Dementia Village Viability Within the Current U.S. Healthcare System

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Dementia villages are an emerging form of residential long-term dementia care. The aim of these facilities is to provide a de-institutionalized residential setting and promote independence among residents who have dementia. Dementia villages have been expanding globally, but have not yet been established in the United States. The objective of this paper is to research dementia villages and determine their viability in the U.S and potential changes to the current U.S. healthcare system that would increase dementia village feasibility. Research analyzed studies that evaluated dementia village facility attributes and costs were extracted from the Genworth Cost of Care Survey and Medicare, Medicaid, and state-specific Medicaid websites. It was found that dementia village facilities have attributes that can contribute to improved quality of life, improved behavioral and psychological symptoms of dementia, and reductions in medications and hospitalizations. However, neither Medicare nor Medicaid would be able to sustain the U.S. estimated costs for dementia villages ($12,000 per resident per month). More research needs to be conducted to evaluate the cost-effectiveness of dementia villages to persuade Medicare or Medicaid to alter their existing payment structures to accommodate dementia villages and to offset the projected high costs.

Keywords: dementia village; Hogeweyk; Avandell; hospitalization; assisted living costs.

Background

In the United States, there are several established senior care options for dementia patients. In the early stages of the disease, home care, assisted living, or memory care might be suitable. As the disease progresses, however, a long-term nursing home residence may become necessary if other forms of care prove inadequate. Currently, fewer than five percent[1] of nursing home beds in the US are in dementia special care units, and only four percent[1] of nursing homes care almost exclusively for dementia residents. When considering the prospect of nursing home entry, many seniors fear the stereotypical nursing home: stark white walls, isolation from loved ones, and the loss of individual freedom.

One possible solution lies in dementia villages, potentially a new public health breakthrough, which have begun to emerge across the globe. All residents in the village have dementia. Dementia villages are available for people with all stages of dementia. In the villages, dementia residents are accompanied by specially trained aides. Under the leadership of founder Jannette Spiering, the world's first ever dementia village, Hogeweyk, opened in 2008 in Weesp, Netherlands. Hogeweyk's main goal? Normalize the dementia village environment and reduce stigma surrounding the dementia community. In essence, dementia villages are a more creative solution to some of the pitfalls of regular nursing homes, and they provide a more comfortable, home-like, and stigma-free dementia care environment.

Although there is currently no established research proving whether or not dementia villages have substantial medical or long-term benefits, early research, such as that being done in a dementia village in France, can give global dementia village stakeholders insight into whether or not such establishments are worthwhile.

Methods

This paper gathered data about currently existing dementia villages by extracting information from the respective dementia villages' websites. Key search terms included: "dementia village", "Hogeweyk", "Avandell", "nursing home hospitalizations dementia", "nursing home costs", "assisted living costs", "hospitalization costs dementia", and "issues with nursing home care dementia". Targeted information was extracted by the aforementioned key search terms from PubMed and Google Scholar. Predicted costs of nursing homes and assisted living facilities were taken from the annual Genworth Cost of Care Survey[2]. Information about the U.S. healthcare system with respect to dementia care was gathered from the Medicare, Medicaid, and state-specific Medicaid websites[3–6] in order to analyze payment options.

Results

Hogeweyk

Dementia village Hogeweyk strives to recreate a realistic living environment while allowing residents to maintain their personal freedoms [7]. Hogeweyk is a small (4 acre), anachronistic village set in the 1950s and is home to 188 elderly residents. The residents share restaurants, gardens, a grocery store, pub, theater, cinema, and hair salons. Founder Jannette Spiering places an emphasis on staying away from the semblance of a hospital; she doesn't want people believing they are in a hospital, which is suggestive of needing treatment for an acute illness. This means that the trained aides and staff at Hogeweyk remove the white coats and instead wear regular street clothes. In each of Hogeweyk's 27 homes, six to seven residents live together and have access to a living room, kitchen, bathrooms, a laundry room, private bedrooms, and an outdoor space. Additionally, residents can choose different housing themes, such as "homey," Christian, craftsman, arts and culture, aristocracy, Indonesia/colonial (interested in nature, spirituality, and Indonesian food), or urban, depending on where residents feel most "at home." Many residents and their family members like the idea of the comforting and humanizing care the dementia village can provide and for good reason: according to Hogeweyk officials [8], after a few weeks, residents improve dramatically, becoming calmer and requiring less medication.

