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Implications of the COVID-19 Pandemic on Adult Day Services and the Families They Serve

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Abstract

The COVID-19 pandemic forced adult day services (ADS) to close and abruptly end in-person services to clients. To understand the effect of the pandemic on ADS, a 20-item survey was used to examine services provided, staffing, finances, and plans to reopen. Data came from 22 sites participating in the Adult Day Service Plus a national randomized controlled trial. Of the 22 ADS sites responding to the survey, most (86.4%, n = 19) closed due to COVID-19 with nearly half closing due to a state mandate (52.6%, n = 10). Most sites reported the need to furlough or terminate staff (63.6%, n = 14). Services that sites continued to provide included telephone support (n = 22, 100%), delivery of food (n = 8, 36.4%), medical check-ins (n = 9, 40.1%), and activity via Zoom or YouTube (n = 14, 63.6%). Most of these services were provided without reimbursement. Adult day services have considerable potential as a platform for service innovation in community-based services.

Keywords

COVID-19; Alzheimer's disease and related dementias; home- and community-based services; supports; interventions

Due to the COVID-19 pandemic, many home- and community-based services (HCBS) for people living with dementia (PLWD) and their family caregivers were forced to suspend

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services in a short timeframe.¹ Subsequently, PLWD and their caregivers had to abruptly and over time grapple with limited services to support care needs. ADS are one such HCBS program that support PLWD and families who seek to age-in-place. Adult day services provide socialization, access to many therapies for PLWD such as assistance with vital sign monitoring, nutrition services, medication administration, and engagement in meaningful activities.² The services provided vary widely by program but are typically offered upwards of 8 h a day during weekdays and for some, on weekends.³ As such, ADS provide respite to family caregivers enabling them to work, run errands, attend their own doctor's appointments, and/or recharge.⁴ Utilization of ADS has been shown to reduce caregiver burden and support their wellbeing.⁵

Adult day services are a vital HCBS resource that provides services to vulnerable PLWD and their caregivers who have characteristics that are overwhelmingly associated with deleterious effects of COVID-19.⁶ Nationally, there are over 5000 ADS sites serving 286,300 older adults throughout the United States.⁷ Nearly half of these centers serve racial/ethnic communities.⁸ Clients who utilize ADS tend to have a high prevalence of chronic health conditions that have been associated with risk for severe illness from COVID-19 such as hypertension, diabetes, or dementia.^{6,9,10} Due to their multiple comorbidities, many clients who attend ADS would be eligible for nursing home level care,¹¹ yet due to their preferences to age-in-place remain in the community and utilize ADS.

In March 2020, ADS sites across the nation were forced to close rapidly either by choice or due to state mandates, and thus, in-person services to clients abruptly ended. The closure of ADS left clients particularly vulnerable (as they were already at-risk) and their families were left without access to critical services to manage day-to-day care such as meal preparation, health monitoring, and socialization.¹² In response, many ADS continued to provide telephonic/remote services to clients,¹³ despite limited reimbursement from federal and state-level sources for these services. The cost of ADS care is covered by a combination of public and private funding, grants, and donations; Medicaid is the major public payer source for ADS clients.³ Due to the limited reimbursement and forced closures, many sites were left without a revenue source to pay employees and maintain building costs. Almost a year later, many sites have still not reopened and sites that have reopened have done so with a lower client census, increased costs, loss of staff, and the lingering fear of a second closure.

With COVID-19, much attention has been given to the care of older adults in residential care facilities due to the very high rate of infection in these facilities. However, the plight of ADS and the people they serve has been mostly ignored. Using data from ADS sites participating in a national multi-site trial, the ADS Plus Program,¹² the purpose of this study is to examine the effects of COVID-19 on ADS and the programming offered during the closure. As ADS is a vital HCBS resource for many families that supports aging in place, it is important to understand the impact of COVID-19 on the provision of ADS and the potential policy implications to prepare for the future.

Methods and Sample

This is a cross-sectional study of ADS sites across the United States and their experience during the COVID-19 pandemic. The participating sites are part of the Adult Day Service Plus (ADS Plus) multi-site study which is a randomized controlled trial testing the provision of caregiver support onsite at ADS (ADS Plus). ADS Plus is an intervention provided by ADS staff to family caregivers utilizing ADS. Through face-to-face meetings on site, staff provide tailored disease education, referral and linkages, support, and strategies to manage daily care challenges to families utilizing ADS. A full protocol of the parent study is published elsewhere.¹⁴ The ADS Plus study was reviewed and approved by the Johns Hopkins Medical Institution IRB (ADS Plus Clinical Trial #NCT-2927821).

