

The Use of Health Care and Community-Based Services by People Living With Dementia and Their Caregivers During the COVID-19 Pandemic

Jack F. V. Hunt, MD, PhD; Tamara J. Le Caire, MS, PhD; Molly Schroeder, CSW; Kathleen O'Toole Smith; Katelyn Marschall, MPH; Art Walaszek, MD

ABSTRACT

Introduction: People living with dementia have been particularly affected by the COVID-19 pandemic.

Methods: A survey of dementia care professionals was conducted to assess the use of health care and community-based services by people living with dementia and their caregivers during the first year of the pandemic.

Results: The survey indicated that most services were no longer being used or were being used less during the pandemic, with a few key exceptions.

Discussion: Many barriers and few facilitators were identified to service use for people living with dementia and their caregivers. The results identify potential gaps in the dementia care service network and may inform efforts to improve dementia care during future large-scale public health emergencies in the state of Wisconsin and beyond.

INTRODUCTION

The COVID-19 pandemic has had an outsized effect on people living with dementia and their caregivers. In terms of direct impact, people living with dementia have a greater risk of diagnosis and death from COVID-19 after controlling for age, living arrangements, chronic conditions, and other characteristics.¹ At the same time, dementia care and health care delivery systems have changed substantially as a result of the pandemic,² and people living with dementia and their caregivers have been disproportionately vul-

• • •

Author Affiliations: University of California San Diego, Department of Psychiatry, San Diego, California (Hunt); Wisconsin Alzheimer's Institute, Madison, Wisconsin (Le Caire, Schroeder, O'Toole Smith, Walaszek); Wisconsin Department of Health, Madison, Wisconsin (Marschall); Wisconsin Alzheimer's Disease Research Center and University of Wisconsin School of Medicine and Public Health, Madison, Wisconsin (Walaszek).

Corresponding Author: Art Walaszek, MD, 6001 Research Park Blvd, Madison, WI 53719; phone 608.263.6170; email awalaszek@wisc.edu; ORCID ID 0000-0001-9416-6105

nerable to the negative impact of the pandemic on diagnosis and management of mental and physical health conditions and use of community-based services.^{3,4}

Dementia care professionals, including county dementia care specialists, care managers, and social workers, have a unique vantage point on health care and community-based service use by people living with dementia and may be able to identify needs and opportunities for this population during the COVID-19 pandemic. Wisconsin Department of Health Services contracts with counties to run Aging and Disability Resource Centers (ADRC), which provide older adults with resources and informa-

tion about programs and services. ADRCs employ dementia care specialists to conduct memory screening, to provide information and assistance to adults with cognitive concerns, and to help develop dementia-friendly communities (<https://www.dhs.wisconsin.gov/adrc/dementia-care-specialist-program.htm>).

Early studies during the pandemic based on physician and clinical psychologist expert opinion identified a number of barriers to health care access for people with dementia during COVID-19, including discontinuation of home care services, increased caregiver burden, suspension of nonurgent care in many areas, financial hardship, and disrupted medication supply systems.^{3,4} Studies based on administrative database review have assessed the impact of the COVID-19 pandemic on specific service areas, such as home care⁵ and mental and community physical health services.⁶ However, to our knowledge, an assessment of a broad range of dementia care services during the pandemic—including related barriers and facilitators—from the perspective of dementia care professionals has not been undertaken. Dementia care professionals work directly with people with dementia and families to

facilitate service utilization and, thus, have a unique and valuable perspective that has not been adequately represented in previous literature. This project seeks to address this gap in the literature, with a particular focus on the state of Wisconsin.

