FLEX CEUs

Dementia and Effects of Exercise

Physical exercise improves strength, balance, mobility, and endurance in people with cognitive impairment and dementia: a systematic review

K E Y W O R D S

Dementia
Exercise
Mild cognitive impairment
Physical fitness
Quality of life

A B S T R A C T

Question: Does physical exercise training improve physical function and quality of life in people with cognitive impairment and dementia? Which training protocols improve physical function and quality of life? How do cognitive impairment and other patient characteristics influence the outcomes of exercise training? **Design**: Systematic review with meta-analysis of randomised trials. **Participants**: People with mild cognitive impairment or dementia as the primary diagnosis. **Intervention**: Physical exercise. **Outcome measures**: Strength, flexibility, gait, balance, mobility, walking endurance, dual-task ability, activities of daily living, quality of life, and falls. **Results**: Forty-three clinical trials (n = 3988) were included. According to the Grades of Recommendation, Assessment, Development and Evaluation (GRADE) system, the meta-analyses revealed strong evidence in support of using supervised exercise training to improve the results of 30-second sit-to-stand test (MD 2.1 repetitions, 95% CI 0.3 to 3.9), step length (MD 5 cm, 95% CI 2 to 8), Berg Balance Scale (MD 3.6 points, 95% CI 0.3 to 7.0), functional reach (3.9 cm, 95% CI 2.2 to 5.5), Timed Up and Go test (–1 second, 95% CI –2 to 0), walking speed (0.13 m/s, 95% CI 0.03 to 0.24), and 6-minute walk test (50 m, 95% CI 18 to 81) in individuals with mild cognitive impairment or dementia. Weak evidence supported the use of exercise in improving flexibility and Barthel Index performance. Weak evidence suggested that non-specific exercise did not improve dual-tasking ability or activity level. Strong evidence indicated that exercise did not improve quality of life in this population. The effect of exercise on falls remained inconclusive. Poorer physical function was a determinant of better response to exercise training, but cognitive performance did not have an impact. **Conclusion**: People with various levels of cognitive impairment can benefit from supervised multi-modal exercise for about 60 minutes a day, 2 to 3 days a week to improve physical function.

Introduction

Dementia is an increasingly important public health concern.[1] It is estimated that by 2050 the number of people with dementia will reach 131.5 million worldwide.[1] Apart from deficits in cognition and behaviour,[2] deficits in balance, gait, and movement coordination are also found in people with mild dementia and mild cognitive impairment.[3,4] People with dementia are less likely to participate in regular physical exercise when compared with their counterparts with normal cognition.[5] Physical inactivity may give rise to further decline in physical functioning.[6] These factors may partially explain the higher risk of falls and hip fractures in people with dementia compared with their peers without dementia.[7,8]

Exercise training improves cognitive[9] and physical[10–12] functions in healthy older adults and is feasible for people with cognitive impairment.[13,14] Previous reviews have attempted to examine the effects of exercise on physical function in individuals with dementia, but the heterogeneous participant groups and different outcome measures that were used made conducting and interpreting meta-analyses difficult.[13–21] Meta-analyses were conducted in seven reviews to quantify the amount of improvement gained after exercise training.[14–16,20,22–24] However, non-randomised trials were included in some reviews, which compromised the quality of evidence.[16,23] Other reviews focused on one type of exercise training, one patient subgroup,[14,24] or few domains of physical function.[15,20,22,23] None of the existing systematic reviews conducted sensitivity analysis to specifically examine the effect of subject characteristics (eg, cognitive impairment level) on training efficacy – probably due to the small number of trials included in the reviews. Thus, the existing reviews have not provided a comprehensive understanding of the effect of physical exercise on physical function in people with cognitive impairment. Moreover, a good number of new exercise trials on people with mild cognitive impairment or dementia have been published in the last few years, and it is thus timely to conduct a systematic review on this topic to address the knowledge gaps identified above.

Therefore, the research questions for this systematic review were:

1. Does physical exercise training improve physical function and quality of life in people with cognitive impairment and dementia?
2. Which training protocols improve physical function and quality of life?
3. How do cognitive impairment and other patient characteristics influence the outcomes of exercise training?

Method

Identification and selection of trials

MEDLINE, CINAHL, PubMed, PsycINFO, and The Cochrane Library Databases of Systematic Reviews were searched electronically with search terms related to *cognitive impairment*, *dementia*, *exercise*, *rehabilitation*, and *randomised trial*. An example of the search strategy for one database is provided in Appendix 1 on the eAddenda. Two independent researchers screened the search results for publications about the effect of physical exercise in people with mild cognitive impairment or dementia. Potentially eligible trials were selected for further assessment of eligibility. Relevant reviews and the reference lists of all selected articles were then examined to look for potentially eligible articles. Finally, a forward search was performed on all articles selected in the above process using the Science Citation Index. The last search was performed in May 2016. The inclusion criteria for trials to be included in the review are presented in Box 1. However, trials were excluded if they were published only in conference proceedings or books. Disagreements about eligibility were resolved by the principal researcher.

Assessment of characteristics of trials

Quality

The PEDro score, obtained by searching the PEDro website (www.pedro.org.au), was used to assess the methodological quality of each selected trial. For trials that were not originally listed on the PEDro website, the PEDro team was contacted via email to request them to examine these trials and provide the PEDro scores. Hence, the PEDro scores of all trials included in this review were based on the information obtained from the PEDro website, where studies are rated in duplicate by trained raters.

Participants

To describe the participants in each trial, the following information was extracted from the published report: sample size, mean age, gender ratio, location of participants (community, institution), diagnosis, and cognitive impairment test scores (eg, Mini Mental State Examination).

Intervention

The details extracted from each included study about the exercise intervention were: frequency, intensity, duration and type of physical exercise.

Outcome measures

Outcome data were extracted from each included study if they pertained to any domain of physical function or quality of life.

Corresponding authors were contacted via email in case information needed for the meta-analysis could not be acquired from the original articles. When there were discrepancies between the two researchers responsible for data extraction, the information extracted was confirmed by the principal investigator.

Data analysis

Meta-analysis was performed for a given outcome only if at least three similar trials used the same outcome measure. Meta-analyses were conducted using RevMan software.[a] Random-effect models were used in all meta-analyses, given the large variation in study design across trials (eg, participants' characteristics, exercise protocols).[25] The existence of publication bias was examined using Egger's regression asymmetry test using Comprehensive Meta-analysis software.[b] A *p*-value of <0.1 (two-tailed test)

Box 1. Inclusion criteria.

Design
- Randomised trial
- English language

Participants
- People with a primary diagnosis of mild cognitive impairment or dementia

Intervention
- Physical exercise

Outcome measures
- Measures of physical function
- Measures of quality of life

Comparisons
- Exercise versus no intervention/placebo
- Exercise plus other intervention versus other intervention only

Box 2. Criteria used to downgrade ratings in the Grades of Recommendation, Assessment, Development and Evaluation (GRADE) system. See the Methods section for further details.

Risk of bias
- for outcomes where meta-analysis was possible, fewer than half of the trials included in the primary analysis had a PEDro score of $\geq$6
- for outcomes where meta-analysis was not possible, fewer than half of the trials included for outcome evaluation had a PEDro score of $\geq$6

Inconsistency
- for outcomes where meta-analysis was possible, $I^2 \geq 50\%$ in the primary meta-analysis and the meta-analysis that involved only trials with high methodological quality
- for outcomes where meta-analysis was not possible, mixed results were reported

Indirectness
- the participants, intervention, comparator intervention, outcome measure or study design did not match between the included studies and the eligibility criteria for this review

Imprecision
- insufficient studies for meta-analysis
- the number of subjects included in the primary meta-analysis was less than that required by a conventional sample size calculation for a single trial
- the 95% CI spanned zero

Publication bias
- $p < 0.1$ on the two-tailed Egger's regression asymmetry test

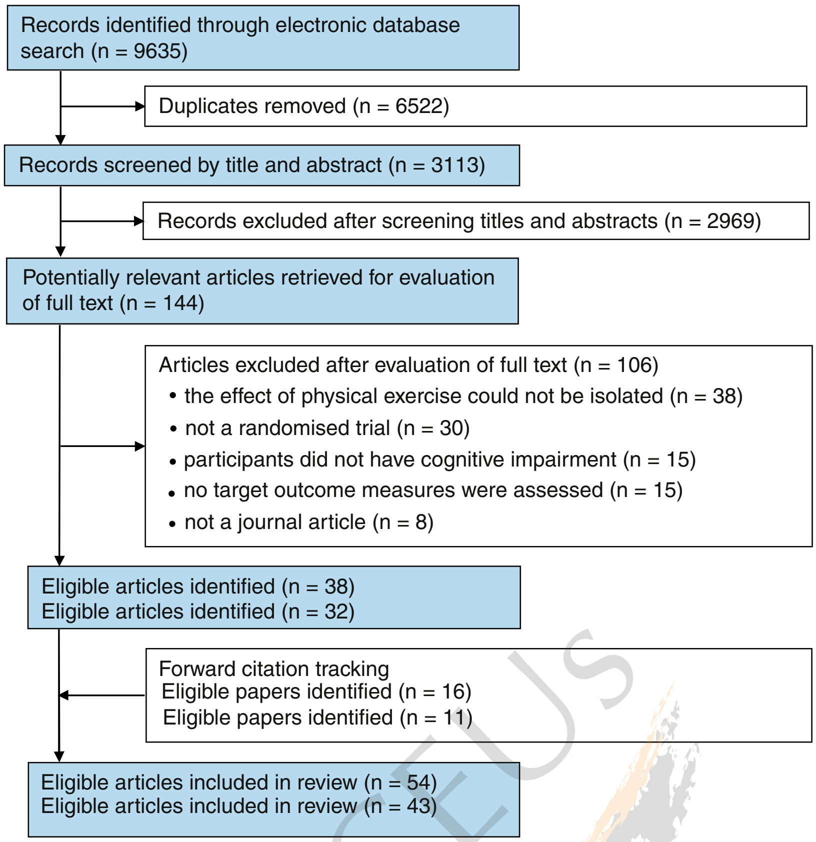

Figure 1. Flow of studies through the review.

indicated the presence of publication bias. The mean difference provided a summary measure of the effect of exercise. Sensitivity analyses were conducted based on different patient subgroups, outcome mono-dimensionality, and methodological quality, if three or more trials remained eligible for the additional analyses.

The level of evidence for each outcome measure was then calculated according to the Grades of Recommendation, Assessment, Development and Evaluation (GRADE) system.[26] The rating for each level of evidence started with 'high quality', as only randomised, controlled trials were included in this review. It was downgraded by one level for each of the criteria shown in Box 2. The quality of evidence was downgraded by two levels if less than half of the trials included in the primary meta-analysis had a PEDro score of ≥4. For outcomes for which meta-analysis was not possible, the same criteria were adopted with reference to the total number of trials reviewed for that particular outcome. Evidence quality was upgraded by one level if the effect size was large. After considering the balance of desirable and undesirable aspects of the available evidence, a strong or weak recommendation would be given according to existing evidence.[26]

Results

Flow of trials through the review

The database searches identified 6935 records. After screening titles and abstracts, 144 potentially relevant articles were obtained in full text and evaluated for eligibility. The 38 articles that were eligible for the review were supplemented by 16 more identified through the reference lists searches. Therefore, 54 articles were included in the review.[27–80] These reported on 43 trials involving a total of 3988 subjects (Figure 1). Three papers were excluded from some of the meta-analyses, as the required information was missing despite efforts to contact the original authors.[36,48,58]

Characteristics of included trials

The methodological quality of the included studies is summarised in Table 1. A more detailed version of this table is available in Appendix 2 on the eAddenda. The characteristics of their study populations are summarised in Table 2. The physical exercise protocols assessed in the included studies are summarised in Table 3. More details about the study populations, the intervention protocols, and the outcome measures are available in Appendix 3 on the eAddenda.

Quality

The quality of evidence assessed according to the GRADE is provided in Table 4. The results were organised according to the three levels of functioning described in the International Classification of Functioning, Disability, and Health (ICF), namely: body functions and structures, activities, and participation.[81] Outcomes that were reported by less than three trials are listed in Appendix 4 on the eAddenda.

Effect of exercise on body functions and structures

Body mass index (moderate-quality evidence)

Body mass index (BMI) was assessed in three trials (173 participants).[30,35,50] Multimodal exercise[30,50] or specific aerobic train-

Table 1
Methodological quality of the included trials (n = 43).

PEDro total score	Trials n (%)	References
excellent (9 to 10)	0 (0)	
good (6 to 8)	30 (70)	27,28,30–35,37–42,44,45,47,50–53,57,60,61,63–69,71–80
fair (4 to 5)	11 (26)	29,36,38,46,48,49,54–56,59,62,70
poor (0 to 3)	2 (5)	43,58

Percentages do not sum to 100, due to the effects of rounding.

Table 2
Characteristics of the participants in the included trials (n = 43).

Characteristic	Trials n (%)	References
Sample size		
≤50	18 (42)	34,35,44,46–50,52,53,55,56,58,59,61,62,79,80
>50	25 (58)	27–33,36–43,45,51,54,57,60,63–78
Cognitive impairment level		
mild cognitive impairment (mean MMSE > 24)	11 (26)	27–40,74,79
mild dementia (mean MMSE 20 to 24)	11 (26)	41,42,45–53,63,64,80
moderate dementia (mean MMSE 10 to 20)	16 (37)	43,44,54–62,65,71–73,75–78
severe dementia (mean MMSE < 10)	5 (12)	66–70
Setting of the trial		
residential care units	20 (47)	29,43,44,47,49,51,54,56,59,61,65,66,68–71,75–79
community	19 (44)	27,28,30–40,45,46,48,50,52,53,55,60,62,72–74,80
hospital respite care	1 (2)	67
mixed	3 (7)	41,42,57,58,63,64

Percentages may not sum to 100, due to the effects of rounding. MMSE = Mini Mental State Examination.

ing[35] (45 to 90 minutes per session, 2 to 7 sessions per week for 4 to 12 months) were compared to usual care,[50] health promotion,[30] or low-intensity stretching and balance exercise.[35] All three trials reported no significant change in BMI after physical exercise relative to the control intervention.[30,35,50]

Strength (moderate-quality evidence)

Meta-analysis of four trials (278 participants) showed a significant effect of exercise on improving 30-second sit-to-stand performance by 2.1 repetitions (95% CI 0.3 to 3.9).[48,49,71,77] See Figure 2, or for a more detailed forest plot see Figure 3 on the eAddenda. The result remained significant in sensitivity analyses that included only those trials that involved participants in institutionalised settings (three trials, 258 participants). The heterogeneity across trials was high in both the primary and sensitivity analysis, with I^2 values of 82% and 88%, respectively. Together with four other trials that assessed other types of sit-to-stand performance (eg, five times sit-to-stand test),[41,50,52,55] all trials that reported significant training effects adopted multimodal training with a resistance exercise component (30 to 120 minutes per session, 2 to 4 sessions per week, for 9 weeks to 4 months).[41,49,50,71] The intensity of the resistance training was not specified. The training effect appeared to diminish starting at 9 weeks and 3 months after training.[42,71]

Upper limb strength was reported in four trials.[39–42,49] Three of these trials assessed handgrip strength and one used the arm-curl test. The one trial that incorporated resistance training reported results in favour of the exercise group.[49] The other three trials, which all lacked specific upper limb resistance training, reported no significant effects.[39–42]

Flexibility (very-low-quality evidence)

Flexibility was assessed in three trials.[49,58,62] All trials incorporated multimodal exercise with a flexibility training component (2 to 3 sessions per week, 16 weeks to 12 months), and reported significant improvements in the intervention group. Of these, two reported that the improvements in the intervention group were significantly greater than no-intervention controls

Table 3
Characteristics of the physical exercise protocols used in the included trials (n = 43).

Characteristic	Trials n (%)	References
Mode of exercise [a]		
aerobic exercise	11 (23)	34–38,43,45,47,48,61,71,75
walking exercise	3 (6)	39,65,70
dual-task walking	2 (4)	65,69
multimodal	21 (45)	27,28,30,31,40–42,46,49–56,58,60,62–64,66,70–74,76–78
ADL/functional training	2 (4)	57,68
strengthening exercise	2 (4)	36,79
others	6 (13)	29,32,33,44,59,67,80
Duration of session *(min)*		
<30	3 (7)	34,59,75
30 to 40	10 (23)	29,47,48,53,61,65,67,69,71,80
45 to 60	15 (35)	27,36–38,45,54–58,60,66,72–74,76–79
75 to 150	5 (12)	28,30,31,39–42,49,63,64,68
variable (15 to 60)	6 (14)	32,33,35,43,44,62,70
unclear	4 (9)	46,50–52
Frequency *(sessions/week)* [b]		
1 to 2	17 (39)	28,30,31,34,36–42,44,45,48,53,55,57,58,60,63,64,66,72,73,76–78
3 to 4	15 (34)	27,35,43,47,49,51,54,56,59,61,65,71,74,79,80
5 to 7	8 (18)	29,50,52,54,68–70,75
variable or unclear	4 (9)	32,33,46,62,67
Duration [c]		
single session	1 (2)	34
8 to 15 weeks	16 (36)	39,41–47,49,55–57,59,63,64,71,76,77,79,80
16 to 24 weeks	18 (40)	27–29,31,32,35,36,40,48,50,52–54,58,61,65,68–70,78
≥12 months	9 (20)	30,33,37,38,51,60,62,66,72–75
unclear	1 (2)	67

Percentages may not sum to 100, due to the effects of rounding. ADL = activities of daily living.
[a] n = 47. Four of the trials had two exercise groups in addition to the control group: Nagamatsu[36] had aerobic and strengthening groups; Roach[70] had walking and multimodal groups; Tappen[65] had walking and dual-task walking groups; and Bosser[71] had aerobic and multimodal groups.
[b] n = 44. Apart from the control group, Christofoletti[54] had two exercise groups, which had different numbers of exercise sessions per week: 3 and 5.
[c] n = 45. Two trials used interim evaluation: in the 12-month trial by Uemura,[30] a 6-month interim evaluation was reported by Doi,[28] Makizako[40] and Suzuki.[31] Similarly, in the 12-month trial by Lam,[32] a 6-month interim evaluation was also reported.[33]

Table 4
Grades of Recommendation, Assessment, Development and Evaluation (GRADE) quality of evidence.