Although the closures of ADS starting in March 2020 impacted the ability of the parent study (ADS Plus) to continue with in-person recruitment and other in-person research activities, the research team continued to remain in close contact with study sites during the closure. We developed a 20-item survey for sites to complete concerning the services they were able to continue to provide, staffing, finances, and plans to reopen. Items had been developed based upon the study team's engagement with the sites through emails, online forums, and telephone calls and identification of what matters the most to sites and the families they serve. Although there are 57 ADS sites participating in the trial, the survey was only sent to the intervention sites (n = 30) vs control group sites. As part of the research study, the forced closure of ADS programs only impacted the delivery of ADS Plus in the intervention sites. As such, we did not do any additional contact with the control sites. Data collection was completed between September and October 2020, using an electronic survey *via* REDCap. As of the end of October 2020, 22 (73%) sites had completed the survey in part or whole. Each site was provided with a unique link to the REDCap survey and instructions to complete the survey. Sites were sent reminder emails with the link every 3 days for 2 weeks or until the site completed the survey. The data collection process was approved by the Johns Hopkins Medical Initiations' Institutional Review Board.

Measures

Site Characteristics

Descriptors of each ADS site were obtained at the time the site agreed to participate in the parent study. These included the number of years operating, ownership structure (public/government/not-for-profit, private/not-for-profit, and private/for-profit), location of site (urban, rural, and suburban), maximum number of clients, percentage of non-Hispanic White clients, and percentage of clients with dementia diagnosis.

COVID-19 Measures

Questions about closure included date the site closed, whether closure was mandated by county/state or voluntary, and the factors that influenced re-opening. Staffing questions included whether staff had been infected, employment status of staff, ability to work remotely, and staff's willingness to return when the site reopens. Questions about clients included whether clients had been infected, types of support the site provided to clients

(eg, telephone, meal delivery, activity materials, and wellness check in calls), and whether services are being reimbursed. Other questions included financial such as knowledge of the CARES Act, or other funding sources, and emergency planning activities.

Data Analysis

Sample characteristics for the ADS sites were summarized with descriptive statistics. Next, we describe the impact of COVID-19 on ADS Plus sites using descriptive statistics such as means and frequencies. We also provide a description of the supports offered to clients and the reimbursement sources for these supports using means and frequencies. All analyses were completed using STATA 15.

Results

Sample Characteristics

Table 1 describes key characteristics of the 22 sites completing the survey. The ADS sites had been operating an average of 20.6 years (SD = 12.6, range 2–42 years). Most sites were private, not-for-profit agencies (68.2%, n = 15) and were in a suburban setting (54.5%, n = 12). Sites served an average of 69 participants (SD = 29.3, range 30–150) who were predominantly White (65.1%) and diagnosed with dementia (68.6%).

Impact of COVID-19 on ADS Site Closure and Staffing

Of the 22 ADS sites responding to the survey, most (86.4%, n = 19) closed due to COVID-19 with nearly half closing due to a state mandate (52.6%, n = 10). The sites (n = 3) that remained open are located in states or counties that did not have mandatory closures. Most sites reported that COVID-19 resulted in the need to furlough or terminate staff (63.6%, n = 14). Some ADS were able to keep staff employed by transferring them to other facilities or reducing hours of employment. Many sites were able to provide staff the opportunity to work remotely (63.6%, n = 14) and with pay (92.9%, n = 13). Of staff working remotely, many of the duties or roles consisted of daily wellness check-ins (42.9% n = 6) with clients, director/administrative activities (28.6%, n = 4), and/or case management or care coordination (28.6%, n = 4) (Table 2).

Supports Offered to Clients and Reimbursement Sources

As presented in Table 3, although every site (n = 22, 100%) reported providing telephone support, only 12 (54.5%) have received either partial or full reimbursement for the service. Eight sites (36.4%) delivered or prepared food for clients, with the majority being reimbursed in part or full (n = 7, 87.5%). Seven sites (31.8%) engaged in grocery runs for clients, with only one site having received reimbursement for grocery runs (14.3%). Medical check-ins *via* telephone with either a nurse or social worker were provided by 9 sites (40.1%), with 4 sites (44.4%) receiving reimbursement for this activity.

