

“An animated socialization without substance:” experiences of persons living with dementia through the COVID-19 pandemic

Dementia

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Abstract

Background: Like so many others, persons living with dementia have been greatly impacted by the COVID-19 pandemic. A Stakeholder Advisory Council set a research priority to learn more about the experiences of families living with dementia during COVID-19.

Methods: This study was conducted using a multi-method design. Online surveys were completed by 27 persons living with dementia to rate the impact of COVID-19 on their health and healthcare. Additionally, interviews ($n = 3$) and two focus groups were conducted via Zoom with eight participants to explore the experiences of persons living with dementia during COVID-19.

Results: Most participants in this study reported that COVID-19 had some to extreme impact on their anxiety, feelings of isolation, and quality of life. Focus groups and interviews provided context and increased understanding of the main survey findings, with participants also describing other concerns and how they were coping with all of the challenges that came with COVID-19. Five

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themes from the qualitative data were health, isolation, feelings about COVID-19, adapting to COVID-19, and self-reflection.

Discussion: Although persons living with dementia described the ways that COVID-19 impacted on their quality of life, they also described strategies for coping. For those persons living with dementia who are able to utilize technology, this study highlights the ongoing need to provide virtual opportunities for socialization and support. These findings also emphasize the need to create safe opportunities for socialization such as small socially distanced activities that may allow persons living with dementia to maintain social connections through the COVID-19 pandemic and throughout the progression of their disease.

Keywords

dementia, COVID-19, isolation, health, dementia care

Background

There are nearly 6.2 million persons in the US living with dementia ([Alzheimer's disease facts and figures, 2021](#)). Prior to COVID-19, persons living with dementia reported feelings of loneliness ([Alzheimer's Society, 2017](#); [Moyle et al., 2011](#); [Victor et al., 2020](#)) and isolation ([Aldridge et al., 2019](#); [Werner et al., 2020](#)). The construct of loneliness is complex, but can be categorized in two different ways, perceived social isolation and objective social isolation ([Cacioppo et al., 2010](#)). Perceived social isolation is when someone *feels* isolated ([Cacioppo et al., 2010](#)); they could have many social contacts around them but do not feel any meaningful connection from others. On the other hand, objective isolation describes when someone is socially isolated ([Cacioppo et al., 2010](#)); the person has a limited number of social contacts surrounding them. Persons living with dementia had certainly faced objective isolation before COVID-19, although they had access to family visits and social services such as support groups, memory cafes, senior centers, and day centers. These types of services could serve as a way for persons living with dementia to socialize with others and decrease isolation. With the pandemic, however, opportunities for social interactions were limited, leading to objective isolation and potentially increasing perceived social isolation. The findings from a recent study conducted among participants of the IDEAL cohort show significantly higher rates of loneliness among persons living with dementia during the pandemic (37.8%) compared with before the pandemic (20.2%) ([Clare et al., 2022](#)).

COVID-19 Pandemic in the US and in Texas

Shutdowns to mitigate the impact of COVID-19 began in March of 2020 with the closing of all non-essential businesses and organizations. Many of the services that persons living with dementia used, such as support groups or adult day programs, were shut down or changed entirely to a virtual format ([Giebel et al., 2020](#)). People no longer had access in in-person programs of support. Not everyone has means or access to the internet or technologies such as Zoom, ([Giebel et al., 2020](#)), leaving them unable to join activities or support groups that were offered through Zoom or other online platforms. These changes compounded the isolation already experienced by persons living with dementia.

Data for this study were collected between November 24, 2020 and February 27, 2021. As of Fall 2021, both COVID-19 case numbers and associated deaths were continuing to increase in the US, with vaccines just becoming available for anyone over the age of 65 or individuals living with chronic health conditions that put them at greater risk. During the time when focus groups were

conducted, February 2021, there was discussion among state government officials to allow businesses in Texas to resume operations at full capacity. These developments were creating anxieties and uncertainties for many residents across the state and across the country.

Study objective

The purpose of this study was to learn about the experiences of people living with dementia and how the COVID-19 pandemic impacted them. This study is part of a larger project that was conducted to describe the impact of the COVID-19 pandemic on dementia care from the multiple perspectives of persons living with dementia, family care partners, and health and social care professionals. Findings specific to the impact of COVID-19 on family care partners, and the overall impact of COVID-19 on dementia care as perceived by multiple stakeholders, are reported elsewhere (Masoud et al., 2022; White et al., 2022). Results reported here focus on the perspectives and experiences of persons living with dementia during the first year of the COVID-19 pandemic.

