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

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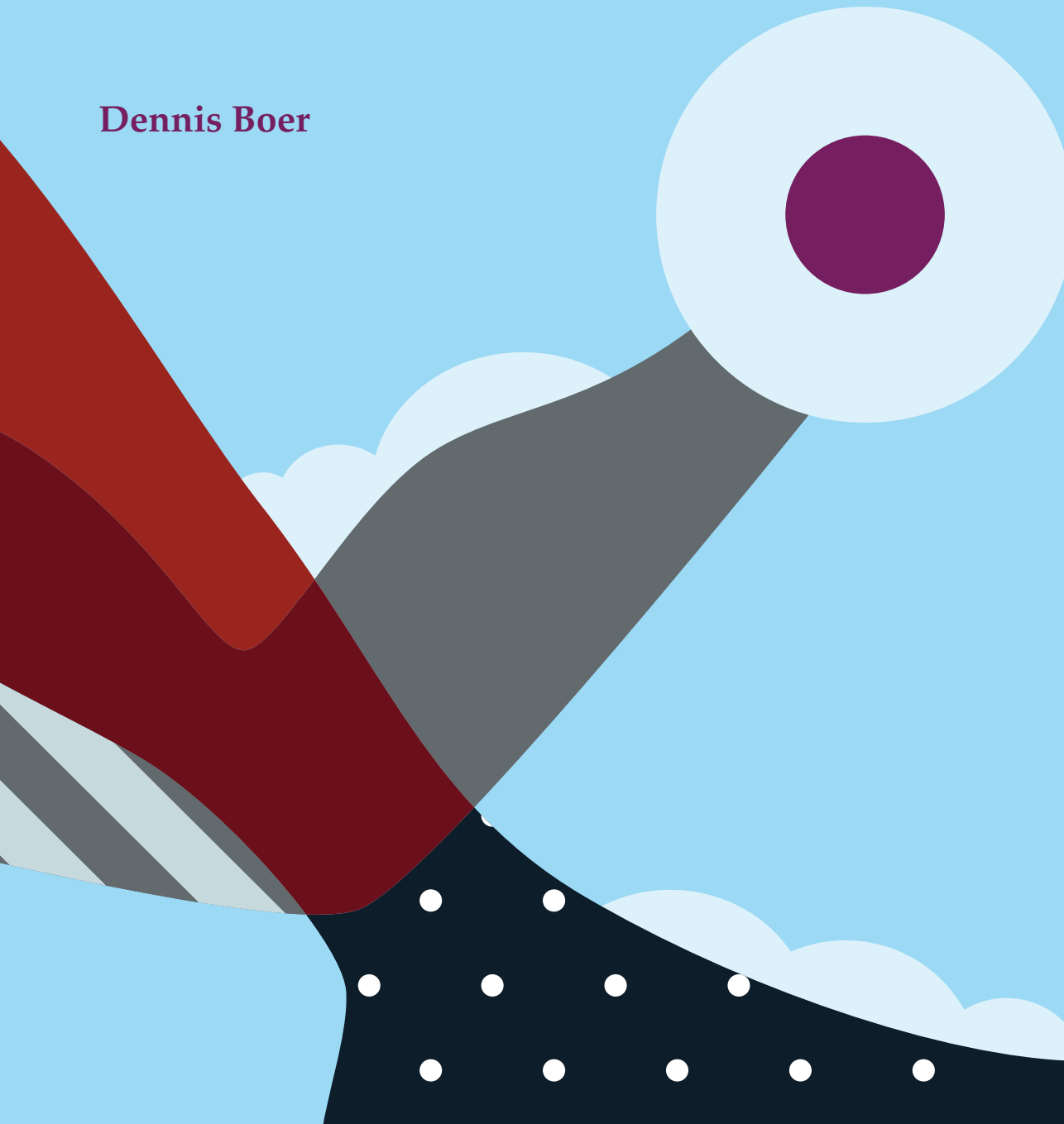

# Exercise and physiotherapy for nursing home residents with dementia: practices and preferences

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

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# 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.

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# Part 1

# Chapter 2:

## Characteristics and effectiveness of physical therapist supervised exercise interventions for nursing home residents with dementia: a systematic review

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## Abstract

**Background and Objectives:** Although physical therapy, in particular exercise therapy, is widely used in nursing home residents with dementia, the literature on this topic is relatively scarce. This systematic review aimed to summarize the literature on the characteristics and effectiveness of exercise interventions supervised by physical therapists in nursing home residents with dementia.

**Research Design and Methods:** Six electronic databases were systematically searched for relevant studies up to the 17th of August 2022. Randomized controlled trials (RCTs) comparing exercise interventions supervised by a physical therapist to any other form of intervention or usual care in nursing home residents with dementia were selected. Data were narratively analyzed and forest plots visualizing exercise effects were created.

**Results:** From the 1377 records retrieved and screened, six RCTs, reported in 11 papers, met the selection criteria. Included studies used multimodal or aerobic exercise interventions, with the frequency, duration and intensity varying across studies. Three of the six studies were at high risk of bias. Due to inconsistency in the findings and variety in outcome measures, results on the effectiveness of the interventions are inconclusive.

**Implications:** Our review emphasizes the need for more robust studies to offer understanding of the efficacy of exercise interventions supervised by physical therapists for nursing home residents with dementia.

## Background and Objectives

Dementia has an estimated prevalence of 48 to 84%[1,2] in nursing home residents in Western countries. Nursing home residents often display multiple geriatric syndromes that result in limited functional performance and mobility and increased care needs.[3] Physical exercise is an important intervention to positively impact their functional capacities, thereby improving daily functional performance.[4]

Exercise guidelines[4–6] have been published for nursing home residents, including those with dementia. Recommendations advocate the use of multicomponent exercise consisting of strength, endurance, and balance exercises to be conducted a minimum of two times per week at moderate intensity, under the supervision of an exercise specialist.[4] In this context, physical therapy services are globally used by 10-67% of nursing home residents.[7] The usage, however, is unevenly spread, with residents without dementia and on temporary stay receiving significantly more physical therapy.[8,9] A rationale for this is unclear, and may result in permanent residents with dementia not receiving sufficient physical therapy.[8]

Of the six known systematic reviews[10–15] on exercise interventions in nursing home residents with dementia, two[10,14] have included studies with physical therapist supervised exercise interventions, while in the other reviews[11–13,15] supervisors were not described. Apart from physical therapists, the interventions were conducted by research assistants,[10,14] occupational therapists,[10,14] psychology students,[10,14] recreational therapists,[10] nurses,[10,14] caregivers[10,14] and an exercise scientist.[14] Furthermore, the characteristics of the included interventions varied widely. Reviews included both traditional physical exercise interventions as well as dance,[10] hand-movement,[10] walking and talking,[10,12,14,15] Tai Chi,[12] and ball-games.[14] This variation in both exercise supervisors and intervention characteristics limits the translation of findings into clinical care.

Regarding the effects of exercise, earlier reviews evaluated the impact of interventions on a wide range of outcomes. While two reviews, specifically targeting depression[12] and cognition,[13] identified potential positive effects, the overall evidence presents conflicting or limited findings on the outcomes independence of daily activities (ADL),[10,15] walking performance and endurance,[10,14,15] cognition,[10] depression,[10,15] behavioral symptoms,[10,15] nutrition,[15] mobility,[10,14] and balance.[14] Explanations for this uncertainty of the effects might stem from methodological flaws of included studies,[14,15] as well as the aforementioned variability in intervention characteristics across studies.[10,13]

A systematic review concentrating exclusively on exercise interventions supervised by physical therapists could reduce the heterogeneity in exercise characteristics. This ap-

proach is more in line with the clinical setting of a nursing home, where physical therapists often oversee exercise programs. In terms of effectiveness, a prior study has shown that the involvement of an exercise specialist improves exercise adherence and intensity, which may potentially lead to better health outcomes for this population.[16]

To summarize, exercise under the supervision of an exercise specialist, such as a physical therapist, is recommended by international guidelines.[4,5] Although physical therapy is frequently used in the treatment of nursing home residents with dementia, its effects are uncertain. Therefore, the aim of the present systematic review was to systematically search the available literature and answer the following questions:

- What are the characteristics of exercise interventions supervised by physical therapists for nursing home residents with dementia as employed in (cluster) randomized controlled clinical trials?
- What is the effectiveness of exercise interventions compared to usual care or any other intervention?

## Research design and Methods

### Study design

This systematic review was registered in the PROSPERO prospective register of systematic reviews (registration number: CRD42022351596) and is reported according to Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.[17]

### Search strategy

The search strategy was designed collaboratively by three authors (DB, TVV, and JS), one of whom is a trained librarian (JS). The search strategy was developed for PubMed/Medline and was then modified for Cochrane Library, Embase, Web of Science, Emcare and the Physiotherapy Evidence Database (PEDro), using MeSH terms and free text. Databases were searched from inception up to the current date (17$^{th}$ of August 2022). Key PI(M)CO-terms included "nursing homes", "dementia", "exercise therapy" and "randomized controlled trials". The full search strategy can be found in the Supplementary materials (see table S1). The database of clinicaltrials.gov was searched for ongoing studies or unpublished data. Previously published systematic reviews and reference lists of the included articles were manually searched to identify eligible articles.

### Selection of studies

Retrieved records were exported to the Rayyan review software (Rayyan Systems Inc., Cambridge, United States of America). After elimination of duplicates, selection of studies

was independently performed by two reviewers (DB, CS). Studies were eligible for inclusion if they included nursing home residents with a diagnosis of dementia irrespective of the specific diagnostic criteria. Only (cluster) RCTs were considered in order to reduce the heterogeneity among studies. Studies were included if they compared an exercise intervention (fully or partially supervised by a physical therapist) to any other intervention or no intervention. Articles written in English, Dutch or Spanish were considered. Studies were excluded if they included patients with dementia who temporarily stayed in a nursing home for rehabilitation; included mixed populations of residents with and without dementia and did not report separately on residents with dementia; concerned an intervention where physical therapy was part of a multi-component intervention (for example a fall-risk program with medication provision, exercise therapy and home adaptations). Selection of studies was conducted in two steps. First, titles and abstracts were screened using the abovementioned criteria, and if deemed relevant or when eligibility was unclear, full text papers were obtained. Full-text papers were subsequently assessed for eligibility using the same criteria. A third independent reviewer (TVV) was consulted in case of discrepancies. Study protocols were reviewed to determine if separate articles belonged to the same study.

## Data extraction

Two reviewers (DB, SS) extracted all data from eligible studies independently according to a pre-specified data extraction sheet in Microsoft Excel (Version 2202 14931.20626). In a meeting, the two researchers discussed their individual extracted data to reach consensus.

The following study characteristics were extracted: study type, age, sex, type of dementia, the nature of the treatment arms, duration of study/follow-up. Extraction of intervention characteristics was based on two templates for the description of non-pharmacological/exercise interventions, i.e. the CERT template[18] and the TIDieR checklist.[19] The characteristics considered in this review consisted of: exercise type, materials used, procedures, exercise conductors, group size, place of delivery, intervention frequency and duration, tailoring, methods of assessing adherence, adverse events, and study length. Regarding the extraction of outcomes, no primary outcomes of interest were defined for this review. We extracted all outcome data (any measures of effectiveness and/or safety) as presented in the studies, including within group and between group difference, confidence interval, (interquartile) range, standard deviation and/or p-value, where appropriate.

## Risk of Bias assessment and assessment of certainty in the evidence

The risk of bias of individual studies was assessed with the most recent version of the Cochrane risk-of-bias tool for randomized trials (RoB 2),[20] or the adapted risk-of-bias tool for cluster-randomized trials (RoB 2 CRT).[21] The RoB 2 tool assesses bias across five do-

mains: randomization; deviations from the intended intervention; missing outcome data; measurement of the outcome; selection of reported results (publication bias). The risk of bias outcome is labeled as "low", "some concerns" or "high". In exercise interventions, it is nearly impossible to blind participants and people who deliver the intervention. Therefore, these criteria were not considered. Two reviewers (DB, CS) independently assessed the risk of bias of included studies. A third assessor (TVV) was available if discrepancies could not be resolved.

The Grading of Recommendations, Assessment, Development, and Evaluations GRADE approach[22] was used to assess the certainty in the evidence of exercise effects on the outcomes reported. The certainty in the evidence was determined for outcomes with a minimum of three studies reporting on it. Certainty was categorized into "High" (high confidence in the found effect), "Moderate" (future research could have an important impact in the estimated effect), "Low" (future research is very likely to have an important effect) and "Very low" (any estimate of effect is very uncertain). According to the GRADE approach, certainty is initially determined by study design (RCTs have a higher initial quality compared to observational studies) and may be affected by factors such as risk of bias, inconsistency, indirectness, imprecision, and publication bias. It can be positively influenced by a large effect, dose response or confounding that reduces the observed effect.

## Data analysis

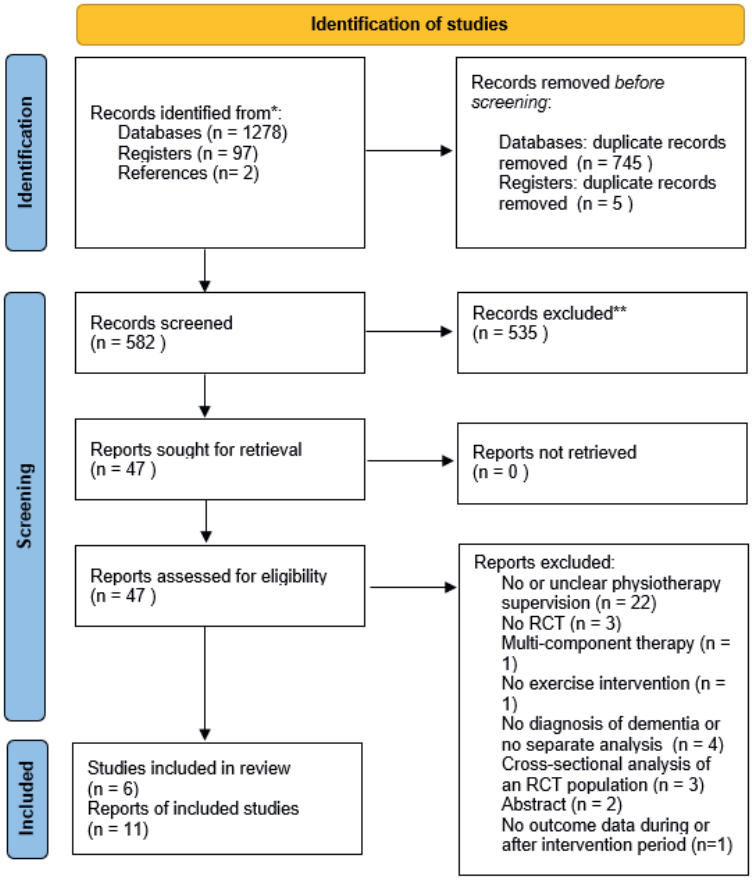
The Synthesis Without Meta-analysis (SWiM) guideline[23] and the Cochrane Handbook for Systematic Reviews of Interventions[24] were used for the narrative synthesis of the data. Due to the high degree of heterogeneity in outcomes and measurements in the studies, a meta-analytic approach was not appropriate. To provide an overview of the results from the individual studies, forest plots with standardized effect sizes were created. The R environment for statistical computing (version 4.2.2) and the package *Metafor*[25] were used to create the forest plots. The mean post-interventions scores of the intervention and control groups and their standard deviations (SD) were used to calculate a standardized mean difference (Hedges G) for each study. In cases where negative mean scores indicated a positive effect, scores were multiplied by −1 to adjust direction of effect in forest plot. If mean post-intervention scores were not available for a study, the change score and corresponding SD were used. If necessary, median and interquartile ranges were converted to means and confidence intervals according to the suggested method in the Cochrane handbook.[26]

# Results

## Selection of studies

We identified 1278 records from databases, 97 from the clinicaltrials.gov register and 2 after screening the included studies and reference lists of previously published systematic reviews. After removing 750 duplicates, 581 titles and abstracts were screened, resulting in the retrieval of 46 full-text articles. From the 46 full-text articles screened, 11 articles reporting findings from 6 studies were eventually included in this systematic review (Figure 1). Authors of five studies were contacted. One author[27] provided additional information on the type of dementia of the participants, two authors provided[28,29] information on the data analysis and study outcomes. The other two authors[10,30] did not reply or were not able to act to our request for additional information on effect estimates. A list of full-text screened but excluded articles can be found in the Supplementary materials (see table S2).

*Figure 1: Flowchart of the selection process of the studies*



## Study characteristics

The main characteristics of the studies are presented in Table 1. The outcomes of one study were presented in four separate articles.[29,31–33] In two studies, the outcomes were presented in two separate articles each,[34–37] and three studies presented all outcomes in one article.[27,28,30] To ensure clarity in this review, we will cite the first published article when discussing study characteristics. There were two cluster-randomized controlled trials,[28,29,36] and four traditional RCTs.[27,30,34] The intervention length ranged from 12 weeks[34] to 15 months,[30] the number of participants from 24[27] to 191[36] and mean average age from 83[27] to 87 years.[28] One study[34] included two intervention groups that are both included in this review. In three studies[28,29,36] the control group performed light sitting recreational activities, in the other three studies[27,30,34] the control group received usual care.

## Characteristics of interventions

Table 2 presents detailed information on the characteristics of the exercise interventions.

*Table 1: Main study characteristics of the six included studies*

| | Study design | Number of Participants | Age, mean (SD) | Duration of study | No (%) Female | Baseline cognitive function, mean (SD) | Baseline physical independence, mean (SD) | Number and nature of treatment arms |
|---|---|---|---|---|---|---|---|---|
| Toots et al.[29,31,32], Bostrom et al.[33] | Cluster RCT | IG: 92; CG: 92 | Total: 85.1 (7.1); Intervention: 84.4 (6.2) Control: 85.9 (7.8) | 4 months | Total: 141 (75.8%) Intervention: 70 (75.3%) Control: 71 (76.3%) | MMSE (0-30) Total: 14.9 (3.5) Intervention: 15.4 (3.4) Control: 14.4 (3.5) | Barthel Index (0-20) Total: 10.9 (4.4) Intervention: 10.7 (4.5) Control: 11.0 (4.4) | Intervention: high-intensity functional weight-bearing exercise program. Control: Sitting activities (conversing, singing, picture viewing, listening to readings or music) |
| Brett et al. [34,35], Australia | RCT | Intervention 1: 17; Intervention 2: 19; Control: 19 | Total: 85 (range 58–100) Intervention 1: 86 Intervention 2: 84 Control: 86 | 12 weeks | Total: 36 (66%); Intervention 1: 13 (76%) Intervention 2: 13 (68%) Control: 10 (53%) | - | - | Intervention 1: multimodal exercise intervention; Intervention 2: short-duration, high-frequency multimodal exercise intervention; Control: Usual care |
| Cancela et al.[30] ,Spain | RCT | Intervention: 73; Control: 116 | Intervention: 80.63 (8.32); Control: 82.90 (7.42); | 15 months | Intervention: 81%; Control: 44% | MMSE (0-30) Intervention: 14.9 (2.4) Control: 15.2 (2.5) | Katz Index (0-6) Intervention: 4.3 (0.9) Control: 4.3 (1.0) | Intervention: very low resistance aerobic cycling program; Control: usual recreational activities |
| Littbrand et al.[36], Conradsson et al.[37], Sweden | Cluster RCT | Intervention: 91 Control: 100 | Total: 84.7 (6.5) Intervention: 85.3(6.1) Control: 84.2(6.8) | 13 weeks | Total: 139 (73%) Intervention: 67 (74%) Control: 72 (72%) | MMSE (0-30) Total: 17.8 (5.1) Intervention: 17.5 (5.0) Control: 18.0 (5.3) | Barthel Index (0-20) Total: 13.1 (4.2) Intervention: 12.8 (4.5) Control: 13.4 (3.8) | Intervention: high-intensity functional weight-bearing exercise program; Post-intervention: daily functional tasks; Control: Sitting activities (watching films, singing, reading and conversation) |

*Table 1: Main study characteristics of the six included studies (continued)*

| | Study design | Number of Participants | Age, mean (SD) | Duration of study | No (%) Female | Baseline cognitive function, mean (SD) | Baseline physical independence, mean (SD) | Number and nature of treatment arms |
|---|---|---|---|---|---|---|---|---|
| Telenius et al.[28], Norway | Cluster RCT | Intervention: 87; Control: 83 | Total: 86.7 (7.4)<br>Intervention: 86.9 (7)<br>Control: 86.4 (7.8) | 12 weeks | Total: 73.6%<br>Intervention: 59 (72%)<br>Control: 61 (75.3%) | MMSE (0-30)<br>Total: 15.7 (5.0)<br>Intervention: 15.6 (5.0)<br>Control: 15.8 (5.0) | Barthel Index (0-20)<br>Total: 13.5 (3.6)<br>Intervention: 13.6 (3.5)<br>Control: 13.4 (3.6) | Intervention: high-intensity functional weight-bearing exercise program; Control: light physical activity, reading, playing games, listening to music and conversations |
| Venturelli et al.[27], Italy | RCT | Intervention 12; Control: 12 | Intervention: 83 (6); Control: 85 (5) | 24 weeks | 86% (total sample, before exclusion and randomization) | MMSE (0-30)<br>Intervention: 13 (2)<br>Control:12 (2) | Barthel Index (0-100)<br>Intervention: 34 (4)<br>Control:35 (6) | Intervention: supervised walking at fastest possible pace; Control: Usual care |

*Notes:* CG = control group; IG = intervention group; MMSE = Mini-Mental State Examination; RCT = randomized controlled trial; SD = standard deviation

*Table 2: Intervention characteristics of the six included studies based on the CERT and TIDieR templates*

| | Exercise type | Materials | Procedures and processes | Supervisors | Individual or group | Place of delivery | Frequency and duration | Tailoring | Method of measuring adherence | Method of measuring intensity | Method of measuring adverse events |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Toots et al.[29,31,32], Bostrom et al.[33] | Strength, balance | Weighted (safety) belts, steps, chairs, cushions, mattresses, balls, bean bags | Five-minute warmup for upper and lower extremities while sitting, at least two lower-limb strength exercises and two balance exercises in two sets | Two physical therapists | Group; three-eight participants. Individually supervised sessions for participants unable to attend the group sessions | 16 residential care facilities in Sweden | Five sessions of 45 minutes per two weeks. | Yes | Evaluated after each session on a predefined scale[28] | Evaluated after each session on a predefined scale[28] | Active monitoring after each session: (1) minor and temporary; (2) serious symptoms; (3) manifest injury or disease; (4) death[28] |
| Brett et al.[34,35] | Strength, balance, endurance, flexibility | Hand weights, balls, cones, and static pedals. | Warming up, strength, balance, aerobic exercises, cooling down. | One physical therapist | Group; maximum of five participants. | Two nursing homes in Australia; intervention was held in a noise-adjustable sitting room | Frequency: intervention 1: one 45 min session /week; intervention 2: three 15 min sessions/week. | Yes | Observation of slight breathlessness | Not reported | Not reported |

*Table 2: Intervention characteristics of the six included studies based on the CERT and TIDieR templates (continued)*

| | Exercise type | Materials | Procedures and processes | Supervisors | Individual or group | Place of delivery | Frequency and duration | Tailoring | Method of measuring adherence | Method of measuring intensity | Method of measuring adverse events |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Cancela et al.[30] | aerobic | Recumbant bicycle geared to low resistance | Minimum of 15 minutes exercise on self-selected pace on very low resistance | Physical therapist | Individual or in pairs | Elderly home-care facilities in Galicia (Spain); intervention took place in the gymnasium | Daily for a minimum of 15 minutes | Yes | Physiotherapist monitored each session and registered the time each individual exercised | Not reported | Not reported |
| Littbrand et al.[36], Conradsson et al.[37] | Strength, balance After group intervention: physical tasks integrated into daily life | Weighted (safety) belts, steps, chairs, cushions, mattresses, balls, bean bags | Five-minute warmup for upper and lower extremities while sitting, at least two lower-limb strength exercises and two balance exercises in two sets | Two physical therapists | Group; three to nine participants | Nine residential care facilities in Sweden | Frequency: five sessions of 45 minutes per two weeks. | Yes | Not reported | Evaluated after each session on a predefined scale [28] | Not reported |

*Table 2: Intervention characteristics of the six included studies based on the CERT and TIDieR templates (continued)*

| | Exercise type | Materials | Procedures and processes | Supervisors | Individual or group | Place of delivery | Frequency and duration | Tailoring | Method of measuring adherence | Method of measuring intensity | Method of measuring adverse events |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Telenius et al.[28] | Strength, balance | Weighted (safety) belts, steps, chairs, cushions, mattresses, balls, bean bags | Five-minute warmup for upper and lower extremities while sitting, at least two lower-limb strength exercises and two balance exercises in two sets | One physical therapist per three participants | Group; three to six participants. | 18 nursing homes in Norway | Frequency: two sessions of 50-60 min per week | Yes | Not reported | Physical therapists documented the intensity after each session | Not reported |
| Venturelli et al.[27] | Aerobic | At the end of the session, cookies were offered to the nursing home resident and caregiver. | Some minutes of informal chatting before the start of the exercise | Caregivers (staff and family) | Individually, guided by a caregiver | Alzheimer Care Unit in Italy; walking sessions were conducted in the hallway. | Frequency: minimum of 30 minutes, 4 times/week. | Yes | Walking times and distance were recorded and checked before and after each visit. | Walking on the participant's own but fastest pace | Not reported |

***Type, materials used and procedures***

In four studies[28,29,34,36] multimodal exercise interventions (interventions comprised of more than one exercise type) and in two studies[27,30] aerobic exercise interventions were used. Regarding multimodal exercise interventions, three studies[28,29,36] employed the same HIFE program.[38] The HIFE program is a high intensity multimodal group exercise intervention that, after a warming up, focusses on lower-limb strength and balance exercises. The program uses weighted (safety) belts, steps, chairs, cushions, mattresses, balls and bean bags. In another study[34] the intervention comprised strength, balance, endurance and flexibility exercises and used static bike trainers, hand weights, balls and cones as materials. Participants performed a warming up and cooling down before and after each exercise session. In the study by Venturelli et al.[27] the intervention comprised an aerobic type of exercise intervention in the form of supervised walking. In their study procedure, cookies were offered to the resident and caregiver after the exercise session as a positive psychological reinforcement. In the study by Cancela et al.,[30] recumbent stationary bicycles were used, where participants performed aerobic exercise in the form of cycling on a very low resistance.

***Exercise supervisors and group size***

Four studies[28,29,34,36] evaluated small-group exercise interventions supervised by one or two physical therapists. Individual sessions for participants unable to attend the group sessions were offered in one[29] of those studies. In another study[30] participants performed exercises individually or in pairs, supervised by a physical therapist. In the study by Venturelli et al.[27], the intervention comprised individual walking sessions provided by caregivers (nursing staff and family caregivers) with the physical therapist giving instructions regarding walking speed, intensity and distance. Family caregivers were not involved in any other studies.

***Place of delivery and tailoring***

All interventions took place in long-term care facilities, described as nursing homes,[28,34] residential care facilities,[29,36] elderly home care facility,[30] or Alzheimer care unit.[27] In two studies it was specified where the intervention took place (noise-adjustable sitting room[34] and gymnasium)[30]. All six studies reported tailoring the exercises to the participants functional capacities.

***Intervention frequency and duration***

The study by Brett et al.[34] included two intervention groups: one group exercised once per week for 45 minutes, while the other group exercised three times per week for 15 minutes per session. In two studies,[29,36] the exercise group exercised five times per two weeks, with sessions lasting 45 minutes. In another study[28] the exercise group exercised two times per week for 50-60 minutes per session. In the study by Cancela et al.[30] partici-

pants exercised daily for a minimum of 15 minutes, and in the study by Venturelli et al.[27] the participants exercised at least four times per week, with sessions lasting a minimum of 30 minutes.

***Methods of measuring adherence, intensity and adverse outcomes***

The measurement of adherence was reported in two studies.[27,29] One study[29] referred to a predefined scale,[38] while in the other study adherence was monitored by recorded walking times and distance.[27] Regarding exercise intensity, in three studies[28,29,36] the exercise intensity was evaluated on a scale that distinguished high, moderate and low. Another study[34] described that intensity was monitored by observing if participants experienced slight breathlessness. One[29] of the six studies described the methodology for defining and monitoring adverse events. That study referred to a protocol[38] in which adverse events were actively monitored during and after each session, whereas the severity of any occurring event was categorized into minor and temporary, serious symptoms (potential risk of severe injury or life-threatening), manifest injury or disease, or death.

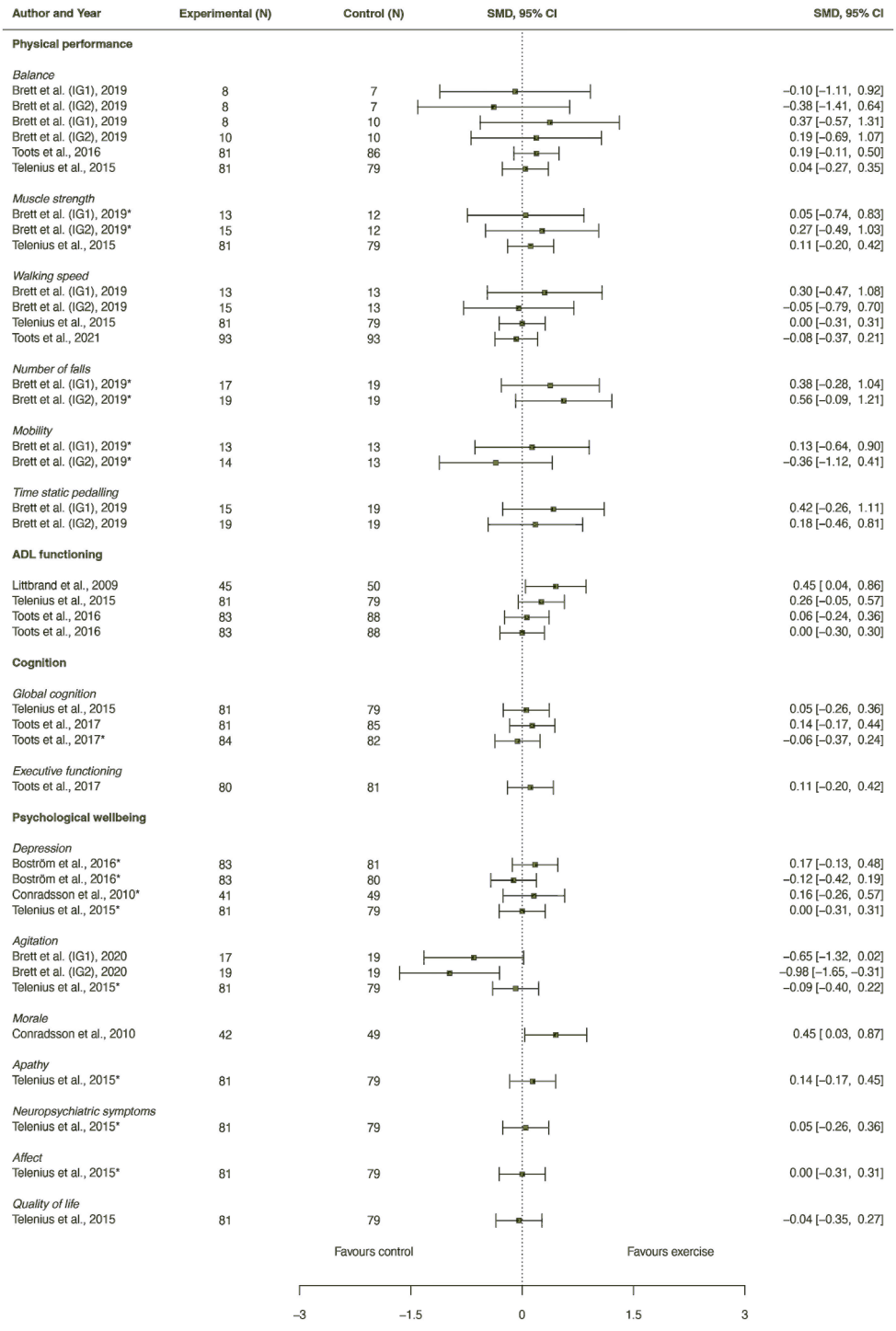
***Results of exercise adherence, intensity and adverse outcomes***

Adherence was reported in all studies and ranged from 72%[36] to 93.4%[27] in the intervention group, and from 69%[28] to 70%[34] in the social activities control groups. Regarding the intensity of exercise, three studies[28,29,36] included exercises at a high intensity level, one study[34] employed exercises at moderate intensity, one[30] at very light intensity, and one[27] at the participant's own, but fastest, pace. Regarding adverse events, one study[29] reported that all adverse events were minor and temporary, two studies[27,30] reported that no adverse events were related to the exercise program, the other three studies reported that there were no adverse events[28,34] or that no adverse event resulting in injury, disease or death.[36]

## Outcomes of multimodal exercise interventions

Exercise effects of multimodal exercise interventions were evaluated on a total of 25 different outcomes which we categorized in "physical performance", "activities of daily living (ADL) functioning", "cognition", and "psychological well-being". Figure 2a, in the form of a forest plot, provides a visual summary of the effect sizes and confidence intervals of individual studies that employed multimodal exercise interventions for all study outcomes. Further details on the outcomes can be found in Supplemental Table S3.

