

Measuring physical activity levels in people with mild cognitive impairment or mild dementia

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### **Abstract**

Measuring physical activity (PA) in people with mild cognitive impairment (MCI) or dementia can be difficult. The aim was to investigate the validity and acceptability of three different PA measurement methods.

The mixed-method analysis included 49 participants with MCI or dementia who completed a daily calendar recording PA, the International Physical Activity Questionnaire (IPAQ), the LASA Physical Activity Questionnaire and wore a Misfit Shine accelerometer.

The quantitative analysis showed equal completion rates for the IPAQ questionnaire and the accelerometer but a lower completion rate for the calendar. Correlations between outcome measures were moderate or strong. The qualitative analysis indicated that all measures were acceptable, though help to complete the calendars or fasten the accelerometers was required for some participants.

The study supported the validity of these methods for people with MCI and mild dementia. Using accelerometers and completing calendars might increase motivation to be active for some people.

**Keywords:** Exercise, accelerometer, physical activity questionnaire, mild cognitive impairment, validity.

## Introduction

Physical activity has multiple benefits in people with mild cognitive impairment (MCI) or dementia; it has shown to improve activities of daily living, behavioural problems, mood and the risk of falls (Chen, Kuo, Chang, Huang, & Cheng, 2017; Forbes, Forbes, Blake, Thiessen, & Forbes, 2015; Pitkala et al., 2013). A health economics cost analysis indicated that participating in a twice a week exercise programme can lead to significant cost savings for health and social services as it reduces the number of falls (Pitkala et al., 2013).

Physical activity levels in people with dementia are lower than in those without a diagnosis of dementia (Soni et al., 2019) and the impact of physical activity and exercise on other domains such as cognition, social activities and carer burden are still being investigated (Heesterbeek et al., 2018; Zülke et al., 2019). Measuring physical activity levels in people with dementia can be difficult with questionnaires asking participants to remember activities over a period of time, and possibly underestimating physical activity levels (Siebeling, Wiebers, Beem, Puhan, & Ter Riet, 2012). Self-report of physical activity using exercise diaries or calendars also relies on memory though if they are completed on a daily basis, activities might be easier to recall. Physical activity monitors (pedometers and accelerometers) have been used in people with MCI or dementia to support engagement in physical activity (Vidoni et al., 2016) as well as to measure physical activity levels in randomised controlled trials (Moyle et al., 2018) but there is limited evidence regarding the experience of using physical activity monitors in people with MCI or dementia. A small study including 25 people with dementia (Farina, Sherlock, Thomas, Lowry, & Banerjee, 2019) indicated that while there were some technical issues with the activity monitors, most participants considered them as acceptable. However, the relationship between levels of physical activity as measured using the monitor and other assessment methods was not evaluated, limiting the validity of the devices for this population.

Accurately measuring physical activity or exercise levels is essential for high quality research data collection. Therefore, instruments need to be valid, reliable, practical and acceptable. The Promoting Activity, Independence and Stability (PrAISED) feasibility study (Harwood et al., 2018) was completed in preparation for a randomised controlled trial investigating the effects of a multicomponent physical activity intervention to support independence and activities of daily living in people with MCI or early dementia. Three methods of assessing physical activity levels were tested to investigate their validity, practicability and acceptability: physical activity monitors (accelerometers), physical activity questionnaires and self-report daily physical activity and exercise calendars.

This study explored three questions; 1) what were the completion or return rates for each of the measurements? 2) Is there relationship between physical activity questionnaire scores, calendar reported exercise levels and physical activity levels recorded on accelerometers? 3) What was the experience of participants regarding wearing the accelerometers and completing the activity calendar?

Completion or return rates provided were used as an indicator for the practicability of measurements. Concurrent validity, which is a type of criterion-related validity (Coaley, 2010) was investigated in a correlation analysis using the outcomes of the different physical activity measures. Acceptability was explored using a thematic analysis of interview data.

