

Community Visioning for Innovation in Integrated Dementia Care: Stakeholder Focus Group Outcomes

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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. In searching for innovative options to create more autonomy and better quality of life in dementia care settings, repurposing existing structures, in particular vacant urban malls, may be 1 option for the large sites needed for the European model of dementia villages. These settings may become sustainable Dementia Friendly City Centers (DFCC), because in the case of enclosed mall construction, the internal infrastructure is in place for lighting, HVAC, with varied spatial configuration of public spaces. This paper describes the community engagement research being conducted by a research team at a Midwestern university, laying groundwork for the DFCC model for centralized dementia programs, services, and attached housing. Using graphics and plans for the DFCC model using an 800 000 ft² closed mall site, focus groups were conducted with family caregivers of individuals with dementia and long-term care residents to gather their input and response to the model. The participants identified both opportunities and barriers in using an adaptive reuse of a large site for an innovative integrated dementia care model and through the cross-case analysis of the focus group findings, 5 themes were identified which include: community education and acceptance; amenities and activities; maintaining family connections; resident adaptation and staffing.

Keywords

dementia, focus groups, geriatrics, long term care, qualitative methods

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Introduction/Background

The double societal hit of dementia and infectious disease outbreaks like the COVID-19 pandemic have raised a convergence of concerns for the future of care settings for people living with dementia.¹ 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.² 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.³

People living with dementia need help with their daily activities in order to enable them to live safely and with dignity, therefore central to the ethics of dementia care is enhancing well-being and making the most of the strengths that are still present within the person.⁴ Yet those living with

dementia may be institutionalized, often with negative outcomes, as the individual with dementia becomes further disconnected from home, family, community, and activities with daily meaning.⁵ These institutional environments are often confining in design and size, with little access to outdoor spaces and other amenities.⁶ While it is imperative that vulnerable populations are provided care settings which allow for support of their physical and mental health, dementia care settings more often are known to increase resident isolation and depression.⁷ The aim of this focus group research is to address opportunities and barriers to a proposed new model

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of dementia care integrating medical care, housing and multiple amenities such as a grocery store, shops, and classrooms, along with outdoor areas for walking and gardening for social interaction as well as autonomy.

In light of COVID-19 images in the media of older adults in care settings confined to a single or shared rooms, autonomy is starting to be seen as an overarching problem in care settings, not only because institutions limit the freedom, but because the existential conditions that create the need for care rail against the autonomy and self-sufficiency.⁸ Barrett et al⁹ describe a holistic approach to dementia care in which the impact of multiple dimensions are individually targeted in specific environments, and one example of this is the European Dementia Village model.

The original Dementia Village opened in Holland in 2009, offering a new care model providing medical and psychosocial care in a community setting without the hospital façade. Several other European countries have since adopted this model which allows for autonomy and continuation of patterns of daily living through housing integrated with large exterior walkways and gardens, restaurants, grocery stores, pubs, and theaters.¹⁰ The Dutch Dementia Village is home to 150 residents and encompasses 4 acres in familiar and normal surroundings, with multiple households of 8 to 10 individuals. These residents live in a secure setting with access to the medical attention they may need, while continuing to receive the daily stimulation from exercising outside and attending classes and clubs.¹¹

To date, there have been no other developments at the scale of the Dementia Village model in the U.S., as 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 costs associated with new construction for a care setting this size. A solution, therefore, may relate directly to the perennial challenge of care providers, planners, and designers: *how do we design with what we have?*

In the healthcare industry, adaptive reuse—the practice of identifying, acquiring, renovating, and placing back into service a building or similar structure for a purpose different than that for which it was originally designed—offers great potential for addressing the spatial expansion needs of healthcare establishments in a unique and mutually beneficial manner.^{12,13} Similarly, adaptive reuse of commercial properties may prove to be a viable option for the large sites needed for the Dementia Village model.

Significant discussions have come out of the COVID-19 pandemic throughout the healthcare industry and governmental agencies about the conversion of existing hotels, community centers, convention centers, and other large unoccupied commercial buildings into quarantine or general patient care spaces.¹⁴ In particular, reuse of vacant

urban malls may provide sites and space for mixed-use developments which include programs, medical services, and attached housing.

