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Identifying Research Priorities in Adult Day Centers to Support Evidence-Based Care of Vulnerable Older Adults

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Abstract

Adult day centers (ADCs) are essential community resources that allow frail older adults to remain in their communities. Research demonstrates that ADC staff have the capacity to leverage their culturally and socially congruent relationships with clients and caregivers, to deliver evidence-based interventions that improve health outcomes. Yet, they remain a largely overlooked neighborhood resource for older adults with complex health care needs. The National Adult Day Services Association (NADSA) created a multistakeholder work group to identify priority areas for research to enhance the quality of services offered in ADCs and the delivery of evidence-based practices to clients. This perspective piece, which presents the workgroup's findings in the form of key research priorities, is intended as practical guide for researchers seeking to align their research questions with the needs of ADCs and those they serve. In addition to identifying areas of further exploration, we discuss current studies being undertaken within the ADC setting.

Keywords

Community Health Partnerships, Health Priorities, Delivery of Health Care, Health Care Quality, Access, and Evaluation, Health Services for the Aged, Community Health Research, United States

By 2034, an estimated 77 million people in the United States will be older than 65.[1] While a majority of adults prefer to age in their communities as long as possible, just 59% feel they would actually be able to do so.[2] Therefore, a critical need exists for planning at national, state, and local levels to determine how to effectively use resources to address the growing demand for community-based services and help older adults avoid higher levels of care, such as skilled nursing facilities. ADCs, of which nearly 5,000 operate in the United States,[3] are non-residential facilities that support the health, nutritional, social, and daily living needs of adults in a professionally staffed, group setting.[4] Individuals served within ADCs today are considered a complex patient population, meaning they have multiple comorbidities with a high risk for poor outcomes and significantly high health care costs.[5] ADC clients experience a high prevalence of high-cost chronic health conditions including hypertension (46%), diabetes (31%), and dementia (46%).[5] Among ADC clients, management of health and cognitive conditions is frequently complicated by poverty, limited English proficiency, transportation barriers, functional disability, and food insecurity. Of the 286,300 ADC clients in the United States, nearly 60% are racial/ethnic minorities and 66% are insured by Medicaid.[5]

ADCs are essential community resources for long-term care. ADC interdisciplinary staff (including registered nurses and social workers) supervise and interact with their clients for up to 8 hours a day.[5] This makes them well-positioned to recognize and holistically address the biopsychosocial factors affecting health, including health services access, medication management, behavioral changes, food insecurity, health

literacy, and social isolation. The care they provide can also support wellness and prevention and reduce caregiver burden.[6]

Despite serving as a relatively low-cost effective option for community-based long-term care, lack of large-scale data on their effectiveness has caused ADCs to remain a largely overlooked neighborhood resource for supporting persons with complex health and social needs.[7] The number of people using ADCs pales in comparison to skilled nursing facilities which care for 1.4 million adults over 65.[3] To maximize the reach and impact of centers, ADC providers must be able to demonstrate the impact and value of ADCs on clients' health and well-being for older adults, caregivers, and policymakers. However, large-scale efforts to conduct research in ADCs have been disjointed and lack replicability and patient-level clinical data.[7] Studies use inconsistent outcome measures, do not incorporate physiological measures, use small sample sizes rather than large datasets, and rarely incorporate stakeholders into the study design process.[8] Moreover, the complexity of ADC clients requires that efforts to deliver evidenced-based care interventions have significant buy-in from the stakeholders being served.

Coordination and engagement between researchers and ADCs are, therefore, critical in expanding access to ADCs among vulnerable groups and incorporating evidence-based programs and interventions. To this effect, NADSA formed a multistakeholder work group to identify priority areas for research that (1) demonstrate the quality of services ADCs offered and (2) identify opportunities for growth and improvement. The purpose of this paper, which presents findings from that work group, is to serve as a practical guide for researchers seeking to engage in research with ADCs to support them in better aligning their research priorities with the needs of the centers and the population they serve. In addition to identifying areas of further exploration, we discuss examples of current scientific studies being undertaken within ADCs that reflect these priorities.

