

A systematic review of the Dementia Research in Sri Lanka

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Review question

The aim of this systematic review is to describe dementia research in Sri Lanka. This information will inform on dementia prevalence, person with dementia and caregiver characteristics, and available dementia care models in Sri Lanka. The following specific objectives were developed in order to achieve the main aim of this review 1. To map the published papers on dementia in Sri Lanka into domains of research 2. To extract research specific to caregiving and describe available care models for dementia in Sri Lanka 3. To explore descriptions and definitions of formal and informal caregivers for those with dementia within the Sri Lankan context 4. To describe the tools or instruments of dementia caregiving within the Sri Lankan context 5. Report on current issues and challenges relating to caregiver practice in Sri Lanka.

Searches

This review will be carried out in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Statement.

Databases: The search will be carried out by using the electronic bibliographic data bases (MEDLINE, EMBASE, PsycINFO, AMED and CINAHL) and the Cochrane Library (Cochrane Central Register of Systematic Reviews and Controlled Trials). In order to obtain the locally published articles; the Sri Lanka Journals Online (SLJOL) database will be accessed. Additionally, the grey literature will be searched for manually from the Post Graduate Institute of Medicine (PGIM) library, Sri Lanka.

Search Strategy: Search terms were selected based on consultation with experts from the systematic review team at the Research Institute, review of key terms used in other literature review papers, and examination of the descriptive terms listed under the MeSH term "dementia". A combination of specific keywords consisted of search terms (dement* OR neuro cognitive disorder* OR alzheimer* OR "lewy bod*" OR "vascular cognitive impair*") AND ("sri lanka*" OR Colombo OR Ceylon) were used in the search strategy.

Search dates: Initial search was carried out during 10 - 15th October 2016. The searches will be re-run just before the final analyses to update on new and relevant literature that can be included.

Restrictions: This review includes all the studies published at present that meet the inclusion criteria (dementia studies conducted in Sri Lanka) regardless of the study design, publication status and date of publication. This will enable us to review all the articles in relation to dementia research. It is anticipated, and shown from preliminary searching, that research output is minimal in Sri Lanka. Articles will be excluded if they are on disease conditions other than dementia, studies involving HIV related dementia and acquired immunodeficiency syndrome dementia complex.

Search strategy

http://www.crd.york.ac.uk/PROSPEROFILES/52071_STRATEGY_20161023.pdf

Types of study to be included

There are no restrictions of the study designs to be included.

Condition or domain being studied

All quantitative and qualitative studies conducted in Sri Lanka will be included if they focus on dementia,

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prevalence of dementia, dementia measurement tools/ instruments, dementia care models, or caregiving for people with dementia.

Participants/population

Participants will be people with dementia caregivers and health care workers for people with dementia. Both formal care and informal care settings will be included (family members, friends, neighbours, health care professionals, ect.)

Intervention(s), exposure(s)

The review will include a full range of studies. We will review any article that studied on dementia, caregivers (i.e formal or informal caregivers (family members, friends, neighbours, health care professionals, ect.), care models of dementia and tools or instruments used in dementia research. This will include epidemiological studies to interventions. Based on the search articles will map the studies and then look at possible outcomes from each study category. For example we may look at factors predictive of caregiver burden and stress from the studies on dementia caregivers. However, many systematic reviews on dementia has looked for patient and caregiver characteristics, effectiveness of interventions and factors associated with caregiver burden (chiao et al., 2015). In our review we will also explore how dementia care is provided within a more culturally-specific context within Sri Lanka.

Comparator(s)/control

As this review will encompass caregiving in the broadest sense, comparisons will be made between formal and informal caregiving, differing caregiver models, measures and assessments and the review's findings will be contextualized within current westernized models of care. This review will focus on all the aspects of dementia, care models and caregivers in Sri Lanka, irrespective of their age, gender, training or period of caregiving.

Primary outcome(s)

The primary outcomes of interest are evidence on dementia prevalence, care models, caregiver measures and assessments, and caregiving for dementia in Sri Lankan context.

Timing and effect measures

Caregiving characteristics may include any form of physical or emotional care that is given to the person with dementia (for example, being a guardian, help with activities of daily living (ADLs) and the administration of medications), issues or challenges related to caregiving.

Secondary outcome(s)

The secondary outcomes of interest include the course of the disease, the caregiver characteristics (for example; definitions of caregivers for those with dementia, and how the caregiving role is described within Sri Lankan context) and the measurements used to assess dementia.

