Exercise and physiotherapy for nursing home residents with dementia: practices and preferences

Boer, D.E.

Chapter 1:

General Introduction

Dementia

Definition, symptoms and epidemiology of dementia

Dementia is a collective term for degenerative cognitive disorders, with more than ten distinct syndromes or illnesses classified under it.[1] The term Alzheimer's disease is commonly associated with dementia; however, it encompasses two distinct constructs: a dementia syndrome and a pathological entity.[2] In 2018, the diagnostic criteria for Alzheimer's disease were revised, distinguishing Alzheimer's disease as a specific neuropathological condition and Alzheimer's dementia as the clinical manifestation of the disease: a form of dementia.[3] Although the precise etiology of dementia is not always fully understood and is often confirmed only postmortem, knowledge of its risk factors has expanded.[2,4] Pathological characteristics directly associated with Alzheimer's dementia include the accumulation of amyloid plaques and tau tangles in the brain. Additionally, cerebrovascular disease, genetic predisposition, cardiovascular risk factors, head trauma, and various sociodemographic and behavioral factors have been implicated in increasing the risk of dementia.[2]

The diagnostic criteria outlined in *the Diagnostic and Statistical Manual of Mental Disorders*, *Fifth Edition* (DSM-5)[5] are commonly used to diagnose dementia. According to these criteria, a dementia diagnosis requires the following: (1) clear evidence of significant cognitive decline from a previous level of functioning in one or more cognitive domains, (2) impairment that interferes with independence in daily activities, (3) cognitive deficits that do not occur exclusively during delirium, and (4) deficits that are not better explained by another mental disorder. The most recognizable features of dementia are difficulties in memory, disturbances in language, psychological and psychiatric changes, and impairments in activities of daily living.[1] In addition to cognitive impairment and difficulties in daily activities, dementia is associated with a decline in mobility, muscle strength and balance[6–8] an increased risk of falls.[9] As dementia progresses and individuals require more assistance, they become increasingly reliant on both formal and informal care, which may eventually result in nursing home admission.[10]

Interventions to treat dementia symptoms

People with dementia often receive active treatment aimed at maintaining their cognitive and physical functions while mitigating the impact of neuropsychiatric symptoms. Although pharmacological interventions are commonly employed, they are associated with significant adverse effects, including an increased risk of falls and mortality.[11–13] Furthermore, the efficacy of pharmacological interventions remains a subject of debate.[14] In contrast, a wide range of non-pharmacological therapeutic interventions is available, broadly categorized into three groups: sensory-oriented, cognition-oriented, and move-

ment-oriented therapies.[15] The focus of this thesis is on movement-oriented therapies, encompassing exercise therapy and physical activity therapy.

Nursing home care for people with dementia

Nursing homes

Nursing homes serve a function in long-term care by offering continuous medical supervision, rehabilitative services including physiotherapy and occupational therapy, and assistance with daily activities to individuals who can no longer live independently.[16] These facilities primarily support older individuals with chronic illnesses, disabilities, or cognitive impairments such as dementia, who require assistance with daily tasks, including personal hygiene, dressing, and medication management. The prevalence of dementia in nursing homes varies globally, ranging from 42% in the United States[17] to 84% in Scandinavia[18] and 97% in Japan.[19] Furthermore, the role of nursing homes within society varies across countries and is influenced by cultural norms, healthcare systems, and government policies. The Netherlands allocates approximately 3% of their Gross Domestic Product (GDP) to nursing home care, nearly twice the expenditure of other high-income countries.[20] In the Netherlands, there are approximately 1,200 nursing homes [21] providing care to 115,000 residents.[22] Among these Dutch nursing home residents, 44% have a formal diagnosis of dementia, while an additional 22% experience frequent memory issues without a confirmed diagnosis.[23] Furthermore, 85% of nursing home residents in the Netherlands experience severe physical limitations.[23]

Informal care in nursing homes

Long-term care and nursing home care systems in Nordic and Western European countries are characterized by a high degree of formalization, whereas countries in Southern and Eastern Europe and Central Asia primarily rely on informal caregiving.[24] At present, this trend is shifting in the Netherlands, where efforts to integrate formal and informal care have increased over the past five years.[22] The national long-term care division of the Netherlands has identified a growing demand for nursing home care alongside a decline in its availability. Additionally, there is increasing concern about the rise of individualism in society. As a response, a transition toward greater collaboration between informal caregivers and nursing home staff, including physiotherapists, is considered necessary.