Outcome	Risk of bias	Inconsistency	Indirectness	Imprecision	Publication bias	Effect size	GRADE quality	Direction of recommendation
Body mass index	0	0	0	−1[f]	0	0	Moderate	Against
Strength: 30-s sit to stand test	0	−1[b]	0	0	0	0	Moderate	For
Flexibility	−2[a]	0	0	−1[f]	0	0	Very low	For
Step length	0	0	0	0	0	0	High	For
Balance: Berg Balance Scale	0	0	0	0	0	0	High	For
Balance: Functional reach test	0	0	0	0	0	0	High	For
Mobility: Timed Up and Go test	0	0	0	−1[g]	0	0	Moderate	For
Mobility: Walking speed	0	−1[b]	0	0	0	0	Moderate	For
Walking endurance: 6-minute walk test	0	−1[b]	0	0	−1[h]	+1[i]	Moderate	For
Dual-task ability	0	−1[c]	0	−1[f]	0	0	Low	Against
Activities of daily living: Barthel index	0	−1[b]	0	0	−1[h]	0	Low	For
Activity level	0	−1[c]	0	−1[f]	0	0	Low	Against
Quality of life	0	0[d]	0	−1[f]	0	0	Moderate	Against
Falls	0	0	−1[e]	−1[g]	0	0	Low	No recommendation

[a] More than half of the trials included for outcome evaluation had a PEDro score ≤ 4.
[b] $I^2 \geq 50\%$ in the primary and high methodological quality analysis.
[c] Mixed result reported across trial and meta-analysis was not possible.
[d] Quality of life is not rated down here, considering that all studies involving multi-modal exercise reported non-significant effect.
[e] The method of collecting falls outcome by the trials may undermine the actual effect of exercise.
[f] Insufficient studies for meta-analysis.
[g] The effect size overlapped zero in the primary or high methodological quality analysis.
[h] Publication bias present.
[i] Large effect size detected.

as assessed by the chair sit-and-reach test[49,58] and back scratch test.[49] Between-group analysis was not conducted in one of these trials.[62]

Step length (high-quality evidence)

Meta-analysis of five trials (296 participants) revealed a significant effect of exercise on improving step length by 5 cm (95% CI 2 to 8).[28,41,56,64] See Figure 4, or for a more detailed forest plot see Figure 5 on the eAddenda. The heterogeneity across trials was low (I^2 = 29%). Sensitivity analyses that included only trials with high methodological quality (four trials, 265 participants), or individuals with mild cognitive impairment and mild-grade dementia (three trials, 183 participants) remained significant and the I^2 was reduced to 0%. Those trials that reported positive outcomes adopted multimodal exercise with walking, aerobic training, or functional training components, or specific aerobic training (60 to 120 minutes per session, 2 to 3 sessions per week for 15 weeks to 6 months).[28,41,56,64] One of the three trials performed long-term follow-up assessments and reported that the improvement was diminished and returned to baseline values 9 months after the intervention.[41,42]

Effect of exercise on activity

Balance (high-quality evidence)

The primary analysis of the effect of exercise on the Berg Balance Scale (six trials, 722 participants) revealed that exercise significantly improved scores by 3.6 points (95% CI 0.3 to 7.0).[33,45,54,59,77,78] See Figure 6, or for a more detailed forest plot see Figure 7 on the eAddenda. Publication bias was noted for this meta-analysis. A sensitivity analysis that included only trials with high methodological quality (four trials, 673 participants) markedly reduced the heterogeneity across trials, with I^2 value dropping from 91 to 17%. There was no publication bias in this analysis but the mean improvement found was reduced to 1.5 points (95% CI 0.1 to 3.0). Another sensitivity analysis that included only studies involving participants with moderate-grade dementia and living in institutions (four trials, 376 participants) also yielded significant results in favour of the exercise group, but the I^2 value was high (80%).

The primary analysis of the effect of exercise on the functional reach test (six trials, 242 participants) showed that exercise significantly improved the reaching distance by 3.9 cm (95% CI 2.2 to 5.5).[45,48,50,52,55,79] See Figure 8, or for a more detailed forest plot see Figure 9 on the eAddenda. Similar results were obtained in sensitivity analyses that included only those trials with: high methodological quality (four trials, 199 participants), participants with mild cognitive impairment and mild-grade dementia participants (five trials, 219 participants), or community settings (five trials, 197 participants). The heterogeneity across trials in all analyses was minimal with I^2 ranging from 0 to 1%.

Together with other trials that used clinical balance assessment scales as outcomes (eg, Tinetti balance assessments), it was found that various types of exercise interventions were effective in improving balance, including multimodal exercise, Tai Chi, resistance and functional training, and walking (20 to 120 minutes per session, at least 2 sessions per week, for a total of 9 weeks to 12 months).[32,33,41,45,48–52,54,58,59,71,77,78] Four trials with follow-up assessments suggested that the training effect was found to diminish at 9 weeks,[71] 3 months,[41,42] or 6 months,[45,76] although the outcomes remained significantly better than controls in three of the trials.[41,42,45,76]

Mobility (moderate-quality evidence)

Meta-analysis (11 trials, 606 participants) showed that exercise significantly reduced the time required to complete the Timed Up and Go (TUG) test by 1 second (95% CI −2 to 0).[41,47,50–55,71,75,79] See Figure 10, or for a more detailed forest plot see Figure 11

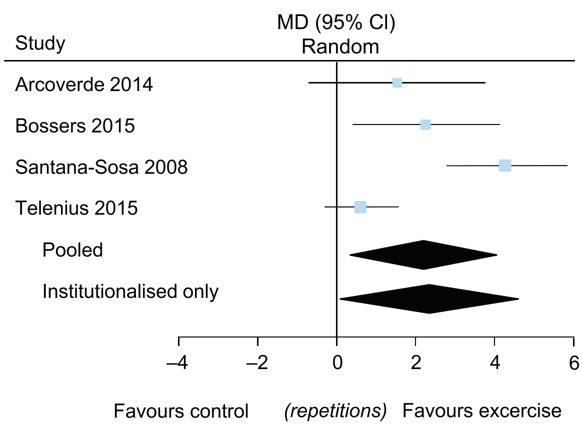

Figure 2. Weighted mean difference (95% CI) in 30-second sit-to-stand test performance (number of repetitions) due to exercise, pooling data from four studies (278 participants).

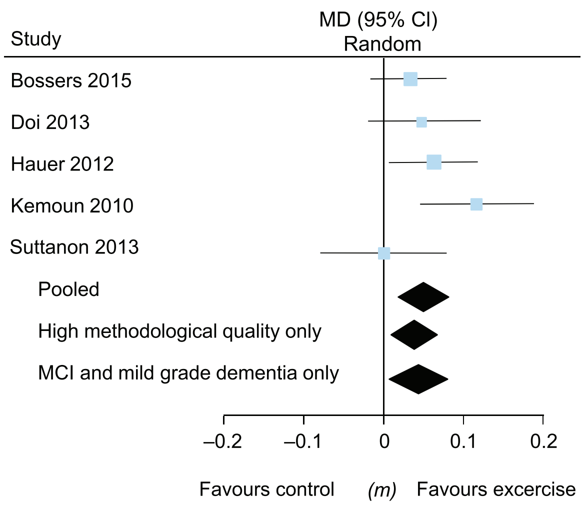

Figure 4. Weighted mean difference (95% CI) in step length (m) due to exercise, pooling data from five studies (296 participants). MCI = mild cognitive impairment.

on the eAddenda. Upon examination of trials that reported significant benefits,[39,41,48–50,58,75,79] most adopted multimodal exercises[41,49,50,58] (15 to 120 minutes per day, at least 2 days/week for a minimum of 12 weeks). The result became marginally significant when only high methodological quality trials (nine trials, 553 participants) were included ($p = 0.08$). The improvement found was also reduced to –1 seconds (95% CI –1 to 0). The group with moderate-grade dementia (four trials, 249 participants) had a tendency to benefit more from training with a marginally significant improvement of –2 seconds (95% CI –5 to 0) compared with individuals with mild cognitive impairment and mild-grade dementia (seven trials, 357 participants) (–1 second, 95% CI –1 to 0). Overall, it was found that aerobic exercise alone (three trials, 236 participants) did not significantly improve TUG performance ($p = 0.35$). The heterogeneity across trials was low, with I^2 ranging from 0 to 32%.

Meta-analysis (seven trials, 568 participants) revealed that exercise improved walking speed by 0.13 m/s (95% CI 0.03 to 0.24).[28,41,52,56,66,71,77] See Figure 12, or for a more detailed forest plot see Figure 13 on the eAddenda. Sensitivity analysis that included only trials with high methodological quality (six trials, 537 participants) yielded a significant but slightly smaller improvement of 0.08 m/s (95% CI 0.01 to 0.15). Improvement in walking speed among individuals with mild cognitive impairment and mild-grade dementia (three trials, 183 participants) was not significant ($p = 0.19$), whereas that in those with moderate-to-severe-grade dementia (four trials, 385 participants) was marginally significant (mean difference 0.14 m/s, 95% CI –0.01 to 0.29). It should be noted that the trials were highly heterogeneous in all analyses ($I^2 \geq 74\%$). The trials that reported significant training effects all adopted multimodal training, with a balance, walking, or functional training component (45 to 90 minutes per day, 2 to 3 days per week for a minimum of 15 weeks).[28,40,41,56,58,64]

Walking endurance (moderate-quality evidence)

Meta-analysis (seven trials, 402 participants) revealed that exercise significantly increased the distance covered in the 6-minute walk test by 50 m (95% CI 18 to 81).[30,45,61,62,65,70,71] See Figure 14, or for a more detailed forest plot see Figure 15 on the eAddenda. Publication bias was noted for this meta-analysis. The results were similar and remained significant in sensitivity analyses that included only trials with: high methodological quality (five trials, 318 participants), participants with moderate-to-severe-grade dementia (five trials, 229 participants), community settings (three trials, 203 participants), or aerobic and walking exercises only (five trials, 283 participants). The effect of exercise on the 6-minute walk distance among patients in an institutionalised setting (four trials, 199 participants) did not reach statistical significance ($p = 0.10$). It was found that aerobic exercise (three trials, 187 participants) led to the largest improvement in 6-minute-walk distance of 75 m (95% CI 25 to 125). The heterogeneity across trials was high in all analyses ($I^2 \geq 56\%$). Trials that reported positive findings adopted either specific aerobic training,[35,36,38,45,61] walking exercise,[65] or multimodal exercise,[30,49,62,71] with a training duration ranging from 30 to 90 minutes/session, 2 to 4 sessions/week, for a total of 9 weeks to 12 months. Reported effective training intensity was 30 to 60% VO_{2max},[62] or 40% of heart rate reserve that gradually progressed to 85%.[30,35,36]

Dual-task ability (low-quality evidence)

Five trials examined the effect of exercise on dual-task ability.[39,40,48,52,63] A dual-task training component was incorporated into the overall exercise program in two trials.[40,63] Only one

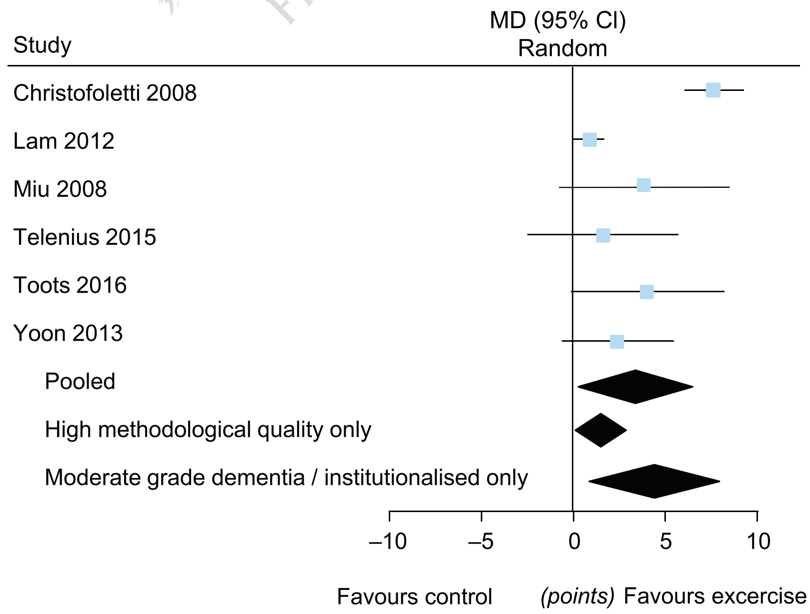

Figure 6. Weighted mean difference (95% CI) in Berg Balance Scale performance (0 to 56) due to exercise, pooling data from six studies (722 participants).

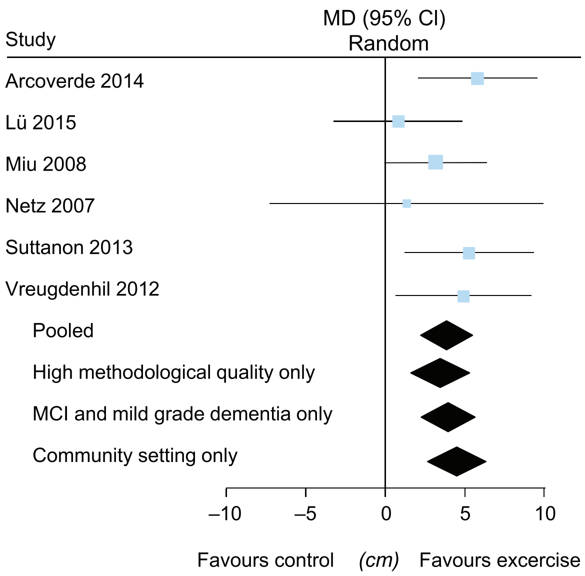

Figure 8. Weighted mean difference (95% CI) in functional reach test result (cm) due to exercise, pooling data from six studies (242 participants). MCI = mild cognitive impairment.

of these trials reported results that favoured the training group.[63] Significantly greater improvements in dual-task gait speed, cadence, stride length, and single support duration were reported in the dual-task training group when compared with non-specific low-intensity exercise. No significant results were found in the other four trials.[39,40,48,52]

Activities of daily living (low-quality evidence)

Twenty-two trials assessed the effect of exercise on activities of daily living (ADL) performance.[29,39,43,44,46,49,50,53,57,59–62,66,68–70,74,75,77,78,80] Sixteen trials reported significant benefits in at least

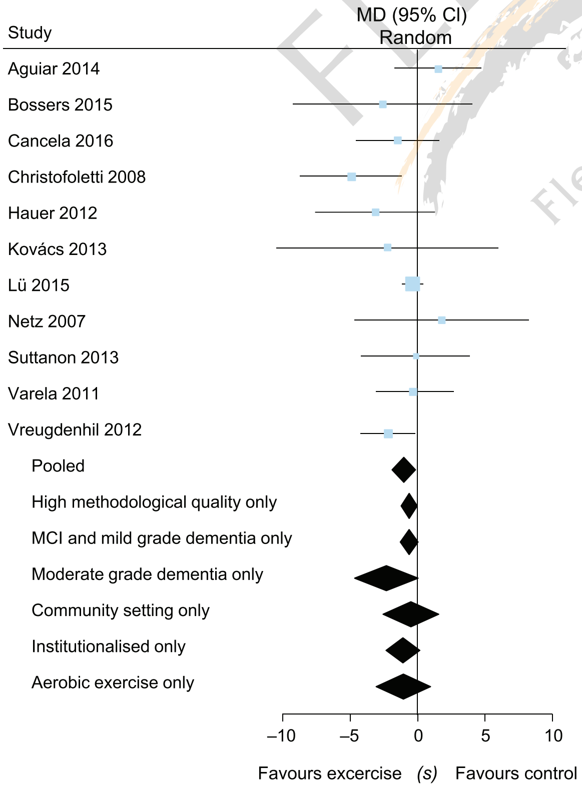

Figure 10. Weighted mean difference (95% CI) in Timed Up and Go test performance (s) due to exercise, pooling data from 11 studies (606 participants). MCI = mild cognitive impairment.

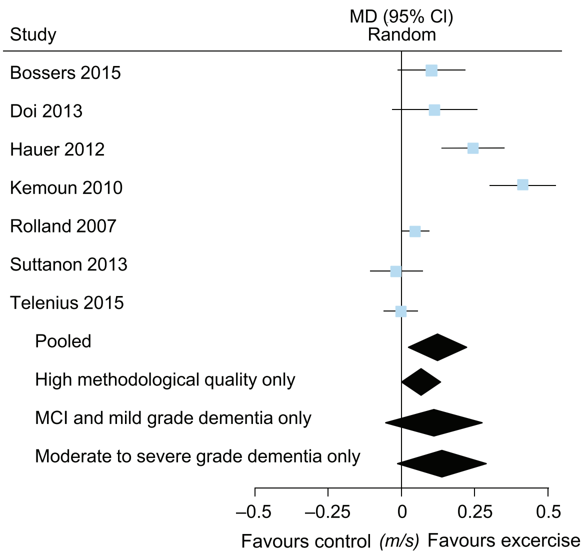

Figure 12. Weighted mean difference (95% CI) in walking speed (m/s) due to exercise, pooling data from seven studies (568 participants). MCI = mild cognitive impairment.

one outcome measure in the ADL category.[29,39,43,44,46,49,50,59–61,66,68,70,75,77,80] Meta-analysis (four trials, 237 participants) found that exercise significantly improved the Barthel Index by 10 points (95% CI 3 to 16).[49,50,61,77] See Figure 16, or for a more detailed forest plot see Figure 17 on the eAddenda. Publication bias was noted for this meta-analysis. Sensitivity analyses that involved only trials with high methodological quality (three trials, 221 participants) or those that were conducted in institutionalised settings (three trials, 197 participants) also yielded results in favour of exercise. The heterogeneity across trials was high in all analyses ($I^2 \geq 72\%$). A wide selection of exercise protocols (eg, ADL training, multimodal exercise, aerobic exercise) were found to improve ADL performance (20 to 150 minutes per session, at least 2 sessions per week, for 12 weeks to 15 months).[29,39,46,49,50,59,61,62,66,68,70,75,80]

Participation

Activity level (low-quality evidence)

Five trials examined the effect of exercise on activity level.[27,39,41,42,46,52] Four trials reported that the exercise training

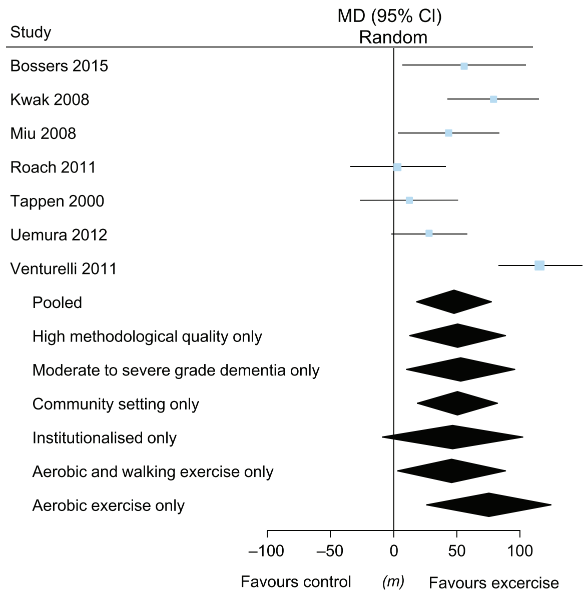

Figure 14. Weighted mean difference (95% CI) in 6-minute walk test results (m) due to exercise, pooling data from seven studies (402 participants).