Malls are buildings or complexes of buildings designed and built to contain many interconnected activities in different areas.¹⁵ Yet due to the 2008 economic downturn and the advent of online shopping, current forecasts suggest 10% of the nation's 1500 enclosed malls will have permanently closed by 2022.¹⁶ In addition, the economic fallout from COVID-19 has had a substantial impact on those retailers that were already in dire circumstances before the current pandemic hit, possibly resulting in higher rates of closures than previously forecasted.¹⁷

Consequently, property owners and developers are looking for other options for closed malls,¹⁸ and currently several existing case studies demonstrate the environmental and social benefits that make adaptive reuse of malls attractive to a variety of stakeholders.¹⁹⁻²¹ For example, Vanderbilt University Medical Center expanded its size—approximately 440 000 square feet—by converting mall space into an additional campus with outpatient facilities, offices, an employee childcare center, and a fitness center.¹⁹ Other malls are being redeveloped into mixed-use (hotels, gyms, apartment complexes, and grocery stores) lifestyle centers.¹⁹

Adaptive reuse of a closed mall properties provides enormous opportunities to provide centralized settings for individuals with dementia and their family which include housing, programs, and services. This proposed model has been labeled a Dementia Friendly City Center (DFCC) by the authors, as malls are centrally located with multiple space types for amenities which go well beyond traditional Continuing Care Retirement Community or memory care settings. Malls environments provide the existing internal infrastructure for lighting, heating, and cooling systems, with varied spatial configuration of public spaces.¹⁵ In addition, malls sites provide ample space for onsite core medical services, as well as a quarantine center, enabling medical personal to make decisions that address testing, isolation, and infection control onsite in the event of future pandemic scenarios. These and other medical services may be provided by a local healthcare network and other site programming may be funded by local, state, and federal funds. In order to better understand the opportunities and barriers to adaptive reuse of malls for the DFCC model, the researchers conducted a series of stakeholder focus groups. This paper provides the results from two of these focus groups, one with family caregivers and the other with older adults currently living in assisted living. The research questions which align with these focus groups include:

1. What are the key organizational factors necessary to create a viable city center solution for residents living with dementia using an existing mall structure?