Given the cognitive and communicative impairments associated with dementia, informal caregivers frequently assist nursing home residents in making therapeutic decisions.[25] In cases where residents are unable to participate in such discussions, healthcare professionals may engage with their representatives. However, informal caregivers of nursing home residents with dementia often report feelings of exclusion and isolation. These negative

feelings can contribute to dissatisfaction with the care provided.[26,27] There is currently limited knowledge regarding their perspectives, needs, and preferences concerning exercise and physiotherapy. Strengthening collaboration between physiotherapists and informal caregivers may help reduce conflict, alleviate workload pressures, and foster more positive staff attitudes toward informal caregivers.[26] Therefore, it is essential to consider the perspectives, needs, and preferences of informal caregivers regarding physiotherapy for nursing home residents with dementia.

Physical activity, exercise and physiotherapy in nursing homes

Physical activity and exercise in the nursing home

Physical activity and exercise are considered important elements in the care of people with dementia, both living independently and in nursing homes.[4,28] Exercise is defined as "a subset of physical activity that is planned, structured, and repetitive and has as a final or an intermediate objective the improvement or maintenance of physical fitness".[29] This distinguishes it from physical activity, which refers to "any bodily movement produced by skeletal muscles that results in energy expenditure".[29] Exercise has been established as a preventive intervention to reduce the risk of neurological and cognitive impairments and cardiometabolic disorders, but also physical dependency. Furthermore, exercise interventions come with minimal adverse effects.[28] The neurological and cognitive benefits of exercise can largely be attributed to improved vascular health, achieved through reductions in blood pressure, arterial stiffness, oxidative stress, and systemic inflammation, as well as enhanced endothelial function, all of which contribute to increased cerebral perfusion.[30] The mechanisms through which exercise influences other outcome measures, including musculoskeletal and psychiatric health, are linked to increased aerobic capacity and muscle strength, ultimately improving physical well-being.[31] Physical exercise promotes muscle protein synthesis and modulates inflammatory processes, generating positive effects on muscle mass and strength.[32]

Although exercise has many health benefits, adherence from nursing home residents with dementia to exercise interventions is a mere 65.4%.[33] Consequently, this may reduce the overall effectiveness of the intervention. Supervision by trained professionals such as physiotherapists can enhance the safety and effectiveness of exercise programs by ensuring appropriate intensity and load while promoting adherence.[33,34] In order to further enhance exercise adherence, supervisors are advised to take the needs and preferences of the residents into account.[33,34] However, these needs and preferences of nursing home residents with dementia regarding exercise and physiotherapy are currently unknown, and can therefore not be implemented in practice.

Contents and effects of exercise interventions

Several reviews have summarized research on exercise interventions designed specifically for nursing home residents with dementia.[35–40] The authors of these reviews highlighted that there is variety in its delivery, limiting the formation of detailed exercise advice. In these reviews, exercise interventions included traditional physical exercise programs, as well as dance,[37] hand movements,[37] handcraft activities,[35] walking and talking programs,[36–39] Tai Chi,[36] or ball games.[38] The effects of these exercise interventions were assessed across a range of outcomes, including independence in activities of daily living (ADL),[37,39] walking performance and endurance,[37,38] cognition,[35,37,40] depression,[35–37] behavioral symptoms,[36,37,39] nutrition,[37] mobility,[37–39] and balance.[37,38] While some individual studies reported beneficial effects, the overall effectiveness of exercise remains uncertain due to methodological limitations of the included studies and the considerable variability in intervention characteristics. The supervision of these interventions was provided by various professionals including research assistants,[37,38] occupational therapists,[37,38] psychology students,[37,38] recreational therapists,[37] nurses,[37,38] caregivers,[37,38] or an exercise scientist.[38] Although professional supervision is suggested and physical therapy is frequently used in the treatment of nursing home residents, it's effects remain uncertain.

