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Exercise and team rehabilitation in older people with dementia: applicability, motivation and experiences

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“Utan tvivel är man inte klok”

Tage Danielsson

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Abstract

The world's population is aging. With the growing population of older people, dementia disorders are becoming increasingly common. Dementia disorders are progressive and include impairments in cognitive and physical function, which lead to increased risks of inactivity, falls, fractures, and comorbidity. Dementia is also the leading cause of dependency in activities of daily living. Therefore, rehabilitation including exercise is needed for this population. To obtain optimal effects on the functional ability of older people, exercise should be task specific, functional, performed at high intensity at sufficient frequency and duration, and include both balance and strength training. Motivation to participate is important for exercise program participation, the fulfillment of exercise recommendations and facilitation of motor learning in order to achieve exercise response. However, exercise recommendations for older people are based mainly on findings from studies conducted with people without dementia. Exercise may be challenging for some people with dementia due to complicating symptoms, such as cognitive deficits, depression, apathy or lack of motivation, and behavioral and psychological symptoms of dementia (BPSD). Studies exploring the applicability of exercise programs have been called for to optimize exercise programs; knowledge about motivation is lacking, and how this together influences exercise response in this group. Additionally, dementia disorders significantly affect all aspects of life for the affected persons and their informal caregivers, friends, and family members in their immediate networks. Furthermore, the care and rehabilitation needs of community-dwelling people with dementia must be considered due to the decreasing proportion of nursing home residents in Sweden today. Scientific knowledge and clinical experiences regarding the use of interdisciplinary team rehabilitation for people with dementia are limited, despite the urgent need for rehabilitation and its proven effects after events such as hip fracture. The effects of person-centered multidimensional interdisciplinary rehabilitation programs for people with dementia, including education and counseling for informal primary caregivers, have not been evaluated and need to be explored.

The overall aim of the thesis was to evaluate exercise and team based rehabilitation among older people with dementia. Specifically, the objectives were to evaluate motivation to participate in and applicability of a high-intensity functional exercise program, and to explore participants' experiences with a multidimensional interdisciplinary team rehabilitation program including high-intensity functional exercise, among older people with dementia.

In the Umeå Dementia and Exercise (UMDEX) study, a cluster-randomized controlled trial including 186 people with dementia in nursing homes, the effects of the High-Intensity Functional Exercise (HIFE) Program and a seated social activity, both lasting for 45 minutes and held five times fortnightly for 4 months, were compared. Participants' motivation to go to activity sessions and motivation during sessions were assessed using a five-point Likert scale. The applicability of the exercise program (with regard to attendance, achieved intensity, and adverse events) was assessed with a focus on dementia type and

reasons for non-attendance and for not achieving high intensity, based on exercise diary data. Balance exercise response was investigated using the Berg Balance Scale, assessed at baseline and 4 month follow-up. In the Multidimensional Interdisciplinary Rehabilitation in Dementia (MIDRED) study, a randomized controlled study, a person-centered multidimensional interdisciplinary rehabilitation program for community-dwelling older people with dementia, including education and counseling for informal primary caregivers, was evaluated. With the aim of exploring experiences with program participation, 16 participants with dementia were interviewed and data were analyzed using qualitative content analysis.

The UMDEX study showed that motivation during activities was quite high, with no overall difference between groups; over time, however, motivation increased in the exercise group and decreased in the social activity group. Motivation during activity sessions was greater than motivation to go to sessions in both groups. The exercise program was applicable, with high attendance rates, moderate to high intensity achieved, and the occurrence of only minor and temporary adverse events. Dementia subtype, low motivation, pain, and presence of BPSD seemed to affect applicability. The exercise response varied widely, with many participants showing improved balance after the intervention. The applicability of the exercise program and motivation did not seem to be associated with paramount balance response. Four categories emerged from the MIDRED study analysis: being empowered through challenges; gaining insight, motives and rising concerns about the future; to participate is worthwhile, if you are seen; and togetherness in prosperity and adversity.

In conclusion, for older people with dementia living in nursing homes, who have a high prevalence of medical conditions and functional limitations, motivation to participate in a high-intensity exercise program was high and did not differ from motivation to participate in a less physically demanding social activity. The exercise program seems to be applicable with regard to attendance, achieved intensity, and adverse events. The prediction of balance exercise response based on program applicability and participant motivation does not seem to be possible. The promotion of strategies to encourage people with dementia to join exercise groups is of great importance, and more knowledge about strategies is needed to overcome low pre-exercise motivation levels. An interdisciplinary rehabilitation program for community-dwelling older people seems feasible, according to reported experiences. The participants had positive experiences and perceived improvement and empowerment due to the rehabilitation, which can influence well-being in daily life in this population. The results of this research support the inclusion of this population in team rehabilitation and high-intensity functional exercise programs.

Sammanfattning på svenska

Världens befolkning blir allt äldre. Den ökade äldre befolkningen leder till att demenssjukdom blir allt mera vanligt. Demenssjukdomen är progressiv och förutom nedsättning av den kognitiva förmågan orsakar sjukdomen bland annat nedsättningar i fysisk förmåga. Detta ökar i sin tur risken för inaktivitet, fall och frakturer. Bland äldre personer runt om i världen är demens dessutom den största orsaken till beroende i aktiviteter i dagliga livet. Till följd av detta finns ett stort behov av rehabilitering och träning för denna grupp. För att äldre personer ska erhålla bästa effekt på fysisk förmåga ska träningen vara uppgiftsspecifik, funktionell och utförd med hög intensitet. Vidare skall den innehålla både balans- och styrketräning och genomföras under tillräcklig lång tidsperiod. Motivation till träning kan vara viktigt för att fullfölja dessa träningsrekommendationer och för att underlätta motorisk inläring. Träningsrekommendationerna för äldre personer är dock främst baserade på personer utan demens. Att delta i träning kan hos personer med demens vara svårt på grund av komplicerande symtom, såsom kognitiva nedsättningar, depression, apati (avsaknad av motivation), samt beteendemässiga och psykologiska symtom vid demens (BPSD). Därför efterfrågas studier som utvärderar genomförande av träning hos olika grupper av personer med demens. Det saknas även kunskap om motivation till träning och hur detta påverkar effekten av träning i denna grupp. Demens påverkar alla delar av vardagen för den som har sjukdomen, men även för familj och vänner. Personer med demens bor i dag i ordinarie boende i större utsträckning till följd av minskat antal särskilda boenden, vilket lägger en stor börda på närstående. Interdisciplinär teamrehabilitering kan vara en framgångsrik väg för att bibehålla bästa möjliga förmåga och kunna leva ett innehållsrikt liv tillsammans med sina närstående. Kunskap och erfarenhet är begränsad, trots stora behov och visad effekt vid till exempel höftfraktur. Rehabilitering för hemmaboende personer med demens och deras närstående behöver därför undersökas.

Syftet med avhandlingen var att undersöka träning och teamrehabilitering för äldre personer med demens; mer specifikt att utvärdera motivation att delta och genomförande av ett högintensivt funktionellt träningsprogram, samt att undersöka upplevelserna av att delta i ett interdisciplinärt rehabiliteringsprogram hos äldre personer med demens.

Denna avhandling innehåller resultat från två studier. Effekterna av fysisk träning hos personer med demens i särskilda boenden undersöktes i en randomiserad kontrollerad studie (UMDEX-studien) som omfattande 186 deltagare. Deltagarna lottades till att delta i ett högintensivt funktionellt träningsprogram (HIFE-programmet) eller till en sittande social aktivitet. Båda aktiviteterna utfördes 2-3 ggr per vecka i 4 månader och leddes av fysioterapeuter respektive arbetsterapeut/arbetsterapibiträde. Deltagarnas motivation innan och under aktiviteterna skattades med en femgradig skala. Genomförandet av träningsprogrammet avseende närvaro, intensitet, och obehag, samt orsaker att inte ha deltagit eller inte kunnat träna med hög intensitet registrerades genom träningsdagbok som fylldes i av ledarna. Träningseffekten på balansförmågan mättes med Bergs balansskala före och efter interventionen. Ett interdisciplinärt

rehabiliteringsprogram för hemmaboende personer med demens med stöd även till närstående studerades i en annan randomiserad kontrollerad studie (MIDRED-studien). Rehabiliteringen utfördes av många olika professioner utifrån deltagarnas individuella målsättningar och inkluderade träning enligt HIFE-programmet i grupp. Sexton personer som deltagit i den individanpassade rehabiliteringen under 16 veckor intervjuades om sina upplevelser av att delta i rehabiliteringen.

I studien på särskilda boenden var motivationen under träningen respektive den sociala aktiviteten generellt hög utan signifikant skillnad mellan grupperna. Motivationen ökade över tid i träningsgruppen medan den minskade i den sociala aktiviteten. Motivationen inför aktiviteterna var lägre än under aktiviteterna. Vidare visar resultaten att träningsprogrammet var genomförbart med hög närvaro, medel till hög intensitet i balans och styrkeövningarna samt att de uppkomna obehagen var små och tillfälliga. Demenstyp, låg motivation, och BPSD föreföll att kunna påverka genomförandet av träningsprogrammet. Det var många som förbättrade sin balans under träningsperioden, men en stor variation i effekt på balansförmåga sågs. Genomförandet av träningsprogrammet samt motivation under träningen verkade inte vara associerat med effekten på balansförmåga. I intervjuer med deltagare i det interdisciplinära rehabiliteringsprogrammet framkom att de erhållit bemyndigande genom utmaningarna i rehabiliteringen. Vidare framkom att rehabiliteringen gav dem insikter och drivkrafter, men också oro inför framtiden. Deltagarna berättade att det kändes värdefullt att delta i programmet, men betonade också vikten av att bli sedd och bekräftad. Träningsgruppen de deltagit i under rehabiliteringen skildrades som samhörighet i med och motgång.

Sammanfattningsvis visar avhandlingen att hos äldre personer med demens i särskilda boende, vilka har stora nedsättningar i förmåga och multisjuklighet, kan motivationen att delta i ett högintensivt funktionellt träningsprogram vara hög och jämförbar med en social aktivitet. Träningsprogrammet går bra att genomföra avseende på närvaro, intensitet och obehag. Balansen kan förbättras av träningsprogrammet, men det går inte att i förväg förutsäga effekten utifrån genomförande och motivation. Ett interdisciplinärt rehabiliteringsprogram för hemmaboende äldre personer med demens verkar genomförbart utifrån deltagarnas egna erfarenheter. Deltagarna hade positiva erfarenheter och upplevde förbättringar i dagligt liv. Denna typ av rehabilitering har möjlighet ge bemyndigande och att påverka välbefinnande i vardagen i denna grupp. Resultaten av avhandlingen stödjer inkludering av personer med demens i teamrehabilitering och högintensiv funktionell träning.

Abbreviations

| | |
|-----------|---|
| AD | Alzheimer´s disease |
| ADL | activities of daily living |
| BBS | Berg Balance Scale |
| BPSD | behavioral and psychological symptoms of dementia |
| CGA | Comprehensive Geriatric Assessment |
| CI | confidence interval |
| DLB | dementia with Lewy bodies |
| DSM-IV-TR | Diagnostic and Statistical Manual of Mental Disorders, 4 th edition, text revision |
| FOPANU | Frail Older People – Activity and Nutrition Study in Umeå |
| GDS-15 | 15-item Geriatric Depression Scale |
| HIFE | High-Intensity Functional Exercise |
| ICF | International Classification of Functioning, Disability and Health |
| IQR | interquartile range |
| MDC | minimal detectable change |
| MET | metabolic equivalent |
| MIDRED | Multidimensional InterDisciplinary Rehabilitation in Dementia |
| MMSE | Mini-Mental State Examination |
| non-AD | non-Alzheimer´s type of dementia |
| NPI | Neuropsychiatric Inventory |
| OR | odds ratio |

| | |
|---------------------|-----------------------------|
| OT | occupational therapist |
| PT | physiotherapist |
| RCT | randomized controlled trial |
| RM | repetition maximum |
| ROM | range of motion |
| SD | standard deviation |
| SDT | self-determination theory |
| UMDEX | Umeå Dementia and Exercise |
| VO ₂ max | maximal oxygen uptake |

Original papers

The thesis is based on the following papers, which will be referred to in the text by their roman number:

- I.** Motivation to participate in high intensity functional exercise compared to a social activity in older people with dementia in nursing homes. Sondell A, Rosendahl E, Nilsson Sommar J, Littbrand H, Lundin-Olsson L, Lindelöf N. *PloS One*. 2018;13(1)e0206899
- II.** The applicability of a high-intensity functional exercise program among older people with dementia living in nursing homes. Sondell A, Rosendahl E, Gustafson Y, Lindelöf N Littbrand H. *J Geriatr Phys Ther*. 2019;42(4):E16-E24
- III.** Is the effect of High-Intensity Functional Exercise Program on functional balance influenced by motivation and applicability among older people with dementia in nursing homes? Sondell A, Littbrand H, Holmberg H, Lindelöf N, Rosendahl E. *J Nutr Health Aging*. 2019; 23(10):1011-1020.
- IV.** Experiences in community-dwelling older people with dementia on participating in a multidimensional interdisciplinary rehabilitation program. Sondell A, Lampinen J, Conradson M, Englund U, Littbrand H, Nilsson I, Lindelöf N. Manuscript

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Introduction

Aging

The world's population is aging; the number and proportion of older people in the population are growing in virtually all countries¹. Today, for the first time in history, most people can expect to live into their 60s and beyond². Between 2015 and 2050, the number of people aged ≥ 60 years is projected to more than double from 901 million, reaching nearly 2.1 billion¹. The number of people aged ≥ 80 years, the "oldest old," is growing even faster than is the number of older persons overall. In 2015, 125 million (14%) people were aged ≥ 80 years; this number is projected to triple to 434 million (20%) by 2050¹. In Sweden, the number of people aged ≥ 80 years will increase by 50% by 2028³. Globally, during 2010–2015, women lived an average of 4.5 years longer than men; women accounted for 54% of the global population aged ≥ 60 years and 61% of those aged ≥ 80 years in 2015¹.

Consequences

At the physiological level, aging is associated with the accumulation of a variety of molecular and cellular damage affecting a broad range of tissues, organ systems, and functions. Over time, this damage leads to gradual declines in physiological reserves, increased risks of many diseases, and general declined capacity². Age-related reductions in maximal oxygen uptake (VO_2 max, the maximum amount of oxygen that a person can utilize during intense exercise) and muscle strength leads to that older people are often required to exert greater percentages of their maximal capacity at submaximal exercise loads⁴. According to an Australian longitudinal study, women reach the disability threshold (indicating when a person requires assistance in daily activities) at the average age of 79 years⁵. Globally, people lost an average of approximately 9 years of healthy life due to disability in 2013¹. However, older populations are characterized by great diversity with respect to health and well-being^{1,2}. These diverse needs of older people are best viewed as a continuum of functioning, as the range of physical functioning is far broader in old age than at younger ages. Although some of the diversity seen in older age reflects genetic inheritance, most arises from lifestyle and environmental factors and the presence of disease. The physiological changes that occur over time are neither linear nor consistent, and are only loosely associated with chronological age^{2,5}, although the rate of functional decline increases with age at the group level⁵. Most health problems in older age are results of chronic diseases, particularly non-communicable diseases (which result from combinations of genetic, physiological, environmental, and behavioral factors and are of long duration), including heart disease, stroke, respiratory disorders, cancer, and dementia². Many of these diseases can be delayed or even prevented by engaging in healthy behaviors, such as physical activity and good nutrition, which can have powerful benefits for health and well-being².

The consequences of aging also involve psychological factors. The relationship between psychological well-being and age is U shaped, with the lowest levels occurring in middle age in most western countries⁶. However, the relationship between physical health and well-being is bidirectional. Older people with diseases show increased depressed mood and impaired well-being, which intensify progressively with the number of comorbidities. Well-being is also associated with longer survival among older people⁶.

Although the aging process varies among individuals, increased age is associated with the deterioration of physical function⁷, cognitive decline, dependency in activities of daily living (ADL)⁸, and multimorbidity⁹, including with dementia¹⁰. It is important to address physical inactivity in older people, with particular focus on age-related and disease-related disuse, such as the loss of muscle strength and function seen in sarcopenia¹¹. The consequences of sarcopenia are serious and life changing; this condition impacts morbidity, disability, health care costs, and mortality¹². Furthermore, functional impairments in balance, mobility, and lower-limb strength are associated with dependency in ADL, falls, fractures, and nursing home admission¹³⁻¹⁵. Therefore, the evaluation of interventions targeting balance, mobility, and lower-limb strength in older people is important.

Older people in nursing homes

The number of older people in need of care and assistance in ADL is increasing in step with population aging¹. Care and support can be provided in the community, such as through home care services, or in institutionalized settings¹⁶. Nursing homes are facilities with domestic-style environments that provide 24-hour functional support and care for persons who require assistance with ADL, and who often have complex needs and increased vulnerability¹⁷. Given the increasing number of older people, the number of people in need of nursing home residence would normally increase. In Sweden, however, a shift toward care provided in the community appears to have occurred, with a reduced number and proportion of older people living in nursing homes today¹⁶. In 2018, more than 88,000 (16%) people aged > 65 years were living in nursing homes and 236,000 received home care services in ordinary housing. Corresponding figures for 2010 were 94,000 and 211,000, respectively¹⁶. This trend, together with the growing aging population, has created a greater demand for care and rehabilitation for older people in ordinary housing in Sweden.

Dementia

The research conducted for this thesis focused on older people with dementia. “Dementia” is an umbrella term encompassing several diseases, most of which are progressive and develop as a result of damage or death of brain cells¹⁸. This disease interferes people’s ability to maintain ADL and is the leading cause of dependency in ADL among older people worldwide¹⁰. Dementia is a major cause of disability and affects memory, cognitive, and physical abilities and behavior¹⁸.

Incidence, prevalence, and cost

In 2015, dementia affected 47 million people worldwide; this number is predicted to increase to 75 million in 2030 and to 132 million by 2050¹⁸. Nearly 9.9 million people develop dementia each year, which translates to one new case every 3 seconds¹⁸. Among non-communicable diseases, dementia accounts for 11.9% of years lived with disability; it is also underdiagnosed worldwide¹⁸. In Sweden, 130,000–150,000 people have dementia disorders, and nearly half of them live in nursing homes. The number of new cases in Sweden each year is 20,000–25,000; dementia affects 8% of people aged > 65 years and nearly half of those aged > 90 years¹⁹. It significantly affects all aspects of life for affected individuals and for informal primary caregivers, friends, and family members in the immediate network¹⁰: nearly 1 million people in Sweden²⁰. Although dementia affects survival negatively, people with dementia can live for many years after the onset of the disease¹⁰. In comparison with other chronic diseases, dementia is the most resource intensive and costly for society²⁰. The total cost for the care and treatment of people with dementia in Sweden has been estimated to be 63 billion Swedish kronor (SEK) per year²⁰. The largest contribution to the cost of dementia care is nursing home living. In Sweden, within 2–3 years after the diagnosis of dementia, about half of those affected must move to nursing homes¹⁹.

Risk factors

The strongest known risk factor for the onset of dementia is age, but dementia is not an inevitable consequence of aging. Lifestyle-related risk factors include physical inactivity, obesity, an unbalanced diet, tobacco use, harmful alcohol intake, diabetes mellitus, and hypertension¹⁸. Other modifiable risk factors more specific to dementia are mid-life depression, low educational attainment, social isolation, and cognitive inactivity¹⁸. Non-modifiable genetic risk factors that increase individuals' risk of developing dementia also exist. Evidence shows that more women than men develop dementia¹⁸. Data suggest that about one-third of Alzheimer's disease (AD) cases worldwide are attributable to potentially modifiable risk factors²¹.

Diagnosis and dementia types

Dementia is usually diagnosed according to criteria in the Diagnostic and Statistical Manual of Mental Disorders (DSM). In the most recent edition (DSM-V), dementia is classified as a major neurocognitive disorder. However, in this thesis, the dementia classification from the fourth edition (DSM-IV-TR) is used, as diagnoses in the included studies were made according to the DSM-IV-TR criteria²². Dementia diagnoses are based on thorough examinations, which can include medical history taking, physical examination, psychiatric evaluation, blood analysis, computed tomography examination, and the assessment of individuals' cognitive abilities, ADL functioning, and social situations¹⁹. The most common dementia diagnosis is AD, accounting for 60–70% of cases¹⁸, followed by vascular dementia, accounting for 10–20% of cases. Vascular dementia becomes more prominent at older ages. Other types are dementia with Lewy bodies (DLB), Parkinson's disease dementia, and frontotemporal dementia. The different types of the disease have slightly different symptom patterns¹⁰.

Insidious symptoms of early AD are deficits in memory, concentration difficulties, disorientation, and aphasia. Vascular dementia may debut hastily and has a stepped course; it usually results from infarcts or bleeding of the brain caused by stroke or small vessel disease, and its symptoms vary depending on the parts of the brain affected¹⁹. DLB has similarities with AD and Parkinson's disease. Fatigue, reduced attention, and spatial disorientation are usually the first symptoms, as well as an increased fall risk and visual hallucinations. Impaired mimicry, rigidity, and bradykinesia, typical symptoms of Parkinson's disease, may also occur. Frontotemporal dementia is characterized initially by personality changes, lack of judgment, and reduced linguistic ability¹⁹. Mixed dementia is diagnosed when symptoms of two or more dementia types coexist¹⁰.

