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Permalink
https://escholarship.org/uc/item/1zc8d8r8

Journal
The Gerontologist, 61(2)

ISSN
0016-9013

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Publication Date
2021-02-23

DOI
10.1093/geront/gnaa201

Peer reviewed

The Gerontologist
cite as: *Gerontologist*, 2021, Vol. 61, No. 2, 251–261
doi:10.1093/geront/gnaa201
Advance Access publication January 6, 2021

Special Issue: Gerontology in a Time of Pandemic, Part II: Research Article

The Effects of the COVID-19 Pandemic on the Lived Experience of Diverse Older Adults Living Alone With Cognitive Impairment

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Received: August 18, 2020; Editorial Decision Date: December 4, 2020

Decision Editor: Barbara J. Bowers, PhD, RN, FAAN, FGSA

Abstract

Background and Objectives: Even before the COVID-19 pandemic, older adults with cognitive impairment living alone (an estimated 4.3 million individuals in the United States) were at high risk for negative health outcomes. There is an urgent need to learn how this population is managing during the pandemic.

Research Design and Methods: This is a qualitative study of 24 adults aged 55 and older living alone with cognitive impairment from diverse racial/ethnic backgrounds. Participants' lived experiences during the pandemic were elicited via 59 ethnographic interviews conducted over the phone either in English, Spanish, or Cantonese. Using a qualitative content analysis approach, interview transcripts were analyzed to identify codes and themes.

Results: Qualitative analysis of transcripts revealed 5 themes: (a) fear generated by the pandemic, (b) distress stemming from feeling extremely isolated, (c) belief in misinformation, (d) strategies for coping during the pandemic, and (e) the importance of access to essential services.

Discussion and Implications: This pandemic put a spotlight on the precarity and unmet needs of older adults living alone with cognitive impairment. Findings underscore the need to expand access to home care aides and mental health services for this population.

Keywords: Health equity, Living arrangements, Precarity, Social isolation, United States

In early 2020, a novel coronavirus was identified as the cause of an acute, severe respiratory syndrome (coronavirus disease 2019 [COVID-19]), which rapidly spread worldwide. Although still in the early stages of the pandemic, multiple studies have found that adults aged 65 and older, those with chronic health conditions, and several diverse racial/ethnic populations are disproportionately affected by COVID-19. People with chronic medical conditions that are common in older adults (e.g., diabetes) are at high risk of serious illness and mortality from COVID-19 (Sands et al., 2020). In the United States, older adults from diverse racial/ethnic backgrounds are overrepresented in both the number of cases and deaths (Kirby, 2020).

Alzheimer's disease and related dementias (ADRD) are another chronic illness that increases with age and disproportionately affects diverse populations (Mayeda et al., 2016). Several risk factors for COVID-19 overlap with those for ADRD, suggesting that older adults with cognitive impairment may be particularly vulnerable to COVID-19 (Wang et al., 2020). High fatality rates have been documented in long-term care facilities where older adults with cognitive impairment are overrepresented (Werner et al., 2020). However, the majority of people living with cognitive impairment reside in the community, of which approximately one-third (4.3 million people in the United States) live by themselves (Edwards et al., 2020); for brevity, we use "lives alone." Older adults who live alone with cognitive impairment are at high risk for negative health outcomes (e.g., self-neglect, falls; Gibson & Richardson, 2017). Compared to those living with others, older adults living alone with cognitive impairment benefit from community services and supports (e.g., home care aides, adult day centers) to help manage essential but cognitively demanding skills, such as taking medications, procuring groceries, and paying bills. Cognitive impairment also affects the ability to manage complex medical regimens and financial decisions (Edwards et al., 2020; Gibson & Richardson, 2017).

Studies from our group underscore the precarity of older adults with cognitive impairment who live alone (Portacolone et al., 2019). Precarity is an emerging theoretical construct in aging studies that underscores the role of public policies and prevailing ideologies in older adults' lived experience (Grenier et al., 2019; Portacolone, 2013). The notion of precarity points to a chronic uncertainty in everyday experience that stems from managing compounding pressures (e.g., managing comorbidities, household tasks) while trying to preserve a sense of independence. Specifically, markers of precarity include: a chronic sense of uncertainty, limited access to appropriate services, importance of being independent, and compounding pressures difficult to manage alone (Portacolone, 2019; Portacolone et al., 2019). While precarity likely intensifies during public health crises, little is known about how older adults living alone with cognitive impairment manage during public health crises, such as the current pandemic.

Public health recommendations that help mitigate the spread of COVID-19, including sheltering-in-place and physical distancing, are likely to increase the unmet needs of older adults living alone with cognitive impairment. For example, access to commonly used services and supports (e.g., senior centers, adult day centers) has been significantly reduced. In addition, the reduced contact with people and health care providers may create unique challenges (Holmes et al., 2020). Thus, there is a need to understand how this population with unique vulnerabilities manage during a public health crisis.

