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At Home in a Nursing Home: An Ethnography of Movement

and Care in Australia

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The publication represents an excellent ethnographic insight into hitherto unexplored areas of the lives of people with various forms of dementia who live in an institution called a "nursing home" or a "social care facility." The author is focused on experiencing this change in their lives and finding a "home" in the foreign environment of the institution. It seeks an answer to the fundamental question of how, through proper care provision, residents with various forms of dementia can feel at home (p. 27). In this publication, home is seen not as a specific place made by "bricks and walls", but as the way a person is treated and where a person feels accepted. The author conceptualizes home as something other than a solid building with some specific functions. This way of "rethinking home" can be seen in Mary Douglas's study *The Idea of a Home: A Kind of Space* (1991). M. Douglas brings a perspective, where home is not only a fixed space but also has a particular structure in time that is connected to the aesthetic and moral dimensions of home (Douglas, 1991: 289).

It focuses on the specific manifestations of care in the nursing home, which the author interprets as supportive for their personal well-being. The author pays special attention to the (im)possibility of movement. Reduction of the ability to move and orient through ageing is standardly perceived in the natural sciences as a natural biological phenomenon (e.g. Ukraintseva et al., 2021). Rong Yang Zhang disputes this stereotype and consistently emphasizes the complexity of movements and the will to walk in the daily life of nursing home residents (p. 47). Movement in institutions often may be seen as uncoordinated and are often considered as symptoms of illness. The author describes the very will to move or walk (often misinterpreted as "wandering" by the employees) as key to the residents' well-being. As I will explore later, the author explores movement in two main frameworks, person-centered care and disease-centered care.

The publication begins with a prologue that contextualizes the provision of social care for older adults in the specific sociocultural environment of Australian suburbia. Hairdressers, cafeterias, and similar additional services are available to residents directly in facility buildings with an entrance lobby and well-trained, polite staff. The rooms for residents are diversified in various standards, including de-luxe. In this case, the investigated facilities are not representatives of the main standard of institutions in Australia. It represents a higher standard, which is also more expensive, and those who can afford this standard usually have higher wealth ratios. Individual activities and care procedures provided are also at a high level. It could be interesting to contextualize such a modernized environment built by the highest demands in Erving Goffman's concept of total institution, as "place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life" (Goffman, 1961: xiii). Goffman also mentions as one of the characteristics of total institution, the loss of social roles in exchange for the acquisition of the unified role of "inmate". This characteristic was mentioned by Rong Yang Zhang only briefly, in connection with the

description of some residents by employees as "dementia full stop", when the personality gradually disintegrates and shatters until it dissolves in the disease itself (p. 52). Maybe the author did not mention the potential parallel between Goffman's concept of total institution and her own experience and I respect, that this perspective was not the aim of her study. Nevertheless, I consider it a bit of a missed opportunity not to connect the theme of how to feel "home-like" in a modern-day facility with a modern care system and the classical framework where "(ones) self is systematically, if often unintentionally, mortified" (Goffman, 1961: 14). I would like to see if the shift in institutional systems resonates in high-end facilities over "classical" care institutions from the mid 60's. Rong Yang Zhang poses key questions of the current discourse in the field of service provision for older adults, such as "When residents call for help and efforts to move are treated as symptoms, and their bodies managed through practices of restraint, whose concerns are being taken care of?" (p. 23).

She states that individual steps in Australian social policies, which "favour the concerns of governments and providers and neglects the immediate bodily experience of people who receive care" (p. 23), are resulting in a "crisis" in providing care to older adults. This crisis is characterized by underfunding and the lack of professional staff, resulting in restrictive care practices that limit the opportunities for clients of these facilities, such as their free movement. The reason for various practices preventing free movement by themselves and in the same time not providing support in movement, is, among other things, the prevention of possible falls and injuries. At the same time, a consequence of the staff's disease-centered approach to residents with a higher stage of dementia is labelling these people's walking as meaningless "wandering" (p. 219). This leads to the strict medicalized risk management of clients with various neurological degenerative diseases. The shift in the perception of residents' needs and their empowerment is thus declared even today mainly externally, through social policies and initiatives, but on a practical level we can still see prioritizing the needs and protection of the institution (if a client falls/gets injured, who is responsible?) and disease-centered model.