Symptoms and consequences

Dementia results in cognitive deficits such as impaired memory, thinking, executive function, orientation, learning capacity, language, and judgement. The impairments in cognition are commonly accompanied by the deterioration of emotional control, social behavior, and/or motivation¹⁰. Depression is also common in people with dementia²³, as are symptoms such as anxiety, aggression, restlessness, hallucination, wandering behavior, and sleep disturbances, referred to collectively as behavioral and psychological symptoms of dementia (BPSD)¹⁹. BPSD causes a great deal of stress in people with dementia, but also in informal primary caregivers, and it is the most common reason that people with dementia move to nursing homes¹⁹. The presence of BPSD, cognitive impairment, and the need for physical assistance places physical and mental strain on primary caregivers²⁴.

Although dementia is considered to be a principally cognitive disorder, its definition includes functional decline, including impairments in gait, mobility, and balance, as well as apraxia²⁵. Evidence indicates that poor gait performance predicts cognitive decline and the development of dementia²⁶⁻²⁸. A person's gait may change up to 12 years before the clinical presentation of cognitive changes that subsequently lead to the development of dementia²⁹. The severity of cognitive impairment is related to the degree of increase in gait abnormalities²⁶. People with dementia display decreased gait speed, decreased step and stride lengths, and increased step variability. Gait disturbances appear to be more predicative of and pronounced in individuals with non-Alzheimer's dementia (non-AD) forms, such as vascular dementia, DLB, and Parkinson's dementia^{26,30,31}. People with dementia demonstrate poorer postural stability, and more rapid declines and lower scores on balance test, than their age-matched peers^{32,33}. A review of postural control in AD suggested that people with dementia display impaired static and functional postural stability, and that influencing factors are increased attention demand (dual tasking) and decreased visual input³⁴.

Gait and balance impairments³⁰ contribute to increased risks of falls, fractures³⁵, physical inactivity³⁶, and dependence in ADL³⁷. People with dementia have about twice the risk of sustaining a fall as do people without dementia³⁸, and approximately 30% of older people who sustain hip fractures have dementia³⁹.

This population also has three times increased risks of adverse consequences after hip fracture and mortality⁴⁰, with a 39% increased risk of mortality 1 year after hip fracture⁴¹. Furthermore, people with dementia are at greater risk of other illnesses and conditions, such as malnutrition, incontinence, and impaired oral health, and they are more likely to be admitted to hospital than are people without dementia¹⁹. Comorbidities and medical conditions such as pain and/or vision or hearing impairment^{10,42-45}, as well as fluctuations in health status and reductions in physiological reserve capacity, lead to greater risks of drug-related side effects^{46,47}. The reduction in functional and cognitive ability and lack of initiative and interest^{48,49} contribute to the risks of low levels of social interaction and daily physical activity³³. As the negative consequences of dementia are numerous and complex, there is an overwhelming need for rehabilitation, including exercise, for this population.

Rehabilitation

Rehabilitation is a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions, in interaction with their environment⁵⁰. It provides opportunities to regain or maintain the best possible functional ability, creating favorable conditions for independent living and active participation in society⁵¹. Every person with dementia may be able to live better with the disease through optimal treatment and adaptation of the best strategies for coping with the difficulties of daily living⁵². People with dementia could be empowered to live in their communities and to receive care and rehabilitation aligned with their values and preferences¹⁸. A holistic and person-centered approach to health and social care for people with dementia may be a successful path. The needs of persons with dementia and their caregivers change over time as the course of the dementia disorder proceeds⁵³. The care system must be responsive to such changes, with the maintenance of regular contact, review of plans, provision of support, and implementation of interventions to meet needs that arise, according to Alzheimer Disease International⁵³. Interventions for people with dementia and their caregivers should be personally tailored to meet specific needs and circumstances, and include individualized goals that are important for recipients⁵².

The International Classification of Functioning, Disability and Health

The International Classification of Functioning, Disability and Health (ICF) is a comprehensive framework for rehabilitation presented by the World Health Organization in 2001⁵⁴. It is based on the evaluation of individuals with disease and/or disability from a holistic perspective, focusing on healthy aspects and strengths, rather than disability. The overall aim of the ICF is to provide a unified and standardized language and framework for the description and definition of components of health, health-related states, and well-being. The ICF can be applied on individual, institutional, and social levels⁵⁴. It can also be used as a clinical tool in the rehabilitation process, to organize thoughts and information about individuals' function in relation to their context, which is how the ICF was applied in this thesis research. ICF use involves the analysis of three components

of health conditions (body function and structure, activity, and participation), with two contextual factors (environmental and personal), all of which are mutually related (Figure 1) ⁵⁴. All ICF components interact, which means that an individual's functioning in a specific domain comprises an interaction or complex relationship between/among health conditions and contextual factors. According to the ICF, activity is the execution of a task or action by an individual, and participation is involvement in a life situation; both are viewed in relation to health-related conditions⁵⁴. Rehabilitation in people with dementia should be carried out with the ICF applied as a background model⁵².

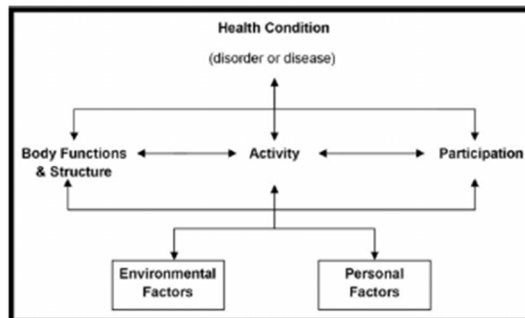


Figure 1. The World Health Organization's International Classification of Functioning, Disability and Health.

Interdisciplinary rehabilitation

Interdisciplinary rehabilitation refers to a process whereby a team consisting of many different professionals conducts comprehensive assessments to identify individuals' problems, needs, strengths, and resources⁵¹. The rehabilitation team then compose individual rehabilitation goals together with the patient and informal primary caregiver, and implements tailor-made interventions based on these goals⁵¹. The characteristics of interdisciplinary team rehabilitation include the cooperation of all participants in a structured way in direction to develop goals and individualized plans and evaluate the progress of these goals. Interdisciplinary rehabilitation is the highest level at which team members work together to achieve shared goals⁵⁵. Assessment is fundamental to determine the optimal level of function that each person can achieve, and to determine the causes of difficulties so that solutions to cope with them can be derived to create the best possible well-being. The Comprehensive Geriatric Assessment (CGA) is used to obtain a holistic view of older people's health and well-being⁵⁶. It is a multidimensional interdisciplinary diagnostic process used to determine to medical, psychological, and functional capacity of older people, to enable the development of coordinated and integrated plans for treatment and follow-up⁵⁶.

Rehabilitation in people with dementia

Interventions for people with dementia should be designed carefully based on individuals' residual capacity, psychological phase, and coping style, in

accordance with the environment and family, to make daily living more manageable. An errorless approach to intervention delivery is important to give people with dementia a feeling of self-efficacy⁵². Research is needed to evaluate preventive efforts, care, treatment, and rehabilitation for people with dementia¹⁸. Scientific knowledge and clinical experiences related to interdisciplinary team rehabilitation for this population, especially in outpatient settings, are limited⁵⁷⁻⁵⁹. Unlike those with other neurodegenerative diseases, such as multiple sclerosis and Parkinson's disease, people with dementia in Sweden are rarely offered rehabilitation for their primary disease⁶⁰. The experiences of people with early-stage dementia suggest that the diagnostic process and post-diagnosis support contribute to disempowerment, which may negatively affect their self-identity, sense of independence and control, level of activity, and view of the future, in turn impacting their social health and quality of life⁶¹.

In clinical settings, persons with dementia seems to have less access to rehabilitation after events such as hip fracture or stroke than do persons with other diagnoses. Studies have shown that people with impaired cognitive function receive considerably less rehabilitation than do cognitively intact people^{62,63}, despite the great need of people with dementia for individual support after acute disease occurrence. Furthermore, rehabilitation after hip fracture has been found to have similar or even greater effects on people with dementia than on those without cognitive impairment⁶⁴⁻⁶⁶. Expert clinicians have agreed unanimously that access to rehabilitation after hip fracture should be based on the ability of the participant to engage in rehabilitation, and not solely on his or her cognitive ability⁶⁷. However, interviews with health professionals in Australia working with older people about their perceptions of multidisciplinary rehabilitation for people with dementia revealed a pessimistic view⁷³. These professionals had difficulty defining worthwhile outcomes of rehabilitation, perceived barriers to participation, and believed that achievable outcomes were not sufficiently worthwhile for investment in this group⁶⁸. Moreover, an important complement to rehabilitation for people with dementia is the provision of information, training, and support for relatives, which can reduce their perceived stress, depressive symptoms, and negative health effects^{69,70}. It might also improve the quality of life for people with dementia living at home⁷¹, and may delay nursing home placement⁷². A fundamental part of team rehabilitation consists of physical activity and exercise.

Physical activity and exercise

Regular physical activity is a well-established protective factor for the prevention and treatment of leading non-communicable diseases, such as heart disease, stroke, diabetes, and cancer⁷³. It contributes to the prevention of disease risk factors such as hypertension and obesity, and it is associated with improved mental health, delayed onset of dementia, and improved quality of life and well-being⁷⁴. Physical activity is defined as any bodily movement produced by skeletal muscle that requires energy expenditure^{4,73}. Exercise refers to planned, structured, and repetitive movement to improve or maintain one or more components of physical fitness⁴.

Consequences of physical inactivity

Physical inactivity is the fourth leading risk factor for global mortality⁷³ and is responsible for 9% of premature mortality worldwide⁷⁵. Strong evidence indicates that physical inactivity shortens the life expectancy and increases the risk of many adverse health conditions, including the world's major non-communicable diseases (coronary heart disease, type 2 diabetes, and breast and colon cancers)⁷⁵. Physical inactivity is associated with declines in physical function, for example in gait speed⁷⁶. Physical activity levels affect rates of decline substantially over the life span, particularly in late life⁷⁷. In nursing homes in which large proportions of residents have dementia, most people are inactive^{78,79}, spending their days in lying or sitting positions in the ward⁷⁹. Sedentary behavior, defined as prolonged and large amounts of sitting time, is also a risk factor for disease⁷³. People with dementia are less physically active in their daily lives than are people without dementia^{80,81}. A large prospective cohort study conducted with older women showed that a physical activity level characterized by as few as approximately 4400 steps/day was related significantly to lower mortality rates than was an activity level characterized by approximately 2700 steps/day. Additionally, taking more steps per day decreased mortality rates before leveling off at approximately 7500 steps⁸². Furthermore, an intervention to reduce sedentary behavior (by breaking up prolonged sitting time) improved functional ability in frail older people in a small randomized controlled trial (RCT)⁸³.

Recommendations for older people, including those with dementia

Global estimates from 2010 indicate that 23% of adults do not fulfill the recommendations for physical activity⁷⁴; in people older than 80 years, the corresponding figure is more than 50%¹¹. Among 64–80-year-old people in Sweden, this proportion is 46%⁸⁴. The recommendation for physical activity for adults, including older people, is ≥ 150 minutes moderate-intensity aerobic activity, or ≥ 75 minutes vigorous-intensity physical activity, or an equivalent combination of both, per week^{4,73,85}. Activity should be performed in ≥ 10 -minute bouts. In addition, muscle strengthening activities involving major muscle groups should be performed on ≥ 2 days per week. Older adults with poor mobility should perform physical activity to enhance balance and prevent falls on ≥ 3 days per week^{4,73,85}. When older people cannot perform the recommended amount of physical activity due to health conditions, they should be as physically active as their ability and condition allow^{4,73}. The rationale for performing strength and balance exercises instead of aerobic exercise strengthens with age and the degree of frailty, given the prevalence of sarcopenia, mobility impairments, and functional dependency¹¹.

However, these recommendations may not be appropriate for people with dementia due to the complicating symptoms of the disease, which may lead to difficulties with participating in and performing exercise. Further research is needed to identify optimal exercise modalities for people with different types and severity of dementia, as well as barriers to and facilitators of exercise⁸⁶. A taskforce report summarized key recommendations for physical activity and exercise for long-term care residents, a large proportion of whom have dementia⁸⁷: to increase physical activity, nursing home staff should adopt

strategies to break up sedentary time twice to three times per day, use simple strategies to stimulate residents to move in their daily activities, and organize group activities that are motivating and pleasant. Recommendations for exercise training for residents with no contraindication and dependence in ADL include the development of personalized exercise programs as parts of individuals' health plans. The best exercise type is multicomponent training, with the core components of muscle strengthening exercises and cardiorespiratory endurance training. Other types of physical activity, such as flexibility and balance exercises, should be added when possible. A moderate intensity is recommended, with activities performed twice a week for 35–45 minutes⁸⁷. The best application of exercise recommendations for people with dementia in various settings needs to be further explored.

Exercise modalities; type, duration, frequency, and intensity

Exercise modalities that are routinely manipulated are the type, duration, frequency, and intensity. Common types include aerobic or endurance exercises, strength exercises or resistance training, and balance and flexibility exercises⁴. Aerobic exercise involves large muscle groups and is conducted to increase endurance. In strength exercise, the muscles work against the applied force of weights to increase muscle strength. Balance exercise is different exercises to improve balance and reduce falls. Flexibility exercise is exercises to preserve or increase the range of motion (ROM) around joints⁴. Duration refers to the length of the period during which an exercise is performed (e.g., session length or number of weeks), and frequency refers to how often the exercise is carried out (e.g., three times per week)⁴. The intensity of exercise can be measured in absolute terms of energy expenditure, for example in metabolic equivalents (METs), kilocalories, and watts, or in relative terms in relation to individuals' maximum capacity⁸⁵.

High-intensity exercise is performed near an individual's maximum capacity. For aerobic exercise, high intensity is characterized approximately as >60% of VO_2 max⁴, >6 METs⁷³, or a score of 14–17 on the Borg Rating of Perceived Exertion Scale^{85,88}. For strength exercises, intensity can be measured relative to the repetition maximum (RM), i.e., “the maximum number of times a load can be lifted before fatigue using good form and technique”⁸⁹, as high (8–12 RM or 60–80% of 1 RM for older people), medium (13–15 RM), and low (>15 RM)^{4,85}. According to the American College of Sports Medicine, the intensity of balance exercise should be defined based on the level of postural stability challenge exhibited, and should include 1) progressively more challenging postures with a gradually reduced base of support, 2) dynamic movement that perturbs the individual's center of gravity, 3) specific exercises for postural muscle groups, or 4) the reduction of sensory input⁴. The literature, however, lacks description of methods that can be used to describe balance intensity. Recommendations commonly relate to the difficulty of balance tasks, rather than the intensity of activities relative to individuals' abilities⁹⁰. In addition, optimal exercise modalities for different groups of people with dementia have not been identified; this research topic needs to be explored further.

Functional exercise and exercise specificity

Exercise effects are also related to the principle of specificity. To have an optimal effect on daily activities, exercise should be performed in weight-bearing positions and be similar to everyday tasks, such as rising from a chair, walking, and stairclimbing^{91,92}. Functional weight-bearing exercise is a type of task-specific exercise that has shown wide-ranging effects on physical function among people with moderate impairment⁹²⁻⁹⁷. It can improve the performance of daily tasks⁹², balance and functional ability⁹³, and the ability to stand up⁹⁶ more than non-functional weight-bearing exercise. Such exercise programs appear to be suitable for older people in nursing homes, including those with dementia, because the exercises are easy to follow and no specific exercise facility is required. Task specificity may be of particular importance for people with dementia, as they have reduced transfer ability when learning new skills and are more dependent on implicit procedural learning⁹⁸. Thus, the consideration of task specificity may be more important in the design of exercise programs for this population relative to those for older people in general⁹⁸.

Exercise effects in older people and people with dementia

Strong evidence has accumulated for the benefits of exercise, such as improved VO₂ max, endurance, muscle strength, muscle power (i.e., the product of force and velocity), walking, balance, ROM, cognition, well-being, bone density, and mood, as well as, fewer falls, in older people⁴. Strength exercise is an effective intervention to improve muscle strength, muscle power, and functional performance in older people^{4,99-101}. Strength exercises can also improve gait speed⁹⁹ and reduce dependency in ADL⁹⁹ in older people. Higher intensity and volume seem to yield greater gains in muscle strength and muscle power^{101,102}, but effects on functional measures can be seen at lower intensity and frequency^{101,102}. In frail older people, strength exercise alone or in multimodal combination (i.e., with endurance, balance, and gait exercises) improves muscle strength, muscle power, and functional outcomes¹⁰³. Frailty entails weight loss, weakness, poor resistance, poor gait ability, and low physical activity levels, and is associated with high levels of dependency and difficulty in performing ADL¹⁰³.

Strong evidence indicates that exercise reduces the rate and number of falls in older community-dwelling people. The performance of multiple types of exercise (e.g., balance, functional, and strength) seems to be even more effective³⁵. Balance training improves balance^{104,105} and reduces falls³⁵ in older people. However the most effective type (e.g., multidimensional, reaching, center of mass control, mobility, stepping), frequency, and intensity of balance exercise remain uncertain. In one review of research conducted with community-dwelling older people, the exercise program modality inadequately explained the balance effect¹⁰⁶. In contrast, another review of balance exercise in healthy older adults identified a balance training protocol comprising exercise modalities (11–12 weeks, three 31–45-minute sessions per week) as effective¹⁰⁵. Additionally, an earlier review of exercise regimes aiming to prevent falls showed that exercise programs that challenged balance and provided higher frequencies and duration of exercise had greater effects on fall prevention¹⁰⁷. Aerobic exercise of sufficient intensity (>60% of VO₂ max) frequency, and length (≥3 times/week for ≥16

weeks) increases VO₂ max in older people⁴. Physical activity and exercise, mainly aerobic, also seem to reduce the risks of dementia and age-related cognitive decline^{108,109}. Lastly, exercise studies conducted with older people have revealed that individuals respond differently to the same types of exercise^{4,110-112}. This phenomenon needs to be explored further in people with dementia.

In nursing home– and community-dwelling older people with dementia, exercise can improve the ability to perform ADL^{86,113-115} and improve physical functions¹¹⁶ such as muscle strength^{113,117-119}, balance^{114,117,118}, and gait^{113,114,118,120}; in community-dwelling adults with dementia, it can reduce falls¹²¹. In interviews about their experiences, exercise participants have noted the positive physical effects of exercise¹²²⁻¹²⁴. However, evidence for the ability of exercise to improve cognition in this group is inconclusive^{86,125}. Older people with dementia, who form a heterogeneous group, may encounter challenges with regard to exercise, due to complicating symptoms of the disease, especially in the later stages. A variety of cognitive deficits, physical impairments, BPSD, comorbidities, and other medical conditions, as well as, depression and reduced reserve capacity, may impede exercise performance and exercise program participation. In this group, factors other than the exercise modality may be important for the achievement of exercise response, and may alter the association between the exercise modality and effects seen in older people in general.

The High-Intensity Functional Exercise (HIFE) Program

Littbrand, Lindelöf, and Rosendahl^{126,127} developed the High-Intensity Functional Exercise (HIFE) Program in the Frail Older People – Activity and Nutrition Study in Umeå (FOPANU) RCT to improve balance, mobility, and lower-limb strength. The program includes lower-limb strength and balance exercises performed in functional weight-bearing positions (i.e., while standing and walking), which are intended to be performed at high intensity. The collection of exercises was developed according to four criteria; applicability without access to special facilities; performance in functional weight-bearing positions; adaptability for older people with different functional and cognitive capacities; and the possibility for progression in exercises¹²⁷. The FOPANU study showed positive effects of the program on performance in ADL, balance, gait ability, and lower-limb strength for older people living in nursing homes, including those with dementia^{120,128-132}. The HIFE Program has since been used in several exercise studies conducted in different countries (Sweden, Norway, Germany, and Australia) and settings^{117,123,133,134}, including clinical settings in Sweden and Norway. The HIFE Program has intensity scales for the strength training and balance components of the program. The use of the HIFE Program for people with dementia needs to be evaluated further in terms of applicability, motivation, effects, and experiences.

Motivation

Motivation concerns energy, direction, persistence, and equifinality – all of which are aspects of activation and intention¹³⁵ – and refers to the need, drive, or desire to act in a certain way to achieve a certain goal. The action or behavior directed at

a goal is commonly considered to be the manifestation of motivation¹³⁶. Motivation to participate in exercise is important for the maintenance of an exercise program^{87,137} to fulfill exercise recommendations⁴ and even to facilitating motor learning¹³⁸. Several motivation theories have been used in relation to physical activity and exercise; self-determination theory (SDT)¹³⁹ and the concept of self-efficacy from Bandura's social cognitive theory¹⁴⁰ are commonly used in relation to physical activity and exercise in older people. These two theories were applied in this research to interpret the findings on the motivation to exercise. The concept of self-efficacy has been used previously to examine exercise in people with dementia¹²³. The SDT has not, to my knowledge, been applied previously to a population with dementia. However, it could be interesting to apply SDT concepts to people with dementia, as the dementia disorder can reduce autonomy, competence, and relatedness, which are important SDT concepts.

