Realising dementia-friendly communities:

the role of nursing homes and care professionals

Suzanne Portegijs

Realising dementia-friendly communities:
the role of nursing homes and care professionals

Op weg naar een dementievriendelijke gemeenschap
de rol van verpleeghuizen en zorgmedewerkers
(met een samenvatting in het Nederlands)

Suzanne Portegijs

Realising dementia-friendly communities:
the role of nursing homes and care professionals

alzheimer
nederland

VRIJE UNIVERSITEIT

REALISING DEMENTIA-FRIENDLY COMMUNITIES:

the role of nursing homes and care professionals

ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad Doctor aan
de Vrije Universiteit Amsterdam,
op gezag van de rector magnificus
prof.dr. J.J.G. Geurts,
in het openbaar te verdedigen
ten overstaan van de promotiecommissie
van de Faculteit der Geneeskunde
op woensdag 19 februari 2025 om 11.45 uur
in een bijeenkomst van de universiteit,
De Boelelaan 1105

door

Suzanne Portegijs

geboren te Diemen

Contents

1

General introduction

Dementia statistics and impact

Dementia is a global health concern affecting around 55.2 million persons worldwide in 2019, with 14.1 million living in the European region. It is estimated that there will be about 78 million persons with dementia worldwide in 2030 and about 139 million in 2050. (1) Dementia is one of the leading causes of care dependency and disability in old age (1, 2), and is associated with complex care needs and high levels of dependency and morbidity in its later stages. Dementia also requires a range of services, such as primary health care, specialist medical care, community-based services, rehabilitation, long-term care and palliative care. (1) Persons with moderate to severe dementia are often living in residential care settings. In Europe, it was estimated that in 2016-2017, there were 64,741 nursing homes, rehabilitation centres and mixed long-term care facilities, representing a total of 3,440,071 beds. (3)

Dementia-friendly communities

The increase of persons with dementia asks for another approach towards dementia within society. Worldwide dementia is related to stigma which negatively affects persons with dementia and their family members, who are often also caregivers. (1) Improving public understanding is a key strategy to improve help-seeking and reduce the fear and stigma associated with dementia. (4, 5) One way to reduce this stigma is the development of dementia-friendly communities.

Dementia-friendly communities are defined as a concept that enhances the degree of participation in daily life for persons with dementia and provides a feeling of being valued and safe. (6) Dementia-friendly communities aim to improve the communication between generations, general knowledge and attitudes towards persons with dementia. Furthermore, working towards a better understanding of dementia, facilitating normalisation and decreasing stigma are key features. (6) Dementia-friendly communities also focus on social inclusion, where this is viewed as a dynamic process where persons engage with, and are part of, their social networks in the community to maintain meaningful social relations. (7)

In a recent pilot study, Philipson et al. (2019) found that direct involvement of persons with dementia as spokespersons and educators was effective in improving positive attitudes towards persons with dementia and in reducing the negative stereotypes associated with living with dementia. (4) However, they also concluded that further research is needed to compare different approaches and look at how local interventions can be used to raise awareness at a national level. (4)

Healthcare settings are also part of dementia friendly communities. Lin (2017), defines being dementia-friendly in health-care settings as the inclusion of persons with dementia

in treatment discussion, decision-making and delivering person-centred care within a suitable physical environment, such as hospitals, care homes and health centres. (9) At the moment, little is known about how nursing homes for persons with dementia support change and improve dementia-friendly communities. This lack of knowledge is visible in research on communities and neighbourhoods, but also in research in nursing home care.

In this thesis the change process, context and results of a nursing home striving for an open dementia-friendly community will be investigated.

What is already known?

With regard to communities, Hebert & Scales (2019) concluded that there is a research gap between the field of dementia and the build environment of neighbourhoods. (10) They argued that the following design aspects are important: 1) Easy visual access to frequently used rooms; 2) Opportunities for privacy and community engagement; 3) Appropriate levels of stimulation; 4) Support for movement and engagement in activities and 5) Presence of familiar objects and furniture. (10) In addition, in the scoping review of Gan et al. (2022), it was found that the built environment is a critical aspect of dementia-friendly communities. (11) Charras et al. (2016) - in an ethnographic evaluation of the dementia-friendly physical design of three dementia care units - concluded that congruency between care practices and design of setting is the key to success. (12) In this evaluation the following primary dimensions in the use of space were identified: 1) Organisation of space; 2) Space induced social cohesion; 3) residential ambiance, 4) Privacy; 5) Display of care; and 6) Control and attention provided to residents. (10, 12)

With regard to nursing home care, little is known about the role of nursing homes within dementia-friendly communities. Smith et al. (2016) conducted interviews with 26 residents living in both the community and long-term care facilities in New Zealand. (13, 14) She concluded that residents with dementia found stimulating and colourful outdoor spaces important and that residents living in both facilities and communities like to go outdoors. However, due to the built environment this is not always possible. For instance, in some long-term care facilities persons with dementia live above the ground floor. Moreover, some long-term care facilities restrict access to communal gardens for persons with dementia. These restrictions are mainly the result of safety concerns with regard to physical activity of residents. (13) These safety concerns are, as found in other research, mainly attributable to the fear of injury for both the resident and the professional caregivers themselves. (15)

In the next sections, we will first discuss physical activity of persons with dementia in nursing homes , and then discuss research on safety concerns of nursing staff.

Physical activity of residents with dementia in nursing homes

It is commonly known that nursing home residents (with or without dementia) are largely sedentary. (16-21) While sufficient physical activity positively influences various health-related outcomes, such as cognitive functioning, independency in activities of daily living, physical performance, mobility and functional ability. (22-24) In addition, physical activity also decreases agitated behaviour and could therefore potentially contribute to enhancing residents' psychological well-being and quality of life. (22, 25-28)

Multiple factors influence the physical activity of nursing home residents, both personal and environmental. Reduced initiative is often part of the clinical picture of dementia, resulting in difficulties initiating movement and activity. (27, 29) Furthermore, reduced physical mobility occurs often in (mostly) later stadiums of dementia, (27, 29) making residents largely dependent on the daily guidance and support of caregivers and nursing staff to be physically active (29-31). Physical activity is therefore substantially influenced by the mindset and approach of caregivers regarding physical activity and active engagement in daily care. (30-32)

In recent years, there has been increasing research on the use of trackers and accelerometers to measure – among others – physical activity. Skender et al. (2016) state that accelerometers appear to provide slightly more consistent results in relation to self-reported physical activity. (12) Yet, it is unclear if these findings are generalisable to others settings and measuring instruments, such as the nursing home and manual observations. Furthermore, much is unknown about the practical implications regarding the use of accelerometers and the burden for residents with dementia in nursing homes.

The role of nursing staff

> Resident A approaches a staff member in the kitchen and points to the walker.
> Staff member: "Do you want to go for a walk? Do you have a moment? Then we will go for a walk in a minute." The staff member continues transferring applesauce from small containers into large glass bowls for dinner.
>
> Resident B returns from the toilet and sits back down at the table. Resident A points to the walker again and says: "I want to take a walk." The staff member responds: "Would you please stay seated? That's not your walker. You are only able to walk with the high one." Resident A sits down again after which the staff member continues with the applesauce.
>
> A second staff member walks into the kitchen. The staff members discuss that resident A fell a day earlier while walking. "We really have to pay close attention," they say to each other. After which the staff member continues preparing dinner. Resident A does not walk until dinner.

Nursing staff are crucial to facilitate physical activity among nursing home residents, as they are most involved within the daily lives and care of residents compared to others, such as family members and volunteers. (32) In fact, nursing staff often provide the only opportunities for residents with dementia to leave their wards or facility. Subsequently, the behaviour and attitudes of nursing staff towards and interaction with nursing home residents are of great influence when encouraging physical activity of residents. (38-40) Physical activity is mainly facilitated by nursing staff having sufficient knowledge about residents, having a 'person-centred mindset' and subsequently recognizing them as a whole person and approaching them in a respectful manner, encouraging autonomous behaviour. (38-40)

An important hindering factor to enable physical activity, is the experienced fear of harm for residents by nursing staff, which often results into taking over (daily) activities and/ or activity restrictions or even physical restraints. (32, 41, 42) Even though nursing staff find physical activity of residents important and state that it is feasible to realise more physical activity within daily care. (42, 43), studies show that finding a balance between safety and freedom and/or autonomy is challenging. (44-47)

The role of nursing homes

Older persons with dementia seek understanding and inclusion in public services and spaces for social connection. (13) This understanding and inclusion can be achieved through the engagement within meaningful activities with other persons. (52) Meeting these other persons should be possible as long-term care facilities are often connected to the local community. (53) Though, the interactions of nursing home residents are often limited to those with nursing staff, family members and other residents. The connections between residents, family members and nursing staff are imperative, as

they influence quality of care and the provision of person-centred care. (54) Strong connections between nursing staff and family members – for instance – contribute to the knowledge nursing staff have about residents with dementia leading to more person-centred care. (55) Also, these contacts seem to result in nursing staff prioritising the interests of residents above their own. (54)

> We walk clockwise through the park, so we can walk in the sun. Mrs. talks extensively about her children. She has seven, six daughters and one son and a lot of grandchildren. "I couldn't tell you exactly how much." Mrs. says that her son works in construction and has contributed to the construction of the nursing home she is currently living in and a number of other buildings in the village. Many of Mrs.'s daughters and granddaughters work in healthcare. Mrs. herself comes from the village where the nursing home is located, her husband from the nearby village. They have met each other at the market.
>
> We take a seat on a bench in the sun that overlooks the building and the chapel. When I ask her if she has visited this place before, she tells me that she used to live opposite of the building in an apartment with a balcony. She sometimes went for dinner in the old mission house (which used to be located on the site where the nursing home is now situated). Then, in the same breath, she tells stories about the war. She talks about the bombings that took place in the village and the people who survived or not. "Many people were also shot."
>
> I then point out that a lot has changed here on the ground. "Well I don't think much has changed. This has always been the same. They only built paths. That is where the gardens are." She points to the vegetable gardens. She thereafter talks about her children and grandchildren. She says that her children actually all live close to her and mentions several nearby villages. Mrs. then points to the buildings at the back of the park and says that her son lives there. "They drive very fast on that street. A motorway also passes there. I used to cross there sometimes, but I'm not allowed to do that anymore."
>
> We get up to continue our walk towards the entrance of the nursing home. In the meantime, Mrs. talks about the different people she knows in the village, mentions them by name and where they are now. She says that a volunteer will come by tomorrow to go to the market in the village. I ask if it is a big market. "I don't really know that. I haven't been there in a long time." When we get to the entrance, she says: "I am going to have a quick drink in the living room." When we enter the living room, I help her take off her coat and scarf. "Look, so this is where we always play bingo." I make her a cup of coffee and bring it to the table where she has taken a seat, joined by two fellow residents. We say goodbye to each other.

Social connections have the potential to lower the barrier between communities and nursing homes and include residents with dementia within society. Though, research on this topic is scarce and much is unknown about the mechanisms that underly these connections and the embeddedness of long-term care facilities within social networks.

Change and innovation in nursing homes

To change the way in which physical activity is seen in nursing homes - and to focus on the benefits of the social networks of residents, their family members and nursing staff - change is needed. Yet, achieving sustainable change in nursing homes is difficult in general. This is particularly illustrated in quality improvement projects in long-term care. The set-up of such projects is complex and subject to various factors on different organisational (macro -, meso- and micro) levels, including health care policy, funding, culture, staff characteristics and general attitudes. (57-60) Furthermore, the needs, attitudes and viewpoints of residents and their relatives – in addition to those of staff- are important key features. (58, 60)

As yet, there is no research on how nursing homes relate to dementia friendly communities and what is needed to change care processes to become part of these communities. In this study, we look at one nursing home in the Netherlands, observing their change process to become part of a dementia friendly community. In the next section, we will first discuss dementia care in the Netherlands. Subsequently, we will describe the case study we conducted in the nursing home.

Dementia care in the Netherlands and the complex case study

In the Netherlands, the prevalence of dementia is estimated to be 300,000 persons, which will have doubled in 2030. (61, 62) Traditionally, in the Netherlands, older persons (with dementia) are admitted to a nursing home. These are traditionally large organisations, though the number of smaller organisations in local communities is rising. (63) At present, there are around 400 long-term care organisations in the Netherlands, with approximately 2400 facilities for a population of 17 million. (64, 65) Around 80,000 persons with dementia reside in these facilities. (62)

Most Dutch nursing homes traditionally have a closed character. This means that residents are not able to leave the facility independently. (31) Furthermore, the use of restraints within daily care is relatively higher compared to other countries. Multidisciplinary teams provide daily care, consisting of nursing staff (mostly certified nursing assistants) and multiple specialists, including among others physical-, occupational- and speech therapists and elderly care physicians. (49, 66, 67)

Due to the aging population, there is an increasing focus on reducing costs of long-term care and providing care to older persons in the community. (64) Furthermore, there is an increasing emphasis by municipalities on being dementia-friendly and creating dementia-friendly communities. (68, 69)

Case study in the Netherlands

In order to close the research gap on dementia-friendly communities in relation to nursing homes, a quality improvement project was set-up in a nursing home in the south of the Netherlands from 2018-2021 by a care organisation that wanted one of their nursing homes to become part of the surrounding community by creating a new living concept. The project focusses on social cohesion, autonomy and increasing quality of life for persons with dementia. With the new living environment the care organisation aimed to connect residents, family members, informal caregivers, nursing staff, volunteers and all other members of the local community, and to bring long-term care back in the heart of the community. In order to achieve these aims, multiple changes were realized.

Firstly, the old building was demolished and rebuilt into individual apartments where persons with and without dementia live together. An open long-term care environment was realised that allows residents to leave the building independently. Secondly, the facility grounds were turned into a freely accessible green park that provides meeting opportunities for residents with dementia and persons from the local community through among others, the realisation of broad walking paths, fishing pond, playground for children and allotment gardens. Lastly, the chapel was rebuilt into a restaurant and serves as a central meeting place for both residents and persons from the community.

Aim and outline of this thesis

This thesis provides insight into whether nursing homes can contribute to dementia-friendly communities and the subsequent necessary change in nursing home care. More specifically, we provide insight into the change process and results of the nursing home of our case study. It identifies important stakeholders and mechanisms within long-term care facilities that are conducive to changing the organisation of care.
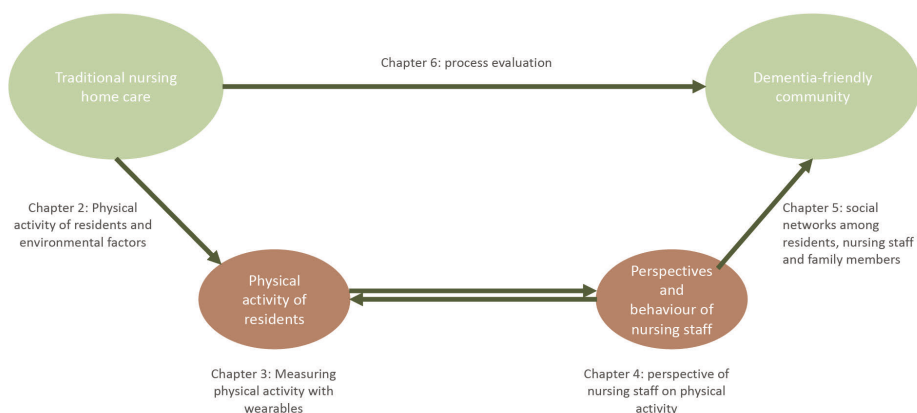
Figure 1. Outline of this thesis and its articles

We will investigate the role of nursing homes in dementia-friendly communities by looking at physical activity of residents, environmental factors of nursing homes, behaviour of nursing staff and care processes and social networks between nursing staff, residents with dementia and family members in the community. To study these aspects, we use a mixed-method approach that includes - among others- observations, focus groups, interviews and quantitative data.

The central research question of this thesis is: Can traditional nursing home care in long-term care facilities be part of dementia-friendly communities and which underlying mechanisms are important in realising this? Within the different chapters the central research question (Chapter 6) and following underlying research questions were addressed:

- What is the physical activity of residents with dementia in nursing homes and how is this related to environmental factors in long-term care facilities? In addition, we studied how physical activity can be measured and if it is related to agitated behaviour of residents. (Chapter 2&3)
- How is physical activity of residents with dementia related to perspectives and behaviour of nursing staff on autonomy and safety in long-term care facilities? (Chapter 4)
- To what extent are there social networks between nursing staff, residents with dementia and their family members in the community, and which possibilities are there through these networks for dementia-friendly communities? (Chapter 5)

In Chapter 7 we will discuss the overall results of this thesis and its implications for further research and clinical practice.

1

References

1. Organization WHO. Global status report on the public health response to dementia. Geneva; 2021.

2. WHO. Global action plan on the public health response to dementia: 2017-2025. 2017.

3. Blain H, Rolland Y, Schols JMGA, Cherubini A, Miot S, O'Neill D, et al. August 2020 Interim EuGMS guidance to prepare European Long-Term Care Facilities for COVID-19. European Geriatric Medicine. 2020;11(6):899-913.

4. Phillipson L, Hall D, Cridland E, Fleming R, Brennan-Horley C, Guggisberg N, et al. Involvement of people with dementia in raising awareness and changing attitudes in a dementia friendly community pilot project. Dementia (London). 2019;18(7-8):2679-94.

5. Vernooij-Dassen MJ, Moniz-Cook ED, Woods RT, De Lepeleire J, Leuschner A, Zanetti O, et al. Factors affecting timely recognition and diagnosis of dementia across Europe: from awareness to stigma. Int J Geriatr Psychiatry. 2005;20(4):377-86.

6. Shannon K, Bail K, Neville S. Dementia-friendly community initiatives: An integrative review. J Clin Nurs. 2019;28(11-12):2035-45.

7. Wiersma EC, Denton A. From social network to safety net: Dementia-friendly communities in rural northern Ontario. Dementia (London). 2016;15(1):51-68.

8. Hung L, Hudson A, Gregorio M, Jackson L, Mann J, Horne N, et al. Creating Dementia-Friendly Communities for Social Inclusion: A Scoping Review. Gerontol Geriatr Med. 2021;7:23337214211013596.

9. Lin SY. 'Dementia-friendly communities' and being dementia friendly in healthcare settings. Curr Opin Psychiatry. 2017;30(2):145-50.

10. Hebert CA, Scales K. Dementia friendly initiatives: A state of the science review. Dementia (London). 2019;18(5):1858-95.

11. Gan DRY, Chaudhury H, Mann J, Wister AV. Dementia-Friendly Neighborhood and the Built Environment: A Scoping Review. Gerontologist. 2022;62(6):e340-e56.

12. Charras K, Eynard C, Viatour G. Use of Space and Human Rights: Planning Dementia Friendly Settings. J Gerontol Soc Work. 2016;59(3):181-204.

13. Smith K, Gee S, Sharrock T, Croucher M. Developing a dementia-friendly Christchurch: Perspectives of people with dementia. Australasian journal on ageing. 2016;35(3):188-92.

14. Smith K. Developing a Dementia-Friendly Christchurch: perspectives of people with dementia. 2017.

15. Galik EM, Resnick B, Pretzer-Aboff I. 'Knowing what makes them tick': motivating cognitively impaired older adults to participate in restorative care. Int J Nurs Pract. 2009;15(1):48-55.

16. den Ouden M, Bleijlevens MH, Meijers JM, Zwakhalen SM, Braun SM, Tan FE, et al. Daily (In)Activities of Nursing Home Residents in Their Wards: An Observation Study. Journal of the American Medical Directors Association. 2015;16(11):963-8.

17. van Alphen HJ, Volkers KM, Blankevoort CG, Scherder EJ, Hortobágyi T, van Heuvelen MJ. Older Adults with Dementia Are Sedentary for Most of the Day. PloS one. 2016;11(3):e0152457.

18. Parry S, Chow M, Batchelor F, Fary RE. Physical activity and sedentary behaviour in a residential aged care facility. Australasian journal on ageing. 2019;38(1):E12-e8.

19. Marmeleira J, Ferreira S, Raimundo A. Physical activity and physical fitness of nursing home residents with cognitive impairment: A pilot study. Experimental gerontology. 2017;100:63-9.

20. Moyle W, Jones C, Murfield J, Draper B, Beattie E, Shum D, et al. Levels of physical activity and sleep patterns among older people with dementia living in long-term care facilities: A 24-h snapshot. Maturitas. 2017;102:62-8.

21. Portegijs S, van Beek S, van Tuyl LHD, Wagner C. Physical Activity in People With Dementia Living in Long-Term Care Facilities and the Connection With Environmental Factors and Behavior. J Aging Phys Act. 2022:1-9.

22. Brett L, Traynor V, Stapley P. Effects of Physical Exercise on Health and Well-Being of Individuals Living With a Dementia in Nursing Homes: A Systematic Review. Journal of the American Medical Directors Association. 2016;17(2):104-16.

23. Blankevoort CG, van Heuvelen MJ, Boersma F, Luning H, de Jong J, Scherder EJ. Review of effects of physical activity on strength, balance, mobility and ADL performance in elderly subjects with dementia. Dementia and geriatric cognitive disorders. 2010;30(5):392-402.

24. Groot C, Hooghiemstra AM, Raijmakers PG, van Berckel BN, Scheltens P, Scherder EJ, et al. The effect of physical activity on cognitive function in patients with dementia: A meta-analysis of randomized control trials. Ageing research reviews. 2016;25:13-23.

25. Beerens HC, Zwakhalen SM, Verbeek H, Ruwaard D, Hamers JP. Factors associated with quality of life of people with dementia in long-term care facilities: a systematic review. Int J Nurs Stud. 2013;50(9):1259-70.

26. Jing W, Willis R, Feng Z. Factors influencing quality of life of elderly people with dementia and care implications: A systematic review. Arch Gerontol Geriatr. 2016;66:23-41.

27. Scherder EJ, Bogen T, Eggermont LH, Hamers JP, Swaab DF. The more physical inactivity, the more agitation in dementia. International psychogeriatrics. 2010;22(8):1203-8.

28. Staedtler AV, Nunez D. Nonpharmacological therapy for the management of neuropsychiatric symptoms of Alzheimer's disease: linking evidence to practice. Worldviews Evid Based Nurs. 2015;12(2):108-15.

29. van Alphen HJ, Hortobagyi T, van Heuvelen MJ. Barriers, motivators, and facilitators of physical activity in dementia patients: A systematic review. Archives of gerontology and geriatrics. 2016;66:109-18.

30. Douma JG, Volkers KM, Engels G, Sonneveld MH, Goossens RHM, Scherder EJA. Setting-related influences on physical inactivity of older adults in residential care settings: a review. BMC geriatrics. 2017;17(1):97.

31. de Boer B, Beerens HC, Katterbach MA, Viduka M, Willemse BM, Verbeek H. The Physical Environment of Nursing Homes for People with Dementia: Traditional Nursing Homes, Small-Scale Living Facilities, and Green Care Farms. Healthcare (Basel, Switzerland). 2018;6(4).

32. den Ouden M, Kuk NO, Zwakhalen SMG, Bleijlevens MHC, Meijers JMM, Hamers JPH. The role of nursing staff in the activities of daily living of nursing home residents. Geriatric Nursing. 2017;38(3):225-30.

33. Auerswald T, Meyer J, von Holdt K, Voelcker-Rehage C. Application of Activity Trackers among Nursing Home Residents-A Pilot and Feasibility Study on Physical Activity Behavior, Usage Behavior, Acceptance, Usability and Motivational Impact. Int J Environ Res Public Health. 2020;17(18).

34. Airlie J, Forster A, Birch KM. An investigation into the optimal wear time criteria necessary to reliably estimate physical activity and sedentary behaviour from ActiGraph wGT3X+ accelerometer data in older care home residents. BMC geriatrics. 2022;22(1):136.

35. Breasail M, Biswas B, Smith MD, Mazhar MKA, Tenison E, Cullen A, et al. Wearable GPS and Accelerometer Technologies for Monitoring Mobility and Physical Activity in Neurodegenerative Disorders: A Systematic Review. Sensors (Basel). 2021;21(24).

36. Zhai Y, Li D, Wang D, Shi C. Seniors' Physical Activity in Neighborhood Parks and Park Design Characteristics. Front Public Health. 2020;8:322.

37. Skender S, Ose J, Chang-Claude J, Paskow M, Brühmann B, Siegel EM, et al. Accelerometry and physical activity questionnaires - a systematic review. BMC Public Health. 2016;16(1):515.

1

38. Boumans J, van Boekel LC, Verbiest ME, Baan CA, Luijkx KG. Exploring how residential care facilities can enhance the autonomy of people with dementia and improve informal care. Dementia (London). 2022;21(1):136-52.

39. Boumans J, van Boekel LC, Baan CA, Luijkx KG. How Can Autonomy Be Maintained and Informal Care Improved for People With Dementia Living in Residential Care Facilities: A Systematic Literature Review. Gerontologist. 2019;59(6):e709-e30.

40. de Boer B, Buist Y, de Bruin SR, Backhaus R, Verbeek H. Working at Green Care Farms and Other Innovative Small-Scale Long-Term Dementia Care Facilities Requires Different Competencies of Care Staff. Int J Environ Res Public Health. 2021;18(20).

41. Fitzgerald TG, Hadjistavropoulos T, MacNab YC. Caregiver fear of falling and functional ability among seniors residing in long-term care facilities. Gerontology. 2009;55(4):460-7.

42. Brett L, Traynor V, Stapley P, Meedya S. Exercise and Dementia in Nursing Homes: Views of Staff and Family Carers. J Aging Phys Act. 2018;26(1):89-96.

43. Benjamin K, Edwards N, Guitard P, Murray MA, Caswell W, Perrier MJ. Factors that influence physical activity in long-term care: perspectives of residents, staff, and significant others. Can J Aging. 2011;30(2):247-58.

44. Evans EA, Perkins E, Clarke P, Haines A, Baldwin A, Whittington R. Care home manager attitudes to balancing risk and autonomy for residents with dementia. Aging Ment Health. 2018;22(2):261-9.

45. Davison TE, Camões-Costa V, Clark A. Adjusting to life in a residential aged care facility: Perspectives of people with dementia, family members and facility care staff. J Clin Nurs. 2019;28(21-22):3901-13.

46. Buist Y, Verbeek H, de Boer B, de Bruin SR. Innovating dementia care; implementing characteristics of green care farms in other long-term care settings. International psychogeriatrics. 2018;30(7):1057-68.

47. Sturge J, Janus S, Zuidema S, Frederiks B, Schweda M, Landeweer E. The moral and gender implications of measures used to modulate the mobility of people with dementia living in residential care environments: a scoping review. Gerontologist. 2023.

48. Rantz MJ, Hicks L, Grando V, Petroski GF, Madsen RW, Mehr DR, et al. Nursing home quality, cost, staffing, and staff mix. Gerontologist. 2004;44(1):24-38.

49. Ribbe MW. Care for the elderly: the role of the nursing home in the Dutch health care system. International psychogeriatrics. 1993;5(2):213-22.

50. Scott-Cawiezell J, Schenkman M, Moore L, Vojir C, Connoly RP, Pratt M, et al. Exploring nursing home staff's perceptions of communication and leadership to facilitate quality improvement. J Nurs Care Qual. 2004;19(3):242-52.

51. Hingstman T, Langelaan M, Wagner C. De dagelijkse bezetting en kwaliteit van zorg in instellingen voor langdurige zorg. Utrecht: Nivel 2012.

52. Phinney A, Kelson E, Baumbusch J, O'Connor D, Purves B. Walking in the neighbourhood: Performing social citizenship in dementia. Dementia (London). 2016;15(3):381-94.

53. Ivanova D, Wallenburg I, Bal R. Care in place: A case study of assembling a carescape. Sociol Health Illn. 2016;38(8):1336-49.

54. van Beek APA, Wagner C, Frijters DHM, Ribbe MW, Groenewegen PP. The ties that bind? Social networks of nursing staff and staff's behaviour towards residents with dementia. Social Networks. 2013;35(3):347-56.

55. Mitchell JI, Long JC, Braithwaite J, Brodaty H. Social-Professional Networks in Long-Term Care Settings With People With Dementia: An Approach to Better Care? A Systematic Review. Journal of the American Medical Directors Association. 2016;17(2):183.e17-27.

56. Hulscher ME, Laurant MG, Grol RP. Process evaluation on quality improvement interventions. Qual Saf Health Care. 2003;12(1):40-6.

57. Jeurissen P, van Ginneken E. The Dutch health system in 2019: Many major reforms, but still work in progress. Health Policy. 2019;123(3):249-51.

58. Low LF, Fletcher J, Goodenough B, Jeon YH, Etherton-Beer C, MacAndrew M, et al. A Systematic Review of Interventions to Change Staff Care Practices in Order to Improve Resident Outcomes in Nursing Homes. PloS one. 2015;10(11):e0140711.

59. Maarse JA, Jeurissen PP. The policy and politics of the 2015 long-term care reform in the Netherlands. Health Policy. 2016;120(3):241-5.

60. Zwijsen SA, Smalbrugge M, Eefsting JA, Gerritsen DL, Hertogh CM, Pot AM. Grip on challenging behavior: process evaluation of the implementation of a care program. Trials. 2014;15:302.

61. Francke A, van der Heide I, de Bruin S, Gijsen R, Poos R, Veerbeek M, et al. Een samenhangend beeld van dementie en dementiezorg. Kerncijfers, behoeften, zorgaanbod en impact. . Nivel; 2018.

62. Alzheimer Nederland. Factsheet cijfers en feiten over dementia 2024 [Available from: https://www.alzheimer-nederland.nl/factsheet-cijfers-en-feiten-over-dementie, accessed 22-05-2024]

63. Actiz. Zorgorganisaties aan de slag met nieuwe woonzorgvormen: 6 inspirerende voorbeelden van rollen van zorgorganisaties. 2021.

64. Kroneman M, Boerma W, Berg van den M, Groenewegen P, Jong de J, Ginneken van E. The Netherlands: health system review. 2016.

65. Zorgkaart Nederland. Verpleeghuis en verzorgingshuis 2024 [Available from: https://www.zorgkaartnederland.nl/verpleeghuis-en-verzorgingshuis#:~:text=Op%20dit%20moment%20zijn%20er,en%20verzorgingshuizen%20in%20Nederland%20bekend, 22-05-2024].

66. Clemens S, Wodchis W, McGilton K, McGrail K, McMahon M. The relationship between quality and staffing in long-term care: A systematic review of the literature 2008–2020. International Journal of Nursing Studies. 2021;122:104036.

67. Schols JMGA, Crebolder HFJM, van Weel C. Nursing home and Nursing home Physician: the Dutch Experience. Journal of the American Medical Directors Association. 2004; 5: 207-212.

68. Alzheimer Nederland. Gemeenten aan zet in 2023: focusbrief voor gemeenten. 2023.

69. Alzheimer Nederland. Jaarverslag 2022. 2023.

1

2

Physical activity in people with dementia living in long-term care facilities and the connection with environmental factors and behavior

Suzanne Portegijs, Sandra van Beek, Lilian H.D. van Tuyl and Cordula Wagner.

Abstract

This study is conducted in order to gain a better understanding of the relationship between physical activity and agitated behavior among older people with dementia, and physical activity and characteristics of long-term care wards. Data were collected among people with dementia living in long-term care facilities (N=76) by conducting observations at the wards and distributing questionnaires among professional caregivers. The results show that participants are largely inactive (82.8%) and a significant relation was found between the degree of physical activity and characteristics of the ward such as 'Taking sufficient time', which relates to the time caregivers take when interacting with residents. This study supports the existing knowledge about the degree of physical activity among people with dementia in long-term care and adds information about the potential influence of organizational factors that could be valuable for daily practice.

Keywords: Cognition, mobility, nursing home

Background

Physical activity can positively affect numerous health outcomes of people with dementia, including cognitive functioning, independency in Activities of Daily Living (ADL) and physical performance (1, 2). Research specifically focused on people with dementia in long-term care facilities, shows additional valuable effects such as increased mobility and functional ability and lower risk of depression and agitation (3). Despite the benefits of physical activity, nursing home residents and especially people with dementia are mostly inactive (4-8). Furthermore, the relatively low number of activities undertaken are mostly of low intensity and limited to activities of daily living (ADL), such as mobility, eating and drinking (4-8).

As physical activity decreases agitated behavior, it could potentially contribute to enhancing residents' psychological well-being and quality of life (3, 9-12). Yet, agitated behavior in people with dementia is complex and is also associated with less beneficial forms of physical activity such as compulsive walking (13). Compulsive walking in itself enhances the degree of physical activity, but is also connected to multiple negative health outcomes including malnutrition, sleep disturbance and injuries from fall incidents (14).

In addition to several personal features described above, various other factors influence the degree of physical activity of residents with dementia in long-term care facilities. For instance the environment's compatibility with the abilities of a resident, including: the accessibility, security, comfort and aesthetics (15). In addition, external factors are also vital, mostly related to caregivers and include staffing levels, available time, the amount and type of care being provided and difficulties with guiding and organizing physical activity (15, 16).

As the environment is an important factor regarding the degree of physical activity, the organization of institutionalised care is important. In the Netherlands various forms of long-term living for people with dementia exist, which can roughly be categorized as large-scale and small-scale facilities. Research shows that the physical environment of small-scale living facilities are generally more beneficial for people with dementia, especially with regard to independency in ADL activities and general well-being, in comparison with traditional large scale nursing homes (17, 18). In addition, providing a 'home-like environment' has a positive effect on numerous outcomes, especially on behavior (18). Despite the already established positive effects of small-scale facilities, the influence of different types of facilities on the degree of physical activity remains unclear.

In summary, a relatively large number of studies has been conducted on the degree of physical activity of people with dementia (4-8). However, research on the connection between various environmental factors and agitated behavior on physical activity is lacking and is needed to further understand the complexity of physical activity

2

within long-term dementia care. Therefore, the aim of this study is to gain insight into the relations between the degree of physical activity, agitated behavior and living environment among people with dementia living in long-term care facilities. Additionally, this study includes qualitative descriptions of the included wards to provide more information and context on the participating wards.

Methods

Study design
This study is conducted in light of a larger research project in collaboration with a care organization in the Netherlands that wants to improve the living conditions of people with dementia by providing more freedom and autonomy and enabling social interaction with the surrounding neighborhood. A part of this research project is this mixed-methods study, using observations for both physical activity and ambiance on the wards conducted by researchers, and questionnaires completed by nursing staff. The study was conducted between June 2018 and September 2019 within five long-term care facilities in two different regions in the Netherlands.

Participants
The participants included within this study were recruited from the care organization involved in the larger research project and the residents of two other long-term care facilities. The managers of both facilities were contacted by the researchers and invited to participate. The study was conducted solely at the wards specifically for people with dementia. Information letters and informed consent forms for participation within this study were send by mail to the first legal representatives of all residents of the included wards by the care organizations. If the first legal representative agreed on participation, the informed consent forms were signed and send back to the researchers. All nursing home residents with dementia of whom the informal caregivers gave consent for participation were eligible for inclusion.

Setting
This study included five long-term care facilities from two different care organizations in different regions of the Netherlands. Detailed descriptions of the location are attached in *Appendix 2*. Locations were visited one at a time for approximately one week or multiple days within a short period of time. Location 1 was visited during June and July 2018, Location 2 at the beginning of September 2018, Location 3 at the end of September 2018 and Location 4 and 5 during the middle of September in 2019. During data collection a maximum of three researchers were present on the locations each day.

Measures

Physical activity
Observations as method for quantifying physical activity were chosen, as this is a reliable, unobtrusive method that has previously been used within long-term care research (4, 19), with little impact on the daily routine of residents (20), in particular when compared to sensor technology. Moreover, observations are not susceptible to social desirability, recall bias or poor response rates associated with self-reported measures. (21, 22)

Observations of physical activity were conducted by researchers visiting the wards. Observations were carried out with a maximum of 30 minutes each and were conducted within three different timeframes: morning/breakfast (08:00-11:00), mid-day/lunch (11:00-14:30), and afternoon/dinner (14:30-19:00). Some observations took longer or shorter due to daily circumstances on the ward. Different specific time slots were chosen in order to gain a more accurate overview of the physical activity during different parts of the day. Furthermore, every time slot includes a meal that often stimulates physical activity and other aspects of long-term care such as care routine (morning/after lunch/ evening) and (leisure) activities (late morning/early afternoon). Researchers aimed to observe all participating residents at least once during every time frame. Observations were carried out on different days within the same week, excluding weekends as daily care is organized differently during the weekends due to the larger presence of family members and less available professional caregivers, which would result in more heterogeneity during data collection. Observers scored the degree of physical activity per minute using four different categories: (a) lying, (b) sitting, (c) standing and (d) walking. During the time that a resident moved out of sight either independently or assisted by professional caregivers the minutes were scored as 'non-observable'. As not all residents were sufficiently present in the shared rooms of the wards, a total of 57 residents were observed for physical activity. Furthermore, 27 observations were conducted simultaneously by two observers to establish the inter-observer reliability. When checking for inter-observer reliability few differences were found, with a match in activities of over 91% . Small differences in inter-observer reliability were found when a resident changed their form of (in)activity during the start of a new minute of observation. For example when a resident changed from sitting to standing around the start of the 6th minute of observation, both observers registered this differently.

Questionnaire for nursing staff
Nursing staff were asked to complete a questionnaire about all participating residents with questions about age, gender, functioning in ADL, cognitive functioning and psychological well-being (specifically agitated behavior). The questionnaires were placed in the nurses' office with a return box. An e-mail with information and instructions was send by the manager to the nursing staff of the ward, all of whom were eligible for participation within this research. Under Dutch legislation (Medical Research Involving

Human Subjects Act), ethical approval by a medical ethics committee was not required since the research subjects were not subjected to actions and no rules of behavior were imposed on them (https://english.ccmo.nl). Participant consent was assumed upon return of a completed questionnaire. The questionnaire data were stored and analyzed anonymously, in accordance with the General Data Protection Regulation. Nursing staff were asked to fill in the questionnaires in pairs to ensure an accurate reflection of daily reality.

ADL-H. ADL functioning was scored with the Activity of daily living hierarchy (ADL-H) index of the MDS Short Form (23, 24). The inter-rater agreement of the ADL-H is 0.80 with an internal consistency of 0.84 (24). The ADL-H consists of four items: mobility on ward, eating and drinking, toilet use and personal hygiene, which can be scored from 0 *(independent)* to 4 *(totally dependent)* or 8 *(activity did not occur during the last 7 days)*. The final score can be a final classification ranging from 0 *(independent)* to 6 *(totally dependent on others)* or a summation of the scores of the 4 items. Both outcomes were used within this study.

CPS. Cognitive functioning was assessed by using the Cognitive Performance Scale (CPS) (25). The inter-rater agreement of the CPS is 0.85 (25), with an internal consistency of 0.74 (24). The CPS consists of five items: comatose state (yes/no), long and short term memory (good and impaired), cognitive abilities for daily decision making and making oneself understood (4-point Likert scale). The final classification ranges from 0 *(intact)* to 6 *(very severe impairment)*.

CMAI-D. Agitated behavior was measured using the Cohen-Mansfield Agitation Inventory – Dutch version (CMAI-D) (26). The observation scale consists of 29 items with scores ranging from 1 *(never)* to 7 *(several times an hour)* and results in an overall score and sub scores for aggressive behavior, physically nonaggressive behavior and verbally agitated behavior. The inter-observer reliability of the CMAI-D is 0.91 (26). Within this study, only the scales for nonaggressive and aggressive behavior were used, since these types of behavior are most likely to influence the degree of activity. The Cronbach's alpha in this study of nonaggressive behavior was 0.82 and for aggressive behavior 0.79.

Walking aid and wheelchair use. As the use of walking aids and wheelchairs gives an indication of a person's physical functioning and influences the degree of physical activity, both aspects were inventoried within the questionnaire for nursing staff. The use of walking aids and wheelchairs was scored on a 5-point Likert scale from '*never'* to '*always'*. Walking aids include walking sticks, crutches and walkers. Wheelchairs include self-driven, manually pushed and electric wheelchairs.

Ward observations
The observations on the wards were conducted using an observation list with 32 items, which focused on safety of residents, physical activity and ambiance on the ward, *see Appendix 1*. The observation list was derived from a list that was based on the aspects of quality of care defined by Rantz et al. (1998) (27, 28). Eight items were used within this study: 2) 'taking sufficient time', 5) 'calling residents by name', 6) 'visibly present', 7) 'active caring', 16) 'independent walking', 17) 'guided walking', 30) 'having a home-like environment' and 31) 'lively ward'. Other items of the observation list focussed on, for example, the interaction between caregivers, personalization of residents' rooms and the presence of unpleasant smells. Each item was scored on a five-point scale, with five representing the most positive score. The observations were conducted during three different time periods: morning, mid-day and afternoon spread out over different days in order to gain a more accurate overview of the ward on different points in time. The ward observations were performed separately from the physical activity observations. All the wards were observed by two researchers simultaneously. The participating wards and nursing staff were informed about the presence of the researchers, but received limited information about the focus and aim of the research. However, in order to recruit the wards some information provision was necessary. Therefore, the researchers shared that the study was part of a larger research project on quality of care, physical activity and change management within long-term care. The researchers tried to minimize their interaction and interference with the residents and staff members. Though, this could not be totally avoided due to communication initiatives by residents and staff members and incidental safety concerns. Findings were discussed afterwards. In total, 9 researchers conducted the observations on the five units included within this study. Always accompanied by one of the two main researchers of the study. The nursing teams were not informed when the observations would take place. A score for each item was computed based on the average score of the two researchers over all three observation-moments. In total, 42 observations were conducted simultaneously by two researchers. Interobserver reliability varied between 0.64 and 0.91 and was calculated using a linear mixed-effects model, with a mean of 0.77. Cronbach's alpha for the combined items is 0.75.

Descriptions of the included wards
Of all the included locations, detailed descriptions were made by the researchers based on their experience and clinical expertise, *see appendix 2.* In Table 1 the most important aspects of the locations are highlighted.

