Participation in group outings, gender related profiling and preferences of outings for carers of individuals living with dementia: systematic review

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Citation

Review question
1. What are the participation levels and preferences in group outings for individuals living with dementia and their unpaid carers?

2. What gender differences are there in participation in group outings for individuals living with dementia and their unpaid carers?

Searches
Articles and reports related to the topic of outdoor / physical activity of carers of individuals with dementia will be identified through searches using electronic databases. The purpose of the current systematic review is to synthesize all relevant available knowledge. To provide a comprehensive overview of this research topic, all existing literature will be included, e.g. primary research studies, systematic reviews, meta-analyses, letters, guidelines, websites etc. The search will be limited to literature written in English. No date restrictions will be applied.

The following electronic databases will be searched:

1. PubMed
2. SPORTDiscus
3. PsycINFO
4. CINAHL

Additionally, grey literature will be searched in OpenGrey. The search term “outdoor activity where carers bring carees with dementia” will be used to identify grey literature because they were identified as the most relevant terms in the exploratory and database searches. In addition, reference lists of all relevant studies, reviews and reports will be searched and we will consult experts in the field.

Types of study to be included
The search will include both quantitative and qualitative studies. There will be no restrictions on study design.

Condition or domain being studied
Participation in outdoor physical activities for carers of individuals with dementia

Participants/population
Eligible participants include:

i) Carers for individuals suffering from/diagnosed with any type of dementia

ii) Carers must not be caring for the individual as part of their professional vocation i.e. they will be unpaid family members or friends
iii) Carers can be from any age group (including ageing carers of 65+, working age carers aged 25-65, and young carers <25)

iv) Carers are bringing/taking their carees to outdoor outings where walks or other exercise is involved

**Intervention(s), exposure(s)**
Group outings organised for people living with dementia and their carers, where any type of physical activity is included

**Comparator(s)/control**
None

**Main outcome(s)**
The primary outcomes of interest are:

- Gender of carers bringing their caree with dementia

- Unpaid carers’ perceived barriers to attending the outdoor / physical activity with the caree suffering from dementia (e.g. lack of time, lack of available respite care, lack of energy, lack of suitable space, lack of money, medical conditions, lack of social support)

- Unpaid carers’ perceived facilitators to attending the outdoor / physical activity with the caree suffering from dementia (e.g. suitable respite care, support from family / friends, health concerns, nearby parks / trails).

Physical activity has been shown to provide clear health benefits including reduced risk of cardiovascular disease, certain cancers, stress and depression, and improved mental / cognitive health, wellbeing and sleep (Reiner et al., 2013; Warburton et al., 2006). Therefore, knowing the barriers and facilitators to physical activity for carers allows researchers to develop targeted interventions to improve the mental and physical wellbeing of this specific population. Furthermore, physical activity per se is now recognised as a health outcome by major funding councils and government organisations.

* Measures of effect
Not applicable

Additional outcome(s)
None

* Measures of effect
Not applicable

**Data extraction (selection and coding)**
Study selection (both at title/abstract screening and full text screening) will be performed by two reviewers. Any disagreements will be solved by consensus or by the decision of a third reviewer where necessary. After eliminating the duplicates, an initial screening of titles, abstracts, and summaries (if applicable) will be undertaken to exclude records that clearly do not meet the inclusion criteria. Each record will be classified as ‘include’ or ‘exclude’ or ‘maybe’ with comments to identify relevant and exclude irrelevant literature. The researchers will be inclusive at this stage and, if uncertain about the relevance of a publication or report, it will be left in. The full text will be obtained for all the records that potentially meet the inclusion criteria (based on the title and abstract/summary only). In a second step, all the full text papers will be screened against the inclusion criteria, using a standardized tool. Studies that do not meet the inclusion criteria will be listed with the reasons for exclusion. An adapted PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) flow-chart of study selection will be included in the review.

