Experiences of home and institution in a secured nursing home ward in the Netherlands

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Keywords:

- Home
- Total institutions
- Nursing home
- Person-centred care
- Qualitative methods
- Participatory approach

Highlights

- We used Goffman's conceptualisation of total institutions and the literature on home as a framework for analysis.
- We conclude that while home and institution may seem to be opposites, they can actually be seen as two ends of a continuum.
- We explore interventions that were implemented to increase the sense of home on a secured nursing home ward.
- The interventions aimed to increase residents' control over everyday, rather than to implement home-like aesthetics.

- We conclude that it is possible to increase the home-like character of a secured nursing home ward through interventions.

Experiences of home and institution in a secured nursing home ward in the Netherlands: A participatory intervention study

Abstract

Nursing homes have been criticised for not providing a home for their residents. This article aims to provide insight into (1) the features of home and institution as experienced by residents and caregivers of a secured ward in a nursing home, and (2) how interventions implemented on the ward can contribute to a more home-like environment. For this purpose, a participatory intervention study, involving both caregivers and residents, was carried out. We collected data through qualitative research methods: observations, in-depth interviews and diaries to evaluate the interventions over time. We adopted an informed grounded theory approach, and used conceptualisations of total institutions and home as a theoretical lens. We found that the studied ward had strong characteristics of a total institution, such as batch living, block treatment and limited privacy. To increase the sense of home, interventions were formulated and implemented by the caregivers to increase the residents' autonomy, control and privacy. In this process, caregivers' perceptions and attitudes towards the provision of care shifted from task-oriented to person-centred care. We conclude that it is possible to increase the home-like character of a secured ward by introducing core values of home by means of interventions involving both caregivers and residents.

1. Introduction

Both the meaning and experience of home change over the life course. The home becomes ever more significant in the everyday lives of many older adults, especially those with constrained mobility or chronic illness (Dyck, Kontos, Angus, & McKeever, 2005; Sixsmith et al., 2014). The importance of home is reflected in the wish of many older adults to ‘age in place’– to live and eventually die in their own home. Ageing in place enables older adults to maintain relatively high levels of independence and autonomy, and a social network. Current policy in the Netherlands supports older people's wish to remain in their own dwelling or community rather than to move into residential care. This also reduces

costs of institutional care (Kamerbrief over langer zelfstandig wonen, 2014). However, people with physical and mental problems, such as dementia, most often reside in nursing homes (Nakrem, Vinsnes, Harkless, Paulsen, & Seim, 2012). Nursing homes are often criticised for not providing a home-like environment (Miller et al., 2013). This can be explained, at least in part, by the fact that they have been developed within a medical model, resembling hospitals rather than a home (Hauge & Heggen, 2007). Care is provided as efficiently as possible to accommodate large numbers of people, and so nursing homes typically lack certain core qualities of home such as control, autonomy, choice, privacy and self-determination (Cooney, 2012; Custers, Westerhof, Kuin, Gerritsen, & Riksen-Walraven, 2012; Granbom et al., 2014; Kasser & Ryan, 1999; Persson & Wasterfors, 2009; Stabell, Eide, Solheim, Solberg, & Rustoen, 2004). As a result, it is difficult for many older adults to make themselves 'at home' in a nursing home (Granbom et al., 2014; Shin, 2014). Several studies have found that the core qualities of home are positively linked to the well-being of older people, including those in long- term care settings (Boyle, 2008; Cooney, 2012; Sixsmith et al., 2014). This suggests that feeling at home can enhance the well- being of older adults in long-term care (Cooney, 2012).

McCormack (2003, cited in O'Dwyer, 2013) argued that caregivers should attempt to understand their clients' key-values in life, in order to provide meaningful care. Caregiver and care recipient are thus to engage in a meaningful relationship in which the caregiver provides both practical and personal support. Through such meaningful support, person-centred care could contribute to an increased sense of home for nursing home residents. Person-centred care means listening to and respecting residents' needs, as well as showing genuine interest in and openness towards them. Brownie and Nancarrow (2013) wrote that "person-centred approaches to aged care should create the conditions for older people to participate in meaningful lives, and potentially improve their well-being" (p. 7). Hence, caregivers can play a key-role in facilitating and hindering the sense of home that residents experience in a nursing home setting. Harnett (2010) demonstrated in an ethnographic study that a routine culture in nursing homes tends to be reproduced through both staff and resident compliance.

She found that it was very difficult for residents to achieve exemptions from nursing home routines, especially when these exemptions implied a disruption or disturbance to the caregivers' activities.

We conducted a participatory interventions study on feeling at home in a nursing home setting, in which both the caregivers and residents were involved. In the study, the perspectives of both residents and caregivers on daily life on the ward were analysed first. Subsequently interventions to increase its home-like character were discussed, implemented and monitored in close collaboration between the researchers and caregivers. This article aims to gain insight into (1) features of home and institution as experienced by the residents and caregivers of a secured ward in a nursing home in the north of the Netherlands, and (2) how interventions on the ward can contribute to a more home-like environment.

2. Framing the analysis: (lack of) aspects of home within institutional care settings

2.1 Nursing homes as total institutions

Two seminal works published in the 1960s have shaped our thinking on home and institutions: Asylums by Erving Goffman (1961) and The last refuge by Peter Townsend (1962). Goffman (1961) developed a theory of 'total institutions', which he defined as places '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' (p. xiii). Based on his ethnographic study of mental hospitals, Goffman argued that 'total institutions' are characterised by 'block treatment' in which each phase of daily life is tightly scheduled, with one activity leading at a prearranged time into the next. It is enforced by a responsible authority, typically the management of the institution, and imposed through a system of explicit formal rules. Each phase is carried out in the immediate company of a large batch of others, all of whom are treated alike and required to do the same activities at the same place and time. This is called 'batch living'. It also enforces a strict distinction between residents and staff. Although Goffman did not explicitly discuss nursing homes as total institutions, other authors have done so (Clark & Bowling, 1990; van der Horst, 2004).