Methods

The stakeholder advisory council

Funded by the Patient Centered Outcomes Research Institute, a stakeholder advisory council was initially created in 2018 with the purpose to identify stakeholder-driven priorities for research in dementia care (Masoud et al., 2021b; Patel et al., 2021). The stakeholder advisory council was composed of persons living with dementia, family care partners, and health and social care professionals. As the initial project to identify research priorities was coming toward an end, the COVID-19 pandemic began. At this time, Patient Centered Outcomes Research Institute announced a call for proposals to leverage existing project infrastructures to explore the COVID-19 pandemic and its impact on patients, families, communities, and systems. The stakeholder advisory council discussed how they were impacted by COVID-19 and felt that understanding how other families living with dementia were experiencing the pandemic was an important research priority that needed to be addressed. In June 2020, the stakeholder advisory council and project team were awarded a Patient Centered Outcomes Research Institute enhancement award to conduct this research.

Design

This study was conducted using a multi-method approach including a cross-sectional survey, focus groups, and semi-structured interviews. Quantitative data were collected using surveys. Survey respondents were invited to participate in either a focus group or an individual semi-structured interview, based on their preference.

Participants

To be eligible for this study, participants needed to identify as a person living with dementia. Participants were not asked about their specific diagnosis or stage of dementia, but most appeared to be in early-stage dementia, ascertained through conversation with the person living with dementia or with their family caregiver. Additionally, all participants were community-dwelling.

Using a convenience sampling approach, the survey was sent to community partners, academic partners, and through personal and professional networks, including support groups and a monthly

newsletter sent to family caregivers. Focus group and interview participants were recruited by reaching out via email or phone to those who had completed the survey and expressed an interest in participating in an interview or focus group.

Data collection

Surveys

The stakeholder advisory council participated with the research team in the development of the survey and focus group/interview guides for persons living with dementia. This was an iterative process, and the survey and guide were revised several times based on their feedback. Brief surveys were conducted with persons living with dementia to get a broad understanding of what health concerns they had related to COVID-19 and how COVID-19 impacted their care. Surveys were administered with an online link through RedCAP (an electronic data capture tool hosted at UT Health San Antonio) or ‘face-to-face’ via Zoom. Surveys were interviewer-administered via Zoom when a family member or person living with dementia contacted the research team and felt it would be easier for them to complete the survey in this way. These two methods were offered to support the participation of persons living with dementia. Interviewer-administered surveys took approximately 15 minutes to complete.

Variables

Demographics Participants were asked their age, gender, and race/ethnicity.

Survey items Questions in the survey were focused on their perceptions of how their health was affected and their healthcare, including visits with healthcare providers during COVID-19 (e.g., “*how much do you think the COVID-19 pandemic has affected your overall health?*”). Most questions had 5-point Likert response options. To improve clarity, answer choices were modified to be specific for each question. For example, for the previous question about health, the answers included 1) ‘no effect on physical health’ to 5) ‘major effect on physical health’. See [Supplement](#) for complete survey.

Focus groups and interviews

After collecting the quantitative data, a focus group/interview guide was created by the research team and members of the stakeholder advisory council to further explore how COVID-19 impacted the health and social care persons living with dementia received. Open-ended questions included asking participants about their current concerns and experiences during the COVID-19 pandemic, how the pandemic has impacted their health including their memory, emotional, and social health, and how COVID-19 had affected their day-to-day lives. Based on previous experience, some persons living with dementia do well in groups while others can experience increased anxiety and discomfort in group settings. Mindful of this, participants were given the choice of being part of a focus group or participating in an individual interview.

At the time of data collection, COVID-19 restrictions were still in place, so all focus groups and interviews were conducted through Zoom. Visual cues, like body language, are more difficult to interpret in online video conferencing environments than in-person. As such, the online focus groups were kept small (2 to 3) to minimize crosstalk and allow participants more time to contribute.

Some participants were well acquainted with Zoom and had no challenges joining and engaging using the application. For those who were not able to log on to the focus group themselves, a care partner was asked to help them but then left as the discussion started. Focus groups and interviews ranged from 45 to 90 minutes each. Before beginning the focus groups and interviews, participants were informed about the purpose of the study, what the procedures were, and the confidentiality of their information. All sessions were video and audio recorded through Zoom after receiving permission from the participants and later transcribed using Otter.ai (Otter ai., 2021).

Data analysis

Surveys. Survey data were analyzed using frequencies and proportions for categorical data. All data were analyzed in Stata Version 17.0. (StataCorp, 2021).