METHODS

A survey was created to assess the impact of the COVID-19 pandemic on 2 related areas: (1) changes in use of health care and community-based services by people living with dementia and their caregivers and (2) factors affecting use of these services—from the perspective of dementia care professionals—to inform on quality improvement opportunities across the state. Changes in the use of 14 services were assessed using the response stem: “Please indicate how the use of the following health care or community-based services has changed for your clients with dementia and their caregiver(s) during the COVID-19 pandemic.” Respondents chose from an ordinal scale with the following response options: (1) “Clients with dementia and caregiver(s) are no longer using this service;” (2) “Clients with dementia and caregiver(s) are using this service less than usual;” (3) “Clients with dementia and caregiver(s) are using this service the same as usual;” and (4) “Clients with dementia and caregiver(s) are using this service more than usual.” Fifteen factors affecting service use were assessed using the response stem: “How have the following factors changed the use of dementia care professional services, health care, and community-based supportive services for clients with dementia or their caregivers during the COVID-19 pandemic?” Respondents chose from an ordinal scale with the following response options: (1) “This has been a barrier to service use;” (2) “This has not affected service use;” and (3) “This has facilitated service use.” “I don’t know” was included as a response option for both survey topics to encourage respondents to provide information only about items for which they had professional or personal knowledge.

Survey questions were developed based on input from an interdisciplinary team with direct experience working with people living with dementia, including dementia care professionals, clinical social workers, physicians, and mental health providers. The survey was piloted with a small group of dementia care professionals working within the Wisconsin Department of Health Services and was edited for relevancy of content and question clarity before being administered on a larger scale.

The survey was administered online via 2 networks of dementia care stakeholders: the Wisconsin Dementia Resource Network (WDRN) and a dementia care network supported by the Wisconsin Department of Health Services (DHS) comprising county dementia care specialists, tribal dementia care specialists, and dementia care leads throughout the state. These networks are made up of clinical and community-based service providers, as well as caregivers for people living with dementia. The survey was administered between August 28, 2020, and October 9,

Table 1. Demographic Characteristics of Survey Respondents

Characteristic	N (%)
Sex	
Female	94 (92.2)
Male	5 (4.9)
Prefer not to answer	3 (2.9)
Race	
White	88 (88.0)
American Indian or Alaska	2 (2.0)
Asian American	1 (1.0)
Black or African American	2 (2.0)
Hispanic or Latino	2 (2.0)
Prefer not to answer	5 (5.0)
Profession	
Dementia care specialist	34 (34.0)
Dementia lead	13 (13.0)
Dementia lead supervisor	12 (12.0)
Social worker	6 (6.0)
Administrator	5 (5.0)
Manager	5 (5.0)
Outreach specialist	5 (5.0)
Service specialist	5 (5.0)
Care coordinator	4 (4.0)
Other	11 (11.0)
Work Setting	
Aging and Disability Resource Center	54 (53.5)
Nonprofit community organization	20 (19.8)
Managed care organization	4 (4.0)
State or County Health Department	4 (4.0)
Long-term care	3 (3.0)
Memory clinic	3 (3.0)
Health and Human Services	2 (2.0)
Health care organization	2 (2.0)
Tribal Health Services	2 (2.0)
Other	7 (7.0)
Work location	
Rural	61 (60.4)
Rural and suburban	2 (2.0)
Rural, suburban, and urban	4 (4.0)
Suburban	12 (11.9)
Suburban and urban	2 (2.0)
Urban	20 (19.8)

2020. The project was conducted for quality improvement and therefore did not require Institutional Review Board (IRB) review, according to the University of Wisconsin Health Sciences IRB and federal regulations. Data were collected and managed using REDCap electronic data capture tools hosted by the University of Wisconsin–Madison^{7,8} and analyzed using the R language and environment for statistical computing,⁹ Version 4.1.0. All reported frequencies for survey items were calculated based on the number of respondents for that survey item, not including those reporting “I don’t know.”

RESULTS

The survey was sent to 331 dementia care professionals from the

Table 2. Changes in Health Care and Community-Based Service Use by People Living With Dementia and Caregivers During the COVID-19 Pandemic