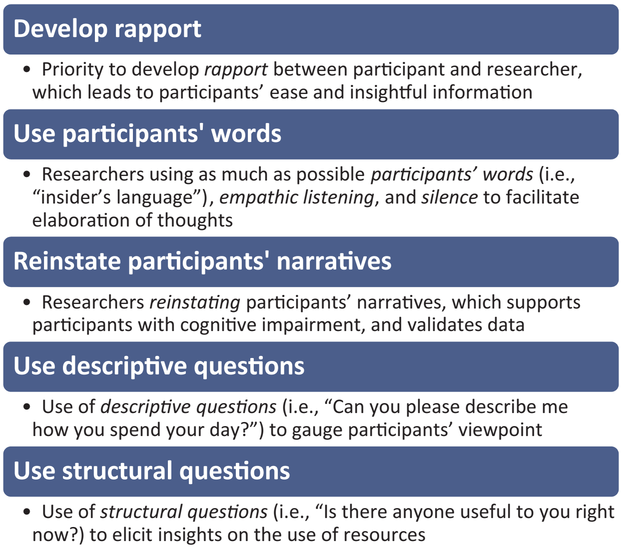
To better understand the early-stage effects of the current pandemic, we examined the lived experiences of diverse older adults living alone with cognitive impairment. Building on our prior research involving this population (Portacolone et al., 2018, 2019), we proposed four research questions: (a) How are older adults living alone with cognitive impairment managing during the early stages of the pandemic? (b) What are their priorities, concerns, and coping strategies? (c) What services and supports are important to them? (d) Are they experiencing a sense of precarity?

Design and Methods

We used qualitative research methods to understand, in depth, the subjective experience of living alone with cognitive impairment during a pandemic. Qualitative research studies usually seek to evaluate the way in which individuals interpret their worlds (Creswell, 1998) and the meanings they assign to events. In particular, ethnographic interviews were used in this study because they are designed to elicit an in-depth understanding of participants' perspectives, also described as "a profound sense on being on the inside of another way of life" (Spradley, 2016, p. 23) through five techniques (see Figure 1).

Recruitment

We recruited a subset of participants from diverse races/ethnic backgrounds from an ongoing qualitative study about living alone with cognitive impairment. Inclusion criteria for the parent study that began in 2016 were: (a) age ≥55; (b) medical diagnosis of Alzheimer's disease, mild cognitive impairment or dementia, or a score of ≤24 on the Montreal Cognitive Assessment; and (c) living



Develop rapport

- Priority to develop *rapport* between participant and researcher, which leads to participants' ease and insightful information

Use participants' words

- Researchers using as much as possible *participants' words* (i.e., "insider's language"), *empathic listening*, and *silence* to facilitate elaboration of thoughts

Reinstate participants' narratives

- Researchers *reinstating* participants' narratives, which supports participants with cognitive impairment, and validates data

Use descriptive questions

- Use of *descriptive questions* (i.e., "Can you please describe me how you spend your day?") to gauge participants' viewpoint

Use structural questions

- Use of *structural questions* (i.e., "Is there anyone useful to you right now?) to elicit insights on the use of resources

Figure 1. Techniques to gain in-depth participants' perspectives through ethnographic interviews.

alone. The parent study recruited 68 individuals (mean age = 81 years; 72% women; 15% White; 60% high school or less education). See Portacolone and colleagues (2018) for details. Soon after the pandemic started, we initiated interviews over the phone about the effects of the pandemic (study approved by UCSF Committee on Human Research, number 13-11181). Three methods were used to recruit participants. The first involved phone calls and text messages in English, Spanish, or Cantonese from bicultural and bilingual researchers. If we received no response, we mailed a letter. If these two approaches failed, we contacted informants (e.g., friends, siblings).

Setting

The study took place in the San Francisco Bay Area. On March 17, 2020, the San Francisco Department of Public Health public ordered—almost overnight—a shelter-in-place following 35 infections and the deaths of six people due to COVID-19 in California. Two months later, an order was issued to wear face coverings in public. The shelter-in-place and mask orders are indefinite.

Data Collection

Data were collected using ethnographic interviews (Spradley, 2016) conducted over the phone because in-person interviews were prohibited by university policies. Researchers interviewed participants with whom they already established rapport during the parent study. Researchers explained that they wanted to learn how participants were managing during this period, without mentioning the pandemic. Using descriptive and structural consistent questions that followed participants' train of thought, participants were asked to describe resources that were important to them, strategies they used to manage during the pandemic, and their priorities and concerns (see Supplementary Material). Interviews were audiotaped, designed to last 30 min, and were adapted for persons with cognitive impairment; questions were short, and used simple words. Interviews conducted in Spanish and Cantonese were professionally translated and transcribed. Researchers who conducted the interview reviewed the transcripts for accuracy. If available, informants were interviewed. Participants received a $30 gift card. Potentially identifying features of participants were slightly changed.

