CHAPTER 7

SUMMARY AND
GENERAL DISCUSSION
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The aim of this thesis was twofold: (1) to gain insight into the demographic and clinical factors associated with care dependency, independence in activities of daily living (ADL), and quality of life (QoL), and (2) to explore the potential benefits of different movement stimulation interventions on ADL performance, QoL, cognitive and physical functions, and mood and behavioral problems in nursing home (NH) residents with moderate to severe dementia. The present chapter provides an overview of the main findings, a reflection on the findings, a discussion of methodological considerations, and implications for future policy, practice, and research.

SUMMARY

PART I: Cross-sectional studies in nursing home residents with dementia

Chapter 2 examined which demographic and clinical factors were associated with care dependency in NH residents with moderate to severe dementia. Care dependency was measured with the staff-rated care dependency scale (CDS), and ADL ability was measured with the performance based Erlangen ADL (E-ADL). Apathy, lower physical endurance, higher number of comorbidities, and lower global cognition were important independent predictors associated with more care dependency, with apathy and physical endurance being the most predictive. Furthermore, there were some indications that executive functions (i.e., category fluency) may also play an important role in predicting care dependency. Global cognition was the only predictor of ADL ability, explaining a large proportion of the variance (60%). The results suggest that a multifactorial intervention may be the most effective intervention to maintain a residents’ highest level of independence.

Chapter 3 investigated the relationship between demographic and clinical factors and different domains of QoL. QoL was measured with the staff-rated Qualidem, which covers nine domains of QoL. Different domains of QoL showed associations with different predictors, highlighting the multidimensionality of QoL. Agitation, depression, and apathy were the most important predictors associated with a lower QoL. Moreover, male gender was found to be associated with having worse social relations. The presence of comorbid neurological diseases was associated with more social isolation, a worse care relationship, and lower total QoL. Last, the presence of endocrine/metabolic diseases and pulmonary diseases was associated with less restless tense behavior. The results suggest that attention should be given to persons with mood and behavioral problems in combination with comorbid conditions, as these persons may be at the greatest risk of reduced QoL.
PART II: Movement stimulation interventions in nursing home residents with dementia

This part of the thesis focused on the effects of different movement stimulation interventions on ADL performance, QoL, cognitive and physical functions, and mood and behavioral problems.

Chapter 4 compared the effects of a 12-month movement-oriented restorative care program (MRC) to care as usual in 61 NH residents with moderate to severe dementia. MRC used a multidisciplinary care approach to integrate movement into the daily lives of residents and stimulate independent functioning. The objective of the study was twofold: (1) to assess the effectiveness of MRC in preservation of ADL independence and QoL, and (2) to examine the degree of implementation and the barriers to the implementation process. The study provided no clear evidence for the effectiveness of 12 months of MRC in improving ADL independence or QoL, apart from a higher positive self-image in the MRC group compared to the care-as-usual group after 12 months. The process evaluations indicated that MRC was not applied according to its core principles. Although all permanent staff members of the psychogeriatric ward were trained in MRC, the amount of stimulation varied from three times per week to several times per day. Understaffing and limited time available for personalized care made optimal implementation of MRC challenging.

Chapters 5 and 6 described the results of a 6-month double parallel randomized controlled trial with three movement stimulation interventions: (1) ADL training, (2) multicomponent aerobic and strength exercise training, and (3) a combined ADL and multicomponent exercise training. The study in chapter 5 focused on the effects of the movement interventions on ADL performance and QoL. Compared to care as usual, six months of ADL training positively affected overall QoL, and multiple aspects of QoL, including care relationship, positive self-image, and feeling at home. No effects were found of ADL training on ADL performance, although a trend was observed that showed a maintenance in ADL performance in the ADL group, and a decline in the care-as-usual group. No benefits were observed of exercise training or a combined ADL and exercise training on QoL or ADL performance. Chapter 6 investigated the effect of the movement interventions on cognitive functions, physical functions, and mood and behavioral problems. Compared to care as usual, six months of ADL training benefitted executive functions (EF) and physical endurance. Exercise training benefitted only grip strength of participants with mild to moderate cognitive impairment. Contrary to our expectations, we did not find any significant effect of the exercise intervention on cognition, physical functions, ADL ability, QoL, or mood and behavioral problems. There were some benefits of a combined ADL and exercise training over ADL only training (i.e., improved functional mobility), exercise only training (i.e., improved depressive symptoms and agitation), and no movement stimulation (i.e., improved physical endurance). However, the ADL intervention was hypothesized to be the driving force for positive outcomes of the combined intervention.
GENERAL DISCUSSION