Self-determination theory

The SDT is a macro-theory of motivation, personality, and optimal functioning. It was developed by Deci and Ryan^{135,141} and has been applied in different areas of research, including physical activity and exercise¹³⁹. The basic assumption of this theory is that humans have essential psychological needs for optimal functioning: autonomy, competence, and relatedness. As put forth in the SDT, a person experiences autonomy when he or she is the perceived origin or source of his or her behavior, competence when given opportunities to execute his or her capacities in interaction with the social environment, and relatedness when feeling connected to others in that context. Individualized exercise and rehabilitation programs have the potential to fulfill these needs. SDT proposes that the degree to which any of the three needs is unsupported or thwarted in a social context will affect motivation in that context. Satisfaction of these three psychological needs leads to greater self-determined motivation^{135,139,141}.

The SDT makes a central distinction between autonomous and controlled motivation^{135,139,141}. Controlled motivation is essentially "a carrot on a stick." A person can experience controlled motivation when he or she feels pressured, coerced, or compelled to do something to avoid punishment or feelings of guilt. A person subjected to controlled motivation tends to take the shortest path to the goal. In contrast, autonomous motivation involves a person's own choice, endorsement, interest, and deeply valued elements. The person is fully willing to behave in a manner that allows him or her to meet a goal. Being autonomously motivated leads to greater creativity, problem solving, performance, positive emotions, and psychological well-being. In addition, SDT defines three main types of motivation – amotivation, extrinsic motivation, and intrinsic motivation – and a continuum of motivation forms ranging from the most controlled, non-self-determined to the most autonomous, self-determined motivation^{135,139,141}.

Self-efficacy

Self-efficacy is the subjective belief in one's ability to succeed in a specific situation or to accomplish a task; it bestows a sense of personal control and empowerment¹⁴⁰. Self-efficacy is a critical component of motivation and affects task choices, effort, persistence, and achievement; it is included in Bandura's

social cognitive theory¹⁴⁰. Perceived self-efficacy is concerned not with the number of skills a person has, but with the person's belief in what he or she can do under a variety of circumstances. People acquire information to assess their self-efficacy from four primary sources: 1) mastery experiences (interpretation of actual performance), 2) vicarious (model) experiences, 3) forms of social persuasion, and 4) physiological and affective states¹⁴⁰. Mastery experience is the most powerful source of self-efficacy. Successful performance increases self-efficacy, whereas failure reduces it. The influence of actual performance depends on factors such as task difficulty, effort expended, aid received, and perception of one's capabilities. The cognitive interpretation of the result of one's action is the important factor. Vicarious modeling refers to social comparison with others; similarity to other people increases self-efficacy, and observing similar others succeed can increase self-efficacy and motivation, whereas observing similar others fail has the opposite effect. Furthermore, individuals rely on persuasive messages from others. However, the messages must be credible for a person to believe it to be true. Positive feedback can increase self-efficacy, but this increase will not be sustained if one performs poorly. Factors that influence persuasive messages include the credibility of the source and the frequency and valence of the message. Physiological and emotional reactions, such as anxiety and stress, provide cues for the anticipation of success or failure. Negative thoughts and fears about one's capabilities reduce self-efficacy, whereas positive emotions and excitement can motivate a person¹⁴⁰. Self-efficacy can increase during exercise in older people with¹²³ and without dementia, and has been associated with exercise adherence¹⁴². Self-efficacy and the SDT concept of competence are similar to its nature.

Motivators for and barriers to physical activity in older people with dementia

According to a review¹⁴³, motivators for physical activity in community-dwelling people with dementia include possible and perceived benefits, the meaningfulness of physical activity routines, positive feelings of being active, enjoyment, a sense of commitment, keeping the body in the best shape possible, past experiences of exercise, minimization of the caregiver burden, and being with people in the same situation. Barriers include impaired body function; fatigue; negative feelings (anxiety, feeling down); problems with orientation, attention, and memory; loss of motivation; concerns regarding safety; and burdens on caregivers. The authors of the review concluded that the consideration of exercise program characteristics, method of delivery, and how a program can be personalized according to and synchronized with individuals' needs is important. They also called for further studies conducted with institutionalized people with dementia¹⁴³. Interestingly, age and global cognition were not associated with physical activity participation in community-dwelling people with dementia¹⁴⁴. Furthermore, older adults with cognitive impairment have expressed preferences for simple, light, and safe exercises in accessible settings; they identified memory and the lack of a companion as barriers¹⁴⁵. In interviews about facilitators of and barriers to the motivation of cognitively impaired older adults to exercise, staff emphasized the need to know people's past experiences, or "knowing what makes them tick and move"¹⁴⁶. They also

emphasized that teamwork and the utilization of resources available in the nursing home facilitated exercise¹⁴⁶.

Motivation in people with dementia

Lack of motivation or apathy and lack of interest in activities affect more 70% of persons with dementia. Apathy is a neurocognitive syndrome of reduced goal-directed behavior and an important cause of disability in people with neurodegenerative disorders⁴⁸. Symptoms of apathy include a blunted emotional response, indifference, a low level of social engagement, and diminished initiation and poor persistence, all of which are common symptoms of dementia¹⁴⁷. Symptoms of depression may also include lack of motivation and apathy; thus, these conditions are related to each other⁴⁸. Lack of motivation or apathy might be a barrier to participation in exercise and rehabilitation among people with dementia. In addition, the motivation of people with more advanced stages of dementia to participate in exercise and rehabilitation may be challenging because many of these people live mostly in the present moment and may not recognize the future benefits of exercise⁴⁸. Insight into the applicability of interventions and how it is associated with the needs, characteristics, and preferences of people with dementia may aid the application of interventions in a more person-centered manner¹⁴⁸. Harmer and Orrell¹⁴⁹ observed that people with dementia in care homes found meaning in activities that addressed their physiological and social needs, which was related to the quality of the activity experience rather than the specific type of activity. The motivation to exercise might increase while exercising and finding meaning in the activity. Cedervall et al.¹²⁴ found that physical activity, apart from maintaining body functions, could sustain well-being and selfhood in people with mild AD. Motivation in relation to different kinds of exercise needs to be explored further among people with dementia. To my knowledge, no quantitative study has investigated motivation while participating in any type of exercise, including high-intensity functional exercise, among people with dementia. This type of exercise seems to be the most effective exercise type, but it is demanding.

Rationale

The world's population is aging, and the number and proportion of older people in the population are growing rapidly worldwide. Dementia disorders are common among older people and the leading cause of dependence in ADL. Dementia disorders are progressive and include the impairment of cognitive and physical function. These impairments lead to increased risks of inactivity, falls, fractures, comorbidity, personal suffering, reduced well-being, and increased societal costs. Thus, rehabilitation including exercise is needed in this population.

Exercise recommendations for older people to improve functional ability include balance and strength training. To obtain optimal effects, exercise should be task specific, functional, and performed at high intensity (near the individual's maximum capacity) at sufficient frequency and duration. The motivation to participate is also important for the maintenance of an exercise program, fulfillment of exercise recommendations and facilitation of motor learning to achieve an exercise response. However, exercise recommendations for older people are based mainly on findings from studies including people without dementia, and their fulfillment may be challenging for some people with dementia due to complicating symptoms of the disease. Cognitive deficits (e.g., impaired memory and executive function, concentration difficulties, perception disorders, and apraxia); apathy (i.e., lack of motivation); depression; and BPSD, including anxiety, aggression, and restlessness may impede participation in exercise. Further, due to reduced reserve capacity, people with dementia are at greater risk of the development of other acute medical conditions and occurrence of adverse events, and are more likely to be admitted to hospital. People with dementia in nursing homes, where large proportions of residents have more advanced dementia and other comorbidities, may face further difficulties with participation in exercise. Additionally, community-dwelling people with dementia have additional care and rehabilitation needs due to the decreasing proportion of nursing home residents in Sweden today.

Individuals with cognitive impairment have expressed preferences for simple, light, and safe exercises, and thus might not be motivated to participate in high-intensity exercise. Additionally, the motivation of people with more advanced stages of dementia might be challenging, as they may live only in the present moment. To my knowledge, no study has investigated motivation during exercise, including high-intensity functional exercise. This type of exercise seems to be most effective, but is more demanding. Studies exploring the applicability of exercise programs have been called for to enable the optimization of programs for people with different types and severity of dementia. Furthermore, factors other than applicability and motivation may be of importance to achieve exercise response in this population. Complicating symptoms might further affect responsiveness and alter the associations of applicability and motivation seen in older people in general; these topics need to be explored.

Dementia disorder significantly affects all aspects of life for affected persons and their informal caregivers, friends, and family members in their immediate

network; rehabilitation for this population is needed. Interdisciplinary team rehabilitation, including the CGA, might be a successful approach to management of the complexity of impairment present in this group. However, scientific knowledge and clinical experience of rehabilitation for people with dementia are limited, despite urgent needs and the proven effect of rehabilitation after events such as hip fracture. An important complement to rehabilitation for people with dementia is the provision of information, training, and support to informal primary caregivers. Person-centered multidimensional interdisciplinary rehabilitation for people with dementia, including education and counseling of informal primary caregivers, has not been evaluated and its effects need to be explored. Consideration of the experiences of persons with dementia who take part in rehabilitation can be a good way to evaluate aspects of feasibility.

Aims

The overall aim of this thesis was to evaluate exercise and team based rehabilitation among older people with dementia. Specific objectives were to evaluate the motivation to participate in and applicability of a high-intensity functional exercise program, and to explore experiences of participation in a multidimensional interdisciplinary team rehabilitation program including high-intensity functional exercise, among older people with dementia.

The specific aims of the research conducted for this thesis were:

- I.** To evaluate the motivation of older people with dementia to participate in a high-intensity functional exercise program compared with those participating in a social group activity. More precisely, to evaluate motivation to go to sessions and during the activity, as well as variation in motivation over time.
- II.** To evaluate the applicability of a high-intensity exercise program among people with dementia in nursing homes, with regard to attendance, achieved exercise intensity, and adverse events, and with a focus on the type of dementia. A secondary aim was to evaluate whether symptoms of dementia or other medical conditions common in this population were associated with the applicability of the program.
- III.** To evaluate whether the applicability of exercise (in terms of attendance, exercise intensity, and adverse events) and motivation influenced the effect on functional balance of a high-intensity functional exercise program among people with dementia in nursing homes.
- IV.** To explore the experiences of community-dwelling older people with dementia who took part in a person-centered multidimensional interdisciplinary rehabilitation program.

Methods

This thesis reports on data from the Umeå Dementia and Exercise (UMDEX; Papers I–III) and Multidimensional InterDisciplinary Rehabilitation in Dementia (MIDRED; Paper IV) studies, two RCTs conducted in Umeå, Sweden (Table 1).

Table 1. Overview of studies reported in this thesis

| Study | Paper I UMDEX | Paper II UMDEX | Paper III UMDEX | Paper IV MIDRED |
|---|---|---|---|------------------------------------|
| Sample size | 186 | 93 | 81 | 16 |
| Intervention | Exercise or Social Activity | Exercise | Exercise | Rehabilitation |
| Participants: | | | | |
| Age , mean±SD | 85.1±7.1 | 84.4±6.2 | 84.1±6.2 | 76.9 |
| Women , n (%) | 141 (75.5) | 70 (75.3) | 60 (74.1) | 10 (62.5) |
| MMSE , mean±SD | 14.9±3.5 | 15.4±3.4 | 15.4±3.5 | 21.9 |
| Outcome | Motivation | Applicability of the exercise program | Functional balance response | Participants experiences |
| Measurement | Motivation to go to and during activity | Attendance rate, intensity rate, adverse events rate | Berg Balance Scale difference: Responders≥5 p. Non- responders <5p. | Individual interviews |
| Comparisons and target variables | Exercise vs. Social activity | Dementia type and medical conditions | Attendance, intensity, adverse events, and motivation | NA |
| Analyze methods | Cumulative link mixed models | Mann Whitney U test, Spearman rank correlation | Logistic regression | Qualitative Content Analysis |

UMDEX, Umeå Dementia and Exercise study; MIDRED, Multidimensional InterDisciplinary Rehabilitation in Dementia study; SD, standard deviation; MMSE, Mini-Mental State Examination; NA, not applicable.

Papers I–III (UMDEX study)

The UMDEX study was a cluster-RCT in which the effects of a high intensity functional exercise program in people with dementia living in nursing homes were evaluated. The intervention was conducted in the municipality of Umeå in 2011 and 2012¹³³. The study protocol (ISRCTN31767087) has been published in the ISRCTN registry. The Regional Ethics Review Board of Umeå approved the study (2011-205-31M).

Settings and participants

Nursing homes with ≥ 30 residents in the municipality of Umeå were eligible for screening. In total, 864 residents were eligible for inclusion and were screened by physiotherapists (PTs) and physicians (Figure 2). A total of 186 people with dementia at 16 nursing homes were included in the study. The nursing homes contained 9 general and 10 dementia units, all with private rooms and staff on hand, as well as private apartments with access to on-site nursing and care. Inclusion criteria were a diagnosis of dementia according to the DSM-IV-TR criteria²², age ≥ 65 years, dependence in one or more personal ADL according to the Katz Index¹⁵⁰, ability to stand up from a chair with armrests with help from no more than one person, Mini-Mental State Examination (MMSE) score ≥ 10 ¹⁵¹, the ability to hear and understand Swedish sufficiently to participate in assessments, and approval from the resident's physician. Included people with dementia gave oral informed consent to participate, which was confirmed orally by their next of kin. Age ($p = 0.19$) and MMSE score ($p = 0.71$) did not differ between study participants and those who declined participation ($n = 55$). A larger proportion of men (34%) than women (18%) declined participation ($p = 0.008$).

Randomization

Two researchers not involved in the study performed randomization after the completion of enrollment and baseline assessment, to ensure that allocation was concealed to avoid selection bias. To avoid contamination between activities, 36 clusters, each comprising 3–8 inhabitants of the same wing, unit, or floor, were defined. Randomization was stratified to ensure that clusters receiving both interventions were present in each facility, reducing the risk that facility-related factors would influence the outcomes. Randomization was performed by drawing lots in sealed opaque envelopes; first, the order in which clusters were allocated was determined, followed by random allocation of participants to the exercise and social activity groups¹³³. All 186 participants were included in the analyses reported in Paper I. Participants randomized to the exercise intervention ($n = 93$) were included in the analyses reported in Paper II, and those randomized to the exercise intervention who underwent baseline and follow-up Berg Balance Scale (BBS) assessments ($n = 81$) were included in the analyses reported in Paper III.

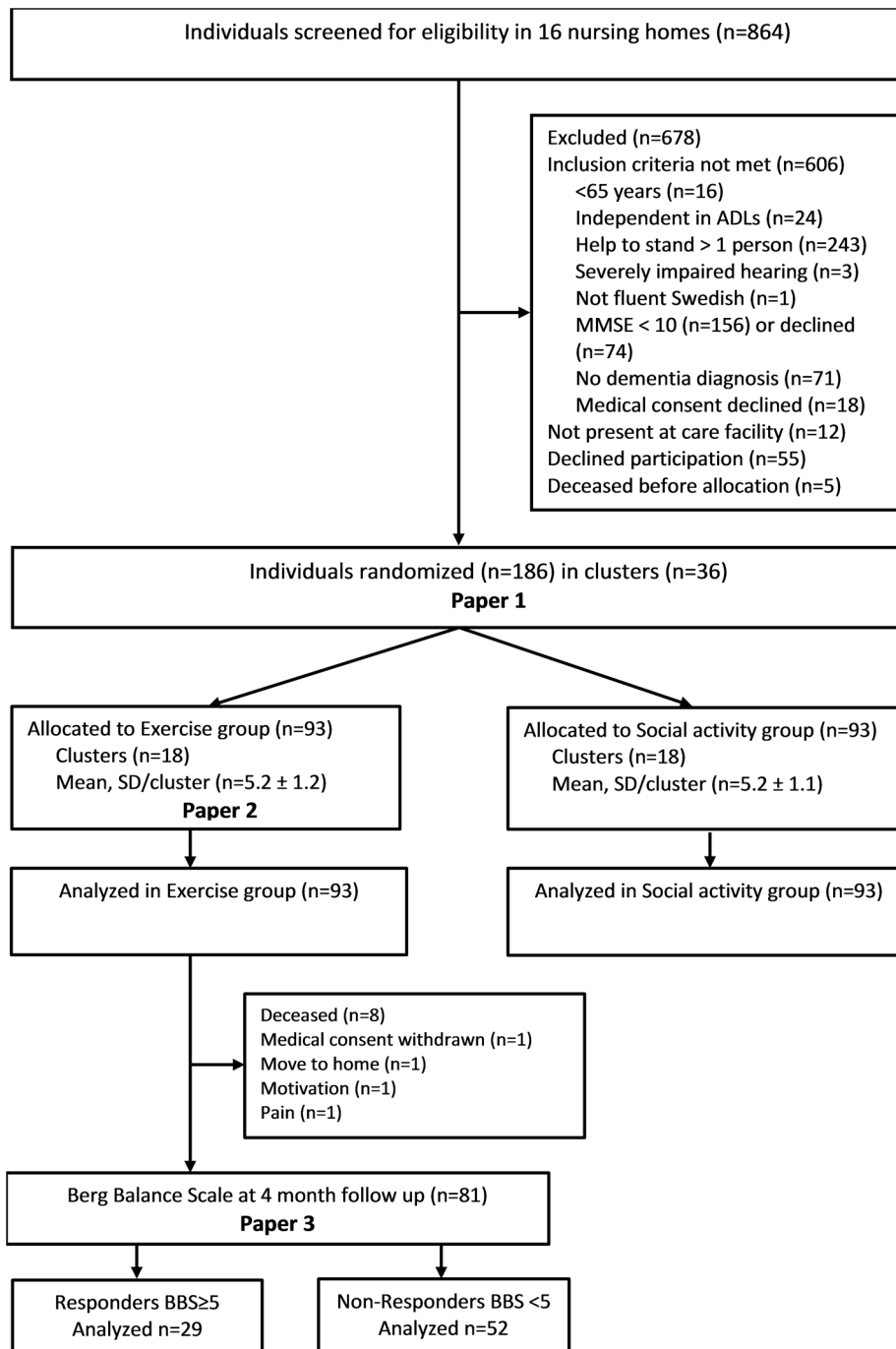


Figure 2. UMDEX study flow.

Abbreviations: UMDEX, Umeå Dementia and Exercise study; ADL, activities of daily living; MMSE, Mini-Mental State Examination; BBS, Berg Balance Scale.

Interventions

The exercise and social activities were conducted at the nursing homes in groups of three to eight participants supervised by two PTs or one occupational therapist (OT)/OT assistant, all experienced in working with older people with cognitive impairment. Sessions of approximately 45 minutes were held 5 times per 2-week period for 4 months, with a total of 40 sessions held for each group. The activity leaders obtained updates on participants' health status from nursing home staff before the sessions, and were able to contact physicians or nurses when necessary. Before starting each activity session, the activity leader or nursing home staff gave participants verbal reminders and/or aided transfer to the session; when needed, they also motivated the participants to join the activity session.

Exercise activity

The exercise intervention was based on the HIFE Program¹²⁷, designed to improve lower-limb strength, balance, and mobility and available as a booklet¹²⁶ and on a webpage (www.hifeprogram.se)¹²⁷. The HIFE program is comprised of 39 exercises performed in functional weight-bearing positions, similar to those used in everyday situations (e.g., rising from a chair, trunk rotation, walking, climbing stairs)^{126,127,130}. The exercises are distributed over five categories (A–E; Table 2), and exercise planning is guided by individuals' degrees of functional deficit and according to a hierarchical model based on the level of support required while walking a short distance (5–10 m). Participants who walked unsupported performed exercises in categories A and B, those who walked with supervision or minor physical support from one person performed exercises in categories A–C, and those walking with major physical support or not able to walk performed exercises in categories C–E¹²⁷.

Each group session started with seated warmup exercises for all participants. Thereafter, the participants were supervised individually to safely promote achievement of the highest possible exercise intensity. Participants took turns exercising and resting during each session. It was recommended to perform at least two sets each of two lower-limb strength exercises and two balance exercises each session¹²⁷. The intensities of these exercises were predefined as low, medium, and high, with exercise at high intensity being the aim of the HIFE program. Strength exercise intensity was defined in relation to the RM (high, 8–12 RM; medium, 13–15 RM; low, >15 RM). Strength exercises progressed through load and performance adjustments, for example by stepping higher, rising from a lower chair, or using a weighted belt (maximum, 12 kg; Table 2). Participants performed moderate-intensity strength exercises for the first 2 weeks as a build-up period¹²⁷.

