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The Role of Dementia and Residential Service Agency Characteristics in the Care Experiences of Maryland Medicaid Home and Community-Based Service Participants and Family and Unpaid Caregivers

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Abstract

In Maryland, residential service agencies deliver Medicaid Home and Community-Based Services (HCBS) to older adults with disabilities through direct care workers (e.g., personal care aides). Leveraging survey data from residential service agency administrators, linked to interRAI Home Care assessments for 1,144 participants, we describe agency characteristics, and participant and family caregiver experiences by participant dementia status. Most (61.7%) participants experienced low social engagement, and roughly 10.0% experienced a hospitalization

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or emergency room visit within 90 days. Few (14.4%) participants were served by agencies requiring dementia-specific direct care worker training, and most were served by agencies offering supplemental services, or in which direct care workers helped with health information technology (81.2% and 72.8%, respectively). Few caregivers reported negative care experiences. Participants with dementia and those served by agencies with training and supports more often reported negative care experiences. Findings lay the foundation for future longitudinal and embedded interventions within Medicaid HCBS.

Introduction

Medicaid Home and Community-Based Services (HCBS) enable low-income older adults and people with disabilities to live in community settings of their choice by accommodating their need for assistance with daily activities (e.g., bathing, dressing) (Peebles & Bohl, 2014). HCBS are aligned with preferences of older adults who wish to remain in community-based settings (Kasper, 2018). Older adults with dementia comprise more than one-third of HCBS participants; this group has an especially high need for services and are more likely to experience worse quality of life outcomes and greater health care utilization (e.g., hospitalizations) relative to those without dementia (Fabius, Wolff, et al., 2020; Gorges et al., 2019; Reckrey et al., 2020).

HCBS are delivered by a direct care workforce comprised of personal care aides, home care attendants, and home health aides who provide hands on assistance with daily activities to persons with disabilities (Scales, 2020). Unlike home health aides, personal care aides and home care attendants are not required to complete training and are generally not credentialed to help with health care management tasks, such as medication administration. Maryland is not unlike the rest of the country in its increasing demand and limited supports for direct care workers – between 2014 – 2024, an estimated 40% more direct care workers will be needed to meet growing long-term services and supports (LTSS) demands (Scales, 2018). Direct care workers are usually contracted by independent home care agencies (Government Accountability Office, 2016). In Maryland, these non-Medicare participating home care agencies are referred to as “residential service agencies” that are defined by the provision of at least one home health care service (e.g., skilled nursing, personal care, durable medical equipment) for compensation to individuals with disabilities (Maryland Department of Health, 2018). Despite calls for more information about the direct care workforce (Government Accountability Office, 2016; National Institute on Aging, 2020), and a growing appreciation of the importance of paid care to the well-being of older adults and their family caregivers (Reckrey et al., 2021a), little is known about residential service agencies, their workforce, and consequences to the care experiences of older HCBS participants and their family caregivers.

Knowledge regarding the care experiences of older HCBS participants has generally been limited to individual (e.g., disability, self-reported outcomes) or care environment (e.g., availability of family) characteristics, with less attention on other important factors, such as organizational characteristics of agencies or direct care workers. Existing literature on agency organizational factors and care quality has been primarily limited to Medicare skilled

home health services, rather than longer-term HCBS involving direct care (Fashaw-Walters et al., 2022; Schwartz et al., 2019; Schwartz et al., 2021). Available knowledge regarding outcomes of HCBS programs has predominately focused on specific programs, such as the Money Follows the Person (MFP) Program, which transitions Medicaid-enrolled individuals from institutions into community settings to receive HCBS (Harrington et al., 2012). One study found that older MFP participants receiving live-in services had both lower odds of re-institutionalization and choice and control 12 months after moving into the community (Fabius, Shugrue, et al., 2020). Another study demonstrated that quality of life and life satisfaction improves following transitioning into the community (Robison et al., 2015). Evidence regarding experiences of family caregivers of HCBS participants is sparse, with one notable exception being that in the Connecticut MFP program, family and unpaid caregivers of MFP participants reported less stress and burden after transitioning from the nursing home (Robison et al., 2021). These studies have not included considerations for agency level factors, likely because information about agencies is not often readily available or easily accessible.