ADL AS A STRATEGY TO SLOW DOWN DEMENTIA-RELATED DECLINE

Although more and more studies focus on NH residents with moderate to severe dementia, this patient group is still underrepresented in research. However, it is important to include persons with moderate to severe dementia in research, as such research could contribute to the development of interventions specifically developed for persons with advanced dementia, who require different intervention strategies than people with mild dementia. The pragmatic nature of the intervention studies discussed in this thesis offers useful information regarding the effectiveness and implementation in daily clinical practice. When interpreting the results, it is relevant to bear in mind that the study population consisted of NH residents with moderate to severe dementia. This means that large effects of the ADL and multicomponent exercise interventions on patient outcomes (i.e., cognitive and functional abilities, mood, behavior, QoL) were not expected. The small to medium effects of the ADL intervention on physical endurance, EF, and QoL that were found are therefore encouraging.

A striking finding of the study in chapter 5 was that the ADL intervention did not lead to improvements in ADL performance. The ADL intervention was expected to improve ADL functions either directly through practice and repetition of the specific tasks, or indirectly by improving EF, as EF are involved in ADL (e.g., choosing clothes to wear, planning and cooking a meal). However, despite improvements in EF, no significant differences were found between the care-as-usual group and the ADL group on ADL performance. To further examine this result, additional analyses were performed which looked at within group changes in both groups. The results showed that performance-based ADL declined significantly within 6 months in the care-as-usual group (decline of 3.76 points on a scale from 0 to 30, \( p = 0.005 \)), while the ADL group remained stable. Taking into account the advanced study population, and the fact that NH residents with dementia typically show a decline in ADL performance over a 6-month period (which is also confirmed by the care-as-usual group in this study), a maintenance in ADL following an ADL intervention is a relevant finding and underlines the importance of stimulating residents to perform their self-care independently.

In addition, it is important to consider how clinically relevant a small to medium effect on EF (i.e., category fluency) is for NH residents with moderate to severe dementia. Performance on the category fluency task can be regarded as an indicator of independent functioning (i.e., executive control ability which regulates goal directed behavior) and relates to daily production tasks (e.g., making a shopping list). A study by Farina et al. also found improvements on verbal fluency after skill training, however the size of the effect is unknown. Although this EF task may not necessarily directly translate to daily life of NH residents with advanced dementia, EF are among the most important cognitive functions involved in
maintaining independent functioning, and together with a maintenance in ADL and a slower decline in physical endurance, the results suggest that an ADL intervention can positively influence domains which enable persons to function more independently. For instance, the 6-minute walk test (used to measure physical endurance) has been suggested to be reflective of the requirements of ADL performance, as walking difficulties can limit activity and participation in everyday life. 

**UNDERLYING MECHANISMS OF AN ADL INTERVENTION**

It is difficult to identify exactly which aspects of the ADL intervention were responsible for the reported benefits. However, based on previous research, several underlying mechanisms may be involved.

