

Expert Meeting on Understanding the Supply Side of Professional Care Providers of Persons with Dementia

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Acronym Definitions

ABS	Address Based Sampling
ACO	Accountable Care Organization
ADSC	adult day services center
AMA	American Medical Association
APRN	advanced practice registered nurse
BHCS	Board on Health Care Services
BSR	National Institute on Aging, Division of Behavioral and Social Research
CHW	community health workers
CMS	Centers for Medicare & Medicaid Services
COVID-19	coronavirus disease 2019
EHR	electronic health records
EMT	emergency medical technologists
MD-PPAS	Medicare Data on Physician Practice and Specialty
MDS	Minimum Data Set
NIA	National Institute on Aging
NHATS	National Health and Aging Trends Study
NP	nurse practitioner
NPALS	National Post-acute and Long-term Care Study
OASIS	Outcome and Assessment Information Set
PA	physician assistant
PBJ	Payroll Based Journal

RCC residential care community

RN registered nurse

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Executive Summary

On March 23, 2021, the Board on Health Care Services of the National Academies of Sciences, Engineering, and Medicine convened an expert panel to address the Supply Side of Professional Care Providers of Persons with Dementia. The panel's six presenters provided insight into workforce research priorities that may help improve care for people living with dementia.

Presenters emphasized that an adequate understanding of supply side issues requires better measurement tools that can capture the dimensions of the dementia care workforce, from the demand for dementia care services to the relative contributions of different kinds of care providers. Better measurement tools would help shape strategies to address three significant supply side challenges: recruitment and retention of dementia care specialists, alignment of workforce development with team-based models of dementia care, and examination of structural influences on supply side needs.

Developing Better Measurement Tools

Supply side-related data remain very difficult to collect and interpret. One of the most significant obstacles is the volume of unpaid and unmeasured caregiving provided by family members and friends, whose invisibility obscures the true demand for caregiving labor at the regional and national levels. Even within professional medical systems, however, research is hindered by important gaps. Major established sources of data—including Medicare claims and electronic health records (EHRs)—are not designed to collect care provider information at a level of detail necessary to support supply side research. Although workforce surveys can be a valuable source of information, they are hindered by sampling challenges, such as the difficulty of identifying participants and of tracking their movement across institutions. Presenters discussed potential ways to improve data collection.

Research Opportunities

1. Evaluate ways to improve the content of EHRs, including their collection of more precise information about family caregivers
2. Assess regional data-sharing practices as models for a potential national EHR system that would broaden use of EHRs and connect them across nursing homes and external medical care providers
3. Explore ways to incorporate additional workforce information into Medicare claims, including potentially the identification of multiple care providers beyond supervising physicians and the ownership categories of care providers' employers
4. Develop and pilot systems to track geriatric training and specializations of social workers, counselors, physical and occupational therapists, nurse practitioners, and physician assistants
5. Explore ways to leverage proprietary data from corporate health care providers (e.g., human resource records, payroll systems, work logs, and cost reports), as well as data

from the Payroll Based Journal and Bureau of Labor Statistics in order to determine industry workforce needs

6. Assess the potential to establish data linkages between the National Health and Aging Trends Study and Medicare and Medicaid claims to assemble a more comprehensive picture of provider trends in long-term care facilities
7. Improve identification of potential survey respondents by using records of the Society for Post-Acute and Long-term Care Medicine (for directors of skilled nursing facilities); Medicare Data on Physician Practice and Specialty, the American Medical Association Masterfile, or CarePrecise (for physicians); and American Medical Directors Association (for physicians, nurse practitioners, and physician assistants)
8. Apply address-based sampling to build relevant sampling frames by targeting areas of the country with a particularly high concentration of older adults
9. Develop measures of facility, staff, and care quality tailored specifically to dementia care

Improving Recruitment and Retention

The health care workforce faces challenges in recruiting and retaining two main classes of dementia care providers: the majority of providers who do not require a college degree and the highly trained professionals who are responsible for most dementia diagnoses and care plans. Pay and benefits depress recruitment and retention of both of these groups: those without college degrees receive compensation that is often little better than minimum wage labor for more difficult work, and those with advanced training receive lower pay and benefits compared to other medical specializations. As a result, dementia care facilities grapple with continuous turnover in less-skilled positions and with a persistent shortfall of geriatricians, registered nurses with geriatric certifications, and other care providers with specialized geriatric training. Presenters discussed ways that researchers can define the scope of the recruitment and retention challenge and evaluate potential solutions.