*Figure 2a: visual summary of the effect sizes and confidence intervals of individual studies that employed multimodal exercise interventions for all study outcomes*



***Physical performance***

Three studies[28,29,34] evaluated the effects on physical performance outcome measures. Outcome measures and the number of studies that reported on physical functioning were: balance (three studies),[28,29,34] falls (one study),[34] mobility (one study),[34] muscle strength (two studies),[28,34] timed static pedaling (TSP)(one study),[34] and walking speed (three studies).[28,32,34] Two studies[28,29] found a significant positive effect of multimodal exercise on balance, when compared to sitting recreational activities, one[34] study found a significant positive effect on falls, when compared to usual care. No significant effects were found on mobility, muscle strength, TSP and walking speed.

***ADL functioning***

Three studies evaluated the effects on ADL functioning.[28,29,36] All studies used the Barthel Index (BI), one study[29] additionally used the Functional Independence Measure (FIM). One study[36] reported a positive exercise effect compared to sitting recreational activities, while two studies[28,29] found no effect.

***Cognition***

Two studies[28,31] evaluated the effects on cognition. Outcome measures and the number of studies reporting on it were global cognition (two)[28,31] and executive functioning (one).[31] Both studies compared multimodal exercise to sitting recreational activities and found no significant effects.

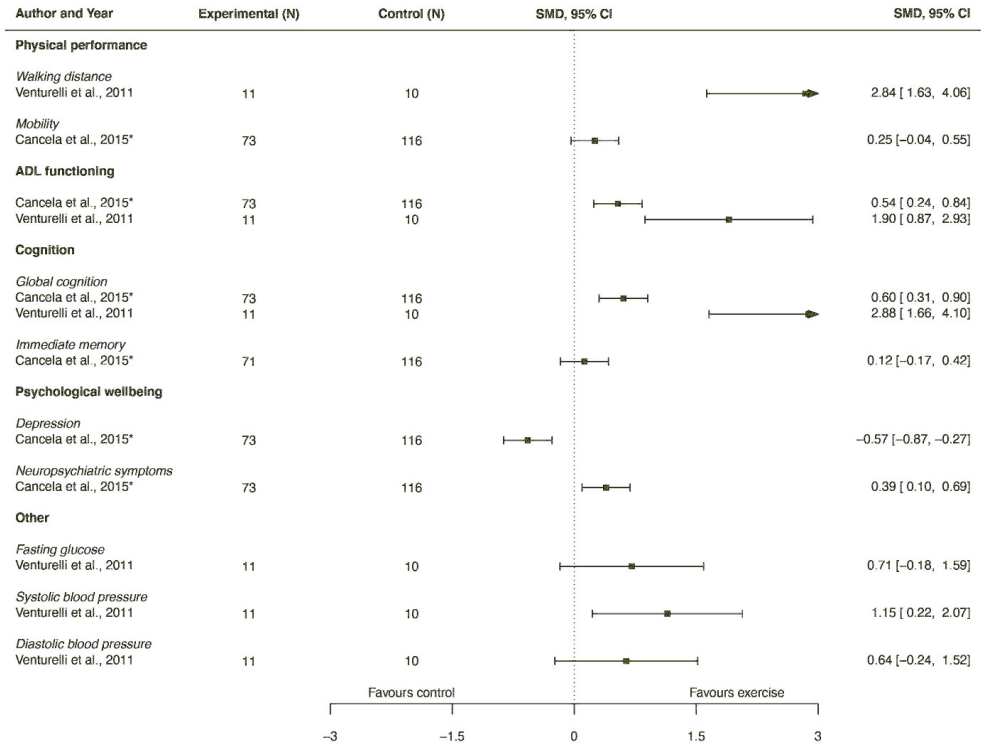
***Psychological well-being***

Four studies[28,33,35,37] evaluated the effects on psychological well-being. Outcome measures and the number of studies were depression (three),[28,33,37] agitation (two),[28,35] morale (one),[37] apathy (one),[28] behavioral and neuropsychiatric symptoms (one),[28] affect (one),[28] and quality of life (one).[28] Positive effects were found on the outcomes morale[37] and apathy[28] compared to sitting recreational activities. No effect was found on other outcomes.

## Outcomes of aerobic exercise interventions

Aerobic exercise effects were evaluated on a total of 11 different outcomes which were categorized in "physical performance", "activities of daily living (ADL) functioning", "cognition", "psychological well-being" and "others". Figure 2b, in the form of a forest plot, provides a visual summary of the effect sizes and confidence intervals of individual studies that employed aerobic exercise interventions for all study outcomes. Further details on the outcomes can be found in Supplemental Table S3.

*Figure 2b: visual summary of the effect sizes and confidence intervals of individual studies that employed aerobic exercise interventions for all study outcomes.*




### *Physical performance*

Two studies[27,30] evaluated the effects on physical performance. One study[30] evaluated the effect of aerobic exercise on mobility, the other on walking distance.[27] In both studies significant positive effects were found.

### *ADL functioning*

Two studies evaluated the effects on ADL functioning with one study using the Katz Index[30] and one study using the Barthel Index.[27] In both studies significant positive effects were found.

### *Cognition*

Two studies[27,30] evaluated the effects on cognition. One study[30] measured global cognition and immediate memory, one study[27] measured global cognition only. Positive effects were found on global cognition,[27,30] and on immediate memory.[30]

***Psychological well-being***

One study[30] evaluated the effects on psychological well-being. It evaluated the effects on depression and neuropsychiatric symptoms. No significant effects were found.

***Others***

One study[27] evaluated the effects on the outcomes glycemia and blood pressure (systolic and diastolic). No significant effects were found.

## Risk of bias

Assessment of the risk of bias in the six included studies is presented in Table 3. Three of the six studies[27,30,34] were considered to be at high risk of bias. Causes of a high risk of bias were regarding an inappropriate analysis,[27,34] missing outcome data,[30,34] no assessor blinding,[27,30,34] and the selection of the reported result.[27,30] One study[28] had some concerns regarding risk of bias due to missing outcome data. Two studies[29,36] were considered at a low risk of bias. Additionally, of the risk of bias screening, sources of funding for the included studies were investigated. No conflicting interests were found.

*Table 3: Assessment of the risk of bias in the six included studies*

| | Randomisation process | Deviations from intended interventions | Missing outcome data | Measurement of the outcome | Selection of the reported result | Overall |
|---|---|---|---|---|---|---|
| Toots et al.[29,31,32]; Boström et al.[33] | | | | | | |
| Brett et al.[34,35] | | | | | | |
| Cancela et al.[30] | | | | | | |
| Littbrand et al.[36]; Conradsson et al.[37] | | | | | | |
| Telenius et al.[28] | | | | | | |
| Venturelli et al.[27] | | | | | | |

Low risk of bias
Some concerns
High risk of bias

## Certainty in the evidence

Certainty in the evidence was determined separately for multimodal exercise interventions regarding outcomes with a minimum of three studies reporting on it. The outcomes physical performance (balance[28,29,34] and walking speed[28,32,34]), ADL functioning,[28,29,36] and depression,[28,33,37] all had three studies reporting on its respective outcome. For all

outcomes, the certainty in the evidence was determined as very low. Causes for low certainty in the evidence could be attributed to risk of bias (balance, walking speed, ADL functioning, depression), inconsistency in the results (balance, ADL functioning, depression), indirectness in the results (balance, walking speed) and imprecision in the results (balance, walking speed, depression). Table 3 in the Supplementary materials provides more detail on the determination of the certainty in the evidence (see table S3).

# Discussion

## Summary

Previous systematic reviews[10–15] on exercise interventions for nursing home residents with dementia included all kinds of exercise interventions, regardless of their supervision. Although some previous reviews[10,14] included physical therapist-supervised exercise interventions, none synthesized their characteristics and effectiveness.

Regarding study characteristics, the studies included in our review showed variation in population size, length and composition of the intervention and the outcome measures used. Regarding intervention composition, exercise with strength, balance and aerobic modalities at moderate or high intensity for at least 30-45 minutes, two to three times per week is recommended by dementia organizations and international geriatric working groups.[4–6] None of the interventions in the studies in the present systematic review fulfilled these recommendations. When it comes to study length, in three[28,34,36] of the six studies, the length of the intervention was not longer than 13 weeks. To our knowledge, no minimal duration of exercise length has been determined. However, a review on physical activity, cognition and brain plasticity,[39] has suggested an exercise length of 6 to 12 months to attain cognitive benefits. Indeed, although at high risk of bias, the two in our review included studies[27,30] that lasted at least 6 months did both find positive effects on physical performance, ADL functioning and cognition.

Despite the strong promotion of physical exercise for nursing home residents with dementia,[4–6] our review revealed heterogeneous results on a wide range of outcomes. The larger studies that contained multimodal exercise interventions seem to suggest a positive effect on physical performance[28,29] and ADL functioning,[28,29,36] although not in all studies a significant difference was found. Because of varying outcome measures and a small amount of methodologically sound studies, no effect size could be calculated (Forest plot 2.a). The studies incorporating aerobic interventions[27,30] both found significant positive effects on physical performance, ADL functioning and cognition. However, since our search strategy identified no more than two studies, and both of the studies were at high risk of bias, conclusions about the effectiveness cannot be made.

To some extent, the findings of our review are in line with the existing evidence. A previous systematic review[10] (that included both physical therapists supervised exercise interventions and non-physical therapist supervised exercise interventions) found some positive effects, as well as our review. However, that review did not fully report non-significant findings, and emphasized positive findings. By emphasizing positive findings, the exercise effects might appear larger than they actually are.[17,40]

Regarding the outcome cognition, a prior review[13] identified evidence of a positive effect. Within our review, the two studies[28,31] implementing multimodal exercise interventions did not demonstrate a significant effect. However, the two studies[27,30] that employed aerobic exercise did show a positive effect. The two studies employed aerobic exercise without cognitive tasks, although one study[27] did involve social interaction with a caregiver during walking.

In a previous review[14] on exercise interventions for nursing home residents with dementia, significant issues of bias were identified, similar to those found in our own review. Despite that all the RCTs included in our review were published after, the number of RCTs of satisfactory quality remains insufficient to offer a clearer understanding of the subject. Similar to the review of Littbrand et al.[14] we found a lack of transparency about adverse events and the method of assessing them in our included studies. Incomplete or unclear information on the safety of exercise interventions can be harmful. The study by Brett et al.[34] described that recruitment for their study was difficult, since family caregivers were concerned with the safety of the residents, and thought residents were 'too old' to exercise. Careful consideration and registration of adverse events can help objectify the risks of an exercise intervention, and inform participants and their caretakers about the (absence of) possible harms.

## Strengths and limitations

There are some limitations to this systematic review and its evidence base. Due to the risk of bias issues, inconsistency in the findings and a low number of studies, we could not form a conclusion on the effectiveness of physical therapist supervised exercise interventions for this particular population. However, this review does describe the current evidence base and its limitations, and thereby forms clear implications for future research. Furthermore, some studies only provided differences in change scores to estimate the effect of the exercise program. This resulted in slight disparities between the study results as reported in the original studies, and the visual representation of the effects in the forest plots based on the post-intervention scores. Nevertheless, the forest plots illustrate a valuable aspect of our review, namely the incongruity among the findings of the studies. A strength of this review is that it fulfills all quality criteria of the AMSTAR II (A MeaSurement Tool to Assess systematic Reviews).[41] Our review is also at low risk of bias

in the four domains assessed by the Risk of Bias in Systematic reviews (ROBIS)[42] tool. Not fulfilled criteria are 1.5 (language restrictions) and 4.5 (robustness by funnel plot). We applied language restrictions by only including studies written in English, Spanish or Dutch. Since almost all studies are published in English, or later translated to English, we think it is unlikely that we missed eligible studies by our language restrictions. We also did not conduct a funnel plot to assess for publication bias. The small amount of included studies (four studies that used multimodal exercise interventions and two studies that used aerobic exercise interventions) give us legitimate reasons to not create a funnel plot.[24] We did sufficiently screen our studies on selective reporting, to limit the risk of publication bias.

## Implications

In conclusion, the literature on the characteristics and the effect of physical therapist supervised exercise interventions in nursing home residents with dementia is heterogeneous and limited. Study length, composition of the intervention and outcome measures used varied. We included four studies that used a multimodal group exercise intervention and two studies that used an aerobic exercise intervention, with three of the six studies at high risk of bias. Exercise effects varied between studies, and were reported on a wide range of health outcomes. No conclusion can be drawn on the effectiveness of exercise interventions based on the studies included in our review. Future studies of high methodological quality can help determine the effects on health outcomes in nursing home residents with dementia.

### Translational significance

While exercise therapy, especially under the supervision of a physical therapist, is extensively employed for nursing home residents with dementia, its contents and effects have not been thoroughly investigated. We found six RCTs consisting of multimodal and aerobic exercise interventions targeting a variety of outcome measures. Because of inconsistencies in the results and the presence of bias, a conclusion regarding the effectiveness of the interventions could not be reached. By identifying gaps and emphasizing the need for methodologically robust studies, this review contributes to the development of interventions that can positively impact the well-being of nursing home residents with dementia.

### Funding

None.

### Conflict of interest

None.

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# TABLES

## Supplementary material tables

*Table S1: Complete Search Strategy*

| | |
|---|---|
| P | ("Nursing Homes"[Mesh] OR "Nursing Homes"[tw] OR "Nursing Home"[tw] OR "Care Homes"[tw] OR "Care Home"[tw] OR "Intermediate Care Facilities"[tw] OR "Intermediate Care Facility"[tw] OR "Skilled Nursing Facilities"[tw] OR "Skilled Nursing Facility"[tw] OR "residential care facilities"[tw] OR "residential care facility"[tw] OR "Residential Facilities"[Mesh] OR "Residential Facilities"[tw] OR "Residential Facility"[tw]) ("Dementia"[Mesh] OR "Dementia"[tw] OR "Dementias"[tw] OR "Dement*"[tw] OR "senile"[tw] OR "amentia"[tw] OR "amentias"[tw] OR "Alzheimer Disease"[tw] OR "Alzheimer"[tw] OR "Alzheimers"[tw] OR "Alzheimer*"[tw] OR "Primary Progressive Aphasia"[tw] OR "Primary Progressive Nonfluent Aphasia"[tw] OR "Creutzfeldt-Jakob Syndrome"[tw] OR "CADASIL"[tw] OR "Diffuse Neurofibrillary Tangles with Calcification"[tw] OR "Frontotemporal Lobar Degeneration"[tw] OR "Pick Disease of the Brain"[tw] OR "Primary Progressive Nonfluent Aphasia"[tw] OR "Huntington Disease"[tw] OR "Huntington"[tw] OR "Huntington*"[tw] OR "Kluver-Bucy Syndrome"[tw] OR "Lewy Body Disease"[tw]) |
| I | (("Exercise Therapy"[Mesh] OR "Exercise Therapy"[tw] OR "Exercise Therapies"[tw] OR "Exercise Therap*"[tw] OR "therapeutic exercise"[tw] OR "therapeutic exercises"[tw] OR "Remedial Exercise"[tw] OR "Remedial Exercises"[tw] OR "Rehabilitation Exercise"[tw] OR "Rehabilitation Exercises"[tw] OR "Blood Flow Restriction Therapy"[tw] OR "Continuous Passive Motion Therapy"[tw] OR "Endurance Training"[tw] OR "Muscle Stretching Exercise"[tw] OR "Muscle Stretching Exercises"[tw] OR "Plyometric Exercise"[tw] OR "Plyometric Exercises"[tw] OR "Resistance Training"[tw] OR "Exercise Movement Techniques"[Mesh] OR "Exercise Movement"[tw] OR "Breathing Exercises"[tw] OR "Qigong"[tw] OR "Dance Therapy"[tw] OR "Tai Ji"[tw] OR "Yoga"[tw] OR "Exercise"[Mesh] OR "Exercise"[tw] OR "Exercises"[tw] OR "Circuit-Based Exercise"[tw] OR "Circuit-Based Exercises"[tw] OR "Cool-Down Exercise"[tw] OR "Cool-Down Exercises"[tw] OR "Endurance Training"[tw] OR "Exergaming"[tw] OR "Gymnastics"[tw] OR "High-Intensity Interval Training"[tw] OR "Jogging"[tw] OR "Marathon Running"[tw] OR "Muscle Stretching Exercise"[tw] OR "Muscle Stretching Exercises"[tw] OR "Nordic Walking"[tw] OR "Physical Conditioning"[tw] OR "Plyometric Exercise"[tw] OR "Plyometric Exercises"[tw] OR "Preoperative Exercise"[tw] OR "Preoperative Exercises"[tw] OR "Resistance Training"[tw] OR "Running"[tw] OR "Stair Climbing"[tw] OR "Swimming"[tw] OR "Walking"[tw] OR "Warm-Up Exercise"[tw] OR "Warm-Up Exercises"[tw] OR "psychomotor activation"[tw] OR "psychomotor activat*"[tw] OR "motor activation"[tw] OR "motor activat*"[tw]) |
| M | (randomized controlled trial[pt] OR controlled clinical trial[pt] OR randomized controlled trials[mh] OR random allocation[mh] OR double-blind method[mh] OR single-blind method[mh] OR clinical trial[pt] OR clinical trials[mh] OR "clinical trial"[tw] OR "RCT"[tw] OR "trial"[tw] OR ((singl*[tw] OR doubl*[tw] OR trebl*[tw] OR tripl*[tw]) AND (mask*[tw] OR blind*[tw])) OR "latin square"[tw] OR placebos[mh] OR placebo*[tw] OR random*[tw] OR research design[mh:noexp] OR comparative study[pt] OR evaluation studies[pt] OR follow-up studies[mh] OR prospective studies[mh] OR cross-over studies[mh] OR control[tw] OR controll*[tw] OR prospectiv*[tw] OR volunteer*[tw]) |
| C | - |
| O | - |

*Table S2: List of excluded studies*

| | Titel | Authors | Year | Reason |
|---|---|---|---|---|
| 1 | Effects of a high-intensity exercise program on well-being among older people with dementia living in care facilities: A cluster-randomized trial | Conradsson, M.; Gustafson, Y.; Holmberg, H.; Lindelof, N.; Littbrand, H.; Nordstrom, P.; Rosendahl, E. | 2015 | Abstract |
| 2 | Can the onset of dependency in activities of daily living (ADLs) be delayed in cognitively impaired older adults with short total sleep time? | Lorenz, R. A.; Richards, K. C.; Rose, K. M.; Cole, C. | 2010 | Abstract |
| 3 | Effect of a high-intensity functional exercise program on functional balance: preplanned subgroup analyses of a randomized controlled trial in residential care facilities | Littbrand, H.; Carlsson, M.; Lundin-Olsson, L.; Lindelöf, N.; Håglin, L.; Gustafson, Y.; Rosendahl, E. | 2011 | Cross-sectional analysis of an RCT population |
| 4 | Is the Effect of a High-Intensity Functional Exercise Program on Functional Balance Influenced by Applicability and Motivation among Older People with Dementia in Nursing Homes? | Sondell, A.; Littbrand, H.; Holmberg, H.; Lindelöf, N.; Rosendahl, E. | 2019 | Cross-sectional analysis of an RCT population |
| 5 | Walking Aids Moderate Exercise Effects on Gait Speed in People With Dementia: A Randomized Controlled Trial | Toots, A.; Littbrand, H.; Holmberg, H.; Nordström, P.; Lundin-Olsson, L.; Gustafson, Y.; Rosendahl, E. | 2017 | Cross-sectional analysis of an RCT population |
| 6 | People living in nursing care facilities who are ambulant and fracture their hips: description of usual care and an alternative rehabilitation pathway | Killington, M.; Davies, O.; Crotty, M.; Crane, R.; Pratt, N.; Mills, K.; McInnes, A.; Kurrle, S.; Cameron, I. D. | 2020 | Multi-component intervention |
| 7 | A high-intensity functional weight-bearing exercise program for older people dependent in activities of daily living and living in residential care facilities: evaluation of the applicability with focus on cognitive function | Littbrand, H.; Rosendahl, E.; Lindelöf, N.; Lundin-Olsson, L.; Gustafson, Y.; Nyberg, L. | 2006 | No diagnosis of dementia or no separate analysis |
| 8 | Evaluating the effects of an exercise program (Staying UpRight) for older adults in long-term care on rates of falls: study protocol for a randomised controlled trial | Taylor, L.; Parsons, J.; Taylor, D.; Binns, E.; Lord, S.; Edlin, R.; Rochester, L.; Del Din, S.; Klenk, J.; Buckley, C.; Cavadino, A.; Moyes, S. A.; Kerse, N. | 2020 | No diagnosis of dementia or no separate analysis |

*Table S2: List of excluded studies* (*continued*)

| | Titel | Authors | Year | Reason |
|---|---|---|---|---|
| 9 | Postural stability and quality of life after guided and self-training among older adults residing in an institutional setting | Tuunainen, E.; Rasku, J.; Jäntti, P.; Moisio-Vilenius, P.; Mäkinen, E.; Toppila, E.; Pyykkö, I. | 2013 | No diagnosis of dementia or no separate analysis |
| 10 | A randomized outcome evaluation of group exercise programs in long-term care institutions | Lazowski, D. A.; Ecclestone, N. A.; Myers, A. M.; Paterson, D. H.; Tudor-Locke, C.; Fitzgerald, C.; Jones, G.; Shima, N.; Cunningham, D. A. | 1999 | No diagnosis of dementia or no separate analysis |
| 11 | Why Not a Global Postural Reeducation as an Alternative Therapy Applied to Alzheimer's Patients in Nursing Homes? A Pioneer Randomized Controlled Trial | Todri, J.; Todri, A.; Lena, O. | 2019 | No exercise intervention |
| 12 | The Effects of Exercise on Falls in Older People With Dementia Living in Nursing Homes: A Randomized Controlled Trial | Toots, A.; Wiklund, R.; Littbrand, H.; Nordin, E.; Nordström, P.; Lundin-Olsson, L.; Gustafson, Y.; Rosendahl, E. | 2019 | No outcome data during or after intervention period |
| 13 | A 9-Week Aerobic and Strength Training Program Improves Cognitive and Motor Function in Patients with Dementia: A Randomized, Controlled Trial | Bossers, W. J.; van der Woude, L. H.; Boersma, F.; Hortobágyi, T.; Scherder, E. J.; van Heuvelen, M. J. | 2015 | No PT |
| 14 | A randomised controlled trial testing the impact of exercise on cognitive symptoms and disability of residents with dementia | Stevens, J.; Killeen, M. | 2006 | No PT |
| 15 | Conversation Intervention with Alzheimer's Patients: Increasing the Relevance of Communication | Tappen, R. M.; Williams, C. L.; Barry, C.; Disesa, D. | 2002 | No PT |
| 16 | Effect of Exercise on Behavioral Symptoms and Pain in Patients With Dementia Living in Nursing Homes | Maltais, M.; Rolland, Y.; Vellas, B.; Haÿ, P. E.; Armaingaud, D.; Cestac, P.; Rouch, L.; Cesari, M.; de Souto Barreto, P. | 2019 | No PT |
| 17 | Effect of exercise on mood in nursing home residents with Alzheimer's disease | Williams, C. L.; Tappen, R. M. | 2007 | No PT |
| 18 | Effects of Hand Exercise on Eating Action in Patients With Alzheimer's Disease | Chen, L. L.; Li, H.; Chen, X. H.; Jin, S.; Chen, Q. H.; Chen, M. R.; Li, N. | 2019 | No PT |
| 19 | Effects of Physical Activity in Nursing Home Residents with Dementia: A Randomized Controlled Trial | Henskens, M.; Nauta, I. M.; van Eekeren, M. C. A.; Scherder, E. J. A. | 2018 | No PT |

*Table S2: List of excluded studies* (*continued*)

| | Titel | Authors | Year | Reason |
|---|---|---|---|---|
| 20 | Exercise or Social Intervention for Nursing Home Residents with Dementia: A Pilot Randomized, Controlled Trial | de Souto Barreto, P.; Cesari, M.; Denormandie, P.; Armaingaud, D.; Vellas, B.; Rolland, Y. | 2017 | No PT |
| 21 | Exercise program for nursing home residents with Alzheimer's disease: a 1-year randomized, controlled trial | Rolland, Y.; Pillard, F.; Klapouszczak, A.; Reynish, E.; Thomas, D.; Andrieu, S.; Rivière, D.; Vellas, B. | 2007 | No PT |
| 22 | Physical and functional implications of aquatic exercise for nursing home residents with dementia | Henwood, T.; Neville, C.; Baguley, C.; Clifton, K.; Beattie, E. | 2015 | No PT |
| 23 | REHABILITATION OF MOBILITY AND MOTOR FUNCTION IN NURSING HOME RESIDENTS WITH DEMENTIA | Aizen, E.; Lubosky, E.; Sobeh, S.; Ibrahim, R.; Pressburger, D.; Oliven, R. | 2018 | No PT |
| 24 | The Effect of Exercise and Social Activity Interventions on Nutritional Status in Older Adults with Dementia Living in Nursing Homes: A Randomised Controlled Trial | Maltais, M.; Rolland, Y.; Haÿ, P. E.; Armaingaud, D.; Cestac, P.; Rouch, L.; de Souto Barreto, P. | 2018 | No PT |
| 25 | The effects of movement stimulation on activities of daily living performance and quality of life in nursing home residents with dementia: a randomized controlled trial | Henskens, M.; Nauta, I. M.; Drost, K. T.; Scherder, E. J. | 2018 | No PT |
| 26 | Therapeutic Effects of Exercise Training on Elderly Patients With Dementia: A Randomized Controlled Trial | Liu, I. T.; Lee, W. J.; Lin, S. Y.; Chang, S. T.; Kao, C. L.; Cheng, Y. Y. | 2020 | No PT |
| 27 | Walking and night-time restlessness in mild-to-moderate dementia: a randomized controlled trial | Eggermont, L. H.; Blankevoort, C. G.; Scherder, E. J. | 2010 | No PT |
| 28 | Walking the line: a randomised trial on the effects of a short term walking programme on cognition in dementia | Eggermont, L. H.; Swaab, D. F.; Hol, E. M.; Scherder, E. J. | 2009 | No PT |
| 29 | Improvement of cognitive function after physical movement training in institutionalized very frail older adults with dementia | Thurm, F.; Scharpf, A.; Liebermann, N.; Kolassa, S.; Elbert, T.; Luchtenberg, D.; Woll, A.; Kolassa, I. T. | 2011 | No PT |
| 30 | "Bring me sunshine, bring me (physical) strength": The case of dementia. Designing and implementing a virtual reality system for physical training during the COVID-19 pandemic | Matsangidou, M.; Frangoudes, F.; Hadjiaros, M.; Schiza, E.; Neokleous, K. C.; Papayianni, E.; Avraamides, M.; Pattichis, C. S. | 2022 | No PT |
| 31 | Effects of a 16-week multimodal exercise program on activities of daily living in institutionalized individuals with dementia A multicenter randomized controlled trial | Bezold, J.; Trautwein, S.; Barisch-Fritz, B.; Scharpf, A.; Krell-Roesch, J.; Nigg, C. R.; Woll, A. | 2021 | No PT |
| 32 | Effect of a comprehensive exercise program on function in nursing home residents with Alzheimer's disease | Tappen, R. M.; Roach, K. E.; Touhy, T. A. | 2000 | No PT |

*Table S2: List of excluded studies* (*continued*)

| | Titel | Authors | Year | Reason |
|---|---|---|---|---|
| 33 | Effect of Centella Asiatica and Aerobic Exercise in Older Women With Dementia: A Randomized Controlled Trial | Fitriana, Lisna Anisa; Irma, Darmawati; Nasution, Lina Anisa; Suci Tuty, Putri; Rohaedi, Slamet; Anggadiredja, Kusnandar; Iwan, Setiawan; Nur, Fauziyah; Adnyana, I. Ketut; | 2021 | No PT |
| 34 | Factors predictive of adherence to a non-pharmacological intervention in nursing home research: a substudy of the LEDEN trial | Chrusciel, J.; Letty, A.; Armaingaud, D.; Barreto, P.; Berrut, G.; Rolland, Y.; Sanchez, S. | 2022 | No PT |
| 35 | Effects of 1 Year of Lifestyle Intervention on Institutionalized Older Adults | Magistro, D.; Carlevaro, F.; Magno, F.; Simon, M.; Camp, N.; Kinrade, N.; Zecca, M.; Musella, G. | 2021 | No RCT |
| 36 | Effects of a multicomponent exercise program in institutionalized elders with Alzheimer's disease | Sampaio, A.; Marques, E. A.; Mota, J.; Carvalho, J. | 2019 | No RCT |
| 37 | Effectiveness of individually tailored exercise on functional capacity and mobility in nursing home residents | Bertoncello, C.; Sperotto, M.; Bellio, S.; Pistellato, I.; Fonzo, M.; Bigolaro, C.; Ramon, R.; Imoscopi, A.; Baldo, V. | 2021 | No RCT |

*Table S3: Outcomes, within and between group differences between baseline and follow-up of the six included studies*

| | **Outcome** | **Within group differences** | **Between group differences[a]** |
|---|---|---|---|
| **Multimodal exercise interventions** | | | |
| **Physical performance** | | | |
| Brett et al.[34] | Balance ((M)FR) | median (Q1-Q3): IG 1: pre 12 (8–35) post 28 (17–35) p=0.204; IG 2: pre 16 (9–29) post 26 (12–30) p=0.673; CG: pre 21 (18–31) post 27 (24–33) p=0.271 | p=0.69 |
| | Balance (FR) | median (Q1-Q3): IG1: pre 12 (0–23) post 18 (11–30) p=0.263; IG2: pre 16 (8–22) post 15 (8–28) p=0.612; CG: pre 15 (12–21) post 13 (7–22) p=0.373 | p=0.60 |
| | Falls (Number of falls) | median (Q1-Q3): IG 1: pre 0 (0–1) post 0 (0–2) p=0.496; IG2: pre 0 (0–1) post 0 (0–1) p=1.000; CG: pre 0 (0–2) post 1 (0–4) p=0.011 | p=0.02(IG 2 compared to CG) |
| | Mobility (TUG) | median (Q1-Q3): IG 1 pre 26 (15–36) post 24 (12–29) p=0.045; IG2 pre 26 (17–48) post 27 (19–46) p=0.615; CG pre 23 (17–33) post 21 (16–34) p=0.807 | p=0.53 |

