Open Access

OBM Neurobiology

LIDSEN Publishing Inc.

Original Research

"Welcome to Our World": Experiences of Persons Living with Dementia Prior to and During the COVID-19 Pandemic

Melissa L. Harris-Gersten [1, 2, 3, 4, *], Florence U. Johnson [4], Josephine R. Granner [4, 5], Susan N. Hastings [1, 6]

1. Center of Innovation to Accelerate Discovery and Practice Transformation (ADAPT), Durham VA Health Care System, Durham, NC, USA; E-Mails: Melissa.Harris@va.gov; Melissa.L.Harris@duke.edu; susan.hastings@va.gov; susan.hastings@duke.edu
2. Duke University, School of Nursing, Durham, NC, USA
3. Duke University Clinical and Translational Science Institute, Durham, NC, USA
4. University of Michigan School of Nursing, Ann Arbor, MI, USA; E-Mails: fujohnso@umich.edu; josephine.granner@yale.edu
5. Yale University School of Medicine, New Haven, CN, USA
6. Duke University School of Medicine, Durham, NC, USA

* **Correspondence:** Melissa Harris-Gersten; E-Mail: Melissa.L.Harris@Duke.edu

Academic Editors: Ines Testoni, Adriano Zamperini and Lorenza Palazzo

Special Issue: How COVID-19 Changed Individual and Social Life: Psychological and Mental illness Studies on the Pandemic Outcomes

OBM Neurobiology
2023, volume 7, issue 3
doi:10.21926/obm.neurobiol.2303178

Received: June 20, 2023
Accepted: August 07, 2023
Published: August 10, 2023

Abstract

People diagnosed with dementia are experts on living with the disease, yet their perspectives are often overlooked in research and practice. The pandemic has amplified health inequities among older adults, but the impact of the pandemic on the lived experience of people living with dementia remains unclear. This qualitative study used a series of 2 virtual focus groups with people living with dementia (N = 7) to explore challenging situations and emotions experienced by community-dwelling people living with dementia prior to and during the pandemic. Focus group transcripts were analyzed using narrative thematic analysis with themes finalized through consensus among a 3-member coding team. Two themes with corresponding subthemes emerged: humanizing dementia (subthemes: early experiences with cognitive impairment, health care experiences, overstimulation, activism, tools to live well with dementia) and “welcome to our world” (subthemes: loss, stress, health impacts). Participants faced challenges prior to and during the pandemic that impeded their ability to live well with the disease. In the midst of the disruption of the pandemic, society saw a glimpse of what it was like to live with dementia due to restrictions that limited access to supports, resources, routines, and socialization. Despite significant barriers, people living with dementia identified many strategies to humanize their experience including the use of humor, activism, and social support. Insights of people living with dementia in this study can be used to inspire a shift in the narrative of dementia as a disability to one of strength, ability, and living well.

Keywords

Dementia; qualitative research; focus groups; COVID-19; pandemic

1. Introduction

Over 55 million people worldwide live with dementia - a chronic, cureless condition associated with cognitive, physical, functional, and psychological detriments that impact every aspect of a person’s health and well-being [1]. People diagnosed with dementia and their families bear the majority of the physical, emotional, and financial toll of this disease [2, 3]. Although individuals diagnosed are the experts on living with dementia [4], their perspectives continue to be overlooked in research and clinical practice. Due to longstanding false assumptions that cognitive impairment limits a person’s ability to report their own experiences with a disease, the voice of this population is deafened even in spaces that aim to promote the health and well-being of families living with dementia, including healthcare systems. For these reasons, national organizations, federal funders, and policy initiatives are calling for changes to actively engage people living with dementia to leverage their experiences and expertise [5-7].

Prior exploratory studies have sought to understand the diagnosis experiences, decision-making processes, coping strategies, and views on healthcare interventions and support services from the perspectives of people living with dementia [8-10]. Many studies have focused on people with dementia residing in long-term care settings [11], but fewer have focused on those living outside of long-term care even though the majority (65%) of older adults with dementia reside in the community [12]. Several factors such as access to community supports and proximity to members within a care network likely differentially impact the lives of community-dwelling people living with dementia compared to those in long-term care. A deeper understanding of the experiences of community-dwelling people living with dementia is critical to identifying supports already being used that may be leveraged to better support individuals living with dementia and their families.

The coronavirus disease (COVID-19) pandemic shed light on the healthcare inequities among vulnerable populations [13], including people living with dementia. The long-term impacts are still unclear due to the prolonged duration of the active phase of the pandemic [14]; however, the financial, emotional, and physical consequences are expected to last for decades. Understanding lived experience is needed to illuminate the primary needs, potential supports, and areas for improvement identified by people living with dementia to promote their ability to live well with this disease, even during challenging times marked by disruption.