Focus groups and interviews

A thematic analysis (Braun & Clarke, 2006) was used to analyze focus group and interview data. Six researchers, including members of the stakeholder advisory council, coded and analyzed the transcripts using analysis software of their choice, including Microsoft Word, Excel, and Quirkos (Quirkos, 2021). Each transcription was coded independently by two members of the team and then reviewed with the whole team. Any coding discrepancies were resolved with the team. The coding theme was developed from the analysis of the focus groups and applied to the individual interviews. After completing a preliminary analysis, categories and subcategories were presented to the stakeholder advisory council for their input and to evaluate if they felt the data were well represented.

Ethics

This study was approved by the University of Texas Health Science Center at San Antonio Institutional Review Board as exempt research (HSC20200790E).

Related to the exempt nature of the approval and the virtual conduct of the study, participants were not required to give written consent. For the survey, participants read through an information sheet prior to completing the survey. This information sheet explained the purpose and that this was research and their right not to participate if they chose not to participate. Their completion implied consent. However, verbal consent or assent was obtained prior to conducting focus groups and interviews (Black et al., 2010). All study team members who conducted focus groups and interviews have extensive knowledge about dementia and have worked with persons living with dementia in prior studies.

Results

Participants

All participants were living with Alzheimer's disease or a related type of dementia. A total of 27 participants completed the survey. Most survey participants were female ($n = 15$; 56%) and identified as White ($n = 17$; 63%). Of 15 survey participants contacted for a focus group or interview, eight participants were available and agreed to participate. Most of these participants were male ($n = 5$; 63%) and half identified as White ($n = 4$; 50%) while the other half identified as

Latino (n = 3; 38%) or African American (n = 1; 13%). Please refer to [Table 1](#) for more demographic information.

Surveys

As seen in [Table 2](#), all survey data was organized into two separate categories, ‘health’ or ‘healthcare’. The ‘health’ category included physical health, mental health, cognitive health, and spiritual wellbeing. The ‘healthcare’ category included how participants felt about their healthcare overall, healthcare appointments, and the COVID-19 vaccine.

Health

Health in this survey was measured as physical, mental, cognitive, and spiritual wellbeing. Most participants reported that the pandemic had at least some to a great deal of effect on their physical health (n = 15; 56%). In reference to mental health, most participants reported that the pandemic had caused them to have somewhat to extreme anxiety (n = 17; 63%), but little to no depression (n = 15; 56%). Additionally, most participants reported that the COVID-19 pandemic had made them feel somewhat to extremely isolated (n = 17; 63%), with 30% feeling extremely isolated. Most felt that the pandemic had little to no effect on their memory (n = 16; 59%). Most participants (n = 16; 59%) thought the pandemic had little or no effect on their spiritual health. The majority of participants felt that the COVID-19 pandemic had a somewhat to extreme effect on their quality of life (63%) and that their quality of life was somewhat or much worse than it was prior to COVID-19 (59%).

Healthcare

Most participants felt somewhat to extremely concerned about the impact of the pandemic on their healthcare (n = 16; 62%). However, most participants were not worried at all or only a little worried about COVID-19 affecting their healthcare appointments (n = 14; 54%). This could be an indication

Table 1. Participants.

Demographics	Survey N (%)	Focus Groups N (%)	Interviews N (%)
Gender			
Female	15 (56)	1 (13)	2 (25)
Male	12 (44)	4 (50)	1 (13)
Age			
19–34	1 (4)		
35–49	1 (4)	1 (20)	
50–69	7 (26)	1 (20)	
70–79	8 (30)	3 (60)	2 (67)
80+	5 (18)		
Missing data	5 (18)		1 (33)
Race/Ethnicity			
White	17 (63)	3 (38)	1 (13)
Latino/Hispanic	7 (26)	1 (13)	2 (25)
African American/Black	2 (7)	1 (13)	
Other	1 (4)		

Table 2. Health related survey data.

Health		
How much did COVID-19 impact your...	None to a little n (%)	Some to extremely n (%)
Physical health	12 (44)	15 (56)
Anxiety	10 (37)	17 (63)
Depression	15 (56)	12 (44)
Isolation	10 (37)	17 (63)
Quality of life	10 (37)	17 (63)
Healthcare		
How much did COVID-19 impact your...	None to a little n (%)	Some to extremely n (%)
Healthcare	10 (38)	17 (62)
Healthcare Appointments	14 (54)	13 (46)

of telehealth appointments substituting for in-person appointments. About half ($n = 14$; 52%) reported cancelling an appointment due to the pandemic, of which most ($n = 8$; 57%) reported they cancelled from fear of COVID-19. When asked if they would be willing to take a vaccine if available, most ($n = 19$; 70%) participants reported that they would take it. Additionally, most participants ($n = 16$; 70%) reported being somewhat to extremely worried about their family contracting COVID-19. All questions, response choices, and data can be seen in the Supplement.