Balance exercise intensity was defined according to the level of postural stability challenge exhibited: high, fully challenged (i.e., near the limit of maintaining an upright position); medium, not fully challenged or fully challenged in a minority of exercises; and low, not challenged. Balance exercises progressed by, for example, narrowing the base of support or altering the surface (Table 2)¹²⁷. Exercises and intensity were adapted throughout the intervention to meet

changes in participants' health status, symptoms, and physical and cognitive status. When possible, supervised individual sessions were provided for participants unable to attend group sessions. The PTs could adjust attendance and modify exercise intensity based on participants' health status. Participants wore belts with handles for safety reasons, so that PTs could provide support when needed, thereby preventing falls. Unnecessary support was avoided, as postural control is affected by even light touch¹⁵². All exercise equipment used (e.g., foam mats or rolls, step boards, and weighted belts) was portable.

Table 2. The HIFE Program categories, with examples of exercises and progression

| Category description | Examples of exercises | Examples of progression by increasing load and/or challenging postural control |
|--|---|---|
| A. Static and dynamic balance exercises in combination with lower-limb strength exercises | Squats; in parallel, or in walking stance Step-ups Lunges; forward, or to the side | - Add weights to weight-belt around waist - Increase height of step-up board - Increase step length - Deepen squats and lunges - Reduce base of support |
| B. Dynamic balance exercises in walking. | Walking; forward on a flat surface, in various directions, over obstacles, on soft surfaces, with numerous turns, or in circles | - Reduce base of support - Reduce stability of surface - Increase walking speed - Increase no. of turns, and changes in direction - Increase height, and no. of obstacles |
| C. Static and dynamic balance exercises in standing | Trunk rotation Body-weight transfer; in parallel, or in walking stance Side step and return | - Reduce base of support - Reduce stability of surface - Increase walking speed - Increase step length - Close eyes |
| D. Lower-limb strength exercises with continuous balance support | Squats; in parallel, or in walking stance Standing-up from sitting Heel-raises | - Add weights to weight-belt around waist - Increase step length - Deepen squat - Reduce seat height of chair |
| E. Walking with continuous balance support | Walking; forward on a flat surface, in various directions, or with numerous turns | - Reduce stability of surface - Increase walking speed - Increase no. of turns, and changes in direction |

Social activity (Paper I)

The OT and OT assistant participating in the study developed the group social activity. The sessions were structured around topics believed to be of interest to older people with dementia (e.g., seasons and holidays, wildlife, gardening, the royal family, baking, leisure activities, crafts, and well-known authors and artists). In the sessions, participants sat together in a group and engaged in activities including conversation, singing, listening to music or poetry, and

looking at pictures and objects associated with the topics (e.g., newspapers, books, spices, plants, and crafts); the activity did not involve exercise. The activity leader had an active role in paying attention to and encouraging each individual to participate (interact) during each session.

Outcome variables

Motivation (Paper I)

In the research conducted for this thesis, motivation was conceived of as participants' eagerness to participate in the activities. Motivation during the activities and motivation to go to sessions were the outcomes evaluated. The activity leaders assessed each participant's motivation during each session based on their observations and interpretations of participants' expressions, verbal prompts, and body language. Each participant's eagerness to participate was classified using a five-point Likert scale [0, no motivation (is present without participating); 1, low motivation (needs to be convinced to participate); 2, moderate motivation (attends the activity without being positive or negative); 3, high motivation (participates positively); 4, very high motivation (participates very positively)].

Motivation to go to activity sessions was assessed four times (A–D) over the intervention period by the persons who most often helped participants to the sessions (i.e., nursing home staff members or activity leaders – who sometimes varied over the intervention period). At each time point, the previous 2 weeks' average motivation to go to the activity was assessed (A, sessions 3–7; B, sessions 13–17; C, sessions 23–27; D, sessions 31–35) using a five-point Likert scale [0, very negative (never wants to or usually does not want to go to sessions, despite motivating attempts); 1, negative (needs to be motivated to go to sessions, which s/he usually does); 2, neither positive nor negative (goes to sessions without being motivated); 3, positive; 4, very positive]. The motivation scales were based on the eagerness scale used in studies conducted in similar settings with similar participants, in which PTs assessed participants' motivation during exercise¹⁵³.

Applicability of the exercise program (Paper II)

Attendance, intensity of lower-limb strength and balance exercises, and adverse events were the outcome variables used to evaluate the applicability of the HIFE Program. At the end of each exercise session, the activity leader completed a structured protocol for each participant, including intensity achieved in strength and balance exercises (low, moderate, or high)¹²⁷, reason(s) for not achieving high intensity, effective workout time without rest, and, when applicable, reason(s) for non-attendance or adverse event occurrence (i.e., development or worsening of discomfort during the exercise session, as observed by a leader or expressed by a participant spontaneously or upon questioning). Leaders assessed whether moderate- to high-intensity strength exercises strained primarily the peripheral (muscular) or central (cardiorespiratory) systems. They assessed by observation or questioning whether the primary reason for stopping exercise was lower-limb muscle fatigue or shortness of breath. This thorough approach to data collection

using the structured protocol was applied to enable evaluation of the program applicability from different angles. Two geriatric medicine specialists and one PT assessed adverse event severity in consensus as 1) minor or temporary (incurred or worsened by exercise), 2) serious (potential risk of severe injury or life threatening), 3) causing manifest injury or disease, and 4) causing death. During adverse event assessment, these professionals had access to medical records to follow the course and severity of symptoms.

Balance response (Paper III)

Functional balance response to the exercise program was the outcome assessed in Paper III. Balance was measured using the Berg balance Scale (BBS). A participant's ability to maintain an upright position during 14 activities typical of everyday living (e.g., sitting, rising up from sitting, transfer between two chairs, reaching while standing, standing with the eyes closed) was rated from 0 to 4, with 4 reflecting independence and 56 being the maximum total score¹⁵⁴. The BBS is a valid, reliable instrument for the measurement of balance function and evaluation of intervention effects in older people living in nursing homes, including people with cognitive impairment¹⁵⁵. Furthermore, the BBS score is recommended as a core outcome in clinical settings, and for research in adult populations¹⁵⁶.

Differences in BBS scores between baseline and follow-up assessments were dichotomized to represent responders (≥ 5 point increase) and non-responders (< 5 point increase, no change, or decrease), according to the minimal detectable change (MDC) approach. The cut-off was selected in accordance with an evaluation of intrarater test-retest reliability for BBS scores for people in residential care facilities, in which a 5-point difference revealed a genuine change with a confidence interval of 80%¹⁵⁵. PTs blinded to allocation and previous test results assessed balance at baseline and after the 4-month intervention [median, 15 days (range, 3–40 days) after the intervention ended, with no difference between responders and non-responders ($p = 0.83$)].

Intervention-related measures (Paper III)

The target variables for paper III were attendance (number of sessions attended), intensity (numbers of sessions in which strength and balance exercises, respectively, were performed at high intensity), adverse events (number of sessions with adverse events), and motivation (number of sessions with high or very high motivation). New medical diagnoses and hospital stays during the intervention period were followed through physician review of participants' medical records. Falls occurring during the intervention were followed through medical records and fall incidence reports filed by physicians at the nursing homes. A fall was defined as an event in which the participant unintentionally came to rest on the floor or ground, regardless of whether an injury was sustained or what caused the fall. Data on serious illness events without hospitalization (including stroke and central nervous system symptoms, mental illness, heart and lung diseases, diabetes, osteoarthritis, fracture, infection, and malignancy) that occurred during the intervention (which might have influenced applicability, motivation, and exercise effect) were merged into a single dichotomous variable.

Target variables, baseline characteristics, and new medical conditions that might have influenced the balance response are presented in Figure 3.

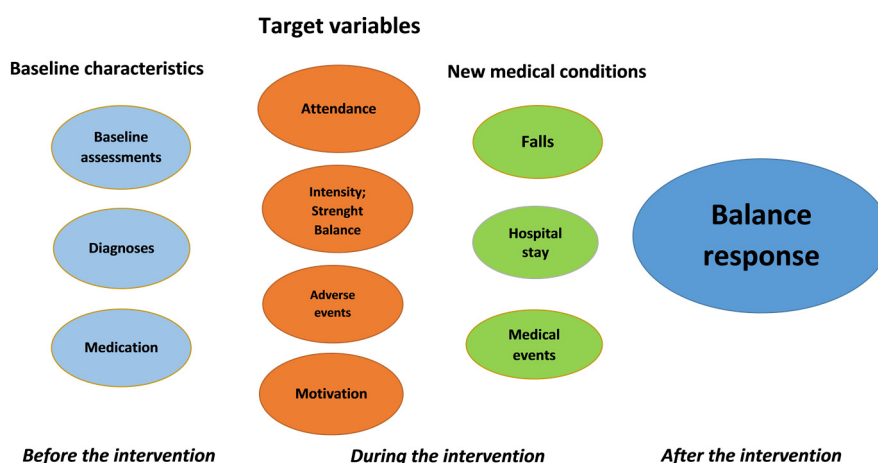


Figure 3. Target variables, baseline characteristics, and new medical conditions that might have affected balance response.

Baseline assessments

PTs and physicians performed all baseline assessments before randomization. ADL were assessed using the 10-item Barthel ADL Index¹⁵⁷, a well-established and valid measure of functional independence. Index items cover personal care and mobility, summed to a total of 20, with the highest score reflecting independence. Functional balance capacity was measured with the BBS¹⁵⁴. Usual gait speed was assessed over 4 m, from a standing start and with use of participants' ordinary walking aids. Self-reported pain while walking was also recorded. Depressive symptoms were assessed using the 15-item Geriatric Depression Scale (GDS-15)¹⁵⁸; item response options are yes and no, and total scores range from 0 to 15, with higher scores indicating more depressive symptoms. Cognitive function was assessed using the MMSE (range, 0–30), with higher scores indicating greater function¹⁵¹. BPSD were measured using the Neuropsychiatric Inventory (NPI). Twelve symptoms (e.g., delusion, hallucination, and aggression) are each graded in frequency (0–4), which is multiplied by severity (0–3) to yield total scores of 0–144, with higher scores indicating more symptoms¹⁵⁹. Nutritional status was assessed using the Mini Nutritional Assessment (0–30)¹⁶⁰, a screening instrument used to detect malnutrition in elderly individuals, with higher scores indicating better status. Eyesight (ability to read 5-mm-tall text) and hearing (ability to hear conversation at 1 m) were tested. Participants were also asked questions about their general health, previous exercise habits, and perceived loneliness. Diagnoses were based on information gathered from assessments, medical records, and drug

prescriptions. A physician specialized in geriatric medicine diagnosed the type of dementia according to the DSM-IV-TR²².

Data analyses

All analyses were performed using IBM SPSS software (versions 21–25; Papers I–III) and R Core Team software (Papers I and III)¹⁶¹, with a two-tailed significance level of $p < 0.05$.

Paper I

Baseline characteristics were compared between the exercise and social activity groups using Student's t test and the chi-squared test. Descriptive statistics were used to compare motivation during attended sessions and motivation to go to sessions in assessment periods A–D (total, 20 sessions/participant, i.e., 3720 possible comparisons in the total sample). Individual differences in motivation to go to each session and motivation during that session were categorized as lesser, equivalent, or greater [total, 2551 comparisons (1235 for exercise, 1316 for the social activity)]. Missing data were due mainly to non-attendance.

Motivation to go to activity sessions and during the sessions was also examined using cumulative link mixed models, with the individual serving as the random effect. Results were reported as odds ratios (ORs) for motivation being rated above any category comparing different sets of covariate values. The estimates were expressed as cumulative ORs, i.e., ORs for motivation > 0 vs. 0 , >1 vs. ≤ 1 , >2 vs. ≤ 2 , >3 vs. ≤ 3 , and >4 vs. ≤ 4 . Thus, the odds of greater motivation were assumed to be proportional when comparing the exercise group with the social activity group. This assumption was evaluated by relaxing it and performing comparisons based on the Akaike information criterion. Motivation to go to activities was compared with motivation during activities by modeling these motivation assessments in relation to an indicator variable for motivation during activities. Confidence intervals (CIs) were based on 1000 bootstrap samples, which were sampled with replacement.

Paper II

Individual attendance rates were calculated as the number of sessions attended divided by the total number of sessions offered ($n = 40$), regardless of study completion. Intensity and adverse event rates were calculated as the numbers of sessions attended with exercise performed at specific intensities and with adverse event occurrence, respectively, divided by the number of attended sessions. Baseline characteristics of participants with AD and non-AD were compared using Student's t test or the chi-squared test, given existing evidence for differences in exercise effects between these groups¹³³. Attendance, high intensity, and adverse event rates and effective workout time were compared using the Mann–Whitney U test (due to skewed distribution). Spearman rank correlations between outcome variables and medical conditions were examined.

Paper III

Baseline participant characteristics, target variables, other applicability measures, new medical diagnoses, falls, and hospital stays during the

intervention were compared between responders and non-responders using univariate logistic regression. Variables differing between responders and non-responders in univariate logistic regression at $p < 0.10$ were included in multivariate logistic regression models with response status serving as a dependent variable. Independent variables included in each model were attendance, MMSE score, Barthel ADL Index item 7 score, and one target variable (attendance, high intensity in strength and balance exercises, adverse events, or high motivation). All models except the first (which included attendance) were adjusted for attendance because the variables were related to overall attendance. Previous hip fracture was significant ($p < 0.10$) in the univariate logistic regression analysis, but was excluded because its inclusion inflated the standard error and other estimates, particularly the Barthel ADL Index item 7 score. The Barthel ADL Index total score was not entered in the models because item 7 was chosen as a measure of independence in walking. Furthermore, the Barthel ADL Index total score showed bivariate correlation with the BBS ($r = 0.685$) and MMSE ($r = 0.348$) scores. Peripheral strain in strength exercises was not entered in the model with high-intensity strength exercise performance because strong bivariate correlation was detected ($r = 0.868$). Correlation between all variables in the multivariate model was tested using the Spearman rank correlation coefficient, and no strong bivariate correlation was found ($r > 0.65$).

Multivariable linear regression was also performed with the difference in baseline and follow-up BBS scores serving as a continuous dependent variable. Independent variables were the same as in the multivariate logistic regression models. This analysis was performed to evaluate whether the BBS cut-off values used in the logistic regression models led to misleading results when equalizing decreasing score changes with increasing score changes below the cut-off values.

Paper IV (MIDRED study)

Study context

The research reported in Paper IV was part of the MIDRED study conducted in Umeå, northern Sweden, to evaluate a person-centered multidimensional interdisciplinary rehabilitation program for community-dwelling older people with dementia, including education and counseling for informal primary caregivers. The study protocol is published online at <http://www.isrctn.com/ISRCTN59155421>. The Regional Ethics Review Board of Umeå approved the study (Dnr: 2015-293-31M, 2015-450-32M). MIDRED participants were referred by local Health Centers and registered as patients at the outpatient unit of the Geriatric Center in University hospital in Umeå. Inclusion criteria were a diagnosis of dementia (according to the 10th revision of the International Statistical Classification of Diseases and Related Health Problems), age ≥ 60 years, MMSE score ≥ 10 ¹⁵¹, ability to stand up from a chair with armrests with help from no more than one person, approval from the participant's physician, ability to hear and understand Swedish sufficiently to participate in assessments, expected survival time > 6 months, and no initiation of a move to a nursing home. Study participation was offered to a maximum of two informal primary caregivers for each participant with dementia. Informal

primary caregivers could be relatives or others, such as neighbors or friends, who helped the participants with dementia. The participants were given written and oral information about the study, and were told that participation was voluntary and could be discontinued at any time without the need to provide a reason. Included participants gave oral informed consent to participate, which was confirmed orally by their next of kin. The participants were assigned randomly to usual care or to a person-centered multidimensional interdisciplinary rehabilitation program for 16 weeks. Sixteen older adults with dementia from the intervention group were invited to participate in an interview-based study.

Interventions were conducted at appropriate rehabilitation facilities and, when necessary, at participants' homes and/or in the community. The team staff included physician, nurse, assistant nurse, PT, OT, social worker, dietician, neuropsychologist, dental hygienist, and pharmacist. This team identified problems, needs and strength in the following areas: functional capacity, cognitive function, ADL performance, falls, and participation in society, physical activity, nutrition, medical conditions, BPSD, and drug use. The findings were used to determine which professionals were involved in individual participants' rehabilitation teams. The team, together with each person with dementia and his or her informal primary caregiver(s), formulated individual rehabilitation goals and planned specific interventions based on these goals.

The 16-week rehabilitation program involved:

1. Individually tailored goal-oriented interventions based on individuals' rehabilitation goals, performed by the relevant rehabilitation team professionals. For example, the OT could order cognitive technical devices and introduce participants with dementia a day-care center, or provide support to informal primary caregivers on coping with participants' ADL impairments. The physician could correct participants' medication regimes, and the dietician could provide support on the prevention of malnutrition.

2. Physical activity interventions consisting of two 45-minute individual exercise sessions per week at the clinic, with the goal of improving muscle strength, balance, and gait ability. The individualized exercise was based on the HIFE program¹²⁷. The exercise was conducted in groups of 3 or 4 participants led by two PTs. When possible, supervised individual sessions at home were offered when participants were unable to attend group sessions. The participants in each group could have different stages of dementia. The groups were organized primarily in to accommodate participants' preferred weekdays and times. An assistant nurse was responsible for organizing transportation to the clinic, by taxi when needed. The assistant nurse, with support from other professions when needed, assisted the participants when they arrived at and left the clinic, and organized and participated in coffee breaks after the exercise sessions to make sure that participants felt confident and welcomed. Participants also received individual recommendations for the achievement of physical activity levels in accordance with health promotion recommendations^{4,73,85}.

During the intervention the informal primary caregivers were offered six group sessions consisting of education and discussion about dementia, with the aim of

improving their self-management skills. They also received support and counseling with a social worker when needed.

Participants

Semi-structured interviews were conducted with 16 older adults with dementia at the end of the 4-month rehabilitation period. These individuals were members of the MIDRED intervention group and were invited to participate in the interview-based study; all who were invited accepted study participation. One researcher (NL) selected participants to achieve variation with regard to age, sex, family relationship, physical and cognitive function, depressive symptoms, attitudes toward program activities, and participation rates. Nine participants had AD and seven had non-AD (vascular dementia, DLB, and unspecified dementia).

Data collection

Three researchers (NL, IN, and AS) conducted one-on-one semi-structured interviews with open-ended questions in close relation to the rehabilitation in the clinic or in participants' homes during the last 2 weeks of the intervention. Two of these researchers (NL and IN) had experience in qualitative research and interviewing. The participants were shown pictures of the team members during interviews to facilitate their recollection of activities in which they had taken part. To further facilitate recollection, the interviewers also had brief descriptions of the activities in which participants had taken part and the team members whom they had met during the intervention. The main questions according to an interview guide, were "What is your experience of taking part in the rehabilitation program?" and "In what way have the activities you participated in affected your everyday life today?" The interviewees were encouraged to speak freely in responding to the questions, and the interviews continued as conversations. Follow-up questions were asked when necessary. The interviews were audio recorded and lasted 15–43 minutes (median, 28.5 minutes); they were transcribed verbatim by a person not involved in the study.

Data analysis

Data from individual interviews were analyzed using qualitative content analysis. This method involves the stepwise, systematic analysis of communication, and a process of interpretation that focuses on similarities and differences that emerge from the material, resulting in the organization of data into categories and themes⁶². The unit of analysis was all interviews. The interview transcripts were read several times to obtain a sense of the whole. The audio recordings were also listened to obtain further information from interviewees' tones, voices, and pauses. Next, the interview data were divided into meaning units consisting of constellations of words and statements with the same meanings. The researchers (AS, JL, and NL) then condensed and coded the units, with discussion until consensus was achieved. Coded units with similar content and meaning across all interviews were clustered. The researchers (AS and JL) then interpreted the codes, identifying differences and similarities and sorting the units into preliminary subcategories. Content that was not relevant to the aim of the study was omitted. The preliminary subcategories were abstracted, merged, and

organized into eight subcategories that were further abstracted. This interpretive process was conducted in several steps, with the supervision of researchers (IN and NL), and yielded four categories. At meetings attended by all coworkers the classification of all interview data, including the formulation of codes and creation of subcategories and categories, was discussed and changes were made until consensus was achieved. The analytical process involved back-and-forth movement between the whole and parts of the texts.

To further ensure trustworthiness, all coworkers independently read some transcripts and listened to some recordings to get a sense of the data. Each researcher had a different knowledge base, preunderstanding, and experience; “insider” and “outsider” perspectives were represented. All coworkers had experience working with older people with physical and cognitive impairments. The researchers were from the fields of physiotherapy (AS, NL, HL, and MC), occupational therapy (JL, IN) and geriatric medicine (UE). They were involved in the planning of the MIDRED study (HL, MC, NL, IN, and JL), implementation of the intervention (JL and MC), and performance of the interviews (AS, NL, and IN). Five researchers (HL, NL, AS, JL and UE) had experience with person-centered multidimensional interdisciplinary rehabilitation and two authors (NL, IN) had extensive experience in the design and theoretical underpinnings of qualitative content analysis.