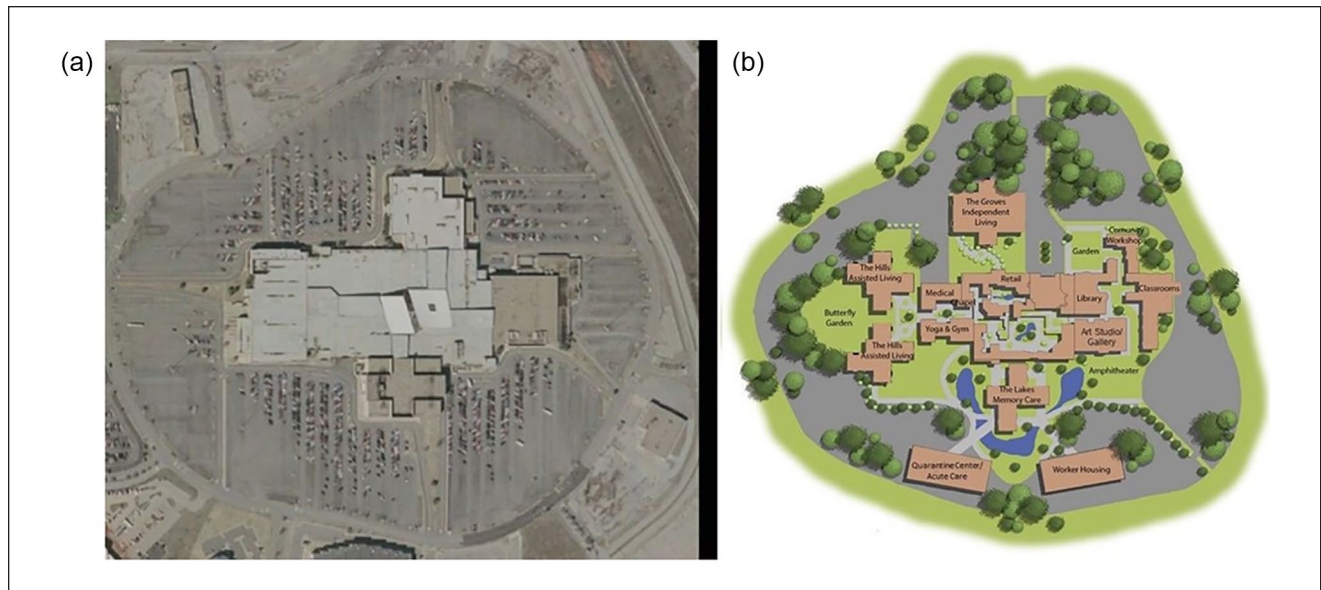


Figure 1. (a) Existing case study site and (b) conceptual site plan.

2. What are the space types and amenities which could be housed in a DFCC and how can they be integrated with housing to create a walkable, accessible community?
3. What are the types of innovative community public/private partnerships which can be created (ie, community gardens, library, intergenerational classrooms, medical offices, etc.)?

Methods

Research into the DFCC initiative began with community engagement activities to explore opportunities for use of underutilized real estate assets in the community. A working group of stakeholders in healthcare, design, and development identified several vacant or partially closed mall sites that could align with community needs with respect to location, size, and layout.

A closed 800 000 ft² mall located in a mid-size Midwestern city ultimately was chosen to serve as a case study site for further investigation. This mall site originally opened in 1974 and ceased operation in 2017 after several failed attempts at re-branding. DFCC conceptual designs were developed for this site and the site amenities in the designs included are a supermarket, library, full-service restaurant, and several outdoor areas for eating and socializing. Pedestrian streetscapes with secure entrances connect adjacent housing and the removal of several sections of the existing roof provide large secure courtyards. The conceptual site plan includes an integrated medical complex to provide general medical care, as well as a specialized medical and quarantine unit. Three types of

purpose-built memory care housing are proposed, including independent living apartments for caregiver/care recipient dyads, assisted living, and 24/7 memory care. Similar to the Netherlands Dementia Village, all are housing and care buildings are connected to the city center amenities through pedestrian walkways (See Figures 1 and 2).

Following the development of DFCC case study plans and renderings, a community stakeholder workshop was held with approximately 60 individuals from backgrounds such as design, medicine, public health, and memory care. In addition, family caregiving and assisted living residents were in attendance. Following the workshop, interested participants were invited to participate in a series of focus groups for stakeholder feedback and this paper focusses on the outcomes from assisted living residents and family caregivers' participants.

Stakeholder groups within communities provide a source of resilience, access to support, opportunities for participation, and added control over their lives; they have the potential to contribute to psychosocial well-being and as a result to other health outcomes.²² The intent of focus groups is not to infer but to understand and provide insights about how people in groups perceive a situation.²³ Each focus group session was 1 h in length and included at least 4 participants. The focus groups were conducted at a community conference center and the same researcher led each of the sessions. The protocol for this study was approved by the University Institutional Review Board (IRB). Participants received written information sheets about the research and consent forms to sign if they wished to participate.

The family caregiver focus group was comprised of 2 male caregivers and 2 female family caregivers. The