Peter Townsend studied residential care for older people in England and Wales, and his findings resemble the total institution defined by Goffman. He described how people who reside in residential care live an isolated life, with limited mobility and access to society. Residents submit to orderly routines, with a lack of creative occupation and little opportunity to exercise self-determination (Townsend, 1962). Goffmann and Townsend both criticised the routinisation and depersonalisation of institutional life which result from both block treatment and batch living (Higgins, 1989).

2.2 Block treatment

In the follow-up study, Revisiting 'The Last Refuge', Johnson, Rolph, and Smith (2010) found that nearly 50 years after Townsend's study not much had changed in residential care, especially with regard to block treatment: the routinisation of everyday life and lack of autonomy for residents. Overall, life in institutional nursing homes follows a set routine prescribed by the organisation, in which residents lack personal choice, privacy and dignity (Ragsdale & Mcdougall, 2008). Other recent studies have also reported characteristics of total institutions in nursing homes: care is routinised and residents have little control over their day, such as whether or not to have a bath and when to get up in the morning, which constrains their autonomy (Cooney, 2012; Harnett, 2010; Persson & Wasterfors, 2009).

Tension exists between the institutional routines and the residents' personal desires. Cooney (2012) showed that nursing home residents tried to maintain continuity by performing their normal activities and day-to-day rituals as they did before being admitted to the nursing home. However, the institutional routines that were task- and scheduled-oriented, rather than person-oriented, hindered residents from achieving this and made them less independent. Residents who needed help getting up in the morning and into bed in the evening, in particular, were dependent on the staff's routines (Nakrem et al., 2012).

Routines and regulations are part of a nursing home culture which aims to avoid risks of poor quality of care and neglect (Cohen-Mansfield et al., 1995; Persson & Wasterfors, 2009). However, such rules and regulations constrain development towards person-centred homes with more individual choice

and autonomy (Miller et al., 2013). Higgins (1989) found that the prevailing culture in nursing homes is paternalistic and overprotective. In nursing home environments, all normal risks are blocked out and residents are protected to a level that would never be achieved at home. In order to allow residents autonomy, staff need to give up some of their own power and control and move towards risk management, that is, incurring an element of calculated risk, rather than risk avoidance (Bland, 1999). However, many nursing homes are still very much concerned with providing a safe environment for their patients (Thomas et al., 2012). This is in itself a laudable aim, but could be taken too far, creating a care environment that is guided by rules and bureaucracy, which carries its own risks. Ulsperger and Knottnerus (2008) found that bureaucracy in a nursing home context can lead to the development of rituals that facilitate physical neglect.

2.3 Batch living

Institutional life is often characterised by batch living, in which everyday life takes place in the company of a batch of other people who are all treated in the same way. All activities of daily living, such as eating and sleeping, are carried out together (Higgins, 1989). Because all the residents are treated the same, and because of the lack of individual choice, personal autonomy and privacy within institutions, residents' self-determination is curtailed (Goffman, 1961). Townsend (1962) and Goffman (1961) both described a process of depersonalisation that occurs when people become part of the institutional system, because individuals are only treated as part of a group, rather than as an individual. Older adults in nursing homes are typically subjected to batch living.

Another characteristic of total institutions identified by Goffman (1961) is the separation between staff and residents, both socially and spatially. Within a typical total institution, staff and residents form two different groups with limited interaction. Some argue that a professional distance between staff and residents is necessary to cope with the demanding work, and to protect staff from stress and tension (Buckley & McCarthy, 2009). In nursing home life today, however, this separation is not clear-cut. Several studies have reported how nursing home residents, particularly in small-scale homes, develop

125 connections with staff, especially as a kind of substitution for a lack of contact with family and friends
126 (Buckley & McCarthy, 2009; Cooney, Dowling, Gannon, Dempsey, & Murphy, 2014; Custers et al., 2012;
127 Hauge & Heggen, 2007; Wilkinson, Kiata, Peri, Robinson, & Kerse, 2011). More specifically, Hauge and
128 Heggen (2007) found that nursing home residents preferred to discuss everyday matters with
129 caregivers, rather than with fellow residents, and that residents actively sought contact with caregivers
130 for a private chat. This is related to the observation that nursing home residents seldom develop close
131 friendships with co-residents. The social relationships developed between residents in nursing homes
132 have been compared with the superficial contacts people have on the bus or in a dentist's waiting
133 room. Such relationships are characterised by a degree of formality and distance, and residents say
134 they are friendly, rather than friends, with other residents (Higgins, 1989). Buckley and McCarthy
135 (2009) suggested that staff could play a role in facilitating friendships between residents, since they
136 know the residents well. They also argued that residents who prefer to be alone should not be pushed
137 to engage in social activities.