## Method

This analysis was based on follow-up data from the PrAISED multi-site feasibility randomised controlled trial (RCT; Harwood et al., 2018). The aim of the feasibility study was to test and refine procedures in preparation for a fully-powered RCT, including the practicalities and acceptability of using different methods of data collection (i.e. questionnaires, calendars and accelerometers). Recruitment and data collection methods have been described in detail elsewhere (Harwood et al., 2018). In brief, the study compared the practicability and feasibility of two multi-component interventions that aimed to support activities of daily living. Multi-disciplinary therapy programmes were delivered at the participants' homes and follow-up assessment took place 12 months after randomisation. Only data from the 12 month follow-up assessments have been used for this analysis as we tried different models of accelerometer at baseline, which might have introduced differences in recordings (Vanhelst, Gottrand, Baquet, & Béghin, 2012).

### Participants

Forty-nine participants (out of 60 randomised) completed the follow-up assessments 12 months after baseline. Participants were recruited from Memory Assessment Services and the National Institute of Health Research online Join Dementia Research register in the East Midlands, UK. Research assistants from the local Clinical Research Networks and the study team supported the recruitment by contacting those who had indicated that they would be interested in participating in research. When visiting interested participant candidates, research assistants explained the study to and gave participants and family carers the opportunity to ask questions before checking eligibility. Inclusion criteria were having a diagnosis of MCI or dementia (of any type; other conditions leading to cognitive impairment were ruled out during the diagnostic assessment), a Montreal Cognitive Assessment score of 15-25/30 or a standardised Mini Mental State Examination score of 18-26/30, or an Addenbrooke's Cognitive Examination score of 60-90/100 ; able to walk without human assistance and able to communicate in English; no co-morbidities that prevented cognitive assessment or exercise participation; capacity to give consent and agreement to participate; vision, hearing and dexterity sufficient to complete neuropsychological tests; availability to take part in an exercise intervention, and not terminally ill. Where possible, a family member or carer was recruited as an informant. A sub-sample of 20 participants took part in semi-structured interviews, participants were selected based on adherence to the intervention (high and low adherers).

### Ethics

The study had ethical approval from the UK Yorkshire and the Humber - Bradford Leeds Health Research Authority Ethics Committee. Participant information letters were sent ahead of the baseline assessments and interviews to give the participant sufficient time to consider the study. Mental capacity was assessed in line with the Mental Capacity Act 2005. Informed consent was signed prior to the first assessment and additionally for participation in the interviews.

### Procedures

All assessments took place at the participant's home. The feasibility trial assessments included a range of questionnaires, physical performance tasks and computerised tests to assess activities of daily living, independence, physical activity levels, cognition, mobility, balance, mood, quality of life, falls efficacy, and demographic characteristics. Of particular interest for this analysis were the physical activity outcome measures. These included two questionnaires (the International Physical Activity Questionnaire (IPAQ) (Committee, 2005) and the Longitudinal Aging Study Amsterdam (LASA) Physical Activity Questionnaire (Stel et al., 2004)), wrist-worn accelerometers and a monthly self-report calendar to report time spent daily engaged in PrAISED exercises and physical activities. The timeline of these assessments is presented in Figure 1.