Physiotherapy in nursing homes

Physiotherapy (referred to as physical therapy in the United States and certain regions of Canada) is often utilized in nursing homes, but it's provision varies across countries,[41] regions,[42] care settings,[41,43] and individual therapists.[42,43] In the Netherlands, physiotherapists in nursing homes primarily supervise individual exercise programs, but they also provide an advisory role for residents, formal and informal caregivers, and organizational boards on a broad range of health topics.[42] According to the study's authors and respondents, encountered variations of physiotherapist roles were primarily attributed to structural and organizational factors. A 2019 systematic review on the international application of physiotherapy in nursing homes identified pain management in Australia and pressure ulcer care in the United States as the only described interventions.[41] Additionally, separate trials indicate that exercise-based interventions are incorporated into physiotherapy treatments in Sweden [44] and Norway.[45] Regarding the availability of physiotherapy, the proportion of Dutch nursing home residents with dementia receiving physiotherapy ranges from 23% to 69%, though this estimate varies due to different research methods, with some studies including residents admitted for rehabilitation.[42,46] Nevertheless, this rate is higher than in other high-income countries, where an average of 14% of nursing home residents receive physiotherapy.[41] The variation in the contents, availability and provision can potentially result in suboptimal treatment. To reduce this variation, calls for guidelines on physiotherapy for nursing home residents with dementia have been made.[41,47] Before guidelines can be developed, more knowledge about factors that cause variation is necessary.

A recent Delphi study examined the core competencies required for physiotherapists working with individuals with dementia.[48] The study included 35 physiotherapy experts from 11 countries, of whom 83% reported current or past working experience in nursing home settings. This research identified 137 core competencies spanning five domains: (1) knowledge and understanding of dementia, (2) assessment, (3) management, interventions, and prevention, (4) communication, therapeutic relationships, and person-centered care, and (5) physiotherapists' self-management and professional development. The breadth of variables involved, and the level of expertise required highlight that physiotherapy for nursing home residents with dementia constitutes a complex intervention.[49]

Research questions of this thesis

To address the knowledge gaps surrounding exercise and physiotherapy for nursing home residents with dementia, we use a framework designed to structure research of complex interventions. In 2021, the UK Medical Research Council has developed this framework.[49] The MRC framework views complex interventions as dynamic and context-dependent, and anchors their development, evaluation, and implementation in six core guiding elements: *context* (how the surrounding system influences and is influenced by the intervention), *programme theory* (the mechanisms and assumptions underlying how the intervention is expected to work), *stakeholder engagement* (active involvement of those affected in shaping the intervention), *key uncertainties* (identifying and prioritizing knowledge gaps), *intervention refinement* (iterative adaptation to improve fit and effectiveness), and *economic considerations* (assessing resource use, cost-effectiveness, and sustainability). Recognizing the identified knowledge gaps, particularly in the context of physiotherapy and exercise for nursing home residents with dementia, the research questions addressed in this thesis are:

1. What are the contents and effectiveness of physiotherapist-supervised exercise interventions for nursing home residents with dementia, and which contextual factors influence their implementation?
2. What are the perceptions, needs, and preferences of nursing home residents, informal caregivers and health care professionals regarding physiotherapy and exercise for nursing home residents with dementia, including their mutual collaboration?
3. What is the feasibility of a physiotherapist-supervised exercise intervention for nursing home residents with dementia?

The first research question is addressed in two chapters:

- Chapter 2: Describes a systematic review on the characteristics and effectiveness of physical therapist supervised exercise interventions for nursing home residents with dementia.
- Chapter 3: Outlines the structure and process of physiotherapy services for nursing home residents with dementia in the Netherlands

The second research question is addressed in three chapters:

- Chapter 4: Concerns the perceptions, needs and preferences of informal caregivers of nursing home residents with dementia regarding physical therapy.
- Chapter 5: Explores the physiotherapy and exercise needs and preferences of nursing home residents with dementia.
- Chapter 6: Investigates the barriers and facilitators of family involvement in physiotherapy and exercise for nursing home residents with dementia.