Focus groups and individual interviews

During focus groups and interviews, participants were asked about concerns they had related to COVID-19 and their health, concerns about COVID-19 and activities, and what strategies they had used to cope with these concerns and challenges. From the large number of codes identified from the data, codes with similar meanings were merged and then codes were grouped into conceptually similar themes. This was an interactive process with the research team. There were five main themes related to the consequences of the COVID-19 pandemic as seen in [Figure 1](#). Themes included health, isolation, feelings about COVID-19, adapting to COVID-19, and self-reflection.

Consequences of COVID-19

Health To elucidate more context on survey responses related to health, participants were asked how the effects of the COVID-19 pandemic had affected their health. They reported a wide range of effects including physical, mental, cognitive, and spiritual.

Physical Health Participants often described changes to their pre-pandemic physical exercise routines. Some adapted to new routines, while others had no choice but to stop exercising entirely.

You know, I could swim, that would, that was why it was so good for me because I was exercising in the water. And now I don't have water. (Participant 3, Interview)

Mental Health As reflected in the survey results, participants' mental health was also greatly affected by the COVID-19 pandemic. Participants reported feeling more anxious or depressed. For some, the anxiety was a new feeling since COVID-19 began. The idea of going out and being around people was causing them to feel anxious. Isolation due to COVID-19 was mentioned consistently

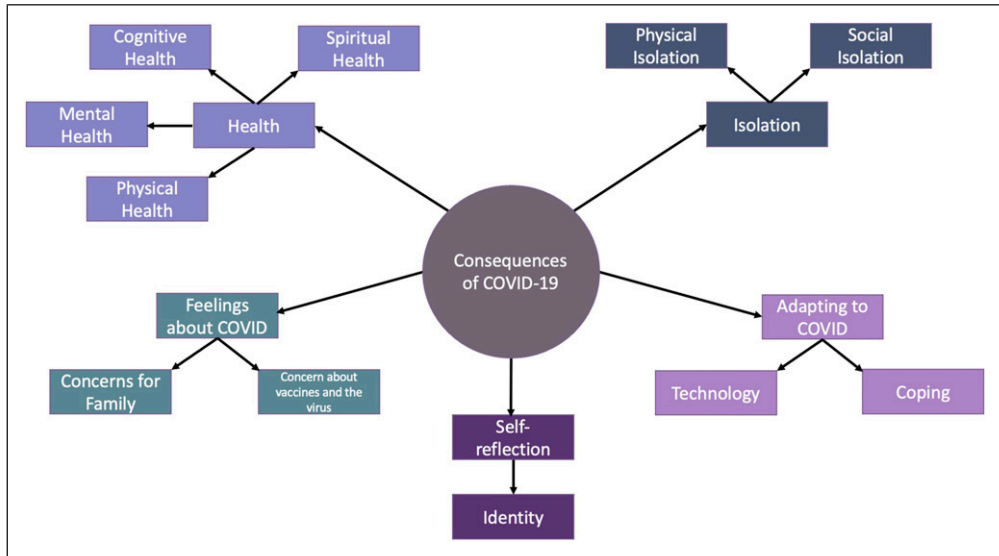


Figure 1. COVID-19 and its perceived impact on persons living with dementia.

across focus groups and interviews. Participants were not seeing children, grandchildren, friends, or other supportive relationships due to concerns about COVID-19.

I think for me, I have also noticed a level of anxiety. When it comes to going out that I didn't have before.... And she [the doctor] said it's due to anxiety. And she said a lot of her patients have increased anxiety since COVID. And I feel like one thing is that my anxiety has gone up when I get ready to go to church because it's like you haven't seen people you're not around people. And then here I am being a greeter 'cause churches opened up. So, I have all these people around me, you know, even though we're all wearing masks, but you know, then I get a hot flash [laughs]. But on top of the brain fog, now I have anxiety. (Participant 6, Focus Group)

Cognitive Health Participants in this study were very aware of their cognitive health and how COVID-19 had impacted them personally. Some worried that contracting COVID-19 could worsen their dementia symptoms. Most participants in this study already had implemented routines and practices to help maintain their cognitive health, such as puzzles or reading. However, there was a change in how some participants described an increased sense of importance to stimulate their brain due to the isolation they were experiencing.