It is plausible that residential service agency and direct care worker characteristics affect the experiences of HCBS participant and family caregivers. Direct care workers often report challenges in the care of older adults with dementia, such as managing difficult behaviors and working with family caregivers (Leverton et al., 2021). However, training of direct care workers, especially related to caring for people with dementia, may affect their ability to engage in meaningful activities and the well-being of their family caregivers (Reckrey et al., 2022). Additionally, many direct care workers are informally involved in tasks that might stand to help them better integrate into care delivery, such as, using health information technology to track health needs and appointments, reporting health status to health care providers, and communicating with physicians (California Long-Term Care Education Center, 2016; Reckrey et al., 2019). As a result, the integration of direct care workers into interdisciplinary care teams has garnered attention in efforts to improve both job and care quality for direct care workers and participants (Stone & Bryant, 2019). Care quality might also be improved by the provision of supplemental services (e.g., family caregiver training) to support families in the community (Burgdorf et al., 2022).

Conceptual Framework

This study examines residential service agency characteristics and supports, and the care experiences of HCBS participants and their family caregivers in Maryland. We leverage the Convoys of Care Model (Kemp et al., 2013), which proposes that convoys are affected by individual, social, economic, and political factors (Kemp et al., 2013). Convoys are defined as, “dynamic networks of close personal relationships through which social support is distributed or exchanged” (Kemp et al., 2013). Our adapted model proposes that older adult and family caregiver experiences are a result of multiple factors, including state policy influences (i.e., Medicaid HCBS availability), residential service agency characteristics (e.g., direct care worker training requirements and use of health information technology, availability of and agency making referrals to dementia-specific supplemental services), characteristics of older adults (e.g., dementia status, age), and assistance from family caregivers and direct care workers (Figure 1). Leveraging this framework, this study had

two objectives that included 1) understanding how attributes of older HCBS participants and residential service agencies in Maryland varied by dementia status, and 2) examining care experiences of older adults (e.g., social engagement) and family caregivers (e.g., reported inability to continue caregiving) across residential service agency training and support characteristics.

Methods

This study used an observational research design and draws on two data sources that characterize Maryland residents ages 65 and older receiving Medicaid-funded HCBS through the Community Personal Assistance Services or Community First Choice, and the residential service agencies and direct care workers who assisted them. The study was approved by the Bloomberg School of Public Health Internal Review Board (IRB #00014456) and the Maryland Department of Health IRB. First, we relied on 2020 interRAI Home Care (HC) Assessment data for Maryland Medicaid HCBS participants, which is completed by residential service agency nurses to collect information about every HCBS participants' function, social factors, caregiver burden, and health care utilization on an annual basis (Morris, Fries, et al., 2013). interRAI assessments are also used to track changes that may warrant revisions to participant's service care plans.

The second data source was a cross-sectional, survey of residential service agency administrators, Maryland conducted between February 2021 to June 2021. Survey and HCBS participants were not consented for the study as personal information could not be identified directly or indirectly. The survey instrument was developed by the study team (Supplement) and iteratively revised and pilot-tested with residential service agency administrators who were members of a local homecare association. The research team obtained contact information for residential service agencies from a publicly available registry from the Maryland Department of Health. The resultant survey was approximately 20 minutes and primarily self-administered online or by mailed survey; approximately 1% of responses were completed by telephone with experienced data collectors. Agencies were first sent the survey via U. S. postal mail along with a pre-stamped, labeled return envelope, with an option to complete the survey online. After two weeks, the research team contacted administrators by telephone. Up to two follow-up phone calls were conducted with each agency to provide reminders to complete the survey or email the survey link to agency administrators. All survey responses were recorded in REDCap (Harris et al., 2009). Participants received a \$15 gift card.

The survey was distributed to 1,089 agencies. Thirty-seven agencies were unable to be contacted due to the mailed surveys being returned to sender, or no returned phone call from the agency following a voicemail or a disconnected business number. Of the 1,052 remaining mailed surveys, 177 were complete by administrators from municipalities across the state, resulting in a 16.8% response rate. Ninety-one residential service agency administrators reported their agency was a Medicaid-provider and seven did not provide contact information for their agency, resulting in a final sample of 84 direct care agencies, 57 of whom employed direct care workers. Of the 57 residential service agencies, 25 agencies

were identified through administrative data sources as providing services to 1,144 adults aged 65 and older with an available interRAI HC assessment completed in 2020.

Outcome measures

Participant care experiences.—Participant care experiences refer to participants' social engagement and use of acute care services. Participants who responded that it had been 30 or more days since they were last able to participate in social activities of longstanding interest were categorized as having low social engagement. Services use refers to participant reports of any hospitalization or emergency room utilization within the prior 90 days (yes or no).