The third research question is addressed in one chapter

- Chapter 7: Describes a feasibility study of a physiotherapist supervised exercise intervention for nursing home residents with dementia.

References

1. Burns A, Iliffe S. Dementia. *BMJ*. 2009; 338: 405-409. doi:10.1136/bmj.b75
2. James BD, Bennett DA. Causes and Patterns of Dementia: An Update in the Era of Redefining Alzheimer's Disease. *Annual Review of Public Health.* 2019; 65–84. doi:10.1146/annurev-publhealth
3. Jack CR, Bennett DA, Blennow K, et al. NIA-AA Research Framework: Toward a biological definition of Alzheimer's disease. *Alzheimer's and Dementia.* 2018; 14: 535–562. doi:10.1016/j.jalz.2018.02.018
4. Arvanitakis Z, Shah RC, Bennett DA. Diagnosis and Management of Dementia: Review. *JAMA.* 2019; 322:1589–1599. doi: 10.1001/jama.2019.4782
5. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders*. 2013. doi: 10.1176/appi.books.9780890425596.744053.
6. Tolea MI, Morris JC, Galvin JE. Trajectory of mobility decline by type of dementia. *Alzheimer Dis Assoc Disord.* 2016; 30: 60–66. doi: 10.1097/WAD.0000000000000091
7. Kido T, Tabara Y, Igase M, et al. Postural instability is associated with brain atrophy and cognitive impairment in the elderly: The J-SHIPP study. *Dement Geriatr Cogn Disord.* 2010; 29: 379–387. doi: 10.1159/000255106
8. Sverdrup K, Selbæk G, Bergh S, et al. Physical performance across the cognitive spectrum and between dementia subtypes in a population-based sample of older adults: The HUNT study. *Arch Gerontol Geriatr*. 2021;95:104400. doi:10.1016/j.archger.2021.104400
9. Van Doorn C, Gruber-Baldini AL, Zimmerman S, et al. Dementia as a Risk Factor for Falls and Fall Injuries Among Nursing Home Residents. *J Am Geriatr Soc*. 2003 Sep;51(9):1213-8. doi: 10.1046/j.1532-5415.2003.51404.x. PMID: 12919232.
10. Gaugler JE, Duval S, Anderson KA, et al. Predicting nursing home admission in the U.S: a meta-analysis. *BMC Geriatr.* 2007;7:13. doi:10.1186/1471-2318-7-13
11. Gill SS, Bronskill SE, Normand S-LT, et al. Antipsychotic Drug Use and Mortality in Older Adults with Dementia, *Ann Intern Med. 2007* Jun 5;146(11):775-86. doi: 10.7326/0003-4819-146-11-200706050-00006. PMID: 17548409.
12. Seppala LJ, van de Glind EMM, Daams JG, et al. Fall-Risk-Increasing Drugs: A Systematic Review and Meta-analysis: III. Others. *J Am Med Dir Assoc.* 2018; 19: 372.e1-372.e8. doi: 10.1016/j.jamda.2017.12.099
13. Seppala LJ, Wermelink AMAT, de Vries M, et al. Fall-Risk-Increasing Drugs: A Systematic Review and Meta-Analysis: II. Psychotropics. *J Am Med Dir Assoc.* 2018; 19: 371.e11-371.e17. doi:10.1016/j.jamda.2017.12.098
14. Koch J, Amos JG, Beattie E, et al. Non-pharmacological interventions for neuropsychiatric symptoms of dementia in residential aged care settings: an umbrella review. *Int J Nurs Stud.* Epub ahead of print 2022 Apr 1. doi: 10.1016/j.ijnurstu.2022.104187.
15. Wang G, Albayrak A, Van Der Cammen TJM. A systematic review of non-pharmacological interventions for BPSD in nursing home residents with dementia: from a perspective of ergonomics. *Int Psychogeriatr.* 2019; 31: 1137–1149. doi: 10.1017/S1041610218001679
16. Colombo F, Llena-Nozal A, Mercier J, et al. Help wanted? Providing and paying for long-term care. *OECD Health Policy Studies*, 2011, p. 327. doi: 10.1787/9789264097759-en
17. Mukamel DB, Saliba D, Ladd H, et al. Dementia care is widespread in US nursing homes; facilities with the most dementia patients may offer better care. *Health Aff.* 2023; 42: 795–803. doi: 10.1377/hlthaff.2022.01263

