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MOVING TOWARD BETTER QUALITY OF CARE FOR PEOPLE WITH DEMENTIA

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ABSTRACT

Dementia and cognitive impairment, along with other conditions of the mind and brain, are the leading chronic disease contributors to dependence, and, in high-income countries, to transitions from independent living in the community into costly care homes. Consequently, governments are struggling to find ways to sustain high levels of social protection in the context of stagnant economic growth, aging populations, and rapidly increasing demand for cost-intensive services. Here we provide an overview of estimates for the cost of dementia care across a selection of high-income countries, evidence of best practice to promote care quality and research, and policy and practice recommendations for improving care. Evidence indicates there are concrete actions that can be implemented to improve the quality of dementia care. While high-quality care can be both complex and resource-intensive, systems and services must be made simple, seamless, transparent, and accessible to help individuals to live well with dementia.

INTRODUCTION

Dementia and cognitive impairment, along with other conditions of the mind and brain, are by far the leading chronic disease contributors to dependence, and, in high-income countries, to transitions from independent or supported living in the community into costly care homes (1). Projections based on current epidemiological evidence suggest that over the next 40 years, the number of people living with dementia will increase more than threefold from 44.35 million in 2013 to 135.46 million in 2050. Nearly half of those older people with needs for care are likely to be living with and experiencing the effects of dementia (1).

As a result, in high-income countries, governments are struggling to find ways to sustain the high levels of social protection that are the cornerstone of their welfare states (entitlement to pensions, benefits, and comprehensive health and social care) in the context of stagnant economic growth, aging populations, and rapidly increasing demand for cost-intensive services. There are some emerging data that suggest that age-specific dementia prevalence may be declining slightly, but, in terms of demand, this is more than outweighed by the increase in absolute numbers driven by population aging (2). There are significant consequences for expenditure in the future in terms of health care, long-term care, and for individuals with dementia and their families—even in scenarios where there is a marginal decrease in prevalence (3, 4).

Unlike most other long-term conditions, people with dementia can develop needs for care during the early stages of the disease, and they become increasingly reliant on caregivers throughout the course of the disease due to the progressive nature of the disorder (5). While older people can often cope well and remain reasonably independent even with marked physical disability, the onset of cognitive impairment quickly compromises their ability to carry out complex but essential tasks and to meet their basic personal care needs. This includes the frequent resistance to accept help that is particular to dementia, with a lack of insight into the disorder common. In a cohort study of Medicare recipients in the United States, the onset of dementia at 12 months was strongly associated with the onset of dependence by 36 months (adjusted odds ratio [OR] 7.5), with low body mass index (OR 6.1), psychiatric disorder (OR 4.5), stroke (OR 2.5), and obesity (OR 2.1) also being independently associated. The onset of coronary heart disease, cancer, hypertension, lung disease, diabetes, and hip fracture did not predict dependence (6). Similar findings were reported from a three-year follow-up of a population-based cohort study in Sweden, with dementia identified as the main risk factor for onset of functional dependence (7).

People with dementia receive care from a variety of sectors including health, social, and informal/unpaid sectors and are overrepresented among older users of those services. In the United States, people with dementia account for 37 percent of older people who use nonmedical home care services, at least half of attendees at adult day centers, and 42 percent of residents in assisted living and residential care facilities (8). In a U.S. study of older people who needed help with personal care or instrumental activities of daily living, those with cognitive impairment were more than twice as likely to receive paid home care and used the services twice as intensively as those without cognitive impairment (9). Approximately 30 percent to 40 percent of older Americans with dementia live in a care home, compared with just 2 percent of older adults without dementia (8).

Many, mainly high-income, countries are beginning to make significant progress toward the recognition of dementia as a health and social care priority, as evidenced by the development of National Dementia Strategies in countries such as France, the United Kingdom, Japan, and the United States with the National Alzheimer's Planning Act. There are only small differences in prevalence and care needs across high-income countries, and there is increasing recognition among governments that developing a continuum of care across the disease course for dementia is a high priority. There is, however, more variation across countries in terms of responses to tackle dementia. Differences in health and social care systems and underlying financing arrangements and resource allocation influence how dementia is identified, diagnosed, and treated, and countries vary in regards to policies around treatment delivery and balance of formal care services and reliance on informal (family) support.

