qualitative content analysis approach, interview transcripts and fieldnotes were analyzed to identify codes and themes.

Results—Twenty-nine older adults and 6 members of their social circles completed 114 ethnographic interviews. Core themes included: relief, distress, ambiguous recollections, and not knowing what to do. Participants sometimes felt uplifted and relieved by the diagnostic process. Some participants did not mention having received a diagnosis or had only partial recollections about it. Participants reported that, as time passed, they did not know what to do with regard to the treatment of their condition. Sometimes they also did not know how to prepare for a likely worsening of their condition, which they would experience while living alone.

*Correspondence to: Elena Portacolone, MPH, MBA, PhD, Institute for Health & Aging, University of California San Francisco, 3333 California Street Suite 340, San Francisco, CA 94118, USA. Tel.: +1 510 830 9309; elena.portacolone@ucsf.edu.

Authors' disclosures available online (<https://www.j-alz.com/manuscript-disclosures/17-0723r2>).

SUPPLEMENTARY MATERIAL

The supplementary material is available in the electronic version of this article: <http://dx.doi.org/10.3233/JAD-170723>.

Conclusion—Findings suggest the need for more tailored care and follow-up as soon as MCI or AD is diagnosed in persons living alone.

Keywords

Alzheimer’s disease; cognitive dysfunction; diagnosis; health services; residence characteristics

INTRODUCTION

An estimated one third of older adults with cognitive impairment live alone in the United States [1] and Canada [2]. Older adults living alone with cognitive impairment are at high risk for poor health outcomes [3]. They are less likely to use health services [4], and they are more exposed to self-neglect [5, 6] and falls [6] than counterparts living with others. Older adults living alone with cognitive impairment also report a higher number of unmet needs in managing money, medications, and mobility [6], and they are less likely to seek a diagnosis for their cognitive impairment [3, 7]. Very little is known about the effect of receiving a diagnosis of mild cognitive impairment (MCI) or Alzheimer’s disease (AD) for older adults living alone. A recent study [8] reported that older adults living alone with cognitive impairment distrusted and avoided healthcare providers (e.g., physicians, social workers, nurses) whom they believed did not understand their priorities. Providers, on the other hand, described the tension of meeting their responsibilities with their patients living alone with cognitive impairment as “walking the tight rope.” In particular, providers reported their unease about telling patients that they had to stop driving or relocate. They also expressed their frustration about their inability to further support their patients because of lack of appropriate and affordable services in the community as well as a lack of support from family members. Evidence of difficult relationship between older adults living alone with cognitive impairment and their providers also emerged in recent studies of our group ([9] and Portacolone et al., unpublished results). In particular, some older adults mentioned that they did not feel properly supported by their healthcare providers.

Knowledge about the effects of a diagnosis of MCI or AD derives from international investigations of healthcare providers, caregivers, and patients living with others, mostly a spouse. These investigations highlighted the positive, as well as negative, effects of this diagnosis. Some investigations emphasized the positive effect of knowing “the truth” about one’s cognitive health [10–13]. A common theme among the participants’ responses was that they felt “vindicated” by the diagnosis because their spouses often misunderstood their forgetfulness as a sign of indifference. Other investigations emphasized the distress of receiving a diagnosis of AD or other dementias from medical providers often poorly trained in breaking bad news [14–16]. Others underlined a sense of “uncertainty” stemming from receiving a diagnosis of a condition without an effective treatment [17, 18] and the related ambivalence of providers in communicating a diagnosis without an effective treatment [19]. The limited and fragmented services available post-diagnosis increased the distress of patients [15, 20, 21], as well as providers [15, 19]. The role of providers’ and patients’ social context in influencing the effects of the diagnosis emerged in a few studies [15, 16, 22]. Specifically, providers who felt supported by colleagues during the diagnostic process were better able to assist their patients. Similarly, people with dementia who felt supported by

their social circle coped better with the diagnosis. Interestingly, Brossard and Carpentier [23] noted the influence of patients' living arrangement in the timing of the diagnosis. Whereas older adults living with someone were diagnosed in the early stages of their condition, older adults living alone often received a diagnosis of dementia later, once serious manifestations of symptoms occurred, such as hygiene problems.

Indeed, older adults living alone differ from their counterparts living with others. Those living alone are often responsible for their household [23, 24], and they might lack informal caregivers nearby [25]. Further, older adults living alone are often independent and eager to remain in their home as long as possible [26], a goal which can be threatened by a diagnosis of MCI or AD. This is a realistic threat because older adults living alone with cognitive impairment are at high risk for institutionalization [27–29].

