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PERSPECTIVE

The dementia care workforce: Essential to care but large research gaps exist

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Abstract

People living with dementia and their care partners benefit from services and supports from a wide variety of healthcare and social service professionals. This article provides an overview of the dementia care workforce and highlights gaps and opportunities for data collection and research to advance the workforce and its contributions to high-quality care. The authors provide an analysis of literature, trends, research gaps, and research opportunities, drawing from the literature and their own research. There are notable gaps in our ability to track career pathways, assess the impact of training, identify best practices for recruitment and retention, and understand attributes of the workforce that may affect the quality of both workers' lives and the care they provide to people living with dementia. There are many opportunities for new research to help direct care workers meaningfully contribute to the health and well-being of people living with dementia and their care partners.

KEYWORDS
dementia care, direct care workers, healthcare workforce, home care, long-term services and supports, nursing assistants, nursing homes

Highlights

- The dementia care workforce works in multiple settings and includes many occupations.
- There are gaps in knowledge regarding the workforce and its role in high-quality care.

- Evaluation research is needed to improve direct care worker recruitment, retention, and knowledge.
- Research on caregiving teams including direct care workers, other workers, and families is needed.

1 | INTRODUCTION TO THE DEMENTIA CARE WORKFORCE

People living with Alzheimer's disease or related dementia (collectively referred to as "dementia" in this article) and their care partners benefit from services and supports from a variety of healthcare and social service professionals. These services and supports are provided in many settings, including personal residences, assisted living and continuing care communities, nursing homes, rehabilitation facilities, primary care and specialty practices, adult day services centers, hospital inpatient units, emergency departments, and urgent care centers. Within these settings, a myriad of professionals are employed, including physicians, advanced practice clinicians such as nurse practitioners (NPs) and physician assistants/associates (PAs), registered nurses (RNs), licensed practical/vocational nurses (LPNs), social workers, psychologists, physical and occupational therapists and assistants, nursing assistants, home health aides, personal care assistants, and other specialized professionals.

Although there has been rising attention to the roles of various health professionals in meeting the needs of people living with dementia, there are significant gaps in knowledge regarding the characteristics of this workforce, their training, and knowledge in dementia care, their relationships and interactions with each other, what training and education would best enhance the quality of care, and the factors that support recruitment and retention. The National Institute on Aging (NIA) has demonstrated its recognition of the importance of understanding this workforce through a Notice of Special Interest (NOSI) titled "Dementia Care Workforce for Those Living with Alzheimer's Disease and Alzheimer's Disease-Related Dementias (AD/ADRD)" (NOT-AG-21-049). The NIA also supports the Advancing Workforce Analysis and Research for Dementia (AWARD) Network (R24AG077014), which has developed a set of resources and activities to bring together researchers focused on the dementia care workforce and to accelerate new studies in this area.

This article provides an overview of the dementia care workforce, including its demographics, education, and employment. It then delves into the two settings of care where much of the daily support provided to people living with dementia occurs: nursing homes and personal residences. Within nursing homes, the most numerous professionals are certified nursing assistants (CNAs), and thus, focused attention is paid to their background, training, and roles. Within home and community settings, a larger variety of professionals provides support. For these settings, as well as the workforce as a whole, we highlight research gaps and identify opportunities to advance research to understand how to support workers to advance the health and well-being of people living with dementia and their care partners.

2 | DEMOGRAPHICS AND EMPLOYMENT OF THE DEMENTIA CARE WORKFORCE

2.1 | Employment settings and occupation sizes

Information about the size and composition of the dementia care workforce is limited for a variety of reasons. First, most national data sources do not identify workers who specifically care for people living with dementia, and thus, our understanding is based on employment within specific industry sectors that are broadly defined. Second, many healthcare professionals are not licensed and, thus, are not regularly identified and tracked by state licensing boards. Third, even when licensing data are available, they rarely provide information about the current employment and roles of those licensed. Fourth, there is a wide range of job titles used across employers and regulatory agencies, making it difficult to ensure that data sources comprehensively describe the workforce of interest. Finally, some healthcare organization types, such as assisted living communities, track their own human resources but are not required to report data publicly if they do not receive federal funding.

