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Experiences of American Older Adults with Pre-existing Depression During the Beginnings of the COVID-19 Pandemic: A Multicity, Mixed-Methods Study

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ABSTRACT

Objective: To determine the effect of the COVID-19 pandemic on the mental health of older adults with pre-existing major depressive disorder (MDD).

Participants: Participants were 73 community-living older adults with pre-existing MDD (mean age 69 [SD 6]) in Los Angeles, New York, Pittsburgh, and St Louis.

Design and Measurements: During the first 2 months of the pandemic, the authors interviewed participants with a semistructured qualitative interview evaluating access to care, mental health, quality of life, and coping. The authors also assessed depression, anxiety, and suicidality with validated scales and compared scores before and during the pandemic.

Results: Five themes from the interviews highlight the experience of older adults with MDD: 1) They are more concerned about the risk of contracting the virus than the risks of isolation. 2) They exhibit resilience to the stress and isolation of physical distancing. 3) Most are not isolated socially, with virtual contact with friends and family. 4) Their quality of life is lower, and they worry their mental health will suffer with continued physical distancing. 5) They are outraged by an inadequate governmental response to the pandemic. Depression, anxiety, and suicidal ideation symptom scores did not differ.


INTRODUCTION

The World Health Organization recently warned of a looming mental health crisis due to the novel SARS-CoV-2 virus (COVID-19) pandemic, with the assertion that older adults, and those with pre-existing mental health conditions, such as depression, are at higher risk.1 The relative risk of physical distancing versus COVID-19-related morbidity and mortality remains a topic of active public debate, with concern for serious negative mental health impacts weighed against the importance of pandemic control.2 This debate is particularly acute for older adults who are at highest risk of deleterious outcomes from COVID-19.3,4 Data informing this debate are limited, and we know of no published studies about the experiences of vulnerable older adults like those with major depressive disorder (MDD). Therefore, we conducted a mixed-methods study in older adults with MDD to assess their experience during the pandemic, including changes in quantitative depression and anxiety scores from scores obtained before the pandemic. Our mixed-methods approach allows us to understand both objective effects on mental health, as well as the individual lived experience that informs those effects.

METHODS

This study comprises a semistructured qualitative interview, contemporaneous depressive and anxiety scores, and comparison of these scores to prepandemic scores. Between April 1 and April 23, 2020, 73 older adults with MDD were recruited among the 743 participants in the Optimizing Outcomes of Treatment-Resistant Depression in Older Adults (OPTIMUM) clinical trial. OPTIMUM’s methods have been described in detail elsewhere.5 In brief, OPTIMUM is a multisite comparative effectiveness study of various antidepressant treatment strategies for treatment-resistant MDD in older adults (age >60). Of relevance to the current study, OPTIMUM participants are administered both the Patient Health Questionnaire item 9 (PHQ-9) and the Patient-Reported Outcomes Measurement Information System (PROMIS) anxiety scale upon entry into the study; the PHQ-9 is repeated throughout their participation. We drew upon their most recent prepandemic scores for comparison to PHQ-9 and PROMIS anxiety scores obtained at the time of the qualitative interview for this study.

Participants

IRBs in Los Angeles (UCLA), New York (Columbia), Pittsburgh (University of Pittsburgh), and St. Louis (Washington University in St. Louis) approved contacting OPTIMUM participants by phone and inviting them to complete this mixed-methods study. We oversampled participants in the New York region because it was the epicenter of the U.S. epidemic at the time of the study. We selected 110 OPTIMUM participants from the four sites, and 73 consented to be interviewed (Table 1).

Qualitative and Quantitative Outcomes

The interview script assessed perceived access to physical and mental healthcare, depression, anxiety, social isolation, quality of life, and coping (see Appendix A). We measured symptoms with the PHQ-96 and the PROMIS anxiety scale.7 We also examined suicidal ideation from the PHQ-9 item 9, which evaluates passive thoughts of death and self-injury within the past 2 weeks. After 10 interviews, we added a question asking participants to forecast how they would cope if shelter-in-place orders continued for an extended duration, and how long they could continue to shelter-in-place before they experienced negative mental health effects.

Raters who were already conducting assessments with OPTIMUM participants conducted the interviews.
Prior to conducting interviews, they were trained in qualitative interviewing techniques. Early interviews were reviewed for quality, with feedback provided to all interviewers. Interviews were audio-recorded except when participants declined audio-recording, in which case it was summarized by the interviewer immediately after completion.