Baseline assessments

The PT performed baseline assessments of the participants (Table 3). The Functional Independence Measure¹⁶³ was used to assess dependency in ADL, the MMSE was used to assess cognitive function¹⁵¹, the GDS-15¹⁵⁸ was used to assess depression, and the BBS¹⁵⁴ was used to assess functional balance. Diagnoses were based on information gathered from assessments, medical records, and medication prescriptions. Physician specialized in geriatric medicine diagnosed types of dementia according to the DSM-IV-TR²². The team staff estimated participants’ degree of adherence to the program as low, medium, and high, and their attitudes toward the program as negative, neutral, and positive.

Table 3. Participant characteristics in Paper IV (*n* = 16)

| | |
|--|--------------|
| Age, median (range) | 78.5 (63-89) |
| Women, n (%) | 10 (62.5) |
| Alzheimer’s Disease, n (%) | 9 (56.3) |
| Non- Alzheimer’s Disease, n (%) | 7 (43.7) |
| Mini Mental State examination, median (range) | 22 (15-30) |
| Berg Balance Scale, median (range) | 51 (33-46) |
| Functional Independence Measure, median (range) | 78.5 (52-90) |
| Geriatric depression Scale 15, median (range) | 2 (0-10) |
| Adherence: high, (range low – high), n (%) | 12 (75.0) |
| Attitude: positive, (range negative – positive), n (%) | 12 (75.0) |
| Living alone, n (%) | 5 (32.3) |
| Number of years in school, median (range) | 10 (6.5-18) |

Results

Motivation and applicability (Papers I and II)

In total, 186 individuals (141 women and 45 men) were included in the UMDEX study; 93 participants were allocated to each group. Sixty-seven (36%) participants had AD and 119 (64%) had a non-AD, including vascular, mixed vascular/AD, DLB, frontotemporal, and Parkinson's dementias. The mean [\pm standard deviation (SD)] MMSE score was 14.9 ± 3.5 . More than half of the participants had depressive disorder (57.5%) and delirium in the week preceding baseline assessment (54.8%), respectively, and 30.6% had had strokes. More than one-quarter (28.5%) of the participants had sustained previous hip fractures, and 78.9% used mobility devices, such as wheelchairs and walkers (Table 4). Among baseline characteristics, only antidepressant use differed significantly between the exercise and social activity groups. In the exercise group, participants with non-AD had greater global cognitive function (MMSE score 16.0 vs. 14.4), greater occurrence of previous stroke (50.8% vs. 8.8%), more mobility device use (93.2% vs 61.8%), more prescribed medications (9.1 vs. 7.3), and worse balance function (BBS score 25.9 vs. 28.6) relative to participants with AD (Table 4).

Table 4. Baseline characteristics of participants in Paper I-II

| Characteristics | Total n=186 | Social activity n=93 | Exercise n=93 | Exercise AD n=34 | Exercise Non-AD n=59 |
|---|----------------|----------------------------|------------------|------------------------|----------------------------|
| Paper | I | I | I-II | II | II |
| Age, mean ± SD | 85.1±7.1 | 85.9±7.8 | 84.4±6.2 | 84.9±6.6 | 84.1±6.0 |
| Female | 141 (75.8) | 71 (76.3) | 70 (75.3) | 27 (79.4) | 43 (72.9) |
| Dementia type: | | | | | |
| Alzheimer | 67 (36.0) | 33 (35.5) | 34 (36.6) | | |
| Vascular | 77 (41.4) | 41 (44.1) | 36 (38.7) | | |
| Others types | 27 (14.5) | 12 (12.9) | 15 (16.1) | | |
| Mixed AD/vascular | 15 (8.1) | 7 (7.5) | 8 (8.6) | | |
| Diagnosis and medical conditions | | | | | |
| Depressive disorders | 107 (57.5) | 54 (58.1) | 53 (57) | 18 (52.9) | 35 (59.3) |
| Delirium, previous week | 102 (54.8) | 54 (58.1) | 48 (51.6) | 15 (44.1) | 33 (55.9) |
| Previous stroke | 57 (30.6) | 24 (25.8) | 33 (35.5) | 3 (8.8) | 30 (50.8)** |
| Heart failure | 56 (30.1) | 32 (24.4) | 24 (25.8) | 6 (17.6) | 18 (30.5) |
| Angina pectoris | 49 (26.3) | 28 (30.1) | 21 (22.6) | 5 (14.5) | 16 (27.1) |
| Previous hip fracture | 53 (28.5) | 25 (26.9) | 28 (30.1) | 7 (20.6) | 21 (35.6) |
| Chronic lung disease | 39 (21.0) | 19 (20.4) | 20 (21.5) | 6 (17.6) | 14 (23.7) |
| Osteoarthritis | 61 (32.8) | 26 (28) | 35 (37.6) | 12 (35.3) | 23 (39.0) |
| Vision impairment | 26 (14.0) | 16 (17.2) | 10 (10.8) | 9 (26.5) | 11 (18.6) |
| Hearing impairment | 32 (17.2) | 20 (21.5) | 12 (12.9) | 6 (17.6) | 4 (6.8) |
| Pain while walking | 35 (18.8) | 20 (21.5) | 15 (16.1) | 7 (20.6) | 8 (13.6) |
| Prescribed medications, n (%) | | | | | |
| Analgesics | 112 (60.2) | 57 (61.3) | 55 (59.1) | 19 (55.9) | 36 (61.0) |
| Antidepressants | 102 (54.8) | 44 (47.3) | 58 (62.4)* | 22 (64.7) | 36 (61.0) |
| Benzodiazepine | 40 (21.5) | 21 (22.6) | 19 (20.4) | 8 (23.5) | 11 (18.6) |
| Diuretics | 88 (47.3) | 47 (50.5) | 41 (44.1) | 13 (38.2) | 28 (47.5) |
| Cholinesterase inhibitor | 40 (21.5) | 15 (16.1) | 25 (26.9) | 13 (38.2) | 12 (20.3) |
| Neuroleptic | 31 (16.7) | 20 (21.5) | 11 (11.8) | 5 (14.7) | 6 (10.2) |
| Number of medications mean±SD | 8.3 ± 3.8) | 8.2 ± 3.7 | 8.4 ± 4.0 | 7.3 ± 3.6 | 9.1 ± 4.1* |
| Assessments | | | | | |
| MMSE,(0-30) [§] | 14.9±3.5 | 14.4±3.5 | 15.4±3.4 | 14.4±3.0 | 16.0±3.6* |
| Barthel ADL Index, (0-20) [§] | 10.9±4.4 | 11.0±4.4 | 10.7±4.5 | 11.0±4.5 | 10.6±4.5 |
| BBS (0-56) [§] | 28.9±14.5 | 29.3±14.7 | 28.6±14.3 | 28.6±14.3 | 25.9±14.5* |
| Gait speed 4 m, m/s | 0.45±0.2 | 0.45±0.2 | 0.45±0.2 | 0.5±0.2 | 0.45±0.2 |
| NPI (0-144) | 3.8±3.2 | 14.4±12.6 | 15.2±15.8 | 15.7±12.9 | 15.0±17.4 |
| GDS -15, (0-15) | 3.8±3.2 | 3.6±2.9 | 4.0±3.4 | 3.2±3.0 | 4.4±3.5 |
| MNA (0-30) [§] | 21.1±2.7 | 20.9± 2.6 | 21.3±2.8 | 21.1±2.9 | 21.3±2.7 |
| Self-reported health as good | 119 (64.0) | 59 (63.4) | 60 (64.5) | 21 (61.8) | 39 (66.1) |
| Perceived loneliness | 104 (55.9) | 54 (58.1) | 50 (53.8) | 17 (50.0) | 33 (55.9) |
| Use of mobility devise | 145 (78.9) | 69 (74.2) | 76 (81.7) | 21 (61.8) | 55 (93.2)** |

Values are expressed as means ± standard deviations or n (%). Available measurements when values were missing.

* $p < 0.05$, ** $p < 0.01$, social activity vs. exercise or AD vs. non-AD in the exercise group.

[§]Higher scores indicate better status.

^{||}Lower scores indicate better status.

AD, Alzheimer's disease; non-AD, non-Alzheimer's type of dementia; SD, standard deviation; MMSE, Mini-Mental State Examination; ADL, activities of daily living; BBS, Berg Balance Scale; NPI, Neuropsychiatric Inventory; GDS-15, 15-item Geriatric Depression Scale; MNA, Mini Nutritional Assessment.

Motivation to go to activity sessions

Participants' motivation to go to activity sessions total and in individual assessment periods is shown in Figure 4. Positive or very positive motivation to go to activity sessions was noted in 43.4% of cases in the exercise group and 49.5% of cases in the social activity group. Corresponding figures for negative or very negative motivation were 35.1% and 21.5%, respectively.

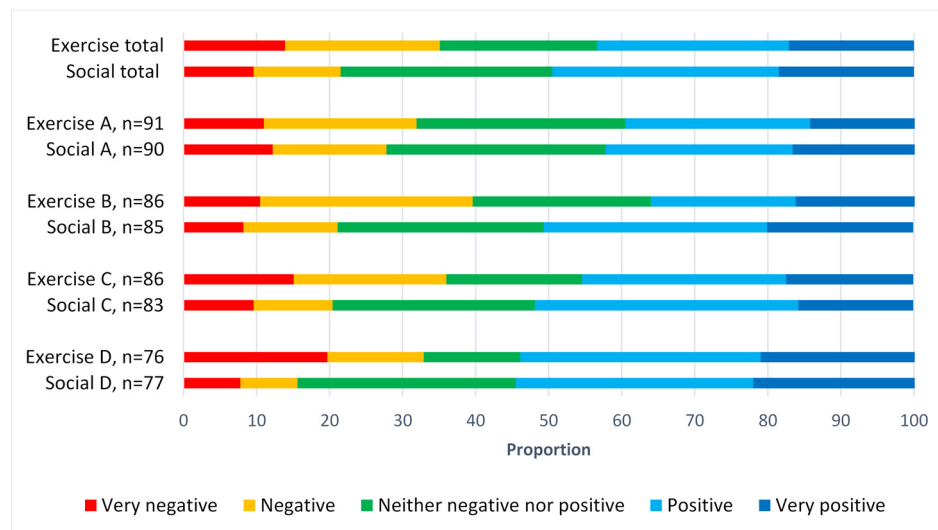


Figure 4. Motivation to go to activity sessions in the exercise and social activity groups, total and in assessment periods A–D.

On average, the cumulative odds of greater motivation to go activity session were significantly lower in the exercise group than in the social activity group (OR, 0.71; 95% CI, 0.63–0.80). The cumulative odds of greater motivation increased over time, but less so in the exercise group. Cumulative ORs for differences in greater motivation to go to sessions were higher in the social activity group and differed significantly between groups in all assessment periods ($p < 0.001$). The cumulative OR for greater motivation to go to sessions in the exercise group relative to the social activity group in period A was 0.79 (95% CI, 0.59–1.41). The cumulative odds were 55%, 25%, and 32% lower in the exercise group than in the social activity group for periods B, C, and D, respectively.

Motivation during activity sessions

High or very high motivation was recorded for 61.0% (1662/2726) of attended sessions in the exercise group and 62.6% (1618/2586) of attended sessions in the social activity group (Figure 5). Corresponding percentages for no or low motivation were 11.5% and 10.0%, respectively. Motivation during sessions did not differ significantly between groups. On average, the cumulative OR for greater motivation in the exercise group relative to the social activity group during the 40 sessions was 0.86 (95% CI, 0.44–1.70). These odds were found to be constant

over categories of motivation. Linear trends in average motivation during activities over the course of the intervention period were found. An increase in the cumulative odds of greater motivation during each subsequent activity session was seen in the exercise group (OR, 1.01; 95% CI, 1.01–1.02), and a decrease was seen in the social activity group (OR, 0.98; 95% CI, 0.97–0.99). These temporal trends differed significantly, and the additional cumulative OR for the exercise group compared with the social activity group was 1.03 (95% CI, 1.02–1.04). At the first activity session, the cumulative odds of greater motivation were 51% (95% CI, 2–76%) lower in the exercise group than in the social activity group; at the last session, these odds were 62% (95% CI, -15–230%) higher, with a 3% increase per session observed.

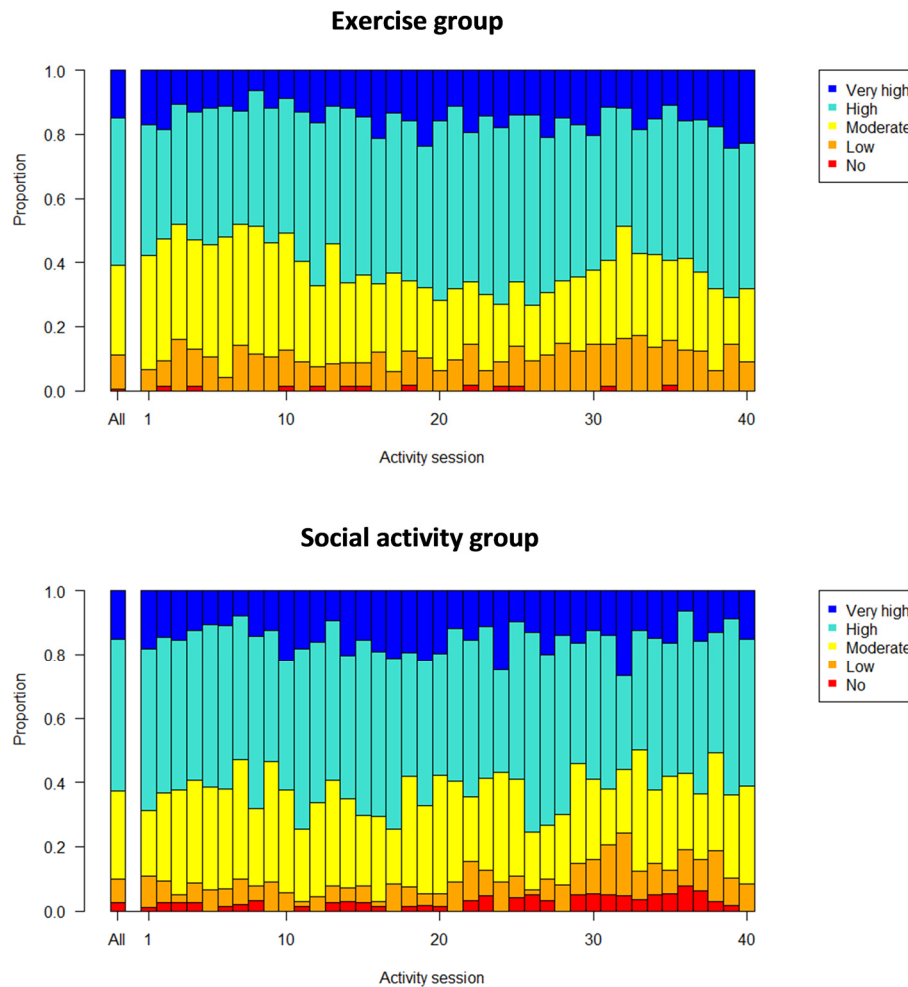


Figure 5. Motivation during activity sessions, total and by session.

Motivation scores were the same as in the previous session in 67% of cases in the exercise group and 58% of cases in the social activity group. Single-category changes were seen in 28%, two-category changes in 5%, and three-category changes in 0.6% of cases in the exercise group. Corresponding proportions in the social activity group were 38%, 4%, and 0.4%, respectively. At least one motivation score of two or more categories between consecutive sessions was seen in 40% of attending participants in the exercise group and 38% of participants in the social activity group. This degree of change occurred once for 13%, twice for 10%, three times for 4%, and 5–10 times for 13% of participants in the exercise group.

Motivation during vs. to go to activity sessions

Motivation during sessions were greater than motivation to go to sessions in 36.2% of cases in the exercise group and 27.9% of cases in the social activity group. Corresponding figures for lower motivation were 21.9% and 25%, respectively (Figure 6). Motivation during activities was significantly greater than motivation to go to activities in both groups. The cumulative ORs for greater motivation during sessions compared with motivation to go to sessions were 2.39 (95% CI, 2.38–2.40) in the exercise group and 1.50 (95% CI, 1.32–1.70) in the social activity group. A significant difference between groups is indicated by the lack of overlap in the confidence interval.

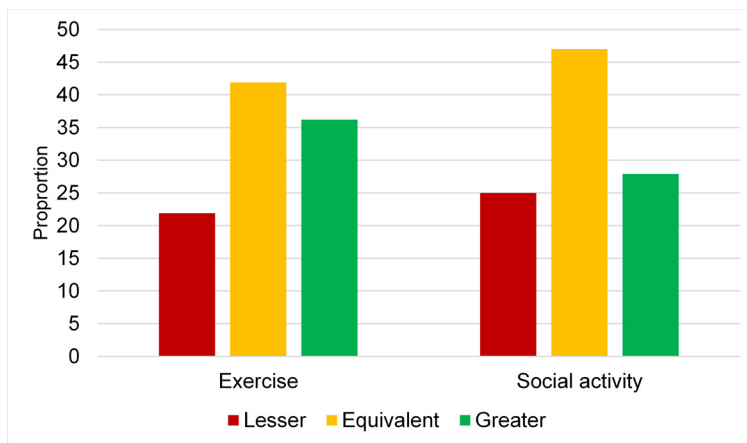


Figure 6. Motivation during activity sessions relative to motivation to go to activity sessions in the exercise and social activity groups. Individual differences for each session were categorized as lesser, equivalent, or greater motivation during the session than to go to it.

Attendance

The overall attendance rates were 73.4% (2729/3720 sessions) in the exercise group and 69.5% (2587/3720 sessions) in the social activity group. The median [interquartile range (IQR)] individual attendance rate in the social activity group

was 77.5% (57.5–90.0). In the exercise group, the median (IQR) individual attendance rate and effective workout time per session were 82.5% (70.0–92.5%) and 17.0 (15.0–19.5) minutes, respectively, with no significant difference between participants with AD and non-AD ($p = 0.308$) and $p = 0.640$, respectively). The most common reasons for non-attendance were lack of motivation (9.7% of all sessions), illness (4.0%), and tiredness (3.6) in the exercise group (Figure 7). Where as in the social activity group tiredness (8.4 % of all session), low motivation (6.8%), and psychological reasons (5.6%) in the social activity group.

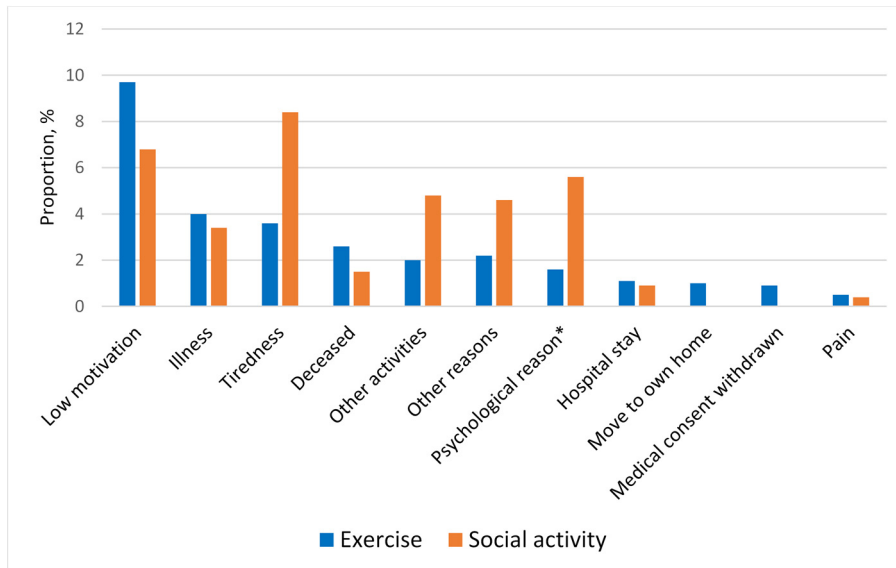


Figure 7. Reasons for activity session non-attendance, as percentages of all sessions.*Includes anxiety, restlessness, and delirium.

Exercise intensity

Lower-limb strength exercises were performed at high intensity in 49.4% ($n = 1349$), moderate intensity in 39.7% ($n = 1084$), and low intensity in 10.8% ($n = 296$) of attended sessions ($n = 2729$). Corresponding figures for balance intensity were 67.6% ($n = 1845$), 26.5% ($n = 722$), and 5.9% ($n = 162$), respectively. At the individual level, the median (IQR) rate of high intensity for lower-limb strength exercises was 47.2% (12.5–77.8%) of attended sessions, and that for high or medium intensity was 94.7% (77.8–100%). Balance exercises were performed at high intensity at 75% (33.3–88.6%) of attended sessions, and at high or medium intensity at 100% (91.2–100%) of these sessions. High-intensity strength and balance exercises were performed in the same session in 28.6% (9.1–40.5%) of cases. A significant difference between participants with AD and non-AD was observed in the high-intensity strength rate [34.9% (2.0–62.9%) vs. 53.8% (25.7–80.0%); $p = 0.035$], but not in the high-intensity balance rate ($p = 0.771$).