*Table S3: Outcomes, within and between group differences between baseline and follow-up of the six included studies (continued)*

| | Outcome | Within group differences | Between group differences[a] |
|---|---|---|---|
| | Muscle strength (FTCST) | median (Q1-Q3): IG1 pre 27 (17–41) post 18 (13–44) p=0.130; IG2 pre 25 (20–46) post 21 (15–31) p=0.050; CG pre 22 (18–28) post 26 (18–34) p=0.107 | p=0.63 |
| | Timed Static Pedalling (TSP) | median (Q1-Q3): IG 1: pre 11 (7–28) post 28 (11–44) p=0.005; IG2: pre 10 (8–29) post 20 (11–34) p=0.040; CG: pre 19 (13–30) post 20 (9–27) p=0.407 | p=0.45 |
| | Walking speed (Six meter walk test) | median (Q1-Q3): IG1 pre 0.55 (0.46–1) post 0.67 (0.50–1.20) p=0.161; IG2 pre 0.55 (0.38–0.86) post 0.60 (0.33-0.86) p=0.177; CG: pre 0.60 (0.48–0.86) post 0.55 (0.41–0.93) p=0.724 | p=0.53 |
| Telenius et al.[28] | Balance (BBS) | mean + (SD): IG: pre 34.3 (14.5), post 37.2 (14.0). CG: pre 35.4 (13.7), post 36.6 (14.4) | p=0.02 |
| | Muscle strength (CST) | mean + (SD): IG: pre 6.0 (3.1), post 7 (3.3). CG: pre 6.2 (2.9), post 6.6 (3.7) | p=0.11 |
| | Walking speed (Six meter walk test) | mean + (SD): IG: pre 0.5 (0.2), post 0.5 (0.2). CG: pre 0.5 (0.2), post 0.5 (0.3) | p=0.86 |
| Toots et al.[29] | Balance (BBS) | MD + (SE): IG: 2.39 (0.88) CG: -1.82 (0.86) | MD + (95% CI): 4.20 (1.79-6.61) p=<0.001 |
| Toots et al.[32] | Walking speed (Backward walking speed) | MD + (SE): with or without WA: IG: 0.005 (0.013); CG: 0.000 (0.013); without WA: IG: 0.026 (0.018); CG: -0.004 (0.017) | MD + (95% CI): with or without WA: 0.005 (-0.031-0.041) p=0.788; without WA: 0.030 (–0.019, 0.079) p=0.231 |
| **ADL functioning** | | | |
| Littbrand et al.[36] | ADL performance (BI) | MD + (SD): IG: -0.13 (2.11) p=0.67; CG: -1.10 (2.28) p=0.001 | MD (95% CI): 1.13 (0.12-2.13) p=0.03 |
| Telenius et al.[28] | ADL performance (BI) | mean + (SD): IG: pre 13.6 (3.5), post 13.7 (3.6); CG: pre 13.4 (3.6), post 12.7 (4.1) | p=0.085 |
| Toots et al.[29] | ADL performance (BI) | MD + (SE): IG: -0.79 (0.31); CG: -1.39 (0.30) | MD + (95% CI): 0.60 (-0.24-1.44) p=0.16 |
| | ADL performance (FIM) | MD + (SE): IG: -3.10 (1.07); CG: -4.44 (1.04) | MD + (95% CI): 1.34 (-1.56-4.25) p=0.36 |
| **Cognition** | | | |
| Telenius et al.[28] | Global cognition (MMSE) | mean + (SD): IG: pre 15.6 (5.0), post 15.5 (5.5); CG: pre 15.8 (5.0), post 15.2 (5.4) | p=0.69 |
| Toots et al.[31] | Global cognition (MMSE) | MD + (SE): IG: –1.15 (0.41); CG: –0.93 (0.4) | MD + (95% CI): -0.27 (-1.4-0.87) p=0.644 |
| | Executive functioning (VF) | MD + (SE): IG: –0.74 (0.32); CG: –0.21 (0.32) | MD + (95% CI): -0.53 (-1.42-0.35) p=0.241 |

*Table S3: Outcomes, within and between group differences between baseline and follow-up of the six included studies* (*continued*)

| | Outcome | Within group differences | Between group differences[a] |
|---|---|---|---|
| | Global cognition (ADAS-Cog) | MD + (SE): IG: 1.51 (1.06); CG: 2.55 (1.07) | MD + (95% CI): -1.04 (-4-1.92) p=0.491 |
| **Psychological wellbeing** | | | |
| Bostrom et al.[33] | Depression (GDS-15) | IG: MD + (95% CI) 0.03 (–0.53, 0.59) p=0.91; CG MD + (95% CI) 0.08 (–0.49, 0.64) p=0.78 | MD + (95% CI) -0.05 (-0.84, 0.75) p=0.91 |
| | Depression (MADRS) | IG: MD + (95% CI) 0.40 (–0.77, 1.57) p=0.50; CG: MD + (95% CI) 0.33 (–0.85, 1.52) p=0.58 | MD + (95% CI) 0.06 (-1.60, 1.73) p=0.94 |
| Brett et al.[35] | Agitation (CMAI) | IG 1: pre 28 (9) post 26 (10) p=0.03; IG 2: pre 26 (9) post 24 (8) p=0.23; CG: pre 36 (8) post 32 (8) p=0.02 | p>0.05 |
| Conradsson et al.[37] | Depression (GDS-15) | MD + (SD): IG: 0.03 (2.3) p=0.92; CG: -0.10 (1.9) p=0.62 | MD + (95% CI): -0.33 (-1.20, 0.55) p=0.46 |
| | Morale (PGCMS) | MD + (SD): 0.35(2.7) p=0.25 CG: 0.02 (2.3) p=0.93 | MD + (95% CI): 1.12 (0.09 to 2.16) p=0.03 |
| Telenius et al.[28] | Agitation (NPI-Agitation) | mean + (SD): IG: pre 1.7 (2.1), post 1.5 (2.2); CG: pre 1.3 (1.7), post 1.7 (2.3) | p=0.07 |
| | Apathy (NPI-Apathy) | mean + (SD): IG: pre 0.5 (0.8), post 0.3 (0.6); CG: pre 0.39 (0.7), post 0.4 (0.8) | p=0.048 |
| | Neuropsychiatric symptoms (NPI) | mean + (SD): IG: pre 5.8 (5.9), post 5.1 (6.0); CG: pre 4.8 (4.6), post 5.4 (6.5) | p=0.17 |
| | Affect (NPI-depression and anxiety) | mean + (SD): IG: pre 1.1 (1.4), post 1.0 (1.4); CG: pre 0.8 (1.3), post 1.0 (1.4) | p=0.31 |
| | Depression (Cornell scale) | mean + (SD): IG: pre 4.7 (4.6), post 3.8 (5.2); CG: pre 4.9 (4.3), post 3.8 (3.8) | p= 0.39 |
| | Quality of life (Qualid) | mean + (SD): IG: pre 18.3 (6.1), post 17.1 (7.0); CG: pre 17.7 (5.5), post 17.4 (6.6) | p= 0.97 |
| **Aerobic exercise interventions** | | | |
| **Physical performance** | | | |
| Cancela et al.[30] | Mobility (TUG) | Mean difference + 95%CI: IG: -2.11 (-3.86,-0.36); CG -0.56 (-1.45, 0.33) | p=0.03 |
| Venturelli et al.[27] | Walking distance (6mwt) | mean + (SD): IG: pre 245 (31) post 294 (49) p<0.05 CG: pre 238 (47) post 168 (34) p<0.05 | p<0.05 |
| **Psychological wellbeing** | | | |
| Cancela et al.[30] | Depression (Cornell Scale) | Mean difference + 95%CI: IG: 1.84 (-0.80, 4.48); CG: -2.71 (-3.52, -1.91) | p=0.22 |
| | Neuropsychiatric symptoms (NPI) | Mean difference + 95%CI: IG: -0.84 (-3.76, 2.08); CG: 4.60 (1.96, 7.24) | p=0.08 |

*Table S3: Outcomes, within and between group differences between baseline and follow-up of the six included studies* (*continued*)

| | Outcome | Within group differences | Between group differences[a] |
|---|---|---|---|
| **ADL functioning** | | | |
| Cancela et al.[30] | ADL functioning (Katz Index) | Mean difference + 95%CI: IG: 0.22 (-0.05, 0.49); CG: -0.25 (-0.36, -0.14) | p=0.03 |
| Venturelli et al. (2011) | ADL functioning (BI) | mean + (SD): IG: pre 34 (4) post 42 (4) p<0.05; CG: pre 35 (6) post 32 (6) p>0.05 | p=0.003 |
| **Cognition** | | | |
| Cancela et al.[30] | Global cognition (MEC -Spanish MMSE) | Mean difference + CI: IG: 0.09 (-0.32, 0.60); CG: -2.11 (-2.90,-1.32) | p=0.01 |
| | Memory (FOME) | Mean difference + 95%CI: IG: 1.99 (-1.93, 4.33); CG: -1.31 (-3.57, 7.95) | p=0.01 |
| Venturelli et al.[27] | Global cognition (MMSE) | mean + (SD): IG pre 13 (2) post 12 (2) p=>0.05; CG: pre 12 (2) post 6 (2) p<0.05 | p<0.001 |
| **Others** | | | |
| Venturelli et al.[27] | (Fasting) Glycemia (mg/dl-1) | mean + (SD): IG: pre 94(5) post 90(3) p=0.784; CG: pre 92(5) post 93(5) p=0.345 | p=0.143 |
| | Systolic blood pressure (mmHg) | mean + (SD): IG: pre 132(10) post 126(8) p=0.05; CG: pre 133(6) post 135(7) p=0.368 | p=0.108 |
| | Diastolic blood pressure (mmHg) | mean + (SD): IG: pre 84(5) post 82(3) p=0.550; CG: pre 84(3) post 84(3) p=0.334 | p=0.376 |

[a]Mean difference with 95% CI or p-value of test of between group difference if mean difference with 95% CI was not available.

(M)FR=(Modified) Functional Reach test, TUG= Timed Up and Go test, FTSTS= Five-Times-Sit-to-Stand, TSP= timed static pedalling, BBS= Berg Balance Scale, CST= Chair Stand Test (30 sec), MD= Mean difference, WA= walking aid, GDS 15= Geriatric Depression Scale 15-item version, MADRS= Montgomery–Åsberg Depression Rating Scale, CMAI= Cohen-Mansfield Agitation Inventory, PGC-MS= Philadelphia Geriatric Center Morale Scale, BI=Barthel Index, FIM= Functional Independence Measure, MMSE= Mini-Mental State Examination, NPI-Q= The Neuropsychiatric Inventory questionnaire, QUALID= Quality of life in late-stage dementia scale, VF= Verbal fluency, ADAS-COG= Alzheimer's Disease Assessment Scale-Cognitive Subscale, 6mwt= six minute walking test, FOME=Fuld Object Memory Evaluation, mg/dl=milligrams per decilitre, mmHg= millimetre of mercury

*Table S4: Certainty in the evidence according to the GRADE approach*

| **Multimodal exercise interventions** | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | **No of studies** | **N total** | **Study design and execution** | **Inconsistency** | **Indirectness** | **Imprecision** | **Publication bias** | **GRADE** |
| **Physical performance** | | | | | | | | |
| Balance | 3 | 355 | -2 (one study at high risk of bias) | -1 (2 in favor of intervention, 1 no effect) | -1 (differences in intervention duration and frequency, differences in control groups) | -1 (one study with a large confidence interval) | - | Very low |
| Walking speed | 3 | 387 | -2 (one study at high risk of bias) | - | -2 (differences in intervention duration and frequency, differences in control groups. difference in outcome measure) | -1 (one study with a large confidence interval) | - | Very low |
| **ADL functioning** | | | | | | | | |
| ADL functioning | 3 | 421 | -1 (one study with RoB concerns) | -2 (1 in favor of intervention, 2 no effect) | - | - | - | Very low |
| **Psychological wellbeing** | | | | | | | | |
| Depression | 3 | 314 | -1 (one study with RoB concerns) | - 1 (different directions of effect) | - | -1 (one study with a large confidence interval) | - | Very low |

*Table S5: Prisma Chart*

| Section and Topic | Item | Checklist item | Location where item is reported (Line) |
|---|---|---|---|
| **TITLE** | | | |
| Title | 1 | Identify the report as a systematic review. | 13 |
| **ABSTRACT** | | | |
| Abstract | 2 | See the PRISMA 2020 for Abstracts checklist. | 48 |
| **INTRODUCTION** | | | |
| Rationale | 3 | Describe the rationale for the review in the context of existing knowledge. | 107-110 |
| Objectives | 4 | Provide an explicit statement of the objective(s) or question(s) the review addresses. | 111-115 |
| **METHODS** | | | |
| Eligibility criteria | 5 | Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses. | 139-149 |
| Information sources | 6 | Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted. | 126-129 |
| Search strategy | 7 | Present the full search strategies for all databases, registers and websites, including any filters and limits used. | Sup 1 |
| Selection process | 8 | Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process. | 138-139 |
| Data collection process | 9 | Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process. | 156-171 |
| Data items | 10a | List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect. | 168-171 |
| | 10b | List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information. | 160-167 |

*Table S5: Prisma Chart (continued)*

| Section and Topic | Item | Checklist item | Location where item is reported (Line) |
|---|---|---|---|
| Study risk of bias assessment | 11 | Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process. | 173-183 |
| Effect measures | 12 | Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results. | 203-210 |
| Synthesis methods | 13a | Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)). | 197-202 |
| | 13b | Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions. | 203-210 |
| | 13c | Describe any methods used to tabulate or visually display results of individual studies and syntheses. | 207 |
| | 13d | Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used. | 199, 200 |
| | 13e | Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression). | - |
| | 13f | Describe any sensitivity analyses conducted to assess robustness of the synthesized results. | - |
| Reporting bias assessment | 14 | Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases). | - |
| Certainty assessment | 15 | Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome. | 190-194 |
| **RESULTS** | | | |
| Study selection | 16a | Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram. | Figure 1 |
| | 16b | Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded. | Sup 2 |
| Study characteristics | 17 | Cite each included study and present its characteristics. | Table 1 |

*Table S5: Prisma Chart* (*continued*)

| Section and Topic | Item | Checklist item | Location where item is reported (Line) |
|---|---|---|---|
| Risk of bias in studies | 18 | Present assessments of risk of bias for each included study. | Table 4 |
| Results of individual studies | 19 | For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots. | Table 3, Figure 2a, 2b |
| Results of syntheses | 20a | For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies. | Table 3, Figure 2a, 2b, Table 4 |
| | 20b | Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect. | Figure 2a, 2b |
| | 20c | Present results of all investigations of possible causes of heterogeneity among study results. | - |
| | 20d | Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results. | - |
| Reporting biases | 21 | Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed. | - |
| Certainty of evidence | 22 | Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed. | Sup 3 |
| **DISCUSSION** | | | |
| Discussion | 23a | Provide a general interpretation of the results in the context of other evidence. | 434-485 |
| | 23b | Discuss any limitations of the evidence included in the review. | 487-493 |
| | 23c | Discuss any limitations of the review processes used. | 496-508 |
| | 23d | Discuss implications of the results for practice, policy, and future research. | 512-520 |

*Table S5: Prisma Chart (continued)*

| Section and Topic | Item | Checklist item | Location where item is reported (Line) |
|---|---|---|---|
| **OTHER INFORMATION** | | | |
| Registration and protocol | 24a | Provide registration information for the review, including register name and registration number, or state that the review was not registered. | 120 |
| | 24b | Indicate where the review protocol can be accessed, or state that a protocol was not prepared. | 120 |
| | 24c | Describe and explain any amendments to information provided at registration or in the protocol. | - |
| Support | 25 | Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review. | 523 |
| Competing interests | 26 | Declare any competing interests of review authors. | 526 |
| Availability of data, code and other materials | 27 | Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review. | - |

# Chapter 3:

## The structure and process of physiotherapy services for nursing home residents with dementia in the Netherlands

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## Introduction

In addition to memory loss, dementia poses significant healthcare challenges, including diminished physical function and increased care dependency.[1] As care dependency grows, the transition from residential to nursing home care may become inevitable.[2] Physiotherapy services are frequently employed to maintain or improve the physical functioning of nursing home residents with dementia.[3]

Although physiotherapy is a prevalent therapeutic modality, previous literature indicates significant variation in its employment.[4] This variation can potentially result in suboptimal treatment. To reduce this variation, calls for guidelines on physiotherapy for nursing home residents with dementia have been made.[5,6] Before guidelines can be developed, more knowledge about factors that cause variation is necessary. The aim of this study was therefore to explore the presence of practice variation in physiotherapy services for nursing home residents with dementia in the Netherlands.

## Methods

We used a cross-sectional study design utilizing an online survey to collect data from physiotherapists working with nursing home residents with dementia. We aimed to include 10% of the approximately 830 Dutch nursing homes which have facilities for people with dementia, with one responding physiotherapist per nursing home. In the Netherlands, nursing home care is integrated into the national insurance scheme. The costs associated with physiotherapy treatment are encompassed within standardized care packages, which are uniform across care providers in the country. Physiotherapists were recruited from November 2022 to March 2023. To prevent repetitive submissions from the same nursing home, the four digits from the postal code were gathered. In case of repetitive submissions, either the survey with the largest number of completed questions, or in case completion was similar, the last survey received was included.

The survey was based on the healthcare framework by Donabedian,[7] describing the quality of care by its "structure", "process" and "outcome", and was created by two authors experienced in physiotherapy for nursing home residents with dementia. Survey data output was analyzed in SPSS version 25 (Armonk, NY: IBM Corp.). Descriptive statistics were calculated for all variables. The practice variation thresholds were set in a consensus meeting at >75% and <25% for data presented in percentages. For data expressed as mean and standard deviation the coefficient of variation was calculated, and the thresholds COV >0.8 as variation, COV >0.5 and ≤0.8 as possible variation, and <0.5 as no variation were used.[8]

## Results

A total of 109 physiotherapists representing 109 nursing homes participated with a median age of 36 years (range 30-53) and a median working experience 10 years (range 5-19).

In terms of structure (Table 1), nursing homes offered an average of 24 hours of physiotherapy per week for an average of 60 residents with dementia. A physician's referral was required to start treatment in 43% of cases. Multidisciplinary team meetings were attended regularly by 93% of participants, with occupational therapists, psychologists and specialized geriatric physicians being the most frequently involved professionals.

Table 1: Reported structure of physiotherapy services for nursing home residents with dementia in nursing homes in the Netherlands

| **Characteristics of the nursing home** | ***N respondents*** | **Results** |
|---|---|---|
| Number of residents with dementia in the nursing home; mean (SD) | 109 | 60.1 (31.4) |
| Availability of physiotherapy (hours/week) for residents with dementia per nursing home; mean (SD) | 109 | 24.4 (21.2) |
| Availability of PT (hours/week) per resident; mean (SD) | 109 | 0.3 (0.2) |
| Number of PT's providing therapy; mean (SD) | 109 | 2.4 (1.4) |
| Availability of physiotherapy is related to the residents' care package; *n* respondents (%) | 109 | 45 (41.3%) |
| **Protocols or regulations in PT; *n* respondents (%)** | | |
| Referral needed to start PT | 108 | 46 (42.6%) |
| Protocols or regulations in place regarding starting PT | 108 | 49 (45.4%) |
| Formal regulations for starting PT | 49 | 29 (59.2%) |
| Protocols or regulations in place regarding stopping PT | 108 | 38 (35.2%) |
| Formal regulations for stopping PT | 38 | 27 (71.1%) |
| Protocols or regulations in place regarding evaluating PT | 108 | 46 (42.6%) |
| Formal regulations for evaluating PT | 46 | 21 (45.7%) |
| **Multidisciplinary team; *n* respondents (%)** | | |
| Physician | 108 | 77 (71%) |
| Specialized geriatric physician | 108 | 102 (94%) |
| Nurse practitioner | 107 | 72 (67%) |
| Occupational therapist | 108 | 106 (98%) |
| Psychologist | 108 | 106 (98%) |
| Social worker | 107 | 66 (62%) |
| Speech therapist | 108 | 96 (89%) |
| Dietician | 108 | 97 (90%) |
| Exercise therapist | 108 | 63 (58%) |
| Creative therapist | 107 | 62 (58%) |

Table 1: Reported structure of physiotherapy services for nursing home residents with dementia in nursing homes in the Netherlands (*continued*)

| **Characteristics of the nursing home** | ***N respondents*** | **Results** |
|---|---|---|
| Spiritual counselor | 108 | 17 (16%) |
| Recreational worker | 108 | 10 (9%) |
| Therapy assistant | 108 | 4 (4%) |
| **Multidisciplinary meetings** | | |
| Periodic multidisciplinary meetings; *n* respondents (%) | 108 | 100 (93%) |
| Yearly frequency of multidisciplinary meetings; mean (SD) | 95 | 2.0 (0.61) |
| **Presence of specialized PT's; *n* respondents (%)** | | |
| Geriatric PT | 107 | 50 (47%) |
| Manual PT | 107 | 3 (3%) |
| Pelvic floor PT | 107 | 0 (0%) |
| Psychomotor PT | 107 | 2 (2%) |
| Pediatric PT | 107 | 1 (1%) |
| Oncology PT | 107 | 2 (2%) |
| Sport PT | 107 | 2 (2%) |
| Master degree not recognized by the Royal Dutch Physiotherapy Association (Musculoskeletal echography, Healthy Aging, Physiotherapy sciences, Movement sciences, Neuro-rehabilitation) | 107 | 11 (10%) |
| **Non-treatment related activities** | | |
| Providing training; *n* respondents (%) | 107 | 79 (74%) |
| Providing training; hours spent monthly (SD) | 107 | 6.0 (16.3) |
| Physiotherapy meetings; *n* respondents (%) | 104 | 102 (98%) |
| Physiotherapy meetings; hours spent monthly (SD) | 104 | 3.7 (6.6) |
| Multidisciplinary team meetings (resident care); *n* respondents (%) | 105 | 100 (95%) |
| Multidisciplinary team meetings (resident care); hours spent monthly (SD) | 105 | 5.8 (13.6) |
| Multidisciplinary team meetings (non-resident care); *n* respondents (%) | 106 | 99 (93%) |
| Multidisciplinary team meetings (non-resident care); hours spent monthly (SD) | 106 | 4.7 (8.7) |
| **Topics of trainings; *n* respondents (%)** | | |
| Transfers | 79 | 73 (92%) |
| Risk of falls | 79 | 35 (44%) |
| Compression materials | 79 | 31 (39%) |
| Pressure ulcers | 79 | 23 (29%) |
| Occupational health and safety | 79 | 49 (62%) |
| Sensory Integration | 79 | 6 (8%) |
| Geriatric syndromes education (Parkinsons. dementia) | 79 | 6 (8%) |
| Passive mobility techniques | 79 | 5 (6%) |
| Movement and exercise | 79 | 4 (5%) |

Regarding the process (Table 2), an average of 24% of residents received physiotherapy with a mean frequency of 1.7 times per week. Assessment instruments were used by 70% of respondents, with the POMA Tinetti test being the most prevalent instrument. All respondents reported employing individual exercise therapy sessions. Besides exercise therapy, therapeutic advice to nursing home staff (95% of respondents) and family (57% of respondents) was reported.

Table 2: Survey results on the process of physiotherapy services for nursing home residents with dementia in nursing homes in the Netherlands

| **Treatment frequency; mean (SD)** | ***N respondents*** | **Results** |
|---|---|---|
| Number of individual residents treated in the last month | 105 | 12.3 (8.4) |
| Weekly treatment frequency | 97 | 1.7 (0.8) |
| % of residents receiving physiotherapy | | 23.6 (18.4) |
| **Utilization of assessments and measurements; *n* respondents (%)** | | |
| Number of respondents that used a test or measurement in the last month | 105 | 70 (67%) |
| **Type of assessment or measurement; *n* respondents (%)** | | |
| Visual Analog Scale – functioning | 68 | 13 (19%) |
| Numeric Pain Rating Scale | 69 | 28 (41%) |
| Visual Analog Scale – Pain | 68 | 18 (26%) |
| Barthel Index | 68 | 10 (15%) |
| Six minute walk test | 69 | 29 (42%) |
| Berg Balance Scale | 69 | 23 (33%) |
| Functional Ambulatory Categories | 70 | 48 (69%) |
| Range of motion by goniometer | 68 | 9 (13%) |
| Modified Ashworth Scale | 68 | 6 (9%) |
| Handheld dynamometer | 68 | 26 (38%) |
| Medical Research Council - strength scale | 70 | 43 (61%) |
| Timed Chair Stand Test (variations of) | 69 | 30 (43%) |
| Timed Up and Go test | 69 | 38 (55%) |
| Performance Oriented Mobility Assessment (Tinetti Test) | 68 | 53 (78%) |
| Short Physical Performance Battery | 67 | 19 (28%) |
| Motricity Index, Figure 8 walk test, Two Minute Step test | 67 | 2 (3%) |
| Ten meter walk test, Ficsit 4 | 67 | 3 (4%) |
| Elderly Mobility Scale | 67 | 5 (7%) |
| One Repetition Maximum, PACSLAC-D, Nijmegen Orthopedic Gait Analysis, Paratonia Assessment Scale, Trunc Control Test, | 67 | 1 (1%) |
| **Therapy outcomes; *n* respondents (%)** | | |
| Mobility | 104 | 94 (90%) |
| Pain | 104 | 41 (39%) |

Table 2: Survey results on the process of physiotherapy services for nursing home residents with dementia in nursing homes in the Netherlands (*continued*)

| **Treatment frequency; mean (SD)** | ***N respondents*** | **Results** |
|---|---|---|
| Risk of falls | 104 | 76 (73%) |
| Transfers | 104 | 86 (83%) |
| Pressure ulcers | 104 | 7 (7%) |
| Sarcopenia/muscle strength | 104 | 13 (13%) |
| Paratonia | 104 | 9 (9%) |
| Behavioural symptoms | 104 | 17 (16%) |
| Oedema | 104 | 11 (11%) |
| Wound management, pelvic funtion, weight control | 104 | 0 (0%) |
| **Composition of exercise therapy; *n* respondents (%)** | | |
| Individual exercise therapy | 104 | 104 (100%) |
| Group exercise therapy | 104 | 37 (36%) |
| **Therapeutic modalities; *n* respondents (%)** | | |
| Exercise | 104 | 104 (100%) |
| Therapeutic modalities (cold/heat/electro/light), dry needling, acupuncture | 104 | (< 5%) |
| Medical taping | 104 | 17 (16%) |
| Manual therapy (manipulations/passive mobilisations/massage) | 104 | 42 (40%) |
| Relaxation and breathing exercises | 104 | 34 (33%) |
| Prescribing unsupervised exercises | 104 | 40 (38%) |
| Recommendations on mobility and walking aids | 104 | 97 (94%) |
| Advice/coaching | 104 | 97 (94%) |
| **Location of treatment; *n* respondents (%)** | | |
| Gymnasium | 104 | 83 (80%) |
| Examination room | 104 | 24 (23%) |
| Residents' room | 104 | 95 (91%) |
| Common room | 104 | 84 (82%) |
| Garden from the nursing home | 104 | 30 (29%) |
| Public outdoors | 104 | 27 (26%) |
| **Advisory role; *n* respondents (%)** | | |
| Advice to healthcare staff | 104 | 99 (95%) |
| Advice to informal caregivers | 104 | 59 (57%) |
| **Involvement of informal caregivers in decision making** | | |
| Involved informal caregiver in decision making last month; *n* respondents (%) | 104 | 79 (76%) |
| Frequency of involvement per month; mean (SD) | 104 | 4.0 (4.1) |
| **Involvement of residents in decision making** | | |
| Involved resident in decision making last month; *n* respondents (%) | 104 | 81 (78%) |
| Frequency of involvement per month; mean (SD) | 104 | 5.9 (7.6) |

Table 2: Survey results on the process of physiotherapy services for nursing home residents with dementia in nursing homes in the Netherlands (*continued*)

| **Treatment frequency; mean (SD)** | ***N respondents*** | **Results** |
|---|---|---|
| **Method of communication with informal caregivers; *n* respondents (%)** | | |
| Phone | 104 | 69 (68%) |
| Face to face | 104 | 83 (81%) |
| Digital patient file | 104 | 42 (41%) |
| E-mail | 104 | 26 (25%) |
| Whatsapp | 104 | 10 (10%) |
| Via nursing staff | 104 | 3 (3%) |
| **Initiative of communication with informal caregivers; *n* respondents (%)** | | |
| Physiotherapist | 104 | 90 (88%) |
| Physician | 104 | 23 (22%) |
| Nursing staff | 104 | 46 (45%) |
| Informal caregiver | 104 | 58 (57%) |
| Residents | 104 | 13 (12%) |

Practice variation was detected in 44% of the structure elements and 36% of the process elements of the survey.

## Discussion

The findings highlight both similarities and variations in the delivery of physiotherapy services for nursing home residents with dementia. Variation in the availability of physiotherapy services aligns with the findings of previous studies.[4] Consensus was present regarding multidisciplinary collaboration, which can be perceived as beneficial, since many geriatric syndromes like sarcopenia, depression and risk of falls require a multidisciplinary approach.[9,10] Besides exercise therapy, physiotherapists have a large advisory role on mobility, risk of falls, waking aids and occupational health and safety. This is new information, since physiotherapy services in previous reviews were limited to pain management and treating pressure ulcers.[4] Our study answers previous research questions, namely which factors attribute to practice variation.[4,5] Future research could explore which elements are favorable and should be incorporated into daily physiotherapy practice.

Despite the diverse characteristics within the population of nursing home residents with dementia, we emphasize the importance of defining physiotherapy and nursing home standards. Future studies should focus on examining which elements of the structural and procedural framework are favorable and should be integrated into daily practice.

## Author contributions

DB, CS, SS and TVV conceptualized the study. DB and SS developed the survey. DB, CS, SS and TVV drafted the manuscript. DB and SS performed the data analysis. All authors read, provided feedback and approved the final manuscript.

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## Conflict of interest statement

The authors have no conflicts.

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None

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# Part 2

# Chapter 4:

## The perceptions, needs and preferences of informal caregivers of nursing home residents with dementia regarding physical therapy: a qualitative study

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## Abstract

**Introduction:** Informal caregivers often support nursing home residents with dementia in making therapeutic decisions. We explored the perceptions, needs and preferences of informal caregivers of nursing home residents with dementia regarding physical therapy.

**Method:** We conducted eleven semi-structured interviews. Thematic analysis was used.

**Results:** Five themes emerged: 1) visibility and familiarity; 2) communication; 3) aim and content; 4) dosage and location; 5) level of expertise and the role of the physical therapist within the interdisciplinary team. Informal caregivers' perceptions of physical therapy included a lack of visibility and familiarity. They needed more communication, and empathic communication skills of the physical therapists. Preferences included physical therapy to be enjoyable, accessible and tailored to the needs of the resident.

**Conclusion:** Physical therapists need to involve informal caregivers in physical therapy care. Implementing shared decision-making will help to get informal caregivers more involved, but has yet to be studied in this setting.

## Introduction

With the aging of the population, the global demand for long-term care institutions such as nursing homes increases simultaneously.[1] It is estimated that 84% of nursing home residents have dementia.[2] Apart from cognitive and communicative problems,[3,4] many nursing home residents with dementia have physical disabilities, including reduced muscle strength,[5–7] decreased mobility,[5,6,8] an increased risk of falling[5,7–9] and limitations in Activities of Daily Living (ADL).[5,7,10]

Residents in nursing homes depend on interdisciplinary care in which physical therapists, nursing staff, physicians, occupational therapists, and other care providers work closely together in order to treat the problems caused by physical disabilities. For example, an estimated 69% of Dutch nursing home residents receive physical therapy.[11] According to a systematic review performed in 2019, this is noticeably more than other high-income countries, where on average 14% of the nursing home residents receive physical therapy.[12] In the Netherlands, most nursing homes have separate wards for long-term physical care (somatic wards), and for residents who receive long-term psychogeriatric care (psycho-geriatric wards). A previous study has shown that residents residing on a psycho-geriatric ward are less likely to receive physical therapy than residents residing on a somatic ward.[11]

Given the problems in cognitive functioning and communication, informal caregivers often support nursing home residents with dementia in making therapeutic decisions.[13,14] For this reason, healthcare professionals can collaborate with informal caregivers or resident representatives if the resident is unable to discuss therapeutic matters. Currently, little is known about the perceptions, needs and preferences of informal caregivers of nursing home residents regarding physical therapy. One study explored the views of informal caregivers of nursing home residents regarding a physical therapist-led exercise intervention.[15] The results indicated that family caregivers who understand the benefits of physical exercise have a more positive attitude towards physical exercise. Another study found that informal caregivers of nursing home residents with dementia often feel excluded and isolated, which can result in dissatisfaction with the provided care.[16] Regarding healthcare professionals, findings indicate that they do recognize the importance of working in partnership with informal caregivers, but have difficulties putting this into practice.[17]

Improving the relationship between the interdisciplinary team and informal caregivers can potentially reduce conflict, reduce work pressure and improve staff attitudes towards informal caregivers.[16] Furthermore, involvement of informal caregivers in nursing homes can positively affect the resident's well-being.[18] Optimized collaboration between family

caregivers and physical therapists has previously been proven beneficial for older people and their families in a Transition Care setting.[19]

It is important to gain insight in the perceptions, needs and preferences of informal caregivers.[20,21] This can lead to a better involvement of the informal caregivers and may benefit the treatment of nursing home residents with dementia. Therefore, the aim of this study is to explore the perceptions, needs and preferences of informal caregivers of nursing home residents with dementia regarding physical therapy.