Care for people living with dementia is provided in multiple settings. Dementia may first be detected in a primary care provider's or geriatrician's office. Other times, a patient may be identified with dementia while being seen in an emergency room. Offices of specialty providers such as neurologists are another common setting of care for people living with dementia, providing diagnosis and care plans. Long-term services and supports (LTSS), commonly referred to as long-term care, also play an important role in the care of people living with dementia. LTSS provided in facilities (i.e., skilled nursing facilities [SNFs], assisted living, and continuing care communities) and in-home care coordinated by home health agencies are subsumed under the healthcare industry according to the North American Industry Classification System (NAICS). Hospice and palliative care services span across these settings. In-home care not involving home health agencies and community-based services, including adult day services centers and respite care services, are also critical settings for patients living with dementia and their caregiving partners. In this article, we collectively refer to these facilities, personal residences, and community-based services as the LTSS sector.

TABLE 1 Occupational distribution in the health care industry.

NAICS description	Hospital	Ambulatory care	Ambulatory care (excluding home health)	Home health care services	Skilled nursing facilities	Assisted living & CCRC	Individual & family services	Personal care services
NAICS code	622,000	621,000	621,000 (except 621600)	621,600	623,100	623,300	624,100	812,100
Total number of workers	6,234,730	8,337,190	6,735,250	1,601,940	1,379,430	923,770	2,983,600	732,500
Physicians	3.2%	5.1%	6.3%	0.1%	0.02%	0.01%	0.04%	0.03%
Physician assistants	0.6%	1.2%	1.5%	0.0%	0.0%	0.0%	0.01%	0.03%
Nurse practitioners	1.1%	2.2%	2.6%	0.5%	0.0%	0.0%	0.1%	0.1%
Registered nurses	29.7%	7.3%	6.3%	11.2%	9.0%	3.3%	1.3%	0.3%
Licensed practical/vocational nurses	1.6%	2.4%	1.8%	4.9%	12.4%	4.5%	0.3%	0.1%
Rehabilitative therapists	4.3%	3.3%	3.4%	2.9%	2.6%	0.5%	0.3%	0.0%
Pharmacists	1.5%	0.2%	0.2%	0.2%	0.01%	0.0%	0.01%	0.0%
Healthcare social workers	0.8%	0.6%	0.0%	1.5%	1.1%	0.4%	0.8%	0.0%
PT/OT assistants	0.5%	1.1%	1.2%	0.9%	1.2%	0.2%	0.03%	0.0%
Nursing assistants	7.2%	1.5%	0.6%	5.1%	35.2%	15.8%	1.4%	0.0%
Home health and personal care aides	0.4%	11.4%	0.3%	58.1%	3.6%	26.6%	64.0%	0.3%
Community health workers	0.1%	0.1%	0.2%	0.1%	0.02%	0.02%	0.3%	0.0%

Abbreviations: CCRC, Continuing Care Retirement Communities; NAICS, North American Industry Classification System; PT/OT, physical therapy/occupational therapy.

Multi-profession teams are essential for services for people living with dementia, with teams varying in size and composition based on the stage of disease and complexity of need. At any given time, multiple licensed health professionals may be involved, such as physicians, nurses, advanced practice clinicians, pharmacists, physical therapists, and social workers, alongside unlicensed professionals such as nursing assistants, home health and personal care aides, and community health workers. Table 1 presents the occupational distribution of the healthcare workforce and its main employment settings, as reported by the U.S. Bureau of Labor Statistics. The largest group of professionals in the healthcare industry, accounting for approximately 22% of the total number of workers, is broadly called "direct care workers" – composed of CNAs, other nursing assistants, home health and personal aides, medication aides, and others who provide daily, ongoing services. Direct care workers collaborate with all other health professionals and can be found in nearly every healthcare setting that serves people living with dementia. In addition, care partners such as family members and friends are also important to care team members.

2.2 | Education of the dementia care workforce

Education required for workers to enter jobs caring for people living with dementia ranges from a high school degree for many of those in aide and assistant roles to master's or doctoral degrees for physicians, NPs, and pharmacists. With a high concentration of direct care workers that require minimal formal education to enter their roles, the LTSS sector has the lowest average education levels of the healthcare industry[1]; higher average education levels are found in settings such as hospitals and ambulatory care that have higher concentration of, for example, RNs with bachelor's degrees and physicians with doctorates.

