




“A Different Way to Survive”: The Experiences of Family Caregivers of Persons Living With Dementia During the COVID-19 Pandemic

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Sara Masoud, MPH¹ , Ashlie A. Glassner, BSN, RN¹,
Mayra Mendoza¹, Shanae Rhodes, BSN, RN¹ ,
and Carole L. White, PhD, RN, FAAN¹

Abstract

Family caregivers of persons living with dementia often experience challenges to their health and quality of life related to their caregiving role. The COVID-19 pandemic added substantially to the responsibilities of family caregivers, potentially putting them at greater risk of poor health outcomes and impeding quality of life. To better understand the impact of the pandemic on the experiences of family caregivers, a multimethods study was conducted. Family caregivers of persons living with dementia were invited to complete a cross-sectional survey and a subset of survey respondents were invited to participate in focus groups for added insight. A total of 161 caregivers responded to the survey and 30 participated in the focus groups. Qualitative data from focus groups were used to elucidate deeper insight into quantitative findings from the survey. Findings reflect that the pandemic affected family caregiver health and wellness, access of care and resources, identity, and resilience.

Keywords

dementia, family caregiving, COVID-19

Family caregivers are the most important resource for their family members/friends living with dementia, providing more than 80% of their care (Friedman et al., 2015). Yet, providing this care is often a stressful experience for family caregivers (“2021 Alzheimer’s Disease Facts and Figures,” 2021), with approximately one third of family caregivers reporting symptoms of depression and almost one half reporting high levels of anxiety (Sallim et al., 2015). Compared with family caregivers of persons without dementia, caregivers of persons living with dementia are more likely to take on multiple responsibilities, including assisting with activities of daily living, coordinating health care services, and managing finances as well as other instrumental activities of daily living (National Alliance for Caregiving and AARP, 2020).

The COVID-19 pandemic and necessary precautions to prevent spread have added significantly to the roles and responsibilities of family caregivers. Research has indicated the extreme vulnerability of older adults, and particularly those living with dementia, who are at increased risk of complications from COVID-19, including mortality (Cipriani & Fiorino, 2020; Wang et al., 2021; Yao et al., 2020). The related public health interventions to mitigate

the spread of COVID-19 such as physical distancing or lockdown have had major adverse effects on the well-being of both people living with dementia and their family caregivers (Bacsu et al., 2021; Frangiosa et al., 2020; Hwang et al., 2021; Roach et al., 2021; Tuijt et al., 2021). Family caregivers have been at the “front line,” increasingly vigilant to protect their family members from COVID-19 and providing continuous care with little or no assistance from other family members and health and social care services (Frangiosa et al., 2020; Phillips et al., 2020; Vaitheswaran et al., 2020).

Caregiving research describes the impact of burden on caregiver health outcomes (Abdollahpour et al., 2014; Liew et al., 2019) as well as the adverse effects on care recipient outcomes (Fields et al., 2019; Isik et al., 2018; Kuzuya et al., 2011). The demands of caregiving combined with barriers to

¹The University of Texas Health Science Center at San Antonio, USA

Corresponding Author:

Sara Masoud, Community Outreach Coordinator, School of Nursing, The University of Texas Health Science Center at San Antonio, 7703 Floyd Curl Dr., San Antonio, TX 78229, USA.
Email: masoud@uthscsa.edu

caregiver resources put caregivers of persons living with dementia at increased risk of psychological distress, poor health outcomes, and even increased risk for mortality among distressed caregivers (Arthur et al., 2018; Robison et al., 2009; Schulz & Beach, 1999; Zwerling et al., 2016). Individuals living with dementia whose caregivers are experiencing burden and stress related to their caregiving role may be at increased risk of poor health outcomes, injuries, and increased likelihood for institutionalization (Afram et al., 2014; Isik et al., 2018; Quinn et al., 2020). The pandemic has added to caregiver burden and stress with early studies describing the tremendous challenges caregivers are experiencing. Studies describe their high levels of burden and stress, with caregivers reporting sleep disturbances, difficulty concentrating, vigilance/being “super alert,” and trouble experiencing positive feelings (Frangiosa et al., 2020; Hwang et al., 2021). The results from two qualitative studies conducted with family caregivers during the lockdown provide greater detail about the challenges for family caregivers and some of the sources of their stress (Tuijt et al., 2021; Vaitheswaran et al., 2020). Caregivers described challenges around restructuring care to manage COVID-19 risk, including the loss of outside care support, the need to continuously reinforce lockdown restrictions for their family member living with dementia, and the loss of social engagement opportunities both for the person living with dementia and the caregiver.

Despite the tremendous challenges coupled with the uncertainty surrounding the pandemic, several studies reported resilience among family caregivers and identified factors associated with resilience (Altieri & Santangelo, 2021; Carbone et al., 2021; Hanna et al., 2021). Altieri and Santangelo (2021) reported an association between higher levels of resilience and lower levels of depression. Themes from interviews conducted with 42 family caregivers identified protective factors of resilience that included effective communication with social/health services, being able to adapt to technology, preexisting social networks, and habits of previous coping mechanisms such as exercise (Hanna et al., 2021).

Findings from the literature suggest the need to examine more broadly the impact of COVID-19, including both the challenges caregivers are experiencing and factors that are associated with coping and resilience. Quality of life is a construct that encompasses a wide array of domains, including health and role functioning, psychological/spiritual, social and economic, and family (Ferrans, 1996).

The purpose of this report is to contribute to our understanding of the experiences of family caregivers of persons living with dementia living across settings (community-dwelling and in memory care institutions that provide specialized care exclusively for persons living with advanced dementia) during the first year of COVID-19, how it affected their ability to provide care, and the impact on their overall quality of life.

Method

This study was conducted using a participatory research design that involved direct partnership and collaboration with community members to ensure the process and findings were informed and relevant to the community of interest (Key et al., 2019; Vaughn & Jacquez, 2020; Wallerstein et al., 2017). The study was conducted in collaboration with a Stakeholder Advisory Council (SAC) comprised of persons living with dementia ($n = 2$), family caregivers ($n = 4$), and health and social care professionals ($n = 7$; Masoud et al., 2021). Members of the project team represented a caregiver support organization and a geriatric palliative care clinic so were well positioned to invite the initial members of the SAC. All who were invited were asked to recommend others who they thought would be a good fit for the project and invitations were extended to those persons. The two persons living with dementia on the SAC were diagnosed with Alzheimer’s disease and Lewy Body dementia, both in the early stages of their dementia progression. Family caregivers included those who were currently caregiving for persons living with dementia and those who were formerly caring for persons who had since died. Recruitment and engagement methods used to establish and partner with the SAC are reported elsewhere (Masoud et al., 2021). Examining the impact of COVID-19 on dementia care was identified by the SAC as a priority and they participated in all aspects of the study. This article reports on the data from family caregivers. A multimethods approach was used to explore and develop a deeper understanding of the experiences of family caregivers during the COVID-19 pandemic. Family caregivers were invited to participate in a cross-sectional survey, followed by focus groups with a subset of caregivers who had participated in the survey.