METHODS

NADSA is a professional membership association and the leading voice of the growing adult day services industry. NADSA responded to calls for a more rigorous and systematic approach to research in ADCs with the creation of an ad hoc research committee whose goal was to develop and centralize its research agenda. The research committee was expanded in 2018 to better address the effects of ADCs across the spectrum of ADC providers, ADC clients, and stakeholders. The committee envisioned a collaborative environment where stakeholders could participate in and promote research opportunities and benefit from the resulting data. This interdisciplinary working group included ADC providers, caregivers, government agencies, and academic researchers among others (Table 1).

The committee met in person in Fall of 2017 and began monthly conference calls to expand the framework of the research agenda based on the input of stakeholders. The committee convened more than a dozen times through 2018 and into 2019. The draft of the research agenda was distributed widely for revisions and input from stakeholders beginning in April 2019. After nearly two years of input the research agenda and five-year plan was approved in August of 2019.

RESULTS

The workgroup identified four major research priority domains (Table 2). These essential domains reflect an ongoing cycle of research, analysis, implementation, and evaluation that aims to continually improve the delivery of quality and innovative services to the vulnerable adults who use ADCs.

DISCUSSION

The priorities identified pave the way for more community-based research among vulnerable persons in ADCs who come from diverse communities. A small body of recent studies have emerged that reflect these key priority areas and also reflect academic and community-partnerships. Some of these are described elsewhere in this article.

Identifying Research Areas

Identifying research areas in partnership with stakeholders allows researchers to identify unmet needs and explore areas requiring change among vulnerable older adults. Sadarangani et al.[9] conducted a secondary analysis of data collected by 12 California ADCS serving an ethnically diverse cohort of older adults. The authors identified significant disparities in nutritional risk between racial groups and high rates of food insecurity. This led to a subsequent community-based

Table 1. NADSA Research Committee and Stakeholder Group Members

Affiliation	Role	Type
NADSA Board Member	CEO, American Senior Care Centers, Inc.	Provider
NADSA Board Member	Executive Director, Alliance for Leadership and Education	Provider
NADSA Board Member	Independent Consultant, Aging Services	Provider
Johns Hopkins University	Assistant Professor	Research
New York University	Assistant Professor	Research
Ohio State University	Professor	Research
University of Montana	Professor	Research
Centers for Disease Control	National Center for Health Statistics, Division of Health Care Statistics	Government
Brain Links, Tennessee Disability Coalition	Brain Injury Specialist	Caregiver
Davis Keulthau, Attorneys at Law	Aging Services Attorney	Other Stakeholder
NADSA Board Member	Director, Evergreen Commons	Provider, Caregiver
Recruitment Partners	Principal, Splaine Consulting	Research
ADC Provider, NADSA Board Member	Research Director, Active Day	Provider, Caregiver
CARF International	Managing Director, Aging Services	Other Stakeholder
NADSA Executive Director	NADSA Executive Director	Caregiver
NADSA Board Member	COO, SarahCare	Provider
NADSA Board Member	Regional Vice President, Easter Seals	Provider
NADSA Board Member	Independent Consultant	Caregiver
University of Minnesota	Professor, Principal Investigator	Research
Active Day	COO, Active Day	Provider
Mentor Network	Director of Business Development, Mentor Network	Provider
International Association for Indigenous Aging	Board President, IAIA	Other Stakeholder
International Association for Indigenous Aging	Executive Director, IAIA	Other Stakeholder
ARCH National Respite Network	Director, ARCH National Respite Network	Other Stakeholder
Kirk and Associates	Principal, Kirk and Associates	Physician
LeadingAge New York	Executive Director, Adult Day Health Care Council	Other Stakeholder

Table 2. Adult Day Services Research Priority Domains and Descriptions

Identifying Research Areas	Promoting collaboration among ADC stakeholders to gather, interpret, and act on empirical ADC evidence will improve funding, organization, implementation, and impact across diverse ADS delivery models
Promoting research in ADCs using Standardized Outcome Measures	Promoting the collection, interpretation, and dissemination of outcomes data in ADCs using standardized measures
Incorporating Research to Practice	Supporting the research-to-practice continuum by (a) making research findings more accessible to ADC providers (b) using research findings to inform care of ADC clients
On-going Evaluation of Best Practices	Implementing evidence-based practices and constantly evaluating and refining them as needed through collaborative efforts with ADC stakeholders and researchers

participatory study in which authors collaborated with ADCs serving Chinese and Vietnamese older adults[10] and used one-on-one interviews with multiple stakeholders (caregivers, ADC clients, dieticians, etc.) to identify opportunities at the individual, community, and policy level to strengthen nutritional offerings in ADCs.