Other Dementia Villages

Inspired by the Netherlands' Hogeweyk, several other countries have opened their own dementia villages. Like Hogeweyk, dementia village Carpe Diem in Baerum, Norway focuses on reducing stigma surrounding dementia by enabling the village to be open to the public. NewDirection Care, a dementia village in Bellmere, Australia, has the goal of integrating younger residents with dementia into the community. Village Landais in France is a dementia village combined with a Resource and Research Center where research is being conducted to assess the effectiveness of dementia villages. While there are no dementia villages in the U.S. that are currently open, Holmdel, New Jersey may hold the key to the U.S.'s entry into the dementia village realm. With a planned opening of the Avandell facility in the next two or three years, the dementia village will house 105 residents in 15 homes with a farmhouse aesthetic (to reflect the rural surroundings), will have a town center with a grocery store, bistro, and community center, and a planned neurocognitive clinic and senior resources hub, which will offer services to the public. Families will be offered training to provide better care for their loved ones while at home. Avandell is projected to cost residents $12,000 per month [9]. Ten percent of its 105 beds will be reserved for New Jersey state Medicaid residents [9].

Environment

The physical environment of the dementia village is ideal in that it eliminates hospital-like attributes [10]. Modeling dementia villages after Hogeweyk would mean that there could be different house "themes" that residents can choose from that most directly match their home style preference. A study [11] has demonstrated the importance of maintaining a sense of "home" and familiarity in order to establish belonging, meaningfulness (in life), safety and security, and autonomy. A meta-analysis [11] found that people in long-term care defined belonging as being familiar with the setting and being "in the right place". Reflecting on the long-term care environment, persons with dementia claimed that the ability to become familiar with a setting depended on how well they felt accepted by the other residents and healthcare personnel, their ability to maintain contact with family and uphold familiar activities, as well as the loosening of rules to promote individuality. In order to maintain meaningfulness in their lives, some residents in long-term dementia care facilities preferred to participate in social activities, while others longed for privacy. People with dementia emphasized that being familiar with the environment was important to maintain daily activities and retain some sense of independent living. In one study [12], familiar feelings within an environment were correlated with a decrease in wandering behaviors. Safety and security in a long-term care facility meant familiar, calm, and peaceful surroundings. "Old-style" interiors provided a sense of security and comfort [13]. Autonomy was defined as the ability to maintain well-known activities, as well as being able to retain independence and self-expression, accept dependence but still be included, and have the opportunity for connection [14]. Reflecting these study findings, Hogeweyk understands the importance of familiarity. Based on its ability to let residents choose between different home styles, have access to the outdoors, participate in regular and familiar activities (excursions to the grocery store, hair salons, restaurants), and have a social life (sharing a house with a small number of residents), while also maintaining privacy (private bedrooms), it allows residents to maintain a sense of belonging, meaningfulness, safety, security, and autonomy [15]. Being able to share living spaces with other individuals may help residents reduce feelings of isolation and loneliness. Additionally, having designed space specifically for individuals with dementia, residents' living spaces are not susceptible to crowded places, excessive noise, and a change of landmarks, all which reduce feelings of accessibility and lead to difficulty in carrying out activities in public spaces among people with Alzheimer's [16].

A study has suggested that smaller units with a noninstitutional environment and fewer crowding gave less behavioral challenges among residents with dementia. There has been evidence that single rooms with individual and home-like characteristics, personal furnishing, and objects led to less psychiatric

symptoms[17]. Gardens have also been shown to result in positive effects on quality of life, and behavioral and psychological symptoms of dementia[18,19]. The dementia-friendly village style promotes independence and outdoor exploration, and thus physical exercise. Studies have shown that more independence with performing activities of daily living (ADL) positively affects cognitive, physical, and mood outcomes[11,20]. Exercise has also been shown to reduce behavioral and psychological symptoms of dementia such as depressed mood, agitation[21], and wandering[22]. Extended periods of time (30 minutes) walking several times a week can enhance these positive results[23]. Some studies, however, did produce a contradictory null result for the effect of exercise on behavior, psychological, and cognitive symptoms of dementia[24,25].