The aim of this investigation, therefore, was to understand the effects and meanings of receiving a diagnosis of AD or MCI on the lived experience of older adults living alone. The primary rationale for including both MCI and AD in the same study is because we were interested in the experience of receiving a diagnosis in persons who have cognitive impairment. Even though a portion of persons with MCI may revert to normal cognition, MCI is often a precursor to AD [30]. We acknowledge that the experience may be different. However, our study is the first to specifically focus on receiving a diagnosis of MCI or AD, independent of the specific diagnoses. Improved understanding in this area could eventually better align medical protocols with the specific priorities of older adults living alone with cognitive impairment. The choice of qualitative research methods was driven by the experiential nature of the information we planned to collect. Qualitative research methods are the methods of choice when examining the lived experience of study participants [31]. Qualitative research studies seek to evaluate individual perspectives, the way individuals interpret their world, and the meaning they assign to specific events [32], in this case a diagnosis of MCI or AD.

METHODS

Study design

Ethnographic interviews and participant observation, two qualitative methods, were chosen because they are the most appropriate to expand the body of knowledge on unexplored areas where hypothesis generation is premature and to understand in-depth subjective experiences [33]. An in-depth ethnographic interview involves tailoring questions to respondents' trains of thought, seeking detailed explication of each point of experience that is mentioned [34]. During such interviews researchers engage study participants and create rapport with them using a combination of approaches, which include expressing a deep interest in learning from study participants as well as admitting cultural ignorance and asking for clarifications. Other recommended approaches include using long silent pauses to allow the processing of participants' thoughts as well as incorporating as much as possible participant's language in questions and observations [34]. In addition, during ethnographic interviews, researchers consistently repeat and reinstate the participants' answers to assist them with their trains of thought, a technique particularly appropriate with study participants with cognitive impairment. Data from interviews were supplemented with data from participant observation

of participants' daily routines. In this mode, researchers use their experiences in relation to the studied population as part of the data [31].

Interview and participant observation protocol

The first author developed the in-depth ethnographic interview protocol and a co-author (RLR) reviewed it to assure that the questions elicited information on the effects and meanings of the diagnosis of MCI or AD over multiple interviews. The study of the effects of the diagnosis was part of a larger investigation on the overall lived experience of older adults living alone with cognitive impairment [9]. Therefore, the interview protocol also included questions on the overall lived experience of study participants. All interviews were conducted by the first author. The Institutional Review Board at the University of California San Francisco granted permission to present the project as an investigation of living alone in old age, without mentioning the diagnosis of AD or MCI. This omission was necessary for two reasons. First, the research team was unaware whether the diagnosis had been disclosed to study participants. Second, the research team did not want to introduce the study as an investigation on living alone "with cognitive impairment" because such framing would have magnetized the attention of study participants to their (disclosed or not) cognitive impairment. Instead, to understand in depth the role played by the cognitive impairment in the lived experience of study participants, it was critical to observe whether and how narratives about the cognitive impairment spontaneously emerged. In this study, almost half of participants did not acknowledge having received a diagnosis.

The first interview started with general questions about living alone and then continued to a first set of questions about health. Participants were asked specific questions about the effects and meanings of the diagnosis only after they mentioned having received a diagnosis of MCI or AD. The second set of descriptive questions focused on the experience of receiving a diagnosis. However, if the participant did not mention the diagnosis earlier, a specific question was asked about memory ("How is your memory?") to stimulate reflections and recollections of the diagnosis. When possible, the investigator probed reflections related to the diagnosis of MCI or AD and its effects and meanings in the subsequent interviews. Other interviews included questions about social support, services used, and management of money and the household. The interview protocol related to the effects and meanings of the diagnosis is included in the Supplementary Material. Interviews were audio-recorded and transcribed verbatim. Most interviews occurred in the homes of participants. Participants were compensated with a \$30 gift card at the end of the first interview. Research protocols were developed for persons with cognitive impairment: background noise was avoided, transcripts of interviews were made available to participants, and a photo of the first author was displayed on all forms [35].

As a supplement to the ethnographic interviews, the researcher recorded observations of the participants. Fieldnotes were captured in an audio-recorder at the end of each encounter and contained a description of each participant (clothes, demeanor, appearance), their surroundings (temperature, noise, odors), and investigators' reactions to each encounter (unease, confusion, surprises). To ensure reflexivity, the researcher recorded her reactions to what was observed, as well as her possible bias and role in encounters [33]. For example, the

researcher recorded her unease about being frequently asked for advice from study participants about what they should do about their cognitive impairment. Most of the times, the researcher explained that she was not a clinician, and used body language, silence, or words to express her empathic understanding of the situation. To test an understanding and enhance the credibility of the data, the researcher often shared with participants what was genuinely understood from them, a technique named “respondent validation” [35]. Furthermore, to test the strength of observed patterns, during data collection the researcher sought for disconfirming evidence [36]. When possible, the investigator also observed participants’ experience receiving their diagnosis in clinical settings. In addition, when possible, members of the study participants’ social circle were interviewed.