...because when you're isolated, you're not challenging your brain either. You know, unless you come up with different activities and things like that, like I've tried to do, but you missed that social piece that works your brain that works, those parts of the brains that are that are being affected by the Alzheimer's or dementia. (Participant 6, Focus Group)

I'm not able to make memories because of COVID-19. My time is limited because of the Alzheimer's and not having the opportunity to make memories with my family has been hard. (Participant 2, Interview)

Spiritual Health Spiritual health appeared to be a great concern for participants in the focus groups and interviews. Many participants described how they relied on their faith for support in daily life. Since COVID-19, participants could not attend church in the same way they used to. Participants described how they used to go to church and now had to rely on Zoom for church services or watch services on TV, leaving them longing for those prior connections. On the other hand, some participants appeared to be fulfilled and had their spiritual needs met when attending church on Zoom.

And the problem was we, we can see the people at the church or at their home, but I mean, we're not together. We just know where they are and were on. (Participant 1, Interview)

You know, our Bible study class is on Zoom, a lot of us are and it's a fairly large class. And many of them in fact, for a while, we didn't have it, except online. Because we couldn't get together downtown. You just couldn't because of COVID. Now, they're, they're doing it now. Just started on a very limited basis. But I've got to where I enjoy it. I like it better than driving downtown. 'Cause I get to see them just like this. You know, it's on zoom, we get, you know, we talk. (Participant 4, Focus Group)

Isolation Isolation was described in two different ways by participants, as a physical isolation and a social isolation. In regard to physical isolation, participants described how they were quarantined and physically separated from others. This was a more objective loneliness felt by participants. On the other hand, social isolation was described more as a longing to see others and socialize with them. Even though some participants could see friends over Zoom or interact with a care partner they lived with, they still felt lonely and isolated. This was more of a subjective loneliness.

Physical isolation Many participants struggled with self-quarantine and social distancing from others. They were very aware of the dangers of COVID-19 and wanted to stay safe. However, they felt the impact of being unable, with the exception of rare occasions, to leave their home. Being cut off from others also left some participants aware of how much their care partner was having to do for them, that their care partner could no longer have a break from them.

And with [wife], you know, being, she gets the brunt of my discussions of the world. And she needs a break once in a while too, I'm sure. But neither one of us can get a break, you know, because darn COVID is out there and you're afraid to get it. (Participant 7, Focus Group)

No, I have not had any experiences with the COVID. I have been - Honestly, I've been in this little house not going anywhere except going to doctors and dentists and such. So I've been here a year indoors. I have a little garden, I have deck – two little decks, and I have plants. And I'm looking at them. They're completely covered in ice right now. (Participant 3, Interview)

Social isolation From a subjective stance, many participants described how they might see others through Zoom, but it was not a true sense of socialization compared with in-person connection. One participant also acknowledged that for some persons living with dementia, communication tools such as Zoom are inaccessible, thus leaving them even more isolated. Some participants turned to alternative ways of communicating with others, for example, one participant kept in touch with friends through letters and phone calls.

“And then all of a sudden, you know, the world start getting smaller and smaller and smaller. And so now, what was once you know, a large room has been reduced to maybe a 23-inch diameter screen. And so it's,

it's a different thing. And you can still socialize on zoom. But it's just, it's like, it's an animated socialization without substance. And after a while, I think the substance just, you know, you really miss it." (Participant 8, Focus Group)

I think it's important that people understand the impact of COVID on those of us that have dementia, because a lot of us are kind of isolated, and some may not even have access to, you know, phones and computers and things like that to stay engaged. So I just don't want us to be forgotten. (Participant 6, Focus Group)

With my Alzheimer's, the social interaction that I have with people, that would keep me going... we're not doing any kind of interaction with people now and that was keeping my brain active so I guess you can only watch so much TV. So it has been difficult. (Participant 2, Interview)

Feelings about COVID-19 Participants in this study were quite aware of the dangers of COVID-19. They described worrying about their family's safety, their own safety, and the safety of the general community.

Concerns about the vaccine and the virus Participants described being worried about their future in relation to COVID-19 and how it could affect them personally, expressing concern related to their vulnerability with dementia.

And then my other concern is the COVID itself, because they don't know how that COVID will affect the brain. And if we're already having challenges, we definitely don't want to get it. (Participant 6, Focus Group)

Participants also expressed frustration with political leaders and new policies related to COVID-19. This included reopening of businesses to 100% capacity while portions of the population remained unvaccinated, and many others were still not eligible for vaccination. Other participants described an acceptance of COVID-19, that they could only do so much, and they had to move on with life.