Table 1. Descriptions of the locations included

	Location 1	Location 2	Location 3	Location 4	Location 5
Setting	Psychogeriatric ward of a nursing home	Small scale department, part of residential care setting	Small scale facility	Large scale department, part of large nursing home	Small scale facility
Number of residents	28	35	28	40	24
Sufficient room to move	Very spacious	Moderate space	Moderate space	Very spacious	Limited space
Outdoor area	Two fenced gardens	Balcony	Small garden (patio)	Unsafe balcony	Small balcony
Type of environment	Dated temporary building with home-like objects	Home-like environment	Home-like environment	Clinical environment	Home-like environment

Data analyses

All quantitative analyses were conducted using STATA (version 15). Descriptive analyses were performed for all five wards together as well as independently. Percentages were calculated for gender, CPS, ADL-H and wheelchair and walking aid use. Mean scores were calculated for age and quantitative ward observations. Median scores were calculated for CMAI-D. The percentages of inactivity (lying, sitting) and activity (standing, walking and other activities) were calculated using the total amount of minutes observed by the researchers and the minutes spend inactive, and active, by the residents. Percentages for the type of physical activity were calculated for the entire day, and the three time frames separately. Furthermore, overall inactivity and activity percentages were calculated for the five locations separately. Overall correlations were calculated for physical inactivity (as activity was rarely observed among residents), CMAI-D scores for aggressive and physically nonaggressive behavior, ADL Short form scores, total score for ward observations, and CPS using Spearman's rank order correlation coefficient when the variable showed no linear correlation or when categorial variables were analyzed, and Pearsons' correlation coefficient when the variable did show a linear correlation. Alpha for these analyzes was set on 0.05. Specific correlations between settings could not be calculated due to the small sample size.

Ethical considerations

The medical research ethics committee of UMC Utrecht approved the study protocol. The privacy of the residents within this study was respected by only observing while

the resident stayed in one of the living rooms or the outside area. Residents were not followed into private areas such as their personal rooms and/or bathrooms.

Results

A total of 145 residents from five long term care facilities were invited for participation within this study. Informed consent was received back from the informal caregivers of 83 residents (57.2%). Of these residents, eight eventually did not participate in the study: five residents died before the start of the study and the observation lists of three residents were not received back from nursing staff resulting in incomplete data. However, one of these participants was included in the physical activity observations and the subsequent analyses. This resulted in a total of 76 residents being included in this study (52.4%), see Table 3 for the number of participating residents in each facility.

Table 2. Characteristics of the research population

	Research population (N=76)
Age (N=75) (mean, sd)	82.4 (12.0)
Gender female (N=75) (%)	48 (64)
CPS (N=67) (%) 1 (Borderline) intact Mild – moderate severe impairment (Very)severe impairment	11 (16.4) 26 (38.8) 30 (44.8)
ADL Short Form (N=66) (mean, sd) 2	7.2 (5.0)
ADL Self-performance Hierarchy (N=71) (%) 3 Independent Supervision Limited Extensive 1 Extensive 2 Dependent Total dependence	5 (7.0) 9 (12.7) 9 (12.7) 26 (36.6) 6 (8.5) 12 (16.9) 4 (5.6)
Walking aid use (N=70) (%) 4 Wheelchair use (N=67) (%) 5	33 (43.4) 33 (44.0)

[1] Combining categories 0&1; 2, 3&4; 5&6. [2] Summation of scores of all 4 items of the ADL Short Form, ranging from 0-16. [3] Index scores of the ADL Self-performance hierarchy index. [4] Stick, scroller or crutch defined as 'sometimes', 'often' and 'always. [5] Self driven, electric or manually pushed defined as 'sometimes', 'often' and 'always'

2

Characteristics of residents

Demographic characteristics of the nursing home residents are presented in Table 2. The mean age of the residents is 82.4 (sd=12.0) years, 48 residents (64%) were women. Most residents have a higher CPS score; 30 residents (44.8%) are classified as 'severely impaired' or 'very severely impaired'. A fairly large group of 26 residents (38.8%) is classified as 'mild impairment' to 'moderate severe impairment'. The smallest group classifies as having a '(borderline) intact' cognition. Hierarchy and general ADL-scores are calculated. Mean score is 7.2 (sd=5.0). A third of the residents were classified as 'Extensive 1' (36.6%), 32.4% as 'Independent', 'Supervision' or 'Limited' and 31% as 'Extensive 2', 'Dependent' and 'Total Dependence'. A large number of residents use a walking aid (43.4%) or a wheelchair (44%) in their daily life, at least sometimes, and at most always.

Table 3. Characteristics of the research population per included ward

	Location 1 (N=14)	Location 2 (N=20)	Location 3 (N=14)	Location 4 (N=21)	Location 5 (N=6)
Age (mean, sd)	84.7 (7.0)	84.2 (5.0)	83.9 (5.6)	79 (20.3)	79.8 (9.5)
Gender female (%)	64.3	70	71.4	57	50
CPS (%) [1] (Borderline) intact Mild – moderate severe imp. (Very)severe imp.	2 (16.7) 4 (33.3) 6 (50.0)	2 (10.5) 9 (47.4) 8 (42.1)	0 (0) 7 (53.9) 6 (46.2)	6 (33.3) 4 (22.2) 8 (44.4)	1 (20) 2 (40) 2 (40)
ADL Short Form [2]	7.1 (5.2)	7.4 (5.6)	6.3 (3.7)	7.5 (5.3)	8.6 (5.9)
Walking aid use (%) [3]	7 (53.9)	9 (50.0)	6 (46.2)	7 (43.8)	4 (66.7)
Wheelchair use (%) [4]	8 (57.1)	11 (55.6)	7 (50)	7 (53.3)	0 (0)

[1] Combining categories 0&1; 2, 3&4; 5&6. [2] Summation of scores of all 4 items of the ADL Short Form, ranging from 0-16. [3] Stick, scroller or crutch defined as 'sometimes', 'often' and 'always'. [4] Self driven, electric or manually pushed defined as 'sometimes', 'often' and 'always'

When comparing the demographic characteristics of the nursing home residents independently, small differences appear (see Table 3). The mean age of the residents at location 4 is lower (79 years) and there is a relatively larger variety regarding the ages of the residents (sd=20.3). CPS scores somewhat vary across the different locations with a relatively larger group of residents with a '(borderline) intact' cognition at Location 4. However, when comparing the amount of residents with a '(very) severe impairment' hardly any differences occur. Small differences can be found within the ADL-scores of the location, with Location 5 having the highest score (8.6, sd=5.9) and location 3 the lowest (6.3, sd=3.7).

Degree of physical activity

Table 4 presents the percentages of the observed activity of the residents included. In total, 57 of all residents were observed. The results are based on all observations conducted at the five different wards. Residents were observed to be mostly inactive during the day by either laying or sitting (82.8%). The degree of activity and inactivity hardly varied between the different time frames. The percentage of non-observable minutes however is higher during mid-day.

Table 4. Observed daily activities on all included nursing home wards

(N=57)	Overall	Morning	Mid-day	Afternoon
Total Observed minutes	5629	1549	2684	1396
Laying (%)	3.8	2.0	3.4	6.6
Sitting (%)	79.0	82.5	77.8	77.4
Standing (%)	1.4	0.6	1.2	2.7
Walking (%)	5.9	6.0	5.7	5.9
Other (%)	0.4	0.8	0.5	0
NO[1] (%)	9.5	8.1	11.4	7.4

[1] Non observable minutes during the observations

The different locations show some small differences with regard to the degree of physical activity, see Table 5. The percentage of residents observed walking at Location 3 (10.9) is relatively high compared with the other locations, but remains low. Furthermore, Location 3 and Location 4 have a higher percentage of non-observable minutes (18.9 and 12.5) in comparison with the other wards. During the investigation of potential correlations, no significant correlation is found between physical inactivity and cognition.

Table 5. Observed overall percentages of daily activities for each included nursing home ward separately

	Location 1	Location 2	Location 3	Location 4	Location 5
Laying (%)	0	0	0	8.4	0.1
Sitting (%)	89	89	66.5	71.7	90.2
Standing (%)	3	0.5	1.6	1.3	0.4
Walking (%)	4.6	4.5	10.9	5.6	5.1
Other (%)	0	0	2.1	0.5	0
NO[1] (%)	3.4	6.0	18.9	12.5	4.2

[1] Non observable minutes during the observations

Agitated behavior

Agitated behavior was assessed in 73 residents, see Table 6. The median total score of the CMAI-D for physically nonaggressive behavior is 10 (IQR=7-17). For aggressive behavior the total median score is 9 (IQR=8-14).

Table 6. CMAI-D sub-scores for entire research population

	CMAI-D sub-score
Aggressive behavior (N=71), (median, IQR) [1]	9 (8-14)
Physically nonaggressive behavior (N=73), (median, IQR) [2]	10 (7-17)

[1] Range 8-56, percentile 95 >24. [2] Range 7-49, percentile 95 >28

When comparing CMAI-D scores, Location 1 and Location 2 have slightly higher scores, for physically nonaggressive be havior (11.5, IQR=7-17 and 13, IQR=8-24), see Table 7. When calculating correlations, no significant result is found between physical inactivity and agitated behavior (both aggression and physically nonaggressive behavior).

Table 7. CMAI-D sub-scores for included wards separately.

	Location 1	Location 2	Location 3	Location 4	Location 5
Aggressive behavior (median, IQR) [1]	8 (8-9)	10 (8-13)	11 (8-15)	8 (8-19)	11 (8-13)
Physically nonaggressive behavior (median, IQR) [2]	11.5 (7-17)	13 (8-24)	9.5 (8-25)	8 (7-16)	10 (7-12)

[1] Range 8-56, percentile 95 >24. [2] Range 7-49, percentile 95 >28

Observations on the wards

In total, 86 observations were conducted at the five wards included within this study, see Table 8. 'Taking sufficient time' and 'Calling residents by name' is lower at Location 4 and Location 5. Differences in 'Visibly present' are small between the different locations, with Location 3 having the highest score (4.4, sd=1.0). 'Active caring' is the highest at Location 1 (4.5, sd=0.4). All locations score low on 'Independent walking', but this score is the highest at Location 4 (2.5, sd=0.7). 'Guided walking' is scored low on every location and hardly differs. Location 4 scores much lower in comparison to the other locations on 'Home-like environment' (2.3, sd=0.2). 'Lively ward' scores midrange on all locations, but is the highest at Location 2 (3.1, sd=0.7). Moreover, a significant correlation is found between inactivity and the total score of the characteristics of the ward ($r_s(51)$= - 0.28, p=0.04), with a specific correlation between inactivity and 'Taking sufficient time'($r_s(51)$= - 0.2, p=0.01). Finally, there is no significant relation between CMAI-D scores for physically nonaggressive behavior and the total score of the ward observations.

Table 8. Mean scores with SD of the observations on the wards of all time moments.

	Location 1 (N=14)	Location 2 (N=26)	Location 3 (N=18)	Location 4 (N=12)	Location 5 (N=16)
Total [1]	27.4 (3.0)	26.3 (3.7)	28.1 (2.8)	23.3 (5.8)	26.8 (8.3)
Taking sufficient time	4.1 (0.5)	3.7 (0.6)	4.0 (0.5)	2.9 (0.8)	3.8 (1.2)
Calling residents by name	4.6 (0.5)	4.0 (0.5)	4.1 (0.7)	3.3 (1.2)	3.6 (2.1)
Visibly present	3.6 (1.1)	3.8 (1.0)	4.4 (1.0)	4.0 (0.9)	4.4 (2.0)
Active caring	4.5 (0.4)	3.7 (1.0)	3.8 (0.7)	3.6 (1.1)	4.4 (1.6)
Independent walking	1.9 (1.1)	2.0 (0.8)	2.4 (0.8)	2.5 (0.7)	2.2 (1.7)
Guided walking	1.6 (0.8)	1.8 (0.6)	1.7 (0.7)	1.8 (0.8)	1.4 (0.4)
Home-like environment	4.2 (0.3)	4.0 (0.1)	4.7 (0.4)	2.3 (0.2)	4.6 (1.3)
Lively ward	2.9 (0.7)	3.1 (0.7)	3.0 (0.6)	2.8 (1.7)	2.4 (0.8)

[1] All items based on a 5-point likert scale (1-5)

Discussion

People with dementia living in long-term care facilities are physically inactive with limited variations in activity during the day. Physical activity is positively connected with some aspects of the ambiance and physical environment of the wards. However, as the number of participants is relatively low in this study, results should be interpreted with caution.

In addition to the results described, an already expected strong correlation was found between the degree of physical activity and ADL. Calculating reliable correlations between physical activity and ADL is challenging as most measurements include aspects about physical capabilities. One of four items of the ADL-H is 'Locomotion on unit' and has a strong overlap with physical activity. This correlation is, therefore, not included in the results section.

Results found within this study with regard to the degree of physical activity in people with dementia in long-term care facilities do not differ from other studies conducted in long-term dementia care (4-8). Even though efforts are undertaken to facilitate physical exercise by organizing weekly group activities within Dutch Nursing homes, the day-to-day physical activity of people with dementia living on long-term care wards remains very low. The study of Den Ouden et al. (2015), which also reported on daily physical activity of nursing home residents by conducting manual observations, found similar percentages for active and passive activities (4). Therefore, this study supports the general finding that people with dementia in long-term care facilities are mostly inactive.

Previous research shows a connection between physical activity and agitated behavior (3, 29, 30), which differs from the findings within our study. This could be explained by various aspects. First of all, previous studies are not always conducted exclusively in nursing homes, but also include home dwelling or hospitalized older adults with dementia (29, 30). More agitation is expected within a hospital setting as people with dementia are less familiar with the environment and staff. Furthermore, studies focusing on physical activity and agitation in the nursing home mainly include intervention studies and provide structural exercise programs, which differ from normal day-to-day physical activity. Finally, most of the average CMAI-D scores of our study population are within or below the 50th percentile and only a fairly small amount of people within our study show severe agitated behavior which makes it more difficult to reveal a strong connection. However, our study shows a clinical and realistic view of day-to-day physical activity and agitation and the results are therefore valuable for daily care.

Evidence on the influence of the physical environment on the degree of physical activity is limited (31). A systematic review of (31) focussing on the effect of the nursing home environment on physical activity in people with dementia found that a home-like environment seems to have a positive impact on the degree of physical activity and self-initiated activities. However, a sufficient number of studies to fully support this finding is lacking. Moreover, the influence of small-scale living facilities and the footprint of the building on physical activity remains unclear. These findings are supported by this study as we found the lowest percentage of inactivity within both a large-scale and small-scale facility.

Our study also found no connection between the degree of agitated behavior and the lay-out of the ward. A finding that is partially supported by the existing literature, which shows that the influence of the physical environment on the behavior of people with dementia in long-term care facilities is still conflicting (18). These conflicting results can partially be explained by the impact the physical environment may have on the well-being of professional caregivers and their attitude and behavior towards people with dementia (32). Furthermore, the inconclusive findings could also be explained by the influence of the professional caregivers on the utilization of the physical environment (17).

Of further importance is the different methods of data collection used during the study. Some data are collected by the researchers, namely the general observations on the ward and the physical activity observations of the residents. The observation methodology is reliable, unobtrusive and less prone to social desirability, recall bias or poor response rates associated with self-reported measures. Although it is not an objective measure of physical activity, several other studies in similar settings have adopted the same methodology (4, 19), as it is more reliable than self-reported measures and has a relatively low impact for residents compared to e.g. sensor technology. (20, 22) Large validation

studies to provide more insight into the validity of observations compared to objective measures using sensor technology within this specific population are currently lacking. As we have studied a vulnerable population, we aimed to minimize the impact for the residents and have therefore chosen observations as the preferred methodology

The more personal data on the residents however, is collected using questionnaires completed by professional caregivers and might facilitate more personal interpretation, errors and subjectivity (20). In order to enhance the objectivity of the data, validated questionnaires were used and completed by two professional caregivers. Proxy data collection is common within long-term (dementia) care (20) and is of added value when gaining insight into physical activity and other health-related outcomes. Results found within this study are promising and emphasize the need for research on this subject.

This study has a mixed-methods approach and incorporates quantitative analyses and extensive qualitative descriptions of the wards, which provides broader insight into the setting in which the study has been performed and the influence of organizational factors. Also, this study was conducted within multiple care organizations in different regions in het Netherlands and included both large-scale and small-scale facilities which provides a more holistic view of the Dutch long-term care for people with dementia. Even though the sample size might be too small to be representative of the entire long-term dementia care in the Netherlands, a common finding is that despite of setting, residents are very physically inactive. The degree of activity was measured with reliable manual observations during three different time frames by multiple researchers and were complemented with quantitative observations on the wards. Finally, the observations of the wards are conducted by multiple observers and has a high inter-rater reliability which provides consistent data on safety, physical activity and ambiance.

However, this study also has some weaknesses. Firstly, the study cohort is quite small and limited the use of more robust analyses. Consequently, the results of this study should be interpreted with caution. Nonetheless, several interesting results were found which provide inside into the coherence of physical activity and organizational factors and shows the need for larger and higher impact studies about this topic. Secondly, the availability of residents differed due to their time schedules or preference to stay in their room, it was therefore not always possible to observe a resident during three different time frames. Moreover, the physical activity observations of the residents are conducted in shared areas of the wards only. Hence, possible physical activity during the night, morning care or other ADL-activities are not taken into account. Furthermore, the percentage of non-observable minutes are the highest during the afternoons and at the wards with the largest walking space and/or more confusing lay-out. It is likely that residents are partially walking on the ward during the non-observable minutes or are engaged in other activities that take place out of sight of the researchers. Some residents could therefore be more physically active than shown by the current results. However,

the overall conclusion of this study will not differ as the degree of physical activity is still low when the non-observable and active minutes are combined, which was the main reason to include these minutes and the high possibility that a resident is performing an activity when out of sight of the researchers. Most residents were taken away during observations for daily care, toileting, physical therapy or leisure activities. Thirdly, as the amount of physical activity was low among the residents, all correlations were calculated using physical inactivity. However, all correlations were also calculated using the variable physical activity and the results hardly differed. In order to take a potential type 1 error into account, the Bonferroni method was applied to the results from the correlation analyses. However, as the sample size within this study is small, this method is less applicable and all results turned out not significant as expected. These findings were therefore not included in the results section. Fourthly, the presence of the researchers on the wards could potentially have influenced the degree of physical activity, both positively and negatively, as unfamiliar faces and additional people can cause more unrest among the residents. However, the researchers involved within this study have extensive experience within long-term dementia care and research, monitored the general atmosphere on the wards and left when needed. Fifthly, despite the percentage of non-observable minutes, the absence of observations during the night and morning care and the potential influence of researchers' presence, manual observations are a widely used method to determine the degree of physical activity (4, 33). Finally, participants were recruited for this study by asking their informal caregivers for consent, which might have influenced the study population. Informal caregivers are possibly more likely to participate when residents are more physically independent. However, the ADL-H index scores show a representation of participants with various levels of independency within our study and reflects the average nursing home population in the Netherlands.

Conclusion

People with dementia living in long-term care facilities are generally inactive in daily life. The physical environment and ambiance of the ward seems to have an influence on the degree of physical activity. This study supports the existing knowledge about the degree of physical activity among people with dementia in long-term care and adds information about the influence of organizational factors that could be valuable for daily practice. However, more research is needed to further explore the connection between physical activity, agitated behavior and organizational factors, and to incorporate the influence of professional caregivers.

References

1. Blankevoort CG, van Heuvelen MJ, Boersma F, Luning H, de Jong J, Scherder EJ. Review of effects of physical activity on strength, balance, mobility and ADL performance in elderly subjects with dementia. Dementia and geriatric cognitive disorders. 2010;30(5):392-402.

2. Groot C, Hooghiemstra AM, Raijmakers PG, van Berckel BN, Scheltens P, Scherder EJ, et al. The effect of physical activity on cognitive function in patients with dementia: A meta-analysis of randomized control trials. Ageing research reviews. 2016;25:13-23.

3. Brett L, Traynor V, Stapley P. Effects of Physical Exercise on Health and Well-Being of Individuals Living With a Dementia in Nursing Homes: A Systematic Review. Journal of the American Medical Directors Association. 2016;17(2):104-16.

4. den Ouden M, Bleijlevens MH, Meijers JM, Zwakhalen SM, Braun SM, Tan FE, et al. Daily (In)Activities of Nursing Home Residents in Their Wards: An Observation Study. Journal of the American Medical Directors Association. 2015;16(11):963-8.

5. van Alphen HJ, Volkers KM, Blankevoort CG, Scherder EJ, Hortobagyi T, van Heuvelen MJ. Older Adults with Dementia Are Sedentary for Most of the Day. PLoS One. 2016;11(3):e0152457.

6. Parry S, Chow M, Batchelor F, Fary RE. Physical activity and sedentary behaviour in a residential aged care facility. Australas J Ageing. 2019;38(1):E12-e8.

7. Marmeleira J, Ferreira S, Raimundo A. Physical activity and physical fitness of nursing home residents with cognitive impairment: A pilot study. Experimental gerontology. 2017;100:63-9.

8. Moyle W, Jones C, Murfield J, Draper B, Beattie E, Shum D, et al. Levels of physical activity and sleep patterns among older people with dementia living in long-term care facilities: A 24-h snapshot. Maturitas. 2017;102:62-8.

9. Beerens HC, Zwakhalen SM, Verbeek H, Ruwaard D, Hamers JP. Factors associated with quality of life of people with dementia in long-term care facilities: a systematic review. Int J Nurs Stud. 2013;50(9):1259-70.

10. Jing W, Willis R, Feng Z. Factors influencing quality of life of elderly people with dementia and care implications: A systematic review. Arch Gerontol Geriatr. 2016;66:23-41.

11. Scherder EJ, Bogen T, Eggermont LH, Hamers JP, Swaab DF. The more physical inactivity, the more agitation in dementia. International psychogeriatrics. 2010;22(8):1203-8.

12. Staedtler AV, Nunez D. Nonpharmacological therapy for the management of neuropsychiatric symptoms of Alzheimer's disease: linking evidence to practice. Worldviews Evid Based Nurs. 2015;12(2):108-15.

13. Robinson L, Hutchings D, Corner L, Finch T, Hughes J, Brittain K, et al. Balancing rights and risks: Conflicting perspectives in the management of wandering in dementia. Health, Risk & Society. 2007;9(4):389-406.

14. Cipriani G, Lucetti C, Nuti A, Danti S. Wandering and dementia. Psychogeriatrics. 2014;14(2):135-42.

15. Douma JG, Volkers KM, Engels G, Sonneveld MH, Goossens RHM, Scherder EJA. Setting-related influences on physical inactivity of older adults in residential care settings: a review. BMC geriatrics. 2017;17(1):97.

16. van Alphen HJ, Hortobagyi T, van Heuvelen MJ. Barriers, motivators, and facilitators of physical activity in dementia patients: A systematic review. Archives of gerontology and geriatrics. 2016;66:109-18.

17. de Boer B, Beerens HC, Katterbach MA, Viduka M, Willemse BM, Verbeek H. The Physical Environment of Nursing Homes for People with Dementia: Traditional Nursing Homes, Small-Scale Living Facilities, and Green Care Farms. Healthcare (Basel, Switzerland). 2018;6(4).

2

18. Marquardt G, Bueter K, Motzek T. Impact of the design of the built environment on people with dementia: an evidence-based review. Herd. 2014;8(1):127-57.

19. de Boer B, Beerens HC, Zwakhalen SM, Tan FE, Hamers JP, Verbeek H. Daily lives of residents with dementia in nursing homes: development of the Maastricht electronic daily life observation tool. International psychogeriatrics. 2016;28(8):1333-43.

20. Lam HR, Chow S, Taylor K, Chow R, Lam H, Bonin K, et al. Challenges of conducting research in long-term care facilities: a systematic review. BMC geriatrics. 2018;18(1):242.

21. Westerterp KR. Assessment of physical activity: a critical appraisal. European Journal of Applied Physiology. 2009;105(6):823-8.

22. Lim SER, Ibrahim K, Sayer AA, Roberts HC. Assessment of Physical Activity of Hospitalised Older Adults: A Systematic Review. J Nutr Health Aging. 2018;22(3):377-86.

23. Morris JN, Fries BE, Morris SA. Scaling ADLs within the MDS. J Gerontol A Biol Sci Med Sci. 1999;54(11):M546-53.

24. Gerritsen D, Ooms M, Steverink N, Frijters D, Bezemer D, Ribbe M. [Three new observational scales for use in Dutch nursing homes: scales from the Resident Assessment Instrument for Activities of Daily Living, cognition and depression]. Tijdschrift voor gerontologie en geriatrie. 2004;35(2):55-64.

25. Morris JN, Fries BE, Mehr DR, Hawes C, Phillips C, Mor V, et al. MDS Cognitive Performance Scale. J Gerontol. 1994;49(4):M174-82.

26. Cohen-Mansfield J, Marx MS, Rosenthal AS. A description of agitation in a nursing home. J Gerontol. 1989;44(3):M77-84.

27. Rantz MJ, Mehr DR, Popejoy L, Zwygart-Stauffacher M, Hicks LL, Grando V, et al. Nursing home care quality: a multidimensional theoretical model. Journal of nursing care quality. 1998;12(3):30-46; quiz 69-70.

28. Beek Sv. Social networks of nursing staff and organizational performance: A study in long-term care facilities 2013.

29. Ishimaru D, Tanaka H, Nagata Y, Takabatake S, Nishikawa T. Physical Activity in Severe Dementia Is Associated With Agitation Rather Than Cognitive Function. American journal of Alzheimer's disease and other dementias. 2020;35:1533317519871397.

30. Thuné-Boyle ICV, Iliffe S, Cerga-Pashoja A, Lowery D, Warner J. The effect of exercise on behavioral and psychological symptoms of dementia: towards a research agenda. International Psychogeriatrics. 2011;24(7):1046-57.

31. Anderiesen H, Scherder EJ, Goossens RH, Sonneveld MH. A systematic review-- physical activity in dementia: the influence of the nursing home environment. Appl Ergon. 2014;45(6):1678-86.

32. Woodbridge R, Sullivan MP, Harding E, Crutch S, Gilhooly KJ, Gilhooly M, et al. Use of the physical environment to support everyday activities for people with dementia: A systematic review. Dementia (London, England). 2018;17(5):533-72.

33. Harper Ice G. Daily life in a nursing home: Has it changed in 25 years? Journal of Aging Studies. 2002;16(4):345-59.

Appendix 1 – Observation list ward observations

A. Interaction between nursing staff and residents

1. Do nursing staff and residents engage into friendly conversations?

1	2	3	4	5
Never observed	Almost never	Occasionally	Frequent	Very frequent

2. Do nursing staff take sufficient time with residents?

1	2	3	4	5
Never observed	Almost never	Occasionally	Frequent	Very frequent

3. Do nursing staff treat residents respectfully?

1	2	3	4	5
Never observed	Almost never	Occasionally	Frequent	Very frequent

4. Do nursing staff and resident smile at each other and seem at ease with each other?

1	2	3	4	5
Hardly	A few	Some	Regularly	Mostly

5. When nursing staff talks to residents, do they call them by name?

1	2	3	4	5
Hardly	A few	Some	Regularly	Mostly

6. Is nursing staff visibly present?

1	2	3	4	5
Rarely observed	Sometimes	Occasionally	Frequent	Very frequent

7. Is nursing staff actively caring for residents?

1	2	3	4	5
Rarely observed	Sometimes	Occasionally	Frequent	Very frequent

8. Do nursing staff ensure the privacy of the residents?

1	2	3	4	5
Never observed	Almost never	Occasionally	Frequent	Very frequent

2

9. Do nursing staff interact with residents with (very severe) cognitive impairment? (When not present than indicate as not applicable)

1	2	3	4	5
Seemed to ignore these residents	Hardly interaction	Some interaction	Frequent interaction	Very frequent interaction

10. Do nursing staff respond to residents that shout or scream? (when there are not residents that shout or scream than indicate as not applicable)

1	2	3	4	5
Seemed to ignore these residents	Hardly interaction	Some interaction	Frequent interaction	Very frequent interaction

B. Care of residents

11. Are residents dressed, clean and look well taken care off?

1	2	3	4	5
Mostly not	A few	Some	Many	Mostly do

C. Interaction between nursing staff

12. Are the nursing staff friendly to each other?

1	2	3	4	5
Did not seem to be	Almost never	Occasionally	Frequent	Very frequent

13. Do nursing staff help each other without being asked?

1	2	3	4	5
Did not seem to be	Almost never	Occasionally	Frequent	Very frequent

14. Are certified nurses aware of and do they direct care for residents? (May need to check with nursing staff)

1	2	3	4	5
Did not seem to be	Almost never	Occasionally	Frequent	Very frequent

D. Activities of residents

15. Are resident up and out of bed? (If not applicable, indicate here…….…..)

1	2	3	4	5
Mostly not	A few	Some	Many	Mostly do

16. Do residents walk or move independently through the institution (possibly with walking aids: canes, walkers, braces, wheelchairs)?

1	2	3	4	5
Rarely observed	Almost never	Occasionally	Frequent	Very frequent

17. Do the staff help residents to walk or move through the institution (possibly with walking aids: : canes, walkers, braces, wheelchairs)?

1	2	3	4	5
Rarely observed	Almost never	Occasionally	Frequent	Very frequent

18. Are therapeutic staff (physio-, occupational- and speech therapists, activity counsellors), actively working with residents to improve or restore function? (Restore of function is probably not applicable, ask staff if necessary).

1	2	3	4	5
Did not seem to be	Almost never	Occasionally	Frequent	Very frequent

19. Do residents (with cognitive impairments) have an adequate safe place to roam indoors?

1	2	3	4	5
No clear space	Very small	Some, but not enough space	Adequate	More than adequate

20. Do residents (with cognitive impairments) have an adequate safe place to roam outdoors?

1	2	3	4	5
No clear space	Very small	Some, but not enough space	Adequate	More than adequate

E. Characteristics of the ward

22. Are there any odours of urine or faeces perceptible when walking on the ward?

1	2	3	4	5
Penetrating everywhere	Almost always	Frequently	Occasionally	Almost never

23. Are there other unpleasant odours (for example from cleaning agents) perceptible when walking on he ward?

1	2	3	4	5
Penetrating everywhere	Almost always	Frequently	Occasionally	Almost never

24. Are residents' rooms, corridors and public spaces not cluttered?

1	2	3	4	5
Very cluttered	Cluttered	Somewhat cluttered	Neat and not cluttered	Very neat and not cluttered

25. Are residents' rooms, corridors and public spaces clean?

1	2	3	4	5
Filthy	Somewhat filthy	Somewhat clean	Clean	Very clean

26. Are the rooms of residents sufficiently spacious?

1	2	3	4	5
Very tight	Somewhat tight	Sufficiently spacious	Spacious	Very spacious

27. Is there room for residents to withdraw (possibly with family members)?

1	2	3	4	5
Not present	Sometimes present when space is available	Available on request	A space has been allocated for this	There are several spaces available for this

28. Are the buildings, grounds and furniture in good conditions and well-maintained?

1	2	3	4	5
Need a lot of attention	Need attention	Fairly good condition	Good condition	Very good condition

29. Are the residents' rooms personalized with furniture, pictures, and other things from their past?

1	2	3	4	5
Not personalized	Almost never	Occasionally	Frequent	Very frequent

30. Does the ward make a homely impression (due to the presence of plants, furniture)?

1	2	3	4	5
Cold impression	Somewhat cold impression	Somewhat homely impression	Homely impression	Very homely impression

31. Does the ward make a lively impression (due to the presence of volunteers, family members, children)?

1	2	3	4	5
Quiet impression	Somewhat quiet impression	Somewhat lively impression	Lively impression	Very lively impression

32. Is the area well lit?

1	2	3	4	5
Heavily shaded	Poorly lit	Some light but not enough	Well lit	Exceptionally well lit

2

Appendix 2 – Description of the locations

Location 1 is a psychogeriatric ward of a nursing home. The psychogeriatric ward is housed in a dated emergency building in the garden. The psychogeriatric ward consists of one unit on the ground floor, split into two sections, and provides dementia care to 28 residents in total. Both sections have their own living room, with the connecting individual rooms located in the surrounding corridors. The corridors are long and most corridors have a dead end. The location provides more than enough walking space for its residents. Several seating areas have been created and are decorated with older and 'home-like' objects. The ward is accessible through double automatic doors secured by a code. Both living rooms have a kitchen, seating area and multiple dinner tables. Both living rooms have access to two medium size fenced gardens with some seating areas and restricted walking space. All residents have their own individual room and bathroom. Residents have the opportunity to bring their own furniture and personal belongings from home.

Location 2 is a small-scale dementia facility, part of a residential care setting. The facility is situated on two separate floors, with 35 residents in total. The ward has multiple smaller units (either 2 or 3 on each floor) for up to 7 residents, secured by a code. Every dementia unit has its own living room, which has a seating area, dinner table and kitchen. Lastly, every floor also has one larger living room for all residents where daily activities are organized with multiple seating areas. Due to the lay-out of the ward, there is limited walking space for residents. The nursing home has a large garden for all residents and staff on the ground floor. The residents of the dementia care ward can only visit the garden under supervision. The ward has a balcony attached to the large living room, which residents can access independently. All residents have an individual room with bathroom which can be personalized but is quite small and therefore provides limited space for personal belongings.

Location 3 is a small-scale dementia facility, located in the middle of a residential area with a total of 28 residents. The dementia facility consists of a building split into four smaller units with up to 7 residents each. Three units are situated on the ground floor and are connected through a garden room. The fourth unit is on the first floor. The first floor is accessible through an elevator or by stairs. The stairs are secured by a code. Every unit has its own living room with a kitchen, dinner table and seating area. The location is recently build and therefore has a very modern look. The choice of furniture and objects create a very warm and home-like environment. The location is small, but due to its lay-out there is fairly sufficient space to move. The facility has a relatively small garden(patio) on the ground floor in the middle of the units, which can be accessed individually by the residents. The unit on the first floor has a large balcony, which is not always accessible individually due to locked doors, but can be used by residents under supervision. Residents have large individual rooms with own bathrooms with enough space for personal belongings and furniture.

Location 4 is a psychogeriatric ward in a large scale nursing home. The ward for dementia care is located on the third floor, houses 40 residents and is secured by a code. The ward consists of two different units, both at the other end of a connecting corridor. Each unit houses 20 residents. The lay-out of both units are similar, with the entire floor having long corridors. Some of the corridors have a dead end and no windows. The ward has three living rooms for each unit and a separate kitchen area with a large table. In between the two units alongside the connecting corridor a large balcony/roof terrace is located. The doors to the balcony are open on an irregular basis. The balcony is mainly used by staff during breaks and isn't entirely safe due to gaps between the tiles and objects laying around. The residents have own individual rooms that vary in size, but are usually quite spacious. The bathrooms are situated on the corridors and shared by residents.

Location 5 is a small-scale dementia facility. The location contains four units situated from the third up until the sixth floor, houses 24 residents and is secured by a code. Of the four units, one is a somatic and the other are psychogeriatric wards. Each unit houses six residents. All units have the same set-up and only vary in colour. The setup of each unit is quite small and contains mainly one dead-end corridor with individual rooms on both sides and one living room with kitchen, dinner table and seating area. The walking space for residents is quite limited. The corridor has no windows and lacks daylight. A "home-like environment" is created by the choice of comfortable furniture and multiple details such as baskets for magazines, birthday calendars and a pet bird in the living room. A small balcony is attached to each living room which residents can access individually. The third floor has access to a large shared roof terrace, which can only be accessed under supervision of family members or professional caregivers. Residents have individual rooms with a private bathroom, which are quite spacious and provide enough room and opportunity to bring own furniture and objects from home.

2

3

Using consumer wearables to estimate physical activity of nursing home residents with dementia

Daniela Gawehns, Suzanne Portegijs, Sandra van Beek and Matthijs van Leeuwen.

Abstract

Aim: Physical activity of nursing home residents can be assessed with tools such as questionnaires and standardized fitness tests. For residents with dementia, however, those tools can be cognitively challenging and difficult to administer. Consumer wearables could potentially aid as an affordable tool for ubiquitous assessment.

Methods: In this pilot study with 16 participants, we explore how measurements with an off-the-shelf wearable relate to structured observations of physical activity. We collected both processed and raw tri-axial accelerometer data from Samsung, wrist-worn fitness trackers. To anchor those data in the free living environment, we compare the measurements with the physical activity scale of the Medlo behavioral observation scheme.

Results: We show that consumer wearables are a valid tool for long term data collection in this vulnerable patient population.

Conclusions: Regarding the movement intensity, the data collected by fitness trackers is overall in accordance with the data collected with the observational tool. Regarding the type of movement, we conclude that the automatic activity classification on the wearables is not yet ripe for use in a mostly sedentary patient population.

Keywords: Dementia, Activity Estimation, Nursing Home

Introduction

Physical activity (PA) of nursing home residents is researched in the context of increasing health outcomes and wellbeing (1). Examples are the association of PA with sleep (2), number of falls (3), or energy expenditure and intake (4). Dementia and PA influence each other. Depression and apathy might manifest in passivity and low PA, while restless behavior will manifest as higher PA (5). Any measurement tool for PA will hence have to be able to account for a large range of activity levels.

Additionally, residents with dementia have more non-psychiatric comorbidities than other residents (6). Comorbidities affecting the heart function might make PA estimation based on heart rate less reliable if they are not taken into account. As in other geriatric patient populations, any measurement tool will have to account for the use of walking aids, such as walkers or canes.

Here, we report on the feasibility and the limitations of measuring PA with a consumer wearable in a Dutch nursing home. The presented data were collected as part of a research project that assessed the impact of providing unobstructed access to green spaces to residents with dementia. The main research question was how more access to green spaces affects the residents' quality of life, as well as the embedding of dementia care in the local community. We therefore assessed PA of the residents with different measurement tools and collected data on how people used the park of the nursing home with sensors and observations.

Commonly used assessment tools for PA of nursing home residents without cognitive impairment can be divided into three categories: observations of functional fitness tests, questionnaires, and technical measures (1). The first two types of tools require the participant to understand and follow instructions. For residents with dementia, this might pose a problem if the test is performed at the wrong moment, e.g. after a troubling experience for the resident. Furthermore, a participant's willingness to cooperate can fluctuate by day and time of the day. Achieving a consistent assessment is hence difficult with one-point-in-time measures.

Technical measures, on the other hand, come with fewer and simpler instructions. According to Wootten et al.'s categorization, technical measures include tests with sensing technology for grip and muscle strength, body composition tests, as well as assessment with accelerometers. (1)

Wearable accelerometers have been used to estimate sleep and PA of nursing home residents with dementia before (7). According to Cote et al.'s review from 2021, studies in nursing homes used wearables built for laboratory settings (e.g., Actigraph, Actiwatch). For our study, we opted for a consumer-grade fitness watches as they were not only

3

cheaper, but also designed for durability in daily life, which was an important requirement from the nursing staff. Furthermore, they are often outfitted with more sensors, such as magnetometers, barometers or GPS receivers.

Those additional sensors collect useful data for activity recognition methods (8). The option of tracking location outside by GPS was used to assess the use of green spaces by residents in another part of the study.

To anchor the sensor data in real life observations, we used data collected with the Medlo observational tool. The Medlo tool (9) was developed to capture daily life activities of residents in nursing homes and day care centers. Observations are logged per minute in 30-min sessions and observers use an observation sheet covering four dimensions of daily life activities in seven variables: Activities (type, engagement, physical activity), Physical Environment (location, interaction with environment), social interaction (occurrence, type, interaction partner), and emotional well-being (mood, agitation). For the aim of this paper, we focused on the variable "physical activity", which is scored on a 7-point Likert scale.

We used Samsung, off-the-shelf fitness wristbands with our own data collection app (10) to record accelerometer and barometer readings, and GPS location information. Additionally, we recorded manually the "24hrs log" of the watch, which are movement categories that are calculated and displayed on the device (low activity, medium, high activity, sleep, run, swim, cycle). We wanted to find out if those movement categories are useful in a mostly sedentary patient population. Furthermore, we wanted to compare PA estimates based on raw accelerometer with the modelled movement categories and observed activity levels.

Materials and Methods

Study Design, Setting and Participants
We report the results of a prospective and observational study. This study is part of the project "Dementia back in the heart of society - a complex case study". In this project, the impact of a renovation of a nursing home and reorganization of the care management on residents, staff and family members were assessed. We are presenting here tools used within the study protocol to assess PA of nursing home residents. The data collection for the overall project was in fall 2018, spring 2019, spring 2021 and fall 2021. In this paper, we present data collected in spring 2021.

For the overall project, participants were recruited in two waves in 2019 and in 2021. All residents with a diagnosis of dementia were invited to join the study by a letter to their legal representatives. In spring 2021, 54 residents were invited, leading to a 26 participants consenting to participate in the study. Unfortunately, due to informed

consent letters reaching us too late, we only managed to collect the following data: for 12 participants, we collected both wearable and observational data; for 4 participants, we collected only wearable data and for one participant only observations. Participants were between 72 and 91 years old on the day of data collection (Mean: 82, SD: 5.3 years). Overall, 15 women and 1 man participated in the data collection with the wearables.

Ethics

The study protocol was approved by the Ethics Review Board at Utrecht Medical Center (protocol 18-127). The legal representatives of all potential participants received a letter explaining the goal of the data collection and the types of data that were to be collected: Observations, Questionnaires, Medical Records, Wearables and Interviews. They could consent to all data being collected or just parts of the data collection. While collecting data on site, all research assistants and present nursing staff were instructed to remove wristbands as soon as residents requested this or were visibly bothered by it.

To safeguard the participants' privacy, all data was exclusively stored on the smartwatches themselves and on the researchers laptops. None of the collected data was shared with a third party or the watch manufacturer.

Preprocessing and Variable selection

Wearables We adjusted the settings of the wearables based on the expected participants' characteristics and set the watches to: gender "female", birthdate 1st January 1935, height 170 cm and weight 65 kg. We refrained from setting the watches to the true participant characteristics as this would not only prolong the exchange moment of the watches but is also prone to errors as we kept rotating the watches between participants. We followed the residents' wishes regarding which wrist they wanted to wear the wristband on.

Data from the wearables were collected with our own software and manually. Our software "WEARDA" (10) saved accelerometer data, barometer data and GPS recordings. The data were saved in .txt files on the watches and downloaded from the watches onto the researchers' computer. No cloud storage service or other third party was involved while storing and processing the data. Data of the app called "24 hrs log" were copied manually directly from the watch onto a data collection sheet on a research computer.