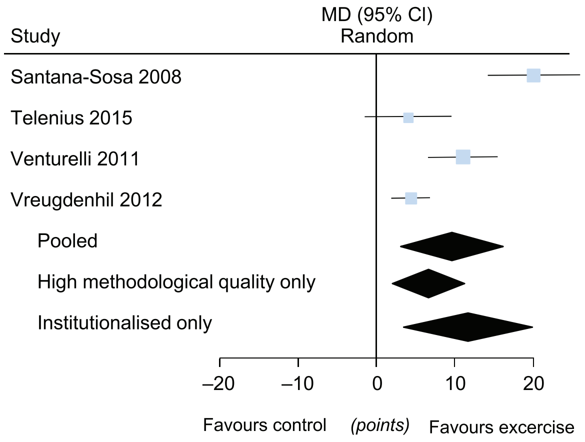

Figure 16. Weighted mean difference (95% CI) in Barthel Index score (0 to 100) due to exercise, pooling data from four studies (237 participants).

did not result in higher activity level than controls,[27,39,46,52] except for one of the outcome variables (ie, total steps per week) reported by Lautenschlager and colleagues.[27] One trial reported a significantly greater improvement in the exercise group immediately after training, but the effect was not maintained at 3 or 9 months.[41,42]

Quality of life (moderate-quality evidence)

Eight trials measured quality of life.[27,37,39,45,46,52,53,76] All six trials that used multimodal exercise as the experimental intervention (at least two 40 to 60 minute sessions/week for 12 weeks to 6 months) reported no significant results.[27,45,46,52,53,76] In the other two trials,[37,39] a walking program was adopted; one of these trials reported improvement in satisfaction in daily life.[39] While the trial that reported no significant improvement adopted moderate-intensity walking exercise (60 minutes/day, 2 days/week, 1 year),[37] the trial that reported significant improvement in quality of life administered a 90-minute walking program once a week for 3 months. In the latter program, the participants were also encouraged to walk daily and organise walking events with other group members.[39]

Falls (low-quality evidence)

Four trials examined the effect of exercise on falls.[42,51,52,60,72,73] Meta-analysis (three trials, 191 participants) showed that exercise did not reduce the number of fallers compared to controls (OR 0.98, 95% CI 0.49 to 1.95).[42,51,52] See Figure 18, or for a more detailed forest plot see Figure 19 on the eAddenda. The heterogeneity across trials was low in this analysis ($I^2 = 26\%$). For other fall-related outcomes, three trials reported that the exercise group did not differ from the controls in cumulative falls, fall rate, fall risk score and time to first fall.[42,51,52] Pitkälä and colleagues[60] reported that 12 months of multimodal exercise resulted in a significant lower number of falls per year when compared with no-intervention

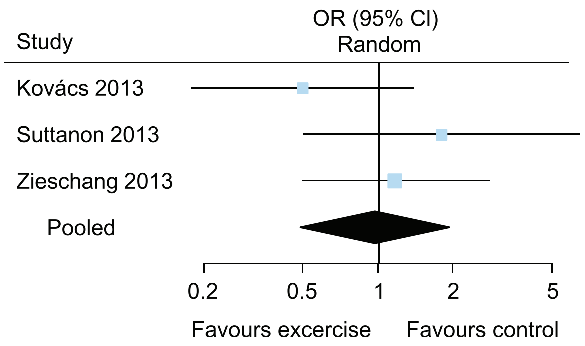

Figure 18. Odds ratio (95% CI) of number of fallers in the exercise versus control groups, pooling data from three studies (191 participants).

controls, while the incidence of fractures or hospitalisation did not differ between groups.

Attendance

Twenty-three trials reported participants' attendance to exercise.[27,28,30,31,36–40,46,48,49,52,55,60,61,63–67,71,74–80] Among these, the mean attendance rate ranged from 33 to 99%. Most trials reported an attendance rate between 70 and 90%.[27,28,30,31,38,39,46,55,60,65,67,71,74–80] Two trials reported an attendance rate <70%.[65,66] Three trials reported reasons for low attendance, which included acute disease, disagreement or unwillingness to continue,[66] behaviour disorders,[66] increased disability in ADLs,[66] and health-related problems.[37,52] One trial showed that women had a better attendance to exercise training than men.[74] Better baseline cognitive ability also showed a weak association with better attendance.[74]

Safety

In almost all of the reviewed trials, the exercise training was conducted under the supervision of either the caregiver (four trials)[46,50,52,61] or professional staff (eg, research staff, certified exercise instructors, therapists) (33 trials).[28–45,47–49,51,53–60,62–79] The only exception was the trial by Lautenschlager and colleagues,[27] in which the participants with mild cognitive impairment were taught the exercises and advised to do them independently at home. Of the four trials in which the caregiver provided supervision, three involved participants with mild-grade dementia[46,50,52] and one involved moderate-grade dementia.[61] The remaining trials did not provide information on supervision of the exercise.[44,56,59,62,80]

Nineteen trials explicitly reported if any adverse effects occurred.[27,29,31–33,36,37,41,42,46,48,49,52,53,60,61,63,64,66,72,74,76–79] Among these, 10 trials reported that no adverse event occurred.[29,37,41,42,46,48,49,61,63,64,74,76,77,79] Four trials reported few adverse events in the exercise group (ie, foot pain,[27] falls,[31,33,60,72] hospitalisation[31]) that were considered unlikely to be related to the intervention by the original authors.[27,33] Five trials reported adverse events that may be related to exercise.[36,52,53,66,78] These adverse events included a higher number of hospitalisations per patient,[66] falls,[36,66] shortness of breath,[36] erythema,[53] and pain or discomfort, which eased as time progressed or by slight modification of the exercise.[52] One trial reported that one of the participants fell ill one day after an exercise session and later passed away with a diagnosis of circulatory failure and general atherosclerosis.[78]

Discussion

This systematic review summarised the evidence on the effects of exercise on physical functioning and quality of life in individuals with mild cognitive impairment and dementia. The large number of trials involved in this review made sensitivity analyses possible, which was missing in previous reviews.[13–18,22,82–84] Sensitivity analysis allowed the effects of exercise on patient subgroups to be determined, and the potential factors that may affect training outcomes to be identified.

Overall, very few adverse events were reported with exercise. Hence, according to the quality and direction of the evidence, there was strong evidence to support the use of exercise in improving strength, step length, balance, TUG, walking speed, and endurance in people with mild cognitive impairment, or mild-to-moderate-grade dementia. On the other hand, the evidence for supporting the use of exercise in improving flexibility and ADL was weak. There was weak evidence against the use of non-specific exercise in improving BMI, dual-tasking ability and activity level, and strong evidence against the use of non-specific exercise in improving quality of life. The review provided no recommendations on the effect of exercise on falls, as most trials collected fall data during the intervention period.[51,52,60] This data collection method is prone to inaccuracy, as the effect of exercise may not appear in the initial periods of intervention. The meta-analysis also may not have had sufficient power to detect a significant between-group difference in fall rate, given the limited sample size. The results of this review can be generalised to people with mild cognitive impairment or mild-to-moderate-grade dementia.

Specificity of training appears to be an important factor in obtaining beneficial effects on impairment-level outcomes (eg, strength, flexibility) and certain activity-level outcomes (ie, walking endurance). For example, among all trials that reported favourable results on lower limb strength and walking endurance, 100% and 71% included specific training for the respective outcomes. Indeed, the sensitivity analysis showed that specific aerobic training led to the greatest improvement in the 6-minute walk distance. On the other hand, for lower limb strength, two[48,55] out of five trials[46,48,52,55,76,77] that did not identify a treatment benefit did not incorporate training that specifically targeted lower limb muscle strength. For endurance, all trials that did not identify a treatment benefit did not include an aerobic training component in their training program.[67,69,70] All trials that measured flexibility also included flexibility exercise as part of the overall training, and reported positive results.[49,58,62] For more complex activity-level outcomes such as balance, the specificity of training seemed to be less important. Sixty-four per cent of the trials that reported favourable results on balance outcomes incorporated specific balance training. However, two trials[45,48] that adopted aerobic exercise, and one trial that incorporated aerobic and resistance exercise[71] also reported positive effects on balance. On the other hand, although Tai Chi[33] and cycling exercise[59] were reported to induce significant effects on balance, the improvement was very small and markedly less than the minimal clinically important change.[85]

For even higher levels of function like ADL, various forms of exercise other than specific ADL training were found to be beneficial, including aerobic walking training,[61] cycling exercise,[75,80,59] multimodal training without a specific ADL training component,[18,46,49,50,66] handball training,[29] and dance and movement therapy.[44] This could be because ADL ability can be influenced by many impairment variables.

Based on the overall evidence, it can be deduced that regular multimodal exercise with a combination of resistance, aerobic, balance, flexibility and functional training for around 60 minutes a day, 2 to 3 days a week is effective in improving various aspects of physical functioning (lower limb strength, mobility, balance, walking endurance). Considering that specific training is more important for impairment level outcomes, a comprehensive assessment of physical functioning is required to determine the specific areas of deficit, so that the appropriate type of exercise (flexibility, aerobic, resistance) can be incorporated into the overall program to address the impairments identified. The training program duration varied (ie, 8 weeks to 15 months), but the overall evidence indicated that positive training effects on physical function can be obtained in 9 to 16 weeks. Based on the few trials that included follow-up assessment, the improvements in strength, step length and balance diminished from 9 weeks to 9 months after the intervention. Continuous exercise programs may be required to maintain the treatment effect.

With respect to the frequency, intensity and duration of training, no clear differences in these parameters were identified between the trials that yielded larger effect sizes and those with smaller effect sizes for all outcomes, except lower limb strength and walking endurance. For strength, one trial suggested that 30 minutes of specific strength training of 12 repetition-maximum could lead to significant strength improvement.[71] However, among the trials that incorporated multimodal exercise, those that reported no significant results tended to use a shorter total training duration per session (non-significant: 30 to 60 minutes;[48,55,76,77] significant: 75 to 120 minutes).[41,42,49] This suggests that the strength training component cannot be too short in a multimodal training program if benefits on muscle strength are desired. For walking endurance, trials that reported negative findings also tended to adopt a shorter training duration per session (10 to 30 minutes).[67,69,70] A longer exercise duration in each session ($\geq$30 minutes of aerobic training) is required to induce a positive training effect.

With a large number of trials included in our review, it was possible to conduct sensitivity analyses for people with different levels of cognitive impairment. Indeed, sensitivity analyses that involved only people with mild cognitive impairment or mild-grade dementia did not show superior benefits of exercise in improving step length and functional reach when compared with the primary analysis. On the contrary, when compared with the primary analyses, the moderate dementia group tended to have a slightly better improvement in BBS and the moderate-to-severe dementia group had a better improvement in 6-minute walk distance. When compared with the mild cognitive impairment and mild-grade dementia group, the moderate dementia group also showed more improvement in TUG, while the moderate-to-severe dementia group showed slightly more improvement in walking speed. It should be noted that the response in the moderate-to-severe-grade dementia subgroup also tended to be more heterogeneous (eg, TUG, walking speed, 6-minute walk test). This finding challenges the previous finding that better cognitive ability is associated with greater improvement in TUG performance within a group of patients with mild cognitive impairment.[86] However, it should be noted that this comparison involved a much greater between-group difference in baseline cognitive ability (ie, mild cognitive impairment and mild-grade dementia versus moderate-to-severe-grade dementia) rather than comparing individuals within the same diagnostic category (eg, within mild cognitive impairment only). As the cognitive decline was found to be associated with poorer physical function, the group with more advanced cognitive impairment may indeed have a larger potential for improvement in physical function with exercise training. For example, a previous trial revealed that the effect of exercise on fall reduction is more potent in people with advanced dementia due to their inherent high fall rate.[73]

Taken together, these results suggest that people with moderate-grade cognitive impairment are still likely to respond positively to exercise training. The response to exercise training among people with severe-grade cognitive impairment remains largely uncertain, as only five trials[66–70] were conducted in this patient subgroup and only one was included in the meta-analysis of walking speed[66] and 6-minute walk test distance,[70] respectively.

Participants' physical ability at baseline also appears to influence training outcome. For TUG, the sensitivity analysis involving those trials that included only community-dwelling individuals yielded non-significant results. This could be because community-dwelling participants tended to have better baseline mobility level (mean TUG: 10 to 18 seconds) and thus have less room for improvement,[50,52,53,55] when compared with most of the other trials included in the primary meta-analysis (mean TUG: 15 to 33 seconds).[41,47,51,54,71,75] Perttila et al[72] also suggested that while the worsening of ADL performance was attenuated in both the prefrail and frail subgroups of people with dementia upon exercise training, a significant effect was achieved at the sixth month of training for the advanced frailty group but only at the twelfth month for the prefrail group. The fall reduction effect was also greater in the advanced frailty group (incidence rate ratio: advanced frailty: 0.43; prefrail: 0.63). This suggested that cognitively impaired individuals who have deteriorated physical performance could potentially benefit more from exercise training.

Exercise attendance appeared to be generally acceptable across trials. Two trials reported an attendance rate $<$70%.[65,66] Upon examining the training protocols and the participants' characteristics, no obvious relationship could be found between the training protocols used and attendance rates. However, in the two trials that reported exceptionally low attendance, the cognitive ability of the participants was also the poorest (mean MMSE = 8.8 and 11.1, respectively).[65,66] However, two other trials that involved participants with relatively low cognitive ability (mean MMSE = 13) reported good attendance.[55,61] Therefore, no consistent trend could be identified regarding the relationship between cognitive ability and exercise attendance. Taken together, the difference in attendance rate could possibly be due to complex interaction of factors such as the exercise training protocol adopted, cognitive ability, level of physical functioning and involvement of the family/caregiver.

Unfortunately, other aspects of adherence (eg, intensity level, training duration) were seldom reported in the included trials. Therefore, the influence of patient or intervention-related factors on patients' adherence to the prescribed protocol could not be deduced. The influence of exercise adherence to treatment outcomes also remains uncertain.

It is recommended that exercise training be supervised by professional staff. For those with mild cognitive impairment or mild dementia, the training may be supervised by a properly trained caregiver.[46,50,52,61] Less than half of the trials included in this review included information regarding adverse effects. Only five out of 14 trials reported adverse effects that were related to exercise.[36,52,53,66,78] Most adverse events reported were mild and subsided quickly.[36,52] A higher hospitalisation rate in the exercise group was reported by Rolland et al[66] but it remains unclear if the between-group difference in hospitalisation rate was already present prior to commencement of the exercise intervention. The single death event reported by one trial was not directly related to exercise training.[78] In summary, no evidence suggests that exercise poses an substantial risk to individuals with mild cognitive impairment or dementia.

Research in people with severe dementia is scarce. The results of this review are therefore better generalised to people with mild cognitive impairment, and mild or moderate dementia. Details on the training protocol, such as the specific exercises performed, training intensity and progression rules, and the time devoted to different types of exercise in a multimodal program are crucial pieces of information, but were seldom reported. Delineating the factors that are important determinants of successful training outcomes is therefore difficult. Detailed information on adherence to exercise training (ie, degree of deviation between the actual exercise conducted by the participants and the prescribed exercise protocol) was also rarely reported in the included trials. Long-term follow-up trials were few and so the carry-over effects of exercise were not well evaluated.

This review had some limitations. We used the mean baseline cognitive outcome scores to classify the selected trials into different patient sub-groups. There may be potential inaccuracy with this approach, as heterogeneity of the sample within the same trial was not considered. Most trials used multimodal exercise as the experimental intervention, and so it was difficult to single out the effect of a particular exercise type. We did not perform any economic analysis and hence could not comment on the cost-effectiveness of the exercise programs studied. We did not separate the trials that tended to examine 'efficacy' (training performed in a highly controlled environment) from those that tended to examine 'effectiveness' (training performed under real-world conditions) on the continuum from efficacy to effectiveness. To assist readers in judging whether the findings of the present review apply to 'real-world' conditions in their respective contexts, other relevant information of the trials (key subject characteristics, attendance, adverse effects, and supervision level) was provided. Many trials did not contain adequate details necessary for meta-analysis. Meta-analysis could not be performed for several outcomes, due to the small number of trials. Publication bias was present in a small number of analyses. A definite conclusion could not be made on the effect of exercise in severe-grade dementia because there is less research in this subgroup of the dementia population. This may also be due to the way that the different dementia grades were classified (Table 2). Finally, only trials reported in English were included in this review.

Despite the large number of trials that have been conducted, determinants of successful training outcomes are still unclear for many of the outcome measures. More effort could be put into identifying key factors (ie, training type, and parameters) that determine the favourable treatment outcomes. Good quality trials are needed to study the effects on exercise on falls and dual-tasking ability, which are important concerns in individuals with cognitive impairments. Mediators or strategies that are required to translate the improvement in body functions/structures-level outcomes into improvement in activity/participation-level outcomes should be identified. Long-term effects of exercise training also await further investigations. More economical ways of providing exercise training (eg, through educating the caregiver) should be further investigated. More research on people with severe dementia should be conducted.

In conclusion, this review demonstrated that physical exercise training is a feasible intervention for people with mild cognitive impairment and dementia, and that the benefits far outweigh the risks. Strong evidence was found to support the use of physical exercise in improving strength, step length, balance, mobility, and walking endurance. There was weak evidence supporting the use of exercise for improving flexibility and ADL, and against the use of non-specific exercise for improving dual-tasking ability and increasing activity levels. The evidence against the use of non-specific exercise alone for improving quality of life was strong. Taken together, supervised multimodal exercise for about 60 minutes a day and 2 to 3 days a week was beneficial in improving physical functioning in individuals with mild cognitive impairment or mild-to-moderate-grade dementia. The effect of exercise in severe-grade dementia was less certain, due to paucity of research.

What is already known on this topic: Exercise training improves cognitive and physical function in healthy older adults, and is feasible and beneficial for people with cognitive impairment. Patients with dementia are less likely to participate in regular physical exercise when compared with their counterparts with normal cognition.
What this study adds: Strong evidence now indicates that exercise for people with mild cognitive impairment or mild to moderate dementia improves sit to stand, step length, balance, mobility and walking endurance. People across these levels of cognitive impairment are more likely to achieve these benefits with supervised multi-modal exercise for about 60 minutes a day, 2 to 3 days a week.

Footnotes: [a] Review Manager 5.3, The Nordic Cochrane Centre, The Cochrane Collaboration, Copenhagen, Denmark; [b] Comprehensive Meta-analysis version 3, Biostatc, Inc., Englewood, NJ, USA.

eAddenda: Figures 3, 5, 7, 9, 11, 13, 15, 17 and 19 and Appendices 1, 2, 3 and 4 can be found online at https://doi.org/10.1016/j.jphys.2017.12.001

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Competing interests: The authors declare that there is no conflict of interest.

