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Views of key stakeholders on deprescribing preventive medication in people living with dementia: a qualitative systematic review protocol

Clare Bates ,[1,2] Nikolaos Efstathiou ,[1] Claire Sutton,[1] Nesrein Hamed,[3] Ian Maidment [3]

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[1]School of Nursing and Midwifery, University of Birmingham, Birmingham, UK
[2]ENRICH, West Midlands RRDN, NIHR, Birmingham, UK
[3]Pharmacy, Aston University, Birmingham, UK

Correspondence to
Mrs Clare Bates;
clare.bates@nihr.ac.uk

ABSTRACT

Introduction As people get older, they tend to take more preventive medication such as statins, beta-blockers and anti-coagulants to help prolong their lives. The risks of taking medication can start to outweigh the benefits in older people, and whether those with comorbidities want to extend these years of poor health is another consideration. One-third of older people will develop dementia, and they may not have the mental capacity to decide whether to continue or withdraw preventive medication. In these cases, deprescribing is left to advocates, such as healthcare professionals and family members. This systematic review will look at the views of stakeholders, including advocates, people living with dementia and any other people involved in the decision-making process for deprescribing preventive medication in dementia.

Methods and analysis A systematic review of qualitative evidence using thematic synthesis and an inductive approach will be conducted. The following databases and platforms will be searched: Embase, HMIC, MEDLINE, PsycINFO, CINAHL, PubMed, Cochrane Central Library, OATD, ProQuest, Scopus and the Web of Science, along with manual searches through citation mining and grey literature. Only primary qualitative studies (or the qualitative elements of mixed method studies) will be used. There will be no date limit, and the search will be completed by April 2025. Only English-language articles will be used. The included studies will present views and experiences about deprescribing specifically preventive medication in dementia cases. Principles identified by Cochrane for qualitative studies will be used as guidance. Covidence will facilitate two independent reviewers to identify relevant studies, and the Critical Appraisal Skills Programme and Mixed Methods Appraisal Tool will be used to assess quality. NVivo will be used to manage the extracted findings from the included studies.

Ethics and dissemination Ethical approval is not applicable for this study as no original data is going to be collected as it is a systematic review. The findings will be disseminated in a peer-reviewed open-access publication and at conference presentations.

PROSPERO registration number CRD42023476394. Any changes made to the protocol will be reported on PROSPERO.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ The study will be reported using Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines, alongside the ENTREQ (Enhancing transparency in reporting the synthesis of qualitative research) statement and Cochrane guidance will be used to conduct the review.
⇒ Only English language articles will be used.
⇒ Although all reasonable efforts to find all relevant qualitative articles will be made, there is a possibility that articles will be missed.
⇒ The ability to generalise the findings will be dependent on the quality and quantity of the studies found.

INTRODUCTION

One in three people who reach the age of 65 will have dementia when they die,[1] and most of these people will still be taking preventive medication.[2] For this review, preventive medication will be defined as medication given with the intention of prolonging life. 92% of people with dementia have comorbidities,[3] and 82% of people when first diagnosed with dementia are already taking three or more medications for other illnesses.[4] Paradoxically, medications given to older people to prolong their lives can often reduce their quality of life.[5] So, medication decisions in this group of people are extremely complex with the added complication of mental capacity for those with dementia.

Not everyone with dementia lacks mental capacity (the ability to make decisions), as each individual needs to be assessed at the time and for each specific decision.[6] However, Lui *et al*'s[7] study shows that decision-making abilities regarding medications are generally impaired before someone is even diagnosed with dementia. Due to the complexity of making decisions regarding deprescribing in people with dementia, this means that people may continue to take preventive medication

when they may not have wished to.[8] Welie and ten Have[9] argue that for any medical intervention, particularly towards the end of life, 'ethically, the default position is *not* to treat. It is the initiation or continuation of medical interventions that must be ethically justified (p. 7)'. But the continued re-prescribing of medication appears to be the norm.[10] Under the Mental Capacity Act,[6] everyone has the right to refuse treatment—unless they have impaired mental capacity. So, when someone might want to discontinue their life-prolonging medication (ie, in advanced dementia), they will no longer be mentally able to make that decision or have the legal right to.