From the collected wearable data, we used the accelerometer data and the "24 hrs log" data to estimate activity levels. The "24-hrs log" records per minute the activity intensity as estimated by a Samsung-owned algorithm. The categories are: "not on wrist", "sleeping", "inactive", "light", "heavy", "biking" and "running". Per resident, we created seven data points analogue to the seven categories by summing up the minutes spent per category. Because not all residents had the same wear time of the wristband, we divided the count by wear time in minutes and multiplied it by 30 min to standardize it.

3

Accelerometer data were collected at 100 Hz. Analogue to previous studies (11), we chose to calculate the Mean Amplitude Deviation (MAD) metric over 5 second intervals and to derive several summary parameters from those data. The MAD is a measure of movement intensity and calculated based on the magnitude of acceleration within a predetermined interval (12). We calculated the following measures from the MAD: mean (MADmean), standard deviation (MADsd), median MAD (MADmedian) and 95th percentile of MAD (MADqant). Furthermore, we calculated per participant the time spent above 100 milligravitational units (MADrel), and the fragmentation rate of the MAD (MADfrag). The fragmentation rate is the standard deviation of the first derivative of the MAD time series and is an indicator for intensity changes of PA, with a higher value indicating more changes.

Structured Observations To ground the physical activity estimates from the wristbands, we used the PA scale of the Medlo observational tool (9). The PA scale is an ordinal, 7-point Likert scale. Per observed minute, the research assistant notes the observed movement category. The movement categories are: ML01 = lying/no movement, ML02= sitting quietly, ML03= light to moderate sitting, ML04= standing, ML05= standing activity/ walking around, ML06= walking activity/ cycling, ML07=sports/whole body movement. In a related study, we checked for interrater reliability of observed activity classifications and found that the collected data matched in 91% of the registered activities (13). The data were transformed into seven data points per resident, by summing up the minutes a resident spent per category. Analogue to the "24 hrs log" data, we divided the sums per category by the total observation time and standardized it to 30 min.

Results

Summary Statistics

For both the Medlo and the 24hrs categories, we see mainly sedentary behaviors. Residents spent most time in the categories "inactive" for the wearable categories (Figure 1) and "sitting quietly" for the Medlo (Figure 2). The wearables detected approximately the same amount of "light" activity than the Medlo observations of "ML04 = standing" and "ML05 = standing activity / walking around" combined.

We collected almost no observations for the Medlo categories ML03 = "sitting moderate", ML06= "active walk" and ML07= "sports/full body movement" as well as for the 24hrs categories of "heavy", "biking" and "running". We therefore removed those variables from further analysis.

The MAD has an overall mean of 11.15 milligravity units (range: 4.5 to 20.4 milligravity units). This is in accordance with Bakrania et al. (12) who found a mean between 6 and 12 milligravity units (depending on the device) in their sample for sedentary behaviors.
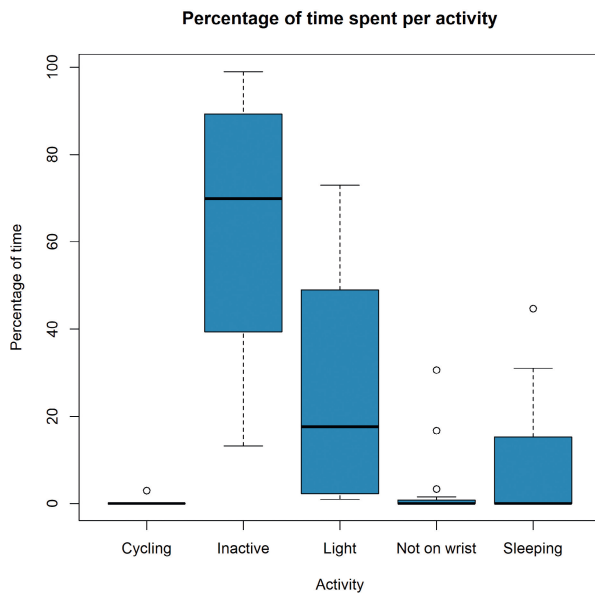
Figure 1. Boxplots of the collected 24hrs data of all participating nursing home residents (N=16). Per activity, we plotted boxplots of the average percentage of measurement time that a residents was active in one category.
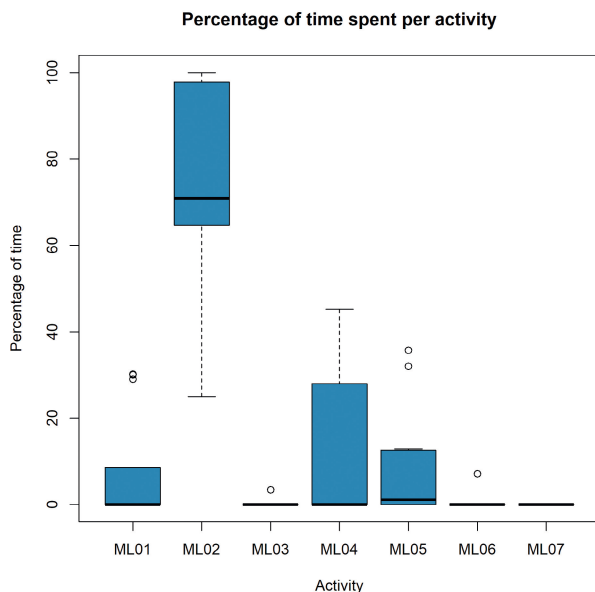
Percentage of time spent per activity

Figure 2. Boxplots of the collected Medlo data of all participating nursing home residents (N = 13). Per Medlo Activity Category, a boxplots shows the percentage of time that residents were active in one category. Categories are: ML01 = lying/no movement, ML02= sitting quietly, ML03= light to moderate sitting, ML04= standing, ML05= standing activity/ walking around, ML06= walking activity/ cycling, ML07= sports/whole body movement

Correlation analysis

We correlated all variables with each other after preprocessing the raw data. The correlation matrix in Figure 3 is sorted by hierarchical clustering using the complete linkage method. The clusters show clearly that the MAD derived metrics correlate somewhat positively with the more active categories of the Medlo and the "light" activity of the watches' activity classification. There is also a positive correlation with the category "not on wrist". They correlate negatively with the less active categories of the watches' model (sleeping, inactive) and the Medlo (ML01,ML02). While all MAD parameters correlate highly with each other, there are differences in association strength with the other variables. The standard deviation and 95th percentile seem to differentiate best between the more active and more inactive Medlo and watch categories. There are larger positive and negative correlations with the watch categories than with the Medlo categories. The directions of the correlations are as expected; positive with the more active categories and negative with the less active categories.

The watches' and Medlo variables also correlate with each other in the expected way. An interesting case is the sleeping and "not on wrist" categories of the watches' model. Those have in general very low correlations with the other activity variables, apart from a positive correlation between Sleeping and ML01 (.66) and between Not On Wrist and ML 05 (.65).
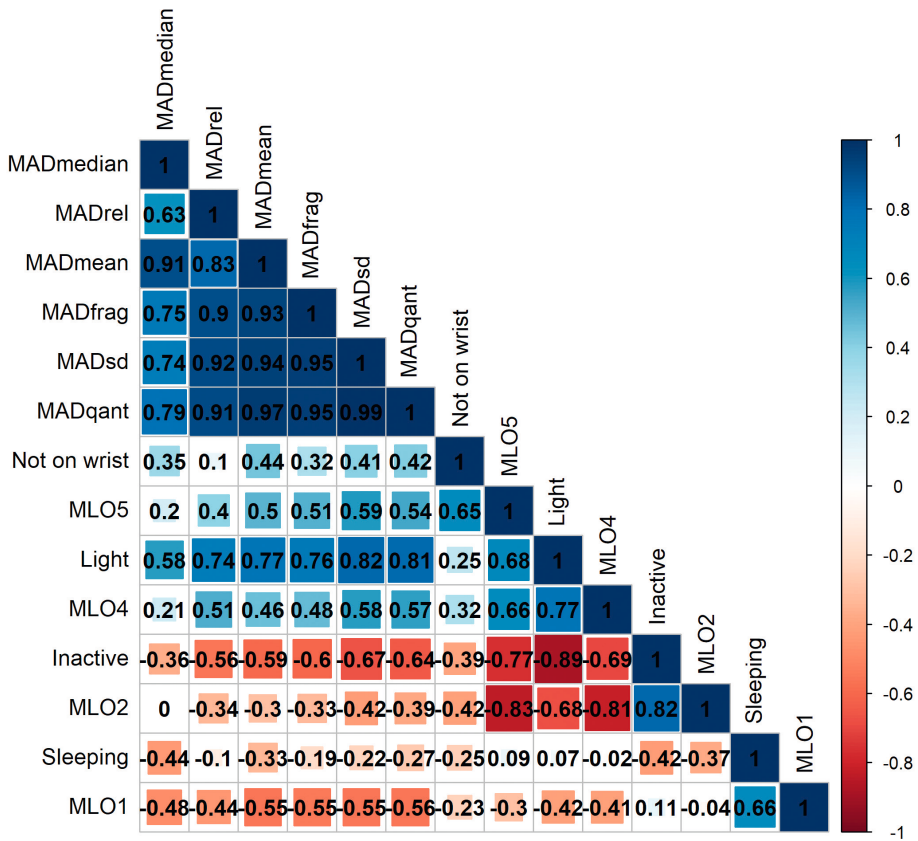
Figure 3. Correlation matrix of all variables. The correlation matrix is sorted hierarchically, which yields two clusters, one with the MAD derivates and three active categories plus "not on wrist" and another cluster of the least active movement categories.

Discussion

Our main question was if we can use consumer wearables to estimate activity levels in nursing home residents with dementia, and how those estimations would relate to observational data. The summary statistics confirmed our expectation of a rather sedentary sample. For the Medlo scores, this is also an artifact of the data collection process, where Medlo observations took place in shared living rooms, which invite residents to sit down and generally do not encourage physical activities. Activities outside the observer's field of view were registered as "non-observable", which might cause an underestimation of PA (13). The wearable data confirm low activity levels over the entire measurement period, which includes time spent outside shared living spaces and outside registered observations. We did not collect data during morning and evening routines, which we would expect to come with a big share of PA, such as

walking to and from the living room, moving in and out of bed, and bathroom routines. In future research, one could use wearables during those moments to collect data without breaching residents' privacy. This would give a more complete picture of the residents' PA throughout the day.

Overall, the found correlations are according to our expectations, with higher scores on MAD metrics being associated with more time spent in higher activity categories. We found positive correlations between the MAD metrics and the active Medlo categories (ML04 and ML 05). It is noteworthy that the correlations between the watches' "light" activity category and the Medlo categories are more pronounced than the correlations between the MAD metrics and the Medlo categories. In our sample, conclusions based on any of the collection tools will be very similar.

Apart from PA levels, researchers might be interested in how engaged participants are when performing certain activities or in which context the activity takes place. Observational tools can generate such additional information. We argue that PA scores can be estimated similarly well with observations and wearables. A combination of both however would allow researchers to set the results of the observation period into the context of an entire day of PA. Data from wearables can provide this context without having to rely on carers' or residents' memory of that day. For our analysis, we derived several MAD metrics. From the correlation matrix, we see that there are differences in how those metrics correlate with the activity categories. Especially, the standard deviation and the fragmentation rate seem to differentiate better between categories. We suggest including derivatives for the spread of MAD when using raw accelerometer data in predictive models to increase predictive performance.

We see that sleep has a positive association with the lowest observed activity category (ML01) and is negatively associated with the "inactive" category. We interpret this as the wearable detecting very low activity levels as sleep instead of inactive. The association with the MAD derived features are not very coherent, the negative correlation with the median of the MAD however supports our interpretation. Sleep is often used as an outcome variable in health care research. We argue that for mainly sedentary populations, more validation studies are needed to use commercially available sleep categorizations, as they cannot distinguish well between sleep and very little activity.

The presented data are limited by a rather small sample. However, we collected per person a long interval of movement data with the wearables. This makes the found associations between the watch-derived data points more robust. We would like to point out that the Medlo is not the only observational tool to assess activity levels amongst dementia patients. Any future research should include other tools (surveys, diaries, medical records) to compare the wearable data with and to ground the conclusions drawn based on wearable data.

Conclusions

In this study, we showed that collecting movement data with commercial, consumergrade wearables in a population of nursing home residents with dementia is possible. The watches allowed us to collect movement data outside shared living spaces and for several hours at a time. The collected wearable data are in general in accordance with the data collected with an observational tool.

The data was collected with a commercial wearable but in a GDPR proof manner, as none of the collected data, nor the settings of the watch was shared with a third party (for example by sending it via a cloud service for access). This opens opportunities for similar research with other vulnerable patient groups. Using wearables for ubiquitous, long-term assessment of activity levels in a population of dementia patients living in a nursing home is possible and holds many opportunities for assessing PA in real life situations.

3

References

1. Wootten, S., Wiseman, N., Harris, N.: Measuring the outcomes for aged care residents' participation in physical activity interventions: A systematic review of randomised controlled trials. Australasian Journal on Ageing 41(2), 165–187 (2022) https://doi.org/10.1111/ajag.13026 . Accessed 2023-05-15

2. Vogel, O., Niederer, D., Wilke, J., El-Rajab, I., Vogt, L.: Habitual Physical Activity and Sleep Duration in Institutionalized Older Adults. Frontiers in Neurology 12 (2021) https://doi.org/10.3389/fneur.2021.706340 . Accessed 2023-05-15

3. Diener, J., Rayling, S., Bezold, J., Krell-Roesch, J., Woll, A., Wunsch, K.: Effectiveness and Acceptability of e- and m-Health Interventions to Promote Physical Activity and Prevent Falls in Nursing Homes—A Systematic Review. Frontiers in Physiology 13 (2022) https://doi.org/10.3389/fphys.2022.894397 . Accessed 2023-05-15

4. Murphy, J., Holmes, J., Brooks, C.: Measurements of daily energy intake and total energy expenditure in people with dementia in care homes: The use of wearable technology. The journal of nutrition, health & aging 21(8), 927–932 (2017) https://doi.org/10.1007/s12603-017-0870-y . Accessed 2023-05-15

5. Anderiesen, H., Scherder, E.J.A., Goossens, R.H.M., Sonneveld, M.H.: A systematic review - physical activity in dementia: The influence of the nursing home environment. Applied Ergonomics 45(6), 1678–1686 (2014) https://doi.org/10.1016/j.apergo.2014.05.011

6. Duthie, A., Chew, D., Soiza, R.L.: Non-psychiatric comorbidity associated with Alzheimer's disease. QJM: An International Journal of Medicine 104(11), 913–920 (2011) https://doi.org/10.1093/qjmed/hcr118 . Accessed 2023-05-15

7. Cote, AC. Phelps, RJ. Kabiri, NS. Bhangu, JS. Thomas, KK. Evaluation of Wearable Technology in Dementia: A Systematic Review and Meta-Analysis 7 https://doi.org/10.3389/fmed.2020.501104

8. Aguileta, A.A., Brena, R.F., Mayora, O., Molino-Minero-Re, E., Trejo, L.A.: Multi-Sensor Fusion for Activity Recognition - A Survey. Sensors 19(17), 3808 (2019) https://doi.org/10.3390/s19173808 . Accessed 2023-08-08

9. Boer, B. Beerens, H.C. Zwakhalen, S.M.G. Tan, F.E.S. Hamers, J.P.H. Verbeek, H. : Daily lives of residents with dementia in nursing homes: development of the Maastricht electronic daily life observation tool. International Psychogeriatrics 28(8), 1333–1343 (2016) https://doi.org/10.1017/S1041610216000478 . Accessed 2022-04-04

10. Dijk, R.M.K., Gawehns, D., Leeuwen, M.: Wearda: Recording wearable sensor data for human activity monitoring. Journal of Open Research Software (2023) https://doi.org/10.5334/jors.454

11. Schmidle, S., Gulde, P., Koster, R., Soaz, C., Hermsdörfer, J.: The relationship between self-reported physical frailty and sensor-based physical activity measures in older adults – a multicentric cross-sectional study. BMC Geriatrics 23(1), 43 (2023) https://doi.org/10.1186/s12877-022-03711-2 . Accessed 2023-02-14

12. Bakrania, K., Yates, T., Rowlands, A.V., Esliger, D.W., Bunnewell, S., Sanders, J., Davies, M., Khunti, K., Edwardson, C.L.: Intensity Thresholds on Raw Acceleration Data: Euclidean Norm Minus One (ENMO) and Mean Amplitude Deviation (MAD) Approaches. PLOS ONE 11(10), 0164045 (2016) https://doi.org/10.1371/journal.pone.0164045 . Accessed 2022-11-07

13. Portegijs, S., Beek, S., Tuyl, L.H.D., Wagner, C.: Physical activity in people with dementia living in long-term care facilities and the connection with environmental factors and behavior. Journal of Aging and Physical Activity 31(2), 214–222 (2023) https://doi.org/10.1123/japa.2021-0459

4

"We usually choose safety over freedom": results from focus groups with professional caregivers in long-term dementia care

Suzanne Portegijs, Adriana Petronella Anna van Beek, Lilian Huibertina Davida van Tuyl and Cordula Wagner.

Abstract

Background People with dementia living in nursing homes are mostly sedentary, which is a consequence of various personal, environmental and organizational factors. Until now, studies on physical activity and safety in dementia have focused on residents and caregivers from the viewpoint of (individual) care provision and health benefits. There has been little to no focus on the possible influence of group dynamics between care providers with regard to physical activity and safety. The aim of this study is to gain more insight into the viewpoints and intentions of groups of professional caregivers towards safety and physical activity and the potential influence of the group-oriented setting in long-term care on physical activity of individual residents.

Methods A qualitative study comprising three focus group discussions including professional caregivers (n=15) was conducted within two long-term care organizations in the Netherlands. Focus group discussions were structured using an interview guide derived from a preliminary framework, based on existing literature and complemented with clinical expertise.

Results Seven themes could be derived from the focus group discussions that influence physical activity and safety: 1) Individual health and abilities; 2) Balancing physical activity and safety; 3) Physical restraints; 4) Group interests versus the individual interests; 5) Organization of care and physical environment; 6) Perceived responsibilities and tasks of professional caregivers and 7) Change is challenging.

Conclusions Due to multiple influencing factors, the balance for care providers in long-term care generally tends towards safety over physical activity. Furthermore, in order to stimulate physical activity various limitations are experienced, including the organization of care, the general health of the residents and difficulty to achieve changes in daily care. Most importantly, the group interests of both the professional caregivers and the residents have a substantial influence on the incorporation of physical activity in daily care.

Keywords Dementia, Long-term care, Physical activity, Group dynamic, Professional caregivers, Safety

Introduction

Physical activity positively influences multiple health outcomes of people with dementia (living in long-term care facilities), including cognitive functioning, independency in activities of daily living, physical performance, mobility, depression, agitation and functional ability. (1-4) Despite the positive effects, physical activity is generally low in nursing home residents (5-9). This is a consequence of numerous influential factors such as the environment's compatibility with the abilities of a resident, accessibility, security and comfort. (10) Also, the physical health of the residents, cognitive functioning and perceived feeling of understanding and personal freedom are imperative for the degree of physical activity among residents with dementia. (11, 12)

When it comes to improving the degree of physical activity, care teams of nursing staff in long-term care facilities are a crucial influencing factor, as they spend the largest amount of time with residents compared to other caregivers involved. (13) However, various organizational factors impede the improvement of physical activity including staffing levels, available time and the amount and type of care provided. (10, 11) Due to insufficient staffing levels and/or (perceived) limited amount of time, professional caregivers are tended to use short cuts to meet basic care needs. Commonly at the expense of physical exercise and/or functional activities. (14-16) Furthermore, lack of clinical and administrative support, insufficient communication and team effort, concerns regarding anxiety and agitated behaviour of residents and injury for both residents and professional caregivers are also imperative barriers. (12, 15, 17) Despite the experienced barriers, most professional caregivers are conscious of the benefits of physical activity and state that it is feasible to improve the degree of physical activity in daily long-term care. (14, 18)

The composition of care teams and organization of care within long-term care facilities is unique in comparison to other health care settings due to the educationally diverse care teams including registered nurses, Certified Nursing Assistants (CNAs) and assistants without a healthcare-related education. (19-22) While scientific studies on this topic present varying results, a diverse mix of caregivers and skills within a supportive context seems to have a positive influence on the quality of care. (21, 23, 24)

Currently, the existing body of literature on the influence of group dynamics on long-term care is scarce and broadly focussed. (19, 25) However, from current studies and clinical practice it is evident that the organization of long-term institutionalized (dementia) care is mostly provided on closed wards (26) and largely group-oriented for both residents and professional caregivers. (20, 22, 27) The group-orientation for residents is mainly characterized by the majority of their time spend in shared spaces or 'living rooms' where the meals are served at set times and leisure activities are undertaken that fit the majority of the group. (24) Furthermore, daily care provided by the professional caregivers has

4

a group character due to their shared responsibility for the care tasks to be performed (20, 22) and close proximity to each other.

Even though research on group dynamic within long-term care facilities is limited, available studies in general show that socially cohesive care teams positively influence job and organizational performance, job satisfaction and quality of care. (19, 25, 28-32) Yet, scientific studies on the views of groups of professional caregivers towards physical activity and the potential influence of the group-oriented setting in long-term care are lacking.

Methods

Aim
The aim of this study is to gain more insight into the viewpoints and intentions of groups of professional caregivers towards safety and physical activity and the potential influence of the group-oriented setting in long-term care on physical activity of individual residents.

Reporting guidelines
In order to ensure an accurate description of the methods followed within this study, the Consolidated criteria for reporting qualitative research (COREQ) was used. (33) This checklist consists of 32-items reflecting three important domains regarding qualitative research, namely: research team and reflexivity, study design and analysis and findings.

Design
This study is part of a larger research project in collaboration with a care organization in the Netherlands that wants to improve the living conditions of people with dementia within one of their nursing homes by providing more freedom and autonomy and facilitating social interaction with the surrounding neighbourhood. This care organization is included within this study. In addition, in order to gain a more broad view on this topic and include a more accurate reflection of the Dutch long-term care system, two additional nursing homes (both a large-scale and small-scale facility) were asked to participate. In these organizations, located in both a rural and urban area in the Netherlands, three focus groups were conducted in September 2019.

Sample and invitation procedure
Nurses, Certified Nursing Assistants (CNAs), trainees and recreational coaches working at the long-term dementia care ward within the three included nursing homes were eligible for inclusion. All professional caregivers working on the ward were invited to participate in the focus group through an e-mail send by the care manager. Subsequently, the majority of the professional caregivers present on the specific day participated. A few (mostly two or three) professional caregivers remained at the ward to provide care for the residents. This resulted in a total of 15 participating professional caregivers. Group

size varied between 3 and 7 participants and consisted of CNAs (n=7), supplemented with recreational coaches (n=2), nurses (n=2), nurse in training (n=1) and CNA trainees (n=3). One participant was male and all others were female. The ages of the participants ranged from 22 to 64 and the years of experience in care from 0.5 up to 40.

Setting
Two researchers were present at each focus group. The researchers introduced themselves before the start of the focus group and explained the aim of the research to the participants. The focus groups lasted for about one hour and were conducted around the change of shift in the afternoon as the largest number of professional caregivers is present at the wards around this time. Furthermore, the focus groups took place in a room on or near the wards and was conducted during work-time in order to lower the threshold to participate. All focus groups were audio recorded. After finishing the focus groups, the obtained data was discussed among the researchers. The initial plan for this study included three focus groups in total with the aim to achieve saturation. The researchers were able to discuss all topics adequately and many recurring themes were found within the focus groups.

Interview guide
An interview guide was created based on literature review and expert opinion (*see Appendix 1*). In addition to the input obtained from the existing literature, expert opinion was obtained from both authors SP and AvB. Author SP is a physiotherapist with almost ten years of experience in long-term dementia care. Author AvB is a very experienced researcher and policy advisor within long-term care, specifically dementia care. Moreover, author CW is a professor in the field of patient safety and provided valuable insight and contributed meaningfully in the development of the preliminary framework and subsequent interview guide. The assumption within the preliminary framework is that some form of decision-making takes place between the degree of physical activity and safety by professional caregivers before they activate people with dementia. Another assumption is that the degree of physical activity and safety are influenced by both the professional caregivers and the residents.

Data analyses
Transcripts were coded manually in Word. Subsequently, all quotes were categorized in Excel with a different tab for every individual code. The focus group discussions were analysed using a combination of deductive and inductive content analysis. (34) Firstly, a preliminary framework was created based on the interview guide to conduct deductive analyses of a-priori anticipated constructs. In parallel, inductive analysis included open and unstructured coding of constructs that did not fit into the a-priori constructs. Two researchers independently coded all transcripts (SP, AvB) and findings were discussed in weekly meetings.

4

The preliminary framework for deductive analysis included 10 codes. The inductive analysis added another 6 codes. This resulted in a final framework of 16 codes (see Table 1). Codes were subsequently grouped into themes by two independent researchers. All quotes that were not coded equally into one of the themes by the two researchers were discussed until consensus was reached. Quotes used within the article were translated from Dutch to English by an external native speaker and translated back by one of the researchers (LvT) and subsequently discussed by three researchers (SP, AvB and LvT) involved within this study to ensure an accurate translation.

Table 1. The initial ten codes and final 16 codes used during the analyses of the data.

Initial ten codes	Final 16 codes
1. Residents	1. Resident
2. Quality of life	2. Well-being
3. Safety	3. Health
4. Physical activity	4. Activities
5. Independency in ADL	5. Safety
6. Autonomy	6. Physical activity
7. Decision-making	7. Independency in ADL
8. Professional caregivers	8. Autonomy/Freedom
9. Organization of care	9. Tools
10. Attitude/behaviour	10. Physical environment
	11. Outdoors
	12. Building
	13. Decision-making
	14. Professional caregivers
	15. Organization of care
	16. Attitude/behaviour

Ethical considerations

This research has been conducted in accordance with the ethical standards of the Declaration of Helsinki, the Conduct Health Research (https://www.federa.org/codes-conduct) and the relevant guidelines regarding informed consent and the review of research ethics committees in the Netherlands. Furthermore, this study has been reviewed as part of the ZonMw dementia research and innovation program 'Memorabel', part of the 'Deltaplan for Dementia'. Permission to conduct the research was provided

by the location and care managers of the wards. Informed consent was obtained from all participants before the start of the focus group and recorded. All focus groups were recorded and transcribed verbatim. For privacy reasons, names of residents, professional caregivers, wards and care organizations were anonymized.

Results

Based on the 16 codes derived from the data seven themes could be identified, namely: 1) 'Individual health and abilities', 2) 'Balancing physical activity and safety', 3) 'Physical restraints', 4) 'Group interests versus the individual interests', 5) 'Organization of care and physical environment', 6) 'Perceived responsibilities and tasks of professional caregivers', 7) 'Change is challenging'. In the following section, all themes are described and their interrelationship is reflected in Figure 1.
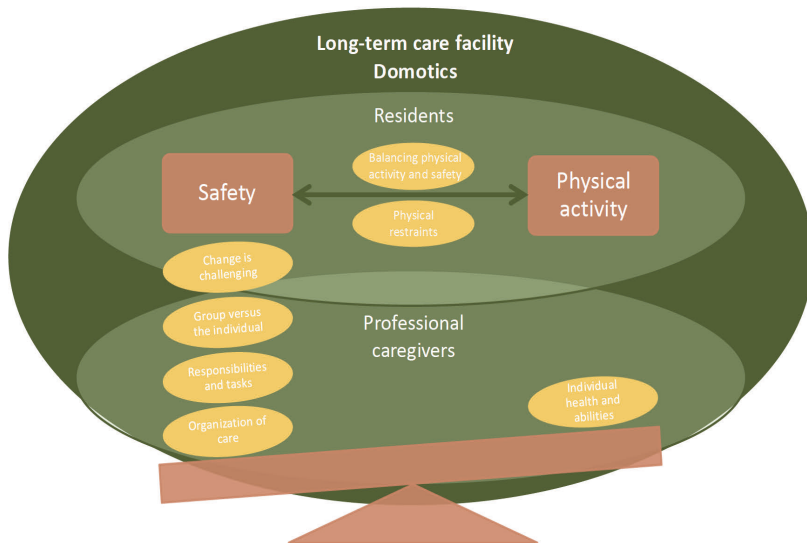

Figure 1. Aspects influencing the degree of physical activity and safety, within the context of long-term care facilities

Individual health and abilities
Many different forms of physical activity are mentioned by the participants during the focus groups, including independency in- or assisting during daily care, meals and housekeeping, walking, swimming, group activities such as yoga or active games, dancing, drawing or painting and making music. In general, participants consider physical activity to be important due to its health benefits for residents such as preventing contractures, maintaining their independency and less uncomfortable daily care.

> *"The less they move, the stiffer they get you know. That's unpleasant. Moving is pretty important.."*
>
> *[Certified nursing assistant]*

Participants mention that there is a large variety among residents with regard to their independency in physical activity. Especially the lack of initiative among some residents is considered challenging.

> *"Well, some of our residents have a very strong urge to walk while with others we have trouble getting them to move. Uh. they sit, they walk from point A to point B and then sit down again until we tell them that we go to the room or the toilet. So the rest of the time, they don't do much.."*
>
> *[Certified nursing assistant]*

However, providing care that suits residents who tend to compulsively walk long distances every day also requires attention from the professional caregivers.

> *"We try to use the walker and every now and then, we give it to them. But sometimes… eh.. we are short staffed and we don't always see everything so that lady fell for some reason… eh.. Sometimes we have people walking around all the time, then you have to supervise all the time and be alert because when they get exhausted they might fall. Some people have an urge to keep walking and we can't calm them down.. at some point they get all tired and are more at risk of falling down."*
>
> *[Certified nursing assistant]*

Furthermore, the degree of physical activity and the ability to assist during daily life activities differs among the residents.

> *"Because on 6 [red: floor 6 of nursing home] we have a gentleman, well he loves to help. We will give him a cloth and he instantly starts to clean the tables. He loves it when we ask him if he wants to go downstairs to help do grocery shopping, another lady loves to help too. She doesn't like it when we make coffee for her, she likes to help with the laundry. Every person is different that way."*
>
> *[Certified nursing assistant]*

Maintaining independency is considered challenging. In order to prevent functional decline, constant maintenance and stimulating physical activity is necessary for some residents.

> *"My opinion is that they stay mobile as long as they keep moving. When we let them sit in chairs then they.. eh.. in no time they will experience difficulty moving, much more passive. We have someone in room 43 who we had to medicate for her behaviour and*

she slept all the time because of it. Within two weeks she stopped walking. We're talking about two weeks. That's how fast it can happen."

[Certified nursing assistant]

"They get hospitalized and thus get spoiled. So at some point, when they get dressed by someone else all the time, they tend to stop helping or dressing themselves at all. So you have to let people keep doing their own things as long as possible."

[Nurse in training]

Alternative ways to stimulate physical activity are mentioned in order to make it more attractive for residents and provide a more diverse program.

"A.. eh.. pillow fight, I think this is a way you can let them move without them knowing. Because it's a game they move more then they know."

[Recreational coach]

During the focus groups the influence of residents on daily care, safety and physical activity is mentioned to be of importance. One aspect that influences the degree of physical activity is their general health and physical abilities. A poorer health and/or physical ability influences physical activity in a negative way.

"The eh… general deterioration. It just simply doesn't eh… for example, when they have a fractured bone and they have to recover and be rehabilitated and they usually don't get out of their wheelchair or even their bed anymore."

[Nurse in training]

Furthermore, tailoring activities to the residents' interests and hobbies is also mentioned to be very important to stimulate more physical activity.

"I make… I usually make some sort of vague image… then he.. he..he is fully awake. He (name of resident) looks at me and I ask 'What do you think? Does it need any more work?' He tells me that my perspective is pretty good.. but this area needs work. He goes on to tell me about all different kinds of painting techniques and how to preserve your paint. Everything is sorted by colour… then he laughs and starts to make jokes.. then he sits upright, he shuffles to the front of his seat… It doesn't have to represent anything, it doesn't matter."

[Recreational coach]

Providing and organizing activities that suit the interests of residents is found to have a positive influence on their general well-being. Alongside with a tailored approach for every individual resident during daily care.

4

"Just some of those little activities that you can do on a daily basis. There's something to do every day. Sometimes you just put the resident in a room and give them a puzzle. You just watch and see what they do with it. Or maybe someone loves to do math, then you give them some equations to do."

[Certified nursing assistant]

"Yes… eh…. I love to use humour in my work, when I think it's appropriate of course… Some resident have a need for it. There's this man who lets us know that he likes it when we use humour. He said that he has a low mood, but this helps him…. Happiness and cozyness. "

[Certified nursing assistant]

Lastly, the importance of maintaining the identity of the individual person is mentioned to be a part of daily care provided by professional caregivers.

"She's just being herself. That's what I like, people just being themselves. Despite of them forgetting, sometimes we can help them find themselves and to love the things they do and experience. Authenticity."

[Recreational coach]

Balancing physical activity and safety

Within the previous theme, the benefits of physical activity are clearly stated by the participants. Though, they also experience safety concerns and distinguish two points of view: their own safety and the safety of the residents. With regard to their own safety, there are certain conditions the ward should meet in order to create a safe environment for the professional caregivers. For instance locking all the cabinets, the cutlery drawer, making sure no sharp objects are laying around and not feeling threatened by residents. Especially during certain time periods during the day or night when there is less staff present on the ward.

"It used to be different. There are moments where we eh.. mostly during the night. We only have two persons working at the same time. They have felt really threatened. At that moment, when there is a new resident coming in, who was feeling uncomfortable and then for instance chases personnel with a metal bar… Those moments are not safe, luckily this doesn't happen very often."

[Nurse in training]

Although they do mention the occurrence of threatening situations or aggressive behaviour, these situations are rare and overall they feel safe.

With regard to the safety of residents, various physical conditions are mentioned: no wet floors, not fully opening windows, having sufficient fire prevention and having well-

working tools such as wheelchairs and walking aids. Furthermore, the necessity to know the residents is mentioned in order to provide a safe environment and being able to address their needs. Despite the awareness for safety, participants mention they are not always able to provide a fully safe environment.

> *"We try to cover everything, to make sure that we give every patient what we think they need. Despite of doing that, we can't be 100% sure that everyone gets what they need."*
>
> *[Nurse]*

A major concern with regard to the safety of residents mentioned by the participants is the risk of falling and their efforts to prevent that from happening. Perspectives and views on this topic vary among the participants. Some participants mention that safety and fall prevention is more important than providing autonomy for the residents and should be the main focus of care.

> *"Of course we have a lot of patients that walk very badly, even with a walker. So we have to watch them all the time, we keep giving them the walker and make sure they don't walk unsupervised by themselves."*
>
> *[Certified nursing assistant]*

4

While others argue that almost all residents are at a higher risk of falling and that it is impossible to provide a fully safe environment.

> *"For example, we have patients who walk all the time but are at risk of falling. We can't supervise them 24/7, you know. "*
>
> *[Certified nursing assistant]*

Some participants mention that they are torn between wanting to protect the residents, making sure they are safe and prevent falls, and the benefits the residents have by having more autonomy and physical activity in their daily life.

> *"Well, sometimes eh.. sometimes we just let them walk and they eventually fall. Then we take care of the wounds.. eh.. they still walk.. why would we limit them?"*
>
> *[Nurse in training]*

> *"I think that's it.. the freedom we can give these people. The freedom that they can choose to walk around, which we try to give them that as much as possible, of course as safe as possible. That's the only thing that comes to mind. The degree of freedom that is still possible, we want to give that to them."*
>
> *[Recreational coach]*

Physical restraints

The use of physical restraints in order to prevent falling and provide safety for the residents is mentioned by the participants. The main focus is on bed railings, fall mats and sensors. However, some also mention other physical restraints, such as sedating medications and the use of a Global Positioning System (GPS). Most participants comment that physical restraints are not used often in order to limit the residents, but to address their own needs and provide support and assistance. For instance: bed railings are fully up during the night at a residents' own request or using a sensor during the evenings to be able to assist residents to the toilet. Participants also mention the possible health disadvantages that the use of physical restraints can cause and state that physical activity has a higher priority.

> *"With agitated patients we don't use medication very often. Movement, getting them to move, is the most important for us. Because when you give them medication they tend to fall a lot more, that has a lot of consequences."*
>
> *[Certified nursing assistant]*

Group interests versus the individual interests

Balancing the need of the individual and the larger group is challenging for professional caregivers and makes them face ethical dilemmas with regard to safety and physical activity in daily care. Despite the focus on the needs of the individual, the solution is usually based on the interests of the group.

> *"Yes, we used to have a resident that couldn't go downstairs to join the activities because of the risk of running away. So.. this was discussed and we also wrote it down in the treatment plan. He couldn't participate in any of the activities. It's sad, but.. if he would run away…"*
>
> *[Certified nursing assistant]*

> *"What I sometimes find difficult is… there's this one lady and she really wants to go outside, but I know she doesn't want to come back inside. So for her own safety and the safety of the other people I take outside, it's a problem. I feel this is an ethical dilemma. Should I refuse to take her outside so that I don't endanger the group?"*
>
> *[Recreational coach]*

Participants also face safety challenges with regard to their colleagues when organizing more individual activities for residents. They feel like they cannot leave other professional caregivers behind at the ward due to safety issues. Subsequently resulting in that the interests of the group take precedence over that of the individual.

> *"And because of this it is limiting people to move. Or just to walk around the block. That's not possible. Not in this department. Because of the types of residents we have here, you can't leave your colleagues alone even with the two of them."*
>
> *[Certified nursing assistant]*

Organization of care and physical environment

A subject that is discussed a lot during the focus groups is the influence of the organization of care on the degree of physical activity. Mainly sufficient staffing levels on the wards is mentioned to be of great importance in order to stimulate physical activity and independence during daily care.

> *"Eh..yes.. eh.. what you said.. so for example.. eh.. someone is putting on their pants really slowly.. then I would eh.. But what do you do when you are understaffed? So eh.. we quickly put on the pants, the pants and the inco [red: incontinence garments], and we let him finish the rest himself. So we helped a little bit so he can hurry up."*
>
> *[Certified nursing assistant]*

Also the organization of activities on the wards is considered challenging due to lower staffing levels.

> *"I don't think we are the only one with a problem, I think a lot of nursing homes encounter the same things. The budget cuts are the cause of us being understaffed and too busy to do certain things with our residents. That's a shame. We work all day until the evening shift comes in, then we can breathe again."*
>
> *[Certified nursing assistant]*

> *"Of course there are activities, and we do have quite days with sufficient staff, but it just happens too often that the staffing levels is not arranged well, or cannot be arranged, which makes that you can't do many things with elderly, things we were able to do in the past."*
>
> *[Certified nursing assistant]*

The inclusion of multiple disciplines is typical for the Dutch long-term care and is considered valuable by the professional caregivers. For instance by having hosts and/or nutrition assistants during the meals and evenings to support the professional caregivers. Working with multiple disciplines is not only mentioned valuable for stimulating more physical activity, but also for daily decision making with regard to the care provided. For instance by consulting a psychologist if a residents shows challenging behaviour.

> *"So eh… we often consult the psychologist, you know. So first we observe and then we report on the matter. And then we gather our team together and she (the psychologist) gives us advise. Sometimes really small things can agitate a patient. So we try and we*

> *try. But sometimes the doctor has to take action, sometimes after all this trying we just don't know."*
>
> *[Nurse]*

Or for determining whether physical restraints need to be used in the daily care of a resident.

> *"Somethings… somethings are also physical restraints. So you are not allowed to put the bed railings up.. those types of things. We really have to ask the doctor about this.. they make the decision and after that we can perform certain restrictions. "*
>
> *[Certified nursing assistant]*

Some participants state that due to their lower staffing levels they are not able at all to stimulate physical activity or organize activities for the residents on the wards and need support from either activity counsellors, volunteers, physiotherapists or family members.

> *"So we tell them; If you want more, you have to come here and do it yourself. You have to take him out, walking, every day. We can't do that.. we don't have the staff available to do that."*
>
> *[Nurse in training]*

The benefits of going outside for residents' well-being is mentioned by the majority of the participants.

> *"Oh, I would love to go outside. When the weather is nice, going outside would be wonderful. They would love it, they really enjoy it."*
>
> *[Certified nursing assistant]*

Furthermore, multiple aspects with regard to the inner physical environment of long-term care wards for people with dementia are mentioned by the participants. Such as having a separate space where larger group activities can be organized. Furthermore, sufficient walking space, making sure no physical barriers on the wards are visible for residents, providing seating areas and interactive corners which draws the attention of the residents are considered important to reduce challenging behaviour.

> *"In their experience, that happens a lot. When people have the feeling they can go somewhere, that they're not being restricted… then the agitation is gone."*
>
> *[Certified nursing assistant]*

Lastly, some participants mention that a ward that gives residents the opportunity to go outside independently and walk unobstructed has a positive influence on challenging behaviour.

> *"That's our advantage. That our halls are pretty wide, and our building is a bit bigger. So people can walk more rounds outside. There are certain people that walk a marathon every day. So we oblige by that. You could eh…. Eh.. the only movement they get is in our department and they can move freely there. If they want to go outside, someone should join them. So family or caretakers, sometimes they take them outside. So.. a lot of movement?... No."*
>
> *[Certified nursing assistant]*

Perceived responsibilities and tasks of professional caregivers

Some participants state that organizing activities and stimulating physical activity is not their responsibility or duty.

> *"For example going outside in a group. Now they only get to be inside. In the past they got to do that more often. Or there used to be more exercise inside. With activities. That is happening less than before. That's a shame. But we can't do anything about it."*
>
> *[Certified nursing assistant]*

Similar statements are made with regard to the use of physical restraints. Participants seem to transfer the full responsibility for the use of physical restraints towards the geriatric specialists and legal authorities and claim that physical restraints provide safety for residents.

> *"We don't do that. The doctor does it. The doctor makes the decision to limit their freedom. Because the restrictions of their freedom are for their own safety."*
>
> *[Nurse in training]*

On the contrary, the participants are aware of the laws and regulations on the use of physical restraints and mention that that is partially the reason they favour physical activity over safety.