**Underlying neural and vascular pathways**

Firstly, the ADL intervention focused on training daily activities which rely on physical functions. For instance, tasks such as making the bed, standing up from a chair, or getting dressed rely on, amongst others, endurance and upper and lower extremity strength. Studies have shown that physical activity (e.g., aerobic and strength training) can favorably influence brain vitality (i.e., cognitive functions) by enhancing neurogenesis and angiogenesis, cerebral blood flow, brain volume, and levels of important neuroprotective factors such as BDNF and IGF-1. For instance, physical activity has consistently been found to improve EF, and specifically verbal fluency. This association between physical activity and verbal fluency can be explained in part by the selective improvement hypothesis, which suggests that physical activity leads to selective benefits in frontal-lobe dependent tasks. Verbal fluency is an EF task which is mediated by the frontal lobe. The frontal functions that are involved in verbal fluency (i.e., working memory, processing speed, self-initiation, inhibition, and switching ability) are also those that are especially vulnerable for age-related decline. The selective improvement hypothesis proposes that the tasks which show the largest age-related declines (e.g., frontal lobe-mediated executive control tasks) also show the largest exercise-related improvements, as they have the most room for improvement. Moreover, performance on the category fluency task may not only reflect executive processes but also semantic networks. Semantic networks also show impairments in early stages of dementia, and for this reason, category fluency tends to demonstrate a faster decline than, for instance, letter fluency. Taken together, the evidence provides an explanation for why the category fluency task may be most prone to improvements caused by exercise.

The threshold at which ADL training can induce neurobiological change is unknown, however, animal studies provide some evidence that frequent, intermittent, low intensity exercise training can already increase hippocampal levels of BDNF. Moreover, the benefits of exercise on EF that are consistently found are found regardless of the intensity.
of exercise.\textsuperscript{9} For instance, Scherder et al.\textsuperscript{9} observed medium to large effects on verbal fluency following mild physical activity (hand/face exercises). Compared with activities taken from the Compendium of Physical Activities,\textsuperscript{20} self-care and household activities (e.g., light cleaning, washing the dishes, setting the table, making the bed, eating, getting dressed, brushing teeth) are generally classified as light intensity activities, while brisk walking and light-to-moderate weight lifting are classified as moderate intensity activities.\textsuperscript{20} However, some self-care activities, such as taking a shower, are also considered moderate intensity activities.\textsuperscript{20} Altogether, it is conceivable that the intensity of the ADL intervention, which was provided daily in different aspects of self-care and household activities, may be high enough to induce neurobiological change. However, investigating the underlying mechanisms of the relationship between ADL training, neurobiological change, and physical and cognitive functioning was beyond the scope of this thesis. Future studies could consider studying these underlying mechanisms.

**Personalized care approach**
Second, and perhaps most importantly, the personalized and motivational nature of the ADL intervention as well as the focus on remaining capabilities, may have provided residents with autonomy, control, trust, and meaningfulness; aspects which persons with dementia consider important.\textsuperscript{21} We therefore hypothesize that these aspects of the ADL intervention positively influenced several domains of QoL, including care relationship, feeling at home, and positive self-image. Indeed, studies have suggested that providing residents with autonomy, control, and trust positively influences care relationship.\textsuperscript{22, 23} An improved care relationship may in turn reduce aggressive or uncooperative behavior and positively influence the residents' sense of feeling at home.\textsuperscript{22} Performing familiar activities from ones previous home life has also been found to positively influence feeling at home.\textsuperscript{22} Therefore, the focus of the ADL intervention on creating meaningfulness (e.g., stimulating participation in domestic chores and self-care) and stimulating autonomy and control may positively influence the well-being of the resident.

**IMPLEMENTATION OF ADL IN DAILY CLINICAL PRACTICE**
The results have important implications for clinical practice, as nursing staff play a key role in assisting in the performance of activities and in encouraging independent functioning in daily activities.\textsuperscript{24} Previous studies have shown that when nursing staff were involved in residents' ADL and IADL, they completely took over care tasks 45\% of the time.\textsuperscript{25} This high percentage is alarming, especially considering the fact that taking over care tasks instead of offering assistance (e.g., verbal instructions) with ADLs may perhaps further enable functional decline and care dependence.\textsuperscript{26} The results of our study suggest that persons with advanced dementia are capable of performing ADLs independently (or with verbal instructions) and are still able to show improvements in domains which have been previously found to positively influence independent functioning.\textsuperscript{2, 6} Moreover, the important role which nursing staff have
in stimulating and encouraging autonomy is emphasized, as their personalized assistance and motivation may play a key role in improving QoL.