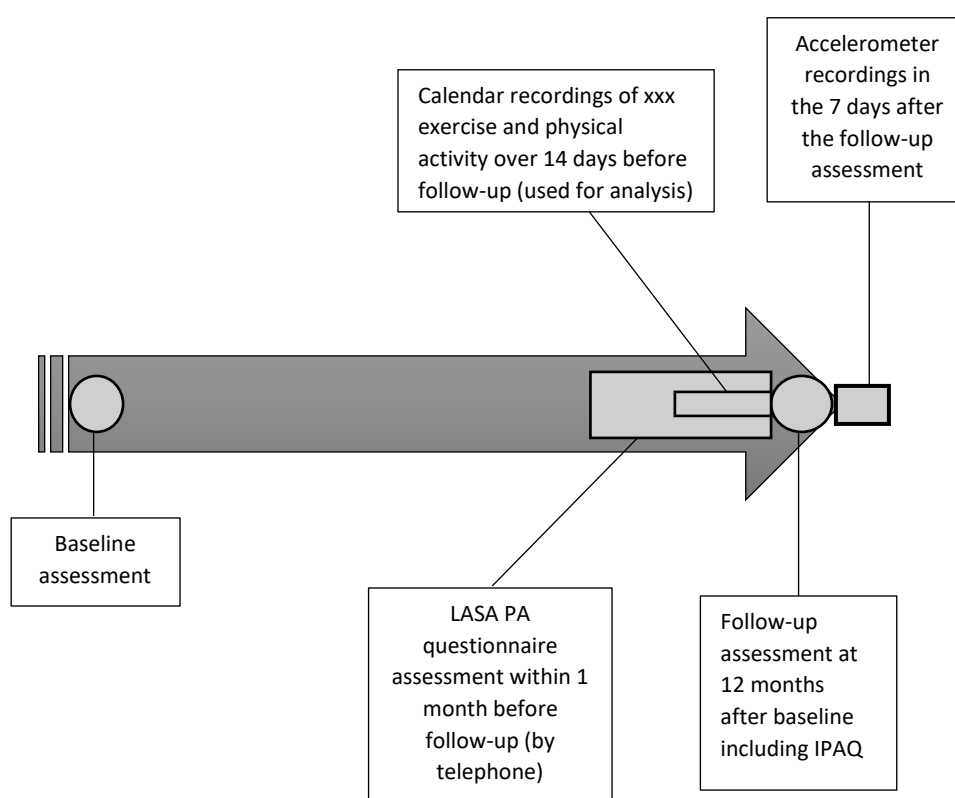


Figure 1: Timeline of physical activity assessments

Trained research assistants and Clinical Research Network Support Officers who had experience in the assessment of people with dementia visited the participants in their homes and completed the assessments. The International Physical Activity Questionnaire (IPAQ) (Committee, 2005) was completed by the informant. The LASA Physical Activity Questionnaire (Stel et al., 2004) was completed in month 11 of the study in a telephone interview with the informant. Accelerometer activity monitors were given to participants during assessments with instructions to return them to the research team after seven days using a stamped and addressed envelope. Participants were asked to wear the accelerometers at all times except when showering, bathing or swimming, though they could take it off when sleeping. All participants were shown how to wear the accelerometer on

their wrist and were encouraged to put it on and off themselves to practice with the researcher present. They were asked to subsequently ignore the device as step counts were not visible to the participant. PrAISED exercise and physical activity calendars were given to participants at baseline; the procedure on how to complete the calendar and return the sheets each month was explained at that point. At the end of each month, they would receive a letter with a stamped and addressed return envelope reminding them to send the calendar sheet to the research group. Those who had not returned the calendar sheet after one week, were contacted by telephone to remind them. Carers were asked to assist if needed.

### **Assessments**

The International Physical Activity Questionnaire (IPAQ; (Hallal & Victora, 2004)) includes 20 questions about activities from four domains, work-related, transportation, housework/gardening and leisure time. The questions asked about time spent doing moderate and vigorous intensity physical activities in the last seven days. For example, the questions included 'During the last 7 days, on how many days did you do moderate activities like carrying light loads, washing windows, scrubbing floors and sweeping inside your home?'), and then questions regarding the time per day spent for the activities followed (e.g. 'How much time did you usually spend on one of those days doing moderate physical activities in the garden or yard?'). Vigorous and moderate activities were recorded separately and weighted using Metabolic Equivalent of Task scores (Committee, 2005).

The LASA Physical Activity Questionnaire (Stel et al., 2004) was added at a later stage of the follow-up assessments as research assistants reported that participants found the wording of the IPAQ ambiguous and feedback suggested that some questions might have been difficult to answer. The LASA Physical Activity Questionnaire has been validated for the use in older people (Siebeling et al., 2012) and includes 18 questions relating to six activity domains, walking outside, cycling, gardening, light and heavy household activities and sport activities. The questions relate to activities one might have completed in the last two weeks (e.g. 'Do you have a garden?'), and for each activity the time spent per activity was asked ( 'How many times did you work in the garden during the past two weeks?' and 'How long did you usually work in the garden each time?'). The individual activities were weighted using Metabolic Equivalent of Task scores (Ainsworth et al., 2000).