Some professions have specialized knowledge related to dementia, such as geriatricians, neurologists, and adult-gerontology NPs. However, these specialists account for small numbers within their professions and within the overall healthcare workforce. Of the 949,658 active physicians in the U.S. in 2021, only 6149 (0.6%) were geriatric medicine specialists, and 13,853 (1.5%) were neurologists. Among 253,181 licensed NPs in 2022, only 20,868 (8.2%) indicated they had certification in gerontology or adult-gerontology.[2] Many generalist physicians, NPs, and PAs have some education in geriatric-related competencies, including caring for people living with dementia. However, surveys of U.S. medical schools have reported an average of only 14.4 h of didactic instruction in geriatric competencies, only 27% of schools with required geriatrics clerkships, and 17% of schools relying on clinical exposure to older adults without any formal curriculum.[3] NPs who do not specialize in adult-gerontology do not have any specific geriatric competencies mandated in their curriculum, and only some PA programs include a geriatrics curriculum. Across all professions, critical gaps remain in dementia-specific education, including a need for interprofessional education and training, to provide high-quality, evidence-based, coordinated care for people living with dementia.[4]

2.3 | Diversity and socioeconomic status of the dementia care workforce

The healthcare workforce, including those caring for people living with dementia, is largely female-identifying, with the share of women ranging from 50% among those with doctorates to nearly 90% among those with less than a high school degree.[5] There is higher representation of Black and Hispanic/Latino/a workers, particularly Mexican American workers, in aide and assistant roles as compared to healthcare jobs requiring higher levels of education and to the rest of the working population.[5,6] A large percentage of the direct care workforce is foreign-born, especially in nursing homes.[7] As such, LTSS organizations tend to have a more diverse working population than other types of healthcare organizations.

Direct care workers are also among the lowest paid in the healthcare industry and have higher reliance on social assistance programs such as Medicaid or Supplemental Nutrition Assistance Program ("food stamps") compared to workers in other healthcare sectors.[8] In 2022, 12% of home care workers and 11% of nursing assistants were uninsured compared to 7.9% of the U.S. population being uninsured.[9,10] Compared to 21.1% of the U.S. population, 36% of home care workers and 25% of nursing assistants were covered by Medicaid in 2022.[9,11] One-third of home care aides and nursing assistants reported relying on the Supplemental Nutrition Assistance Program compared with 12.3% of the U.S. population.[9,12] Direct care workers also face tough work environments, with increasing concerns about workplace violence.[13,14]

3 | THE WORKFORCE WITHIN PERSONAL RESIDENCES, THE COMMUNITY, AND NURSING HOMES

Many people living with dementia and their care partners express a strong preference to remain living in the community, including in their home, rather than moving to nursing homes, even as their disease advances and functional impairment grows.[15] As a result, there is growing interest in models of both clinical and long-term dementia care delivered in the home and community. Systems of community-based care include community-based clinical services (e.g., outpatient specialist and primary care, physical and occupational therapy) as well as community-based long-term care (e.g., adult day care, assisted living). Systems of home-based care include home-based clinical services (e.g., skilled home health, home hospice, and home-based primary care) as well as home-based long-term care services (e.g., functional support from family caregivers and/or direct care workers).[16] Among people living with dementia, 44% use home-based clinical care, compared with 14% of older adults without dementia.[17] Similarly, people with dementia living in the community are more likely to receive support from direct care workers in the home compared to people without dementia.[18] Among those with dementia and significant self-care impairment, about half receive paid care in the home with an average of 50 h per week.[19] Without direct care to support the day-to-day needs of people living with dementia, other forms of home and community-based clinical care are not possible.[20]

For people living with dementia whose needs are not adequately met in their homes and in the community, nursing homes are an essential setting of care. It has been estimated that more than half of residents in nursing homes have dementia, making the care needs of nursing home residents living with dementia a priority.[21] To meet these needs, a growing number of nursing homes have developed special care units focused on the care of people living with dementia that include special activities, meals, and care provided by staff with specialized training in dementia care, social workers, and an activity director. Special care units have been shown to improve the quality of care delivered to people living with dementia.[22] Approximately 15% of nursing homes have a dementia or memory care unit, while less than 1% of nursing homes serve only residents with dementia.[23] Regardless of whether there are special dementia care units, CNAs are an instrumental occupation in meeting the care needs of people living with dementia. Working alongside licensed nurses and with guidance from clinicians, CNAs provide assistance with activities of daily living, such as eating, dressing, walking, and toileting, along with care that is often not quantified or qualified, such as care specific to the residents' preferences, goals, and values. Often knowing the resident the best, CNAs can discern a resident's change in condition almost immediately and, specifically for the resident living with dementia, they address many dementia-related behaviors that are best managed by someone who is most familiar with the resident.