When the author writes about "nursing homes", she means a specific type of social service facility – "residential aged care facility". As she later explains, she uses both terms in the study because the term "residential aged care facility" is used mainly in aged care policies, while the term "nursing homes" clearly prevails in the field, i.e., among the clients and employees of the facilities.

The publication *At Home in a Nursing Home* encourages reflection on the vocabulary used in the field of care for older adults in Slovakia as well. The names of institutions that provide services for the elderly had a similar development in our Slovak environment. Even though the name "facility for seniors" (zariadenie pre seniorov) has been legislated for over a decade, almost no residents and employees call this institution anything other than "nursing home" (domov dôchodcov), which was the earlier legal name of these facilities. Not only in the Slovak context, however, these institutions providing care for older adults are currently going through paradoxical changes when the names are modified in a way of removing the association with a "home". On the other hand, the inner workings of these facilities throughout Europe and North America are undergoing a transformational process called deinstitutionalization. Rong

¹ Act 448/2008 Coll. on social services, the individual temporal versions of the law, which contain the names of residential facilities for social services for persons of retirement age, are available at https://www.slov-lex.sk/pravne-predpisy/SK/ZZ/2008/448. In 2009, the name of the nursing home was changed to a facility for seniors.

Yang Zhang assumes that the connection of a medical institution with residential housing, despite the indisputable positives, creates a categorical ambiguity for the people who live and work in it. While the term "home" (from the term "nursing home") has connotations towards private property, independent living, and intimate relationships, the term "nursing" is more associated with vulnerability, disability, and the decline of the physical body. According to the author, this ambiguous relationship to institutions providing care does not disappear even with a change of terminology, and moreover, the development in care provision towards individualized, "home-like" provision of care services connected with housing amplifies this ambiguity even more. In the Slovak context, we can see efforts to eliminate institutionalization in long term care in a way, when a person is either provided with care and support directly at home by caregivers, or situated in an institutional



environment, but with modern methods of care working. These modern approaches emphasize person-centered care over disease-centered care, among other things, by changing the terminology and the physical environment to be more "home-like". Person-centered elements of care in Slovakia, as well as in Australia, include listening to and supporting residents with their desires and expressed wishes.² The author also mentions "they need the kind of care that responds to their innermost drive to move, by generating for them new ways of walking with relative ease" (p. 44) as an important need for feeling a sense of being-at-home.

In terms of content, the publication is divided into two content parts: Walking and Care. I think it's important to mention that the ability to move, or the degree of the ability to move, is one of the determinants for admission to the facility for older adults.

As I outlined above, the first part of the publication focuses exclusively on the contextualization of walking, which not only serves as a coping mechanism or means of self-realization. She perceives walking as one of the dimensions of care, which also plays a key role as an additive element in acquiring a feeling of "home" in the institution and which is closely connected with the need for mutual cooperation between individual actors, both human and non-human. It is a pity that the publication does not explain why the author chose the clients she uses as model cases in her study. Nevertheless, it's extremely interesting with what consistency and depth she approaches the description and analysis of movement, i.e., the possibility of walking and free movement of the nursing home residents. An interesting

Act 448/2008 Coll. on social services includes quality standards of the service provided. Among them, there is preparation of an individual plan for the resident, including a plan of expressed wishes and the way he/she can achieve them.

finding is the specific social dimension of walks. Walking residents returning from a walk report the length of the walk and any experiences to others after returning. The length of the walk becomes a measure of success and a part of the which individual's history with which others will be compared in their future walks. Such and similar examples are a dense and unique body of findings providing an overall picture of the importance of walking in the lives of older adults.