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Correspondence: Marco YC Pang, Department of Rehabilitation Sciences, Hong Kong Polytechnic University, Hong Kong. Email: Marco.Pang@polyu.edu.hk

Long-term effects of a 12 weeks high-intensity functional exercise program on physical function and mental health in nursing home residents with dementia: a single blinded randomized controlled trial

Abstract

Background: Research indicates that exercise can have a positive effect on both physical and mental health in nursing home patients with dementia, however the lasting effect is rarely studied. In a previously published article we investigated the immediate effect of a 12 weeks functional exercise program on physical function and mental health in nursing home residents with dementia. In this paper we studied the long-term effect of this exercise program. We explored the differences between the exercise and control group from baseline to 6 months follow-up and during the detraining period from month 3 to 6.

Methods: A single blind, randomized controlled trial was conducted and a total of 170 nursing home residents with dementia were included. The participants were randomly allocated to an intervention ($n = 87$) or a control group ($n = 83$). The intervention consisted of intensive strengthening and balance exercises in small groups twice a week for 12 weeks. The control condition was leisure activities. Thirty participants were lost between baseline and six-month follow-up. Linear mixed model analyses for repeated measurements were used to investigate the effect of exercise after detraining period.

Results: The exercise group improved their scores on Berg Balance Scale from baseline to 6 months follow-up by 2.7 points in average. The control group deteriorated in the same period and the difference between groups was statistically significant ($p = 0.031$). The exercise group also scored better on NPI agitation sub-score after 6 months ($p = 0.045$).

Conclusion: The results demonstrate long-time positive effects of a high intensity functional exercise program on balance and indicate a positive effect on agitation, after an intervention period of 12 weeks followed by a detraining period of 12 weeks.
Identifier at ClinicalTrials.gov: NCT02262104

Keywords: Exercise, Dementia, Nursing home, Aged, Balance, Activities of daily living, Neuropsychiatric symptoms, Agitation

Background

The world population is rapidly aging and as a result, health and social care services will come under pressure to provide services for older people with dementia as well as persons with a wider range of other chronic diseases. Dementia is among the leading causes of disability and death in the elderly [1, 2]. There is no cure for dementia [3] and the on-going degeneration of brain tissue in older adults with neurodegenerative dementia disorders eventually leads to a loss of cognitive and physical functions [4, 5]. About 80 % of nursing home residents in Norway suffer from dementia [6], and it is the most common main diagnosis in the nursing home population in Norway [7].

Individuals with dementia have higher levels of functional dependence than others and are therefore more likely to require assistance in activities of daily living (ADL) [8, 9]. In addition to impaired cognition, reduced ADL function and changed behaviour, dementia normally affects balance, mobility, and gait performance [10–15]. Reduced balance increases the risk of falling, and falls and fractures are common among nursing home residents with dementia [10, 11, 16, 17]. People with dementia have a two-fold increased risk of falls compared with non-demented elderly [16]. Fear of falling itself is a risk factor for inactivity and can create a vicious circle [18]. Therefore, improvements in balance may potentially reduce the risk of falling and increase mobility through increased confidence.

As dementia progresses, cognitive and functional impairments are followed by neuropsychiatric symptoms (NPS) [19]. Studies show that more than 80 % of persons with dementia in nursing homes have at least one clinically significant NPS [20, 21] and behavioural symptoms are one of the main reasons for institutionalization [22]. The most prevalent symptoms in patients with dementia in nursing homes are agitation, apathy and affective symptoms [20, 21, 23]. These symptoms cause discomfort and reduced quality of life for people with dementia and they are predictors of fall for nursing home patients, causing considerable morbidity and mortality [24, 25]. NPS also give distress to family and carers .

The effect of exercise on mental health is well established in other groups, however in the population of nursing home residents with dementia, most studies focus on the impact of exercise on physical functioning and mobility, rather than neuropsychiatric symptoms and cognition. Therefore research on the effect of exercise on agitation in dementia is scarce. In a systematic review of non-pharmacological interventions for agitation in dementia from 2009, no exercise interventions were included due to low methodological quality [26]. Historically, these symptoms have been managed with anxiolytic and antipsychotic medications [27]. Although potentially effective, such medication has been used too widely and may be associated with serious adverse side effects and increased mortality [28]. According to Ballard et al., 2006, over prescribing has become a major problem, especially in residential and nursing home environments. It is reported that 42–66 % of people with dementia are taking antipsychotic drugs [6, 29–31], often inappropriately and usually with little monitoring [32]. Antipsychotic drugs have substantial adverse effects such as increased risk of falls [33, 34] and increased mortality [35]. Consequently, there is a need to evaluate non-pharmacological therapies for behavioural and neuropsychiatric symptoms in this population [36].

Reviews have concluded that there is insufficient evidence for the effectiveness of physical activity on function, cognition, neuropsychiatric symptoms and depression in older people with dementia [36–40]. Difficulties with measurements and instructions and lack of compliance have led the majority of studies on physical exercise to exclude people with dementia. In a previous study we demonstrated the effect of high intensity functional exercises on balance, strength and apathy in nursing home residents with mild and moderate dementia, as measured after a 12 weeks program [41]. Muscle strength gains induced by resistance training programs are lost after short detraining period [42–45] and there are reasons to believe that this will happen even more rapidly in nursing home residents due to the sedentary lifestyle [46]. The detraining effect on balance is less investigated, but it seems that the balance function as well declines abruptly after completion of an exercise program [47–49]. There are several reasons as to why it is important to investigate the detraining period. First of all, elderly people are more prone to interrupt exercise program due to ill health, and information about what happens to the exercise effects and when, is important to optimize quality of care. Research studies often have a rather short intervention period, e.g. 12 weeks and some have shown that the immediate effect of exercise can be different from the effect weeks later [50]. It has been suggested that different types of exercise, intensity and age may also influence detraining effects [43, 45, 51] and this needs to be investigated. From an economic point of view, it can be interesting to find out how little you can "get away" with.

As demonstrated above, randomized, controlled trials with physical exercise among nursing home residents with dementia are limited and knowledge about long-term effects are lacking. In a previously published article we investigated the immediate effect of a 12 weeks exercise program on physical function and mental health in nursing home residents with dementia [41]. An effect of exercise on balance, the primary outcome, was demonstrated. In this paper we would like to study the long-term effect of this exercise program. Is there still a significant difference in balance function between the two groups 3 months after exercise cessation? We aimed to investigate the change in physical function and mental health from baseline to 6 months follow-up and during the detraining period, in the two groups.

Methods

Design

Exercise and dementia – EXDEM – was a 12-week single blinded parallel multi centre randomized controlled trial, followed by a 12 weeks detraining period, conducted among nursing home residents with dementia. Participants in 18 different nursing homes were randomly allocated to two groups: physical exercise and control activity. We used a block randomization procedure with six to 12 participants from each nursing home. Due to great heterogeneity between the nursing homes regarding residents' demographics, care staff awareness concerning importance of physical activity and physical activity-opportunities, we considered it to be most appropriate to use block randomization.

Identifier at ClinicalTrial.gov: NCT02262104, registered November 2013.

Participants

The study took part in 18 nursing homes in Oslo city areas in Norway between May 2012 and September 2013. Each nursing home was given the opportunity to recruit up to 12 participants each, which gives a total of 216 possible participants. Inclusion criteria were: being above 55 years of age, having dementia of mild or moderate degree as measured by the Clinical Dementia Rating scale (CDR 1 or 2), being competent to consent to participation, being able to stand up alone or by the help of one person and being able to walk six meters with or without walking aid. Exclusion criteria: patients being medically unstable, psychotic or having severe communication problems.

In total, 182 persons (84 %) agreed to participate. Twelve persons (6.6 %) dropped out of the study before the first assessment and randomization was carried out: eight withdrew and four were excluded because the inclusion criteria were not met (See flowchart Fig. 1). Thus, the study population consisted of 170 participants. A further 16 participants were lost to follow up at 12 weeks (3 died, 7 withdrew, 4 moved to another nursing home and 2 became seriously ill). At 24 weeks follow-up a further 14 were lost (3 died, 3 withdrew, 1 moved and 7 became seriously ill). See Flowchart, Fig. 1. The participants who were lost to follow-up were excluded from the analysis.

Randomization

An independent trial secretary performed the randomization procedure. Following completion of the pre-intervention assessments the participants from each nursing home were randomly assigned to either intervention or control group by picking name from a container. The randomization codes were kept in sealed envelopes with consecutive numbering by the trial secretary and blinded to those who assessed the patients.

Physical exercise program

Three to six participants at each nursing home exercised twice a week for 12 weeks with physiotherapists (1 physiotherapist per 3 participants). The exercise program was the High Intensity Functional Exercises (HIFE) –program developed in Umeå, Sweden [52]. The exercise sessions lasted 50–60 min and consisted of: 5 min warm-up, at least two strengthening exercises for the muscles of lower limb and two balance exercises. All exercises were individually tailored, instructed and supervised. The intensity of strengthening exercises aimed to be 12 repetitions maximum (RM). The balance exercises intended to be "highly challenging". The physiotherapists kept detailed records of all exercise sessions and reported the type and number of exercises performed, the intensity (low, moderate or high) and any adverse occurrences. For more information about HIFE and the exercise sessions, see [52] Local physiotherapists (i.e. employed at the nursing home) were used wherever possible. Nine nursing homes (50 %) received help from one ($n = 7$) or two ($n = 2$) external physiotherapists to be able to participate in the study. In total, 27 physiotherapists were involved in the intervention program and all of them had attended a course to learn about the HIFE-program. The course lasted three hours and included practical exercises. The importance of targeting high intensity was emphasized. Adjustable weighted belts (0.5–12 k) were made available to all participating nursing homes. The project leader kept in touch with all physiotherapists during the intervention period through meetings (one obligatory), observation of exercise sessions (often in conjunction with the obligatory meeting), and by phone and email. This was done to optimize quality, high intensity and uniform execution in all nursing homes

The participants were not blinded after assignments to intervention.

Control program

The control participants met in groups twice a week for 50–60 min and the activities were led by occupational therapists ($n = 11$), nursing staff ($n = 5$), volunteers ($n = 1$) or activity-leader ($n = 1$). The control activities were light physical activity in sitting (mostly mobility exercises and stretches), reading, playing games, listening to music and making conversations.

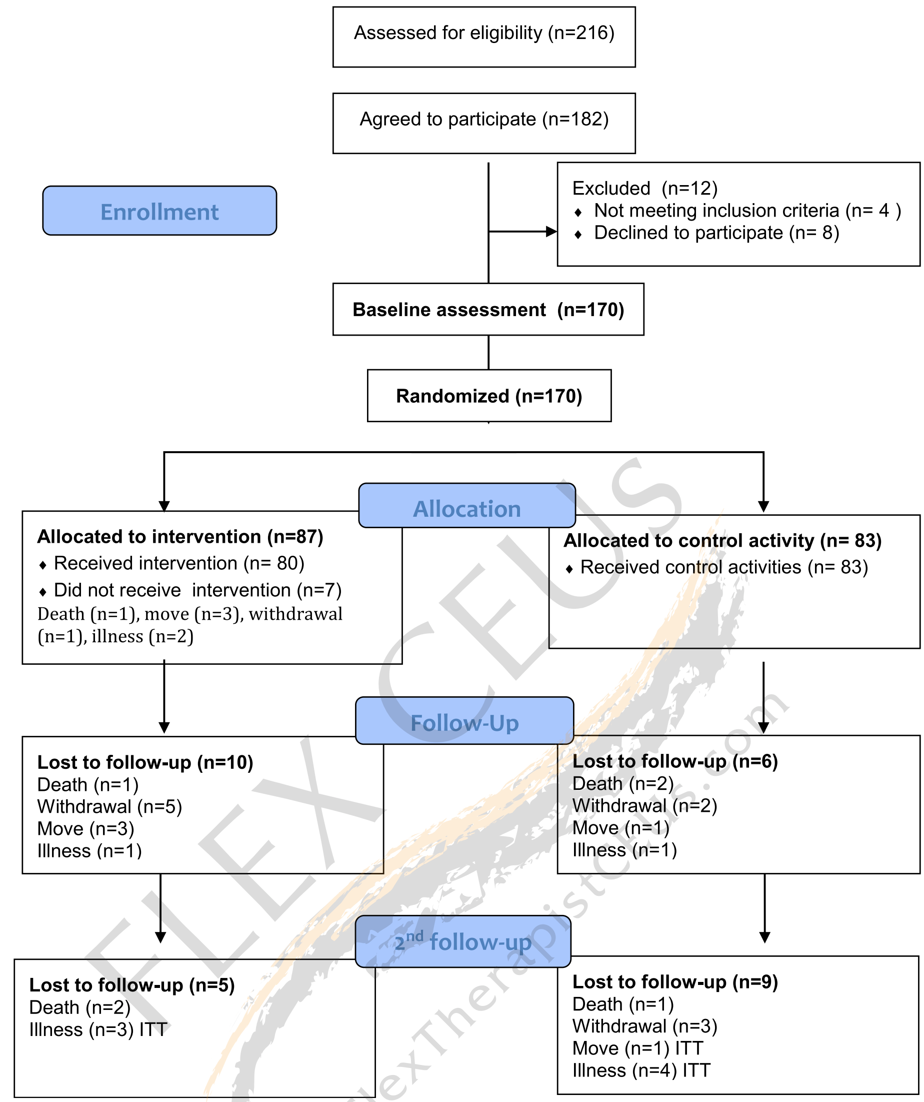

Fig. 1 Flowchart of the study population

Detraining

After the 12-week intervention (HIFE and control program) the participants received no further intervention or attention from any of the physical or occupational therapists. No specific advice about physical activity during the detraining period was given, except that there should be no difference between the participants of the two groups.

Assessments

After enrolment, but before randomization, all 170 participants were assessed. A member of the nursing staff, who knew the participant well and was in regular contact with him/ her, filled in the Case Record Form. Nursing staff members that were not familiar with the questionnaires were encouraged to contact the project leader with any questions. An occupational therapist or specially trained nurse performed the Mini-Mental State Examination (MMSE). Four physiotherapists from the research team without knowledge of group allocation (blinded) performed all physical tests. Information about the testers training can be found in a previous paper [41]. The assessment procedure was repeated after 12 weeks (intervention completion) and 6 months and was carried out December 2012 to September 2013.

Instruments

Physical function-tests

The primary outcome was *balance* measured by the Berg Balance Scale (BBS). The test assesses performance on a 5-level scale from 0 (cannot perform) to 4 (normal performance) on 14 different tasks involving functional balance control, including transfer, turning and stepping [53]. The six-meter walking test at comfortable speed with or without a walking aid tested *mobility* in the participants. The time in seconds was recorded and calculated as meters per second [54]. *Muscle strength* was measured by the 30-s chair stand test (CST). The score equals the number of rises from the chair in 30 s [55]. The physical tests used in this study were tested for inter-tester reliability in 33 of the participants. The tests were found to have high inter-tester reliability (ICC ≥ 0.97 on BBS, CST and NWS) [56]. To measure the patients' dependence in the *ADL,* we employed the Barthel Index (BI), a widely used measure of the activities of daily living [57, 58]. The BI consists of 10 activities focusing on the patient's level of dependence on aid. The scores range from 0 (completely dependent) to 20 (independent). Professional caregivers filled out the BI-questionnaire based on their observations of the participants.

Dementia, cognition and neuropsychiatric symptoms

The Clinical Dementia Rating Scale (CDR), and the Mini-Mental State Examination (MMSE) were used to measure *cognition*. We used the CDR to validate the dementia diagnosis of the patients. CDR is a six-point scale used to assess six domains of cognitive and functional performance applicable to Alzheimer's disease and related dementias [59–61]. Two Norwegian studies have shown that CDR staging is a valid substitute for a dementia assessment among nursing-home patients to rate dementia and dementia severity [60, 61]. The MMSE was used to assess global cognition and consists of 20 items concerning orientation, word registration and recall, attention, naming, reading, writing, following commands and figure copying. It can be scored between zero and 30, where a higher score indicates better performance [62]. The Neuropsychiatric Inventory questionnaire (NPI-Q) was used to assess the presence and severity of *behavioural and neuropsychiatric symptoms* common in dementia [63, 64]. The scale consists of 10 items. Each item represents a symptom and is rated as present or not (zero). If present, the severity is graded as mild (1) , moderate (2) or severe (3). Thus the minimum score is 0 (no symptoms at all) and the maximum score is 30. We also used sub- scales of the NPI-Q in the analyses, based on a previous large principal component analysis conducted with data from Norwegian nursing home patients [23]. The subscales were: 1) agitation: consisting of the items agitation/ aggression, irritability, and disinhibition (range: 0–9) 2) affective: consisting of the items depression and anxiety (range 0–6), and 3) apathy: The symptom apathy was analysed on its own.

Depression and quality of life

Cornell Scale for Depression in Dementia [65] was used to assess *depression* in the participants. The scale contains 19 depressive symptoms and each item is rated on a scale from 'absent', 'mild/ intermittent' to 'severe'. The minimum score is thus zero and maximum score is 38. According to a Norwegian nursing home study, a Cornell scale score of more than 7 points signifies depression [66]. "The quality of life in late-stage dementia scale", QUALID [67] a proxy-rated scale was used to measure the QoL. The informants were professional caregivers who knew the patient well and had spent at least three of the last seven days with the patient. The scale consists of 11 items with a possible score of one to five on each item, which gives a total possible score range from 11 to 55. A lower score indicates a higher quality of life.

Demographic factors: participant age, gender, previous and present medical history, and the length of stay in a nursing home (from date of admission at the current nursing home).

Ethics

The study was approved by the Regional Committee for Medical Ethics in south east of Norway September 2012. The nursing staff at the respective participating nursing home allocated eligible candidates, provided information about the study and gathered written consent. Primary caregiver provided written and verbal information about the study to the patients and their relatives. All the participants gave written consent to participate. Surrogate consent procedure was not used. The Regional Committee for Medical Ethics in south east of Norway approved this consent procedure.

Data analysis

A power calculation was made using the BBS results of a pilot study from a nursing home in Norway. An analysis with 80 % power, alpha of 0.05, and an average difference of 2.5 points (SD = 4.2) between the intervention group and the control group, indicated that we should include 70 participants in each group to account for some degree of lost to follow-up. We did a complete responder analysis: all the participants who dropped out during the intervention and follow-up period were excluded (see flow chart Fig. 1). We assessed variables at baseline to establish whether the randomization procedure was successful.

The long-term effects of the intervention and detraining on each outcome were assessed with a linear mixed model for repeated measurements. The statistical model contained a random intercept, the outcome variable at baseline as a covariate and the fixed factors effects group affiliation, time and the interaction between time and group affiliation. We used the robust estimation of the standard error. The adjusted means at time 1 (immediately after intervention completion) and time 2 (3 months after intervention completion) and the mean differences within and between groups were estimated from the statistical model using estimated linear combinations. All statistical analyses were performed with the IBM SPSS Statistics version 20 or STATA version 14.