Many professionals play essential roles in providing care to people living with dementia, but the direct care workforce is particularly important due to its size and its day-to-day contact with residents and clients. Yet, existing research about the direct care workforce in general, and for people living with dementia in particular, is limited. There is a need for research to guide solutions to the challenges this workforce faces, including low wages, insufficient dementia care training, low job quality, staff shortages, and lack of integration of families and care partners.[24]

3.1 | Low wages among direct care workers

Direct care workers in all settings are paid low wages and experience high levels of job turnover. On average, CNAs in nursing homes make only $18.33 per hour,[25] and direct care workers working in the home earn even less: an average of $16.13 per hour in 2023.[9] Furthermore, direct care workers experience limited access to employee benefits, including health insurance coverage, sick leave, and retirement benefits, making it difficult to afford basic necessities and plan for the future. A recent study found that about 50% of Black and Latina female CNAs earn less than $15 per hour, and only 10% have employer-based health insurance coverage.[26] It has been documented that many CNAs either must work a significant amount of overtime or multiple jobs, and even might live in poverty despite holding multiple jobs.[27] Direct care workers often forego important wellness needs such as exercise, time with family, and participating in leisure activities due to not having the time and/or finances to engage in these activities.[27] Challenges

associated with meeting financial needs have been highlighted by multiple studies as a key motivator for direct care workers leaving long-term care jobs.[28,29]

Meaningful discussions about compensation for direct care workers are hampered by a lack of a clear understanding of the work they perform. CNAs play an essential role in the daily care of nursing homes, and their turnover makes it difficult for nursing homes to provide high-quality care.[30] Research on the direct care workforce's value in home and community settings is comparatively limited. Although direct care workers often first enter the home to perform discrete functional tasks (e.g., shopping, bathing), evidence suggests that they frequently provide other forms of support including identifying new health issues (e.g., changes in mental status), assisting with chronic disease management (e.g., monitoring blood pressure), supporting mental health (e.g., supportive counseling), and supporting general wellness (e.g., assisting with exercises).[31] The importance of these health-related tasks may be even greater for people with dementia who frequently cannot self-manage their own health conditions due to cognitive impairment. For people living with dementia, direct care workers are also frequently tasked with ensuring safety at home and must manage behavioral and psychological symptoms of dementia including agitation and wandering.[32] Yet, research about home-based dementia care is often limited to simply noting if someone has any direct care. Specific aspects of direct care should be measured, including how much care is received, the intersection of paid care and the larger care network, the tasks performed, whether care is of sufficient quantity to meet the care needs of the person living with dementia, and the specific individualized care provided by direct care workers.[33] This is an essential step to ensure that compensation for direct care workers appropriately reflects the complex care they provide.

There are several approaches that have been undertaken by states to improve pay for CNAs in nursing homes and direct care workers in home and community settings. Given the high share of residents with dementia in nursing homes and a large number of people living with dementia who hire personal care aides, any strategy that increases direct care workers' pay will affect the services received by people living with dementia.

1. Wage pass-throughs: A wage pass-through is an additional allocation of funds provided through Medicaid reimbursement that mandate a specific share of the funds must be used to increase direct care workers' wages. Twenty-seven states have implemented wage pass-through programs.[34]
2. Quality incentive programs: These programs tie incentive payments to nursing homes that meet or exceed quality benchmarks, with the expectation that some of these funds will be used to increase staff wages. States might choose to target dementia care quality.
3. Appropriating funds to staffing: This approach involves allocating additional state funds specifically for the purpose of increasing nursing home staffing levels.
4. Direct stipends: States can offer supplemental stipends or payments directly to CNAs and other direct care workers who work in dementia-specific units or with people living with dementia.

The Geriatric Workforce Enhancement Program, which provides federal funds to support the growth of the workforce meeting the needs of older populations, encourages nursing homes to allocate additional Medicaid funding to dementia care initiatives, including higher wages for CNAs who care for residents living with dementia. Other initiatives to improve CNA wages can be implemented directly by nursing homes and home- and community-based providers, such as establishing higher pay rates for staff who provide specialized dementia care and pay raises or bonuses for staff who complete specialized dementia care training or obtain certifications.