Research Opportunities

1. Leverage the National Post-acute and Long-term Care Study—including existing data and potential new questions—to identify trends in staffing decisions, training and compensation, and turnover
2. Add measures to existing longitudinal studies (e.g., the Baccalaureate and Beyond Longitudinal Study) to identify factors shaping career choices generally and the choices of individuals who become dementia care professionals
3. Design and deploy survey and interview studies with dementia care facility physicians, nurse practitioners, and physician assistants to build a deep knowledge base regarding the factors that shape offer acceptance and turnover
4. Identify medical school- and residency-based programs that may introduce physicians to geriatrics and counter negative perceptions of the specialization
5. Evaluate the potential impact of workforce investments (including staffing levels and standards, staff payment and benefit structures, and facility-specific training) on dementia patient outcomes

6. Evaluate the impact of new care models, such as Accountable Care Organizations, on retention, turnover, and staffing needs

Aligning Supply Side Strategies with Team-based Care Models

Although the professional dementia care workforce can be viewed as a set of discrete functional roles (e.g., physicians, nurse practitioners, home health aides, emergency medical technicians), this view does not reflect the team-based care delivery model that many researchers consider the most promising approach to dementia care. Research methodologies that deliberately conceptualize, measure, and study members of the workforce as members of *care delivery teams* are therefore needed. These methods can deliver a more accurate understanding of the overall workforce supply and define the specific factors shaping its quality and productivity.

Research Opportunities

1. Develop research protocols to track team-based care (including definitions of a care practice and standards for identifying appropriate survey respondents within practices)
2. Conceptualize workforce planning techniques that do not revolve around separate occupational silos but instead around integrated health care teams
3. Identify inter-professional, multidisciplinary, team-based care configurations that are efficient, effective, and straightforwardly implementable
4. Explore regulatory policies that remove restrictions on health aides' and nursing assistants' ability to provide services such as wound dressing or insulin pump assistance
5. Conduct surveys of facility medical directors to gather information about the structure of the professional dementia care workforce, proportion of care provided by different staff and relationships among them, and roles of specialists

Assessing Structural Influences on Supply Side Needs

The supply of dementia care providers is fundamentally shaped by large-scale economic, social, and regulatory forces that influence the business structure of dementia care facilities across the country and their staffing strategies and investments. Modeling the impact of these forces on supply side issues is critical to defining and assessing policy changes (e.g., training standards and payment structures) that may alter the landscape of dementia care. These impacts may include, for example, racial and other social inequities within the dementia care workforce that mirror inequities among people living with dementia. Although many of these structural dimensions of supply side issues are longstanding, researchers may also examine how the COVID-19 pandemic may be amplifying or altering these trends in both the short and long term.

Research Opportunities

1. Conduct simulation studies of projected supply of and demand for caregivers in order to identify staffing shortages in specific specialties or geographic regions
2. Explore potential definitions of minimum staffing standards for dementia care in private health care facilities (e.g., tiered staffing sensitive to percentage of patients with dementia)

3. Assess the incorporation of dementia care provider information on facility report cards as a tool for incentivizing nursing home and home health agency investment in the dementia care workforce
4. Conduct regulator surveys to analyze the feasibility and implications of potential regulatory reforms
5. Perform economic analyses of cost functions to determine the true costs of caring for dementia patients that are not reflected in current payment systems
6. Model and simulate different payment structures that account for dementia care to reveal the incentives for and consequences of an Alzheimer's disease-centric payment model
7. Prioritize health care workforce investments that might be incorporated into national infrastructure policy and spending
8. Assess the relationship between workforce and patient-related racial and socioeconomic disparities
9. Assess the impact of the COVID-19 pandemic on overall demand for dementia care, long-term preference for care models (e.g., telehealth), and consolidation

Summary

Understanding the Supply Side of Professional Care Providers of Persons with Dementia

Joanne Spetz

Obstacles to developing a robust long-term care (LTC) workforce include low pay, low retention rates, and an inability to attract workers. Low pay drives potential workers away from LTC jobs, as does the perception that working with older patients is unpleasant. Productivity among the LTC workforce suffers from inadequate training practices, high turnover, and regulatory restrictions that prevent home health aides and nursing assistants from providing basic daily care for patients living with dementia.

Labor Statistics and Data Gaps

Data about the long-term care workforce are scarce, but the U.S. Bureau of Labor Statistics provides a breakdown of the workforce by occupation. Many of these occupations require postsecondary education, but there is a shortfall of geriatricians and registered nurses (RNs) with geriatric certification. As of 2019, not quite half of all geriatrics fellowship positions were filled, reinforcing the projected shortfall of 13,000 practicing geriatricians by 2030. Even if all the fellowship positions were filled every year for the next decade, the supply of geriatric physicians would be less than the demand. Physicians choose specialties other than geriatrics for several reasons, including lack of exposure to the geriatrics specialty in medical school and residency, lower pay than other specializations, and the perception that caring for older populations is unpleasant.