Eligibility criteria and recruitment

Eligibility criteria included: living alone (living without others); age 65; a medical diagnosis of AD or MCI; and the ability to provide consent. After reviewing the consent form with study participants, the researcher asked five specific yes/no questions to assess their ability to consent (e.g., “Can you stop being in the study at any time, even after you start?”). Participants were deemed unable to consent if they did not answer all questions correctly after three attempts. The consent form stated that if the investigator became aware of any abuse, including self-neglect, she had to report the event to the Long Term-Care Ombudsman. Before doing so, she would have consulted with two coauthors (KEC and JH), both with medical degrees. Participants provided consent only at the beginning of the first interview. During subsequent interviews, they were reminded that they were participating in a research and that they could stop participating in the research at any time. Administrative staff, physicians, and social workers of healthcare organizations based in Northern California referred potential participants. The members of the social circle were referred to the study by the participants. The Institutional Review Board of the Human Research Protection Program of the University of California San Francisco approved the study. To preserve participants’ anonymity, all names used in this paper are pseudonyms and some features were altered so as to disguise specifics.

Data analysis

Qualitative content analysis [37] of transcripts of interviews and fieldnotes was initially used to identify the effects and meanings of receiving a diagnosis of MCI or AD. This method of analysis of qualitative, narrative, and ethnographic data focuses on the information that emerges from the data without the use or creation of a priori theoretical constructs [38]. Transcripts were imported in Atlas-ti, a software program for qualitative data analysis. The first author coded a subset of transcripts, created the codebook with the description and example of each code, and wrote memos to reflect on the data. A research assistant coded the remaining transcripts with frequent iterative discussion with the first author to review the interpretation of the data [39]. In the first stage of the analysis, transcripts of interviews and fieldnotes were analyzed line by line to identify positive and negative effects or meanings of the diagnosis. Portions of texts related to the diagnosis were coded as “diagnosis.” These portions were also coded with one or more of these three labels: “bad” to identify negative effects or meanings; “good” to identify positive effects or meanings, and “neutral” to identify effects or meanings that were neither positive or negative. In qualitative studies, it is

often helpful to first use simple codes to help identify high-level distinctions. After these simple, high-level codes are identified, it is then possible to both examine the details and generate overarching themes [40]. To refine the analysis, in the second stage, two additional codes were created to label sections of texts coded as “diagnosis”: “blurred” for instances where study participants had blurred recollection of their diagnosis and “withheld” for sentences indicating that the diagnosis might have been withheld from them. Attention was also placed in identifying any differences between participants with MCI and those with AD. As the coding progressed, the first author discovered themes through the process of connecting codes and writing memos [41]. For example, the first theme “relief” emerged by the gradual discovery that the majority of sentences coded as “diagnosis” and “good” related to a sense of relief experienced by older adults living alone with cognitive impairment. Thematic saturation was found with regard to four themes. Saturation is found when no new types of information or themes are added as new informants come to be interviewed [42].

To ensure rigor and validity in qualitative analysis, the first author’s reflexivity, i.e., her “role, possible bias, and influence on the research and interpretation” [43], was essential because of her lead role in data collection and analysis. Finally, rigor and validity were also ensured with triangulation (data collected through interviews and observations), respondent validation (researcher explaining to participants what she understood from them), seeking disconfirming evidence, and iterative discussions in data analysis [33].

RESULTS

This study included 29 older adults living alone and 6 members of their social circles. Thirteen older adults living alone had a diagnosis of AD, while 16 had a diagnosis of MCI. Table 1 summarizes the demographic characteristics.

Older adults living alone were interviewed an average of four times per person for a total of 114 interviews. The number of interviews per study participant are reported in Table 2.

On average, participants were interviewed during a 10-month period. Each interview lasted approximately 1.5 h and each home visit lasted approximately 2.5 h. Members of the social circles included four adult children, one sibling, and one partner; they were interviewed only once. The interviews occurred between November 2013 and January 2017. Qualitative analysis of transcripts revealed four primary themes: 1) “relief,” which was the overarching positive effect of the diagnosis; 2) “distress,” the main negative effect of the diagnosis; 3) “ambiguous recollections,” which highlighted instances where clear recollections of the diagnosis were missing, and 4) “not knowing what to do,” another negative effect of the diagnosis. These themes were often not exclusive: participants often reported more than one theme.