General practitioners (GPs), nurses, pharmacists and family members are left to make decisions about medication choices for people at the various stages of dementia. The research shows that these advocates feel uncomfortable making these decisions, especially in deprescribing medicine.[11 12] In a care home setting, it is the nurse who is daily accountable for giving medication to people with dementia,[13] in a home setting, it may be carers or family members who take responsibility.[14] The GP is usually the person who makes overall deprescribing decisions, with the advice of the pharmacist, often during medication reviews, but these may not happen often, sometimes as infrequently as once a year.[15–17]

Deprescribing is an emerging field in healthcare, with related research increasing at an exponential rate. The definition of deprescribing is the withdrawal of a medication by a health professional to improve patient health outcomes.[18] The term 'deprescribing' was first used in 2003, and until 2014, only 89 studies had ever been published that used this term.[18] The number of studies has grown dramatically; in 2024, in the Embase database alone, there were over 2600 articles containing the keyword 'deprescribing'. The concept of deprescribing has become more familiar within healthcare, and the infrastructure (such as guidelines and tools) has been developed to support the process.[19]

Most of the research around deprescribing is in situations of polypharmacy (the taking of more than five medicines[20]) or in the use of potentially inappropriate medications in older people.[21] The evidence for the safety of giving medication to older people and the frail population is weak, as most drug trials are done on younger and healthier people.[22] Polypharmacy can cause iatrogenic harm to older people,[23] and in the USA, polypharmacy is one of the main 10 causes of death.[24] In the UK, 16.5% of hospital admissions are due to adverse drug reactions.[25 26] As the body ages, physiological changes may occur, such as reduced liver and kidney function, and this affects the pharmacokinetics and pharmacodynamics of medications, causing harm to older people.[27]

This will be the first systematic review exploring the views of stakeholders for deprescribing preventive medication in dementia. There have been systematic reviews about deprescribing in life-limiting conditions (defined as having less than 1 year to live). Although these might include people living with dementia, they have not looked at dementia specifically.[28–30] There was a narrative review about dementia and deprescribing published in 2015,[8] but as deprescribing has evolved over the past 9 years, our review will add to that body of knowledge. Also, we will look specifically at deprescribing preventive medication as opposed to symptom-controlling medication.

Views and opinions on deprescribing at the different stages of dementia may be very different.[31] For example, there may be a reluctance to deprescribe medication when someone is showing early signs of dementia, whereas, for someone who has had severe dementia for many years and is completely bedridden and unable to recognise family, deprescribing may be seen as more acceptable.[32] Timeframes are useful in deprescribing; for instance, in palliative care for oncology patients, discontinuing preventive medication at the point when the cancer can no longer be controlled, when they are classed as dying, is a normal event.[33] However, although dementia is a life-limiting disease requiring palliative care, there is not a specific point when someone would be classed as dying, at least not until their final days or weeks, and therefore, deprescribing may get overlooked.[31]

This systematic review aims to retrieve, appraise and synthesise the qualitative evidence from qualitative and mixed methods studies to answer the question: what are the views and experiences of key stakeholders on deprescribing preventive medication in people living with dementia?

Further objectives would be to explore what the stakeholders' views are on:

1. The differences in views for deprescribing in mild, moderate or severe dementia.
2. Is there a difference in viewpoints depending on where the study is based (ie, home, care home, hospice or hospital)?
3. Is there a difference in viewpoints depending on the type of healthcare professional or the type of family member or the person living with dementia?
4. Are there differences in views depending on the country the study was conducted in?

METHODS

This will be a qualitative systematic review using thematic synthesis and an inductive approach. The principles for systematic reviews of qualitative evidence provided by Cochrane[34] will be used to conduct the review. The number of studies identified in the systematically searched databases will be reported on a flow diagram using Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA),[35] to demonstrate how the relevant studies were narrowed down to the final included studies. Covidence, a web-based screening references tool, will be used to screen the studies using clear inclusion and exclusion criteria. The final included studies will be appraised using CASP (Critical Appraisal Skills Programme) or MMAT (Mixed Methods Appraisal Tool) and NVivo will be used to extract relevant findings. To ensure the qualitative