Two reviewers will independently extract data from each included study and insert this into the Excel spreadsheet. Disagreements between the reviewers will be resolved by discussion, or by a third reviewer. Study authors will be contacted to resolve any uncertainties. The extraction sheet will include authors, year of study/report, aim/purpose, type of paper (e.g. journal article, annual evaluation report, etc), geographical
area, study population (e.g. age of carers and condition of individuals being cared for), sample size, study
design, and key findings that relate to the systematic review question. Two reviewers will independently
extract data using a structured data extraction form. Disagreements between review authors will be resolved
by discussion or a third author.

**Risk of bias (quality) assessment**

Two reviewers will independently assess the risk of bias using the Cochrane risk of bias tool, which includes
the following domains: random sequence generation, allocation concealment, blinding of outcome assessors,
completeness of outcome data, and selective outcome reporting. We also plan to assess the following
additional sources of bias: baseline imbalance and inappropriate administration of an intervention as
recommended by the Cochrane Handbook for Systematic Reviews of Interventions. Studies will be judged at
high risk of bias if there was a high risk of bias for 1 or more key domains and at unclear risk of bias if they
had an unclear risk of bias for at least 2 domains. Authors of papers will be contacted if information is
missing.

**Strategy for data synthesis**

Findings from included studies will be synthesized narratively. The ‘Guidance on the Conduct of Narrative
Synthesis in Systematic Reviews’ will be used to advise the narrative synthesis. A preliminary synthesis will
be conducted to develop an initial description of the findings of included records and to organize them so that
patterns across records can be identified. Thematic analysis will be used to analyse the findings. The
following five steps of thematic analysis will be followed adopting a recursive process:

a) Familiarization with the extracted data

b) Generation of initial codes

c) Searching for themes

d) Reviewing themes

e) Defining and naming themes

Depending on the findings available, the reviewers will aim to provide a flow chart mapping the physical
activity of carers. This review will highlight the outdoor physical activity of carers, as well as the need for
more high-quality research in this field. The information presented in this review may be considered, in the
future, by primary care providers and funding bodies when planning future support for this growing
population of carers.

Meta-analysis will be conducted if data is found to be sufficiently homogeneous. We will decide if it is
appropriate to pool our measures of effect by assessing if the included studies are similar enough (in terms
of their population, intervention characteristics, and reported outcomes) to draw meaningful conclusions. If a
meta-analysis of the included studies is indicated, we will assess statistical heterogeneity by visual
inspection of the scatter of effect estimates in the forest plot and by calculating the I² statistic, after using the
inverse variance method. In the case of a high degree of heterogeneity (I² greater than 50%), we will explore
possible reasons for variability by conducting subgroup analysis. Where we detect substantial clinical,
methodological or statistical heterogeneity across included studies, we will not report pooled results from
meta-analyses.

**Analysis of subgroups or subsets**

None planned

**Contact details for further information**

Dr Joanna Horne
jo.horne@open.ac.uk

**Organisational affiliation of the review**

The Open University
Review team members and their organisational affiliations
Dr Joanna Horne. The Open University
Dr Nichola Kentzer. The Open University
Dr Lee Smith. Anglia-Ruskin University
Mr Mike Trott. Anglia Ruskin University
Ms Jane Abington. The Open University
Dr Jitka Vseteckova. The Open University

Type and method of review
Narrative synthesis, Systematic review

Anticipated or actual start date
29 June 2020

Anticipated completion date
30 October 2020

Funding sources/sponsors
The SRA Health and Wellbeing Fund within The School of Health, Wellbeing and Social Care at the Open University funded the time of academic staff to design and conduct this review. No other external funding was received.

Conflicts of interest

Language
English

Country
England

Stage of review
Review Ongoing

Subject index terms status
Subject indexing assigned by CRD

Subject index terms
Caregivers; Dementia; Humans

Date of registration in PROSPERO
16 July 2020

Date of first submission
25 June 2020

Stage of review at time of this submission
The review has not started
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<td>Data extraction</td>
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The record owner confirms that the information they have supplied for this submission is accurate and complete and they understand that deliberate provision of inaccurate information or omission of data may be construed as scientific misconduct.

The record owner confirms that they will update the status of the review when it is completed and will add publication details in due course.

Versions
16 July 2020

PROSPERO
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