This paper sets out to provide an overview of: 1) estimates of the associated costs of care for dementia across a selection of high-income countries; 2) evidence of best practice to promote the quality of care provided to people with dementia; and 3) research, policy, and practice recommendations for improving care for people with dementia around the world in general and in the United States in particular. Our review focuses on the following four areas for action:

- Measuring and monitoring quality;

- Promoting autonomy and choice (including advance care planning, making information available to consumers, incorporating service users' values and preferences, and making care person-centered);
- Coordinating and integrating care; and
- Valuing and developing the dementia care workforce.

OVERVIEW OF FINANCIAL COST OF DEMENTIA

The direct cost of dementia—that is, the cost of health care and other services—is measurable in principle. In most countries, when someone is admitted to hospital (or has another interaction with the health system), this event is recorded along with some information about the person, such as their age and gender, the reason for admission, or any other medical conditions. In theory, the cost of all the interactions linked to dementia could be added up to give the total direct cost. As will be discussed below, there are, however, problems when many with dementia are not recorded as having dementia, so there may be bias in estimates, and they may underestimate true costs.

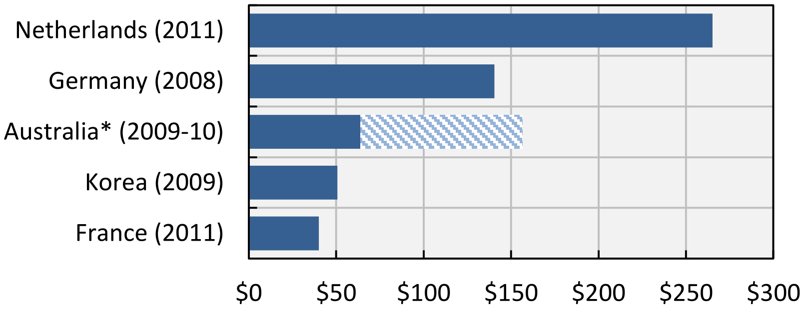
The System of Health Accounts (SHA) is a global standard jointly developed by the Organisation for Economic Co-Operation and Development (OECD) and the World Health Organization. It provides a framework for consistent international reporting of health expenditure (10). However, reporting by disease is still in its infancy, and while there has been progress in recent years, the resource requirements and technical challenges mean that dementia costs have only been measured in a handful of countries and for a subset of years. Here we examine the latest OECD data (for the Netherlands, Germany, and Korea) alongside similar estimates produced by others countries (Australia and France).

Dementia also has significant indirect costs, such as time spent by families on informal care. Informal care is not recorded, and it is not obvious how to assign a monetary value. Nonetheless, a number of studies have estimated these costs, for example by taking the results of small-scale trials and extrapolating to wider populations, and here we summarise some of the results.

The direct costs of dementia are driven by long-term care costs

As shown in Exhibit 1, of the countries with available data, the Netherlands has the highest direct expenditure on dementia, at over $250 per capita per year. It also spends the greatest proportion of its health budget on dementia (5.5%, compared to 3.7% in Germany and 3% in Korea).

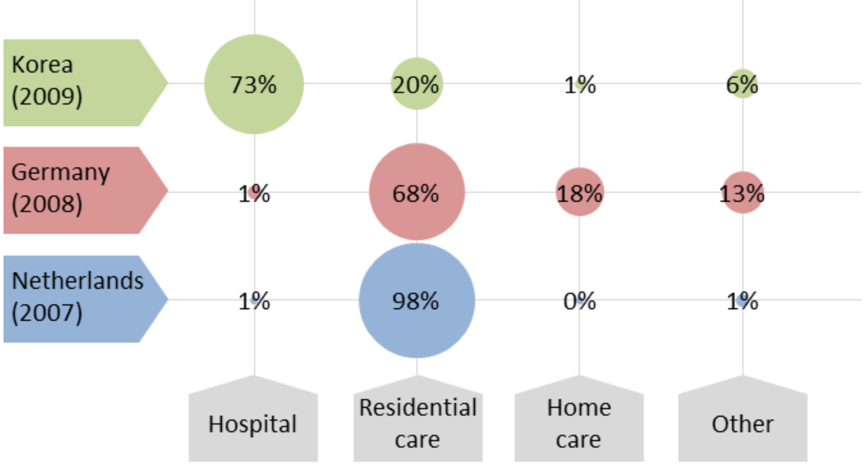
Exhibit 1. The Direct Costs of Dementia Across Five High-Income Countries (USD per capita, PPP)



* Australia: The dark bar represents costs directly attributable to dementia, and the light bar represents other expenditures on people with dementia.
Sources: OECD Health Expenditure by Disease (2014), CNAMTS (2013), Australian Institute of Health and Welfare (2012).