Caregiver experiences.—interRAI assessors collected information about caregiver experiences from participant or caregiver respondents, if present at the time of the assessment. Respondents indicated (yes/no) whether the caregiver (1) felt overwhelmed by the HCBS participant's illness, (2) expressed feelings of distress, anger, or depression, or (3) was unable to continue caregiving. Independent measures

Participant characteristics.—We examined older adult age (65–74, 75–84, 85+), gender, marital status (married/unmarried) and race/ethnicity (Non-Hispanic White, Non-Hispanic Black, Asian, and Hispanic/American Indian/Alaska Native, Native Hawaiian/Other Pacific Islander). Older adults were categorized as having moderate or severe dementia if they scored a twelve or less on the Brief Interview of Mental Status (BIMS), using established cut points (Resnick et al., 2018). A small percentage of participants (approximately 2%) were either unable to complete the BIMS or were missing data. For these participants, we defaulted to their self-reported Alzheimer's Disease and Related Dementias status, either reported by the participant or their caregiver. Finally, we included a composite measure reflecting level of disability ranging from 0 (independent) to 11 (dependent) with higher scores indicating greater disability, on the basis of activities of daily living (ADLs; bathing, dressing, eating, toileting, locomotion, bed mobility, and transferring), and instrumental activities of daily living (IADLs; meal preparation, housekeeping, managing finances, medication management, and shopping) from the interRAI HC IADL-ADL Functional Hierarchy Scale (Morris, Berg, et al., 2013).

Residential service agency characteristics.—Residential service agency characteristics included agency tenure (less than one year, 1–4 years, 5–9 years, 10 or more years), numbers of participants (≤ 50 ; 51–100; ≥ 101), percentage of participants ages 65 years and older ($< 50\%$ versus 50% and greater), experiences with dementia, direct care worker dementia-specific training requirements and use of health information technology, and residential service agency dementia-specific supplemental supports, as further described in the following text. Experiences with dementia included affirmative responses (yes/no) of managing dementia related behaviors, issues communicating with participants with dementia and handling issues with other family as well as a dichotomous measure indicating administrators reporting any of the defined challenges. Direct care workers' use of health information technology includes viewing sections of the electronic health record, performing health management tasks, interacting with clinicians, and a dichotomous measure reflecting any involvement in identified tasks. Supplemental services for older adults with dementia

and their family caregivers, include: dementia-specific training, referrals to supportive services, and information about other supportive services, as well as a dichotomous measure reflecting any supplemental services.

Analysis

We first described the study sample and compared residential service agency participant characteristics, and participant and caregiver care experiences by dementia status. Next, we examined associations between HCBS participants and caregiver care experiences and residential service agency training requirements (i.e., dementia-specific training) and supports (i.e., direct care worker assistance with health information technology; residential service agency offering any dementia-specific supplemental services). Pearson's chi-square tests were used to test for statistically significant differences across categorical measures, while Student's t-test was used to compare means between groups. A p -value of <0.05 indicated significance for all comparisons. All data were analyzed in SAS Version 9.4 (SAS Institute Inc, 2013).

Results

More than half of residential service agency participants were living with dementia (53.8%) based on interRAI HC assessments. Most participants were ages 75–84 (39.2%) or 85 and older (38.6%), female (73.1%) and Non-Hispanic White (65.6%; Table 1). A little more than a quarter were married (28.2%). On average, residents scored 7.21 (SD 1.84) of 11 on the Functional Hierarchy Scale (higher scores indicate more dependency). Most participants reported experiencing low social engagement (61.7%). Nearly 1 in 10 (7.8%) participants reported having a hospitalization or emergency room visit (8.4%) in the last 90 days. A smaller percentage of caregivers reported negative care experiences – including feeling overwhelmed (12.9%), feeling distressed, angry, or depressed (4.6%), and unable to continue caregiving (4.6%).

Compared to those without dementia, older adults with dementia were more likely to be 85 or older (46.0% vs. 30.1%, $p = 0.001$), non-Hispanic Asian (16.8% vs. 10.6%, $p = 0.001$) or Hispanic and other (4.4% vs. 2.3%, $p = 0.001$), and had more ADL and IADL limitations (mean 7.6 vs 6.7, $p = 0.001$). There were no significant differences by dementia status across participant experiences of low social engagement, hospitalizations, or emergency room visits. However, older adults with (versus without) dementia were more likely to report that caregivers felt overwhelmed (16.9% vs. 8.3%, $p = 0.001$), experienced distress, anger, or depression (6.0% vs. 3.0%, $p < 0.01$), or unable to continue caregiving (6.2% vs. 3.8% $p = 0.001$).