138 *2.4 Public and private space*

139 The ambiguity of public and private space in institutions has been discussed more recently (Hauge &
140 Heggen, 2007; Nord, 2011a,b). Many of the residents' everyday activities are public, in the presence
141 of other residents, rather than private, making it difficult to maintain a private life (de Veer & Kerkstra,
142 2001; Hauge & Heggen, 2007; Nord, 2011a). Gubrium (1997) found that nursing home residents
143 typically feel at home in their own private space, but not in the public spaces of the nursing home. The
144 bed-sitting room, if available, is often the most important private space for residents; there residents
145 are most 'in charge' (Nord, 2011a). When an individual has control over a place, it becomes 'defensible
146 space', while lack of control undermines such a sense of 'ownership' (Barnes, 2002; Cooney, 2012).
147 Personalisation of a private room marks a sense of territory and control, and is a visual expression of
148 the resident's identity and lifestyle (Cutchin, Owen, & Chang, 2003; Hauge & Heggen, 2007; Higgins,
149 1989; Rechavi, 2009; Shin, 2014). Cooney (2012) suggested that people 'who "created" their own

space usually considered the facility their home' (p. 192). A sense of privacy and control over a place has been found to enhance quality of life (Willcocks, Peace, & Kellaher, 1987).

Alternations that are being done in traditionally hospital-like nursing homes to provide a home-like setting are, for example, the creation of smaller residential units and/or providing single rooms (Peace, Kellaher, & Willcocks, 1997). Other studies have shown that even in nursing homes where residents have single bedrooms and home-like interiors, residents have limited opportunities to develop a private daily life (de Veer & Kerkstra, 2001; Hauge & Heggen, 2007; Peace et al., 1997). Privacy, in terms of control, especially the power to include or exclude other people, is often violated, by caregivers entering the room without waiting for permission, for example (Allan & Crow, 1989; Nord, 2011a). Even when private space is available, access to this space is difficult. Hauge and Heggen (2007) found that feeling at home in a nursing home was associated with the freedom to withdraw from the shared space to a private room, which enabled residents to maintain a private life. Immobile residents in particular are often unable to withdraw to a more private place.

Based on the literature, we conclude that while home and institution may at first seem to be opposites, they are rather two ends of a continuum. Institutions such as nursing homes can have many home-like features, as described above, and private homes can also have some characteristics of institutions (see also Nord, 2011a). When older adults receive home care, due to ill health or immobility, their sense of home may be disrupted and their private space violated. In such a case, the institutional characteristics of the private home increase (Gillsjo, Schwartz-Barcott, & Von Post, 2011). Acknowledging this fluidity of home and institution-like features will open up a more multi-faceted and nuanced perspective on both nursing homes and private homes. Furthermore, this prevents looking at home-like features as 'good' and features of institutions as bad, which could be a tendency when looking at nursing homes from the perspective of person-centred care.

3. Methodology

3.1 Study setting

In this article, we focus on a ward for people suffering from Korsakov syndrome. The ward, which we will call 'Riverside', is part of a larger nursing home 'Fairview' which also houses two wards for somatic and psychogeriatric patients. Korsakov syndrome is a chronic memory disorder typically caused by long-term alcohol misuse. The syndrome causes problems with processing new information, inability to remember recent events and long-term memory gaps. Because of its relation to alcohol misuse and its similarity to dementia, Korsakov is also known as alcohol dementia. Although learning is difficult for Korsakov patients they are able to learn new things, especially if the information is introduced explicitly and gradually, and if their living environment is quiet, structured and with fixed routines (Kopelman, Thomson, Guerrini, & Marshall, 2009). Many Korsakov patients need help with personal hygiene, since they tend to neglect their appearance. Caregivers have to encourage Korsakov patients, or pro- vide assistance, with changing their clothes and showering Korsakov (Kenniscentrum, 2014).

Twenty people live at Riverside, of whom 19 are men. The mean age of the residents is 65 years. Riverside consists of two units with 10 residents each, separated by a corridor. Both units have a permanent team of about 10 caregivers who specialise in caring for Korsakov patients and people with similar syndromes. Other professionals involved in various aspects of the residents' lives include a medical team led by a nursing home doctor, general services providing food and cleaning, and a team of occupational therapists and physiotherapists.

3.2 Approach and data collection methods

This article is part of a larger participatory research project on the well-being of nursing home residents on three geriatric care wards located in different villages in the north of the Netherlands but which are part of the same health care organisation. In this project, no extra financial means or time were provided, besides the fact that caregivers who had to come back to the ward for team meetings were paid for their time. The team of caregivers working at the Korsakov ward signed up for the project voluntarily.

199 The ethical committee of the Faculty of Spatial Sciences reviewed the research proposal. Data
200 collection for the project was undertaken during a period of one year, from June 2011 to June 2012.
201 The project can broadly be divided into four partly overlapping phases, as distinguished by Kindon
202 (2010):

203 (1) exploring the situation, (2) setting up a commonly defined intervention, (3) intervention, and
204 (4) evaluation and future developments. In the following, we briefly discuss the four phases and the
205 methods of data collection used in each phase. The aim of the situational analysis was to get more
206 insight into daily life at Riverside. For that purpose, we collected data through participant observation
207 and interviewing Participant observation was conducted during visits on all days of the week during
208 day and evening hours. MK observed daily life in the communal areas of Riverside and participated
209 in daily activities, such as lunch and dinner, recreational activities, and special events (such as
210 Christmas dinner). During the observations, she conducted conversational interviews to clarify the
211 observations. In-depth interviews were held with five residents and three caregivers, which made it
212 possible to ask follow up questions to the observations. The in-depth interviews were open-ended
213 and addressed a wide range of topics. Each interview began with a broad question: 'Please tell me
214 what it is like to live/work here', followed by questions regarding participants' perceptions of the
215 provision of care, housing, daily life (including routines and procedures at Riverside), activities, social
216 contacts and atmosphere. Informed consent was obtained from the participants for all in-depth
217 interviews.

