BMJ Open

Sex-, gender- and ethnically-sensitive aspects of psychosocial interventions for people living with dementia and BPSD: A protocol for a participatory umbrella review

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To cite: Yigit G, Michel E, Rommerskirch-Manietta M, *et al*. Sex-, gender- and ethnically-sensitive aspects of psychosocial interventions for people living with dementia and BPSD: A protocol for a participatory umbrella review. *BMJ Open* 2026;**16**:e114162. doi:10.1136/bmjopen-2025-114162

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (https://doi.org/10.1136/bmjopen-2025-114162).

Received 19 November 2025
Accepted 27 March 2026

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ABSTRACT

Introduction Behavioural and psychological symptoms of dementia (BPSD) affect up to 80% of people with dementia and pose significant challenges in the context of care. Psychosocial interventions have been recommended as first-line strategies, but the roles of aspects of sex, gender and ethnicity in this context remain underexplored. This umbrella review, which will be conducted as part of the GenderDem project, aims to synthesise existing reviews on psychosocial interventions for BPSD and to investigate the potential sex-, gender- and ethnicity-sensitive differences among them.

Methods and analysis Our GenderDem project follows the methodology of the James Lind Alliance for Priority Setting Partnerships. As part of this approach, this participatory umbrella review actively involves people living with dementia, their caregivers and/or loved ones and healthcare professionals in examining the existing review literature.

Different types of reviews on this topic will be identified by reference to the databases MEDLINE (via PubMed), CINAHL (via EBSCO) and PsycInfo (via Ovid) databases. Two reviewers will independently screen titles, abstracts and full texts using Rayyan. Data will be extracted in line with the Criteria for Reporting the Development and Evaluation of Complex Interventions in healthcare: revised reporting guidelines, supplemented with items pertaining to gender, sex and ethnicity. The results will be summarised descriptively, and relevant intervention types (including whether sex/gender/ethnicity has been taken into consideration), the characteristics of the study populations, outcomes and research gaps will be highlighted.

Ethics and dissemination Ethical approval is not required, as this umbrella review will include only data from published studies. The findings of this review will be disseminated through a publication in a peer-reviewed journal and conference presentations.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This umbrella review analyses psychosocial interventions related to under-represented aspects such as sex, gender and ethnicity, which have rarely been considered through an intersectional lens in dementia care studies.
- ⇒ By including all types of reviews on psychosocial interventions for behavioural and psychological symptoms of dementia, the collected evidence is synthesised at a high level, thereby providing a comprehensive overview of current knowledge.
- ⇒ Sex, gender and ethnicity are under-represented. Therefore, we anticipated that most reviews focus only on one aspect rather than on the intersection of sex, gender and ethnicity, thus limiting the extent to which conclusions can be drawn on the basis of such studies.

INTRODUCTION

The number of people living with dementia worldwide is projected to increase from 44 million in 2013 to 135 million by 2050.[1] In Germany, the number is expected to increase to between 1.65 million and 2 million by 2033, posing significant challenges to the healthcare system because of the high costs associated with dementia care.[2 3] Symptoms associated with dementia, including apathy, depression and anxiety, which are collectively known as behavioural and psychological symptoms of dementia (BPSD), can negatively affect the health and quality of life of people living with dementia and present significant challenges in their care.[4 5] Approximately 80% of people living with dementia are affected by BPSD, although the manifestations of these symptoms vary greatly among individuals and over the course of the disease.[6]

With respect to the roles of sex, gender and ethnicity in the manifestations and treatment of BPSD among people living with dementia, women are more often diagnosed as paranoid or with delusional thoughts, hallucinations, affective and anxiety disorders or phobias, whereas men tend to show higher levels of aggression and disruptions in circadian rhythm.[7 8]

Furthermore, ethnicity appears to be a factor that influences the treatment of BPSD. For example, the ethnic background of people living with dementia can affect whether BPSD are recognised.[9] Considering the results of the systematic review conducted by Shaw *et al*,[10] one reason for this situation could be that ethnic minority groups in general are under-represented in clinical trials on neurodegenerative diseases and that there is little awareness and knowledge of specific ethnically sensitive approaches among healthcare professionals and researchers.