Few studies have explored the lived experiences of people living with dementia during the early phases of the pandemic, most of which combined the experiences of those diagnosed with those of informal caregivers which could diminish the interpretation of the experiences of the experts who are actually living with the disease [15, 16]. Theres been a paucity in research focused on comparing how lives of people with dementia were changed from prior to, to during the pandemic. The purpose of this research was to explore the challenging situations and emotions experienced by community-dwelling people living with dementia before and during the pandemic.

2. Methods

2.1 Study Design

This study used a qualitative, exploratory approach using 2 virtual focus groups with 7 people living with dementia to address the study purpose. The Consolidated Criteria for Reporting Qualitative Research checklist was used to guide reporting of this study [17].

2.2 Study Sample

Eligibile individuals 1) were 60 years of age or older; 2) resided in the community; 3) had access and ability to use a telephone, smartphone, tablet or computer (with internet access and microphone); 4) spoke English. To be as inclusive as possible and to capture a broad range of experiences, individuals were included who reported having a diagnosis of dementia of any type. Individuals were excluded if they had a visual or hearing impairment that limited their ability to participate in a focus group.

A convenience sample was recruited through the National Council of Dementia Minds (NCDM), a not-for-profit organization led by persons living with dementia that aims to transform the worldview of dementia through education, dialogue, and advocacy. NCDM hosts facilitated virtual groups designed to connect members to opportunities to advocate and educate the public on what it means to live with dementia. At the time of recruitment, the NCDM had 3 groups representing over 65 individual members across 15 states. The first author attended 3 scheduled NCDM groups to share information about the study by word of mouth. Interested individuals contacted the first author directly to complete a brief eligibility screen.

Seven individuals contacted the first author and expressed interest in the study, all of whom were eligible and enrolled. Efforts were made to recruit additional participants by attending additional sessions hosted by the NCDM and through an email with the study information that was sent to all members. but no additional members expressed interest. To facilitate timely data collection during a critical point in time of the pandemic (December 2020), the choice was made to continue the focus groups with 7 participants because there is a paucity of research elevating the lived experiences of people living with dementia. We anticipated that the 7 participants would represent information-rich cases that provide a new and richly textured understanding of their lived experiences. The focus groups would thus add value to the literature despite the small sample size and potential uncertainty about data saturation [18].

Participants provided verbal consent for participation after reviewing a study information form. The study PI (MHG) assessed each participant's capacity to provide informed consent by asking them to restate the purpose, voluntary nature, and potential risks of the study [19, 20]. During the consenting discussion, the PI also assessed the participants ability to report on their experiences. Participants had to provide appropriate responses in order to be eligible to provide consent. This study was exempt from ongoing review by the investigators' institutional review board [HUM00189059].

2.3 Focus Group Procedures and Data Collection

Focus groups were selected to allow participants to build upon their experiences through group exploration and discussion [21]. Additionally, the NCDM leads facilitated group discussion, so a focus group stype was already familiar to participants. Two distinct focus group guides were used to elicit information relating to the experiences and perceptions of people living with dementia. The first focus group guide included questions specific to participants' experiences prior to the COVID-19 pandemic (Supplementary File-Appendix A). The second guide focused on participants' experiences during the COVID-19 pandemic (Supplementary File-Appendix B). Guides were reviewed by one person living with dementia and one care partner of a relative living with dementia who provided feedback, which was incorporated before use during the focus groups.

Two groups were convened over Zoom in December 2020. Prior to the first group, participants answered questions relating to their demographics and dementia diagnosis: age, race, ethnicity, gender, education, type of dementia, and duration of diagnosis before the first focus group. All 7 individuals participated in both focus groups as each group focused on a different topic (pre-pandemic experiences, during pandemic experiences). Two separate groups were convened as switching between 2 time periods within the same session could be a barrier to participant engagement. Questions were provided to participants at least 1 week in advance of each focus group to allow participants time to reflect and prepare for the group discussion. Questions were answered round-robin style where each member provided an answer to each question and members were encouraged to respond to/build upon what others shared to allow the group discussion to evolve [21].

Focus groups were led by the first author, who was trained in conducting focus groups and experienced in qualitative research methods. The second author attended and kept detailed notes during both focus groups, which both authors critically reflected on and expanded upon after completing each group. The facilitator and the notetaker both had several years of clinical nursing experience working with people living with dementia. Each group lasted approximately 1 hour and 45 minutes.

2.4 Data Analysis

Descriptive statistics (frequencies, percentiles, means, standard deviations (SDs)) were used to analyze demographic data. Focus groups were audio recorded and transcribed verbatim. Transcripts were managed using Atlas.TI [22].

Focus group transcripts were analyzed inductively and iteratively using narrative, thematic analysis to identify patterns across stories and narratives told by individual participants [23, 24]. A narrative analysis was warranted as participants responded to questions by providing detailed stories interwoven with a broader narrative that spanned a timeline from pre-diagnosis, to after diagnosis, and during the pandemic. Participants' narratives illustrated their experiences, the impact of those experiences, and their interpretations of the broader meaning of those experiences [23].