Data Analysis

Transcripts of audiotaped interviews and fieldnotes were loaded into ATLAS.ti for qualitative data analysis that used collaborative inductive and deductive content analyses. First, researchers conducted inductive content analysis. This allowed for codes to emerge from the data (without a priori codes). Initially transcripts of interviews and fieldnotes were analyzed line by line by the first author to identify specific factors related to participants' lived experience. A code was created every time a particular factor was identified. A senior coder reviewed her codes until interpretative convergence was achieved. Definitions of codes and related categories were documented in a codebook and shared with the research team. Next, other independent coders coded the rest of the transcripts; each coded transcript was reviewed by a coder to achieve interpretative convergence. Additional codes were added with the approval of the research team. Saturated themes were then identified by the first author through making connections among codes, writing memos, and having iterative discussions with the research team. Only after the inductive content analysis was completed was the conceptual framework of precarity applied to the themes. In this deductive portion of the analysis, directed content analysis (Hsieh & Shannon, 2005) was used to understand if the theoretical construct of precarity was present in the themes. In particular, the first author with iterative discussions with the research team purposely looked for four markers of precarity in the quotations of each theme. The four markers were: uncertainty about what to do, importance of maintaining independence, limited access to appropriate services, and cumulative pressures. See details of the analysis in the Supplementary Material. Table 1 provides more details about the themes and their relation with precarity.

Rigor and Validity

Rigor and validity were ensured through five approaches (Miles & Huberman, 2014; Saldana, 2016). First, during data collection, we attended to disconfirming evidence. Second, we used reflexivity where researchers recorded their motivations for the study, assumptions, and their concerns and expectations about participants' lived experience and the pandemic. Third, to reduce bias, researchers regularly sought respondent validation by explaining to participants what they understood. Fourth, we focused on decreasing power differentials between the researchers and participants. Specifically, researchers often repeated that their goal was to "learn" from participants. If asked to reciprocate, researchers self-disclosed details about their lives. Finally, we used a collaborative approach to data analysis and researchers coded transcripts of interviews they did not conduct.

Results

Demographics

From the 40 active participants at the time of the current study, we recruited 24 participants. Table 2 summarizes their characteristics, which were similar to participants in the parent study. Participants were interviewed an average of two times (total of 59 interviews). The interviews

Table 1. Themes, Examples, and Their Relation With Precarity

Theme	Examples	Relation with precarity
Feeling scared	Being scared of dying Worrying about others Being scared by the news Noting external unrest	Uncertainty Cumulative pressures
Extreme isolation	Feeling trapped Missing prior social activities Distress about family members Enjoying interactions with researchers	Cumulative pressures
Beliefs based on misinformation about COVID-19	Reliance on media and informal sources Belief in misinformation Asking researchers for information	Uncertainty Cumulative pressures
Coping	Taking precautions Attending remote religious events Exercising and outdoor routines Media consumption Positive thinking and altruism	Independence
Importance of accessing essential resources	Receiving food Being assisted by public home care aides Limited access to health care services Limited access to mental health services	Limited access to appropriate services

Table 2. Participant Characteristics (*n* = 24)

Characteristic	*n* (percentage)
Age (mean, *SD*, range)	82 years, *SD* = 10.10, 62–97
Sex, female	17 (71%)
Diagnosis	
Mild cognitive impairment	1 (4%)
Alzheimer's disease	3 (13%)
Dementia	1 (4%)
Score of ≤24 on Montreal Cognitive Assessment	19 (79%)
Race/ethnicity	
Non-Hispanic Black American	5 (21%)
Hispanic/Latino	8 (33%)
Asian (Chinese American)	7 (29%)
White	4 (17%)
High school or less education (%)	17 (71%)
Marital status	
Widowed	11 (46%)
Divorced or separated	7 (29%)
Never married	6 (25%)
Monolingual Spanish speaker	7 (29%)
Monolingual Cantonese speaker	6 (25%)
Participants with only in-person support from home care aides[a]	8 (33%)
Participants with only in-person support from family members	10 (42%)
Participants with support from both home care aides and family members	6 (25%)

Note: [a]Of the 14 participants who had home care aides, 13 had public home care aides and 1 had a private home care aide.

lasted an average of 25 min each and were conducted between April 1 and July 27, 2020. Data were supplemented with interviews with two informants (home care aide and sibling).

Themes

Five themes were identified from the analysis. The following sections provide more details about these themes.

Theme 1: feeling scared

When asked to describe their situation, participants often spontaneously talked about their fears, worries, and concerns related to the pandemic. Because of lack of cohabitants, participants usually faced these fears by themselves. Some participants were afraid of dying from the virus because of their health comorbidities and age. "If any pain appears, it seems like it must be pain from the virus," a Latina woman explained. A Latino participant echoed her concerns: "For me it is something very ugly where, if I get it [COVID-19], and with my diabetes, I won't be able to handle it." A Chinese American woman said, "It's scary. Seniors like me have weaker immune systems." Another Chinese American woman was scared to the point that at night she sometimes pinched the skin of her forehead to make sure that she was still alive. In the case of one Latina woman, direct exposure to the virus triggered her fears as she found out that her home care aide had been infected. Her fears were exacerbated by her developing a cough and having to wait 5 days to get tested (the test was negative). Similarly, another participant, a Black American man, became fearful because he had unusual dizzy spells, a high temperature, and a cough. Yet, he reported that his health care provider told him to stay at home without telling him if he had the virus. As a result, he spent 2 weeks alone at home, sick and worried. He explained that, at night, when his symptoms usually worsened, he would ask himself: "Oh boy, what's going on? Am I going to make it through this?" Only after his symptoms subsided was he able to get tested in his neighborhood, discovering that he did not have the virus.