> *"If someone keeps walking we can't stop them. You can't tie people up, so what are we supposed to do? So we tend to put freedom over safety."*
>
> *[Certified nursing assistant]*

Lastly, the collaboration between professional caregivers and being flexible with the daily time schedule is also mentioned to be important in order to have sufficient time for daily care and to stimulate physical activity.

> *"Yes, with some co-workers I work differently than with others. You just know; this is how we do things. So you could work with someone who really takes their time with the patients, and I would be the one who would like to do things quickly. That might clash. I usually think to myself; I can't fight time. So when I start at 7 AM and I work until 4 PM*

4

and I have to help someone to get out of bed at 2:30 PM.. so be it. 4 PM is my time to go. But if you keep your calm and prioritize you get it done. So this is how I work; I have a unit where I have to wash someone in bed and I have to feed people, I usually start doing that so that everyone has eaten. So that's one thing I will never forget, that everyone has eaten and is drinking enough. After that I do the rest, that one person on the bed could be taken out of the bed a bit later. That's the way I see things. I can't create more time than I have."

[Certified nursing assistant]

"If you try to hold on to being done by 10AM and start your break then you will fail. No.. you don't have to finish by 10. You are not a robot. Our residents aren't robots. Yes, than you will forget things, skip things or take on other tasks real easy."

[Certified nursing assistant]

Change is challenging

Participants mention multiple aspects that might influence the absence of intention to stimulate more physical activity. For instance, they acknowledge that their own general well-being might influence their decision-making when providing daily care.

"So in a certain moment… when…. When it's really busy… and eh.. people lack sleep.. then the staff can get a little grumpy and then we choose… eh… we usually choose safety over freedom."

[Nurse in training]

Furthermore, the general attitudes of professional caregivers towards change in general and stimulating physical activity is mentioned to have a large influence on the degree of physical activity of the residents on the wards. Participants mention that physical activity in general is an aspect of daily care that is not a priority for professional caregivers and therefore makes it very difficult to incorporate sufficiently.

"Eh.. the… well now I'm going to be very mean. I only work here for a year and the staff is somewhat hospitalized; they are stubborn and stale, they have their own system and they are not going to change it."

[Nurse in training]

"So when it's about a subject that we all think is important, we usually agree very quickly. But when we talk about smaller adjustments or even tasks that nobody wants to do.. Actually movement is a subject that seems to be neglected a lot of the time.. Those…. The.. Moving, getting people to move is something we neglect. We have to…. It will take a lot of energy."

[Nurse in training]

Facilitating and hindering factors to initiate more physical activity in long-term care facilities

As the seven themes describe, professional caregivers view that physical activity is beneficial for the general health and well-being of residents and their individual abilities. This view is an important fundament to implement more physical activity within the physical environment of long-term care facilities. However, improving the degree of physical activity is complex and influenced by various facilitating and hindering factors. Mostly, the inclination to provide safety for residents is of considerable influence, recurrently resulting in the use of physical restraints or discouraging residents to walk. Though, the way daily care is organized is not beneficial for initiating more physical activity. Professional caregivers tend to put the interests of the group over that of the individual residents and do not always feel that it is their responsibility to facilitate physical activity. Lastly, the experienced challenge to realize change within daily long-term care is also an imperative obstruction and influences the overall balance between physical activity and safety (see Figure 1).

Discussion

This study aimed to gain more insight into the viewpoints and intentions of professional caregivers on balancing physical activity and safety of people with dementia living in long-term care facilities, from a group perspective. Professional caregivers mention safety and physical activity as important elements in the care for people with dementia. Balancing both is difficult and poses ethical dilemmas. Multiple aspects influence the intentions and behaviour of professional caregivers and play a vital role in the decision making process as it generally tends to shift towards safety over physical activity. A finding supported by earlier research from Robinson et al.(2007). (35)

Many benefits of physical activity for people with dementia are mentioned by professional caregivers within our study. These are focused on maintaining and/or improving general well-being and independency and autonomy. In addition, the benefits for the professional caregivers themselves are mentioned when providing daily care, mainly preserving sufficient mobility and preventing stiffness. Our findings are similar to those of other studies which found that most professional caregivers are well aware of the benefits of physical activity for all people involved in daily care. (18) Especially sustaining independency and the 'use it or lose it' principle are widely supported. (14)

Our study confirmed that the individual health and abilities of people with dementia in long-term care influence the degree of physical activity within daily care. Some residents lack the mobility to be physically active or lost their intention to move or undertake activities. Apart from physical health, mental health is mentioned to be important, in particular the occurrence of challenging behaviour, which is in general difficult to manage for professional caregivers. (36)

4

Professional caregivers also expressed concerns regarding a phenomenon regularly seen in people with dementia: compulsive walking. Research shows that this behaviour is associated with several negative outcomes. (37) Compulsive walking and other forms of challenging behaviour might influence the way professional caregivers behave and react towards a resident. (37) Therefore, the relation between the resident and the professional caregiver and a personalised approach are essential to gain insight into the reasons for compulsive walking and provide tailored support and care. (38) Our study underlines this point from the perspective of the professional caregivers in dementia care.

The organization of care is mentioned to be important by the professional caregivers. Despite their awareness of the benefits of physical activity for residents and themselves, low staff levels and time restraints influence the incorporation of physical activity in daily care. When experiencing time restraints, professional caregivers mention using shortcuts in daily care in order to make up for lost time. These findings are supported by earlier research. (14) However, even though professional caregivers are aware of the benefits and use shortcuts only when time restraints are experienced, the overall degree of physical activity is still low in long-term care (5-9), which implies that other mechanisms also have an influence.

One of these mechanisms is, according to the findings within this study, the high priority on group interests instead of those of individuals. There is a general believe that it is unacceptable to conduct individual activities with one resident if it results into leaving other colleagues behind to provide daily care for the remaining group of residents. Moreover, another aspect that is mentioned by the professional caregivers within our study is that they do not consider physical activity as their primary responsibility. The existing norm within a group is difficult to break through and requires adequate skills and courage from the particular person or group who addresses them. Care providers in the focus groups mentioned these difficulties. This view is supported by the existing literature, which states that power dynamics are very important when changing social norms. A successful change depends on the view of influential people within the group and the position of the person who wants to realize change within the social hierarchy. (39) It is therefore essential to include key professional caregivers when trying to achieve change within the working culture of a department and to be aware of group dynamics when trying to improve physical activity.

Care teams in long-term (dementia) care are educationally diverse and therefore differ from other health care settings. The potential influence of educational background on safety and physical activity was not mentioned by the participants in this study. Although it is regularly argued that the advanced knowledge and skills of registered nurses (RN) are more beneficial for the overall quality of care, a systematic review of Clemens et al. (2021) states that the results on this topic remain mixed. (21) For instance, no differences are found between CNAs and RNs regarding the use of physical restraints which is strongly

linked to physical activity and communication with residents. (21) An important finding of this study is the prioritization of group interests, which may suggest that the group dynamic within care teams is more important than the education or competencies of individual professional caregivers. However, as the job activities of the CNAs are largely care-oriented, they have the largest amount of interaction with residents compared to other professional caregivers and are probably important stakeholders when enhancing physical activity in long-term care. (28, 40) It would be interesting for future studies to further explore this topic.

To the best of our knowledge this is one of the very few studies to provide more insight into the difficulty of balancing between physical activity for individual residents and safety in relation to group interests and group dynamics from the point of view of professional caregivers working in long-term dementia care. Yet, this study also has some weaknesses; as the focus groups were conducted around the change of shift, some time restraints were experienced. Though, the researchers managed to discuss the topics sufficiently. Furthermore, the recruitment of the participants was based on convenience and depended on availability during the specific day. This may have introduced a selection bias. However, all focus groups included sufficient participants with varying backgrounds and years of experience, and the constitution reflected the mix of caregivers in daily practice.

4

Due to the broad scope of the research topic, it is important for future studies -when building upon these findings- to use different and more extensive research methods. A more holistic understanding of the complex aspects of care addressed in this study, can be obtained by studies with a participatory or ethnographic design. In addition, studies that include more inclusive and objective components will provide the opportunity to approach this topic from a different angle. It will be valuable to connect the current findings on group dynamics and future studies to the existing body of research on physical activity within long-term residential care.

Conclusions

Most professional caregivers consider physical activity important for people with dementia living in long-term care facilities. However, due to multiple influencing factors, the balance in long-term care generally tends towards safety over physical activity. Furthermore, in order to stimulate physical activity various limitations are experienced, including the organization of care, the general health of the residents and difficulty to achieve change in daily care. Most importantly, the group interests of both the professional caregivers and the residents have a substantial influence on the incorporation of physical activity in daily care.

References

1. Brett L, Traynor V, Stapley P. Effects of Physical Exercise on Health and Well-Being of Individuals Living With a Dementia in Nursing Homes: A Systematic Review. Journal of the American Medical Directors Association. 2016;17(2):104-16.

2. Henskens M, Nauta IM, van Eekeren MCA, Scherder EJA. Effects of Physical Activity in Nursing Home Residents with Dementia: A Randomized Controlled Trial. Dement Geriatr Cogn Disord. 2018;46(1-2):60-80.

3. Groot C, Hooghiemstra AM, Raijmakers PG, van Berckel BN, Scheltens P, Scherder EJ, et al. The effect of physical activity on cognitive function in patients with dementia: A meta-analysis of randomized control trials. Ageing Res Rev. 2016;25:13-23.

4. Blankevoort CG, van Heuvelen MJ, Boersma F, Luning H, de Jong J, Scherder EJ. Review of effects of physical activity on strength, balance, mobility and ADL performance in elderly subjects with dementia. Dement Geriatr Cogn Disord. 2010;30(5):392-402.

5. den Ouden M, Bleijlevens MH, Meijers JM, Zwakhalen SM, Braun SM, Tan FE, et al. Daily (In)Activities of Nursing Home Residents in Their Wards: An Observation Study. Journal of the American Medical Directors Association. 2015;16(11):963-8.

6. van Alphen HJ, Volkers KM, Blankevoort CG, Scherder EJ, Hortobagyi T, van Heuvelen MJ. Older Adults with Dementia Are Sedentary for Most of the Day. PLoS One. 2016;11(3):e0152457.

7. Parry S, Chow M, Batchelor F, Fary RE. Physical activity and sedentary behaviour in a residential aged care facility. Australas J Ageing. 2019;38(1):E12-e8.

8. Marmeleira J, Ferreira S, Raimundo A. Physical activity and physical fitness of nursing home residents with cognitive impairment: A pilot study. Experimental gerontology. 2017;100:63-9.

9. Moyle W, Jones C, Murfield J, Draper B, Beattie E, Shum D, et al. Levels of physical activity and sleep patterns among older people with dementia living in long-term care facilities: A 24-h snapshot. Maturitas. 2017;102:62-8.

10. Douma JG, Volkers KM, Engels G, Sonneveld MH, Goossens RHM, Scherder EJA. Setting-related influences on physical inactivity of older adults in residential care settings: a review. BMC Geriatr. 2017;17(1):97.

11. van Alphen HJ, Hortobagyi T, van Heuvelen MJ. Barriers, motivators, and facilitators of physical activity in dementia patients: A systematic review. Arch Gerontol Geriatr. 2016;66:109-18.

12. Galik EM, Resnick B, Pretzer-Aboff I. 'Knowing what makes them tick': motivating cognitively impaired older adults to participate in restorative care. Int J Nurs Pract. 2009;15(1):48-55.

13. den Ouden M, Kuk NO, Zwakhalen SMG, Bleijlevens MHC, Meijers JMM, Hamers JPH. The role of nursing staff in the activities of daily living of nursing home residents. Geriatr Nurs. 2017;38(3):225-30.

14. Benjamin K, Edwards N, Guitard P, Murray MA, Caswell W, Perrier MJ. Factors that influence physical activity in long-term care: perspectives of residents, staff, and significant others. Canadian journal on aging = La revue canadienne du vieillissement. 2011;30(2):247-58.

15. Resnick B, Simpson M, Galik E, Bercovitz A, Gruber-Baldini AL, Zimmerman S, et al. Making a difference: nursing assistants' perspectives of restorative care nursing. Rehabil Nurs. 2006;31(2):78-86.

16. Ries J. Rehabilitation for Individuals with Dementia: Facilitating Success. Current Geriatrics Reports. 2018;7:59-70.

17. Resnick B, Petzer-Aboff I, Galik E, Russ K, Cayo J, Simpson M, et al. Barriers and benefits to implementing a restorative care intervention in nursing homes. Journal of the American Medical Directors Association. 2008;9(2):102-8.

18. Brett L, Traynor V, Stapley P, Meedya S. Exercise and Dementia in Nursing Homes: Views of Staff and Family Carers. Journal of aging and physical activity. 2018;26(1):89-96.

19. van Beek AP, Gerritsen DL. The relationship between organizational culture of nursing staff and quality of care for residents with dementia: questionnaire surveys and systematic observations in nursing homes. Int J Nurs Stud. 2010;47(10):1274-82.

20. Scott-Cawiezell J, Schenkman M, Moore L, Vojir C, Connoly RP, Pratt M, et al. Exploring nursing home staff's perceptions of communication and leadership to facilitate quality improvement. Journal of nursing care quality. 2004;19(3):242-52.

21. Clemens S, Wodchis W, McGilton K, McGrail K, McMahon M. The relationship between quality and staffing in long-term care: A systematic review of the literature 2008-2020. Int J Nurs Stud. 2021;122:104036.

22. Ribbe MW. Care for the elderly: the role of the nursing home in the Dutch health care system. Int Psychogeriatr. 1993;5(2):213-22.

23. Koopmans L, Damen N, Wagner C. Does diverse staff and skill mix of teams impact quality of care in long-term elderly health care? An exploratory case study. BMC Health Serv Res. 2018;18(1):988.

24. Hingstman T, Langelaan M, Wagner C. De dagelijkse bezetting en kwaliteit van zorg in instellingen voor langdurige zorg. Utrecht: Nivel 2012.

25. van Beek AP. Social network of nursing staff and organizational performance: a study in long-term care facilities Utrecht, the Netherlands: Nivel 2013.

26. de Boer B, Beerens HC, Katterbach MA, Viduka M, Willemse BM, Verbeek H. The Physical Environment of Nursing Homes for People with Dementia: Traditional Nursing Homes, Small-Scale Living Facilities, and Green Care Farms. Healthcare (Basel, Switzerland). 2018;6(4).

27. Rantz MJ, Hicks L, Grando V, Petroski GF, Madsen RW, Mehr DR, et al. Nursing home quality, cost, staffing, and staff mix. Gerontologist. 2004;44(1):24-38.

28. Gray M, Shadden B, Henry J, Di Brezzo R, Ferguson A, Fort I. Meaning making in long-term care: what do certified nursing assistants think? Nurs Inq. 2016;23(3):244-52.

29. Aloisio LD, Coughlin M, Squires JE. Individual and organizational factors of nurses' job satisfaction in long-term care: A systematic review. Int J Nurs Stud. 2021;123:104073.

30. Squires JE, Hoben M, Linklater S, Carleton HL, Graham N, Estabrooks CA. Job Satisfaction among Care Aides in Residential Long-Term Care: A Systematic Review of Contributing Factors, Both Individual and Organizational. Nursing Research and Practice. 2015;2015.

31. Kuo HT, Yin TJ, Li IC. Relationship between organizational empowerment and job satisfaction perceived by nursing assistants at long-term care facilities. J Clin Nurs. 2008;17(22):3059-66.

32. Barry TT, Longacre M, Carney KO, Patterson S. Team inclusion and empowerment among nursing staff in long-term care. Geriatr Nurs. 2019;40(5):487-93.

33. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care. 2007;19(6):349-57.

34. Boeije H. Analysis in Qualitative Research: SAGE; 2010.

35. Robinson L, Hutchings D, Corner L, Finch T, Hughes J, Brittain K, et al. Balancing rights and risks: Conflicting perspectives in the management of wandering in dementia. Health, Risk & Society. 2007;9(4):389-406.

36. Evripidou M, Charalambous A, Middleton N, Papastavrou E. Nurses' knowledge and attitudes about dementia care: Systematic literature review. Perspect Psychiatr Care. 2019;55(1):48-60.

37. Cipriani G, Lucetti C, Nuti A, Danti S. Wandering and dementia. Psychogeriatrics. 2014;14(2):135-42.

38. Gerritsen D. Ode aan kwetsbaarheid. Nijmegen: Radboud University; 2020.

4

39. Legros S, Cislaghi B. Mapping the Social-Norms Literature: An Overview of Reviews. Perspectives on psychological science : a journal of the Association for Psychological Science. 2020;15(1):62-80.

40. Li X, Dorstyn D, Mpofu E, O`Neill L, Li Q, Zhang C, et al. Nursing assistants and resident satisfaction in long-term care: A systematic review. Geriatric Nursing. 2021;42(6):1323-31.

41. Evans EA, Perkins E, Clarke P, Haines A, Baldwin A, Whittington R. Care home manager attitudes to balancing risk and autonomy for residents with dementia. Aging Ment Health. 2018;22(2):261-9.

42. Fitzgerald TG, Hadjistavropoulos T, MacNab YC. Caregiver fear of falling and functional ability among seniors residing in long-term care facilities. Gerontology. 2009;55(4):460-7.

43. Koren MJ. Person-centered care for nursing home residents: the culture-change movement. Health affairs (Project Hope). 2010;29(2):312-7.

44. Low LF, Fletcher J, Goodenough B, Jeon YH, Etherton-Beer C, MacAndrew M, et al. A Systematic Review of Interventions to Change Staff Care Practices in Order to Improve Resident Outcomes in Nursing Homes. PLoS One. 2015;10(11):e0140711.

45. Mitchell G, Agnelli J. Person-centred care for people with dementia: Kitwood reconsidered. Nursing standard (Royal College of Nursing (Great Britain) : 1987). 2015;30(7):46-50.

46. Davison TE, Camões-Costa V, Clark A. Adjusting to life in a residential aged care facility: Perspectives of people with dementia, family members and facility care staff. J Clin Nurs. 2019;28(21-22):3901-13.

47. McGreevy J. Implementing culture change in long-term dementia care settings. Nursing standard (Royal College of Nursing (Great Britain) : 1987). 2016;30(19):44-50.

Appendix 1: Questions included in interview guide

When talking about physical activity on the wards. What comes to mind?

What do you consider as physical activity?
How is this implemented on the ward?

What is your opinion on physical activity for people with dementia living in nursing homes?

What do you consider as most important for residents?
Is it feasible to achieve this?
What challenges do you face?
Do you have suggestions and/or solutions to overcome these challenges?

How would the ideal situation look like when it comes to physical activity of residents on the wards?

What is needed to achieve this?
Who should be involved?
Do you see a role for professional caregivers?

When talking about safety on the wards. What comes to mind?

Do you consider the ward as safe?

Do you ever face difficult decisions regarding the safety of residents?

Could you give an example?

What considerations are taken into account during the decision-making regarding the safety of residents?

Whom are involved in these decisions?

What is your general view on safety and freedom?

Could you come up with an example of a situation wherein you faced an (ethical) dilemma?
What do you consider as most important?
How do you handle (potential) dilemmas?

What would be the ideal situation for you regarding safety and freedom of residents?

Do you see a connection between safety, freedom and physical activity?

If so, how?
Could you give an example?
How do you handle these situations?

Interview guide based on scientific literature (10-14, 16, 18, 35, 36, 41-47) and expert opinion.

4

5

Social networks of neighbourhood inhabitants, residents of a care facility, and nursing staff: a case study in two long-term care facilities in the Netherlands

Adriana Petronella Anna van Beek, Suzanne Portegijs, Peter Groenewegen, Martine Wilhelmina Johanna Huygens and Beate Volker.

Abstract

The pressure on long-term care (LTC) facilities, because of population ageing and personnel shortages, may be relieved by using the social network resources that are already available to the facility. The aim of this study is to give insight in existing social networks and relationships between residents and their family members, care staff and persons in the local communities of nursing homes.

In this paper we describe these social networks and the relationships of which they consist in two LTC facilities in the Netherlands, thereby illustrating the social capital of both facilities.

The results show there are multiple direct and indirect relationships between nursing staff, family members of residents and inhabitants of the neighbourhood. Although it may be difficult for residents with dementia to maintain their social networks as part of their illness, there are numerous ties that attest to the social roles of persons with dementia in the community. These ties can be used to provide person-centred care, but are also an important resource in finding and retaining personnel and volunteers.

Key words: Long-term care, social networks, community resources, dementia

Introduction

In the Netherlands – as in many other countries – the population is ageing and overall the need for care increases. This puts much pressure on long-term care (LTC) facilities such as nursing homes. We argue that this pressure can be reduced by using the social resources embedded in the networks of LTC facilities. LTC facilities do not exist in a social vacuum but are connected to the local community (Ivanova, Wallenburg, Bal, 2016). Residents of LTC facilities often used to live in the same area where the facility is located, before admission. Staff members, who work in LTC facilities, often have their home and family close to the facility, have direct and indirect informal relationships with neighbourhood inhabitants, or have professional contacts with LTC residents and their informal carers. Importantly, residents of LTC facilities and staff members may also be connected via common network members in the neighbourhood, directly or more indirectly, by knowing each other's friends or family. These contacts are especially important in dementia care. Persons with dementia are, due to their illness, often unable to maintain their social ties. As a result, it is crucial for these patients' wellbeing to maintain social roles and social support from others in the beginning of dementia (Maki et al. 2018), but also when they are admitted to a nursing home (Heggestad et al., 2015). Such direct and indirect social ties between nursing staff and residents with dementia, increase the information nursing staff have about the residents and are thus important for person centred care (Van Beek et al., 2013).

Another important consequence of the network embeddedness of a facility is that quality of care may be enhanced through employment of social resources in relationships. Firstly, LTC facilities, such as nursing homes, need involvement of relatives and volunteers from the local community. Previous research revealed that about 75 percent of the residents of nursing homes receive help from patients' relatives and 40 percent from volunteers (Verbeek-Oudijk & Van Campen, 2017). Relatives often help with domestic and personal care, while volunteers often offer company or emotional support, assist in indoor or outdoor activities, or assist in transport (de Klerk et al., 2015).

Secondly, facilities may be better able to attract and retain staff if they are integrated in the local community. Many facilities currently face difficulties in attracting enough and adequately skilled personnel (Van Harten, 2016; Veld et al., 2010). In the Netherlands, most employees in LTC facilities are educated at intermediate vocational level. They often search for employment in the area where they are educated and live (Van der Velden et al., 2018). Employees who live near the workplace with many family ties or community commitments tend to stay longer with the organisation (Mitchell et al., 2001; Zainuddin & Noor, 2019).

More general, many studies have shown that the embeddedness of organisations crucially impacts their functioning. For example, Uzzi (1996) demonstrated the

5

importance of embeddedness of organisations for their performance, while others (e.g., Lee et al 2004) showed that embeddedness also impacts organisational citizenship, absenteeism, and voluntary turnover (see Flap, Bulder and Völker, 1998 for an overview). While there is much research on networks in and around organisations, research on social networks in and around institutions such as an LTC facilities is rare. LTC facilities differ from other organisations because of the frailty of the patients and an educationally diverse staff (Scott-Cawiezell et al., 2004); an important characteristic of care in nursing and residential homes is that the 'demarcation between healthcare (medical component) and social care (non-medical component) is often blurred' (European Commission, 2008, see Buljac-Samardzic et al., 2016).

The aim of this paper is to describe the social networks between the local communities of two LTC facilities and residents and nursing staff of these LTC facilities. The focus of our study is on the dementia ward in each of the two LTC facilities.

Our overall research question is:
What are the network connections between staff members and residents with dementia of LTC facilities with inhabitants of the local neighbourhood at the place where the facility is located?

We will start with describing the networks connecting nursing staff and residents with dementia, either with residents with dementia directly or indirectly through family members or other persons in the community. These types of ties are important because it has been shown that they improve quality of care. In units where nursing staff reported ties with relatives and acquaintances of residents, nursing staff treated residents more often with respect and approached residents in a friendly manner both by being at ease and by starting friendly conservations with residents (Van Beek et al, 2013). We will explore these connections in three steps. First by describing the connections between the facility's staff members with the neighbourhood inhabitants. Next, we explore the connections of the facility residents with dementia with the neighbourhood. Finally, we will look at the opportunities that LTC facilities provide to neighbourhood inhabitants to meet residents and staff through the provision of services at the premises.

The answer to our general question constitutes the basis for a further development of hypotheses about the resources in social networks of LTC facilities, about the effects of the social embeddedness of LTC facilities, as well as about the way social embeddedness may be stimulated.

Materials and Methods

Data collection

Data were collected in May and September 2018 in two LTC facilities that provide dementia care in two small, rural villages in the south of the Netherlands. Data collection made use of standardized survey questions and entailed gathering information from neighbourhood inhabitants, nursing staff, and family members of residents with dementia. The questionnaires were developed for this study in collaboration with the facilities.

Questionnaire for nursing staff: The questionnaire for nursing staff was based on earlier studies on social networks of nursing staff in nursing homes (Van Beek et al., 2013) Nursing staff members were asked if they were born in the village and if they currently lived in the village. In addition, we asked whether residents of the neighbourhood talked to them about the LTC-facility and about their conversations with family members of residents with dementia. In addition, we asked about existing ties between nursing staff and residents with dementia through relatives and acquaintances of patients with dementia in the community.

Questionnaire for the neighbourhood inhabitants: This questionnaire was developed in cooperation with the two LTC facilities. It asked how often neighbourhood inhabitants visited the LTC facility, the aim of their visits, if they knew persons living in the facility, in what relation and how often they visited these persons. Regarding staff, we asked if neighbourhood residents knew staff members, the type of relationship and if they worked as a volunteer in the facility. In addition, to gain insight in the connectedness to the neighbourhood we asked if they were born in the village were the LTC facility was located and how they viewed the neighbourhood they lived in. Demographic questions focused on gender, age, and education-level. In total, 500 questionnaires were distributed together with an information letter in the neighborhoods of the two LTC facilities: 250 for each facility.

Questionnaire for family members of residents with dementia: We asked family members how often they talked to nursing staff when they visited the LTC facility and what they talked about. We also asked if they talked to staff members on other occasions and if they knew staff before the resident with dementia was admitted to the facility. In addition, we asked if family members were born in the village, and if they lived in the village at this moment.

Analysis

In this article we describe the networks between residents, staff, and inhabitants of the neighbourhood. We use the answers to open questions to characterise the direct and

5

indirect ties between LTC staff on the one hand and residents and their relatives on the other hand.

Research ethics

All persons participated in the study on a voluntary basis and after they were informed about the study. There was no obligation to fill out the questionnaires and respondents could stop at any moment without any consequences. Respondents could send the completed questionnaire to the research team by freepost. There were no exclusion criteria for participation. Data was analysed anonymously. The study was undertaken in accordance with the declaration of Helsinki, the Code of Conduct for Health Research (code-of-conduct-for-health-research.eu). The overall research project to which this study belongs has been approved by the Medical Ethical Committee of the University Medical Centre Utrecht, the Netherlands (MEC number: 18-127/C).

Results

Participation in the study

The questionnaire for nursing staff was completed by 38 staff members of the two dementia wards in the two facilities. In total, 141 and 119 questionnaires for neighbourhood residents were returned resulting in a response rate of 56% (facility 1) and 48% (facility 2).

The questionnaire for family members was returned by 9 respondents in facility 1 (32%), and 16 respondents in facility 2 (46%).

Descriptive demographics of the responders to the questionnaire among LTC staff (n=38) are in *Appendix table 1*; those of the responders to the neighbourhood resident's questionnaire (n=260) can be found in *Appendix table 2*. The family member questionnaire was filled out by 25 family members; demographic questions were only asked from family members of residents of one of the LTC facilities. Therefore, we have not tabulated the responses.

Network connections between nursing staff and patients with dementia before admission to the LTC facility

Ten out of 36 staff members (28%; 2 missing) said they knew residents with dementia already before their admission. These could be direct or indirect ties. Examples of direct contacts were:

> *"I knew Mr. C., he used to have a shop in the village; I also knew his sons"*
> *"I knew Mrs. W., she is my aunt. She has made many clothes for us on her sewing machine, as well as the first communion dress for my daughter"*

Indirect contacts exist when the staff member and the patient with dementia have a contact in common. Examples of indirect contacts are:

> *"I did not know Mr. Z. personally before admission, but his son in law had been my teacher"*
> *" I did not know Mrs. W., but her daughter works here, she is a close colleague"*
> *"I did not know Mr. C. personally, but I knew his daughter"*

Some of the staff members also named multiple direct or indirect connections:

> *"Mrs. C. is my great aunt. In addition, I knew Mrs. Y., Mrs. O., Mrs. T., and Mrs. S. from residential care [before they developed dementia]"*
> *"One of the residents I knew personally and also the children of this resident. Some residents or family members knew my parents"*
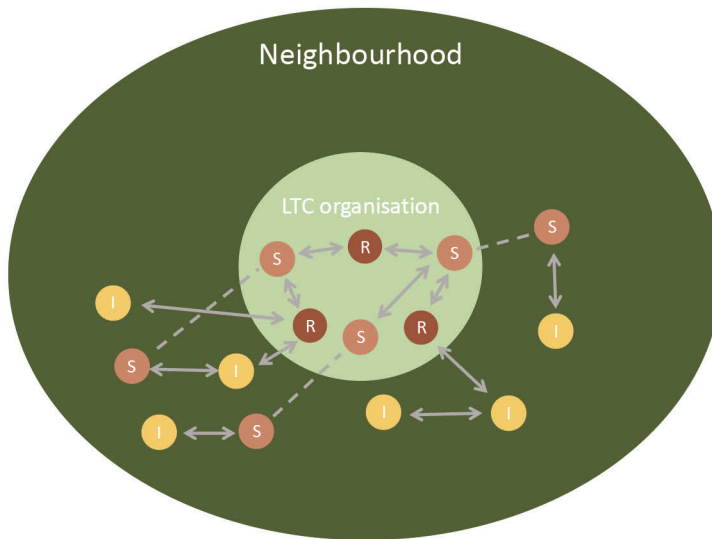
We depict these networks in Figure 1.

Figure 1: Pre-existing networks between residents and staff and indirect networks through family members and acquaintances of residents in the neighbourhood.
Note Figure 1: dotted line indicates same person, i.e. staff members. Solid lines with arrows are relationships within or outside the LTC organisation (R= resident; S= staff; I= neighbourhood inhabitant).

There are not only pre-existing links between nursing staff and residents with dementia, but also between family members of residents with dementia and nursing staff in the LTC facilities. We have asked family members of residents about this. Nearly half of them (48%) have pre-existing relations with staff members. Some examples are:

> *"I [daughter of a resident with dementia of the LTC facility] knew several staff members from the past, being former neighbours or just knowing them from the village"*
> *"One of the staff members lives in the same neighbourhood as me"*

We asked if nursing staff talked to family members and acquaintances of residents with dementia when they visited the ward. Almost all staff members (87%) report that they frequently talk to family members and acquaintances on their visits to the facility. In addition to the health of and care provision to the residents with dementia, staff report that they talk also about the family occasions in the life of family members, such as the birth of a grandchild. Almost 1 in 3 members of nursing staff (29%, 4 missing) also talk to family members outside work.

We asked nursing staff who lived in the village where the LTC-facility was located, if they are approached by neighbourhood inhabitants with positive or negative viewpoints about the facility. In total, 11 out of 37 (30%) of the staff members said they were approached sometimes or often about positive and negative aspects of the facility; for 26 staff members this happened seldom or never.

Networks of nursing staff and the local community

Eleven staff members or nearly one third (30%; 1 missing) were born in the village where the LTC facilities are located. Just over half (51%; 1 missing) is currently living in the village.

Many of the inhabitants of the neighbourhoods were born in or live already for quite some time in the neighbourhoods surrounding the two LTC facilities, on average 33 years in the neighbourhood around LTC 1 and 25 years in the neighbourhood around LTC facility 2 (*Appendix table 2*).

Of the neighbourhood inhabitants, 22% (n=56) know staff members of the dementia wards in the LTC facilities; 36% (n=20) of the persons responded that they talk to these staff members at least once a week. When we look at the total of personnel working in the LTC facilities, the numbers are higher. Of the neighbourhood inhabitants, 53% (n=134) know persons working in the LTC facility. In one fifth of the cases (21%) the staff member is a neighbour; 13% is a family member; 24% a friend or acquaintance; 11% a (former) colleague; and in 33% there was another relation to the staff member. However, the possibility that people live in the same neighbourhood as staff members but do not consider them a direct neighbour should be considered.

Eight percent of the neighbourhood inhabitants in our sample work as a volunteer in the LTC facility. Figure 2 shows this aspect of embeddedness.
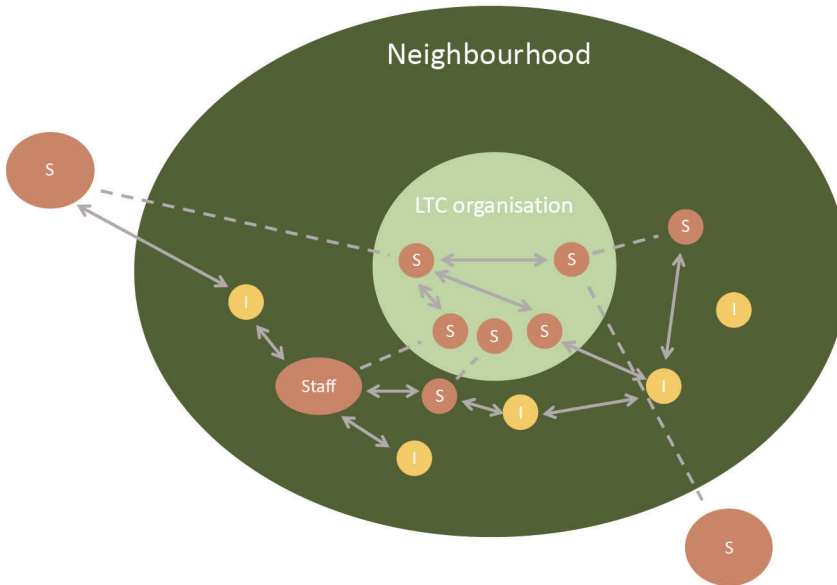

Figure 2: Neighbourhood embeddedness of LTC staff
Note Figure 2: dotted line indicates same staff member. Solid lines with arrows are relationships within or outside the LTC organisation (S= staff; I= neighbourhood inhabitant).

5

Ties between neighbourhood inhabitants and residents of the LTC facility

Two out of five inhabitants (42%) know residents in the LTC facility. Their relationship with residents of the LTC facilities is in almost equal frequency a family member (30%) or friend (27%); in 20% of the cases, it concerns a neighbour; the rest are other relationships (including (former) colleagues). Given the fact that relatives and friends may also live in the neighbourhood, certainly more than 20% of the relations are linked to the common neighbourhood. Figure 3 schematises this aspect of embeddedness.
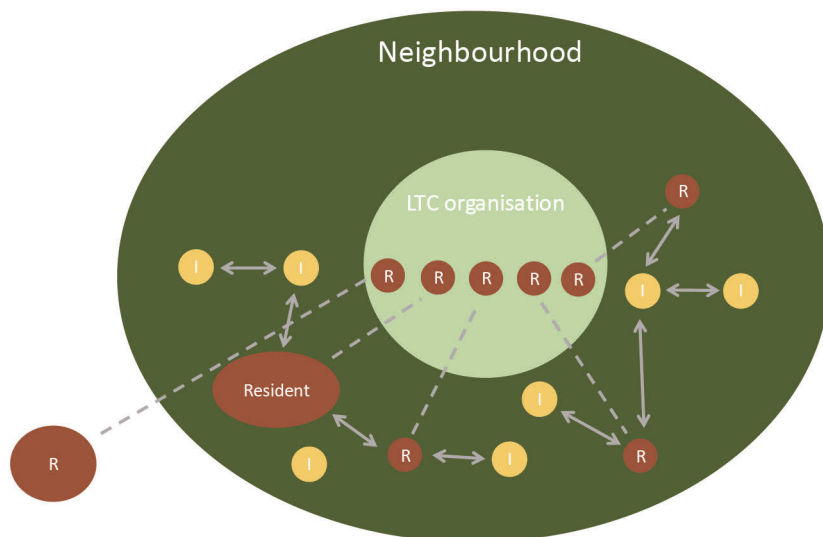
Figure 3: Neighbourhood network of residents. Residents used to live in the neighbourhood of the LTC organisation and may maintain existing ties.
Note Figure 3: dotted line indicates same resident. Solid lines with arrows are relationships within or outside the LTC organisation (R= resident; I= neighbourhood inhabitant).

Opportunities to meet residents and nursing staff via service provision

Close to half of the neighbourhood inhabitants (46%) visited the LTC facility during the past 12 months. One third of those visiting the facility (32%) did so more than once per week. Over one third (38%) visited the LTC facility for a visit to a relative or friend; a quarter (24%) for (voluntary) work. The two facilities differ in how they are located as well as in the services and amenities that are accessible for the people in the neighbourhood. Facility 1 lies adjacent to a park area that is used by local people for recreation, allotment gardens or to walk the dog, and there is a chapel that is rebuilt as a restaurant for residents and persons in the community. The chapel also has meeting rooms that are used by staff for courses and other meetings. The location of Facility 2 lies in the centre of the village and, in addition to providing LTC dementia care, also provides office space for other health care providers, such as a physiotherapist, and evening meals for residents living in the building and persons living nearby. Both locations also serve as polling station for local, regional and national elections. In both cases this contributes to the number of local people visiting the LTC facility. Figure 4 schematises this aspect of embeddedness.
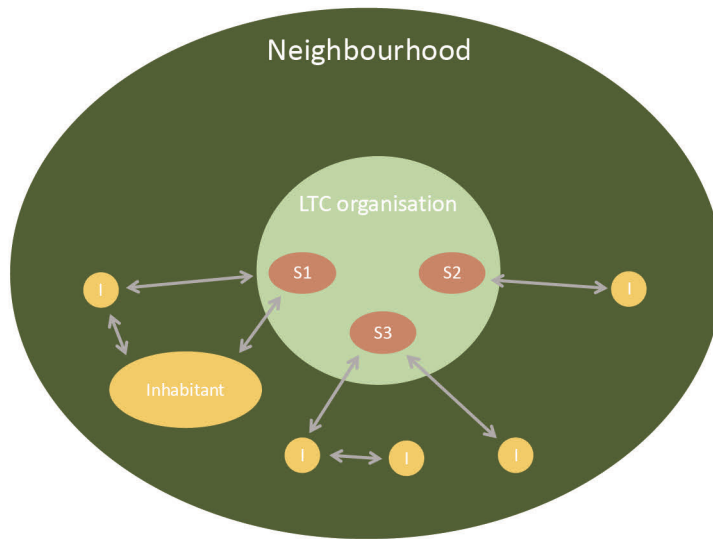
Figure 4: Service provision to neighbourhood inhabitants provides opportunities to meet residents and staff members
Note Figure 4: Service 1,2,3= service provided by the LTC organisation; I= neighbourhood inhabitant).

Conclusions

Our description of the social embeddedness of LTC organisations shows the existence of network connections between nursing staff on the one hand and the residents with dementia they care for and their relatives on the other hand. These connections have often been existing for long, and exceed the duration of time the residents live in the facility. Depending on the perspective, over a quarter (staff members) to nearly half (family members of residents) reported such pre-existing connections. Such connections that cross the boundaries of the LTC facility are related to better quality of care (Van Beek et al., 2013). At the background of these productive networks may be that staff members and neighbourhood inhabitants are members of local networks and are connected through direct and indirect social ties. The examples given by nursing staff give insight in the social roles or social identity of residents with dementia in the community. For instance, as seen in the results, by describing the former jobs of residents or activities that they carried out for the local community. The direct or indirect networks between staff and residents with dementia thus contain *information* that may help staff in caring for residents. This is particularly important for residents in dementia wards who are less able to communicate their wishes and worries. Interestingly, these descriptions may also help in *maintaining social citizenship* of residents with dementia, so that they are seen as individuals worthy to engage with by nursing staff, instead of marginalised members of society (Brannelly, 2011), focusing not on the illness itself but on social inclusion instead (McParland et al, 2017).

5

Staff members and neighbourhood inhabitants know each other and every now and then talk about the LTC facility. Neighbourhood inhabitants visit residents and are perhaps able and motivated to *support* staff. This is a resource that may translate in a high number of volunteers.

The social networks of neighbourhood inhabitants and staff may connect staff to the neighbourhood and through this connection also to their employment at the LTC facility. The fact that these networks also contain residents, and that -as we found in our study- staff and inhabitants talk about work may provide staff with *recognition* for their work.

The social embeddedness of LTC facilities may be enhanced by giving neighbourhood inhabitants reasons to visit the facilities and opportunities to meet. Many neighbourhood inhabitants visit the LTC facilities, partly to visit relatives, friends, and neighbours but also for other reasons, related to services and amenities at the locations. Hence, there are multiple reasons to visit the LTC locations (Völker, Flap, Lindenberg, 2007). This results in familiarity with the facilities, its staff, and the residents. As the wards of the two LTC facilities we focused on in this study, are caring for people with dementia, this familiarity is important. By organizing dementia care in long-term care institutions, such as nursing homes and homes for the elderly over the past decades, people with dementia have largely disappeared from the community. People in the community often don't know how to interact with people with dementia and how to help them. They have become ill at ease in (accidental) meetings with people with dementia. Part of feeling at ease is what Blokland and Nast (2014) have called public familiarity. The fact that people from the neighbouring residential areas see people with dementia, possibly greet them and see them interact with other people, makes people with dementia familiar again, which may lead to more *positive attitudes towards dementia*, which is in turn is a critical factor for 'dementia friendly societies' (see Keady et al., 2012; Mitchell et al, 2003).

Knowledge about the local networks around LTC facilities is also important for other reasons. Unfortunately COVID-19 has shown that connections between nursing staff and residents were also the major source for infections in nursing homes. In their study on social networks using data from smart phones, Chen et al. (2020) showed how nursing staff working in multiple nursing homes were related to the transmission of COVID-19 between homes.

Local networks are also related to the recruitment and retainment of staff, one of the major challenges in many European countries, where different approaches are necessary for nursing homes due to different local situations (Devi et al., 2021).