Strength exercises strained primarily the peripheral muscular system (in 82.9% of attended sessions); they strained the central cardiorespiratory system in 17.1%

of attended sessions. The most common reasons for not achieving high intensity in lower-limb strength and balance exercises were build-up training at the beginning of the exercise period and after periods of absence due to, e.g., illness (14.5% and 10.3% of attended sessions, respectively), low motivation (11.4% and 9.3%, respectively), and pain (11.0% and 6.1%, respectively). For balance exercises, fear (8.7 %) was the third most common reason not achieving high intensity (Figure 8).

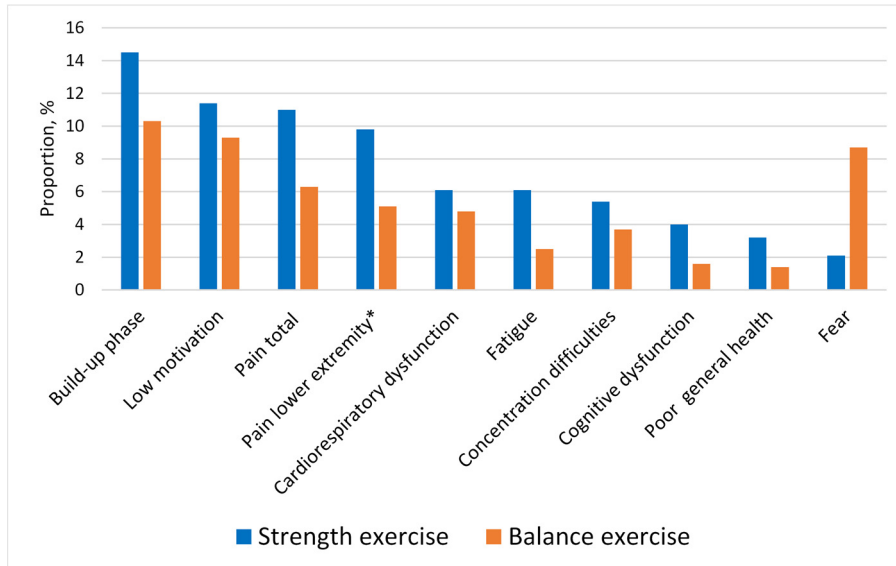


Figure 8. Reasons for not achieving high intensity, as percentages of all attended sessions.

More than one reason per participant could be recorded.

*Included in the pain category.

Adverse events

In the exercise group, adverse events were recorded in 446/2729 (16.3%) attended sessions and affected 72 (77.4%) participants. All adverse events ($n = 455$) were minor or temporary. The median (IQR) individual adverse event rate was 10.0% (2.6–27.3%) of attended sessions, with no significant difference between participants with AD and non-AD ($p = 0.821$). Adverse events were musculoskeletal (pain, soreness; 64.0%), general/unspecified (e.g., fatigue, headache, stomach pain, nausea; 13.6%), psychological (e.g., anxiety, restlessness, anger; 13.3%), dizziness (5.2%), and cardiorespiratory (e.g., breathlessness, chest discomfort; 3.9%). In the social activity group, adverse events were recorded in 148/2588 (5.7%) attended sessions and affected 29 (31.2%) participants. All adverse events ($n = 155$) were minor or temporary. The median (IQR) individual adverse event rate was 0% (0–7.7%) of attended sessions. Adverse events were musculoskeletal (14.9%), general/unspecified (39.9%), psychological (43.2%), and dizziness (2.0%).

Correlations between outcome variables and medical conditions

Lower attendance rates correlated with the occurrence of more BPSD ($p = 0.037$) and apathy, according to the NPI ($p = 0.037$; Table 5). Lower balance intensity rates correlated with more BPSD ($p = 0.005$). The occurrence of more adverse events correlated with analgesic use ($p = 0.023$) and pain while walking ($p = 0.041$). Neuroleptic use correlated with higher attendance rates ($p = 0.012$). Angina pectoris diagnosis correlated with higher intensity of strength exercises ($p = 0.034$).

Table 5. Correlations between outcome variables and medical conditions

| Variable | Attendance rate | High-intensity strength rate | High-intensity balance rate | Adverse event rate |
|----------------------|------------------------|-------------------------------------|------------------------------------|---------------------------|
| MMSE † | -0.016 | 0.182 | 0.153 | 0.027 |
| GDS-15 † | 0.009 | 0.014 | 0.163 | 0.057 |
| NPI, total † | -0.217* | -0.150 | -0.295** | 0.063 |
| NPI, apathy † | -0.216* | 0.067 | 0.055 | -0.082 |
| BBS † | 0.055 | -0.001 | 0.093 | -0.085 |
| MNA † | -0.026 | 0.028 | -0.048 | -0.061 |
| Pain while walking | 0.016 | -0.119 | 0.013 | 0.215* |
| Analgesic use | -0.064 | 0.183 | -0.041 | 0.238* |
| Neuroleptic use | 0.185* | 0.107 | 0.185 | 0.036 |
| Heart failure | -0.025 | 0.175 | 0.040 | -0.006 |
| Angina pectoris | -0.107 | 0.223* | 0.034 | 0.049 |
| Chronic lung disease | -0.193 | 0.043 | -0.094 | 0.091 |
| Vision impairment | 0.166 | -0.070 | -0.178 | 0.053 |
| Hearing impairment | 0.077 | 0.074 | -0.164 | 0.026 |
| Sex (female) | 0.043 | -0.097 | -0.016 | 0.148 |

* $p < 0.05$, ** $p < 0.01$, Spearman rank correlation.

† Higher scores indicate better status.

‡ Lower scores indicate better status.

MMSE, Mini-Mental State Examination; GDS-15, 15-item Geriatric Depression Scale; NPI, Neuropsychiatric Inventory; BBS, Berg Balance Scale; MNA, Mini Nutritional Assessment.

Balance response (Paper III)

Data from 81 participants (60 women and 21 men) were included in the analysis of balance response. The mean \pm SD baseline and follow-up BBS scores were 28.6 ± 14.3 and 31.2 ± 15.3 , respectively. The range of differences between follow-up and baseline BBS scores was -35 to 24 points; scores of 17 participants decreased, those of 5 participants were unchanged, and those of 59 participants increased. Figure 9 shows univariate associations between the baseline BBS score and the difference in scores. The association between the differences in BBS scores and attendance (one of the target variables) is shown in Figure 10.

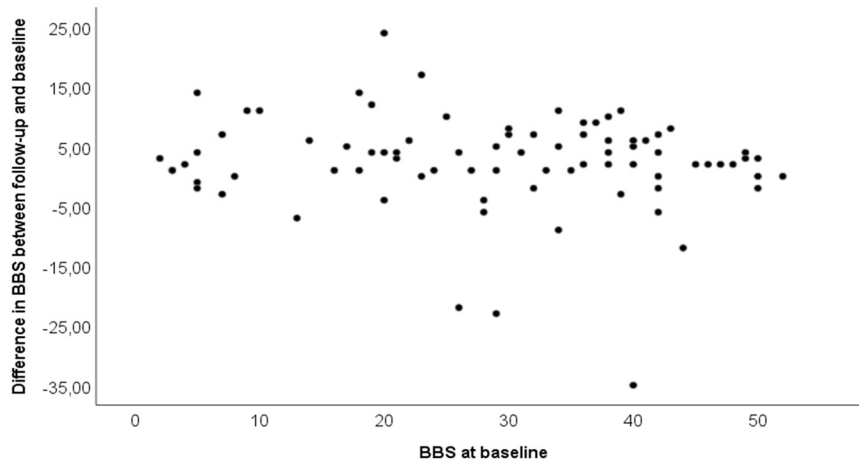


Figure 9. Associations between differences in baseline and follow-up BBS scores and baseline score. Positive values on the y axis indicate increases, and negative values indicate decreases. BBS, Berg Balance Scale.

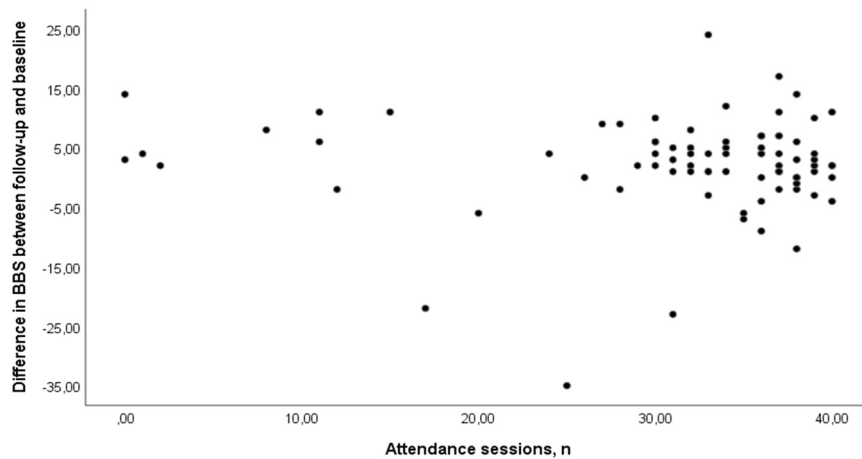


Figure 10. Associations between differences in baseline and follow-up BBS scores and attendance. BBS, Berg Balance Scale.

Twenty-nine (35.8%) participants were classified as responders (≥ 5 point increase) and 52 (64.2%) participants were classified as non-responders (< 5 point increase). The mean \pm SD (range) BBS score differences for responders and non-responders were 9.1 ± 4.2 (5–24) and -1.3 ± 7.8 (–35 to 4), respectively. These participants' baseline characteristics and ORs for responders vs. non-responders are shown in Table 6. The only significant difference was in the Barthel ADL Index, responders having higher scores (12.3 ± 7.1 vs. 10.0 ± 4.7 , $p = 0.034$). No other variable or measure differed significantly between responders and non-responders in the univariate regression analysis (Table 7).

Table 6. Baseline characteristics of participants in Paper III

| Characteristic | Responders | Non-responders | OR (95 %CI) | p value |
|---|---------------------------|---------------------------|------------------|----------------|
| | BBS ≥5 increase (n=29) | BBS <5 increase (n=52) | | |
| Age, years | 84.5±7.1 | 83.8±5.7 | 1.02 (0.95-1.10) | 0.636 |
| Sex, female | 22 (75.9) | 38 (73.1) | 1.16 (0.41-3.30) | 0.784 |
| Dementia type | | | | |
| AD | 10 (34.5) | 20 (38.5) | 1.19 (0.46-3.06) | 0.722 α |
| Non-AD | 19 (65.5) | 32 (61.5) | | |
| <i>Vascular</i> | 13 (44.8) | 18 (34.6) | | |
| <i>Mixed-AD/vascular</i> | 1 (3.4) | 5 (9.6) | | |
| <i>Other</i> | 5 (17.3) | 9 (17.3) | | |
| Diagnoses and medical conditions | | | | |
| Depressive disorders | 16 (55.2) | 32 (61.5) | 0.77 (0.31-1.93) | 0.576 |
| Delirium, previous week | 13 (44.8) | 29 (55.8) | 0.64 (0.26-1.61) | 0.346 |
| Previous stroke | 12 (41.4) | 15 (28.8) | 1.74 (0.67-4.51) | 0.253 |
| Heart failure | 9 (31.0) | 12 (23.1) | 1.50 (0.54-4.15) | 0.435 |
| Angina pectoris | 9 (31.0) | 8 (15.4) | 2.48 (0.83-7.36) | 0.103 |
| Previous hip fracture | 5 (17.2) | 19 (36.5) | 0.36 (0.12-1.11) | 0.074 |
| Rheumatic disease | 6 (20.7) | 7 (13.5) | 1.68 (0.51-5.57) | 0.399 |
| Chronic lung disease | 8 (27.6) | 10 (19.2) | 1.60 (0.55-4.65) | 0.388 |
| Osteoarthritis | 11 (37.9) | 21 (40.4) | 0.90 (0.36-2.29) | 0.829 |
| Hearing impairment | 7 (24.1) | 10 (19.2) | 1.34 (0.45-4.00) | 0.604 |
| Vision impairment | 2 (6.9) | 7 (13.5) | 0.74 (0.37-1.47) | 0.392 |
| Pain while walking | 4 (13.8) | 7 (13.5) | 0.99 (0.76-1.30) | 0.935 |
| Prescription medications | | | | |
| Analgesics | 17 (58.6) | 31 (59.6) | 0.96 (0.38-2.42) | 0.930 |
| Antidepressants | 16 (55.2) | 34 (65.4) | 0.65 (0.26-1.65) | 0.366 |
| Benzodiazepine | 3 (10.3) | 12 (23.1) | 0.53 (0.16-1.84) | 0.319 |
| Diuretics | 12 (41.4) | 22 (42.3) | 0.96 (0.38-1.42) | 0.935 |
| Anti-dementia drugs | 6 (20.7) | 19 (36.5) | 0.45 (0.16-1.31) | 0.144 |
| Neuroleptics | 3 (10.3) | 7 (13.5) | 0.74 (0.18-3.12) | 0.683 |
| Number of medications | 8.5±4.7 | 8.2±3.4 | 1.02 (0.91-1.15) | 0.700 |
| Assessments | | | | |
| Barthel ADL Index (0–20) [§] | 12.3± 4.0 | 10.0± 4.7 | 1.13 (1.01-1.26) | 0.034* |
| Barthel ADL index, item 7; able to walk independently | 20 (69.0) | 24 (46.2) | 2.59 (1.00-6.75) | 0.051 |
| MMSE (range 0–30) [§] | 16.3±3.4 | 14.9±3.5 | 1.13 (0.99-1.29) | 0.075 |
| BBS (range 0–56) [§] | 27.9± 11.6 | 29.3±15.2 | 0.99 (0.96-1.03) | 0.654 |
| Gait speed 4 m, m/s, | 0.47±0.2 | 0.48±0.2 | 0.69 (0.07-7.24) | 0.758 |
| NPI (range 0–144) | 16.4±16.4 | 15.6±16.3 | 1.00 (0.98-1.03) | 0.823 |
| GDS-15 (range 0–15) , | 4.5±3.8 | 3.6±2.9 | 1.09 (0.95-1.25) | 0.244 |
| MNA (range 0–30) [§] | 21.5±2.7 | 21.2±2.7 | 1.04 (0.87-1.23) | 0.690 |
| Use of mobility device | 24 (82.8) | 42 (80.8) | 1.02 (0.79-1.31) | 0.901 |
| Self-reported health, good | 18 (62.1) | 34 (65.4) | 0.87 (0.34-2.22) | 0.765 |
| Life-space, daily transfer out of the ward | 6 (20.7) | 17 (32.7) | 0.54 (0.18-1.56) | 0.254 |

Values are expressed as means ± standard deviations or *n* (%).

α AD vs. non-AD.

**p* < 0.05.

[§]Higher scores indicate better status.

^{||}Lower scores indicate better status.

BBS, Berg Balance Scale; BBS ≥ 5 increase, difference between follow-up and baseline scores ≥ 5; BBS < 5 increase, difference between follow-up and baseline scores < 5; OR, odds ratio; CI, confidence interval; AD, Alzheimer's disease; ADL, activities of daily living; MMSE, Mini-Mental State Examination; NPI, Neuropsychiatric Inventory; GDS-15, 15-item Geriatric Depression Scale; MNA, Mini Nutritional Assessment.

Table 7. Intervention-related measures in Paper III

| | Responders BBS ≥5 increase (n=29) | Non-responders BBS <5 increase (n=52) | OR, 95% CI | p value |
|---|---|---|------------------|---------|
| Target variables | | | | |
| Attendance, n | 34.0 (29.0-37.0) | 35.0 (30.3-38.0) | 0.98 (0.94-1.03) | 0.418 |
| High Intensity strength, n | 15.0 (3.0-23.5) | 21.0 (6.5-27.8) | 0.97 (0.93-1.01) | 0.167 |
| High Intensity balance, n | 21.0 (9.0-28) | 24.0 (14.3-33.0) | 0.97 (0.93-1.01) | 0.116 |
| Adverse event, n | 3.0 (0-9.5) | 2.0 (1.0-5.0) | 1.02 (0.96-1.10) | 0.498 |
| High Motivation, n | 10.0 (4.5-28.5) | 23.0 (9.5-31.0) | 0.97 (0.94-1.01) | 0.158 |
| Other applicability variables | | | | |
| HI strength + balance, n | 9 (3.0-22.8) | 19.0 (5.0-26.0) | 0.97 (0.93-1.02) | 0.217 |
| HI+MI strength, n | 30.0 (20.0-34.0) | 33.0 (24.3-36.8) | 0.97 (0.93-1.01) | 0.172 |
| HI+MI balance, n | 31 (26.0-35.5) | 33.5 (28.3-37.0) | 0.98 (0.94-1.02) | 0.319 |
| Effective workout time/session minutes | 16.6 (14.1-19.3) | 17.9 (15.3-19.7) | 1.00 (1.00-1.00) | 0.362 |
| Peripheral strain*, n | 8.5 (2.5-22.5) | 19 (8.5-25.0) | 0.96 (0.91-1.01) | 0.075 |
| New medical conditions † | | | | |
| Falls | 13 (44.8) | 23 (44.2) | 1.02 (0.41-2.56) | 0.959 |
| Hospital stay | 5 (17.2) | 5 (9.6) | 1.52 (0.62-3.73) | 0.357 |
| Serious illness without hospital stay | 11 (37.9) | 26 (50.0) | 0.61 (0.24-1.54) | 0.297 |

Values are expressed as medians (interquartile ranges) or *n* (%).

*Number of sessions during which high-intensity strength exercises were performed in which participants stopped due to lower-limb muscle fatigue.

†During the intervention.

BBS, Berg Balance Scale; BBS ≥ 5 increase, difference between follow-up and baseline scores ≥ 5; BBS < 5 increase, difference between follow-up and baseline scores < 5; OR, odds ratio; CI, confidence interval; HI, high intensity; MI, moderate intensity.

Multivariate logistic regression models 1–5 showed no significant association between response status and any target or adjustment variable (Table 8). The multivariate linear regression models revealed no significant association between differences in BBS scores and any target or adjustment variable (data not shown).

Table 8. Multivariable logistic regression results for associations between response status (according to Berg Balance Scale scores) and target and adjustment variables

| Model | Target Variable | OR | 95% CI | p value |
|-------|--------------------------------------|-------|-------------|---------|
| 1 | Attendance [‡] | 0.996 | 0.986–1.007 | 0.510 |
| 2 | High-Intensity Strength [‡] | 0.992 | 0.981–1.003 | 0.149 |
| 3 | High-Intensity Balance [‡] | 0.989 | 0.977–1.001 | 0.089 |
| 4 | Adverse Event [‡] | 1.009 | 0.992–1.026 | 0.329 |
| 5 | High Motivation [‡] | 0.992 | 0.982–1.002 | 0.104 |

Response status served as the dependent variable in the models. Independent variables were attendance, Mini-Mental State Examination score, Barthel ADL Index item 7 score, and one target variable per model.

[‡]Number of sessions.

[‡]Number of attended sessions with the target variable.

ADL, activities of daily living; OR, odds ratio; CI, confidence interval.

Experiences with a rehabilitation program (Paper IV)

The interview analysis revealed eight subcategories and four categories (Table 9). The categories were; Being empowered through challenges; Gaining insight, motives and rising concern about the future; To participate is worthwhile, if you are seen; and Togetherness in prosperity and adversity. Quotes related to subcategories in italic are attributed to participants with fictions names in brackets with in the text below. In the quotations presented below, ellipses indicate pauses.

Table 9. Subcategories and categories emerging from interviews

| Sub-category | Category |
|--|--|
| Being challenged is rewarding Daring and coping provide satisfaction and self-esteem | Being empowered through challenges |
| Generation of new insight and reflection Striving for maintaining improvements and hoping for continuation Fearing the future | Gaining insights, motives and rising concerns about the future |
| Participation is viewed as a privilege Responsiveness and support create security Perceiving unfulfilled needs and expectation | To participate is worthwhile, if you are seen |
| Experiencing joy and friendship Perceiving obstacles to interaction | Togetherness in prosperity and adversity |

Being empowered through challenges

Being challenged is rewarding

The participants described examples of everyday activities that they now felt more capable doing, or that they could manage again; for example, being able to walk upstairs or rise from a chair without difficulty. Participants also discovered physical improvements that they had made during the exercise sessions as the program progressed. They expressed increased awareness of how much they could push themselves during exercise and in everyday life: “Well...and so here I can go by myself...I have my hairdresser here and the supermarket...it is not so

far away and I manage it” (Sally). One woman stated that she prevented a fall when vacuuming due to her increased balance and leg strength.

