Use of physical activity questionnaires in people with dementia: A scoping review

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Abstract

Physical activity questionnaires are an important means to assess habitual physical activity. It remains unclear what questionnaires are used and whether they are appropriate for people with dementia who have impaired information recall but are also often largely sedentary. This scoping review aimed to identify and quantify the use of physical activity questionnaires within a dementia population. Eighteen studies met the inclusion criteria for this review. The majority of studies used questionnaires that were validated for use within an older adult population (e.g., Modified Baecke Questionnaire for the Elderly), though none had specifically been validated for use in people with dementia. Interestingly, just over half of studies (N= 10, 55.6%) adapted the questionnaires from the original validated version by allowing a proxy to provide input into the responses. Future research needs to robustly validate the use of proxy-report measures of physical activity in people with dementia.

Keywords: measures, exercise, Alzheimer's disease

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Measuring physical activity is complicated, with trade-offs between the different types of available measures in terms of accuracy, acceptability, and feasibility (Prince et al., 2008; Sylvia, Bernstein, Hubbard, Keating, & Anderson, 2014). Physical activity questionnaires have a distinct place in research, being standardised, quick to use, low burden and cost effective, particularly in large, epidemiologic cohort studies (Strath et al., 2013). These self-report tools also permit the segmentation of total activity into type, such as work, household, leisure and transport that more objective tools such as accelerometers, fail to capture (Ahn et al., 2015). It is therefore unsurprising that physical activity questionnaires are still widely used, despite being readily critiqued (Janz, 2006; Sallis & Saelens, 2000; Shephard, 2003). Some of these shortcomings are exacerbated in older adults, with a tendency to participate in lower-intensity, more frequent, unstructured physical activity (e.g., household chores and gardening) which are more difficult to recall than high-intensity, structured activities (Harada, Chiu, King, & Stewart, 2001). As a result, many questionnaires used with older adult samples do not have proven reliability and validity in this population (Falck, McDonald, Beets, Brazendale, & Liu-Ambrose, 2015; Kowalski, Rhodes, Naylor, Tuokko, & MacDonald, 2012).

People with dementia not only perform less physical activity than healthy older adults (Boyle et al., 2015; Zanco et al., 2016), but their cognitive impairment limits information-related recall (Wadley, Harrell, & Marson, 2003). This raises the question of the appropriateness of using self-report physical activity questionnaires in people with dementia. Systematic reviews of self-report measures of physical activity in older adults and patients with chronic disease have not identified measures specifically developed for those with

dementia (Forsén et al., 2010; Williams et al., 2012). Despite this, we are aware that physical activity questionnaires continue to be used in research involving people with dementia. The extent to which physical activity questionnaires are used in people with dementia, and how they are adapted and successfully implemented, remains unknown.

A recent scoping review compiled a list of physical performance measures used in exercise interventions in people with dementia (McGough et al., 2017), though physical activity measures were outside the scope of the review. The current scoping review seeks to explore the current choice of subjective questionnaire-based measures of physical activity used in people with dementia, and how these measures have been adapted for use in dementia research. The aim of this study is therefore to identify and quantify the use of physical activity questionnaires within a dementia population.

Methods

Design

We adopted a scoping review design (Rumrill, Fitzgerald, & Merchant, 2010) to enable the mapping of the current state of the literature. A scoping review enables researchers to identify the location and size of the topic, as well as identifying gaps in the literature (Arksey & O'Malley, 2005).

Search Strategy

On 9th January 2018 two electronic databases (PubMed and Scopus) were searched for the terms related to physical activity and dementia. We also expanded the search to include terms of measures of physical activity (e.g., International Physical Activity

Questionnaire (IPAQ), Community Healthy Activities Model Program for Seniors (CHAMPS) questionnaire, and the Rapid Assessment of Physical Activity (RAPA). An example search in Scopus:

> TITLE (dementia OR Alzheimer) AND TITLE-ABS-KEY ("Physical Activity" OR exercise) AND ALL (questionnaire OR YALE OR PASE OR RAPA OR PAQE OR baecke OR IPAQ OR CHAMPS)

Extensive lateral searches and snowballing techniques were also adopted, in which we searched the reference lists of included studies and used the 'cited by' function within Google Scholar. Selection of studies was independently completed by two researchers (XX and XX).