Program	No Longer Using This service				Using This Service Less Than Usual				Using This Service the Same as Usual				Using This Service More			
	N (%)				N (%)				N (%)				N (%)			
	Total	Rural	Sub	Urban	Total	Rural	Sub	Urban	Total	Rural	Sub	Urban	Total	Rural	Sub	Urban
Senior center programs	52 (60.5)	29 (59.2)	8 (72.7)	10 (55.6)	32 (37.2)	18 (36.7)	3 (27.3)	8 (44.4)	2 (2.3)	2 (4.1)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Adult day programs	34 (40.5)	17 (37.0)	6 (54.5)	8 (42.1)	41 (48.8)	22 (47.8)	4 (36.4)	11 (57.9)	8 (9.5)	7 (15.2)	1 (9.1)	0 (0)	1 (1.2)	0 (0)	0 (0)	0 (0)
Companion/friendly visitor services	31 (38.8)	14 (29.8)	6 (66.7)	9 (52.9)	40 (50.0)	28 (59.6)	2 (22.2)	7 (41.2)	7 (8.8)	4 (8.5)	1 (11.1)	1 (5.9)	2 (2.5)	1 (2.1)	0 (0)	0 (0)
Caregiver education classes	11 (14.3)	7 (14.6)	1 (14.3)	2 (12.5)	51 (66.2)	32 (66.7)	5 (71.4)	11 (68.8)	9 (11.7)	5 (10.4)	1 (14.3)	2 (12.5)	6 (7.8)	4 (8.3)	0 (0)	1 (6.3)
Caregiver support/respite services	8 (10.1)	5 (10.4)	0 (0)	2 (12.5)	59 (74.7)	34 (70.8)	6 (75.0)	13 (81.3)	6 (7.6)	5 (10.4)	0 (0)	1 (6.3)	6 (7.6)	4 (8.3)	2 (25.0)	0 (0)
Caregiver counseling services	6 (8.8)	2 (4.7)	1 (16.7)	2 (14.3)	54 (79.4)	34 (79.1)	5 (83.3)	11 (78.6)	5 (7.4)	4 (9.3)	0 (0)	1 (7.1)	3 (4.4)	3 (7.0)	0 (0)	0 (0)
Transportation services	6 (7.6)	2 (4.2)	1 (11.1)	3 (17.6)	52 (65.8)	32 (66.7)	7 (77.8)	9 (52.9)	18 (22.8)	12 (25.0)	1 (11.1)	4 (23.5)	3 (3.8)	2 (4.2)	0 (0)	1 (5.9)
Homecare services	4 (4.9)	1 (2.0)	1 (12.5)	2 (11.1)	58 (70.7)	35 (70.0)	4 (50.0)	14 (77.8)	15 (18.3)	11 (22.0)	1 (12.5)	2 (11.1)	5 (6.1)	3 (6.0)	2 (25.0)	0 (0)
Physical therapy visits	4 (5.9)	2 (4.9)	0 (0)	1 (6.7)	53 (77.9)	30 (73.2)	8 (100)	12 (80.0)	11 (16.2)	9 (22.0)	0 (0)	2 (13.3)	0 (0)	0 (0)	0 (0)	0 (0)
Assistance with medication	2 (3.1)	0 (0)	0 (0)	1 (9.1)	28 (43.8)	20 (47.6)	1 (16.7)	6 (54.5)	29 (45.3)	20 (47.6)	4 (66.7)	4 (36.4)	5 (7.8)	2 (4.8)	1 (16.7)	0 (0)
Counseling/behavioral health visits	1 (1.4)	0 (0)	0 (0)	0 (0)	61 (87.1)	35 (83.3)	8 (88.9)	14 (100)	5 (7.1)	4 (9.5)	1 (11.1)	0 (0)	3 (4.3)	3 (7.1)	0 (0)	0 (0)
Primary care visits	1 (1.3)	0 (0)	0 (0)	0 (0)	71 (88.8)	40 (87.0)	9 (100)	16 (88.9)	7 (8.8)	5 (10.9)	0 (0)	2 (11.1)	1 (1.3)	1 (2.2)	0 (0)	0 (0)
Medical specialist visits	0 (0)	0 (0)	0 (0)	0 (0)	66 (88.0)	38 (84.4)	8 (88.9)	15 (93.8)	8 (10.7)	6 (13.3)	1 (11.1)	1 (6.3)	1 (1.3)	1 (2.2)	0 (0)	0 (0)
Meal delivery services	0 (0)	0 (0)	0 (0)	0 (0)	15 (18.3)	12 (23.5)	1 (12.5)	2 (12.5)	30 (36.6)	13 (25.5)	4 (50.0)	11 (68.8)	37 (45.1)	26 (51.0)	3 (37.5)	3 (18.8)

Abbreviation: Sub, suburban.