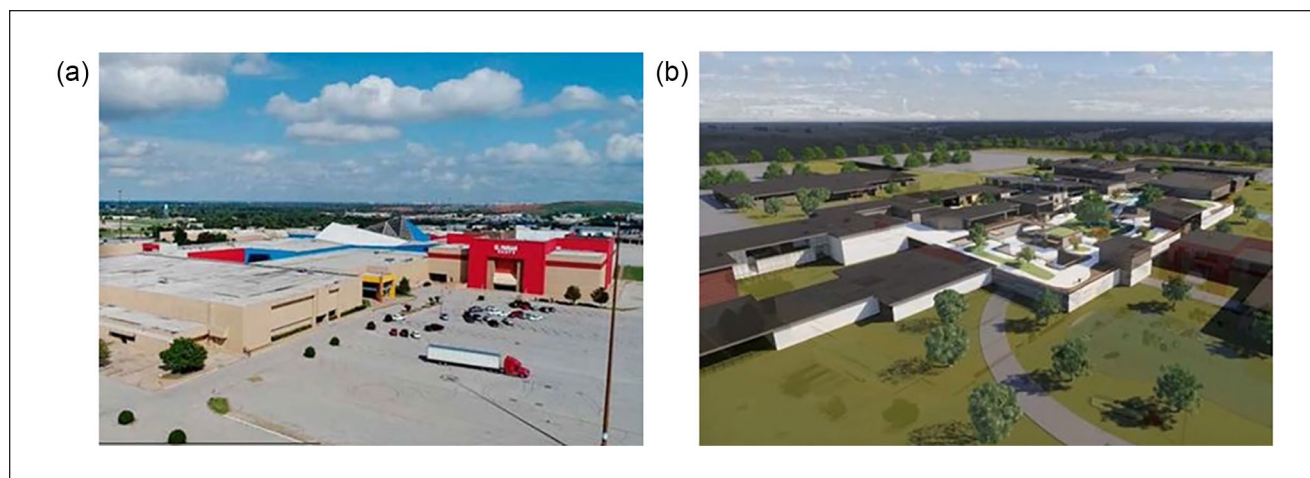


Figure 2. (a) Birdseye view of existing mall site and (b) conceptual model.

Table 1. Focus Group Questions.

Number	Question
1	Can you please share your initial reaction to the Dementia Friendly City Center concept?
2	Please share any experiences that you have with a family member with dementia
3	Please share your experiences in care facilities for you or a family member
4	What are the opportunities which you see in retrofitting existing enclosed malls for projects such as the Dementia Friendly City Center?
5	What are the barriers which you see in retrofitting existing enclosed malls for projects such as the Dementia Friendly City Center?
6	Using the case study mall site in the images on the easels, what are your ideas for additional amenities for the Dementia Friendly City Center?
7	Using the case study mall site in the images on the easels, what are your ideas for housing types to be included in the Dementia Friendly City Center
8	Would you consider moving to or having a family member move to a site similar to the Dementia Friendly City Center?
9	Please explain your reasons for the answer to 8, whether yes, no, or not sure
10	Would you like to be a part of further research and discussions for this and future dementia care models?

assisted living resident focus group consisted of 4 male residents and 4 female residents. The participants were asked open-ended semi-structured questions regarding adaptive reuse of the case study mall for a DFCC and the complex issues for a project of this scale. Each participant had an opportunity to answer all of the 10 protocol questions and there were follow-up questions when a specific topic needed further investigation or detail (See Table 1). The questions and answers were audio recorded, then transcribed verbatim. An inductive content analysis was then used,²³ with words, sentences, or strings of words that conveyed the same meaning assigned to essence-capture the codes. This allowed new themes to emerge from the transcription. Strategies used to enhance the trustworthiness of the findings included all researchers participating in coding, categorizing, and triangulating the findings. Disagreements in these processes were solved by discussions and consensus

between the researchers. Quotes from participants were used to illustrate the themes and to keep the interpretation closely linked to the original data. Numbered pseudonyms based on the 2 focus groups (ie, Assisted Living 1, AL1, Caregiver 3, CG3) were then assigned to participants to ensure their confidentiality. Codes were then compared in a cross-case analysis between the 2 focus groups based on the frequency of their use during the focus group sessions.

Results

Following the focus group transcription and cross-case analysis, several themes regarding opportunities' and barriers to the DFCC were identified, with the 5 major themes being: community education and acceptance; amenities and activities; maintaining family connections; resident adaptation; and staffing (See Table 2).