Types of Studies

We included all peer-reviewed research in which physical activity was measured using questionnaires in a dementia population (e.g., interventions, observational studies). Systematic reviews, conference proceedings, and documents from the grey literature were excluded. Protocol papers were accessed to provide supplementary information about the design of included studies.

Types of Participants

Studies were required to have a sample, or subsample, of participants with dementia. There were no exclusion criteria based on the type of dementia, however, diagnostic criteria were required to have face validity. To be eligible for inclusion, there needed to be sufficient description of the dementia sample to extract basic demographic information (e.g., age,

cognitive status). There were no other exclusion criteria based on cognitive severity, living situation, physical fitness, comorbidities, or physical activity level.

Types of Outcome

Eligible studies were required to have a description of the questionnaire as a means to measure physical activity. We excluded studies in which the authors reported the questionnaire as only measuring Activities of Daily Living, motor function, or broader leisure activities. Studies that utilised physical activity questionnaires that had no evidence of validity (e.g., single item questions, self-devised) were also excluded.

Language

Studies were not excluded based on language. All non-English language studies were reviewed after translation into English by Google Translate.

Quality Assessment

As per previous guidelines of scoping reviews (Rumrill et al., 2010), we did not formally judge or weight the quality of studies identified in this review.

Data Extraction

Description of the study population (e.g., age, cognitive status) were extracted. In circumstances where this information was split between two or more subgroups, we combined the means and standard deviations. Details concerning the choice of questionnaire

were extracted (e.g., name, adaptation from validated measure). Evidence of the validity were also extracted when reported.

To avoid duplication of results, articles utilising the same participants were counted as a single study. Participant demographics were extracted from the earliest published article, though details about the physical activity questionnaire were extracted from all relevant articles to maximise completeness.

A single author extracted data (XX) which was independently verified by another researcher (XX). If data were not reported, this was highlighted. Additional information was not requested from authors.

Data Synthesis

The results were synthesised narratively due to the exploratory nature of the scoping review. Information regarding the choice of questionnaire, administration format, and validity were described and discussed.

Results

We identified 18 studies that met our inclusion criteria and used physical activity questionnaires in people with established dementia (Table 1). The earliest study identified was published in 2005. The majority of studies investigated physical activity in Alzheimer's disease (AD) subtype exclusively (n=13). Studies that reported the average MMSE (Folstein, Folstein, & McHugh, 1975) score had a tendency to explore physical activity in people with a mild (mean MMSE ≥ 21) (n=8) and moderate severity of dementia (mean MMSE 11-20) (n=7). Whilst some studies did include participants with a more severe impairment (e.g.,

MMSE < 11, Clinical Dementia Rating = 3), no study exclusively explored participants with severe dementia.

Physical Activity Questionnaires

The most popular questionnaire used in people with dementia was the Modified Baecke Questionnaire for the Elderly (MBQE) (n=6), followed by the Physical Activity Scale for the Elderly (PASE) (n=5). The remaining eight studies used other physical activity questionnaires including, International Physical Activity Questionnaire (IPAQ) – Short Form (n=1), the IPAQ - Long Form (n=1), the Yale Physical Activity Survey (YPAS) (n=1), Baecke Habitual Physical Activity Questionnaire (BHPAQ) (n=1), Physical Activity Questionnaire for Elderly (PAQE) (n=1), Incidental and Planned Exercise Questionnaire (IPEQ) (n=1) and a physical activity questionnaire "based on the modified Yale Physical Activity Questionnaire and the Baecke Questionnaire"(n=1).