Numerous contacts and relations of staff in the community are important for *job-embeddedness* (Mitchell et al., 2001). Staff turnover is low in our study, at least measured from how many years they already work at the LTC facility. However, this may be both

a cause and a consequence of embeddedness. In particular in wards with people with dementia, personal continuity in the person of the staff members may be important. There is also a potential for help, resulting in neighbourhood inhabitants acting as volunteers in the LTC facilities.

Based on these findings, we formulate different hypotheses on how performance of LTC facilities may be improved. First, on the level of care provision, our hypothesis is that quality of care is enhanced by social networks through information exchange about residents and support for staff members. Secondly, on the level of the community, we hypothesize that social networks aid in maintaining social citizenship of residents and positive attitudes towards dementia among local inhabitants. As we have seen that LTC facilities are part of the community through numerous ties, we expect that both aspects will influence social inclusion and thus performance of LTC facilities. Finally, we hypothesize that that social networks positively influence job embeddedness, leading to less staff turnover and more participation of volunteers. Future research needs to elaborate and test these hypotheses, preferably in a longitudinal and/or comparative design.

Our description of the social embeddedness of two LTC facilities is particularly relevant in view of recent policy changes, especially the devolution of care and support to municipalities. These policies place more emphasis on living longer independently, with support from family, neighbours, and other persons in the social networks of the older person. Consequently, people with dementia will be living in the community more often in the near future. Many people with dementia, however, will still live in a LTC facility at some stage of their life. It is a societal challenge to provide long-term care for people with dementia in a way that fosters their rights to have a high quality of life, including as much autonomy as possible in an environment that is safe and stimulating.

Strengths and limitations of our study
To our best knowledge, our study is the first to describe the embeddedness of LTC facilities in local social networks. We have approached embeddedness from different perspectives, asking questions to staff members, family members of LTC residents with dementia, and inhabitants of the surrounding neighbourhoods.

Given the new and exploratory character of our study, we compared only two LTC-facilities and the surrounding networks in relatively small communities. The situation in urban areas is different in terms of the stability of the inhabitants of the neighbourhoods, the recruitment of personnel and the place where residents of the facilities used to live. However, also urban LTC facilities have to connect to the surrounding neighbourhoods and are developing policies to do so. For instance, by making visiting the LTC facility more attractive for neighbourhood inhabitants by co-locating other services and amenities.

5

A weakness of our study is that we don't have information on full networks and on the strength of network ties, but only on the ties, reported from different perspectives. We were therefore not able to analyse the structural aspects of the networks, such as density, which may also be important for the performance of organisations (Moran 2005). Yet, although our numbers of participant were relatively small, our results show the usefulness of studying networks from different perspectives at one moment in time using questionnaires. Further studies can use this approach.

In conclusion, LTC facilities are linked to their social environment through social networks. Neighbourhood inhabitants are also family members of residents with dementia and several of the inhabitants work as staff members in the facility and know residents and their family members through community connections. These connections form extensive networks that cross the boundary of the LTC facility and may exist over a long period of time. These networks constitute the social resources of the facility and can be employed to improve quality of care for older people, in particular those with dementia. Some of these relationships can be supported by active policies of the LTC facilities and the local authorities. Expanding LTC facilities to new locations or the decision to re-locate facilities may take into account the network resources that will be destroyed or can be activated at a given or future location.

References

Van Beek APA, Wagner C, Frijters, DHM, Ribbe MW, Groenewegen PP. The ties that bind? Social networks of nursing staff and staff's behavior towards residents with dementia. Social Networks: 2013, 35(3), 347-356.

Blokland T, Nast J. (2014) From public familiarity to comfort zone: The relevance of absent ties for belonging in Berlin's mixed neighbourhoods. Int J Urban and Regional Res 38:1142-59

Branelly T. (2011) Sustaining citizenship: People with dementia and the phenomenon of social death. Nurs Ethics 18: 662DOI: 10.1177/0969733011408049.

Buljac-Samardzic M, Van Wijngaarden JD & Dekker–van Doorn CM. (2016) Safety culture in long-term care: a cross-sectional analysis of the Safety Attitudes Questionnaire in nursing and residential homes in the Netherlands. BMJ quality & safety, 25(6), 424-431.

Chen MK, Chevalier JA & Long EF. (2020) Nursing home staff networks and COVID-19. Economic Sciences 118 (1) e2015455118, https://doi.org/10.1073/pnas.201545511

Devi R, Goodman C, Dalkin S, Bate A, Wright J, Jones L & Spilsbury K. (2021) Attracting, recruiting and retaining nurses and care workers working in care homes: the need for a nuanced understanding informed by evidence and theory. Age and Ageing, 50 (1). pp. 65-67. ISSN 0002-0729

European Commission. Long-term care in the European Union. (2008) Luxembourg: Office for Official Publications of the European Communities.

Flap H, Bulder B, Volker (1998). Intra-organizational networks and performance: A review. Computational & mathematical organization theory, 4(2), 109-147.

Harten J van. (2016) Employable ever after: Examining the antecedents and outcomes of sustainable employability in a hospital context (PhD thesis, Utrecht University).

Heggestad AKT, Nortvedt P, Slettebø Å. (2015) Dignity and care for people with dementia living in nursing homes. Dementia. 14(6):825-841. doi:10.1177/1471301213512840

Ivanova D, Wallenburg I, Bal R. (2016) Care in place: a case study of assembling a carescape. Sociology of Health and Illness 38(8): 1336-1349.

Keady J, Campbell S, Barnes H, Ward R, Li X, Swarbrick C, Burrow S & Elvish R. (2012) Neighbourhoods and dementia in the health and social care context: a realist review of the literature and implications for UK policy. Reviews in Clinical Gerontology; 22:150-163.

Klerk M de, Boer A de, Plaisier I, Schyns P, Kooiker S (2015) Informele hulp: wie doet er wat? Omvang, aard en kenmerken van mantelzorg en vrijwilligerswerk in de zorg en ondersteuning in 2014. Den Haag: SCP.

Kromhout M, Kornalijnslijper N, Klerk M de (2018) Veranderde zorg en ondersteuning voor mensen met een beperking. Landelijke evaluatie van de Hervorming Langdurige Zorg. Den Haag: SCP.

Maki Y, Sakurai T, Okochi J, Yamaguchi H, Toba K. (2018) Rehabilitation to live better with dementia. Geriatr. Gerontol. Int. 18:1529–1536. https://doi.org/10.1111/ggi.13517

McParland P, Kelly F & Innes A. (2017) Dichotomising dementia: is there another way?. Sociol Health Illn, 39: 258-269. https://doi.org/10.1111/1467-9566.12438

Mitchell L, Burton E, Raman S, Blackman T, Jenks M, Williams K. (2003) Making the outside world dementia-friendly: design issues and considerations. Environment and Planning B; 30: 605-632.

Mitchell JI, Long JC, Braithwaite J, Brodaty H. (2016) Social-professional networks in long-term care settings with people with dementia: an approach to better care? A systematic review. JAMDA 17 183.e17e183.e27.

5

Mitchell TR, Holtom BC & Lee, TW. (2001) How to keep your best employees: Developing an effective retention policy. Academy of Management Perspectives, 15(4), 96-108.

Moran P. (2005) Structural vs. relational embeddedness: Social capital and managerial performance. Strategic management journal, 26(12), 1129-1151.

Scott-Cawiezell J, Schenkman M, Moore L, Vojir C, Connolly RP, Pratt M & Palmer L. (2004) Exploring nursing home staff's perceptions of communication and leadership to facilitate quality improvement. Journal of nursing care quality, 19(3), 242-252.

Uzzi B. (1996) The sources and consequences of embeddedness for the economic performance of organizations: The network effect. American sociological review, 674-698.

Veld M, Paauwe J, Boselie P. (2010) HRM and strategic climates in hospitals: does the message come across at the ward level? Human Resource Management Journal, 20 (4), 339-356.

Velden L van der, Versteeg S, Batenburg R. (2018) Ramen voor de toekomst. Onderzoek ter ondersteuning van het strategisch arbeidsmarktbeleid van V&VN. Utrecht: Nivel.

Verbeek-Oudijk D, Campen C van. (2017) Ouderen in verpleeghuizen en verzorgingshuizen. Landelijk overzicht van hun leefsituatie in 2015/'16 Den Haag: Sociaal en Cultureel Planbureau.

Völker B, Flap H, Lindenberg S. (2007) When are neighbourhoods communities? Community in Dutch neighbourhoods. European Sociological Review 23 (1) 2007: 99-114.

Zainuddin B, Noor A. (2019) The Role of Job Embeddedness and Organizational Continuance Commitment on Intention to Stay: Development of Research Framework and Hypotheses. FGIC 2nd Conference on Governance and Integrity 2019, KnE Social Sciences, pages 1017–1035. DOI 10.18502/kss.v3i22.5108

Appendix

Table 1: Characteristics of the staff members of the two LTC organisations

	LTC facility 1(n=18)	LTC facility 2 (n=20)
Age	46.8 (sd= 14.1, range 21-63)	45.6 (sd=13.5, range 20-65)
Sex, percentage female	94.4%	95%
Education		
Intermediate vocational training	77.8%	80%
Bachelor	5.6%	10%
Other	17%	10%
Years working in this facility	10.6 (sd=10.7, range:0-41; missing 1)	8.8 (sd=10.7, range 0-30; missing 3)
Born in the village	27.8%	31.6% (1 missing)
Currently living in the village	44.4%	57.9% (1 missing)

Table 2: Characteristics of the inhabitants of the neighbourhoods surrounding the two LTC facilities

	LTC facility 1 (n=141)	LTC facility 2 (n=119)
Age	59.9 (sd=15.5, range 25-92; 2 missing)	59.8 (sd= 15.0, range 18-96)
Sex, percentage female	61.9%	71.1%
Education		
Low	31.2%	16.0%
Middle	37.7%	58.9%
High	25.4%	22.3%
Other	5.8%	2.7%
Missing	3	7
Years living in this neighbourhood	33.2 (sd=20.6, range 0-82)	25.2 (sd=16.2, range 0-74, missing 17)

5

6

Implementing a new living concept for persons with dementia in long-term care: evaluation of a quality improvement process

Suzanne Portegijs, Adriana Petronella Anna van Beek, Lilian Huibertina Davida van Tuyl en Cordula Wagner.

Abstract

Background Improving quality of nursing home care for residents is a constant focus of stakeholders involved within quality improvement projects. Though, achieving change in long-term care is challenging. Process evaluations provide insight into the nature, exposure and experiences of stakeholders and influencing mechanisms for implementation. The aim of this study is to gain insight into the process and facilitating and hindering mechanisms of implementing a quality improvement project that seeks to create a dementia-friendly community with a nursing home at its core.

Methods For the process evaluation we planned a case study design with an ethnographic approach. Various research methods were used: qualitative observations, focus groups, interviews and questionnaires for various stakeholders and document review. Data collection and analyses in this study is based on the Consolidated Framework for Implementation Research.

Results Four main lessons were learned. Firstly, nursing staff are crucial to achieve more freedom for residents. Secondly, high-impact changes in daily care need strong and sustainable focus from the care organisation. Thirdly, dementia-friendly societies should be deployed from multiple actors, which entails long-term collaborations with external stakeholders. Fourthly, the transition to a dementia-friendly society requires meeting spaces for and a focus on both residents and people from the community. Consequently, local residents are shifting from external to internal stakeholders, extending beyond the regular involvement of informal carers and volunteers within the nursing home.

Conclusions Nursing homes are part of the local community and provide opportunities to collaborate on a dementia-friendly society. However, the change that is required (promoting freedom, residents' autonomy and the redesign of care processes) is complex and influenced by various mechanisms. Understanding these mechanisms can benefit other care organisations that strive to implement a similar initiative.

Key words: Dementia; Long-term care; Autonomy, Ethnography; Mixed-methods; Quality improvement; Open environment; Process evaluation

Introduction

Improving the quality of nursing home care for residents (with dementia) is a permanent focus of many stakeholders involved, such as persons with dementia and their relatives, nursing staff and policy makers. Therefore, attempts to implement innovative concepts are frequently pursued, and often structured and evaluated using the Plan Do Check Act cycle (PDCA). PDCA is a method that ensures a continuous cycle in quality management. (1) Despite numerous efforts, achieving sustainable quality improvement in long-term care is challenging. This is partially because interventions are not always transferable, as most interventions are effective in some settings but not in others. To design potentially successful quality improvement interventions, it is important to make use of a detailed breakdown of the implementation process of multiple successful and unsuccessful interventions. (2)

There are various mechanisms that influence quality improvement initiatives on micro, meso and macro level. On macro level, changes in healthcare policy on a national and regional level influence the potential success of quality improvement projects, such as available budgets and restrictions in healthcare provision. (3, 4) Mechanisms on meso level include organisational aspects such as funding, logistic and infrastructure difficulties; and flexibility of the organisational culture. Furthermore, a high number of quality improvement projects at the same time is disadvantageous for successful implementation. (5, 6) Micro level mechanisms of influence include characteristics of care staff, e.g. turnoverrate, absenteeism, workload, education level, communication and support, and general attitudes towards change. (5, 6) Also, care needs of residents and attitudes and viewpoints of residents and their family members are important aspects to take into consideration. (5-7)

Large quality improvement projects in long-term care are scarce (8), particularly in creating dementia-friendly communities. It is therefore valuable for both future research and clinical practice to gain insight into the relevant mechanisms in which quality improvement of the healthcare organisation relates to changes in the community of which the organisation is part.

A way to effectively evaluate quality improvement initiatives and the possibilities for implementation in other organisations is conducting a process evaluation. Process evaluations enable researchers and implementers to (1) describe the intervention in detail, (2) check actual exposure to the intervention, and (3) describe the experience of those exposed. (2) A theoretical framework suitable for process evaluations focusing on quality improvement in healthcare is the Consolidated Frame for Implementation Research (CFIR) framework (9), which has been used earlier to describe interventions in long-term care. The framework asks for a reconstruction of a complex reality, in which quality improvement is influenced by organisational and contextual mechanisms. (9)

The added value of the CFIR (9) is its strong emphasis on the organisational level and comparison between the intervention as intended and eventually implemented. (2) Moreover, it provides an immediate insight into the outcome of the intervention and has sufficient focus on the individual level. This makes it a suitable framework to monitor and evaluate the process of quality improvement projects, especially regarding dementia-friendly initiatives. (10)

Ethnography forms -since many years- an important method within healthcare research and focusses on human social action within its specific context. (11) According to Gertner et al. (2021), the use of ethnographic approaches are well accepted within implementation research and are regularly combined with theoretical frameworks in order to gain insight into interactions and context within implementation processes. (12) Also, ethnography focusses on context-specific mechanisms that give the opportunity to gain an in-depth understanding of the underlying change processes. (13) Methods used within ethnography are mixed and take place over a longer period of time, and contribute to reflexive interpretation of change processes in terms of how these shape and construct the organisation in its environment. (13) Making ethnography well suitable for the purpose of gaining an in-depth insight into process evaluations. (12)

Persons with dementia in long-term care facilities have complex care needs that often derive from multiple health problems. Due to their health problems, the majority of persons with dementia living in long-term care facilities reside in closed units and are not allowed to move freely outside the facility (without supervision). (14-18) This impacts their possibilities for social interaction and participation in the community, and limits their physical activity, consequently, leading to a lower quality of life. (19-22) In the Netherlands, as the organisation of care for persons with dementia takes place in closed units in long-term care facilities, they have largely disappeared from society. As a result, people in the community often do not know how to interact with persons with dementia and how to help them if necessary. (23) Due to this, a care organisation within the Netherlands wants to change the way their long-term care is organised by carrying out a large quality improvement project that focusses on improving the participation of persons with dementia within the community. In the next section we will describe this project.

The quality improvement project: Towards a dementia-friendly nursing home that is part of the local community
In this study, we evaluate a quality improvement project in the south of the Netherlands during the period 2018-2021, initiated by a care organisation. The aim of the project was to improve quality of care for persons with dementia by integrating one of their long-term care facilities into the community. The changes of the organisation focused on 1) social cohesion; 2) person-centred care, and 3) increasing quality of life. The project was carried out in a nursing home and focused on improving quality of care and participation

of residents with dementia within the local community. This focus translated into four core elements that were aimed to be altered during the quality improvement project; 1) Construction of the building; 2) Grounds surrounding the building; 3) The use of the Chapel on these grounds; 4) Place in the community. By changing these elements, the care organisation aims to create a new long-term living concept that allows persons with dementia to live in large individual apartments among both persons with and without dementia and by creating an open long-term care environment in which residents can leave and enter the facility independently. Furthermore, the project aims to place persons with dementia 'back in the heart of the community' by stimulating interaction between community members and residents of the care facility. As this is the initial study that follows such a large change initiative towards the creation of a dementia-friendly community with a nursing home at its core, the findings of this study can provide valuable insights into the feasibility of such a project and the relevant influencing themes and mechanisms.

Methods

Aim of the study
The aim of this study is to gain insight into the process and facilitating and hindering mechanisms of implementing a quality improvement project that wants to create a dementia-friendly community with the nursing home at its core. Subsequently, this study reflects on the lessons learned and implications for future initiatives and clinical practice.

Research questions
Through this study, efforts are undertaken to provide answers to the following research questions:
- What interactions and mechanisms influence changes in care processes and quality improvement in nursing homes aimed at dementia-friendly communities?
- What are the perspectives and experiences of the various stakeholders involved regarding the quality improvement project, changes in care processes and implementation process?

Reporting guidelines
To ensure a full description of the methods of this study, the reporting guidelines for ethnographic approaches according to Gertner et al. (2021) were used. (12) Based on the Consolidated criteria for reporting qualitative research (COREQ) (24), but with additional emphasis on certain items within the three domains: research team and reflexivity, study design, and analyses and findings.

Setting at the start of the quality improvement project
Below we will describe the setting of the nursing home at the start of the quality improvement project according to the four core elements: 1) Construction of the building;

2) Grounds surrounding the building; 3) the use of the Chapel on these grounds; 4) Place in the community.

Construction of the building
The nursing home was formerly a residential care setting for older persons and build in the 1970's. Due to the healthcare reform in 2015 (3, 4) it officially became a nursing home. The nursing home is build on the location of a former seminary; this accounts for the large grounds and chapel that accompany the building. Over the years a temporary building for persons with dementia was build on the grounds, providing psychogeriatric nursing home care in a closed setting, *see Additional file 1 for a description.*

Grounds surrounding the building
The grounds surrounding the temporary building were poorly maintained and consisted of dated allotment gardens and a field with horses. The grounds also contained a small cemetery for priests, a small lane consisting of trees that was used for prayer and housed a bee keeper. Additionally, the nursing home had a strong focus on social entrepreneurship and had multiple ties with local businesses and associations, including (among others) the butcher, baker, flowershop, the local youth club, and the allotment gardeners. Many residents of the community conducted voluntary tasks within the nursing home.

The use of the Chapel on these grounds
The grounds also included a Catholic chapel build in the 1930's. The chapel had a rectangular shape, stone floors and two rows of wooden church benches leading up to the altar. The church was still fully operational and used for religious services and funerals. On a local website more information about the history of the chapel is provided. Formerly, the chapel was part of a seminary that was used to educate boys to become missionaries.

Place in the community
The nursing home already had multiple ties with the community, for instance, many residents with dementia lived within the community before admission. Also, nursing staff live in close proximity of the nursing home, either in the community or nearby villages. Several community activities were organised in collaboration with the nursing home.

Research team and reflexivity
The research team consisted of SP, AvB, LvT and CW. Author SP has a background as a physiotherapist and currently works as a quality advisor and researcher within long-term care. AvB has a background in sociology, extensive experience as a researcher within long-term care and ethnographic research, and has a job function in both policy and research. LvT has wide experience within the field of research and has worked on

numerous research projects with both qualitative and quantitative natures. CW is a professior in patient safety.

At the start of the innovation, a collaboration agreement was formed with the care organisation, Alzheimer Netherlands, ActiZ (sector association) and two scientific institutes, including Nivel, the Netherlands Institute for Health Services Research. As a result, researchers SP and AvB had prior encounters with stakeholders within the care organisation before the start of the study. Due to their (practical) experiences within the long-term care setting, both SP and AvB coordinated and conducted the various research methods. Though, to ensure as much objectivity as possible, LvT and CW had hardly any involvement with the collaboration partners and did not take part in the data collection.

Study design
We made the decision for a case study design due to the complex and multidimensional approach in this quality improvement project. Our design is in line with the approach of Stake. (25) Within this study, an ethnographic (open holistic) approach is used combined with the CFIR (9) to structure data collection, thematic identification and outcomes from an extensive set of research methods, *see Table 1.*

CFIR
The Consolidated Framework for Implementation Research (9), distinguishes five domains: 1) The 'Intervention Unadapted' is the intervention as it is originally intended and the 'Intervention Adapted' as eventually realised, both consisting of the core components and an adaptable periphery. 2) The 'Inner Setting' focusses on the structural, political and cultural context within an organisation. 3) The 'Outer Setting' represents the financial, political and social context. 4) The fourth domain 'Individuals Involved' includes the individuals that are both actively and passively involved in the intervention and/or implementation process. 5) The fifth domain 'Process' refers to the active change process that consists of multiple subprocesses. (9)

Ethnographic approach
To address the complexity of the quality improvement intervention central within this study, the implementation process was studied from an ethnographic point of view using thick description. 'Thick description' is an essential part of an ethnographic approach, referring to the description of human social action (11) and is not limited to physical behaviours. It also comprehends the context in which these behaviours take place. (11) Leslie et al. (2014) have adapted the approach of thick description for research into healthcare quality improvement, where it refers to the aim of investigating how contextual and organisational mechanisms contribute to changes in professional behaviour, organisational culture and inter-organisational networks. (13) As this study comprehends a large change initiative that takes place over a long period of time, involves various stakeholders, is setting-specific, and requires a change in organisation

6

of care and culture and involves the network surrounding the nursing home, we chose ethnography as our research method. The research method provides the opportunity to fully grasp the underlying mechanisms and interactions that are essential to achieve the intended change. (12)

Data collection

Data was collected during different points in time over the course of the study, *see timeline in Figure 2*. The methods include observations, focus groups discussions with nursing staff and management, interviews with family members and residents, questionnaires conducted by nursing staff, family members and community members, and document analyses. The various data collection methods are described in more detail below.

Observations

Observations were conducted during separate time periods (May-July 2018, May 2019, and May and October 2021), *see timeline Figure 2*. Various types of observations were conducted, including both ethnographic observations and observations using a predetermined observation list. During observations, the researcher aimed to make themselves as 'invisible as possible' to ensure representivity of the usual course of events. Nursing staff and family members of residents were notified that the researchers would be present and that they follow the implementation process. Though, nursing staff were not informed about the specific aim and focus of the study.

Ethnographic observations

Observations were conducted in May-July 2018, May 2019, and May and October 2021. The observations were conducted within different settings of the nursing home and surrounding grounds including the wards, shared rooms, hall ways, restaurant (the chapel) and the park area. The aim of these observations was to gain a holistic view of the new long-term living concept and the accompanying new organisation of care, the social interactions of nursing staff and residents and their daily (working) life. Likewise, it gave the researchers the opportunity to closely follow the intended changes. Field notes were taken and expanded soon after into extensive and detailed reports. These reports included among others information about the location, atmosphere, individuals present and their interactions and conversations. Findings were discussed regularly within the research team to interpret the findings, provide context and determine whether a follow-up was necessary. During the observations, the researchers also conducted small informal interviews with nursing staff, residents, family members and community members to gain insight into their perspective and experiences regarding the new long-term living concept and physical surroundings.

Predetermined observations lists
The predetermined observation list (32-items) was used during observations on the wards and included items about ambiance, safety of residents, social interaction and physical activity. The observation list was derived from the aspects of quality of care defined by Rantz et al. (1998). (26, 27). Items were scored on a five-point scale. The observations were on three separate moments during the morning, mid-day, and afternoon. All observations were carried out by two researchers simultaneously and discussed directly after. The results of these observations have been published in an earlier study, part of the larger research project. (15)

Focus groups, interviews and questionnaires
Various focus groups and interviews were held with nursing staff, management, family members and residents, s*ee Table 1 for an overview.* All focus groups were recorded and transcribed verbatim.

In addition to the three focus groups with the management team, an online informal conversation took place with the project leader in January 2021 about the shift in job function, the corporate merge, COVID-19, and the organisation of care within the new living concept. A summary of the interview was made directly after by the two involved researchers.

6

Table 1. Overview of focus groups and interviews and specifications

Participant group	Research method	Inclusion/exclusion criteria	Participants	Focus	Important (decisional) information
Nursing staff	**Focus group 1** *September 2019 **Focus group 2** *October 2021 *Both focus groups lasted 90 minutes*	All nursing staff of the nursing home were eligible for inclusion and recruited through the manager of the nursing home.	**Focus group 1** *Certified nursing assistents (n=2) *Age = 33 en 49 years *Working experience in care = 16 and 30 *All female **Focus group 2** *Certified nursing assistants (n=4), care assistants (n=2) and a recreational therapist (n=1) *Age = 49-65 *Working experience in care = 3-34years *All female	**Focus group 1** *Quality improvement project *Perspectives on autonomy and freedom *See Additional File 2 for the interview guide **Part of larger research project, see earlier publication (7)* **Focus group 2** *Quality improvement project from the 'individuals involved'-perspective of the CFIR *Questions derived from earlier collected data *See Additional File 2 for interview guide*	The research team specifically asked for a mix in job function, experience in care and years of employment at the nursing home to ensure an accurate reflection of the entire group of nursing staff was invited.
Nursing staff	**Questionnaires** *June 2018 *May 2021	All nursing staff working at the nursing home were eligible for inclusion	2018 *n=18 2021 *n=14	*Perspective on long-term dementia care and quality improvement project *Social connections with the local community *Attitude towards persons with dementia.	The questionnaires were placed in the office of the nursing staff. It is therefore unknown how many questionnaires were handed out.

Management	**Three focus groups** *October 2019 *March 2021 *November 2021 *All focus groups lasted 2 hours*	Participants were only eligible for inclusion if they had a position in management within the care organisation/ nursing home	4 to 6 participants with either a policy, management or director position	An interview guide was used based on the five domains of the CFIR (9) and information retrieved from other research methods *See Additional File 3*	-
Family members	**Three online and telephone interviews in November 2021** *All interviews lasted 30 minutes*	All family members of nursing home residents with dementia were eligible for inclusion and invited through a letter	*Spouse (n=1) *Child (n=1) *Informal caregiver (n=1) All participants were connected to different residents	*Experiences with and attitudes towards the changes *The implications of the changes for the residents *The implications of the merge for the (intended) changes	The response was too low to organize a focus group. To ensure an informal setting, but at the same time describe the information provided accurately, summaries were made directly after the interviews, including the field notes of the researcher.
Family members	**Questionnaires** *May 2018 *October 2021	" "	2018 *n=9/56 2021 *n=16/50	*Health of their relative *Social connections with nursing staff *Perspective on the quality improvement project ***Regarding social connections: part of larger research project, publication currently under review*	-

6

Table 1. Overview of focus groups and interviews and specifications - *continued*

Participant group	Research method	Inclusion/exclusion criteria	Participants	Focus	Important (decisional) information
Residents	**Six 'Go-along' interviews** *June 2018 (2 interviews) *October 2021 (4 interviews) *Interviews took 45-60 minutes*	*All residents with dementia that lived in the nursing home were eligible for inclusion. *Written consent from family members. *Interview only took place when residents agreed upon invitation	*1 male *5 female	To gain insight into how they experience their environment and whether they see a connection with their own personal life.	*A form of in-depth qualitative research to explore the experiences of persons with their familiar environment. (28) *As persons with dementia often express extensive forms of non-verbal communication, summaries of the interviews were made instead of recordings, including field notes and observations.
Community members	**Questionnaires** *June 2018 *October 2021	Community members that live in close proximity of the nursing home	2018 *141/250 2021 *63/340	*Social connections of community members with residents and staff *Frequency of visits to the nursing home *Perspective on the quality improvement project **Regarding social connections: part of larger research project, publication currently under review*	The questionnaire for the community members was developed in cooperation with the nursing home

Relevant documents
Various documents were received from the care organisation, including minutes of project group meetings, strategic orientations and vision documents. Moreover, several documents were retrieved from other sources, such as the internet and local news papers containing publically available quality reports, videos, vision documents and news items. In the context of privacy, direct reference is not always made within the results section. As an alternative we indicate from which type of source the information is retrieved. Documents on the Dutch Healthcare System were also used.

Quotes used from various data sources
All quotes were translated using freely available translation software and checked by a bilingual speaker.

Analyses
In order to derive the core findings from the research methods used and ensure an iterative process, the research team held regular scientific meetings over the multi-year course of the quality improvement project. Within these meetings, the research methods, thematic identification (using CFIR) and outcomes were discussed and reflected upon. Scientific meetings were increased during data collection weeks. When needed, the approach for data collection and/or research methods were altered, *see Figure 1*. For instance, over the course of the project it became apparent that the information from the focus groups with the management team were largely one-sided and slightly rosier than observed by the researchers. As a result, the emphasis on other research methods, especially the ethnographic observations, became stronger.

6

As described under 'Research team and Reflexivity', to borrow sufficient objectivity, LvT and CW were hardly involved in the data collection and communication with the care organisation. Using an inductive approach, the continuous discussion of and reflection on the identified themes and outcomes by the research team subsequently resulted into the core findings of this study. These core findings, were reported back to the care organisation in May 2022 through a consortium meeting. Multiple persons from the management team that were also involved in the focus groups were present, alongside different other involved parties such as representatives from a collaborating university and national branche organisation. The core findings were discussed and reflected upon by all parties present. As the care organisation acknowledged the core findings and agreed with the results of this study, no alterations were made.
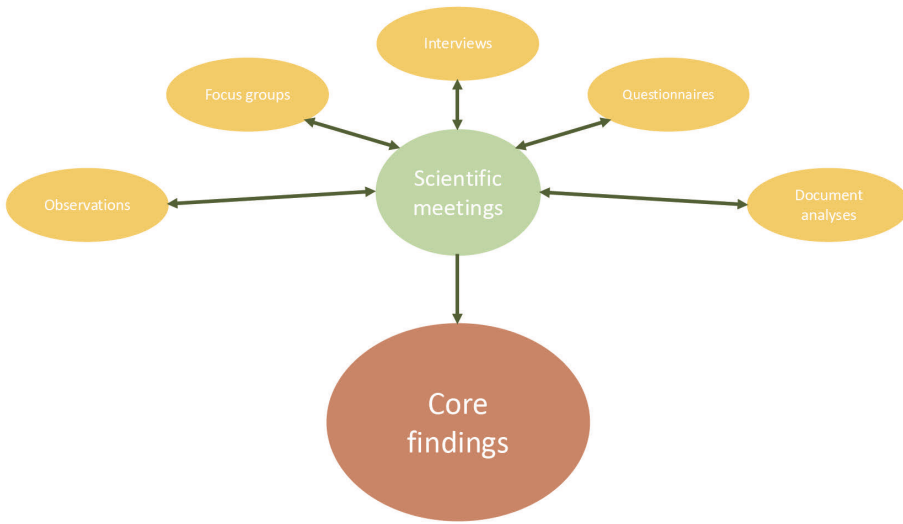
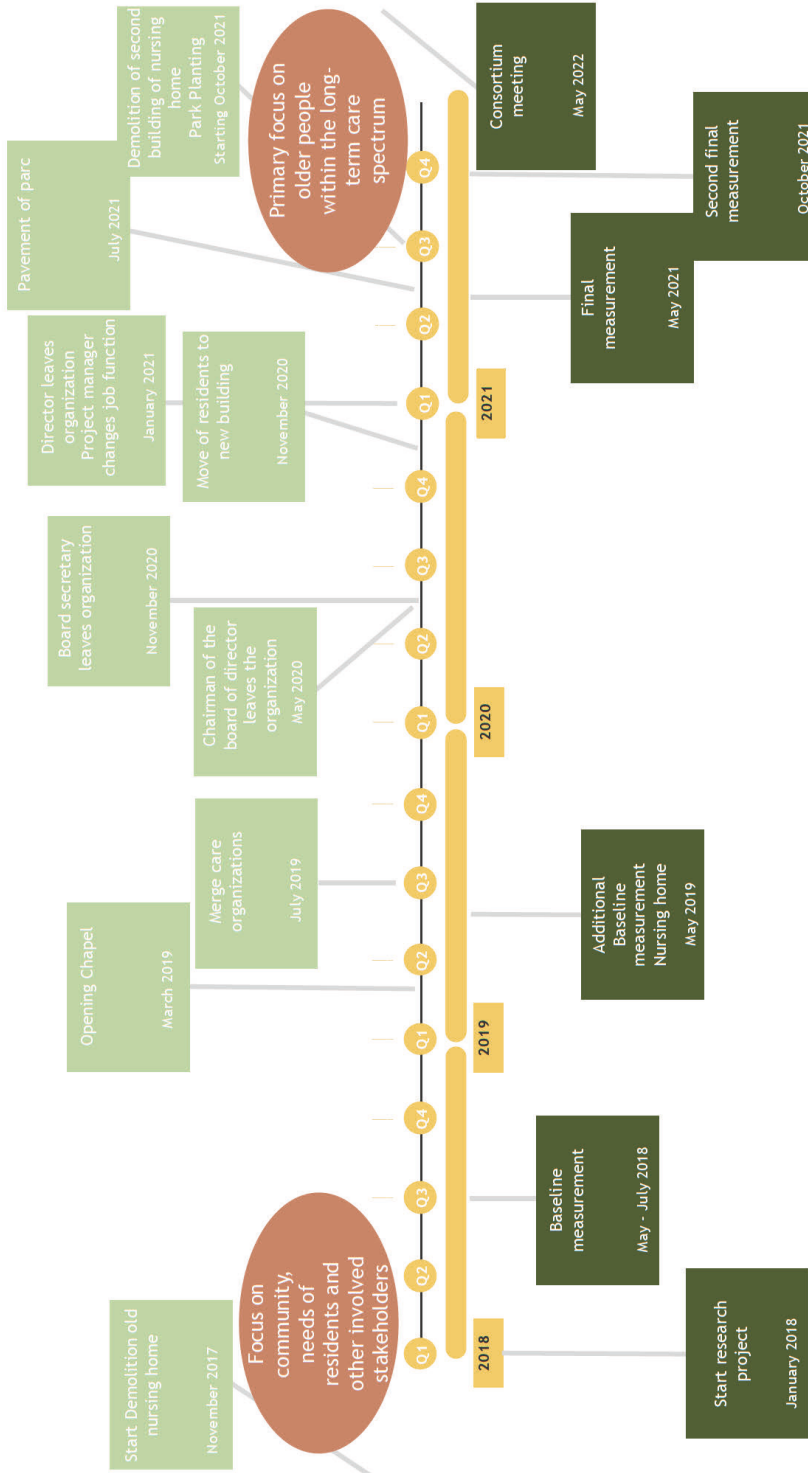Figure 1. Analyses process of ethnographic approach using different research methods

Figure 2. Timeline of the project with the most important milestones for the organisation (light green) and the research team (dark green).

6

Results

The care organisation that is followed within this study aims to implement a new long-term living concept and bring long-term care back in the heart of the community by altering four core elements: 1) Construction of the building; 2) Grounds surrounding the building; and 3) The use of the Chapel on these grounds 4) Place in the community. In the following sections the results will be structured by the five domains of the CFIR. (9) Firstly, the changes as initially planned ('Intervention unadapted') and eventually realised ('Intervention adapted') are presented, *see also Box 1*. We then describe the results divided in process, inner setting, and outer setting.

Intervention Unadapted and Adapted

The initially planned changes (Intervention Unadapted) and the changes eventually realised (Intervention Adapted) are illustrated in detail in *Box 1*. The findings are described according to the four core elements of the quality improvement project.

Box 1. Overview of 'Intervention unadapted' and 'Intervention Adapted'

Core element	Intervention unadapted	Intervention adapted
Construction of the building	As determined prior to the start of the study, the nursing home was going to be structurally reorganised in multiple ways.	The new nursing home, that was part of the rebuild, has been opened in November 2020 and currently provides long-term care for residents with and without dementia. Residents live in large spacious individual apartments with innovative technology. The old building is not yet demolished and the building of the individual apartments for persons -with and without care- on the grounds has not started.
	First, the old building (+/- 25 years old) was to be demolished and rebuild into 150 individual apartments in several buildings. Part of these buildings were going to be realised by the housing corporation. In-house sensors, innovative wearable sensor technology were going to be installed in all buildings as part of usual care to ensure the safety of older persons with dementia.	
	In the new buildings, persons with dementia and persons without dementia will be living together. Older persons from the local community could live in one of the apartments even when no care was required or when they wanted to accompany a spouse with dementia that is admitted to the nursing home.	The open long-term care environment has been realised, meaning that all doors are open for residents and they have the freedom to leave the facility independently and roam around the park and surrounding neighbourhood. Despite the original plan to let persons with and without dementia live next to and amongst each other, these groups are currently clustered on separate floors. This limits the social interaction between residents with different care demands.

Box 1. Overview of 'Intervention unadapted' and 'Intervention Adapted' - *continued*

Core element	Intervention unadapted	Intervention adapted
Construction of the building - *Continued*	Furthermore, an open long-term care environment was to be created that gives all residents the opportunity to leave the building independently and roam freely on the surrounding grounds and neighbourhood. Residents would uphold their own individualised daily schedule, group activities would be optional.	Persons living in the nursing home without dementia have the opportunity to choose their own individual daily schedule. Yet, the persons with dementia spend the majority of their day in shared living rooms that uphold a daily time schedule and structure, mostly focusing on group activities.
Grounds surrounding the building	The facility grounds with an area of 6 hectares, were going to be restructured into a green park to make it attractive for residents and people from the surrounding neighbourhoods. The park area aimed to provide meeting opportunities for residents with dementia and people from the local community through the realisation of broad walking paths, benches, fishing pond, playground for children and a day centre for community members in need of care. Moreover, the existing allotment gardens would be renewed and the bee keeper -already on the grounds- would be preserved. The municipality had decided that some elements should be retained. These included the cemetery for former priests and the old lane of trees, that was used for prayer. The vegetation of the park would be improved by placing many bushes, plants, greenery and large old trees. The park area was to have no external barriers and be freely accessible for all to stimulate interaction between residents from the nursing home and people from the local community.	The surrounding grounds have been turned into a large park-like area with new allotment gardens and green house, a fishing pond, walking lanes and a few benches for visitors to sit. The bee keeper, cemetery and trees on the grounds are preserved in accordance with the plans. However, there is limited additional vegetation and not all areas of the park and walking paths are accessible for persons with physical disabilities. A very small number of residents leave the facility independently and visit the park area. The interaction between nursing home residents and community members in the park is limited.

6

Box 1. Overview of 'Intervention unadapted' and 'Intervention Adapted' - *continued*

Core element	Intervention unadapted	Intervention adapted
The use of the Chapel on these grounds	The chapel was to be rebuild into a restaurant for both residents with dementia and persons from the local community. The restaurant aimed to have a terrace, employ a permanent chef and serve both lunch and dinner. The chapel is to be visible from all corners of the grounds and serve as a central meeting place for both residents and people from the community.	The chapel has been renovated and was turned into a restaurant that opened in March 2019. The chapel serves both lunch and dinner for residents and community members, has an open terrace near the front door of the new nursing home and employs a permanent chef. Residents visit the restaurant often with family members and visitors. Also the care organisation uses the restaurant regularly for smaller and larger meetings with external partners and nursing staff and large events. The care organisation has created multiple ties with local associations that repeatedly use the restaurant for their meetings and rehearsals.
Place in the community	In the initial stage, the care organisation had a strong focus on social ties with the community and social entrepreneurship. As the facility is situated within a small rural village, there is a strong social cohesion within the community resulting in extensive involvement of volunteers and mutual relationships between residents and people in the community. The care organisation wanted to broaden this social network and create a dementia-friendly community with the nursing home at its core, with a focus on well being for both residents and persons in the community.	The original involvement of volunteers and family members has been preserved and multiple collaborations with local entrepreneurs are still in place. Yet, the involvement of the community is not intensified and the aim towards a dementia-friendly society has been realigned.

The comparison between the 'Intervention Adapted and Unadapted' shows that not all aims have been realised. When we look closer into the different events and aspects, we can dissect several reasons for this. We will discuss these results in the following sections, structured by the CFIR-domains 'Process', 'Inner Setting' and 'Outer Setting'. An overview of the main findings per domain is specified in *Table 2.*

Table 2. Overview of main findings per CFIR-domain

CFIR-domain	Main findings
Process	*Working culture of nursing staff *The commitment of participants towards the change that the project aimed to achieve *Changing role of community (members)
Inner Setting	*The corporate merge with another long-term care organisation and its consequences
Outer Setting	*Collaboration with external stakeholders *Influence of the COVID-19 pandemic

Process

When we look at the results from our study three important mechanisms that influenced the quality improvement project emerge: 1) Working culture of nursing staff, 2) commitment of participants towards the change that the project aimed to achieve, and 3) Changing role of community (members).

Management name the working culture of nursing staff as a hindering factor in the project.

> *"Because it is just very difficult, you know. If you start explaining it in theory, theory does not really catch on with the employees on our work floor. Because they are not used to thinking in theoretical concepts. That is not their job at all. That is not what they chose at all. That is not what makes them happy. […] You have to give employees tools and knowledge about dementia, because some really do not have that enough. But you also have to take that doom thinking away a bit: "but what if someone". […] Yes someone can indeed fall anywhere and that can also happen in the park."*
>
> *(Focus group with management, October 2019)*

Working culture of nursing staff
The shift in working culture was seen as highly complex and the involvement of nursing staff and their guidance towards a new way of working was found crucial by the care organisation. The new care concept requires extra or more complex care tasks for nursing staff, such as monitoring basic care needs of residents while they are not in close proximity.

When we look at the results from the nursing staff themselves, it is clear that they had doubts from the start about the building, the open living environment for people with dementia and the new care concept. These doubts hinder the implementation process and are still evident at the end of the project.