At Hogeweyk, where 100% of residents have dementia, there have been reports of significant improvements in residents' well-being ever since the village switched to the village format, which exhibited many of the environmental characteristics defined above. Once Hogeweyk transformed from a traditional long-term care model to the current village model, the proportion of residents on antipsychotic medication decreased from 50% during 1993 to less than 10% in 2022[26]. A study found that being able to engage in everyday activities, specifically eating out, going to the cinema, and shopping, is an important aspect of maintaining a normal life[27]. Since their community is solely dementia-based, Hogeweyk provides residents with these opportunities and eliminates the risk of stigmatization of individual with dementia.

Larger Dementia Resident to Overall Resident Ratios—Medications and Hospitalizations

Costs - Medicaid

In evaluating dementia village viability, analyzing costs is essential. Of course, Hogeweyk is not offered for free. The cost of care is nearly $8,000 per month. However, unlike the private-pay market of the U.S., the Netherlands, along with the rest of Europe, has socialized medicine. Thus, Hogeweyk is subsidized by the Dutch government to varying degrees, and residents pay on a sliding scale[28]. The amount that each individual family pays is based on income, but never exceeds $3,600 per month[29].

Costs for care in a dementia village in the U.S. would be high. Resident costs at Avandell are projected to be $12,000 per month—a large increase from the current U.S. average monthly cost for memory care facilities of around $7,000[30], although the cost varies geographically. Ten percent[30] of spots are reserved for Medicaid recipients; however, it is still unclear how much of the cost would be covered by Medicaid.

If Medicaid considers dementia villages to be assisted living facilities, there would be minimal financial support for residents and families under the current payment structure, as Medicaid generally does not cover assisted living. Some state Medicaid programs do provide assisted living waiver (ALW) programs. A specific dementia village would need to become eligible as a facility that accepts ALWs. There are facilities with some features similar to Hogeweyk's dementia village that have become eligible for ALW programs. One example in California is Lafayette Gardens memory care[31], which has home-like interiors (although without customizable themes like Hogeweyk), private bedrooms, and care providers that undergo dementia care certification programs. Outside of the ALWs, and without Medicaid support, residents and families would have to pay out of pocket.

Costs - Medicare

The more common form of payment supplements would be from Medicare since the benefits are provided based on age (65 and older) rather than income (like Medicaid). Medicare benefits, however, are limited, as a benefit period only covers up to 100 days. For those living with dementia seeking long-term care in a dementia village supplemented by Medicare, the financial aid is limited. With Original Medicare, the first 20 days in a care facility are fully covered. From day 20 through 100, Medicare continues to cover the costs, but not fully; members are required to pay copays of $200 each day that they stay in the facility[3]. If Medicare considers dementia villages as skilled nursing facilities (SNFs), then Medigap plans can fully cover (Medigap plans C, D, F, G, M, and N) or partially cover (plans K or L) these $200 copay amounts[4]. However, to renew a Medicare benefit period (100 days), the member has to have a medically necessary inpatient hospital stay of three consecutive days[5] or more. Most likely, Medicare does not consider dementia villages SNFs[6], and thus would not cover dementia villages[32]. Dementia villages would be considered long-term assisted living. Neither Medigap nor Medicare Advantage plans cover assisted living.

Lack of Established Research

With so few dementia villages available globally, there is nearly no existing established research on their effectiveness[33]. France's Village Landais is one of the first to pioneer research projects to document the benefits of dementia villages[34]. Village Landais has a Resource and Research Center which "[brings] together French specialists in Alzheimer's disease and the training of health professionals and medico-social care in order to disseminate best therapeutic practices"[35]. Researchers[35] are calling on village residents, relatives of residents, professionals, and volunteers, and administering questionnaires and interviews across five separate occasions spaced six months apart. Researchers[35] are exploring the world of dementia villages and investigating several inquiries: Does Landais' Alzheimer's village have a positive impact on its residents' quality of life, social participation, and health? Does it improve the quality of work-

ing life for professionals in the caregiving industry? Is it based on a viable and reproducible model? A medicoeconomic study assessing the cost-effectiveness of the establishment is included in the research.

