A systematic review on the barriers and facilitators to physical activity in informal / unpaid carers worldwide

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Citation

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Review question

What are the barriers and facilitators to physical activity in unpaid / informal carers worldwide?

Searches

The search will include both quantitative and qualitative studies. There will be no restrictions on study design or date. Language will be limited to English only. The search strategy will be created by an expert in systematic review searching, in collaboration with the authors. A draft PubMed search is shown in the table below. Once this strategy is finalised, it will be adapted to the syntax and subject headings of the other databases.

Draft PubMed search:

Key words:

('Carer' OR 'caregiver' OR 'family member' OR 'informal carer') AND ('physical activity')

Syntax:

(carer[Title/Abstract] OR caregiver[Title/Abstract] OR family member[Title/Abstract] OR informal carer[Title/Abstract]) AND (physical activity[Title/Abstract])

The following electronic databases will be searched:

1. PubMed

2. SPORTDiscus

3. PsycINFO

4. CINAHL

Additionally, grey literature will be searched in OpenGrey, Google and Google Scholar. The search term "physical activity of carers" 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.

Types of study to be included

Articles and reports related to the topic of physical activity of carers 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 and based on carers outside of the UK. No date restrictions will be applied.

Condition or domain being studied

This review will focus on informal (unpaid carers). The New Policy Institute states that "Informal carers provide care on an unpaid basis, often to family members… Formal care, in contrast, is provided in return for payment" [1]. However, although frequently used, there are objections to the term 'informal carers' as "the caring service provided by 'informal' carers is formal in everything but the receipt of pay, and many carers feel that they have had little choice in taking on their role" (p. 1) and so the term 'unpaid carer' is often used instead [2]. This review will utilise both the terms 'informal' and 'unpaid' carer and will include anyone "who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid" [3].

Participants/population

Participants

Eligible participants include:

i) Carers for individuals suffering from any condition requiring care

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 must be based outside of the UK

Intervention(s), exposure(s)

Interventions

Correlates of physical activity - all physical activity (both outside of their caring role and/or carried out as part of their caring role) will be included.

Comparator(s)/control

Not applicable

Main outcome(s)

The primary outcomes of interest are the barriers and facilitators to physical activity in unpaid / informal carers for individuals with any condition requiring care. To be included in the review, records will be required to report at least one of the following outcome measures:

1. Carers' perception of barriers to them taking part in physical activity

2. Carers' perception of facilitators to them taking part in physical activity

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)

The primary outcomes of interest relate to the perceived barriers and facilitators to taking part in physical activity by unpaid carers outside of the UK. It is expected that outcomes will be diverse and context-specific, therefore it is not possible to produce an exhaustive list at the outset. However, examples of primary

outcomes may include:

• Perceived barriers to physical activity stated / selected by unpaid carers (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)

• Perceived facilitators to physical activity stated / selected by unpaid carers (e.g. suitable respite care, support from family / friends, health concerns, nearby parks / trails)

Secondary outcomes relate to the levels of barriers and facilitators to physical activity experienced by unpaid carers outside of the UK. Again, these are expected to be context-specific, but secondary outcomes may include:

• Experience of barriers (e.g. percentage of participants who perceive there to be barriers preventing them from undertaking physical activity)

• Availability of support to engage in physical activity (e.g. percentage of participants who have experienced some support to engage in physical activity)

* Measures of effect

Not applicable

Data extraction (selection and coding)
After eliminating the duplicates (studies that are identified more than once by the search engines), 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. A data extraction sheet will be developed which will be tailored to the requirements of the review. The data extraction sheet will be tested on three included papers and, where necessary, it will be revised to ensure it can be reliably interpreted and can capture all relevant data from different study designs. We plan to extract data on the participants, interventions, comparators, and outcomes. In addition to that 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. 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 too, 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. First, 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. In a second step, 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 correlates of physical activity of unpaid carers. This review will highlight the barriers and facilitators to physical activity amongst unpaid 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.

Analysis of subgroups or subsets
Not applicable

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Type and method of review
Narrative synthesis, Systematic review

Anticipated or actual start date
01 April 2020

Anticipated completion date
31 December 2021

Funding sources/sponsors
Not applicable

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; Exercise; Humans

Date of registration in PROSPERO
26 June 2020

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04 May 2020

Stage of review at time of this submission

Stage	Started	Completed
Preliminary searches	Yes	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
26 June 2020