Most HCBS participants received services from agencies that had been in operation 10 or more years (83.1%) and that served more than 100 participants (78.0%) (Table 2). Nearly all participants were served by agencies in which administrators reported their staff had challenges working with families of older adults living with dementia (95.7%), including managing dementia-related behaviors (94.1%), and communicating with participants with dementia (30.3%). Fewer than two in ten (14.4%) participants were served by agencies that required direct care workers to complete dementia specific training. Nearly threequarters

(72.8%) of participants were served by agencies where direct care workers helped with health information technology. This assistance included: viewing sections of the electronic health record (72.0%), performing health management tasks (11.9%), and interacting with clinicians (11.8%). Finally, most participants were served by agencies that offered supplemental services (81.2%) that included referrals to other supportive services (74.5%), followed by information about other supportive services (73.2%), and family caregiver dementia-specific training (13.6%).

Participants with (versus without) dementia were more likely to receive services from residential services agencies serving a participant base primarily comprised of older adults (97.9% vs 94.1%; $p = 0.01$) in which direct care workers assisted with health information technology (76.9% vs. 68.1%; $p = 0.001$) (Table 2). Differences were specifically observed for viewing sections of the electronic health record (75.9% vs. 67.5; $p = 0.01$). Participants living with (versus without) dementia were also more likely to be receiving services from residential services agencies offering dementia-related supplemental services (84.4% vs. 77.5%; $p = 0.01$), including dementia-specific training (15.6% vs. 11.3%, $p = 0.05$), referrals to other supportive services (78.5% vs. 69.8%, $p = 0.01$), and information about other supportive services (78.4% vs. 67.1%, $p = 0.001$).

Residential Service Agency Training and Supports

Residential Service Agency Participants.—Participants' experiences of low social engagement and services use were higher among agencies that required direct care worker training and provided supports (Table 3). For example, low social engagement was more common among participants receiving services from residential service agencies that did – versus did not require dementia specific training (16.2% versus 11.1%; $p=0.02$), and those reporting that direct care workers assist with health information technology (75.2 vs. 68.7; $p=0.02$) and offering supplemental services (83.4% vs. 76.7%; $p = 0.01$). Similarly, hospitalizations and emergency room visits in the last 90 days were more common among those receiving services from agencies that did (versus did not) require dementia specific training (23.6 vs. 13.7%; $p=0.01$ and 22.9% vs 13.7%; $p=0.01$, respectively).

Residential Service Agency Caregivers.—Most (81.8%) caregivers who were overwhelmed were caring for participants receiving care from agencies that required dementia training, compared to 71.5% of those who were not overwhelmed ($p = 0.01$) (Table 4). Nine out of ten (90.0%) caregivers who were reported to be overwhelmed were helping older adults who were receiving services from agencies that offered supplemental services, compared to 79.9% of caregivers who were not overwhelmed ($p = 0.01$). No other statistically significant relationships were observed.

Discussion

In response to the growing older adult population, the increasing demand for care and supports for older adults and their family caregivers, and the general desire of aging adults to remain in the community, states have worked to expand HCBS over the last several decades (Colby & Ortman, 2015; Robison, 2014). Still, little is known about the HCBS service delivery environment as it pertains to residential service agency and direct care

worker characteristics. We describe results from a novel crosssectional study linking data on residential service agency characteristics to participant and caregiver characteristics in Maryland. Our most striking findings underscore the high prevalence of dementia among Medicaid HCBS participants – as well as the challenging care experiences of both participants and family caregivers. Findings collectively shed light on residential service agency dementia related challenges, training requirements, and supports. Comparisons examining participant, caregiver, and agency characteristics by participant dementia status yield important findings that call attention to the need for greater support for older adults living with dementia and their family caregivers.

We find that more than 6 in 10 residential service agency participants studied reported experiencing low social engagement while nearly 1 in 10 experienced a hospitalization or emergency room visit within the 90 days leading up to their annual assessment. While efforts to maximize HCBS participant quality of life and community integration have increased over the last few years, study findings are supported by earlier work that highlights the vulnerable nature of community-dwelling older adults receiving home care (Gorges et al., 2019; Kane & Cutler, 2015). The rates of low social engagement are high in relation to the general population of community-dwelling older adults, in which about a quarter experience moderate to severe social isolation (Cudjoe et al., 2020) and alarming given the strong connection to lower life satisfaction and poorer health outcomes (Robison et al., 2015). The use of technology to connect with family, friends and valued activities to enrich HCBS participants' social networks is a potential strategy to address low social engagement, although access to and usability of technology remain challenges for many older adults, particularly those living with disabilities (Ofei-Dodoo et al., 2015). Additionally, one straightforward, existing recommendation to improve social engagement is specific to Medicare home health, calling on agencies to permit direct care workers to help consumers move about the wider community (Kane & Cutler, 2015). Similar approaches could be implemented in Medicaid HCBS, although this may prove more challenging for participants living with dementia – nearly all participants were served by residential service agencies where administrators indicated that their agency experienced dementia related challenges.