Total (%) are row percents. Work setting percents are row percents for all with data in that setting. Respondents working in more than one setting were excluded from the setting counts; therefore, totals may not equal the sum of rural, suburban, and urban counts.

WDRN and DHS networks and was completed by 102 individuals (response rate 31%). The respondents predominantly identified as female (92.2%), White (88.0%), served rural settings (66%), half worked at ADRCs (53.5%); and 34.0% were employed as dementia care specialists, reflecting all or nearly all dementia care specialists in Wisconsin. See Table 1 for the full demographic characteristics of the survey sample.

Nearly all services queried, with a few notable exceptions, were reported by a majority of respondents as not being used or being used less than usual during the COVID-19 pandemic. Senior center programs were reported as the most negatively affected, with a majority of respondents reporting people living with dementia and caregivers were no longer using these services (60.5%). A large proportion of respondents also reported that people living with dementia and caregivers were no longer using adult day programs (40.5%) and companion/friendly visitor services (38.8%). A majority of respondents reported only 2 services—medication

assistance (53.1%) and meal delivery (81.7%)—as being used the same or more than usual by most respondents. Response data for the changes in health care and community-based service use during the pandemic are summarized in Table 2 in aggregate and stratified by area of service provision.

Several factors were identified by a majority of respondents as barriers to health care and community-based services for people living with dementia and caregivers during the pandemic. Some of the most frequently reported barriers included changes in access to other natural supports in their network (eg, friends, other family members, neighbors, religious organization members) (80.7%), changes in caregiver support/respite services (78.0%), knowledge of technology/virtual tools (72.9%), compassion fatigue/caregiver burnout (71.8%), and access to technology/virtual tools (67.8%). Factors that most respondents reported had not affected service use included changes to language services (91.2%), changes to insurance status (84.5%), changes to employment status (63.2%),

Table 3. Factors Affecting Health Care and Community-Based Service Use by People Living With Dementia and Their Caregivers During the COVID-19 Pandemic

Factors	This Has Been a Barrier to Service Use				This Has Not Affected Service Use				This Has Facilitated Service Use			
	N (%)				N (%)				N (%)			
	Total	Rural	Suburban	Urban	Total	Rural	Suburban	Urban	Total	Rural	Suburban	Urban
Changes in access to other natural supports	67 (80.7)	38 (80.9)	10 (90.9)	14 (77.8)	10 (12.0)	6 (12.8)	1 (9.1)	2 (11.1)	6 (7.2)	3 (6.4)	0 (0)	2 (11.1)
Changes in caregiver support/respite services	64 (78.0)	38 (79.2)	8 (88.9)	13 (72.2)	13 (15.9)	7 (14.6)	1 (11.1)	3 (16.7)	5 (6.1)	3 (6.3)	0 (0)	2 (11.1)
Knowledge of technology/virtual tools	62 (72.9)	37 (75.5)	10 (83.3)	11 (61.1)	11 (12.9)	6 (12.2)	1 (8.3)	3 (16.7)	12 (14.1)	6 (12.2)	1 (8.3)	4 (22.2)
Access to technology/virtual tools	59 (67.8)	33 (67.3)	10 (83.3)	12 (63.2)	12 (13.8)	7 (14.3)	1 (8.3)	3 (15.8)	16 (18.4)	9 (18.4)	1 (8.3)	4 (21.1)
Compassion fatigue/caregiver burnout	56 (71.8)	31 (70.5)	6 (66.7)	14 (77.8)	11 (14.1)	7 (15.9)	2 (22.2)	1 (5.6)	11 (14.1)	6 (13.6)	1 (11.1)	3 (16.7)
Changes in familial obligations	51 (66.2)	32 (69.6)	6 (66.7)	8 (53.3)	18 (23.4)	10 (21.7)	2 (22.2)	4 (26.7)	8 (10.4)	4 (8.7)	1 (11.1)	3 (20.0)
Changes in appointment availability	49 (65.3)	32 (72.7)	5 (55.6)	9 (60.0)	20 (26.7)	11 (25.0)	3 (33.3)	3 (20.0)	6 (8.0)	1 (2.3)	1 (11.1)	3 (20.0)
Changes in access to primary caregiver	44 (57.1)	28 (62.2)	6 (60.0)	5 (31.3)	27 (35.1)	15 (33.3)	3 (30.0)	8 (50.0)	6 (7.8)	2 (4.4)	1 (10.0)	3 (18.8)
Changes to mental health	44 (58.7)	25 (58.1)	5 (55.6)	9 (56.3)	22 (29.3)	13 (30.2)	3 (33.3)	4 (25.0)	9 (12.0)	5 (11.6)	1 (11.1)	3 (18.8)
Changes in transportation	39 (51.3)	24 (52.2)	7 (77.8)	7 (43.8)	36 (47.4)	21 (45.7)	2 (22.2)	9 (56.3)	1 (1.3)	1 (2.2)	0 (0)	0 (0)
Changes to physical health	36 (48.6)	19 (44.2)	5 (62.5)	8 (50.0)	34 (45.9)	22 (51.2)	3 (37.5)	6 (37.5)	4 (5.4)	2 (4.7)	0 (0)	2 (12.5)
Changes to financial resources	29 (40.8)	16 (31.4)	6 (50.0)	6 (31.6)	40 (56.3)	25 (49.0)	4 (33.3)	7 (36.8)	2 (2.8)	1 (2.0)	0 (0)	1 (5.3)
Changes to employment status	23 (33.8)	11 (26.8)	3 (50.0)	7 (43.8)	43 (63.2)	29 (70.7)	3 (50.0)	8 (50.0)	2 (2.9)	1 (2.4)	0 (0)	1 (6.3)
Changes to insurance status	9 (15.5)	4 (11.1)	1 (14.3)	3 (30.0)	49 (84.5)	32 (88.9)	6 (85.7)	7 (70.0)	0 (0)	0 (0)	0 (0)	0 (0)
Changes to language services	5 (8.8)	3 (9.1)	0 (0)	2 (15.4)	52 (91.2)	30 (90.9)	6 (100)	11 (84.6)	0 (0)	0 (0)	0 (0)	0 (0)