A 3-member team trained in qualitative methods (1 PhD prepared nurse scientist, 2 PhD nursing candidates) conducted the analysis. Each analyst reviewed the transcripts multiple times to familiarize themselves with the data. The first and second authors independently reviewed each focus group transcript to identify and map participant narratives and stories onto individual timelines. Individual narratives and timelines were then compared to search and code for patterns observed across participants [24]. Codes reflective of patterns were independently grouped into minor themes and discussed amongst the 2 coders. Each coder then independently grouped minor themes that clustered together and named each cluster (major themes). Regular team meetings were held to discuss and reach a consensus on minor and major themes throughout the analysis process [25]. A codebook was developed with names and detailed definitions of minor and major themes, along with exemplar quotations selected by the 2 coders. The third analyst (Author #3) then audited the final codebook to ensure themes reflected the actual data and that key points were captured in the themes. Field notes were referred to throughout the analysis for verification.

Several strategies were used to promote rigor in the analysis [26, 27]. We conducted peer examination and member checking to enhance the credibility or confidence that one can place in the truthfulness of the findings. To promote dependability, or likelihood of replicating findings, we maintained an audit trail and had an analyst acting as an auditor. We used multiple quotation exemplars reflective of the broader group's narratives for confirmability or representativeness of the findings relating to participants' experiences. To address the transferability or applicability of findings to other contexts/settings, we have included a detailed description of the methods, sample, and thick description in the results section.

2.5 Member Checking

We used member checking techniques to enhance the trustworthiness of the findings [26, 27]. We prepared a synthesis of the emerging codes and themes and presented it virtually to over 30 National Council of Dementia Minds members. All 7 of the participants also attended the session. Feedback on the themes and further exploration of all members' experiences were explored through a group discussion held at the end of the presentation. The presentation and discussion were recorded, and the analytic team summarized the feedback and integrated it with the original findings. Data saturation was assessed throughout the data collection and analysis process. The member checking session suggested that data saturation was reached, as the large group discussion offered insights that only verified and expanded upon the themes that had already been identified through the original analysis. No new or emergent themes were identified through the member checking process.

3. Results

3.1 Participant Characteristics

Seven people living with dementia took part in 2 focus groups (Table 1). Most were male (n = 6), Non-Hispanic White (n = 6), and reported some college education or more (n = 6). Average age was 63.6 (SD = 4.5). Participants had diagnoses of vascular dementia (n = 2), Alzheimer's disease (n = 2), mixed vascular and Alzheimer's (n = 1), Lewy Body dementia (n = 1), and chronic traumatic encephalopathy (CTE) with an average diagnosis duration of 5.7 years (SD = 1.9) (Table 1).

Table 1 Sociodemographic and Dementia Diagnosis Characteristics (N = 7).

Participant	Age	Race/Ethnicity	Gender	Education	Dementia Type	Years Since Diagnosis
1	60	N-H White	Male	College and above	Mixed VD/AD	6
2	68	N-H White	Male	High school diploma	VD	6
3	60	N-H White	Female	Some college	VD	2
4	68	N-H White	Male	Some college	AD	6
5	60	N-H White	Male	Some college	LBD	7
6	60	N-H White	Male	College	CTE	8
7	69	Black	Male	College and above	AD	5

Note. AD Alzheimer's disease, CTE chronic traumatic encephalopathy, LBD Lewy Body dementia, VD vascular dementia

3.2 Qualitative Themes

Two major themes emerged from the analysis, **humanizing dementia** and **"welcome to our world".** Humanzing dementia encompasses participants' experiences living with dementia, their emotions, and responses to the world around them, while "welcome to our world" represents participants' interpretations of the impact of the pandemic on their own lives and on society. Each **theme** is described in the narrative below with corresponding subthemes and codes that are illustrated by participant example quotations. Additional exemplar quotes are included in Supplementary File-Table S1.

3.3 Humanizing Dementia

Participants described their experience in a way that focused on how they humanized their experience of living with dementia and their hopes for society to focus less on their diagnosis/disease and more on their experiences as humans. Five subthemes emerged relating to humanizing dementia: early experiences with cognitive impairment, healthcare experiences, overstimulation, activism, and tools to live well with dementia (Supplementary File-Table S1).

Participants described their early experiences with cognitive impairment, including how their awareness and emotional responses changed. One participant said:

> “Well, I walked into the store, and like at Christmas time, most of the stores have somebody standing out front like a greeter to kind of help you out or almost all you in or point out sales or things like that. Well, there was a gal standing there. She looked at me and she said, “Hi.” I said, “Hi,” and then I just kept walking by, and I went into the store looking around for my wife. Well, that person happened to have been my wife that I said hi to, and I walked past. So I didn’t even recognize her, it was a very hard.” (P6, M 60 y.o.)

These experiences prompted many participants to seek testing for a diagnosis. Participants described their experiences with being diagnosed, and many highlighted the challenges they experienced in receiving and accepting the diagnosis.

> “I got my diagnosis, uh, sitting in that chair, I sunk right to the floor. Reality hit me in the side of the head like a big brick.” (P2, M, 68)

But for one participant, the diagnosis was eventually viewed as a positive life-changing event.