Other occupations in the LTC setting that require postsecondary education include nurses, social workers, and various therapists. The number of nurses dedicated to providing geriatric care is not known, because RNs are trained as generalists, and no system exists to track nurse practitioners' (NPs) specializations. The major deterrent to practicing adult-gerontology nursing is the lower pay compared to other medical industry sectors. Social workers, counselors, and physical and occupational therapists play a vital role in the care of people living with dementia, but data about specific geriatric or dementia training in these occupations are also lacking.

The caregivers who provide day-to-day care for people living with dementia generally work in occupations that do not require a college degree. These occupations include personal care aides, nursing assistants, licensed practical nurse, home health aides, paramedics and emergency medical technologists (EMTs), and community health workers (CHWs). Personal care aides, home health aides and nursing assistants often overlap in their work, making it difficult to determine who is providing what care. These occupations suffer from high turnover rates—up to 67 percent in 2017—due to very low pay, poor working conditions, and little opportunity for career advancement. Furthermore, the people working in these occupations often rely on the social safety net and are socioeconomically vulnerable. The role that EMTs and paramedics play in providing care to people living with dementia is growing, following the advent of “community paramedicine” and “mobile integrated health” models. However, the

turnover rate among EMTs is also high, disrupting the potential to develop a sustainable workforce.

Family and friends often play an outsized role in caring for people living with dementia. However, this unpaid labor remains difficult to quantify, potentially distorting the true number of professional caretakers required to sustain the dementia care workforce.

Productivity of the Dementia Care Workforce

The productivity of dementia care providers is reduced by a myriad of issues, including high turnover rates among the occupations who provide the majority of care, a lack of specific training in dementia care, a poor system for information exchange and EHRs, and regulatory restrictions that prevent home care aides and advanced practice registered nurses (APRNs) from performing certain essential daily activities associated with caring for a person with dementia. Even though home health aides, personal care aides, and nursing assistants provide the majority of daily care to people with dementia, they are restricted by many states from performing fundamental care tasks, such as nail clipping, wound dressing, and insulin pump assistance.

Future Data Needs

More comprehensive data collection regarding the dementia care workforce and the factors that affect it should be a priority. Some methods for collecting more robust data include surveying medical and nursing directors as well as staff of nursing facilities. Some researchers have started to increase data collection: for example, Laura Wagner and colleagues asked a large sample of nursing home staff from 98 urban nursing homes in five states a variety of questions about their social status and work environment, such as immigration status and the workplace safety culture of their facility. They then linked the responses to Centers for Medicare & Medicaid Services (CMS) nursing home and quality data.

Researchers can also utilize Medicare claims to track clinicians via the National Provider Identifier and determine which types of physicians provide the most care to nursing home patients. Proprietary data from corporate health care providers can be used to assess human resource records, payroll systems, and work logs to determine industry supply needs.

Issues in Measuring and Projecting Workforce Supply in Care Teams for Older Adults with Dementia

Karen Donelan

Although data on demand for dementia care services is incomplete, with fewer than 40% of clinical practices routinely assessing cognition in adults aged 65+, available data do show that geriatric-focused professions are in chronic undersupply. Moreover, significant unpaid care work by family and friends is left unmeasured, and its absence (for individuals without a family or friend caregiver) increases LTC needs. In keeping with these trends, primary care physicians regularly indicate that they need additional support to care for people with dementia, and many researchers consider team-based care a preferred approach to care delivery. A team-based care model requires better measurement of the work of all caregivers, paid and unpaid,

to define supply needs, and it requires workforce planning that is not conducted in separate occupational silos, profession by profession.

Demand for Services: Older Adults in the Community

An estimated 46 percent of people over age 75 have dementia or symptoms of dementia. During the past few decades, the number of people over age 65 using specialty care has increased markedly (to 62% of visits), while the number using primary care has decreased (to 38% of visits). High-cost/high-need algorithms are often used to manage care for vulnerable populations, but they do not effectively identify under-utilizers and homebound people living with dementia (e.g., many women over age 75, almost half of whom live alone). Almost 35 percent of people with dementia have no identified caregiver; coupled with a decline in the number of middle-aged family caregivers available to care for older adult family members, the demand for dementia care services continues to grow.

Measures of Unpaid Caregiving for Older Adults

Although national surveys are the best data source for measuring workforce supply, they likely still undercount both the number of people living with dementia and the number of people providing care—the latter of whom often do not recognize themselves as caregivers. The use of claims-based algorithms to measure the number of people with dementia is unreliable because algorithms often fail to capture the undiagnosed or low utilizers. EHRs also do not directly represent caregivers, missing them entirely or capturing them only through other categories, such as next of kin or health proxy. Privacy concerns and family conflict can affect the reliability of surveys given to family caregivers, further complicating efforts to accurately measure workforce supply. Furthermore, family caregivers are not consistently identified and their unpaid labor is not measured, making it impossible to track the amount of care they provide.

