

Experiences of self-managing progressive neurological conditions in people living in rural and remote communities: a systematic review of qualitative evidence
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Review question

To identify, evaluate and synthesise qualitative evidence that has explored the experiences of people living with neurological conditions in rural and remote areas regarding self-management.

To utilise this data to identify and explore positive and negative experiences relating to self-management of neurological conditions in rural and remote areas.

Searches

Sources to be searched: MEDLINE; CINAHL; PsycINFO; Scopus; Web of Science; EMBASE.

Grey Literature: ProQuest Dissertations and Theses Global; EThOS; British Library; HMIC; NICE; Opengrey

Search Dates: from February - August 2019

Publication period: none

Any Restrictions: English Language only

Search strategy

https://www.crd.york.ac.uk/PROSPEROFILES/122453_STRATEGY_20190117.pdf

Types of study to be included

Inclusion: Qualitative and mixed methods papers which report direct quotes from participants.

Exclusion: Quantitative papers

Condition or domain being studied

The following definition of self-management will be used in this review;

'Self-management refers to the individual's ability to manage the symptoms, treatment, physical and psychological consequences and life style changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one's condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. Thus, a dynamic and continuous process of self-regulation is established (Barlow et al., 2002).

Barlow, J., Wright, C., Sheasby, J., Turner, A., and Hainsworth, J. (2002) Self-management approaches for people with chronic conditions: a review. *Patient Education and Counselling*. 48, 177-187. Available from www.ScienceDirect.com/science/article/pii/S0738399102000320?via%3Dihub [accessed 9 January 2019].

Participants/population

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International prospective register of systematic reviews

Inclusion: Adults (18 years +) who have a diagnosed neurological condition.

Exclusion: Adolescents and children under the age of 18 with or without a diagnosed neurological condition. Studies that focus on informal carers (i.e. family or friends), or health and social care professionals experiences of self-management.

Intervention(s), exposure(s)

Inclusion: Individual self-management practices and behaviours, at any stage of the patient journey, within a home environment.

Exclusion: Studies that focus on the diagnosis or clinical treatment of neurological conditions. Studies that focus on group based or course based self-management programmes.

Comparator(s)/control

None

Context

Inclusion: Studies that draw sample populations from rural or remote locations (in whole or in part) will be included.

Exclusion: Studies that include populations from only urban areas, or where the geographical location of the participants is unclear will be excluded.

Main outcome(s)

A qualitative synthesis of the self-management (as defined by Barlow et al, 2002) experiences of individuals with progressive neurological conditions who reside in rural and remote communities, to explore positive and negative experiences relating to self-management of neurological conditions in rural and remote areas.

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Inclusion: Qualitative and mixed methods papers which report direct quotes from participants.

Exclusion: Quantitative papers

Additional outcome(s)

Not Applicable

Data extraction (selection and coding)

- Removal of duplicates

- Title and abstracts independently checked by two reviewers (KS and DN) according to the inclusion and exclusion criteria

- Those not meeting the eligibility criteria based on title or abstract screening will be excluded.

- Potentially eligible articles will be read in full and reviewed independently against the inclusion/exclusion criteria by two reviewers (KS and DN)
- Those not meeting the criteria after full text assessment will be excluded.
- If the two reviewers cannot reach an agreement, they will discuss the paper in an attempt to reach a consensus.
- Any further discrepancies will be resolved with the assistance of a third reviewer (TG or MR).
- Data will then be extracted from the included studies using a standardised form. Test of standardisation form has been completed. Criteria for extraction will include:
 - o Author name
 - o Year published
 - o Country where the research is conducted
 - o Population description (age, gender, neurological condition)
 - o Aims, objectives and research question(s)
 - o Method of data collection and analysis
 - o Method of recruitment
 - o Sample size
 - o Study setting
 - o Rural or remote location definition as reported by the authors
 - o Self-management definition as reported by the authors
 - o Types of self-management practice discussed
 - o Positive experiences relating to self-management (to include direct participant quotes and authors' analysis)
 - o Negative experiences relating to self-management (to include direct participant quotes and authors' analysis)

o Authors limitations

o Authors conclusions

Risk of bias (quality) assessment

The CASP Qualitative Checklist will be utilised to assess the risk of bias in the included articles. It should be noted that quality will not be a means of exclusion instead a discussion on the quality of the articles will be included in the final review. Quality assessment will be performed by two reviewers independently with discrepancies being resolved by a third reviewer.

Strategy for data synthesis

A narrative synthesis of the included papers will be produced. Additionally, a thematic analysis of primary qualitative findings in relation to the experiences (positive and negative) of people living with neurological conditions in rural and remote areas regarding self-management will be reported in the review. The primary data (participant quotations) will be extracted and imported into the qualitative software package NVivo and will be coded and organised into related areas. Next, these codes will be developed to generate descriptive themes. Lastly, analytical themes will be developed and discussed by 2-3 reviewers to reach consensus.

Analysis of subgroups or subsets

None Planned

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Organisational affiliation of the review

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Anticipated or actual start date

04 February 2019

Anticipated completion date

31 October 2019

Funding sources/sponsors

None

Conflicts of interest

Language

English

Country

England

Stage of review

Review_Ongoing

Subject index terms status

Subject indexing assigned by CRD

PROSPERO
International prospective register of systematic reviews**Subject index terms**

Humans; Nervous System Diseases; Rural Health Services; Rural Population

Date of registration in PROSPERO

06 February 2019

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

Versions

06 February 2019

PROSPERO

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