In addition to being concerned about their own health, some participants worried about others. Repeated media consumption often fed these fears. The same Chinese American woman who pinched her forehead explained, "I watch the news every day. I am scared. When you watch the news, you feel scared … I feel scared when I see others dying." The uncertainty and the death toll were a source of concern, as a Chinese American woman noted: "How long are we going to be like this? Every day I hear that the number of dead increases." The spread of the virus throughout the world often intensified this fear. "It's the whole world," a Latino participant reflected.

Long lines in front of grocery stores reminded some participants of past experiences during wars and famines. Seeing family members, physicians, and other people worried or tense—either in real life or on the news—exacerbated these fears. "Everyone looks sad and depressed," noted a Chinese American woman. Watching people not taking precautions, whether on the streets or broadcast by the media, was also concerning. The riots stemming from instances of systemic racism fueled additional fear in a few participants. "I heard the racket," a Latina woman recalled. Similarly, a Chinese American woman said:

> Two weeks ago, some rioters smashed the windows of the [local] bank there. They also destroyed a few stores there. They broke their glass windows and doors. I don't know what was going on. The pandemic and riots really upset me.

Furthermore, racially based attacks also worried one Chinese American woman whose niece lives in North America and was attacked on her way to work because she was Chinese. Afterwards, the niece warned the participant to be careful about racial attacks in her own neighborhood.

A few participants were not fearful about the pandemic. Because of their cognitive impairment, some participants could not fully comprehend the situation. For example, when the researcher asked a White woman, "Why do we need to stay home?," she replied, "Because, well, they're trying to find … I don't know, they're looking into …, I really don't know, to tell you the truth. I don't know why." Similarly, a Black American woman said: "I don't know there is a virus." She added, "I wonder why the church has closed." Finally, a few participants noted that it would be a relief to get the virus and die, so that they could finally end their struggles. The Latino participant with diabetes said: "I am fed up with the life that I have been given." A White man extremely concerned about his diagnosis of Alzheimer's disease and with prior suicidal ideations echoed him by saying, "And if the pandemic takes me, I'd go: 'Great. I have an escape plan.'"

Theme 2: extreme isolation

All participants noted experiencing increased isolation in the context of living alone. "There is a big difference right now with being in isolation," said a Latina participant. This sentiment was shared by most participants. In addition, those participants who could not explain the virus noted their decreased ability to see others. Being isolated was associated with feeling trapped and being distressed about decreased interactions and social activities while living alone. Many participants felt trapped inside their homes. For example, a Latino man explained: "It is very terrible to be just closed up inside here." His sense of being trapped was intensified by the fact that some participants resided in cramped or inhospitable settings. For example, his apartment was poorly insulated and exposed to the sun in the afternoons. "It is terribly hot," his home care aide explained, adding, "It is an inferno." In the past he had visited with his friends at a nearby fast-food restaurant to escape the heat of his apartment, but now the establishment was closed, and his friends were sheltered in place. Similarly, a Chinese American woman repeated: "I sit at home all day and think too much. I didn't think so many things at the senior centers." She added, "I am so useless now, Miss. I am confused so often. I forget things." Her home is a 60-square-foot room with a tiny window overlooking another building; she shares a communal bathroom and kitchen. She said, "Everything is shared here. It's not convenient for me at all. People are so loud in the kitchen. I can do nothing about it." A few participants with family members abroad felt this sense of being trapped due to travel restrictions. For example, a Latina woman said: "If I start to think about how I am not going to see my children again, I am not going to hug my children again, I would get desperate and I would start to scream."

Most participants missed engaging in social activities. "I am the saddest man in the world," said a Latino participant. The main source of distress for him was no longer being able to go to a nearby senior center. He explained, "I would go there to waste four or five hours. [laughter] Playing and all of that. I would always entertain myself there." A Black American woman echoed his concern when she said, unprompted, "I get lonesome sometimes." She reported missing going to church, attending Bible studies classes, and engaging in activities with other residents in her senior housing. Her new routine involves staying in her apartment all day, except when she goes to the lobby to get her mail and briefly sit at a table in the community room. Similarly, a Latina woman missed interacting with her neighbors. She recalled, "If I go out and walk down the corridor, another woman comes out and we talk for a little while. But it is difficult now. All the doors are closed, and you don't see anyone."

Some participants were distressed that they could not interact with family members who lived nearby; others did not have family members involved. For example, a Chinese American woman said, "I didn't see any of them [adult children]. They didn't call or ask me about me. I don't even want to mention this. [pause] I feel angry inside when I talk about this. I don't want to talk about this."