218 Table 1: Interventions implemented at Riverside categorized by aim

Aim of the interventions	Interventions
To increase residents' autonomy and control	• Residents decide when to get up, where to eat, and what to eat. • Residents visit the doctor with the support of caregiver.

	• Residents attend multi-disciplinary meetings in which their case is discussed.
To minimise disturbance in public space and increase the sense of privacy	• The placement of a door that detaches the ward from the greater facility. • Residents are not disturbed by professionals during recreational activities. • More opportunities within the structure for residents to withdraw from the 'batch'.
To increase home like practices	• Meals are cooked by the caregivers at the ward. • Caregivers have meals together with the residents. • Residents are involved in domestic tasks such as cooking and doing groceries.
To decrease the feeling of being locked up	• Residents spend more time outside the facility. • Residents are coached more intensively to go for a walk outside the facility on their own.
To provide person-centred care	• Caregivers listen to residents' wishes and needs. • Decisions are made in consultation with the residents. • Caregivers decide what rules and regulations they need to provide high quality of care. • Caregivers calculate the risks they take, rather than avoiding risky situations

219

220 In the second phase MK presented the perspectives of the residents, i.e. the results of the situational
221 analysis, to the caregivers. The information on what was important to the residents in their daily lives,
222 and on what they wanted to improve, was used by the caregivers to discuss the interventions they

wanted to set up to increase residents' well-being. Through discussion, they decided together which interventions to prioritise. For an overview of the developed interventions, see Table 1. We categorised the interventions according to their aims, to provide a clear overview. These categories, however, overlap and are not mutually exclusive. Unlike most other studies on nursing home care, older adults' perceptions and descriptions of daily life in the care facility were thus included in the study (see Wadensten, 2007). In the third phase, the interventions were implemented. The third phase consisted of cycles of action and reflection. The interventions were imple- mented, evaluated by the team, and subsequently accepted, revised or discarded. Some of the interventions were complex and difficult to carry out, such as changes to make safety regulations less bureaucratic and time consuming, while others were simpler and easier, for example, rules established by the team itself, such as where residents could have dinner.

In the fourth phase, five caregivers kept diaries for 10 days in which they were asked to write freely about changes in work practices, how they experienced the interventions and how the residents responded. The data from the diaries were used as input for semi-structured, in-depth interviews with the care- givers. This enabled the researchers to go deeper into the issues brought up by the caregivers. Furthermore, the caregivers' experiences and perceptions of the project were also discussed during the interviews.

Conversational interviews were held with residents during observations to gather information about life at Riverside at that point of time. Conducting in-depth interviews with the residents in this phase was challenging, because many had difficulties comparing their current life on the ward with how it had been previously, in part due to their cognitive impairments. As an alternative, MK conducted a focus group discussion with nine residents, in which concrete interventions were discussed and evaluated. Although the focus group discussion provided some information on the residents' experiences, the evaluation of the interventions is mainly based on the detailed accounts of the ten caregivers, the head of the ward, and observations on the ward by MK.

The progress of the project was monitored throughout all the phases. MK visited Riverside every two weeks, was present at team meetings, meetings between caregivers and other professionals such as physiotherapists, and conducted observations to monitor how the participants experienced the progress of the project. During the project, caregivers reflected together on how they provide care, when they trust and are supported by each other (or not), and how they feel supported by the management (or not). We found that through these discussions, the caregivers developed a shared vision, and felt ownership for the project and where motivated for the project to succeed. At the start of the project, not all caregivers were enthusiastic about it. This changed gradually as the project progressed, and towards the end, even the most sceptical caregiver told us how her opinion had changes, and how she felt she had become an ambassador of the project.

To provide a complete picture of the project and its evaluation, LM conducted three in-depth interviews each with the director of the health care organisation and the project manager, at the beginning, middle and end of the project. These interviews were held to monitor their perceptions of the process over time, their expectations and experiences with the project, and ideas for the future.

Through this monitoring, it became clear that some, but not all, of the ideas raised in the situational analysis were addressed in the interventions. Some ideas were recognised as valuable by all participants but were difficult to put into practice, such as the desire of some residents to have their own mailbox. This suggestion stemmed from caregivers opening residents' mail before giving it to them, which residents experienced as a violation of their privacy. In principle, the caregivers agreed that the residents should be in charge of their own mail. However, in practice this had resulted in problems, such as residents not paying bills on time, so the caregivers chose to leave the situation as it was. Overall, we found that the caregivers prioritised interventions that were relatively quick and easy to implement.

3.3 Data analysis

The observational notes and transcripts of the recorded in-depth interviews resulted in written texts. The data were stored on a network space to which only the two authors had access. The names of the residential home, residents and staff have been anonymised and pseudonyms are used in this article. Data analysis was carried out during the first and fourth phases of the research. The process of analysis began with careful reading of the transcripts, followed by open coding (Strauss and Corbin, 1998). In the process of open coding, we found that aspects of home and institution emerged from the data, and that residents related these to their well-being. Subsequently, we used the concepts of home and institution in the process of axial and selective coding. The analysis enabled us to systematically evaluate how the implemented interventions affected both institutional and home-like features within Riverside. We can thus say we adopted an informed grounded theory approach, which means that we used literature on total institutions and home as a framework for the analysis, while also being open to new themes that emerged (Bowen, 2006; Thornberg, 2012). Both authors were involved in the process of data analysis, discussing emerging themes, categories and concepts. Where our interpretations differed, we discussed them until we found common ground, thus improving our understanding and interpretation of the data.