Differences between countries can be largely explained by their approaches to long-term care (broadly defined as help with activities of daily living and sometimes called social care). The Netherlands has one of the highest levels of long-term care expenditure among OECD countries, at 3.5 percent of gross domestic product in 2008 (10). The Netherlands has a high density of nursing home beds per older person, and these homes often provide high-quality care, including on-site geriatricians to monitor and treat chronic conditions (11). But this comes at a price, and, as shown in Exhibit 2, spending on residential care is the main driver of dementia cost in the Netherlands. Costs in Germany are spread across residential and community long-term care, while in Korea, a large proportion of long-term care is provided in hospitals (see Exhibit 2).

Exhibit 2. Proportion of Dementia Costs Accrued in Different Settings for Korea, Germany, and the Netherlands



While Exhibit 1 uses 2011 data for the Netherlands, the latest year that is split by care setting is for 2007.
Source: OECD Expenditure by Disease, Age and Gender (2014).

The cost of dementia is rising

With aging populations driving increases in dementia prevalence, the cost of dementia is rising. Direct costs in the Netherlands were €2.4 billion in 2005 but had risen to €3.7 billion by 2011; in Germany, costs have risen from €7.8 billion in 2004 to €9.4 billion in 2008. These increases have outstripped growth in other areas of health spending, so that the proportion of health spending attributed to dementia rose from 5.2 percent to 5.5 percent in the Netherlands and from 3.5 percent to 3.7 percent in Germany.

Existing collections may understate costs

Estimating costs by disease is complex, and these results should be treated with caution. In particular, there are a number of reasons to believe these results may underestimate the true cost of dementia.

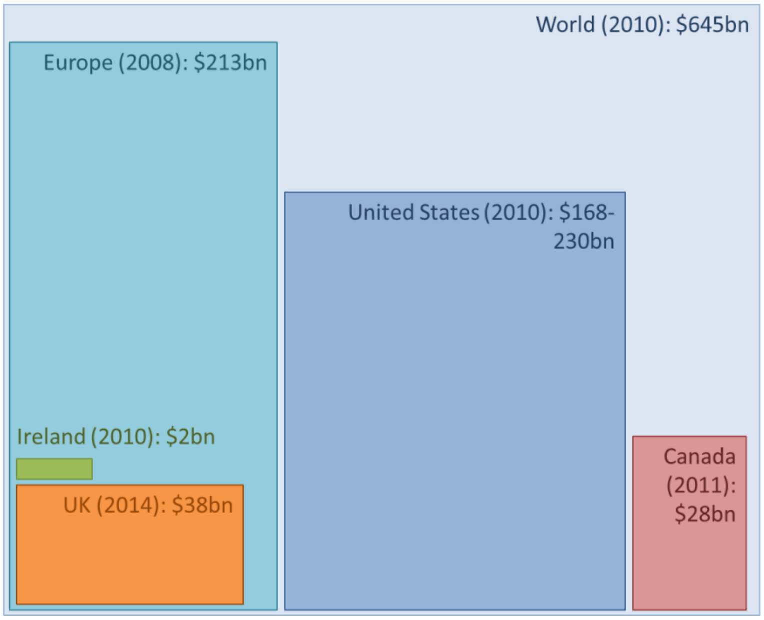
Dementia is underdiagnosed and under-recorded, with diagnosis rates in England estimated at less than half (12) and similar figures in other countries. Some people may have multiple comorbidities, and it is not always clear which is responsible for the cost, and some long-term care services do not classify people by medical diagnosis at all. As a result, much dementia expenditure may not be linked to the disease, and this might explain the low costs recorded for home care services. The coding of dementia is categorized in a disease category different from that of Alzheimer’s disease. This further complicates estimating the total direct cost of dementia. Meanwhile, a significant proportion of long-term care spending is out of pocket and may not be recorded by governments. Some countries explicitly limit their estimates to government or social security spending, so some dementia costs will not be included in the source data at all (13).

Addressing some of these issues will improve the accuracy of collections. However, while collating these data remains resource-intensive, it is unlikely that many more countries will report these costs regularly. Improvements to data systems and dementia diagnosis may make it easier to collate data in the future, and the ability to monitor the costs of conditions like dementia should be considered in the design of these systems.