> “The most challenging thing was to accept the diagnosis. I laid in bed for three months, grieving because. I thought my life was over…But luckily, I attended a class that AARP was giving on life reimagined. So, they taught you that once a bump comes in your life, you can make a choice of moving forward, changing career, or stay stagnant. And so, I decided to move forward, and I’m glad I did. And I must say, and people think this is strange, but being diagnosed with Alzheimer’s was the best thing that has ever happened to me. I didn’t belong to any groups before. I didn’t socialize. I didn’t have any friends. Having the diagnosis and changing my life and changing my outlook has given me a purpose.” (P7, M, 69 y.o.)

Participants also described their <u>healthcare experiences</u>, including their experiences with healthcare providers (Supplementary File-Table S1). Participants generally described feelings of being misunderstood and de-humanized due to a lack of knowledge and empathy from providers.

> “He made me feel lesser of a person. He made me feel a whole multitude of things. I never did feel like I was a patient of his, nor was I ever going to be a patient of his. I don’t need someone telling me just because I talk well doesn’t mean I have this disease. The diagnosis process has to become, and I say has to because it really does. It has to become more patient-friendly.” (P1, M, 60 y.o.)

Some participants described their experiences with medications, but overall, medications were described as less than helpful. In some cases, side effects inhibited participants continued use of medications.

> “They give you this diagnosis, and they’ll give you Aricept and Namenda or whatever, and these drugs don’t really do anything… They say it’s going to slow down the progression, or it’s going to do this, or it’s going to do that. It never did… I took both of them when I was first diagnosed, and I got horribly sick. And so, I just stopped. I stopped taking them.” (P1, M, 60 y.o.)

Feelings of being <u>overstimulated</u> when in public and during social events were frequently described by participants (Supplementary File-Table S1).

> “Sometimes it feels like we are always asking for changes to be made to make the environment more manageable for us. But it often goes unheard; nothing changes. We are still suffering when in public. So even before the pandemic, I just didn’t go out.” (P3, F, 60 y.o.)

Participants managed or mitigated overstimulation by adjusting how and to what degree they interacted with others and society. Participants gave examples of ways that society does not recognize the impact of overstimulation on people living with dementia, which caused them feelings of frustration and of being "unheard" (See Supplementary File-Table S1).

> "We were doing the presentations at the Alzheimer's Association banquet, and they had us sitting right in front of the speakers. And they thought it would be really cool to just blare out all of this high volume music. I got up and left, and about half the people had to get up and leave because they just couldn't take what was going on…that just stuck to me and this is the Alzheimer's Association, you know, and the volume of music they had in that place was just basically atrocious for people who have problems with overstimulation." (P4, M, 68 y.o.)

With the rise of virtual engagement opportunities amid the pandemic, participants described needing to "unplug" at times to reduce the potential for overstimulation.

> "I had an AARP Christmas party that was virtual. And there was 35,000 people. I mean 35 people all talking at the same time trying to… I had to leave. I stayed for about ten minutes, and it just became so overwhelming for me." (P7, M, 69 y.o.)

Partcipants described activism as a key component of humanizing their experiences with dementia (Supplementary File-Table S1). Most participants acknowledged that being an activist was an important identity they had accepted since being diagnosed.

> "I've become an activist, public speaker and have really, really made an effort to give a face as an African-American person living with Alzheimer's." (P7, M, 69 y.o.)

Through their activism, participants sought opportunities to educate others on humanizing dementia and that people living with dementia can live well with this chronic disease.

> "You know, it's hard talking about knowing what's happening to you, but we also know it can help people understand why people with dementia do certain things, and if you didn't hear from people like us, then it would just kind of keep on going like it has been for decades where people don't understand anything about living with a dementia-related illness." (P1, M, 60 y.o.)

Another said:

> "Whenever I'm out, I'm very open about what I have, and I have dementia. And by using humor people can see that I understand what I have, but yet I can accept it, and I can still enjoy the time. And what that does it takes the sympathy and the tragedy narrative and throws it out the window where it belongs and allows them the opportunity to ask questions and it's actually provided a lot of really meaningful conversations." (P4, M, 68 y.o.)

Opportunities to participate in activism were limited by public health restrictions during the pandemic, which was a detriment to their previous routines.

> "I'm an international dementia advocate and I used to travel all over the place. Now I travel from basically from the kitchen to the sofa, and sometimes I go from the sofa to the kitchen and that's like a big deal." (P1, M, 60 y.o.)

Participants described several tools to live well with dementia, including the importance of humor (Supplementary File-Table S1).

> "I will take things that I've done, um, that dementia kind of makes you do or whatever the term is, um, turn it into humor, and it becomes a little bit easier to deal with. It's

> not like it, um… it's not like it makes it go away, which I wish it did. Um, but it does. It makes it a little bit easier to live with." (P1, M, 60 y.o.)

