A Conversation About the Ethics of Past and Future Memory Care Models: Perspectives from the First Two European Dementia Villages

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Abstract

Dementia care organizations face a range of daunting environmental changes and challenges. Internationally, there is a long history of efforts to improve quality of care and life for individuals with dementia. In a time of particular attention to 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 such as chronic disease, cognitive decline, and the need for general support with activities of daily living (ADLs) rail against the autonomy of independent self-sufficiency. Additionally, these environments are institutional in design and size, with little access to outdoor spaces and other amenities. This perspective manuscript addresses the ethics of past and future memory care models, looking specifically at the European Dementia Village (DV) model. This model allows for autonomy and continuation of patterns of daily living through housing integrated with exterior walks, gardens, restaurants, and amenities within familiar and normal surroundings. This pioneering health care experiment negotiates rivaling discourses of intimacy, professionalization, and medicalization. In order to get a deeper understanding of the culture and ethics of this integrated care model, the first two dementia village sites were visited which included meetings with care staff and administrators. Those conversations and observations led to a series of aligned themes relating to the ethics of the DV model which include: the strength of the social approach, clinical support, resident/staff collaborations, and advocating for ethical dementia care. Rethinking the ethics of dementia care entails individual perspectives and group discussions on what can keep individuals social connected within their care community, including focusing on strengths of the individual and normalized daily routines.

Keywords

dementia, memory care, ethics, autonomy; integrated care

What do we already know about this topic?
Dementia care models often lead to disengagement and loneliness due to the ethics of the care model

How does your research contribute to the field?
This paper lends a voice to an important distinction in the ethics of care for individuals with dementia and what the future of care could look like

What are your research implications toward theory, practice or policy?
The work describes a new model for provision of memory care which focusses on the strengths of the individual and normalized daily routines

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Introduction

Globally, more than 50 million people are diagnosed with dementia. With one new case occurring every 3 seconds[1] and without a known cure, dementia has emerged as a pandemic in an ageing society.[2] 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.[3] Activities which stimulate of a sense of well-being, create a sense of personal fulfillment, and promote both physical and

mental health generate this meaning[4]; however, institutional settings for dementia care are generally characterized by social distance between residents and staff, with the requirements of organized routines trumping personal preference and choice.[5] 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.[6] In particular in the United States, this is the case because of the ageist attitudes which exist create "us and them" attitudes about what it means to live with dementia. Despite the fact that aging is a lifelong experience, not just a later life occurrence, the current narrative speaks to a focus on loss and decline rather than opportunity for autonomy and growth. Changing the current narrative on dementia care is not an easy task, because societal and personal views of aging are extremely entrenched.[7]

Yet the design of care settings is a modifiable risk factor that can facilitate better outcomes and a care model has been developed in Europe which focuses on an integrative model of dementia care which is made up of the buildings, staffing and a social perspective of dementia care. This paper examines the ethics of past and future memory care models based on lessons learned in meeting with care staff and the founders of the first two of such forward thinking care sites which are designed within a Dementia Village (DV) model.

Living with Dementia

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 dementia, with a cluster of symptoms and signs linked to the deterioration of cognitive abilities as a person ages.[8] Quality of life for a person with dementia is always partly subjective and is somewhat a matter of emotional adjustment facilitated by interactions and environment. 12 dimensions of care environments have been analyzed, three of which are the physical environment of the facility, medical services, and the philosophy of care.[9] This suggests individual intrinsic capacity may be augmented by combining empowerment provided by the physical environment, the support of the caring/social environment, and treatment through medical means.[10] These interrelationships indicate that the challenge in memory care environments is to provide residents appropriate settings for social interaction in order to buffer against social isolation, while balancing medical/safety care needs with autonomy and proactive responses to personal competency changes.[11] These

competency changes include age-related losses in vision, mobility, and cognitive capacity, making the older adult with dementia particularly vulnerable to environmental demands.[12]

The Biomedical Approach to Dementia Care Settings

Dementia care organizations face a range of daunting environmental changes and challenges. Internationally, there is a long history of efforts to improve quality of care and life for individuals with dementia.[13] In a time of particular attention to 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 such as chronic disease, cognitive decline, and the need for general support with activities of daily living (ADLs) rail against the autonomy of independent self-sufficiency.[13] Additionally, these environments are institutional in design and size, with little access to outdoor spaces and other amenities (Figure 1).[14]

This biomedical approach to dementia care focuses on symptoms, deficits, and emotionally charged metaphors about dementia that have influenced the overall public perception.[15]

Institutionalization often has negative outcomes, as the individual with dementia becomes further disconnected from home, family, community, and activities with daily meaning.[16] While care facilities are required to provide activities for residents, often these areas can be merely for show as in a recently visited United States facility with an empty workbench and a hat rack pushed into a corner (Figures 2 and 3).