Participants

Family caregivers were eligible to participate if they spoke English and were caring for a person living with dementia during the COVID-19 pandemic. We included both family caregivers of care recipients who were community-dwelling and those who were living in memory care facilities. Memory care facilities are institutions that provide specialized care to individuals affected by Alzheimer’s or related dementias in need of long-term support and care. Memory care is sometimes integrated into assisted living facilities, nursing homes, or other institutions that provide care services for older and/or disabled communities. In this article, we distinguish between memory care institutions that exclusively support persons affected by dementia from other forms of dementia care that are incorporated within assisted living, nursing care, or other institutions. The caregivers recruited to participate in this project were caring for persons living within memory care institutions that provide full-time care exclusively to persons living with dementia. Given the reports

related to caregiving for someone in an institution during COVID-19, the perspectives of caregivers of persons living in memory care institutions were important to capture in this study. Several caregivers whose care recipients with dementia had passed away during the pandemic participated in the focus groups and reflected on their experiences of caregiving and navigating loss in the context of COVID-19.

The SAC members reached out to their wider constituent networks and shared information about the study through their personal and organizational networks via email and social media. Diverse representation on the SAC allowed for wide recruitment efforts among members' networks that connected the project to caregivers across settings. Caregivers of individuals living with dementia in memory care facilities were specifically recruited to the project through SAC member connections to facilities who extended invitations among their residents' families. The study team was based in Texas, although participants from other states were welcomed to participate in the online surveys and focus groups. Upon completion of the survey, respondents were asked whether they were interested in participating in a focus group. If they opted in, respondents were linked to a separate form to provide information needed to arrange the focus group. Participants of surveys and focus groups were offered electronic gift cards for their involvement in the study.

Ethical Considerations

This study was reviewed and approved by the UT Health San Antonio Institutional Review Board (IRB; HSC20200790E). Given the virtual nature of the study, the IRB-approved verbal consent for both the surveys and the focus groups. Family caregivers were provided an information sheet to review prior to completing the survey and participating in focus groups.

Procedures

Family caregivers from the SAC partnered with the research team to develop the initial study instruments, with SAC members drawing on their personal experiences during the pandemic to inform the development of the initial survey and focus group questions. This was an iterative process until the SAC and research team were satisfied that the survey and focus group guide sufficiently aligned with the experiences of family caregivers during the pandemic. A small group of caregivers from the council were asked to complete the survey and provide feedback for improvement before distributing among wider networks. The survey was developed using Research Electronic Data Capture (REDCap) with the link to the survey distributed through different networks reaching family caregivers, as described above (Harris et al., 2009). Caregivers were offered the option to complete printed versions of the survey as an alternative to online. In the instances where a printed version was preferred, data were collected in

person and entered manually into REDCap by a member of the research team.

Caregivers' experiences during COVID-19 were assessed with an anonymous 49-question survey, including demographic questions. Caregivers responding to the survey were asked to share their relation to their care recipient and their living arrangements (i.e., community-dwelling vs. in a memory care facility). Surveys were collected between November 2020 and January 2021. Survey questions examined their experiences related to the pandemic, including, but not limited to, the effects of social distancing and shelter-in-place policies; the impact on their own emotional, physical, and mental health; changes in their quality of life; their perceived quality of care for their care recipients provided by them and health professionals; concerns related to the impact of the pandemic on their care recipient(s) health; and their perceptions about the impact on dementia care services and supports. Response options to the survey items included "yes/no," 5-point Likert-type scales (e.g., *not at all* to *extremely*), and checklist options.

Five focus groups were conducted in January and February 2021. Four included caregivers of community-dwelling recipients and one group included caregivers to individuals living in memory care facilities. Focus group guides asked caregivers about their experiences during the COVID-19 pandemic, their perceived impact of the pandemic on their own health and access to health care as well as that of their care recipients, how they feel the pandemic may have affected how they provided care, and how they plan for the future amid the pandemic. In addition to sharing demographic information about themselves, participants in the focus groups were also asked to share kin relationship to and the living arrangements of their care recipients. Focus groups were co-facilitated by at least one member of the research team and one family caregiver from the SAC. While typical focus groups that are conducted in person allow for participants to crosstalk and interpret body language for deciding when to speak or allow others to speak, the online approach necessitated a more intentional approach. Participants were asked to activate their cameras so they could raise their hands when ready to speak. If they were unable to use their cameras, they were instructed how to use the "raise hand" function in Zoom when they wished to speak. The lead facilitator guided the conversation to prevent interruptions among focus group participants, creating a dynamic where all participants could share without confusion or interruption from others.

Data Analysis

Data from the surveys and focus groups were analyzed separately. All quantitative analyses were performed using statistical software Stata 16.1 (StataCorp, 2019). Survey data were analyzed using descriptive statistics. Unadjusted odds ratios (ORs) and 95% confidence intervals (CIs) were calculated to

measure associations between items related to caregiver health and experiences with care and perceived impact of the COVID-19 pandemic on caregiver quality of life. Impact on caregiver quality of life was recoded to reflect two dichotomous groupings: “not at all” and “a little” versus “somewhat,” “very much,” and “extremely.” Items hypothesized to be associated with the perceived impact of COVID-19 on caregiver quality of life were also dichotomized. For example, when measuring impact on depression or sleep, we followed the same dichotomized groupings used for impact on quality of life, “not at all” and “a little” to reflect little or no impact versus “somewhat,” “very much,” and “extremely” to reflect greater impact. The survey and full responses can be accessed in Supplemental Table S2.

The focus groups were audio-recorded, transcribed, and analyzed using thematic analysis. To establish a coding structure that could be modified with new data, the research team all reviewed the same transcript separately and developed initial codes through a group discussion. The research team then assigned two individuals to separately code each of the remaining transcripts, gathering as a group to compare and discuss their coding decisions. Through these discussions, the list of codes expanded and the research team conferred with each other, including a family caregiver from the SAC, to develop groups of similar data connected by a common overarching theme (Polit & Beck, 2019). Credibility of the data analysis was established through the experience of the team as well as the inclusion of a family caregiver in the analysis and interpretation.