Theme 1: Relief

Receiving the diagnosis of MCI or AD resulted in some participants feeling relieved. This effect was more common in participants who received a diagnosis of AD. The process of obtaining a diagnosis sometimes offered an opportunity for family discussion and shed light on treatments. For example, Mr. John Muir, 78, had such a positive experience that he and

his two daughters literally applauded the interdisciplinary team of providers after they spent half a day reviewing his charts and giving him batteries of tests to conclude that he is likely to have a “*slow, slow form of Alzheimer’s disease.*” The fieldnote reads:

Once the clapping subsided, the neurologist stated, “We will sort through this, and it is good to have the conversation open up. I want you to get the best way you can [sic].”

The diagnosis brought clarity on many levels. The medical team reviewed Mr. Muir’s medications, a process that mattered to him because some interfered with his sleep. In an interview one week after receiving the diagnosis he said, “*Just that small thing was a very big thing for me.*” The daughters were given time to express their concerns. The opportunity to “*open up the box,*” as the neurologist put it, was one positive effect of the diagnosis. A diagnosis can become an occasion where concerns that may have been concealed are finally aired in the open. In Mr. Muir’s case, his daughters were able to express guilt about being far away and concerns about not being too invasive with helping their dad manage money. The attentive care of the neurologist tempered Mr. Muir’s apprehension about the lengthy diagnostic process. The following week Mr. Muir talked about his anxiety about the procedure, especially in terms of processing all the new information. “*Was I... able to understand what I was being told by the people at the table?*” was his concern. His apprehension was addressed by his daughters taking notes and by the neurologist’s attentiveness. Mr. Muir said, “*[the neurologist] listened very carefully for a good long time and then she began ... to suggest things that might work for me. And I find that very comforting.*”

A sense of immediate relief coming from the diagnosis was noted by other participants. The relief usually was focused on the present moment. For example, Ms. Anne Smith, 79, described being “*much relieved*” after receiving her diagnosis of AD. She said about the neurologist who gave her the diagnosis: “*He was very nice and he was very open. He said, ‘You’re not as bad [to need a specific treatment].’ I could’ve kissed him right then.*” Her relief stemmed from knowing that she did not have to undergo an aggressive treatment that “*scared [her] to death.*” Rather than focusing on the long-term implications of AD, the emphasis was on the short-term uplifting news of not needing the treatment. Another participant, Ms. Miranda Well, 80, was also relieved from knowing that a medical condition caused her forgetfulness. In her words, “*I was doing something I just took on myself and should not have.*” Her diagnosis of AD made her feel less responsible about her forgetfulness. Gaining knowledge was a positive effect of receiving a diagnosis as well. As she noted, “*It’s better to know. In that way I can prepare my family and they won’t think I’ve just gone off the deep end. They can know that I might have mental problems eventually.*” Participants also often valued their providers’ depth of analysis and perspicacity. In Ms. Smith’s words, “*I thought he did an excellent analysis of what was going on.*” Her boyfriend echoed, “*I was impressed with him. I thought he hit everything – the nail on the head.*”

With regard to the future, the new knowledge about their condition sometimes came with suggestions on “*steps to correct the problem,*” as Ms. Smith put it. The fieldnotes captured the neurologist’s take on those steps, as well as Ms. Smith’s positive reaction:

“I would like to see a few things. One, repeat the testing ... Then I’d love to see some approach to your gait problems. So you should be doing more exercise. You should be stretching the legs. Find the right trainer and do some cardiovascular fitness. Some of the problems may just reverse. [You need to take] some medicines to use for Alzheimer’s disease; it’s an Alzheimer disease-like pathology ... A social worker can help you stabilize in the home environment.” “Go ahead!” Ms. Smith replied to these suggestions, as if she was granting him permission.

Here, the suggestion of involving a social worker demonstrated attention to the fact that Ms. Smith lived alone and essentially needed someone to support her with her living arrangement. One week later, as a result of the diagnosis, she started physical therapy and recalled, *“I left feeling very good about everything, I did.”* Like Ms. Smith, other participants adopted healthier behaviors, such as walking more regularly or watching their diets. Lacking a medical treatment to treat cognitive impairment, providers usually invited patients to follow healthy diets and to be physically active. Some participants valued attending educational classes about their condition (a benefit that came with their diagnosis). To improve her memory, Ms. Green, 73, a participant diagnosed with MCI, appreciated taking mnemonic exercise classes in her local community center, even though she could only afford to take these classes once a week. Ms. Owsby, 80, a woman with limited social ties and a diagnosis of AD, greatly appreciated her homecare aide who cooked for her and provided good company, which helped relieve her isolation.