Most sites reported providing clients with activity ideas (n = 17, 77.3%), fourteen sites (63.6%) provided virtual activities using technology such as YouTube or Zoom, and twelve sites (54.5%) provided bags of activities to clients. Although the majority of the sites provided these services, they were rarely reimbursed if at all for this support. Only 17.6%

(n = 3) received full or partial reimbursement for activity ideas, 35.7% (n = 5) received reimbursement for virtual activities, and 2 (16.7%) received reimbursement for the activity bags. Sites indicated that reimbursement for their services during COVID has come from a variety of sources including Medicare/Medicaid, Veterans Affairs, private pay, third parties or grants, and sometimes a combination of these (Table 3).

Discussion

Relying on the responses of 22 ADS sites participating in the ADS Plus parent trial, we examined the impact of COVID-19 on their operations. Most sites (86.4%) closed due to the COVID-19 pandemic, and many had to furlough or terminate staff (63.6%). While the sites were closed to in-person services, many however were able to continue to provide daily wellness check-ins and case management or care coordination to their clients *via* telephone along with providing activity ideas or opportunities for engagement via telephone or Zoom. Despite staffing challenges and other issues due to having to abruptly close, all sites indicated ways that they attempted to stay in touch with and engage with clients and their caregivers. In most cases, the services provided during their closure were done so with little to no funding.

COVID-19 has presented both significant challenges to ADS programs as well as opportunities for sites to be innovative with care delivery. ADS are considered a non-essential HCBS, and because of this designation, sites were unable to remain open during the pandemic. As a non-essential service, forced closures adversely impacted staff, clients, and their families. Sites were impacted by the loss of employment and revenue to maintain site expenses. This resulted in staff terminations, furloughs, and/or reductions in work hours. Many programs elected to continue to provide services to clients and families, with limited reimbursement from federal and grant programming. In these cases, staff and administrators volunteered their time demonstrating extraordinary commitment to their clients. Some states allowed reimbursement for daily telephonic wellness check-ins through Medicaid HCBS waivers. Such waivers allowed programs to pivot their in-person social and activity-based services to online platforms and provide care-coordination services.

Several recommendations for practice and policy can be drawn from this survey. Adult day services have considerable potential as a platform for service innovation. Reimbursement for activities including telephone support and home visits should continue once ADS are allowed to reopen. Although COVID-19 allowed for remote and flexible services during the pandemic, it is critical that these innovative modes of care delivery be reimbursed and included as part of routine ADS offerings. This would also allow ADS to expand its reach and continue to provide critical services to vulnerable older adults that desire to age-in-place. Second, states should extend the definition of essential services to include home- and community-based supports like ADS. Adult day services provide crucial services to clients with dementia as well as their family caregivers. Although sites were forced to close because of COVID-19, they also implemented innovative methods to continue to provide vital health promotion and social engagement services to clients. Many of these services were provided with limited to no reimbursement, putting these vital services at danger for permanent closure due to severely curtailed revenue sources. It is unknown how

clients would have fared if these services were not available. The closure of these sites had the potential to have considerable, and potentially negative, impacts on clients and their families. Some potentially difficult decisions that families might grapple with include taking time away from work or institutionalizing the family member living with dementia. It is unknown at this time the direct impact of ADS closures on these decisions, and future research is required to examine these topics.

Although this novel study demonstrated the effects of COVID-19 on ADS staffing and services offered to clients, it is not without limitations. One limitation is that the ADS sites participating in the survey were selected from those participating in a non-pharmacological clinical trial. It is unclear whether these sites are representative of others who are not participating in the trial. Due to the time-sensitive nature of the study, we were unable to complete follow-up surveys and other modes of data collection to capture the ongoing changes in ADS delivery during the pandemic. There may have been additional changes that have occurred that the current study did not capture. For example, we do not know at this point in time how many sites will have to close permanently or when sites will be able to open and operate at full census and whether families will return to their ADS and when.

The COVID-19 pandemic has emphasized the nation's heavy reliance on HCBS to provide care to vulnerable PLWD and their families. Although there were many challenges presented in light of COVID-19 causing forced closure and termination of staff employment, many sites were innovative in providing critical care to their clients. With limited reimbursement for these services, ADS provided essential care to clients who would have otherwise been forced to grapple with limited (or no) sources of care.