4. Results

4.1 Block treatment

The Korsakov ward contained elements of both home and institution. Our results focus on the institutional elements and the interventions carried out to make Riverside more home- like. The daily life of the residents is clearly structured and the routines are determined by the staff. The residents are woken up, (helped to) get out of bed and dressed, and all have breakfast together. In the morning and afternoon, residents participate in recreational activities on the other side of the facility, and coming back to Riverside for lunch in between. At the end of the day, the residents have dinner together in the communal dining area. Daily life at the Korsakov ward is highly routinised and the

residents have little control over their own lives. Mr Davis stated: ‘Everything is decided for me. I'm not a small child!’ (Interview, phase 1, Mr Davis, resident).

The caregivers understood that the structure is not what residents wanted:

Yes, that is how some people feel. Most people want to do their [own] thing: lying in bed, smoking, and especially doing nothing. The majority. And when we then say: you have to get up at 9 o'clock, a quarter to 10 you have to go to the workplace, half past 11 you come back again, 12 o'clock you have to eat, yes, then their life is lived for them (Team meeting, phase 2, Julia, caregiver).

Although the caregivers understood some of the residents' frustrations, they decided to maintain the general daily structure at Riverside, reasoning from the specific needs of people with Korsakov syndrome: ‘If you give them no structure, you provide no safety, and then they will become an unguided missile’ (Interview, phase 4, Julia, caregiver).

What the caregivers did change was their style of working. They provided the residents with more control and choice within the daily routines by listening more carefully and by consulting the residents:

I have learned to listen more to the residents. In the past I was used to determining everything for the residents. Now I discuss everything with them: at what time would you like to take a shower, how would you like to eat your sandwich? (Diary, phase 4, Paula, caregiver). I can make an agreement [with a resident] that he will shower before going to bed, and not exactly at 7 o'clock … when it is most convenient to me. Now, when it is most convenient for the resident, that is what I now think is very important. It's not about me finishing my work on time, but that the resident can have a say for himself, ‘I would rather take a shower before I go to bed or early in the morning when I wake up’ (Interview, phase 4, Maria, caregiver). The caregivers found that this way of providing care made the residents feel heard and respected: ‘Mr W. commented that since the project, he is more listened to and above all, “I'm taken seriously”’ (Diary, phase 4, Julia, caregiver). Linda explained:

It's a more open conversation. It may not be your own norms and values, but it's about [the residents'] well-being. So, being open to their ideas (Team meeting, phase 4, Linda, caregiver).

As an example of respecting the residents' wishes, one resident preferred to sleep in his bed with his clothes and shoes on. Before the project this was not permitted and every night there was a struggle to get him into his pyjamas. During the project, the caregivers decided to allow the resident to do as he wished. They reasoned that there were no direct risks involved as long as certain hygienic standards were met,and came to an agreement with the resident about when to change and wash his clothes. This made it possible for the resident to continue his preferred habit. Through respecting the residents' wishes, the caregivers provide room for residents' self-determination.

To increase residents' participation in decisions about their treatment and care, residents were allowed to take part in the multi-disciplinary meetings and to visit the nursing home doctor themselves. At Riverside it had been customary for the caregivers to discuss a resident's medical condition with the doctor without the resident being present. The head of the ward commented:

Let our clients visit the doctor, let a [Mark Williams] go to the doctor and say I don't feel that well … Why not? I mean, why should we tell a doctor how our residents feel? I mean, I don't let my husband go to the doctor's to tell him how I feel … Our residents are not treated with dignity (Team meeting, phase 2, Helen, head of ward).

The caregivers thought that some residents were capable of participating in doctor's visits and multi-disciplinary meetings with the guidance of a caregiver. Although not many residents made use of this new opportunity, it is left to the resident to choose whether he/she wants the caregiver to talk to the doctor.

4.2 Batch living

The residents shared their daily life with other residents. The participants typically described their fellow residents as acquaintances rather than friends, though a small number of residents said that

there were others with whom they got along. Our observations confirmed this. Some patients were occasionally seen in each other's company, or helped each other during dinner, for example, with cutting meat. Several residents felt disturbed and irritated by the presence of other residents. One resident described the others: 'It is all about me, me, me and [for me] to eat at first' (Interview, phase 1, Mr Davis, resident).

One characteristic of Korsakov syndrome is self-centredness, which makes it especially difficult for patients to spend much time in a group. Mr Edwards, who had difficulty coping with environmental stimuli, thought the group of 10 people was too large. He and some other residents expressed a desire to eat in their own rooms, rather than in the communal dining room, which was the common practice.

The observations showed that not much interaction occurred between the residents. Some residents would sit together, several smokers would sit next to each other to smoke, for example, but there would not be much conversation. As in many nursing homes, being part of a group which provides a sense of solidarity, companionship, relaxation and fun (Cooney, 2012) was not achieved in our study setting. Our study showed that the presence of a caregiver had an important effect on the atmosphere in the communal room. Caregivers mentioned this:

[The residents] would probably not say they need our company, but they will make use of it.… When you leave [the communal room], and return after 15 min or so, the living room will be empty…. But if you stay, make some small talk, watch TV together, make the place comfortable with some food and drinks, then people will stay there much longer (Interview, phase 1, Emma, caregiver).

In line with Hauge and Heggen (2007), we found that conversations between the residents came to a standstill when the staff members left the room, while in the company of the caregivers, residents took part in group conversations and made jokes. The caregivers became aware of their impact on the use and atmosphere of the common space and tried to be more present. Besides cooking, they would also eat or drink coffee with the residents. Some of the caregivers already did this before the project, but afterwards it became common practice.