Indirect costs such as informal care are at least as important as direct costs

Exhibit 3 summarizes some existing estimates of the total cost of dementia, including indirect costs such as informal care. There are considerable differences between the methodologies used and the types of cost included, so these numbers should be treated as indicative only. Nonetheless, the headline figures are broadly consistent and show that the global cost of dementia is huge—$645 billion.

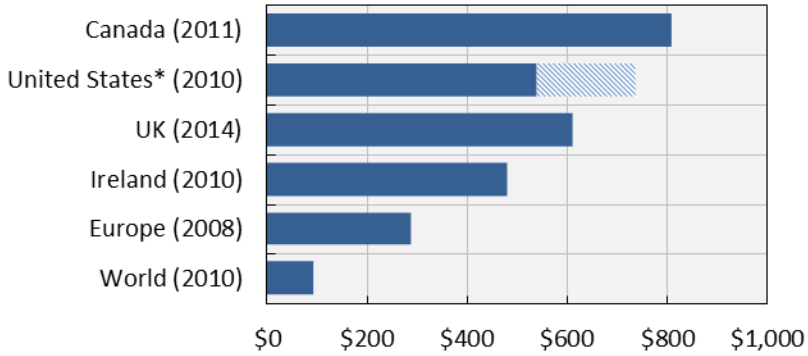
Exhibit 3. An Overview of Existing Estimates of the Total Cost of Dementia (USD, PPP, 2013 prices)



Sources: Wimo A, et al., 2013; Wimo A, et al. (2011); Connolly S, et al. (2014); Prince M, Knapp M, et al. (2014); Hurd, et al. (2013); Canadian Institutes of Health Research.

Exhibit 4 shows what these estimates imply in terms of cost of dementia per capita. A comparison with Exhibit 1 shows that these estimates are much higher than measurement of direct costs. Although the two sets of cost estimates are for different countries, total costs appear to be around three times as large. There are two possible reasons for this. First, as already discussed, the direct costs may be underestimated, but this will only account for part of the difference. The size of the difference implies that the indirect costs of dementia—especially the contribution of informal caregivers—are at least as important as the indirect costs.

Exhibit 4. The Total Cost of Dementia Per Capita, Based on Estimates From the Academic Literature (USD per capita, PPP, 2013 prices)



* United States: the study gives two estimates based on alternative methodologies for valuing informal care.
Sources: Wimo A, et al., 2013; Wimo A, et al. (2011); Connolly S, et al. (2014); Prince M, Knapp M, et al. (2014); Hurd, et al. (2013); Canadian Institutes of Health Research; UN World Population Prospects: The 2012 Revision.

EVIDENCE FOR THE QUALITY OF CARE PROVIDED TO PEOPLE WITH DEMENTIA ACROSS HIGH-INCOME COUNTRIES

Measure and monitor quality of care

To improve care quality, we need valid measurement tools that incorporate relevant indicators and are routinely collected. Assessment of care quality for people with dementia has mainly focused on regulating facilities to ensure safety and prevent harm and abuse, such as is done by the Care Quality Commission in England (14). Thus, indicators in relation to these standards may detect deficiencies, but may not identify centers of excellence. In the United States, the Centers for Medicare and Medicaid Services has developed a minimum data set of quality indicators for residents of care homes (15). These indicators are more outcome-focused and thus better equipped to identify good care; however, the outcomes tend to focus on biomedical processes and impairments and therefore may miss essential components of quality of care valued by residents and their family members. More recently, assessments are being implemented that focus on satisfaction with quality of care (see Exhibit 5). Innovative strategies have also been developed that look at the person holistic ally. Person-Centered Care prioritizes approaches that assess and optimize factors such as personal worth, agency, social confidence, and hope (16); however, evidence for real-world efficacy is still lacking. Dementia Care Mapping (DCM) is an observational assessment tool that promotes and evaluates implementation of person-centered care. A key component of DCM is the engagement of care staff to be active and accountable in the process of change. There is also ongoing feedback, analysis, and planning. This process is time- and cost-intensive, given the need for staff training, observation, data collection, and external consultants. There is a need to see if the insights from such approaches can be delivered in a more efficient manner using less highly trained staff for data collection and analysis. Assessments in the quality of life of people with dementia are also advancing. The DEMQOL system is an example of a measurement tool reflecting those areas that British people with dementia considered important to their quality of lives (17). Despite development and validation of the tool, we have little understanding of the determinants of quality of life for people with dementia, (1) but the evidence base is growing (18).