Measuring and Building Care Teams

The growth of RNs, NPs, and physician assistants (PAs) is outpacing the growth of the physician workforce by a wide margin, and this trend is expected to continue for the foreseeable future. However, less than 1 percent of RNs have geriatric certification and only 9 percent of NPs have geriatric/adult gerontology certification. Most of the RNs with geriatric certification work in nursing homes; very few family practices employ RNs and social workers certified in geriatric practices. In addition, only about half of geriatric physician fellowships are filled, and only about 1,250 geriatric psychiatrists are practicing. Experts in geriatric care provide the bulk of assessment and identification services and care plan development for geriatric syndromes, but the low supply of these experts makes it difficult to include them on care teams. PACE is an inter-professional, multidisciplinary team-based model, but such models are rare in primary care practices—40% of which have neither a nurse nor social worker.

Team-based clinical care poses some specific supply side measurement challenges. Researchers must consider how to define and find a clinical practice; track who is actually providing care and who should respond to care-related surveys; assess what new models of care may be utilized but underreported; and identify optimal care configurations that are efficient, effective, and straightforward.

Supply Issues in ADRD Care in Nursing Homes and Home Health Agencies

Dana B. Mukamel

Understanding nursing homes' and home health agencies' staffing decisions and the constraints under which they function enables policy makers to identify effective supply side policy. This understanding in turn gives impetus and direction to workforce research agendas and methods.

In general, nursing homes and home health agencies make staffing decisions along three dimensions. They must choose the mix of staff (e.g. ratio of registered nurses to certified nurse assistants); the quantity of employees they will hire, or staffing levels; and the quality of care they wish to provide. These choices determine the quality of the staff they want to hire and the level of on-the-job training they provide. These decisions, which are all interrelated, are based on the business plan of the organization, which depends on its mission (e.g. for profit-versus non-profit), and the demand and local competition. In addition, these decisions are constrained by local labor markets, which may make certain staff positions difficult to fill.

This heuristic model suggests several areas of research, discussed below.

Markets, Information, and Competition

Nursing homes and home health agencies compete in local markets and compare their performance to that of their competitors by using industry-wide quality report cards. These publicly available report cards create an incentive to perform, which has implications for staffing choices. Report cards often also include some information about staffing levels. The report cards are limited, however, for two reasons: they do not offer information specific to health outcomes for patients with ADRD nor do they offer information about staff specifically caring for patients with ADRD. In fact, they offer no information about the percentage of patients with ADRD in a nursing home or among the patients served by a home health agency. Thus, consumers requiring this care cannot differentiate among providers along this dimension, and thus there is no incentive for providers to specialize staffing to the specific care required for patients with ADRD.

National data sets provide useful information about patients and staff that can drive decisions made by these providers. Examples include the Minimum Data Set (MDS), which provides information about patient function and needs; the Outcome and Assessment Information Set (OASIS), which provides useful information about patient outcomes; and the Payroll Based Journal (PBJ), which provides information on staffing and wages. However, these data sets do not offer AD-specific information. Developing facility and quality-of-care measures based on data for patients with AD, as well as quality measures for AD staff based on the percentage of AD patients, would inform understanding of staffing needs in nursing homes and home health care agencies.

State and Federal Regulations

Staffing patterns in nursing homes are also shaped by state and federal regulations that set minimum standards for registered nurses and licensed nurses in nursing homes. However, no minimum staffing requirement is specific to the percentage of AD patients in a facility. Because

of the large variation in numbers and proportions of AD patients across nursing homes, the existing minimum staffing standard is not particularly useful for nursing homes and home health agencies thinking about proper staffing with the appropriate types and numbers of direct care employees.

Regulation is one way to improve the staffing models utilized in nursing homes and by home health agencies. Existing regulations do not establish minimum standards for staff who care for AD patients in these settings. Insight into potential regulations might be gained by utilizing the data and analyses from CASPER, OSCAR, MDS, and OASIS. In addition, regulator surveys and policy and clinical analyses of the feasibility and implications of regulatory reforms would be useful. One regulatory modification might be to require tiered staffing in organizations depending on the percentage of AD patients in their care.