While direct wage increases are critical, offering comprehensive benefits like health insurance, paid time off, childcare support, transportation support, and retirement plans are also important in making direct care roles more financially appealing. However, little is known about workers' preferences for different combinations of wages and benefits. Wage pass-through programs have been evaluated, finding that they succeed in their aims of increasing the wages and staffing of CNAs.[35] However, there have not yet been rigorous analyses of the effectiveness of other policy and organizational strategies to increase direct care workers' pay in achieving the end goal of improving recruitment and retention rates.

3.2 | Training direct care workers to provide high-quality dementia care

CNAs have little or no training specific to the care of residents with dementia, and training and supervision for direct care workers in the home and community is highly variable and depends on the circumstances of employment as well as state- and national-level policies and regulations.[36] CNAs are federally required to have only 75 h of state-approved training, a competency evaluation, and 12 h per year of continuing education. These requirements have been scrutinized for decades for the care of residents without dementia, not even considering care for those with dementia.[37] The low level of CNA training may be associated with neglect and abuse in nursing homes, especially for residents with behavioral difficulties associated with dementia.[38] For direct care workers in home- and community-based settings, training often focuses on how to provide physical support and does not emphasize the broader range of tasks in which direct care workers are engaged. As for CNAs, training in dementia care specifically is often lacking, and research is needed to inform which educational approaches most improve direct care workers' dementia knowledge as well as outcomes for the people living with dementia who receive care.[39]

A key barrier to meaningfully improving care outcomes for people living with dementia is a lack of research that aligns direct care worker training with established measures of high-quality care. Compared to other healthcare sectors, including nursing homes, the measurement of quality in home care is in its infancy.[40] Although the Centers for Medicare and Medicaid Services recently released quality measures for Medicaid-funded home and community-based services, these measures do not describe the perspectives of people living with dementia

and their care partners. Development of meaningful measures of quality is made more difficult by the work environment of the home itself, where opportunities for direct supervision of direct care workers are limited, and tasks may vary greatly. Moreover, people living with dementia may not be able to accurately report the quality of the care they receive. Yet, meaningful assessment of quality in direct care at home is essential: while high-quality direct care can positively impact both people living with dementia and their care partners, poor-quality care can leave people living with dementia unsafe and vulnerable to exploitation.

It is important to acknowledge that different members of the care team may have different perspectives on what constitutes high-quality care and what training is required to achieve it. For example, families may prioritize a direct care worker who is patient and respectful, while a home care agency may prioritize the timely completion of tasks listed in the care plan.[40] Researchers should identify measurable aspects of the direct care experience that impact outcomes and experiences for people living with dementia and create competency-based training programs aligned with these goals.

Financial barriers often prevent direct care workers from pursuing further education and advancing their careers. In-service continuing education and formal mentorship can advance skills acquisition. In addition, implementing free tuition programs can support an important career ladder, particularly to enable CNAs to become LPNs or RNs. Such investments can benefit employers by boosting retention rates and incentivizing nurses to stay with their employers. However, there has been little evaluation of the degree to which CNAs want to become licensed professionals, versus being more highly skilled and respected in their CNA roles. Most studies have found that few CNAs later become licensed nurses, even when efforts are made to facilitate doing so, suggesting that there are additional barriers to the effectiveness of career ladders.[41]

3.3 | Integration with the care team and improving job quality

Direct care workers frequently interact with other healthcare professionals, yet they are not well integrated into the healthcare team, even in home-based care teams like home hospice.[42] Because people living with dementia may not be able to self-report their own history, symptoms, and care due to cognitive impairment, direct care workers, who often spend more time with the person with dementia than any other person, are a particularly invaluable asset to the care team. To improve direct care worker collaboration within the care team, it is important to explicitly consider the ideal role of the direct care worker. The existing literature on direct care workers in home settings sometimes describes workers as "like family" and other times describes them as "the eyes and the ears of the healthcare team;" these roles have different implications for how communication occurs within the dementia care team. Clarifying roles helps ensure effective teamwork in any setting and is particularly important for direct care workers who have not traditionally been included in the team.