Nearly three-quarters of participants were served by residential service agencies where direct care workers were helping with health information technology, especially as it relates to viewing sections of the electronic health record. These novel findings present potential opportunities for better inclusion of direct care workers into interdisciplinary care teams (e.g., residential service agency nurses, physicians) responsible for the health care management of older adults in the community, especially little research has examined direct care worker use of health information technology. Direct care workers often complete tasks that they have not been trained or prepared for, such as keeping track of medications and interacting with clinicians (Reckrey et al., 2019). With an emphasis of increasing older adult and caregiver access to patient portals (Wolff et al., 2018), especially in the wake of the COVID-19 pandemic, one potential way to better engage direct care workers in care delivers for older adults with disabilities might be to identify them in the older adult's electronic health record as well as provide guidance and training on how to support participants. States might consider opportunities to better integrate direct care workers into

care delivery – as has been modeled in California, where direct care workers were identified in participant’s electronic health records and completed a state-wide training and integration program (California Long-Term Care Education Center, 2016).

Findings also demonstrate the benefits of Medicaid HCBS for family caregivers. Overall, caregivers in this study experienced few negative care experiences despite caring for a highly impaired and socio-economically vulnerable subpopulation. Just over 1 in 10 participants reported having caregivers that were overwhelmed with caregiving, while fewer than 5% were distressed, angry, depressed, or were unable to continue caregiving. These estimates are lower than the general population of caregivers of community dwelling older adults, where prior work has shown that many times, at least one in five caregivers report challenges like emotional difficulty with caregiving (Fabius, Wolff, et al., 2020). Prior work examining caregiver outcomes in other Medicaid HCBS programs highlight caregivers’ positive experiences in Medicaid HCBS. One study examining caregiver experiences was set in the Money Follows the Person Program (Robison et al., 2021). Findings from the study are similar to ours – despite experiencing high caregiving intensity, caregivers experienced less burden, anxiety, and depression than shown in the literature for the general caregiving population (Robison et al., 2021).

Not surprisingly, caregiving experiences vary by dementia status of participants, emphasizing the need to target supportive interventions and strategies toward dementia caregivers. Recent work examining the use of paid care in a nationally representative sample of older adults living with advanced dementia found that caregivers reported a reduction in caregiving strain, but only if paid care was provided on a full-time (40 hours of care or more per week) basis (Reckrey et al., 2021b). Full-time assistance may be harder to obtain for those receiving Medicaid HCBS, where individuals are provided services that fall within a specific budget that is created based on their level of need for services, rather than based on what they can afford (Harrington et al., 2012). Additionally, family caregivers of older adults with greater needs who require more hours of care may feel more overwhelmed when they themselves having to substitute for workers when they are absent or late (Fabius, Shugrue, et al., 2020). Findings may also be explained by the fact that family caregivers often report feeling like they have to manage direct care workers in the home (Reckrey et al., 2022). Further, while the support of direct care workers can be a form of respite that may both ease the demands of caregiving and help older adults with disabilities remain in the community (Vandepitte et al., 2019), the relationships between family caregivers and direct care workers is often fraught due to misalignment in role expectations, gaps in information about the older adults’ care plan, and preferences relating to daily activities and routines (Shaw et al., 2020). Future interventions to reduce caregiver burden might learn from the COPE-CT study, a cost-saving initiative which provided older adults with dementia receiving Medicaid HCBS and their family caregivers with caregiver education, a nurse, and several visits with an occupational therapist (Fortinsky et al., 2020). After four months, relative to those receiving usual care, caregivers receiving the intervention reported greater well-being, and older adults with dementia experienced less frequent and less severe behavioral and psychological symptoms (Fortinsky et al., 2020).