Accordingly, there appear to be differences in the perception and treatment of BPSD depending on sex, gender and ethnicity. However, the combined effects of these factors are still under-represented in dementia research, although initial evidence suggests that the effectiveness of treatment may depend on the sex, gender and ethnic background of the person living with dementia.[11–14]

With respect to the treatment of dementia-related symptoms, psychosocial interventions are considered the 'gold standard'. Psychosocial interventions (such as reminiscence) aim to enhance emotional and psychological well-being, support cognitive function, reduce behavioural symptoms and improve everyday functioning and quality of life. Psychosocial interventions are rarely provided in isolation and are typically delivered alongside other measures designed to address the evolving needs of the person.[15 16] These interventions are usually developed in an interdisciplinary manner, with comprehensive assessment and a needs-based approach being essential. In both development and implementation, caregivers and/or loved ones as well as healthcare professionals are involved. However, they may appear to uphold gender stereotypes (eg, knitting or flower arranging for women and sports reminiscence groups for men) and are often grounded in a Western theoretical understanding of person-centred care.[17–20]

To date, evidence of the effectiveness of these interventions seems to be one of the focal points of research on this topic, and therefore, it is not surprising that many systematic reviews on the effectiveness of psychosocial interventions for BPSD exist.[21–24] However, the sensitivity of these interventions to sex, gender and ethnicity remains underexplored. Taking this gap into account, an umbrella review could provide an opportunity to take an innovative look at a very well-researched topic through new lenses. This provides the opportunity to rethink aspects that until recently have not been systematically considered in psychosocial interventions for addressing the BPSD of people living with dementia.[25] We deem an umbrella review as a suitable method for our purpose, as it presents and compares the evidence across different interventions. At the same time, an umbrella review provides a comprehensive picture of the strengths and weaknesses of the evidence for each intervention. In addition, it allows the identification of gaps in a specific research field.[26]

The planned participatory umbrella review will be conducted as part of our GenderDem project, which focuses on psychosocial interventions that address BPSD in a sex-, gender- and ethnicity-sensitive manner. We strive for an overall intersectional approach that regards diversity across different dimensions simultaneously.[27] The overall aim of the project is to identify the top 10 research priorities in this field for future dementia care research, following the methodology of the James Lind Alliance (JLA) for Priority Setting Partnerships (PSP).[28]

The aim of our planned participatory umbrella review is to work together with people living with dementia, their caregivers and/or loved ones and healthcare professionals (e.g., physicians and nurses) to examine the literature, particularly various types of reviews, on psychosocial interventions for the treatment of BPSD in people with dementia, with a focus on the sensitivity of these interventions to sex, gender and ethnicity. This review protocol aims to provide a transparent and reproducible description of the planned methodology for conducting the planned participatory umbrella review.

METHODS AND ANALYSIS

We employ the methodology of the JLA for PSP.[28] In our study, the steering group consists of people living with dementia, their caregivers and/or loved ones and clinicians who act as coresearchers. The steering group collaborates throughout the entire study and makes decisions on procedures on an equal basis.

For our planned participatory umbrella review, starting in December 2025 and scheduled to end in October 2026, we have defined the following preliminary research question, which will be finalised in consultation with the steering group (people living with dementia, their caregivers and/or loved ones and clinicians): *Which sex-, gender- and/or ethnically-sensitive aspects are embedded in psychosocial interventions for addressing BPSD in people living with dementia?* This research question will be discussed with the steering group (e.g., people living with dementia, their caregivers and/or loved ones and healthcare professionals) at the start of the project and adjusted accordingly.

Whenever applicable, we follow the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA-P) guidelines to report this protocol.[29]

PARTICIPATORY APPROACH AND RECRUITMENT OF CORESEARCHERS

To determine the influence of sex-, gender- and/or ethnically-sensitive aspects in psychosocial interventions for people living with dementia and BPSD, we additionally apply a participatory approach based on the DECIDE-SR framework.[30] In this approach, the members of the steering group can choose their individual level of involvement in the various steps of the umbrella review. They decide which research tasks they would like to engage in (e.g., active involvement in the screening of titles and abstracts) and what kind of support they require from researchers (e.g., support in using screening software) at the DZNE (. Depending on the degree of involvement, ranging from receiving to leading, the umbrella review will be planned and conducted collaboratively with the steering group. This participatory approach makes it possible to align the research more closely with the actual needs of people living with dementia. A detailed figure that illustrates the workflow of the DECIDE-SR framework is presented in figure 1.

To ensure a balanced involvement of people living with dementia, caregivers and/or loved ones and healthcare professionals, we will apply several strategies to recruit coresearchers for the steering group. Potential coresearchers for the steering group will be contacted through the patient advisory boards of the DZNE in Witten and Bonn, as well as through existing DZNE networks established in other projects, such as Dementia Leaders.[31] In addition, members of the research team will draw on their personal networks to identify suitable coresearchers. In line with GenderDem's focus on sex, gender and ethnicity, as well as an overall intersectional perspective, recruitment will not only target the three stakeholder groups (people living with dementia, their caregivers and/or loved ones and healthcare professionals) but also seek to include individuals of diverse gender identities, age groups and ethnic minority backgrounds. Our aim is to recruit up to 10 coresearchers, with two representatives from each stakeholder group. To implement the intersectional approach as comprehensively as possible, we will develop a survey that, in addition to the already mentioned characteristics, includes further aspects such as educational status, religion or the scope of professional activity (Michel *et al*, manuscript submitted).