18. Røen I, Selbæk G, Kirkevold Ø, et al. Resourse use and disease couse in dementia - nursing home (REDIC-NH), a longitudinal cohort study design and patient characteristics at admission to Norwegian nursing homes. *BMC Health Serv Res.* Epub ahead of print 2017. doi: 10.1186/s12913-017-2289-x.
19. Japanese Ministry of Health L and W. *The Situation of Users of Nursing Care Insurance Facilities*, http://www.mhlw.go.jp/toukei/ saikin/hw/kaigo/service16/dl/kekka-gaiyou_05.pdf. (2016, accessed 2 February 2025).
20. United Nations. *World Social Report 2023: Leaving No One Behind In An Ageing World*. 2023. ISBN 978-92-1-130458-9
21. Patiëntenfederatie Nederland. Zorgkaart Nederland. *2023*, https://www.zorgkaartnederland.nl/verpleeghuis-en-verzorgingshuis?typezorg%5B0%5D=Langdurig%20verblijf&specialisatie%5B0%5D=Dementie (accessed 25 August 2023).
22. Raad voor Volksgezondheid & Samenleving (RVS). Van zelfredzaam naar samenredzaam: Signalement Passende langdurige zorg. Diemen, Nederland. August 2024.
23. Verbeek-Oudijk D, Koper I. *Het leven in een verpleeghuis*. Den Haag, www.scp.nl (February 2021). ISBN:9789037709650
24. WHO Regional Office for Europe. *Rebuilding for sustainability and resilience: strengthening the integrated delivery of long-term care in the European region*. Copenhagen, 2022. Licence: CC BY-NC-SA 3.0 IGO
25. Miller LM, Whitlach JC, Lyons KS. Shared decision-making in dementia: A review of patient and family carer involvement. *Dementia.* 2014; 15: 1141–1157. doi: 10.1177/1471301214555542
26. 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: 60–85. doi: 10.1177/1074840718754314
27. Bramble M, Moyle W, Mcallister M. Seeking connection: family care experiences following long-term dementia care placement. *J Clin Nurs.* 2009; 18: 3118–3125. doi: 10.1111/j.1365-2702.2009.02878.x
28. Izquierdo M, de Souto Barreto P, Arai H, et al. Global consensus on optimal exercise recommendations for enhancing healthy longevity in older adults (ICFSR). *J Nutr Health Aging.* 29. Epub ahead of print 1 January 2025. doi: 10.1016/j.jnha.2024.100401.
29. Caspersen CJ, Powell KE, Christenson GM. Physical Activity, Exercise, and Physical Fitness: Definitions and Distinctions for Health-Related Research Synopsis. *Public Health Rep.* 1985 Mar-Apr; 100: 126–131. PMID: 3920711; PMCID: PMC1424733.
30. Forbes D, Forbes SC, Blake CM, et al. Exercise programs for people with dementia. *Cochrane Database Syst Rev*. 2015;(4):CD006489. doi:10.1002/14651858.CD006489.pub4
31. Pedersen BK, Saltin B. Exercise as medicine - Evidence for prescribing exercise as therapy in 26 different chronic diseases. *Scand J Med Sci Sports.* 2015; 25: 1–72. doi: 10.1111/sms.12581
32. Vandewoude M, Bautmans I. Sarcopenia: Is it preventable? *Sarcopenia* 2012; 324–337. doi: 10.1002/9781118338032.ch21
33. Di Lorito C, Bosco A, Booth V, et al. Adherence to exercise interventions in older people with mild cognitive impairment and dementia: A systematic review and meta-analysis. *Prev Med Rep.* 2020; 19: 101139. doi: 10.1016/j.pmedr.2020.101139
34. Vseteckova J, Deepak-Gopinath M, Borgstrom E, et al. Barriers and facilitators to adherence to group exercise in institutionalized older people living with dementia: a systematic review. *Eur Rev Aging Phys.* 2018;15:11. Published 2018 Nov 9. doi:10.1186/s11556-018-0200-3
35. Da Silva JL, Agbangla NF, Le Page C, et al. Effects of Chronic Physical Exercise or Multicomponent Exercise Programs on the Mental Health and Cognition of Older Adults Living in a Nurs-

ing Home: A Systematic Review of Studies From the Past 10 Years. *Front Psychol.* Published 2022 May 13. doi: 10.3389/fpsyg.2022.888851.