Payment Systems

AD-specific staffing decisions are inevitably shaped by payment models approved for AD-related care. In many states, Medicare and Medicaid pay nursing homes based on prospective payment system (PPS) with risk adjustment. However, that adjustment does not explicitly account for AD patients. CMS plans to implement Value-Based Purchasing systems over the next few years, but these will also not be adjusted for AD patients. If payments are not adjusted to adequately account for the higher costs associated with providing care to people living with AD, then care organizations will have little incentive to increase AD-related staffing levels—which then limits their ability to provide optimal care to AD patients. Economic analyses of cost functions are necessary to determine the costs of caring for AD patients. Modeling different payment structures and conducting simulations that explicitly account for AD patients would reveal the incentives for and potential unintended consequences of implementing an AD-centric payment model.

Labor Supply and Demand

Local labor markets limit hiring by nursing homes and home health agencies. These organizations must compete with other health care providers, including not only hospitals and private health care practices but also other industries that may recruit from the same skill pool, particularly home health aides and other less skilled workers. Simulation studies that compare the projected supply of and demand for AD caregivers is one useful method to gather data that identify staffing shortages in specialty providers, or within a specific geographic location. Other data and analyses that will inform research into local labor markets include PBJ for retention and staffing data, cost reports, surveys on the barriers to entering AD care occupations, and the Bureau of Labor Statistics for information about employment by geography and industry.

Understanding the Supply Side of Professional Care Providers for Persons with Dementia: Barriers to Entry, Retention, and Turnover

Lawrence P. Casalino

Underexplored areas are crucial to understanding staffing supply needs. In general, data about assisted living facilities are insufficient. Although general information is relatively available, data specific to who provides what proportion of care to patients with dementia, who owns care

facilities, and who actually employs facility staff do not exist. To close these information gaps, researchers could use interviews to gain deep knowledge and surveys to develop broadly representative knowledge.

Identifying Barriers to Entry and Retention Challenges

Surveying the professional staff in dementia care facilities would help to identify the reasons why medical professionals avoid working in certain facilities or in the field, or why they leave a facility or the field. Physicians, NPs, and PAs would be the most useful survey respondents, because they provide care to a high proportion of patients with dementia and/or have a high proportion of claims in a relevant facility.

To identify physicians to participate in surveys, researchers can use Medicare Data on Physician Practice and Specialty (MD-PPAS) and Medicare claims, as well as the American Medical Association (AMA) Masterfile or CarePrecise. However, these data sources are sometimes inaccurate. Dismal physician response rates also make it difficult to gather publishable information about the staffing needs of facilities that care for people with dementia. Beyond issues with physician surveys, no single source exists to gather information about NPs and PAs, or the services they provide, in part because claims list only a supervising physician's name. Facility medical directors would also be useful information sources, but no publicly available list of Skilled Nursing Facility (SNF) directors exists. Despite these difficulties, collecting information from professional facilities staff about career choices, facility management and quality, and other factors that impact employment remains the most valuable and efficient method to learn about the workforce.

Identifying Causes and Effects of Turnover

Using Medicare claims to identify physician turnover is difficult. Casalino's group has developed a reliable algorithm using MD-PPAS data that identifies physicians who either move to another practice or leave medical practice entirely. The algorithm should be published in the next few months. Once turnover is identified, researchers can look for its predictors and effects. To develop a complete understanding of turnover, researchers should collect information about not only the various health care providers, but also the facilities where they work and their employers, which can have an enormous influence on staff retention and turnover.

Although general information about facilities is available, significant gaps remain. For example, the owner of a facility can be difficult to ascertain. Although Casalino and colleagues created a database listing private equity firms that own facilities, the creation of such databases is a time-consuming solution; moreover, a facility owner may contract with another group that serves as the employer of care providers. Other useful facility-level information includes the structure of the professional workforce within a facility, the proportion of care provided by various professional staff (such as NPs and PAs), the working relationship between physicians and NPs and PAs, and the role of specialists. Most of this information is not readily available and must be gathered via surveys of facility medical directors.

To support more transparent information gathering, every Medicare claim could include the ownership category of a care provider's employer, the legal name of the provider's employer,

and an accounting of who was involved in providing care beyond the physician. Clarifying these data points would enable researchers and medical directors to better understand the motivations of medical professionals who enter or exit the dementia care landscape.

Impact of Care Models on Turnover and Retention in Dementia Care Settings

Identifying the impact of new care models, such as Accountable Care Organizations (ACOs), on the facilities that care for dementia patients, and the patients themselves, would enable a broader understanding of retention, turnover, and staffing needs. Another area in need of greater exploration is dementia care in outpatient practices—specifically, patient outcomes based on type of physician and type of provider organization. Finally, Medicare Advantage and Medicaid managed care could provide a wealth of information, but data collection from these sources is hampered by incomplete claims data.