Eligibility criteria

Our planned umbrella review will include all types of reviews that focus on psychosocial interventions for people living with dementia and BPSD. The eligibility criteria, which have been defined to ensure a structured and transparent selection process, are presented in table 1.

In addition to publications in German and English, articles in Turkish are included. Turkey-origin people in Germany represent the largest group of people with a migration history.[32] Since our review team includes native Turkish speakers, we are able to incorporate publications in Turkish. Where necessary, summaries of these articles will be translated into German for the steering group.

Information sources

We will mainly use the MEDLINE (via PubMed), CINAHL (via EBSCO) and PsycInfo (via Ovid) databases. In addition to searching electronic databases, a forward and backward citation tracking search will be conducted via Google Scholar/reference lists to identify further relevant reviews.

Search strategy

A comprehensive search strategy will be applied to identify all relevant reviews on psychosocial interventions for BPSD. The search string was developed by the first author (GY) and reviewed by all other researchers of the research group using the PRESS (Peer Review of Electronic Search Strategies) criteria.[33] The search string will be discussed in a meeting with the steering group, and according to their response, it will be modified. All search strategies will be fully documented to ensure reproducibility. The detailed PubMed search strategy is presented in online supplemental appendix 1.

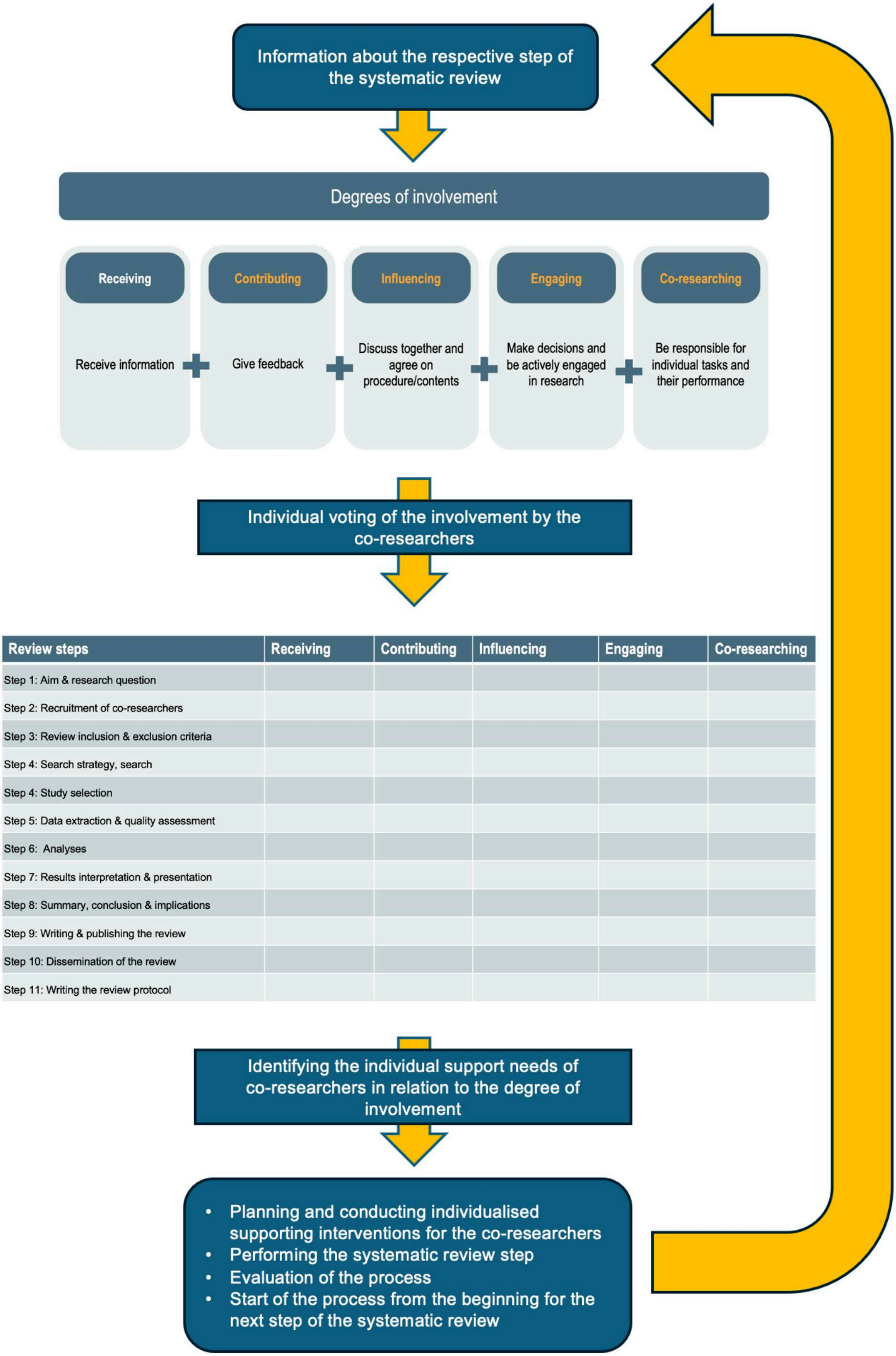
Study selection/screening

As stated above, the exact research questions for this review will be finalised with the steering group to ensure a joint and focused approach to the literature analysis. Literature screening will be conducted by two members of the steering group, each paired with a member of the research team, to form screening tandems.[34] Screening will be facilitated via Rayyan,[35] allowing an independent review and the tracking of inclusion decisions by the two reviewers. The screening process will be performed independently to ensure the transparency and traceability of study selection. Reasons for exclusion at the full-text stage will be recorded. Disagreements will be resolved through discussion between the two reviewers or by consulting a third reviewer if consensus cannot be reached.

Eligibility criteria will first be tested on a subset of 25 records to ensure clarity and consistency between reviewers. If disagreements between the two reviewers exceed the level of 25%, the criteria will be revised accordingly. Any modifications made during the screening process will be documented and reported in future publications. The process of study selection will be illustrated via a PRISMA flowchart.[36]

Data management and extraction

All records identified through the search will be exported to EndNote 2025 reference management software[37] for deduplication and stored in a shared Nextcloud[38] folder. Relevant information from the included reviews and their psychosocial interventions will be extracted via the Criteria for Reporting the Development and Evaluation of Complex Interventions in healthcare: revised reporting guidelines, supplemented with the items sex, gender and ethnicity, to examine potential embedded aspects within the interventions.[39] The extraction will be carried out by the researchers and subsequently presented to the steering group. The primary aim of our umbrella review is not to evaluate the effectiveness of interventions/quality of the reviews themselves but to examine whether and how aspects of sex, gender and/or ethnicity are addressed in the interventions reported in the included reviews. This includes whether these factors are explicitly addressed in the intervention



