# Making the Case for Centralized Dementia Care Through Adaptive Reuse in the Time of COVID-19

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#### Abstract

It is estimated that 5.4 million Americans have some form of dementia and these numbers are expected to rise in the coming decades, leading to an unprecedented demand for memory care housing and services. At the same time, infectious disease outbreaks like the COVID-19 pandemic have raised great concerns for the future of care settings for people living with dementia. In searching for innovative options to create more autonomy and better quality of life in dementia care settings, while at the same time improving infectious disease control, repurposing existing structures, in particular vacant urban malls, may be one option for the large sites needed for the European model of dementia villages. This editorial paper makes the case for the Dementia Friendly City Center model for centralized dementia programs, medical services and housing. By working across multiple disciplines, this research team has simultaneously addressed numerous issues, including community revitalization, building sustainability, and the strengthening of infectious disease control in care sites which are inclusive, progressive and convergent with the needs of an aging population.

#### Keywords

dementia care, infectious disease control, adaptive re-use, person-centered care, small house model, skilled nursing facilities, Alzheimer's disease, housing, vulnerable populations, COVID-19

What do we already know about this topic?
The double societal hit of dementia and COVID-19 have raised concerns for dementia care.
How does your research contribute to the field?
Dementia-friendly initiatives support inclusive and enabling environments.
What are your research's implication toward theory, practice, and policy?
Mall adaptive reuse offers potential for spatial expansion needs for dementia care with expanded infection control.

### Introduction

The double societal hit of dementia and infectious disease outbreaks like the COVID-19 pandemic has raised great concerns for the future of institutional care settings for people living with dementia.<sup>1</sup> In addition to improved safety precautions for infection spread, it is imperative that mental health and psychosocial support be concurrently delivered, calling attention to the urgent need for alternatives to traditional care settings.<sup>2</sup> Globally, more than 50 million people have dementia, and one new case occurs every 3 seconds.<sup>3</sup> Without a known cure, dementia has emerged as a pandemic in an ageing society.<sup>4</sup> It is estimated that 5.4 million Americans have Alzheimer's disease or some form of dementia and this number is expected to rise in the coming decades leading to an unprecedented demand for memory care housing and services.<sup>5</sup>

Memory care settings specifically focus on long-term skilled nursing care services for activities of daily living (ADL) and support individuals with Alzheimer's disease, dementia and other types of cognitive impairment.<sup>6</sup> Prevention and management of infections are vitally important in these facilities, as infection is the leading cause of morbidity and

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mortality among the 1.7 million residents of U.S. care facilities. Between 1.6 and 3.8 million infections occur each year, with almost 388 000 deaths attributed to infections, resulting in significant costs estimated from \$673 million to \$2 billion.<sup>7</sup> Yet the confined living arrangements (2 if not sometimes 3 or 4 residents to a room), combined with understaffing and failure to comply with infection-control guidelines, are associated with high infectious disease rates in memory care and other skilled nursing settings.<sup>8,9</sup> The challenge for our nation's long-term care system is to determine how to (further) reduce rates of infection and hospitalization and whether alterations in facility characteristics can play a role in that reduction, while at the same time supporting quality of life for residents with dementia.<sup>10</sup>

#### Background

Evolving pressures in contemporary U.S. cities include density, affordability, and the need for strengthening of community, and for individuals with dementia and their families, the burden of living with dementia in this context can be overwhelming.<sup>11</sup> Once family caregivers no longer feel competent in their caregiving role, the individual with dementia may be institutionalized, leading to many negative outcomes; (i.e., becoming further disconnected from home, family, community and meaningful activities).<sup>12</sup> Activities which stimulate of a sense of well-being, create a sense of personal fulfillment and promote both physical and mental health create daily meaning.<sup>13</sup> Although it is imperative that vulnerable populations are provided care settings which allow for personal fulfillment, memory care settings more often are known as places of isolation and depression.<sup>14</sup> Dementia care organizations, therefore, face a range of daunting environmental changes and challenges.