Table 1 Search strategy for the Embase database on Ovid

#	Embase on Ovid platform
1	exp dementia/
2	(aging or ageing).ti,ab,kf,hw.
3	aged.ti,ab,kf,hw.
4	('care home' or "'long-term care' or 'long-term care').ti,ab,kf,hw.
5	'nursing home'.ti,ab,kf,hw.
6	('residential home' or "assisted living").ti,ab,kf,hw.
7	'mental capacity'.ti,ab,kf,hw.
8	'mental deteriorat*'.ti,ab,kf,hw.
9	cognit*.ti,ab,kf,hw.
10	elderly.ti,ab,kf,hw.
11	older.ti, ab,kf, hw.
12	veteran.ti,ab,kf,hw.
13	alzheimer*.ti,ab,kf,hw.
14	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13
15	exp deprescription/
16	deprescri*.ti,ab,kf,hw.
17	de-prescri*.ti,ab,kf,hw.
18	"withdraw medic*".ti,ab,kf,hw.
19	'discontinue medic*'.ti,ab,kf,hw.
20	'stop medic*'.ti,ab,kf,hw.
21	15 or 16 or 17 or 18 or 19 or 20
22	exp personal experience.
23	thought.ti,ab,kf,hw.
24	perspective.ti,ab,kf,hw.
25	opinion.ti,ab,kf,hw.
26	view.ti,ab,kf,hw.
27	exp experience/
28	(qualitative or attitude or barrier).ti,ab,kf,hw.
29	22 or 23 or 24 or 25 or 26 or 27 or 28
30	stakeholder.ti,ab,kf,hw.
31	(GP or 'physician assistant' or 'physician associate').ti,ab,kf,hw.
32	("general practitioner" or 'primary care provider' or pcp).ti,ab,kf,hw.
33	exp doctor/
34	exp nurse/
35	exp pharmacist/
36	('nurse practitioner" or prescriber).ti,ab,kf,hw.
37	'health care professional'.ti,ab,kf,hw.
38	'social care professional'.ti,ab,kf,hw.
39	person.ti,ab,kf,hw.
40	people.ti,ab,kf,hw.
41	(family or carer).ti,ab,kf,hw.
42	exp caregiver/
43	exp proxy/
44	advocate.ti,ab,kf,hw.
45	30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44
46	14 and 21 and 29 and 45

synthesis methods are reported clearly, the ENTREQ (Enhancing transparency in reporting the synthesis of qualitative research) statement[36] will also be used. The PRISMA Protocols[37] checklist has been used to write this protocol (see online supplemental information 1). The review will commence in March 2025 and be completed in July 2025.

Search strategy

The 'PICO' (Population-Issue-Context-Outcome) key term identification tool for qualitative evidence will be used to find all the search terms that will be used in the searches in the different databases (see online supplemental informations 2 and 3).[38 39]

Stage A1: To achieve a comprehensive search of the available literature across a variety of professions and specialisms, the following electronic bibliographic databases will be searched: Embase, HMIC, MEDLINE, PsycINFO (all four on the Ovid platform), CINAHL on EBSCO and PubMed. The platforms ProQuest (ProQuest and ProQuest Central), Web of Science, OATD (Open Access Theses and Dissertations) and the Cochrane Central Library will also be searched. An experienced medical librarian will review the search terms and choice of databases. Table 1 is an example of the search strategy to be used. The search strategy will be modified for each database to ensure the search is not too broad or too narrow, and each database search will be reported separately in the systematic review.

Stage A2: From the final selected papers for inclusion, the references cited will be checked for relevance (using the same inclusion and exclusion criteria), as well as studies that have cited them (citation mining). Scopus and Web of Science will be used to assist with this. Any closely related systematic or narrative reviews will have their reference list checked also.

Stage A3: OATD and ProQuest will be used to identify suitable theses and dissertations. Deprescribing networks' and dementia organisations' websites will be explored for any further studies. Conference material from the Alzheimer's Association International and the International Conference on Deprescribing will be checked to ensure there are no relevant primary studies outside our searched databases. Grey literature will be sourced using OpenGrey (now DANS (Data Archiving and Networked Services) EASY archive) and the National Grey Literature Collection (allcatsrgrey.org.uk) funded by Health Education England. The first 200 hits on Google Scholar

will also be searched as a minimum and continue until 10 consecutive irrelevant results are found. There is no precedent set in the literature about how extensive to search Google Scholar, so this technique will be used and amended if it is thought more useful studies can be unearthed by continuing.