Results

Family caregivers ($N = 161$) submitted surveys and 30 caregivers participated in the focus groups. Of the 161 caregivers who completed at least the demographics portion of the surveys, 125 responded to most survey items, resulting in just under 20% missing overall data. Focus groups were determined based on convenience, although one focus group deliberately included only caregivers of individuals residing in memory care facilities. The four focus groups of caregivers of community-dwelling care recipients ranged in size from five to seven caregivers per group and the focus group of caregivers whose care recipients lived in memory care facilities was comprised of six participants. Basic demographic data are presented in Table 1. Close to half of caregivers in the survey and focus groups identified as White, non-Hispanic (survey 48.7%, focus group 51.9%) and approximately half of the respondents identified as ethnic minorities, including Hispanic, Latino, or of Spanish origin (survey 32.1%, focus group 25.9%); Black or African American (survey 10.9%, focus group 18.5%); or as other ethnicities (survey 8.3%, focus group 3.7%). Most respondents identified as female (survey 86.3%, focus group 86.7%), were caring for a parent or grandparent (survey 55.7%, focus group 46.7%), and were 50 to 69 years

old (survey 58.9%, focus group 60%). Survey participants typically resided with the care recipient (60.8%) although several participants were caregiving for an individual living with dementia who lived with someone else (23.2%), others were caring for individuals living with dementia who were living alone (8%) or in a memory care institution (8.8%). Data collected from the surveys and focus groups for this study give a deeper understanding about the various facets of caregivers' experiences during the pandemic, contributing to our understanding of this perceived impact.

Survey Findings

Impact on caregiver health and well-being. Of caregivers who responded to the survey, 94.4% felt that the pandemic had some impact on their quality of life and 44.8% of caregivers felt their quality of life was “somewhat” to “much” worse than before the pandemic. Caregivers reported that the pandemic had at least “a little” impact on their physical health (89.6%) and 29.6% felt it had “very much” or “extremely” affected their physical health.

Data reflect that the pandemic also took a substantial toll on the emotional and mental health of family caregivers to persons living with dementia. Most caregivers (96%) felt the pandemic had affected their anxiety, and of those caregivers, 45.2% reported the pandemic had “very much” or “extremely” affected their anxiety. When asked whether they felt the pandemic affected their depression, 87.1% reported at least “a little” impact or greater. Increased anxiety experienced by caregivers may be partly attributed to a fear of contracting COVID-19 themselves and worry about their recipient contracting it. About 91.6% of survey respondents shared they had at least a little worry about getting COVID-19 themselves and 96.8% felt at least a little worried about their recipient getting it. Survey respondents (93.6%) reported that they felt isolated or cut off from family and friends since the pandemic began and 50.4% felt “very much” to “extremely” isolated or cut off.

As seen in Table 2, the perceived impact of COVID-19 on items related to caregiver health was strongly associated with caregivers' perceived impact of COVID-19 on their overall quality of life. Caregivers who reported a greater impact of COVID-19 on depression, sleep, and feelings of isolation were significantly more likely to report an impact of COVID-19 on their quality of life (OR = 8.71, 95% CI = [3.17, 26.08]; OR = 13.51, 95% CI = [3.72, 72.67]; OR = 10.67, 95% CI = [3.8, 30.52], respectively), among other health-related variables.

Caregiver experiences with care services. In terms of health care, 64.8% of survey respondents reported canceling or delaying appointments during the pandemic. The majority of these cancelations were attributed to fear of COVID-19 (59.5%) while some canceled because they decided it could wait (16.5%) or for other reasons, including the clinic/doctor

Table 1. Participant Demographics.

Demographic variables	Survey		Focus groups	
	(N = 161)	%	(N = 30)	%
Race/ethnicity	(n = 156)			
Non-Hispanic White	76	48.7	14	51.9
Hispanic, Latino, or Spanish origin	50	32.1	7	25.9
Non-Hispanic Black	17	10.9	5	18.5
Other ^a	13	8.3	1	3.7
Gender	(n = 161)			
Female	139	86.3	26	86.7
Male	22	13.7	4	13.3
Relation to care recipient	(n = 124)			
Spouse or partner	38	30.65	14	46.7
Parent or grandparent	69	55.65	14	46.7
Adult child	3	2.42	0	0
Friend	7	5.65	0	0
Other recipient ^b	7	5.65	2	6.7
Age	(n = 158)			
19–34	15	9.5	0	0
35–49	18	11.4	3	10
50–69	93	58.9	18	60
70–79	28	17.7	7	23.3
80+	4	2.5	2	6.7
Living arrangement	(n = 125)			
Lives with recipient	76	60.8	18	60
Recipient lives alone	8	6.4	3	10
Recipient lives with someone else	29	23.2	1	3.3
Recipient lives in institution	11	8.8	8	26.7
Other arrangement	1	0.8	0	0
State	(n = 154)			
Texas	139	90.3	29	96.7
Other	15	9.7	1	3.3

^aOther races and ethnicities include American Indian, Asian, and Middle Eastern. ^bParents-in-law, siblings, aunts/uncles, and friends.

canceling for them and not being able to get an appointment during the pandemic. Most survey respondents (75%) had used telehealth appointments for their care recipients. Those who had used the virtual or phone alternatives to health care were generally very satisfied with the remote option. 61.9% reported feeling “mostly” or “completely” satisfied with their care recipients’ telehealth appointments, and 33.3% were “a little” to “somewhat” satisfied. Caregivers were asked to identify which type of assistance resources and services, if any, became harder for them to access during the pandemic. Most identified medical care, including physician appointments, as becoming harder to access (36.5%). They also identified other important services that became more challenging for them to access, including respite by family or friends (17.4%), day activity programs for the person living with dementia (17.4%), paid respite (6.1%), skilled residential facilities (4.4%), and other services (14.8%) such as home health care and social engagement activities.

Despite extensive closures during the pandemic, caregivers tended to feel generally satisfied (43.9%) with the

community resources (e.g., support groups and education classes) that they were receiving since COVID-19. Just over half of survey respondents (50.8%) reported that they had utilized some form of tele-education or support via online videoconferencing (45.1%) or over the phone (5.7%) since the pandemic. Those who had utilized virtual resources reported feeling “mostly” or “completely” satisfied with the experience (84%).

The relationship between items related to dementia care services and the impact of COVID-19 on caregiver quality of life is less strong than associations between health-related items. Caregivers who reported, however, that they worry about health care costs more frequently were more likely to report a greater impact of the pandemic on their quality of life (OR = 2.97, 95% CI = [1.05, 9.6]). Caregivers who reported greater feelings of worry about taking their care recipient to health care appointments because of COVID-19 were over 8 times more likely to report that the pandemic had an impact on their quality of life (OR = 8.75, 95% CI = [3.25, 23.78]).

Table 2. Associations Between Impact of COVID-19 on Caregiver Quality of Life and Items Related to Health, Care Services, and Caregiving.