Table 2. AL/CG Shared Focus Group Themes

Theme	Definition	
	Discussion of the barriers and opportunities for the Dementia Friendly City Center (DFCC) model of care	Example
Community education and acceptance	Discussion relating to the need for community education for acceptance of the DFCC initiative	I think these conversations need to be a part of our culture. You don't go "whoops tomorrow I'm going to need to be in a facility." Somehow rather it needs to be education between both the family members and the person about the realities of all of this and the options. What is dementia friendly? We need to be more succinct, making sure that your definition is the same as my definition.
Amenities and activities	Discussion relating to the types of amenities and activities appropriate in the DFCC model of care	Having people that are running a shop or a doggy daycare or an art class will help out both the residents and the caregivers I'm thinking that you've got to have psychological sources available. Yeah, something for us, for everyone.
Maintaining family connections	Discussion relating to the potential for maintaining family connections through the DFCC model of care	I like the concept because I'm at a point where my wife's living in a memory care facility and I'm living in my home and my home is outgrowing me and I need to do something different. But at the same time, it would be nice if we could both be in the same place you know, even to find somewhere in an apartment around the block. If we're both in the same place I can walk and see her. I can go have dinner with her all the time without having to drive.
Resident adaptation	Discussion relating to the issues relating to resident adaptation in the DFCC model of care	People don't want to take the step to the next level of care because they see it is a step toward their mortality Financially being able to afford this kind of care would be difficult, my husband is on Medicaid and we haven't found a place that we both agreed would be good for him What concerns me about the open spaces I see in the DFCC, I had a family member with dementia and in open spaces she often couldn't remember where she was
Staffing	Discussion relating to the staffing of the DFCC model of care	Training, hiring, and then keeping the staff that enjoys the work and wants to come to work at 11 o'clock at night and get off at 7:00 in the morning. That's the hard part.

Community Education and Acceptance

In general, the participants expressed a need for community education about dementia and dementia care settings. Several participants highlighted the necessity to increase public awareness about dementia in order to promote people's acceptance of the DFCC project. AL1 said:

I think these conversations need to be a part of our culture. I just finished helping a friend of mine to go into a care facility, helped her children put her in. But for probably five, six years we have urged her to go into the care facility. You don't go "whoops tomorrow I'm going to need to be in a facility." There needs to be education between both the family members and the person about the realities of all of this and the options.

Similarly, CG1 described the general need for initiatives to support caregivers and care recipients:

As a city, we are going to need to make an effort to train people that work at banks and restaurants and the general community

about dementia. Then we can bring our husbands and wives and go around in our city. If it's a dementia friendly city hopefully we won't feel ostracized.

CG2 did report that the phrase "*Dementia Friendly City Center*" might not be clear to the public. He commented, "What is dementia friendly? We need to be more succinct, making sure that your definition is the same as my definition." Despite this concern, all focus group participants expressed an acceptance of a number of positive benefits in the DFCC initiative and praised its potential usability. AL4 spoke of her personal reaction to the initiative, "This sounds like a place I'd rather be than in a hospital setting situation." She continued to describe her reaction in being introduced to the Dementia Village precedent for the first time:

When I saw something like this called the Dementia Village I thought it was absolutely wonderful to see the people strolling outside after watching people in our current system of memory care. The outside areas in the Dementia Village are

just tremendous. People were walking around with their pets and there were lots of green trees, that kind of thing, I was thrilled.

AL2 agreed that the open concept of the DFCC model creates benefits for the residents:

Most of our experience with memory care is a room with one or two people in them and they're just one next to the other and a dining room and that's it. And it's terrible. . .but this idea where it is open, it's just tremendous and it's hard to comprehend, but it's great.

CG4 described the project as a "eutopia" for older people and had a very visceral reaction, "I really like the Dementia Friendly City Center concept. When I first saw it, I said, 'that works.'"

Amenities and Activities

All participants commented on the potential for an abundance of amenities and activities in the large DFCC site and many felt that the site could accommodate the wants, needs, and preferences of residents helping them live with the highest sense of normalcy. In particular, there was appreciation that the site would support walking and wandering in a safe setting. CG4 noted the importance of a safe, contained setting:

To have a safer place that has things contained and it is all gated, this would be ideal. For us [the person with dementia and the caregiver] it's really important to be physically active. And that's hard because a lot of the resources don't take that into consideration at all.

Participants had ideas for a wide range of amenities and activities for residents, such as a massage therapist and pet shelter. Other suggestions included farm activities such as a small working area to have livestock such as cows and chickens, while others thought amenities with décor to align with their life in previous decades would be beneficial.