Others missed their usual walks, which they avoided due to a fear of being infected. Still, a few participants shared that their life had not changed much because of the pandemic. These participants had either been homebound or already isolated before the pandemic.

Overall, all participants enjoyed the researchers' calls and spontaneously expressed appreciation. A Latina woman felt better after talking saying, "Well, Miss, I have enjoyed talking with you because now I feel unburdened and relieved. ... Talking with someone is calming." Another Latina woman shared, "I feel like I have company and like I am not forgotten about." She added: "Please don't forget me." Finally, a statement that is representative of all participants came from a Chinese American woman: "Thank you so much for calling and checking in on us."

Theme 3: beliefs based on misinformation about COVID-19

Most participants discussed how they acquired knowledge about the pandemic and the ways in which they incorporated this information into their beliefs, behaviors, and daily lives. They reported obtaining information about the pandemic from multiple sources, including the television, radio, newspapers, the internet (e.g., YouTube, Google), and mobile phone applications (e.g., WhatsApp, FaceTime). In addition to the media, participants obtained the majority of information about the pandemic from friends, family members, and home care aides either in person, over the phone, and through text messages.

Many participants developed beliefs about the coronavirus based on information that was often inaccurate or misleading. A Latina woman received a message with misinformation about a cure for the coronavirus via the mobile phone application WhatsApp (Figure 2).

She wondered if the coronavirus would disappear if she gargled with salt water. In the context of this message, the participant said, "They [family and friends] send so many of them." She added, "Some of them are positive and others are negative. We use some of them and don't use others." A suggestion to forward this information to others often accompanied these inaccurate messages. As a strategy to manage this misinformation, she deleted messages she thought were untrue, explaining that the trustworthiness of a message depended on whether she knew who sent the message. In a similar situation, a Latino man learned from a Mexican television program that researchers at a Mexican university had "discovered a remedy" for COVID-19. He said, "They already cured 15 [people], I think."

LEANLO: URGENTE
ALEMANIA: descubre q al hacer 4 veces al dia gargaras de
AGUA CON SAL en 7 dias el virus desaparece..
COMPARTELO POR FAVOR.. NO TE QUEDES CON EL MENSAJE.
PASALO SALVA VIDAS

READ THIS: URGENT
GERMANY: discovers that by gargling 4 times per day some
WATER WITH SALT in 7 days the virus disappears..
SHARE THIS PLEASE.. DO NOT KEEP THIS MESSAGE
SPREAD [THE MESSAGE] SAVE LIVES

Figure 2. WhatsApp message.

Other participants shared their beliefs about COVID-19 symptoms and the consequences of not following public health guidelines. A Black American man believed that COVID-19 could be associated with different symptoms depending on whether one got the "COVID" or "19" aspect of the disease. He feared that he had contracted the "COVID," which, he explained, had "milder symptoms" than the "19." He said that he obtained this information from his physician, which suggests confusion about the different clinical manifestations of COVID-19. Similarly, a Black American woman incorrectly believed that the police would send people to jail for not wearing masks. At the time of the interview, face coverings were recommended but not required in San Francisco. A Chinese American woman echoed her concerns as she claimed that she learned from television and newspapers that "if old people go out and get caught, the fine will be $200 and now it's even increased to $400," which was not true.

Other participants made decisions about their future behaviors during the pandemic based on information they acquired. A Latina woman said that she had decided not to get vaccinated (if developed) because a Latino doctor on a local television program dissuaded her. She recalled, "He said 'no' [to being vaccinated] very gracefully." A Chinese American woman asked the researcher: "How long do you think this will go on?" and "Should I take the vaccine?"

With regard to health precautions, some participants seemed unaware of the risks associated with having in-home visitors because they invited researchers to come to their homes. "When are you going to come?" asked a Latina woman. One Latino man was unaware of travel restrictions and believed it would be easy to fly abroad. San Francisco was under a shelter-in-place order at this time, and travel was discouraged. He was also unaware of deaths related to COVID-19 in San Francisco, despite reports of the deaths of approximately 40 San Franciscans at the time of the interview.

Despite these accounts, participants accessed some accurate information. For example, some made an effort to pronounce the exact name of the virus, as a Chinese American woman explained, "I know the name of the 'Wuhan Virus.' It is called coronavirus. I heard others saying it, so I learned it gradually." All participants were also aware of some precautions to take to avoid infection. "I listen to the government and stay home," said another Chinese American woman.

Theme 4: coping

Older adults living alone with cognitive impairment described a range of strategies they used to cope during the pandemic, from taking precautions to entertaining and reassuring oneself and others. Almost all participants said that they were taking precautions, even those who did not fully grasp the situation. For example, the Black American woman who did not understand why the church closed noted, "When we go out, we wear that mask. I don't know. I just do what they say." With regard to taking precautions, a Chinese American woman said that it feels like regressing to "swordsman" times when people had to put on layers of clothing and accessories before venturing outside. Another participant noted that it was odd to take a shower after returning home because she was used to showering before going out. One Chinese American participant wore two masks at the same time, saying, "I am not sure if one is enough, so I wear one extra to protect myself. That's my idea."