Researcher field notes also reflected the importance of humor, as many contextual comments were made that reflected group laughter, playful banter, and jokes that were not fully captured in the transcripts. In addition to using humor to cope with challenging experiences living with dementia, one participant also described how it was used to humanize himself.

> "It's one of these things that it just helps and I wish more people would understand that and that's with in every presentation that I give there's always humor because when you use humor, especially aimed at yourself, you make yourself more human." (P6, M, 60 y.o.)

Participants detailed how support from others, including family and each other, were essential tools to help them live well with the disease.

> "I know; thank goodness I have (stated the first name) for a wife because I can go and talk to her about it, and that relieves the rest of the degree of being upset. And I'm not upsetting her if she's just my sounding board, and I treat her with a great deal of respect for that because I know it's… all of us will say our spouses have an awful, awful responsibility." (P2, M, 68 y.o.)

One participant described a unique type of support from a life coach:

> "I was fortunate enough to find a life coach whose specialty was dealing with people with dementia and Alzheimer's. We would discuss many of these feelings and emotions that I was going through, and she really helped me in looking at them and realizing that, number one, they were not as bad as I thought they were, and then some of the behaviors were just normal that comes with the diagnosis…she really got me through some really rough patches when I was having a very difficult time." (P7, M, 69 y.o.)

More broadly, socialization and opportunities to engage with others were described as critical to living well with dementia.

> "I always say, "The number one prescription we should be getting is social engagement." This is our medicine." (P3, F, 60 y.o.)

Socialization became even more important, but was difficult to attain during the pandemic.

> "I'm at home because nobody's coming over. We're not going to visit anybody or whatnot so losing that socialization is huge because we used to always go out and see somebody or plan the next vacation trip or do this or that." (P5, M, 60 y.o.)

A few participants described using cannabidiol products and medical marijuana to manage symptoms including anxiety, sleep disturbances, and frustration. When asked for an example of how to manage symptoms and live well with the disease, one participant said:

> "I run for my medical marijuana. Truthfully, I'll just take a gummy because I don't have anxiety pills per se that will set you back. And believe me, I did not have much experience with, um, marijuana prior to this, so." (P3, F, 60 y.o.)

3.4 "Welcome to Our World"

Participants' experiences and perceptions regarding the pandemic were described to suggest that society as a whole was now faced with challenges that people living with dementia experienced even before the pandemic began.

> “Well, in the beginning, when it first came, I told folks it was like **welcome to our world**. You know, because this has been what we experience every single day… you know, everybody is kicking and crying and screaming “Oh, we have to stay home,” but that’s what we do every single day.” (P1, M, 60 y.o.)

Participants described how society was now experiencing loss, stress, and health impacts, but that, in many ways, their own experiences with these feelings were just compounded by the pandemic (Supplementary File-Table S1). Participants described a loss of activity and engagement during the pandemic, which inhibited their ability to live well with dementia.

> “I haven’t been out of the house… maybe once in the last three weeks just because it’s too risky and there’s nowhere to go. There’s nothing to do. You know, I can walk out and walk up and down in front of my house for so many times.” (P5, M 60 y.o.)

One participant described how living in a multi-generational household during the pandemic reduced the impact that loss of activity and engagement had in his daily life:

> “I hate to say this, but I’m very, very, very, very fortunate because, even though my movement has been restricted, I still have half of my family here, my daughter’s family, on the other side of the wall.” (P2, M, 68 y.o.)

Participants described a loss of interaction, which was significant as social interaction was previously described as a critical tool to living well with dementia.

> “I’ve become a hermit, you know, sitting on the sofa, working on social media, I do a lot of research and all that stuff, but then after about an hour, you get tired of that. So, I’m playing solitaire, and I’m coloring pictures, and you’re just doing things…I don’t want my brain to turn to mush, and that’s exactly what part of this is doing.” (P3, F, 60 y.o.)

Participants frequently described stress (Supplementary File-Table S1), including how stress impacted how they lived with and experienced dementia.

> “We’re already under a lot of stress with just having the disease. And now, you’re locked in a house with somebody or sometimes by yourself. It can really amplify the symptoms that you have, you really have to work to stay on top of it because it can be very catastrophic to people like us.” (P4, M, 68 y.o.)

Many also described their perceptions of increased stress in society during the pandemic.

> “It’s the unrecognizable stress or the stress you don’t even think about on a daily basis that you're dealing with, that you don’t even realize you’re dealing with just because of COVID. You’re still trying to stay positive, but there’s just some days you just can’t do it; just COVID alone that just puts it in a whole different league” (P5, M, 60 y.o.)

Participants reflected on how the pandemic impacted their health (Supplementary File-Table S1), including how the pandemic influenced their dementia progression.

> “Every single one of us have a progressive disease, so it’s almost like we’ve lost a year of life, and I know I’ve progressed. And I know my family thinks I have. Not a great deal, but a step-down. So, even though we’re home, we still have progression in our diseases, and a whole year is a long damn time.” (P3, F, 60 y.o.)