The participants initially felt unsure or hesitant about participating in the intervention program, but they gradually changed their minds. They expressed that being challenged was rewarding, when this in turn led to successful management of achievable rehabilitation activities. *“She [the occupational therapist]...I told her we walked together me and my husband...and so she said...she thought I should try to walk by myself...well it is not far, she thought it should work...So we said I would try and then I have been trying and it worked...so...if they were afraid that this with the memory...that I would go wrong as well, but now I have walked so much so there is all the time when I go out...It's like a sense of freedom.” (Sally)*

It felt important for the participant that all rehabilitation activities offered were at an appropriate level and adjusted to individuals. The participants described the exercises as individualized and gradually increasing in difficulty to challenge them to improve further. The challenging exercises gave the participants a positive feeling after performing them: *“...it is something very positive when you increase your strength all the time” (Andrew).* Participants were surprised that the exercises made them sweat and have sore muscles. The exercise and activities were sometimes very demanding and felt slightly hazardous. The participants realized that they would not have been able to practice at the same challenging level by themselves: *“...and there have been difficult things that may have been a bit dangerous so that you would fall and so we had a belt with a handle in the back in case...” (Betty).*

Daring and coping provide satisfaction and self-esteem

Participants perceived themselves as being more competent in daily activities than before the rehabilitation, which led to feelings of increased self-esteem. One participant mentioned that she had obtained credit for her progress, and another felt that she had blossomed again. Participants expressed that they were happier and more satisfied when they dared to do more things, as they did in the rehabilitation, and they felt strong and experienced. One woman said, *“Yes...so...I think about how I would have been if I had not been in the project, I think that I am much more alert and happier and dare to do more things than I would otherwise” (Bridget).* They mentioned that they could handle their life situations better and felt joy when others thought they were more capable: *“One might have become a little bit freer...when others think that you are capable...” (Elsa).*

Another positive aspect that participants mentioned was the opportunity to change their environments when they traveled to the day rehabilitation unit. They described it as invigorating and reported that it strengthened their self-esteem and confidence in going outside their homes by themselves. They described that being welcomed and awaited at the day rehabilitation unit aroused positive emotions: *“Yes, but for me, it is to get out...because I have been so tied up at home...because I have sickness...and then you become bound...Yes...really...” (Nea).* Participants also expressed that the digital memory aids they received

facilitated their everyday lives, for example by reminding them to take their medication or clarifying whether it was day or night: *"It is incredibly good I think...the clock shows time, day, and morning or afternoon...it is perfect...it is easy to check if one is unsure"* (Boris).

Gaining insight, motives, and rising concern about the future

Generation of new insight and reflection

The participants reported that the rehabilitation had resulted in new insight and reflection. They expressed, for example, that they had the ability and desire to improve their situations, despite their illness: *"and you feel that you are good and see that you are at least as good...it is so...what is it...the ability to want to be a little better..."* (Eric). The participants realized that engaging in regular activities had a positive impact on their mood: *"...yes...and to feel satisfied when I get home and feel how nice it was that I did that today"* (Karen). Participants emphasized that the continuation of exercise was easier when they experienced improvements during the rehabilitation process, and that this experience created motivation to continue. To be active and to have something in which to participate twice a week gave them a sense of satisfaction, and was something for them to look forward to. The participants also realized that they were not alone in having dementia, and that dementia had many manifestations and affected people in different ways. They compared themselves to others in the group and reflected on the fact that some were in worse condition than others. The realization that they could be worse was a positive insight: *"The most important afterward was you realize maybe that you are not so affected yourself...you are quite good compared to the other ones who are in the group..."* (Adam).

Striving to maintain improvements and hoping for continuation

The participants described that they were striving to maintain the improvements that they had achieved during the rehabilitation. They felt that it was important for them to take responsibility and to plan to continue exercising after the rehabilitation period, on their own or in another form. Some participants wished to continue in the program after the rehabilitation period, and to have some kind of follow up. To be persistent was described as valuable; participant said, *"I do not think I have any problem so to say, forcing me to do regular exercise when I notice that it gives results so that...it is important that you hang in there."* (Boris).

Some participants had already made plans for continued engagement in activities, and others stated that were going to continue with previously appreciated activities, such as visiting the library. They were also expected to continue exercising in other regimes, but some felt uncertain about how to carry out activities in the future. Some participants felt unsure about activities in general and about which activities to do, as well as doubts about daring to go to activities in the community by themselves. One woman hoped to include her husband in her training regime for support and togetherness: *"I will try to get my spouse to come with me, but he does not want to train. He might be able to help me a little...set things up..."* (Bridget).

Fearing the future

Participants expressed concern and uncertainty about the future, which may have been elicited during the course of rehabilitation. They emphasized that they were fearing the future and expressed anxiety about what the future might hold for them and how they would end up. Some participants saw no solution to their situations. Participants expressed anxiety and fear about not being able to understand things in the future and about losing the ability to engage in everyday life. They perceived having an incurable and accelerating disease as scary. Furthermore, some participants had emotional responses to being in a group of participants with different stages of dementia. One woman described feeling grief when she compared herself to fellow participants, and when she realized what the next stage of the disease might be: “...so I have felt a sadness in being in a group that..is not constructive for me...but constructive for the purpose in this case...so I never thought that I would quit or say that I won't do this, but then I already had that feeling in me that now I am on the threshold of something that becomes much, much worse...” (Betty).

To participate is worthwhile, if you are seen

Seeing participation as a privilege

Participants expressed that participation in the intervention was a privilege. They stated that they experienced the program as a fantastic and generous venture that gave silver linings to their everyday lives. Participation was described as a great benefit and as nice, luxurious, and positive: “Yes, all of this arrangement is absolutely amazing.. to be part of it...makes a difference...you get a status how you stand really...so I think...I have also pointed out that it is incredible to be part of such a group” (Boris). The participants appreciated the invitation to participate, and felt privileged to have been selected for the rehabilitation program. They were also grateful for the ability to contribute to the research project, and felt that it was important to take part in what the rehabilitation program offered.

Some participants experienced no rehabilitation-related change or influence in their everyday lives, but still perceived that the project had been good for them. They could continue with their previous activities, such as attending lectures or continuing with chi-gong lessons, in the same way as they had before. Some participants could not express whether any change had occurred, and said that this was for others to decide.

Responsiveness and support create security

The participants appreciated that the staff had appropriate skills and characteristics for the rehabilitation, and commended them for their qualities, which contributed to their well-being. The staff's support and care were responsive (sensitive) to their individual problems, which created security. The participants emphasized that the rehabilitation team provided great overall service and that the staff had been handpicked for the purpose: “I think what we have done has been good in many ways....and...the people who have been

there...it has felt like...yes you feel that they are used to dementia, so you relax...they have been...It has felt as normal when we have sat and talked” (Bridget). According to the participants, the staff was able to see each person’s progress, and had the ability to adapt treatment to personal needs. The participants expressed that the size of the team was appropriate for the purpose: “Yes it is nice people...they have been attentive...if you ask you get answers to everything you ask about...helpful in every way...so that...but I think that is a suitable size team anyway to try to do something like this...” (Adam).

The participants appreciated being greeted by staff members at the entrance of the rehabilitation unit, which made them feel safe and welcomed. They very much appreciated the assistant nurse. She assisted with practical things, such as travel plans for session attendance and the organization of coffee breaks. Participants also mentioned that leaving their partners at home when traveling to the day rehabilitation unit was a positive aspect, as it gave them opportunities to miss their partners: *“I think it is good...and then it may be good that we get to be apart for a while...then I'm there half a day, so she can find something else to do, then maybe some hour when I miss her...ha ha...just a thing like that...” (Eric). They described the taxi trips as a privilege that solved the logistical problem of getting to and from the day rehabilitation unit, and thus reduced potential feelings of anxiety before leaving home.*

Perceiving unfulfilled needs and expectations

Some participants stated in the interviews that they had needs that were not met by the rehabilitation program. They voiced, for example, wishes for more information about dementia, more help from the doctor, and more strength training. One woman expressed that she did not feel she was seen as a capable individual, and that the focus of the rehabilitation was on participants’ relatives. *“We are not alike and have not come as far in our illness, this should be the least you think of there...or most people think ...” (Eva). Participants had constructive suggestions for changes to the rehabilitation, such as group allocation based on functional level and disease stage, which would result in the formation of a group for those in the early stage of the disease.*

Participants had different expectations about the content of the rehabilitation and what it would lead to. Expectations mentioned were taking part in lectures given to relatives instead of being on one’s own in the exercise session, and having coffee together with relatives afterward. One woman wanted to find a friend during the rehabilitation. The difference in the focus of the program between participants and their relatives was also mentioned. Some participants described difficulties in adapting to the logistics of traveling between their homes and the day rehabilitation unit. The travel caused stress and uncertainty, for example when having to wait for the taxi, and when the taxi came long before the scheduled time.

Togetherness in prosperity and adversity

Experiencing joy and friendship

The participants described having fun and forming friendships in the group at the day rehabilitation unit. They described the atmosphere as relaxed, with support and boosting of spirits. They characterized the group as stimulating, which implied a sense of being comfortable. This comfort, in turn, led them to dare to contribute to the group: *"I think it is important for such activities in the future also, that it is a slightly smaller group that stimulates each other, because it is not every day you think positively, there are days that are negative and you lie low...to alternate each other is important"* (Adam).

The coffee break after the exercise was highlighted. Having coffee together and talking was described as a pleasant experience. Participants felt positively about the conversations that occurred during the break, and expressed that everyone felt included and involved in the dialog. They felt able to talk like "ordinary" people and to discuss current topics. However, when the participants talked about all of these positive aspects, sad feelings emerged that the rehabilitation program would end soon. They expressed that they would miss the activities, the staff and the other participants in the group: *"...but I will miss the others in the group...I will do that...well I think it has been good...better than if you were alone"* (Bridget).

Perceiving obstacles to interaction

The participants also perceived obstacles to interaction in the group setting, describing the group situation as complex given the variation in participants' abilities and personalities, which meant that it was not always easy to interpret others. They emphasized the importance of contributing and communicating with each other in the group. They also mentioned feeling sad because they had not gotten to know each other well during the rehabilitation period. They also described grief about being unable to communicate actively in dialog with everyone in the group, or to keep conversations going, as some in the group could not actively engage in the dialogue. *"...then we sit together around this table, and they are very nice those who take care of us, but then...it can be fun if you find a topic of conversation, but it all ends...it is not possible for these people to respond, but the nurses try to keep it going further so we get some views on what we are talking about and so, but then no one comes with their own point of view associated with the topic...or maybe something completely outside...so the conversation stops from its own lack of...fuel, so to say"* (Betty).

Discussion

This thesis contributes new insights about applicability, motivation, and exercise response of high-intensity functional exercise and experiences with rehabilitation, among people with dementia. Older people with dementia in nursing homes who participated in high-intensity functional exercise motivation during sessions was generally assessed high, which did not differ from the motivation to engage in a social activity and increased over time. Many participants had fluctuations in motivation among exercise sessions, and motivation during sessions was greater than motivation to go to sessions. The majority of participants had high attendance rates and could exercise at moderate to high lower-limb strength intensity and high balance intensity. The exercise program caused only minor and temporary adverse events. Participants with non-AD performed strength exercises at high intensity in more sessions than did those with AD. The most common barriers to exercise session attendance were low motivation, illness, and tiredness. BPSD, including apathy, and pain were associated negatively with the applicability of the program. After the exercise intervention, many participants had improved functional balance, but a large degree of individual variance was observed. The applicability of the exercise program and motivation during exercise did not differ significantly between exercise responders and non-responders.

Interviews with community-dwelling older people with dementia who took part in a person-centered multidimensional interdisciplinary rehabilitation program described being empowered through the challenges of the intervention. Through the intervention they gained insight, motive, and raised concern about the future. They felt that participation in the program was worthwhile, if they were seen. They described their experience of being part of a group during the intervention as being together in prosperity and adversity.

The findings of research conducted for this thesis are important for the planning and promotion of exercise and rehabilitation for older people with dementia in various settings and stages of dementia disorder. This population should not be excluded from rehabilitation and high-intensity functional exercise.

Motivation to participate in exercise

To my knowledge, the motivation to participate in high-intensity functional exercise among older people with dementia in nursing homes has not been evaluated quantitatively in previous research. In the UMDEX study, participants' motivation was assessed as high in the majority of the strenuous exercise session despite apathy, cognitive and physical impairments, high age, and medical conditions and was also comparable with the less physically demanding social activity. On the other hand, a functional exercise program might be less cognitively demanding than a social seated activity, and therefore preferable¹⁴⁵. The findings contrast with those of a study in which persons with cognitive impairment preferred less physically demanding exercise, although that study focused on physical activity preferences¹⁴⁵. The fluctuations in motivation

observed in the research conducted for this thesis can be explained by variations in participants' daily conditions and the development of new acute medical conditions, which are common in this population⁴⁶. The increase in motivation over time in the exercise group may be explained by perceived improvements in physical function over the course of the intervention, and the previous exercise habits of 70% of participants. Past experience, perceived benefits, the positive feeling of being active, the feeling of meaningfulness acquired by routines, and the sense of commitment were facilitators of physical activity in community-dwelling people with dementia¹⁴³. In interviews, participants in the UMDEX study emphasized that they experienced improvements in mental and bodily strength due to the exercise, and that the exercise evoked body memories of exercise¹²². Given that the individually tailored exercise program was performed in small groups with the same leaders and participants each time, motivation also may also been increased by the routine, familiarization, and sense of commitment.

The significantly lower motivation to go to activity sessions than during activity session, especially in the exercise group might be contributed to apathy and low initiative⁴⁸, as well as, anxiety about upcoming events¹⁶⁴, well-known symptoms in people with dementia. The difference in motivation to go to sessions between groups might be explained by feelings of anxiety and unease in the more physically demanding exercise¹⁴⁵. This have been described as barriers to physical activity before^{124,143} and these barriers might not have been equally decisive in the group attending the seated social activity. As motivation seems to increase during exercise and over time, it is important to encourage people with dementia to join exercise.

Applicability of the exercise program

The high-intensity functional exercise program seemed to be applicable with regard to attendance, achieved exercise intensity, and the occurrence of adverse events in people with dementia in nursing homes. The attendance rate in the UMDEX study was high, considering participants' significant cognitive and mobility impairments, and the high prevalence of medical conditions and it was similar to those reported for other of high-intensity functional exercises among people with dementia in similar settings^{117,120}. Furthermore, the attendance rate was only slightly lower than reported for community-dwelling sedentary older adults participating in various exercise regimes¹⁶⁵. In our study, the activity leaders and staff helped the participants to the sessions when needed, which probably contributed to the high attendance rate, as demonstrated previously¹⁶⁶. The leaders probably made important contributions to motivation during the exercise sessions, as shown in Paper I, which also may have contributed to the high attendance rate. Another factor contributing to attendance was the ability to conduct individual sessions. Similar to the findings of other studies of exercise for people with dementia in nursing homes, and in accordance with barriers to physical activity in community-dwelling people with dementia¹⁴³, low motivation, illness, and tiredness were the most common reasons for non-attendance^{114,118}. Such low motivation is reported in Paper I. Furthermore, BPSD, including apathy, affected program applicability negatively in this study.

In accordance with exercise recommendations, and similar to the findings of other studies conducted with this population^{117,130}, participants achieved moderate to high intensity in strength and balance exercises in almost all attended sessions^{4,87}. Factors potentially contributing to this result are the ease of following the program's functional exercises for people with cognitive impairment, and the individual adaptation of the exercises. However, many participants did not reach high intensity, especially in strength exercises. That participants with non-AD were able to perform strength exercises to a greater extent may have contributed to the superior effects on ADL and balance compared with those seen in participants with AD, as shown previously¹³³. Lower-limb strength is important for functional performance^{99,100}. Despite comorbidities, including cardiorespiratory diseases, strength exercises strained mostly peripheral lower-extremity muscles. This effect may be considered to be positive, as exercising to muscle fatigue is prerequisite for increasing muscle strength. Fear was a common reason for not achieving high intensity in balance exercises, and the build-up period, low motivation, and pain were common barriers for not achieving high intensity in both strength and balance exercises. Pain while walking and analgesic use were also associated with adverse events. To help this population exercise at high intensity, addressing motivation and treating pain may be important.

Not surprisingly, the proportion of adverse events was larger in the exercise group than in the social activity group. The most common adverse events in the exercise group were musculoskeletal, likely due to the high prevalence of osteoarthritis and the desired high intensity of exercise. The most common adverse events in the social activity group were psychological and general/unspecified, not musculoskeletal, likely because the activity was more cognitively than physically demanding. The incidence of recorded adverse events during exercise sessions in the study was higher than reported in a study involving people with dementia in nursing homes¹³⁰. Reasons for this difference may be the greater prevalence of medical conditions, greater dependency in ADL, and more severe cognitive impairment in our study group⁴⁶. Nevertheless, all adverse events were minor and temporary. The use of waist belts with handles, the PTs' ability to modify exercises according to participants' health status, and PTs' close attention to participants' non-verbal communication¹⁶⁷ were factors important for the safe achievement of the exercise. The PTs were also able to obtain updates on participants' health status by communication with nursing home staff, and to contact physicians or nurses when needed.

Balance response among older people with dementia

The applicability of the exercise program and the motivation during exercise did not differ significantly between those responding and not responding to the program. The associations of exercise effects with motivation, exercise intensity, and the occurrence of adverse events in people with dementia has, to my knowledge, not been evaluated previously. However, the association between attendance and exercise effect has been evaluated^{117,119}. One study¹¹⁷ revealed that an attendance rate $\geq 50\%$ was associated significantly with improvement in the chair-stand test, but not with improvement in the BBS score. The chair-stand test

is a functional measure that involves lower-limb strength and balance, and is included in the BBS assessments. However, direct comparison of this finding with our results is not possible, as the control group was included in the assessment and the participants had fewer comorbidities and better physical function than did our population¹¹⁷. In accordance with our findings, one study¹¹⁹ showed that attendance was not a significant predictor of successful training response for the chair-stand test. That study was conducted in outpatient facilities, and most participants were community-dwelling older people with dementia with higher levels of cognitive and physical function and fewer comorbidities than in our population¹¹⁹.

In accordance with our result, a review demonstrated that the exercise program modalities inadequately explained effects of balance exercises in older people¹⁰⁶. In contrast, a review of the effects of balance exercise in healthy older adults identified an effective balance training protocols¹⁰⁵. Exercise intensity was not evaluated in those reviews because it was not reported in the included studies. This factor has been noted previously, with a call for further research⁹⁰, and intensity is included in the HIFE Program. Lastly, greater effects on fall prevention was shown, in exercise programs that challenge balance and include higher doses of exercise, in an earlier review¹⁰⁷. Given the inconclusive nature of reported findings, more research exploring how exercise modalities affect balance exercise responses in various groups of older people, including those with dementia, is needed.

The lack of association between exercise effect and applicability or motivation in this study has several possible explanations. People with dementia living in nursing homes form a heterogeneous group with progressive diseases along with comorbidities and additional new medical conditions⁴⁶, which can confound and reduce responsiveness to exercise, as seen in the present study. We found, however, no difference between responders and non-responders in baseline characteristics or the development of new medical conditions during the intervention in the univariate analysis, with the exception of greater ADL function among responders. One reason may be the participants' daily physical activity levels, as most people with dementia living in nursing homes are inactive throughout the day⁷⁹. The extra physical activity that they performed during the intervention, including transfer to the exercise session locations, might have benefitted some participants with low physical activity levels, regardless of exercise intensity during the sessions. The social activity in the UMDEX study, which consisted of seated activity at the same frequency and duration as the exercise, also involved transfer to the activity location¹³³. In the social activity group, BBS scores decreased by a mean of 1.8 points (in contrast to a mean increase of 2.3 points in the exercise group)¹³³, but a large degree of individual variability (range, -25 to 21) was observed.

Furthermore, discrepancies may have existed between participants' physical capacity (what they could do) and their physical performance in daily life (what they actually did)¹⁶⁸. Nursing home residents may receive help even when they are able to do things themselves, and thus may not use their full physical capacity

in daily life¹⁶⁸. Additionally, the lack of opportunity, intention, and suitable activities in nursing homes may prevent residents from using their full physical capacity¹⁶⁹. The lasting effects of the intervention might have been blurred by non-use of participants' improved capacity in their daily lives, even if the participants who exercised at high intensity and had high attendance rates achieved the most improvement during exercise sessions. The importance of being able to use one's own capabilities, without support from others, in achieving a lasting exercise effect has been mentioned previously¹²³, and was reflected in our study by responders' higher Barthel ADL Index scores and the greater proportion of participants who walked independently (according to the univariate regression results).

Although participants met exercise recommendations, their functional balance responses showed a large degree of individual variance. Such individual variance in exercise responses from group means has also been found in exercise studies conducted with older people without dementia¹¹⁰⁻¹¹². Individual factors proposed to be associated with exercise response include hereditary factors, the pre-training phenotype, characteristics of the exercise program (intensity, frequency, and duration), activity level, functional level, lifestyle factors, recovery and sleep between sessions, dietary intake, and measurement-associated factors¹⁷⁰. Furthermore, exercise response in terms of functional measures can also be obtained at lower intensity and frequency, as shown in a meta-analysis of resistance training in older people, in which the effect was independent of exercise intensity¹⁰¹. Additionally, the normal course of dementia involves a decline in functional ability over time. In one study, nursing home residents' BBS scores decreased by an average of 2% per month¹⁷¹, translating to an expected approximately 8% decrease over a 4-month period. This factor might also have contributed to the variance in exercise response seen in our study population.