In addition to taking precautions, participants described other specific coping strategies. Trusting God and remotely attending religious services was common. "From the morning to the noon, we listen to priests from our church on WhatsApp," a Chinese American woman, explained. Most participants made an effort to exercise, which usually involved walking. "I walk around in my room … I go in circles doing exercises," explained a Latina woman. Walking outside was a cherished activity because it gave the opportunity to enjoy nature. A Chinese American woman said, "I need walking. I can't stay home. I may die if I sit at home forever." Most entertainment came from television and radio programs, with some participantas explaining their avoidance of the news. A Chinese American woman kept the television on when she went to sleep because the sound soothed her. Similarly, the home care aide of a Latino man left the television on before leaving so that he would not feel lonely. Positive thinking was another coping strategy, which included being grateful for one's and others' health: "I feel happy that my children are here. All of them are well and working," reflected a home-bound Latina woman. Some participants resorted to "grit" ("*valentía*" in Spanish) which involved showing strength to avoid worrying oneself and others. For example, a Latina woman explained that she tells her adult children abroad who are concerned about her, "I am going to win [against COVID-19] … We all have to be brave." She added that she makes an effort to distract herself with structured routines involving telenovelas and other relaxing television shows to avoid thinking about it. In her words, "I want to get it out, because if it gets to the point where I am concentrating on it, I would start to cry." Structured activities helped participants cope. These included house cleaning, crocheting, people-watching, taking baths, and decluttering. Finally, altruism was also a coping strategy, which included calling friends to check on them, and sending good thoughts to others, as a Black American man explained, "I am going to keep on praying for people, just make sure each person can wake up and see a brand new day."

Theme 5: the importance of accessing essential resources

All participants reported that their basic needs were being met thanks to the efforts of home care aides, family members, as well as friends, neighbors, church members, and local programs. Some participants only had support from home care aides; other had support only from family and some had both sources of support (see Table 2). Interestingly, the participants who had family support reported less distress than those only relying on home care aides. Participants who were particularly confused about the pandemic had support from family members. All participants received food since the beginning of the pandemic, which pleased them. As a Chinese American participant noted, "I am lucky to get the senior food delivery service, so I don't have to go outside. ... And the food bank gives out fruits and vegetables as well, like tomatoes, chicken, meat, eggs. I feel so happy having all these." A Latina woman said, "Maria [a friend] has bought me things. ... My son has brought me a lot of food. And the food bank as well, they brought us food last Monday."

Public home care aides continued to provide assistance during the pandemic, often playing a major role, especially for those participants who did not have support from family members, which is common among older adults living alone. For example, the home care aide of a Latino man was committed to ensuring that her client was strong enough to survive the pandemic. In her words, "He tells me what to bring home when I do errands. I make liver, meatballs, beef soup, chicken soup. I want him to enjoy it … And thanks to God, we get along." She added, "We're not going to let him fall to that battle. No, we are going to beat it. ... 'Keep moving forward,' I tell him." In another case, a Chinese American woman described the support her home care aide provided, ranging from relieving her leg pain to reminding her to wear a mask and providing companionship. The participant explained, "I have the medical oil, so she rubs it on my leg. She helped me with my laundry and cleaned my floor. She also did a cupping treatment on me." Another time, the same participant reported,

> [My] home care aide came over around 8:30 am to 9:00 am. Then she went in the kitchen and started cooking the fish I bought. ... While cooking, she asked me if I would like to keep the head. I said we could fry it in the pan. Then I offered her some fish, and she ate it with me. ... After lunch she took a walk with me around 12:00.

In contrast, access to health care providers was more sporadic. Some participants were satisfied about their interactions over the phone with their physicians. However, the inability to use technology was a barrier for using teleconferencing for others. Whereas a Black American woman was looking forward to seeing her physician in person, other participants were reluctant to enter clinics because they feared COVID-19. Other participants expressed frustration or confusion. For example, a Latino man with diabetes was concerned about not being able to see his physician in person. In his words:

> Now they gave me a phone appointment. What is that going to do? It isn't the same as seeing someone. … I don't agree with that. … I don't even answer the phone. I tell my doctor, "Don't do those things for me … First, I don't like it. Secondly, I have a poor mind."

When asked, "When you say that you have a poor mind, what does that have to do with a phone appointment?," the participant replied, "I don't understand what they say to me." Similarly, the interactions with an ophthalmology office confused a Chinese American woman. In her words: "I called them again. But I don't understand what they were saying. They didn't give me any appointment. They told me they recently don't have such services." She added, "I was wondering when I could get another appointment. The appointment was very difficult to make. It took about 3 or 4 months to finally make an appointment." Language barriers were also mentioned. For example, a Chinese American woman noted: "How do you communicate with her [clinic receptionist] if you don't speak English? You can't even argue."