Exhibit 5. Assessment of Care Quality: UK Care Home Sector "Your Care Rating" Survey

Aim: To design and conduct an independent, confidential, and standardized annual survey of residents living in United Kingdom care homes to give them the opportunity to provide their views and feedback regarding the care they received (19).

Implementation: The initiative was driven by the U.K. care home sector, Your Care Rating, an independent, not-for-profit organization established for the purpose. The funding for the survey was provided by the care providers, 13 of whom joined the program in the first year, entering all of their care homes into the survey, covering more than 45,000 residents in over 850 homes. There were nearly 14,000 responses.

Evaluation: The questionnaire covered: living here (i.e., aspects of life and services in the care home); staff (focusing on care and support in the care home); and overall views. Overall performance ratings ranged from 0 (worst possible) to 100 (best possible). The average score across respondents was 87.5 (range: 82.5–91.3). However, for individual care homes, variation was greater (range: 54.2–100). The questionnaire also used the "Friends and Family" test (i.e., whether they would recommend the care home), which has now been rolled out across the British National Health Service as a key indicator of care quality. Responses were rated from 0 (not at all likely) to 10 (extremely likely). Fifty-nine percent rated 9 or 10, 45 percent rated 7 or 8, and 14 percent rated 0 to 6. Likelihood of recommending the home was most strongly associated with residents' perceptions that they had a real say in how staff provided care and support and that staff had time to talk with them. These data provide some reassurance regarding care quality; however, ratings may also be influenced by low expectations among family members and staff.

Strengths and weaknesses: The main strengths of the exercise are that the opinion of residents was sought directly, using a robustly developed and validated tool and demonstration of feasibility to obtain standardized information regarding care satisfaction. While ratings were generally positive, there was variation between individual care homes. This could help consumers select the best homes and help providers identify problems and improve standards. Weaknesses included a relatively low response rate, uncertainty around self-completion, and overrepresentation of those with more advanced dementia among nonresponders.

Future directions: A significant challenge will be rolling surveys out to cover the whole care home sector. Providers participating in the Your Care Rating survey were self-selected, and therefore the findings cannot be taken as representative of the U.K. care home sector in its entirety. Care quality standards may have been much worse among nonparticipating providers.

Promote autonomy and choice

As highlighted in recent reports by the U.K. National Institute for Health and Care Excellence, people with dementia and their caregivers should have more choice and control over decisions regarding their care and support (20). A key feature of such guidelines is advance care planning (ACP). Forms of ACP first appeared in the 1960s in the United States, but it was not until 1990 that they became more widespread, after the introduction of the Patient Self-Determination Act, stipulating that patients should be told by Medicaid and Medicare providers that they have the right to make an advance directive at time of admission (21).

A recent systematic review, including three studies that assessed health outcomes, provides some evidence for the effectiveness of ACP (22). In two studies, use of ACP was associated with a reduction of unnecessary hospital admissions (23, 24), and in one study there was a significant increase in hospice use in the ACP group (25). A more recent study showed that ACP resulted in having end-of-life wishes more likely to be followed, and, in particular, that ACP was associated with an improvement in caregivers' stress, anxiety, and depression (26). A key issue is whether individuals have the mental capacity to make the decisions needed in the end-of-life phase of the illness due to the progressive nature of cognitive decline in dementia. There is emerging evidence supporting incorporating ACP into the care planning in the initial phase of service contact when diagnoses are made, communicated to the person with dementia and to families. Following this, future care can be discussed. Evaluations suggest that this is acceptable to patients, families, and staff (27).

Making information available to consumers is also recommended. Nursing Home Compare (http://www.medicare.gov/nursinghomecompare/search.html), run by the U.S. government regulating authority, provides detailed information on every Medicare and Medicaid certified nursing home. The Alzheimer's Society in the United Kingdom has cast some light on family caregivers' use of information in locating a care home for a relative with dementia (28). One-quarter of caregivers interviewed reported finding it difficult to find a suitable home. Many caregivers (45%) stressed the importance of visiting the home and meeting with staff, and the care home providers were the leading source of information influencing choice of home (59%). A better understanding of the values attached by individuals to particular service configurations could inform more efficient resource allocation.