The Misfit Shine accelerometer (Misfit Wearables, Burlingame, California, USA) was used to record steps in the 7 days after the follow-up visit. The total number of steps over the 7-day period was used in the analysis. This particular physical activity monitor was chosen as it did not show activity levels (e.g. number of daily steps) without being linked to the software. Therefore, it was assumed that wearing the monitor would be less likely to influence activity levels. For the current analysis, only activity data from the 12 month follow-up period was used as different participants used different accelerometers at the previous assessments (at baseline and 6 months).

The PrAISED exercise and physical activity calendar recorded daily minutes of engaging in exercises and/or physical activity (PA min; this recorded physical activity related or unrelated to the PrAISED intervention). Participants were asked to record minutes of their physical activities and hang the A3 calendar at a prominent place in their house and complete it daily. The total minutes of physical activity in the last 14 days before the follow-up visit were calculated. If calendars had been returned and daily entries were missing, it was assumed that the participant had not done any physical activities and therefore this was counted as zero minutes for this day.

## Interviews

Twenty participants with dementia and their carers had completed semi-structured interviews regarding their involvement in the PrAISED feasibility study. Most participants (n=15) were interviewed along with their carer(s). Interviews lasted approximately two hours and were audio-recorded. A structured interview guide was used to guide the conversation. Questions also explored the acceptability of the research procedures including the accelerometer use and calendar completion. The LASA Physical Activity Questionnaire was added at a later stage and was not discussed in the interviews. Interviews were conducted face-to-face in the participants' home by the second author.

## Analyses

### **statistical analysis.**

Descriptive statistics including sex, age, education, global cognition scores (sMMSE (Vertesi et al., 2001)) at baseline, IPAQ, LASA Physical Activity Questionnaire, accelerometer scores and calendar physical activity data were computed and normality assumptions for physical activity data checked. Zero scores on the accelerometer were treated as recording fault and excluded from the analysis. Completion rates were computed for IPAQ, LASA Physical Activity Questionnaire and accelerometer scores as well as calendar recorded physical activity data. Two tailed Spearman's correlations between the physical activity outcome measures were calculated. All analyses were completed in SPSS 24.0.

### **qualitative analysis.**

Interview recordings were transcribed verbatim and anonymised. All transcripts were imported into NVivo (Version 11, QSR, Southport, UK) and coded into themes and sub-themes using inductive thematic analysis (Braun & Clarke, 2006).

## Results

The follow-up assessments included 49 participants, 17 (35%) of those were women, 44 (90%) had a co-resident family carer and 47 participants (96%) described themselves as white. Further descriptive statistics are presented in table 1. Completion rates for IPAQ and activity monitors were over 80% but lower for the return rates of the calendar recordings. For calendars, the return rates varied between 63% and 93% per month, with a return rate of 63% for month 12 of the study. Calendar return rates per month for the feasibility study are presented in Figure 2.