# Method

## Design of the study

We performed a descriptive, qualitative study with semi-structured interviews. Within the context of this study, we defined *perceptions* as a personal and subjective way of viewing a topic.[22] A *need* refers to an implicit, communicated or perceived state of deprivation,[23] and a *preference* is defined as a wish or desire, but is under no circumstances absolutely necessary.[24] The consolidated criteria for reporting qualitative research (COREQ) were used for the reporting of this study.[25]

## Ethical aspects

In the Netherlands, only scientific studies in which participants are imposed to interventions or restrictions require approval of an ethics review board, according to the Medical Research Involving Human Subjects Act (Wet Medisch-wetenschappelijk Onderzoek (WMO)).[26] Approval to undertake this study was provided by the local research committee of the participating nursing home organization. This study was conducted according to the principles of the Declaration of Helsinki (World Medical Association, 2000). All study data were handled confidentially and in accordance with the General Data Protection Regulation (GDPR).[27] All participants gave their written informed consent.

## Setting

The study was conducted in 2021 and took place in four nursing homes that are part of the healthcare organization "Kennemerhart", located in and around the urban area of the Dutch city Haarlem. The selected homes accommodate between 60 and 110 residents. The long-term care wards for residents with dementia are similar in all nursing homes, and all have the characteristics of a small, domestic-style care setting. Every ward has multiple households. Each household is shared with a maximum of ten residents. All nursing homes hold personal care-plan meetings twice a year in which care and therapeutic topics are discussed. Informal caregivers can participate in care-plan meetings at two of the four locations. In the other two locations the care-plan meetings are first held with

the medical staff, and the results of this meeting are later discussed between informal caregivers, a licensed nurse and the physician in charge. In all nursing homes, authorized informal caregivers can access the electronic medical record in which the physical therapists report.



At the time the study was conducted, seven physical therapists worked a combined total of 98 hours per week, delivering care to 184 residents on eleven long-term wards (on average 0.53 hours per resident per week). The physical therapists evaluated basic physical functions and the risk of falling of every new resident. This evaluation is used to decide if the resident needs physical therapy treatment. The content of physical therapy treatment in the nursing homes was comparable to other Dutch nursing homes and predominantly consisted of exercise therapy.[28] Besides exercise therapy, physical therapists provided (lymph drainage) massage, relaxation exercises and consultations on pain and mobility problems. All physical therapy sessions or consultations were individual, no group sessions were conducted. Apart from interventions aimed at the resident, physical therapists advised staff and informal caregivers of residents on a variety of health-related issues such as fall-prevention, behavioral and psychological symptoms in dementia, mobility in ADL and transfer-techniques during daily care.[28]

## Participants

Potential participants for the study were informal caregivers related to residents with dementia living in the four previously described nursing homes. The seven physical therapists working in the nursing homes provided a list of informal caregivers of nursing home residents with dementia who were living in the nursing home between March 31st and May 10th, 2021. We invited the informal caregivers by email to participate in the study, in accordance with the terms and conditions for scientific research in Dutch nursing home care.[29] The invitations included information about the study and a hyperlink to an online questionnaire (which was used to map the characteristics of the participants) in order to screen for eligibility. Informal caregivers were eligible if they: 1) Were involved in the decision-making process regarding the health and wellbeing of the resident; 2) Did not have mental or physical problems that could impede with the interview; 3) Spoke Dutch. If no response was obtained after the first e-mail, a maximum of two reminder e-mails were sent. Potential participants were ensured that their participation in the study was voluntary and that participation or non-participation would not affect the care for their relative.

## Data collection

The interviews were conducted by four female physical therapy students (MG/AK/AL/SM) who were supervised by two senior researchers who are experienced in qualitative research (FL/AH). We created an interview guide that covered topics of interest in line with

the study. The interview guide consisted of six topics (physical therapy treatments, expertise, collaboration between the physical therapist and the informal caregiver, level of support, communication, role of the physical therapist in the interdisciplinary team). The interview guide was pilot tested with the first author before use, but no major changes were made (Appendix 1). The semi-structured interviews took place between April 15th and May 18th, 2021 and were conducted digitally.

During each interview three persons were present: the interviewer, the observer and the participant. The interviewer conducted the interview, while the observer checked for completeness. The Jitsi-meet website (https://meet.jit.si) was used to digitally communicate with participants and audio-recordings were made with the Apple recording program OBS Studio 26.1.0 (Open Broadcast Software Studio Contributors, San Francisco, United States of America). The recordings were temporarily stored on a password secured Google OneDrive and were destroyed after transcription and analysis. No personal information from participants was visible in the transcripts of the interviews.

There was no existing personal or other relationship between the students and the participants prior to this study. Previous research has shown that data saturation can occur between six and twelve interviews.[30] In order to achieve data saturation, we aimed to conduct at least ten interviews, and to continue with the interviews until no new topics were raised on two consecutive interviews. No unforeseen problems arose during the interviews, therefore none of the interviews had to be repeated.

## Data analysis

We used descriptive statistics to present basic characteristics of informal caregivers.

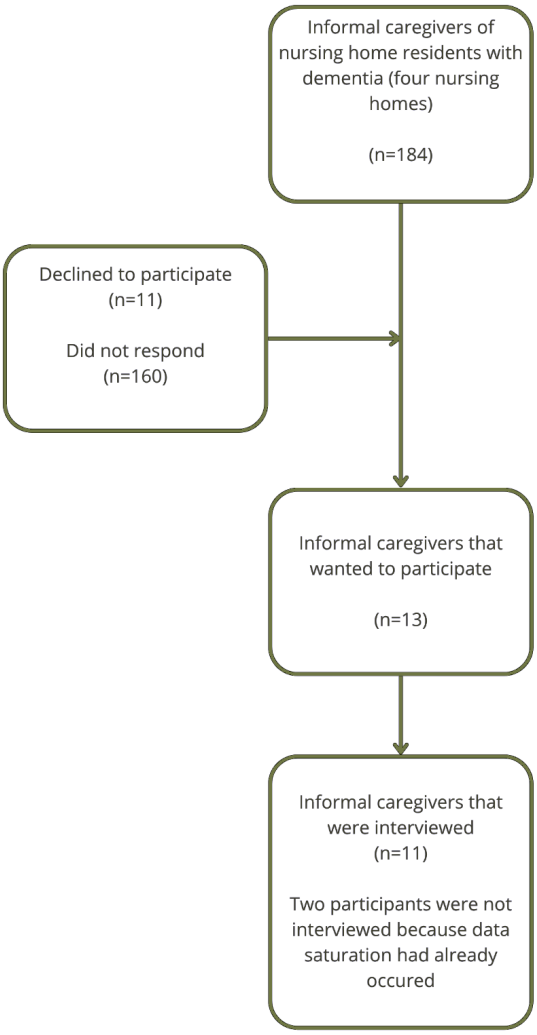
Regarding the interviews, the audio files of all interviews were transcribed verbatim. Transcripts were not returned to the participants for correction. The transcripts were qualitatively analyzed by an alternating team of two researchers (AL/MG/AK/SM) according to the guidelines for qualitative research in healthcare by Rapport et al.[31] We used thematic analysis, in which the researchers select and code interesting features of the data and later collate codes into potential themes.[32] An alternating set of two researchers (AL/MG/AK/SM) independently performed all coding using ATLAS.ti web (https://atlasti.com). Discrepancies in codes between researchers were discussed in order to reach consensus. Codes with comparable content were merged into minor themes, and minor themes with comparable content were subsequently merged into major themes. The contents of the major themes were similar to the contents of the interview guide, but after the data collection the contents were reorganized. During the data analysis we made separate divisions of the needs and preferences. The combined analysis was then reviewed by the principal investigator to ensure accuracy and clarity of the themes and subthemes.

# Results

## Participants

A total of 184 informal caregivers received the invitation to participate in the study. Eleven caregivers (6%) explicitly declined to participate, whereas 160 (87%) informal caregivers did not respond to the first email and reminder emails. Ultimately, thirteen caregivers agreed to participate (response rate 7%) (Figure 1). The participant characteristics are described in Table 1. As Table 1 shows, the majority of the respondents had a daughter/son relationship with the resident (84.6% of the sample) and most caregivers were female (69.2%).

Figure 1: Flowchart of inclusion of participants in the study



After eleven interviews no new issues were raised and the researchers concluded that data saturation had occurred. The interviews lasted between 30 and 58 minutes (on average 43 minutes). The results of the six topics were merged and divided into five major themes: 1) visibility and familiarity; 2) communication; 3) aim and content; 4) dosage and location; and 5) level of expertise and the role of the physical therapist within the interdisciplinary team. The major themes, the minor themes, the condensed results categorized in perceptions, needs and preferences and selected participant's quotes are presented in Table 2.

Table 1: Characteristics of informal caregivers of residents of nursing homes with dementia, participating in a qualitative study on nursing home physical therapy (n=13)

| | | **n =13 (%)** |
|---|---|---|
| Age | 46-55 years | 2 (15.4) |
| | 56-65 years | 5 (38.5) |
| | 66-75 years | 6 (46.2) |
| Gender | Male | 4 (30.8) |
| | Female | 9 (69.2) |
| | Other | - |
| Educational level * | Low | 2 (15.4) |
| | Middle | 4 (30.8) |
| | High | 7 (53.8) |
| Nationality | Dutch | 13 (100) |
| Duration of provision of informal care | 1-5 years | 5 (38.5) |
| | > 5 years | 8 (61.5) |
| Relationship to resident | Daughter/son | 11 (84.6) |
| | Aunt | 1 (7.7) |
| | Daughter/son in law | 1 (7.7) |
| Years of resident living in nursing home | < 1 year | 4 (30.8) |
| | 1-3 years | 6 (46.2) |
| | > 3 years | 3 (23.1) |
| Weekly hours as informal caregiver | < 10 hours | 8 (61.5) |
| | 10-20 hours | 5 (38.5) |
| How demanding is being an informal caregiver? | Lightly demanding | 7 (53.8) |
| | Moderately demanding | 5 (38.5) |
| | Very demanding | 1 (7.7) |

## Theme 1: Visibility and familiarity

***Perceptions***

Regarding perceptions, most informal caregivers indicated that they knew little about physical therapy in the nursing home. According to them, this was partly because they had no medical background themselves, but also because they were not informed about the activities of a physical therapist in the nursing home. Some caregivers indicated that they were unaware that physical therapy was provided by the nursing home. Only few had met the treating physical therapist in person.

***Needs***

Nearly all informal caregivers mentioned a need for more frequent information about physical therapy. For example, they would like to be informed when the physical therapist starts, stops or modifies the treatment. Furthermore, they expressed the need to have more information about the progress of the treatment and which interventions are used to achieve healthcare goals.

***Preferences***

Some informal caregivers mentioned that gaining more insight in the decision-making process of the physical therapist could lead to a higher satisfaction about physical therapy.

Table 2: Major themes, minor themes and selected participant's quotes after the analysis of eleven interviews with informal caregivers of nursing homes residents with dementia

| Major theme | Minor theme | Results | | | Participants quotes |
|---|---|---|---|---|---|
| | | Perceptions | Needs | Preferences | |
| Visibility and familiarity with physical therapy in the nursing home | Understanding of physical therapy | Limited knowledge about physical therapy in the nursing home. | More frequent information about physical therapy and their activities. | More insight in the decision-making process of physical therapists. | *"I don't have enough understanding about physical therapy, because I do not know what they [the physical therapists] do. Since my father has dementia, I can't always rely on him to tell me." (Informal caregiver (I) 4) (Perceptions)* |
| | Information provision on physical therapy | Lack of information from the physical therapists or the nursing home staff about physical therapy. | More frequent information about the progress of the treatment and the used interventions. | | *"Occasionally an open day or introduction day is held in nursing homes […] it might be interesting for the physical therapists to present themselves as well." (I 13) (Needs)* |

Table 2: Major themes, minor themes and selected participant's quotes after the analysis of eleven interviews with informal caregivers of nursing homes residents with dementia (*continued*)

| Major theme | Minor theme | Results | | | Participants quotes |
|---|---|---|---|---|---|
| | | Perceptions | Needs | Preferences | |
| | Visibility of physical therapists | Lack of visibility; Not seen the treating physical therapist personally. | | | *"I don't see any physical therapists. Maybe there's someone walking around in uniform, but I don't know what their function is. I don't know whether he or she belongs to the nursing staff or to physical therapy." (I5) (Perceptions)* |
| Communication between informal caregivers and physical therapists | Moments of communication | Little or no communication with the physical therapists of the nursing home. | More communication with physical therapists. | | *"I don't have prejudice against the physical therapists. In my experience they [the physical therapists] are all clear and empathic. But at the moment I do miss communication" (I 6) (Needs)* |
| | Care plan meeting | Different experiences whether physical therapy was discussed at the care-plan meetings. | Discuss physical therapy matters | | *"In my opinion, a physical therapist should be present at every care-plan meeting" (I 4) (Needs)* |
| | Ways of communication | | Understandable language, no medical jargon | The digital patient file can be used to communicate. | *"If I could read updates, for example a monthly update, in the digital patient file, that would be sufficient for me" (I 8) (Needs)* *"I prefer face-to-face communication, in a way that they will take time for a conversation. But nowadays digital meetings have been a good alternative" (I 6) (Preferences)* |
| | Subjects of discussion | | All physical therapy matters. | Physical therapy appointments are visible, to help plan a visit. | *"I wish to be kept informed about whether something is or is not going well. Or to discuss what is important to me, because my father usually does not indicate it himself." (I 3) (Needs)* |

Table 2: Major themes, minor themes and selected participant's quotes after the analysis of eleven interviews with informal caregivers of nursing homes residents with dementia (*continued*)

| Major theme | Minor theme | Results | | | Participants quotes |
|---|---|---|---|---|---|
| | | Perceptions | Needs | Preferences | |
| Aim and content of physical therapy | Goal and contents of physical therapy | Physical therapy is aimed at preserving the physical functioning of the resident, mostly by exercise training. | Tailored to the individual needs of the resident; Advice on how to stay healthy themselves; Exercise needs to be enjoyable. | Improving posture and maintaining a healthy day-night rhythm | *"I envision the physical therapist analyses the mobility of the resident and where necessary, tries to improve it" (I 1) (Perceptions)* *"I personally find it incredibly hard to push a wheelchair. A physical therapist might be able to give me tips and tricks on [how to do] that" (I 1) (Needs)* *"I think regular exercise is what is best for the residents, to try to decelerate the process of Alzheimer's and to also maintain their day-night rhythm" (I 9) (Preferences)* |
| | Individual or group therapy | | Individual and group therapy, suited to the needs of the resident. | | *"I think it can be very stimulating for a resident to attend therapy with multiple residents. Having group therapy and seeing others exercise can have a stimulating effect." (I 1) (Needs)* |
| | Tailoring to the resident | | Including elements of sports and games. | E-health, such as a virtual bike trainer | *"Cycling by means of a digital home trainer through the neighborhood she grew up. Of course, that's fantastic! Thus, you have a combination of physical and cognitive exercise" (I 9) (Preferences)* |
| Dosage and location of physical therapy | Duration of the treatment | About 30 minutes. | Tailored to the individual needs and capacities. | | *"Because the attention span of elderly people is not that long, I think fifteen minutes of exercise is enough for them." (I 4) (Needs)* |

Table 2: Major themes, minor themes and selected participant's quotes after the analysis of eleven interviews with informal caregivers of nursing homes residents with dementia (*continued*)

| Major theme | Minor theme | Results | | | Participants quotes |
|---|---|---|---|---|---|
| | | Perceptions | Needs | Preferences | |
| | Frequency | Once or twice a week. | | At least once a week exercise, even if it is not guided by a physical therapist. | *"It depends on the nature of the treatment. If it is a severe injury, I assume treatment could take place twice or three times a week. But as I said, the frequency depends on the necessity of the treatment." (I 11) (Perceptions)* |
| | Location of the treatment | The apartment of the resident, exercise room or outside. | When necessary, a low stimulus environment. | When weather allows, physical therapy in the outdoors. | *"I never met a person who doesn't like being outside. By being outside people are stimulated to do something which they may find difficult, but will try it anyway." (I 9) (Preferences)* |
| Level of expertise and the role of the physical therapist within the interdisciplinary team | Level of expertise | A Bachelor's degree of physical therapy | Empathy for the residents with dementia; Communicate in a calm and friendly manner. | | *"I assume therapists have both affinity and training on the subject of geriatric care and related topics" (I 1) (Perceptions)* |
| | Interdisciplinary care | The physical therapist discusses physical functioning with other healthcare professionals. | Discuss interdisciplinary treatments that influence the physical functioning of the resident. | | *"I would like direct involvement of the physical therapist, so that the physical therapist can discuss his observation immediately within the multidisciplinary team" (I 10) (Needs)* |
| | Supplementary courses | | | Courses for a fitting attitude to nursing home residents with dementia. | *"It's not necessarily having a degree in geriatrics; it mainly has to do with the conduct or attitude towards residents" (I 2) (Preferences)* |

## Theme 2: Communication

***Perceptions***

Most participants indicated that there had been little or no communication with the physical therapist of the nursing home. One caregiver stated that he/she was informed about physical therapy for the resident during a periodic care-plan meeting. Other informal caregivers mentioned that they had attended periodic care-plan meetings, but these meetings were without the presence of a physical therapist or without discussing physical therapy.

***Needs***

Nearly all informal caregivers expressed the need for more communication with the physical therapist. They also indicated that they needed opportunities to discuss physical therapy and physical therapy treatment matters. According to some informal caregivers, these matters could be discussed during the periodic care-plan meeting.

***Preferences***

Some participants preferred to exchange information by use of the electronic medical record. However, the current way of reporting by physical therapists was also perceived as insufficient, brief and with medical jargon which is difficult to understand. Regarding the frequency of reporting in the record, some informal caregivers preferred a report after every physical therapy session, while one report every two or three months would suffice for others. Some informal caregivers also requested that the physical therapy appointments would be visible to the caregivers, to help plan their visits to the resident.

## Theme 3: Aim and content

***Perceptions***

Most informal caregivers perceived that physical therapy is aimed at preserving the resident's physical functioning. They assumed that the treatment would consist of various modalities, of which the following were mentioned: strength training; exercises related to everyday life movements; endurance training; gait training with attention for walking aids; breathing therapy; relaxation therapy and massage.

***Needs***

All informal caregivers considered it of importance that treatment was tailored to the individual's needs. Moreover, they thought that physical therapy should be offered in both groups and individually. The needs of most caregivers regarding the content of physical therapy were similar to the abovementioned expressed perceptions of current therapy, but multiple informal caregivers suggested to include elements of sports and games in

the therapy. They speculated that it would make the therapy more accessible and more enjoyable. Regarding the aim of the treatment, multiple informal caregivers expressed a need that physical therapy attends the posture of the residents. They expected that an improved posture would reduce the risk of falling. Besides treatment aimed at the resident, a need for interventions directed at informal caregivers was expressed. For example, one informal caregiver wanted advice on how to push a wheelchair without inflicting harm to her/himself (see quote in Table 2).

***Preferences***

Some caregivers indicated a preference to improve the day-night rhythm of the residents by reducing sedentary behavior during the day. They specified that stimulating residents to be more active during the day is not the responsibility of the physical therapist, but they suggested that the physical therapist can make an interdisciplinary strategy to reduce sedentary behavior. To make physical therapy more accessible, some participants suggested the use of e-health, for example a virtual bike ride.

## Theme 4: Dosage and location

***Perceptions***

Most informal caregivers expected a physical therapy session to last for around 30 minutes, as this is the duration they experienced when receiving physical therapy themselves. Some caregivers expected the treatment to last closer to fifteen minutes. For them a fifteen-minute treatment duration would be in line with a diminished attention span which is common in nursing home residents with dementia (see quote in Table 2). Most caregivers thought that physical therapy treatment took place once or twice a week. Regarding the location of the treatment, informal caregivers had the perception that treatment takes place in the residents' apartment, in the exercise room of the nursing home, or outside.

***Needs***

All participants expressed the need for a sufficiently long treatment duration, in order to guarantee the quality of the treatment. The duration of the treatment should be tailored to the individual's situation, with a possible duration ranging from fifteen minutes to one hour. Regarding location, some informal caregivers mentioned that, if necessary, a low-stimulus environment should be provided.

***Preferences***

Multiple informal caregivers stated their preference for a weekly program that contains at least some form of physical exercise. They also mentioned that exercise interventions do not always have to be guided by a physical therapist. Exercise interventions could

be given by nursing home assistants, and a physical therapist could help design the exercise intervention to ensure quality and effectiveness. Regarding location, several informal caregivers preferred that physical therapy occasionally will be held outside, when weather allows.

## Theme 5: Level of expertise and the role of the physical therapist within the interdisciplinary team



***Perceptions***

Most participants perceived that besides holding a bachelor's degree in physical therapy, the physical therapist would need additional competences in how to treat nursing home residents with dementia. Regarding the role of the physical therapist in the interdisciplinary team, most informal caregivers expected physical therapists to be concerned with the resident's physical functioning and to communicate with other professionals from other disciplines regarding topics such as mobility or balance.

***Needs***

Almost all informal caregivers thought it was important for the physical therapist to empathize with people with dementia, and to communicate with the residents in a calm and friendly manner. Not all informal caregivers considered it necessary for physical therapists to specialize in geriatrics or obtain a master's degree after completing the bachelors physical therapy degree.

Regarding the role in the interdisciplinary team, several informal caregivers indicated that physical therapists should inform other disciplines if their interventions interfere with the physical functioning of the nursing home resident. For example, if medication prescribed by the geriatrician makes the resident unstable and increases their likelihood of falling, the physical therapists are expected to communicate with the involved geriatrician and discuss the matter at hand.

***Preferences***

Regarding *preferences*, some informal caregivers in this study expressed the wish for physical therapists to follow additional courses aimed at creating a "fitting attitude and approach" to nursing home residents with dementia. By this they mean that physical therapists get taught on how to deal with the behavioral and communication disorders that can be present in residents with dementia.

Several years of work experience in geriatrics and creativity in treatment were considered as preferred characteristics for physical therapists.

## Discussion

The perceptions, needs and preferences regarding physical therapy expressed by informal caregivers of nursing home residents with dementia were identified and then categorized into five major themes: 1) visibility and familiarity; 2) communication; 3) aim and content; 4) dosage and location; and 5) level of expertise and the role of the physical therapist in the interdisciplinary team.

The findings presented in the first two themes showed that the majority of the informal caregivers lacked knowledge about physical therapy in the nursing home, and had therefore difficulties providing perceptions on several topics. Furthermore, most informal caregivers experienced insufficient communication with physical therapists. International policies and previous research recommend the involvement of informal caregivers of people with dementia, and advise to make efforts to understand their needs.[20,21] Our findings support the need for informal caregivers to be involved and to be understood. Most studies about the involvement and needs of informal caregivers in the nursing home are about daily care.[33] Our study shows that working together with informal caregivers is not only necessary for nurses, who communicate more about daily care, but also for other healthcare professionals of the interdisciplinary team such as physical therapists. A possibility to involve and to understand informal caregivers is to implement shared decision-making. In shared decision-making, the healthcare professional and the patient and/or their informal caregiver make decisions together. It is a way of asking informal caregivers about their needs, and it can prevent disappointment or dissatisfaction about the outcome of a treatment.[21] Discussing treatment with the person, or the representative of that person, is standard in almost every field of healthcare, but does not yet seem common among physical therapists who treat nursing home residents with dementia.

International differences in physical therapy provision could however influence the implementation of shared decision-making. The systematic review by Brett et al. demonstrated that massage, electrotherapy and pressure ulcer management are common physical therapy treatments used in Australia and the US, respectively.[12] These are treatments that might involve less collaboration with informal caregivers than for example physical exercises, which are more common in the Netherlands and Europe.[12, 28] Even though (physical therapy) treatments differ internationally, involving informal caregivers is a necessary task for all healthcare professionals who work with nursing home residents with dementia.[33,34]

Themes three, four and five address the needs of informal caregivers regarding the skills of physical therapists, the content of physical therapy and the location of treatment. Informal caregivers indicated that they need physical therapists to communicate with empa-

thy, and that they prefer pleasure elements in physical therapy such as sports, games and outdoor therapy. These findings differ from a study from 2008, where informal caregivers of nursing home residents with dementia placed greater meaning in the functional use of an activity.[34] The difference in findings may be explained by the time when the study was conducted. In recent years there has been more attention to the quality of life and the needs of nursing home residents with dementia.[20,35,36] Informal caregivers could therefore also be more concerned about enjoyment and pleasure elements in activities than they were before. A recent review shows that bringing enjoyment to exercise interventions and making adequate use of communication skills does increase adherence to exercise in nursing home residents with dementia.[37] If physical therapists pay more attention to pleasure elements in exercise and effective communication, the adherence to exercise therapy can be higher and the intervention could be more effective.

A strength of our study is that, to our knowledge, this is the first study to explore the perceptions, needs and preferences of informal caregivers regarding the interdisciplinary team. Many studies have been conducted on the needs of informal caregivers regarding nursing home staff, but the needs regarding the interdisciplinary team have not been included.[33,35,38] The interdisciplinary team has a substantial role in the care for nursing home residents with dementia, and the needs of informal caregivers regarding the interdisciplinary team should not be overlooked. A second strength of our study is that by using the COREQ criteria for reporting, we were able to present our method, findings and implications in a comprehensive and complete way.

There are several limitations. Firstly, all informal caregivers were invited to participate, regardless of whether their relative had received physical therapy. This could mean that informal caregivers based their perceptions on physical therapy, that was not being provided. However, in this nursing home sample, all physical therapists are supposed to evaluate the physical functioning and risk of falling with every new resident and before every care-plan meeting. It is therefore not likely that the lack of communication experienced by informal caregivers is caused by a lack of opportunities for physical therapists to reach out to them. A second limitation concerns the generalizability of our findings. The geriatric health care system in the Netherlands is managed differently than in many other countries. A key difference is that nursing home staff includes, among others; physicians, physical therapists, occupational therapists, speech therapists and psychologists.[39] The way of health care and nursing home care management will likely influence the perceptions, needs and preferences of informal caregivers of nursing home residents with dementia. Furthermore, the informal caregivers that participated in our study were all Dutch and lived in an urban environment, and most of them have attended higher education. Previous studies have shown that demography, culture and the education level influence the needs of informal caregivers.[39,40] Exploring the needs of informal caregivers of health-

care professionals in other regions and countries could discover additional information not addressed in our study.

Taking the abovementioned strengths and limitations into account, this study brings the following implications for future practice:(1); Physical therapists and other healthcare professionals working with nursing home residents with dementia need to be more aware of the needs and preferences of the informal caregivers. This can be achieved by implementing shared decision-making. (2); Regarding the contents of the physical therapy, physical therapists should try to bring enjoyment in therapy, and utilize ways of communication that are appropriate for nursing home residents with dementia.

Future research could explore the collaboration preferences of informal caregivers, specifically with physical therapists working in nursing homes. Investigating the effect of shared decision-making and what kind of role informal caregivers prefer in collaboration with healthcare professionals can provide useful practical information.

## Conclusion

Most informal caregivers lacked knowledge about the provision of physical therapy in the nursing home, and needed more communication. Informal caregivers need physical therapists to communicate calmly and with empathy with the nursing home residents. They preferred physical therapy to be enjoyable, accessible and tailored to the needs of the resident. Involving informal caregivers in the care of the residents is not only the responsibility of nurses or doctors, but of other members of the interdisciplinary team as well. Implementing shared decision-making is a way to involve informal caregivers, but has yet to be studied in the context of interdisciplinary care of nursing home residents with dementia.

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### Declarations of interest

none

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# Appendices

Appendix 1: Interview guide for the semi-structured interviews

| Topic | Perceptions | Needs/Preferences |
|---|---|---|
| **Physical therapy treatments** | What is your perception of the current physical therapy treatments for nursing home residents with dementia? (In your perception, what kind of treatments are offered by physical therapy) | What do you need from physical therapy for the nursing home residents with dementia? What kind of treatments need to be provided by physical therapists according to you? |
| | What is your perception of the duration of one physical therapy session? | What duration do you need the physical therapy to be? (What are your desires regarding the duration of the physical therapy sessions) |
| | In your perception, is physical therapy offered in group sessions or in individual sessions? | What composition do you prefer for the physical therapy sessions (Individual/group/different) |
| | In your perception, how often do residents get physical therapy? | How often do you prefer physical therapy takes place (weekly) |
| | In your perception, what kind of goals or outcomes are targeted by physical therapy? | Which goals or outcomes do you feel physical therapy should target? |
| | Where do you expect the physical therapy sessions take place? | In which place(s) do you want physical therapy to take place? It doesn't always have to be the same place, it could be multiple options. |
| | In your perception, do informal caregivers get informed about the status of the physical therapy of the resident? | In what extend do you need to be informed about the physical therapy of the resident? Could you elaborate? |
| **Expertise** | In your perception, what is the level of education of the physical therapists (bachelor or master) (elaborate) | What is your desired education level of the physical therapists? |
| | Do you perceive that the physical therapists have other qualifications regarding the treatment for the residents? (elaborate) | What other qualifications do you need from physical therapists? (courses, attitude, etc.) |
| | What are your perceptions regarding the empathy and compassion of the physical therapists towards the nursing home residents with dementia? | What are your needs regarding the empathy and compassion of the physical therapists towards the nursing home residents with dementia? |
| **Collaboration between the physical therapist and the informal caregiver** | How do you perceive the collaboration between physical therapist and the informal caregiver? According to you, what is the current state of collaboration of physical therapists and informal caregivers? (elaborate) | What do you need in the collaboration between physical therapists and informal caregivers? (elaborate) |

Appendix 1: Interview guide for the semi-structured interviews (*continued*)

| Topic | Perceptions | Needs/Preferences |
|---|---|---|
| | What is your perception about the current level of shared decision making? Currently, in what way do you perceive informal caregivers can influence physical therapy? | What are your needs regarding shared decision making? |
| **Level of support** | What are your expectations regarding getting supported by physical therapists? In your perceptions, do informal caregivers currently receive support from physical therapists? (elaborate) | What do you need regarding support from physical therapists? |
| | Currently, on what domains do informal caregivers receive support from physical therapists? | On what domains do you need or desire support from physical therapists? |
| **Communication** | What is your perception of the current communication between physical therapists and informal caregivers? | What do you prefer regarding the communication between physical therapists and informal caregivers? |
| | How often do you perceive physical therapists and caregivers currently communicate? | How often do you prefer physical therapists and informal caregivers communicate? |
| | According to your perception, what form of communication is currently used? | Which form of communication has your preference? (Multiple options, elaborate) |
| | In your perception, is there direct communication or indirect communication (As in through nurses, doctors, other staff members but also by using patient files, notebooks in the resident's room) | Could you elaborate on the preferred communication, direct or indirect? |
| **Role physical therapists in the interdisciplinary team** | According to your perception, could you describe the role of the physical therapist in the interdisciplinary team? | What is your preferred role of the physical therapist in the interdisciplinary team? |
| | In your perception, what influence does the physical therapist have in the interdisciplinary team? | What influence do you need from the physical therapist in the interdisciplinary team? (Or in what way? Elaborate) |
| | In your perception, how is the physical therapist involved in the interdisciplinary team? (direct, or through the head nurse, other options? elaborate) | In what way do you want the physical therapist to be involved in the interdisciplinary team? (direct or indirect, other options) |
| **Summary question** | | To what extend are you satisfied with your current experiences with physical therapy? |
| | | Do you have any recommendations regarding physical therapy for nursing home residents with dementia? |
| | | Would you like to address further topics? |

# Chapter 5:

## Exploring the physiotherapy and exercise needs and preferences of nursing home residents with dementia: a qualitative study

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## Abstract

**Background:** Exercise is widely employed to prevent functional decline in individuals with Alzheimer's disease and other forms of dementia. Exercise interventions are often supervised of physiotherapists, particularly in Western countries. However, adherence to exercise-based interventions remains suboptimal, particularly among nursing home residents.

**Objective:** To investigate the needs and preferences of nursing home residents with mild to moderate dementia concerning physiotherapy and exercise interventions.

**Methods:** Semi-structured individual interviews were conducted with 12 residents from various nursing homes who had been diagnosed with mild to moderate dementia, were proficient in Dutch, and capable of providing informed consent. Data from the interviews were analyzed using thematic analysis.