Adaptation of Questionnaires

Just over half of the studies (n= 10, 55.6%) explicitly reported to have adapted the physical activity questionnaire from the original validated measure. In all instances the adaptation was that the questionnaire was completed by a proxy (e.g., carer), rather than self-report. The severity of the sample population did not appear to determine whether a proxy-report approach was utilised. Notably, some of these studies did not use a standardised method of data administration. For example, in one study the questionnaire was completed by either the person with dementia or their carer (Winchester et al., 2013).

Evidence of Validity

Only one study provided any evidence of the validity of the questionnaire in the dementia population, and its administration format being used (Lima, de Freitas, Smethurst, Santos, & de Barros, 2010). Whilst not a comprehensive evaluation, the authors indicated that the questionnaire (IPAQ long form, proxy-administered) correlated with pedometer generated, step count over 7 days (Yamax, Digi-walker SW-200), r= 0.57 (95% CI: 0.24-0.79), p<0.01.

Discussion

Measuring physical activity in dementia is a growing area of interest, particularly as researchers seek to understand the beneficial role of lifestyle factors in people with dementia. This scoping review highlights that to date, there is no standard method of measuring physical activity using questionnaires in a dementia population. However, the majority of studies did make adaptions to the administration format of existing self-report questionnaires, thus potentially impacting their validity.

In studies included in this review, physical activity was commonly captured using questionnaires that had been developed or previously validated for use with older adults, including the MBQE (Voorrips, Ravelli, Dongelmans, Deurenberg, & Van Staveren, 1991) and PASE (Dinger, Oman, Taylor, Vesely, & Able, 2004). Importantly, there was no indication that any of these questionnaires had been validated for use in dementia or attempted to account for error associated with cognitive impairment. To our knowledge, only a single measure has been validated for use in an older adult, cognitively impaired population, namely the Assessment of Physical Activity in Frail Older People (APAFOP) (Hauer et al., 2011). The measure was designed to be an interview administered 24-hour

recall measure, in an effort to support recall and promote completeness in responses. The APAFOP was validated in a cognitively impaired population (MMSE<24), though such a dependency on short term memory recall, even using a highly structured interview process, is likely to be problematic in more severe cognitive impairment. Since publication in 2011, no studies identified in this review used the APAFOP, to date it appears to have a limited uptake.

Interestingly, just over half of the studies used questionnaires that were adapted to require input from the carer (i.e., proxy-report) rather than first person recall. Whilst not explicitly stated within many of the identified studies, the use of a proxy is likely to result from concerns regarding recall accuracy in people with dementia. Agreement between self and proxy questions on retrospective lifestyle questions are relatively poor (Friedland et al., 2001; Kondo, Niino, & Shido, 1994), though there is no evidence that proxies systematically over- or under-report on these questions (Debanne et al., 2001; Friedland et al., 2001). Instead poor agreement is likely to be a result of the impaired recall of the person with dementia as highlighted in using functional questionnaires in which discrepancies between self and proxy-report increase based on cognitive severity (Farias, Mungas, & Jagust, 2005; Ostbye, Tyas, McDowell, & Koval, 1997). It is therefore unsurprising that the use of proxy-report questionnaires have previously been suggested as an important means of assessing physical activity in those who may struggle to accurately self-report on their own levels (Middleton, Kirkland, Mitnitski, & Rockwood, 2010; Prince et al., 2008). It should be noted that the utilisation of proxy-report physical activity questionnaires in dementia have not been robustly validated, with none of the studies reviewed here providing a detailed rationale about when a proxy-report measure should be used or who is the best person to act as informant. As commented elsewhere (Sallis & Saelens, 2000), the accuracy of such proxy-reports may be dependent on the opportunity for the proxy to observe the physical activity of the participant.

Importantly, even if there is a consistent bias or inaccuracies introduced through proxy-reports, this could be accounted for in statistical methods.

