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Effects of the COVID-19 pandemic on healthcare and community-based service use for people living with dementia: Perspectives from dementia care professionals

Jack FV Hunt[1] | Molly Schroeder[2] | Tamara LeCaire[2] | Kathleen O'Toole Smith[3] | Katelyn Marschall[4] | Art Walaszek[2,5]

[1] Medical Scientist Training Program, University of Wisconsin School of Medicine and Public Health, Madison, WI, USA

[2] Wisconsin Alzheimer's Institute, Madison, WI, USA

[3] Wisconsin Alzheimer's Institute, University of Wisconsin School of Medicine and Public Health, Madison, WI, USA

[4] Wisconsin Department of Health Services, Madison, WI, USA

[5] Wisconsin Alzheimer's Disease Research Center, University of Wisconsin School of Medicine and Public Health, Madison, WI, USA

Correspondence
Jack FV Hunt, Medical Scientist Training Program, University of Wisconsin School of Medicine and Public Health, Madison, WI, USA
Email: jfhunt2@wisc.edu

Abstract

Background: Dementia care and healthcare delivery systems have changed substantially as a result of the COVID-19 pandemic (Wang et al., 2020). Experts have identified a number of barriers to health care access for people living with dementia (PLWD) during the pandemic, including difficulty implementing telemedicine practices, discontinuation of home care services, increased caregiver burden and financial hardship (Brown et al., 2020; Greenberg et al., 2020). Assessment of dementia care providers' perceptions of the change in use of healthcare and community-based services by PLWD is needed to identify gaps and to improve care for this vulnerable population during the COVID-19 pandemic.

Methods: We designed an online survey asking about changes to PLWD and caregiver use of 14 healthcare and community-based services during the COVID-19 pandemic and about 15 factors that may have contributed to these changes. The survey was distributed to a network of dementia care professionals across the state of Wisconsin between August 28th and October 9th, 2020.

Result: A total of 102 individuals completed the survey. Most respondents worked in the Wisconsin Department of Health Services dementia care specialist system, were employed by Aging and Disability Resource Centers (53.5%), identified as female, White race and worked in rural settings. Services most frequently reported as no longer in use included senior center programs, adult day programs, and companion/friendly visitor services, while meal delivery was reported as having increased use by PLWD. Factors identified most frequently as barriers to service use included changes in access to caregiver support/respite services, access to natural supports, compassion fatigue/caregiver burnout and both knowledge of and access to technology/virtual tools.

Conclusion: The results highlight the increased demand for certain services like meal delivery and the need to find alternatives to in-person enrichment/recreational and caregiver respite opportunities such as senior center and adult day programs that are being used less. Access to and knowledge of technology and increased stress on caregivers and support systems were identified as some of the more frequent barriers to service use, thus allocating resources towards these areas may be particularly impactful towards improving service use for PLWD during the COVID-19 pandemic.

TABLE 1

Table 1. Survey participant demographics (N = 102)	
Demographic	**%**
Gender	
Female	92.2
Male	4.9
Prefer not to answer	2.9
Race/Ethnicity	
White	88
Other	7
Prefer not to answer	5
Work setting	
Includes rural setting	66.4
Includes suburban setting	19.9
Includes urban setting	25.8
Profession	
Dementia Care Specialist	34
Dementia Lead	13
Dementia Lead Supervisor	12
Social Worker	6
Administrator	5
Manager	5
Outreach Specialist	5
Service Specialist	5
Other	15
Employer	
Aging and Disability Resource Center	53.5
Non-profit Community Organization	19.8
Other	27
Note: Respondent categories with <5 responses were regrouped into "Other"	

TABLE 2

Table 2. Changes in healthcare and community-based service use by people living with dementia and their caregivers during the COVID19 pandemic					
	Number of participant responses				
Service use	Clients are no longer using service	Clients are using service less	Clients are using service the same	Clients are using service more	I don't know
Senior center programs	52	32	2	0	6
Adult day programs	34	41	8	1	7
Companion/friendly visitor services	31	40	7	2	11
Caregiver education classes	11	51	9	6	15
Caregiver support/respite services	8	59	6	6	13
Caregiver counseling services	6	54	5	3	23
Primary care visits	1	71	7	1	12
Medical specialist visits	0	66	8	1	16
Counseling/behavioral health visits	1	61	5	3	22
Transportation services	6	52	18	3	11
Homecare services	4	58	15	5	10
Physical therapy visits	4	53	11	0	24
Assistance with medication	2	28	29	5	27
Meal delivery services	0	15	30	37	10
Factor affecting service use	Barrier to service use	Hasn't affected service use	Facilitated service use	I don't know	
Changes in access to other natural supports	67	10	6	5	
Changes in caregiver support/respite service	64	13	5	7	
Knowledge of technology/virtual tools	62	11	12	3	
Access to technology/virtual tools	59	12	16	2	
Compassion fatigue/caregiver burnout	56	11	11	10	
Changes in familial obligations	51	18	8	12	
Changes in appointment availability	49	20	6	14	
Changes in access to primary caregiver	44	27	6	12	
Changes to mental health	44	22	9	14	
Changes in transportation	39	36	1	13	
Changes to physical health	36	34	4	14	
Changes to financial resources	29	40	2	18	
Changes to employment status	23	43	2	21	
Changes to insurance status	9	49	0	31	
Changes to language services	5	52	0	32	
Note: Color shading indicates relative number of responses (red = more responses, blue = fewer responses)					