Many participants remarked on the opportunities to provide amenities to serve the staff and the surrounding community such as a school, children's playground, and affordable housing for staff. In addition, having community members be a part of the DFCC would create more of a village atmosphere, as AL2 put it, "Having people that are running a shop or an art class will help out both the residents and the caregivers."

All participants stressed the importance of having medical and psychiatric facilities on-site which would serve residents, staff, and the wider community. CG1 said, "I'm thinking that you've got to have psychological sources available. Yeah, something for us, for everyone."

Maintaining Family Connections

Because the DFCC initiative proposes having independent living apartments as one of the onsite housing options, the participants discussed the benefits of family members being able to live in the same place or in the vicinity of care recipients in order to maintain family relationships. Some caregivers proposed housing which could accommodate other family members as well spouses in order to preserve and promote normalcy their lives. CG1 described the benefits this way:

I like the concept because I'm at a point where my wife's living in a memory care facility and I'm living in my home and my home is outgrowing me and I need to do something different. But at the same time, it would be nice if we could both be in the same place. That way I can walk and see her. I can go have dinner with her all the time without having to drive.

CG2 agreed, "Yes, just to be able to drop by and say hello and not feel like we're walking in to a facility."

Resident Adaptation

Despite positive perceptions of the DFCC, the participants did express many areas of concern about the initiative. Several participants questioned the feasibility of accommodating people with all types and stages of dementia, as levels of care needs change dramatically as the disease progresses. While the DFCC houses several housing types for specific stages of dementia, some participants were worried that residents may not want to move to a different section when their disease advances. AL7 put it this way, "People that I know are going to have to move somewhere else because of their changing needs, but they're clinging to their apartments for dear life. Literally!" AL5 mirrored that by saying, "People don't want to take the step to the next level of care because they see it is a step toward their mortality." To overcome come this issue, AL4 suggested adopting an easy and smooth transition process, "Make it easier for residents to come to terms with these transitions through communication and education, rather than just one day the facility administrator coming in and saying 'you know what, you have to move from here.'"

Environmental factors. Another concern discussed by participants was a need for adaptation of the indoor and outdoor physical environments to ensure residents with dementia safety and well-being. CG2 described her husband's responses in large spaces, "He doesn't feel comfortable when he is in big areas, it is noise, it is how crowded it is and having people walking back and forth." AL5 expressed concerns for the ability of the resident with dementia to be able to find their way in a large site, "What

concerns me about this is the open space, I had a family member with dementia and in open spaces she often couldn't remember where she was."

Financial costs to residents. Most participants were concerned about how residents would afford to live in developments similar to the DFCC, with questions related to affordability of a model with multiple amenities and levels of care, similar to a Continuing Care Retire Community. For profit models were discussed within the AL focus group and AL 4 noted, "Even if this is for profit, I would like to see something that is developed with a percentage of space for those on Medicaid." The caregiver participants discussed financing as well, and CG2 said, "Financially being able to afford this kind of care would be difficult, my husband is on Medicaid and we haven't found a place that we both agreed would be good for him." Aside from the proposed independent apartments and worker housing, opportunities for adjacent low-income housing were discussed by the caregivers. Using the affordable housing model would allow those who could not qualify for Medicaid and could not afford to live in the purpose-built housing in the DFCC to still be close enough to take part in the DFCC programs, medical amenities, and services.

Staffing

Many caregiver participants spoke of staffing concerns based on past experiences with family members in residential care settings. Several brought up issues around low staff to resident ratios, staff not being passionate about their work and a lack of compassion which may result in staff not having the skill set to manage people with dementia. CG3 described her experiences with care staff at a previous care facility her husband had lived in, "The CNAs were not compassionate. Even though they had been trained for caregiving they were not empathetic. From my experience this may be because of poor education." CG4 agreed and said, "Yes, training and screening staff would be really important to find out how much these workers really care about people, the training is going to be key." CG1 pointed out the difficulties in finding and retaining CNAs who can keep up with the demands of the job, "Training, hiring and then keeping the staff that enjoys the work and wants to come to work at 11 o'clock at night and get off at 7:00 in the morning. That's the hard part."

Participants made suggestions for few strategies to overcome these issues. For example, recruiting paid companions and volunteers may help to address staff shortages. In addition, adopting a rigorous and highly selective recruitment process could ensure motivated and emphatic staff; and offering paid on-site training courses could help to improve CNA skills in understanding the needs of the residents.