Infectious Disease Control in U.S. Nursing Homes. Internationally there is a long history of efforts to improve quality of care and life for individuals with dementia in memory care settings.15,16 The resident population in care settings consists of very frail and susceptible elders, many with chronic comorbidities. Disease outbreaks occur frequently, endemic rates of infection are substantial, and antibiotics are often inappropriately prescribed, increasing the susceptibility to antibiotic-resistant organisms.9 According to inspection data from the Centers for Medicare and Medicaid Services (CMS), the federal agency that regulates these settings, affected facilities span 35 states. In particular nursing homes with higher cases and deaths from COVID-19 are more likely to have been given low ratings in the CMS rating system, therefore facilities with poor infection control compliance history or poor survey history are more likely to have larger outbreaks.17

Zimmerman et al<sup>10</sup> analyzed 12 dimensions of infection control in care environments, including the physical environment of the facility, medical services, therapeutic service frequency, activity services, staff and family involvement, philosophy of care with respect to aide integration, resident autonomy, specialized dementia care services, administrative priorities, physical and psychotropic restraint use, as well as resident, staff and visitor activity/interaction.

This suggests individual intrinsic capacity may be augmented by combining empowerment provided by the physical/technological environment, the support of the caring/ social environment and treatment through medical means.<sup>10</sup>

*Current Memory Care options*. Barrett et al<sup>18</sup> describe a holistic approach to dementia care in which the impact of all these dimensions need to be individually targeted in specific environments. This is, of course, how people experience daily life - not in discrete environmental elements, but through their combined impact.<sup>17</sup> These interrelationships indicate the challenge in memory care environments is to provide residents appropriate settings for social interaction in order to buffer against social isolation, while encouraging autonomy and proactive responses to personal competency changes.<sup>19</sup> In light of the images of older adults confined to a single or shared room in a care facility due to COVID-19, autonomy becomes the overarching problem, not only because in general institutions limit the freedom of frail elders, but because the existential conditions that create the need for long term care in the first place. Chronic disease, cognitive decline, and the need for general support with activities of daily living (ADLs) rail against the autonomy of independent selfsufficiency.<sup>20</sup> While frail elders share distinct needs,<sup>21</sup> past institutional settings are generally characterized by social distance between residents and staff, with the requirements of organized routines trumping personal preference and choice issues.<sup>22</sup> Additionally, these environments are institutional in design and size, with little access to outdoor spaces and other amenities.<sup>23</sup> Filling these gaps is crucial if the holistic approach set out above is to be operationalized; therefore, we propose a broad intervention using the Dementia Village care precedent developed in the Netherlands.

The Netherlands Dementia Village. The Dementia Village opened in Holland in 2009, offering a new care model providing medical and psychosocial care in a community setting without the hospital facade. Several other European countries have since adopted this model.<sup>24</sup> The Dementia Village model allows for autonomy and continuation of patterns of daily living through housing integrated with large exterior walks and gardens, restaurants, grocery store, pub and theater. The Dutch Dementia Village encompasses 4 acres in familiar and normal surroundings, reducing resident anxiety and fear.<sup>25</sup> This pioneering health care experiment negotiates rivaling discourses of intimacy, professionalization and medicalization, while allowing the general community to take part in programs and amenities like the restaurant, bar and movie theater onsite.<sup>26</sup> Residents continue to receive the daily stimulation from the things they enjoy like exercising outside and attending classes and clubs, while simultaneously having access to the medical attention they may need.<sup>27</sup>

To date, there have been no other developments at the scale of the Dementia Village model in the United States, as dementia care providers may not have the appropriately sized property to offer multiple activities and advanced medical services for residents, nor the funding to develop them. Providers are also concerned about the bottom-line development and building costs associated with new construction for a care setting the size and scope of the Dementia Village. A solution, therefore, may relate directly to the perennial challenge of medical administrators, planners and designers: *how do we design with what we have?* 

#### The Dementia Friendly City Center Model

Repurposing existing structures, in particular vacant urban malls, provides one option for the large sites needed for developments similar to the Dementia Village. Enclosed mall settings may become sustainable Dementia Friendly City Centers (DFCC), as internal infrastructure is in place for lighting, heating and cooling systems, with varied spatial configuration of public spaces. Malls were built to provide sensory stimulation, safety, comfort, convenience, and social interactions.<sup>28,29</sup> Baby Boomers met friends at malls, learning about diversity in goods and people.<sup>30,31</sup> America's peak mall years were from the 1960s through the 1980s, By 2005, there were 1500 malls creating a per capita excess of retail space.<sup>32</sup> Due to the 2008 economic downturn and online shopping, current forecasts suggest 10% of the nations enclosed malls will close by 2022.30 Communities all over America are rethinking these properties and determining whether to rehabilitate, re-tenant, refinance and reposition the property, or tear down the structure and rebuild other place types.32