Culture Change in Memory Care

In sharp contrast to past models of care, the concepts of "culture change" and "person centered care" describe changes in the philosophy, architecture, and organizational patterns of institutions of the past.[3] Culture change has been defined as a transformation anchored in values and beliefs that return control to residents in care settings. Its ultimate vision is to create a culture of aging that is life-affirming, satisfying, humane, and meaningful, seeking to transform a "facility" into a "home," a "resident" into a "person," and a "schedule" into a "choice".[17] Culture change relies heavily on the incorporation of person-centered care, referring to the practice of basing key decisions on resident needs, desires, and

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Figures 1–3. Institutional model of care with activity stations.

preferences in the areas ranging from how meals are served and how bathing is offered to how work is structured in an organization.[18-20] Major systematic changes occur at all levels: the physical environment, meal times, relationships, and the flattening of the traditional staff hierarchy to allow for more opportunities for caregivers to get to know the residents in order to understand and meet their needs.[21]

Within the culture change movement, there are distinctions of neighborhoods and households. Neighborhoods are also sometimes referred to as clusters of households that share common community areas.[22] Features in this culture change built environment may include 8–12 residents living under one roof. In this household, all residents share a living room and dining room. There is also an open kitchen where food is prepared by the care staff to order for each resident. Residents have the freedom and choice of meal times and food, helping with the meal preparation, and dining individually or together. In addition, these households may provide single-resident bedrooms so that the individuals can choose to have privacy.[17] This change in the design of the physical environment has been shown to have substantial effect on resident patterns of social behavior, as it is widely recognized that social and physical environments can profoundly influence quality of life of older adults.[23] In the early 1980s through 2000 internationally several care settings began to incorporate culture change including the Corinne Dolan Alzheimer Research Center as well as Green House Model in the United States and the CADE units in Australia.[21,24,25]

While the culture change movement has made significant inroads to person-centered care at the institutional level internationally, few care organizations in the United States have the funding or land to allow residents a physical environment which enables a full indoor/outdoor daily experience. Some care settings such as the Lantern Assisted Living facility in Ohio have "outdoor-like" amenities such as front porches, street lamps, and carpeting to reflect outdoor colors and textures, yet these attempts at the creation of a set of experiences is only that, and leaves short the efforts to allow true autonomy in one's day in experiences in inside and outside environments.[26] For an individual who wants to spend time outside, what is the benefit of green turf carpet that is designed to look like grass and a fiber optic ceiling that mimics the day and night skies similar to the interior of a Disneyworld setting? Filling these gaps in the ethics of care is crucial if the holistic approach set out above is to be operationalized; therefore, this author proposes a broad intervention using the DV care precedent developed in the Netherlands 2009 and replicated in Denmark 2016 and several other sites internationally in the years since.

The Dementia Village Precedent

The first DV opened in Holland in 2009, offering housing, medical and psychosocial care in a community setting without the hospital façade. Since 2009, several other European countries have since adopted this model.[27] The Dutch DV is home to 187 residents and encompasses 4 acres in familiar and normal surroundings, with multiple households of 7 individuals living with dementia.[28] Residents live in a secure setting having access to the medical attention they may need, while continuing to receive the daily stimulation from exercising outside and attending classes and clubs.[29] Housing is integrated with large exterior walkways and gardens, restaurants, a grocery store, pub, and theater (Figures 4–6). The DV 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 a theater within familiar and normal surroundings, reducing resident anxiety and fear.[30] This pioneering health care experiment negotiates rivaling discourses of intimacy,

Figure 4. Dementia village 1 supermarket.

Figure 5. Supermarket interior.

Figure 6. Dementia village 1 outside walkway.

Figure 7. Dementia village 2 Courtyard.

professionalization, and medicalization.[8] It demonstrates that people can live in a secure setting while continuing to receive the daily stimulation from the things they love to do like exercising outside and attending classes and clubs, with simultaneous access to medical attention they may need.[27]

The second DV opening in Denmark in 2016 and provides care for 225 residents within 125 residences and is inspired by the DV in the Netherlands. The Danish model has a total of 56 residences for individuals with dementia, 43 assisted living residences, 7 short-term residences, and 19 residences for people with mental and/or physical disabilities. The residences are leased out by the local housing association; therefore, the apartment is covered by the same regulations that apply to other rental apartments. There is an activity center and a large garden with a pond and seating areas. There is a general store, hairdresser, restaurant café, music library, country kitchen, physical training facilities, and a hobby room (Figures 7–9).