6

> *"I am very curious whether we can protect the safety of the residents in the open care environment."*
>
> *(Questionnaire for nursing staff, June 2018)*

> *"Yes, but if someone has already left. I think to myself: I find that scary. That scares me. Because there's a pond over there. Yes, they say: people don't walk in the water. Yeah, I'm not so sure. When it's dark and they don't see anything."*
>
> *(Focus group with nursing staff, October 2021)*

In our observations we find that nursing staff tend to immediately follow residents when they leave the floor or the building and subsequently limit residents' ability to move around, *see box 2.* This tendency reflects the absence of the culture change within the care teams that is essential to realise the necessary shift in the organisation of care.

Box 2. Qualitative observations conducted by the researchers at one of the living rooms in May 2021

A living room attendant, a care worker and 8 residents are present in the meeting room, spread across 3 tables. Sitting at one of the tables is a male resident with advanced dementia. In front of him is a plate with 2 half-eaten sandwiches. The living room attendant walks over to Mr. "Would you like some coffee?" She removes the plate and puts the uneaten sandwich in the hand of Mr. Then goes to the kitchen to make coffee. Puts milk and sugar in it, stirs it and brings it to the resident and puts it on the table.

At another table sits a male resident in a transport wheelchair. I have not yet seen this resident sitting in a wheelchair. The resident prepares to get up. "Sir (….), please sit down for a while, dear", says the living room assistant. She then sits down opposite the resident and has a chat. The resident again prepares to stand. "Lord (….), You have to sit in the chair for a while, because you are not feeling well. After eating a sandwich, you can go to bed. I think you want to go to bed, don't you? Yes, you are really not feeling well. Just wait until after dinner. I made delicious chicken soup."

A resident at one of the other tables stands up. "(first name resident) will you stay seated? We're going to eat soon," says the living room attendant. The resident walks towards the door of the meeting room. The living room attendant stands up and stands in front of her and asks: "Dear, where are we going? Will you help me with the soup?" The living room attendant and the resident then have a conversation about chicken soup; whether vermicelli belongs in there or not and she takes the resident to the kitchen unit.

Commitment of participants towards the change that the project aimed to achieve
Nursing staff indicate that their involvement in the change process was too limited. Hence, their commitment to the changes was also limited, which is not beneficial for the intended outcome. The involvement of nursing staff was initially characterized by

face-to-face meetings and collaboration projects initiated by the care organisation. These were not continued during the project. Within the focus groups with management multiple reasons are mentioned, in particular the COVID-19 pandemic.

> *"And then of course the lockdown came on March 15th. So the actual plan, the timeline that we prepared, we had to revise it a bit. So the preparation for the move and the approach that involved exchange days, shadowing days, meetings as a team. All sorts of things that, especially in that first wave, when digital working was not as common as it is now, we also genuinely did not know what was possible and what was not possible. And we were very careful, especially in our sector, because it was already clear at that time that our residents are the most vulnerable.[….]"*
> *(Focus group on management, March 2021)*

In the results it becomes evident that nursing staff find it the responsibility of management to organise the involvement of nursing staff within the project. At the same time, the management of the organisation indicates that the commitment of nursing staff to the changes was limited. These contradicting views are illustrated in the following citations from a staff member and a member of management.

> *"I feel they should ask… "Gosh, how are you doing? Just like with you now, like: "Gosh how do you experience the workload? Is everything still working out for you? I also think that it should come from upper management."*
> *(Focus group with nursing staff, October 2021)*

> *"[…] But I think what is still needed, of course, and that is one of the important things we focus on in those six working groups, is that there really is a lot that has to be changed in these heads of the employees."*
> *(Focus group with management, October 2019)*

6

In addition, the results show that commitment of family members and persons in the community during the project was also limited, which is highly important in order to achieve successful change. From the beginning they have concerns about the safety of residents, which are not taken away during the project. At the start of the project, there was frequent communication with family members and members of the local community. However, during the course of the project, this communication came to a halt. According to management, this was again due to the COVID-19 pandemic. The lack of contact resulted into uncertainty for family members about the safety of their relatives and doubts about the care concept in general. Community members mentioned the lack of follow-up and their limited involvement in the changes that were made.

> *"Everyone who was involved is either somewhere else or gone. […] They don't ask us anything […]. The idea is good, but the follow-up is not."*
> *(Owner allotment garden, October 2021)*

Changing role of community (members)
Part of the change process was also to create a new role and place for the nursing home within the community, in order to work towards a dementia-friendly community. This included a focus on family and community members as part of the care concept. The aim was that residents with dementia were free and stimulated to walk into the village so that they could meet other persons. The results show that this aim is only partially realised. Residents are indeed able to walk outside the nursing home, which is facilitating for their participation within the community. Conversely, walking into the village is difficult as the old building still stands and forms a boundary between the new nursing home and the village. As a result, the park is also not so easily reached by persons in the community and limitedly used, which hinders the social interaction between community members and residents.

The results also show that community members and family members use the restaurant in the former chapel regularly, which is highly beneficial for the stimulation of social interaction and subsequent creation of a dementia-friendly environment. At the start of the project there were already many connections between the nursing home and persons and organisations in the community. These connections are also evident at the end of the project and therefore facilitating for the intended outcome of the project, *see Box 3.*

The quality improvement initiative aimed to transfer community members from the external social network of the care organisation to internal stakeholders within the new concept. Though, it is evident that this is not realised at the end of the project while it is crucial for successful implementation of the new care concept. This is also illustrated in the way in which management speak about persons in the community at the end of the project. In the next section we will discuss the reasons for this change in orientation.

> *" […] That community concept in which, we are there for everyone and everyone is welcome, and everyone can join here. We no longer have the capacity for that at this time."*
>
> *(Focus group with management, November 2021)*

Box 3. Summary of walk-along interview with resident with dementia in October 2021

Mrs. points to the vegetable gardens and says that they used to come here often. I mention that the park has changed a bit lately. Mrs. confirms: 'Yes, definitely. Some say it will get even better. I hope I will still be here to experience that.' When I ask her what she thinks of it now, she says: 'I like it already.' We talk about needlework again. Mrs. says that she once made a scarf for the father. When asked whether the lady ever comes to The Chapel, she says that some people eat there in the evening, but the lady does not. 'It is very cozy inside and we eat with a whole club. I like it very much. I like living here. I like to participate in things and have a chat.' Mrs. used to go to church on Sunday. She still does this sometimes, her children pick her up afterwards.

We walk back to the entrance via the gravel path. The lady says that her children do not allow her to walk alone: 'I am not allowed to walk alone. I might fall. Someone always has to go with me.' Mrs. says she sometimes walks in the park and points to the gravel path. We continue along the path past the entrance of The Chapel. Mrs. looks at her feet: ' It's also difficult to walk here, isn't it, for us it is. There's all sorts of things on the floor.' Mrs. points to the twigs and acorns on the floor.

When we enter the location we meet the location manager. We say hello. The location manager points to the knitting and says she really likes it. Then the doctor arrives. Mrs. exclaims enthusiastically: "Ah, doctor van T. Will you come and visit me for a while?" The doctor says that he wanted to drop by, but that the door was locked and that he has to go now. A healthcare worker sees the doctor and speaks to him. They walk down the hallway together. When I walk with the lady towards her room, we pass the doctor again. Then she asks: "Hey doctor van T, did you come to see me?" The doctor again replies that he came by but that the door was locked. "I'll come again next time. Then we'll have a cup of coffee together.

Inner setting
The focus of this section is the corporate merge with another long-term care organisation and its consequences.

During the course of the project a corporate merge took place in July 2019 with another long-term care organisation in the region. Multiple reasons for the merge were given by the organisation, including financial benefits, more diverse care provision, more opportunities for innovation and mutual learning from each other's strengths.

This corporate merge has been a major hindering event within the implementation process. Almost all employees on the administrative and management level that were directly involved in the development and execution of the quality improvement project received a new job function or left the organisation, including the chairman of the board of directors, the director of care, the project manager and the secretary of the board,

6

see timeline in Figure 2. As a result, the advocates for the quality improvement project disappeared.

The merge also affected the organisation of daily care, including the introduction of new care teams and new job profiles. After the merge, a clear distinction was made between care-related tasks and (leisure) activities that benefit the well-being of the residents. Many staff members that were originally involved within the project left the organisation or were reassigned.

> *"But it is true, all the people involved and you mention [several names that have been discussed before] but then I would like to also mention the project team that was involved is gone. The last one will leave in a moment. She has her last day at work today. The collegiate team will then cease to exist."*
>
> *(Focus group with management, March 2021)*

This resulted into new employees being involved in the implementation (but not the initiation) of the quality improvement project. The remaining original employees – management and nursing staff- struggled with the changes, and as the new employees raised new ideas that did not always suit the original plans, it created the perception that ownership was lost.

> *"This is a nice project, trajectory, also for the people who are closely involved, they also think wow, who will be joining the trajectory now and what are their ideas?" [red: sarcasticly spoken]*
>
> *(Focus group with management, March 2021)*

The results show a shift in the vision regarding the quality improvement project. Initially, the care organisation focused on interaction with the community. This can be described as a community-driven approach where residents and community members are all part of the dementia-friendly community, focusing on the well-being of all*, see Box 4.* An open environment for persons with dementia and the new building - with living apartments for residents with and without dementia - were aspects to achieve this aim. During the project we see a shift in this focus. The open environment for persons with dementia and the new building became aims in itself. This results in residents moving to other care locations when their care needs (either perceived by family members or care staff) do not fit the open environment and living arrangements of the facility.

Box 4. Shift in focus within care organisation during the course of the project

Focus of care organisation in 2018	Merger statement November 2018	Focus of care organisation in 2021
"[Name care organisation] not only provides care to its clients, but also sees it as its mission to bring together people's desires and needs. The care demand of the clients and the needs of all those involved in the environment are guiding principles. We think and act from the point of view of the community. *That is more than just the teams and the clients. The community, that's what we are together:* *our locations and all those involved around them. When speaking about our locations, we tend to call it communities. [...]* *Enjoyment, a twinkle in the eye, feeling at home and belonging. Those are important valuses in [name care organisation]'s vision. [Name care organisation] wants to become more at the heart of the community with its various locations. A central place in a village or neighbourhood, where people can meet and enjoy.*	*"An important starting point for the collaboration is the preservation of the local customs, village traditions, so that people can continue their lives in their own familiar residential and living environment. A nice place in a village or neighbourhood where people enjoy themselves and can meet each other and where we value the enjoyment of life for clients and a twinkle in the eyes of clients, employees, volunteers and other stakeholders above anything else. The continuity and quality of care will of course be maintained and will even improve in a number of areas.* *Both organisations embrace the concept of housing and living in freedom. With the new organisation, they have the ambition to also enable people with dementia to move freely within an open yet safe living environment."*	*"[Name care organisation] is a solid, resilient and progressive care organisation for clients with complex care needs [name of region]. Older people who need intensive care and support can count on us. We offer a nice and sheltered place to reside and live. But clients who still live at home with complex care needs, or people who need temporary care and support, can also rely on our care, expertise and reliable and expert employees.* *We do not do that alone. Employees and volunteers work closely with care partners and the social network of the clients. Think of family, friends, acquaintances and neighbors. Together with that environment, we want to contribute to a valuable life for a client. Employees talk to clients and their environment to determine together what aspects could be a valuable contribution to this phase of someone's life. Clients keep control as much as possible. Because if you are vulnerable, you are also entitled to your own freedoms and wishes. You want to 'matter'; to do things independently for as long as possible.*

6

> *Basically, our general principle is 'no, unless'. That's just how we do it. We see domotics as an intervention that is part of the care and treatment plan. Not as a basic facility. That is already a very important point of view. Very different from how it is sometimes used at other facilities. If the behaviour of the resident is so extreme that you want to intervene, that is not possible in our organisation. We do have solutions elsewhere, but that will not happen here. We think that often it leads to restrictions for other residents.*
> *(Focus group with management, October 2019)*

In addition, the overall focus of the organisation shifted from community-based care to residential long-term (dementia) care. Family members and community members are no longer considered as main stakeholders by the care organisation, but mainly as informal caregivers for residents of the organisation. There is a new focus on care-related tasks, instead of wellbeing and individual activities for residents. At the end of the project separate 'hospitality staff' are in charge of supervision on the living rooms and leisure activities. This results in group-oriented activities and daily care that is provided in the living room in which the freedom of resident is limited. These internal group-oriented activities make participation of the community hardly possible. Joint activities are only realised in the chapel, while divestment of the restaurant has been considered by the care organisation.

Outer setting
This section describes 1) the collaboration with (external) stakeholders, and 2) influence of the COVID-19 pandemic.

Collaboration with external stakeholders
From the start, multiple external stakeholders were involved in the quality improvement project, including an architect for the design of the new facility and church, the local church for the take-over of the chapel, a constructor to execute the build, the provincial council (to retrieve permits for the fishing pond), the domotica supplier, community members and the allotment garden association.

Another important external stakeholder within the quality improvement project was the municipality. From the beginning, they were very positive about the quality improvement project. The multi-year vision of the municipality state that they are aiming to become dementia-friendly and therefore embrace the initiative. Certain elements of the project relied on this intention of the municipality, such as the day centre for community members. Based on the municipality finance structure that was introduced in 2015, financing these day centres is a responsibility of municipalities. (3, 4) Despite willingness from both the care organisation and the municipality to realise these elements, the funds available turned out to be financially insufficient for the initial plans. Eventually resulting in reduced support from the municipality and cancellation of the day care centre, which had major negative consequences for the intended change.

Collaboration with the municipality was also needed for the build of the new buildings and to receive permits for among others the restaurant within the chapel. In order to build the new buildings, the construction traffic had to go through the park area and created nuisance for the neighbourhood residents. The permits for the Chapel took a long time to receive for the care organisation as its destination plan did not fit the plans for the restaurant.

Another important aspect regarding the involvement of external stakeholders is that some are not familiar with the long-term care setting, which is impeding and makes it challenging and complex to facilitate collaboration. Despite the extensive investment in these collaborations from the care organisation. The complexity became apparent within, among others, the collaboration with the technology supplier.

> *"[….] the system offers us many possibilities and many things are going quite well, but we have also learned some things. For example that it is very important to really be on the same page with your domotics supplier and to look at things from the viewpoint of the user. We have come across a problem were some devices on paper look completely functional, but the reality is that something cannot be charged conveniently or you have to press a button for 3 seconds with a certain force that our residents simply do not have. You know, those are learning points."*
>
> *(Focus group with management, March 2021)*

Influence of COVID-19 pandemic
An important environmental factor that should be mentioned is the COVID-19 pandemic, which had a massive effect on the (long-term) care sector in the Netherlands and subsequently influenced the course of this new long-term living concept negatively. For instance regarding the move of the residents with dementia from the old building to the new. It was set to take place in the fall of 2020 in the midst of the second wave of the pandemic in the Netherlands. As multiple residents had COVID-19 during the move, all residents were moved as cohorts and placed on separate wards, which did not fit the new concept where residents were able to walk around freely, live among and interact with residents with different care demands. As a result, many residents with dementia live almost exclusively among other residents with dementia.

> *[….] Because they moved as a cohort you miss that moment, that moment of moving that you wanted to seize from and say: okay now those doors are open. […] They really had the idea of: we are going to mix it up right away and then we're going to incorporate them right away. And now you actually start with a delay and that was a shame. […] That was really due to COVID, that was so different from what we had thought of beforehand*
> *(Focus group with management, October 2019)*

6

Furthermore, the COVID-19 pandemic resulted into restricted access to the nursing home for multiple months in 2020. This is at odds with the initial intentions of the research project. Afterwards it was very difficult to restore the contact as COVID-19 created uncertainty within care organisations and a strong focus on many challenges within the inner setting such as the organisation of vaccinations.

Discussion

The aim of this study was to gain insight into the process of implementing a quality improvement project that wants to create a dementia-friendly society around a nursing home. Additionally, this study reflects on the lessons learned and implications for future initiatives connecting institutionalised nursing home care with dementia-friendly communities. We structure the discussion section using the core findings of this study.

Core finding 1 – Crucial role of nursing staff
More freedom for persons with dementia to stimulate physical activity is crucial, however, simply creating more freedom is not enough to make a change. Nursing staff are key to provide freedom and a culture change from traditional nursing home care is essential. In order to achieve this, nursing staff have to be involved intensively within the change process and facilitate them to new ways of working. It is imperative that sufficient safety and comfort is offered by the care organisation during the transition process.

This core finding corresponds mainly with the 'Process'-domain of the CFIR, as it refers to the degree of involvement of nursing staff and the preconditions needed to let hem become familiar with the new care concept.

This project again shows that realising change in long-term care organisations is challenging and is dependent of many themes and mechanisms. (5, 6, 29, 30) These findings are similar to other studies. In the study by van Haeften et al. (2015) (29), which focused on an initiative to increase the freedom and autonomy and person-centred care for persons with dementia in six nursing home-based day care centres in the Netherlands, it was found that the nursing staff on the micro level play a crucial role in enhancing freedom and autonomy. This is also supported by other studies. (7, 16, 31) Van Haeften et al. (29) experienced limited flexibility and ability to adopt the new way of working among the nursing staff involved, which impeded the implementation process. A finding that is similar to our study, as we noticed a consistently present fear of harm for residents among the nursing staff, which hindered them to adopt the new organisation of care. Fear of harm for residents with dementia when providing freedom is also found in other studies (7, 32, 33) and an imperative aspect to take into account when aiming to change the organisation of institutionalised long-term dementia care.

An important note that should be made is that within this quality improvement project, a working-group-structure was used to engage nursing staff within the change process. This structure might not be sufficient enough to realise a shift within the long-term care culture, essential for these types of innovations. Realising such large changes within the 'core' of the long-term care culture requires a safe and comfortable environment provided by the care organisation and policy that supports innovation and new care models. (8, 30, 31, 34) We found that this has not been provided within this project.

Core finding 2 – Importance of management commitment

Constructing a dementia-friendly society around a nursing home requires a clear focus from the nursing home and preparedness to let go of traditional nursing home care. This requires a long-term investment from people at all levels of the organisation, including financially. Long-term care organisations are regularly subject to changes due to internal organisational events and mechanisms (6, 35) (e.g. mergers), making it difficult to maintain the same focus over a longer period of time. In line with the reflection on the first core finding, it is therefore of great importance when implementing a large-scale innovation that personnel and management are commited and personnel changes are kept to a minimum.

As this core findings mainly focusses on organisational events, such as mergers, it fits best within the 'Inner Setting'-domain of the CFIR. Mergers in health care settings and their consequences are mainly an internal matter and influence all levels of the organisation.

It is vital that care organisations have stable management with a clear long-term vision and are willing to deploy additional resources (financial or staffing) to give nursing staff the opportunity to adjust to the new situation. (29, 36) This lacked within this quality improvement project due to mainly the corporate merge, the changing financial and political climate and to some extent to the COVID-19 pandemic.

Regarding sustainable funding, a major element was the municipal finance structure on which certain elements of the project were based, such as the day care centre for persons from the community. This element was not realised, which had a major influence on achieving the original goals of the quality improvement project. Sustainable and reliable financial structures are essential to realise and secure quality improvements within (long-term) care. Though, the nature of the political and subsequent financial climate is that they are subject to change. (4)

All mechanisms and events (merge, funding and COVID-19) combined resulted into limited commitment from management to the original aims of the quality improvement project. This finding is also supported by van Haeften et al. (2015) (29), stating that insufficient commitment from managers and project leaders hampers the implementation process.

6

Core finding 3 – Collaboration with new stakeholders

In order to create an environment wherein persons with dementia are truly part of society it is important that the external stakeholders understand, support and share the concept. These are mainly new stakeholders within the long-term care environment, such as municipalities, architects and the local church. It is important that a dementia-friendly society is deployed from multiple actors – not just the nursing home – and that long-term complex collaborations are sought to collectively implement the innovations.

The collaborations with external partners are the main focus of core finding 3, which is therefore mainly linked to the 'Outer Setting' – domain.

The construction of dementia-friendly communities requires the involvement of stakeholders at different levels, with a prime focus on the persons with dementia themselves and their informal caregivers. (10, 21, 22) Intersectoral collaborations of among others research institutions, local and regional governments, policy makers (from care organisations) and local businesses and organisations are crucial for successful realisation, as they have to potential to create a supportive environment and combine knowledge and resources. (10, 21, 22, 37)

However, due to their varying backgrounds, we found that these collaborations can also pose challenges as some of the stakeholders are not familiar with the long-term care setting and/or lack knowledge about (persons with) dementia. Moreover, we found that the involvement of some of these stakeholders is partially dependent on the resources provided (e.g. municipalities), which poses challenges when seeking long-term sustainable collaborations. A finding that is supported by other studies, which state that stakeholder involvement is rather unpredictable and that insuffient time and funding hamper processes and outcomes in this regard. (22)

Core finding 4 – Shift of community members

The transition to a dementia-friendly society means that spaces must be created where persons with dementia and local residents can meet. To do this well, it requires a focus not only on residents, but also on the people in the community. This means that local residents are shifting from external to internal stakeholders. This turnaround extends beyond the regular involvement of informal carers and volunteers within the nursing home.

The community is the primary focus of core finding 4 and therefore falls under the 'Outer Setting – domain', especially because this core finding comprehends the necessary shift of community members from external stakeholders to inner stakeholders. A shift that is key when realising a dementia-friendly community.

Successes achieved within this quality improvement project are the restaurant, the new nursing home and the open long-term care environment for residents with dementia.

Though, changing the place of the nursing home within the community and the subsequent focus on the well-being of community members and their central role as main stakeholders in the change process was not realised. As a result, the shift towards a dementia-friendly society has not taken place. A finding that is among others reflected in the reduced response rates for the questionnaires for community members between 2018 and 2021.

The inclusion of community members as internal stakeholders, as is the aim of dementia-friendly societies, is challenging. Current studies on social networks of residents (with dementia) living in long-term care facilities, mainly focus on the 'Caregiving triangle' with only nursing staff, residents and their family members. (16, 38, 39) Furthermore, these caregiving triangles put a strong emphasis on the practical engagement of family members within daily care to support nursing staff and facilitate person-centred care for their relatives. (31, 39, 40) Though, to realise a dementia-friendly society, the role of community members should extend beyond task-oriented and requires a changed focus on social capital and involvement in long-term care. This 'new' way of involvement is an absolute necessity to live among each other instead of next to each other, both in- and outside the facility. More insight into strategies to truly include community members in the inner setting of a nursing home is much needed.

As described within the four core findings, some important elements that were part of the original project plan are not achieved, most importantly the lack of realisation of a 'community approach'. Remarkably, the management of the care organisation and other involved stakeholders within the quality improvement project are content with the eventual realisation of the project, even though the transcending aim has not been achieved. Being able to provide new nursing home apartments and more autonomy for residents in their physical movement are seen as important improvements in quality of care. Nevertheless, nursing staff, family members and community members were more critical about the safety of the residents and their involvement within the change.

Also, residents hardly visit the park area on their own and there is still a strong emphasis on group-activities, instead of individualised daily activities. However, these aspects were not found to be problematic by the management of the care organisation. This is mostly attributable to the shift in management and the change of vision over time from community-oriented in 2018 towards a focus on long-term institutionalised care in 2021.

Reflection on methodological approach

To gain a broad view of the implementation process and the stakeholders involved, ethnographic thick description for quality improvement and safety according to Leslie et al. (2014) (13) was combined with the CFIR. The CFIR has been used regularly as a theoretical framework within long-term care studies and was combined with varying research methods (36, 41-43) and is especially well suitable to evaluate dementia-friendly

6

initiatives. (10) We noticed that it is challenging to use both the CFIR and ethnographic approach alongside each other, as they have their origin in different research paradigms. The encountered challenges are reflected within our analyses approach. Initially, we qualitatively analysed the focus groups with the management team using data coding. Yet, this approach was not feasible to structure all the data collected in this paper. For this reason we made the decision to base our analyses of all the data collection on theme identification.

We did experience that using theme identification provided us with the possibility to gain an in-depth understanding of the involved mechanisms. Process evaluations increase the chance of successful implementation of quality improvement projects, by having the ability to conduct a structured evaluation and provide insight into the nature and exposure and the experiences of those exposed. (2) Furthermore, using ethnography is notably valuable when studying unplanned and unexpected changes during implementation (12), e.g. global pandemics and corporate mergers.

Due to this structured evaluation, vital facilitating and hindering mechanisms for implementation can ultimately be indicated. (2) As ethnographic evaluations have the potential to support leaders during the implementation of quality improvement projects (44), more research on the complexity and the added value of ethnography would therefore be beneficial for future studies.

Strengths and limitations

To the best of our knowledge, this is one of the very first evaluation studies of an extensive change process that aims to enhance the autonomy and freedom and integration of persons with dementia living in long-term care facilities. We found that using various research methods and valuing them as equal (according to the ethnographic approach) is very useful to study complex change processes. It supports researchers to gain a nuanced understanding of the social context in which the change process takes place (13) and provides insight into underlying mechanisms that other methods cannot. (12) As we used a variety of research methods, the research team often visited the nursing home and gained therefore substantial insight into the change process, which might be beneficial for future studies.

This study also has its weaknesses. An evaluation study was part of this research project. Though, due to the limited number of residents involved, it was not possible to test the differences before and after the project statistically. Moreover, due to the methodological decisions, not all interviews were audio recorded and transcribed verbatim. Though, in line with the foundation of ethnography, informal interviews are part of data collection and considered valuable for analyses. (12) Lastly, in this project we used the original CFIR (9) instead of the updated version based on user feedback (45) as the original framework

was already used from the beginning of the project, which started a few years before the updated version was published.

When research is an important part of an implementation process and scientific institutes are collaboration partners within the research project, it is nearly inevitable that this dynamic has some kind of influence on the progress. To fully reflect on the implementation process, it is important to take the role of the researchers involved in this study into account. Within the collaboration agreement that was formed (as described within the methods section), it was established that Nivel carried the main responsibility for the project and was in the lead regarding the reports towards the funding organisation. Nivel was, therefore, the most dependent on sufficient progress of the project in order to be able to develop the deliverables. As some of these deliverables consisted of reports and articles regarding the last (and final) phase of the project, the time line of the process and organisation of data collection was regularly discussed during meetings with the care organisation. This external pressure from the researchers might have influenced the course and the advancement of the project and subsequent implementation process. Possibly resulting into a care organisation that stayed closer to the initial innovation. Furthermore, the care organisation potentially felt the need to realise some core components of the project that were otherwise neglected and meet the previously set deadlines.

Conclusion

This study provides meaningful insight into the process of implementing a new long-term living concept for persons with dementia and is therefore an important contribution to the existing knowledge on the implementation of quality improvement projects within long-term institutionalised care. As nursing homes are part of the local community, it provides opportunities to collaborate on a dementia-friendly society. However, the change that is required (promoting freedom, residents' autonomy and the redesign of care processes) is complex and is influenced by various mechanisms at different levels. Understanding these mechanisms is beneficial for other care organisation that want to implement a similar initiative.

6

References

1. Schroeder P. Using the PDCA cycle. Nurs Qual Connect. 1992;2(1):1, 8.
2. Hulscher ME, Laurant MG, Grol RP. Process evaluation on quality improvement interventions. Qual Saf Health Care. 2003;12(1):40-6.
3. Jeurissen P, van Ginneken E. The Dutch health system in 2019: Many major reforms, but still work in progress. Health Policy. 2019;123(3):249-51.
4. Maarse JA, Jeurissen PP. The policy and politics of the 2015 long-term care reform in the Netherlands. Health Policy. 2016;120(3):241-5.
5. Low LF, Fletcher J, Goodenough B, Jeon YH, Etherton-Beer C, MacAndrew M, et al. A Systematic Review of Interventions to Change Staff Care Practices in Order to Improve Resident Outcomes in Nursing Homes. PLoS One. 2015;10(11):e0140711.
6. Zwijsen SA, Smalbrugge M, Eefsting JA, Gerritsen DL, Hertogh CM, Pot AM. Grip on challenging behavior: process evaluation of the implementation of a care program. Trials. 2014;15:302.
7. Portegijs S, van Beek APA, van Tuyl LHD, Wagner C. ''We usually choose safety over freedom'': results from focus groups with professional caregivers in long-term dementia care. BMC Health Serv Res. 2022;22(1):677.
8. Boersma P, van Weert JC, Lakerveld J, Dröes RM. The art of successful implementation of psychosocial interventions in residential dementia care: a systematic review of the literature based on the RE-AIM framework. Int Psychogeriatr. 2015;27(1):19-35.
9. Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander JA, Lowery JC. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. Implement Sci. 2009;4:50.
10. Hung L, Hudson A, Gregorio M, Jackson L, Mann J, Horne N, et al. Creating Dementia-Friendly Communities for Social Inclusion: A Scoping Review. Gerontol Geriatr Med. 2021;7:23337214211013596.
11. Geertz C. The Interpretation of cultures: Basic Books; 1973.
12. Gertner AK, Franklin J, Roth I, Cruden GH, Haley AD, Finley EP, et al. A scoping review of the use of ethnographic approaches in implementation research and recommendations for reporting. Implement Res Pract. 2021;2.
13. Leslie M, Paradis E, Gropper MA, Reeves S, Kitto S. Applying ethnography to the study of context in healthcare quality and safety. BMJ Qual Saf. 2014;23(2):99-105.
14. de Boer B, Beerens HC, Katterbach MA, Viduka M, Willemse BM, Verbeek H. The Physical Environment of Nursing Homes for People with Dementia: Traditional Nursing Homes, Small-Scale Living Facilities, and Green Care Farms. Healthcare (Basel). 2018;6(4).
15. Portegijs S, van Beek S, van Tuyl LHD, Wagner C. Physical Activity in People With Dementia Living in Long-Term Care Facilities and the Connection With Environmental Factors and Behavior. J Aging Phys Act. 2022:1-9.
16. Boumans J, van Boekel LC, Verbiest ME, Baan CA, Luijkx KG. Exploring how residential care facilities can enhance the autonomy of people with dementia and improve informal care. Dementia (London). 2022;21(1):136-52.
17. Lange dJ, Willemse B, Smit D, Pot A. Monitor Woonvormen Dementie; tien factoren voor een succesvolle woonvoorziening voor mensen met dementie. Utrecht: Trimbos Instituut; 2011.
18. Schot vdA, Prins M, Hartstra E, Erp vJ, Stobbe E, Overbeek A, et al. Trends in de verpleeghuiszorg voor mensen met dementie; Monitor Woonvormen Dementie 2008-2020. Utrecht: Trimbos Instituut; 2020.

19. van den Berg MEL, Winsall M, Dyer SM, Breen F, Gresham M, Crotty M. Understanding the Barriers and Enablers to Using Outdoor Spaces in Nursing Homes: A Systematic Review. Gerontologist. 2020;60(4):e254-e69.

20. Scherder EJ, Bogen T, Eggermont LH, Hamers JP, Swaab DF. The more physical inactivity, the more agitation in dementia. Int Psychogeriatr. 2010;22(8):1203-8.

21. Steels S. Key characteristics of age-friendly cities and communities: A review. Cities. 2015;47:45-52.

22. Shannon K, Bail K, Neville S. Dementia-friendly community initiatives: An integrative review. J Clin Nurs. 2019;28(11-12):2035-45.

23. Francke A, van der Heide I, de Bruijn S, Gijsen R, Poos R, Veerbeek M, et al. Een samenhangend beeld van dementie en dementiezorg: kerncijfers, behoeften, zorgaanbod en impact. Utrecht: Netherlands Institute for Health Services Research; 2018.

24. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care. 2007;19(6):349-57.

25. Yazan B. Three Approaches to Case Study Methods in Education: Yin, Merriam, and Stake. The Qualitative Report. 2015;20:134-52.

26. Beek Sv. Social networks of nursing staff and organisational performance: A study in long-term care facilities 2013.

27. Rantz MJ, Mehr DR, Popejoy L, Zwygart-Stauffacher M, Hicks LL, Grando V, et al. Nursing home care quality: a multidimensional theoretical model. Journal of nursing care quality. 1998;12(3):30-46; quiz 69-70.

28. Carpiano RM. Come take a walk with me: the "go-along" interview as a novel method for studying the implications of place for health and well-being. Health Place. 2009;15(1):263-72.

29. van Haeften-van Dijk AM, Meiland FJ, van Mierlo LD, Dröes RM. Transforming nursing home-based day care for people with dementia into socially integrated community day care: process analysis of the transition of six day care centres. Int J Nurs Stud. 2015;52(8):1310-22.

30. Pronovost PJ. Navigating adaptive challenges in quality improvement. BMJ Qual Saf. 2011;20(7):560-3.

31. Rosteius K, de Boer B, Staudacher S, Schols J, Verbeek H. How the interrelated physical, social and organisational environment impacts daily life of residents with dementia on a Green Care Farm. Front Public Health. 2022;10:946962.

32. Buist Y, Verbeek H, de Boer B, de Bruin SR. Innovating dementia care; implementing characteristics of green care farms in other long-term care settings. Int Psychogeriatr. 2018;30(7):1057-68.

33. Robinson L, Hutchings D, Corner L, Finch T, Hughes J, Brittain K, et al. Balancing rights and risks: Conflicting perspectives in the management of wandering in dementia. Health Risk & Society - HEALTH RISK SOC. 2007;9:389-406.

34. Koren MJ. Person-centered care for nursing home residents: the culture-change movement. Health affairs (Project Hope). 2010;29(2):312-7.

35. Lam HR, Chow S, Taylor K, Chow R, Lam H, Bonin K, et al. Challenges of conducting research in long-term care facilities: a systematic review. BMC Geriatrics. 2018;18(1):242.

36. Coffey A, Hartigan I, Timmons S, Buckley C, Lehane E, O'Loughlin C, et al. Implementation of evidence-based guidance for dementia palliative care using participatory action research: examining implementation through the Consolidated Framework for Implementation Research (CFIR). Implement Sci Commun. 2021;2(1):137.

37. WHO. Creating age-friendly environments in Europe: a tool for local policy-makers and planners. 2016. Report No.: ISBN: 9789289052122.

6

38. de Rooij AH, Luijkx KG, Spruytte N, Emmerink PM, Schols JM, Declercq AG. Family caregiver perspectives on social relations of elderly residents with dementia in small-scale versus traditional long-term care settings in the Netherlands and Belgium. J Clin Nurs. 2012;21(21-22):3106-16.

39. Koster L, Nies H. It takes three to tango: An ethnography of triadic involvement of residents, families and nurses in long-term dementia care. Health Expect. 2022;25(1):80-90.

40. Puurveen G, Baumbusch J, Gandhi P. From Family Involvement to Family Inclusion in Nursing Home Settings: A Critical Interpretive Synthesis. Journal of family nursing. 2018;24(1):60-85.

41. Fakha A, de Boer B, van Achterberg T, Hamers J, Verbeek H. Fostering the implementation of transitional care innovations for older persons: prioritizing the influencing key factors using a modified Delphi technique. BMC Geriatr. 2022;22(1):131.

42. Gillam J, Davies N, Aworinde J, Yorganci E, Anderson JE, Evans C. Implementation of eHealth to Support Assessment and Decision-making for Residents With Dementia in Long-term Care: Systematic Review. J Med Internet Res. 2022;24(2):e29837.

43. Hung L, Mann J, Upreti M. Using the Consolidated Framework for Implementation Research to Foster the Adoption of a New Dementia Education Game During the COVID-19 Pandemic. Gerontologist. 2023;63(3):467-77.

44. Black GB, van Os S, Machen S, Fulop NJ. Ethnographic research as an evolving method for supporting healthcare improvement skills: a scoping review. BMC Med Res Methodol. 2021;21(1):274.

45. Damschroder LJ, Reardon CM, Widerquist MAO, Lowery J. The updated Consolidated Framework for Implementation Research based on user feedback. Implement Sci. 2022;17(1):75.

Additional file 1:
Description of the original temporary building
(qualitative observation)

The care for people with dementia is situated in a dated temporary building on the grounds and includes two psychogeriatric units. The psychogeriatric ward consists of one unit on the ground floor, split into two sections, and provides dementia care to 28 residents in total. Both sections have their own living room, with the connecting individual rooms located in the surrounding corridors. The corridors are long and most corridors have a dead end. The location provides more than enough walking space for its residents. Several seating areas have been created and are decorated with older and 'home-like' objects. The ward is accessible through double automatic doors secured by a code. Both living rooms have a kitchen, seating area and multiple dinner tables. Both living rooms have access to two medium size fenced gardens with some seating areas and restricted walking space. All residents have their own individual room and bathroom. Residents have the opportunity to bring their own furniture and personal belongings from home.

6

Additional file 2:
Questions included in interview guide for focus groups with nursing staff

Focus group September 2019

Physical activity

When talking about physical activity on the wards. What comes to mind?
- What do you consider as physical activity?
- How is this implemented on the ward?

What is your opinion on physical activity for people with dementia living in nursing homes?
- What do you consider as most important for residents?
- Is it feasible to achieve this?
- What challenges do you face?
- Do you have suggestions and/or solutions to overcome these challenges?

How would the ideal situation look like when it comes to physical activity of residents on the wards?
- What is needed to achieve this?
- Who should be involved?
- Do you see a role for professional caregivers?

Safety

When talking about safety on the wards. What comes to mind?
- *Do you consider the ward as safe?*

Do you ever face difficult decisions regarding the safety of residents?
- *Could you give an example?*

What considerations are taken into account during the decision-making regarding the safety of residents?
- *Whom are involved in these decisions?*

What is your general view on safety and freedom?
- *Could you come up with an example of a situation wherein you faced an (ethical) dilemma?*
- *What do you consider as most important?*
- *How do you handle (potential) dilemmas? What would the ideal situation look like for you when it comes to the safety and freedom of residents?*

Overarching

What would be the ideal situation for you regarding safety and freedom of residents?

Do you see a connection between safety, freedom and physical activity?
- If so, how?
- Could you give an example?
- How do you handle these situations?

Experiences with/attitude towards change at [name care facility]

What do you think of the (intended) changes at [name care facility], specifically:
- The new building
- The chapel
- The grounds/park

How will these changes affect residents do you think?

How are you involved within the change process?
- Was this sufficient?

Focus group October 2021

Icebreaker for introduction

We put a number of objects on the table such as toy scrap truck, walking stick, plant, face mask, stethoscope, board game, sausage roll / food, toy dolls. There are some items on the table. We ask you to briefly introduce yourself, name and function within [name care facility], and then choose 1 object on the table that you most associate with [name care facility]and explain why you associate it with [name care facility].

Experiences with/attitude towards the changes at [name care facility]

Much has changed at [name care facility] in recent times. How did this go?
- Are there factors that have positively or negatively influenced the changes at *[name care facility]?*
- What do you think of the changes at [name care facility], specifically:
- The new building
- The chapel
- The grounds/park

The consequences of the changes at [name care facility] on residents

How do you think the changes have affected residents?
- Do residents walk more or less?
- Do residents go out more or less?
- Do you feel that residents feel more or less comfortable in their new environment? (welfare)
- Do residents have more or less social contacts with their neighbours/family?
- Do you see more or less residents walking compulsively/being restless?

The consequences of the merger on the changes at [name care facility]

There has also been a merger between [name care organization 1] and [name care organization 2]. How did this go?
- What do you think of this merger?
- What do you notice in practice?
- In your opinion, has the merger influenced the (planned) changes at [name care facility]? Can you explain how or in what way?

The consequences of the changes at [name care facility] on the work (satisfaction) of care providers

Has your way of working changed due to the changes at [name care facility]? Can you explain how or in what way?
- How do you experience the new interpretation of your work?
- Do you feel more comfortable or not?

How were you involved within the change process?
- Was this sufficient?

Additional file 3:
Questions included in interview guides from three focus groups with management

Focus group one

Opening question

- What is your role within the quality improvement project at [name care facility]?

Intervention Unadapted

Can you tell us about the context in which this nursing home was created?

What are the core elements of the quality improvement project?
- How are these designed?

Who do you think are the most important parties with whom you have been in contact from the start?
- What is your view on these collaborations?

On which aspects has there been a lot of consultation/discussion?
- What was ultimately done with these aspects?
- What considerations have been made in this regard?

What do you think characterizes the changes at [name care facility]?

Individuals involved/Inner setting

How have residents and their relatives, local residents and care workers been involved in the change process and what are their views?

How do you think the change process has gone so far?
- Which aspects are you proud of?
- What were the challenges?
- How did you deal with these challenges?

Process

In what way is/will be the change process monitored and evaluated?

6

Focus group two

Opening question

What happened at [name care facility] the past year?

Outer setting

What important choices did you have to make this year?

What are the experiences regarding the collaborations with the municipality and the province in the past year? For example, the construction of the fishing pond.

How has the COVID-19 outbreak affected the new construction and relocation?
- Did this lead to changes in planning?
- What measures have been taken to ensure that the renovation and relocation run as smoothly as possible?
- How is contact with local residents maintained?
- How is contact with family members of residents maintained?

Individuals involved/Inner setting

In the past period, many people involved in the project left the organization or started a different position within [name care organization]
- When did the various employees leave or were reassigned?
- What impact does this have?
- Who has taken over his/her role?

Did the change of management influence the quality improvement project?
- Were any changes made to the original set-up as a result of the merger?

During the previous focus group, the importance of including healthcare workers in the project and changes was discussed in detail.
- How has attention been paid to this in the past year?
- Which events/elements did or did not take place?

Process

The residents' move was postponed to the end of November.
- What were the reasons for this?
- How did the move go?

What is your view on the change process so far?
- Which aspects are you proud of?
- What were the challenges?
- How did you deal with these challenges?

What challenges are there right now?

What will the planning for the upcoming period be?

Focus group three

Opening question

What is the most important topic within [name care facility] at the moment?

Outer setting

What is the current status of the renovation and the park? What does further planning look like at this point?
- Park
- Old buildings
- Individual apartments? Social rent?

During the last focus group it emerged that contact with local residents and family members has been limited over the past 1.5 years.
- What is the current status?
- What initiatives have there been?
- How will this be continued?

Intervention adapted

During the previous focus group it was stated that there was tension regarding the summer and the expectation that more residents would go outside. How did this go?
- Do the residents actually go outside? If so, can a distinction be made which residents?
- How is this integrated within the organization of care?
- Do residents visit the park?

During the previous focus group it emerged that the technology was not working optimally yet. What is the current status?
* Do residents have living circles?
* Can residents now enter the facility independently?

Individuals involved/Inner setting

During the previous focus group, the importance of including healthcare workers in the changes was discussed, and in particular the challenges that still lie with regard to this subject.
* How has attention been paid to this in the past year?
* What are you facing?
* What plans do you have for the future?