**Descriptive, Quantitative, and Qualitative Analyses**

Days since the pandemic was declared were the number of days between March 11, 2020 and the date of the interview; days since shelter-at-home are based on the date it was instituted in the region (Los Angeles 3/19/2020; St. Louis 3/21/2020; New York 3/22/2020; Pittsburgh 4/1/2020). Two-tailed paired t tests compared PHQ-9 and PROMIS scores at the time of the interview and at baseline (i.e., pretreatment) or immediately before the pandemic (i.e., the most recent score prior to March 1). Significance level was set a priori at $p \leq 0.05$.

To analyze the interviews, we utilized elements of Rapid Qualitative Inquiry, which foregoes transcription and uses a team-based approach to ensure triangulation of interpretation among multiple analysts. Interviewers’ summaries were used for the three interviews for which participants declined audio-recording; three analysts (MH, FC, and AD) listened to and summarized the other 70 interviews and met to discuss findings (Appendix B). We then utilized traditional qualitative analytical methods with the 73 summaries. The primary qualitative analyst (MH) created a codebook based on the content of the summaries and constructs of interest (summaries are presented in full, with identifying details redacted, in Appendix C). Using this codebook, the primary and secondary analysts coded five summaries with the assistance of Atlas.ti software. After comparing coding and refining code definitions, they coded 15 additional summaries. The range of Cohen’s kappas reflecting inter-rater reliability for each code was 0.61–1.00, with an average of 0.83, indicating “strong” agreement. The primary analyst then coded the remaining 53 summaries and conducted a thematic analysis$^{10,11}$; the identified themes were reviewed and approved by the other analysts as a form of investigator triangulation.

**RESULTS**

Table 1 summarizes the participants’ characteristics; the response rate was lower among minority participants. The themes from the 73 interviews were consistent across races, ethnicity, and regions, except that two African American participants expressed concern that minorities were being disproportionately affected. While participants from New York did not express more distress than those from other regions, they expressed more concerns that they might have experienced COVID-19 symptoms. We found no notable gender-based response differences in responses.
Some participants reported they were experiencing increased depression (n = 32) or increased anxiety (n = 33) during the interview. Additionally, 26 reported being isolated — i.e., living alone without in-person contact with anyone. For the truly isolated, this experience was difficult: they worried that they had to, or eventually would, break distancing measures for the sake of their mental health. However, overall depression and anxiety scores at the time of the interviews were significantly lower than during the OPTIMUM study baseline and not higher than before the pandemic (Table 2), indicating that participants are not displaying a relapse to pretreatment levels of depression and anxiety during the pandemic. Further, examination of PHQ-9 item 9 (thoughts of death or self-harm) revealed no increase in suicidal thoughts: of 72 with scores available in the immediate prepandemic period, 59 (82%) had no thoughts of death (score of 0) both beforehand and currently; 5 (7%) had current thoughts of death (all had score of 1) but none beforehand; while 7 (10%) had reduced thoughts of death currently compared to before the pandemic (score of 0 currently vs. 1 beforehand in 5 participants, score of 1 currently vs. 3 beforehand in 2); 1 refused to answer.

Fifty-three participants described reduced quality of life from physical distancing, mostly due to decreased in-person social interaction and restrictions on leaving one’s home. However, most participants were effectively coping and adapting, and in a few cases (n = 4), thriving.

We identified five main themes in the interviews:

1. Older adults with MDD were more concerned about contracting the virus than risks from isolation.

When asked to weigh the risks of contracting the virus against the risks of isolation, only 5 participants felt that the risks of isolation were worse; 13 felt that both risks were balanced; 2 could not choose which was worse; and 55 felt that the risk of the virus was worse. Physical distancing was regarded as something to be “endured” for the sake of containing and avoiding the virus. One participant said, “I don’t like [distancing], but I can cope with it.” Many (n = 28) described being able to shelter-in-place for as long as they “have to” without becoming distressed by it. As one woman said: “I’ve [coped with depression and anxiety] before, so I know I can do that again, but I can’t...”
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fight off an invisible enemy.” Some participants believed they were at high risk because of age or medical conditions, with a few feeling certain that they would die if they got the virus, making isolation preferable.

(1) Older adults with MDD exhibited resilience in response to the stress of physical distancing.

While many participants described increased depression and anxiety related to the pandemic, their prior experiences with depression had provided them with coping strategies to deal with those feelings. They emphasized the importance of such strategies as maintaining regular schedules; distracting themselves from negative emotions with hobbies, chores, work, or exercise; and utilizing mindfulness, focusing on immediate surroundings and needs without thinking beyond the present. As one participant said: “I don’t want to make myself crazy thinking about what’s going to happen, I just go day by day.”

Some participants reported that because of their depression, they were not especially social. As a result, staying home was not difficult. As one described: “I’ve spent a lot of time by myself […] I’m relatively acclimated to a level of isolation that I think is greater than most people.” A handful (n = 4) indicated that they were thriving as a result of pandemic-related changes, such as not having to commute or socialize.