Total (%) are row percents. Work setting percents are row percents for all with data in that setting. Respondents working in more than one setting were excluded from the setting counts; therefore, totals may not equal the sum of rural, suburban, and urban counts.

and changes to financial resources (56.3%). Interestingly, although they were reported as barriers by a majority of respondents, the most commonly reported facilitators to service use were access to technology/virtual tools (18.4%) and knowledge of technology/virtual tools (14.1%). Response data for perceived barriers and facilitators to services are summarized in Table 3 in aggregate and stratified by area of service provision.

DISCUSSION

In this quality improvement project, dementia care stakeholders were surveyed to gain insight into how the COVID-19 pandemic affected service use for people living with dementia and their caregivers. The findings suggest that almost all health care and community-based dementia services have seen a decrease in use during the pandemic. One possible explanation of this finding is that the dementia care infrastructure in Wisconsin initially was not

equipped to meet the new challenges presented by the COVID-19 pandemic, resulting in a decrease in availability of desired services. Supporting this point, the 2 services that were reported by a majority of respondents as being used the same or more during the pandemic were medication assistance and meal delivery, which already had existing infrastructure in place for at-home and contact-free access. Another explanation for the decrease in service use may have been concerns about exposure to COVID-19 in public or health care settings and subsequent self-imposed limitations on treatment utilization. Changes to social support networks and the more prominent role of technology during the pandemic were the most commonly identified barriers to service use. Although telemedicine has been proposed as a solution to dementia care delivery during the pandemic,¹⁰ our results suggest that it can also be a barrier to service use.