During the previous focus group, it was mentioned that residents with dementia live together on the first floor, since they moved in cohort due to COVID. The plan was to have the residents live on multiple floors among residents without dementia. What is the current status of this intention?
* How will this be further shaped in the future?

Process

In your opinion, is the concept of [name care facility] still relevant and is it still supported by the organization?

A number of elements have been previously mentioned by [name care organization]. To what extent are these elements still important elements for the new (merged) organization?
* Connection with the neighborhood?
* Emphasis on well-being and activities
* Organizing supply from the Wmo
* Collaboration with local middle class

What is the current status of the implementation of the new vision and new way of working?
* What is currently going well?
* What are you facing?
* What does the further planning look like to achieve implementation?
* How will the new vision and way of working be safeguarded within the organization of care?

Overall

How do you view the course of the process?
- Which aspects are you proud of?
- What were the challenges?
- How did you deal with these challenges?

What would you like to pass on to other organizations that want to go through a similar process?

What are the points of attention for [name care facility] in the next two years?

6

7

Summary,
Nederlandse samenvatting
and general discussion

Summary

Introduction
Chapter 1 International society faces major challenges in the coming decades. The number of persons affected by dementia is increasing rapidly, while the working population is slowly decreasing. Dementia is (in its more advanced stages) associated with a high degree of dependency in the performance of daily activities. Therefore, many persons with a moderate or severe form of dementia stay in a long-term care facility.

The increase in the number of persons affected by dementia and the decrease in the number of nursing staff requires a different approach from society. Dementia is related to stigma, which has a negative effect on both persons with dementia and their caregivers. Improving knowledge and understanding of dementia can help reduce this stigma. Dementia-friendly communities have the potential to provide a meaningful contribution in this regard.

Dementia-friendly communities are defined as a concept that improves the participation of persons with dementia and increases their sense of security and appreciation. The aim of dementia-friendly communities is to improve communication and the knowledge and attitudes of persons from this community. This facilitates the normalisation of dementia in society. In addition, dementia-friendly communities also focus on social inclusion, defined as a dynamic process in which persons are involved and are part of the social networks within a community.

Long-term care facilities are also part of dementia-friendly communities. Currently, knowledge is limited how nursing homes relate to dementia-friendly communities and their potential contribution. However, nursing homes are often still designed in such a way that residents cannot leave them independently, which limits residents with dementia to venture outside and meet other persons.

This thesis attempts to answer the question whether nursing homes can contribute to dementia-friendly communities and the changes that are required. This thesis also identifies important stakeholders and underlying mechanisms within nursing homes that are important in changing the organisation of care. To gain insight into these stakeholders and mechanisms, research was conducted into the physical activity and agitated behaviour of residents, environmental factors of nursing homes, perspectives and behaviour of nursing staff regarding safety and autonomy and social networks between nursing staff, residents with dementia and family members in the community .

Physical activity of residents with dementia, environmental factors, potential measurement instruments and agitated behaviour
Chapter 2 The results of this chapter show that nursing home residents with dementia are very inactive and spend the majority of their time in the communal areas of the ward, such as the living room. The results also show that physical activity is related to the physical environment and its ambiance. Residents are more active if departments have a better ambiance and when care workers spend more time with them.

Chapter 3 examines whether the use of accelerometers is feasible in persons with dementia living in a nursing home. The study shows that accelerometers are a valid instrument for measuring physical activity and that the physical activity of residents with dementia is very low. An important finding is also that the accelerometers were well accepted by residents.

Physical activity and the relationship with the perspective of nursing staff with regards to autonomy, safety and care processes
Chapter 4 provides insight in the perspective of nursing staff with regards to autonomy and safety of nursing home residents with dementia. Nursing staff attempt to find an even balance between safety and physical activity (and with that comes autonomy) for residents. Emphasis is put on ensuring the safety of residents, despite the fact that nursing staff indicate that physical activity (and freedom) is important is for residents in order to maintain their autonomy and independence. Increased physical activity is also important for nursing staff as it contributes to a higher level of independence in residents. This in turn means that the daily (support with) personal care becomes less of a burden for nursing staff. Nursing staff have declared that due to the current organisation of care, and the perceived time limitations as a result of staff shortages, the introduction of more physical activity is not possible at this point in time.

This chapter also shows that the collective group needs of both residents and staff are prioritised above individual needs. This results in reticence among nursing staff to organise individual activities for residents. The deeply imbedded and rigid structures on dementia wards also play a role.

Social networks between nursing staff, residents with dementia, family members and neighbourhood inhabitants
Chapter 5 shows that there are many direct and indirect connections between nursing staff, residents with dementia and their family members. Direct connections exist when persons know each other personally. Indirect connections exist through a shared contact, for example by knowing each other's friends or family. These connections can exist simultaneously. For example: a staff member knows a resident directly through their care relationship, but also went to school with one of the resident's children. These connections often exist much longer than the time the resident lives in the nursing home.

7

Our findings also showed that there is an overlap between nursing staff and family members. Meaning that some family members also work as a staff member at the facility. Nursing staff often have lived for a long period of time in the surrounding community, resulting in many prior ties with residents and family members. Also, many community members conduct volunteer work at the facility.

Transition from traditional nursing home care towards dementia-friendly communities

Chapter 6 describes the core of this thesis, namely the shift from traditional nursing home care to a dementia-friendly community. For this chapter, a process evaluation was carried out in which an existing nursing home was followed during such a transition. Within this change project there are 4 important elements, namely: 1) construction of the building, 2) the grounds surrounding the building, 3) the use of the chapel as a restaurant on this site, 4) place within the community.

A number of elements have been successfully realised, for example a new living environment has been built with large individual apartments for persons with and without dementia. In addition, an open long-term care environment has been implemented. The chapel has been converted into a successful restaurant that serves as a central meeting point. The restaurant is visited daily by residents for their evening meals and by members of the community. Despite the successes of the project, a number of important elements were not achieved:

1) To change the use of the physical environment, a change in the working culture among nursing staff is necessary. Nursing staff are still most comfortable when residents stay in close proximity and spend their time in the communal living room. They remain hesitant when residents leave the nursing home independently and actively try to prevent this on a regular basis.

2) It is very important that healthcare organisations have stable management with a clear long-term vision and are prepared to deploy additional resources (financial and/or personnel) during large-scale change projects. During the duration of the project, a merger with another healthcare organisation took place. As a result, knowledge about the original objectives of the project disappeared and many changes occurred on all levels within the organisation, both in management and certain elements of the project that were in place to create more freedom for residents.

3) Achieving dementia-friendly communities requires the involvement of stakeholders at different levels. These collaborations are complex due to the unfamiliarity of some stakeholders with the long-term care setting and their dependence on the available financial resources.

4) Changing the place of the nursing home within the community and the subsequent focus on the well-being of community members and their central role as key stakeholders in the change process has not been achieved. This is - among others – due to the insufficient inclusion of the surrounding community within the change process. This can be partly explained by the COVID-19 pandemic, but has also been influenced by the merger.

Discussion

This thesis is – to the best of our knowledge - the first to follow the entire change process from traditional nursing home care to a dementia-friendly community. The innovative nature of this research, in which an organisation is closely monitored, provides valuable insights. However, due to the nature of this project, the decisions made by stakeholders during the course of the project and the COVID-19 pandemic, a small(er) number of residents, nursing staff, community and family members participated. As a result, the quantitative studies within this thesis are largely descriptive and have limited application to other healthcare settings. Additionally, due to the low number of participants, it was not possible to test the differences before and after the project statistically. However, the qualitative studies provide additional and valuable context for the quantitative findings and has provided us with a broad view of the entire change process and all the underlying sub-processes. From the results it can be concluded that multiple mechanisms can influence the shift from traditional nursing home care towards dementia-friendly communities, both directly and indirectly. Due to these influencing mechanisms, the transition is complex. The vital simultaneous chance processes require dedication in terms of involvement, but also implementation from long-term care organisations on different levels, including that of the community, the care organisation as employer, the internal structure within the care organisation, but also on the individual level within the direct interaction between nursing staff and residents.

Realising the necessary changes on all these different levels, demands a clear long-term vision and willingness to engage in these processes. Additionally, it also demands long-term commitment from the surrounding local community to make a shift in their position and support the nursing home during its transition and afterwards.

Conclusion

Nursing homes have the potential to contribute meaningfully to dementia-friendly communities. Yet, the transition from traditional nursing home care towards dementia-friendly communities is highly complex and influenced by various mechanisms. Mutual interaction between persons with dementia and community members is a vital element of dementia-friendly communities. This interaction requires a shared easily-accessible meeting space and sufficient physical activity for residents. However, realising both is

7

not sufficient to stimulate autonomy and quality of life of residents. The interaction between nursing staff and residents is crucial to fully utilise the potential of the physical environment, both on the level of individual care as well as on the group-level in which nursing staff and residents also interact. Furthermore, the already existing social networks between nursing homes and the community – that are formed by ties between residents, nursing staff and members of the community - are inadequately used and provide opportunities for changing the organisation of care and the position of nursing homes within communities. A successful transition from a traditional nursing home towards a dementia-friendly community requires extensive and lengthy change processes on the level of individual care processes, the nursing home and society. In order to achieve successful transition, more research is essential to gain sufficient insight into the elements that are needed to realise these changes and its successful implementation within both practice and policy.

Nederlandse samenvatting

Inleiding

Hoofdstuk 1 De internationale samenleving staat de komende decennia voor een grote uitdaging. Het aantal mensen met dementie neemt fors toe, terwijl de beroepsbevolking afneemt. Dementie is (in de verder gevorderde stadia) geassocieerd met een hoge mate van afhankelijkheid in het uitvoeren van dagelijkse activiteiten. Veel mensen met een gematigde of ernstige vorm van dementie verblijven daarom in een instelling voor langdurige zorg.

De toename in het aantal mensen met dementie en de afname in het aantal zorgmedewerkers vraagt om een andere benadering vanuit de samenleving. Dementie is gerelateerd aan stigma, wat een negatief effect heeft op zowel mensen met dementie als hun mantelzorgers. Het verbeteren van de kennis over en het begrip voor dementie kan bijdragen aan het verminderen van dit stigma. Hier kunnen dementievriendelijke gemeenschappen een belangrijke bijdrage aan leveren.

Dementievriendelijke gemeenschappen worden gedefinieerd als een concept dat de mate van participatie van mensen met dementie bevordert en hun gevoel van veiligheid en waardering vergroot. Het doel van dementievriendelijke gemeenschappen is om de communicatie en de kennis en attitudes van mensen uit deze gemeenschap te verbeteren. Dit faciliteert het normaliseren van dementie in de samenleving. Daarnaast focussen dementievriendelijke gemeenschappen ook op sociale inclusie, gedefinieerd als een dynamisch proces waarin mensen betrokken zijn bij en onderdeel zijn van de sociale netwerken binnen een gemeenschap.

Zorginstellingen zijn ook onderdeel van dementievriendelijke gemeenschappen. Momenteel is er nog weinig bekend over hoe verpleeghuizen gerelateerd zijn aan dementievriendelijke gemeenschappen en welke rol zij hierin kunnen innemen. Verpleeghuizen zijn echter momenteel vaak nog op een dusdanige manier ingericht dat bewoners deze niet zelfstandig kunnen verlaten, waardoor bewoners met dementie beperkt de mogelijkheid hebben om naar buiten te gaan en mensen te ontmoeten.

Dit proefschrift probeert antwoord te geven op de vraag of verpleeghuizen kunnen bijdragen aan dementievriendelijke gemeenschappen en de verandering die daarvoor nodig is. Dit proefschrift identificeert tevens belangrijke stakeholders en onderliggende mechanismen binnen het verpleeghuis die van belang zijn bij het veranderen van de organisatie van zorg. Het onderzoek naar deze stakeholders en mechanismen is uitgevoerd door te kijken naar fysieke activiteit en geagiteerd gedrag van bewoners, omgevingsfactoren van verpleeghuizen, perspectieven en gedrag van zorgmedewerkers ten aanzien van veiligheid en autonomie en sociale netwerken tussen zorgmedewerkers, bewoners met dementie en familieleden in de gemeenschap.

Fysieke activiteit van bewoners met dementie, omgevingsfactoren, meetmogelijkheden en geagiteerd gedrag
Hoofdstuk 2 De resultaten van dit hoofdstuk laten zien dat verpleeghuisbewoners met dementie erg inactief zijn en een groot gedeelte van hun tijd verblijven in de gemeenschappelijke ruimtes op de afdeling, zoals de huiskamer. De resultaten laten ook zien dat fysieke activiteit is gerelateerd aan de fysieke omgeving en de sfeer op de afdeling. Bewoners zijn actiever op een afdeling met een betere sfeer en als zorgmedewerkers meer tijd met hen spenderen.

In **Hoofdstuk 3** is onderzocht of het gebruik van accelerometers haalbaar is bij mensen met dementie woonachtig in een verpleeghuis. De studie toont aan dat accelerometers een valide meetinstrument zijn voor het meten van fysieke activiteit en dat de fysieke activiteit van bewoners zeer laag is. Een belangrijke bevinding was tevens dat de accelerometers goed geaccepteerd werden door bewoners.

Fysieke activiteit en de relatie met perspectieven van zorgmedewerkers ten aanzien van autonomie, veiligheid en zorgprocessen.
Hoofdstuk 4 geeft inzicht in de perspectieven van zorgmedewerkers ten aanzien van autonomie en veiligheid voor verpleeghuisbewoners met dementie. Zorgmedewerkers proberen een goede balans te vinden tussen veiligheid en fysieke activiteit (en daarmee autonomie) voor bewoners. De nadruk ligt op het zorgen voor veiligheid van bewoners, ondanks dat zorgmedewerkers aangeven dat fysieke activiteit (en vrijheid) belangrijk is voor bewoners voor het behoud van autonomie en onafhankelijkheid. Ook is meer fysieke activiteit van bewoners van belang voor zorgmedewerkers, aangezien meer fysieke activiteit bijdraagt aan een hogere mate van zelfstandigheid van bewoners. Hierdoor wordt de (begeleiding bij de) dagelijkse ADL-zorg minder belastend voor zorgmedewerkers. Zorgmedewerkers geven aan dat de huidige organisatie van zorg en de daaruit voortvloeiende ervaren tijdsbeperkingen door personeelstekorten maken dat de implementatie van meer fysieke activiteit nu niet mogelijk is.

In dit hoofdstuk is tevens naar voren gekomen dat de collectieve groepsbelangen van zowel bewoners als medewerkers worden geprioriteerd boven de individuele belangen. Dit resulteert in terughoudendheid bij zorgmedewerkers om individuele activiteiten te ondernemen met bewoners. Ook de diep ingebedde en vaste structuren op dementieafdelingen spelen hierin een rol.

Netwerken tussen zorgmedewerkers, bewoners met dementie, familieleden en inwoners van de gemeenschap
Hoofdstuk 5 laat zien dat er veel directe en indirecte connecties bestaan tussen zorgmedewerkers, bewoners met dementie en hun familieleden. Directe connecties bestaan als personen elkaar persoonlijk kennen. Indirecte connecties bestaan door middel van een gemeenschappelijk contact, bijvoorbeeld doordat je elkaars vrienden

7

of familie kent. Deze connecties kunnen tegelijkertijd bestaan. Bijvoorbeeld: een zorgmedewerker kent een bewoner direct door middel van hun zorgrelatie, maar ging ook naar school samen met één van de kinderen van de bewoner. Deze connecties bestaan vaak al veel langer dan de tijd dat de bewoner in het verpleeghuis woont.

Uit de bevindingen blijkt ook dat er sprake is van overlap tussen zorgmedewerkers en familieleden. Dit betekent dat sommige familieleden ook in het verpleeghuis werken. Zorgmedewerkers wonen vaak al langere tijd in de gemeenschap, waardoor er al veel banden zijn met bewoners en familieleden. Ook doen veel leden van de gemeenschap vrijwilligerswerk in de faciliteit.

Verschuiving van traditionele verpleeghuiszorg naar dementievriendelijke gemeenschap

Hoofdstuk 6 beschrijft de kern van dit proefschrift, namelijk de verschuiving van traditionele verpleeghuiszorg naar een dementievriendelijke gemeenschap. Voor dit hoofdstuk is een procesevaluatie uitgevoerd waarbij een bestaand verpleeghuis gevolgd is tijdens zo'n transitie. Binnen dit veranderproject zijn er 4 belangrijke elementen, namelijk: 1) constructie van het gebouw, 2) het terrein rondom het gebouw, 3) het gebruik van de kapel als restaurant op dit terrein, 4) plek binnen de gemeenschap.

Een aantal elementen zijn succesvol gerealiseerd. Er is een nieuwe woonomgeving gebouwd met grote individuele appartementen voor mensen met en zonder dementie. Bovendien is er een 'open-deuren-beleid' gerealiseerd. De kapel is verbouwd tot een succesvol restaurant dat fungeert als centraal ontmoetingspunt. Het restaurant wordt dagelijks bezocht door bewoners voor hun avondmaaltijden en door leden van de gemeenschap. Ondanks de successen van het project zijn een aantal belangrijke elementen niet gerealiseerd:

1) Om het gebruik van de fysieke omgeving te veranderen, is een verandering in de werkcultuur onder de zorgmedewerkers noodzakelijk. Zorgmedewerkers zijn nog steeds het meest op hun gemak als de bewoners dicht bij elkaar blijven en hun tijd doorbrengen in de gedeelde woonkamer. Zij blijven terughoudend als bewoners het verpleeghuis zelfstandig verlaten en proberen dit regelmatig actief te voorkomen.

2) Het is van groot belang dat zorgorganisaties een stabiel management hebben met een duidelijke langetermijnvisie en bereid zijn extra middelen (financieel en/of personeel) in te zetten tijdens grootschalige veranderprojecten. Gedurende de doorlooptijd van het project heeft er een fusie met een andere zorgorganisatie plaatsgevonden. Hiermee verdween de kennis over de oorspronkelijke doelstellingen van het project en zijn er veel wisselingen en veranderingen geweest op alle niveaus binnen de organisatie, zowel in management als in bepaalde elementen gericht op vrijheid voor bewoners.

3) Het realiseren van dementievriendelijke gemeenschappen vergt de betrokkenheid van stakeholders op verschillende niveaus. Deze samenwerkingen zijn complex vanwege de onbekendheid van sommige stakeholders met de langdurige zorg en de afhankelijkheid van de beschikbare financiële middelen.

4) Het veranderen van de plaats van het verpleeghuis binnen de gemeenschap en de daaropvolgende focus op het welzijn van de leden van de gemeenschap en hun centrale rol als belangrijkste stakeholders in het veranderproces is niet gerealiseerd. Dit komt – onder andere – doordat de omliggende gemeenschap onvoldoende is meegenomen in het veranderproces. Dit kan gedeeltelijk verklaart worden door de COVID-19-pandemie, maar is ook beïnvloed door de fusie.

Discussie

Dit proefschrift heeft - zover bij ons bekend - als eerste het gehele veranderproces van traditionele verpleeghuiszorg naar een dementievriendelijke gemeenschap binnen een langdurige zorginstelling gevolgd. De bevindingen van dit proefschrift geven daarmee inzicht in beïnvloedende mechanismen, welke relevant zijn voor zowel toekomstig onderzoek als voor zorgorganisaties die een vergelijkbaar concept willen implementeren.

Het innovatieve karakter van dit onderzoek, waarin een organisatie op de voet gevolgd, wordt geeft waardevolle inzichten. Echter, het gebruik van een complex case study design geeft naast waardevolle inzichten ook een aantal uitdagingen. De aard van dit project heeft er onder andere toe geleid dat er een klein(er) aantal bewoners, zorgmedewerkers, familieleden en mensen vanuit de gemeenschap deelnamen aan de verschillende onderzoeken. Als gevolg hiervan zijn de kwantitatieve onderzoeken in dit proefschrift grotendeels beschrijvend en daarmee beperkt generaliseerbaar naar andere (zorg)settings. Het was tevens niet mogelijk om de verschillen voor en na het project statistisch te testen. De kwalitatieve onderzoeken geven echter aanvullende context voor de kwantitatieve bevindingen. Hierdoor hebben we een breed beeld gekregen van het gehele veranderproces en alle onderliggende deelprocessen.

Uit de resultaten van de verschillende deelstudies binnen dit proefschrift kan geconcludeerd worden dat meerdere mechanismen de verschuiving van traditionele verpleeghuiszorg naar dementievriendelijke gemeenschappen beïnvloeden, zowel direct als indirect. Hierdoor is deze transitie complex. Verschillende elementen moeten tegelijkertijd en over een lange periode veranderen. Deze vitale processen vergen veel qua betrokkenheid, maar ook implementatie van langdurige zorgorganisaties op verschillende niveaus, waaronder dat van de gemeenschap, de zorgorganisatie als werkgever, de interne structuur binnen de zorgorganisatie en in de directe interactie tussen zorgmedewerkers en bewoners. Het realiseren van de noodzakelijke veranderingen op al deze verschillende niveaus vereist een duidelijke langetermijnvisie

7

en de bereidheid om deel te nemen aan deze processen. Daarnaast vraagt het ook een betrokkenheid voor de langere termijn van de lokale gemeenschap om hun positie ten opzichte van het verpleeghuis te veranderen en het verpleeghuis te ondersteunen tijdens de transitie en daarna.

Conclusie

Verpleeghuizen kunnen potentieel een waardevolle bijdrage leveren aan het creëren van dementievriendelijke gemeenschappen. De transitie van traditionele verpleeghuiszorg naar dementievriendelijke gemeenschappen is echter zeer complex en wordt beïnvloed door verschillende mechanismen. Alleen het aanpassen van de fysieke omgeving is niet toereikend om de autonomie en kwaliteit van leven van bewoners te stimuleren. De interactie tussen zorgmedewerkers en bewoners is cruciaal om de fysieke omgeving volledig te benutten op zowel het individuele- als het groepsniveau. Bovendien worden de bestaande sociale netwerken (gevormd door connecties tussen bewoners, zorgmedewerkers en buurtbewoners) tussen verpleeghuizen en de gemeenschap beperkt benut en bieden veel mogelijkheden om de organisatie van de zorg en de positie van verpleeghuizen binnen gemeenschappen te veranderen. Een succesvolle transitie van traditionele verpleeghuiszorg naar een dementievriendelijke gemeenschap vereist langdurige veranderprocessen op het niveau van individuele zorg, het verpleeghuis en de samenleving als geheel. Dit onderzoek geeft een beeld van welke knelpunten en mogelijkheden er zijn bij de veranderingen op deze verschillende niveaus. Meer onderzoek is nodig om de succesvolle implementatie ervan binnen de praktijk en het beleid voldoende te realiseren.

General discussion

The question on how to create a dementia-friendly community is central to this thesis. The concept of dementia-friendly communities is subject to different definitions and a wider set of elements. (1) In general, dementia-friendly communities are a place where persons with dementia are respected and understood, feel valued and safe and engage in the community in a meaningful way. (2, 3) Furthermore, the concept consists of places where both persons with dementia living at home or in long-term care facilities have the ability to connect with the community and receive support when needed. (3, 4) Dementia-friendly communities stimulate social inclusion, which gives persons with dementia the opportunity to have meaningful social relationships and engage with and be part of social networks. (1, 3, 4) The relationships and connections of persons with dementia with these social networks are important, as they create a sense of belonging and contribute to the general well-being of persons with dementia and their quality of life. (5)

Dementia-friendly communities and institutionalised long-term care
Although there is increasing interest in dementia-friendly communities, there is little known about how traditional nursing homes for persons with dementia contribute to these communities. In the Netherlands, as in many other countries, traditional nursing home care is largely institutionalised, meaning that residents live at a care facility and receive 24-hour care for physical and/or cognitive support that is beyond the range of home care services. (6, 7) Institutionalised dementia care has a closed character in which residents mainly reside within the home and its immediate surroundings. (8) Yet, to engage with others in a meaningful way, persons with dementia must be able to meet other persons. This requires at least a shared easily-accessible space that both persons from the community and persons with dementia can visit (independently). (3, 9)

The way in which nursing homes are part of the community is an important element for participation of residents in dementia-friendly communities. Over the last decades, nursing homes in the Netherlands opened their doors for visitors and - for instance - organise meals and leisure activities for (older) community members. However, knowledge on the position of nursing homes within local communities is scarce. More research on this topic is important as many nursing homes in the Netherlands aim to enhance their connection with the surrounding community and realise an open, but at the same time safe environment for persons with dementia that allows them to move freely beyond the barriers of the facility

Complex case study
As yet, knowledge on how institutionalised long-term care can be transformed towards a dementia-friendly community is absent. This thesis aims to provide insight into how nursing homes can contribute to dementia-friendly communities and shed light on the

requisite change in organisation of care that is therefore needed. In order to do this, a complex case study was conducted during 2017-2022.

In this case-study we followed a long-term care organisation in the Netherlands that initiated a quality improvement project. The project aimed to place the nursing home more prominently within the local community. To do this, the traditional nursing home with closed dementia wards was rebuild into individual apartments, while at the same time a large surrounding park area was redesigned for use by residents with dementia and community members from the surrounding neighborhood. Also, a restaurant for residents and community members was initiated in the old chapel that was historically part of the nursing home.

In addition to studying this quality improvement project, supplementary data collection was conducted within four other nursing homes in the Netherlands to be able to reflect on the findings in a broader context. Over the course of the project, researchers visited the nursing home regularly for data collection. To obtain an in-depth insight into the change process from different perspectives, a mixed-methods approach was used that included observations, focus groups, interviews, questionnaires and document analyses. Due to this approach, we gained insight into the perspectives of the stakeholders involved and the relevant influencing mechanisms that are conducive to transforming the organisation of long-term care.

Outline of this thesis

The object and themes of this thesis are depicted in *Figure 1*. We studied how traditional nursing home care can contribute to dementia-friendly communities, looking at direct and indirect relationships between nursing homes and communities. We examined the direct relationship by studying the manner in which the nursing home changed the organisation of care towards a dementia-friendly community. This part of the study is shown in the upper part of *Figure 1*. We also examined the indirect relationship between traditional nursing home care and dementia-friendly communities through various underlying concepts, including physical activity of residents with dementia, environmental factors, and how these are related to the perspectives and behaviour of nursing staff. Both physical activity and perspectives and behaviour of nursing staff interact with each other; these concepts together determine the degree of autonomy that residents have in daily care. Subsequently, we studied how nursing staff are related to residents and family members of residents in the community and what possibilities these relations create for dementia-friendly communities. This part of our study forms the lower part of *Figure 1*. The chapters of this thesis are also depicted in *Figure 1*.
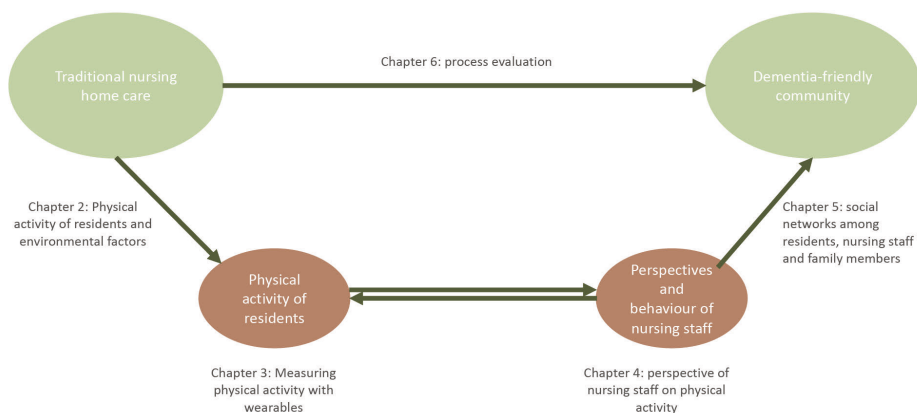
7

Figure 1. Outline of this thesis and its chapters

Research questions

The central research question of this thesis is: Can traditional nursing home care in long-term care facilities be part of dementia-friendly communities and which underlying mechanisms are important in realising this? Within the different chapters the central research question (Chapter 6) and following underlying research questions were addressed:

- What is the physical activity of residents with dementia in nursing homes and how is this related to environmental factors in long-term care facilities? In addition, we studied how physical activity can be measured and if it is related to agitated behaviour of residents. (Chapter 2&3)
- How is physical activity of residents with dementia related to perspectives and behaviour of nursing staff on autonomy and safety in long-term care facilities? (Chapter 4)
- To what extent are there social networks between nursing staff, residents with dementia and their family members in the community, and which possibilities are there through these networks for dementia-friendly communities? (Chapter 5)

In the following paragraphs, we will first reflect on these questions using the findings from Chapter 2 to 5. Subsequently, we will discuss the direct relationship between traditional nursing home care in long-term care facilities and dementia-friendly communities in Chapter 6. Following this, we will outline the strengths and limitations of our study and comment on the interconnectivity between the themes to formulate practical, policy and scientific implications.

Main findings and reflections

Physical activity, environmental factors, measurement possibilities and agitated behaviour (Chapter 2 and 3)

Another important element for participation in dementia-friendly communities is the physical activity of residents with dementia. Important questions in this regard are: are they able to move around and go to places by themselves? And is this safe for them? Over the last decennia there has been increasing focus on physical activity of persons with dementia and its positive effect on health-related outcomes and quality of life. (10) However, concerns about autonomy and safety are related concepts that may improve - but also hinder - the ability of residents with dementia to be physical active.

Chapter 2 and 3 describe the studies in which we conducted observations on the physical activity of residents and environmental factors in nursing homes. Also, we studied how physical activity can be measured using accelerometers. The results of the accelerometers and observations were compared. Lastly, we studied agitated behaviour of residents, using the CMAI observation list that was completed by nursing staff.

Findings
Nursing home residents with dementia in our study were largely inactive (82.8%). Residents spend the majority of their time in the shared spaces of the wards, such as the communal living room. Physical activity was related to the physical environment and ambiance of the ward. Residents were more physically active on wards with a better ambiance. Analyses on the specific elements of the physical environment showed that on the wards where residents are more physically active, nursing staff take more time to engage with them.

We also measured physical activity using accelerometers, in the form of a wristband. We found that wristbands were well-accepted by residents. They proved to be a valid tool, as the data collected with the accelerometers generally corresponded with the data obtained through manual observations.

We expected that there would be a correlation between (non-aggressive) agitated behaviour and physical activity, mainly through compulsive walking. However, we found no such relationship. This may be due to the fact that very few residents showed agitated behaviour in our study.

Reflection
The scientific literature shows that – similar to our findings - nursing home residents are largely sedentary. (11-15) This is attributable to the often advanced stages of dementia of nursing home residents, which limits them to be physically active. (11) Yet, research on the relation between physical activity and the physical and social environment for

7

persons with dementia living in long-term care facilities is scarce and often inconclusive. (16-18) Our results regarding the connection between the environment and physical activity are supported by the systematic review of Anderiesen et al. (2014), stating that several environmental characteristics seem to have a positive impact on physical activity, such as a home-like environment. (17) The more recent systematic review of Narsakka et. al (2022), adds the importance of open doors and integration of the facility within the community as important aspects to stimulate physical activity. (16) In line with our findings, they also found that the way nursing staff approach residents is important to stimulate physical activity. (16)

There are multiple methods to measure physical activity among nursing home residents. Besides manual observations, the use of accelerometers seems promising and has additional and/or different benefits. Accelerometers have the ability to detect certain activities that manual observations cannot. For instance, due to privacy issues, manual observations are often not performed within the (bath)rooms of residents where daily care takes place. Accelerometers can be used to measure physical activity during these moments to receive a more comprehensive overview of physical activity of residents. Furthermore, it is difficult to continuously observe residents that are compulsively walking due to the design of most long-term care wards and following them might reinforce the agitated behaviour. The use of wearables and their potential benefits for persons with dementia experiencing challenging behaviour has been studied by Peeters et. al (2021). (19) Their results showed that wearables are a promising tool, but require further development on among others the design and the possibility for real-time stress detection to make them truly valuable within daily care. (19)

An important precondition for the implementation of accelerometers within daily care is the acceptance of these wearables by nursing home residents. The study of Auerswald et al. (2020) found - similar to our findings - that the use of accelerometers is feasible in nursing home care, with high acceptance rates (94.4%). (20) However, the perspectives and experiences of nursing staff are essential with regard to the implementation of accelerometers. While we did not study this, de Leeuw et al. (2020) shows that the use of technology within the daily work of nursing staff is complex and often results into stress, frustration, postponement and avoidance. (21)

Physical activity and its relation to perspectives and behaviour of nursing staff regarding autonomy and safety (Chapter 4)

To gain insight into the perspectives and behaviour of nursing staff regarding safety and physical activity of nursing home residents with dementia in long-term care facilities, a qualitative study was conducted using focus groups with nursing staff.

Findings
Nursing staff aimed to balance safety, physical activity and subsequent autonomy of residents. This balance was found to be challenging. The strongest emphasis was placed on safety, despite the perspective of nursing staff that physical activity is beneficial for residents and feasible to implement in daily care. Nursing staff also mentioned that a higher physical activity of residents was beneficial for themselves, as it makes the provision of daily care less burdensome. Organisational aspects were indicated as important hindering factors to stimulate more physical activity within daily care, such as time restraints of nursing staff due to shortage of personnel and the increasing complexity of care for residents.

Our most remarkable finding is that we found that group interests were structurally prioritised over those of individuals, both in residents and nursing staff. This was reflected in reluctance of nursing staff to undertake individual activities with residents, as this meant that they left their colleagues 'behind' to take care of the remaining group of residents. Some nursing staff also adhered very tightly to the fixed structures on the wards, which limited them to provide person-centred care.

Reflection
Most long-term institutionalised dementia care in the Netherlands is provided on closed wards. (6) This automatically adds a group-component to the provision of care, as both persons with dementia and nursing staff live and work in a shared and enclosed space. This makes long-term care largely group-oriented (22-24), resulting in clear group structures, planning and leisure activities that fit the majority of residents (25) and a shared responsibility for care tasks by nursing staff. (23, 24)

These dynamics are also related to the relationships between resident, family member(s) and nursing staff. Traditionally, these connections are described in the 'caregiving triangle' which is mainly used with regard to quality of care and performing care tasks. (26-31). Yet, two reviews by Boumans et al. (2019) and van der Weide et al. (2023) found that the importance of the caregiving triangle is also essential with regard to the autonomy of residents. (9, 32) They found that the triangle actually consists of multiple reciprocal connections between the persons involved, which are equally important and interdependent. (32) The connections in the triangle have multiple underlying and sometimes mutually influencing mechanisms that contribute to familiarity and subsequently enhance the degree of person-centred care and decisional and executional autonomy of residents. (9) Advocating strategies to change the group dynamics within long-term care facilities with regard to the autonomy of residents therefore should also include these relationships between residents, nursing staff and family members.

7

Networks between nursing staff, residents with dementia and family members and it possibilities for dementia-friendly communities. (Chapter 5)

The caregiving triangle which includes the resident, family member(s) and the staff member on dementia wards consists in reality of multiple different triangles. These triangles together form social networks that exist within and outside the nursing home. To gain insight into these different networks from the community perspective, we have studied the social networks of nursing staff in two nursing homes using questionnaires for nursing staff, family- and community members in the vicinity of the long-term care facility. These questionnaires focussed on the degree of interaction among each other, ties of residents with the community prior to admission and participation of community members in the nursing homes.

Findings

Our findings showed that there are many direct and indirect connections between nursing staff and residents with dementia and their relatives. Direct ties exist when persons know each other personally. Indirect ties exist when persons have a common contact, for instance knowing each other's friends or family. We saw that these ties can also exist simultaneously. For instance, a professional caregiver knows a resident directly through their care relationship and went to school with one of the children of the resident. Another example is that a professional caregiver knows a residents from before their admission, because the resident used to ran a local business. These connections often have existed longer than the time that residents live in the facility. Our findings also showed that there is an overlap between nursing staff and family members. Meaning that some family members also work as a staff member at the facility. Nursing staff often have lived for a long period of time in the surrounding community, resulting in many prior ties with residents and family members. Also, many community members conduct volunteer work at the facility.

Reflection

All these mutual ties between nursing staff, residents and community members provide many opportunities for dementia-friendly communities and maintaining the quality of care. Research shows that improved social connections within nursing homes are related to better quality of care. (33) The relation between social networks and quality of care can be explained by two different mechanisms. Firstly, these networks support nursing staff during the performance of daily care as they provide knowledge about the residents they care for and subsequently enhance the provision of person-centred care. (26, 29) Secondly, a study in the Netherlands found that nursing staff tend to treat all residents better when they have more indirect ties that extend beyond the boundary of the organisation of the nursing home. (29) Even when these ties only exist with some family members of residents. This mechanism is attributable to the reputation of the nursing home and the involved staff member. A higher number of connections results into an increased embeddedness of the nursing home within the community. This

subsequently increases the importance of reputation as it will become more likely that nursing staff will be addressed by community members about the (negative aspects) of the nursing home. (33)

An important aspect of the embeddedness of the nursing home and subsequent social ties with the community is a shared space that provides meeting opportunities. Outdoor areas often serve as such a meeting place for residents, friends and family and facilitate social ties for residents with dementia with other members of the community. These ties enable residents to connect with the world outside the nursing home and meet other persons. (34) The reciprocal and often long-lasting ties result into a strong social cohesion within a community. Strong social cohesion with communities is therefore an important foundation for realising dementia-friendly communities.

Shift of traditional nursing home care towards dementia-friendly societies (Chapter 6)
The core of this thesis was to get insight into the contextual factors needed to shift the traditional nursing home to become part of a dementia-friendly community. For several years we followed a quality improvement project initiated by a long-term care organisation. In order to gain an in-depth insight into the influencing mechanisms, an ethnographic (open holistic) approach was used, combined with the Consolidated Framework for Implementation research (CFIR). (35) Mixed-methods data was obtained, using questionnaires, (ethnographic) observations, interviews and focus groups and document analyses. Multiple primary stakeholders were part of the data collection, including management, community members, family members, nursing staff and residents. The focus of the quality improvement project was to place the nursing home more prominently into the community by changing the following elements: 1) Construction of the building; 2) Grounds surrounding the building; and 3) The use of the chapel as a restaurant on these grounds 4) Place in the community.

Findings
Certain elements were successfully realised in the project. The new facility was built with large individual apartments for persons with and without dementia. Furthermore, an open long-term care environment was realised in which residents could walk freely in and out of the building and into the non-gated park area. The chapel was turned into a successful restaurant and serves as a central meeting point. The restaurant is visited daily by residents for their evening meals and by community members. Nonetheless, multiple important elements were not realised. These elements and the underlying influencing mechanisms are explained below.

Firstly, to change the utilisation of the physical environment, a shift in working culture is necessary. Even though the front door of the facility was opened, nursing staff were still most comfortable when residents stayed in close proximity and spent their time in

7

the communal living room. Nursing staff remained hesitant about residents leaving the facility independently and regularly undertook action to avoid them doing so.

Secondly, it is vital that care organisations have stable management with a clear long-term vision and are willing to deploy additional resources (financial or staffing). The corporate merge with another care organisation resulted in many changes at all levels in the organisation, including managements, which resulted in the disappearance of knowledge about the initial aims and vision of the project.

Thirdly, the construction of dementia-friendly communities requires the involvement of stakeholders at different levels. Multiple stakeholders from different sectors within the project, requiring mutual collaborations. These collaborations are complex due to the unfamiliarity of some stakeholders with the long-term care setting and dependence on financial resources.

Finally, changing the place of the nursing home within the community and the subsequent focus on the well-being of community members and their central role as main stakeholders in the change process was not realised. The COVID-19 pandemic temporarily hampered their involvement as many nursing homes closed their doors for external visitors. However, the limited involvement of neighbourhood inhabitants was also attributable to a merge with another care organisation and subsequent loss of knowledge about the initial aims.

Reflection
As we found that the utilisation of the physical environment by nursing staff is an important element when realising more freedom for residents, more knowledge on (potential) influencing factors in this regard is imperative. Research shows that culture (among nursing staff) is an important aspect when stimulating the utilisation of the physical environment and changing the organisation of daily care. (8) Though, changing culture (within long-term care) is complex and requires extensive involvement of multiple individuals. (36) Resistance and difficulties to achieve (culture) change is also found in other studies. (37, 38) Often this resistance is attributable to a lack of leadership support, which can be improved through, among others, communication that fits the different stakeholders, involvement of staff and joint decision-making. (36-38) Furthermore, Brouwers et al. (2024) indicate that finding the right balance between freedom and safety is difficult for nursing staff both during and after the transfer to an altered or new facility. (38) Nursing staff experience feelings of being 'lost' both physically and emotionally and need practical guidelines to adjust their traditional way of working. (38)

Not only the culture among nursing staff is imperative, also the culture in an organisation as a whole is important and influences the way leadership support is provided. Research by van Beek and Gerritsen (2010) shows that there are multiple organisational cultures

within long-term care facilities. (39) Market culture, focussing mainly on profitability and productivity, provides the lowest quality of care. Clan culture comprises shared values and goals, strong cohesion and participation, and is related to the highest quality of care. (39) We did not specifically examine the organisational culture within our study. Yet, the process evaluation shows that building quality improvements on available financial structures is risky and negatively influences the realisation of care improvements when these structures turn out to be insufficient.

In addition to the importance of involving internal stakeholders, large quality improvement projects also require the involvement of external stakeholders. Intersectoral collaborations of among others research institutions, local and regional governments, policy makers, local businesses and organisations are crucial for successful realisation of quality improvement projects, as they have to potential to create a supportive environment and combine knowledge and resources. (3, 40-42) These collaborations are also complex, due to the unfamiliarity of some stakeholders with the setting and dependence on available financial resources. (3)

Part of the larger group of external stakeholders are the community members living in close proximity of the nursing home. As described earlier, the involvement of family members (and others) is usually focussed on the performance of care tasks. However, a dementia-friendly community requires a different approach and needs the inclusion of community members and a broader focus than provision of care. Transferring community members from external to internal stakeholders is pivotal. Unfortunately, knowledge on this topic is scarce as most studies mainly focus on creating a community inside the facility. (43) In order to truly integrate long-term care facilities within the community, the involvement of community members requires a strong emphasis on social capital and involvement in long-term care over a long period of time.