Well, exactly what she said, you know, you don't want to add misery to misery. And then the frustration with the population, some of the population and some of our leaders who, okay, the numbers start turning good... Every time they let this loose, they see this spiral of people getting sick and dying., We're still opening up and doing away with masks and, and all this when the doctors are saying keep the mask on even after you get vaccinate. It's just I get frustrated with people. I know people have jobs that they worry about or how they're losing their houses. But you know, lose your life, your family, you got nothing. And it's just understand it at the same time. I can't believe it. Yeah, so I guess frustration. (Participant 7, Focus Group)

It certainly is. It's one of those things where I go, "boy, I hope they can get the whole thing straightened out." I don't know. I mean, I just can't believe that all of this problem we've had has been really, still, it's less less... We haven't had anything bad like this. We're going for a whole year. I mean, you know, that's, there's got to be something that we can get taken care of and get it to the point where people can come and be here. I don't know (Participant 1, Interview)

Concerns for Family In addition to the concerns above, many participants described how they worried about their family members. Participants understood who was at high-risk for catching

COVID-19 and having more severe illness. They worried that their family members would catch COVID-19 or about the possibility of transmitting COVID-19 to family members.

Yeah, I'm, the one I'm worried about is my daughter. She's a school. Like I said, She's a teacher...And, you know, she hasn't been able to get the vaccine...So she, and it worries me because she is, there are some teachers there at the schools and a few students also that have come down with COVID....I worry about her that she has not been able to, to get the shot. But there's a lot of people out there that haven't been able to. (Participant 2, Interview)

Adapting to COVID-19 Participants described the various ways that they coped with all of the changes occurring throughout the pandemic. They had a resiliency to keep moving forward and adapt.

Technology Participants discussed how they were staying in contact with others through programs such as Zoom. This became a way for them to stay connected to others, including attending a virtual dementia support group. It was not a replacement for seeing someone in person, but they appeared to have an appreciation for at least being able to connect virtually. Participants further described other ways they had adapted to COVID-19 and using other technologies such as Facebook to stay connected to others or using Amazon to get eBooks to read. Participants also described their concern for other individuals and their ability to connect online, knowing that some persons living with dementia are not able to get onto Zoom or social media unless they have help from others or may not have access at all.

But missing people face to face, it's not to say, this is great. (Participant 7, Focus Group)

But, yeah, I think my most concern is for, like, we, we have the ability, and we know how to use IT and technology. But I think my most concern is for like, the more elderly people that do have dementia that are not able to be connected. (Participant 6, Focus Group)

Coping Participants were remarkably resilient in how they adapted to the COVID-19 pandemic. They found ways to cope with the changes occurring around them. Some talked about getting exercise to help decrease anxiety. Others talked about going out for drives with a companion or care partner to get out of the house or doing hobbies to get their mind off their troubles or to find something to do. Participants described how being part of the study was beneficial for their wellbeing. It provided them with a guided opportunity to connect with others living a similar experience with dementia. It gave them a chance to connect with others who are living with dementia and express their worries and concerns about COVID-19 that they may have not been able to discuss before.

I um, I exercise, because I try to get some of those anxieties out. And I still exercise but what I do is I sit on the porch, on nice days to get that oxygen and I don't, most of the times I don't even put the radio on. I just listen to the birds listen to the trees, and I find that that stimulates my brain a little bit. (Participant 6, Focus Group)

No, I think, you know, this is, this has been a good session, it's been, you know, kind of therapeutic, it's kind of, you know, allowed me to get things out to people that understand. And that's, that's helpful. A lot of times you want to share things that you're feeling, but you're either apprehensive because, "well, I don't think they'll understand." And then you say, well, I'll take a chance, and then you find out, they

don't understand. Especially someone, you know, when you're dealing with Alzheimer's...(Participant 8, Focus Group)

Self-reflection Although it was not the focus of this study, many participants mentioned personal things about themselves during focus groups and interviews. Participants seemed to have taken time during the pandemic to reflect on themselves and what changes they had gone through since developing dementia. Their responses suggest that the study gave them a unique opportunity to express these reflections.

Identity Participants brought up multiple examples of things that describe who they are. Participants also described how they missed who they used to be and what has changed since they developed dementia. They also talked about how they have still remained themselves through the brain changes they endure from their dementia.