Access to medications and medical supplies also varied among participants. For example, whereas one Latina woman received "some new masks" from her health care provider, a very low-income Chinese American woman paid out-of-pocket for her masks, ending up purchasing half a box of masks at $20 because she could not afford to purchase the full box at $40. She also paid out-of-pocket for heating pads for her arthritis. She explained, "I try to save money. I am not willing to buy food. I need money to buy plasters [bandages] for my legs."

Participants seldom received support for psychological distress triggered by the pandemic. A social worker gave one Chinese American woman with a recent history of suicidal ideations "toy blocks to keep my hands busy and to stop me from thinking too much," the participant explained from her cramped single-occupancy room. Another Chinese American woman who was extremely isolated and scared was connected by our research team to Cantonese-speaking friendly visitors over the phone. Two events prompted our initiative. First, on the weekend of July 4, the participant experienced so much anxiety that she thought she was going to die overnight. After the holiday, she called her physician who was unavailable; the substitute nurse dismissed her concerns, instead telling her to get medications for acid reflux to treat her symptoms.

Discussion and Implications

The results from this study of diverse racial/ethnic older adults, the majority of whom were monolingual non-English speakers, conducted during the early stages of the COVID-19 pandemic suggest that older adults living alone with cognitive impairment in the United States often experienced distress, including fear and confusion. They also experienced extreme isolation and associated loneliness. Repeated media consumption often intensified their distress. Their beliefs about the pandemic, which developed rapidly over a few months, were often based on misinformation. Older adults living alone with cognitive impairment reported using a number of coping strategies and highlighted the importance of essential services and supports, especially visits from home care aides and food delivery. They reported difficulties accessing health care providers. These findings suggest that the pandemic intensified the precarity of older adults with cognitive impairment who live alone.

A major contribution of this study is to illuminate the experience of diverse older adults with cognitive impairment while living alone *during* a public health crisis. Most studies on public health crises (e.g., SARS epidemic, floods, hurricanes) have been conducted *after* the event and never focused on older adults living alone with cognitive impairment, let alone racial/ethnic minorities (Parker et al., 2016; Sands et al., 2018).

The participants of this study often expressed distress, including fear, extreme isolation, and confusion related to the pandemic. The construct of precarity manifested in this theme because of the consistent presence of markers of uncertainty and cumulative pressures (e.g., being scared and having comorbidities) in the narratives. In our prior investigations of older adults living alone with cognitive impairment, distress emerged mostly when participants discussed noticing the symptoms of cognitive impairment and reflected about their future (Portacolone et al., 2018, 2019). However, the same participants seldom discussed their distress so openly. Our findings about distress align with other studies about sheltering-in-place during epidemics conducted among health care providers and adults living with others (Brooks et al., 2020). Our findings also underscore the extreme isolation of older adults living alone with cognitive impairment during the pandemic. The isolation was intensified by the fact that these older adults were often socially isolated prior to the pandemic due to their living arrangements and cognitive impairment (Portacolone et al., 2019). The extreme isolation experienced during the COVID-19 pandemic evokes the isolation that older residents of Chicago, mostly living alone, experienced during a heat wave in Klinenberg's (2002) "social autopsy of disaster." However, his study relied on analysis of the belongings of deceased older adults, without capturing their perspectives while they self-isolated during the fatal heat wave.

The results from our study also found that older adults with cognitive impairment who lived alone acquired information about the pandemic from multiple sources (ranging in accuracy), often forming false beliefs and experiencing confusion. These false beliefs included inaccurate information about COVID-19 symptoms and possible cures. It is important to note that some participants expressed accurate beliefs about the pandemic, but they typically shared a mix of both accurate and false beliefs. The spread of misinformation has been a particular challenge during the current pandemic (Love et al., 2020). For example, a participant's belief that gargling with salt water is a cure for COVID-19 is a widely reported misconception during this pandemic (Fortin, 2020). Concern has been raised about the potential reliance on misinformation by people with cognitive impairment during this pandemic (Holmes et al., 2020). On a related note, the spread of misinformation among older adults has also been a concern during other public health crises, such as HIV (Hawryluck et al., 2004). In our prior research, we found that some older adults with cognitive impairment struggled to identify authoritative sources of information to understand symptoms of their cognitive impairment and expressed confusion about processing information (Portacolone et al., 2018, 2019). The uncertainty associated with not knowing where to go for accurate information about their cognitive symptoms was included in our prior conceptual framing of precarity (Portacolone, 2019). Therefore, it is not surprising that they had also difficulty obtaining and comprehending accurate information about the pandemic. Susceptibility for using misinformation will be added to our conceptualization of precarity.

Our study highlighted the dependence on several critical long-term services and supports and the need for additional services. Our study highlighted the critical role of home care aides to support older adults living alone with cognitive impairment. Home care aides were often an essential lifeline because participants had limited cognitive abilities to manage the restrictions of shelter-in-place by themselves, missed cohabitants, and often could not rely on informal support of family members and friends. We also noted that family members' support helped alleviate a sense of precarity, and further research is needed to understand the benefits of different sources of supports. In addition, the participants discussed using several coping strategies, which is a marker of independence also described in prior studies of public health crises (Fletcher et al., 2013). In contrast, primary and specialized health care, as well as mental health services, were more difficult to access, as other studies on epidemics also reported (Cameron & Rainer, 2003). Thus, a marker of participants' precarity was limited access to appropriate services.

