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Invited Perspective

Human Rights to Inclusive Living and Care for Older People With Mental Health Conditions

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ABSTRACT

Although older persons wish to age at home, many older persons with mental health conditions and psychosocial disability (MHC-PSD) spend the last few years of their life in residential facilities. This paper will examine the impact of ageism and human rights violations manifested in environmental design, specifically regarding social isolation, loneliness, inadequate psychosocial, environmental, recreational and spiritual support. This is compounded by failure to meet basic care needs-nutrition, hydration, pain and medication support. This paper highlights two innovative initiatives from the Netherlands, which show that older persons' rights can be maintained in innovative, collective living arrangements. It is concluded that the creation of inclusive and safe environments for older persons with MHC-PSD can facilitate the enjoyment of Human Rights. (Am J Geriatr Psychiatry 2021; 29:1015–1020)

Highlights

- This paper presents a human-rights based approach toward inclusive housing with care arrangements for older persons with mental health conditions and psychosocial disability (MHC-PSD)
- Green care farms and a community-based model of housing with care (Livv-Inn) are presented as care alternatives that fulfill the human-rights of older persons to a better extent than traditional care settings. They are focused on key values such as reciprocity, building on remaining strengths and capacities, dignity and fostering inclusion and participation within the broader social context.

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- These innovative forms of collective living arrangements are promising as they support the human rights of older persons, are inclusive and use a neighborhood approach to long-term care.

INTRODUCTION

Human rights are at the heart of the push for the provision of inclusive physical and social living for older people.[1,2] Inclusive policies, structures and services aim to enable older persons to live in security, enjoy good health and continue to participate fully in society.[1,3] Although most older persons wish to age in place at home, this is not always feasible and residential care may be required as care needs increase. The Universal Declaration of Human Rights refers to several environmental design principles, with the goal of promoting dignity (article 1), liberty and security (article 3), privacy (article 12), freedom of movement (article 13), access to own property (article 17), a standard of living adequate for health and well-being, including food, housing, medical and social services (article 25) and access to participation in community life (article 27).[4,5] Key human rights articulated in the United Nations Convention on the Rights of Persons with Disabilities relevant to older people with mental health conditions include autonomy, respect for will and preferences, family and relationships, and access to the highest attainable standard of healthcare, including meeting needs arising on account of disability.[6] Older persons with mental health conditions and psychosocial disabilities (MHC-PSD), are subsumed within the Convention on the Rights of Persons with Disabilities and therefore have full entitlement to all the rights the Convention enshrines.[7] Though, in practice we see violation of these rights, exacerbated by the coronavirus disease 2019 crisis, especially for older persons living with dementia.[8–11] This paper aims to identify gaps in knowledge using a human rights approach toward environmental design for older persons with MHC-PSD and presents recent examples of alternative care settings that promote human rights and inclusive housing with care.

The residential and care environment is a critical determinant of the extent that the human rights of older persons are respected, especially those with MHC-PSD, and particularly those living with dementia. The individual person's autonomy, independence, choices and preferences must be consonant with their care needs, their abilities and environmental demands to support everyday functioning, also referred to as person–environment fit.[12] Although most older persons wish to age in place,[13] this is not always the case. Having a mental health condition, such as dementia, serves as a particular risk for placement in a residential setting.[14] The care environment consists of physical (built environment, outdoor areas, interior design, sensory elements), social (interactions with others including residents, staff, family, friends, the wider community); and organizational components including care service delivery and culture (values, expectations, attitudes that guide staff's behavior in care settings).[15] Individual physical and social environmental components impact residents' daily life and influence onset and manifestation of neuropsychiatric symptoms.[16–18] Furthermore, the built environment contributes to a sense of home.[19] Consistently, organization components also play a major role in older persons' health and well-being and have become particularly prominent during the recent pandemic.[9]

Current evidence indicates that traditional residential care settings are overall not effective in supporting everyday functioning and may even be harmful.[20,21] These are typically large-scale buildings, in which residents are segregated and confined within the residence, separated from the community at large and often from other residents as well.[11] Environmental restraints are put in place, such as locked doors and fences. This negatively impacts the emotional safety with feelings of displacement, sense of imprisonment and social isolation.[7,22,23] These traditional, large-scale care environments have been associated with poor outcomes for residents with dementia, including inactivity,[24,25] high levels of agitation, depression and other neuropsychiatric symptoms,[26,27] use of physical restraint,[28] high levels of psychotropic drugs,[29] loneliness, and stigmatization.[30,31] Organizational

routines in traditional residential care settings can be rigid, with little opportunities for residents for autonomy or engagement.[32,33] During the coronavirus disease 2019 pandemic, these outcomes have even worsened.[9,34,35]

Congruence is needed between the different environmental components (physical, social and organizational), in order to promote well-being and adapted behaviors for residents with dementia and their caregivers.[15] Often, this is difficult to accomplish within existing traditional care environments as a cultural change is needed.[36,37] This paper highlights two examples of radical redesign of care environments in the Netherlands, that have implemented a human rights-based approach to residential long-term care.