Understanding the Supply Side of Professional Care Providers of Persons with Dementia: Data from the National Post-acute and Long-term Care Study

Manisha Sengupta

The National Post-acute and Long-term Care Study (NPALS) provides useful data about the supply side of professionals who provide care to people with dementia. NPALS gathers a variety of data from residential care communities (RCCs) and adult day services centers (ADSCs) including about the facility's dementia-focused care programs, the number of residents with dementia, and the type and number of specific staff employed by the facility. These data help illuminate various issues in staff training, workforce retention and turnover, and other factors that affect staffing supply.

Data Collection Methods

NPALS provides data from a range of care providers, including hospice agencies, nursing homes, home health care agencies, inpatient rehab hospitals, LTC hospitals, RCCs, and ADSCs. For hospice agencies, nursing homes, home health care agencies, inpatient rehab hospitals, and LTC hospitals, NPALS' data sources originate from CMS administrative claims, assessment, and regulatory data, as well as from the CASPER, MDS, OASIS, IRFPAI, and IPBS data sets. NPALS conducts primary surveys to collect data from ADSCs and RCCs.

Findings

NPALS data for 2018 reveal that almost 304,000 people with Alzheimer's disease and other dementias (ADOD) received care in RCCs and more than 69,000 people with ADOD received care in ADSCs. The data also reveal that RCCs and ADSCs employed about 474,000 and 24,000 full-time nursing and social workers, respectively.

NPALS found that 74 percent of RCCs do not have dementia care units and 87 percent of ADSCs do not provide specialized care for dementia care and treatment. Health aides comprise the majority of the support staff, well above the numbers of RNs, LPNs, and social workers employed by care facilities with dementia patients. Greater than 77 percent of RCC residents require assistance with bathing, 62 percent with dressing, and 26 percent with eating; all these activities are assisted overwhelmingly by health aides. NPALS found that in both sectors, aides

received similar hours of training if they worked in a dementia special care setting or a general setting. A bright spot in the data is the high percentages of LTC RCCs and ADSCs that reported providing employee benefits to health aides.

Data Gaps

Despite the findings that can be gleaned from NPALS data, gaps persist in data on staffing supply needs. Researchers require more data on dementia care training, insight into strategies to improve staff recruitment and retention, and details about workforce involvement in providing person-centered care.

Despite these limitations, NPALS is a useful tool for collecting data on the staffing needs of facilities providing care to people living with dementia because it is the only ongoing nationally representative study collecting data from RCCs and ADSC, and it also includes EHR data from selected providers. Moreover, additional content and study components could easily be added to the NPALS infrastructure to accommodate future staffing supply studies.

Understanding the Supply Side of Professional Care Providers of Persons with Dementia: Research Strategies

Jill A. Dever

To effectively study the supply side of professional care providers of people living with dementia, NIA should arrive at an ultimate set of research questions and tools on which to focus. In addition, decisions about what existing data, ongoing studies, and new data should be used to answer these questions would ensure efficient deployment of resources.

Defining NIA's Research Needs

The causes and effects of staff turnover and the aging workforce are important issues requiring further investigation. Existing surveys such as NPALS could be supplemented with questions designed to enhance understanding of how turnover and an aging workforce affect the staffing supply of dementia care providers. In addition, external factors—federal and state policies, facility staffing needs, services to address turnover and retention of employees, and studies on the beneficial synergies across the spectrum of care—could be evaluated to identify the reasons for and effects of high turnover in the dementia care sector.

Statistical Tools for Supply Side Research

To achieve NIA's research goals, researchers could use Address Based Sampling (ABS) to target areas of the country with a particularly high concentration of older adults. RTI International has developed and enhanced an ABS sampling frame that contains census information and model-based household characteristics. Several supplemental resources for targeted sampling include the American Medical Directors Association, which can provide a partial list of physicians, NPs, and PAs working in LTC facilities, and treatment reimbursement records from CMS. Overlaying these data sources might provide NIA with valuable information regarding dementia care services in rural areas of the country.

Further, efforts to improve the generalizability of existing estimates would support determination of staffing needs. Researchers may adjust existing data by incorporating enhanced survey weights for analyses, use multiple imputation gathered from administrative information when possible, and combine data from multiple surveys to provide new avenues for analysis.

Using and Adjusting Existing Studies

Barriers to workforce entry are one key supply side issue. The Baccalaureate and Beyond Longitudinal Study (BBLS), an existing study conducted by the National Center for Education Statistics (NCES), follows trained health care workers and could provide in-depth information about their employment experiences. NIA could collaborate with NCES to survey (1) high school students about their career aspirations and what motivates and informs their career choices and (2) a subset of BBLS participants who pursued a career in dementia care to understand their motivations to choose that career. Surveys of schools, training program directors, and students with questions focused on curricula and barriers to pursuing a career in the dementia care field might produce valuable information about provider supply.