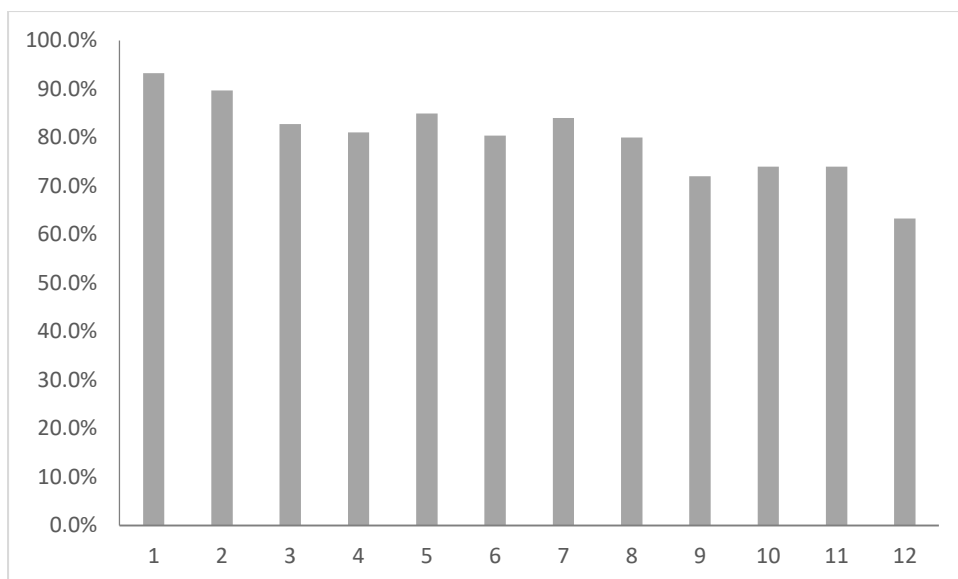


Figure 2: Return rates for calendars per month from baseline to follow-up assessment

Reasons for not completing the IPAQ were feeling unable or refusing to answer (n= 3) and mobility problems at the time of the assessment (n=1).

Table 1 Descriptive statistics

	N (completion/ return rate)	Mean (SD)	Range
Age in years	49 (100%)	77 (6.9)	66-92
Years of education	49 (100%)	12.8 (3.5)	9-23
sMMSE***	49 (100%)	25.9 (3.1)	19-30
IPAQ	42 (86%)	1314 (1380)	30-6366
LASA PAQ*	21 (55%)	4079 (5223)	240-20820
Accelerometer steps	40 (82%)	28147 (19211)	1808-91354
PA min**	33 (63%)	1450 (1882)	90 - 8180

\*LASA PAQ: LASA Physical Activity Questionnaire; this questionnaire was added after follow-up assessments had been commenced; completion rate based on 38 participants who potentially could have completed the questionnaire; \*\*PA min: calendar recorded total minutes of physical activity within the last 14 days before the follow-up assessment; \*\*\*sMMSE: Standardized Mini Mental State Examination;



As the distributions for most measures of physical activity were not normal, Spearman's rank correlations were used to investigate relationships. The results indicated significant moderate and strong correlations between all physical activity measures (for correlations see table 2).

Table 2 Spearman's correlations

		LASA PAQ	Accelerometer	PA min
IPAQ	rho	.88**	.58**	.53*
	p value	.00	.00	.00
	n	20	35	30
LASA PAQ	rho	-	.73**	.76**
	p value	-	.00	.00
	n	-	18	15
Accelerometer	rho	-	-	.67**
	p value	-	-	.00
	n	-	-	28

\*correlation is significant at 0.05 level; \*\* correlation is significant at 0.01 level

### Experience of completing outcome measures

Participants were a subsample of 20 individuals (16 male, 4 female; mean age = 76.6 years, range = 68-91 years) and their carers (n = 19; 17 female, 2 male). Themes identified included 'motivation due to using the measure' and 'acceptability', which related to both the calendar and accelerometer use. 'Workload' and 'support from family carer' were additional themes related to calendar use only.

The theme 'motivation due to using the measure' emerged in the discussion with several participants. The calendar seemed to have a positive effect on emotion, whilst the other measures did not seem to affect motivation.

*"I think it [calendar] makes you aware that you've not done much exercise,..."* (family carer)

For some participants, the calendar just acted as a reminder to do the PrAISED exercises and/or physical activities. However, for others, reporting high levels of activity on the calendar seemed to elicit a sense of achievement, which then motivated them to do more. This potentially could have led some to overestimating their total minutes of physical activity in order to feel that sense of achievement.

*"He cleaned all the kitchen cupboards the other day...It's all so he can write it down on that [calendar]". (family carer)*

Others wanted to avoid feeling guilty about not having done the exercises.

*"..he hates to put 'no' on that form. It's like an admission he's not done something." (family carer)*

However, not everyone was influenced by completing the measures.