**Results:** Four key themes were identified: perceptions of physiotherapy and preferences for physiotherapy sessions, defining physiotherapy and exercise, exercise without physiotherapist supervision, and communication. In general, residents preferred physiotherapy that incorporated exercise and guidance aimed at preserving their independent physical functioning. Physiotherapy was perceived as more intensive than general exercise classes, and not necessarily suitable for all residents. Participants indicated that, provided safety and quality were maintained, they were willing to perform exercises independently. Residents expressed a desire for their family caregivers to be kept informed about their therapy, although they largely preferred to exercise with another person.

**Conclusions:** Nursing home residents with mild to moderate dementia expressed distinct preferences regarding physiotherapy sessions, communication, and family caregiver involvement. Addressing these preferences may improve adherence to and the effectiveness of exercise interventions. Additionally, the findings suggest a potential shift toward a more supervisory role for physiotherapists, rather than the traditional hands-on approach.

## Introduction

Physiotherapy is commonly utilized to reduce functional decline in nursing home residents with dementia. In Western countries, the proportion of nursing home residents receiving physiotherapy ranges from 10% to 67%, varying by country, ward type, and facility characteristics.[1] Exercise constitutes a core component of physiotherapy interventions for this population.[2,3] A comprehensive guideline offering evidence-based recommendations on exercise for nursing home residents has been developed by experts in geriatrics and exercise science.[4] While the guideline underscores the importance of incorporating residents' needs and preferences into physiotherapy interventions, it does not provide detailed insights into the specific nature of these needs and preferences.



Previous studies have demonstrated that nursing home residents with dementia are frequently able to articulate their needs and preferences concerning therapy and healthcare decisions.[5,6] However, other evidence indicates that these needs are not consistently addressed, and residents with dementia are often excluded from medical decision-making processes.[7] Such exclusion may be viewed as both ethically problematic and detrimental to adherence, as the lack of consideration for residents' needs and preferences can compromise engagement with interventions.[8,9] Consequently, this may reduce the overall effectiveness of the intervention.

To our knowledge, three studies have explored the perceptions of nursing home residents with dementia regarding physiotherapy or physiotherapist-guided exercise interventions.[10–12] In one study[10] interviews were conducted with individuals with dementia and their family caregivers, including three residents in long-term care. Although the study primarily focused on person-centered care, it highlighted the role of mutual understanding and clear communication between patients and physiotherapists.[10] In another study,[11] ten nursing home residents with dementia who had completed a physiotherapist-supervised high-intensity exercise program shared their experiences, emphasizing the significance of effective communication, empathy, and tailoring therapy to their individual needs. A follow-up study two years later, involving 21 nursing home residents with dementia who participated in the same exercise program, reaffirmed these findings, underscoring the importance of clear communication and the incorporation of residents' personal preferences in physiotherapy.[12]

The aforementioned studies have underscored the importance of integrating the needs and preferences of residents with dementia into physiotherapy. However, these investigations primarily focused on the experience of person-centered care[10] and reflections on a specific high-intensity exercise program.[11,12] Further research is needed to explore residents' needs and preferences concerning future physiotherapy or exercise sessions, which may aid in the design of interventions that enhance adherence. Further insights into preferences regarding the FITT-VP factors[13] (Frequency, Intensity, Time, Type, Volume, and Progression), which constitute the fundamental elements of exercise, could inform future interventions. Additionally, a previous study identified a gap in knowledge among individuals with dementia concerning the perceived role of physiotherapists.[10]

Therefore, the objective of our study is to examine the needs and preferences of nursing home residents with mild to moderate dementia in relation to physiotherapy and associated exercise interventions.

## Materials and Methods

This study utilized a descriptive qualitative design, employing face-to-face semi-structured interviews. No a priori hypothesis was formulated; instead, concepts and theories were developed inductively from the collected data. Ethical approval was obtained from the scientific committee of the orthopedics department at Leiden University Medical Center (LUMC). The study was conducted in accordance with the ethical principles outlined in the World Medical Association's Declaration of Helsinki.[14] The Consolidated criteria for Reporting Qualitative research (COREQ) guidelines[15] were adhered to in both the study design and reporting.

### Setting

Participants were recruited from three nursing homes affiliated with the long-term care organizations "Kennemerhart" and "Aafje," located in urban areas in the western Netherlands. Collectively, these organizations oversee 27 nursing homes across the provinces of Noord Holland and Zuid Holland, accommodating approximately 1,100 residents with dementia. The nursing homes offer small-scale care settings, consisting of private bedrooms and shared common areas designed for groups of up to 10 residents.

### Participants and sampling

Nursing home residents with dementia who were receiving physiotherapy at the time of recruitment were selected by the supervising physician based on the following criteria: a physician-confirmed diagnosis of dementia documented in the medical record, proficiency in the Dutch language, and the capacity to provide informed consent for participation

in an interview, as determined by both the supervising physician and the physiotherapist. Participants received physiotherapy in accordance with standard physiotherapy practices in Dutch nursing homes.[3,16] The therapy primarily consists of supervised individual exercise sessions; however, group exercise sessions and manual passive mobilizations may also be utilized. The primary goals of physiotherapy are to improve mobility and reduce the risk of falls.[3]



In the Netherlands, clinicians commonly use the umbrella term "dementia" without further specifying the subtype, such as Alzheimer's disease, vascular dementia, frontotemporal dementia, or mixed-type dementia. Residents were excluded from the study if they had a non-dementia pathology significantly affecting their functional status, exhibited behavioral or communication issues that could hinder participation in an interview, were expected to experience heightened behavioral problems (e.g., agitation or distrust) when presented with an informed consent form and study protocol, or had a life expectancy of less than 12 weeks.

Physiotherapists informed eligible residents by providing an information leaflet and verbally explaining the study procedures. Residents were given a one-week consideration period before being formally invited to participate. Written informed consent was obtained from those who agreed to take part. With the residents' permission, the principal investigator contacted their designated family caregivers to explain the study procedures and provided an information leaflet. Two versions of the information leaflet were created: one simplified version for residents with dementia, using the term "memory problems and difficulties with daily structure" instead of "dementia," and a standard version for family caregivers containing the core study information without simplified language. A total of 24 eligible residents were contacted in two rounds ($n = 22$, $n = 2$). After conducting 10 interviews in the first round, data were coded to assess saturation (see Procedure). An additional two participants were recruited in the second round. All participants provided written informed consent.

## Procedure

The interviews were conducted between October and December 2023. Data collection continued until saturation was achieved, defined as the point at which no new codes or themes emerged, and the information gathered from subsequent interviews was consistent with previously identified patterns.[17] Based on prior qualitative research, we anticipated saturation to occur after 12 to 15 interviews,[18,19] which was confirmed following the 12th interview. Consequently, no additional interviews were conducted after data saturation was reached. On the day of each interview, a familiarization period was arranged to allow residents to become comfortable with the researchers, who engaged in routine activities such as sharing coffee or lunch with the residents. All interviews were

conducted in the participants' private rooms. Before commencing the interviews, the study's objectives and procedures were reviewed, and participants were reminded that there were no "right" or "wrong" answers. They were assured that their responses would remain confidential and would not affect their ongoing physiotherapy or care.

The interview guide (see Supplemental file 1) was developed based on a previous study examining the needs and preferences of informal caregivers of nursing home residents with dementia regarding physiotherapy,[19] on the FITT-VP factors[13] and a desire to examine the perceived role of the physiotherapist. The guide covered four main topics: physiotherapy modalities, non-physiotherapy exercise, communication, and family involvement. Two authors (DB, RN) conducted the interviews, alternating between the roles of interviewer and observer. The observer monitored for signs of discomfort and was authorized to halt the interview if necessary. Both interviewers (DB, RN) had prior experience communicating with nursing home residents with dementia. The observer also took field notes and provided a summary of the key findings to the participant at the end of the interview for accuracy confirmation. If a pre-existing relationship with one interviewer was present, the other interviewer conducted the session; this occurred with three participants. Informal caregivers were allowed to attend the interview if desired by the resident, which happened in one instance. Interviews were audio-recorded using Microsoft Teams (version 24165.1414.2987.41), and recordings were deleted after transcription. All study data were handled confidentially in accordance with the General Data Protection Regulation (GDPR).[20]

## Data analysis

Participant characteristics were collected from the supervising physician with the participant's consent. These characteristics included age, gender, length of stay in the nursing home, number of medications, number of comorbidities, dementia subtype, religious background, and functional status, which was assessed using the Barthel Index.[21] The Barthel Index, ranging from 0 to 20, measures independence in daily activities such as transferring, bathing, and dressing, with higher scores indicating greater independence.

Data were analyzed using thematic analysis following the methodology outlined by Braun and Clarke.[22] Transcripts were reviewed repeatedly by the researchers (DB, RN) to ensure familiarity with the content. Relevant data were independently coded through open coding. Coding was performed using AtlaS.ti software (version 9, Scientific Software Development GmbH, Berlin). After initial independent coding, a consensus meeting was held between the two researchers to group codes through axial coding. If consensus was not achieved, a third researcher (CS) was consulted. However, in this study consensus was reached without the need for additional adjudication. In a subsequent consensus meeting, grouped codes were linked to form overarching themes. These themes were further

discussed and refined in collaboration with two additional authors (CS, SS) based on their feedback.

## Results

In two rounds of interviews, a total of 12 participants were interviewed (see Figure 1 for recruitment details). Baseline characteristics of the participants and interview specifics are summarized in Table 1. Participants' ages ranged from 75 to 95 years, and their length of stay in the nursing home varied from 2 to 86 months. The number of medications taken by participants ranged from 3 to 10, while the number of comorbidities ranged from 2 to 29. Interview durations varied between 13 and 58 minutes, with a mean duration of 40 minutes. Thematic analysis yielded 82 unique codes, which were consolidated into four major themes: (1) perceptions of physiotherapy and preferences for physiotherapy sessions, (2) defining physiotherapy and exercise, (3) exercise without physiotherapist supervision, and (4) therapist-resident interaction and family involvement.

Figure 1: Flowchart describing the recruitment and inclusion process.

Table 1:Characteristics of the twelve participating nursing home residents with mild to moderate dementia

| | n=12 |
|---|---|
| Age (mean + SD) | 83.9 (6.6) |
| Female (%) | 7 (58%) |
| Length of nursing home stay in months (mean + SD | 15.3 (23.2) |
| Number of medications (mean + SD) | 7.3 (3.4) |
| Number of comorbidities (mean + SD) | 11.7 (8.1) |
| Dementia type | |
| Alzheimer's disease (%) | 3 (25%) |
| Vascular (%) | 2 (16.7%) |
| Mixed (%) | 3 (25%) |
| Alcohol related (%) | 1 (8.3%) |
| Not specified (%) | 3 (25%) |
| Functional status (Barthel Index mean + SD) | 12.3 (3.4) |



## Theme 1: Perceptions of physiotherapy and preferences for physiotherapy sessions

The most common perception of physiotherapy was that it involves exercises, particularly those focusing on walking and movement of extremities. Additionally, several participants expressed a preference for physiotherapists to offer information, guidance, and motivation during exercise sessions.

- P11 (76-year-old male): *"That is important to me. That she says: "Hey sir!, can you walk a little bit more like this?"*

Participants indicated that the goals of physiotherapy were typically aimed at maintaining or improving physical function. Some participants found it difficult to articulate if there was a specific physiotherapeutic goal, and most were unable to specify how such goals are established or who is responsible for setting them.

- P1 (90-year-old male): *"Well, yes, to be able to keep moving for as long as possible. Yes. That's the goal in the end."*

A preference for one-on-one physiotherapy sessions was expressed by some participants. They explained that group physiotherapy could become chaotic or that they were simply accustomed to individual sessions. However, other participants preferred group sessions, noting that exercising in a group setting was more enjoyable. Regardless of the setting, the importance of receiving adequate personal attention was emphasized.

- P10 (84-year-old female): *"Yes. It's enjoyable, in a group. But when it comes to therapy, I'd prefer one-on-one."*

A preference for a minimum of two physiotherapy sessions per week was mentioned, scheduled at consistent times and days. A card or note with the scheduled appointments was deemed useful. Residents emphasized that sessions should be of appropriate duration: too long could lead to exhaustion, while too short might leave them feeling unfulfilled, as if they had not achieved anything.

- P12 (91-year-old female): *"I think two or three times. That's what I prefer. Then you stay in a bit of a rhythm."*

Some participants thought that physiotherapy should always be continued, even after achieving the therapy goals. Others recommended a gradual reduction of therapy once the primary health issue has been addressed.

- P5 (88-year-old female): "*If someone wants to stay fit, you see… People who never do anything, they are as stiff as a dried fish."*

Most participants preferred physiotherapy sessions in a gymnasium (a place in the nursing home designated for physical exercise), primarily due to the availability of exercise equipment. Participants suggested that physiotherapy could also take place in the common room, but expressed concerns about potential sensory overload in crowded spaces. Participants specifically preferred therapy locations other than their bedrooms, deeming these spaces too personal for such activities.

- P10 (84-year-old female: *"Here, you don't have any equipment. So, with him (the physiotherapist), you do. Because I also had to learn to walk between those parallel bars."*

## Theme 2: Defining physiotherapy and exercise

The general opinion among participants was that physiotherapy is primarily for individuals with health problems. It was argued that those without health issues can exercise independently without a physiotherapist's supervision. Nonetheless, it was also argued that physiotherapy should be available to everyone, as long as the therapist receives reimbursement.

- P5 (88-year-old female): *"You see, the physiotherapists who work there, they want to get their money, of course. And whether it comes from the patient or their insurance, it doesn't matter to them. As long as they get paid".*

Participants distinguished physiotherapy from gymnastics or exercise classes, noting that physiotherapy sessions are typically more intense than gymnastics classes, which are generally considered recreational.

- P9 (86-year-old female): *"One is more feisty, the other one is more calm. That is the difference."*

## Theme 3: Exercise without physiotherapist supervision



Some participants indicated that they perform exercises independently, without the supervision of a physiotherapist. They maintained their pre-existing exercise routines established prior to admission to the nursing home and expressed no need for help from the physiotherapist. Although some participants performed exercises without direct supervision from a physiotherapist, there was a desire for guidance from a physiotherapist beforehand in the form of demonstrations of exercises or the provision of written instructions and illustrations to facilitate independent exercise sessions. Some participants did not perform unsupervised exercises because of safety concerns.

- P12 (91-year-old female): *"I'm afraid to do too much. [...] Because I'm scared of falling. They just need to hold me."*

The majority of participants felt confident exercising under the guidance of a competent non-physiotherapist. Nonetheless, most preferred not to be supervised by a family caregiver. They cited reasons such as family members being busy with their own responsibilities or living too far away. Participants preferred to spend quality time with family on enjoyable activities rather than having family members supervise or be present during structured exercise sessions.

- P3 (83-year-old female): *"They don't have time to be here. They have their work too."*

## Theme 4: Communication

Most participants expressed the preference of having a friendly, familiar and personal relationship with the physiotherapist. Some preferred to be addressed informally instead of formally. Although communication is preferred to be informal and friendly, the relationship needs to remain professional.

- P9 (86-year-old female): *"I would begin by addressing him as "Sir." However, I would likely soon ask if I could use his first name."*

Participants emphasized the importance of the physiotherapist being mindful of their limitations during physiotherapy and when communicating, such as speaking slowly and clearly and maintaining eye contact during conversations.

- P8 (91-year-old female): *"I'm not as quick anymore. I'm slower. He (the physiotherapist) shouldn't force me to do this or that. I need to be able to do it at my own pace."*

Most participants expressed a preference for the regular involvement of family members or informal caregivers in physiotherapy, in the form of updates on the progress of therapy sessions.

- P12 (91-year-old female): *"When the therapist comes, I also inform the children. I think it's important that they know what's going to happen."*

## Discussion

This study identified four major themes reflecting the preferences of nursing home residents with mild to moderate dementia concerning physiotherapy and related exercise interventions. The themes included: (1) characteristics of physiotherapy, such as goals, content, dosage, and mode of delivery; (2) distinction between physiotherapy and general exercise; (3) preferences regarding supervision, whether by a physiotherapist or otherwise; and (4) communication preferences, including the resident's desired level of interaction and the involvement of family members.

To the best of our knowledge, this is the first study to specifically explore nursing home residents' perceptions and preferences regarding physiotherapy and exercise outside the context of a specific intervention. Previous research has examined the experiences of residents who had already received physiotherapy.[10–12] While direct comparison is challenging, certain similarities, differences, and novel insights emerged. Consistent with earlier studies, our findings underscore the importance of effective communication and an empathetic understanding of residents' limitations. Additionally, participants in our study, similar to those in prior research, emphasized the need for appropriate support and coaching in conjunction with prescribed exercises.

Regarding exercise goals, participants in our study expressed a desire to remain physically active and delay dependency, aligning with findings from the two Scandinavian studies.[11,12] Another noteworthy similarity is that residents in both our study and the Scandinavian studies did not express a clear preference regarding who supervises the

intervention, provided that the supervisor is competent and ensures safety. This finding suggests the potential for future research exploring a model where physiotherapists adopt a more supervisory or coaching role, delegating the practical aspects of therapy to trained assistants. Given the rising healthcare costs,[23,24] such a model could reduce financial burden while maintaining care quality. Since participants did not exhibit a strong preference for a specific supervision style, future studies could investigate whether similar levels of safety, satisfaction, and clinical outcomes can be achieved when physiotherapists primarily focus on coaching rather than direct intervention delivery.



Some discrepancies were observed when comparing the results of our study with previous literature. Participants in the Scandinavian studies specifically expressed a preference for group exercise, whereas, although our participants also reported enjoying group exercise, they preferred individual physiotherapy sessions. This difference may be attributed to the residential settings of the participants. In the Scandinavian studies, participants lived in private rooms and expressed feelings of loneliness, whereas our participants resided in small-scale, family-like wards. Although loneliness was not explicitly addressed in our study, it is plausible that residents in shared, small-scale settings experience less loneliness, which may reduce their need for social interaction during exercise activities.

The participants in the study by Hall et al.[10] expressed dissatisfaction with the physiotherapy they received, citing factors such as insufficient resources and a lack of personalized care. This contrasts with the preferences of participants in our study, who generally expressed satisfaction with the services provided. A potential explanation for this discrepancy lies in the differing healthcare systems. A review of physiotherapy availability indicated that approximately 11% of nursing home residents in the UK receive physiotherapy, compared to 67% in the Netherlands, which likely influences satisfaction levels.[1]

Our study was conducted and reported in accordance with qualitative research guidelines. Additionally, when drafting the study protocol and implementing the methods, we carefully considered ethical literature regarding research involving individuals with dementia, which likely enhances the validity of our findings. The primary aim of our study was to explore residents' perceptions and preferences regarding future physiotherapy interventions, with the goal of informing physiotherapy and exercise guidelines. This study has provided insights into the perspectives of nursing home residents with dementia regarding the desired delivery of exercise therapy. However, since participants were recruited while receiving physiotherapy, it cannot be ruled out that participants may have reflected more on their experiences with current physiotherapy rather than exclusively providing preferences for future interventions. No quantitative details regarding duration, intensity, or related aspects were collected, as participants found these difficult to articulate. To preserve interview rapport, the researchers intentionally chose not to

explore this matter further. As noted earlier in the discussion, physiotherapy services and reimbursement practices vary significantly across countries. Although we cannot provide objective data, the reality is that many nursing homes in various countries either do not employ physiotherapists or do so under precarious conditions. Therefore, we believe the findings from this study are most applicable to physiotherapy and nursing home systems similar to those in the Netherlands.

The results of our study can inform the development of future physiotherapy and exercise interventions. Many of the preferences expressed by participants can be incorporated into practice, potentially enhancing adherence to exercise interventions. Additionally, the findings provide insight into residents' perceptions of the role of physiotherapists in their lives. The need for understanding and personalized advice, which emerged as important to participants, is not yet a prominent aspect of physiotherapy quality standards. Given that residents are the primary recipients of physiotherapy, communication and understanding should be prioritized alongside more easily measurable outcomes, such as increases in muscle mass or improvements in balance.

In conclusion, this study explored the preferences of nursing home residents with dementia regarding physiotherapy and exercise. In addition to preferences related to therapy goals, duration, location, and individual supervision, participants expressed a desire for information from the physiotherapist and for being coached, as well as for maintaining a professional yet friendly relationship. Most participants indicated that exercise sessions could be supervised by non-physiotherapists, provided that safety and quality are ensured. While residents wanted to keep family members informed about their physiotherapy, they preferred not to exercise with them. Given that residents are key stakeholders in physiotherapy, their preferences should be considered in future studies and current practice. Incorporating these preferences has the potential to enhance both adherence to therapy and its overall effectiveness. As residents expressed no need for direct physiotherapy supervision during exercise, provided safety is maintained, the role of the physiotherapist warrants further evaluation. Shifting the physiotherapist's role from a traditional "hands-on" approach to a more supervisory or managerial role could contribute to strategies aimed at improving healthcare cost-effectiveness.

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# Chapter 6:

## Novel barriers and facilitators were identified for family involvement in physiotherapy and exercise for aged care facility residents with dementia: a qualitative study.

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## Abstract

**Questions:** This study aimed to identify barriers and facilitators for involving family members of aged care facility residents with dementia in physiotherapy and exercise.

**Design:** reflexive thematic analysis with semi-structured interviews to explore the subjective experiences of physiotherapists and aged care staff, grounded in a constructivism ontology.

**Methods:** We conducted 28 semi-structured interviews with 19 physiotherapists and 9 aged care facility staff members concerned with family participation. Participants were selected from Dutch aged care facilities providing care for residents with dementia. Interviews were recorded and transcribed and subsequently analysed using inductive thematic coding.

**Results:** The perceived barriers included the burden placed on family caregivers, particularly during the transition to an aged care facility, and the need for adequate information and guidance to ensure successful involvement. Additionally, it was found that an unwelcoming environment fostered by physiotherapists and staff hinder family members participation. Facilitators included a proactive approach of physiotherapists regarding the collaboration, and information provision on practical aspects of exercise, particularly when supported by technology or exergaming. Other facilitators were the family caregivers' prior healthcare experience and cultural factors emphasizing the importance of family support.

**Conclusion:** The study identified barriers to family caregiver involvement, such as perceived caregiver burden and role unclarity, alongside facilitators like prior caregiving experience, culturally rooted family values, and strong social or religious networks. Physiotherapists and aged care facilities could improve collaboration by proactively discussing family caregiver roles, adopting flexible approaches, and employing inclusive (digital) communication methods to support ongoing caregiver engagement.

## Introduction

Aged care facilities play an essential role in providing care for individuals with dementia, particularly those in advanced stages of the condition.[1] After institutionalization, family caregivers often continue to provide care for their loved ones, collaborating with formal caregivers to deliver integrative care.[2,3] This collaborative approach, grounded in the principles of person-centred care, is recognized as the gold standard for high-quality dementia care, offering benefits to residents, families and formal caregivers.[4–6] Despite international variation in dementia care practices,[5,6] research consistently demonstrates the importance of family caregivers' involvement in aged care facilities, particularly in mobility support and socio-emotional care.[3,7]



Physiotherapy is a commonly used intervention for individuals with dementia, both in the community and in aged care facilities.[8–10] Multiple reviews have reported positive or promising effects of regular exercise on physical performance,[10] cognition,[11] and activities of daily living (ADL).[10,12] Additionally, there is also emerging evidence, both from effectiveness trials and qualitative studies, that family caregiver involvement in physiotherapy and exercise programs may be desirable[13] and potentially beneficial in reducing caregiver burden.[12]

However, studies investigating physiotherapy in other care contexts reveal barriers to meaningful family engagement. For example, two studies focused on post-stroke care[14] and transitional care from hospital to home[15] found that while family members were willing to assist with exercise delivery, their involvement was rarely structured or formally supported. Although these studies were not conducted in aged care or dementia-specific settings, their findings highlight systemic and contextual factors that may similarly affect caregiver collaboration in residential dementia care. A recent study on transitional care emphasized the importance of respecting family members' autonomy in deciding whether and how to participate in therapy.[16] In the only qualitative study to date that directly explored family caregiver perspectives of physiotherapy in aged care settings, caregivers expressed a desire for greater engagement, not only in exercise supervision, but also in care planning and evaluation.[13]

In addition to understanding family perspectives, the views of healthcare professionals are critical to understanding collaborative dynamics. Prior research on staff–family relationships highlights various challenges: healthcare professionals may find family involvement demanding,[17,18] may make limited efforts to facilitate engagement, [2] and formal mechanisms for family participation are often lacking.[2] In many Western aged care systems, where staffing is increasingly reliant on paid care workers, collaboration with family members can be especially complex. [6] As the cost of institutional care continues to

rise, and greater caregiving responsibility shifts to families, [6] these challenges are likely to intensify.

Although evidence suggests benefits in favor of involving family caregivers in physiotherapy and exercise, collaboration remains difficult in practice. Limited research has explored how physiotherapists and aged care staff themselves perceive this collaboration. Understanding the barriers and facilitators from their perspective is essential for informing more effective and inclusive care practices. This study therefore aimed to explore how physiotherapists and aged care facility staff perceive the barriers and facilitators to involving family caregivers in physiotherapy and exercise for residents with dementia.

## Materials and Methods

This study employed a reflexive thematic analysis approach as outlined by Braun and Clarke[19] utilizing semi-structured interviews with physiotherapists and aged care facility staff. Reflexive thematic analysis is a flexible method for identifying and analysing patterns of meaning across qualitative data and is particularly well-suited for applied health research exploring participants' subjective experiences. The study is grounded in constructivism ontology[20], which assumes that knowledge is co-constructed through the interaction between researcher and participant. This perspective aligns with our aim to understand the meanings participants assign to their experiences and practices related to caregiver collaboration.

Besides physiotherapists, we interviewed staff members not employed as physiotherapists but involved in overseeing family involvement in the care facility or managing/leading physiotherapy and exercise services. This selection was done since family involvement in aged care facility is strongly influenced by organizational structures.[2,3] As the study consisted solely of single, minimally invasive interviews, it was exempted from the requirements of the Medical Research Involving Human Subjects Act (WMO) and review by a designated regional Medical Ethical Research Committee. To ensure the quality and feasibility, the research board of the organization Kennemerhart approved the study protocol. Informed written consent was obtained from all participants, The privacy of the participants was protected in accordance with the Dutch General Data Protection Regulation. All findings were reported according to the COnsolidated criteria for REporting Qualitative research checklist (COREQ).[21]

### Participant Recruitment

Participants were recruited through the professional and personal networks of the researchers. A generic purposive sampling strategy was employed, with participants

selected a priori based primarily on geographical location within the Netherlands, and secondarily on age and work experience. This approach differs from theoretical purposive sampling, which is more closely aligned with grounded theory methodology, where participant selection is guided by the emerging need to develop categories, their properties, and theoretical relationships.[20] Eligibility criteria: Able to understand and speak Dutch, being able to use an online videoconferencing program Microsoft Teams (Microsoft Company 2024), and willing and able to spend at least 45 minutes on the interview.

A recruitment e-mail containing an information leaflet with the background, aims and methods of the study was sent to eligible individuals within the networks of the authors, with a request for referrals to other potential participants.



Initially, physiotherapists and staff from various provinces across the Netherlands were approached. After conducting interviews with participants from at least 10 of the 12 Dutch provinces, and at least 5 physiotherapists and 5 staff, an initial analysis of interviews was done to determine whether saturation had been reached. If needed, additional interviews were conducted.

## Data Collection

An interview topic guide (supplement Appendix 1) was developed based on the framework of Grol and Wensing, which identifies barriers and facilitators for implementing evidence-based practice in healthcare.[22] To ensure the guide's comprehensibility, six pilot interviews were conducted with physiotherapists and staff, leading to minor adjustments for a better interview flow. The pilot interviews were not included in the analysis. All interviews were conducted online platform to eliminate geographical barriers in scheduling and conducting the interviews. Given the platform's wide acceptance, it was anticipated that both interviewers and participants would feel comfortable using it. All video and audio data of the interviews were recorded. These recordings were securely stored in a network folder that was protected and only accessible to the project team. Video recordings were fully transcribed, and any identifying information was removed to ensure anonymity. Transcripts were not returned to participants for comment or correction, in part to reduce the likelihood of socially desirable responses or retrospective editing. Instead, clarification and validation of meaning occurred during the interviews themselves through active probing and participant reflection (e.g., member checking in real time).[20,23] This decision is also consistent with our interpretive approach, which understands meaning as co-constructed during the research process, rather than as a fixed account that participants can later confirm or correct.[19] All interviews were conducted in Dutch, with relevant quotes and data translated into English for this paper. No financial compensation was offered to participants.

### Research team and reflexivity

Two members of the research team, DB and LG, conducted all interviews. DB is a male physiotherapist and PhD student with prior experience in qualitative research while LG, also a male physiotherapist, is pursuing a Master's degree in Geriatric Physiotherapy. He received training in interview techniques prior to this study. DB primarily provides physiotherapy to aged care facility residents with dementia and their families, while LG's clinical work focuses mainly on stroke rehabilitation. To support reflexivity, a field journal was maintained throughout data collection to capture initial impressions and potential assumptions. These reflections were revisited and discussed within the research team, aligning with Braun and Clarke's view that "the researcher's subjectivity is a resource, not a problem to be managed.[19]

### Data Analysis

Inductive thematic coding was used to analyse interview data, using a professional account of ATLAS.TI Web software [v8.4.1-2024-08-12]. Two researchers (DB and CS) independently coded all transcripts, and in case of disagreement, a third reviewer (SS) was consulted. An open coding method was used, allowing codes to be created directly from the text without pre-determined themes.[19] These codes were then grouped, and merged into broader themes by DB and LG, with regular process evaluations by CS and SS. Data collection and analysis were conducted iteratively until theoretical sufficiency was achieved. Theoretical sufficiency indicates the point at which according to the researchers interviews no longer generated new insights relevant to the research question.[24] Initially, the perspectives of physiotherapists and staff members were analysed independently. However, during the initial stage of data analysis, it became evident that there were no notable discrepancies between their viewpoints. Consequently, the interview data were subsequently analysed collectively to provide a comprehensive and integrated overview. Back-translation of the quotes was performed with the help of an external native English-speaking scientific colleague and reviewed by multiple members of the research team to ensure the intended meaning was preserved and no nuances were lost in the translation process.

## Results

A total of 28 interviews were conducted, including 19 with physiotherapists and 9 with aged care facility staff. Participant characteristics are summarized in Table 1. On average, staff members were older and had more years of professional experience in the aged care sector compared to physiotherapists. Staff roles included manager of allied health professional services (*n*=3), location manager (*n*=2), advanced practice nurse (*n*=2), manager of innovation and paramedical services (*n*=1), and board member (*n*=1).

Table 1: Demographic characteristics of the study participants

| | Physiotherapists | Staff |
|---|---|---|
| *n* (Total = 28) | 19 | 9 |
| Mean age in years (SD) | 40 (11) | 48 (11) |
| Number of females (percentage) | 13 (68%) | 5 (56%) |
| Mean years of experience in aged care facilities (SD) | 13 (10) | 25 (16) |
| Scale of the facility | | |
| Small | 8 | 5 |
| Large | 3 | 1 |
| Small & large | 8 | 3 |
| Culture of the facility | | |
| General | 8 | 6 |
| Mixed | 7 | 2 |
| Rural | 2 | 1 |
| Catholic | 1 | |
| Reformed | 1 | |
| Mean interview duration in minutes (SD) | 48 (9) | 43 (7) |



Participants were employed in care facilities providing care to residents from diverse geographical, cultural, and religious backgrounds, including urban and rural facilities with residents from Dutch, Turkish, Moroccan, Cabo Verdean, Pakistani, Surinamese, Syrian, Islamic, Christian, Reformed, Hindustani, and Jewish communities. Data saturation was reached after 26 interviews, but in addition the 27th and 28th interviews were conducted as they had already been scheduled, further confirming data saturation.

Thematic analysis revealed three major themes: The physical, personal, emotional and relational dimensions of family involvement; the importance of information sharing; practical aspects of involving family caregivers. Participant' quotes are displayed in Table 2.