The central court contains several areas where residents can sit and walk outside on a network of paths, covered pavilions, a large pond, and a parked camper which residents can use to remind themselves of camping with their families. Relatives are welcome to visit and initiate activities throughout the site, such as baking in the country kitchen, gardening, feeding the chickens and rabbits, and participating in bike rides to the downtown on dual bikes with volunteers.

Methods

In order to get a deeper understanding of the culture and ethics of the DV model, the first two DV sites were visited in the Netherlands and Denmark respectively and included observations and meetings with care staff and administrators. A daylong meeting was set up at each site prior to the visit, and took place in a private meeting room as well as on site walks within each DV. The same questions were asked of the administrators and staff in both sites and the following analysis of those conversations and observations led to a

Figure 8. Dementia village 2 Pond.

Figure 9. Dementia village 2 walkways.

series of aligned themes relating to the ethics of the DV model.

Outcomes

Based on the conversation and observations at both DV sites, four overarching themes were identified about the DV model which include: the strength of the social approach, clinical support, resident/staff collaborations, and advocating for ethical dementia care.

Strength of Social Approach

The DVs are integrated models of care, comprised not of just the buildings and construction but more importantly on an integrated vision of daily living. This is a universal living environment promotes a social approach which allows for the community around residents to take part in responsibility for them and to play an important role in their lives. The normalization of daily routines is a primary strength of the model and there has been a natural growth of how onsite amenities are being used. In the first DV, the onsite restaurant is a normal restaurant open to residents, as well as the public from the outside community. The theater is a multifunctional room for presentations and gatherings and also can be used by the outside community. The supermarket is a real market with food and sundries that residents need in their household, and is also used by the staff who often shop there before heading home. In the second DV, the general community around the site is invited to come in and use the resources such as the general store, restaurant, and outside walking paths and seating areas.

The social approach to care addresses the abilities residents still have and want to keep and is focused on patterns of living rather than just the care that individuals need. In essence, there is an understanding that there is quality in days and it is the individual's choice how they want to spend those days. This positive health approach allows for individual resilience in a setting where residents can strengthen their abilities and not mourn what abilities they may have lost. This is the distinction between the social rather than clinical approach. While there is clinical care support when needed, social needs are addressed on a daily basis within the group housing, as well as the ongoing activities and social clubs. That is one of the outcomes of the model, for instance on a sunny day residents can be seen socializing outside. This is quite different from memory care settings where people are primarily treated for dementia through an institutional model. People are people, they are human beings and the DV shows that the creation of care settings where people can live with different care needs and are supported in the social aspects of normal life is a viable goal.

Clinical Support

Officially both DV sites are skilled nursing facilities so the average resident may need clinical support and medication management. If they don't have these needs, then they cannot get the permission from the government care system to live there. There is a multi-disciplinary medical team on each site with a geriatric specialist, nurse practitioners, psychologist, and physiotherapist. The basic support and care and medication is given and supported by the care workers who are highly trained who work alongside the medical staff. Minor clinical support is done onsite with the nurse practitioners that can take care of basic clinical needs in individual resident bedrooms, there is no onsite clinic per se in either site.

There is a physical therapy space in both settings, but these are not used too often. The focus instead is keeping people active without the need to calling it physical therapy. For instance, activities such as residents bringing the coffee cup to sinks, assisting in laundry, cleaning their own bedroom, or walking to supermarket can be part of a physical

therapy regimen. This is a new way of thinking about activity, particularly for new physical therapists starting their work within the DV model. New therapists often show concern about residents spending so much time outside. In actuality, this model of care often transforms their job as they start to understand that there is less onsite physical therapy than in traditional nursing home, yet the residents are just as active or more. This person-centered approach allows staff to let go of old routines and use their professionalism in a new way.

Resident/Staff Collaborations

The administrators and care staff manage the expectations of those who want to live in the DV and their families. They are very clear about what they will not do such as confining people to their houses or their beds or restraining them with chemical restraints. They take the position that if you as a family member don't feel comfortable with that, it's not the right place for you or your family member. Of course, there have been situations where a resident has taken a fall, and the family wants their family member to be restrained. They are told by the administrators, " We won't do it. If you don't feel comfortable with that, we will help you find another nursing home for your father or mother."

Residents are able to leave their households at any time to take part in activities or just enjoy the weather. They are not supervised by their household care workers when they are outside, but all of the staff onsite are trained to work with people with dementia. This is in essence the care model in that everyone who works onsite is seen as collaborator in the care of the residents. So for a resident who is taking a walk outside, those staff who are also outside are there to work with them as a part of their support system.