PROMOTING RESEARCH IN ADCS USING STANDARDIZED OUTCOME MEASURES

Using standardized outcome measures supports a higher standard of care by allowing ADCs, payors, and others to ensure equity in the delivery of community-based long-term care services. Anderson et al.[8] proposed a set of uniform outcomes measures intended to standardize data collection. The development of these outcomes was done jointly by academic researchers and ADC operators and reflect three priority domains: participant well-being, caregiver well-being, and health care utilization. Participant well-being includes standardized measures of functional health, physical health, and emotional health, such as the Katz Index of Independent Activities of Daily Living,[11] the Montreal Cognitive Assessment,[12] and the Geriatric Depression Scale.[13] Health care utilization was assessed in terms of hospitalizations, emergency department visits and prescribed medications. The Modified Caregiver Strain Index was recommended to assess the impact of ADCs on caregivers' well-being.[14]

Incorporating Research into Practice

Given the population they serve, ADCs can incorporate research to ensure that vulnerable older adults with complex needs are benefitting from evidence-based practices. For example, ADS-Plus is an ongoing pragmatic trial that enhances services provided in ADCs through the implementation of an evidence-based program for family caregivers of persons with dementia in the ADC.[15] In its pilot test, ADS-Plus was associated with improvements in caregiver well-being, increased ADC attendance, and reduced nursing home placement.[15] Currently, ADS-Plus is being randomized in more than 49 ADCs nationally and is presently being translated into Spanish to expand participation.

On-going Evaluation of Best Practices

On-going evaluation of current practices is critical to advancing community-based care for vulnerable groups, as it supports improved health care delivery through innovation and advancement. The California Association of Adult Day Services (CAADS), with funding from SCAN Health Plan (formerly known as the Senior Care Action Network), used the infrastructure of the ADC to serve as a community-based health home to improve outcomes for medically complex vulnerable adults ($N = 128$) by using a trained registered nurse navigator to coordinate their care across settings (home, ADC, provider office, hospital). CAADS partnered with researchers at New York University to evaluate the results of their project using a mixed-methods format.[16] After 12 months, participation in the health home was associated with significant ($p < 0.05$) reductions in loneliness, depression, nutritional risk, and emergency department utilization in an ethnically diverse sample. In follow-up interviews with stakeholders, ADC users, caregivers, and staff attributed these results to early clinical intervention by nurses and individualized communication with providers across settings, as opposed to facsimile or voicemail. This has led to on-going research on how centers can improve communication with outside providers for all clients.

While these studies represent recent advances in research taking place in ADCs, much remains to be done. Of the 5,000 ADCs in the United States, just a handful are engaged in formal research. Centers rarely have the capacity and resources to undertake research independently. There continues to be an unmet need for academic researchers to engage with centers, using a community-based participatory action framework to identify strengths and opportunities within ADCs. As the aging population grows and diversifies, there is an increasing need for innovative, culturally appropriate programs like the ones described that meet their complex health and social needs. Researchers and academicians must collaborate regarding the development and implementation of evidence-based programs to meet vulnerable populations' needs; these collaborations should be guided by the vision and priorities of ADCs and outlined in the above research agenda.

CONCLUSIONS

ADCs across the United States are playing a vital role in supporting frail older adults' ability to remain in their communities as long as possible. Research taking place in these settings has the potential to advance the health care needs of community-dwelling older adults through the delivery of evidence-based interventions to vulnerable populations and support aging in place. It is, therefore, imperative that meaningful academic/community partnerships exist between researchers and ADCs and that research reflects the priorities of those served within the centers. These partnerships, the resulting publications, and the translation and implementation of applied research will elevate the status of ADC across communities, providing the needed validation of its effectiveness, and thus include ADCs as an essential aspect of the continuum of long-term care.

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