## The Physical, Personal, Emotional and Relational Dimensions of Family Involvement

### *Barriers*

A frequently mentioned barrier was the concern that involving family caregivers in physical activity programs might place an additional burden on them, particularly during the emotionally and logistically challenging transition to residential aged care. Physiotherapists and aged care facility staff expressed hesitation to initiate collaboration out of fear of overwhelming family members at an already difficult time. Furthermore, if their involvement includes performing exercises similar to those in physiotherapy sessions,

Table 2: Participant quotes on the barriers and facilitators for family involvement in physiotherapy and exercise for aged care facility residents with dementia, categorized by theme.

| Theme | Barrier or facilitator | Participant | Quote |
|---|---|---|---|
| The Physical, Personal, Emotional and Relational Dimensions of Family Involvement | Barrier | Physiotherapist 4 | *'If the exercises are not very intensive, it should be fine. However, there are times when we need to explain to family caregivers that certain exercises are not safe for their father.'* |
| | Barrier | Physiotherapist 5 | *Uh, yes, and I notice that caregivers are often already exhausted. Many of them are older, so it is sometimes unrealistic to expect too much from them.'* |
| | Facilitator | Aged care facility staff 3 | *'I also find that, particularly with residents with dementia, maintaining a connection can sometimes be incredibly challenging. In such cases, engaging in an activity together is both valuable and deeply meaningful.'* |
| | Facilitator | Aged care facility staff 9 | *'Yes, and it's also wonderful to have a team that genuinely supports and encourages families to get involved. It's important to give them the opportunity to take charge of certain aspects and make decisions.'* |
| The Importance of Information Sharing | Barrier | Physiotherapist 8 | *'But during the studies, no attention was given to that at all. For us, there was actually no focus on family members or informal caregivers. I wanted to work in this field, and it is clearly important.'* |
| | Barrier | Aged care facility staff 4 | *'Sometimes, things appear very black and white on paper, but when you explain them in person, they become completely grey. Yes. So, I would definitely see that as a disadvantage.'* |
| | Facilitator | Physiotherapist 3 | *'What you notice more with them is that they are better informed about what's going on. They're not caught off guard as easily. They don't ask, "Why is this happening? Why do I suddenly need to arrange different clothing? I don't understand" Yes, it shouldn't come as a surprise.'* |
| | Facilitator | Physiotherapist 11 | *'But yes, I do explain that... I always try to put a positive spin on it, highlighting that they can actually do something together, rather than just sitting in their parent's room.'* |
| Practical Aspects of Involving Family Caregivers | Barrier | Physiotherapist 7 | *'The caregiver needs to make time for this in their schedule. And, yes, they have to be there at the agreed-upon time. That can certainly be difficult for them.'* |

Table 2: Participant quotes on the barriers and facilitators for family involvement in physiotherapy and exercise for aged care facility residents with dementia, categorized by theme. (*continued*)

| Theme | Barrier or facilitator | Participant | Quote |
|---|---|---|---|
| | Barrier | Physiotherapist 1 | *'I'm not going to contact the entire network, and you often notice that the legal representative isn't in touch with other family members either. Yes, I find that challenging. Because perhaps someone else, like a neighbour or an old school friend, might want to be involved. It doesn't necessarily have to be family at all.'* |
| | Facilitator | Physiotherapist 11 | *'Yes, what we do is ask the caregivers to get involved as well. We have an exercise room, and the residents are housed in separate wards, so moving back and forth to the practice room takes up a lot of time. (...) Therefore, we ask if they can be involved in that process. This way, we can use our time more efficiently, rather than constantly walking back and forth. I also think that some exercises can be delegated to them.'* |
| | Facilitator | Physiotherapist 16 | *'Yes, it's important that both of them feel good about it, that they can experience something together. For example, with exergaming on a virtual route. Shared experiences can also include activities like listening to music. We even have a wooden box that plays music when you move your hand over it.'* |



it may give the impression that physiotherapy is unnecessary, potentially undermining the physiotherapists' role. Participants also expressed concerns about the well-being and safety of the resident when involving family caregivers in physical activities.

According to the participants, family caregiver involvement can be hindered by the caregiver's own health issues, language barriers with the therapist, or a lack of interest in physical activity. Participants also noted that complex care needs of the resident, particularly those associated with behavioural and psychological symptoms of dementia, may present significant barriers. Additionally, it was mentioned that a lack of proactivity from physiotherapists in fostering collaboration or a perception that such collaboration offers no benefits further impedes involvement. Moreover, it was expressed that some physiotherapists may find it challenging to adapt to a role that places greater emphasis on communication.

***Facilitators***

Participants in our study pointed out several advantages of collaborating with family caregivers. For residents, this involvement could increase physical activity and provide more comfort through the presence of a familiar and recognizable caregiver. For family caregivers, participation may offer an enjoyable and meaningful way to connect with

their loved ones. Participants stated that exercising together can reinforce their sense of actively contributing to the resident's care and overall well-being, rather than being a passive observer as a family member.

A strong social network and a positive relationship between residents and family caregivers were identified as key facilitators for family involvement by the participants. An additional described facilitator was family access to care resources such as the exercise gymnasium. Creating a welcoming environment where family caregivers are treated as active participants rather than as guests was reported by our participants to facilitate collaboration. Furthermore, participants expressed that having a non-Western cultural background and some level of healthcare knowledge were supportive factors.

## The Importance of Information Sharing

***Barriers***

Participants identified the absence of clear policies regarding family caregiver involvement as a barrier. For example, uncertainty about the identity of the resident's legal representative was mentioned. Additionally, a lack of clarity regarding the roles and responsibilities of family caregivers may also hinder their involvement. Physiotherapists in specific reported insufficient information and support from societal and educational institutions regarding family caregiver involvement. According to them, professional physiotherapy networks, physiotherapy education programs, and policymakers do not give enough attention to family caregiver involvement.

Participants noted that physiotherapists report in patient files, which are frequently accessible by family caregivers, are sometimes perceived as "rigid" or overly filled with medical terminology, which can cause confusion or come across as impersonal.

***Facilitators***

Participants viewed physiotherapy and exercise as enjoyable and accessible opportunities for family members to enhance their involvement in care. According to them, engaging family caregivers helps them to stay informed about their loved one's well-being, reducing the risk of being surprised by changes in health status. Participants furthermore mentioned that this involvement promotes a more holistic approach, as family caregivers can provide valuable feedback on physiotherapy and exercise practices.

Participants considered family caregivers as a valuable source of information about the resident. Early collaboration and information exchange were seen as crucial for fostering family caregiver involvement. Participants mentioned that family caregiver participation could be supported through various channels, such as informational leaflets, family eve-

nings, and regular team meetings with family caregivers. Participants emphasized that family caregiver involvement could be further facilitated by presenting information in a positive manner, highlighting potential benefits rather than focusing on challenges.

## Practical Aspects of Involving Family Caregivers

***Barriers***

The additional task for physiotherapists to inform and prepare caregivers to exercise in a safe manner was deemed a burden according to our participants. Participants additionally shared the experience that it is often difficult for family caregivers to commit to fixed-time responsibilities.



Physiotherapists indicated that collaborations with a family caregivers were sometimes short-lived, lasting only a few weeks due to the residents' fragile health. Other barriers indicated by the participants included the geographic distance of family caregivers and situations where the resident's legal representative is not a family member, such as an appointed mentor. Participants had mixed views on the impact of the privacy legislation on communication with family caregivers. Some physiotherapists reported that the General Data Protection Regulation (GDPR) posed a significant obstacle, as they were unable to share information with family members who visited the resident most frequently but were not legal representatives. Some participants suggested that the GDPR was not perceived as an obstacle in their practice because they did not fully adhere to its regulations.

***Facilitators***

Participants expressed that from a practical standpoint, family caregivers could assume certain exercise-related tasks, helping to reduce the workload of physiotherapists. This would allow physiotherapists to focus more on their strict physiotherapy responsibilities. Participants reported that clarifying the roles and tasks of family caregivers prior to aged care facility placement is helpful in facilitating a smooth transition and ensuring continuity of care during and after the placement.

According to the participants, family caregiver involvement could be supported by providing practical tools, such as exercise instruction manuals and user-friendly exercise equipment. Several participants identified exergaming as a facilitator for creating shared exercise opportunities between caregivers and residents. Furthermore, having an easily accessible physiotherapist or designated contact person, particularly someone who is physically present, was noted as a factor in further facilitating family caregiver involvement.

## Discussion

This study explored the barriers and facilitators perceived by physiotherapists and aged care facility staff regarding family caregivers' involvement in physiotherapy and exercise for residents with dementia. Perceived barriers included the burden placed on family caregivers, particularly during the transition to an aged care facility, as well as unclear family caregiver roles, lack of guidance for effective engagement and concerns about resident safety. Facilitators included the meaningful role family caregivers can play in supporting residents with exercise, particularly when aided by technology or exergaming. Prior caregiving experience and/or supportive cultural, religious or social influences of family caregivers were also expressed as facilitators for successful involvement. Furthermore, an inviting and welcoming atmosphere fostered by physiotherapists and staff was seen as essential for encouraging collaboration.

Regarding barriers, participants expressed concern about unclear family responsibilities and their role, as well as boundaries and liability, while families were inconsistently informed or engaged. The lack of structured opportunities and formal recognition for family caregiver collaboration reflects a broader care issue. Studies in post-stroke care[14] and transitioning to home after hospital admission[15] found that while families are often willing to assist with exercises, they are rarely involved in a formal or sustained way. Syntheses of the literature[3,18] encompassing 64 studies published between 1988 and 2016, have consistently highlighted the barriers of unclear caregiver roles and the absence of formal policies supporting family caregiver involvement. Similarly, the importance of creating a welcoming environment, previously reported in both older and recent reviews,[3,18] and a 2021 qualitative study,[25] was reaffirmed by the physiotherapists and staff members in the present study.

Another perceived barrier was the fear of overburdening family caregivers, especially in the period immediately following their loved one's transition to the care facility. Participants expressed caution about initiating involvement in physiotherapy or exercise during this sensitive time, stating that families were already navigating emotional stress and adjustment demands. To address this concern, participants suggested a facilitating strategy: engaging family caregivers in conversations about the roles they held prior to placement and allowing them to choose which responsibilities they wished to maintain and which they preferred to relinquish. This aligns with a 2023 study that emphasized the importance of respecting family caregivers' autonomy in deciding whether, and to what extent, they wish to participate in therapy.[16] Previous literature suggests that family caregivers often prefer engaging in leisure activities, supporting mobility and providing socioemotional support.[2,3] Participants in the present study noted that exercise sessions, particularly those incorporating exergaming or care technology, could fulfil this shared

interest, making them an appealing activity for both parties. Another facilitator was prior caregiving experience or supportive cultural influences, particularly among non-Western family caregivers. While language barriers were recognized as obstacles, both in our study and previous research,[26] a non-Western background was also seen as a facilitator due to the strong family-centred cultural values. Interestingly, while earlier studies framed non-Western ethnicities as potential barriers to collaboration,[2,17] our findings suggest a more nuanced perspective, where cultural influences can also serve as facilitators. Beyond ethnicity and social background, religion was identified as a potential facilitator for collaboration. Participants observed that residents belonging to religious communities often benefit from larger, more engaged social networks, which can facilitate family caregiver involvement.



Mutual access to a digital patient file was another facilitator, allowing physiotherapists to document their findings while simultaneously keeping family caregivers informed about the resident's progress. However, the style of reporting remains an area for improvement,[13] as some family caregivers perceive the language used by physiotherapists as too rigid or technical. Shared digital patient files have recently been introduced in some Dutch aged care facilities, and two prior qualitative studies indicated that family caregivers expressed a desire for greater access to these files to stay informed about residents' care.[13,25] This aligns with international research highlighting the importance of transparent, reciprocal information-sharing in long-term care settings to support family involvement and trust.[2] Digital tools that enable two-way communication can enhance caregivers' sense of partnership in care, reduce uncertainty, and foster continuity between formal and informal care providers.[27] Nonetheless, successful implementation depends not only on technical access but also on the clarity, tone, and relevance of the content shared, underscoring the need for inclusive and plain-language communication.[28]

A strength of this study is the diversity of the participant sample, which included a broad range of geographical regions, age groups and experience levels, within aged care facilities in the Netherlands. Despite the absence of financial incentives, recruitment proceeded smoothly, with many participants highlighting the relevance of family caregiver collaboration as a pressing issue in clinical practice. This underscores the practical significance and external relevance of the study. However, a key limitation is that, while the qualitative design was well-suited to explore perceived barriers and facilitators, it does not provide evidence on the most effective strategies for enabling collaboration between family caregivers and physiotherapists or other staff in the context of exercise. Moreover, given the variability among aged care facilities and regional practices, the transferability of findings may be constrained. Despite this, several themes that emerged, such as concerns about overburdening caregivers and the positive influence of culturally ingrained family values and strong social or religious networks, are likely to be relevant across

different institutional care settings internationally. These insights could also benefit practices in other care environments, such as rehabilitation services, where enhancing family caregiver involvement remains a central goal.

## Conclusions

This study explored the perceived barriers and facilitators to family caregiver involvement in physiotherapy and exercise for residents with dementia, as experienced by physiotherapists and aged care facility staff. Key barriers included concerns about overburdening family caregivers, especially during the transition to aged care facilities, unclear family roles, and insufficient guidance for engaging caregivers. Facilitators encompassed strategies such as consulting caregivers about their preferred involvement, fostering a welcoming environment, and leveraging care technologies such as exergaming and shared digital patient records. Additional factors that supported collaboration included prior caregiving experience, culturally rooted family values, and strong social or religious networks.

While transferability may be limited due to the national context, the findings from this study offer practical implications for physiotherapists working in aged care settings. Specifically, physiotherapists may enhance collaboration by proactively discussing roles with family caregivers and incorporating flexible approaches. Digital tools and structured communication channels may serve as effective supports for sustaining engagement. Recognizing these perceived barriers and facilitators can guide physiotherapists in tailoring their practice to foster family caregiver involvement.

**What was already known on this topic:**

Providing care in collaboration with relevant stakeholders, in alignment with the principles of person-centred care, is widely recognized as the gold standard for high-quality care and yields benefits for all involved.

**What this study adds:**

This study explored the barriers and facilitators of family involvement in physiotherapy and exercise for aged care facilities residents with dementia, as perceived by physiotherapists and staff members.

Several previously unidentified barriers and facilitators were uncovered, providing new insights. These findings create opportunities for physiotherapists and researchers to both implement and further investigate integrated physiotherapy and exercise interventions for residents with dementia.

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Supplemental file 1: Topic guide for the interviews

| | | |
|---|---|---|
| Innovation | Benefits of involvement | What is your opinion on involving family caregivers of aged care facility residents with dementia? Do you believe it has benefits?<br>*Previously identified benefits include:*<br>• *Establishing a good relationship.*<br>• *Gaining previously unknown information through the caregiver.*<br>• *Caregivers contributing to therapy by performing exercises themselves.*<br>*Are there any disadvantages to involving family caregivers, in your opinion?*<br>*Previously identified disadvantages include:*<br>• *Do caregivers take over part of your work?*<br>• *Are you concerned about losing your job if caregivers take on more tasks typically performed by physiotherapists?* |
| | Feasibility | Is it feasible to involve family caregivers in physiotherapy? |
| | Trust/Confidence in Implementation | |
| | Accessibility | Is it easy to collaborate with family caregivers? If so, why is it easy? If not, why is it difficult?<br>(For example: frequent contact, caregivers are easy to work with, etc.) |
| | Attractiveness | Is involving family caregivers appealing?<br>Do you think effective collaboration with family caregivers adds value to patient care?<br>Do you believe that collaboration with family caregivers adds value to your/the role as a physiotherapist?<br>Does it have added value for other aspects, such as for the organisation? |
| Individual Professional Context | Awareness | How does involving family caregivers fits in your daily practice? |
| | Experience/Routine | What has your experience been so far in involving family caregivers?<br>What is your usual routine when involving family caregivers? |

| | | |
|---|---|---|
| | Motivation to change | To what extent are you willing to adjust your approach to enable more intensive collaboration with family caregivers? |
| Family caregiver context | Knowledge | What do you think are the wishes of family caregivers? Do they want to be closely involved, or do they prefer not to be?<br>Do caregivers possess knowledge about the resident that supports or hinders the treatment of aged care facility residents with dementia?<br>(Skip this if already addressed under benefits of involvement.)<br>Is there a difference between family members as caregivers (children, partner, niece/nephew) and professional mentors as caregivers? |
| | skills | Are family caregivers capable of collaborating effectively with the physiotherapist?<br>Should caregivers acquire new skills, such as through training, to be more effectively involved in physiotherapy? |
| | Attitude | What is the family caregiver's attitude toward collaboration with the physiotherapist?<br>Do you feel that family caregivers are open to improved collaboration or communication? |
| | Commitment | - |
| Social context | Colleagues' opinions | How do your colleagues view the involvement of family caregivers within your organisation? |
| | Organisational culture and collaboration | Do you think your organisation is open to change?<br>Do you think other disciplines are also involved in engaging family caregivers? If so, how do they influence this process?<br>(For example: client advisors, team leaders, welfare staff, management. Family caregivers might already be contacted by other colleagues, requiring interdisciplinary collaboration.) |
| | Leadership | Who do you think should take the lead in involving family caregivers? |
| Organisational context | Care process organisation | - |
| | personnel | - |
| | Capabilities | - |

| | | |
|---|---|---|
| | Resources | Are there specific resources you use in your daily work that influence how family caregivers are involved?<br>*For example, I've heard it is sometimes possible to communicate with caregivers via a digital record. What impact does this have on involving family caregivers?* |
| | Structures | Are there existing procedures that influence how family caregivers are involved? (e.g., multidisciplinary meetings - MDMs).<br>Do physiotherapists participate in MDMs? Is physiotherapy discussed? |
| Economic and political context | Financial | Is it feasible for you to involve family caregivers in physiotherapy within your working hours? |
| | Regulations | Are there external protocols or guidelines for contact with family caregivers?<br>Does the current General Data Protection Regulation (GDPR) impact how family caregivers are involved? If so, could you describe how? |
| | Policy | Does the policy of encouraging older adults to live at home longer affect how family caregivers are involved?<br>*(For instance, consider how the patient's and caregiver's advancing age might affect this dynamic.)* |

# Part 3

# Chapter 7:

## A 10-week physical therapist-supervised exercise program for nursing home residents with dementia: a single arm, observational feasibility study

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## Abstract

**Background:** Evidence on the effectiveness of exercise interventions for nursing home residence with dementia is scarce with considerable practice variation with respect to their contents and dosage. This study aimed to evaluate the feasibility of an adequately dosed, personalized exercise intervention with respect to the assessment instruments, participants' adherence and the occurrence of serious adverse events (primary feasibility outcomes) and the participant recruitment and participants' and supervisors' participants' perceptions and experiences (secondary feasibility outcomes).

**Design:** Single-arm observational study.

**Setting:** Two nursing homes in Haarlem, the Netherlands.

**Participants:** Nursing home residents with a confirmed diagnosis of dementia who were able to walk 50 meters (with or without walking aid), without expected resistance to the intervention.

**Intervention:** 10-week program, with two group-based sessions including strength and balance exercises, and two individual exergaming cycling sessions per week. The sessions were tailored to the participant via standardized assessments and supervised by a physical therapist.

**Results:** Of 59 residents screened, 11 enrolled. Four of six clinical assessments were completed by all, and two by nine and ten participants, respectively. Nine participants completed both components, one only the individual exergaming part, and one participant dropped out. Adherence rates were 92% for the group and 87% for the individual sessions. Among 137 reported adverse events, nine were possibly related to the intervention, all minor and transient. The median participant appraisal score was 4.3 (out of five). Supervisors highlighted dementia-specific knowledge, individualized communication, and tailored approaches as facilitators, while scheduling conflicts posed challenges.

**Conclusion:** A 10-week, personalized, physical therapist-led exercise program for nursing home residents with dementia is feasible, with high adherence and positive evaluations. A pilot study to refine the recruitment and intervention procedures as well as pre-and post-intervention outcome measurements is needed prior to scaling up to a larger clinical trial assessing effectiveness.

## Introduction

Dementia is highly prevalent among nursing home residents, with rates between 42% and 84% depending on country and facility type.[1–3] Beyond cognitive decline, dementia is associated with reduced mobility, strength, balance, and endurance,[4,5] leading to greater dependency in activities of daily living (ADL)[6] and an increased risk of falls.[7] Physical therapy, especially exercise-focused, is commonly used to address physical impairments in this population.[8,9] Physical therapists are considered the experts on exercise therapy, as endorsed by both physical therapists' professional organizations[10] and by patients.[11] However, exercise interventions vary widely in content and supervision, limiting their comparability.[12–16]



A recent review of physical therapist-supervised exercise interventions for residents with dementia included six studies: four multimodal, and two aerobic-only.[17] Aerobic interventions showed some benefits but had high bias risk. Multimodal programs showed mixed effects on performance and independence. Furthermore, the variation in outcome measures and inconsistencies in observed effects limited the strength of the conclusions. With the interpretation of the results, it must also be taken into account that none of the interventions met the recommendations from international guidelines on exercise and physical activity for nursing home residents[18] and older adults,[19,20] both suggesting the incorporation of aerobic, strength, flexibility and balance exercises, with a minimum duration of 20 minutes and frequency of 3 times per week. This raises questions about their therapeutic validity.[21]

Low adherence to exercise sessions is another concern. A meta-analysis found an average 62.3% adherence rate among residents with dementia.[22] Some high-quality programs achieved higher rates (73–75%)[23,24] but overall, suboptimal adherence may limit effectiveness. Exergaming, combining physical and cognitive stimulation through interactive games,[25] shows promise in improving engagement.[26] An example is the use of stationary bicycles with digital video images of the environment such as *Bike Labyrinth®*. A recent qualitative study[27] explored residents' preferences, revealing a preference for professional oversight, though not necessarily by a physical therapist at all times, provided safety and quality were maintained. Building on these findings, a future intervention could incorporate a flexible supervision model, combining professional supervision with trained non-professional support.

In summary, while therapist-supervised exercise can improve function in residents with dementia, most studies fall short of guideline standards, and adherence strategies like exergaming remain underexplored. A well-designed, individualized intervention incorporating exergaming and flexible supervision may reveal its full potential, however

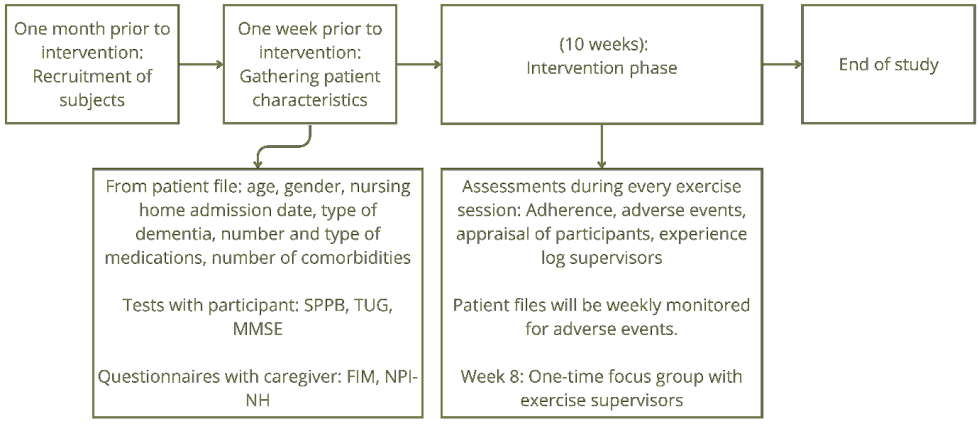
first its feasibility must be assessed. Therefore, this study aimed to assess the feasibility (assessment completion, session adherence, adverse events, recruitment, participant appraisal, and supervisor experiences) of a 10-week physical therapist-supervised exercise intervention for nursing home residents with dementia.

# Methods

## Study design

We conducted a single-arm, observational study at two sites of a nursing home care organisation. The study methodology was developed in accordance with the extended Consolidated Standards of Reporting Trials (CONSORT) criteria for feasibility studies.[28] Furthermore, the intervention was described using the Template for Intervention Description and Replication (TIDieR) checklist and guide.[29] The study duration and sample size was based on two previous feasibility studies involving exercise interventions for older adults with dementia.[30,31] The study planning is depicted in Figure 1. The primary feasibility outcomes were: administration and completion of assessment instruments, with an a priori threshold of >80%; adherence to the intervention, with a threshold of >75%; and absence of serious adverse events attributable to the intervention. The secondary feasibility outcomes were: participant recruitment, participants' appraisal of the intervention, and supervisors' experiences.

Figure 1: Study flow including recruitment, study length and study procedures




## Study ethics

Ethical approval for the study protocol was obtained from the Medical Ethics Assessment Committee – Leiden Den Haag Delft (METC-LDD) [NL87232.058.24]. The study procedures were informed by existing literature on the ethical inclusion of individuals with dementia

in research.[32] Given the severity of cognitive impairment among the target population, all residents were deemed unable to read, comprehend, and provide informed consent for participation in medical research. Therefore, the legal representatives of potentially eligible residents were informed about the study and asked to provide written informed consent. While consent from the legal representative is legally sufficient, verbal assent from the residents was also sought to support their involvement in the decision-making process. All supervisors provided written informed consent.

## Setting and Population

Participants were recruited and data was collected from two sites of a nursing home organization located in the urban area of Haarlem, the Netherlands during February June 2025. Both facilities share similar characteristics, including size, range of activities, staffing levels, and small-scale, homelike nursing wards. Each site has specialized units dedicated to residents with severe cognitive impairment, offering continuous supervision. Exercise therapy was provided by physical therapists or movement therapists (collectively referred to as physical therapists), who are professionals trained to promote and guide physical activity in particular for people who are dependent on supervision. Physical therapy services in these nursing homes were consistent with standard Dutch practice.[33]



### *Eligibility of participants*

Eligibility for participation in the study exercise sessions was limited to residents diagnosed with dementia who resided in the designated wards and were not expected to return to independent living. The attending physician assessed eligibility based on the following inclusion criteria:

- A confirmed medical diagnosis of dementia documented in the patient's medical file
- Ability to walk at least 50 meters without human assistance (use of walking aids permitted)
- No anticipated resistance to participation in the intervention, as judged by the attending physician

Exclusion criteria included:

- Behavioral problems likely to interfere with participation in a group intervention, as determined by the physician
- Any other factors identified by the physician that could render participation inadvisable for the resident

Throughout the study period, participants were allowed to continue receiving any treatments deemed appropriate in consultation with their attending physician.

## Recruitment

***Nursing home residents***

At each ward, the attending physician compiled a list of potential participants based on the study's eligibility criteria. The legal representatives of the eligible residents were contacted by the ward's physical therapist via telephone. If the legal representative expressed interest and agreed to receive further information, an informational leaflet outlining the study was sent. One week after the initial contact, a follow-up call was made to address any questions. Additional inquiries were managed by the study coordinator (DB).

If the legal representative remained interested, an informed consent form was provided. Upon receipt of the signed consent form, the attending physical therapist informed the resident about the study and sought verbal assent. Once verbal assent was obtained, the resident was formally enrolled in the study by the study coordinator.

***Supervisors***

Supervising physical therapists were selectively recruited based on their affiliation with the participating locations and wards, postgraduate training in dementia care as well as their interest in the study. Supervisors attended one introductory meeting and two training sessions to prepare for the intervention. In addition, four fourth year physical therapy students (University of Applied Sciences, Leiden) were selectively recruited to assist with supervision. These students participated in two theoretical sessions and two practical training sessions and attended one expert lecture on dementia. Before the study, the coordinator assessed and confirmed their competency to supervise the intervention.

## Intervention

The intervention was designed by a team of physical therapists with experience in nursing homes and in clinical research, with its contents, dosage and mode of delivery being informed by recommendations of relevant professional guidelines,[18,19] a recent systematic review on physical therapy for nursing home residents with dementia,[17] two studies exploring the needs and preferences of nursing home residents and their family caregivers regarding physical therapy and exercise,[27,34] as well as clinical experience of members of the research team with this population. The program was individually designed regarding its contents and dosage according to the FITT-VP principle: Frequency, Intensity, Time, Type, Volume, and Progression.[35] The resulting intervention comprised four sessions per week: two group exercise sessions and two individual exergaming sessions. A detailed summary of the intervention is provided in Supplemental Table 1. In short, group sessions were 45 minutes long, held in the nursing home gym, and supervised by two physical therapists. They focused on strength, balance, and flexibility at moderate intensity, with exercises progressively adapted every two weeks. Individual exergaming sessions

involved 20 minutes of supervised cycling on a stationary ergometer (Tigo 562, Thera-Trainer®, Germany) equipped with personalized virtual routes using Bike Labyrinth® software [Version: V5.4.1]. These sessions were tailored to each participant's preferences and adjusted regularly for resistance and engagement.

## Standardized clinical assessments for the individual design of the intervention

Six instruments were selected to assess physical functioning, cognition, neuropsychiatric symptoms of dementia, and ADL, that were administered one week prior to the start of the intervention (see Supplemental Table 1 for details). The assessment results were communicated to supervisors to enable personalization of the exercise sessions according to each participant's individual needs and abilities. The results were further used to contribute to the external validity of the intervention by providing detailed information on the participant characteristics. The physical functioning performance tests were administered by a physical therapist not involved in the intervention supervision (IP), the cognitive assessments by a psychologist (BW) and the instruments for independence in ADL assessments and neuropsychiatric symptoms by nursing home caregivers (supervised by BW and DB).



## Feasibility Outcomes

### *Primary outcomes*

*Completion of the clinical assessments*

For completion of the clinical assessments, the recorded test results were used. While there is no universally accepted threshold for determining the feasibility of a clinical instrument, in this study, an instrument was considered feasible if it could be administered and completed by at least 80% of participants. An attempt was considered valid if the participant understood the test procedure, even if they were physically unable to complete it. In addition, the number of attempts was recorded. This criterion was informed by the National Institute for Health and Care Research (NIHR) progression criteria [36] and the extended CONSORT guidelines for feasibility studies.[28]

*Adherence to the intervention*

Adherence was recorded dichotomously (yes/no) for session completion by the attending physical therapists using standardized exercise logs. Although, to our knowledge, no standardized cut-off value exists to define sufficient adherence, we considered adherence to be feasible when exceeding 75%, as this corresponds to completing, on average, at least three exercise sessions per week.

*Adverse events*

Adverse events are defined as any undesirable experience occurring in a participant during the study, regardless of whether it is related to the experimental intervention. Adverse events were assessed during each session through direct observation and by asking participants whether they experienced any negative effects from the exercise sessions. Additionally, the treating physical therapist monitored participants' patient files to identify any adverse events reported by nursing home staff. Adverse events were documented by means of a modified classification system based on a previous study involving nursing home residents with dementia,[37] and according to the Central Committee on Research Involving Human Subjects (CCMO).[38] Events were categorized into four types: 1) Minor and temporary, not requiring treatment by a physician or specialist, 2) Minor and temporary, requiring treatment by a physician or specialist, 3) Serious injury or illness, potentially life-threatening, 4) Death. All adverse events were discussed with the supervising physician. Adverse events classified under categories 3 and 4 were deemed serious adverse events and were handled in accordance to national guidelines.[38] In specific circumstances, an independent monitoring committee has the authority to terminate the intervention before its planned completion. The physician and the study coordinator determined whether the event was unrelated, possibly related, or most likely related to the intervention. We considered the absence of serious adverse events related to the intervention to be feasible.

***Secondary outcomes***

*Participant Recruitment*

To assess recruitment feasibility, we documented the number of residents screened, the number of eligible individuals approached, the number who consented to participate, and, when available, the reasons for non-participation.

*Participants' appraisal of the intervention*

Participants' appraisal of the exercise intervention was assessed at the end of each exercise session using a specifically for this study developed 5-point Likert scale. The scale is an adaptation of the End-of-Life in Dementia Satisfaction Scale (EOLD)[39] and the Smiley Face Assessment Scale.[40] The adaptation consisted of a printed page with the question: "How did you perceive the exercise session you just participated in?", answered on a 5-point Likert (1= Very unpleasant, 2=Unpleasant, 3=Neutral, 4=Pleasant, and 5=Very Pleasant). If a participant was unable to respond, a 3-point Likert scale consisting of the options Unpleasant, Neutral, and Pleasant in red, yellow, and green, respectively were provided.

*Supervisor's experiences and acceptance*

Supervisor's experiences regarding facilitators and barriers in the acceptance of the intervention were assessed using a mixed-methods approach:

- Logs documenting exercise observations: After each session, supervisors recorded their observations in the participant's report form. These notes included perceptions of participant engagement, challenges encountered, and any notable events during the session. Two persons (KS and JK) independently checked the notes and coded relevant information.
- Focus group discussion: In week 8 of the intervention, all supervisors participated in a structured focus group to further explore their experiences. The discussion was led by one of the physical therapy students (JK) and supervised by the study coordinator. The focus group was audiotaped with Microsoft Teams [Version 25153.1010.3727.5483], transcribed with [TurboScribe.ai] and checked for correctness by JK and BW. The focus group data were initially independently thematized by two persons (JK and BW), subsequently discussed jointly by them, and checked for correctness by the study coordinator.