They also described how the pandemic influenced their physical health (Supplementary File-Table S1).

> “Since the pandemic, my sugars were spiking sometime around two or three o’clock in the morning, and I would wake up, and the sheets were completely wet, and you know, I would feel my chest, and I mean I was just covered in sweat.” (P1, M, 60 y.o.)

4. Discussion

People living with dementia experienced profound loss, stress, and debilitating health impacts even before the pandemic began, many of which were amplified by it. They described how society had a glimpse of what it was like to live with dementia during the pandemic due to restrictions that limited access to supports, resources, routines, and socialization. Despite significant barriers, participants identified new opportunities to humanize the disease prior to and during the pandemic. There is much knowledge to be gained by leveraging the expertise of people diagnosed with the disease to better support them on their journeys of living with dementia, particularly during public health crises when barriers to care are exacerbated.

This study found that families living with dementia experienced increased feelings of loss, stress, and declines in health during the pandemic that were attributed to limited engagement and socialization. Social isolation and it's psychological sequelae were pervasive among older adults even before the pandemic began [28, 29]. The pandemic compounded barriers to socialization inherent to cognitive impairment (e.g., decreased ability to tolerate and respond to stressful stimuli) by adding widespread contextual and environmental barriers (e.g., limited or no access to vital dementia-specific supports and services) [30, 31]. Offering opportunities to engage with society and increasing socialization are critical to promoting the health and well-being of people living with dementia.

Early phases of the pandemic were marked by disruption, uncertainty, and restrictions that paralleled participants experiences' throughout their journeys of living with dementia. Societal pressure, judgement, misinformation, and social exclusion loomed over people diagnosed with the virus and those who cared for COVID-19 patients, comparable to what people living with dementia and other debilitating health conditions experienced during pre-pandemic times [32, 33]. It remains unclear if the collective experience of the pandemic influenced society's stigmatizing views on aging, disability, and memory loss. The analogy "welcome to our world" could be a powerful tool to shed light on the many challenges experienced by people living with dementia and prompt a call to action to address systemic barriers that prevent people from living well with this disease.

Participants identified many gaps in healthcare and society that left them feeling less human. This included lack of empathy, knowledge of the disease, and referrals for dementia-specific supports and services. Negative experiences with healthcare systems and providers prompted people living with dementia to seek new opportunities to humanize their experiences with the disease. They collaborated to advocate and improve the lives of all people living with dementia in the present and future by sharing their own tools and strategies on how to live well with the disease. Their commitment and innovation can inspire healthcare leaders, clinicians, and researchers to reimagine dementia care and shift the narrative of disability to one of strength, ability, and living well.

4.1 Clinical Implications

Dementia care providers must have knowledge of complementary, non-pharmacologic approaches in order to offer resources and referrals to holistically support people on their journeys of living with dementia. Findings illustrate how people living with dementia are using many innovative approaches at home even during times of disruption (e.g., virtual support, peer-to-peer empowerment, advocacy, life coaches, humor, CBD products). Clinicians should assess what strategies are already used by patients and connect them to other supports that may enhance their ability to live well with the disease at home.

Participants also expressed caution for providers not to lose focus on those diagnosed, or rely solely on care partners for information about the lived experience of people living with dementia. This may mean expanding appointment times to allow people with dementia more time to communicate their experiences and having separate appointments to address care for the caregivers vs. care for the person diagnosed. Given the continued uncertainty surrounding the pandemic, dementia care providers must continue to assess for and address longer-term mental and physical effects on people living with dementia.

4.2 Research Implications

With the number of people living with dementia expected to increase over the coming decades [12], it is paramount that gaps in care identified by people living with dementia be propelled to the forefront of the aging research agenda. Advancing evidence-based dementia care requires additional research focused on the recommendations of the experts living with dementia. Researchers need to amplify the voice of people living with dementia through co-creation of research, stakeholder engagement, and by using approaches to fully engage individuals across the disease continuum. Modifications, adapatations, and flexibility in study protocols and eligibility criteria can promote inclusivity, which is needed to enhance representation of people living with dementia in all types of aging research. Increased flexibility is particularly important during times of society-wide disruption, like the pandemic.

Activism can be a powerful tool to reduce stigma, enhance understanding, and ignite change. People living with dementia may experience individual and collective benefit by engaging in educational and advocacy activities [34]. Interventions that connect people living with dementia with opportunities to advocate and educate is a promising research area to explore to enhance well-being of people living with dementia and to transform society’s approach to dementia care. This is one example of how incorporating the perspectives and recommendations of persons living with dementia can be leveraged to gain insight into novel areas for research.