The purpose of this scoping review was to gauge the current use of physical activity questionnaires in people with dementia. During our literature search, it was evident that studies utilised a number of different techniques to measure physical activity including diaries (Cedervall, Kilander, & Åberg, 2012; Lowery et al., 2014; Wang et al., 2004), items embedded within broader leisure activity questionnaires (Boyle et al., 2015; Treiber et al., 2011), self-created or single-item questionnaires (Allan, Ballard, Rowan, & Kenny, 2009; Allan, McKeith, Ballard, & Kenny, 2006; Dal Bello-Haas, O'Connell, & Morgan, 2014; Eshkoor, Hamid, Nudin, & Mun, 2013; León-Ortiz, Ruiz-Flores, Ramírez-Bermúdez, & Sosa-Ortiz, 2013; Shih, Pai, Huang, & Wang, 2017) and perhaps most prominently using accelerometer technology (van Alphen et al., 2016; Varma & Watts, 2017; Watts, Walters, Hoffman, & Templin, 2016). Although, activity monitors do resolve certain shortcomings of measuring physical activity with self-report questionnaires, they also have limitations in their use (Prince et al., 2008). Most notably, whilst they may be more accurately able to determine the frequency, intensity and duration of activity, these monitors are unable to tell us what types of physical activities are being completed and may not capture certain types of physical activity depending on sensor placement such as cycling or water-based sports (Schrack et al., 2016). Despite evidence suggesting that use of these devices in dementia are acceptable (Erickson, Barr, Weinstein, & Banducci, 2013), others have raised concerns about poor adherence (Hauer et al., 2011). One study notably reported that 53.7% of people with severe dementia did not meet the valid wear-time for their study (Moyle et al., 2017). Further research is needed to better understand factors that may influence better adherence and compliance in people with dementia. Outside of a dementia population, the respective shortcomings of questionnaires and activity monitors have led to the recommendation that

both should be used simultaneously in research to provide complementary data (Skender et al., 2016). Notably, it may not always be feasible for activity monitors to be implemented, once again raising the distinct place physical activity questionnaires have in research.

It is important to acknowledge that people with dementia, particularly during the earlier stages, may be able to complete self-report physical activity questionnaires to some degree of accuracy. Self-report questionnaires may also be the only option for some participants because a carer (or other informant) is unavailable, whilst having the added benefit of empowering people with dementia by providing their own information about their own habits. Successful use of self-report questionnaires for people with dementia requires:

1. Shortened questionnaire length to minimise burden on the person with dementia.
2. In light that people with dementia remain relatively sedentary, a greater focus on light physical activities rather than more intense activities.

In addition, it is worth acknowledging that autobiographical memory and episodic memory deficits are common in people with dementia (Fromholt & Larsen, 1991; Greene, Hodges, & Baddeley, 1995; Morris & Kopelman, 1986) that results in less detail and more overgeneralization (Fromholt & Larsen, 1991; Moses, Culpin, Lowe, & McWilliam, 2004). Accuracy of recall could also be aided by selecting (or designing) a questionnaire that is better suited for people with dementia, including:

3. Use of prompts, cued recall or recognition (rather than spontaneous recall).
4. Use of more general questions about physical habits, rather than the recall of specific activities based on their duration and timing. Avoiding the recall of more specific elements of physical activity habits will reduce missing and

erroneous data, at the cost of not being able to calculate more detailed physical activity profiles (e.g. frequencies and durations).

