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

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

Joanna Horne, Nichola Kentzer, Lee Smith, Mike Trott, Jane Abington, Jitka Vseteckova

Citation

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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 I^2 statistic, after using the inverse variance method. In the case of a high degree of heterogeneity (I^2 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

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Organisational affiliation of the review

The Open University

Review team members and their organisational affiliations

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Ms Jane Abington. The Open University
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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

Stage	Started	Completed
Preliminary searches	No	No
Piloting of the study selection process	No	No
Formal screening of search results against eligibility criteria	No	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

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

This information has been provided by the named contact for this review. CRD has accepted this information in good faith and registered the review in PROSPERO. The registrant confirms that the information supplied for this submission is accurate and complete. CRD bears no responsibility or liability for the content of this registration record, any associated files or external websites.