Volunteer network. Volunteers are brought in from the community in both DV sites to help build on the network of support. Extensive training is provided for the volunteers, as it is important that they know what dementia means, and how to work and socialize with residents. For instance, training is provided on how to work with wheelchairs as well as being given an understanding of the DV organization, so if volunteers need help they know who to contact. An agreement is signed describing certain duties, and the volunteers are counted on for certain tasks because of this agreement. There is a very active DV club life such as baking, woodshop, and music clubs, so there are many volunteers who assist the club leaders. They help pick people up and are part of the club life or guide people to the activity areas within the DV. In addition, volunteers hold administrative jobs, or drive the bus, work in the restaurant, or are in the households helping the care staff. Within the DV 2 community there are volunteer bike riders who will take residents out around their town on three-seater bicycles.

The responsibility of the volunteer network stays with the administration, there is a structure provided for the volunteers who are mostly older adults. Many began their initial visits when a family member lived in the village, staying on when their loved one may have passed away. They become a part of the larger network inside of the DV, socializing with staff and residents, and are often provided a meal if they are there for several hours. All of the volunteers feel seen and are a valued, often staying on for multiple years as they become a part of the fabric of village life.

Advocating for Ethical Dementia Care

From the inception of the DV model, there was a shared vision and mutual understanding of the goals among the founders and architects. Bringing in the people who understand the need and who want to create an environment which was a nice place to live with or without dementia. The goal has been provide communities where people can be seen and socialize in any way that they are capable of, with choice in daily activities and how they want to live their life as part of the integrated model.

The care staff and administrators of both DVs are working within a belief system where they address the issues involved in dementia care from the perspective of all of us. The medical model is everywhere, yes we need clinical care support, but residents don't need the medical model to live the life that they want with their own choices. What has kept the care staff within this model going is the strong belief that quality of life is not a long life but a happy life. We all want to choose want to do in our day, we don't want to be confined.

Advocates for ethical changes in dementia care emphasize the need for the public to know about dementia and to experience social comfort with people having dementia. This kind of stakeholder advocacy requires establishing networks of people representative of the local community and involving people affected by dementia, while at the same time gaining commitment from organizations and the sharing of idea. We are starting to see that the current generation of older adults will not accept to be locked up against their will. This change will continue to evolve in society, but takes time. Thinking of people with dementia as patients who must be kept safe at all costs in their life is not realistic. If you age well and you age without a diagnosis of dementia, then you can live with any risk that you want, you can go bungee jumping and sky diving. But if you have a dementia diagnosis often it may seem that everything stops around you. That may be society's biggest ethical challenge, not to see people living with dementia as patients but just as someone who has a set of needs and requires support to live with those needs.

To date, the difficulty of sharing this perspective lies in talking to people about something that they don't understand. This means that being a good listener is of core importance in sharing of any new idea, along with having a deep understanding of what the problems and issues are and why they

are important. Stakeholders that might consider an integrated DV to be infeasible in a real-world setting must appreciate that this model is quite possible with commitment and perseverance from a dedicated project team. We are responsible for our own future and health care developers and government agencies will only follow when they see something that can be done. Finding precedents like the DV models in Europe and clearly articulating how and why they are successful may be those next steps.

Conclusion

The lessons learned from the two DV site visits point to individualized, person-centered care which takes into consideration the likes and dislikes of the residents, offering opportunities for socialization within a care model which keeps residents socially connected. The social, psychological, and physical benefits from the use of the indoor/outdoor environment in the DV model are numerous and the proximity to outdoor natural landscapes allow for socialization, meaningful activities, and sensory stimulation which encourage engagement beyond the precedents of person-centered care household models. What happens outside of the home, where one can explore and socialize become distinct and powerful benefits of the DV model.

Rethinking the ethics of dementia care means opening your mind and thinking about how you would want to be living with dementia, yet that is often difficult for people to do, particularly due to dogma of what memory care has been for decades. Legislators and developers are taught to be objective, and not embed their own vision into what could be next, yet without a shift of ageist perspectives from "us/them" to the notion of "we" in our nation's dementia care policy, important changes may not be achieved. The DV model requires a complete flip not only of the philosophy of care but how policy makers view the importance of the life with dementia from a personal perspective. When in discussion about care ethics it then becomes important to ask, "What are the things that you would want to see in your future?" This kind of visualization may help others understand what is at stake, as transformative action needs to be preceded by critical thinking and reflection.[30] In addition to discussion, extensive research is needed in order to inform policymakers and stakeholders about best practices within the current DV locations. This will help to develop a comprehensiveness in the expectations of not only what the model represents today, but what it can become in the future.

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