Variable	Somewhat/extreme impact, <i>n</i> = 90 (72%)	No/little impact, <i>n</i> = 35 (28%)	Odds ratio (95% CI)
Caregiver health & wellness, somewhat/extreme (%)			
Physical health (63.2%)	66 (52.8%)	24 (19.2%)	4.65 [1.89, 11.66]
Anxiety (67.74%)	71 (57.26%)	18 (14.53%)	6.68 [2.61, 17.29]
Depression (54.84%)	61 (49.19%)	28 (22.58%)	8.71 [3.17, 26.08]
Sleep (43.55)	51 (41.13%)	39 (31.45%)	13.51 [3.72, 72.67]
Isolation (76%)	80 (64%)	10 (8%)	10.67 [3.8, 30.52]
Spirituality (36.8%)	45 (36%)	45 (36%)	34 [5.12, 1411.68]
Worry about getting COVID (62.6%)	61 (57%)	13 (12.15%)	12.51 [4.30, 37.39]
Worry about care recipient getting covid (81.45%)	80 (64.52%)	10 (8.1%)	4.95 [1.71, 14.39]
Worry about getting ill & unable to care (62.6%)	64 (52.03%)	25 (23.33%)	4.14 [1.67, 10.38]
Ability to take breaks for self-care (49.19%) ^a	43 (34.68%)	47 (37.9%)	0.81 [0.34, 1.93]
Experiences with dementia care services, somewhat/extreme (%)			
Confidence in making care decisions (83.87%)	75 (59.68%)	15 (12.1%)	0.86 [0.22, 2.8]
Delayed or canceled care (64.8% yes)	63 (50.4%)	27 (21.6%)	2.2 [0.91, 5.29]
Worry about taking care recipient to appointments (70.73%)	75 (61%)	15 (12.2%)	8.75 [3.25, 23.78]
Confidence in care services their care recipient is receiving (87.9%)	79 (63.71%)	11 (8.87%)	0.96 [0.21, 3.56]
Satisfaction with the support they receive as caregiver (71.54%)	62 (50.41%)	28 (22.76%)	0.6 [0.2, 1.63]
Feeling the health system is adapting and improving (79.7%)	72 (59.35%)	17 (13.82)	1.3 [0.43, 3.66]
Worry about health care costs (33.06%) ^a	35 (28.23%)	55 (44.35%)	2.97 [1.05, 9.6]
Caregiving during COVID-19, somewhat/extreme (%)			
Ability to provide care to their recipient (55.2%)	58 (46.4%)	32 (25.6%)	3.95 [1.6, 10.07]
How caregiver can provide care since COVID-19 (63.2% more difficult)	65 (52%)	25 (20%)	3.9 [1.59, 9.62]
Hours spent caregiving (44% increased)	40 (32%)	50 (40%)	1.07 [0.45, 2.55]
Ability to adapt to the pandemic (87.8%) ^a	77 (62.6%)	12 (9.8%)	0.62 [0.11, 2.53]
Disruption to daily life (81.6%)	85 (68%)	5 (4%)	18 [5.33, 68.5]
Confidence in the care they provide to their recipient (82.26%)	74 (59.68%)	16 (12.9%)	0.99 [0.29, 3.02]
Confidence in weighing risks about socializing (84.8%)	76 (60.8%)	14 (11.2%)	0.0 [0.23, 3]
Difficulties could not be overcome (44.35%) ^a	48 (38.4%)	42 (33.6%)	4.41 [1.64, 13.11]
Feelings of inability to cope with responsibilities (59%) ^a	53 (42.4%)	37 (29.6%)	6.92 [2.46, 22.13]
Feeling “on top of things” (69.35%) ^a	65 (52.42%)	25 (20.16%)	1.61 [0.64, 3.97]
Worry about financial impact (47.2%) ^a	50 (40%)	40 (32%)	3.61 [1.43, 9.7]
Perceived decline in quality of life of care recipient (66.4%)	69 (55.2%)	21 (16.8%)	4.93 [1.98, 12.38]
Perceived decline in memory of care recipient (69.6%)	66 (52.8%)	24 (19.2%)	1.83 [0.73, 4.48]
Perceived decline in behaviors of care recipient (65.6%)	67 (53.6%)	23 (18.4%)	3.88 [1.58, 9.58]

Note. CI = confidence interval.

^aSome/all of the time (%).

Caregiving during COVID-19. Eighty-four percent of caregivers felt the pandemic had an impact on their ability to provide care. Only around 30% of caregivers felt that the pandemic did not change how they provide care and a small portion of survey respondents (5.6%) felt it was easier to provide care in the pandemic. However, most survey respondents (63.2%) felt that caregiving became “somewhat” or “extremely” more difficult than before the pandemic. When asked whether their hours spent providing care to their care recipient had changed after the pandemic, 44% reported an increase in hours caregiving, 39.2% stayed the same, and 16.8% reported a decrease in hours caregiving. About 50.8% of caregivers

felt they could take breaks from their caregiving role to care for themselves “none of the time” to only “a little of the time.” Most reported that they had perceived a decline in their care recipients’ behaviors since the pandemic, with only 7.2% stating they did not perceive decline at all. However, caregivers generally felt as though they could adapt to the changes and uncertainty caused by the pandemic. In rating how much caregivers felt they could adapt in caring for their recipient, only 12.2% reported “not at all” to “a little.”

When asked how often in general they found they could not cope with their responsibilities during the pandemic, 25.6% of caregivers reported they did not feel that way while

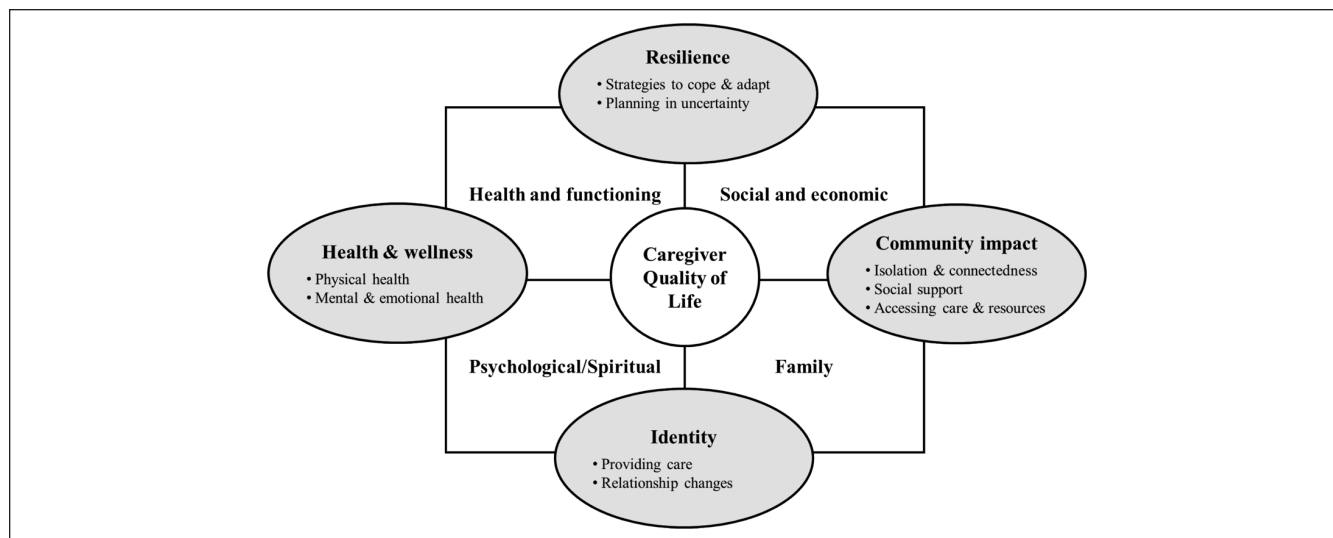


Figure 1. Contextualizing focus group findings within domains of quality of life.