Direct care workers face numerous challenges in the workplace, although a larger body of research has examined CNAs within nursing homes than workers in home and community settings. CNAs frequently encounter poor relationships with supervisors, lack of respect from other healthcare professionals, and limited opportunities for advancement.[43,44] Additionally, CNAs often have little discretion or input into care planning, despite being responsible for most resident care hours. This lack of autonomy can lead to a sense of disenfranchisement and a feeling that their contributions are undervalued.[43] High levels of stress, coupled with the potential for on-the-job injuries, can lead to burnout and exhaustion, which can, in turn, affect the quality of care that direct care workers provide.

Research shows a clear link between staff empowerment and CNA retention, with facilities scoring high on empowerment having a 64% advantage compared with low-scoring facilities.[45] Empowerment practices include keeping CNAs informed of resident care plan changes, involving them in quality improvement teams, and offering opportunities for decision-making and skill development. Recognizing and appreciating the hard work of CNAs is essential for fostering a positive and supportive work environment, although the literature does not provide guidance about the most impactful and cost-effective interventions for either CNAs or direct care workers in homes and community settings.

3.4 | Staffing shortages

The growing need for paid support for people living with dementia, alongside the support needs of people living with other disabilities, is dwarfing the growth of the direct care workforce, resulting in widespread shortages and portending an ongoing workforce challenge. Even after increasing wages and offering bonuses, many nursing homes still struggle to hire staff. Staffing shortages are particularly acute in nursing homes with a higher share of Black residents and those located in disadvantaged neighborhoods[46] and include all staff important to dementia care including clinicians, licensed nurses, physical, occupational, recreational, and speech therapists, social workers, and leadership. Staffing shortages greatly impact the quality of care for residents living with dementia, since people living with dementia account for 31% to 80% of residents in most nursing homes.[47]

The expansion of home- and community-based delivery of long-term care is creating similar challenges with shortages of home care providers.[48] Because people with dementia have high levels of care need for longer periods of time as compared to people without dementia,[18] they may be particularly impacted by direct care workforce shortages.[49] Direct care workers in the home and community-based face some unique challenges that likely contribute to ongoing workforce shortages in this sector, including unstable work hours and shorter shifts that must be pieced together to create full-time employment.

Long-term investments and programs are necessary to attract individuals to serve our nation's growing population living with dementia. There are several approaches employers can take to improve the

recruitment and retention of staff, including improving the work environment by creating a safe workplace, respecting and recognizing their staff, involving direct care workers in teams, valuing their work, and ensuring they feel seen, heard, and treated respectfully. To expand the recruitment pool, direct care employers should offer more attractive benefits packages and schedules, explore faith and mission-based recruiting, and provide opportunities for younger individuals to have experiences with people living with dementia through volunteer opportunities and high school employment.[50] In addition, employers should prioritize retention, which includes using screening processes to assess applicants' motivation and attitudes toward persons living with dementia, offering mentoring programs for staff caring for people living with dementia so that they are able to get input and support on their care activities, investing in workplace culture, offering childcare and other benefits to support employment throughout the life course, and providing career advancement opportunities specific to dementia care.[51]

3.5 | Collaboration between direct care workers and family and care partners

Families and care partners play a vital role in the lives of people living with dementia, going far beyond casual visits; however, care partners have not been integrated as part of the care team in the way that they should.[24,52] Acknowledgment of the interconnection between direct care workers and care partners is rapidly growing. In home and community settings, direct care does not simply substitute for family care; care partners are intimately involved in the hiring and supervising of direct care workers in the home.[53] Direct care workers impact the experiences and outcomes of care partners, including caregiver burden and ability to work outside of the home.[54] Conversely, direct care workers report that interactions with family caregivers are an important and sometimes challenging part of their job.[55]

Collaboration between direct care workers and families is also important in nursing homes. To fully engage care partners in care teams, nursing homes should provide them with opportunities to participate in daily resident life, share stories, and advise CNAs about preferences and routines specific to the resident living with dementia. Nursing homes, clinician offices, and direct-care service organizations can facilitate communication between direct care workers and care partners, as well as clinicians, through support groups and family councils, care team video-conferencing, and inclusion of direct care workers in discussions about care planning {Travers, 2022 #36}. Clinicians such as NPs, physicians, and PAs are pivotal to this integration, but their role in dementia care has not been well defined beyond clinical management, advanced assessments, and education.