Discussion

"Home-like" interiors and living with other dementia residents where residents receive specialized care seem to be beneficial. Although correlative, but not necessarily causative, currently existing nursing homes with dementia village attributes have seen decreases in hospitalizations and antipsychotic medication use. Though dementia villages are not nursing homes, the positive results of increased proportions of residents with dementia in long-term care facilities suggests that dementia villages would be beneficial to residents because the facilities would be occupied solely by people with dementia. In dementia villages, residents may receive more highly differentiated care than in a standard long-term facility, such as in a nursing home. It is possible that the large populations of dementia residents call for more specialized aides who can provide better care for dementia residents. In dementia villages, the village administrators train caregivers to properly care for residents with dementia. Villages like Hogeweyk have mentioned that even their store staff are trained on how to interact with dementia residents. If dementia villages were to become more prevalent, residents could consider moving into dementia villages even in their mild stages of dementia in order to become better familiar with the environment and to develop belonging, meaningfulness, safety, security, and autonomy before the disease becomes more severe and the ability to develop that familiarity is lessened.

Although trends such as decreased hospitalizations and higher-skilled nursing hours documented in nursing homes with higher proportions of residents with dementia may not necessarily be generalized to dementia villages, the fact that dementia villages also have high proportions of residents with dementia—one hundred percent of residents have dementia—and a high proportion of highly specialized aides suggests that dementia villages could also demonstrate similar improvement results. In fact they have, at Hogeweyk.

Hogeweyk is more manageable cost-wise because the Netherlands has socialized medicine. Taxes supplement the care payments. In the U.S., however, assisted living memory care is mostly privately paid. For dementia villages to be successful and accessible in the U.S., the government would need to subsidize the costs facing residents and their families. If substantial research into the effects of dementia villages compared to other forms of dementia care reveal a significant improvement in the lives of people with dementia or improvement in dementia care costs to the government (less hospitalizations or less medication), then this would help to create a more convincing argument for the government to consider the investment in dementia villages. In France, researchers at Village Landais and its Resource and Research Center are emerging as dementia village research pioneers. When it opens, Avandell in Holmdel, New Jersey, could consider including a research aspect in its launch because researchers would be able to analyze the effects of dementia villages on residents under U.S. conditions and determine whether more dementia village facilities would be worthwhile and cost-effective.

If Medicaid considers dementia villages to be nursing homes, there is a chance that Medicaid could provide some financial aid for Medicaid residents. However, the projected cost for Avandell is around $12,000 dollars per month. If dementia villages are considered, by Medicaid standards, to be an assisted living-type facility, residents will receive no subsidies under the current payment structure. Thus, for dementia villages to be viable in the current U.S. healthcare system, beyond a structural overhaul of the dementia care payment system, dementia villages would either need to be considered a nursing home, to receive Medicaid benefits, or the dementia villages would need to apply for assisted living waivers. The other option would be for Medicare to start covering the dementia village form of care. However, since dementia villages would be considered assisted living rather than any SNF, it would be difficult for long-term dementia village residents to use Medicare benefits that require a benefit period renewal process of hospital admittance because dementia village residents would not be moving in and out of hospitals and the dementia village. Thus, the most financially beneficial strategy would be to obtain an Medicaid ALW program for a dementia village facility.

Hogeweyk was the original dementia village and inspired other countries to open their own. Public health officials globally should investigate the viability of dementia villages in different areas of the world. Ideally, public health officials and researchers should consider why more countries with existing dementia villages haven't opened new facilities and whether or not dementia villages are actually sustainable. Further experimental research is required to assess dementia villages and their impact.

Conclusions

Currently available research suggests that dementia villages would be beneficial to the health and well-being of residents with dementia. Whether or not they would realistically work in the U.S. healthcare system requires an analysis of cost. Realistic analysis of the costs and current healthcare payment system suggests that Medicare or Medicaid would have to subsidize costs to make dementia villages accessible to the larger populus. Dementia villages could be beneficial in the U.S., particularly if the costs were partially or even wholly subsidized by the government. This is unlikely, however, since Medicare currently doesn't cover assisted living or long-term care besides SNFs,

and Medicaid does not cover assisted living that is not eligible for a waiver program. More research needs to be conducted to establish the efficacy of dementia villages in improving the well-being of residents with dementia in comparison to existing care facilities. If persuasive research is gathered, Medicare or Medicaid may be more likely to alter their payment structure to accommodate dementia villages.

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