the remainder reported feeling they could not cope “a little of the time” (27.2%), “some of the time” (33.6%), “most of the time” (11.2%), and “all of the time” (2.4%). Caregivers were asked how often they felt that difficulties were piling so high that they could not overcome, with 57.3% reporting this feeling “a little” to “some” of the time and 11.3% reported “most” or “all” of the time. The financial impact of the pandemic did not cause concern for 36% of survey respondents, although 44.8% were worried “a little” or “some” of the time and 19.2% reported feeling worried “most” or “all” of the time. Survey respondents were asked how often they worried about being able to pay for their family member’s health care costs related to the financial impact pandemic, to which 46.8% reported they did not worry at all about this.

Table 2 reflects several strong associations between items related to experiences with caregiving during the pandemic and perceived impact of COVID-19 on caregiver quality of life. Caregivers who felt that the pandemic had disrupted their daily life were 18 times more likely to report that the pandemic had a greater impact on their quality of life (OR = 18.0, 95% CI = [5.33, 68.5]). Caregivers who felt that they were unable to cope with their caregiving responsibilities or that the pandemic affected their ability to provide care to their recipient were more likely to report that the pandemic affected their quality of life (OR = 6.92, 95% CI = [2.46, 22.13]; OR = 3.95, 95% CI = [1.6, 10.07], respectively). In addition, caregivers who reported that they perceived declines in their care recipient’s behaviors were more likely to report an impact on their own quality of life (OR = 3.88, 95% CI = [1.58, 9.58]).

Focus Group Findings

Figure 1 reflects an overview of key qualitative findings grouped by themes and subthemes that were informed by

focus group and survey data. Data from focus groups were analyzed to elucidate nuanced and deeper insights into quantitative findings from the survey. Themes that emerged from focus group data about the experiences of family caregivers of persons living with dementia during the first year of the COVID-19 pandemic were organized into four groups related to caregivers’ quality of life during the pandemic: (a) health and wellness, (b) community impact, (c) identity, and (d) resilience.

Health and wellness. This theme includes the impact of the pandemic on the physical, mental, and emotional health of family caregivers. Caregivers shared that the pandemic created and heightened barriers to care for themselves, causing many of them to experience repercussions to their overall health. Often, respondents attributed the impact on their health to their role caregiving without opportunities or resources for respite. One caregiver stated,

. . . my physical and emotional health is probably definitely declined. And I think without COVID, again, I would have I already had the paid care person come in. . . So that’s probably. . . I know, I’m declining some physically and emotionally right now. (Caregiver 12)

Physical health. Caregivers attributed difficulties specific to their physical health (e.g., weight fluctuations) to a number of challenges, including increasingly limited opportunities for self-care, being unable go outside or to gyms, and the physical consequences of increased stress during the pandemic:

So the big difference for us was not being able to go to the gym. Because that. . . it’s difficult to find a safe place where they can, your loved ones can be active, engaged, and interact with other people. . . (Caregiver 20)

So it was just a lot of stress, a lot of fear, a lot of unknowns. And it definitely took a toll on me. I gained weight. . . (Caregiver 11)

Mental health & emotional health. Caregivers described a number of factors related to the pandemic that may have affected their mental and emotional health such as isolation, increased caregiving responsibilities, and having too much interaction with their care recipient without any respite:

So needless to say, I feel physically mentally exhausted after all of this. And, yes, I am thankful that I was able to take care of my mom, and she lived with me, but there was a lot, a lot of learning with the future care for her. . . I have been feeling downhill myself. (Caregiver 21)

So I definitely had to reel things in and figure out the health care for myself and mental health, and COVID. You know, positive and negative, but it's definitely affected me taking care of myself. (Caregiver 25)

Caregivers of persons living in memory care facilities discussed experiences of added anxiety and stress due to separation from their family member. Many caregivers had been unable to visit with their care recipient living in memory care for several months due to rigid safety guidelines to protect those living and working in the facilities:

. . . the fear of going back [in-person] is the fear, even though we have the COVID shots, you know, the fear of getting COVID or giving your loved one that. So, that's still kind of there. (Caregiver 27)

Community impact. Caregivers reported experiences of social isolation and connectedness, the impact of the pandemic on social support from friends and families, and their experiences accessing care and community resources. In both positive and negative ways, the pandemic affected the ability of caregivers to connect with their families, friends, and community resources. Experiences of social and physical isolation were prevalent for many caregivers, social support systems often changed considerably with safety restrictions around in-person interactions, and the proliferation of entirely virtual adaptations of important care and support services altered the way caregivers navigated care for themselves and their recipients.

Isolation & connectedness. Caregivers reflected that isolation was felt in different ways, such as needing an outlet for emotional sharing, a break from caregiving responsibilities, or something to give structure to their days:

. . . just the isolation of not having the ability to get with the girlfriends. . . and share that incredibly therapeutic time with others. So that just really, has impacted me, to not have that, that connection, that the outlet. . . there is just something about that human contact. . . (Caregiver 4)

Although most caregivers discussed the negative impact of the pandemic, there were some caregivers who saw it as beneficial for them in terms of connectedness, giving them the opportunity to enjoy activities they were not able to pre-pandemic. Many attributed this to their increased ability to connect socially with friends, family, and new people online. Caregivers also expressed that they had more spare time while not having to coordinate outings, in-home care, and commute for their care recipient:

I think one of the things for me socially, it's actually COVID has been better, because I don't, I was, I'm retired also, I retired a year and a half ago. And I write and so I, and I do some volunteer work with these women in prison. And so I used to be away from the house a lot. Well, now I can't be because of COVID. . . (Caregiver 23)

Social support. Caregivers reported changes to social support from friends and family during the pandemic. Safety precautions restricted the ability for different households to interact, limiting the type of tangible, hands-on support, and interaction they could rely on from others. Family and friends who lived out of state were no longer able to travel and those who lived within the same cities were hesitant to risk exposing older caregivers to the virus. For many, this meant taking on the caregiving responsibilities that typically fell to other family members and friends:

We have our son [who] lives with us, thankfully, and only works part-time, because of COVID. But there's, there's no one else. . . (Caregiver 5)

So it was very hard and then I needed a break and no one came because no one wanted to get sick. . . (Caregiver 13)

Accessing care and resources. Health care and community resources (such as education, support groups, and social opportunities) were affected by the pandemic and often shut down completely or adapted to virtual models. Caregivers shared that they had to be selective about the appointments they scheduled to minimize exposure to the virus. Often, caregivers would cancel or delay their own care to prioritize their care recipient's care needs:

Well, it's been very, very difficult because I don't get to do a lot of my appointments. We both have medical issues. And I postpone a lot of mine. So she can go to hers because she doesn't like the Zoom calls. . . So I postponed mine so she can go to hers. (Caregiver 10)

Caregivers shared that the virtual and telephone options were often preferred by them and their care recipient due to convenience and safety. Many shared their relief to be connected to resources without the obligation to leave their home and tackle the coordination and commuting required pre-pandemic:

... Zoom has been a big benefit, because we have taken advantage of Memory Cafes, and I'll put in a plug for the community choir ... you figure it takes 45 minutes to go over and the program's an hour and 15 minutes ... And so the zoom platform has really been a benefit to our community. (Caregiver 20)

We're four hours from the medical center from where we are. So when we would schedule [appointments], they were very good about scheduling virtual ... that's great because I didn't have to drive there. (Caregiver 9)

However, while caregivers expressed appreciation for virtual medical appointments and other forms of nonmedical support, many caregivers also highlighted that it was simply not comparable with in-person models:

And the few virtual telemedicine appointments we had were okay. They're not great. But on the other hand, I appreciated that the doctors were making the effort to do it. (Caregiver 8)

Identity. A prominent theme that emerged from discussions with caregivers involved the impact of the pandemic on their identities in several ways. This theme reflects how the pandemic influenced participants' identities as caregivers in terms of their ability to provide care and how the pandemic influenced changes in their relationships with their care recipients. Several participants shared that the pandemic influenced their confidence and their perceived ability to provide care. Focus group participants also expressed that due to the restrictions of the pandemic and the increased responsibility as caregivers, their opportunities to engage in activities to express themselves outside of the caregiving role were limited.

Providing care. The impact on caregiver identities was attributed by some to an increased need to provide care without respite while adhering to public safety restrictions. Caregivers reported increased time spent caregiving, increased need to engage with and redirect persons living with dementia, and having to navigate challenging behaviors more often since the pandemic. Some caregivers shared that they took on added caregiving hours by deciding not to place their care recipient in memory care out of fear of COVID-19:

I said, there is no way I'm taking my mom to any facility so that I can take a break, then she can get COVID over there. . . Is it worth it, me getting a break at the expense of my mom being somewhere else with strangers? So I guess I was very possessive of her care and with COVID I said forget it. I don't even feel comfortable about it. (Caregiver 21)

Relationship changes. Perceived decline in a care recipient's memory and/or challenging behaviors was often tied to statements related to changes in their identity within the context of their relationship to their recipient. Caregivers often found themselves taking on new role responsibilities

that affected their relationship to the recipient. The increased intensity and added hours of one-on-one caregiving required caregivers to plan engaging activities with limited resources for their recipient:

... I think with my mom, you know, it was just so emotional because I was very close to her. I mean, I still am. . . But it's a different closeness now. It is more of a medical closeness. And it's almost sad because I feel like I lose her like she's not there. (Caregiver 4)

... my mother-in-law is constantly bored and I'm, I'm her daughter-in-law, and I have become the cruise director ... I'm the one that tries to come up with activities or things that we can do. (Caregiver 4)

Resilience. This final theme reflects how caregivers adapted to the ever-changing context of the pandemic such as the strategies they used to cope with and adapt to the effects of COVID-19 and how they felt the pandemic influenced their ability to plan for the future legally and financially. Caregivers exemplified their resilience through their confidence and ability to adapt to the changing dynamics of the pandemic. Caregivers shared many strategies they used to cope with and adapt to challenges related to caregiving during a pandemic:

So we as a human I find we're very resilient, we because we can find a different way to survive and you know in the beginning it is very stressful because we don't fully understand what COVID is and how to attack it but now we get more information and then you could get on websites and look for stuff and you know about different shots, side effects, and what not to do. (Caregiver 7)

Strategies to cope and adapt. Focus group participants provided insight into the strategies they use to cope with the pandemic and manage the difficulties it presented, many of which involved using online support services:

I joined a caregiver group, they just, everybody was very supportive because they understand, I had to find people that understood and said it was okay. So for my mental health, because that was a positive thing that came out of Corona, the pandemic, I was able to reach people who I probably would never have reached if it was not a pandemic. (Caregiver 25)

I keep reminding myself that it is important for me to see my therapist, to attend 12-step meetings on Zoom, to get all the support I can get if I'm going to be of any use to him ... Take breaks when I need them, and I put the support in place for him to be cared for. . . So, you know, it's a, it's critical for me to, to really practice self-care. And otherwise, he'll get the short end of the stick for me and I don't want to do that. (Caregiver 29)

Caregivers shared that some of the emotional and behavioral challenges experienced by the person living with dementia that they cared for were related to difficulties

communicating the need for safety precautions and limitations on their ability to leave the home. For some caregivers, it was a challenge to convey to their care recipient why they needed to wear face masks in public and why their routines had changed due to COVID-19. Some caregivers shared examples of how they adapted their communication approach about the pandemic with the person living with dementia:

I related it to her like polio. . . And she kind of got it. She kind of got it. And you know, it's, I don't know, it's weird, but it made it seem like it made her transition more bearable. (Caregiver 16)

She'd watch [the news] maybe 12–14 hours a day. And she struggled because there was so much news about COVID. . . And she would just get very, very frustrated that she would have to wear a mask. . . So because it was on news all the time, we actually ended up going to country and western music. And she listened to that all the time. And she was much more relaxed. . . (Caregiver 22)

Caregivers also highlighted that their care recipients struggled with unmet needs and opportunities to engage in the activities they enjoyed before the pandemic. Concerned about preserving the identity and dignity of their care recipients, several caregivers shared creative approaches to engage and support persons living with dementia during the pandemic:

And I did have to get the cutest masks that were ever available. Because if it wasn't cute, she wasn't wearing. . . That's the one thing that she had. You know, she wanted to keep up her looks and had to have her lipstick. (Caregiver 16)