Mall demolition is costly and demolition-waste in landfills is environmentally unsustainable. Regulatory and financing structures for vacant malls are evolving to allow more of these properties to be productively repurposed.<sup>33</sup> Consequently, options for property owners and developers for closed commercial sites include mixed-use developments and medical facilities.<sup>34</sup> Currently there is significant discussion throughout the healthcare industry and governmental agencies about the possibility of converting existing hotels, dormitories, classrooms/schools, community centers, convention centers, or other large unoccupied commercial buildings into COVID-19 or general patient care spaces, as the economic impact of the current pandemic continues to negatively affect commercial retail establishments.<sup>35</sup>

Repurposing Malls for Dementia Friendly City Centers. The delivery of healthcare services is site based, requiring physical space for physicians, nurses, administrators, etc. to provide medical care and attention. This space consumes financial resources which otherwise could be directed toward patient care. Savings are possible through adaptive reuse, permitting more resources to be directed toward fulfilling mission critical activities.<sup>36</sup> Adaptive re-use of malls for the DFCC model addresses these issues in a centrally located venue, with variable opportunities created for a medical center, art and music venues, indoor/outdoor garden spaces, theaters and dining areas, and attached housing. Core medical services and programming may be funded by local, state and federal funds, similar to those available for the national Program for All Inclusive Care for the Elderly (PACE). Similarly, public/private funding may be offered by larger medical or physical/occupational therapy providers. Multiple levels of care may be provided in attached housing linking with core services and integrating into the larger DFCC. The result would be a completely accessible, secure, mixed-use city center with onsite advanced medical services.<sup>37</sup>

Reducing Staff Turnover for Improved Infection Control. In biomedical terms, dementia is not a disease, but a syndrome produced in large part by diseases such as Alzheimer's, Parkinson's and vascular disease, with a cluster of symptoms and signs linked to the deterioration of cognitive abilities as a person ages.<sup>38</sup> People living with dementia need help with their daily activities to enable them to live safely and with dignity. Central to the ethics of dementia care is enhancing well-being and making the most of a person's present strengths.<sup>21</sup> Similar to the Dementia Village housing, rather than large, open double-loaded corridors with shared rooms and bathrooms seen in traditional nursing care, the DFCC attached housing will be comprised of multiple households of 6 to 12 residents, with each household having its own kitchen, living room, dining room and single resident bedrooms with attached bathrooms. This small house (SH) concept is organized in a way that personal care is integrated into daily routines, so daily life is as normal as possible. This means that health care staff perform care tasks as well as domestic tasks such as cooking and cleaning.<sup>39</sup> SH nursing care is beneficial for the physical and psychosocial wellbeing of residents and has elicited great interest among policy, provider, and research stakeholders, offering an alternative to traditional nursing home care. This model is consistent with the "culture change" movement by focusing on personcentered care and deinstitutionalizing care settings.<sup>40,41</sup>

With respect to infection control, the consistent assignment of universal worker direct care staff, and the SH built around a central living area, allow familiarity with residents, as only care staff who work in each household may enter, reducing the number of prospects for infectious disease transmission. Compared to other models, direct care staff in the SH report being more familiar with residents and better able to detect changes in resident condition earlier.<sup>42</sup> Furthermore, previous studies show that staff working in SH care models experience more job satisfaction, a higher motivation, and less burnout than staff working in regular nursing homes.<sup>43</sup> As staff become engaged with their SH universal

duties, they often build a sense of empowerment, resulting in lower turnover rates.<sup>44</sup> This is important, as studies of the relationship between rates of infection, and infection related hospitalization document that a variety of process characteristics relate to the care staff turnover. Care staff that get to know residents better due to more contact are better able to observe changes in individual physical and mental health. It has been reported that with respect to registered nurse (RN) turnover, with each proportionate loss of an RN (per FTE/100 beds), the risk of infection increases almost 30% and the risk of hospitalization increases more than 80%.<sup>10</sup> Furthermore, high turnover rates make it difficult to establish and maintain effective infection control policies; a problem that intensifies in care facilities that do not require immunization of new employees.<sup>8</sup> Another infection control study reported that 48% of hospitalizations from 3 care facilities could have been avoided with better staff training, more diagnostic services, less pressure from staff and family for transfer, and better nurse-physician communication.45 The interrelationships between these variables reflect a socio-medical philosophy of care.