The study described in chapter 4 indicates that there were some barriers to the implementation of MRC, with the amount of stimulation varying from three times per week to several times per day. Similarly, mean compliance with the ADL intervention described in chapters 5 and 6 was 68%. These results indicate that although a personalized ADL training is feasible in the NH setting, there is room for improvement. The most important barriers and facilitators for implementation are discussed below.

Understaffing and limited time available for personalized care and stimulation were important barriers to implementation. Nursing staff indicated that it was sometimes quicker to take over care tasks, and doubts were expressed about the ability of residents to understand certain tasks, and about the point at which stimulation becomes a burden for the participants. Moreover, fear for resident falls or injury may have prevented nursing staff from implementing MRC and ADL in all aspects of care. Previous studies have shown that although fear of falling and injury is a common barrier to implementation, such care interventions do not increase fall risk. From the results described in chapter 4, we conclude that additional training sessions, more time for implementation, and more consultations with other disciplines (e.g., more involvement from medical staff and physiotherapists on how to stimulate movement safely) are important factors for better implementation.

Important facilitators for implementation of the ADL interventions were commitment of the team manager, motivation of nursing staff, and sufficient knowledge about the benefits of ADL training. This is also highlighted by previous studies who suggest that more staff guidance may improve compliance to the intervention. Personalized care approaches such as MRC and ADL training describe a philosophy of care in which care is provided with as opposed to for residents. Although the Dutch long-term health care system is in the middle of a shift in care policy in which a person-centered care approach and stimulation of self-reliance, autonomy, and independent functioning is key, implementing such a change in care philosophy in the organization is not always easy and takes time. Our studies show that in general, staff were enthusiastic about stimulating ADL, that they were very prepared to deliver MRC, and 89.5% were willing to continue with MRC.
METHODOLOGICAL CONSIDERATIONS

Exercise not effective or an implementation error?
An important distinction should be made between ineffectiveness of the exercise intervention and an implementation error. An implementation error in this thesis refers to low compliance to the intervention and a considerable deviation from the original study protocol. Such deviations can mask possible effects of the intervention. The most obvious explanation for the lack of intervention effects in our study is related to a violation of the methodology and a low adherence to the protocol. This section addresses considerations regarding methodological strengths and limitations of the studies presented in this thesis. First, the design of the study is discussed. Furthermore, issues related to outcome measurement are addressed.

Study design and compliance
When carrying out an exercise intervention, the intensity, frequency, and duration are crucial aspects that should be well thought-out. However, in research including NH residents with dementia, the designs of exercise interventions are often heterogeneous and there is growing recognition that insufficient attention has been paid to developing standardized study designs. Literature reviews report limitations in their analyses due to heterogeneity in assessment (measurement tools and outcome measures), design and intervention (type of activity, duration, frequency, intensity), sample size, and environmental and personal factors (setting, type of dementia, stage of disease progression). Studies frequently fail to report compliance to the intervention, and the limited studies which do report compliance show large variation in their adherence rates. Moreover, the intensity of physical activity interventions is rarely reported in studies, and therefore, it is difficult to draw conclusions regarding the optimal intensity necessary to improve functioning in NH residents with dementia.