Theme 2: Distress

Another recurring theme among participants was their distress. The news of having an irreversible condition, the limits it caused, as well as the manner in which the diagnosis was given were often the sources of this distress. To convey the brashness of the geriatrician to deliver the diagnosis of AD, the brother of a participant recalled, *“It was slam bam thank you ma’am. It was very quick.”* Some participants even expressed “shock” generated by the diagnosis. For instance, Ms. Well said, *“It was a shock to know that Alzheimer’s is in the future.”* She then explained, *“[The neurologist said to] make sure I take the medicine every day and try to get out and socialize more. And get out and walk more. And that was about it. See him in six months. So that’s it.”* However, Ms. Well did not receive a home care aide or other support to help her follow these recommendations over the next 10 months. Receiving a letter that revoked her driving license was a further blow: *“It was a shock but I can see, from a safety point of view, that I could become a detriment.”* Similarly, Ms. Left, 80, was distraught by her diagnosis. A few months after her husband died, she visited a neurologist after being referred by her primary care doctor. She said:

I was very upset by this woman [neurologist]. She told me right off the bat I had Alzheimer’s, dementia ... But the lady never explained anything. I was so shocked that I had no idea – and the first thing she said after that, “I have no choice but to inform the DMV [Department of Motor Vehicles] because that’s the law. The law requires it.” ... And I’m left not knowing what to do about myself.

Another source of her distress was the speed of the process. In Ms. Left’s words, *“The staff gave me a test that took like 25 minutes. Very short. Very short. And on that basis they said that I was Alzheimer’s, dementia ... That doesn’t seem very solid basis to come to this*

conclusion.” Living in a rural setting, an immediate negative consequence of the diagnosis was that she had to discontinue going to the gym because she could no longer drive. As Ms. Left alluded, receiving little explanation about her diagnosis of AD and having to quit driving was extremely upsetting. Furthermore, she was told to take medications without a reason: “*The lady never explained anything,*” she said. As a result, after two months, Ms. Left stopped taking the medications because she did not feel any benefit. This was a mistake, she later realized, after she spoke with her primary care physician.

After being told to take medications for her forgetfulness but given no other guidance or information, another participant, Ms. Candice Amber, 74, a study participant with a diagnosis of MCI, did not return to her doctor. She explained:

You can't be on drugs forever ... That's just like putting gas in the car constantly. And if you don't, what happens? You crash. So I don't want that. I only want it if I'm in pain. So I don't like that. But that's what she [doctor] was really kind of basically doing, and I was like “No, I can't be going through this. Because I'm not a pill dropper. I can't tolerate that.”

For some participants, the lack of comprehensive information provided at the time of diagnosis was also concerning. Ms. Julia Morgan, 81, a study participant with a diagnosis of MCI in her medical records, recalled: “*They showed me the parts in the brain that relate to the memory, and so on and so forth, which was informative. But that's about it.*”

Our findings on distress illustrated how a diagnosis of MCI or AD can deeply unsettle the lived experience of people living on their own, or their caregivers, if they are delivered abruptly or with little explanation or follow-up.

Theme 3: Ambiguous recollections

Some participants had blurred recollections of their diagnosis, as well as blurred memories of the sequence of events leading up to it, making it difficult to gauge the effects and meanings of their diagnosis. For similar reasons, it is also difficult to confirm the accuracy of their narratives. For instance, Ms. Well joined this study because of her diagnosis of MCI; seven months after her first interview she received a diagnosis of AD. Two weeks after her diagnosis of AD, Ms. Well talked about the shock of the news, as well as the relief of having a medical justification to her forgetfulness. However, nine months after the diagnosis, she did not recall the process of receiving her diagnosis when prompted by the researcher. Similarly, Ms. Sandra Moss, 79, a study participant with a diagnosis of AD, stated, “*I think it's safe to say I don't remember him [physician] giving me any diagnosis.*” This lack of recall may have been enhanced by providers' difficulties in formulating a clear-cut diagnosis. For instance, Ms. Moss stated, “*I think at one point they were considering early-onset Alzheimer's, but then they changed their minds.*” Ms. Left was also somewhat confused, stating, “*I had dementia and Alzheimer's. One or both or whatever. It's a complicated field anyhow.*” Furthermore, from some narratives, providers seemed to be reluctant to fully disclose a diagnosis. Ms. Alice Oswald, 81, a participant with a diagnosis of AD, recalled, “*I don't think [my physician] said much of anything. She just said, ‘I'm going to subscribe you to some medicine for your memory loss.’*” While cognitive impairment might diminish the memories of some participants' diagnosis, interviews with

five participants with MCI indicated that some might not have received a diagnosis because they talked with clarity about their health status without mentioning any diagnosis, even after probing. In one case the diagnosis of MCI was missing in the document with the list of health conditions that the physician handed to the participant at the end of medical visits. In another case, the adult child of a participant referred to this study as a patient with MCI described the avoidance of a medical provider to give a clear-cut diagnosis to her parent. Still other participants had their own interpretations of the diagnosis. Some participants retained a sense of humor and playfulness in the face of their impairment. For instance, Ms. Green did not recall the name of her condition, which she called, "*mild cognitive, whatever it is.*" Another speculated that her condition was named after "*Mr. Alzheimer,*" saying, "*I just made that up. I always have a joke every day.*"

In sum, these narratives suggest that studying the effects and meanings of diagnosis is restricted by both the evolving and complex nature of cognitive impairment and by the apparent reluctance of providers in clearly disclosing their diagnosis. The interplay of these factors sometimes made it difficult to understand the exact sequence of events and their effects on study participants.