(1) Most participants were not isolated socially, and some reported increased contact with loved ones.

Only 26 participants reported being isolated. Most were sheltering-in-place with partners, family, or roommates. Others were living alone but seeing loved ones or caregivers regularly even though they had curtailed most public interaction. Additionally, many (n = 26) described pets as a relief from loneliness.

Even those who were physically isolated described maintaining social contact via phone and video calls, including remote happy hours and dinners. Some participants attended support groups online. Virtual interactions were considered inferior to in-person interactions, but sufficient given the circumstances. Some participants were hearing from loved ones more frequently than before the pandemic, and were reaching out more. Continuation of contact was considered essential to continued physical distancing. One participant described: “If I was unable to reach my kids and my boyfriend […] I probably would get in my car and defy all the rules.” Inability to see grandchildren was a particular source of sadness for some participants (n = 16).

(1) Despite their resilience, most participants’ quality of life was lower, and they worried their mental health would suffer with continued isolation.

Fifty-three participants, including some who reported no increased depression or anxiety, described a lower quality of life. Lowered quality of life was multicausal and varied individually. Lack of face-to-face contact and decreased activities outside the home were a common cause. One participant explained that she previously enjoyed walking in a mall: “It wasn’t a great pleasure, but it was my pleasure, and now I can’t even do that.” Although described as an inconvenience rather than a source of distress, restrictions related to going out were identified as contributors to worse quality of life, as were boredom and a lack of activities. Many participants kept busy to cope. However, those not working from home missed meaningful activities beyond housekeeping and hobbies. One participant who routinely volunteered said she would like to “find a way to feel helpful and not just waste this time.” Financial worries were relatively rare (10 of 73 interviews), but were distressing to those who experienced them.

Deferred healthcare was also problematic: 48 participants reported effects on access to physical healthcare, usually cancelled visits and tests, or a shift to telehealth, which half of these participants (n = 24) found upsetting. Mental healthcare was less affected, with 29 participants reporting a change in care (usually a shift to telehealth), and 14 finding these changes problematic. Those without a therapist worried about finding one if necessary.

Participants thought that the longer shelter-in-place went on, the more likely they would be to experience negative mental health effects. Nonetheless, they would rather shelter-in-place than risk getting the virus. Tolerance for continued shelter-in-place ranged from “until tomorrow” to “3–5 years from now” with most describing being able to continue for a “few more months.” When asked what they would need from others should shelter-in-place continue for “a long time,” participants overwhelmingly responded that they would need continued or increased social contact.
Many participants spontaneously reported outrage about the governmental handling of the pandemic.

Spontaneously reported concerns about the governmental (usually federal) leadership and the response to the pandemic were another source of distress for participants. Almost half (n = 33) described anger or worry that the United States was unprepared for the pandemic and has not responded appropriately.

The comments about the federal government response to the pandemic were striking, given that this was not a question asked by interviewers—it was commonly, and spontaneously, brought up by participants. Spontaneous political commentary is highly unusual in the experience of the qualitative analysts. A typical comment was: “The most dangerous thing, and that really upsets me, [is] that we have the president of the United States saying in the beginning that it’s a hoax, [...] when he knew that this had the potential to be explosive, and now he has other people thinking and believing what he said, and those are the people who are not practicing social physical distancing. [...] I think it’s a disservice to lie to the American public about something like this, and that upsets me.”

DISCUSSION

We examined effects of the pandemic on the mental health of older adults with pre-existing MDD in four U.S. metropolitan areas. Contrary to expectations that they would demonstrate negative psychosocial consequences from physical distancing, most were coping well. While some participants qualitative reported that they felt more depressed or anxious, we found no evidence of increased clinical depression, anxiety, or suicidal thoughts compared to symptoms assessed before the onset of distancing. This suggests that coping is possible during this national crisis when older adults have knowledge of how to self-care when distressed, access to mental healthcare and support groups, and continued social interaction, as our study population generally did. Older adults weighed fears of COVID-19 illness as greater than concerns from the distancing requirements. These findings should help clinicians and policy-makers who have to balance competing issues when supporting the mental health of older adults.

While our participants were doing relatively well, most of them forecasted that their mental health will deteriorate as physical distancing continues, which is consistent with recent survey data indicating that individuals with mental illness are concerned that their mental health conditions will worsen as a result of the pandemic. Interviews occurred shortly after World Health Organization declared the pandemic (average 32 days) and the distancing orders (average 20 days). This provides support for an emotionally positive “honeymoon phase” of the disaster response. While this concept has been used to describe psychological response following acute disasters, the COVID-19 pandemic is likely to last months or years; continued follow-up may find indications of worsening mental health. Also, participants could be demonstrating a positive emotional bias and focus away from negative events—an emotional regulation strategy seen in older adults. While this bias might be protective early on during a stressful event, it may reduce over time. In conclusion, older adults with MDD are showing resilience during the first 2 months of the COVID-19 pandemic in the United States, a finding echoed in recent survey data from older adults in Spain—but further follow-up of this and other vulnerable populations is critical.