*Interviewer: "Did it [accelerometer] influence your motivation at all?" – Participant: "Nah" (person with dementia)*

*Interviewer: "To what extent has knowing that a calendar's been completed influenced your willingness to exercise?" – Participant: "Not at all really. Not at all." (person with dementia)*

The theme 'acceptability' included the sub-themes 'tolerability', 'ease of use' and 'workload'.

Participants reported both measures calendars and accelerometers to be tolerable, ranging from enjoyable to boring.

*"Oh, quite fun, actually" [accelerometer]. (person with dementia)*

*"It's no bother at all" [calendar]. (family carer who assisted with completing the calendar)*

*"Boring" [calendar]. (person with dementia)*

Also, the 'ease of use' included a range of experiences for both measures.

*"No trouble, it's easy enough" (accelerometer). (person with dementia)*

*"A little bit difficult to put on so he did do it but ...it's not easy" (accelerometer). (family carer)*

*"Well, it's easy" (calendar). (person with dementia)*

*"It's very difficult to estimate the amount of times I am doing it [physical activity],... I exaggerate some and I don't do others. I can't count the minutes going down to the garden there and watering the garden and things like that,...it's only a guess" (calendar) (person with dementia)*

'Workload' was a theme that emerged for the calendar but not the accelerometer. For some people, completing the calendar was more of a burden than for others.

*"It's just a routine, in our lives really". (person with dementia)*

*"I suppose it's a bind. To [do] it on a regular basis". (family carer)*

'Support from family carer' was a theme that emerged in relation to completing the calendar, which was sometimes done by the family member.

*"I haven't completed it, ... she fills it in" (person with dementia)*

*“I’m putting what he’s telling me down on the paperwork. And sometimes I knock a bit off, because I know he’s not done that” (family carer).*

For some participants it might be a choice to let the family carer complete the calendar, for others their memory problems might limit their ability to complete the task. However, one family carer outlined how she enabled her spouse to learn to do it himself.

*“we have a sort of a diary on the desk, on the table, normally, so that K can see what we’re going to do each day, and I tend to write on there now, what we’ve done so that K can take that responsibility of filling out his own form. When we first started, I did a few, just to get him into the habit, but it has taken six months, to be able to do it without an oversee, because of, I think that’s helped writing it in the diary, because he just needs to take it from there and copy it. But it has, that has taken six months” (family carer).*

In general, most participants seemed to feel comfortable with completing the measurements, though this might have affected their motivation to increase physical activity levels. However, not all participants found the estimation of minutes of physical activity easy, which could have been due to their memory problems. For these participants, the support, which they received from the family carers to complete the calendar, was essential. In addition, the wristband of the accelerometers can for some people be difficult to adjust.

## Discussion

The findings indicated similar completion rates for the IPAQ questionnaire and the accelerometer but a lower completion rates for the LASA physical activity questionnaire. Return rates for the calendar were higher at the beginning of the study and lower in the last months when all participants were at the end of their involvement in the study.

All outcome measures were significantly associated, the two questionnaires showing the strongest correlation (Spearman’s  $\rho = 0.88$ ). The moderate to strong correlations between the accelerometer scores and the physical activity questionnaires support the concurrent validity of these instruments for measuring physical activity levels in people with mild cognitive impairment and dementia. Concurrent validity is a type of criterion validity that evaluates the relationship between two measures that are expected to measure the same concept (Coaley, 2010).

The qualitative interviews with participants indicated that completing the physical activity calendar and wearing the accelerometer was generally acceptable but might increase the motivation of participants to be physically active. However, not everyone found them easy to use and help from the family carer was common. It is important to note that most participants had a family carer who lived with them. It might not be practical or acceptable to use accelerometers or calendars in people with MCI or mild dementia who live on their own.