Research that examines collaboration between direct care workers and care partners is important to understand and improve the care of people living with dementia in all settings. In such research, it is important to consider the circumstances of the employment arrangement; for example, family caregivers who privately hire direct care workers, especially on the gray market, have to navigate responsibilities as an employer.[49] Research is also needed on the training and support needs of care partners who are employed to provide direct care as part of Medicaid-funded self-direction programs; while some research supports the acceptability and efficacy of these programs, evidence to guide program development and expansion is lacking.[56] Early research on the Cash and Counseling model found that consumer-directed care was associated with decreased nursing home entry, but this research has not been replicated or expanded to other related programs.[57] Moreover, the contributions of clinicians in leading and coordinating interdisciplinary care teams and receiving training specific to dementia care also have not been carefully explored in research.[24,58,59]

4 | RESEARCH GAPS AND OPPORTUNITIES

Rising attention to ongoing shortages of direct care workers and other professionals serving people living with dementia has spurred proposals for policy and practice change. However, improvements have been hampered by financial constraints, ongoing workforce instability, a lack of best practices for training, leadership gaps in prioritizing the workforce, and a lack of recognition of the importance of direct care workers in all care settings.

A number of research gaps related to the direct care workforce have been highlighted in this paper, including:

1. Workers' preferences regarding wages, work schedules, and benefits;
2. Effectiveness of policies intended to increase wages and reduce turnover;
3. Components of training most desired by direct care workers and that have the strongest impact on quality of care;
4. Effectiveness of strategies to increase recruitment into direct care careers;
5. Understanding direct care workers' long-term career goals;
6. Best practices to improve working conditions for direct care workers; and
7. Effectiveness of approaches to improve integration of direct care workers with other members of the clinical care team and care partners.

Many of these knowledge gaps apply to other professions engaged in the care of people living with dementia. For example, the roles of geriatricians as team leaders and consultants have not been broadly evaluated to guide organizational practices amidst shortages,[60] and the contributions of clinicians in leading and coordinating care teams in nursing homes, home health, community programs, and home-based primary care remain to be fully understood.

There is a lack of data to support research to fill these important research gaps, and thus, we are limited in our ability to understand attributes of the workforce that affect the quality of both workers' lives and the care they provide to people living with dementia. The federal government needs to develop data systems that support tracking of workforce education, training, diversity, experience, skills, staffing

levels, service to diverse communities, and satisfaction. Data sources need to go beyond counting the number of people providing care to include information about the specific aspects of care for which direct care workers have responsibility, including activities that address behavioral and psychological symptoms of dementia and overall personal safety and well-being. In addition, linking workforce data with other data sources would foster research on the relationship between the workforce and person-centered outcomes for people living with dementia and their care partners. The recently launched National Dementia Workforce Study, funded by the NIA (U54AG084520), will fill some of these data gaps by surveying clinicians, nursing home staff, assisted living community staff, and home care staff, and linking the survey data with administrative data on processes, quality, and costs of care.

Improved data would also support research on strategies and programs – such as career ladders, expanded training in dementia care for all health professionals, minimum staffing standards for residential facilities, and higher skill certifications – to learn whether and how they impact retention and quality of care for people living with dementia and their care partners. Researchers need to identify and evaluate interventions and strategies to advance and equitably support all members of the dementia workforce to encourage the replication and dissemination of the most successful approaches.

There is also a need for improved measures and research methods to understand the interactions of caregiving teams that include direct care workers and care partners and to support the analysis of the best approaches for advancing equitable person-centered care and workforce policies. Direct care workers face low wages, insufficient benefits, and poor working conditions, and this occupation is disproportionately composed of minoritized women – particularly Black women. Research on policy changes intended to improve the quality of direct care jobs should evaluate policies' impact on equity and systemic racism in the healthcare workforce. Studies also should consider both the extrinsic rewards of direct care work – compensation and career opportunity – and the intrinsic rewards associated with being empowered to meet the needs of people living with dementia.

As we build the research base to advance care for people living with dementia and their care partners, it is essential to consider the healthcare workforce overall and the direct care workforce in particular. The presence and importance of direct care workers as key team members providing daily support to people needing help across many settings must be incorporated into new data and research. This will help direct care workers meaningfully contribute to the health and well-being of people living with dementia and their care partners.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest. Author disclosures are available in Supporting information.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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