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Significance Statement

- Reimbursement for home-based activities should continue once ADS are allowed to reopen.
- Adult day services (ADS) can expand its reach to more vulnerable adults allowing them to age-in-place.
- States should extend the definition of essential services to include community supports like ADS.

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Table 1. Select Demographics from Adult Day Service Sites in the ADS Plus Study, (n = 22).

| Site (n = 22) | |
|--|-------------------------------|
| Years operating (mean, SD, range) | 20.6 years (12.6, Range 2–42) |
| Ownership structure (n, %) | |
| Public/government, not-for-profit | (1, 4.5%) |
| Private, not-for-profit | (15, 68.2%) |
| Private for-profit | (6, 27.3%) |
| Site location | |
| Urban | Urban (7, 31.8%) |
| Rural | Rural (3, 13.6%) |
| Suburban | Suburban (12, 54.5%) |
| Maximum number of participants (mean, SD, range) | 69.5 (29.3, Range 30–150) |
| Non-Hispanic White participants* (mean%, SD, range) | 65.1 (32.7, Range 0–100) |
| Participants with dementia diagnosis* (mean%, SD, range) | 68.6 (30.2, Range 7–100) |

Notes:

* Sites were asked to provide the percent of participants who were non-Hispanic White and percent of participants diagnosed with dementia. The numbers here represent the mean percentages across the 22 sites.

Table 2.

Impact of COVID-19 of ADS Site Closures and Staffing Among ADS Plus Sites, (n = 22).

| Closures | |
|--|-----------|
| Closed site | |
| Yes, n (%) | 19 (86.4) |
| No, n (%) | 3 (13.6) |
| Decision for closure | |
| State mandate, n (%) | 10 (52.6) |
| Chose to close, n (%) | 9 (47.4) |
| Staffing | |
| COVID-19 impact on employment | |
| No change, n | 5 |
| Furloughed, n | 11 |
| Terminated, n | 3 |
| Other, n | 10 |
| Staff able to work remotely | |
| Yes, n (%) | 14 |
| No, n (%) | 8 |
| Ability to pay staff to work remotely | |
| Yes, n (%) | 13 |
| No, n (%) | 1 |
| Duties/role of remote staff | |
| Daily wellness check-in, n (%) | 6 |
| Director/administration, n (%) | 4 |
| Case management/care coordination, n (%) | 4 |

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Table 3. Impact of COVID-19 of ADS Site Supports Offered to Clients and Reimbursement Sources, (n = 22).

| | | Reimbursement | |
|-------------------|----|----------------------|--|
| | | Full/Partial | Sources of Reimbursement, (n) |
| Telephone support | | | |
| Yes | 22 | 12 | Government (Medicare/Medicaid) 5 Grant/third party 5 Combination 2 Client/private pay 0 |
| No | 0 | | |
| Prepared meals | | | |
| Yes | 8 | 7 | Government (Medicare/Medicaid) 2 Grant/third party 4 Combination Client/private pay |
| No | 14 | | 0 1 |
| Grocery run | | | |
| Yes | 7 | 1 | Government (Medicare/Medicaid) 1 Grant/third party Combination Client/private pay |
| No | 15 | | |
| Medical check-in | | | |
| Yes | 9 | 4 | Government (Medicare/Medicaid) 1 Grant/third party Combination Client/private pay 3 |
| No | 13 | | |
| Activity ideas | | | |

| Reimbursement | | Sources of Reimbursement, (n) | |
|---------------------|--------------|-------------------------------|--------------------------------|
| | Full/Partial | | |
| Yes | 17 | 3 | 0 |
| | | | Government (Medicare/Medicaid) |
| | | | Grant/third party |
| | | | Combination |
| | | | Client/private pay |
| No | 5 | | |
| Virtual programming | | | |
| Yes | 14 | 5 | 1 |
| | | | Government (Medicare/Medicaid) |
| | | | Grant/third party |
| | | | Combination |
| | | | Client/private pay |
| No | 8 | | |
| Activity bags | | | |
| Yes | 12 | 2 | 2 |
| | | | Government (Medicare/Medicaid) |
| | | | Grant/third party |
| | | | Combination |
| | | | Client/private pay |
| No | 10 | | |