Theme 4: Not knowing what to do

A recurring long-term effect of receiving a diagnosis of MCI or AD was participants' feeling that they did not know what to do with regard to the treatment of their condition. Sometimes they also did not know how to prepare for a likely worsening of their condition, which they would experience while living alone. This effect was noted among participants who were distressed by the diagnosis, as well as those participants who were relieved by the diagnosis. One important reason for this effect was the limited extent of follow-up care the study participants received from physicians and other professionals, a finding that emerged by the observation of participants over time. As participants continued to live alone, limited or non-existent follow-ups from providers often generated or contributed to this sense of not knowing what to do next in response to the diagnosis or the progression of the illness. This was especially difficult for study participants with small social networks and few caregivers to help them. For example, Mr. Muir, the participant who applauded after receiving his diagnosis of AD, was told that the neurologist was going to coordinate his care with his primary care physician and his local neurologist. However, interviews with Mr. Muir over the 15 months following the diagnosis revealed that these follow-up consultations never occurred. Instead, Mr. Muir was left trying to figure out how to coordinate his own care. His two daughters lived far away and he lived alone. He stated, "*I am trying to find a way to connect back and forth between our local person here and [the neurologist] ... I don't know exactly how to correspond back and forth yet.*" He added, "*I just don't know what's next.*" Mr. Muir's difficulty with recalling names and exact sequence of events made this process challenging. For example, he said about his neurologist, "*I'm trying to find Greta's [last] name right now and I don't have that particular paper.*" He then asked the researcher, "*But you must know who she is?*" Statements in which older adults living alone said that they forgot details about their diagnosis or had lost documents are representative of experiences shared by most participants.

A recurring source of frustration for participants was in not knowing what steps to take to address their impairment. As Ms. Amber, the woman with MCI who resisted taking medications, said, *“I have a hard time remembering now. I really hate that. That’s tearing me apart. And I don’t know what to do about that.”* To find answers, she went to the library: *“I’ve tried to read the books, tried to find, I haven’t found any way that you can overcome this.”* To fill these gaps in their knowledge, participants often asked the researcher what they could do about their impairment. For example, Ms. Left remarked, *“You don’t know how to prepare for something that you know is going to come.”* She then asked: *“What am I going to do?”* Eighteen months after the first interview, as her impairment worsened, Ms. Left was appalled by the seeming indifference of her medical providers to her diagnosis of AD. She also tried to join a clinical trial without success. In her words, *“Each time I’ve seen [the neurologist] I’ve said, you know, I’d be willing to take the drugs even if there’s a danger that it could be counterproductive, because what have I got to lose? [chuckle] I have nothing to lose at this point.”* On the one hand, participants talked about the role of healthcare providers, while on the other side, they often pointed to themselves as the ones who should take the initiative, thus diluting the responsibility of their providers. For instance, Ms. Well blamed herself for any shortcomings. Recalling her diagnosis of AD, she said, *“[The neurologist] did give me some numbers [of services] that I could call, which I haven’t done.”* She added:

If I joined the Y [YMCA gym] [so that] I would be with more people. And if I got off my duff in the morning and took a walk around the block I’d get more exercise. But those are things that I have to do. And I’m not doing them. So you’re going to encourage that I do them.

This statement is representative of most participants in the study. As this statement illustrates, older adults living alone often pointed to themselves as the primary person responsible for managing the effects of the cognitive impairment on their daily life, even when this becomes increasingly difficult. They reported receiving limited support from medical professionals or members of their typically small social networks, regardless of whom might be helping them. The medical care system appeared ill-equipped to provide support consistently. Furthermore, informal care providers such as adult children, siblings or friends, often did not seem to understand the concerns of participants. In an extreme case, Ms. Amber, the woman who went to the library, felt that her daughters were so insensitive to her concerns about her memory problems that she hid from them and anyone else. She explained, *“I just hide from everybody ... I’ll go in the bathroom and cry, and try to let it out, the tension out.”*