Strengths and limitations

Research shows that there are different ways to achieve dementia-friendly communities. Hung et. al (2021) indicated four different strategies: 1) active involvement of persons with dementia and caregivers; 2) inclusive environmental design; 3) public education to reduce stigma and raise awareness; and 4) customized strategies informed by theory. (42) The quality improvement project within this thesis focusses on the first two strategies regarding active involvement and environmental design. Though, it is important to acknowledge that there are more strategies than used in this project.

Furthermore, due to the nature of this project, the decisions made by stakeholders during the course of the project and the COVID-19 pandemic, a small(er) number of residents, nursing staff, community and family members participated. As a result, the quantitative studies within this thesis are largely descriptive and have limited generalizability to other settings. Additionally, due to the low number of participants, it was not possible to test

7

the differences before and after the project statistically. Though, the quantitative studies contain valuable findings for other long-term care organisations on important elements within the project: physical activity, environmental factors and social networks.

A strength of the studies in this thesis is the use of a mixed-methods approach. The qualitative studies provide additional context for the quantitative findings and insight into the perspectives of the stakeholders involved and relevant influencing factors. The qualitative studies, especially the ethnographic approach of the process evaluation, allowed us to gain a broad view of the entire change process and all the underlying sub-processes. It gave us the opportunity to reach 'the core' of the influencing mechanisms and understand the interaction among the different stakeholders. Furthermore, our ethnographical approach provided the necessary nuances to grasp the reasons as to why some elements were successfully realised and others were not. These in-depth findings are extremely valuable for other care organisation aiming to realise a similar initiative.

Interconnectivity of the chapters

Multiple mechanisms can influence the shift from traditional nursing home care towards dementia-friendly communities, both directly and indirectly. Due to these influencing mechanisms, the transition is complex and requires more knowledge and insight through scientific research. Despite the need for more research to study this transition, from this thesis it already becomes apparent that numerous different elements need to change simultaneously and over a long period of time.

These elements are imperative for the successful realisation of a dementia-friendly community. They are embedded in both the physical and social setting and demand a symbiosis between care processes and design and ambiance of the environment. (44, 45)

The vital simultaneous chance processes require dedication in terms of involvement, but also implementation from long-term care organisations on different levels, including that of the community, the care organisation as employer, the internal structure within the care organisation, but also on the individual level within the direct interaction between nursing staff and residents.

Realising the necessary changes on all these different levels, demands a clear long-term vision and willingness to engage in these processes. Additionally, it also demands long-term commitment from the surrounding local community to make a shift in their position and support the nursing home during its transition and afterwards.

Practical implications

The studies within this thesis have practical implications and recommendations for other long-term care organisations that want to be part of a dementia-friendly community,

divided in three different categories: 1) Nursing home care; 2) Quality improvement; 3) the place in the local community.

Nursing home care
1) Wearables are a valuable tool to measure the degree of physical activity and provides many opportunities for other purposes within long-term care. Real-time stress detection has the potential to improve the overall well-being of residents, as it allows nursing staff to interfere in an earlier stage and attempt to reduce the agitated behaviour. (19) Yet, care organisations have a puzzling task ahead as it will be challenging to implement these wearables into daily care and involve nursing staff during these changes. It is essential that nursing staff receive targeted training and education about the use of technology in daily care and are aware of the benefits. (21)

2) The quality improvement project has shown that realising an open long-term care environment is feasible. Though, providing the required instrumental and physical preconditions alone is not sufficient to provide more freedom and autonomy for residents. Nursing staff are crucial to achieve the necessary changes within the organisation of care as they are the pivot within long-term care settings and in the daily care of residents. A finding that is also supported through other scientific research. (37) Providing sufficient support to nursing staff during change processes should be the primary focus of long-term care organisations, but is often underestimated. (38, 43)

The way nursing staff approach residents is important to utilise the physical environment and apply person-centred care. (8) Their approach is – among others - affected by the experienced workload, which affects the degree of applied person-centred care and prioritisation of care tasks. Moreover, also the strict schedules on the wards are an underlying mechanism for the way nursing staff approach residents. These structures are influenced by the culture within the facility and financial and staff resources and deeply embedded within the day-to-day work, which makes it difficult for nursing staff to deviate from it. (16, 46) It is therefore essential to sufficiently guide and support nursing staff through the organisational changes and change in working culture, by for instance organising team sessions during and after the implementation of the project and including pioneering nursing staff within the core project team. (47-49)

Quality improvement
1) The pioneers of the original concept underlying the quality improvements should be involved for the entire duration of the project as long-term commitment from management is a necessary precondition in order to achieve successful change. (31, 47, 50-52) When doing so, loss of vision and focus over the course of the project is potentially avoided.

7

2) Sustainable and reliable financial structures are essential to realise and secure quality improvements within (long-term) care. It is crucial that financial opportunities are not the main incentive to achieve change, but are rather a means to an end. The quality improvement itself should always be the primary focus and multiple (back-up) financial strategies to achieve this should be in place. By doing so, this can prevent certain elements of projects from falling through due to disappointing financial structures. Subsequently, sufficient personnel back-up should be organised when adjusting to the new organisation of care to construct a safe environment for nursing staff that supports innovation.

The place in the local community
The process evaluation presented in this thesis showed that to create a dementia-friendly community with a nursing home at its core, two vital aspects can be identified: 1) Social networks; and 2) The built environment.

Social networks
There are many existing social networks between the nursing home and the surrounding community through nursing staff, family members and residents. Despite their potential, these networks are not frequently used. It is important to acknowledge that these networks extend beyond the family members of residents and volunteers and also include the residents of the surrounding neighbourhood. Fostering these social networks should be the focus of both community members and long-term care organisations to change the position of nursing homes in the community and subsequently stimulate the creation of a dementia-friendly community. However, making optimal use of these networks is complex and limitedly studied. This requires a holistic view that removes both the physical and social barriers between the nursing home and the surrounding neighbourhood and acknowledges persons with dementia as full members of society, instead of a 'care problem' that needs to be fixed.

Built environment
As shown within multiple chapters within this thesis, the built environment matters for persons with dementia and other stakeholders involved.

1) This thesis showed that the physical environment is important to create a dementia-friendly community. The creation of a central meeting place, in this case a restaurant, is valuable to stimulate more interaction between residents and community members. The key to success is that a continuous structure was realised through daily dinners for residents that provides meeting opportunities. Also, the restaurant is strategically placed in the centre of the entire grounds and next to the front door of the nursing home and therefore easily findable and accessible for both community members and residents. Furthermore, the park also provides meeting opportunities and invites residents to leave the facility and spent time outdoors. When realising a similar initiative, it is important

to create a central meeting place and outdoor space that fits the specific setting and is accessible for less mobile residents, for instance by using flat pavement and benches. (53)

2) The environment has historical meaning for residents. Most residents lived, prior to admission, in the surrounding neighbourhood and therefore hold memories about the place and surroundings of the nursing home. These feelings and memories contribute to the familiarity of residents with the surrounding environment, have the potential to make them feel at home and create a sense of belonging. It is important to take these memories and meaning into account when interacting with persons with dementia and in decisions about dementia-friendly communities.

3) The environment – both physically and socially - also has meaning for nursing staff. We have seen that the environment can potentially create insecurity and an unsafe feeling for nursing staff. When realising a new (outdoor) environment for residents, it is understandable that long-term care organisations are proud of the changes made and are tended to put a strong emphasis on the positive implications of these changes. Acknowledging and taking into account the associations of the nursing staff with that same environment is vital for the success of the project.

Policy implications
1) Currently - within both society and research - dementia-friendly communities are mainly viewed as a socially desirable concept without taking into account potential side effects. There is little to no attention in both policy and science for the poignant side of dementia care and its effect on those involved, including persons with dementia themselves, their family members, professional caregivers and community members. The provision of daily care can be complicated when residents freely roam the outdoor environment. Some residents with more severe agitated behaviour or apathy (partially) lost their internal sense for basic needs - such as food and drinks – which makes it more difficult for nursing staff to monitor and meet the desirable daily intake. Also, it might be challenging for community members to cope with residents (showing agitated behaviour) roaming around their neighbourhood, as they might experience safety concerns for residents or do not know how to engage with or help them. It is therefore essential for successful implementation that a critical evaluation focussing on the potential negative side effects of dementia-friendly communities will be conducted.

2) The potential negative side effects due to the more distressing side of dementia is also reflected in the reason why nursing homes were initially created. Nursing homes offer the necessary balance between autonomy and safety for persons with (more severe forms of) dementia, as society is currently not yet able to. Dementia-friendly communities aim to change this. However, providing sufficient autonomy and safety does not (solely) depend on the physical environment of communities and nursing homes, but also on

7

the social environment. It requires sincere engagement from community members whom must be willing to acknowledge persons with dementia as full members of their community and are able to let go of the stigmatising views and ideas about persons with dementia and nursing homes. Meaning that not only the nursing home should open up towards community members, but also the other way around.

3) In the Netherlands, there are many aspects that hinder the building of new nursing homes due to among others high prices for land and building, environmental issues and personnel shortages. (54, 55) As a result, there is a limit on the new nursing homes that are built. This makes it difficult to change the way long-term care is organised as current nursing homes are often built and designed according to previous and more traditional standards of closed wards and limited outdoor space. Redesign of existing nursing homes to make the environment more dementia-friendly could provide a (partial or temporarily) solution.

4) The realisation of an open care environment is difficult. It is a challenge in itself and something most organisations are still aiming to achieve, largely helped by the introduction of the Care and Coercion act in 2020. However, the national implementation of the Coercion Care Act is far from realised (56), as care organisations encounter difficulties regarding the persistent traditional long-term care culture (50, 57), implementation of wearables (49) and complexity of the act. (58-60) An amendment of the law is currently being developed that includes – among others – guideline development, opportunities for a more tailored approach and simplification of (some) procedures. Sharing implementation strategies among long-term care organisations could support nursing homes to achieve an open long-term care environment.

5) Despite good and sincere intentions by care organisation to focus on quality of life and well-being of residents, the available and feasible financial structures are often leading incentives in policy making. This stronger emphasis on finance has many reasons that are beyond the scope of this thesis. However, the national and global challenges due to an ageing society and major staff shortages in long-term care are most certainly underlying influencing factors. Despite these financial and staff challenges, it is vital that the importance of sufficient time spent with residents by nursing staff is acknowledged, also in light of dementia-friendly communities. In order to achieve change on the meso- and even macro level, insight into the care processes on the micro level is imperative.

6) There is a strong need for innovation within long-term care due to the stronger emphasis on person-centred care and autonomy. As a result, many (often large) quality improvement projects are initiated. These large projects contain many challenges, as described in *Chapter 6* of this thesis, including difficulty to maintain focus over time and the inclusion of important stakeholders. As a result, the initial aim(s) of projects are often

not (fully) achieved and many care organisations are involved in projects that have an overlap in aim and focus.

It is therefore important to narrow down the amount of projects and make projects more manageable. This gives care organisations the opportunity to follow these projects more closely over time. Furthermore, it is important that these projects are more sufficiently monitored to make sure that the findings of this projects reach other care organisations and/or even other settings. Lessons learned within long-term care may also be valuable and transferable to for instance (institutionalised) disability and mental health care.

Scientific implications
Research in long-term care is highly challenging for various reasons, among others the limited focus on science compared to other (clinical) settings, complicated processes to receive consent, complex health conditions of residents, hesitant family members, time constraints and high turnover rates among nursing staff. (61) Yet, conducting valuable research is feasible and important for enhancing the quality of dementia care and quality of life of residents.

1) Nursing staff have a pivotal role within the long-term dementia care setting, as they spend the most time with residents and have the most contact with family members and other professional caregivers. (62) The connection and interaction between nursing staff and residents is therefore an indispensable underlying mechanism on the micro level within change initiatives. Furthermore, the quality of care provided by nursing staff, including their physical and verbal behaviour, is essential for the quality of life of residents. (63) Large change initiatives, such as described in this thesis, require a change in culture and behaviour among nursing staff. It is therefore vital to create a strong support base among nursing staff for planned innovations that aim to change the organisation of care. Research states that nursing staff should be involved within the change process and should be able to come up with solutions for challenges faced, especially those that have innovative ideas and have a positive mindset. (47) Despite its importance, adequate involvement of nursing staff in change processes and changing their behaviour is found to be challenging and still a relatively unknown field. (38) Research on the involvement of nursing staff and strategies to change behaviour and culture is therefore imperative to make improvement initiatives more successful.

2) In light of behaviour and culture among nursing staff, the strongly embedded group component within the organisation of long-term care should also be taken into account. The long-term care setting is characterised by the educationally diverse background of involved nursing staff, including both registered nurses and certified nursing assistants, of which the latter is usually the vast majority. (24, 64, 65) Certified nursing assistants function as a separate group within the larger team, share group norms and behaviour and are largely unsupported and unappreciated. (65-67) Furthermore, their added value,

7

opinions and vision on organisation of care (for residents) are often not acknowledged by other professional caregivers and larger society. (65-67)

Certified nursing assistants are supportive of one another, which positively influences job satisfaction and helps them cope with incidental verbal and physical aggression expressed by residents. (66) Though, their strong group sense also results in a form of isolation from other groups of colleagues, which contributes to them taking in an under-recognised and under-represented position and strengthens their solidarity with their own 'group. (66) This solidarity also transpires within the provision of daily care, as the needs of staff are often prioritised over those of residents. Also, unfair mutual treatment and bullying occur. (65)

This means that social identity and social norms play an important role in the way daily care is provided by nursing staff. Gaining a better understanding of these group dynamics is important for future research- and change initiatives within long-term care. Additionally, as social norms and social identity are vital elements within the provision of daily care, the creation of dementia-friendly communities do not only need the acceptance of nursing home residents with dementia, but also increased valuation of the work that nursing staff conduct by both in- and outsiders. (65)

3) The findings of this thesis on the role of social networks within dementia-friendly societies is a new topic that – to our knowledge – has not been researched before. Social cohesion is an important element of society and dementia-friendly communities. Yet, social cohesion strongly differs between urban and rural areas with a potential exception within working-class districts. (40) This might result into care organisations in larger cities facing more challenges when constructing dementia-friendly communities than those on the countryside. Furthermore, long-term care facilities in urban areas often have less outdoor space on own grounds, which is perceived to be risky. (47, 58) More research on social networks within communities, their potential for the realisation of dementia-friendly communities and setting-specific characteristics, challenges (and potential solutions) is therefore much needed.

Conclusion

Nursing homes have the potential to contribute meaningfully to dementia-friendly communities. Yet, the transition from traditional nursing home care towards dementia-friendly communities is highly complex and influenced by various mechanisms. Mutual interaction between persons with dementia and community members is a vital element of dementia-friendly communities. This interaction requires a shared easily-accessible meeting space and physical activity for residents. However, realising both is not sufficient to stimulate autonomy and quality of life of residents. The interaction between nursing staff and residents is crucial to fully utilise the potential of the physical environment,

both on the level of individual care as well as on the group-level in which nursing staff and residents also interact. Furthermore, the already existing social networks between nursing homes and the community – that are formed by ties between residents, nursing staff and members of the community - are inadequately used and provide opportunities for changing the organisation of care and the position of nursing homes within communities. A successful transition from a traditional nursing home towards a dementia-friendly community requires extensive and lengthy change processes on the level of individual care processes, the nursing home and society. In order to achieve successful transition, more research is essential to gain sufficient insight into the elements that are needed to realise these changes and its successful implementation within both practice and policy.

7

References

1. Hebert CA, Scales K. Dementia friendly initiatives: A state of the science review. Dementia (London). 2019;18(5):1858-95.
2. Wu SM, Huang HL, Chiu YC, Tang LY, Yang PS, Hsu JL, et al. Dementia-friendly community indicators from the perspectives of people living with dementia and dementia-family caregivers. J Adv Nurs. 2019;75(11):2878-89.
3. Shannon K, Bail K, Neville S. Dementia-friendly community initiatives: An integrative review. J Clin Nurs. 2019;28(11-12):2035-45.
4. Wiersma EC, Denton A. From social network to safety net: Dementia-friendly communities in rural northern Ontario. Dementia (London). 2016;15(1):51-68.
5. Phinney A, Kelson E, Baumbusch J, O'Connor D, Purves B. Walking in the neighbourhood: Performing social citizenship in dementia. Dementia (London). 2016;15(3):381-94.
6. Schols JM, Crebolder HF, van Weel C. Nursing home and nursing home physician: the Dutch experience. Journal of the American Medical Directors Association. 2004;5(3):207-12.
7. Maarse JA, Jeurissen PP. The policy and politics of the 2015 long-term care reform in the Netherlands. Health Policy. 2016;120(3):241-5.
8. de Boer B, Beerens HC, Katterbach MA, Viduka M, Willemse BM, Verbeek H. The Physical Environment of Nursing Homes for People with Dementia: Traditional Nursing Homes, Small-Scale Living Facilities, and Green Care Farms. Healthcare (Basel, Switzerland). 2018;6(4).
9. Boumans J, van Boekel LC, Baan CA, Luijkx KG. How Can Autonomy Be Maintained and Informal Care Improved for People With Dementia Living in Residential Care Facilities: A Systematic Literature Review. Gerontologist. 2019;59(6):e709-e30.
10. Brett L, Traynor V, Stapley P. Effects of Physical Exercise on Health and Well-Being of Individuals Living With a Dementia in Nursing Homes: A Systematic Review. Journal of the American Medical Directors Association. 2016;17(2):104-16.
11. den Ouden M, Bleijlevens MH, Meijers JM, Zwakhalen SM, Braun SM, Tan FE, et al. Daily (In)Activities of Nursing Home Residents in Their Wards: An Observation Study. Journal of the American Medical Directors Association. 2015;16(11):963-8.
12. Marmeleira J, Ferreira S, Raimundo A. Physical activity and physical fitness of nursing home residents with cognitive impairment: A pilot study. Experimental gerontology. 2017;100:63-9.
13. Moyle W, Jones C, Murfield J, Draper B, Beattie E, Shum D, et al. Levels of physical activity and sleep patterns among older people with dementia living in long-term care facilities: A 24-h snapshot. Maturitas. 2017;102:62-8.
14. Parry S, Chow M, Batchelor F, Fary RE. Physical activity and sedentary behaviour in a residential aged care facility. Australasian journal on ageing. 2019;38(1):E12-e8.
15. van Alphen HJ, Volkers KM, Blankevoort CG, Scherder EJ, Hortobagyi T, van Heuvelen MJ. Older Adults with Dementia Are Sedentary for Most of the Day. PloS one. 2016;11(3):e0152457.
16. Narsakka N, Suhonen R, Kielo-Viljamaa E, Stolt M. Physical, social, and symbolic environment related to physical activity of older individuals in long-term care: A mixed-method systematic review. Int J Nurs Stud. 2022;135:104350.
17. Anderiesen H, Scherder EJ, Goossens RH, Sonneveld MH. A systematic review-- physical activity in dementia: the influence of the nursing home environment. Appl Ergon. 2014;45(6):1678-86.

18. Altmeier D, Thiel A, Frahsa A. 'All We Have to Decide Is What to Do with the Time That Is Given to Us' a Photovoice Study on Physical Activity in Nursing Homes. Int J Environ Res Public Health. 2021;18(10).

19. Peeters-Schaap M, Schouten G, Wouters E. Wearables for residents of nursing homes with dementia and challenging behaviour: Values, attitudes, and needs. Gerontechnology. 2021;20:1-13.

20. Auerswald T, Meyer J, von Holdt K, Voelcker-Rehage C. Application of Activity Trackers among Nursing Home Residents-A Pilot and Feasibility Study on Physical Activity Behavior, Usage Behavior, Acceptance, Usability and Motivational Impact. Int J Environ Res Public Health. 2020;17(18).

21. De Leeuw JA, Woltjer H, Kool RB. Identification of Factors Influencing the Adoption of Health Information Technology by Nurses Who Are Digitally Lagging: In-Depth Interview Study. J Med Internet Res. 2020;22(8):e15630.

22. Rantz MJ, Hicks L, Grando V, Petroski GF, Madsen RW, Mehr DR, et al. Nursing home quality, cost, staffing, and staff mix. Gerontologist. 2004;44(1):24-38.

23. Ribbe MW. Care for the elderly: the role of the nursing home in the Dutch health care system. International psychogeriatrics. 1993;5(2):213-22.

24. Scott-Cawiezell J, Schenkman M, Moore L, Vojir C, Connoly RP, Pratt M, et al. Exploring nursing home staff's perceptions of communication and leadership to facilitate quality improvement. J Nurs Care Qual. 2004;19(3):242-52.

25. Hingstman T, Langelaan M, Wagner C. De dagelijkse bezetting en kwaliteit van zorg in instellingen voor langdurige zorg. Utrecht: Nivel 2012.

26. Tuijt R, Rees J, Frost R, Wilcock J, Manthorpe J, Rait G, et al. Exploring how triads of people living with dementia, carers and health care professionals function in dementia health care: A systematic qualitative review and thematic synthesis. Dementia (London). 2021;20(3):1080-104.

27. Puurveen G, Baumbusch J, Gandhi P. From Family Involvement to Family Inclusion in Nursing Home Settings: A Critical Interpretive Synthesis. J Fam Nurs. 2018;24(1):60-85.

28. Cohen LW, Zimmerman S, Reed D, Sloane PD, Beeber AS, Washington T, et al. Dementia in relation to family caregiver involvement and burden in long-term care. J Appl Gerontol. 2014;33(5):522-40.

29. Beek Sv. Social networks of nursing staff and organizational performance: A study in long-term care facilities 2013.

30. Koster L, Nies H. It takes three to tango: An ethnography of triadic involvement of residents, families and nurses in long-term dementia care. Health Expect. 2022;25(1):80-90.

31. Rosteius K, de Boer B, Staudacher S, Schols J, Verbeek H. How the interrelated physical, social and organizational environment impacts daily life of residents with dementia on a Green Care Farm. Front Public Health. 2022;10:946962.

32. van der Weide H, Lovink MH, Luijkx KG, Gerritsen DL. Supporting autonomy for people with dementia living in nursing homes: A rapid realist review. Int J Nurs Stud. 2023;137:104382.

33. van Beek APA, Wagner C, Frijters DHM, Ribbe MW, Groenewegen PP. The ties that bind? Social networks of nursing staff and staff's behaviour towards residents with dementia. Social Networks. 2013;35(3):347-56.

34. van den Berg MEL, Winsall M, Dyer SM, Breen F, Gresham M, Crotty M. Understanding the Barriers and Enablers to Using Outdoor Spaces in Nursing Homes: A Systematic Review. Gerontologist. 2020;60(4):e254-e69.

35. Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander JA, Lowery JC. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. Implement Sci. 2009;4:50.

36. Snoeren M, Janssen B, Niessen T, Abma T. Nurturing Cultural Change in Care for Older People: Seeing the Cherry Tree Blossom. Health care analysis : HCA : journal of health philosophy and policy. 2014;24.

7

37. Tyler DA, Lepore MJ. Barriers and facilitators to adopting nursing home culture change. Journal of Clinical Outcomes Management. 2017;24.

38. Brouwers M, de Boer B, Groen WG, Verbeek H. The Challenges of Moving from Regular Nursing Homes toward Innovative Long-Term Care Settings: An Interpretative Description Study of Staff Experiences. Journal of Aging and Environment. 2024:1-19.

39. van Beek APA, Gerritsen DL. The relationship between organizational culture of nursing staff and quality of care for residents with dementia: Questionnaire surveys and systematic observations in nursing homes. International Journal of Nursing Studies. 2010;47(10):1274-82.

40. Steels S. Key characteristics of age-friendly cities and communities: A review. Cities. 2015;47:45-52.

41. WHO. Creating age-friendly environments in Europe: a tool for local policy-makers and planners. 2016. Report No.: ISBN: 9789289052122.

42. Hung L, Hudson A, Gregorio M, Jackson L, Mann J, Horne N, et al. Creating Dementia-Friendly Communities for Social Inclusion: A Scoping Review. Gerontol Geriatr Med. 2021;7:23337214211013596.

43. Brouwers M, Broekharst DSE, de Boer B, Groen WG, Verbeek H. An overview of innovative living arrangements within long-term care and their characteristics: a scoping review. BMC geriatrics. 2023;23(1):442.

44. Smith K. Developing a Dementia-Friendly Christchurch: perspectives of people with dementia. 2017.

45. Smith K, Gee S, Sharrock T, Croucher M. Developing a dementia-friendly Christchurch: Perspectives of people with dementia. Australasian journal on ageing. 2016;35(3):188-92.

46. Hoek LJM, Verbeek H, de Vries E, van Haastregt JCM, Backhaus R, Hamers JPH. Autonomy Support of Nursing Home Residents With Dementia in Staff-Resident Interactions: Observations of Care. Journal of the American Medical Directors Association. 2020;21(11):1600-8.e2.

47. Buist Y, Verbeek H, de Boer B, de Bruin SR. Innovating dementia care; implementing characteristics of green care farms in other long-term care settings. International psychogeriatrics. 2018;30(7):1057-68.

48. de Boer B, Buist Y, de Bruin SR, Backhaus R, Verbeek H. Working at Green Care Farms and Other Innovative Small-Scale Long-Term Dementia Care Facilities Requires Different Competencies of Care Staff. Int J Environ Res Public Health. 2021;18(20).

49. Sturge J, Janus S, Zuidema S, Frederiks B, Schweda M, Landeweer E. The moral and gender implications of measures used to modulate the mobility of people with dementia living in residential care environments: a scoping review. Gerontologist. 2023.

50. Koren MJ. Person-centered care for nursing home residents: the culture-change movement. Health affairs (Project Hope). 2010;29(2):312-7.

51. Pronovost PJ. Navigating adaptive challenges in quality improvement. BMJ Qual Saf. 2011;20(7):560-3.

52. van Haeften-van Dijk AM, Meiland FJ, van Mierlo LD, Dröes RM. Transforming nursing home-based day care for people with dementia into socially integrated community day care: process analysis of the transition of six day care centres. Int J Nurs Stud. 2015;52(8):1310-22.

53. Zhai Y, Li D, Wang D, Shi C. Seniors' Physical Activity in Neighborhood Parks and Park Design Characteristics. Front Public Health. 2020;8:322.

54. Actiz. Grote zorgen over achterblijven bouwplannen verpleegzorg 2023 [Available from: https://www.actiz.nl/grote-zorgen-over-achterblijven-bouwplannen-verpleegzorg.

55. Zorgkaart Nederland Regiomonitor 2022 verpleegzorg; landelijk. 2023.

56. Legemaate J, Nuijen J, Voskes Y, Ploem M, Kroezen M, Gerritsen S, et al. Eerste evaluatie: Wet verplichte geestelijke gezondheidszorg en Wet zorg en dwang. Den Haag: ZonMw; 2022.

57. McGreevy J. Implementing culture change in long-term dementia care settings. Nursing standard (Royal College of Nursing (Great Britain) : 1987). 2016;30(19):44-50.

58. Actiz. Hoe het staat het met: de Wet zorg en dwang 2022 [Available from: https://www.actiz.nl/hoe-staat-het-met-de-wet-zorg-en-dwang.

59. Jonge Hd. Kamerbrief: Wet zorg en dwang. 2019.

60. PWC. Online monitor Implementatie van de Wet zorg en dwang. 2015-2023.

61. Lam HR, Chow S, Taylor K, Chow R, Lam H, Bonin K, et al. Challenges of conducting research in long-term care facilities: a systematic review. BMC geriatrics. 2018;18(1):242.

62. den Ouden M, Kuk NO, Zwakhalen SMG, Bleijlevens MHC, Meijers JMM, Hamers JPH. The role of nursing staff in the activities of daily living of nursing home residents. Geriatric Nursing. 2017;38(3):225-30.

63. Anderson K, Blair A. What have staff got to do with it? Untangling complex relationships between residential aged care staff, the quality of care they provide, and the quality of life of people with dementia. Archives of gerontology and geriatrics. 2021;94:104378.

64. Clemens S, Wodchis W, McGilton K, McGrail K, McMahon M. The relationship between quality and staffing in long-term care: A systematic review of the literature 2008-2020. Int J Nurs Stud. 2021;122:104036.

65. Booi L, Sixsmith J, Chaudhury H, O'Connor D, Young M, Sixsmith A. 'I wouldn't choose this work again': Perspectives and experiences of care aides in long-term residential care. Journal of Advanced Nursing. 2021;77(9):3842-52.

66. J VL, Schneider J, Scales K, Bailey S, Jones R. Ingroup identity as an obstacle to effective multiprofessional and interprofessional teamwork: findings from an ethnographic study of healthcare assistants in dementia care. J Interprof Care. 2011;25(5):345-51.

67. Scales K, Bailey S, Middleton J, Schneider J. Power, empowerment, and person-centred care: using ethnography to examine the everyday practice of unregistered dementia care staff. Sociol Health Illn. 2017;39(2):227-43.

7

Appendices

List of publications
Portfolio
About the author
Dankwoord

List of publications

Included in this thesis:
Suzanne Portegijs, Adriana Petronella Anna van Beek, Lilian Huibertina Davida van Tuyl, Cordula Wagner. Implementing a new living concept for persons with dementia in long-term care. BMC Health Services Research, 2024. 24:306.
https://doi.org/10.1186/s12913-024-10765-y

Suzanne Portegijs, Adriana Petronella Anna van Beek, Lilian Huibertina Davida van Tuyl, Cordula Wagner. "We usually choose safety over freedom: results from focus groups with professional caregivers in long-term dementia care. BMC Health Services Research, 2022. 22:677.
https://doi.org/10.1186/s12913-022-07952-0

Suzanne Portegijs, Sandra van Beek, Lilian H.D. van Tuyl and Cordula Wagner. Physical activity in people with dementia living in long-term care facilities and the connection with environmental factors and behaviour. Journal of Aging and Physical Activity, 2022. 31, 214-222.
https://doi.org/10.1123/japa.2021-0459

Daniela Gawehns, **Suzanne Portegijs**, Sandra van Beek, Matthijs van Leeuwen. Using Consumer Wearables To Measure Physical Activity of Nursing Home Residents with Dementia. Journal of Medical Systems (submitted).

Adriana Petronella Anna van Beek, **Suzanne Portegijs,** Peter Groenewegen, Martine Wilhelmina Johanna Huygens, Beate Volker. Social networks of neighbourhood inhabitants, residents of a care facility, and nursing staff: a case study in two long-term care facilities in the Netherlands. Health and Social Care in the Community (submitted)

Other international publications:
Suzanne Portegijs, Ariel Yuhan Ong, Nynke Halbesma, Aidan Hutchison, Cathie LM Sudlow, Caroline A Jackson. Long-term mortality and recurrent vascular events in lacunar versus non-lacunar ischaemic stroke: A cohort study. European Stroke Journal, 2021. 7 (I), (57-65).
https://doi.org/10.1177/239698732110620

Bernadette Clara Francisca Maria Schutijser, Irene Paulien Jongerden, Joanne Ewa Klopotowska, **Suzanne Portegijs**, Margaretha Christine de Bruijne, Cordula Wagner. Double checking injectable medication administration: Does the protocol fit clinical practice? Safety Science, 2019. 118, 853-860.
https://doi.org/10.1016/j.ssci.2019.06.026

Publications in Dutch:

Hanneke Merten, **Suzanne Portegijs,** Michel Dückers, Cordula Wagner. Als het mis gaat… Verhalen van patiënten en nabestaanden na het doormaken van een calamiteit. Book, 2020.
1003508.pdf (nivel.nl)

A

Portfolio

Name course, training, activity	Organiser	EC	Completed
Mandatory courses (VU/VUmc specific)			
Course Research Integrity	Amsterdam UMC	2	November 5 -December 2 2020
Conference participation, 35th global conference of Alzheimer Disease International conference (oral presentation)	ADI	2	June 9 - 11 2022
		4	
Elective mandatory courses (APH specific)			
Advanced methodological skills			
Starters course STATA	Nivel	0.5	September 6 & September 10 2018
Course 'Introductie cursus Kwalitatief Onderzoek in de Gezondheidszorg'	Nivel	1	October 21 & October 22 2019
Leiden & Delft Data Carpentry Workshop	4TU. Centre for Research Data	0.9	January 14 - 22 2021
Introduction to systematic review and Meta-analysis	John Hopkins University	0.5	February 19 - March 3 2024
Conducting Ethnographic Research	University of South Hampton	0.6	May 23 & May 24 2024
Advanced course STATA	Nivel	0.5	September 9 & September 12 2024
		4	
Transferable skills			
Course English Writing for Academic Purposes	Babel	2	March 4 - April 15 2021
Course Presenting in English	Babel	1.7	September 28 -November 16 2021

Name course, training, activity	Organiser	EC	Completed
		3.7	
Research meetings, expert meetings, seminars			
Academic meetings 'Wetenschappelijk overleg (WO)	Nivel	2	2018-2021
		2	
Elective courses			
Courses & workshops			
Course 'Persoonlijke effectiviteit'	Boertien Vergouwen Overduin	0.4	November 26 2018
Course Alzheimer Disease and Dementia Care	University of Maryland	1.10	June 1 - August 17 2020
Course 'Kwaliteitssyteem Nivel en het verrichten van interne audits'	Nivel	0.3	November 30 2020
Course 'omgaan met stakeholders'	Boertien Vergouwen Overduin	0.4	September 6 - October 11 2021
Calamiteitenonderzoek	TRIASPECT	0.21	September 22 2023
Opleiding auditvaardigheden	Kerteza Academy	0.3	November 20 2023
		2.71	
Transferable skills			
Masterclass 'Kwetsbare oudere'	NPI	0.21	January 26 2018
Course 'Traumatologie en fractuurbehandeling'	NPI	0.86	March 12 – April 9 2018
Participation in PhD intervision group	Nivel	2	2018-2022
Course 'Paratonie en andere motorische stoornissen bij dementie'	NPI	0.21	April 17 2019

A

Name course, training, activity	Organiser	EC	Completed
Tutoring Master of Science student – Clinical Health Sciences (Physiotherapy)	Nivel	1	January - September 2019
Job coach trajectory	CareerSolution	2	June 8 - December 12 2021
Webinar Getting Published: Effectively Community Your Research Workshop	Nature Research Academies	0.43	February 8 - 10 2022
		6.71	

Conference and symposia attendances

Name course, training, activity	Organiser	EC	Completed
Participation 'Incidenten in de patiëntenzorg)	Amsterdam UMC	0.3	September 20 2018
Participation 'Calamiteiten delen en leren van elkaar' (oral presentation)	NFU	0.3	November 15 2018
Participation 'Colloquium IGJ' (oral presentation)	IGJ	0.5	December 13 2018
Participation 'OPEN netwerk' (oral presentation)	OPEN netwerk	0.5	February 22 2019
Conference participation, CaRe days 2019 (oral presentation)	Netherlands School of Public Health and Care Research	1	May 8 & 9 2019
Conference participation, CaRe online symposium	Netherlands School of Public Health and Care Research	0.3	June 02 2020
Conference participation, CaRe Days 2021	Netherlands School of Public Health and Care Research	1	May 26 & 27 2021
Conference participation, Alzheimer Assocation Internal Conference	AAIC	1	July 26 - 30 2021
Conference participation, 31st Alzheimer Europe Conference	Alzheimer Europe	1	December 1 2021
Conference participation, Nursing Home Research internal conference (poster presentation)	Journal of Nursing Home Research (JNHR)	2	

Name course, training, activity	Organiser	EC	Completed
Conference participation, Alzheimer Association International Conference 2022 (poster presentation)	AAIC	2	
		9.9	
	Total	31.02	

A

About the author

Suzanne was born on the 10th of April 1991 in Diemen, the Netherlands. After finishing secondary school (HAVO), she studied Physiotherapy at the Hogeschool van Amsterdam and graduated in 2012. After receiving her bachelor's degree, she started working at long-term care organisations Zorgbalans and Cordaan as a physiotherapist in rehabilitation, primary care and long-stay dementia - , somatic - and psychiatric care.

In 2015, she started the study Health Sciences at the Vrije Universiteit Amsterdam while continuing her work as a physiotherapist. During her study, she wrote her master thesis at the University of Edinburgh and obtained her Master's degree Cum Laude in 2017.

In 2018, Suzanne started working as a researcher at the Netherlands Institute for Health Services Research (NIVEL) in addition to her work as a physiotherapist. During this year, she was involved in studies on various topics, including the administration of high-risk medication in hospitals and the experiences and perspectives of persons experiencing adverse events. In 2019, she started her PhD trajectory.

In October 2021, she exchanged her job as a physiotherapist for the position of quality and safety advisor at long-term care organisation ViVa! Zorggroep and is currently involved in different topics, including adverse events, geriatric rehabilitation and the medical and paramedical health care staff. Suzanne completed her PhD-thesis in 2024, under supervision of Prof. dr. Cordula Wagner, dr. Sandra van Beek and dr. Lilian van Tuyl.

A

Dankwoord

Hij is af! Nu dan echt. Wat ben ik trots! En stiekem ook wel opgelucht dat het erop zit.

Allereerst wil ik graag de bewoners, familieleden, buurtbewoners en medewerkers bedanken die hebben meegewerkt aan de onderzoeken in mijn proefschrift. De vele vragenlijsten en andere onderzoeksmethoden vergden veel tijd in een setting waarin vaak al tijd te kort komt. Ik waardeer de geleverde bijdrage dan ook enorm.

De leden van de promotiecommissie: prof. dr. B.D. Onwuteaka-Philipsen, prof. dr. D.L. Gerritsen, dr. M.F. Pisters, prof. dr. J.M.G.A. Schols, prof. dr. A. Fagertun en dr. M.J. Smits wil ik hartelijk danken voor hun beoordeling en waardevolle commentaar.

Onderzoek doen, en in het bijzonder het schrijven van een proefschrift, is een lang proces met hoge pieken en soms toch ook wel dalen. Eerlijkheidshalve heb ik af en toe echt wel getwijfeld of ik ooit de dag van mijn verdediging zou halen. Gelukkig is dat moment nu toch echt bijna daar. Ik wil dan ook mijn promotor en copromotoren ontzettend bedanken voor hun begeleiding en steun. De gelijkwaardige samenwerking waarin mijn mening, wensen en kennis altijd serieus werden genomen waardeer ik enorm. Cordula, heel erg bedankt voor de mogelijkheid om bij het Nivel te komen werken en later dit proefschrift te schrijven. Ik heb onze samenwerking binnen de verschillende onderzoeksprojecten als zeer prettig ervaren. Jouw vermogen om het overzicht te bewaren, elk artikel naar een hoger niveau te tillen en kennis over veiligheid zijn van groot belang geweest voor dit proefschrift. Lilian, ik ben heel erg blij dat je mijn promotieteam op een later moment bent komen versterken. Jouw uitgebreide kennis van de verschillende onderzoeksmethoden, gecombineerd met je kritische blik en betrokkenheid hebben mij geholpen om dit proefschrift tot een goed einde te brengen. Ik heb een hele fijne tijd gehad binnen het themagebied Kwaliteit en Organisatie van Zorg onder jouw leiderschap. Je hebt mij alle mogelijkheden geboden om mij verder te ontwikkelen. Ik ben je hier heel erg dankbaar voor. Sandra, ik overdrijf niet als ik zeg dat jouw kennis, expertise en ervaring essentieel zijn geweest voor de totstandkoming en afronding van dit proefschrift. Onderzoek in de langdurige zorg is complex en jouw aandeel hierin was dan ook absoluut onmisbaar. Naast jouw inhoudelijke bijdrage wil ik ook graag mijn waardering uitspreken voor je geduld, persoonlijke betrokkenheid en begeleiding op maat. We hebben het er weleens over gehad dat ik geen doorsnee promovenda ben. Het ontrafelen van theoretische kaders en sociologische theorieën was absoluut niet mijn sterkste punt. Maar jij draaide nooit je hand om voor een zoveelste 'college van Sandra van Beek' om mij hierin op weg te helpen. Ik kan je niet genoeg bedanken.

Ik zou ook graag mijn (oud-)collega's bij het Nivel, Cordaan en ViVa! Zorggroep willen bedanken voor de fijne samenwerking van de afgelopen jaren en hun betrokkenheid bij mij en dit proefschrift.

Lieve Britte, de voorkant van mijn proefschrift is prachtig! Hij is helemaal geworden zoals ik het in mijn hoofd had. Heel erg bedankt voor jouw bijdrage. De lange afstand (Noorwegen is niet om de hoek) maakt dat we elkaar niet maandelijks zien, maar ik koester de momenten die we samen delen. Jouw vriendschap waardeer ik enorm en is mij erg dierbaar.

Lieve Nienke, enorm bedankt voor de hulp bij de vormgeving van de presentatie voor mijn verdediging. Je hebt er iets prachtigs van gemaakt!

Het schrijven van een proefschrift is onmogelijk zonder de steun van je naasten. Ik voel mij enorm gezegend met zoveel lieve mensen om mij heen en wil heel graag een paar mensen in het bijzonder naar voren schuiven. Lieve Sanne, ik denk dat er maar weinig paranimfen zijn die zo'n groot deel van een proefschrift daadwerkelijk hebben gelezen zonder zelf in het onderzoek te werken. Ik ben je enorm dankbaar voor je hulp en ondersteuning en dat jij mijn paranimf wilt zijn samen met Jane. Jullie steun, interesse en betrokkenheid is heel belangrijk geweest tijdens dit hele proces. Onze jarenlange vriendschap is enorm waardevol en koester ik maximaal.

Lieve Steef, het waren pittige jaren waarin er veel op onze schouders terecht is gekomen. Het afronden van dit proefschrift vergde daarbovenop veel en jij hebt van tijd tot tijd een flinke tand bij moeten zetten om dit mogelijk te maken. Extra trots ben ik daarom op jou, ons en alles wat wij bereikt hebben samen. Ik ben je enorm dankbaar voor je liefde en onvoorwaardelijke steun. Zonder jou was dit proefschrift er nooit gekomen.

Het combineren van mijn carrière, proefschrift en het moederschap was af en toe best pittig, maar ik zou het voor geen goud anders gedaan hebben. Lieve Levi, je maakt elke dag en elk moment mooier en waardevoller. We zijn ongelooflijk trots op je en houden heel veel van je. Lieve Frummel, ik vind het heel bijzonder dat je er toch al een beetje bij bent op de grote dag. We kunnen niet wachten om je te ontmoeten!

A