None of the questionnaires identified in the scoping review would fulfil all of these recommendations. Even with such considerations, it is unlikely that people with more severe dementia would be able to accurately recall their own physical activity. Currently the accuracy of physical activity questionnaires in dementia is unquantified, and therefore selecting a cognitive cut-off to determine 'sufficiently accurate' recall would likely be arbitrary. As highlighted in the present review, authors have utilised proxy-report physical activity from people who could be considered to have very mild dementia (Burns et al., 2007). Practically, encouraging the use of proxy-report physical activity questionnaire in all those with dementia avoids the potential of cognition related inaccuracies and provides a standardised measure irrespective of severity. This would be a similar approach to the widely used Bristol Activities of Daily Living Scale (BADLS)(Bucks, Ashworth, Wilcock, & Siegfried, 1996), which captures the activities of daily living in people with dementia from the perspective of the carer. Admittedly, the use of a proxy-report questionnaire introduces additional bias (e.g. observation), which has also been noted in BADLS (Bucks & Haworth, 2002). Another consideration for the use of proxy-report physical activity questionnaires in people with dementia is the potential to disempower those who may be able to recall their own activities, or exclude people from participation if they do not have an appropriate informant (e.g. no cohabiting carer). Irrespective, understanding the accuracy of proxy-reported physical activity questionnaires by comparing responses to objective measures of physical activity is essential prior to broader uptake.

As with previous recommendations, a balanced approach needs to be taken when selecting physical activity measures (Sylvia et al., 2014). Due to memory impairment, it is likely the same instruments used in a cognitively healthy older adult sample cannot be the

same as those used with dementia. The widespread use of physical activity questionnaires, both adapted and unadapted, for use within a dementia population without validation is concerning. It is our recommendation that proxy-reported physical activity questionnaires are used for people with dementia to minimise the risk of inaccurate recall, however, before relying on these measures, rigorous validation studies comparing proxy-report to objective measures should be undertaken to improve confidence regarding the effectiveness of relying on these measures. We also believe that there is the potential to develop and validate a self-report physical activity questionnaire for people with mild dementia, so long that it is developed in a manner best suited for use within this population.

Conflict of Interest

There is no known conflict of interest. The authors declare that results of the study are presented clearly, honestly, and without fabrication, falsification, or inappropriate data manipulation.

Description of Authors' Roles

XXXXX conceptualised and designed the review and wrote the first draft. XXXXX independently shortlisted the articles in the review and assisted in writing the article. XXXXX and XXXXX assisted the design of the review and writing the article.

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Table 1. Description of the studies identified in the scoping review and how they measured physical activity in a dementia sample.

Study	Dementia Sample	Age Mean (SD) [Range]	Global cognitive status Mean (SD) [Range]	Physical activity questionnaire	Reported adaptation to validated measure
(Auyeung et al., 2008)	604 'probable' dementia	Pooled: 74.9 (0.7)	CSI-D = NR (NR) [NR]	PASE	None
(Farina, Tabet, & Rusted, 2014, 2016)	82 AD or Atypical AD	80.7 (6.1)	MMSE = 23.6 (3.9) [NR]	PASE	• "…were administered by questionnaires to the carer of the participant." (Farina et al., 2016) • Adapted for use in the average week.
(Gagliardi, Papa, Postacchini, & Giuli, 2016)	93 AD	77.6 (5.3)	MMSE = 20.1 (4.1) [NR]	PASE	None
The Brain Aging Project (Burns, Cronk, et al., 2008; Burns et al., 2007; Burns, Mayo, Anderson, Smith, & Donnelly, 2008; Honea et al., 2009; Loskutova, Honea, Vidoni, Brooks, & Burns, 2009; Watts, Ferdous,	71 AD	74.9 (6.6)	MMSE = 26.1 (3.5) [NR] CDR = NR (NR) [0.5-1]	PASE	"…were collected from the study participants and their collateral sources." (Loskutova et al., 2009)