There are several considerations in interpreting the findings

of this project. The survey was administered prior to approval by the US Food and Drug Administration of any of the COVID-19 vaccines. Since then, access to vaccination and adaptation of service providers has likely improved access to health care and community-based service. Furthermore, two-thirds of respondents worked in rural areas, while according to the 2010 US Census, only approximately one-third of Wisconsin's population live in rural areas.¹¹ Although we present stratified survey results for the reader's interest in Tables 2 and 3, the sample did not contain enough respondents working in suburban or urban settings to make rigorous comparisons between the groups. Based on the rough differences in survey responses, our preliminary results raise the possibility that rurality/urbanicity may have had a differential impact on availability of services and types of barriers/facilitators during the early pandemic. This topic would be worth exploring further in order to more specifically address the needs of unique geographic populations. The geographic scope of the study within the state of Wisconsin and rural-predominant survey respondents warrant caution when generalizing the study findings to other geographic settings. Findings in other geographic regions or in more urban settings may demonstrate a distinct pattern of changes to dementia care services than observed in this project. Finally, a number of sources of potential response bias exist in this study, including missing responses from dementia care professionals working outside of the survey distribution networks, the length of the survey and/or lack of incentive reducing the likelihood of survey completion by certain individuals, and respondents skewing towards extreme responses. This evaluation provides insight into dementia-related service areas in Wisconsin that are particularly vulnerable to large-scale public health calamities. The results will hopefully inform public health efforts to improve dementia care provision during future pandemics.

Funding/Support: None declared.

Financial Disclosures: None declared.

REFERENCES

1. Lamont H, Samson LW, Zuckerman R, Dey J, Oliveira I, Tarazi W. The Impact of COVID-19 on Medicare Beneficiaries with Dementia (Issue Brief). Office of the Assistant Secretary for Planning and Evaluation, US Department of Health and Human Services; 2021. Accessed July 22, 2022. <https://aspe.hhs.gov/reports/impact-covid-19-medicare-beneficiaries-dementia-issue-brief>
2. Wang H, Li T, Barbarino P, et al. Dementia care during COVID-19. *Lancet*. 2020;395(10231):1190-1191. doi:10.1016/S0140-6736(20)30755-8
3. Brown EE, Kumar S, Rajji TK, Pollock BG, Mulsant BH. Anticipating and mitigating the impact of the COVID-19 pandemic on Alzheimer's disease and related dementias. *Am J Geriatr Psychiatry*. 2020;28(7):712-721. doi:10.1016/j.jagp.2020.04.010
4. Greenberg NE, Wallick A, Brown LM. Impact of COVID-19 pandemic restrictions on community-dwelling caregivers and persons with dementia. *Psychol Trauma*. 2020;12(S1):S220-S221. doi:10.1037/tra0000793
5. Jones A, MacLagan LC, Schumacher C, et al. Impact of the COVID-19 pandemic on home care services among community-dwelling adults with dementia. *J Am Med Dir Assoc*. 2021;22(11):2258-2262.e1. doi:10.1016/j.jamda.2021.08.031
6. Chen S, Jones PB, Underwood BR, et al. The early impact of COVID-19 on mental health and community physical health services and their patients' mortality in Cambridgeshire and Peterborough, UK. *J Psychiatr Res*. 2020;131:244-254. doi:10.1016/j.jpsychires.2020.09.020
7. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform*. 2009;42(2):377-381. doi:10.1016/j.jbi.2008.08.010
8. Harris PA, Taylor R, Minor BL, et al. The REDCap consortium: building an international community of software platform partners. *J Biomed Inform*. 2019;95:103208. doi:10.1016/j.jbi.2019.103208
9. R Core Team. R: A Language and Environment for Statistical Computing. R Foundation for Statistical Computing; 2018. Accessed July 22, 2022. <https://www.R-project.org/>
10. Cuffaro L, Di Lorenzo F, Bonavita S, Tedeschi G, Leocani L, Lavorgna L. Dementia care and COVID-19 pandemic: a necessary digital revolution. *Neurol Sci*. 2020;41(8):1977-1979. doi:10.1007/s10072-020-04512-4
11. US Department of Commerce. *Wisconsin: 2010; Population and Housing Unit Counts*. Economics and Statistics Administration, US Census Bureau; 2012. Accessed July 22, 2022. <https://www2.census.gov/library/publications/decennial/2010/cph-2/cph-2-51.pdf>

advancing the art & science of medicine in the midwest

WMJ

WMJ (ISSN 1098-1861) is published through a collaboration between The Medical College of Wisconsin and The University of Wisconsin School of Medicine and Public Health. The mission of *WMJ* is to provide an opportunity to publish original research, case reports, review articles, and essays about current medical and public health issues.

© 2022 Board of Regents of the University of Wisconsin System and The Medical College of Wisconsin, Inc.

Visit www.wmjonline.org to learn more.