AL6 also pointed out the utmost importance to have open and ongoing communication between managerial staff and residents and that this might not be feasible due to the site size and number residents in the DFCC:

It will be important to talk with and get input from owners, managers, and administrators of facilities. Sometimes in a big facility the manager only stays in the office because they have got so much to deal with. It will be important to have the management out there with the residents too.

Conclusion

This paper describes an innovative integrated dementia care model as one option for optimal aging, with the aim of lending a stronger voice to those with dementia and their families. The input from the caregiver and assisted living resident focus groups covered a broad set of topics relating to adaptive reuse of malls for the model. While all of the focus group participants were positive about the innovative aspects of the DFCC model, some were less sure about the details of its implementation. There was agreement in both focus groups that organizing dementia programs, housing, and services using a closed mall had the potential to create a viable city center solution. The size, diversity of spaces and potential for indoor/outdoor resident engagements was considered a very positive element of the model. With that said, encouraging community buy-in would need to come through education and outreach about dementia, what it means to be living with dementia, and what it means to be a dementia-friendly community.

Both the caregivers and assisted living residents were genuinely enthusiastic about the potential of programs and amenities and adjoining housing. Caregivers were very thoughtful about being able to live with or in close proximity to their loved one with dementia and being able to enjoy a dinner out in an onsite restaurant or an afternoon stroll in a non-institutional setting. While the decisions about amenities would ultimately be specific to the needs of the larger community, certainly in closed mall sites there is ample space for a satellite public library, Pre-K education center or continuing education classrooms or art studios. In addition, medical and psychological services could be made available for use not only by the site residents, but for the larger community as well. The potential for expanded quarantine spaces may also be considered as an integral element of the model, so that in the event of continued or future pandemics, the infrastructure is in place to reduce the impact of relocation due to an infectious outbreak. It is clear that for any entity contemplating development of a DFCC model, a variety of public/private stakeholders will be needed to find the right make-up of amenities, programs, and services for their particular community needs.

Concerns about the environmental factors of the DFCC were raised by participants with respect to the size of site and wayfinding in the development. Existing malls do have to conform to Americans with Disabilities (ADA) architectural guidelines for steps, ramps, door openings, etc. but through the adaptive reuse designs, the DFCC could create a new standard to allow for residents to wander with safety and security within the setting. In addition, innovation in site signage, landmarks, and technology have great potential to make DFCC sites state-of-the-art for resident adaptation and autonomy.

Finally, care staff training and center management were of concern to participants, particularly the caregivers who have had their loved one in care settings previously. Similar to the Netherlands Dementia Village, all staff on site would need to have extensive training on person-centered approaches in working with people with dementia. In a current care system which stresses staff control of the day to day activities of memory care residents, having a model of care which provides multiple opportunities and choice for engagement throughout the day may be onerous for care staff. This is where a very strong network of volunteers to help to guide residents and to support staff will be imperative and should be considered an integral part of the model. Broader community members including students and retirees have potential to create a volunteer network with the DFCC as the hub for this activity.

A known limitation of this study was the small focus group size. To overcome this, the findings from the focus groups will be used to develop an online survey for a larger sample size of stakeholders. In addition, exploration will continue to focus on the 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 for this model. Despite these larger questions, this focus group research has laid the groundwork for these future conversations, helping to delineate the complexities of adaptive reuse of closed mall properties for the DFCC model.

As a society changed forever by the COVID-19 outbreak, awareness of the need for integrated health centers in all levels of care is at a high point. While no one knows the ultimate toll of COVID-19 on the health of the U.S. population and economy, models similar to the DFCC realized have the potential to provide a connected health and wellness community care system which can be further evaluated through the lens of economic renewal, sustainable building practices, and infectious disease control. It is hoped that continued design and research for this new place-type will allow for the rethinking of the way that building reuse and blended urban landscapes support vulnerable populations. And as stakeholders continue to strive to create real community within care communities,

the DFCC model becomes a potential care option designed to be inclusive, progressive, and convergent with the needs of an aging population.

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