Adding questions to existing surveys, such as NPALS, could also shed light on staffing decisions, employment conditions, and turnover. For example, NIA could use existing studies to gain context for how federal and state regulations may impact staffing. In addition, NIA-funded researchers might adjust existing surveys of facility directors to learn more about how staffing needs are determined and what services might combat staff turnover. Studies of the beneficial synergies that exist across the spectrum of care could inform understanding of how family caregivers reduce the burden on professional care providers.

Data could also be gathered through a new longitudinal survey that follows dementia care providers over a period of time, which may provide new insights and shape future supply side research in the dementia care arena.

Discussion

Data Collection

Usefulness of EHRs for Studying Workforce Supply

Participants discussed challenges that researchers face in better leveraging EHRs to measure staffing supply needs. Currently EHRs do not indicate the best contact for day-to-day care—ideally an individual who is aware of the dementia diagnosis and treatment plan. Very few nursing home EHRs connect to external medical providers, which complicates the ability to know the full scope of services a patient is receiving. Moreover, dementia is not always diagnosed, so EHRs may undercount dementia patients, especially those in the early stages of AD. Beyond these challenges inherent to EHRs, only about 25 percent of LTC facilities actually use EHRs; therefore, standardizing their use across facilities should be explored.

Collecting National Workforce-related Data

The retrieval and merging of EHR data from different regional systems may help deliver a national perspective on workforce supply. Data sharing differs greatly by location; in order to develop a national EHR system, researchers should first identify better regional data sharing practices. To derive nationally representative knowledge of where people are receiving dementia care, researchers should also study community-based care as well as LTC providers' evolving role. Because approximately four out of five people living with dementia live in the community, accurate data collection requires family members to be willing to share information about the health and care of a family member living with dementia. A focus on provider-based data may also be useful, because providers can efficiently answer questions about staffing, number of dementia care patients, and other factors impacting staffing supply needs. Integrating all of the data and data sources will be a huge undertaking.

Provider Care Trends in NHATS

The National Health and Aging Trends Study (NHATS) can be a messy data source: it is difficult to determine who is receiving what care and from whom, including whether unpaid individuals are supporting NHATS participants. If NHATS data were more complete, they could be linked to Medicare and Medicaid claims and analyzed to reveal information about people living with dementia and the types of care they are receiving, leading to a more comprehensive picture of provider trends in LTC facilities. Although data linkages take time to establish, and data access is limited for privacy reasons, linked data sets can provide a wider lens with which to study staffing supply for dementia care providers. NHATS may not provide enough data about the spectrum of care to provide a truly national perspective on staffing supply.

Structural Issues

Impact of Build Back Better on Workforce Development

The Biden administration's Build Back Better plan may represent a once-in-a-generation opportunity to invest in health care infrastructure in ways that affect workforce supply. Guidance on how to educate Congress and the Biden administration on workforce issues would likely be welcomed by researchers and policymakers alike.

Conditions of Employment

Conditions of employment—such as variation in employee benefits mentioned in Dr. Sengupta's presentation—influence workforce supply. The large variation across nursing homes in number and proportion of dementia patients is one of these conditions, making it important to identify differences in patient population and type of care. With these distinctions in mind, researchers could explore staff payment and benefit structures, the effect of caring for ADRD patients on retention, and the effect of staffing levels and standards on patient outcomes. Examination of facility-specific training levels for staff caring for dementia patients will also be valuable. Finally, recruiting medical professionals to LTC facilities and maintaining a quality workforce remains a challenge, especially for Medicaid facilities. There is a profound difference in the quality of care received in majority-Medicaid facilities versus non-Medicaid facilities.

Effects of COVID-19

Many issues affecting the dementia care workforce—including turnover, lack of training, low pay, and poverty—existed long before the COVID-19 pandemic. However, COVID-19 has brought some of these issues to the forefront. Several ongoing studies are assessing what percentage of workers displaced during COVID-19 moved to LTC jobs, the experience of family caregivers during COVID-19, and the impact of COVID-19 on family caregivers and paid caregivers in community and residential care settings.

COVID-19 has clearly provoked a shift in demand, away from nursing home care and toward home health care and telehealth care. Home care and community care services are currently booming, but these are the provider types for which researchers most lack workforce data. This trend may have prompted providers to become more innovative in how they provide care. The overall demand for dementia care providers may also have been affected by the pandemic: there appears to be an uptick in dementia among people who were at tipping points, due to COVID-19-related social isolation.

The longstanding trend toward consolidation in the health care industry, which may be accelerated by the COVID-19 crisis, has economic implications for the dementia care industry. Perhaps LTC data and acute care data can only be integrated when providers of both types of care exist within the same organization, because the incentive to coordinate care across different care locations would be shared.