The directionality of our finding that residential service agency participant and caregiver experiences were worse among agencies providing greater training and supports is somewhat counterintuitive but may be explained by selection issues in that agencies with more supports disproportionately serve participants and families with greater needs with greater medical vulnerability, rather than a direct reflection of quality (Fabius et al., 2021). For example, it is possible that those receiving services from agencies with dementia-specific training more often are living with dementia (and seeking dementia-specific care) and therefore at heightened risk of emergency room use and low social engagement. The most important novel contribution of our work is demonstrating feasibility of opportunities for future longitudinal and interventional research embedded in Medicaid HCBS to improve care delivery for vulnerable older adults, especially those living with dementia. Current interventions, including embedded pragmatic clinical trials that aim to improve quality of life and improve care quality of LTSS delivered to older adults and family caregivers have primarily been limited to nursing homes and residential care settings and often include components difficult to execute in community-based settings, where direct care workers deliver care in private homes (Majerovitz et al., 2009). Recent federal-level recommendations call for interventions that support quality of life for persons living with dementia, family caregivers, and direct care workers (The National Academies of Sciences Engineering and Medicine, 2021). This study provides preliminary data in support of the ability to understand the needs and potential modifiable characteristics of residential service agencies delivering HCBS to older adults and their family caregivers.

We acknowledge several limitations. First, we describe experiences of HCBS participants and caregivers in one state. While states vary in the type of available services for older adults living with disabilities in the community, our study is novel in that it considers the contributions of residential service agency characteristics to the experiences of the families they serve. Second, our survey of residential service agency administrators yielded a relatively low response rate, and we are unable to comparatively assess characteristics of agencies that did and did not respond. This may be the result of several factors (e.g., burden due to the COVID-19 pandemic, administrators from agencies with more dementia-related challenges prioritizing completing the survey). Still, study findings contribute to the knowledge-based concerning Medicaid HCBS delivery, for which there is a dearth of information regarding residential service agency characteristics. Third, we cannot determine whether assessments were completed with the assistance of, or solely with a caregiver. However, many of our findings are supported by research in the broader caregiver population that demonstrates that caregiver burden is more often experienced among those who are dementia caregivers and using supplemental services (Fabius, Wolff, et al., 2020). Fourth, we cannot determine the amount, frequency, and type of services that participants are receiving, and the interRAI does not provide information about direct care workers or duration of relationship between participants and direct care workers. Intensity of services is based on needs of participants, but other factors contribute to service delivery, such as the availability of direct care workers. Future studies should examine these factors and their role in participants and caregiver care experiences. Despite these limitations, this yields important findings for better understanding the experiences of Medicaid HCBS participants and their family caregivers.

Conclusion

We present findings that provide information not currently known about Medicaid HCBS delivery, particularly as it relates to residential service agencies and participant and caregiver experiences. Findings from this study have implications for Medicaid HCBS policy and delivery, and the way in which we understand the contribution of residential service agency and direct care worker characteristics in care experiences of older adults and their family caregivers. Given the growing need for services for older adults living with disabilities in the community, the strengthening of HCBS and the delivery of services to improve the experiences of older adults and family caregivers is integral if policymakers and providers are to support families in the community.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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What This Paper Adds

- We present the first analyses linking person-level outcomes to residential service agency organizational characteristics.
- The study provides information not currently known about Medicaid HCBS delivery, particularly as it relates to residential service agency characteristics, including training and supports.
- The present study calls attention to the needs of Medicaid HCBS participants living with dementia and presents potential residential service agency level mechanisms for intervention.

Application of Study Findings

- There is potential to strengthen care delivered by direct care workers in community settings (e.g., training, care team integration).
- Family caregivers are integral to the success of care delivery and innovative strategies are needed to better support them in HCBS.
- Study findings lay the foundation for future longitudinal and embedded interventions aimed at improving care delivery and quality for older adults, family caregivers, and direct care workers, particularly as it relates to caring for persons living with dementia in the community.