36. de Souto Barreto P, Demougeot L, Pillard F, et al. Exercise training for managing behavioral and psychological symptoms in people with dementia: A systematic review and meta-analysis. *Ageing Res Rev.* 2015; 24: 274–285. doi: 10.1016/j.arr.2015.09.001
37. 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. *J Am Med Dir Assoc.* 2016; 17: 104–116. doi: 10.1016/j.jamda.2015.08.016
38. Littbrand H, Stenvall M, Rosendahl E. Applicability and effects of physical exercise on physical and cognitive functions and activities of daily living among people with dementia: A systematic review. *Am J Phys Med Rehabil.* 2011; 90: 495–518. doi:10.1097/PHM.0b013e318214de26
39. Pitkälä K, Savikko N, Poysti M, et al. Efficacy of physical exercise intervention on mobility and physical functioning in older people with dementia: A systematic review. *Exp Gerontol.* 2013; 48: 85–93. doi: 10.1016/j.exger.2012.08.008
40. Learner NA, Williams JM. Can physical activity be used to maintain cognitive function in nursing home residents with dementia? A literature review. *Phys Ther Rev.* 2016; 21: 184–191. doi: 10.1080/10833196.2016.1266138
41. Brett L, Noblet T, Jorgensen M, Georgiou A. The use of physiotherapy in nursing homes internationally: A systematic review. *PLoS One*. 2019;14(7):e0219488. Published 2019 Jul 11. doi:10.1371/journal.pone.0219488
42. Sterke S, Paula A, Oomen H, et al. Physiotherapy in nursing homes. A qualitative study of physiotherapists' views and experiences. *BMC Geriatr.* 2021; 21: 1–9. doi: https://doi.org/10.1186/s12877-021-02080-6
43. Killingback C, Green A, Naylor J. Development of a framework for person-centred physiotherapy. *Phys Ther Rev.* 2022; 27: 414–429. doi: 10.1080/10833196.2022.2129157
44. Toots A, Wiklund R, Littbrand H, et al. The Effects of Exercise on Falls in Older People With Dementia Living in Nursing Homes: A Randomized Controlled Trial. *J Am Med Dir Assoc.* 2018; 20: 835-842.e1. doi: 10.1016/j.jamda.2018.10.009
45. Telenius EW, Engedal K, Bergland A. Effect of a high-intensity exercise program on physical function and mental health in nursing home residents with dementia: An assessor blinded randomized controlled trial. *PLoS One.* 2015; 10: 1–18. doi: 10.1371/journal.pone.0126102
46. De Boer ME, Leemrijse CJ, Van Den Ende CHM, et al. The availability of allied health care in nursing homes. *Disabil Rehabil.* 2007; 29: 665–670. doi: 10.1080/09638280600926561
47. McArthur C, Gibbs JC, Patel R, et al. A Scoping Review of Physical Rehabilitation in Long-Term Care: Interventions, Outcomes, Tools. *Can J Aging.* 2017; 36: 435–452. doi: 10.1017/S071498081700040X
48. Taylor ME, Sverdrup K, Ries J, et al. A core capability framework for physiotherapists to deliver quality care when working with people living with dementia and their families/caregivers: An international modified e-Delphi. *Physiotherapy*. 2025;126:101411. doi: 10.1016/j.physio.2024.07.002.
49. Skivington K, Matthews L, Simpson SA, et al. A new framework for developing and evaluating complex interventions: Update of Medical Research Council guidance. *BMJ*. 2021;374:n2061. Published 2021 Sep 30. doi:10.1136/bmj.n2061