The exercise training described in chapters 5 and 6 consisted of alternating strength and aerobic sessions, which were intended to be provided 3 times per week (72 sessions in 6 months), for 30 to 45 minutes per session, with a progressive increase in intensity. However, as noted in chapters 5 and 6, there were some deviations from the intended protocol. First, mean compliance to the intervention was only 55% (39.5 of the intended 72 sessions were attended). The main reasons for absence were influenza, norovirus, lack of motivation, overlapping activities, and bank holidays. Similar reasons for absence were reported in a comparable study with low compliance. Second, the intensity of the intervention was not consistently reported by the movement therapists, and the intensity reports that were available suggest that mainly 2 sets of repetitions were trained instead of 3, and that the protocol for a progressive increase in intensity was not followed. These results indicate that both the intensity and the frequency of the exercise intervention described in this thesis
were considerably lower than intended. As a result, it is not possible to draw conclusions about the effectiveness of the exercise intervention. However, we can conclude that a combined aerobic and strength exercise intervention is not effective for NH residents with moderate to severe dementia when it is provided approximately once or twice a week for the duration of 6 months, without a structured increase in intensity.

There are several factors that may have contributed to the deviations from the intended protocol. The complex intervention was provided by movement therapists who were supervised by experienced physiotherapists. Although the movement therapists were hired specifically for the current study, we did not clearly specify the profile of the candidate movement therapists, who were not familiar with the current population. Movement therapists indicated that they had difficulty with adhering to the increasing intensity of the exercises due to the nature of the intervention, which was slow in showing results. As the intervention progressed, movement therapists were increasingly confronted with the limitations of the residents, the heterogeneity within the group, and the motivational issues. Altogether, this may have affected the quality of the group sessions and may have served as a barrier in the implementation. We emphasize the importance of the personality and skills of the movement therapist (e.g., empathetic, energetic, good communication skills, experience with the population and group sessions) for successful implementation.

Related, commitment of the physiotherapist and team manager is crucial for successful implementation, which is also confirmed by previous studies. The vision of the researcher, physiotherapists, and team managers should be clearly communicated, and the movement therapists should be continuously supervised, motivated, and monitored during the intervention. In line with this, movement therapists indicated that they desired additional training and support during the training sessions. This could be achieved by organizing monthly meetings with the researcher and all involved physiotherapists, team managers, and movement therapists, in which the movement therapists could share the difficulties which they encounter. In order to stimulate better reporting and adherence to the planned intensity of the protocol, movement therapists should be asked to provide weekly reports of the intensity of each training session. This way the progressive nature can be closely monitored.

Moreover, involvement of the nursing staff in the exercise intervention may also be an important factor for successful implementation. From the adherence logs it was evident that sometimes exercise sessions were not properly noted in the residents’ agendas. The result was that residents were sometimes not dressed or had other appointments. As is the case with the ADL intervention, it takes time before such a complex intervention becomes a structural part of the whole care package. The results highlight the need for a multidisciplinary approach when implementing interventions in the NH. Tight adherence to the complex protocol of
this intervention requires planning and coordination between disciplines. For instance, the movement therapist had to retrieve 4 to 6 residents from different wards. The time it took to gather all residents was dependent on the physical and cognitive capabilities of the resident, the distance to the training location, and the level of involvement of the nursing staff. Perhaps the intervention should be adjusted to what is practical in the NH, rather than the other way around, in order to improve the likelihood of implementation.

**Group-based exercise feasible in daily practice?**

The low adherence to the physical activity intervention shows that there is room for improvement in the implementation of an exercise intervention. Although low adherence seems to be a common problem with NH residents with dementia, increasing adherence is relevant considering that the effectiveness of interventions decrease as a result.\(^{38}\) Considering the low adherence, one may wonder whether implementation of a group-based exercise intervention is feasible in daily practice. Common barriers for exercise adherence are low motivation and self-efficacy.\(^ {39}\) A personalized approach and individual sessions can increase motivation and trust, and take into account the differences in physical fitness between people, and hence increase exercise adherence.\(^ {40}\) Indeed, it has been suggested that frail older persons benefit more from individualized interventions than group exercise programs.\(^ {41}\)