To make matters more challenging, because of the diagnosis of MCI or AD, older adults living alone had to make major decisions about their future, often on their own. For instance, one participant received a notice of eviction and she was trying to understand how and where to relocate. Ms. Left sold her house in the country after she lost her driver’s license, because she thought it was too far from public transportation. Whereas Ms. Left relocated, Ms. Moss, a childless woman without siblings or close friends, wanted to remain in her home despite her diagnosis of AD. To that end, she negotiated an agreement with an acquaintance whereby he would purchase her home and allow her to live there until her death. Alarmed by

Ms. Moss' potential vulnerability to fraud, her social worker reported the agreement to Adult Protective Services. As a result, Ms. Moss had to convince officers from this public agency that she was still able to make proper decisions. In her case, the theme of "not knowing what to do" stemmed from the fact that, because of her diagnosis of AD, she felt at the mercy of different providers who were potentially entitled to make decisions on her behalf. Because of her impairment, she had difficulties recognizing these providers and she did not know how to protect herself from their incursions. In her words:

There just seem to be so many people that have a finger in the works, and I can't always keep track of who has what opinion, and how is that going to affect me. And am I going to get a knock on the door? Am I going to get a summons of some kind? Is the hammer going to fall at some point? That concerns me. And the fact is that I'm physically fine, but that could change, and if that changes, if I get sick, then what happens?

DISCUSSION

The results from this study elucidated the effects and meanings of diagnosis of MCI or AD for those who live alone. The effects ranged from distressing to relieving. Some older adults living alone did not mention having received a diagnosis or had partial recollections about it. Over time, participants often did not know what to do with regard to the care of their impairment, and for many, there was no help available due to small or ineffective social support, inadequate linkage with social services, and poor follow-up and coordination after an initial diagnosis.

With regard to the relief coming from the diagnosis, some older adults living alone felt cared for by their medical providers at the time of the diagnosis. This effect was most noted in participants with AD perhaps because they reported conversations with healthcare providers. In particular, the participants' ability to voice their concerns and have a medical justification to their forgetfulness was comforting. One recent study also suggested that receiving diagnostic information about AD can be associated with feeling of relief [44]. Indeed, a traditional role of diagnosis is to relieve patients from the weight of carrying the burden of symptoms on their own [45]. These findings point to the tremendous potential of a diagnosis in making a positive difference in patients' life. Other studies emphasized the positive effect of "putting a name on the condition" and respecting the right to know "the truth" [10, 11, 14, 46], as well as of being supported by healthcare providers [15]. In a British investigation, study participants with MCI were relieved of not being diagnosed with AD or brain cancer [13].

In contrast, several participants described distress when receiving a diagnosis of MCI or AD, especially since they lived alone. Most times, their distress stemmed from learning that they had a condition for which there is no cure, being told they had to quit driving, the manner in which the news was conveyed, and concerns about their ability to continue living alone. One participant's distress about the short length of the evaluation also points to the variety of clinical contexts in which cognitive impairment can be diagnosed in the United States, including primary care, geriatrics clinics, specialized tertiary clinics (e.g., neurology,

psychiatry), and academic centers [47, 48]. As the participant alluded, the specific diagnostic approach may affect patients' experience in different ways. Overall, studies of elders who live with others also discussed the distress of receiving a diagnosis of MCI or AD [13, 15, 16, 49–52]. However, diagnosed persons living with someone were not particularly worried about their ability to continue to live in their homes. Their concern was often directed towards ways to “fight” their condition, with the cohabitant usually as an ally [53]. Others were concerned about becoming a burden to their spouses [14].

Another contribution of this study is that it points to the possible reasons for a blurred or partial recollection of diagnosis. Whereas some older adults living alone forgot about their diagnosis altogether, others reported that they did not receive a diagnosis or only received partial information about their condition. The combination of these factors often led to a vague or partial understanding of the cognitive impairment. Other studies of people with cognitive impairment had comparable findings. “Making sense of nonsense” generated from confusing or partial information from medical providers was identified as a major theme in qualitative studies of persons with MCI [13, 54]. The ambivalence of medical providers on communicating the diagnosis has also been discussed at length [19, 55].

Finally, a contribution of this investigation was to highlight the sense of not knowing what to do of older adults living alone with cognitive impairment. Evidence from our study shows participants' subjective feelings that healthcare providers provided little support over time. Multiple interviews with participants provided insights on participants' experiences of grappling, often on their own, with the management of their health and with major decisions about where and how to live, despite having a diagnosis of MCI or AD in their medical records. On one side this finding corroborate the idea that people living with cognitive impairment are likely to sense precarity [9, 56], defined as “life worlds characterized by uncertainty and insecurity” [57]. On the other side, this fourth theme sets older adults living alone with cognitive impairment apart from their counterparts living with others who usually had a caregiver supporting them with major decisions. This concerning finding underscores the need for future studies to determine if services were offered, as well as to gauge the quality of services supporting older adults living alone with cognitive impairment. Also, future studies should identify gaps in services and how to tailor follow-up services for persons living alone with forgetfulness. These findings are also critical because of increasing number of international studies underlining the paucity of appropriate services to enable those with a diagnosis of AD or other dementias to continue living in the community [15, 19–21, 58].