The difficulty of predicting who will respond to balance exercises may be related to the nature of balance, a multifaceted function. Reduced motor learning ability due to neurodegenerative disease and cognitive impairment may also influence the effects of exercise in people with dementia^{98,138}. Task specificity may therefore be more important in this group, as they can have a reduced ability to transfer to other situations when learning new skills and is more dependent on implicit procedural learning⁹⁸. Therefore, the HIFE program is a good alternative exercise intervention for this population, as the exercises are similar to positions used in everyday situations.

Rehabilitation experiences: empowerment, insights, worthwhile, and togetherness

The MIDRED intervention is a good example of an interdisciplinary rehabilitation designed according to the ICF, with the consideration of health conditions and contextual factors in intervention implementation for community-dwelling older people with dementia and their informal caregiver⁵⁴. MIDRED participants described the positive experience of being challenged in the physical exercise and in daily activities, similar to reported positive

experiences of being challenged in exercise participation among people with dementia in nursing homes^{122,123}. Coping with challenges increased feelings of competence and self-esteem, and the participants felt empowered. It may be important to feel that one can dare and cope with things in daily life, regardless of whether one has dementia. A sense of empowerment, having something expected of you and being able to accomplish it, improves mood and self-esteem, as shown in an exercise study whose participants had dementia¹²³. The informants in this study also identified the importance of having meaningful activities in life to feel satisfied. Meaningful activities are those that one wants to do, has to do, or need to do during the day¹⁷². This finding is in accordance with those of a study conducted with individuals with mild cognitive impairment, who expressed that a good life was characterized by doing what they want to do, living in the present, being engaged in social and physical activities, and having good relationships¹⁷³. Engagement in activities fills a void, enhances role identity, and helps people with dementia to express themselves positively¹⁷⁴. These factors may in turn provide control over self-identity, a critical attribute of selfhood that may endure throughout the disease process¹⁷⁵. Older people participating in home rehabilitation also emphasized the importance of the ability to perform meaningful activities without feeling dependent on others¹⁷⁶.

The participants gained insight though that they despite their illness, were able to influence their situation. They realized that they had the ability to improve their physical status through exercise. Engaging in regular activities also affected their mood positively and performing meaningful activities in daily life benefitted their well-being. These findings are in accordance with interview data from persons with early-stage dementia attending an activity center¹⁷⁷. That engagement in group activities can trigger reflection and adaptation also has been voiced by members of pre-discharge occupational therapy groups participating in geriatric rehabilitation¹⁷⁸. The participants realized that they were not alone in having the disease, which strengthened them in their situations. This finding is in accordance with the results of the study conducted at the activity center, whose participants emphasized that being included in a fellowship was important¹⁷⁷. Some participants expressed fear about their future situations, including the inability to perform activities later in life, in line with the experiences of individuals living with mild cognitive impairment¹⁷³. These feelings were sometimes evoked by comparison with fellow participants whom they viewed as more stricken by the disease than themselves.

The participants expressed gratitude for being able to participate in the intervention, saw participation as a privilege, and expressed that their ability to contribute to the project was important. People with dementia in nursing homes who participated in an exercise intervention also emphasized the importance of being invested¹²³. These expressions are contrary to those of Australian rehabilitation professionals, who thought that achievable outcomes were not sufficient to make investment in this group worthwhile⁶⁸. Furthermore, participants praised the staff, who they perceived as having been handpicked for the purpose. The staff's responsiveness created security, and participants emphasized the importance of being welcomed and seen. Similar findings were obtained in the study conducted at an activity center, whose participants noted

the value of having the staff see them and treat them as normal people; they also noted that the staff's welcoming attitude was important¹⁷⁷. In the present study, participants raised concern about needs that were not satisfied by the intervention and about not being seen by the staff, and made suggestions for intervention improvements. This feedback is valuable for the improvement of rehabilitation for this population. Some participants also perceived obstacles to interaction in the groups due to their diverse needs, which might be difficult to overcome in a population with a progressive neurodegenerative disease. However, the design of groups with more consideration of function and ability, and the allocation of those in the early stage of the disease to certain groups, as suggested by some participants, might address these obstacles to some extent.

Exercise and rehabilitation in the context of motivation theories

The motivation results from the UMDEX study and reported experiences from the MIDRED study can be interpreted within the framework of motivation theories, according to the concept of self-efficacy from social cognitive theory and SDT. The participants in both studies may have increased their self-efficacy by perceiving improvements and successfully managing exercise and activities (mastery experience)¹⁴⁰. Participants' self-efficacy may also have been increased by watching fellow group members (vicarious models) succeed in the exercise and by receiving positive, encouraging feedback from skilled leaders (one form of social persuasion). The skilled leaders may also have given support and been able to help with eventual physiological and affective states related to the exercise and rehabilitation, as people with dementia can be more prone to feelings of insecurity¹⁴⁰. Being empowered through challenges can be interpreted as having increased self-efficacy¹⁴⁰. The increased self-efficacy after exercise documented in our research is in accordance with interview data from people with dementia in nursing homes who exercised according to HIFE¹²³.

The high motivation levels during exercise and increased motivation over time in the UMDEX study, and the reported empowerment through challenges in the MIDRED study, can be interpreted according to the SDT^{135,141}. The exercise in the UMDEX study and rehabilitation in the MIDRED study may have fulfilled the basic needs of autonomy, competence, and relatedness, which SDT holds are essential for optimal functioning. Although autonomy might be reduced in people with dementia, it may have been strengthened in our study participants by choosing to attend exercise and rehabilitation sessions. In the MIDRED study, the person-centered approach with individual goals, and the opportunity to leave home to participate in exercise, might have further satisfied participants' autonomy. By daring and coping, perceiving improvements in daily activities, and successfully managing challenges and the exercises, participants might have gained competence. Additionally, exercising in the same group of people with the same competent leaders may have strengthened feelings of relatedness. These factors are important to consider, as more than half of participants in both studies population, as in the UMDEX study more than half had experienced loneliness and had symptoms of depression. In a longitudinal study conducted in northern

Sweden, the prevalence of loneliness among the oldest old was related closely to living alone, depressive symptoms, and living in institutional settings¹⁷⁹.

The group as an important factor

The group setting was an important part of the UMDEX and MIDRED interventions. Being in a group with similar people can facilitate and augment positive effects for individuals, and group contexts are emphasized in physical activity and exercise recommendations for older adults living in long-term care facilities⁸⁷. In my clinical experience, being in a group with people in the same situation provides opportunities for a great deal of encouragement. Recognition can strengthen individuals in their current situations, fulfill the need for relatedness in accordance with SDT, and strengthen self-efficacy through the presence of vicarious models. Participants in the MIDRED study realized that they were not alone in having dementia, which strengthened them in their situations. The same was found among people with dementia visiting an activity center, who emphasized the importance of being included in a fellowship¹⁷⁷. Similarly, UMDEX participants expressed in interviews that togetherness gave them comfort, joy, and encouragement¹²². Participants in the MIDRED study also described having fun together, and recognized that they could support each other. Additionally, relationships with other group members and intervention leaders seemed to facilitate participation, as shown previously¹²³. Having a sense of belonging, being included in enjoyable and meaningful activities, and feeling supported have been emphasized as important for the ability to cope with dementia¹⁸⁰. Participation in appreciated activities and a sense of fellowship may have positive influences on health and well-being¹⁷⁷.

The importance of skilled leaders in exercise and rehabilitation

The UMDEX and MIDRED studies confirmed the importance of skilled leaders for the success of exercise and rehabilitation programs, in line with my clinical experience. Leaders seem to have important effects on attendance and increase self-efficacy and motivation, especially in people with dementia, who commonly show low initiation motivation and lack of interest. By giving positive, encouraging feedback and helping with eventual physiological and affective states, leaders can increase self-efficacy. The credibility of feedback is also important in increasing self-efficacy¹⁴⁰. Leaders can also be important for relatedness and competence according to SDT, and can act as external vicarious motivators when motivation is low, especially in the beginning of an exercise or rehabilitation period¹³⁵. All leaders had experience working with people with dementia, as indicated in interviews, which probably contributed to the success of the UMDEX and MIDRED interventions^{122,123}. Participants in the UMDEX study expressed that the exercise program was achievable, albeit challenging, because it was supervised by skilled leaders¹²². Participants in the MIDRED study perceived the staff as having been handpicked for the purpose. These findings are in line with the results of a similar study, in which instructor competence was found to be an important facilitator of exercise¹²³. In interviews, PTs in the

UMDEX study expressed the importance of building relationships and trust through verbal and non-verbal communication in the process of learning to meet participants' unique needs over time¹⁶⁷. Furthermore, the presence of professional exercise instructors in nursing homes was associated significantly with exercise adherence, duration, and frequency¹⁶⁹. Additionally, the UMDEX study participants were dependent in ADLs and required support from others to be able to join the activities; the significance of help has been mentioned previously¹⁶⁶. Another possible factor contributing to intervention success is leaders' internal motivation to do a great job because they believed in the project and strived to carry it out in the best possible way.

Challenges in exercise and rehabilitation for people with dementia

People with dementia may face many challenges when participating in exercise and rehabilitation. Complications of dementia, fluctuations in physical and cognitive function and comorbidities, all of which are common in this population, may affect participation. Dementia disorder is comprised of several diseases with different courses, and disease progress varies at the individual level. Thus, different intervention setups and support systems are needed for people at different points in the course of dementia. In the initial stages of dementia disorder, people may be able to attend regular exercise classes in the community. Further along in the course of the disorder, more individualized support and setups may be needed. Individualized interventions based on individuals' problems, needs, and resources provide pathways by which to navigate this variation. The research conducted for this thesis showed that individualized high-intensity exercise in groups according to exercise recommendations is feasible and fruitful for people with moderate dementia in nursing homes. The HIFE Program appears to be useful for people with dementia in various settings. In addition, rehabilitation is possible and fruitful for community-dwelling older people with dementia. Results from the thesis research and previous studies show the importance of offering personalized exercise and rehabilitation¹⁴⁹ and activities that address physiological and social needs, as it is related to the quality of the experience for people with dementia¹⁴³. Furthermore, knowledge of participants' past experiences when motivating them has been found to be a key factor¹⁴⁶. Addressing people's positive emotions, bodily memories, and past experience might also be an effective approach for this population.

Methodological considerations

In the UMDEX and MIDRED studies, selection bias was a risk due to the inclusion only of people who indicated in advance that they wanted to participate in the intervention. The structured and well-described HIFE program was used in both studies. This program was used in several previous studies conducted with people with physical and cognitive deficits. The testers in both studies had medical training and experience working with older people with cognitive and physical impairment, which minimized the amount of missing data.

Specific issues for Papers I–III

Some limitations of the UMDEX study should be considered. The proportion of men in the study was much smaller than that of women. This imbalance is typical in studies conducted with older people, as women generally live longer than men. In addition, more men than women declined to participate, and the risk of selection bias may have been present. However, the results did not differ according to sex in any analysis. Activity leaders subjectively assessed exercise intensity and motivation, which weakens the validity and reliability of the assessments. Nevertheless, the research group deemed the scales used to have good face validity¹⁶³ and the prerequisites for a high degree of reliability, as they include non-replaceable categories that have been described in detail and the scales were well known to the activity leaders in advance¹⁶³. In the study reported in Paper II, many analyses were performed and the results must therefore be interpreted with caution, but many different variables were included in the analyses. Additionally, the non-AD group was heterogeneous, as it included participants with different dementia subtypes, but further subdivision was not possible due to analytical power issues. The study reported in Paper III may have lacked power due to the small sample. In addition, the results should be interpreted with caution, as the exercise modalities were not randomized, and exercise was analyzed as actually performed. Furthermore, the dichotomization of the outcome variable has disadvantages; data variety is lost, and participants with deteriorated balance were treated as equivalent to those with balance improvement below the MDC. However, we found no significant association when using the total difference in BBS scores as a continuous dependent variable. The MDC may not be a suitable cut-off in a population with a progressive disease, in which the preservation of function can be considered to be a positive result, as nursing home residents show an average 2% decrease in functional balance according to the BBS per month¹⁷¹. A less than 5-point increase in a group with a progressive disease might still have an effect on everyday life over time.

A strength of the UMDEX study is that activity leaders could consult nurses and doctors when needed. Other strengths are the use of an intention-to-treat approach, and the loss of a small proportion of participants, considering the high frequency of comorbidities and other medical conditions. In addition, the study population was characterized by a large degree of variation. The use of randomization and a social activity as a control must also be considered study strengths. Before the study, the leaders reached measurement coherence on intensity scales for the strength and balance exercises in the HIFE Program. The intensity scale for the balance exercises has been requested previously⁹⁰. Another strength of the UMDEX study is the collection and analysis of extensive data on applicability and motivation: Paper I describes the capture of repeated measures over the long intervention period and the use of ordinal regression, which enabled examination of the motivation scales in their original form; Paper II describes the extensive collection of reasons for non-attendance and reasons for not achieving high intensity, and the registration of the amount and types of adverse events; and Paper III describes the broad inclusion of factors that may have affected the balance response to exercise.

Specific issues for Paper IV

MIDRED study participants were from local health centers in Umeå and were registered at the outpatient unit of the geriatric clinic. The intervention was tailored individually based on participants' problems, resources and needs, which made success at the individual level more likely. Reproduction of the study in a different setting would require the same setup, with multiple professionals working together, and the consideration of content. The purpose of this interview-based study was to evaluate the experiences of people with dementia taking part in a person-centered multidimensional interdisciplinary rehabilitation. Some limitations of the study need to be considered. The sample was selected in the sense that all individuals agreed to participate in the intervention. The rehabilitation program was set in northern Sweden and is not currently offered in other parts of the country or the world. The results are not generalizable to other rehabilitation programs. The groups in the rehabilitation program were not designed based on physical and cognitive function; such as design was suggested as an improvement by some participants. When interviewing people with dementia, reduced memory and awareness of the disability might influence responses to questions. However, efforts were made to facilitate interviewees' recollections. The interviews were conducted in close connection to the intervention visits, together with the use of recall cues, such as pictures of the staff.

The strengths of this study include the use of qualitative content analysis, which facilitated the examination of variation in the data. The 16 study participants were selected with consideration of achieving variation in responses and saturation in the analyses. The study also shows that people with dementia can be interviewed. The depth and richness of the conversations showed that the participants, despite their dementia disorder, were able to reflect on and describe the rehabilitation program in which they were participating. To increase trustworthiness, the context, method, and results of the study were described in detail. The interviewers had prior understanding of dementia, the rehabilitation process, and the program being evaluated, but did not participate as intervention staff members. When analyzing the data, a large reference group of people of many professions with inside and outside perspectives was used. All had experience in working with people with dementia and in rehabilitation. The analysis provides good insight on the feasibility of the program as a whole. The consideration of participants' experiences is of great importance when evaluating interventions in general and those for people with dementia.

Ethical considerations

Medical research that involves humans must involve careful consideration of whether the potential benefits of the research exceed the potential risks and burdens, guided by the ethical principles outlined in the Declaration of Helsinki. The UMDEX and MIDRED studies are published on the ISRCTN registry website (www.isrctn.com) to improve transparency in conduct and reporting, thereby reducing the risks of transgression and bias. Regional ethics review boards

approved all studies conducted for this thesis. The potential benefits to individuals involved in the studies exceeded the potential risks involved.

Older people with physical and cognitive impairment and dependence in ADL, including people with dementia, are underrepresented in existing research. The study of interventions that may be effective in these populations, for whom no cure is available, is important. As the populations in the studies conducted for this thesis were composed of adults with reduced capacity to understand or consent to participate in research, special considerations were made to protect their health and rights. Participants were provided with written letter about the studies, including indication of their right to withdraw at any time. These letters were also provided to next of kin. Informed consent was given orally and then confirmed orally with the next of kin.

The testers in both studies had medical training and were able to consult a geriatric medicine specialist when they suspected severe depression or other illness. Participants' physicians granted permission for study participation. In the UMDEX study, all PTs, OTs, and OT assistants had extensive experience in working with people with cognitive and physical impairments, and could consult nurses and doctors when needed. Adverse events occurring during the activities were recorded and followed in medical records. In the MIDRED study, geriatric medicine specialists were part of the rehabilitation team. All team members had extensive experience in working with people with cognitive and physical impairment. Adverse events occurring during the exercise sessions were recorded.

In the UMDEX study, the exercise and social activity sessions were held at the same frequency and duration, with the same activity leaders and participants each time. To promote attendance and compensate for the benefits of participating in an exercise group, efforts were made to develop an enjoyable and stimulating control activity. In this way, social interaction was stimulated in both groups. In the MIDRED study, the control group received usual care.

Clinical implications

The HIFE Program seems to be an applicable and useful tool that influences the functional abilities of community-dwelling and nursing home-resident older people with dementia. The results of the studies conducted for this thesis support the inclusion of people with dementia of various stages in various settings in this beneficial type of exercise program.

The promotion of strategies to encourage people with dementia to join exercise groups is of utmost importance because motivation before exercise may be low in this population; motivation also varies and may increase during the exercise and over time. Many individuals can improve their balance, but the balance response is difficult to predict due to the large degree of individual variation. The exploration of strategies to overcome low motivation, a common reason for non-attendance and for not achieving high intensity, and the prevention and

treatment of pain and BPSD are needed and are important to consider when planning activities in nursing homes.

Exercise should be prescribed for people with dementia according to exercise recommendations, despite the ambiguous findings of the research conducted for this thesis. Emerging evidence shows positive exercise effects when recommendations are followed^{86,117,118,133}. To increase the number of completed exercise sessions per week, thereby meeting exercise recommendations, the provision of additional weekly exercise sessions and individualization of session hours according to participants' daily routines and needs may be effective strategies.

Interdisciplinary rehabilitation seems to be feasible and suitable for community-dwelling older people with dementia. This type of rehabilitation may affect well-being and daily life in this population, as well as in people with dementia in other settings.

Despite facing many challenges, older people with dementia in various settings can participate in interventions, including exercise and rehabilitation. The adjustment of interventions according to individuals' points in the course of the dementia disorder is of utmost importance to obtain successful results in research and clinical practice. Furthermore, the presence of skilled leaders of exercise and rehabilitation programs is crucial to achieve successful results.

Implications for future research

To facilitate exercise participation in clinical settings in the future, more studies evaluating motivation in people with dementia in various settings are needed, as few such studies have been conducted. The evaluation of strategies to overcome low motivation, especially before exercise, is also needed to promote exercise in this population.

To aid clinicians and facilitate the implementation of exercise programs, future studies of the applicability of high-intensity functional exercise program should include participants with various dementia subtypes and stages, and in different settings; they should also involve the implementation of the program in clinical practice. Moreover, the reliability of the intensity scales for the HIFE Program needs to be evaluated. Studies should also involve the examination of factors affecting effective exercise provision, such as instructor qualities, staff and facility barriers, and family support.

To obtain eligible balance response effects of exercise in people with dementia, further examination is needed. Future studies should determine which exercise modalities and individual characteristics are important for optimal exercise response in different groups of people with dementia.

Interdisciplinary rehabilitation for people with dementia maybe a promising path for the future. Although the number of people with dementia is increasing rapidly,

research in this area is lacking. More research is needed to explore and evaluate interdisciplinary rehabilitation for people with dementia in various settings and the adjustment of interventions to individual courses of the dementia disorder.

Conclusions

For older people with dementia living in nursing homes taking part in a high-intensity functional exercise program, this thesis shows that:

- Motivation seems to be high during exercise, to increase over time, and to not differ from the motivation to participate in a less physically demanding social activity. Motivation during exercise sessions can be greater than motivation to go to sessions.
- The exercise program seems to be applicable with regard to attendance, achieved intensity, and adverse events. People with non-AD may be able to perform strength exercises at higher intensity than can people with AD. The application of effective strategies to enhance motivation to participate in exercise and to prevent and treat pain and BPSD important when promoting high-intensity functional exercise.
- Participation in the exercise program may improve balance in many individuals, despite individual variation. High attendance, exercise intensity, and motivation rates, as well as the occurrence of few adverse events during the exercise program, may not be associated with paramount balance response. Accordingly, the prediction of balance exercise response based on applicability and motivation does not seem to be possible.
- The promotion of strategies to encourage people with dementia to join exercise groups is of great importance. The research results lends no support to the exclusion of this group from high-intensity functional exercise programs, even when exercise intensity or motivation to exercise is not high.

For community-dwelling older people with dementia taking part in a person-centered multidimensional interdisciplinary rehabilitation program, this thesis shows that:

- Participants had positive experiences, perceived improvements, and felt empowerment as a result of the rehabilitation program.
- This type of rehabilitation seems to be suitable and may influence well-being and daily life in this population.

Finally, this thesis support the inclusion of people with dementia in team rehabilitation and high-intensity functional exercise programs.

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