Notably, while study participants did not report increased clinical depression or anxiety as measured by the PHQ-9 and PROMIS anxiety scales, many participants did describe themselves as more depressed (n = 32) or more anxious (n = 33) during the qualitative interview. The discrepancies between qualitative and quantitative assessments of depression and anxiety suggest that qualitative self-assessment of feelings is not equivalent to quantitative clinical worsening of symptoms. Our data suggest that participants were actively coping with mental health challenges presented by the pandemic, and thus that their coping had prevented feelings of worsening depression or anxiety from translating into clinical manifestations.

Finally, our findings suggest several strategies to help older adults with MDD to cope:

(1) Due to their experience with mental illness, our participants were aware of mental health maintenance strategies, and used them. Reminders of their importance as the pandemic progresses may
be necessary. Also, providing primary education on these strategies may help to maintain the mental health of the general population.

(2) Suggesting safe ways for older adults to socialize with others could also prevent or alleviate distress. Contacts between separate households increase the spread of COVID-19. However, given the prediction of multiple waves of illness and recurring periods of physical distancing, maintaining meaningful social contact is of paramount importance. Guiding older adults on how to expand social interactions beyond their individual household without assuming the risks of “normal” social interactions could increase the length of time they can tolerate sheltering in place.

(3) Similarly, finding volunteer or paid activities that older adults could do safely from their homes would provide them with a sense of purpose. Social services and other agencies could offer volunteer activities that can be done remotely, or with minimal contact.

(4) A concerted public health effort led by the federal government would ease their concerns about governmental response.

Limitations

Our sample is derived from, and potentially limited by, the OPTIMUM sample and by those we could reach within a relatively short timeframe. It is possible that OPTIMUM participants who could not be contacted or who declined to be interviewed are facing challenges, such as hectic schedules, financial difficulties, or severe depression or anxiety leading them to avoid talking about a distressful topic. Indeed, the lack of financial anxieties among our participants was striking among our findings given the economic impacts of the pandemic, and may be due to refusal to participate by those with more financial stressors, or to relative lack of financial worry early in the pandemic due to reliance on fixed incomes among the age groups represented in our sample. While we found no major differences based on location, race, ethnicity, or gender, the sample is predominantly urban or suburban, white, and female. It is now well documented that African American, Hispanic or Latino, and Native American groups are being disproportionately affected by COVID-19. A more diverse sample including older adults from rural and native communities or more minority participants may have yielded different results. While our study found no differences based on racial or ethnic background, this may be due to the socioeconomic standing of the minority participants we reached; it should not be interpreted as indicating that there are no differences in experience outside of this sample. Indeed, evidence is mounting that for some older adults, particularly those in nursing homes and assisted living facilities, the pandemic and associated physical distancing has been catastrophic. While our results indicate that successful coping is possible, at least in the early stages of the pandemic, it must be emphasized that successful coping is contingent on having the resources to cope — in the case of our sample, this includes prior experience with treatment for depression, routine social contact of some sort, and relative lack of financial worry. Similar studies of less privileged groups of older adults may yield dramatically different results, and are important to conduct. Lastly, the comparison of baseline anxiety levels with current anxiety levels, without the intervening pre-pandemic anxiety score (which was not collected routinely as part of OPTIMUM follow-ups), is a limitation of our quantitative anxiety data.

AUTHORS’ CONTRIBUTIONS

Megan E. Hamm, Ph.D. made substantial contributions to the conception or design of the work, the acquisition, analysis and interpretation of the data, the drafting and revising of the work, and the final approval of the version to be published. She agrees to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Patrick J. Brown, Ph.D. made substantial contributions to the conception or design of the work, the analysis of data, the revising of the work, and the final approval of the version to be published. He agrees to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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Dr. Karp reports personal fees from Otsuka, personal fees from Physician’s Postgraduate Press, personal fees from American Journal of Geriatric Psychiatry, outside the submitted work; and Receipt of medication supplies for investigator-initiated trials from Pfizer and Indivior. Dr. Reynolds reports personal fees from American Association for Geriatric Psychiatry, outside the submitted work. Dr. Lenze reports grants from Janssen, grants from Aptinyx, grants from Acadia, grants from Lundbeck, grants from Takeda, grants from PCORI, grants from Barnes Jewish

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SUPPLEMENTARY MATERIALS

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