Overall, the findings of this study have implications for healthcare providers. First, these findings highlight that a diagnosis of MCI or AD, after sometimes providing some relief, can exacerbate the feeling of distress of older adults living alone. This feeling can be further intensified by the prevailing beliefs in Western societies that older adults should be responsible for managing their own health [59–62]. This responsibility includes making the correct choices related to one's wellbeing [63, 64]. Philosopher Mol pointed how difficult it could be for persons with chronic diseases to make complex choices about their care [58]. She underlined how these choices could have ramifications that are hard to consider, especially for persons with cognitive impairment. Making complex choices to manage one's

wellbeing is even more difficult when one has cognitive impairment and lacks cohabitants. As a result, it is important that medical providers understand that older adults living alone with cognitive impairment have specific needs compared to those living with others. For example, the loss of a driver's license can be particularly devastating for some older adults living alone because they managed their care and home through their driving abilities [65]. Therefore, it would be beneficial for older adults living alone that support services are in place when a driver's license is revoked. Second, findings indicate that the potential positive effects of the diagnosis can be diluted by minimal follow up after the diagnosis. Particular attention should therefore be devoted to the care of older adults living alone *immediately after* they receive the diagnosis. Attention should be placed in creating services truly tailored to support and empower older adults living alone with cognitive impairment. For example, reminders about appointments, easy ways to move around in their communities, as well as empathic and empowering support with managing their household and finances could be useful to them. Third, considering that a cure for AD is not currently available, a series of benefits associated with this diagnosis, for example financial subsidies to hire affordable home care aides well trained in the care of persons with cognitive impairment, could potentially increase its positive effects. Limitations of this study include a sample that was small and not diverse with regards to race/ethnicity, sex, and geographical scope. In addition, the sample was too small to assess in depth the differences between participants with MCI and AD.

Conclusion

Our study suggests that older adults living alone with cognitive impairment have unique needs. Additional research is needed to further understand the effects and meanings of the diagnosis of MCI or AD in larger and more diverse samples of older adults living alone. In particular, it is important to better assess any differences in the effects of the diagnosis between individuals with MCI and those with AD. Furthermore, with regard to healthcare and social services, the findings suggest that older adults living alone with cognitive impairment might benefit from long-term supportive services at the time of diagnosis, including affordable home care aides trained in the care of persons with cognitive impairment, as well as transportation services, reminders, and services to manage household and finances. Special attention should be placed in creating long-term services that are culturally relevant to older adults living alone from diverse ethnic/racial backgrounds. In sum, our study suggests that tailored person-centered protocols should be consistently implemented to allow older adults living alone with cognitive impairment lead meaningful lives and be integrated in their communities.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

The authors wish to express their gratitude to study participants and academic and community partners. A special thank you goes to the two anonymous reviewers, the reviewers of the Works-in-Progress seminar at the Clinical and Translational Science Institute at the University of California in San Francisco (UCSF), and to the editors Susan Griffin and Amy J. Markowitz, JD.

This work was supported by the Career Development Award (EP K01AG049102) from the National Institute on Aging, National Institutes of Health, by the New Investigator Research Grant Award (NIRG-15-362325) from the Alzheimer Association, and by the Pepper Center at UCSF (P30AG044281), which promotes promising new research aimed at better understanding and addressing late-life disability in vulnerable populations. The UCSF Center for Aging in Diverse Communities (P30AG15272) and the Resource Allocation Program also supported this work. No funding source had any role in the study design; collection, analysis, or interpretation of data; writing of the report; or the decision to submit the article for publication. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health, the Alzheimer Association, or the University of California.

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Table 1

Participant characteristics

Characteristics	Participants, No. (%) (<i>n</i> = 29)
Age, median, y	79 (65–92)
Gender, female	21 (72)
Race and ethnicity	
Non-Latino White	20 (69)
Asian	3 (10)
Latino	3 (10)
Non-Latino Black	3 (10)
Education	
High school or less	11 (38)
Some college or AA	6 (21)
Bachelor's degree	5 (17)
Master degree or more	7 (24)
Marital status	
Widow(er)	10 (34)
Divorced or separated	13 (45)
Never married	6 (21)
Married	0 (0)
Relationship status	
Single	26 (90)
Partnered	3 (10)

Table 2

Number of interviews per study participants

Number of interviews	Number of participants	Total interviews
1	2	2
2	3	6
3	7	21
4	6	24
5	7	35
6	2	12
7	2	14
Total:	29	114

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