GREEN CARE FARMING

Originated outside the healthcare sector, green care farms combine agricultural with care activities and aim to enable independence and participation of clients for as long as possible.[38,39] Green care farms are a widely adopted way in an increasing number of countries, providing day care or respite care for a variety of clients including older persons with MHC-PSD.[38] Green care farming has adopted an environmental approach to care, which supports human rights of older persons with MHC-PSD, especially related to dignity, freedom, and individuality. The Netherlands is leading in designing green care farms with 24-hour care services as alternative to traditional nursing homes.[40] Physical environmental components (e.g., animals, plants, natural elements) offer many opportunities to incorporate meaningful activities into daily care practices. Residents can move more freely and have more control over their daily life than in traditional residential care as they can participate in outdoor, domestic, work-related, and other activities. Farmers transfer their care philosophy to staff, by acting as a role model, often showing clinical leadership.[38,41] Staff is selected based on competencies that support the individual green care farm vision and are continuously guided in providing tailor-made care, altering the residents' social environment.[41]

Preliminary empirical evidence regarding the efficacy and value of green care farms suggests a positive impact on older persons, especially related to the human rights domains. For example, persons living with dementia valued their social participation as higher on green care farms compared with traditional day care.[42] They favored being in a normal life setting rather than a care environment, increasing their sense of making meaningful contributions to society. Furthermore, residents of green care farms were more active, more socially engaged and ventured outdoors more often in comparison with residents of traditional nursing homes.[40,43] Time outdoors is an important outcome as it correlated with well-being.[44] The person-centered approach was highly appreciated by informal caregivers and mostly influenced their choice for transition toward a green care farm over traditional nursing home.[45,46] Quality of care indicators such as falls, antipsychotics, pressure ulcers, resident/staff ratio and protocols were comparable with other care settings.[47]

COMMUNITY MODELS

Internationally, there are important examples of how innovative and inclusive care environments can be developed in both rural and urbanized areas.[1,48,49] Using a human rights-based approach, they are embedded within the local community to foster inclusion, equity, and dignity for residents. In the Netherlands, social housing association Habion is at the forefront in developing innovative housing for older persons with care and support services. Adopting a human rights-based design approach, Habion aims to provide a living experience for residents, rather than just accommodation and shelter.[49] If residents' needs change over time, and they become increasingly dependent, the goal of Habion is to maintain the value, flexibility and atmosphere of the living environment. They have developed a specific method to fulfill this process and include the local community: the Røring method.[49] A current example in which this method has been applied is the Liv Inn project (liv-inn.nl), a former assisted living facility redesigned into a new setting for a variety of groups, including older and younger persons, with and without MHC-PSD. Residents are in charge of the building and care they would like to receive and the local community together with the residents make the setting as a home. This type of redesign takes time and develops gradually in interaction with persons

who deem independence, security and their self-identity, choice and memories essential.[49–51] The Røring method facilitates interested actors and residents to be motivated and enthusiastic, while maintaining inclusivity in its nature.

FURTHER DIRECTIONS

There is an urgent need for the development and design of inclusive care environments, in which older persons with MHC-PSD can be supported to enjoy their human rights. Although most older persons wish to age at home, as their conditions deteriorate this is not always feasible or desirable for all.[52] Alternatives including collective living arrangements and residential care, are necessary. Evidence on the effects of small-scale, homelike care models as presented in this paper are inconclusive as only few studies have been conducted.[53,54] Some suggest positive indications for example less psychotropic drugs and more social interaction,[54,55] while no overall effects on quality of life or functional status could be shown.[53,56] None found small-scale, homelike environment worse than regular care, which may suggest this to be the preferred option when available.

More evidence-based knowledge is highly needed to develop innovative housing with care strategies, interventions and programs, preventing ageism, and incorporating intergenerational approaches. The physical, social, and organizational components of long-term care play a major role in ensuring the human rights of older persons with MHC-PSD. First insights indicate that findings of innovative human-rights based approaches can be transferred to regular long-term care services as well.[57,58] We need to overcome the current strict separation between long-term care at home and residential care facilities, with opportunities to create a new, neighborhood perspective to care and being inclusive to all. Innovative, collective living approaches may be developed to accomplish this. Furthermore, the use of technology (e.g., wearables, sensors) and AI-driven approaches may help enable more freedom to support autonomy of older persons living with MHC-PSD. In this way, inclusive living becomes available for all.

AUTHOR CONTRIBUTION

HV drafted the manuscript. All authors contributed to, read, and approved the final manuscript.

DISCLOSURES

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