A study which examined an individualized 6-month walking program offered by family caregivers four times per week for 30 minutes per session reported an adherence rate of 93%.\(^ {42}\) However, individualized training in NH residents is time intensive and possibly costly. Bossers et al.\(^ {40}\) hypothesized that individualized training could be achieved by involving volunteers and family members to offer such a program. Although there are clear benefits to involving volunteers and family members, it has also been suggested that their involvement may hinder self-reliance and independence of residents as volunteers and family members are used to taking over care.\(^ {43}\)

A recent study showed that a group-based, supervised, and individualized moderate to high-intensity functional strength and balance exercise program (2-3 times per week, 45 minutes per session, duration of 4 months) was applicable among NH residents with moderate dementia with regard to attendance (82.5%) and intensity.\(^ {39}\) Factors which were hypothesized to contribute to the high attendance was the possibility of additional individual sessions and help with transfer to sessions. Therefore, in line with this, we believe that a group-based exercise program is feasible in NH residents with moderate to severe dementia, provided that the intervention is multidisciplinary, takes into account individual differences in physical fitness, and minimizes transfer time to sessions.
Assessment instruments

Selecting appropriate outcome measures that are sensitive, reliable, and valid is obviously very important in research. A major strength of this thesis was the use of measurement instruments specifically developed for persons with dementia. For instance, a European consensus study identified the CSDD as the measure of choice for evaluating patient mood in dementia, as it demonstrates sensitivity to change in treatment studies.\footnote{44} Moreover, the global cognitive tests SIB-S and MMSE were found to be reliable and valid tests in dementia patients.\footnote{45} Although the sensitivity to change over time in severe dementia patients is questionable with the MMSE,\footnote{45} the SIB-S was found to be sensitive to change in patients with moderate to severe dementia (MMSE 0-12).\footnote{45}

However, we experienced that some assessment instruments were less appropriate in the current study population. For instance, EF tasks were more difficult to administer and may be subject to limited reliability and validity.\footnote{45} The current population experienced difficulty in remembering and understanding the test instructions. In line with this, studies have shown that memory impairment can affect performance on EF tests in people with dementia as they may not be able to remember the instructions.\footnote{46} While the validity and reliability of the EF tasks have been confirmed for assessing mild EF disturbances in early stages of cognitive impairment,\footnote{47} their reliability and validity has been less clearly assessed in advanced stages of dementia.\footnote{45} During our pilot study, we noticed that participants with an MMSE below 5 had more difficulty understanding the instructions of the EF tasks. Therefore, we chose to use a cut-off score of MMSE \(\geq 5\) for the EF tasks. Despite these limitations, the EF tasks used in this thesis are recommended because these are frequently used in good- or excellent quality RCTs.\footnote{45} Still, the tasks should be used and evaluated with care, and further evaluation of these tasks is needed in persons with more advanced dementia.\footnote{45}