Results

Demographic and baseline scores

The background characteristics and baseline results of the assessments of the participants are reported in Table 1. The intervention and the control group were similar at baseline. The characteristics of the 16 participants who were not included in the ITT analyses were not significantly different from the final ITT population. The average age of the participants was 86.9 years (7.4) and almost three out of four were women. Thirty-one percent was able to walk independently without walking aid and less than 10 % used a wheel chair. The average score on Berg Balance Scale was 35 points points and two thirds scored less than 45 at baseline, which means they are at increased risk of falling [68]. Ninety-four percent of the participants walked slower than 0.8 m per second, which means an increased risk of frailty [69]. The men scored higher than the women at baseline on 30-s CST (6.8 rises vs. 5.8), however the difference was not statistically significant. See Table 1 and Telenius et al., 2015 [41] for more details regarding demographic information and baseline results.

Attendance

The persons in the exercise group participated on average in 18.1 sessions (Minimum 0- maximum 24, SD 6.8). This gives an attendance rate of 75 %. Severity of dementia, depression, functional balance or neurological disease did not influence the attendance rate. No adverse effects of exercise were observed. The control group participated on average in 16.4 sessions (minimum 4- maximum 24, SD 5.8). For more information about the attendance and intensity of exercise sessions, please see Telenius et al., 2015 [41].

Lasting effects *within* the exercise and control group

Table 2 shows the adjusted means at time 1 (T1) and time 2 (T2) for both groups. When considering the within group changes in the EG, the results reveal a non-significant improvement in balance function by 2.7

Table 1 Baseline characteristics

	Whole sample $n = 170$	Intervention $n = 87$	Control $n = 83$	*p*-value
Age years mean (SD)	86.9 (7.4)	87.3 (7.0)	86.5 (7.7)	0.48
Female n (%)	125 (73.5)	63 (72.4)	62 (74.7)	0.74
NH stay months mean (SD)	25.7 (24.5)	23.8 (20.0)	27.6 (28.4)	0.34
Walk independently n (%)	52 (31.1)	25 (28.7)	27 (32.5)	0.70
No of diagnosis mean (SD)	3.4 (1.9)	3.4 (1.9)	3.3 (1.9)	0.78
No of medications mean (SD)	6.4 (3.4)	5.8 (3.1)	6.7 (3.6)	0.10
BBS points mean (SD)	34.8 (14.0)	34.3 (14.4)	35.3 (13.7)	0.65
CST points $n = 161$ mean (SD)	6.1 (3.0)	6.0 (3.1)	6.2 (2.9)	0.73
NWS m/ s mean (SD)	0.5 (0.2)	0.5 (0.2)	0.5 (0.2)	0.93
BI points mean (SD)	13.5 (3.5)	13.5 (3.5)	13.4 (3.6)	0.83
MMSE points mean (SD)	15.6 (4.9)	15.5 (0.6)	15.7 (4.9)	0.81
QUALID points mean (SD)	18.1 (5.8)	18.4 (6.1)	17.7 (5.4)	0.39
Cornell Scala points mean (SD)	4.9 (4.5)	4.9 (4.8)	4.9 (4.2)	0.98
NPI points mean (SD)	5.5 (5.4)	6.1 (6.1)	4.8 (4.6)	0.14
Affective, NPI subscale	1.0 (1.4)	1.2 (1.5)	0.8 (1.3)	0.13
Agitation, NPI subscale	1.5 (1.9)	1.7 (2.1)	1.3 (1.7)	0.16
Apathy, NPI subscale	0.5 (0.8)	0.6 (0.8)	0.4 (0.7)	0.08
Affective symptoms present n (%)	80 (47.1)	44 (50.6)	36 (46.4)	0.35
Agitation symptoms present n (%)	134 (78.8)	69 (79.3)	65 (78.3)	0.88
Apathy symptoms present n (%)	57 (33.5)	34 (39.1)	23 (37.7)	0.12

Independent samples t-test were used for continuous data and χ^2 on categorical data

BBS Berg Balance Scale, *CST* Chair stand test, *NWS* Normal walking speed, *BI* Barthel Index, *MMSE* Mini Mental State Examination, *NPI* Neuropsychiatric Inventory

Table 2 Results from baseline (T0), 3 months (T1) and 6 months (T2) for exercise and control group

Variable	T1: 12 weeks T2: 6 months	Exercise		Control		Difference between groups at T0, T1 and T2	*P*-value T2
		Means (SD)/ Adjusted means (CI)	Within group change T1T2	Means (SD)/ Adjusted means (CI)	Within group change T1T2		
Berg	T0	34.3 (14.4)	−1.5 (−3.1–0.2)	35.3 (13.7)	−2.2 * (−4.2–0.3)	1.0	
	T1	38.4 (36.8–40.1)		36.2 (34.7–37.6)		2.3	
	T2	37.0 (35.0–38.9)		33.9 (32.0–35.9)		3.0	0.031*
CST	T0	6.0 (3.1)	−0.4 (−0.9–0.3)	6.2 (2.9)	−0.3 (−1.1–0.3)	0.2	
	T1	7.1 (6.6–7.7)		6.5 (6.0–7.1)		0.6	
	T2	6.8 (6.2–7.4)		6.2 (5.4–6.9)		1.7	0.175
NWS	T0	0.5 (0.2)	−0.02 (−0.04–0.02)	0.5 (0.2)	−0.01 (−0.1–0.03)	0	
	T1	0.49 (0.46–0.51)		0.49 (0.44–0.54)		−0.001	
	T2	0.47 (0.44–0.51)		0.46 (0.43–0.5)		0.01	0.685
Barthel	T0	13.5 (3.5)	−0.6 (−1.3–0.1)	13.4 (3.6)	−0.8 (−1.6–0.03)	0.1	
	T1	13.7 (13.0–14.3)		12.9 (12.3–13.5)		0.8	
	T2	13.0 (12.3–13.8)		12.1 (11.2–12.9)		1.0	0.082
MMSE	T0	15.5 (0.6)	−1.0* (−1.9–0.2)	15.7 (4.9)	−1.4* (−2.4–0.5)	0.2	
	T1	15.4 (14.5–16.3)		15.3 (14.6–16.1)		0.1	
	T2	14.4 (13.5–15.2)		13.9 (12.9–14.9)		0.5	0.492
NPI sum	T0	6.1 (6.1)	0.03 (−1.3–1.3)	4.8 (4.6)	0.7 (−0.8–2.3)	1.3	
	T1	4.8 (3.7–5.8)		5.6 (4.1–7.1)		−0.9	
	T2	4.8 (3.8–5.8)		6.4 (5.1–7.7)		−1.6	0.059
Affective	T0	1.2 (1.5)	−0.04 (−03–02)	0.8 (1.3)	−0.1 (−0.3–0.4)	0.4	
	T1	0.9 (0.6–1.2)		1.0 (0.7–1.4)		−0.1	
	T2	0.9 (0.6–1.1)		1.1 (0.8–1.4)		−0.2	0.257
Agitation	T0	1.7 (2.1)	0.04 (−0.5–0.5)	1.3 (1.7)	0.2 (−0.3–0.8)	0.4	
	T1	1.3 (0.9–1.7)		1.8 (1.3–2.3)		−0.5	
	T2	1.4 (1.0–1.8)		2.0 (1.5–2.5)		−0.7	0.045*
Apathy	T0	0.6 (0.8)	0.08 (−0.03–0.3)	0.4 (0.7)	0.15 (−0.1–0.3)	0.2	
	T1	0.3 (0.2–0.4)		0.4 (0.2–0.6)		−0.1	
	T2	0.4 (0.3–0.6)		0.5 (0.3–0.7)		−0.1	0.688
QUALID	T0	18.4 (6.1)	−0.2 (−1.6–1.2)	17.7 (5.4)	1.1 (−0.2–2.6)	0.7	
	T1	18.1 (16.8–19.3)		17.7 (16.4–19.0)		0.4	
	T2	17.8 (16.7–19.0)		18.8 (17.3–20.2)		−0.9	0.326
Cornell Scala	T0	4.9 (4.8)	0.8 (−0.8–2.4)	4.9 (4.2)	1.4* (0.1–2.6)	0	
	T1	4.0 (2.6–5.4)		3.8 (2.8–4.7)		0.2	
	T2	4.8 (3.8–5.8)		5.1 (4.0–6.3)		−03	0.668

Results at T0 are given as mean (SD). Results at T1 and T2 are estimated means (95 % confidence interval) or mean difference (95 % confidence interval) derived from the linear mixed model
BBS Berg Balance Scale, *CST* Chair stand test, *NWS* Normal walking speed, *BI* Barthel Index, *MMSE* Mini Mental State Examination, *NPI* Neuropsychiatric Inventory Questionnaire
T0 = baseline, T1 = 12 weeks, T2 = 6 months
$*p < 0.05$

points from baseline to 6 months follow-up. There was also an improvement in leg strength in the same period: The CST-score from baseline to 6 months assessment improved by 0.8 rises in average. The EG deteriorated on both BBS (1.5 points) and CRT (0.4 points) during the detraining period, however, these changes were also non-significant. When considering the mental health variables, the results in the EG demonstrate a non-significant improvement in NPI-Q-scores (including all its sub scores) from baseline to 6 months follow-up. There was a slight improvement during exercise cessation on the subscale of affective symptoms.

The CG reduced their BBS score in both periods: On average they dropped 1.4 points from baseline to 6- months follow-up and 2.2 points ($p = 0.022$) after intervention cessation. The CG deteriorated on ADL-function measured by BI: From baseline to 6 months follow-up the score reduced by 1.3 points and after intervention cessation, 0.8 points. NPI sum score and all sub-scores deteriorated from baseline to 6 months follow-up and the CG also declined significantly on the Cornell Scale ($p = 0.034$).

Comparison of lasting effects *between* exercise and control group

From baseline to 6 months follow-up, the EG improved their BBS score while the CG declined and the difference between the groups was statistically significant ($p = 0.031$). While the CG remained unchanged on the CST during the 6 months period, the EG improved somewhat on CST, but the difference was not significant. After 6 months the EG scored significantly better than the CG on the NPI sub-score agitation ($p = 0.045$). The difference in NPI sum score was close to significant ($p = 0.059$).

Discussion

Long-term effect on physical function

This study demonstrates that a 12-week intensive functional exercise program had a long-term effect after three months of detraining on balance in a population of nursing home residents with dementia. Balance was the predetermined primary outcome. An effect of exercise on balance function was also found immediately after 12 weeks of exercise [41]. The change in BBS from baseline to 6 months follow-up was 2.7 points in the exercise group. To the authors knowledge, clinically meaningful change has not been determined for BBS, however minimal detectable change for dependent institutionalized elderly has been reported to be 7.7 points in a Swedish study [70]. This means that due to intra-person variability of balance function from one day to another, a change in BBS score should be at least 8 or higher in dependent nursing home residents to represent a true change. Even though the EG had a slight improvement in lower limb strength (CST) and the CG deteriorated during the 24 weeks, the difference in change between the groups was not significant and both groups declined during detraining [41]. The deterioration in strength after exercise cessation has been demonstrated in other studies [44, 71]. An RCT using the HIFE-programme in a population of 191 nursing home residents including 50 % patients with dementia demonstrated long-term effect on walking speed, balance (BBS) and lower limb strength (1RM) [50]. The exercise group improved on both balance and strength during the detraining period while the control group improved in balance and declined in strength [50]. In contrast to our study, the design of the study by Rosendahl et al., 2006 [50], included continuous encouragement of the participants to do tasks to maintain physical function for another three months after the intervention period. This could explain their positive long-term effects. In our study, the withdrawal of intervention might have led to a disappointment for some of the EG-participants, they may have lost interest and become inactive which led to the decline in balance and strength after exercise cessation. It is however interesting to notice that, even though both EG and CG deteriorated on almost all variables during detraining period, the CG decline was of greater extent, indicating that even terminated exercise has some effect. Preservation of effect from functional exercises has also been demonstrated in community-dwelling elderly women [43]. DeVreede et al., 2005 [43], found that the group who did functional exercises scored better than resistance-training group and inactive control group on Assessment of Daily Activity Performance (ADAP) six months after training ended. The ADAP provides a total score and five physical domain scores: upper body strength, lower body strength, flexibility, endurance, and balance and coordination. It is likely that the effect is easier to maintain due to the functional nature of these exercises which means that they are repeated throughout the day even when not exercising.

Long-term effect on mental health

From baseline to 6 months assessment, the EG improved on the NPI sum score and all sub-scores while the CG deteriorated on these scores. The differences between groups were significant for the agitation sub-score. An effect of exercise on apathy was found at 12 weeks [41], but at 6 months there was no longer a statistically difference between groups. High quality RCTs are lacking, however smaller uncontrolled and observational studies suggest effect on agitation of walking in groups [72] and continuous program activities including physical exercise [73]. A pilot study with chair-exercises did not demonstrate any effect on agitation [74], but this might be due to too low intensity. A review of effect of exercise on behavioural and psychological symptoms in dementia states that exercise appear to be beneficial in reducing depressed mood, agitation and wandering, however the review emphasizes that the methodological shortcomings of work in this area are substantial [36].

The results from our study show that it is possible to influence on neuropsychiatric symptoms by other means than medication and this is important due to the overuse of antipsychotics to treat behavioural problems in persons with dementia [75, 76]. The modest effect of these drugs coupled with the increase in risk of adverse effects argues for a shift towards other treatment modalities [19, 77]. Encouragement and stimulation to be physically active is of great importance, and access to rehabilitation staff seems crucial to achieve improvements in function among nursing home residents [78]. Nursing home residents are a frail group that often has difficulty carrying out physical training on their own. In order to maintain positive results physical training should be an on-going activity.

Limitations of the study

There are limitations in the present study. First of all our inclusion criteria restrict our findings to nursing home residents with the ability to rise from a chair with the maximum help from one person and being able to walk for 6 m with or without walking aid. This means that the frailest residents have not been included, even though some of the participants used electrical wheel chairs and managed to move six meters only with great help from support walkers.

The recruitment through meetings and direct invitations may also introduce some bias in generalizations. Each nursing home was asked to recruit up to 12 participants. This may have led to recruitment of only the healthiest. However only three out of 18 nursing homes managed to recruit 12 participants, so it is unlikely that this strategy has influenced the characteristics of the population. It is difficult to ensure homogeneity of the intervention since a total of 27 physiotherapists were involved in the execution of the intervention and 18 professional caregivers carried out the control activity.

The amount of formal tests is high in this study and, since this could lead to alpha inflation, the secondary endpoints should be interpreted as descriptive statistics and not formal probabilities. One way to adjust for the high number of variables is to use the Bonferroni correction [79]. According to Bonferroni the modified p-value at 95 % confidence when testing 11 variables is 0.0045. At this significance level the results from the current study are not statistically significant, however there are strong indications of effect of exercise on neuropsychiatric symptoms that should be investigated further as a primary outcome.

The frequency of training sessions and the long period of intervention (12 weeks) strengthened the study, but it may be questioned whether three months of intervention is a sufficient time period for optimal benefit. We did not gather information about the habitual physical activity of our participants, thus we cannot control for whether the level of physical activity in addition to the exercise contributed to the results. The physical outcome measures may have been affected by the reduced amount of motivation and/ or understanding in some participants. It is also a limitation of the study that some of the questionnaires may have been filled out by nursing staff with limited knowledge and experience with the different instruments. Assistance was offered, but it is not certain that all involved felt comfortable to contact project leader to attain wanted information.

Strengths of the study

Strengths of the study are factors such as blinding of testers, randomization and analysis by intention to treat. The linear mixed model for repeated measurements is effective in accommodating missing data [80]. However, a complete case analysis demonstrated the same results as presented, and this indicates that the effect of missing was minimal. In each group, data from T1 or T2, or both, were missing for 15 participants. The participants with missing data were slightly older, scored higher on MMSE and lower on Cornell scale, but the differences were not statistically significant. The high attendance and low dropout rate is a strength of the study, and so is the use of simple and inexpensive equipment. In addition, by employing local physiotherapists, we have demonstrated that effect can be achieved at most nursing homes with access to basic gym equipment and physiotherapy recourses.

Conclusion

The results indicate long-time positive effects of a high intensity functional exercise program on balance. A possible effect of exercise on agitation is demonstrated after an intervention period of 12 weeks followed by a detraining period of 12 weeks. Future research should focus on exploring the effect of exercise on mental health in the population of nursing home residents with mild and moderate dementia.

Experiences of older people with dementia participating in a high-intensity functional exercise program in nursing homes: *"While it's tough, it's useful"*

The objective of the study was to describe the views and experiences of participation in a high-intensity functional exercise (HIFE) program among older people with dementia in nursing homes. The study design was a qualitative interview study with 21 participants (15 women), aged 74–96, and with a Mini-Mental State Examination score of 10–23 at study start. The HIFE-program comprises exercises performed in functional weight-bearing positions and including movements used in everyday tasks. The exercise was individually designed, supervised in small groups in the nursing homes and performed during four months. Interviews were performed directly after exercise sessions and field notes about the sessions were recorded. Qualitative content analysis was used for analyses. The analysis revealed four themes: *Exercise is challenging but achievable*; *Exercise gives pleasure and strength*; *Exercise evokes body memories*; and *Togetherness gives comfort, joy, and encouragement*. The intense and tailored exercise, adapted to each participant, was perceived as challenging but achievable, and gave pleasure and improvements in mental and bodily strength. Memories of previous physical activities aroused and participants rediscovered bodily capabilities. Importance of individualized and supervised exercise in small groups was emphasized and created feelings of encouragement, safety, and coherence. The findings from the interviews reinforces the positive meaning of intense exercise to older people with moderate to severe dementia in nursing homes. The participants were able to safely adhere to and understand the necessity of the exercise. Providers of exercise should consider the aspects valued by participants, e.g. supervision, individualization, small groups, encouragement, and that exercise involved joy and rediscovery of body competencies.

Introduction

People living with dementia can have persistence of self [1], 'a view of a life that is not erased by dementia' [2], and intact feelings and interpersonal responses [3] even though dementia disorders are chronic, progressive, long-lasting and affect all aspects of life for the person and for their families. Nonetheless, dementia is the leading cause of disability in older people worldwide and the most common reason for people to move to nursing homes [4]. The increasing number of people with dementia is placing a significant burden on health care systems and on informal carers [5, 6]. Consequently, dementia has been considered a public health priority by the World Health Organization (WHO) [7].

Older people with dementia often have impaired balance and walking ability [8], and an increased risk of falls and fractures [9]. Many of them are particularly sedentary [10]. Therefore, they would benefit from exercise and other forms of rehabilitation [11]. Exercise programs for people with dementia have, notably, shown a significant positive impact on walking performance, balance and activities in daily living (ADL) [11–16]. It seems important that the exercise is task specific and progressed to a high intensity, i.e. challenges the individual's physical capacity [11, 17]. The High-Intensity Functional Exercise Program (HIFE) is one such intervention that has been shown to have beneficial effects for older people living in residential care, including those with dementia, on gait speed, balance, lower limb strength and a slowing of decline in ADLs [14–16, 18–20].