Review steps	Receiving	Contributing	Influencing	Engaging	Co-researching
Step 1: Aim & research question					
Step 2: Recruitment of co-researchers					
Step 3: Review inclusion & exclusion criteria					
Step 4: Search strategy, search					
Step 4: Study selection					
Step 5: Data extraction & quality assessment					
Step 6: Analyses					
Step 7: Results interpretation & presentation					
Step 8: Summary, conclusion & implications					
Step 9: Writing & publishing the review					
Step 10: Dissemination of the review					
Step 11: Writing the review protocol					

Figure 1 Workflow for implementing the framework for active involvement in systematic reviews.

Table 1 Eligibility criteria

Population	People living with dementia with BPSD
Intervention	Psychosocial interventions (e.g., music, singing and dancing)
Study type	Every type of review (e.g., scoping, integrative and systematic)
Language	Publications in English, Turkish and German
Publication date	No restrictions

BPSD, Behavioural and psychological symptoms of dementia.

design, implementation or analysis, or if they emerge as secondary findings within the reviews.

Analysis and presentation of the results

The extracted data will be presented and described in the form of a table and descriptively based on the research question.[40] The results will also be presented and discussed with the steering group. We expect that there is a substantial body of literature on intervention for BPSD. Our specific focus for the reporting of the outcome lies on explicitly accounting for sex, gender and ethnicity, particularly with regard to their intersection and combined consideration.

ETHICS AND DISSEMINATION

There are no ethical concerns for our umbrella review. However, since we discuss BPSD, it is possible that people living with dementia may feel irritated by the descriptions of these behaviours. In such cases, the issue will be addressed, and support will be provided within the smaller working groups or tandems responsible for selecting and reading the articles.

We will present our results together with the steering group to a variety of stakeholders in Germany and the European Union. Additionally, our results will be presented at (inter)national conferences and published in journals for practitioners and in peer-reviewed journals. Finally, we will address the identified gaps in the current research landscape and incorporate them into possible future projects.

Contributors GY wrote the initial draft of the protocol. EM, KA, SAF, CM, MR-M and MR revised the manuscript. MR-M coordinated this study. MR initiated the study and acted as guarantor. All authors read and approved the final manuscript.

Funding This work is part of the Project GenderDEM funded by the Federal Ministry of Research, Technology and Space (BMFTR) (Grant No. 01GN2510).

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, conduct, reporting or dissemination plans of this research. However, for the upcoming umbrella review, we plan to engage health professionals, their caregivers, and people with dementia.

Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

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