The search strategy will be applied by the first reviewer (CB), who will discuss progress and any issues with the wider team, including the medical librarian. This should reduce bias and error, improving the quality and transparency of the review.[40]

Eligibility criteria

The following inclusion and exclusion criteria have been developed. There will be no date restriction as there was minimal research involving deprescribing prior to 2014, but only English language studies will be included.

Primary qualitative studies and the qualitative element of any mixed methods studies will be used. Quantitative studies and audit/service evaluations will be excluded unless they report qualitative insights. Theses and dissertations will be used if they provide relevant primary research findings. Systematic reviews, conference material, protocols, books, editorials and opinion pieces will be excluded.

Population

The population is very broad and aims to encompass views of any person who is involved in decision-making of deprescribing in dementia, including those with dementia, as well as the main key stakeholders.

Issue

Studies that explore the concept of deprescribing in dementia will be included. Studies that look at deprescribing one specific preventive medication or medication type will also be included, unless that specific medication is used only for symptoms (eg, pain relief or medication for the behavioural and psychological symptoms of dementia).

Context and outcome

Only studies that clearly define that the views (outcome) are about people with dementia (context) will be included. It will not include studies where it is not clear whether the views are about people with dementia (eg, studies about older people or people living in care homes may involve people with dementia, but if the findings do not clearly state which views are regarding people with dementia, then they will be excluded).

Selection process

Stage B1: The articles found in the database searches will be exported to Covidence. Covidence will be used to assist in the screening and selection process so that all reviewers can easily access the retrieved articles. It will also help in tracking reasons for exclusion and any discussions between reviewers so that the selection process is clear and traceable. Covidence will also be used to exclude duplicate articles.

Stage B2: Two reviewers (CB, NH) will independently screen titles and abstracts to remove any articles that do not meet eligibility criteria. If there is any disagreement on which articles are suitable to go through to the next stage, following discussion, an independent third reviewer (IM) will act as arbitrator, and if there is still any doubt, the papers will go through to the next stage.

Stage B3: Two reviewers (CB, NH) will then read all the remaining articles (including any articles found through any other means, eg, citation mining). They will read them independently, in full text and decide whether they meet eligibility criteria. They will meet with the third reviewer to discuss the final selection, and if there are any disagreements, the third reviewer (IM) will act as arbitrator.

Critical appraisal tool for assessment of quality

The CASP[41] qualitative studies checklist will be used to critique the qualitative studies, as this is a well-recognised tool and therefore readers of the review will be able to make comparisons with other reviews.[42] The MMAT[43] checklist will be used to critique any other studies, due to its multifunctionality.

One reviewer (CB) will appraise all studies, and a second reviewer (NH) will review at least 20% of studies (and a minimum of five studies) independently. When consensus is reached on how to use both quality appraisal tools, the first reviewer will continue to appraise all other included studies. This method will ensure a consistent approach. Studies of poorer quality will not be excluded, but their findings will have a lower weighting in the synthesis stage. A third reviewer (IM) will again participate if there are any differences between the first and second reviewers' opinions.

Data extraction

The following data will be reported at this stage on an Excel spreadsheet:

- Author/s
- Date of publication and date when the study was conducted (if different)
- Country and setting
- Professions or specialist areas of the authors
- Population interviewed/surveyed (which healthcare professional or type of family member)
- Number of participants
- Aims and objectives of the study
- Methods (including sampling strategy, data collection and analysis)
- Summarised CASP or MMAT findings
- Summarised findings from the study (main themes)
- Other notes

Initially, three papers will be pilot tested to ensure no amendments need to be made to the above variables.

Strategy for synthesis

As the aim of the review question is to get a broad understanding of people's views on deprescribing, an inductive approach will be used rather than having fixed, preconceived ideas of what will be found.[44] Thomas and Harden's[45] 'thematic synthesis' approach will be used and NVivo software will manage the results from each study, while coding and developing themes, keeping an audit trail to ensure a rigorous process.[46]

Stage C1: The first reviewer (CB) will read and re-read all the study's findings to get a broad understanding of the subject.

Stage C2: Coding will be performed by the first reviewer (CB) who will 'line-by-line' code the first two studies' findings. Each piece of data extract will be given one or more codes and given equal importance. This will be repeated independently by a second reviewer (NH). Any text in the findings that is neither first-order interpretations (participants' views) nor second-order interpretations (authors' views) will not be used. The two reviewers will then discuss their initial coding with the third reviewer (IM) to ensure the robustness of the approach used by the first reviewer. When consensus is reached, the first reviewer will then go on to code the other studies, meeting regularly to discuss coding development and any issues arising.