Planning in uncertainty. The pandemic influenced the way caregivers planned for their futures related to their caregiving role. Many caregivers shared that the pandemic affected the sense of urgency they felt to address long-term planning, including legal and medical preparations. Caregivers in focus groups shared that they felt a fear of the possibility that something could happen to them, such as contracting COVID-19, leaving their care recipient without a plan for care in place:

Financially, legally, wills, power of attorneys. I got the power of attorney signed for [my spouse] probably at the 11th and a half hour. . . So COVID, if nothing else, brought this to everybody's attention that you need to think about your loved one. But as I said earlier, you also need the plan B, thinking about yourself. For example, if anyone taking care of a loved one, something happens to you, what's going to happen to the person? (Caregiver 1)

Focus groups illustrated that financial worries seemed to be predominantly related to costs for their care recipient, particularly when considering a transition to memory care during the pandemic or bringing in paid caregivers:

I have an aunt in Illinois that is in a nursing home, you know who's isolated. . . Because of that, COVID or not, we will keep him here as long as possible. . . I'm not about to drain that to pay seven or \$8,000 a month or even \$5,000 a month to someone who couldn't care for him as well as I can. (Caregiver 5)

Yeah, I guess for me even before COVID, I was kind of recognizing the importance of all these things and taking some action. . . We did meet with an elder care attorney and updated our, all our legal documents. But then, financially, we're not as well as maybe some people. So at some point, we might have to do the, the Medicaid route. (Caregiver 12)

Although several had financial concerns, many caregivers in this study had minimal worries related to the monetary impact of the pandemic. Some focus group participants shared that they in fact had actually saved money as a result of reduced expenses they would have typically spent on socializing, shopping, and dining out:

One of the things for me, with COVID, I used to go out, I am retired now, and I used to go out to lunch, probably two, three times a week with some friends of mine. So all of a sudden, now I have all this money in my bank account. . . (Caregiver 6)

Discussion

Family caregivers are the backbone of our long-term care systems and never has this been truer than during the global pandemic. The findings reported here highlight the significant contributions of family caregivers to their families and to our health care system during the first year of the pandemic, faced with uncertainty and often limited information in making decisions around care. Findings from this study underscore the relationship between caregiver experiences with dementia care and supportive resources during the pandemic and their perceived impact on quality of life caused by COVID-19. There were business closures, stay-at-home orders, and fear of COVID-19 infection, requiring many family caregivers to provide care for their family members 24/7, with little or no help from home health aides, day support programs, or extended families (Phillips et al., 2020). During this time, most caregivers with loved ones in long-term care facilities were restricted from visiting and assessing the health of their family members firsthand. Although there was cause for hope with the information about the effectiveness of the vaccines, data were collected before vaccines were widely available in the United States. The pandemic affected many aspects of the caregiver's quality of life, including their own physical and emotional well-being, their social interactions, and their identity as a caregiver and their ability to provide care. Both the quantitative and qualitative findings from this study are consistent in demonstrating the associations between caregiver health, ability to provide care for their family member, and the impact on their overall quality of life.

Studies conducted in different countries similarly described the impact of the pandemic on caregiver anxiety and distress (Borges-Machado et al., 2020; Frangiosa et al., 2020; Rainero et al., 2020; Tsapanou et al., 2021). Caregivers from the focus groups and surveys in the current study attributed the increased stress and anxiety to the social isolation, disruption in their daily life and ability to provide care, the added responsibilities while being the sole caregiver without support, and separation and a feeling of lack of control for those caregivers whose recipient of care was living in a facility. Several studies reported an association between the level of dementia severity, length of caregiving, level of support, and perceptions of role overload with emotional distress (Cohen et al., 2020; Hwang et al., 2021; Park, 2020; Savla et al., 2021). Survey data from the current study align with previous research, highlighting the association between caregivers' experiences with anxiety and other mental and emotional challenges with their perceptions of their own quality of life during COVID-19.

Despite the challenges facing caregivers, many caregivers in the current study felt they had been able to adapt to the changes caused by the pandemic and demonstrated resilience in their responses concerning its impact. Some caregivers did not perceive that the pandemic and stay-at-home orders had affected their lives in a major way. Loneliness and social isolation are already an issue that family caregivers face (Vasileiou et al., 2017). In interviews conducted with caregivers about the impact of the stay-at-home phase of the pandemic and its impact by Salva et al. (2021), a caregiver aptly described, "I have been in quarantine for years . . . so we are not having any effects from that" (p. e243). Caregivers have shown resilience in the face of the changing context in which they provide care. Examining resilience among caregivers early in the pandemic, Carbone et al. (2021) conducted telephone surveys with 35 family caregivers of persons living with dementia. They reported an association between resilience and changes in caregiver distress scores related to behavioral and psychological symptoms in persons living with dementia, suggesting greater resilience was associated with less worsening of distress. Semi-structured interviews were conducted with family caregivers in Britain to explore resilience factors in the face of both dementia and COVID-19 challenges (Hanna et al., 2021). Similar to our findings, communication links with health and community resources as well as preexisting social networks were protective for resilience. Caregivers also described the role of exercise and being outdoors as important to their coping and resilience. This is consistent with the findings in our study where caregivers emphasized strategies for self-care, including participation in support groups, exercise, and meditation. Furthermore, taken beyond COVID-19, the results of a systematic review of qualitative and quantitative studies with caregivers of persons with chronic, advanced illness, and at the end of life showed the relationship between social and community support, resilience, and quality of life (Palacio et al., 2020)

Strengths and Limitations

There are several strengths to highlight, including the participatory approach with family caregivers from the SAC that was undertaken to conduct this study, including family caregiver input into the development of the survey and focus group guides, participation in all focus groups, and in the qualitative data analysis and interpretation. The diversity in race/ethnicity with almost 50% of the sample in both the survey and focus groups representing Latino, Black, or "other" caregivers is also a strength and is important to building our understanding of the impact of COVID-19 beyond Caucasian caregivers.

Limitations in the conduct of this study include the electronic data collection for the survey and the virtual conduct of the focus groups, which means that we recruited caregivers who had access to technology. We did try to address this with a family caregiver from the SAC collecting survey data by telephone from a small percentage of caregivers, but the numbers were small. Thus, the findings reported here may not represent those caregivers who were unable to access technology and, in particular, may have felt particularly isolated without access to telehealth and other forms of virtual support. Although the survey instrument was co-developed by the council and a small group of caregivers were invited to provide feedback on the survey prior to wider distribution, no formal tests of reliability or validity were conducted.