Data extraction (selection and coding)

Study Selection: After the literature search has been completed, titles and abstracts will be independently assessed by two reviewers to identify studies that potentially meet the inclusion criteria. Studies that do not meet the inclusion criteria will be excluded and duplicates will be removed. Full texts of the remaining studies will be obtained. The full text articles will be assessed for eligibility by the main reviewer based on the study inclusion criteria. The number of articles remaining after each stage will be recorded. The reason for exclusion will be reported in the review. Each phase will be carried out by the main reviewer (KA) and sub-samples will be cross-checked with a second reviewer for consistency. Any disagreements will be discussed and resolved by consensus or through consultation with a third reviewer. The search results and the number of excluded and included studies will be presented in a flow diagram according to the PRISMA criteria.

Data extraction: Two reviewers will independently extract the data from the included studies. Results will be cross-checked by a second reviewer and entered into a data management spreadsheet. The third reviewer will be used to resolve any disagreements. The extraction form will be used to collect general information (authors, year of publication), participant data (sample size, recruitment procedure, age, gender of the

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participants, response rate, dementia type), data on the study methods (design, study setting, inclusion and exclusion criteria, number and times of follow-up measurements [if applicable]), data on the outcome measure (Data collection tools used in study, caregiver burden measures and number of outcomes), data on the key findings, recommendations and limitations. Quantitative results for descriptive and explanatory studies (odds ratio, confidence intervals, p-value, mean and standard deviation) will be recorded in a data extraction spreadsheet.

Risk of bias (quality) assessment

A critical appraisal tool kit will be used for the quality assessment of the studies. Each checklist includes 7–11 questions, dependent on study design type. Checklists will cover the full range of study designs included within the review (<http://joannabriggs.org/research/critical-appraisal-tools.html>). The searched studies will be categorised according to study design and quality assessment will be performed by the main reviewer, and cross checked by a second reviewer. A third reviewer will be used to resolve any disagreements.

Strategy for data synthesis

The narrative synthesis will include the following phases:

- i) Developing a preliminary synthesis of findings of included studies,
- ii) Exploring relationships within and between studies,
- iii) Assessing the robustness of the synthesis.

The initial descriptive summary of reviewed articles will include a table with information about the author, year of publication, study design, sample size, summary of participant characteristics, dementia type, data collection tools used, outcomes and outcome measures and also an indication of study quality or risk of bias. Then we will categorize the articles in order to map the studies (for example prevalence studies, validating instruments, studies on care models or caregivers). Then it will follow a detailed description of the relationships within and between studies. Idea webbing/ conceptual mapping and visual representation of relationship between study characteristics and results will be used to construct groupings and relationships. For example we will look for dementia as a broader concept and then will look in to care models and the dimensions of caregiving. Care models can be formal or informal. The dimensions of caregiving may include dementia diagnosis/ assessment, impact on patient/ family and caregiver burden. These dimensions will be based on the outcomes of the studies. Based on the specific review objectives a critical discussion to address methodologies of the synthesis will be used and will check the synthesis with authors of primary studies. During the quality appraisal, the quality of the studies will be assessed. For example specific measurements and assessments used for dementia patients and caregivers will be assessed and weighed; giving greater credence to the findings of the most methodologically sound studies according to our quality criteria and the study objectives. This will be made in order to minimize as much as possible the introduction of bias. Data synthesis will also include a discussion section providing information about the robustness and generalizability of the synthesis. It will include details on the limitations of the methodologies used for the synthesis and their potential influence on the results, evidence used and the possible sources of bias and their influence on the results, assumptions made, discrepancies and uncertainties identified, expected changes in evidence and aspects that may have an influence on implementation and effectiveness in real settings. Moreover, authors of primary studies could be consulted in order to test the validity of the interpretations developed during the synthesis and the extent to which they are supported by the primary data. The authors of the primary studies may have useful insights into the possible accuracy and generalizability of the synthesis as well. At the end of the narrative synthesis conclusion and recommendations will be described based on the outcomes.

Analysis of subgroups or subsets

We will include a summary table for any specific research studies that produces outcomes related to caregivers. This may include the caregiver burden, stress, meaning of caregiving, caregiver burden measures and associated factors for caregivers' mental and physical health. Factors for caregiver burden will be grouped by patient and caregiver characteristics.

Contact details for further information

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Conflicts of interest

None known

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English

Country

Sri Lanka

Stage of review

Review_Ongoing

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Subject indexing assigned by CRD

Subject index terms

Dementia; Humans; Research; Sri Lanka

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28 February 2017

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07 March 2017

Revision note for this version

The following two names added to list of authors. 1. Opeyemi Babatunde2. Joanne Jordan

Details of any existing review of the same topic by the same authors

Stage of review at time of this submission

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

Revision note

The following two names added to list of authors. 1. Opeyemi Babatunde2. Joanne Jordan

Versions

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