Coordinate and integrate care

Coordination, through case management, is a potential alternative to improve care and reduce costs. The Case Management Society of America describes case management as "a collaborative process of assessment, planning, facilitation, and advocacy for options to meet an individual's health needs through communication and available resources to promote quality cost-effective outcomes (29)." As care provision becomes more complex, an expert care adviser may help patients and caregivers analyze needs and preferences to identify the best options. Case management can thus improve quality of life and functioning and also reduce inefficient use of services. A systematic review of 12 randomized, controlled trials (RCTs), all conducted in high-income countries (30) concluded that there was some evidence to suggest case management may be efficacious in delaying institutionalization in people with advanced dementia; however, there was no evidence that it increased efficiency with which health services are used, and, at best, the economic impact on health care costs seems to be cost-neutral. A more recent review of case management in dementia, (31) which applied more stringent inclusion criteria, included six RCTs. The review found moderate evidence for a beneficial effect on quality of care, quality of life, and satisfaction with services. Evidence regarding impact on resource utilization and costs was again inconclusive. A compelling example of successful integration is the PRISMA model in Quebec, Canada (see Exhibit 6).

Exhibit 6. Canada's PRISMA Care Program: An Integrated Approach to Care

Aim: To develop an integrated service delivery that targets frail dependent older people in general as a way to improve efficiency and efficacy of health service use. Integrated delivery is critical for complex, often fragmented systems where there are multiple providers, competition, and choices to be made about which services to use (e.g., through personal care budgets), and thus a point of contact can help patients and families based on individual preferences and needs. Ultimately, this should improve clinical and functioning outcomes in addition to reducing inefficient use of health and social care resources.

Implementation: In the districts where PRISMA (Program of Research to Integrate the Services for the Maintenance of Autonomy) was introduced, a Joint Governing Board was established of all health care and social services and organizations from the public, private, and voluntary sectors. The Joint Governing Board is responsible for the governance, management, and delivery of all services. There is a single entry point for all PRISMA services via telephone contact or written referral. A case manager is responsible for conducting a needs assessment, planning the required services, arranging access to the services, organizing and coordinating support, directing the multidisciplinary team of practitioners involved in the case, and advocating, monitoring, and reassessing the patient as frequently as necessary according to the needs. Crucially, the case manager works for the local Joint Governing Board and is accredited to work in all institutions and services in the area.

Evaluation: In a four-year, quasi-experimental trial, this "coordination-type integrated service delivery system" was associated with reduction in functional decline (137 fewer cases per 1,000 in the intervention group at year four, $P<.001$), unmet needs (314 fewer cases per 1,000 in the intervention group at year four, *P*<.001), visits to emergency rooms (predicted probability over four years for intervention group 0.49 vs. comparison group 0.54, *P*<0.001), and an increase in service satisfaction (*P*<0.001). Empowerment scores also remained relatively stable in the intervention group (-1% change) compared to a decline in the comparison group (-12%) (32).

Strengths and weaknesses: This provides an example of a feasible and effective system-wide intervention and evaluation that improves dementia outcomes. Effective care coordination, however, depends on health and social care being integrated and care coordinators being empowered to work across all agencies, i.e., multisectorally, but also across public, private, and third sectors.

Future directions: Similar services are being developed in other countries. For example, the innovative MAIA system (Maisons pour l'autonomie et l'intégration des malades d'Alzheimer) will give every patient access to a local “one-stop shop,” and a specifically dedicated case manager will design an integrated plan of health and social care suitable for the patient. The plan aims to increase quality and integration of health and social care and is being rolled out nationally.

Develop, and value, the dementia care workforce

If people with dementia are to live life to the fullest extent possible, awareness, sensitivity, and skills are needed in all sections of the workforce and wider society (see Exhibit 7). This involves understanding and support from health, welfare, and social care agencies, not only specialist dementia services. Evidence suggests staff training programs can improve quality of dementia care in nursing homes (33). In the United States, however, the Institute of Medicine noted that while patient care had become more complex, the federal minimum of 75 hours of training for nurse aides had not changed since 1987, although many states had higher numbers of required hours (34). Home health aides had similarly low requirements. In the United Kingdom, the Care Quality Commission notes persisting concerns regarding the quality and coverage of training among frontline care home staff. One-quarter of registered nursing homes and 16 percent of residential care homes failed to meet minimum standards for training and supervision (35).