The complexity of dementia symptoms can make it more difficult for older people to participate in exercise programs. Positive outcomes from exercise experiences can increase adherence and participation in exercise, which in turn improves future outcomes [21, 22]. People with dementia can often communicate their views and preferences about what is important to them and it is morally and ethically important to consider those views [23–25]. However, little is known about experiences of participation in high intensity exercise or how positive and negative experiences can act as motivators or barriers to exercise, in older people with dementia in nursing homes. Most previous studies considering experiences of exercise in people in nursing homes have not focused solely on older people with dementia [26–29].

The aim was, therefore, to describe the views and experiences of participation in a high-intensity functional exercise program among older people with dementia in nursing homes.

Methods

Context

This qualitative study was undertaken within the context of a randomized controlled trial (RCT) conducted in nursing homes in northern Sweden, the Umeå Dementia and Exercise Study (the UMDEX Study), described in detail elsewhere [16]. The facilities included general and 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 for participation in the RCT were: dementia diagnosis [30]; aged 65 years or over; dependent on personal assistance in one or more personal ADLs [31]; able to rise from a chair with armrests with assistance of no more than one person; Mini-Mental State Examination (MMSE) [32] score of ten or more; able to hear and understand Swedish language sufficiently well to participate in assessments; and a physician's approval. All residents who met the inclusion criteria and gave consent to participation were included. Participants were randomized to an intervention based on the HIFE program or to a control activity. The study protocol is published on the ISRCTN registry (ISRCTN31767087).

Ethics

The UMDEX study, including the present study was approved by the Regional Ethical Review Board, Umeå, Sweden (2011-205-31M).) In accordance with decision from the Ethical Review Board the participants gave oral informed consent to participate, which was affirmed by their next of kin. Before the interviews the participants got renewed verbal information that it was voluntary to participate in the interviews and that they could withdraw at any moment.

Participants

In the present qualitative study, interviews were performed with 21 participants from 10 exercise groups in the UMDEX Study. The sampling was purposive, i.e. the participants had experience of participation in the exercise program. The participants were selected from a total of 93 exercise participants in the RCT. In addition to the RCT criteria described above the exercise supervisors selected participants who they judged should have the ability to remember and verbally describe their experiences of the exercise session that they had participated in during the last hour. The sampling pursued a variety of experiences, by including men and women from different exercise groups and with a range of dementia diagnoses, ages, functional and cognitive abilities, motivation and intensity levels, and adherence to the intervention (Table 1). All 21 participants identified by the exercise supervisors took part in the interviews.

Table 1. Characteristics of the participants interviewed (n = 21).

Age, median (range)	86 (74–97)
Women, n (%)	15 (71)
Barthel Activities of Daily Living Index (0–20), median (range)	13 (5–17)
Mini Mental State Examination, (0–30), median (range)	17 (10–23)
Berg Balance Scale, (0–56), median (range)	37 (4–43)
Mobile indoors:	
Using wheel chair, n (%)	3 (14)
Using walker, n (%)	15 (71)
No walking aid, n (%)	3 (14)
No of drugs, median (range)	9 (0–17)
Alzheimer Disease, n (%)	8 (38)
Vascular, mixed or other dementia, n (%)	13 (62)
Diagnosed depression, n (%)	11 (52)
Previous hip fracture, n (%)	4 (19)
Previous stroke, n (%)	7 (33)
Heart failure, n (%)	3 (14)
Angina, n (%)	6 (29)
Adherence, median % of sessions, (range %)	83 (28–98)
Intensity of strength exercise[a] (% of attended sessions)	
High / Medium	51 / 40
Intensity of balance exercise[a] (% of attended sessions)	
High / Medium	80 / 16
Motivation during sessions[a] (0–4), median (range)	3 (1–4)

[a] As estimated by exercise supervisors.

Interviews and field notes

The interviews were carried out individually by the first author (NL) during the last five weeks of the intervention. The interviewer had training in and experience of qualitative research and in conducting interviews. The participants were interviewed directly after an exercise session and in the same room where the session was held in order to facilitate recall of the exercise. They were asked two specific questions, first to describe their experiences of participating in the exercise and later to describe their experiences of exercising in a group. After each question the interview proceeded as a conversation with follow-up questions if needed. The recorded interviews lasted between 12 and 43 minutes (median 20 minutes), and were transcribed verbatim by a person not involved in the study. The interviewer participated in the exercise session preceding each interview and made field notes based on observations in order to get current information, to increase understanding during the process of analysis, and for familiarization between interviewer and participant. Notes were made about, for example, the participant's exercises, behaviour and comments, and about group dynamics. Field notes also comprised information from exercise diaries of all participants kept by the exercise supervisors.

Analysis

The analysis was performed using qualitative content analysis, a method for analyzing communication in different steps in a systematic manner [33] and a process of interpretation that focuses on similarities and differences and results in the organisation of the data into categories and themes [34]. The unit of analysis was all interviews. To obtain a sense of the content, the interviews were read through several times by the first author, alongside listening to the interviews to obtain further information from tone of voices and pauses. The next step in the analysis was to identify and divide the interviews into meaning units, a constellation of words or statements that related to the same central meaning. The meaning units were then condensed and labelled with codes. The codes were compared, according to similarities and differences, and codes with similar content were sorted into categories. The seven categories that emerged were further interpreted and abstracted into four themes. Although the interview transcripts formed the primary data set, the field notes were analyzed separately and complemented the interviews. The information from the field notes was considered as to whether it confirmed or not the themes and interpretations. Interpretations of the field note data did not result in new categories or themes. The findings from field notes are presented for each theme with the purpose to further describe and illustrate the themes.

To ensure trustworthiness, some steps of the analysis were also performed by three co-authors (BL, ER, LLO). They worked separately, read through some of the interviews, and then created codes, sorted codes and created categories. At meetings with all five authors the classification and formulation of codes, categories and themes were discussed for all interviews and changes were made until consensus was achieved. The authors each brought a different knowledge base, pre-understanding and experience to the study and data analysis. Both insider and outsider perspectives were represented. The disciplines of the researchers were Physical Therapy (NL, ER, LLO), Nursing (BL) and Exercise Physiology (DAS). Three of the authors (NL, ER and LLO) were involved in planning and testing in the UMDEX study and NL and ER were also supervisors in exercise groups. There were participants from four, of the ten, groups where the interviewer (NL) was one of two supervisors. One author (BL) brought extensive experience in the design and theory of content analysis and the other four authors had extensive experience in falls prevention, exercise interventions, motivation to exercise and working with older people with both physical and cognitive impairments.

The context of exercise intervention

The HIFE program contains 39 exercises aimed to improve lower limb strength, balance, and mobility [35, 36]. The exercises are performed in functional weight-bearing positions and including movements used in everyday tasks, for example squatting, walking over obstacles, reaching for objects while standing, and climbing stairs. The exercise is intended to be performed at high intensity, i.e. to fully challenge the individual's ability, and is progressed through increased load or difficulty. High-intensity strength exercises are performed at 8 to 12 repetition maximum (RM), thus progressed by increasing the load when the participant is able to exceed 12 repetitions in an exercise. The load is increased by, for example, stepping higher, rising from a lower chair, or by adding weights onto a belt worn around the waist. High-intensity balance exercises fully challenge postural stability, i.e. are performed at or near limits at which upright position could be maintained, and progressed by, for example, narrowing base of support, altering the surface, or performing more challenging exercises. Physical therapists (PTs) designed an individual program for each participant. Exercises were selected dependent on the degree of functional deficits, and adapted to meet levels of cognition, behavioural and psychological symptoms of dementia, and changes in health and functional status. All participants were individually supervised to encourage high-intensity exercise. Safety was ensured by using a belt, with handles, that participants wore around their waists during balance exercises and thereby the PTs could easily prevent falls. The exercise took place within the facilities, in groups of three to eight participants supervised by two PTs. The sessions lasted approximately 45 minutes, five times per fortnight for four months, with a total of 40 possible sessions per participant. Further insights into the views and experiences of the exercise supervisors delivering HIFE have been previously published [37].

Characteristics

Baseline assessments of participants were performed by PTs and physicians (Table 1). The Barthel Index was used to assess dependency in ADLs [38]. MMSE to assess cognitive function, and Berg Balance Scale to assess functional balance capacity [39]. Adherence to the exercise sessions was documented as a percentage of the total number of possible sessions (n = 40 per participant). Estimates of achieved training intensity and motivation during the sessions were noted in a structured protocol, by the exercise supervisors (PTs), for each participant after each session. Intensity in strength and balance exercises were estimated as high, medium, or low according to a pre-defined scale [35]. Motivation during the exercise sessions was estimated by the exercise supervisors, on a five graded Likert scale from no motivation to very high motivation, based on interpretations of the expressions, verbal prompts and body language of the participants. The participants' individual characteristics are shown in Table 2.

Results

The analysis of the interviews revealed four themes: *Exercise is challenging but achievable; Exercise gives pleasure and strength; Exercise evokes body memories;* and *Togetherness gives comfort, joy, and encouragement.* Quotes related to these themes are attributed to participants (described in Table 2) in brackets within the text below. Dots within the quotes indicate pauses. Summaries of field notes from the observations are presented at the end of each theme. In Table 3 examples of quotes and codes, and all categories for one of the themes are shown.

Table 2. Individual characteristics of the participants.

Interview	Gender	Age	MMSEBaseline/at 4 mo	BBSBaseline/at 4 mo	Adherence[a]Sessions, n	Motivation[b]During sessions,in median
1	Woman	79	16/-	4 / -	33	3
2	Woman	86	20/16	19 / 23	37	4
3	Woman	88	18/17	5 / 19	38	3
4	Woman	96	18/18	43 / 51	31	2
5	Woman	84	17/17	30 / 37	36	3
6	Man	95	14/13	40 / 5	25	4
7	Woman	85	16/14	38 / 44	30	3
8	Man	90	21/16	42 / 40	37	3
9	Man	74	11/6	20 / 44	33	3
10	Woman	79	14/16	37 / 46	13	4
11	Woman	92	23/23	38 / 48	29	3
12	Woman	94	17/10	19 / 31	29	3
13	Man	78	15/19	29 / 30	37	3
14	Woman	86	18/13	39 / 50	32	4
15	Woman	89	19/14	34 / 45	37	3
16	Woman	79	10/8	40 / 42	28	3
17	Man	85	13/15	5 / 3	25	3
18	Woman	97	15/17	21 / 24	26	3
19	Man	84	16/16	41 / 50	36	4
20	Woman	81	18/13	39 / 36	39	4
21	Woman	91	19/18	41 / 47	11	2

MMSE = Mini Mental State Examination (0–30), BBS = Berg Balance Scale (0–54).

[a] Out of 40 possible exercise sessions.

[b]As estimated by exercise supervisors on a five graded Likert scale (0–4).

Exercise is challenging but achievable

Participants described that the exercise was challenging in different ways. The necessity of exercise was expressed, alongside the effort required to maintain fitness: *"While it is tough, it's useful. . ." (20)*. They stated that they should be physically active and emphasized that they

Table 3. Examples of quotes and codes, and all categories for one of the themes identified in the interviews.

Examples of quotes	Examples of codes	Categories	Theme
-Yes, I think it's funny if we can exercise in groups. . . . You feel you have a cohesion. . . (12)-Well, you get contact with some people and it does not hurt. . . it's good. . . you may feel like a stranger else here since this is a completely new area for me anyway. (8)	Provides community Make friends	The exercise provides cohesion	Togetherness gives comfort, joy and encouragement
-You feel relaxed. . . and it is very important. . . it is very, very important.. Very good group. . . very good group. . . (20)	Well-being in a groupPeaceful group	The group creates comfort	
-Yes, but it's been great. . . no problem. . . on the contrary, fun. it has gone smoothly and well and we've laughed and we have been keeping on (14)	More fun in a group Joy with others	Happiness from meeting others	
-You get encouraged to do it and you get praised which is fun (21)-One gets the inspiration from each other too. You see how the others are doing and do as they do (1)	Spurring in a group Positive comparison Uplifting with others	Encouraging group	
-I'm safe when I hear people talk and it is meaningful) (12) -It is important to be in a group and that someone that take care of you (20)	Safe in the group Safe with the supervisors	Feeling of security	

needed to move to keep the body working: "*Probably, one should move while living. . ." (21)*. Some participants mentioned they were getting breathless and that the exercise was strenuous but that exercise was supposed to be that way. To be inactive was described as the worst scenario, causing the loss of both physical function and the mind: *"To sit and lie and just not do anything. . . then you lose your mind. . . I want something to happen and am happy with heavy stuff, that's fine with me. . .. . . To move that's the alpha and omega . . ... to just sit and lie. . . that's nothing. Yes, you lose everything" (9)*.

Other participants commented that they did not like the effort or intensity of the exercises, but still realized it was necessary. One woman said she had been too stubborn and worked too hard and others that the exercise had made them feel insecure and fearful of falling: *"It feels awkward. . . you just have the urge to say NO, now we have to put it off completely. . . it is too hard" (13)*. However, some did not think that the exercise was strenuous at all or felt any discomfort and also that the exercise could have been heavier. Participants seemed to adapt to the exercises during the exercise period: *"Well. . . the first time, I thought NO, this I can never do. . . the second time it went well and the third time it went even better, and then it has gone on the fly" (2)*.

Participants, however, mostly voiced that the exercises worked well, particularly as they had been customized for older people and for them individually. They perceived that the exercise supervisors had expertise and helped to ensure that the exercises were adapted to suit them on that particular day: *"It's just that it is directed, that is what is so useful. . . .. Yeah but I feel, to get instructions to do the movements . . . that's what I want. . . that one is cared for. It is not done the same way when you are alone" (19)*. There were comments that the sessions were well organized, long enough, and 'calm' enough, with many rests and that it could have been risky to exercise by themselves. The participants expressed appreciation that sessions were performed at their facility, so they did not have to travel anywhere. These exercise properties and the supervisors' expertise seemed to be valued and made the exercise achievable.

The observations during the training sessions showed that although some were skeptical in the beginning of the session and the supervisors sometimes had to encourage them to participate, their eagerness most often increased during the session. As in the interviews, participants sometimes voiced that the exercise was important for their chance to have a break in their everyday routines: *"I think it is important to keep going and that something is happening" (14)*. They also expressed that the exercise was supposed to be strenuous: *"You have to feel it, otherwise it is useless" (5)*. There were comments during the exercises reflecting adaptations, such as: *"It is fantastic how you can create different exercises that strain the body" (8)*.

Exercise gives pleasure and strength

Participants expressed feelings of joy and pleasure about exercising, using words such as 'funny', 'nice' and 'agreeable', and phrases like "*I think it is fun, and that's probably why it goes well*" *(16)*. Some participants said that they always looked forward to the exercise sessions, as they were good for body and soul. They voiced that they were getting re-started, boosted, becoming engaged and coming back to normality, that they were able to do more in their daily lives, and had become more alert and more positive.

It was often described that the exercise dealt with what they needed in *"real life"* and the participants perceived that the exercise improved their fitness: "*Yes it has paid off. . . I think if someone would have told me before that I would stand on tiptoe and knee bend with this knee, I would never have dreamed . . . but now it just fine" (2)*. One man described it as if exercise was *"saving the power" (9)*. Participants described that the whole body system worked better: *"I am feeling better. . . blood circulation moving differently. . . the heart beats in a different way. . . the blood in the veins. . . you immediately feel that it feels nice." (6)*.

The observations during the sessions showed that the expressions of engagement during the sessions differed between participants. Some seemed determined and focused on their own exercise, while others seemed happy and engaged. Many of the participants said that it felt good, was nice, enjoyable, and that they needed the exercise: *"This is like the health itself"* (19), *"This is so much fun" (8)*. Some expressed that they would like to have more exercise, for example, sessions every day or longer sessions, or did not want to go back to their room when the sessions were finished.

Exercise evokes body memories

The exercise evoked memories of body movements, physical activities, and heavy jobs that the participants had previously participated in, often many years ago: *"I had brothers, and they wanted me to be out jogging with them . . ." (4)*. Some were also familiar with organized exercise and had been active and competing in sports or had been doing resistance training even into their later years: *"I used to be in a gymnastics group. . . I do not think the difference is so great" (11)*. These previous exercise habits facilitated and motivated for the current exercise: *"Yes. . . because I've been physically active and that is why I . . . can keep that movement. I feel I need to do it because I was so well trained. . ." (19)*.

The exercise reminded the participants about what they had lost in physical capacity but there were also recognition of movements they actually could do. "*Much has deteriorated . . . the balance and. . . a lot of my self-confidence might have disappeared because of that. . ...I just had to be able to come back. . . what I have lost I just have to learn again" (5)*.

Some participants expressed happiness that the exercise had reminded their body how to move and they had rediscovered that they were able and could still participate in activities. They could even be proud about what they could perform when exercising: *"To cope with . . . that you can handle things. . . as an old man it's pretty damn nice to be not completely decayed" (19)*.

The observations during sessions confirmed that several participants had always liked to be physically active and, therefore, they appreciated this exercise. The exercise gave associations to events earlier in life, for example, when a 95 year old man narrated vividly about how his teacher inspired him to be interested in sports: *"He did exactly as you do. He made it pleasurable"* (6). During the exercise sessions some participants expressed amazement and pride that they could perform the exercises and that it went so well: *"I think it is fantastic that we can do this!" (2)*. It was also observed that although the participants said that they did not remember the movements, once a movement was initiated they performed the exercises without problems.

Togetherness gives comfort, joy and encouragement

The participants expressed positive views about being in a group for the exercise and they spoke about this being more fun than exercising alone. It also emerged that they perceived the exercise to be more effective and stimulating in a group than alone *"I do not know if it gives any more, but it is perhaps more fun anyway to be with a few people when we do something. . ...It may well spur. . . so you put in more effort"* (5). Loneliness could be frightening and the group offered safety: "*I'm afraid of loneliness" (12)*. Participants expressed that they were pleased with their group, they felt relaxed and at home, and they all got on well together especially if the group was not too large, indeed the size of the groups were considered a good size. It emerged that some were used to group activities and found it natural while others was not used to groups and felt a bit uncomfortable in the beginning: "*I'm used to sitting alone. . . so I get a little surprised when I have to be with people" (3)*.

The importance of connecting with others in the same situation was emphasized. It gave inspiration and the participants were encouraged and their spirits raised by the others in the group: "*You see and you imitate*" *(1)*. When others in the group were performing better and had their spirits lifted one person felt crestfallen: *Yes*, *I want to do more than they do. . . . one girl is so good so. . . I'm heartbroken that I cannot do as she. . . (18)*.