In addition to the standardized assessments, the following characteristics of the participating residents were retrieved from medical records: age, gender, date of nursing home admission, dementia subtype, number and type of comorbidities, total number of prescribed medications and medication categories. The number of medications and comorbidities was collected cumulatively, meaning that individual participants could be presented with more than one medication or more than one condition within a given category (e.g., multiple musculoskeletal disorders).

## Statistical analysis

Baseline characteristics of the participating residents were summarized using standard descriptive statistics, specifically medians and interquartile ranges for continuous variables and frequencies for categorical variables. An expert in geriatric medicine (SH) aided in categorizing the medical conditions and the medications used. Recruitment feasibility was summarized using descriptive statistics. Adherence to the intervention and completion of evaluation parameters were calculated as the number of sessions attended or instruments completed, divided by the total number of sessions or instruments planned. Adherence rates were calculated both overall and separately for the group exercise sessions and the individual exergaming sessions. Resident-reported experiences using Likert scales were analyzed using means and standard deviations. Supervisors' experiences as documented in the participant report forms were analyzed using thematic analysis.[41] The themes that emerged from this preliminary analysis informed the development of the

topic guide used in the focus group discussions. Focus group data were subsequently coded and organized into minor and subsequently major themes.

## Results

### Participant and supervisor recruitment

A total of 59 residents were screened for eligibility (Figure 1) of whom 14 (24%) were eligible for participation. All legal representatives agreed with participation (in 1 patient with the exception of the individual exercise sessions for logistical reasons), and 11 out of 14 (79%) participants provided verbal assent. Table 1 presents their characteristics. They had a median age of 84 years, 8 were female and 6 participants were diagnosed with Alzheimer's dementia, whereas the most common medical conditions were cardiovascular diseases and musculoskeletal disorders (Table 1).

Figure 2: Flowchart of participant recruitment and completion of the intervention

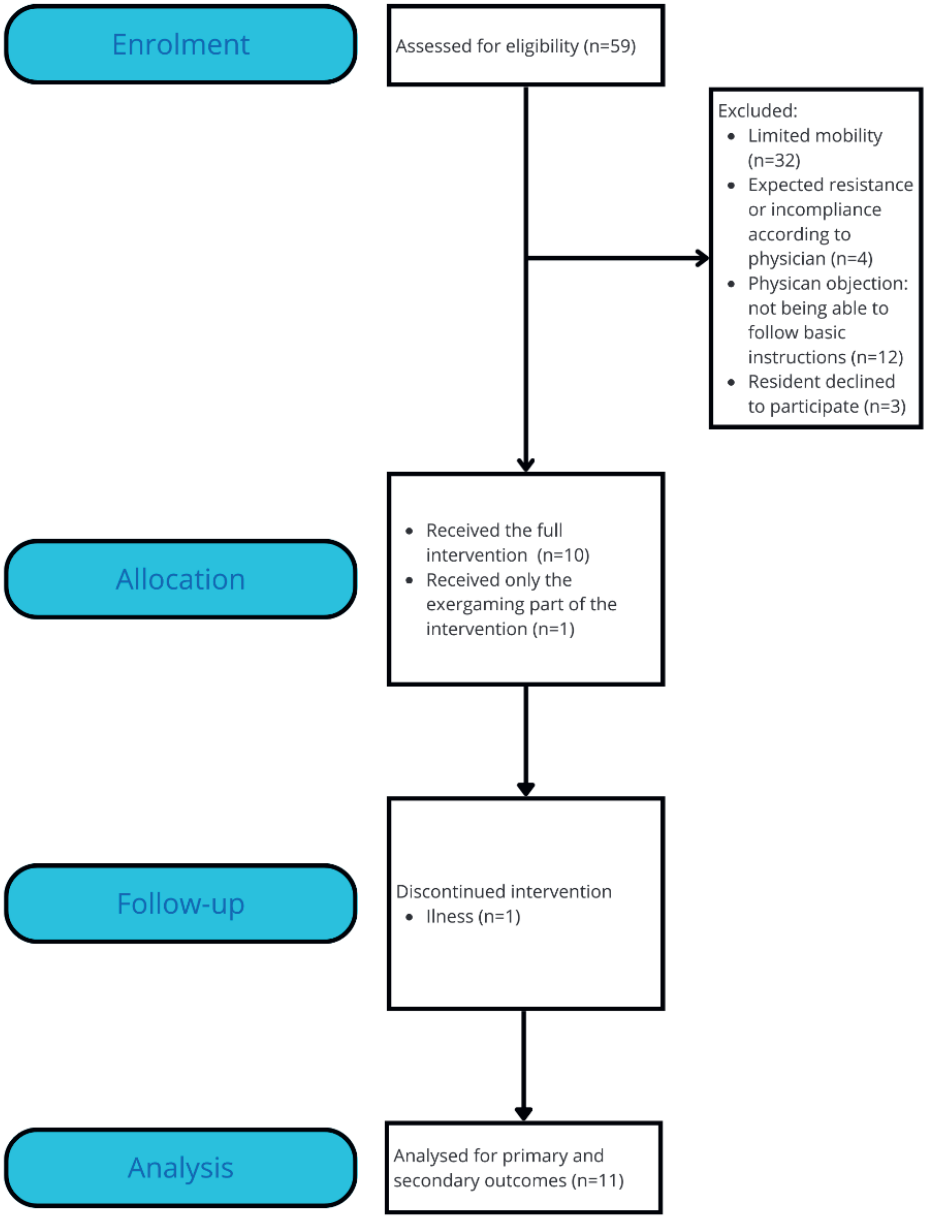


Table 1: Characteristics of eleven nursing home residents with dementia participating in an observational study on a 10-week exercise program.

| Characteristics | Median and range | Number (%) |
|---|---|---|
| Age | 84 (71-96) | |
| Gender (female) | | 8 (84.2%) |
| Length of stay (months) | 16 (2-95) | |
| Dementia type | | |
| Alzheimer's disease | | 6 (54.5%) |
| Vascular | | 1 (9.1%) |
| Mixed Alzheimer's disease and vascular | | 1 (9.1%) |
| Other | | 3 (27.3%) |
| Medical conditions (total number in all 11 participants) | | |
| Cardiovascular disease | | 22 |
| Vitamin deficiency | | 2 |
| Dermatological disorder | | 12 |
| Ear, Nose and Throat disorder | | 1 |
| Gynaecological disorder | | 2 |
| Intestinal disorder | | 4 |
| Metabolic disorder | | 6 |
| Musculoskeletal disorder | | 20 |
| Neurological disorder (excluding dementia) | | 11 |
| Ocular disorder | | 3 |
| Psychiatric disorder | | 5 |
| Pulmonary disorder | | 1 |
| Rheumatic disorder | | 5 |
| Surgical treatment | | 2 |
| Urological/nephrological disorders | | 11 |
| Medication (total number in all 11 participants) | | |
| Analgesics | | 11 |
| Anticoagulations | | 6 |
| Anticonvulsants | | 1 |
| Antidepressants | | 3 |
| Antihypertensive | | 12 |
| Antipsychotics | | 3 |
| Benzodiazepine | | 4 |
| Cholesterol lowering agents | | 1 |
| Cholinesterase inhibitor | | 2 |
| Dermatological cream | | 2 |

Table 1: Characteristics of eleven nursing home residents with dementia participating in an observational study on a 10-week exercise program. (*continued*)

| Characteristics | Median and range | Number (%) |
|---|---|---|
| Diuretics | | 4 |
| Eye drops | | 2 |
| Hormonal treatment | | 1 |
| Inhalers | | 1 |
| Laxative | | 4 |
| Metabolic medicine | | 1 |
| Nasal spray | | 2 |
| Stomach acid reducer | | 3 |
| Vitamin D and calcium supplement | | 11 |
| Use of walking aid (yes) | 3 out of 11 | |
| Rolling walker | 3 (100%) | |



Regarding the supervisors, eight were approached, of whom all eight agreed to participate and take part in the mandatory training. They were four physical therapists and four physical therapy students. Each supervisor guided at least 70% of the planned group or individual training sessions.

## Completion of the assessment instruments

Table 2 presents the completion and outcomes of the clinical assessment instruments. Five of these, i.e. the balance test, the 4-meter walk test at a comfortable pace, the TUG test and the MMSE were completed by all 11 participants, while the FIM and the NPI were completed for all 11 participants by their professional caregiver. The SPPB was completed by 9 participants, due to the inability of 2 participants to complete the 5-times chair test component. In addition, 1 participant could not complete the 4-meter walk test at their fastest pace. In some patients, multiple attempts were needed, in particular for the balance part of the SPPB and the TUG test.

Table 2: Feasibility of 6 assessment instruments administered in 11 nursing home residents with dementia

| | Number of participants completing assessments | Number of attempts (median and range) | Score (median and range |
|---|---|---|---|
| Short Physical Performance Battery (range 0-12) | | | 8 (2-12) |
| - Balance (range 0-4) | 11 | 2 (1-4) | 2 (0-4) |
| - 4 meter walking speed, comfortable (meter/seconds) | 11 | 1 (1-1) | 5.9 (4.5-8.5) |
| - 5 times chair stand test, (seconds) | 9 | 1 (1-3) | 15.7 (10.1–20.4) |
| 4 meter walking speed, fastest (meter/seconds) | 10 | 1 (1-2) | 3.9 (2.3-7.7) |
| Timed Up and Go test (seconds) | 11 | 2 (2-6) | 12.7 (5.9-52.1) |
| Mini Mental State Examination (Range 0-30) | 11 | 1 (1-1) | 12 (7-22) |
| Neuropsychiatric Inventory – Nursing Home version Range (0-144) | 11 | 1 (1-1) | 7 (0-25) |
| Functional independence Measure (Range 18-126) | 11 | 1 (1-1) | 93 (55-107) |

## Adherence

As one participant did not engage in the combined group exercise sessions, ten residents completed the intervention. The overall adherence rate to the intervention was 89%. Participants attended 179 of the 194 planned group exercise sessions (92%) and 186 of the 214 planned individual exergaming sessions (87%). Two participants had an overall adherence rate under 75% (63% and 71%), and three participants completed all sessions (100% adherence rate). Documented reasons for non-adherence included lack of willingness to participate (n=24), medical reasons (n=13), and participant absence from the facility at the time of the session (n=6).

## Adverse events

Table 3 presents the occurrence of adverse events. A total of 137 adverse events were identified, all classified as minor and temporary, with nine requiring treatment. None of these latter nine events were considered likely related to the intervention (pain caused by pressure ulcers (n=6), nighttime falls from bed (n=2) and depressive symptoms requiring further examination to rule out underlying causes (n=1)). Nine of the128 adverse events that did not require treatment were classified as possibly related to the intervention, all described as fatigue or tiredness, with six occurrences reported at least one day after participation in an exercise session (details in Supplemental file 2). The highest number

of reported adverse events for one resident was 21, whereas one participant had no reported adverse events.

Table 3: Frequency of adverse events of a 10-week exercise program for nursing home residents with dementia, categorized according to severity and with possible relation with the intervention

| | Not related to the intervention | Possibly related to the intervention | Likely related to the intervention |
|---|---|---|---|
| CAT 1<br>Minor and temporary, not requiring treatment by a physician or specialist | 119 | 9 | 0 |
| CAT 2<br>Minor and temporary, requiring treatment by a physician or specialist | 9 | - | - |
| CAT 3<br>Serious injury or illness, potentially life-threatening | - | - | - |
| CAT 4<br>Death | - | - | - |



## Participants' appraisal of the intervention

The appraisal instrument was administered after 361 of the planned 408 sessions (88%) and was completed on 361 occasions (100%). On 359 occasions the 5-point Likert scale was used, whereas the simplified 3-point Likert scale was used twice, due to incomprehension of the participant of the 5-point Likert scale. The median scores of the group and individual exercise sessions were 4.4 (range 1-5) and 4.3 (range 1-5), respectively, with 321 of the 359 scores (90%) being 4 or 5 (pleasant or very pleasant) and 8 scores (2%) being 1 or 2 (very unpleasant or unpleasant).

## Supervisor experiences

All eight supervisors participated in the focus group discussion, resulting in four major themes (details in Supplemental File 3):

***1. Motivation of residents:***

According to the supervisors, participants were primarily motivated by the perceived health benefits of the intervention and the enjoyment of engaging in structured activities. Their own encouragement was found to play an important role in shaping participants' positive appraisals of the sessions, as well as adherence to the protocol and the intended intensity levels. Communication techniques were considered particularly important when inviting participants to the sessions. Supervisors reported that most residents required repeated explanations about the purpose of the exercise sessions each

time they were approached. A calm and reassuring manner was found to be effective in encouraging participation.

- Supervisor 1: *"Their motivation seems to come from the general idea that being active is good for their health."*

***2. Social interaction during group exercises:***
Social interaction was found to have both positive and negative effects on participation. On the one hand, seeing others exercise and receiving personal attention were perceived as motivating factors. On the other hand, excessive conversation occasionally distracted participants and disrupted exercise routines. According to the supervisors, this did not hinder adherence to the sessions or the appraisal of the participant, but distractions did cause exercises to be performed at a lower intensity level.

- Supervisor 1: *"But sometimes it's so distracting that they just stare at each other. They laugh, and then nothing happens for like 30 seconds."*

***3. Physical Environment and Setup:***
Environmental factors such as the availability and design of equipment, the spatial layout, and sensory stimuli (e.g., lighting, noise) were considered to influence participation. The exergaming equipment was perceived as a facilitator of engagement, whereas environmental factors such as under-stimulation (e.g., dimly lit rooms or hallways) and over-stimulation (e.g., excessive ambient noise) were identified as barriers to participation. Additional factors included encouragement from relatives or caregivers and convenient scheduling. Conflicting activities scheduled at the same time were noted to reduce participation.

- Supervisor 2: *"If a different activity was happening at the same time, the participants sometimes found it hard to choose between the other activity and the exercise session."*

***4. Supervisory knowledge and experience:***
According to the supervisors, their general knowledge of dementia care but also the ability to adapt communication and interaction styles to the individual needs of each resident positively influenced the motivation of the participants. A person-centered approach was seen as essential for fostering engagement and success during sessions.

- Supervisor 3: *"To one participant we'll say 'we're coming for you.' And then you can see her smile she'll say, 'oh yeah.' And right at that moment, she's on board and comes along."*

## Discussion

This study evaluated the feasibility of a 10-week, physical therapist-supervised exercise intervention in 11 nursing home residents with dementia. Participants constituted one-quarter of screened residents. Over 80% of the planned clinical assessments and exercise sessions were completed, and few adverse events were possibly related to the intervention, all of which were mild and transient. The intervention received a positive average rating from participants. Supervisors identified scheduling conflicts as barriers.

The clinical assessment instruments were largely feasible, consistent with prior validation in this population.[51] Some participants required multiple attempts for the SPPB balance test [42], fastest 4-m walk, and TUG, [43] due to apraxia, fear of falling, or cognitive limitations. While the 4-m walk test in the SPPB is usually administered at a comfortable walking speed, the fastest-speed version is considered a more sensitive indicator of physical performance.[44] Taking preventive measures, such as walking alongside the participant without influencing their pace, may improve the feasibility of the fastest 4-m walk test. Positioning the physiotherapist at the turning point and providing an additional instruction to pivot, walk back to the chair, and sit down helped participants complete the TUG with fewer difficulties.



Intervention adherence exceeded that of prior meta-analyses (62.3%) [22] and therapist-led programs (73–75%). [23,24] Although the study was not designed to compare adherence or enjoyment between exergaming and standard group exercise, supervisors suggested that participants were interested in the exergaming component. The adherence rates were not higher during exergaming than during the conventional exercise sessions, but nevertheless suggest that exergaming is acceptable to participants. While preliminary evidence suggests that exergaming may have beneficial effects on physical, cognitive, and emotional outcomes,[25] whether exergaming enhances adherence or outcomes warrants further study. No serious adverse events occurred. Of all reported mild adverse events, fewer than 10% were deemed possibly related to the intervention, mainly fatigue reported by one participant. Whether fatigue qualifies as an adverse event is debatable, as it is a common and expected response to moderate-intensity exercise.[45]

The recruitment rate in this study was comparable to that reported by Toots et al.,[23] who targeted a similar population using the same selection criteria. Main barriers were logistical: insufficient residents at one site and the requirement to walk 50 m, which prevented attainment of the planned 24 participants. For a future study, expanding the screening pool (e.g., by involving additional nursing homes) would help achieve the desired sample size. Furthermore, because most intervention components can be performed with limited mobility, modifying the inclusion criteria to require only the ability to transfer from

sit to stand without assistance may improve accessibility and recruitment feasibility. Most sessions were rated pleasant or very pleasant, consistent with earlier findings that residents with dementia enjoy moderate-intensity exercise.[46] The use of brief feedback tools, tailored to the cognitive abilities of this group, may warrant further development and validation.

The experiences of the intervention supervisors underscored several facilitators and barriers influencing participant acceptance of the intervention. Positive encouragement from supervisors and family members was perceived as a key facilitator, consistent with existing literature on motivation and adherence among individuals with dementia.[47,48] Additionally, supervisors reported logistical challenges in scheduling exercise sessions without conflicting with other planned resident activities. This finding appears to contrast with previous studies, which more commonly cite a lack of available activities or infrequent family visits as limiting factors.[49,50] The reported scheduling difficulties may be specific to the Dutch long-term care context, where recent policy changes have introduced dedicated funding to expand meaningful daily activities for nursing home residents.[51]

A strength of the study design was that feasibility was systematically assessed across multiple domains, including recruitment, adherence, safety, acceptability, and implementation, allowing for well-founded recommendations for the design of a future larger-scale trial. A limitation of the study was that it involved a relatively small sample size. Therefore, the results must be interpreted with caution. Moreover, no assessments were conducted at the end of the intervention. Thereby, the ability of the assessment instruments to determine changes over time or could not be ascertained and no estimations of effect sizes to be used in power calculations could be made for those instruments that could possibly be used as outcome measures in a future clinical trial.

Although the intervention required considerable time investment and effort from both the residents and nursing home staff, the associated burden was limited and considered proportionate to the knowledge gained. The absence of serious adverse events, combined with the majority of sessions being appraised as pleasant or very pleasant by the participants, suggests that the intervention was experienced more as an enjoyable activity than as a burden. In addition, the supervisors were trained in dementia care in accordance with the study protocol, which not only benefited the intervention itself, but was also beneficial for the supervisors in their broader clinical practice. To the best of our knowledge, this is also the first study to meet the recommendations from international guidelines on exercise and physical activity for nursing home residents[18] and older adults. [19,20] Together, these findings support the rationale for the conduct of a pilot study including pre- and post-intervention outcome assessments, to allow estimation of

change and variability to calculated the sample size and further justifying the required investment of time and effort from staff.

## Conclusion

This study showed that recruitment for a 10-week physical therapist-led exercise program for nursing home residents with dementia was challenging, but the intervention proved to be feasible with respect to execution, adherence, safety and satisfaction. Supervisors suggested various factors affecting adherence and exercise intensity. All of these insights are valuable to improve recruitment, supervision, and personalization in future research evaluating the cost-effectiveness and long-term benefits of the intervention.



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# Chapter 8:

## Summary and general discussion

Physiotherapy, primarily in the form of exercise therapy, is commonly employed in Western countries for the treatment of nursing home residents with dementia.[1,2] This practice is based on the evidence demonstrating that exercise has the potential to positively impact their well-being.[3–5] However, current physiotherapy practices in the nursing home population were found to vary largely, whereas factors underlying this practice variation are largely unexplored.[6,7] Moreover, there is limited understanding of the specific needs and preferences regarding its delivery among residents and their informal caregivers. With respect to the content and dosage of exercise interventions, the feasibility of a physiotherapist-supervised exercise intervention adhering to (inter)national exercise recommendations for this population is currently unknown. Given these gaps in knowledge, this thesis aims to address the following research questions:

*Research question 1*: What are the contents and effectiveness of physiotherapist-supervised exercise interventions for nursing home residents with dementia, and which contextual factors influence their application?



*Research question 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?

*Research question 3*: What is the feasibility of a physiotherapist-supervised exercise intervention for nursing home residents with dementia?

This chapter summarizes and discusses the main findings of this thesis and the methodological choices made. Implications and recommendations for future research, current practice and education are presented.

## Main findings

### Part 1: Effectiveness of physiotherapy and exercise for nursing home residents with dementia and their delivery in daily clinical practice

In the systematic review (**Chapter 2**), randomized controlled trials (RCTs) of exercise interventions for nursing home residents with dementia, supervised by physiotherapists, were identified through searches in six electronic medical databases. Of the 1,377 records retrieved, 6 RCTs reported in 11 publications, met the inclusion criteria and were included in the review. The exercise interventions varied largely with respect to type of exercises, frequency, intensity, and duration. Adherence to the interventions was generally low across studies. Due to further heterogeneity in study designs and outcome measures and

inconsistencies in the findings, the effectiveness of these interventions remains inconclusive.

**Chapter 3** presents the findings of an online survey conducted to examine the structure and process of physiotherapy for nursing home residents with dementia in the Netherlands. A total of 109 physiotherapists, each representing a distinct nursing home, completed the survey. In terms of structure, variations were observed in the requirement of a physician's referral to initiate therapy and in the use of standardized protocols and guidelines. Greater consistency was noted in the composition of the multidisciplinary teams involved. Regarding the process of the delivery of physiotherapy, differences were present in the use of assessment tools and the involvement of informal caregivers. However, there was more agreement concerning the types of treatment modalities that were provided and the intended therapeutic outcomes. It was also found that physiotherapists were not only providing treatment to residents, but were also coaching other healthcare professionals and provided education and support to informal caregivers. Overall, it was concluded that, despite some consistent elements in multidisciplinary collaboration and treatment goals, there was considerable variation in the structure and process of physiotherapy delivery across nursing homes in the Netherlands

## Part 2: Perceptions, needs and preferences of residents with dementia and their family caregivers regarding physiotherapy, and the feasibility of their involvement

**Chapter 4** presents the findings of a qualitative interview study exploring the perceptions, needs and preferences of informal caregivers of nursing home residents with dementia regarding physiotherapy. Thirteen family caregivers were interviewed, and the data were analyzed thematically. Overall, caregivers reported limited familiarity with physiotherapy and expressed a desire for greater collaboration with physiotherapists. They emphasized the importance of individualized therapy, empathetic communication, and exercises that were both enjoyable and accessible for the residents. The conclusion of the study was that informal caregivers of nursing home residents with dementia expressed a need for clearer communication and greater involvement in physical therapy, emphasizing the importance of empathetic interaction, individualized and enjoyable care, and the potential value of shared decision-making within the interdisciplinary team, an approach that remains underexplored in this context.

In **Chapter 5**, the perspectives of nursing home residents with dementia regarding physiotherapy and exercise were investigated. Fifteen residents participated in semi-structured interviews, and the data were analyzed using thematic analysis. Participants generally viewed physiotherapy as a means of maintaining physical function and independence. While they considered supervision important, they were open to exercises

led by others, provided that safety and quality were ensured. Participants preferred that family caregivers be kept informed through reports provided by the physiotherapist; however, they felt that their relatives were too occupied with other responsibilities to assist them with the exercises. In summary, nursing home residents with mild to moderate dementia expressed clear preferences regarding physiotherapy, communication, and caregiver involvement, highlighting the potential for improved intervention adherence, as well as a shift toward a more supervisory role for physiotherapists.

**Chapter 6** explored the barriers and facilitators to family involvement in physiotherapy and exercise among physiotherapists and management. For that purpose, interviews with 19 physiotherapists and 9 nursing home staff members were held. The study was conducted from a constructivist ontological perspective and data were analyzed using reflexive thematic analysis. Identified barriers included the perceived additional burden on family caregivers and an institutional culture that was sometimes perceived as unwelcoming. Facilitators included proactive promotion of engagement of informal caregivers by physiotherapists, clear and accessible information for families, prior positive experience of caregivers with healthcare or exercise, and the influence of family-centered cultural values. The study concluded that proactive role clarification, flexible approaches, and inclusive communication strategies by physiotherapists and aged care facilities could enhance caregiver collaboration and sustained engagement.



## Part 3: The feasibility of a physiotherapist-supervised exercise intervention

**Chapter 7** outlines an observational pilot study on the feasibility of a physiotherapist-supervised exercise intervention. The intervention encompassed four exercise sessions per week (two supervised, small-group sessions focusing on strength and balance exercises and two individual aerobic exergaming sessions using a seated bicycle trainer connected to software displaying a virtual cycling route) for a period of 10 weeks. Feasibility was evaluated based on the percentage of successfully recruited participants from those that were screened, the completeness of assessment instruments, participant adherence with the intervention, the occurrence of adverse events, the participants' appraisal of the intervention and the experiences of the supervisors. Of the 59 potentially eligible residents screened, 11 participated in the intervention, and all but one completing both types of treatment sessions over the intervention period. The average adherence rate with the sessions was high (median92 %), there were no serious and only a few mild adverse events, with transient fatigue being the most frequently reported. Ninety percent of the sessions were rated as pleasant or very pleasant and the exercise supervisors' experiences yielded valuable feedback regarding dementia-specific knowledge, individualized communication, and tailored approaches as facilitators, while sensory overstimulation or understimulation posed challenges. The assessment instruments proved feasible for use

in a larger-scale study. However, the recruitment process requires further optimization to enhance participant inclusion. The intervention was concluded to be feasible, with high adherence and positive feedback, although refinement of the recruitment and intervention delivery is recommended before conducting a larger effectiveness trial.

## Reflection on findings and methodological considerations

### Effectiveness of physiotherapy supervised exercise interventions and their outcomes

**Chapter 2** demonstrated that there is currently a limited body of high-quality research specifically addressing exercise interventions delivered by physiotherapists to individuals with dementia. The existing literature showed substantial variation in intervention characteristics, limiting comparability. While there are indications of potential effectiveness, the evidence was insufficient to draw definitive conclusions.

The evidence for exercise in nursing home residents with dementia is not directly comparable to the extensive body of evidence on the benefits of exercise and physical activity in the general older adult population.[4,8] In this broader population, there is far more evidence available for improving outcomes such as cardiorespiratory fitness[9] or muscle strength.[10] Much of the evidence supporting the overall benefits of exercise and physical activity in the general older population is derived from large-scale epidemiological studies with long follow-up periods, focusing on the prevention or delay of progress of noncommunicable diseases such as obesity, sarcopenia, heart failure, hypertension, cancer, chronic kidney disease, pulmonary disease, osteoporosis, osteoarthritis, depression, dementia, or Parkinson's disease.[4,11,12] For instance, a study by Arem et al. (2015) had a median follow-up of 14.2 years.[13]

Concerning the evidence for specific exercise interventions in elderly people with dementia, a recent systematic review demonstrated beneficial effects of multicomponent exercise interventions in improving activities of daily living, depression, and balance in people with Alzheimer's Disease aged 60 and above.[14] Some of the interventions of the included studies in that review had a duration of 6-12 months, whereas it must be noted that the fewer than half of nursing home residents remain in long-term care for more than 1.5 years,[15] making long-term preventive interventions less feasible or impactful in this population. Most nursing home residents are considered to be in the palliative phase, defined as "the phase that begins when recovery is no longer possible, or when the end of life is approaching due to increasing vulnerability".[16] Consequently, the applicability of findings from community-dwelling older adults either or not with dementia to those elderly with dementia in nursing home settings is limited. In that latter context only

short-term physiotherapy interventions and treatment goals, with meaningful outcomes for that setting are relevant. This aligns with the findings presented in **Chapter 3,** where physiotherapists reported the outcomes their treatment was aimed at. In that survey study and in other literature reporting on physiotherapy outcomes for nursing home residents, treatment was typically aimed at physical performance,[2,6] independence in daily activities,[2] fall prevention,[2,6] mood enhancement,[2,6] pressure ulcer prevention,[1,6] pain management,[1,2,17] end-of-life care,[17] quality of life,[18] and continence care.[2,6] These outcomes are more realistically achievable with short-term, targeted objectives.

***Adherence as a determinant of intervention effectiveness***

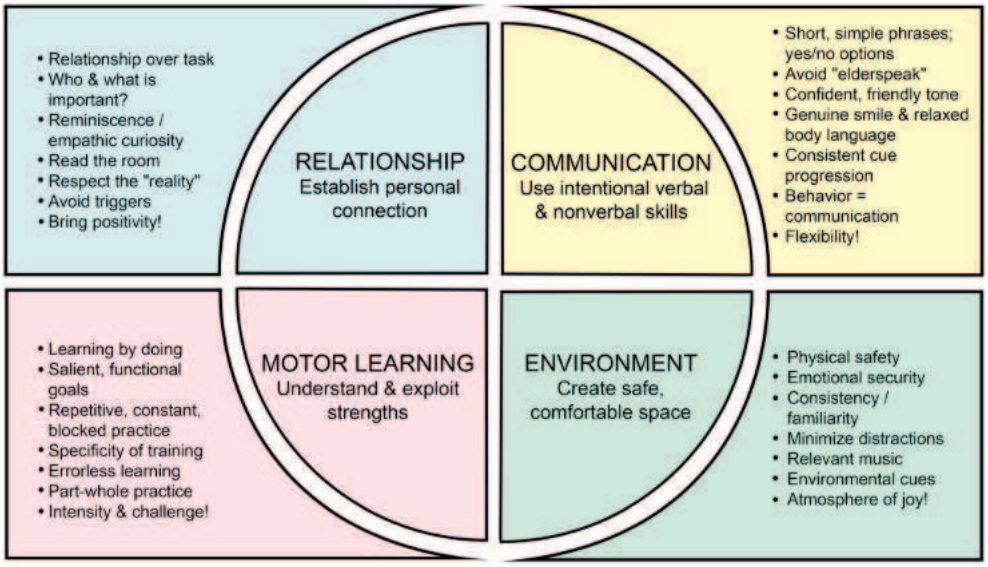
As shown in **Chapter 2** and documented by another review on exercise in dementia,[19] low adherence represents a major barrier to achieving intervention benefits. Adherence is commonly defined as "maintaining an exercise regimen for a prolonged period following the initial adoption phase".[20] A systematic review assessing exercise adherence in nursing home residents with dementia reported an average adherence of 65.4%.[21] Some high-quality randomized controlled trials (RCTs) have reported adherence rates of 73% [22] and 75%,[23] respectively. These studies used an exercise intervention consisting of three sessions per week and a duration of 45-60 minutes. With an average adherence of less than 75%, the participants may not reach the advised frequency of at least 3 times moderate to high intensity exercise per week as recommended in guidelines for older adults in nursing home care.[4,5] **Chapter 5** of this thesis explored residents' preferences regarding physiotherapy and exercise, providing useful insights to increase participation in and adherence with exercise interventions. Residents for example, emphasized the importance of communication and supervision skills of the supervisor of the intervention, while also indicating a preference for exercise sessions in designated areas of the nursing home and for functional exercises aimed at maintaining of increasing their physical performance and independence in daily activities.

The feasibility study described in **Chapter 7** incorporated these strategies, along with recommendations from two systematic reviews on supervisor preparation,[24,25] and achieved an overall adherence rate of 89% of the sessions. A notable difference in our study procedures was that the supervisor training emphasized communication techniques and dementia-specific knowledge, in contrast to the training approaches in previous RCTs,[22,23] which primarily focused on the characteristics of the exercises, such as exercise intensity or the use of weighted belts. This emphasis on communication supervisors' skills and knowledge on dementia, consistent with the preferences expressed by family caregivers in the qualitative study presented in **Chapter 4,** might be an important factor enhancing participant adherence. It is also central to the recently developed framework for physiotherapists working with people with dementia. [18] That framework (Figure 2)

serves as a foundation for defining and promoting best practices and comprises four key components:

1. Establishing a personal relationship
2. Using intentional verbal and nonverbal communication
3. Understanding and optimizing motor learning capacity
4. Creating a safe and meaningful environment

Figure 3: Model or framework by Ries (2022) of physiotherapy for people with dementia




This model, together with the findings of this thesis and other expert perspectives,[26,27] emphasizes the role of physiotherapists in establishing meaningful relationships with care recipients and utilizing effective communication strategies in the nursing home context.