Goffman (1961) talked about the distance between care- givers and residents as being part of institutional life. Because the majority of the caregivers did not wear a uniform, there was no visual distance between caregivers and residents, which provided a rather home-like feel to Riverside. Many residents said in the interviews that they liked to talk to and spend time with the caregivers; trips into town to buy clothes or for an appointment at the hospital were greatly appreciated. Nevertheless, the residents said that during these outings the caregivers would watch the clock all the time, which they found disturbing. The social contact between caregivers and residents changed in the course of the project. During the project, the caregivers learned to take more time for individual contact:

I've been shopping this afternoon with one of the clients. Client wanted new clothes. We went into [name of town] by bike. We shopped the whole afternoon. Client enjoyed it, was happy with the new clothes. Enjoyed the one-to-one attention. Showed this by treating me to coffee and cake. We took all the time that we needed. Client liked this, and clearly appreciated the outing. I also liked it and think this should happen more often, for example, going to the market, etc. The resident was very positive and would like to go more often (Diary, phase 4, Thomas, caregiver).

Other caregivers told us that they saw that residents were satisfied and enjoyed the outings. Staff members, in turn, said they developed an eye for what the residents enjoyed doing, and initiated trips that they knew the residents would enjoy. Thomas is able to take time during the outings, because his colleagues were willing to take up tasks that he could not finish. Documenting the process, we found that the caregivers had to be supported by their colleagues in thinking about and providing care differently. They needed to feel secure and trusted in their professionalism, to be able to go shopping with a resident without being blamed by colleagues for only undertaking fun activities, for instance. Providing good care was not regarded as finishing certain tasks in a shift by one individual caregiver anymore, but rather as a collaborative task with the aim of meeting the residents' needs and wishes. For instance, in the winter, Thomas took a resident ice skating. And [the project] has assisted in that … I handled it much easier. If [the project] had not been there, possibly I would… have gone ice skating

with the client, but in a different way, I guess. [Name of the project] has been an eye-opener, how to do this more easily. Just to spend time and energy in it; rather than only thinking about the cons, also looking at the pros and what it gains. That is such a positive thing, simply looking at the client. That was, in one word, fantastic (Interview, phase 4, Thomas, caregiver).

This quote shows how the project enabled Thomas to undertake an activity that allowed a resident to continue an activity from his previous home life, that is, going ice skating on a cold winter day. Thomas regarded the risks associated with ice skating as part of a 'normal' life, and concluded that he could undertake this activity with the resident (see Higgins, 1989, p.164). The management of the institution played an enabling role in this shift from risk avoidance to risk management: they trusted the caregivers to assess the risks involved at the individual rather than collective level and, if necessary, to take precautions to minimise the risks. In addition, caregivers found that their relationships with the residents became more relaxed. One of the caregivers mentioned:

[On] Valentine's Day, several co-residents asked if I received anything from my children and husband. I laughed and said 'not yet'. I very much like it that they think about this (Diary, phase 4, Catherine, caregiver).

This relates to what Hauge and Heggen (2007) called 'golden moments' in the daily life of nursing home residents, when caregivers shared experiences from their everyday lives with residents, creating a special closeness. Such interactions reshape the relationships between caregivers and residents, closing the gap between them and balancing power relations, making them more equal parties. This development was appreciated by the caregivers, and enhanced their work pleasure.

4.3 Public and private space

Much of the residents' daily life was spent in a public space within Riverside, a common living room which included a seating area, kitchen, dining table and terrace. The living room resembles a private living room in a typical Dutch home, with a sofa, a couple of armchairs, a television, paintings, curtains,

some plants and a cage with a bird, the pet of one of the residents. The room has large windows that provide views of the garden and terrace. During holidays, such as Easter and Christmas, the living room is decorated. The kitchen also resembles a typical Dutch kitchen, although it is larger than average, and the dining table and chairs are more institution- like in that they are scratch-resistant and water-repellent. Outside the ward, the facility has a more institutional look: long corridors with handrails along the walls, with access to individual bedrooms and windows that mainly look onto patios. Our initial observations showed that the staff at Riverside made little attempt to separate themselves from the daily lives of the residents socially and spatially. Spatially, not much has changed. Caregivers already used a PC in the common living room for administrative purposes. The aesthetics of the common areas did not change during the project, but changes were made socially and more domestic tasks are now performed in the public spaces. For example, caregivers began heating up the previous evening's leftovers during lunch time for the residents who enjoy the leftovers very much. This practice evokes a sense of homeliness, because it reminds residents of how they used to act at home. The residents are also more involved in domestic tasks in the common living room, such as cooking. A caregiver commented about this in his research diary:

> The clients like to help with the preparations for dinner: peeling potatoes, cutting or cleaning vegetables, cooking the food. Also, I see that [they] enjoy the food. Clients take the time to eat their dinner. They eat well, and [go back] for a second or third helping. Residents are satisfied with the food. It gives clients satisfaction – that they are able to give a hand (Diary, phase 4, Thomas, caregiver).

These findings confirm those of a recent review by van Malderen, Mets, and Gorus (2013), who showed that resident participation positively affected quality of life. From the interviews with the residents, it became clear that they did not experience control over public space. Residents of the different wards walk freely around Fairview, and occasionally psychogeriatric patients would get lost and enter the Korsakov ward or the private rooms of the Korsakov patients, or they took personal belongings. The Riverside residents experienced the presence of these patients as very disturbing, stressful and a

violation of their privacy. Outside the ward, the workplace, also located in Fairview, formed a different public space, where residents participated in occupational therapy on weekdays. The workplace is small and many of the residents are easily distracted by other residents and by staff. According to a caregiver:

That is also what I noticed with residents, when there is unrest in the workplace, with the coming and going of people, the whole time all around them […]. They like a calm environment, and some find the disturbance very unsettling (Team meeting, phase 2, Maria, caregiver).