#### Community and Student DFCC Work

Information concerning care organizations is important for national and local directors and staff providing care. This knowledge can be used for the development of improved care methods and is essential for policymakers to decide which factors need special attention and could be simulated.43 While commercial adaption research for medical care has been previously conducted, there currently is no literature specific to repurposing closed mall environments for dementia programs and services like the Dementia Village. In response to this need for identification of the organizational, accessible and sustainable practices for the DFCC model, this research team is developing a set general design guide lines for communities grappling with closed mall properties, the need for sustainable building practices and the continuing need of individuals with dementia and their families for integrated dementia programs, housing and medical services with improved infection control. Community engagement for this initiative began when university students and community members in a Midwestern town took part in a 3-day design charrette to initiate design decisionmaking in repurposing mall environments for dementia housing, programs and services. A daylong follow-up workshop took place with the recruitment and programmatic input from interdisciplinary community stakeholders from memory care and medical fields, architects, landscape architects, state health employees, social workers, and family caregivers. Through the community recommendations and university student teams' graphic work, the design groundwork has been laid for an initial site for the DFCC prototype (Figure 1). Further stakeholder focus groups are planned to include participants recruited through the community workshop and these 5 groups are to include: (1) caregiver/care recipients, (2) hospital administrators, (3) home health/community care team, (4) architects/developers, and (5) current assisted-living residents.

Scope of the Redevelopment. Using an existing 800 000 sq ft. enclosed mall site, the DFCC prototype designs include an integrated medical complex which will provide general medical care, as well as infectious disease control with a specialized medical and quarantine unit. This unit is located at the lower section of the site with separate access with room and facilities to accommodate up to 100 quarantined individuals. This will allow for an onsite option to quarantine residents in the event of a future infectious outbreaks. These units have specific requirements for environmental separation for air, power, water, and support spaces to reduce cross-contamination between spaces.<sup>35</sup>

Also included in the design are a supermarket, library, full-service restaurant and several outdoor areas for eating and socializing. Pedestrian streetscapes with secure entrances from adjacent housing and appropriate shade and wayfinding are incorporated throughout. The removal of several sections of the existing roof provides secure indoor/outdoor spaces and large courtyards, a key factor in therapeutic design for individuals with dementia. Three levels of memory care are proposed, including independent living apartments for care-giver/care recipient dyads, assisted living and 24/7 memory care. The assisted living and memory care are designed in the SH model of care.

#### Discussion

Separately and together we can work to deliver a greatly enhanced effective capacity for the person to live well with dementia. Hope lies in the reality that interventions in these areas can make a difference.<sup>18</sup> Particularly in light of the recent Covid-19 outbreak, as a nation, we are now much more aware of the fine line between providing one of our most vulnerable populations a secure setting in a medical emergency, while at the same time seeing the value in the creation of environments which address an individual's psychosocial needs on a day to day basis. The DFCC model is one option for optimal aging, with the aim of lending a stronger voice to those with dementia and their families. Allowing family members the option to live onsite in the independent living housing will create a sense of normalcy for residents who are in need of increased medical and psycho-social services, yet there are questions regarding outcomes for these family members as their loved ones care needs change. These and other questions on more global issues such as sustainable building practices, re-greening urban landscapes, revitalization of urban centers, and the economic impact of these issues will be addressed in the broadened focus group research.

Future project output will be the development of DFCC design tools and methods, with a comprehensive checklist of



Figure 1. Adaptive re-use of closed mall for dementia friendly city center prototype.

factors relating to the design and application of the model for a replicable prototype. It will be important to ensure that the programs and amenities can be used by the residents living there, as well as the community at large. This will require exploration of opportunities to overcome the current regulatory and resource constraints and provision of resources for policy makers to help develop the public health infrastructure and public-private partnerships.

#### Conclusion

Ultimately, the DFCC model realized has the potential to provide a connected health and wellness community system for individuals with dementia and their families. At the same time, its effectiveness and health impact should also be evaluated through the lens of infectious disease control practices. It is hoped that continued design and research on this new place-type will allow for the re-thinking of the way that building re-use and blended urban landscapes support and integrate vulnerable populations into the larger community.

While advancing the model can be seen as an investment not just for older adults now, but for ourselves in the future, it is clear there will be hurdles encountered throughout the process of its development. Often it is problematic to introduce an innovative idea without an understandable precedent or proto-type. As a society changed forever by the implications of the Covid-19 disease outbreak, awareness of the fine balance between the core benefits of an individual's autonomy versus the health of an entire institution or community has been highlighted. Educating current and future stakeholders about *what can be*, rather than *what is*, is imperative when developing dementia care settings with improved infection control which are inclusive, progressive and convergent with the needs of an aging population.

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