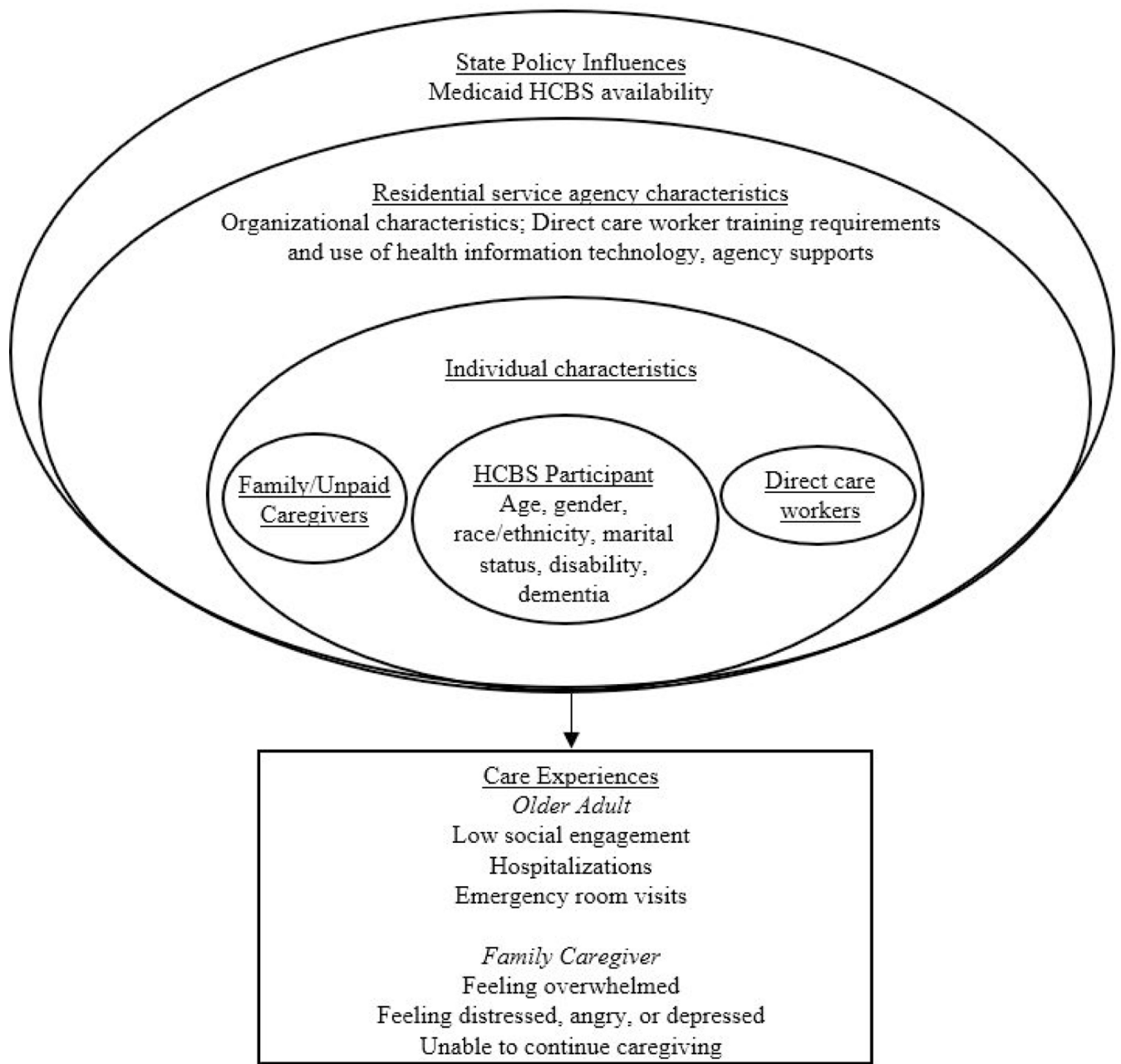


Figure 1.
Conceptual Framework adapted from the Convoys of Care Model (Kemp et al., 2013)

Table 1.

Sociodemographic, Disability, and Care Experiences, by Residential Service Agency Participant Dementia Status

	Total	Dementia	No Dementia	
	100%	53.8%	46.2%	
	1,144	615	529	
	%	%	%	p-value
Residential Service Agency Participant Characteristics, %				
Age				
65–74	22.2	19.2	25.7	<.001
75–84	39.2	34.8	44.2	
85+	38.6	46.0	30.1	
Sex				
Male	26.9	28.6	25.0	0.16
Female	73.1	71.4	75.1	
Race/Ethnicity				
Non-Hispanic White	65.6	64.9	66.4	<0.001
Non-Hispanic Black	17.3	14.0	20.8	
Non-Hispanic Asian	13.9	16.8	10.6	
Hispanic and other	3.4	4.4	2.3	
Married	28.2	29.1	27.0	0.44
ADL Limitations, M (SD)	7.2 (1.8)	7.6 (1.7)	6.7 (1.9)	<.001
Participant Care Experiences, %				
Low Social Engagement	61.7	62.9	60.3	0.39
Health care utilization				
Hospitalizations	7.8	7.5	8.1	0.68
Emergency room visits	8.4	8.9	7.8	0.47
Caregiver Care Experiences				
Caregiver is overwhelmed	12.9	16.9	8.3	<.001
Caregiver is distressed, angry, or depressed	4.6	6.0	3.0	<0.01
Caregiver is unable to continue caregiving	4.6	6.2	3.8	<0.01