QoL instrument

The use of the Qualidem scale requires some reflection. The measurement of QoL in persons with dementia is complex considering the subjective, dynamic, and multidimensional nature of QoL. Although subjective ratings of QoL are generally preferred over proxy ratings for people with dementia, in more advanced disease stages, proxy ratings are considered more valuable, as subjective evaluations may be influenced by cognitive impairment.\footnote{48}, \footnote{49} The Qualidem is a proxy-rated questionnaire developed specifically for institutionalized persons with dementia.\footnote{50} A systematic review of QoL measures specifically designed for use within care homes concluded that the Qualidem is the most appropriate instrument for evaluating QoL in NH residents with advanced dementia, as it has the broadest set of measurement properties and is reliable and well validated.\footnote{49}, \footnote{51}, \footnote{52}
To our knowledge, no studies are available that assessed the responsiveness or clinical significance of Qualidem changes. Therefore, although chapter 5 reported statistically significant effects of a 6-month ADL training on different domains of QoL (i.e., positive self-image, care relationship, and feeling at home) when compared to care-as-usual, the clinical significance is uncertain. Do persons with dementia really experience improved QoL following an ADL intervention? To better answer this question and determine whether the changes in QoL could also be clinically relevant, additional analyses were performed in which within group changes in QoL over time were examined. The results reveal that over six months, a significant increase in QoL was observed within the ADL group in total QoL (increase of 4.27 points, \(p = 0.04\)) and two QoL domains, i.e., care relationship (increase of 1.84 points, \(p = 0.01\)) and positive self-image (increase of 0.81 points, \(p = 0.02\)). Moreover, a trend towards significance was found in the domains restless tense behavior (increase of 0.89 points, \(p = 0.06\)) and feeling at home (increase of 1 point, \(p = 0.06\)). In contrast, no significant changes were found within the care-as-usual group, aside from a trend towards significant decline in the domain care relationship (decline of 1.18 points, \(p = 0.07\)). Although the clinical significance of an increase/decline of these magnitudes remains uncertain, comparing the magnitude of the change to the scale of the domain may provide some clarification. For instance, the increase of 1.84 points on ‘care relationship’ (range 0-21 points) and 0.81 points on ‘positive self-image’ (range 0-9 points) over six months may be more clinically relevant than the increase in total QoL of 4.27 points (range 0-111) over six months.

Still, one could pose the question to what extent persons in advanced stages of dementia are aware of their self-image, and how feasible it is to bring about changes in self-image in this advanced stage, as the image that people have of themselves declines with failing memory and also tends to fluctuate throughout the day. Although the answer to these questions remains uncertain and the construct of ‘self-image’ may not be directly observable, the results of this thesis indicate that nursing staff do observe some indications which suggest that residents have a more positive self-image after ADL training (e.g., residents less often state that: they have nobody that is important to them or who misses them, they can no longer play a part in their social network, they are a burden to others, they need help all the time). The positive changes in self-image reported in this thesis should be interpreted as being observations of all that residents say about the way they act, and not necessarily as thoughts or feelings of the residents.

The relatively small, though significant, improvements in total QoL confirm the hesitation which the Qualidem developers have for using a total QoL score. Therefore, the results in this thesis regarding overall QoL should be interpreted with caution. Nonetheless, we believe that, in addition to a more specific and reliable QoL profile, the total QoL score does provide some additional information regarding overall well-being.
**FUTURE DIRECTIONS**

The results of this dissertation have several implications for future policy, practice, and research.

**Policy**

The results of the ADL intervention confirm the growing notion that future dementia care should shift its philosophy of care to one in which the focus lies on stimulating the residents to perform as much of their self-care as independently as possible, i.e., *offering assistance* during care instead of *taking over* care tasks. The small to medium effects that were found following the ADL intervention show that improvements or maintenance of functions and QoL can still be achieved even in persons with advanced dementia. Considering the progression of the disease, large effects of the ADL intervention were not expected, and maintenance of functions was already considered beneficial. However, it may be possible that the ADL intervention described in this thesis could result in even larger effects when applied to persons with milder dementia. Possibly, improvements at an earlier stage could subsequently favorably influence the rate of progression in the more advanced stages. We therefore propose that the ADL intervention studied in this thesis should also be applied to persons with mild dementia.

Currently by government policy, people with mild dementia are encouraged to stay at home as long as possible. One advantage of this policy is that people can stay in their own home and familiar environment and participate in the community for as long as possible. On the other hand, with a shift to informal care provision, this policy could lead to increased complexity of care to be delivered at home. The consequence may be increased fall risk and hospitalization, and increased burden of informal caregivers. As the opinions about the benefits of early institution are divided, persons with dementia and their caregivers should at least be given the choice of residential care.