There are several limitations to consider for this study, including the samples’ limited variability in sociodemographic (e.g., age, race and ethnicity, gender) and clinical characeristics (earlier onset/diagnoses, dementia type). The pandemic took a disproporotionate toll on the health of marginalized racial and ethnic groups [35], and older people with increased medical complexity [36]. This study’s sample is not large, or varied enough to reflect such differences; however, this study does highlight the perspectives of a vulnerable population often overlooked in research and clinical practice. Efforts were made to assess data saturation throughout the analysis and through member checking, but given the small sample size, we cannot ensure that saturation was achieved. Another limitation is that participants all volunteered for the focus groups, which means the experiences of people living with dementia less able to communicate or willing to share their experiences are likely not captured in these findings. Finally, participants were recruited through one national organization focused on advocacy and education. Although participants were from across the country, their experiences and interpretations of the impact of the pandemic could vary greatly from people living with dementia who do not participate in peer support and advocacy activities.

Despite these limitations, this study expands the understanding of the lived experience of people living with dementia during a critical time period of the early stages of the pandemic. Multiple strategies were used to maintain rigor in the analysis, including member checking. Several approaches were also used to promote engagement by people living with dementia (e.g., feedback on focus group guides, providing questions to participants in advance of focus groups, using 2 separate focus groups to discuss 2 different time points). These findings are among the first to capture how people living with dementia compared their experiences prior to and during the pandemic.

5. Conclusion

People living with dementia experienced significant challenges to living well with a chronic, cureless condition prior to and during the COVID-19 pandemic. As the pandemic upturned the world, society endured feelings of loss, stress, and health impacts that people living with dementia experienced even before the pandemic began. Even in the face of adversity with limited support, strateigies were identified to optimize the experience of living with dementia. This study's findings add to the evidence base by illustrating the lived experiences of those diagnosed with dementia prior to and during the pandemic. Sharing their experiences with the broader community represents a promising opportunity to transform the worldview of dementia and improve dementia-related healthcare and research.

Disclaimer

The contents do not represent the views of the U.S. Department of Veterans Affairs, the United States Government, or the Duke Clinical and Translational Science Institute. Drs. Harris-Gersten and Granner conducted this research while in their doctoral programs at the University Michigan and completed analysis/manuscript preparation while in postdoctoral positions at Duke University and Yale University, respectively.

Acknowledgments

We would like to acknowledge the © National Council of Dementia Minds and executive director Brenda Roberts for their general support in the conceptualization and conduct of this study.

Author Contributions

All authors contributed to varying degrees to the conceptualization, data analysis, and manuscript preparation for this study.

Funding

This work was supported in part by the Predoctoral Fellowship Training Grant (T32 NR016914. Program Director: Titler) Complexity: Innovations in Promoting Health and Safety. 7/1/2017 – 6/30/2022 and the Duke Clinical and Translational Science Institute (CTSI). The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Competing Interests

The authors declare that there are no conflict of interests in relation to this study. This study was determined exempt from ongoing review by the University of Michigan Health Sciences and Behavioral Sciences Institutional Review Board [HUM00189059].

Additional Materials

The following additional materials are uploaded at the page of this paper.

1. Appendix A.
2. Appendix B.
3. Table S1: Major Themes, Subthemes, Codes, and Example Quotations.

References

1. Nichols E, Steinmetz JD, Vollset SE, Fukutaki K, Chalek J, Abd-Allah F, et al. Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: An analysis for the Global Burden of Disease Study 2019. Lancet Public Health. 2022; 7: e105-e125.
2. Jutkowitz E, Kane RL, Gaugler JE, MacLehose RF, Dowd B, Kuntz KM. Societal and family lifetime cost of dementia: Implications for policy. J Am Geriatr Soc. 2017; 65: 2169-2175.
3. Lindeza P, Rodrigues M, Costa J, Guerreiro M, Rosa MM. Impact of dementia on informal care: A systematic review of family caregivers' perceptions. BMJ Support Palliat Care. 2020. doi: 10.1136/bmjspcare-2020-002242.
4. Quinn C, Pickett JA, Litherland R, Morris RG, Martyr A, Clare L. Living well with dementia: What is possible and how to promote it. Int J Geriatr Psychiatry. 2022; 37: 10.1002/gps.5627.
5. Frank L, Jennings LA, Petersen RC, Majid T, Gilmore-Bykovskyi A, Schicker L, et al. Participation of persons with dementia and their caregivers in research. J Am Geriatr Soc. 2021; 69: 1784-1792.
6. Frank L, Shubeck E, Schicker M, Webb T, Maslow K, Gitlin L, et al. Contributions of persons living with dementia to scientific research meetings. Results from the national research summit on care, services, and supports for persons with dementia and their caregivers. Am J GeriatrPsychiatry. 2020; 28: 421-430.
7. Masoud SS, Glassner AA, Patel N, Mendoza M, James D, Rivette S, et al. Engagement with a diverse stakeholder advisory council for research in dementia care. Res Involv Engagem. 2021; 7: 54.
8. Read ST, Toye C, Wynaden D. The participation of people with dementia in the planning of their care and support: An integrative literature review. Dementia. 2018; 19: 691-707.
9. Xanthopoulou P, McCabe R. Subjective experiences of cognitive decline and receiving a diagnosis of dementia: Qualitative interviews with people recently diagnosed in memory clinics in the UK. BMJ Open. 2019; 9: e026071.
10. Reilly JC, Houghton C. The experiences and perceptions of care in acute settings for patients living with dementia: A qualitative evidence synthesis. Int J Nurs Stud. 2019; 96: 82-90.