Among (N=1,144) older adults (65+) receiving Maryland Community Personal Assistance Services and Community First Choice services from (n=25) residential service agencies; Comparisons based on Pearson's chi-square tests and T-tests. Dementia defined as self-reported Alzheimer's Diseases and Related Dementias or a Brief Interview for Mental Status (BIMS) score of 12 or less. Unable (n = 189) and missing (<11) BIMS scores treated as missing. All participants had at least one valid self-reported Alzheimer's Disease and Related Dementias value or BIMS score. "Other" race/ethnicity includes American Indian/Alaska Native, Native Hawaiian/Other Pacific Islander, and those with more than one race selected.

Table 2.**Residential Service Agency Characteristics, by Participant Dementia Status**

	Total	Dementia	No Dementia	
	100%	53.8%	46.2%	
	1,144	615	529	
	%	%	%	<i>p-value</i>
<hr/>				
Residential Service Agency Characteristics, %				
Years of operation				
Less than 1 year	2.1	2.0	2.3	0.11
1–4 years	3.8	2.9	4.7	
5–9 years	11.0	12.7	9.1	
10 or more years	83.1	82.4	83.9	
Number of participants enrolled at this Agency				
<=50	10.6	9.1	12.3	0.13
51–100	11.5	12.5	10.2	
>=100	78.0	78.4	77.5	
Dementia related caregiving challenges				
Challenges managing dementia related behaviors	94.1	95.3	92.2	0.06
Issues communicating with participants with dementia	30.3	53.8	46.2	0.11
Issues with family	95.7	96.3	95.1	0.32
Residential Service Agency Training and Supports				
Dementia-specific direct care worker training	14.4	15.6	13.0	0.22
Assistance with health information technology				
Direct care workers provide any assistance with health information technology	72.8	76.9	68.1	0.001
View sections of electronic health record	72.0	75.9	67.5	0.01
Perform health management tasks	11.9	12.7	11.0	0.37
Interact with clinicians	11.8	12.7	10.8	0.32
Dementia related supplemental services				
Any supplemental services	81.2	84.4	77.5	0.01
Family caregiver dementia-specific training	13.6	15.6	11.3	0.04
Referrals to other supportive services	74.5	78.5	69.8	0.001
Information about other supportive services	73.2	78.4	67.1	0.001

Among (n=1,144) older adults (65+) receiving Maryland Community Personal Assistance Services and Community First Choice services from (n=25) residential service agencies; Comparisons based on Pearson's chisquare tests. Dementia defined as self-reported Alzheimer's Diseases and Related Dementias or a Brief Interview for Mental Status (BIMS) score of 12 or less

Table 3.

Residential Service Agency Training and Supports, by Participant Care Experiences

	Low Social Engagement ^a		Hospitalizations		Emergency room visits	
	Yes	No	Yes	No	Yes	No
	64.6%	35.4%	7.8%	92.2%	8.4%	91.6%
	n=706	n=387	n=89	n=1,055	n=96	n=1,048
	%	%	%	%	%	%
	p	p	p	p	p	p
Dementia specific training required	16.2	11.1	0.02	23.6	13.7	0.01
Direct care workers assist with any health information technology	75.2	68.7	0.02	69.7	73.1	0.49
Residential service agency offers any supplemental services	83.4	76.7	0.01	85.4	80.9	0.29
					85.4	80.8
						0.27

Among (n=1,144) older adults (65+) receiving Maryland Community Personal Assistance Services and Community First Choice services from (n=25) residential service agencies; Comparisons based on Pearson's chi-square tests.

^a . Missing data for low social engagement (n=51)

Residential Service Agency Training and Supports, by Caregiver Experiences

	Caregiver is overwhelmed ^d		Caregiver is distressed, angry, or depressed ^d		Unable to continue caregiving ^d	
	Yes	No	Yes	No	Yes	No
Dementia specific training required	18.2	13.8	0.15	*	22.6	14.0
Direct care workers assist with any health information technology	81.8	71.5	0.01	83.0	0.09	72.5
Residential service agency offers any supplemental services	90.0	79.9	0.01	90.6	0.07	80.8
	</					

^aMissing data for caregiving is overwhelmed (n<11), distressed, angry or depressed (n<11), and unable to continue caregiving (n<11).

* Unable to disclose values <11.