Using Supply Side Dimensions to Address Care Inequities

Facilities with a High Percentage of Minority Patients

Inequities in dementia care remain high, and the COVID-19 crisis has further exposed this weakness. Dr. Donelan highlighted data showing that Massachusetts nursing homes serving primarily Black patients had higher numbers of COVID-19 cases and higher COVID-19 death rates than facilities with a majority white population. Furthermore, half of the nursing home workforce in Massachusetts also worked in other congregate care facilities and home care agencies, implying that these workers did not make a living wage with just one job. In order to understand the disparities in the workforce and in the patient population, researchers should consider the economic status of both workers and patients, because patient-related disparities and workforce disparities go hand in hand. Thinking carefully about the concordance between caregiver and patient has important implications for quality of care and health outcomes in the context of patient-caregiver disparities.

Minority and Immigrant Nurses

Dr. Spetz highlighted her findings that Black and Asian minorities are more likely to work in LTC, which pays less than other medical care sectors. However, Asian nurses are paid somewhat more and are more likely to become nursing directors. These preliminary data suggest that researchers should better link diversity of different occupations who serve people with dementia and the disparities among dementia patients.

Appendix 1: Agenda

March 23, 2021

11:00 Welcome and Opening Remarks
David Blumenthal, HCS Board Chair

Thanks to members who are rotating off the Board:

- David Blumenthal
- Melinda B. Buntin
- Adams Dudley
- Terry T. Fulmer
- Trish Riley

Introduction of Don Berwick as incoming HCS Board Chair

11:10 Update and Discussion of recently released reports and developing new studies
Sharyl Nass

12:00 Addressing Systemic Racism in Health Care
Laurie Zephyrin, Commonwealth Fund

Discussion with Board Members

12:45 Understanding the Supply Side of Professional Care Providers of Persons with Dementia

- Joanne Spetz, University of California, San Francisco
- Karen Donelan, Brandeis University
- Dana B. Mukamel, University of California, Irvine
- Lawrence P. Casalino, Weil Cornell Medical College
- Manisha Sengupta, CDC
- Jill A. Dever, RTI International (Washington, DC)

Discussion with Board Members and NIA Staff

2:45 Wrap up and plan for the Fall 2021 Meeting

3:00 Adjourn

Appendix 2: Meeting Participants

Presenters

Lawrence P. Casalino, Weil Cornell Medical College
Jill A. Dever, RTI International (Washington, DC)
Karen Donelan, Brandeis University
Dana B. Mukamel, University of California, Irvine
Manisha Sengupta, CDC
Joanne Spetz, University of California, San Francisco

Board on Health Care Services Members

Donald Berwick, Incoming Chair
David Blumenthal, Outgoing Chair
Andrew Bindman, University of California, San Francisco
Niranjan Bose, Bill & Melinda Gates Foundation
Melinda Buntin, Vanderbilt University
Neil Calman, Icahn School of Medicine at Mount Sinai
Paul Chung, Cornell University
Patricia Davidson, Johns Hopkins University
Martha Daviglus, University of Illinois Chicago
Richard Frank, Harvard University
Terry Fulmer, John A. Hartford Foundation
Sharon Inouye, Hinda and Arthur Marcus Institute for Aging Research
John Lumpkin, Robert Wood Johnson Foundation
Faith Mitchell, Urban Institute
William Sage, University of Texas at Austin
Hardeep Singh, Baylor College of Medicine

National Institute on Aging, Division of Behavioral and Social Research (BSR)

Lisbeth Nielsen, Director, BSR
Partha Bhattacharyya, Director, The Office of Research Resources
Prisca Fall, Health Specialist, Population and Social Processes Branch
Elena Fazio, Health Scientist Administrator
Melissa Gerald, Program Official
Amelia Karraker, Health Scientist Administrator
Chandra Keller, Social Science Analyst
Jonathan King, Senior Scientific Advisor to the Division Director
Priscilla Novak, Program Official, Population and Social Processes Branch
Georgeanne Patmios, Program Official, Population and Social Processes Branch
John Phillips, Chief, Population and Social Processes Branch
Dana Plude, Deputy Director

Board on Health Care Services Staff

Sharyl Nass, Board Director

Samira Abbas

Francis Amankwah

Alexandra Andrada

Erin Balogh

Lori Brenig

Bernice Chu

Jennifer Flaubert

Adrienne Formentos

Annalee Gonzales

Karen Helsing

Suzanne Le Menestrel

Tracy Lustig

Marc Meisnere

Tochi Ogbu-Mbadiugha

Sarah Robinson

Carol Mason Spicer

Nakita Varman

Roberta Wedge

Anesia Wilks

Emily Zevon

Other Participants

Dana Carluccio, Rose Li & Associates, Contractor

Kelly Clayton, Rose Li & Associates, Contractor