Moore, & Burns, 2015; Watts, Vidoni, Loskutova, Johnson, & Burns, 2013)					
The ADEX study (Hoffmann et al., 2016; Sobol et al., 2016)	200 AD	70.5 (7.4)	MMSE = 24.0 (3.6) [14-30]	PASE	"As judged from the proxy-rated Physical Activity Scale for the Elderly…" (Hoffmann et al., 2016)
(Christofoletti et al., 2011)	59 AD, VaD or Mixed type	76 (NR)	CDR = NR (NR) [1-3] CAMCOG = NR (NR) [0-100]	MBQE	"In addition to the MBQE…the authors directly interviewed caregivers and family members to determine the physical activity of the patients…"
(Christofoletti, Oliani, Gobbi, Gobbi, & Stella, 2006)	6 AD	77.5 (2.3)	MMSE = 13.7 (1.7) [NR]	MBQE	None

PRO-CDA (Garuffi et al., 2013; Pedroso et al., 2016; Stein et al., 2012; Vital et al., 2016; Vital, Hernandez, et al., 2012; Vital, Hernández, et al., 2012)	37 AD	78.8 (7)	MMSE = 17 (4.4) [NR] MoCA = 11.2 (5.4) [NR]	MBQE	"…was answered by the caregiver with respect to the patient's activities." (Vital, Hernandez, et al., 2012)
(Coelho et al., 2014)	21 AD	76.3 (6.2)	MMSE = 21.0 (3.9) [NR]	MBQE	"This measure *[MBQE]* in AD may lose sensibility, because the questionnaire is subjective and influenced by the caregiver interpretation. Therefore, the level of condition was obtained through data from the physical test (incremental test)."
(Andrade et al., 2013)	30 AD	Pooled: 77.7 (6.7)	Pooled: MMSE =19.4 (3.7) [NR] CDR = 1.3 (0.5) [NR]	MBQE	None
(Canonici et al., 2012; Stella et al., 2011)	32 AD	77.8 (5.8)	MMSE = 15.4 (6.0) [NR]	MBQE	None

(Lima et al., 2010)	26 AD	74.4 (6.5)	CDR = NR (NR) [1-3]	IPAQ (Long form)	• "The interview was carried out with the caregiver of the patient" *[Translation]* • Adapted for the elderly in a usual week.
(Zanco et al., 2016)	17 AD	78 (NR)	MMSE = 21 (NR) [12-28]	IPAQ (Short Form)	None
(Kwan, Kwok, Lam, Woo, & Chiu, 2005)	45 AD	76.8 (6.8)	MMSE = 14.5 (7.8) [0-28]	Liu and colleagues Physical activity scale (Liu et al., 2001)	"Family caregivers of the subjects with AD provided surrogate information."
(Winchester et al., 2013)	104 AD	81 (6.5)	MMSE= 24.8 (13.6) [NR]	A modified version of the Yale Physical Activity Survey	"…either the patients or their informants answered questions…"
The Pietà study (Guimarães et al., 2014)	55 dementia	82.8 (5.7)	MMSE = 12.7 (3.9) [NR]	BHPAQ	None.
(Hauer et al., 2012; Zieschang, Schwenk, Oster, & Hauer, 2013)	122 dementia	Pooled: 82.6 (6.8)	Pooled: MMSE = 21.8 (3.0) [NR]	PAQE	None

(Taylor et al., 2017)	42 dementia	83.0 (6.5)	MMSE = 21.2 (4.1) [NR] ACE-R = 58.0 (13.7) [NR]	IPEQ-W	"…was administered with the assistance of carers…"

AD = Alzheimer's Disease, ADEX = The Preserving Cognition, Quality of Life, Physical Health and Functional Ability in Alzheimer's Disease: The Effect of Physical Exercise, BHPAQ = Baecke Habitual Physical Activity Questionnaire, IPAQ = International Physical Activity Questionnaire, MBQE = Modified Baecke Questionnaire for the Elderly, NR = Not Reported, PAQE = Physical Activity Questionnaire for Elderly, PRO-CDA = Programa de Cinesioterapia Funcional e Cognitiva em Idoso com Doença de Alzheimer, RCT = Randomised Controlled Trial, VaD = Vascular Dementia,