Analysis of standardized national full-time monthly wages for care professionals across 17 countries in Europe found only two countries (Denmark and Iceland) where workers in residential care with basic skills earned at least as much as the average worker. For almost half of the countries studied, wages were two-thirds or less than the average (36). The most direct consequence of the low profile, status, and valuation of direct care work is high staff turnover. In England, where national monitoring systems are in place, annual staff turnover is currently 19 percent, with a 3 percent vacancy rate—higher than all other industrial, commercial, and public-sector employment fields (37). A systematic review of 87 studies (1975–2003) indicated a significant relationship between high staff turnover and, among residents, lower functional ability, higher incidence of pressure ulcers, and greater weight loss (38). In analysis of longitudinal data, those homes with improving staffing levels and declining staff turnover rates tended to show greater improvements in the percent of residents experiencing indicators of adverse quality of care: subject to physical restraint, with indwelling urinary catheters; with moderate to severe pain; and with pressure sores (39). Given that in the United States, it is estimated that a 35 percent increase in formal health care providers will be needed by 2030, the existing problem with retention will be amplified if something is not done to improve remuneration and professional status (34).

Exhibit 7. Japan and the United Kingdom: Building Dementia-Friendly Communities
In a “dementia-friendly” community, shops and businesses, housing services, police, utility companies, banks, and lawyers would all have a part to play. Perhaps the most visible and hopeful signs of progress in this regard are the national “Dementia Friends” programs rolled out in Japan (4 million friends recruited and trained in the past eight years) and more recently in the United Kingdom where free coaching is being provided to 1 million people “to spot the signs of dementia and provide support to people with the condition, whether that is a friend, family member, or someone you meet through your job” (http://www.dementiafriends.org.uk/)

RESEARCH, POLICY, AND PRACTICE RECOMMENDATIONS

Some progress is being made toward improving the quality of dementia care across high-income countries, and the systematic assessment of satisfaction with services will help us to track advances**.** There are, however, several areas where we could improve care. Earlier diagnosis enables the person with dementia to make decisions about the care that they will receive, through advanced care directives, which are still underutilized. Personalized care budgets put people with dementia and their caregivers in control of their packages of care and empower them to ensure that their preferences are respected and their needs met. The United States is leading the way in terms of investment in research, but early diagnosis and person-centered care approaches are still underutilized. Moreover, we currently have problems with retention of trained staff, and challenges with recruitment will increase in the future if we do not do something to improve remuneration and professional status.

There are several research, practice, and policy recommendations that could improve dementia care in the United States and other high-income countries. In relation to research/practice, we note four key recommendations: (1) promote early diagnosis as a way to facilitate involvement in care decisions and advance care planning; (2) integrate case managers more into the process of planning, commissioning, and governance to best facilitate effective and efficient coordination and integration of care; (3) promote better understanding of the relative merits of improved compensation versus other strategies for improving the quality and professional status of the jobs; and (4) perform systematic assessments of service satisfaction and quality outcomes (including quality of life and person-centered care elements) and incentivise collaboration and data sharing among institutions and with the public.

In relation to policy recommendations, we have identified five key recommendations: 1) caregivers (paid and unpaid) should be valued by society for the essential, difficult, and demanding care that they carry out and should be recompensed appropriately; 2) policymakers need to pay more attention to dementia as being at the root cause of care needs given its prevalence as an underlying condition among those in long-term care; 3) comprehensive and sustainable long-term care policies, which consider elements of formal and informal care arrangements, and, in particular their integration, are needed rather than piecemeal policies that respond to immediate political or financial problems; 4) dementia policies need to be developed with input from all relevant stakeholders to ensure that care is developed around the needs and preferences of people with dementia and their caregivers, in addition to being evidence-based; and 5) as recommended by the OECD, “It would not be prudent for policymakers to count on future reductions in the prevalence of severe disability among elderly people to offset completely the rising demand for long-term care that will result from population aging.”

CONCLUSION

Evidence reviewed in this paper indicates that there are concrete actions that can be implemented to improve the quality of care and support for people with dementia and their caregivers, from the time of diagnosis and throughout the course of the illness. While good-quality dementia care can be both complex and resource-intensive, systems and services must be made as simple, seamless, transparent, and accessible as possible. Families may need to be guided and supported in accessing information and exercising choice, with case managers playing an important role. The key guiding principles of measuring and monitoring quality, promoting autonomy and choice, improving coordination and care integration, and valuing and developing the dementia care work force are critical areas that can help achieve the aim of living well with dementia.

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