...you know was the Purple Martins are coming back. So you know, I'm a big Purple Martin landlord. So now I'm looking forward to, you know, the next several months focusing on that. (Participant 8, Focus Group)

And then people kind of look at you like, "well, you know, let me help you with that." No - that's not the point. I appreciate your concern, and I appreciate you wanting to help it. That's not the point. I'll, I'll get through the rest of the day. I just, I'm just angry that I can't do what I used to do at the level I used to do it. (Participant 8, Focus Group)

Because I know that my, my brain has been going down as far as how smart it has been... I know, I mean, I really wish I was the person I was. That's just, just something that, it's a little bit tough. But to get right down to it, I don't like it but I can deal with it. That's, that's important. (Participant 1, Interview)

...it was just embarrassing to say I have Alzheimer's. That was my attitude toward it. (Participant 4, Focus Group)

Participants also focused on what they were doing for the community quite often during discussions. The participants in this study showed great altruism and wanted to advocate for others living with dementia. They wanted to contribute to research, not so much for their benefit but to help others.

That's why I've become very vocal about it. Because I think the more that people realize, and it's not only the people themselves like me that has it, also the family. The family needs to understand what the person is going through and how, what they can do to help. I, my husband and my daughter are very aware of that. (Participant 2, Interview)

...they're gonna find the cure, but it's probably gonna be too late for me. And it may not be too late to my kids. That's what I'm pushing for. Although we will talk about it with him about how mom has it. Grandma had it or had the beginnings of it. So more than likely one of you is going to come down with it. That said, we don't talk about that. I don't think I could live with myself if I knew that. (Participant 2, Interview)

I do a lot of things on a volunteer basis. I retired when I was 50. So I retired early, but, but I, I tried to give back my doing a lot of things, I appraised rare and vintage books for the library system, free so

they can sell them and raise money. I do other things with other organizations. (Participant 8, Focus Group)

Discussion

Care partners in previous studies have reported worrying how their family member with dementia would not be able to understand COVID-19 restrictions (Tuijt et al., 2021). However, persons living with dementia have reported how they were quite aware of the COVID-19 pandemic (West et al., 2021). This aligns with the participants of this study where participants were very aware and concerned about the COVID-19 pandemic.

Persons living with dementia reported in the survey that their physical health was affected. The focus groups and interviews provided insight into how their physical health may have been impacted with participants describing that they were unable to do the same exercises they used to prior to COVID-19. Their routines were changed and habits they had prior to COVID-19 to maintain their physical health were impacted. Participants also reported increased anxiety and isolation because of COVID-19 in the survey. In the interviews and focus groups, participants explained how being around people was making them anxious, especially considering the extended isolation they faced. Likewise, in other studies, persons living with dementia reported having increased stress (Tam et al., 2021), anxiety (Hanna et al., 2021; Tuijt et al., 2021; West et al., 2021), and depression (Hanna et al., 2021) due to the pandemic. Participants in this study also reported how the feelings of anxiety and depression continued, but changed, from when shutdowns began to when restrictions were easing up. Likewise, persons living with dementia in other studies experienced feelings of anxiety while restrictions were being lifted (Hanna et al., 2021). From their interviews with 19 people living with dementia, Talbot and Briggs described a ‘shrinking world’ effect (Talbot & Briggs, 2021). People living with dementia, although missing the social interaction, experienced a loss of confidence and increased anxiety in their ability to re-engage with society.

Participants in this study reported feelings of social and physical isolation since the COVID-19 pandemic began, similar to findings from the IDEAL study (Clare et al., 2022). During COVID-19, everyone has struggled with maintaining social connections, and this is especially true for persons living with dementia. Even prior to COVID-19, too often persons living with dementia were becoming more isolated for fear of how others might treat them (Biggs et al., 2019) and wanting to avoid negative attention (Aldridge et al., 2019). Despite how the number of persons living with dementia continues to rise and dementia awareness campaigns are organized world-wide, dementia-related stigma persists. Persons living with dementia have reported feeling “stupid” (Ashworth, 2020) and “shameful” (Aldridge et al., 2019) because of their diagnosis. Therefore, it is understandable then why some persons living with dementia withdraw from others after receiving a diagnosis. On the other hand, it is very common for those around someone with dementia to begin withdrawing and stop calling or visiting because of a person’s dementia (Werner et al., 2020). The findings in this study and from studies before COVID-19 speak to how this problem of isolation has grown (Cacioppo et al., 2010).

To cope with isolation, participants in this study reported how they were able to meet friends and family over Zoom and continue to engage socially. For most, however, this was not filling the need they had to connect with others, especially with family. This coincides with other persons living with dementia who reported feeling lonely and isolated (Clare et al., 2022; Hanna et al., 2021; Tam et al., 2021; Tuijt et al., 2021) during COVID-19, and more isolated than before COVID-19 (Tam et al., 2021).