Focus group guides were not specifically tailored to follow up on quantitative data from the surveys that may have limited the depth of qualitative findings. However, focus group guides were created in partnership with members of the SAC, including family caregivers who reflected on their experiences during the pandemic to develop the study materials. Although 161 caregivers submitted online surveys with at least demographic data, not all participants responded to every survey item that may introduce some bias in some of the responses. For those who responded to items beyond the demographic questions, almost all surveys were complete. However, less than 20% of overall data were missing, which is within the generally accepted range of missing data for online surveys (Enders, 2003). In addition, our study included only English-speaking caregivers so may not represent the perspectives of those from other cultures, although we did have representation of a diverse population of English-speaking caregivers. Although we included family caregivers of persons who were living in institutions as we felt their perspectives were important, the numbers were not sufficient to examine the impact specifically on this group.

Implications

Our findings demonstrate increased caregiving responsibilities, heightened vigilance, and social isolation following the COVID-19 pandemic, affecting caregiver emotional well-being and overall quality of life. There is a need for research that examines the health of family caregivers and the long-term

effects of the added responsibilities during the pandemic. The ability to leverage technology was seen as an important support for families during the pandemic and research is needed to better understand what virtual programs can be of most benefit to family caregivers. Caregivers spoke about their concerns if they contracted COVID-19 and the need to be prepared with a plan that addressed care of their family member in this event. This has practice implications in helping family caregivers to address not only advance directives for their family member living with dementia but also to develop specific plans for care if they were unable to continue to provide care. The lack of respite for family caregivers, a vital concern before the pandemic, only worsened during the pandemic. This underscores the need for policies that recognize and support family caregivers. Research has established the association between caregiver burden and adverse outcomes for both caregivers and their recipients of care (Chiao et al., 2015). The pandemic further underscores the need for interventions and policies that provide support and decrease burden among family caregivers.

Conclusion

Although there is growing recognition of the significant role of family caregivers in supporting persons living with dementia, the pandemic has brought this even more to our attention. Under ordinary circumstances, caregiving can be a complex and stressful role, often with little support, with an impact on the caregiver's overall quality of life and consequences to the health and safety of care recipients. The results reported here show that it has been even more challenging during the pandemic, potentially increasing risk for detrimental effects on the health of caregivers and persons living with dementia. These findings may have broader implications beyond the current pandemic to situations where family caregivers face similar challenges (e.g., other natural disasters, geographically dispersed families, immunocompromised populations, and financial downturn).

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ORCID iDs

Sara Masoud  <https://orcid.org/0000-0002-9936-1302>

Shanae Rhodes  <https://orcid.org/0000-0001-9800-0241>

Supplemental Material

Supplemental material for this article is available online.

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Author Biographies

Sara Masoud, MPH, is a community outreach coordinator at the School of Nursing and Graduate School of Biomedical Sciences, the University of Texas Health Science Center at San Antonio, Texas, USA. She is involved in community-engaged research focused on family caregivers and persons living with Alzheimer's disease or related dementias. Her work supports families affected by dementia through community engagement and program coordination with the Caring for the Caregiver program at the School of

Nursing. She is also a PhD student in translational science at the UT Health San Antonio Graduate School of Biomedical Sciences. Her recent publications include “Engagement With a Diverse Stakeholder Advisory Council for Research in Dementia Care” in *Research Involvement and Engagement* (2021, with A. A. Glassner et al.), “Engaging Multi-Stakeholder Perspectives to Identify Dementia Care Research Priorities” in *Journal of Patient-Reported Outcomes* (2021, with N. K. Patel et al.), and “‘We Don't Feel So Alone’: A Qualitative Study of Virtual Memory Cafés to Support Social Connectedness Among Individuals Living With Dementia and Care Partners During COVID-19” in *Frontiers in Public Health* (with K. N. Meyer, L. Martin Sweet, P. J. Prado, & C. L. White).

Ashlie A. Glassner, BSN, RN, is a doctoral student in nursing science at Graduate School of Biomedical Sciences, the University of Texas Health Science Center at San Antonio Texas, USA. Her research interests include doing research with persons living with dementia, learning more about their experiences, and understanding how the stigma surrounding dementia can affect their mental health and quality of life. She is passionate about including the voices of persons living with dementia in research by including them as partners in developing and conducting studies. Her recent publications include “Engagement With a Diverse Stakeholder Advisory Council for Research in Dementia Care” in *Research Involvement and Engagement* (2021, with S. S. Masoud et al.), “Engaging Multi-Stakeholder Perspectives to Identify Dementia Care Research Priorities” in *Journal of Patient-Reported Outcomes* (2021, with N. K. Patel et al.), and “Fighting Stigma by Engaging Persons Living With Dementia in Research” in *Issues in Mental Health Nursing* (2021).

Mayra Mendoza is a family caregiver and community researcher at the School of Nursing and Graduate School of Biomedical Sciences, the University of Texas Health Science Center at San Antonio, Texas, USA. She serves as adviser on community engagement advisory councils supporting the development of culturally competent community engagement in research. She is interested in research that centers on community strengths, reciprocity, and a culture of care that cultivates trust among health researchers and communities, particularly the Latino- and Spanish-speaking communities. Her recent publications include “Engagement With a Diverse Stakeholder Advisory Council for Research in Dementia Care” in *Research Involvement and Engagement* (2021, with S. S. Masoud et al.).

Shanae Rhodes, BSN, RN, is a doctoral student at the School of Nursing and Graduate School of Biomedical Sciences, the University of Texas Health Science Center at San Antonio, Texas, USA. Her mission is to serve the underresourced and overlooked. She has a research interest in lessening the gap of health inequities by promoting health awareness, health management, and disease prevention in vulnerable populations. Her recent publications include “Technology-Assisted Self-Monitoring of Lifestyle Behaviors and Health Indicators in Diabetes: Qualitative Study” in *Journal of Medical Internet Research*, *Diabetes* (2020, with Y. Du et al.), and “Physical and Psychological Health of African American Women Caregivers: Unmasking the Paradox” in *Issues in Mental Health Nursing* (2020).

Carole L. White, PhD, RN, FAAN, is a professor and Nancy Smith Hurd chair in Geriatric Nursing and Aging Studies, School of Nursing, Glenn Biggs Institute for Alzheimer's and

Neurodegenerative Diseases, the University of Texas Health Science Center at San Antonio, Texas, USA. Her program of science is focused on optimizing outcomes for persons with chronic neurological conditions and their family caregivers, specifically focused on stroke and dementia. She directed the Caring for the Caregiver Program at the School of Nursing, University of Texas Health Science Center at Antonio, with a mission to support the health and quality of life of families caring for

persons with Alzheimer's disease and other dementias. Her recent publications include "Engaging Multi-Stakeholder Perspectives to Identify Dementia Care Research Priorities" in *Journal of Patient-Reported Outcomes* (2021, with N. K. Patel et al.), and "Transitioning Into the Caregiver Role Following a Diagnosis of Alzheimer's Disease or Related Dementia: A Scoping Review" in *International Journal of Nursing Studies* (2019, with K. Lee, P. Puga, C. E. Z. Pickering, & S. S. Masoud).