The participants voiced that the other group members and the exercise supervisors provided encouragement: "*Well it's a boost . . . I think it is fun to be praised. . . (20)*. It was verbalized that the PTs inspired trust and security in the exercises themselves and in the participants' ability to do the exercises: *"I know I am safe with the one helping me. . . so I can join in and do the exercise." (12)*

The observations revealed that participants often lit up when they met the others in the group and that the group members interacted with each other. They seemed happy, were joking, having conversations, and showing interest in the others. There were some negative sides of meeting in a group, such as being irritated by those who had a cold or being self-critical when comparing themselves to others: *"Everybody is so good*, *except me" (17)*. Some participants spread a good atmosphere in the group and were very encouraging and confirming toward the others. Praise from the supervisors seemed to lift the participants and they became excited and encouraged and the supervisors were given reciprocal feedback from the participants.

Discussion

This study describes the views and experiences of older people with dementia in nursing homes who took part in a high-intensity functional exercise program. The depth and richness of the conversations show that older people with dementia, in these settings, are able to describe their experiences of exercise they recently participated in. The interpretations of the interviews revealed four themes of participants' descriptions of their experiences. The exercise was described as challenging, since it was of high intensity, but also that it was achievable because it was adapted to each participant's abilities. The importance to themselves of being physically active was emphasized. Further, the findings show that the participants found pleasure in the exercise program and they experienced improvements and feelings of competence. They wanted to exercise to improve physical capacity and expressed a need for improvements, since they had physical impairments. The exercise evoked memories of previous physical activities and the participants rediscovered that they had bodily capabilities. Supervised exercise and the safety that this created was appreciated. Exercising in a group was described as stimulating and spurring and creating coherence with others in the same situation. The study adds important knowledge to already known benefits of the HIFE program among older people with physical and cognitive impairments in nursing homes [14–16, 18–20].

Although there has been increased interest in the views of people with dementia, there is still a lack of studies considering the exercise experiences of older people with moderate to severe dementia living in nursing homes. Among older people living in residential settings where not all had dementia, one study has considered the experiences of taking part in a falls prevention exercise program [40], and another, the experiences of participation in the HIFE program [26]. In one recent study with eight residents with mild to moderate dementia, interviews were performed about their experiences of participation in the HIFE program [27]. All three studies have some findings that are similar to our study, such as perceptions that exercise gave improved physical functions and mood, as well as opportunity of stimulating meetings with other people, and the possibility to be more active [26, 27, 40]. However, in the present study where the majority had moderate dementia, the participants also expressed that intense exercise and effort was necessary to achieve the desired improvements. This is in contrast to a study about physical activity program preferences and perspectives, which suggested that older people with cognitive impairment preferred simple, light and safe exercise when they gave their views about exercise but without participating in particular programs [41].

An important new finding in the present study was that exercising evoked body memories and participants narrated about old days and previous physical activities and capabilities. They were able to reflect about their present situation and expressed the realization that they still had capabilities they thought they had lost and also that they were able to participate and improve. Participants who had previously exercised compared it with the present exercise program and described that they had missed it and also that they needed physical activity. According to the Continuity Theory of Aging, older people strive to maintain continuity in their sense of self and their self-image, despite impaired function, by continuity of physical activity patterns, i.e. remain physically active during their life-span [29, 42]. Other studies have also found that older people with physical and cognitive impairments, as well as people with mild dementia, strive to remain physically active and thereby achieve well-being [26, 27, 43].

Participants voiced their pleasure in meeting others and a sense of coherence of being in a group. They expressed their feelings of being seen, understood and respected by the supervisors and by the others in the group. Older people, with and without cognitive impairment, prefer individually tailored programs undertaken in a group setting [41]. The role of social interaction, such as being included in enjoyable and meaningful activities, and of feeling supported, has previously been described as important for the ability to cope with dementia [44]. Among community-dwelling older people with dementia exercising together with people in the same situation can act as a motivator [45–47] and with a supervisor as a facilitator for exercise [46, 48]. Experiences of the importance of encouragement from the supervisors and the others in the group could be interpreted within the concept of self-efficacy; according to which 'encouragement from a reliable source' is important for self-efficacy beliefs [49]. Another aspect important for self-efficacy beliefs is 'vicarious experience or role models' [49], which in the present study can be related to participants' positive recollections of exercising in a group and being stimulated by watching others. A previous study with older adults with mild to moderate dementia, interpreted views according to Bandura´s theory of self-efficacy, and came to similar conclusions about the important role of the exercise group and the supervisors [27]. The role of interaction with others is also, within the theory of selfhood, described as one important facilitator for constructing meaning and define an individuals' social world. Selfhood is expressed through social interaction [50], and is defined as a state of having a distinct identity and being an individual, distinct from others. Physical activity has been shown to allow people with mild dementia to remain in touch with their former selves, i.e. sustain a sense of continuity in their lives and their selfhood and to feel like healthy and physically capable persons [43]. Kontos (2005) describes a perspective of selfhood, when using the notion of embodied selfhood, 'which captures the idea that fundamental aspects of selfhood are manifested in the way the body 'moves and behaves', and that humans are embodied beings, that the body is a fundamental source of selfhood, and that people with severe cognitive impairment engage with the world through their bodies [51]. In the present study, participants voiced that exercise evoked bodily memories and it seemed like the body had its own memory, since it was observed, in field notes, that participants could perform exercises even though they said that they did not remember the movements. This finding could be reflected to Kontos' description of the body as a medium of expression, being and knowing, and further that the body has a kind of corporeal awareness that exists below the threshold of cognition [51].

Finally, as reflected in the participants voiced enthusiasm for the exercise supervisors in this study, the importance of supervisor skills, the continuous iterative process of building on existing knowledge, sharing and reflecting, being alert to any alterations needed for individuals that day, communication and building a relationship and trust with residents have been highlighted as important attributes [37]. Instructor qualities have previously been shown to influence attendance to exercise classes [52].

The study has some limitations. The sample was selected, in the sense that all participants had agreed to participate in the RCT study, though, not specifically to the exercise intervention. Further, it was not possible to interview those who had dropped out of the RCT. The transferability to those living with the most severe dementia is limited, since only people with an MMSE score of ≥10 and able to remember and verbally describe their experiences of exercise during the last hour were included in the study. Because of pragmatic reasons all participants were selected before the interviews started, i.e. the participants were not included one by one until saturation was reached. However, saturation within the responses was reached with no new information coming from final interviews. Strengths of the study were, first, that the interviews were performed in the same room where the exercise sessions were held and performed directly after the sessions, which facilitated participant's recall and for the interviewer to keep them focused. The field observations also facilitated the interview situation, created context, complimented and confirmed the discussions in the interviews, and the participants became familiar with the interviewer. For trustworthiness reasons, the supervisors, who were familiar with the participants, were asked to choose participants for the interviews who they judged had the ability to remember and verbally describe experiences of the exercise sessions. That people with cognitive levels down to MMSE scores of 10 can answer questions about their life and express their current feelings in a valid way is supported in the literature [23–25]. The interviews were performed with a range of individuals, including those who had lower motivation or a low exercise participation rate, to avoid bias. Furthermore, the authors' different gender, knowledge base, pre-understanding and disciplines was a strength in the process of analysis.

Conclusions and implications

This study reinforces the positive meaning of exercise to older people with moderate to severe dementia in nursing homes and their expressed pleasure at the opportunity to participate. Participants were able to safely adhere to and understand the necessity of high intensity exercise and progression for improved physical and mental health outcomes. Although they may not always be able to remember an exercise, once initiated they retained a body memory and could perform the exercise with encouragement. Providers of exercise should consider the aspects of delivery that older people with dementia value and appreciate, such as small group sizes, tailoring and adaptation, fun and encouragement, and the rediscovery of body competencies. Future studies should explore motivation in older people with dementia in nursing homes and factors that might affect motivation and attendance to effective exercise provision, such as instructor qualities, staff and facility barriers and family support.

Increased self-efficacy: the experience of high-intensity exercise of nursing home residents with dementia – a qualitative study

Abstract

Background: There has been increasing interest in the use of non-pharmacological interventions, such as physical exercise, to improve the well-being of nursing home residents with dementia. For reasons regarding disease symptoms, persons with dementia might find it difficult to participate in exercise programs. Therefore, it is important to find ways to successfully promote regular exercise for patients in residential care. Several quantitative studies have established the positive effects of exercise on biopsychosocial factors, such as self-efficacy in older people; however, little is known regarding the qualitative aspects of participating in an exercise program among older people with dementia. From the perspective of residents, we explored the experiences of participating in a high-intensity functional exercise program among nursing home residents with dementia.

Methods: The participants were eight elderly people with mild-to-moderate dementia. We conducted semi-structured interviews one week after they had finished a 10-week supervised high-intensity exercise program. We analyzed the data using an inductive content analysis.

Results: Five overreaching and interrelated themes emerged from the interviews: "Pushing the limits," "Being invested in," "Relationships facilitate exercise participation," "Exercise revives the body, increases independence and improves self-esteem" and "Physical activity is a basic human necessity—use it or lose it!" The results were interpreted in light of Bandura's self-efficacy theory. The exercise program seemed to improve self-efficacy through several mechanisms. By being involved, "being invested in" and having something expected of them, the participants gained a sense of empowerment in their everyday lives. The importance of social influences related to the exercise instructor and the exercise group was accentuated by the participants.

Conclusions: The nursing home residents had, for the most part, positive experiences with regard to participating in the exercise program. The program seemed to increase their self-efficacy through several mechanisms. The instructor competence emerged as an important facilitating factor. The participants emphasized the importance of physical activity in the nursing home.

Background

Dementia is a global public health problem. Each year, 7.7 million new cases of dementia are identified worldwide [1]. Prince et al. [2] estimated that 35.6 million people suffer from dementia worldwide, with likely increases to 65.7 million by 2030 and 115.4 million by 2050. Approximately 75 % of the elderly living in nursing homes suffer from dementia [3], which is also the case in Norway [4].

Physical activity is globally recognized as a positive health influence across all ages [5]. Despite this awareness, nursing home residents spend up to 94 % of their time sitting or lying down, although the residents are capable of participating in independent or assisted activities [6, 7]. A growing body of literature has suggested that physical exercise has beneficial effects on the physical [8] and cognitive [9] functions in healthy older adults, as well as in individuals with cognitive impairment [10]. Additionally, several recent clinical trials [11, 12] and systematic reviews [13–15] have demonstrated that individuals with dementia can receive the beneficial effects of physical exercise. A recent meta-analysis identified 16 randomized, controlled trials of exercise interventions in 937 individuals with dementia, supporting evidence that exercise improves the ability to perform basic activities of daily living, such as eating, dressing, bathing, using the toilet, and transferring from bed to chair [16]. For older people living in residential care facilities, regular exercise can reduce activity limitations [12, 17–19], maximize independence [12, 18, 19], likely slow the progression of dementia [12, 20], promote sleep [19, 21], and enhance the quality of life and well-being [19, 22]. A recent study showed that good muscle strength and balance were the most important physical performance variables associated with good quality of life for nursing home residents with dementia [23]. The authors stated that additional studies should be conducted to examine how to improve physical functioning and quality of life in this group [23].

In a recent literature review related to living with dementia, Murphy et al. [24] stated that until the 1990s, the perspectives of persons with dementia were largely ignored in dementia research. The perceptions of persons with dementia were difficult to assess [24], and the inclusion of their perspectives was obstructed by prior judgments that one could not rely on the testimony of persons with dementia [25, 26]. Murphy et al. [24] suggested that carers without dementia could not credibly construct the reality of living with dementia. If the experience and meaning of living with dementia are to be understood, the inclusion of persons with dementia as participants in research studies is essential. Valuing the unique insights of a person with dementia was therefore observed as a validation of persons with dementia. Providing the person with dementia an opportunity to participate in dementia research was deemed to be essential to addressing their vulnerabilities [27–29]. In another literature review, van Baalen et al. [30] emphasized that people with mild-to-moderate dementia are able to talk with clarity and insight about their experiences concerning quality of care. A successful subjective evaluation seems to depend on a minimum level of orientation to place, attention and language skills in the person with dementia. van Baalen et al. [30] concluded that measuring the quality of care from the perspective of people with dementia is in its initial phase and that additional research is warranted. Qualitative research has played a crucial role in improving our understanding of dementia and its impact on individuals, carers, families, and the broader community [31–33]. As our population ages, the impetus for improving dementia care is increasing [34]. Qualitative research is well suited to meet this call [31, 32, 35].

There has been an increasing interest in the use of non-pharmacological interventions to improve dementia symptoms and the well-being of residents with dementia and their carers [3]. One non-pharmacological intervention is physical exercise. Persons with dementia might find it difficult to participate in exercise programs because they depend on assistance during the exercise sessions. Therefore, it is important to successfully promote regular exercise in residential care facilities by encouraging the residents to participate in the available exercise programs and physical activity options. One recent study explored the experience regarding a high-intensity functional exercise program of older people who live in residential care facilities and who are dependent on others in performing daily activities [36]. To the best of our knowledge, no previous qualitative study has explored the participation of nursing home residents with dementia in a high-intensity functional exercise program. Therefore, the aim of this qualitative study was to explore the positive and negative experiences of a high-intensity functional exercise program in nursing home residents with dementia, from the perspective of the residents.

Methods

The participants

This qualitative study followed a pilot study for a randomized controlled clinical trial (RCT) of the High-Intensity Functional Exercise (HIFE) program [18, 37] in an urban nursing home in Norway. The nursing staff at the nursing home located eligible participants and provided information regarding the study. A convenience sample of twelve elderly people with mild-to-moderate dementia participated in the pilot study. The same twelve people also agreed to participate in the subsequent qualitative study. However, only eight informants ended up being interviewed because the study reached saturation. The inclusion criteria were as follows: having mild or moderate dementia, as defined by a score of 1 or 2 using the Clinical Dementia Rating (Table 1). The characteristics of the informants are described in Table 1.

The physical exercise program

The exercise program was the HIFE program developed in Umeaa, Sweden [18, 37]. Each session included five minutes of warm-up, at least two strengthening exercises for the muscle in the lower limb and two balance exercises. The total duration of each session was 50–60 min. All of the exercises, conducted in small groups, were individually adapted, instructed and supervised by a physiotherapist. The intensity of the strengthening exercises was aimed at achieving 12 repetitions maximum (RM). The balance exercises were intended to be “highly challenging,” which meant that the balance exercises challenged the participants to reach their limits of postural stability both in static and dynamic tasks, such as throwing balls, stepping over obstacles and reaching for

Table 1 Characteristics of the participants ($n = 8$)

Participant number	1	2	3	4	5	6	7	8
Age (year)	92	88	69	92	96	86	92	87
Gender	Woman	Man	Woman	Woman	Woman	Woman	Woman	Woman
CDR[a]	1	1	1	2	2	2	2	1
QUALID[b]	17	18	29	17	30	15	15	19
Cornell	10	2	21	6	7	2	6	2
Barthel Index[c]	12	19	9	12	16	15	8	10
Use of walking aid	Rollator	Wheel chair.	Rollator	Not using	Rollator	Rollator	Not using	Not using
Berg Balance Scale[d]	46	1	16	51	24	30	45	51
Timed Up and Go (sec)	17.81	127,28	21,54	13,79	58,42	161,22 s	33,01	19,4
Attendance[e]	26	26	30	21	26	14	14	27

[a]Cognition was measured by the Clinical Dementia Rating Scale (CDR)
[b]The quality of life in late-stage dementia scale: total score range from 11 to 55. A lower score indicates a higher quality of life. Cornell Scale for Depression in Dementia (Scores totaling twelve (12) points or more indicate probable depression)
[c]Consist of 10 activities focusing on the patient's level of dependence on help. The scores range from 0 (completely dependent) to 20 (independent)
[d]The total score ranges from 0 to 56
[e]Number of exercise sessions

objects while standing. The difficulty of each balance exercise was increased, for example, by standing or walking on a more challenging surface. The physiotherapists maintained detailed records of all of the exercise sessions and documented the intensity of the exercises performed at each session. The participants exercised three times a week for 10 weeks. Table 1 shows information regarding how many times each patient participated in the exercise program. No patient exhibited any adverse effect during the exercises. The physiotherapists had been trained in the HIFE program. The importance of targeting high intensity and use of weighted belts was emphasized.

Measurements

To describe the functional characteristics of the participants, we conducted the following assessments at baseline and 10 weeks after baseline. The instruments were chosen because this was a pilot study for an RCT and testing was used to determine the feasibility of outcome measurements.

Balance was measured using *the Berg Balance Scale*. The test assessed performance using a 5-level scale from 0 (cannot perform) to 4 (normal performance) in 14 different tasks involving functional balance control, as well as transferring, turning and stepping. The total scores ranged from 0 to 56 [38].

The Timed Up and Go was used for measuring *functional mobility*. The tester measured the time it took for a person to rise from a chair, walk three meters at a comfortable pace, turn and walk back to the chair and sit down. We allowed a practice trial and we recorded the results of the subsequent trial [39].

To measure the patients' dependence/independence in the *activities of daily living* (ADL), we employed *the Barthel Index*. The scores ranged from 0 (completely dependent) to 20 (independent) [40].

We used *the Clinical Dementia Rating Scale* to validate the patients' diagnosis of *dementia* [41–43].

The Cornell Scale for Depression in Dementia [44] was used to assess *depression* in the participants. Scores totaling 12 points or more indicated probable depression.

"The quality of life in late-stage dementia scale" (QUALID), a proxy-rated scale, was used to measure the *quality of life*. The informants were professional caregivers who knew the patient well and had spent at least three of the last seven days with the patient. Likely scores ranged from 11 to 55. A lower score indicated a higher quality of life [45].

The participants represented different ages (age range, 69–96 years). Three participants were able to walk without walking aids. Their scores on the different outcome measurements are presented in Table 1.

Interviews

The semi-structured, face-to-face interviews were conducted one week after the last physical exercise session to reduce recall bias. When possible, the interview took place in the participants' rooms at the nursing home. An interview guide developed for this study (Table 2), as well as pictures of all the exercises, were used. The pictures were shown during the interviews.

The interviews lasted approximately one hour. We taped all of the interviews, and the secretarial staff transcribed the tape recordings verbatim. The data were analyzed using an inductive content analysis. The inductive approach enables researchers to identify key themes in the area of interest by reducing the material to a set of themes or categories [46]. The intention was to provide a compact yet general description of the phenomenon

Table 2 Key questions forming the semi-structured interview schedule

Question 1	Have you noticed any positive effects from doing the program? (Showing the picture of the different tasks)
Question 2	Have you noticed any negative effects from doing the programme? (Showing the picture of the different tasks)
Question 3	What did you like about the program? (Showing the picture of the different tasks)
Question 4	What did you not like about the program? (Showing the picture of the different tasks)
Question 5	How easy/hard was the program? (Showing the picture of the different tasks)
Question 6	What motivated you to participate in the program? (Showing the picture of the different tasks)
Question 7	Would you like to continue a regular training program? (Showing the picture of the different tasks)
Question 8	Do you have any other feedback/anything else you would like to say?

under investigation. The themes emerged from the raw data by repeated examination and comparison. Using the analysis process, we experienced an increased understanding of the material describing the participants' experiences with the exercise program.