In relation to cognitive health, survey results indicated that persons living with dementia had not noticed changes in their cognitive health. Yet, when participants spoke in interviews and focus groups, some participants did notice a decline in their mental health since isolating because of COVID-19. Some participants also worried about how their cognitive health would be impacted if they were to catch COVID-19. Persons living with dementia in other studies also reported a noticeable decline since COVID-19 began (Tuijt et al., 2021).

Within the interviews and focus groups, participants frequently discussed how their spiritual health was affected by the pandemic. This is in contrast to the results of the survey where participants did not feel that COVID-19 had impacted their spiritual health. In the interviews and focus groups, however, the discussion seemed to be focused on the lack of in-person interactions and it could be that while spiritual needs were being met while attending church on Zoom, it was the social interaction that in-person church attendance brings for people that they were missing. Similarly, in another study, persons living with dementia felt that not getting to go to church was a source of stress (West et al., 2021). Notably, despite all the challenges participants faced during COVID-19, participants in this study showed great resiliency. They developed coping strategies that helped them persevere throughout the pandemic. Participants took up new hobbies and exercise to release their anxieties. Further, technology served as a means for people to stay in contact with friends and family and has been reported as a helpful way for persons living with dementia to stay connected (Hung & Mann, 2020). Memory cafes have been one way for persons living with dementia to stay connected prior to COVID-19. Since the pandemic, some communities have been fortunate enough to have programs like memory cafes transition to virtual platforms. In one study, participants who were living with dementia reported how beneficial one memory café was for them and it helped them stay connected (Masoud et al., 2021b). This aligns with other studies when persons living with dementia reported feeling comfortable with technology (Tam et al., 2021) and had learned how to use the new technologies like Zoom (West et al., 2021). Participants also did well adapting to other technology platforms; they stayed connected to others over Zoom and Facebook.

While participants in this study were able to access technology, it is recognized that many cannot. Throughout this pandemic, members of high-risk and vulnerable populations are falling through the cracks in greater ways. Despite how far we have come with technology during the pandemic, a digital divide remains in the US. As of 2019, four out five people were using the internet, which means that 20% are not (Telecommunications & Information Administration, 2020). Further, African Americans and Latinos are less likely to use the internet (Telecommunications & Information Administration, 2020). Our participants were able to meet over Zoom and others have reported feeling comfortable with Zoom (Tam et al., 2021), but the majority of our and others' participants are educated, non-Hispanic Whites. So, although we have come far in this pandemic, we cannot forget about those who are unable to be connected at all.

Limitations and strengths

Although there was an adequate number of participants for the qualitative phase, the number of participants in the quantitative phase was somewhat small and limits the generalizability of the results. We distributed the survey through a number of channels including a national listserv so do not know the number who may have refused or were unable to complete the survey. Based on the small sample, only descriptive statistics could be used to report the results. Similar to our study, others have struggled to recruit persons living with dementia for research (Sakamoto et al., 2017; Waite et al., 2019), especially considering restrictions in place with COVID-19. However, even though most studies focused on dementia and dementia care are centered around the perspectives of

care partners or health professionals, this study recruited persons living with dementia to learn about their perspectives on the COVID-19 pandemic.

Another limitation of this study was our sample. Our sample mostly consisted of non-Hispanic Whites affecting how our results could be applied to people of diverse races and ethnicities. Nonetheless, a concerted effort was made to recruit a diverse sample, and one-quarter of participants who took surveys and one-third of participants in interviews and focus groups identified as Latino. Further, all participants had access to technology since all data collection occurred exclusively online. This limited who could participate in the study and could have led to more vulnerable individuals not being included in the study.

Conclusion

Too often, persons living with dementia are not included in survey or qualitative research. Within both the quantitative and qualitative findings presented here, participants were able to clearly express how the COVID-19 pandemic impacted them, including the impact on their health as well as their experiences of isolation. Within the focus groups/interviews, participants provided more detail about how their health was impacted, their feelings of isolation and loneliness, and strategies they used to cope during the pandemic. The findings from this study demonstrate the value of including the perspectives of persons living with dementia. Their voices are critical in responses to the current pandemic and other future situations which may require isolation and virtual care. It is imperative that people living with dementia provide input into future technologies and interventions that can reduce social isolation and provide opportunities for cognitive stimulation. For those persons living with dementia who are able to utilize technology, this study highlights the ongoing need to provide virtual opportunities for socialization and support. These findings also emphasize the need to create safe opportunities for socialization such as small socially distanced activities that may allow persons living with dementia to maintain social connections through the COVID-19 pandemic and throughout the progression of their disease.

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Ethical approval

This study was approved by the University of Texas Health Science Center at San Antonio Institutional Review Board as exempt research (HSC20200790E).

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Supplemental Material

Supplemental material for this article is available online.

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