Taken together, our results illustrate mechanisms by which pandemics can exacerbate precarity, thereby refining this theoretical construct. In particular, the pandemic intensified uncertainty and limited access to appropriate services by adding compounding pressures (see Table 3) to the lived experience of older adults living alone with cognitive impairment. Loneliness and extreme isolation increased markedly, contributing strongly to precarity.

Table 3. Example of Compounding Pressures of One Study Participant

Prepandemic pressures	Pandemic-added pressures
• Cognitive impairment • Chronic condition requiring strong adherence to medications • Wheelchair-bound disability • Poverty • No literacy • Limited informal support only from acquaintances	• Fear of fatally contracting the virus • Extreme isolation following the closure of the senior center • Inability to see physician in person • Delays in getting batteries for life-sustaining medical equipment.

The limitations of our study include the small sample from a relatively small geographical area and short timeframe. In addition, we did not collect data about participants' functional status or current cognitive status. Finally, we only interviewed participants who had a phone, which excluded participants without a phone or who had hearing impairments.

There are several implications from this study. First, the finding that older adults living alone with cognitive impairment reported experiencing significant distress, including fear, confusion, loneliness, and yearning for former social activities, highlights the urgent need for increased mental health supports during public health crises (Brooks et al., 2020). The increased suicide rates of older adults during public health crises also underscore the need for robust mental health supports. Extreme isolation likely contributed to the distress (Brooks et al., 2020). The social support provided by interacting with others during regular social activities was abruptly halted by shelter-in-place orders. Innovative efforts to support extremely isolated older adults during this pandemic have emerged, but widespread dissemination has not been achieved. Local efforts included creating pen pals for older residents of assisted living facilities (Free, 2020), adding novel social and cognitive components to food delivery (e.g., gifts, games), and supporting older adults' ability to make video-phone calls. Virtual faith-based services were also appreciated in our study.

This study also highlighted the difficulty in identifying authoritative sources of information, which often increased distress, uncertainty, confusion, as well as unsafe behaviors, thereby exacerbating precarity. These findings indicate the importance of developing clear and consistent public health messages and the need for easy-to-identify authoritative sources of information. For example, aging advocacy organizations may need to identify novel ways to disseminate COVID-19-related public health messages more effectively and possibly partnering with trusted professionals and organizations (e.g., nurses, churches). To alleviate social isolation, local organizations could explore de-densified places where older adults could congregate and receive appropriate information while also following coronavirus precautions. More research is needed to determine the most appropriate options.

Perhaps one of the most actionable implications of this study relates to the critical role that the home care workforce plays in supporting those with cognitive impairment who are living alone. The home care aides in our study were deeply invested in supporting their clients. In addition to household tasks, some home care aides provided much-needed emotional support. A concern is that Medicaid policy in the United States only offers public home care aides to very low-income older adults, leaving most older adults ineligible for this essential service (Shih et al., 2014). Unlike other countries (Portacolone, 2018; Rosenwohl-Mack et al., in press), public home care aides receive limited training and low wages. Home health care workers are considered essential workers during this pandemic (Guerrero et al., 2020), and this policy should continue and expand its reach, given the critical role they serve.

As discussed above, approximately 4.3 million people with cognitive impairment live alone in the United States (Edwards et al., 2020). This represents a sizeable population of vulnerable older adults who do not yet have tailored services and support to help them manage while living alone during a crisis. In the context of a pandemic, there is an urgent need to identify effective services and supports that can be tailored to this population. These individuals should be identified so that they can receive support during and after public health crises. Well-trained and subsidized home care aides should be available to *all* older adults living alone with cognitive impairment, not only those who are very low-income. This pandemic has put a spotlight on the precarity and unmet needs of older adults living alone with cognitive impairment.

Supplementary Material

Supplementary data are available at *The Gerontologist* online.

Funding

E. Portacolone and J. K. Johnson were supported by the National Institute on Aging, National Institutes of Health (K01AG049102, R56AG062165, and R01AG069147 PI E. Portacolone; P30AG15272 PI Karliner). This work was also supported by the New Investigator Research Grant Award (NIRG-15-362325 PI E. Portacolone) from the Alzheimer's Association, and by the Pepper Center at the University of California, San Francisco (P30 AG044281 PI K. E. Covinsky), which promotes promising new research aimed at better understanding and addressing late-life disability in vulnerable populations. 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's Association, or the University of California.

Conflict of Interest

None declared.

Acknowledgments

We are deeply grateful to our study participants, our community partners, and our Community Advisory Board. We also want to acknowledge the support of Ms. Michelle Ng-Wong, Ms. Judy Lofton, Ms. Christie Chu, as well as the insights of the two anonymous reviewers.

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