However, a consequence of the 2015 health care reform in the Netherlands, known as the Long-Term Care Act (in Dutch: *Wet langdurige zorg, Wlz*), is that residential care is only possible for the most severe cases, i.e., elderly in need of 24-hour care. Although the reform aimed to ensure affordability, accessibility, and quality of long-term care in the future, in essence, it comes down to severe budget cuts in the long-term care section, a shift in long-term care responsibilities, and a process of extramuralization in which residential care for persons with lower care-severity is abolished. As a result, many residential care homes have closed. If current policy continues and persons live at home as long as possible, residential care homes will disappear completely, the complexity of informal care will increase substantially, and persons who do eventually move into a NH will be characterized by more complex
care problems, more severe dementia, and more care dependency. The latter is already confirmed by a recent study which reported an increase in the number of Dutch NH residents with a high care-severity package (ZZP5) and a decrease in the number of residents with a low care-severity package (ZZP4).

A consequence of the increased care complexity seen in the NH is that the demands which are placed on the (scarce) nursing staff have increased. This is worrisome, especially considering that the studies in this thesis show that the most prominent barriers for implementation of an ADL intervention are time shortage and understaffing. Therefore, another consequence of the 2015 reform may be that successful implementation of an ADL intervention is hindered in the NH as staff may be more prone to take over care tasks when there is limited time. This does not match the goal of the 2015 reform, which was to improve the quality of the long-term care system by providing appropriate care with attention to individual well-being (i.e., preservation of QoL and prioritizing the wishes and needs of the person with dementia).

Therefore, in order to facilitate the process of shifting the philosophy of care to one in which care is provided with the resident instead of for the resident, we advocate a change in the recently reformed Dutch-long term care, and more specifically, the return of residential care homes. Currently, there is a group of people with dementia in the Netherlands who's care demands are not sufficiently met at home and who would benefit from residential care, but who do not meet the criteria to be admitted in a NH. These elderly should at least have the freedom of choice to be admitted to residential care homes. This way, persons with mild dementia can be signaled earlier in the disease process but still be stimulated to perform their ADLs as independently as possible, which may perhaps slow down the progression of their disease. In addition, the high demands which are currently placed on nursing staff will decrease, leaving more room for successful implementation of an ADL intervention in the NH.

Practice
When implementing an ADL or exercise intervention, we recommend that clear agreements are made from the start with all staff members involved (e.g., nursing staff, physiotherapist, movement therapist, team manager). Agreements should be made with regard to the protocol, supervision hours, commitment, planning, and coordination. We also recommend that per location, a motivated team manager or physiotherapist should lead the implementation. This leader should be motivated to supervise the implementation process, have a personalized care vision, and have enough time to transfer this care vision to other employees. Altogether, this thesis emphasizes the important role of the nursing staff, who form the building blocks for a successful implementation of interventions in the NH.
Research
An important question that remains unanswered in this thesis is: is exercise effective in NH residents when implemented entirely according to protocol?

To answer this question, more studies are necessary to provide clarity about what type, duration, frequency, and intensity of training is most beneficial and feasible in NH residents with dementia. The current heterogeneity in study designs may be the reason why results of exercise interventions are inconsistent. Therefore, before we can analyze the effectiveness of exercise interventions and draw conclusions regarding the optimal exercise parameters, future studies should focus on creating homogeneity in study designs to enable direct comparison of the effects of different interventions for people with dementia, from which clearer clinical guidance can be generated. In line with this recommendation, a recent study made a first step in the development of a core outcome set (COS) to evaluate physical activity interventions for people with dementia. A COS is a standardized collection of outcome measurements which all trials should measure and report. The COS does not imply that all outcomes in a trial should be restricted to those in the COS, but rather that all trials should measure and report at least this agreed minimum collection of outcomes. The review provided a list of the three most commonly used measurement tools per outcome domain (e.g., functional abilities and independence, cognitive function, balance, global behavioral symptoms, and health related QoL) in physical activity research in the past 10 years. However, the most appropriate measurement tools for each of the outcomes included in the COS have yet to be determined. We believe that reducing variation in assessment across studies should be an essential first step in future research to enable comparison of different interventions and determine which type of exercise intervention is most effective for NH residents with dementia.
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