Each piece of data extracted will retain information about the country the study was undertaken in, what year and whose viewpoint it is (eg, spouse, carer, pharmacist). If it is clear, it will also show whether it is the viewpoint about deprescribing in someone with mild, moderate or severe dementia. This link to the 'thick' description will ensure that the context in which the view was made is captured.[47]

Stage C3: Initially, descriptive themes will be recognised in coding along with patterns. From the descriptive themes, links will be made between the themes to help answer the review question. A thematic tree or map will be drawn to clarify how themes connect.

Stage C4: Themes will be reassessed and continue to be refined until no new information or ideas are being developed. All data extracts will be re-read during this time.

Stage C5: Third-order interpretations or analytical themes[45] will then be made first by the first reviewer and then discussed with the second reviewer. Questions developed by Braun and Clarke[48] (p. 94) for analysis of primary qualitative studies can assist with developing a deeper knowledge of the data, creating arguments and ideas, understanding meanings and their implications, to answer the review question. Thomas and Harden[45] describe this stage as where the reviewers 'go beyond': making abstract inferences.

Stage C6: The third reviewer (IM) will then independently ensure that the third-order interpretations are valid and derive fully from the original studies. All the review team will come together to consider the weighting of the themes and based on this, the weighting of the third-order interpretations that are based on those themes. This will be done using the information from the Excel database, looking at the CASP or MMAT findings, the number of studies that reported the same theme and the number of participants in those studies. For example, a theme that was found in only two small studies that were deemed of poorer quality would have less weighting than a theme that was seen in many of the larger studies that were considered good quality. This will be discussed between the review team until a consensus is reached.

Reflexivity

To ensure transparency throughout the review process, the first reviewer (CB) will keep a reflexivity journal. Most important will be the reporting of any personal opinions or biases which might affect how the systematic review is performed. At the beginning of each meeting, with the other reviewers, they will discuss any relevant issues. Likewise, this will also be the time when the other reviewers can discuss any personal influences or any other biases affecting the review.[49]

The author has conducted informal PPI (Patient and Public Involvement) with over 100 people and two sessions at a formal practitioner advisory group with 12 care home staff to get their opinion on this topic. The formal group has said this subject needs to be explored further, but acknowledge it is a sensitive issue that is highly complex. There was complete consensus on both these points. This group, when available, will continue to advise on the interpretations made in the systematic review.

DISCUSSION

The topic of 'deprescribing in dementia' is likely to affect many people at some point in their lives. If one in three people develop dementia over the age of 65, then even if someone does not get dementia themselves, it is likely that they will have been an advocate for their parents or partner.

This review will only explore qualitative evidence: this means that the findings from the completed review will not provide a solution about deprescribing preventive medicine for people with dementia, but it will provide an insight into its complex components.[42] However, without knowing the full complexities of problems, we cannot solve them or find the solutions to successful deprescribing in dementia.[19]

The thematic synthesis approach for systematic reviews will be used as it is suitable for inductive research and is also a transparent approach. It allows for 'thin' or 'thick' data and so we can blend whatever is found.[34] Whether third-order interpretations can be made will only be known when doing the review. In some reviews, this is not always possible, and a comprehensive summary of the descriptive themes will in itself be satisfactory.[45]

Ethical approval is not required for this review as no original data will be collected. The details from the database searches and the coding and analysis process will be available by contacting the author. The findings will

be disseminated in a peer-reviewed open-access publication and presented at both a national and international conference.

With a growing population of people with dementia,[50] it is important that we are making the correct choices regarding their medication. This systematic literature review will build a foundation about the beliefs of the stakeholders regarding deprescribing in dementia on which further research can develop.

X Clare Bates @clarebates74, Nikolaos Efstathiou @NikolaosEfstat2 and Ian Maidment @maidment_dr

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Patient and public involvement Patients and/or the public were involved in the design, conduct, reporting or dissemination plans of this research. Refer to the Methods section for further details.

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ORCID iDs
Clare Bates http://orcid.org/0009-0004-1439-313X
Nikolaos Efstathiou http://orcid.org/0000-0001-5811-8982
Ian Maidment http://orcid.org/0000-0003-4152-9704

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