

# Age-friendly Health Systems for Older Adults With Dementia

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## ABSTRACT

Today, millions of Americans age 65 and older are living with dementia. With the progressive decline in cognition and the incurable nature of Alzheimer's disease and other dementias, patients experience multiple complex conditions and are not able to choose their care priority. In this study we review the unique challenges related to dementia faced by older adults with dementia, their families, and the health system in the United States, and we propose to address or alleviate such issues by building evidence-based, age-friendly health systems for older adults with dementia, including improving patient priority care and transitions and coordination among different care settings.

**Keywords:** age-friendly health systems, aging, Alzheimer's disease, dementia, patient preferences

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## INTRODUCTION

### Dementia and Alzheimer's Disease

Dementia is a general term for a progressive decline in cognitive functioning to a certain degree that impacts an individual's daily life. It is not a certain disease but a syndrome with a group of symptoms and multiple causes.<sup>1</sup> The key symptoms of dementia include the progressive decline and eventual loss in cognitive skills, such as memorizing, thinking, reasoning, and speaking.<sup>1</sup> The impairments of cognitive function are commonly accompanied by deterioration in emotion and social behavior control and other chronic health conditions.<sup>1-3</sup>

Alzheimer's disease (AD) accounts for 60%-80% of dementia cases,<sup>3</sup> and other types of dementia include vascular dementia, dementia with Lewy bodies, and frontotemporal dementia, etc.<sup>4</sup> As the sixth-leading cause of death in the United States, AD gradually worsens over time and is ultimately fatal.<sup>4</sup> AD and other dementias (ADOD) can adversely impact an individual's life in multiple ways as the disease progresses and can be divided into 3 stages:

- Early stage: Individuals may forget familiar vocabularies or daily commutes.<sup>5</sup>

- Middle stage: Individuals start confusing words, behaving unexpectedly, or being emotionally unstable.<sup>5</sup>
- Late stage: Individuals lose the ability to respond to daily activities and need round-the-clock personal care.<sup>5</sup>

### THE DEMOGRAPHY OF DEMENTIA

Today, it is believed that there are 5.5 million Americans who are living with ADOD in the US, including 5.3 million people age 65 and older.<sup>6</sup> According to a population report from the US Census Bureau, the population of older adults (aged 65 and older) is expected to reach 88.5 million in 2050, a nearly 2-fold increase in this age cohort compared with 2010.<sup>7</sup> During this period, the estimated number of older adults with ADOD will reach 13.8 million.<sup>6</sup>

In 2012, World Health Organization (WHO) recognized dementia as a public health priority.<sup>2</sup> A report from Alzheimer's Disease International states that 12 experts provided prevalence estimates of dementia for all 14 WHO regions after systematically reviewing published studies on dementia. Experts estimated that, globally, the number of people with dementia was 24.3 million

in 2001 and is expected to reach 81.1 million by 2040.<sup>8</sup> This will likely result in an immense health issue with increasing economic burdens to health care systems worldwide.<sup>2</sup>

Dementia is incurable and has an irreversible and progressive disease course. According to data analyzed by the National Center for Health Statistics, AD is recognized as the sixth-leading cause of death in the US and the fifth-leading cause of death among older adults, with a dramatically increased mortality risk among the eldest. The mortality rate of older adults with AD showed escalated rates among the oldest-old, given those aged 85 years and older were 50 times more likely to die from AD when compared with their 65- to 74-year-old cohorts.<sup>9</sup>

## CHALLENGES

### Dementia as a Challenge for Older Adults

Older adults with dementia are affected by the deteriorating progression in multiple ways. Another major issue involves the other chronic complex conditions that come along with dementia, including insomnia, falls, bone fractures, frailty, and disturbed behavior. A report from the Alzheimer's Association indicates that 95% of individuals with ADOD live with at least 1 other chronic health condition.<sup>10</sup> In addition, due to the impaired memory and the loss of cognitive skills, older adults with ADOD lose the ability to follow medication and nutritional instructions, and to conduct self-management, which is considered a key skill in dealing with chronic complex conditions.<sup>10</sup>

With the diagnosis of ADOD, older adults are expected to spend nearly half of the time in the most acute stage, with an average life expectancy of 4-8 years.<sup>5,11</sup> It thus leads to older adults living in a long-term state of disability and dependence with multiple other chronic conditions.<sup>1,3,12</sup>

Another critical issue is that the majority of care for older adults with dementia is focused on treatment of the disease itself in spite of the person's unique care preferences and needs to have a good quality of life. Many patients have already lost the ability to make care or treatment decisions after the diagnosis of dementia. For instance, 1 study indicated that, although the majority of dementia patients wish to die while living in their own home,<sup>13</sup> most will die

while in acute care in hospitals where they might not receive the customized care that meets their individual needs, or they will die in nursing facilities where there may be lack of systematic management, staff training, or emotional support for the patient and family.<sup>13</sup>

### DEMENTIA AS A CHALLENGE FOR FAMILIES OF OLDER ADULTS WITH DEMENTIA

In the US, family members and other unpaid caregivers account for 83% of the care provided to older adults with dementia.<sup>14</sup> National Survey of Caregiving data from 2011 show that 18 million family members and other unpaid caregivers provided care to 9 million adults, with nearly half of these caregivers (8.5 million) providing care in the informal community-based environment.<sup>15</sup>

Family caregivers of patients with dementia face unique challenges, as the personality and the behavior of older adults with ADOD are affected as the disease progresses. Caring for a family member with ADOD is associated with increased physical,<sup>13</sup> emotional,<sup>3</sup> and economic stress,<sup>16</sup> and can result in a significant shift in those family caregivers' health-related quality of life.<sup>3,16</sup>

In terms of the physical health conditions, family caregivers of older adults with ADOD are found to be less likely to engage in preventive health behaviors,<sup>13</sup> and to have decreased immune function.<sup>17</sup> Studies have shown that family caregivers of those with dementia are more likely to have self-reported poor health or illness.<sup>18,19</sup>

Regarding emotional stress, research shows that family caregivers of those with dementia are more likely to be exposed to depression, insomnia, and anxiety than caregivers of patients with other conditions.<sup>3</sup> Moreover, these caregivers report feeling isolated and lacking support programs and available resources.<sup>18</sup> It is alarming that there are a number of evidence-based support programs for dementia family caregivers, but health organizations rarely use them due to a lack of comprehensive knowledge about such programs.<sup>20,21</sup> Further, the family caregivers receive little training but are expected to manage complex medical tasks while caring for older adults with dementia (eg, assisting in planned physical exercise, giving injections, or following complicated

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