To ensure transparency and reliability, two researchers read the transcripts independently several times. This reading was performed with an open mind, in the interest of grasping the participants' own views on the subject. An additional analysis was performed using the following procedures: 1) The transcripts were read to gain a contextualized impression of the text and previous preconceptions were highlighted. For this part of the analysis, the hermeneutic approach was obvious because various preconceptions played a part in our understanding. 2) Units of meaning were identified and coded. Inter-rater agreement on the codes was high between the authors. 3) The meaning in the coded groups was then condensed. 4) The descriptions reflecting the participants' experiences were generalized into categories [47, 48]. A consensus regarding the categorization of statements and emerging themes was reached by discussion among all of the authors.

Ethics

The study was approved by the Regional Committee for Medical Ethics in Norway. Written and verbal information regarding the study were given to the patients and their relatives by their primary caregiver. The participants provided their consent to participate in the study, often together with that of their next-of-kin, and they were informed that they could refuse to participate at any stage in the study.

Results

The following five overreaching and interrelated themes emerged from the interviews: 1) *Pushing the limits* 2) *Being invested in* 3) *Relationships facilitate exercise participation* 4) *Exercise revives the body, increases independence and improves self-esteem* and 5) *Physical activity is a basic human necessity—use it or lose it!* (see Fig. 1). Selected quotations from the participants are presented to support and illustrate the five themes.

1. Pushing the limits

Overall, we found that all of the participants reported positive experiences with the exercises. The HIFE program contains high-intensity exercises; however, the participants did not find the exercises overly intense. They believed that the exercises were challenging but fun. They said that the feeling of exhaustion after being physically active was much better than being exhausted from lack of activity. They thought that the exercises were meaningful and relevant for everyday living. One participant emphasized the following point:

> *"The exercises were challenging and seemed relevant to our needs in everyday living".*

Another participant described her own feelings regarding the intensity of exercise in the following manner:

> *"It feels good to exert yourself. Maybe I should have pushed myself even harder. We who are old may not be used to it. There is no harm in exerting oneself. Maybe it is more fun that way. It will lead to more energy and optimism".*

A third participant added:

> *"I believe that it is healthy to exercise. It is much better to be tired after exercises than be tired after doing nothing".*

All of the participants had positive attitudes toward exercise; however, some equivocal statements appeared concerning the undertaking of the exercise sessions. They thought it was important that attendance is voluntary and that no one should be pressured into participating. Several participants felt that exercising three

Fig. 1 An empirical model of nursing home residents' experiences of increased self- efficacy through participating in a high-intensity physical exercise program

times a week was excessive, and they made the following statements:

> *"No one should be forced to participate in exercise sessions. Either way, that did not happen, and it seemed everything went smoothly".*

> *"Twice a week is sufficient. I think three times is too much".*

2. Being invested in

Several participants emphasized that the exercises introduced a feeling of being invested in and being noticed. Additionally, the sense of having an activity to attend to and the feeling of being useful was important. The participants explained that the exercises were important for staying healthy and maintaining everyday function.

The following statements illustrate this perspective:

> *"I thought it was important because I experienced being seen and felt that I was being invested in".*

> *"As an old person in a nursing home, you experience that nothing is invested in you. We were given the impression that what we did would influence our health and everyday living. It gives me somewhat satisfaction that I can still engage in activities. It does. I mean, if I am still engaged in activities, it means that I have not given up".*

It seemed that the capability of conducting the exercises and completing an exercise session provided the participants with a feeling of achievement and a sense of empowerment. This feeling seems to be a particularly important element. One participant explained:

> *"I thought that the exercises were challenging. I was somewhat proud of myself for making it. Obviously, you should be motivated and experience capability. We got the feeling: we can do this".*

> *"… to have something to attend. When we know that something awaits us, that we are useful to them. That is very important. You cannot just walk around with*

the impression that no one is thinking about you. That cannot happen. We experience a sense of importance when we exercise".

3. Relationships facilitate exercise participation

The relationships both with other residents as well as the physical therapist seemed to facilitate exercise participation. Several participants noted the positive aspects of exercising together with other residents. They explained that watching and interacting with other participants were motivating and that the participants were positive role models for each other. Two participants elaborated on this point:

"I experienced a positive encounter with the staff that was not characterized by detachment but rather vitality".

"It is also important that we who are older demonstrate to each other that we can do this and that we are positive role models for each other. We must make this happen! It is positive for our togetherness. We were able to see that the others exerted themselves and were motivated to do the same and sometimes we were surprised what we could do ourselves and what others could do".

The participants emphasized the therapist's ability to adjust and accommodate the exercises to the participants during the sessions. Older people are heterogeneous, and one cannot make the same demand on everybody. Knowledge about elderly people was noted to be an important factor. The therapist must possess this knowledge, be observant, and be able to make adjustments to the exercise program while instructing. The participants made the following comments:

"*Knowledge about the aging body is central. One should know what to do with each individual and make sure that they practice things they find difficult. The person who is instructing must pay close attention and observe how the person is doing, examine if he/she is struggling or grumbling a lot. In that case, they should not push them. That is unnecessary".*

The communication between the therapist and participant also seemed important to the residents. A therapist with extended knowledge about elderly people created feelings of security and trust. The participants emphasized that it was nice to be met with positive expectations. The information that the therapist gave about the exercises was also appreciated. They thought it was important to learn about the purpose of the exercise. The therapist should be understanding and able to communicate with older people. The participants stated the following:

"She seems secure, accepting and knowledgeable. It was nice to be met with positive expectations. Her positive expectations were appropriate without overwhelming us".

"Yes, she knew a lot. That is important. She gained our trust. She taught us about muscles and other things that we use when we engage. It was very encouraging".

"Human knowledge is important, and our instructor was good at communicating with other people".

4. Exercise revives the body, increases independence and improves self-esteem

The residents experienced a positive change after exercising. Several participants noted that exercising improved their mood and boosted their self-esteem. They felt that their body became more alive and vital, their energy level increased and they were more content. The following two quotes illustrate this perception:

"I felt more like a normal person. I was happier. I had more energy to engage in conversations and I also became more positive towards other people".

"I feel energized by the exercises, I am no longer sitting lethargically in a chair. I was proud of myself after the exercises. The body was more present, and that is a good feeling".

Several residents noted that they felt that their independence improved, and they felt less dependent on the nurses after exercising. This feeling positively influenced their self-esteem. One resident elaborated in the following manner:

"To be able to do as much as possible independently is positive for the self-esteem, at least to me. I think it is important to exercise at the nursing home to maintain independence. Most elderly would like to be able to take care of themselves as long as possible".

Exercising had a positive effect on motor function and ADL performance. The participants reported that it was easier to rise from a chair, to walk and to climb the stairs after engaging in exercise. One participant had the following experiences:

"You notice that the exercise has positive effects on both body and mind. It is easier to get up from the

chair, it is easier to walk, and you can manage more in everyday life. The stair-climbing exercises got easier".

Exercise increased the feelings of security and self-esteem and improved self-efficacy, as one individual commented as follows:

"It is important to have confidence that you are not going to fall when you do different things. I know that even if I risk taking a fall, I cannot stay seated. It is good to talk about your fears".

5. Physical activity is a basic human necessity—use it or lose it!

Several residents expressed a desire to be active. They appreciated that the possibilities for activities were more limited because of their functional limitations and nursing home routines. Despite these restrictions, they recognized the importance of being as active as possible. One participant explained the situation as follows:

"... but I want to be as active as I can, and therefore it is important that the nursing home staff encourage activity and exercise".

One resident said that she was aware that her body had deteriorated and that she was not satisfied with the shape she was in. She noticed that her body moved more slowly and that her energy, strength and endurance levels were reduced. She commented as follows:

"Bodily strength gives you an experience of living and not wasting away.... Even living in a nursing home, it is unnecessary to deteriorate to the extent we often see".

This resident did not appreciate the fact that she was becoming increasingly less active and more dependent on others during her stay in the nursing home. Several residents have commented that it was important to be able to move around independently and not rely on others. The ability to walk around provides the resident with the perception of having freedom and more options. One resident remarked as follows:

"Being physically active affects all of me. I gain confidence in myself. I experience increased control over my life even though I live in a nursing home".

Another resident noted that it was especially important to be able to get outside for fresh air. She felt like a prisoner if she could not get outside. She expressed herself in the following manner:

"My problem is that I am mad about being outside in the fresh air. When they talk about having to ask for permission to go outside... I feel like a Belsen prisoner".

The residents expressed a need for energy and strength to be able to move around. If you do not move, your energy levels and muscle strength decrease and this process will start a vicious cycle. The residents communicated that it was important to use the body to maintain function and strength: use it or lose it. One resident noted the following:

"An important part of being an individual is to be able to take charge of your life and not live at the mercy of others. To do this, you need energy. I need energy to think and to move. I need strength to stand and walk. Muscle strength is important for us who are old".

Several residents thought that the staff should focus more on active participation and that they should recognize the functional ability of each individual. The importance of exercise in nursing homes must be recognized and the staff need to be good role models. Several residents argued the following point:

"Too often the staff are not concerned with how much we can do for ourselves. We can do more than they think, if it is facilitated".

"There ought to be more exercise in nursing homes. There is no tradition for physical activity in the nursing home. I think they may be worried that the old persons will take a fall or experience excessive demands".

Discussion

This study provides insight into how older people with dementia experience participating in an exercise program. To date, few studies have reported on the experiences of people with dementia with regard to exercise; to the best of our knowledge, nursing home residents with dementia have never before been asked to relate their experiences of participating in a high-intensity exercise program. We will discuss the results within the framework of self-efficacy. It was unambiguous in the findings that self-efficacy was an important topic. Self-efficacy is the subjective assessment of one's own capability to master certain tasks and situations, a sense of personal control or empowerment [49]. Central to the theory are the following four sources of information, which people draw on when they develop their self-efficacy beliefs: 1) enacted mastery experiences;

2) vicarious experiences; 3) verbal persuasion; and 4) physiological and affective states. Self-efficacy has frequently been used as a framework for understanding how older people experience exercise interventions [49, 50]. Thus, the discussion is presented under the following headings: "increased self-efficacy through exercise" and "increased self-efficacy through involvement".

Increased self-efficacy through exercise

One of the positive experiences reported by the participants was the feeling of achievement that is derived from performing the exercises. This corresponds with the enacted mastery experiences, which, according to Bandura [49], is the most powerful source of self-efficacy. Participating in the exercise program seemed to introduce experiences of mastery, which could have had a positive effect on the participants' self-efficacy and self-esteem. The experience of exercising gave the participants a sense of doing something good for themselves, which in turn seemed to produce a change in emotional states. They reported feeling more "confident," "proud of themselves" and "more positive". According to Bandura [49], self-efficacy can have a profound effect on emotional states. Exercise can also lead to improved emotional states directly through the physiological process in the body, such as increased secretion of endorphins that improves mood [50]. Improved mood was reported by the majority of the participants.

An additional aspect that many of the participants proposed was the relevance of the exercise program to everyday life and the experience of improvement in physical functioning. The HIFE program is specifically designed for improving function. Previous studies have confirmed that this exercise program can improve physical function, such as balance and strength, and can likely improve well-being [18, 51–53]. Several studies have shown that older people may have low self-efficacy beliefs regarding their own capacity to exercise [49, 54, 55]. Improved physical function due to exercise and the experience of relevance to everyday function can cause a sense of mastery and increase self-efficacy [49]. The participants talked about the importance of *'being able.'* In addition to improved physical function, such as stair walking and getting up from a chair, the participants reported several other bodily experiences related to participating in the exercise program. They reported that they felt more "vital," had "increased energy," felt "stronger" and had a better sense of "self-esteem". According to Bandura [49], people rely on somatic information transmitted by physiological and emotional states when altering their self-efficacy. These states represent an important source of self-efficacy, especially in regard to physical capabilities.

Another positive aspect proposed by the participants was the group aspect of the exercise sessions. They enjoyed being with others in the same situation and used each other as role models, benefitting from seeing each other's accomplishments. Bandura [49] emphasized vicarious experiences and modeling as sources of increased self-efficacy. People automatically compare themselves to others, and seeing others achieve something can increase their self-efficacy beliefs about their own capabilities. This perspective resonates well with the experiences of the participants who reported that they felt motivated by the achievements of the other participants in the group. The positive social aspects of group exercise interventions have been widely studied, and many people seem to prefer exercising in groups as opposed to exercising individually. The group experience may also serve as a motivator for exercise adherence [54, 56].

An important finding of this study is the perceived importance of certain instructor skills. The participants emphasized positive communication skills and knowledge concerning the aging body as positive instructor traits that created a sense of trust and safety. Verbal persuasion and the positive social support that one is capable of performing certain activities represent an important source of increased self-efficacy [49]. Furthermore, to be effectively influential, the persuader needs to exert credibility and establish trust [49]. Thus, knowledgeability and trustworthiness seem to be important instructor skills, which could have contributed to increasing self-efficacy for exercise and physical activity among the participants.

Moreover, the participants emphasized the importance of skills in individually tailoring the exercise program. Two central points emerge from the results. The exercises should be safe, meaning one should avoid pushing the participants too hard; however, at the same time, the exercises should be effective, meaning the exercises should be aimed high enough to give the participants a feeling of "being challenged" and having exercised. The exercise program HIFE is designed for continuous supervision of a person skilled in assessing and prescribing exercise for older people [18]. It can be argued that people with dementia, due to typical manifestations, such as memory loss, might have a greater need for supervised exercise than healthier elderly adults who might be able to perform exercises on their own with the appropriate dosage. Several studies have demonstrated that people with dementia are more prone to feelings of insecurity, thus establishing a safe and secure setting for the exercises might therefore be of particular importance [57, 58]. The issue of applying the proper dosage of exercise also has a parallel in the self-efficacy theory. According to Bandura [49], the difficulty of task is a factor in determining self-efficacy. If the task is deemed too difficult or if it is too easy, there will be no mastery experiences. The findings, therefore, suggested that the exercise instructor has an important role to play in moderating the appropriate dosage of exercises, thus serving the role as a facilitator of mastery experiences. This role seems to require skills in communicating with people with dementia as well as experience in prescribing exercise for older adults. Hence, the competence of the instructor seems to play a vital part in the experiences of participating in the exercise program and can be perceived as a facilitating factor. This perspective is consistent with a previous study on facilitators for promoting exercise attendance in older adults [56] and earlier research emphasizing professional competence as an important aspect of dementia care [59, 60].

Increased self-efficacy through involvement

The participants in this study expressed an appreciation of being "invested in" and being informed about the reasoning behind the exercises. The participants stated that the exercise program represented something positive in an otherwise undemanding environment. They stated that being included, being met with expectations, and being informed seemed to create vitality, a sense of mastery and increased self-efficacy: "we can do more than they think, if it is facilitated". When the participants spoke about participating in the exercise program, they related how they experienced life in the nursing home. The participants expressed a need to be physically active and stimulated, be actively involved in their own lives and receive attention. Central to the theory of self-efficacy is the importance of a sense of personal control over one's own life. The inability to exert an influence over life's events can create apprehension and apathy [49]. Research has shown that people with dementia can indeed express their preferences consistently, even in the advanced stages of dementia [26, 30, 61], and they should therefore be involved in decision-making regarding their lives and activities in the nursing home. The participants complained that there was too little physical activity within the nursing home environment. This factor was supported by previous studies showing that nursing home residents are physically inactive most of the day [6, 7]. Furthermore, the decline in functional health status is often mistakenly attributed to the natural biological aging process when, in fact, it is due to physical inactivity [49, 62]. We interpret this undemanding environment as being a barrier to physical activity and exercise. In light of the self-efficacy theory, such institutional constraints can negatively influence self-efficacy beliefs and well-being [49]. The participants perceived the exercise program as a positive counteraction to the physically inactive life in the nursing home, which could have contributed to an increased self-efficacy.

One factor that can stand in the way of involving people with dementia is their increasing cognitive impairment and frailty [61]. However, our results demonstrated that this factor must not lead to automatic assumptions that people with dementia cannot process or do not appreciate information and inclusion in decision-making. McCormack [63] found that for older people, actual decision-making was not as important as being informed and having their values and preferences heard and considered. Our findings showed that the participants were able to perceive the qualifications of the exercise instructor and feel more secure if things were explained to them. Appreciating a competent instructor and learning the purpose and benefits of the exercises can be interpreted as a wish of being included and taken seriously. Environmental and social factors that offer little support of expression of independence can also contribute to dependent behavior and loss of self-efficacy in the elderly [49]. It is important to recognize that even if persons with dementia are dependent on the nursing staff for help, this dependence does not necessarily lead to loss of self-efficacy. Although the ability to make decisions will vary according to the particular stage of the dementia disease and other personal and contextual factors, such patient involvement is suggested to increase autonomy and empowerment [64–66].

Our findings have suggested that nursing home residents generally appreciate participating in exercise programs and that this engagement has important implications for the provision of quality care and user involvement in dementia care. The findings of this study are consistent with the outcomes in many studies providing evidence of the positive effects of physical exercise on the physical, psychological and social aspects of life for older adults with dementia [9, 13, 14, 16]. The exercise program seemed to have an effect on all four sources of self-efficacy. By being involved, "invested in" and having something expected of them, the participants were able to gain a sense of power over their everyday lives and participating in group exercises represented one way of giving meaning and purpose to their lives.

Strengths and limitations

A strength of this study is the exploration of the experiences of people with dementia from the perspective of persons with dementia. The majority of studies explored dementia experiences from the point of view of a family member or carer [24, 30]. Interviewing people with mild-to-moderate dementia required that the interviewer have some aids and possess certain skills. We regard the use of visual aids in the form of pictures of the exercise tasks as a positive contribution to the quality of the interviews. Our findings suggested that cognitive impairment is no reason to exclude people with dementia from research.

This study has several limitations. First, although thematic saturation was achieved with a sample size of eight participants, this small sample may not reflect the views of the larger nursing home community. Second, this study was conducted in an urban nursing home setting with Norwegian speaking residents and may not be generalizable to other settings or populations. Furthermore, in qualitative studies, the role of the researchers as producers of knowledge is important. We realize that our preconceptions of exercise and physical activity constitute an important part in the lives of elderly people with dementia in nursing homes and have influenced our interpretations.

Conclusions

Our findings suggest that the HIFE program may lead to positive physical, emotional and social changes, including greater behavioral coherence, improved social interactions and increased well-being. Physical activity and exercise are rarely prioritized in nursing homes; however, the results of this study showed that the participants had, for the most part, positive experiences with participating in a regular group exercise program that has improved their self-efficacy. A competent instructor with knowledge of the aging body and ability to inform the participants was identified as a facilitator. Being involved and having something expected of them were important positive experiences reported by the participants. An unstimulating nursing home environment may be considered as a barrier.

This outcome is an important finding with clinical implications regarding the care of older people with dementia in nursing homes. Our findings are optimistic relative to the capacities of people with dementia. Healthcare professionals should be aware of the positive aspects of exercise and physical activity among nursing home residents with dementia.