None of the measures was ideal for people with MCI or dementia, and both advantages and disadvantages need to be considered when choosing a physical activity measure for a research study: both questionnaires (IPAQ and LASA-PAQ) rely on the participant remembering physical activities in some detail over the previous 7 or 14 days, which can be difficult. However, despite

asking slightly different questions over different timeframes, the high correlation indicates that both reflect a similar recall of physical activity levels achieved by the participant. Furthermore, the high completion rate of 86% for the IPAQ suggests that the questionnaire might be a suitable instrument for assessing physical activity in people with MCI or mild dementia. Our results reflect the findings of a small study comparing the IPAQ questionnaire with the results of a pedometer in people with dementia (Lima et al., 2010), which indicated a correlation of the two measures of  $r = 0.56$  ( $p < 0.01$ ). The stronger correlation found in our study might be due to the advanced technology of an accelerometer compared to a pedometer. In addition, compared to fitness trackers (accelerometers, pedometers), questionnaires assess a wide range of physical activities measuring duration, frequency, intensity and type of activity.

The accelerometer was worn for one week but not continuously as it was suggested by the research assistants to be taken off for baths and showers, and could be taken off while sleeping. It cannot be ruled out that participants occasionally forgot to re-fasten the accelerometers, which might have led to an underestimation of their activity levels. Future studies should advise to wear the accelerometer constantly. The interview findings also indicated that the wristband of the accelerometers could be difficult to fasten but the accelerometers were not burdensome to wear. These results support the findings of a recent interview study indicating that wearing a wrist-fastened activity monitor is acceptable to people with dementia over the period of one month (Farina et al., 2019).

Accelerometers do not rely on memory of past activities, have shown a high degree of accuracy in measuring step counts (El-Amrawy & Nounou, 2015) and are feasible in people with dementia (Erickson et al., 2013).

The calendars, which the participants were asked to complete daily had the lowest completion rate (63% at the end of the 12 month follow up period) and were partly completed by the informant rather than the participant with MCI or mild dementia. Some participants also experienced completing the calendar every day as a burden, while others considered it part of their daily routine. The accurate completion of the calendar also relies on memory, although this is only over the past day. Similar to the step recordings of the accelerometers, activity intensity was not considered, and both accelerometer and calendar might have motivated participants to be more physically active (van der Wardt et al., 2017). Given the higher return rates at the start of the study, diaries might be suitable for shorter studies and specific activities (e.g. in- and outdoor activities) that cannot be assessed using accelerometers or validated, existing questionnaires.

### **Strengths and limitations**

This study determined the practicability and acceptability of different outcome measures to assess physical activity levels in people with MCI or mild dementia. Although each measure has its own limitations, they all were acceptable to participants with high completion rates for the IPAQ questionnaire and the accelerometer. The calendar might have underestimated the actual physical activity levels, as missing entries were counted as zero minutes of physical activity for that day, therefore introducing a measurement bias. In addition, the reasons for changes in calendar recordings were not assessed, therefore we cannot draw any conclusions regarding these changes. As the LASA physical activity questionnaire was only introduced after the follow-up visits had started, completion rates might not be comparable to those of the IPAQ. Another limitation was that

physical activity was recorded for different time frames (for the 14 or 7 days before, or for the 7 days after the follow-up assessment).

Furthermore, both the accelerometer use and daily completion of physical activity calendars are likely to have increased the motivation to exercise and be physically active, which should be taken into account when planning studies. As we did not ask the participants to specify the intensity of their physical activities on the calendar, it was unclear from the recordings if the activities could be classified as low, moderate or vigorous intensity. More detailed recordings would be able to determine that but would also lead to a higher burden for the participants, which might have reduced completion rates. Similar, the accelerometers did not record intensity levels in our study, although a heart rate function is available in some devices (El-Amrawy & Nounou, 2015). Finally, it is important to note that these results might not be applicable to people with more advanced stages of dementia.

## Conclusion

Both accelerometers and physical activity questionnaires show high completion rates in people with MCI or mild dementia and are suitable instruments for research into physical activity in a population of people with MCI or mild dementia. The use of accelerometers and the daily completion of physical activity calendars might increase the motivation to be physically active in this population and therefore could be used in clinical practice to support people to do more physical activity. However, people with MCI or mild dementia might need support from family carers to complete calendars on a daily basis. Future studies should be aware of the limitations of the different methods of assessing physical activity levels in this population.

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