In the second part, the publication analyses the discrepancy between how care is provided and perceived by staff members and how residents perceive it. It describes two opposing approaches, namely disease-centred care, as it is often seen by family members of residents, and person-centred care, as it is taught by training program providers and claimed by care staff members. Caregiving, described in great detail down to individual work procedures, is later contextualized in the broader context of current discourses and perspectives on proper care. Such care practice, which plays an important role in the lives of residents, is food and the act of eating. Food, just like outside the facility, even for the residents with dementia, is much more than just the necessary intake of nutrients and calories. Food is also a possible source of pleasure and sensory experience. It evokes memories and can be a source of various emotions. The type and consistency of the food served also "plays a role in one's eating or not eating. Seeing, smelling, touching and tasting something good is stimulating and motivating" (p. 197). However, there are some severe limits in the options of food served to residents who have various dietary restrictions, or those who cannot eat on their own. Refusal of food, or closing mouth for various individual reasons, thus becomes a separate phenomenon in facilities for seniors. In this way, for example, residents express dissatisfaction with the way they are fed. "For these residents, as staff said, eating is no longer feeding oneself but is a process of being fed by others. The involvement of staff in the taking in of each mouthful of food profoundly changes how eating is experienced" (p. 203). Sometimes, however, refusing to take food can be one's willing decision, with the aim of starving to death. During the author's research, there was no agreement between the staff and the family as to how much the client should have the right to refuse food in order to hasten death. Especially in the case of clients in the late stages of dementia, as the author also points out, "not eating was marked by ambiguity and ambivalence" (p. 193). It's ambiguous, if these residents can make a deliberate conscious decision to stop eating with the will to die. Thus, "for nursing home residents with severe cognitive impairments, eating and not eating is not about taking control, be it over food or the timing of life and death" (p. 193). Most clients thus have a strict nutrition plan developed, and it is followed as a prevention of malnutrition and death caused by it. Even in the case of food, there is a dissonance between the needs/desires of the residents and the experienced everyday reality.

In this context, we can clearly see the similarities of care currently provided in a high-standard institution with, at that time revolutionary, research that Jaber Gubrium brought into the field of ageing studies in 1975 from the environment of a large capacity, and that time, standard institutional facility (Gubrium, 1975). As Rong Yang Zhang states, "he (Jaber Gubrium) points to the structural barrier between those who manage the lives of the patients and those who are managed. The administrators who make decisions for the patients often do not understand the complexity of care processes from the perspectives of patients and caregivers. A focus on the soft yet imposing power of the institution highlights how elderly residents usually have little control over the ways in which they are cared for" (p. 96). It seems that for almost half a century, the opportunities to make decisions about one's own life and the individual decisions related to meeting the needs of residents in care institutions, have moved

towards a person-centered model and we can clearly see the shift in thinking about the concept of the "right care". However, on a practical level, even today in high-end facilities, we can observe elements of total institutions and fragments of institutional care systems from a strictly medicalized care model.

The author's conclusion about proper care providing has a strong message towards the need of fulfilling residents' desires, even of those with cognitive impairment. "The right care for these residents is thus to care for their chance to live a good life during their last years or months and then to die a good death. In both living and dying, caring for these residents is a matter of attending to them, responding to their innermost drives, and trying to meet their needs. Right care at the end of life is thus associated with relief from suffering and a sense of peace as a person faces imminent death" (p. 217).

The publication is an important contribution to the field of ageing studies. It brings new and much-needed insights into the quality of life of people with cognitive impairment living in institutions. The most important message of the publication is the revelation of the significant importance of walking and the possibility of freely performing various body movements or independent eating, even for clients in higher stages of dementia in various forms, because "despite cognitive changes, as well bodily impairments, productive conditions lived by residents could still be found to help residents move, extend their possibilities and ultimately enable them to feel at home in the nursing home" (p. 223).

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