11. Shiells K, Pivodic L, Holmerová I, Van den Block L. Self-reported needs and experiences of people with dementia living in nursing homes: A scoping review. Aging Ment Health. 2020; 24: 1553-1568.
12. Alzheimer's Association. 2023 Alzheimer's disease facts and figures. Alzheimers Dement. 2023; 18: 700-789.
13. Lee YJ. The impact of the COVID-19 pandemic on vulnerable older adults in the United States. J Gerontol Soc Work. 2020; 63: 559-564.
14. Bianchetti A, Rozzini R, Bianchetti L, Coccia F, Guerini F, Trabucchi M. Dementia clinical care in relation to COVID-19. Curr Treat Options Neurol. 2022; 24: 1-15.
15. Tam MT, Dosso JA, Robillard JM. The impact of a global pandemic on people living with dementia and their care partners: Analysis of 417 lived experience reports. J Alzheimers Dis. 2021; 80: 865-875.
16. Tuijt R, Frost R, Wilcock J, Robinson L, Manthorpe J, Rait G, et al. Life under lockdown and social restrictions-the experiences of people living with dementia and their carers during the COVID-19 pandemic in England. BMC Geriatr. 2021; 21: 301.
17. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007; 19: 349-357.
18. Vasileiou K, Barnett J, Thorpe S, Young T. Characterising and justifying sample size sufficiency in interview-based studies: Systematic analysis of qualitative health research over a 15-year period. BMC Medical Res Methodol. 2018; 18: 148.
19. Cacchione PZ. People with dementia: Capacity to consent to research participation. Clin Nurs Res. 2011; 20: 223-227.
20. Beattie E, O'Reilly M, Fetherstonhaugh D, McMaster M, Moyle W, Fielding E. Supporting autonomy of nursing home residents with dementia in the informed consent process. Dementia. 2019; 18: 2821-2835.
21. Krueger RA, Casey MA. Focus groups: A practical guide for applied research. 5th ed. California: Sage Publications; 2014.
22. Scientific Software Development. Scientific Software Development's ATLAS.ti: The knowledge workbench: Short use's manual. Berlin, Germany: Scientific Software Development; 1997.
23. Riessman CK. Narrative methods for the human sciences. 1st ed. Boston: Sage; 2008.
24. Earthy S, Cronin A. Narrative analysis. In: Researching social life. 3rd ed. London: Sage; 2008.
25. Braun V, Clarke V. Thematic analysis. In: APA handbook of research methods in psychology, vol. 2. Washington, DC: American Psychological Association; 2012.
26. Thomas E, Magilvy JK. Qualitative rigor or research validity in qualitative research. J Spec Pediatr Nurs. 2011; 16: 151-155.
27. Stahl NA, King JR. Expanding approaches for research: Understanding and using trustworthiness in qualitative research. J Dev Educ. 2020; 44: 26-29.
28. Penninkilampi R, Casey AN, Singh MF, Brodaty H. The association between social engagement, loneliness, and risk of dementia: A systematic review and meta-analysis. J Alzheimers Dis. 2018; 66: 1619-1633.
29. Perissinotto CM, Stijacic Cenzer I, Covinsky KE. Loneliness in older persons: A predictor of functional decline and death. Arch Intern Med. 2012; 172: 1078-1084.
30. Curelaru A, Marzolf SJ, Provost JC, Zeon HH. Social isolation in dementia: The effects of COVID-19. J Nurse Pract. 2021; 17: 950-953.

31. Hall GR, Buckwalter KC. Progressively lowered stress threshold: A conceptual model for care of adults with Alzheimer's disease. Arch Psychiatr Nurs. 1987; 1: 399-406.
32. Joachim G, Acorn S. Stigma of visible and invisible chronic conditions. J Adv Nurs. 2000; 32: 243-248.
33. Kristensen K, König HH, Hajek A. The association of multimorbidity, loneliness, social exclusion and network size: Findings from the population-based German Ageing Survey. BMC Public Health. 2019; 19: 1383.
34. Weetch J, O'Dwyer S, Clare L. The involvement of people with dementia in advocacy: A systematic narrative review. Aging Ment Health. 2021; 25: 1595-1604.
35. Babulal GM, Torres VL, Acosta D, Agüero C, Aguilar-Navarro S, Amariglio R, et al. The impact of COVID-19 on the well-being and cognition of older adults living in the United States and Latin America. EClinicalMedicine. 2021; 35: 100848.
36. Ismail H, Marshall VD, Patel M, Tariq M, Mohammad RA. The impact of the COVID-19 pandemic on medical conditions and medication adherence in people with chronic diseases. J Am Pharm Assoc. 2022; 62: 834- 839.e1.