Research has shown that disturbance caused by other residents negatively affects feelings of home (Kane et al., 1997, Fiveash, 1998, cited by Hauge & Heggen, 2007). During the project, a new door with an access code was installed, which makes it much more difficult for the other patients to enter Riverside. As a result, the public areas of the Korsakov ward became quieter and were separated from the public spaces of the rest of the facility. Even though the Korsakov residents still share the living room with their fellow residents, it became more a place of their own, without the presence of people they considered outsiders. In the words of one of the caregivers:

Yes, it has become more relaxed in the living room. It is more cosy, I think that people are becoming more friendly, also more open (Interview, phase 4, Maria, caregiver).

The residents also experienced fewer interruptions during occupational therapy. Work time was previously disrupted by physiotherapists, who would come into the workplace to collect residents for therapy sessions. During the project, it was decided together with the physiotherapists that the residents would not be disturbed during their occupational therapy, but that the physiotherapists would schedule their sessions before or after work time. This intervention illustrates how disruptions in public places have been diminished, and how the residents' (indirect) control over these places has improved.

Many residents mentioned that they felt locked up within the facility. Although the residents are able to move about within the facility, the Korsakov ward is part of a secured care facility, which means that residents are not allowed to enter and leave the facility freely. Mr Stewart compared his living situation with imprisonment, while Mr Davis described it as being in quarantine. Several residents expressed a desire to go outside the facility more often. During the project, more emphasis was placed on activities outside the care facility. Rather than having all activities at the terrain of the institution, a characteristic of total institutions (Goffman, 1961), staff members started to shop for groceries with the residents. Every week two staff members together with two residents take a van and make the trip to the supermarket and the butcher's. Emma commented:

I believe that they will stay sharper, when you just go outside with them. That is why we stimulate [them], we started to do the cooking, to do the groceries, to go to the supermarket together with the clients and that you let them pay and become aware of what is for sale and what has been changed (Team meeting, phase 4, Emma, caregiver).

We like to use this example to illustrate how interventions were implemented. The caregivers discussed what they needed in order to do groceries: transportation, a bank card, a storage room, and a refrigerator. For transportation, the caregivers reserved a van of the health care organisation for one fixed afternoon every week. For storage, they cleaned and emptied a room that was used for other purposes. However, they experienced more difficulties with the purchase of a bigger refrigerator and getting a bank card, because the head of Fairview did not give permission for this at first. In the end, the head of Riverside talked to the project manager, who in turn convinced the Fairview manager to give permission for the purchase of the refrigerator and the use of a bank card. This example illustrates the difficulties that the participants had to overcome as well as the complexity of implementing interventions that involved people outside the ward.

Staff members found that residents behaved less as patients outside the facility:

I went with Mr Moore, it was [his] birthday and he wanted to buy a cake. I went with him to the HEMA [Dutch retail store]. He didn't want to take his walker, he didn't want an arm because he wanted to show me that he could do it independently [laughs]. That is just fantastic…. He becomes a different person outside the facility (Team meeting, phase 4, Julia, caregiver).

The trips enabled residents to participate in everyday life outside the institutional setting, and the reactions from the caregivers demonstrate that they considered this beneficial for the residents' independence and self-esteem.

The residents have one private place: their own room. A typical room contains a bed, television and comfortable chair. The majority of the residents had no problem with the small size of the room. They were allowed to decorate the room according to their own wishes. Caregivers told us that some of the residents were homeless before they moved into Riverside, possessing only the clothes they were wearing, so it was difficult for them to make their rooms more personal and less institution-like. For instance, Mr Henderson, who had not brought his own bed when he moved to Riverside, felt that the bed the institution provided made his room look like a hospital room. The private rooms often contained some personal possessions. Mr Edwards, for example, showed MK a clock which had belonged to his parents, an example of a material connection to the past, which can provide a sense of comfort. The walls of his room were also covered with paintings that he had won at the Bingo games organised at the facility. These possessions encompassed events from both his past and current life.

The private rooms can be conceptualised as defensible spaces (see Barnes, 2002, p.784). Residents were allowed to lock their doors, which gave some residents a sense of control, signified by the key cord they wear around their necks and practised by including or excluding other people from their room. Even in these private places, residents experienced awkward situations where their privacy was at stake. For instance, they had to share a bathroom with one other resident, which resulted in a lack of control around the use of the toilet. A resident might need to use the toilet when it was already in use, or the noise could wake residents up during the night. Because of the clear daily structure and

514 batch treatment, the residents had little time to withdraw from the common areas to their private
515 room, which impinged on their sense of privacy and feeling of home.

516 The caregivers realised that they had established rules to enhance shared activities, because they
517 thought people would get lonely otherwise. However, in response to the lack of private space
518 experienced, the caregivers gave the residents more opportunities to withdraw from public space, for
519 example, to have dinner in their own room. Although recent studies stress the importance of social
520 connectedness for nursing home residents' quality of life (Buckley & McCarthy, 2009; Cooney et al.,
521 2014), this was not confirmed in our study. This may be related to the clinical nature of Korsakov
522 patients.