***Adverse events and their influence on exercise***

While none of the clinical trials on exercise interventions in nursing home residents with dementia in **Chapter 2** provided detailed descriptions of potential side effects, concerns about possible adverse events may limit participation in exercise interventions. Two systematic reviews, on exercise interventions for people with dementia,[28] and specifically about inclusion of people with dementia in research,[29] reported exclusion of residents with dementia due to safety concerns. A randomized controlled trial described a low recruitment rate, related to family representatives' fear of harm.[30] In the feasibility study reported in **Chapter 7**, no such reluctance was observed, as all approached family repre-

sentatives and residents provided consent. Nevertheless, the reporting of adverse events in the literature is in general insufficient for a robust risk evaluation.[19,28,31] In the feasibility study all nine adverse events potentially linked to the intervention concerned fatigue. While fatigue can be a limiting factor for older adults,[32] in this case it raises the question of whether it should be classified as an adverse event or rather as a normal physiological response to physical exertion.[33] Previous research indicates that nursing home residents with dementia may value challenging exercise; this is exemplified by the subtitle "*While it's tough, it's useful*" of a qualitative study exploring exercise experiences in this population.[34] In the feasibility study, no additional interviews were conducted to determine whether the reported fatigue was perceived as an acceptable, or even pleasant, consequence of exercise, or as a limiting and potentially harmful effect.

***Exercise dosage***

In the feasibility study (**Chapter 7**), compliance with exercise intensity, defined as "whether participants exercised at the prescribed intensity",[21] was not formally assessed. This represents a methodological limitation, as exercise intensity, in combination with session frequency, reflects the dosage and is a strong determinant of beneficial outcomes.[35] Although supervisors used physical performance test data to target moderate-to-high intensity exercise, no systematic monitoring of compliance with the intended dosage was undertaken. In other studies explicitly designed to achieve high-intensity exercise, such compliance has indeed been assessed.[22,23] However, compliance was typically estimated by supervisors, similar as the study procedures of the feasibility study, and not by an instrument to measure perceived exertion such as the Borg scale[36] or an objective instrument such as heart rate monitoring .



## Collaboration of physiotherapists with informal caregivers and healthcare professionals

***Collaborating with Informal Caregivers***

While the foundational scope of physiotherapy and its emphasis on exercise is well established, [37,38] the study in **Chapter 3** found that physiotherapists in the Netherlands contribute not only through structured exercise programs but also by coaching other healthcare professionals and by providing education and support to informal caregivers. Collaboration with informal caregivers is an essential, and very much appreciated (**Chapter 4**) component of physiotherapy in dementia care. Family involvement in physiotherapy can have notable advantages. It can provide valuable background information about the residents' history,[17] e.g with respect to participation in sports and physical activity. Family members could also support exercises when the physiotherapist is not present, provided that these are safe without an expert present. In a broader context, family-supported exercise programs in transitional care from hospital to home have been effective, showing

an increase daily step counts.[39] However, the nursing home setting might also be a more challenging context for collaboration in comparison with community of transitional care settings. Informal caregivers are frequently exhausted by the lead-up to nursing home placement of their loved one.[40,41] Following a resident's admission to a nursing home or long-term care facility, there often appears to be a shift in the locus of responsibility for care. Literature on nursing home care has noted that staff members may perceive themselves as the primary caregivers, while family members are sometimes regarded as intrusive or disruptive.[42–44] This dynamic was also reflected in the findings of **Chapter 3**, where 95% of physiotherapists reported providing advice to other healthcare professionals, yet only 57% reported providing advice to family caregivers.

***Collaboration among health care professionals***

Examples of topics where physiotherapists are coaching other healthcare professionals are the appropriate use of mobility aids or the prevention of falls. This contribution has been identified as a physiotherapy service with benefits for both the individual resident and the broader care system.[7,26] The importance of multidisciplinary collaboration is formally acknowledged in the competency guidelines for physiotherapists working with people with dementia.[27] Nevertheless, these guidelines predominantly emphasize aspects that have a direct or immediate impact on the resident. Broader systemic benefits, such as enhanced interdisciplinary communication or other indirect improvements of the quality of care, are less frequently addressed. Indeed, a 2019 systematic review on physiotherapy in nursing homes identified only two studies that clearly described the specific interventions delivered by physiotherapists in this setting, both of which focused solely on resident-centered goals: pain management and pressure ulcer prevention.[1]

## Qualitative interview study design

In **Chapters 4, 5 and 6** qualitative methods were employed with interviews with informal caregivers, residents and professionals (physiotherapists and managers), respectively. It was decided to interview the various stakeholder groups separately. Specifically, the decision to conduct the interview studies **(Chapter 4 and 5)** with informal caregivers residents independently of one another was based on several considerations: the risk that participants with dementia might be overshadowed by their informal caregivers,[45] the possibility that participants with dementia might feel unable to express themselves freely in the presence of their caregiver,[46] and the methodological differences in approaching the two participant groups. From a methodological standpoint it was further decided not to interview residents with dementia during a period when COVID-19 restrictions were still frequently being tightened. Conducting interviews digitally, while wearing face masks, or under visiting limitations was deemed unfeasible. In **Chapter 6**, interviews with physiotherapists and managers were held about the barriers and facilitators for family involvement. The decision to interview professionals separately, rather than in combination

with informal caregivers or residents, was motivated by both practical and methodological considerations. First, professionals were expected to share perspectives related to organizational processes, professional responsibilities, and interprofessional collaboration, which could differ substantially from the lived experiences of informal caregivers and residents. Conducting these interviews separately allowed participants to speak freely about sensitive topics such as institutional constraints, workload, or disagreements with families, without the risk of social desirability bias or conflict in a mixed group.[47] Although focus groups with all stakeholders together might have yielded rich interactive data, this design was considered less appropriate in the context of the research objectives and ethical considerations regarding power dynamics and confidentiality.[48]

With respect to the interviewers, the interviews with the caregivers were conducted by students, while in the other two studies they were conducted by physiotherapists. We recognized that the physiotherapy background of the interviewer in **Chapter 6** had a considerable influence on the interpretation of the data. For that reason, in contrast to the generic thematic analysis founded in realist ontology approach employed in the studies described in **Chapters 4 and 5**, we deliberately chose to apply a reflexive thematic analysis for the study in **Chapter 6**, in which the researcher's perspective and background are acknowledged as playing an active role in the analytic process, and potential biases arising from the researchers background are more thoroughly evaluated.[49]



## Generalizability of the study results

All data presented in **Chapters 3 through 6** were collected in the Netherlands. With regard to the participants in **Chapters 4 and 6**, the average age and proportion of female participants are comparable to those reported in a previous international study involving physiotherapists and experts working in nursing homes,[27] as well as in an interview study involving residents with dementia participating in an exercise intervention from Sweden.[34] Although the results are thus likely to be generalizable to nursing homes in other settings, the specific long-term care landscape in The Netherlands may differ substantially from that of many other countries. Dutch long-term care is characterized by a relatively large amount of formal care provision and relatively high healthcare expenditures. Moreover, the availability of nursing home care reimbursed through public health insurance is relatively unique to the Dutch context,[50] and The Netherlands has been acknowledged as a pioneer in long-term care provision.[51] As such, some of the findings from our studies may not be directly generalizable to countries with different long-term care systems.

# Recommendations

## Recommendations for research

A recent scoping review reported that only 0.6% of physiotherapy research published over the past decade has focused on individuals with dementia.[52] Given that more than 5% of the global population is affected by dementia,[53] and considering its status as a leading cause of disability and dependency globally, the limited volume of physiotherapy research in this area seems disproportionate and highlights a gap in the literature. A first recommendation for future research is to conduct clinical trials on physiotherapist-supervised interventions that align with physical activity recommendations as outlined in expert guidelines.[4,5,8] The pilot study described in **Chapter 7** serves as a first step towards such an approach. To improve replicability and facilitate cross-study comparison, future research should include a clear and detailed description of the setting, including organizational context, staffing structure, and care routines. In addition, a comprehensive characterization of the study population is essential, in order to better understand who benefits most from specific interventions. Consensus on the minimum set of core characteristics of the population that should be recorded with every clinical trial is needed in that respect. To ensure that interventions can be accurately replicated and evaluated, the use of the TIDieR (Template for Intervention Description and Replication)[54] framework is recommended, which provides a standardized format for reporting the essential components of complex interventions. These components include the content, delivery mode, frequency, intensity, tailoring, and fidelity of the intervention. Additionally, a standardized set of appropriate outcome measures for exercise and physical rehabilitation studies involving nursing residents with dementia is needed. Apart from outcomes reflecting effectiveness, such as mobility, performance in activities of daily living, or quality of life. Such a set should also include measures of safety, in particular possible adverse events. In addition, standardization of implementation-related outcomes (e.g., feasibility, fidelity, acceptability, adverse events) The latter type of measures is very relevant to speed up the process of the translation of research findings to daily practice. From that perspective, the consideration of a hybrid implementation-effectiveness study design[55] should be considered in the conceptional phase of each clinical trial.

Another recommendation is to explore further how physiotherapists contribute not only to the direct care of residents with dementia, but can also support the broader care network around them, including family caregivers and other professionals. As highlighted in this thesis, physiotherapists also play an important role in educating caregivers, coaching staff, and supporting interdisciplinary collaboration. Given the growing recognition of the value of integrative and network-based approaches in dementia care, future research should further investigate and define these broader roles of physiotherapists within the care system.

## Ethical considerations

In research practice, individuals with dementia are still frequently excluded from study participation in exercise trials.[2,56,57] Conducting research involving individuals with dementia is subject to rigorous ethical scrutiny, a practice that is undoubtedly rooted in the intention to protect this vulnerable population.[58] Despite these challenges, it is essential to emphasize the importance of conducting research in populations where the potential benefit is greatest.[18] This implies that studies should not necessarily be conducted first in populations without cognitive impairment, but rather where the clinical relevance and impact are most significant. Moreover, the interview study with residents included in this thesis makes it clear that their perspectives, and not only those of informal caregivers and health professionals can and should be considered with the design of the future interventions and their evaluation. In fact, active involvement of patient and public in research is more and more advocated and the reporting of their contribution should be in line with current reporting guidelines.[59]



## Recommendations for current practice

As described throughout this thesis and supported by international physical activity guidelines,[4,5,8] the physiotherapist is considered the expert in movement and mobility within the context of elderly care, including care provided in nursing homes and for residents with dementia. With the fairly recent introduction of movement specialists (*bewegingsagogen*) in long-term care and the upcoming presence of other professions such as personal trainers or exercise physiologists, the number of professionals focusing on movement, physical activity and exercise is increasing. Nevertheless, physiotherapists possess specific competencies to treat individuals with various illnesses and complex disabilities. Those specialized in geriatrics also have particular expertise in working with people with dementia, their families, and the care systems around them. Based on the findings of this thesis, we recommend that these competencies of the physiotherapist will be more explicitly propagated and utilized, including the consideration of a leading role of the physiotherapist in policy development related to physical activity on the organizational level. Such a role includes establishing structured collaborations of physical therapists with formal care professionals and informal caregivers and residents. In doing so, physiotherapists can apply their expertise to advise a wider range of individuals, thereby indirectly extending the reach of movement-related guidance to more residents.

## Recommendations for education

A recent study showed that 59% of Bachelor's and Master's-level physiotherapy curricula in Ireland, the UK and New-Zealand dedicate no more than three hours in total to the topic of dementia care.[60] Dementia is major causes of disability and dependency among older people in primary care and nursing home care, and thus constitute a significant proportion of elderly patients in demand of physiotherapy.[61] Despite this significant

clinical demand, many physiotherapists report feeling inadequately prepared by their basic education to work effectively with this population,[60,62] which may contribute to the development of negative attitudes towards treating people with dementia.[63] This lack of preparedness may partially explain why residents with dementia receive less physiotherapy than their cognitively intact counterparts in nursing homes.[64,65] Similar concerns have been raised internationally, with multiple studies from Canada, [66] Ireland,[17] and Oceania[26,62] highlighting that current physiotherapy education insufficiently equips students to deliver competent and confident care to individuals with dementia.[18]

This raises concerns regarding whether people with dementia, both those living in the community and those residing in nursing homes, receive adequate physiotherapy. In the Netherlands, geriatric physiotherapists are the designated specialists with additional training in dementia-related disorders and their management.[67] There are approximately 1,600 registered geriatric physiotherapists in the Netherlands, all of whom have completed accredited postgraduate education.[68,69] Membership of the national professional society, however, is not mandatory, and there is no comprehensive overview of the sectors in which these physiotherapists are employed, nor of how individuals in need can readily identify and access their services. With approximately one geriatric physiotherapist available for every 1,000 older adults, the Netherlands ranks among the top 10 European countries in terms of workforce availability.[70] Internationally, considerable variation exists in educational programs, workforce capacity, and service provision for geriatric physiotherapy, which complicates direct comparisons both between and within countries.[70] Given the anticipated rise in demand for geriatric physiotherapy, strategic promotion and further development of this specialty are warranted.[71]

## Overall conclusion

In summary, the findings presented in this thesis indicate considerable variation in the delivery of physiotherapy, in particular exercise interventions, to nursing home residents with dementia. The studies in this thesis made it clear that for the future delivery and evaluation of such interventions, both the individual resident and the broader system of formal and informal caregivers should be involved. More research into the effectiveness and safety of such interventions, that should be appropriately dosed and employ all strategies known to enhance participation and adherence, is urgently needed. For the comparability and interpretation of the results of future studies, adherence with the relevant reporting guidelines is essential. Given the scarcity of studies in this area as a whole, funding bodies and relevant policy makers should prioritize research in this field. Eventually, the insights from this thesis may contribute to the development of effective,

evidence-based and person-centered physiotherapy practices for nursing home residents with dementia.

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# Chapter 9:

## Nederlandse samenvatting

Fysiotherapie, voornamelijk in de vorm van oefentherapie, wordt in westerse landen veel toegepast bij de behandeling van verpleeghuisbewoners met dementie.[1,2] Deze therapie is gebaseerd op bewijs dat aantoont dat lichaamsbeweging een positieve invloed kan hebben op hun welzijn.[3–5] Toch blijkt dat de fysiotherapeutische behandeling binnen de verpleeghuispopulatie sterk varieert, zonder bekende verklarende factoren die aan deze praktijkvariatie ten grondslag liggen.[6,7] Bovendien is er slechts beperkte kennis over de specifieke behoeften en voorkeuren van bewoners en hun mantelzorgers ten aanzien van de invulling van fysiotherapie. Met betrekking tot de inhoud en dosering van oefentherapie is ook onduidelijk of een door een fysiotherapeut begeleide oefeninterventie, uitgevoerd volgens (inter)nationale beweegrichtlijnen voor deze populatie, haalbaar is. Gezien deze kennishiaten richt dit proefschrift zich op de volgende onderzoeksvragen:

**Onderzoeksvraag 1:** Waaruit bestaat door fysiotherapeuten begeleide oefeninterventies voor verpleeghuisbewoners met dementie, wat is de effectiviteit, en welke contextuele factoren beïnvloeden de toepassing hiervan?

**Onderzoeksvraag 2:** Wat zijn de percepties, behoeften en voorkeuren van verpleeghuisbewoners met dementie, mantelzorgers en zorgprofessionals met betrekking tot fysiotherapie, bewegen en de onderlinge samenwerking?

**Onderzoeksvraag 3:** Wat is de haalbaarheid van een door een fysiotherapeut begeleide oefeninterventie voor verpleeghuisbewoners met dementie?

In de systematic review **(Hoofdstuk 2)** werden gerandomiseerde studies van oefeninterventies voor verpleeghuisbewoners met dementie, onder supervisie van fysiotherapeuten, geïdentificeerd via zes elektronische medische databanken. Van de 1.377 gevonden publicaties voldeden 6 studies, beschreven in 11 artikelen, aan de inclusiecriteria. De interventies varieerden sterk in type oefeningen, frequentie, intensiteit en duur. De therapietrouw was over het algemeen laag. Vanwege de heterogeniteit in studieopzet en uitkomstmaten, en de inconsistentie in de bevindingen, blijft de effectiviteit van deze interventies vooralsnog onduidelijk.

**Hoofdstuk 3** beschrijft een online vragenlijstonderzoek onder 109 fysiotherapeuten, ieder werkzaam in een afzonderlijk verpleeghuis, welke de structuur en het proces van fysiotherapie bij bewoners met dementie in Nederland in kaart brengt. Variaties werden gevonden in het wel of niet nodig hebben van een verwijzing door een arts voor het starten van fysiotherapie, en het gebruik van protocollen en richtlijnen. Er was meer consistentie in de samenstelling van multidisciplinaire teams. Procesmatig werden verschillen gezien in het gebruik van meetinstrumenten en het betrekken van mantelzorgers, echter was er meer overeenstemming over het type behandeling welke werd toegepast

en beoogde doelen. Naast behandeling aan bewoners gaven fysiotherapeuten ook scholing aan collega's en ondersteuning aan mantelzorgers. Al met al werd geconcludeerd dat er aanzienlijke variatie bestaat in de organisatie en uitvoering van fysiotherapie in Nederlandse verpleeghuizen, ondanks enkele consistente elementen.

**Hoofdstuk 4** behandelt een kwalitatief interviewonderzoek naar de percepties, behoeften en voorkeuren van mantelzorgers van bewoners met dementie. Dertien mantelzorgers werden geïnterviewd. Zij gaven aan weinig bekend te zijn met fysiotherapie en behoefte te hebben aan meer samenwerking. Individuele afstemming, empathische communicatie en plezierige, toegankelijke oefeningen werden als belangrijk aangemerkt. De conclusie was dat mantelzorgers behoefte hebben aan duidelijkere communicatie en grotere betrokkenheid, waarbij gezamenlijke besluitvorming en empathische interactie van belang zijn.

**Hoofdstuk 5** beschrijft de perspectieven van vijftien bewoners met lichte tot matige dementie. Zij zagen fysiotherapie vooral als middel om hun fysiek functioneren en zelfstandigheid te behouden. Hoewel supervisie tijdens de oefeningen belangrijk werd geacht, stonden zij open voor begeleiding door anderen dan fysiotherapeuten, mits veiligheid en kwaliteit gewaarborgd waren. Zij gaven de voorkeur aan terugkoppeling via de fysiotherapeut naar hun mantelzorgers, maar vonden dat hun naasten vaak te druk waren om te participeren in het uitvoeren van de behandeling. Het implementeren van de door de bewoners geuite voorkeuren rondom fysiotherapie en communicatie kan bijdragen aan betere therapietrouw, en bied perspectief voor een meer toezichthoudende rol voor de fysiotherapeut.

**Hoofdstuk 6** richt zich op belemmerende en bevorderende factoren voor familiebetrokkenheid bij fysiotherapie en bewegen, op basis van interviews met 19 fysiotherapeuten en 9 stafleden. Belemmeringen waren onder meer de ervaren extra belasting voor mantelzorgers en een soms weinig gastvrije organisatiecultuur. Bevorderende factoren waren actieve betrokkenheid door fysiotherapeuten, heldere informatie, eerdere positieve ervaringen en familiegerichte waarden van de mantelzorgers. De conclusie was dat duidelijke rolafspraken, flexibele aanpakken en inclusieve communicatie de samenwerking en betrokkenheid kunnen versterken.

In **Hoofdstuk 7** wordt een observationele pilotstudie naar de haalbaarheid van een oefeninterventie beschreven. De interventie bestond uit vier oefensessies per week gedurende tien weken: twee door fysiotherapeuten begeleide groepstrainingen (gericht op kracht en balans) en twee individuele aerobe sessies met een fietstrainer en virtuele route. Van de 59 gescreende bewoners namen er 11 deel. De therapietrouw was hoog (mediaan 92%), er traden geen ernstige bijwerkingen op en sessies werden doorgaans

positief beoordeeld. Uit ervaringen van begeleiders kwamen naar voren dat kennis van dementie en passende communicatie de deelname aan de sessies positief beïnvloede. Kleine aanpassingen dienen te worden gedaan in het wervingsproces, maar de interventie werd haalbaar bevonden.

## Reflectie op bevindingen en methodologische overwegingen

Uit dit proefschrift blijkt dat er slechts een beperkte hoeveelheid onderzoek beschikbaar is naar door fysiotherapeuten begeleide oefeninterventies voor verpleeghuisbewoners met dementie. De bestaande studies verschillen sterk in opzet, inhoud, en kwaliteit, waardoor conclusies over effectiviteit moeilijk te trekken zijn. Echter is er een brede bewijsbasis voor de positieve effecten van bewegen bij de algemene oudere populatie. Veel van deze bewijslast is echter gebaseerd op langdurige en preventieve studies. Voor de verpleeghuispopulatie zijn kortdurende, doelgerichte interventies met betekenisvolle uitkomsten relevanter, gezien de vaak palliatieve fase waarin bewoners verkeren.

De therapietrouw, de hoeveelheid gevolgde sessies in relatie tot het aantal beschikbare sessies, is indicatief voor de effectiviteit van een beweeginterventie. In veel eerdere studies was de therapietrouw beperkt, terwijl in de haalbaarheidsstudie beschreven in hoofdstuk 7 van dit proefschrift een hoge mate van therapietrouw (89%) werd bereikt. Dit kan mogelijk samenhangen met de nadruk op communicatie- en dementiespecifieke vaardigheden van de begeleiders. Deze bevinding onderstreept het belang van persoonsgerichte interactie voor fysiotherapie bij dementie, waarin relatieopbouw, communicatie en een veilige, betekenisvolle omgeving centraal staan.



Fysiotherapeuten zijn niet alleen behandelaar van de verpleeghuisbewoner, maar spelen ook een rol spelen in het coachen van collega's en het ondersteunen van mantelzorgers. De betrokkenheid van familie kan waardevol zijn, maar wordt in de praktijk vaak beperkt benut, mede door organisatorische cultuurverschillen en belasting van mantelzorgers.

## Generaliseerbaarheid van de resultaten

Ten aanzien van de generaliseerbaarheid geldt dat de resultaten grotendeels zijn verzameld in de Nederlandse context, die wordt gekenmerkt door relatief veel formele zorg en publieke financiering van verpleeghuiszorg. Hierdoor zijn de bevindingen waarschijnlijk deels overdraagbaar naar andere landen, maar dienen verschillen in zorgsystemen in beschouwing te worden genomen.

## Aanbevelingen voor onderzoek

Ondanks de wereldwijde hoge prevalentie van dementie is slechts 0,6% van het fysiotherapieonderzoek hierop gericht. Toekomstig onderzoek zou zich moeten richten op fysiotherapeutisch begeleide interventies die voldoen aan richtlijnen voor lichamelijke

activiteit, met duidelijke beschrijving van setting, populatie en interventiecomponenten (volgens gevalideerde structuur). Ook is standaardisatie van uitkomstmaten en implementatie-indicatoren noodzakelijk om vertaling naar de praktijk te versnellen. Daarnaast verdient de bredere rol van fysiotherapeuten in het ondersteunen van zorgnetwerken en interdisciplinair samenwerken verdere verkenning.

## Ethische overwegingen

Personen met dementie worden vaak uitgesloten van oefenstudies. Hoewel dit mede gebeurt vanuit bescherming van een kwetsbare groep, is het juist belangrijk onderzoek te doen in de populatie waar de klinische relevantie het grootst is. De voorkeur en mening van bewoners zelf moet nadrukkelijk worden meegenomen in ontwerp en evaluatie van interventies, in lijn met internationale richtlijnen voor patiënt- en publieksbetrokkenheid in onderzoek.

## Aanbevelingen voor de praktijk

Fysiotherapeuten beschikken over unieke expertise in bewegen en mobiliteit bij ouderen en mensen met complexe aandoeningen, inclusief dementie. Het verdient aanbeveling deze competenties explicieter te benutten en de fysiotherapeut een leidende rol te geven in beleidsontwikkeling rondom bewegen in verpleeghuizen. Daarbij horen gestructureerde samenwerkingen met formele zorgprofessionals, mantelzorgers en bewoners.

## Aanbevelingen voor onderwijs

Internationaal wordt slechts beperkte aandacht besteed aan dementiezorg in fysiotherapieopleidingen. Dit draagt bij aan gevoelens van onvoldoende voorbereiding en soms negatieve attitudes bij fysiotherapeuten. In Nederland zijn geriatriefysiotherapeuten met gespecialiseerde postacademische scholing beschikbaar, maar inzicht in toegankelijkheid en inzetbaarheid ontbreekt. Gezien de verwachte toename in zorgvraag is verdere profilering en ontwikkeling van dit specialisme noodzakelijk.

## Conclusie

Dit proefschrift laat zien dat er aanzienlijke variatie bestaat in de invulling van fysiotherapie, in het bijzonder oefeninterventies, voor verpleeghuisbewoners met dementie. Toekomstige interventies en evaluaties dienen zowel de individuele bewoner als het bredere zorgsysteem te betrekken. Meer onderzoek naar effectiviteit van interventies is dringend nodig, waarbij gestandaardiseerde rapportage en uitkomstmaten essentieel zijn. Beleidsmakers en financiers zouden dit onderzoeksgebied moeten prioriteren. De inzichten uit dit proefschrift kunnen bijdragen aan de ontwikkeling van effectieve, evidence-based en persoonsgerichte fysiotherapie voor verpleeghuisbewoners met dementie.

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# Chapter 10:

## List of publications, Curriculum Vitae, Dankwoord

## List of publications

**Dennis Boer**, Charlotte Schmidt, Thea Vliet Vlieland. Fysiotherapeutische interventies voor verpleeghuisbewoners met dementie: een umbrella review. *Nederlands Tijdschrift voor Geriatriefysiotherapie. 2021;3: 8-25 Dutch*

**Boer DE**, Sterke S, Schmidt CB, Vliet Vlieland TPM. The perceptions, needs and preferences of informal caregivers of nursing home residents with dementia regarding physical therapy: A qualitative study. *Geriatr Nurs*. 2022;44:167-175.

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**Boer D**, Schmidt C, Sterke S, van Bodegom-Vos L, Vliet Vlieland T. Novel barriers and facilitators were identified for family involvement in physiotherapy and exercise for aged care facility residents with dementia: a qualitative study. *J Physiother. 2026;72(1):62-67*.

**Boer D**, Winkler B, Schmidt C, Sterke S, Achterberg W, Vliet Vlieland T. A 10-week physical therapist-supervised exercise program for nursing home residents with dementia: a single arm, observational feasibility study. *J Aging Res Lifestyle.* 2025;14.

## Presentations and abstracts

**Boer DE**, Sterke S, Schmidt CB, Vliet Vlieland TPM. The perceptions, needs and preferences of informal caregivers of nursing home residents with dementia regarding physical therapy: A qualitative study. *Poster presentation at the International Nursing Home Congress, Toulouse, France, June 2022*

**Boer DE**, Sterke S, Schmidt CB, Vliet Vlieland TPM. The perceptions, needs and preferences of informal caregivers of nursing home residents with dementia regarding physical

therapy: A qualitative study. *Poster presentation at the annual meeting of Samenwerkende Academische Netwerken Ouderenzorg (SANO) Wetenschapsdag, Oegstgeest, the Netherlands, September 2022*

**Boer D**, Schmidt C, Sterke S, Schoones J, Elbers R, Vliet Vlieland T. Characteristics and Effectiveness of Physical Therapist-Supervised Exercise Interventions for Nursing Home Residents With Dementia: A Systematic Review. *Poster presentation at the Academic Nursing Congress (Academische verpleegkunde congress) Leiden, the Netherlands, June 2023*

**Boer D**, Nibbering R, Schmidt C, Sterke S, Sizoo E, Achterberg W, Vliet Vlieland T. Exploring the physiotherapy and exercise needs and preferences of nursing home residents with dementia: A qualitative study. *Poster presentation and lightning round oral presentation at the annual European Geriatric Medicine Society (EuGMS) congress, Valencia, Spain, September 2024*

**Boer D,** Schmidt S, Sterke S, Van Bodegom-Vos L, Achterberg W, Vliet Vlieland T. Barriers and facilitators of family involvement in physiotherapy and exercise for nursing home residents with dementia: a qualitative study. *Oral presentation at the annual Dutch Geriatric Physiotherapy Congress (NVFG Congres), Soesterberg, the Netherlands, October 2024*

**Boer D**, Nibbering R, Schmidt C, Sterke S, Sizoo E, Achterberg W, Vliet Vlieland T. Exploring the physiotherapy and exercise needs and preferences of nursing home residents with dementia: A qualitative study. *Poster presentation at the annual Dutch Dementia Research Congress, Utrecht, the Netherlands, November 2024*

**Boer D**, Nibbering R, Schmidt C, Sterke S, Sizoo E, Achterberg W, Vliet Vlieland T. Exploring the physiotherapy and exercise needs and preferences of nursing home residents with dementia: A qualitative study. *Poster presentation at the autumn meeting of the autumn meeting of the British Geriatric Society (BGS), London, England, November 2024*

**Boer D,** Schmidt S, Sterke S, Van Bodegom-Vos L, Achterberg W, Vliet Vlieland T. Barriers and facilitators of family involvement in physiotherapy and exercise for nursing home residents with dementia: a qualitative study. *Oral presentation at the Leiden International (Bio)Medical Student Conference, Leiden, the Netherlands, May 2025*

**Boer D**, Winkler B, Schmidt C, Sterke S, Achterberg W, Vliet Vlieland T. A 10-week physical therapist-supervised exercise program for nursing home residents with dementia: a single arm, observational feasibility study. *Oral presentation at the Leiden International (Bio)Medical Student Conference, Leiden, the Netherlands, May 2025*

## Curriculum Vitae

Dennis Boer werd geboren op 23 oktober 1987 in Gouda. Na het behalen van zijn Havo-diploma aan het Sint Antoniuscollege in Gouda begon hij in 2006 met de opleiding Fysiotherapie aan de Hogeschool Rotterdam. In 2011 rondde hij deze Bacheloropleiding succesvol af. Sinds 2011, kort na het behalen van zijn bachelordiploma, is hij werkzaam als geriatriefysiotherapeut bij zorgorganisatie Kennemerhart, locatie De Molenburg. In September 2015 startte hij een vervolgstudie aan de SOMT University of Physiotherapy in Amersfoort, waar hij in 2018 de Master Fysiotherapie in de Geriatrie behaalde.

In 2019 startte hij, op initiatief van dr. John Verhoef, destijds lector Eigen Regie bij Fysiotherapie en Beweegzorg aan Hogeschool Leiden, een systematisch literatuuronderzoek naar de effectiviteit van oefentherapie voor verpleeghuisbewoners met dementie. Het onderzoek kreeg een vervolg en hij werd lid van de kenniskring van het lectoraat, onder leiding van lector Dr. Petra Siemonsma. In Maart 2022 startte Dennis, naast zijn werk als geriatriefysiotherapeut, zijn promotietraject bij het Leids Universitair Medisch Centrum, afdeling Orthopaedie, Revalidatie en Fysiotherapie en bij Kennemerhart, onder begeleiding van prof. dr. Thea Vliet Vlieland, dr. Charlotte Schmidt (Kennemerhart) en dr. Shanty Sterke (zorgorganisatie Aafje).



Van maart 2022 tot augustus 2025 was Dennis, naast zijn werk als geriatriefysiotherapeut, de uitvoerende onderzoeker van de in dit proefschrift beschreven studies naar de bewijskracht, huidige praktijk en de voorkeuren van alle betrokkenen ten aanzien van fysiotherapie voor verpleeghuisbewoners met dementie. Hij was verantwoordelijk voor het coördineren en plannen van de onderzoeken, het verzamelen en analyseren van de gegevens en het begeleiden van zowel de deelnemende patiënten als fysiotherapeuten en studenten van de opleiding fysiotherapie. De resultaten werden verwerkt tot wetenschappelijke artikelen en abstracts, en hij presenteerde zijn onderzoek op meerdere nationale en internationale congressen en bij verschillende zorgorganisaties in Nederland.

# Dankwoord

*"If you want to go fast, go alone. If you want to go far, go together"*

Dit proefschrift is geen individuele prestatie geweest, maar het resultaat van vele ontmoetingen, gesprekken, steun en gezamenlijke inspanningen. Ik wil graag mijn dank uitspreken aan iedereen die heeft bijgedragen aan dit werk, in het bijzonder een aantal mensen.

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Thea, dank voor je vertrouwen vanaf het begin in een traject dat in zekere zin buiten de gebaande paden van een PhD-student lag. Ik heb altijd het gevoel gehad dat mijn academisch en persoonlijk welzijn jouw hoogste prioriteit had. Je stond altijd voor mij klaar, ondanks de uitdagingen waar je zelf mee te maken had.

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