523 Our results showed how public space on a Korsakov ward can be made more private, confirming
524 findings by other authors who have discussed the fluid nature of public and private space. Nord
525 (2011a), drawing on Sommer (1969), argued that privacy can occur everywhere in a nursing home,
526 even in public space, through the creation of personal space or a 'micro-spatiality of privacy
527 surrounding a person' (p. 937). She showed how staff can support requests for personal space in public
528 by taking into account personal preferences, for example, by allowing residents personal space during
529 the meals in public spaces. Activities that are regarded as private do not always occur away from other
530 people's gaze (Solove, 2002). Nakrem et al.'s (2012) study showed that the nursing home itself is not
531 associated with home; when residents talked about 'going home' they meant their own room and not
532 the nursing home itself.

533 However, other authors argue that the public and the private should be contrasted and juxtaposed
534 rather than integrated, and that the differences between public and private space should thus be made
535 clearer and more explicit. In line with this train of thought, Young (2004, cited by Nord, 2011a)
536 discussed how personal space in residential care is exclusive to the older person's bedroom, and does
537 not extend to other spaces. Similarly, Hauge and Heggen (2007) argued that a common living room in
538 a nursing home can never facilitate privacy, because people have to share the living room with others

539 who are essentially strangers. As a result, the right to control cannot be fulfilled in this space and the
540 boundaries between the public and the private become unclear.

541 **5. Conclusion**

542 Our study have shown that Riverside is a nursing home ward that shares many elements with total
543 institutions. In this article, we have shown that it is possible to increase the home- like character of
544 such a ward through contextualised interventions. However, we have also shown how several features
545 of institutional life remained. Thus, our findings confirm the idea that home and institution are two
546 ends of a continuum, and show that nursing homes can be relatively institution-like in some ways, and
547 more home-like in others. More specifically, our study shows how elements of home can be introduced
548 to provide a much more home-like feel to an institutional setting.

549 At the start of the project, many residents did not feel at home in the Korsakov ward. This was related
550 to:

551 • having no autonomy and control in everyday life, mostly due to the strictly regulated daily
552 activities, the provision of care that was task- and schedule-oriented, and the organisation of group
553 rather than individual activities;

554 • having no privacy, because of the focus on group activities in public spaces, the disruptions
555 experienced within Riverside, the shared bathroom, and the limited opportunities to withdraw to one's
556 own room;

557 • the secured nature of the ward and the limited opportunities to leave the institution.

558 Riverside became more home-like through various interventions. Discussion about the everyday
559 routines and daily structure was initiated, and the caregivers began to listen more carefully to the
560 residents and to consult them about their preferences. As a result, residents felt ‘heard’ and
561 acknowledged. Routines were adapted to suit the residents' wishes, where possible. For example, the

562 residents still had to get up to attend occupational therapy at 10 o'clock in the morning, but they could
563 indicate what time they wanted to get up and have breakfast, rather than having the caregivers decide
564 for them. Also, the caregivers allowed the residents to withdraw from the public space and live more
565 of a private life within the existing structure. Public spaces were also made more pleasant: disruptions
566 have reduced, more domestic practices are carried out, and caregivers are present more often, which
567 contributes to a positive atmosphere and fosters interaction between residents. Finally, the caregivers
568 take residents on trips outside the facility more often, in small groups or individually, to go shopping
569 for groceries or clothes, or for recreational activities.

570 This article contributes to the academic discussions on home and (total) institutions. We have shown
571 how core values and feelings of home, can be enhanced within a secured Korsakov ward. The applied
572 interventions did not so much focus on changing the environmental aspects of the nursing home, but
573 rather on increasing the control of residents over their everyday lives. In line with Molony (2007), we
574 conclude that a sense of home in a long-term care facility is about experiencing autonomy, control,
575 choice and privacy, which can be supported by the layout of living spaces such as the ward, common
576 room and private rooms. Features of institutional life, such as a structured environment with fixed
577 routines, as well as the physical features of a nursing home ward, do not hinder such a ward from
578 becoming more home-like.

579 Through the project, caregivers began working more person-centred through an increasing focus on
580 the residents' individual needs and wishes, rather than treating them all alike (see also de Veer &
581 Kerkstra, 2001; Williams et al., 2015). Our study demonstrates how person-centred care can enhance
582 feelings of home, which confirms other findings (Brownie & Nancarrow, 2013; van Malderen et al.,
583 2013). There is not one ‘optimal’ way of person-centred care for nursing home residents; rather, the
584 best care is always context-dependent and may be different for everyone. This ties in with Custers et
585 al. (2012) who found that taking into account personal preferences of nursing home residents
586 increases their well- being. Thus, achieving person-centred care does require that caregivers depart

from routines from time to time and that the preferences of the clients are central, instead of the risks associated with certain activities. Although other studies showed that this is difficult to achieve (Harnett, 2010; Kontos, 1998), we found that true client-centeredness can be enabled through a participatory intervention study. In such a study, it is important that health care organisations allow caregivers to change their way of working in line with their own professional judgement; and that caregivers are able to discuss what they like to change in their way of working. Thus, caregivers can gain autonomy in their way of working and feel ownership over their work.

We discussed several interventions to make a nursing home setting more home-like. These interventions were developed in the context of a Korsakov ward in the Northern Netherlands and we see them as contextualised. When translating the interventions to different settings, socio-cultural differences must be taken into account. In spite of the importance of the setting, there are three general best practices that emerged from this project: (1) caregivers should give the residents a say in matters that are meaningful to them, in order to enhance residents' control and autonomy, and with that a sense of home;(2) building trust among caregivers and between caregivers and residents, through good and open communication about the project and interventions, is essential in enhancing a sense of home; and (3) caregivers have to be supported by colleagues working in other disciplines within an institution, such as physiotherapists, cooks, cleaners, and managers.

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