

BMJ Open Quality aspects of dementia care counselling from the perspective of people living with dementia, their care partners and healthcare professionals: protocol for a participatory scoping review

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To cite: Rommerskirch-Manietta M, Fahsold A, Manietta C, *et al.* Quality aspects of dementia care counselling from the perspective of people living with dementia, their care partners and healthcare professionals: protocol for a participatory scoping review. *BMJ Open* 2026;**16**:e123586. doi:10.1136/bmjopen-2026-123586

► 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-2026-123586>).

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Received 02 June 2026
Accepted 08 September 2026



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ABSTRACT

Introduction Care counselling for people living with dementia and their care partners provides essential information about dementia and associated symptoms, the challenges of coping with it, access to dementia healthcare services and guidance through the healthcare system. It can therefore be a key component of successful care in the early stages of dementia. For care counselling to be effective, it seems essential that it meets certain quality aspects. Particularly when it comes to providing care counselling to people living with dementia and their care partners, it is important that these aspects are also defined by the individuals themselves, as only they can define what constitutes the quality of tailored counselling for them. To date, there is no comprehensive and consolidated overview of this topic, and it is therefore unclear what quality aspects are important when care counselling people living with dementia.

Methods and analysis Therefore, we will conduct a participatory scoping review on this topic. For this, we will develop our search string following the PCC mnemonic and we will search in the following databases: MEDLINE (via PubMed), CINAHL (via EBSCO) and PsycInfo (via EBSCO). We will also conduct a backward (via reference lists) and forward (via Google Scholar) citation tracking. For active involvement of people living with dementia, their care partners and healthcare professionals we will use the DECIDE-SR framework and involve co-researchers actively in the beginning, at the end of the scoping review and in a workshop with a broader audience of people living with dementia, their care partners and healthcare professionals.

Ethics and dissemination There are no ethical concerns with conducting a scoping review. We will discuss our results regarding quality aspects of care consulting for people living with dementia and their relatives with a variety of stakeholders in Germany. We will disseminate the results in the form of articles in peer-reviewed and non-peer-reviewed journals as well as international and national conferences.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The review will provide a comprehensive overview of the topic what constitutes the quality of tailored counselling for people living with dementia from different perspectives.
- ⇒ People living with dementia, their care partners and healthcare professionals will be actively involved in the development of the review and the discussion of the results.
- ⇒ In contrast to a grey-shaded scoping review, we will refrain from conducting a comprehensive literature search of grey literature.

INTRODUCTION

Care counselling offers people living with dementia and their care partners a first point of contact for specific health information and support. Particularly during the transition phases following a diagnostic process and—ideally—before the disease progresses, people living with dementia and their families may experience uncertainty regarding, for example, how to cope with the first symptoms of dementia and what support services are available.^{1 2} Within different healthcare systems, official and independent care counselling services provide an overview of the various (local) services available and assist individuals in finding or accessing these services.³ In addition to simply providing knowledge and information, care counselling aims to identify and address the needs and requirements of people living with dementia, support them and their families in meeting them, stabilise their care situation by helping them access tailored services and

guide them through an increasingly complex healthcare system.⁴⁵

To meet these requirements for care counselling, a wide range of professionals work together at care counselling service centres, complementing and enriching each other with their diverse expertise and knowledge—for example, in case management.^{4 6 7} Depending on the national background, this may include, for example, nurses, social workers and psychologists.

To ensure that these services reach people living with dementia and their families, there are a variety of structures for care counselling. For example, there exist outreach services, telephone and digital services, as well as traditional in-person services.^{18–10} This tailoring of care counselling services to the individual needs and person's identity (sex, gender, ethnicity)^{11 12} and the variation of symptoms of their specific disease appears to be a key quality criterion for successful care counselling.^{13 14} In particular, for people living with dementia and its associated symptoms, quality aspects of care counselling appear to be different from those faced by people affected of dementia.¹⁴

To date, there has been no comprehensive overview of quality aspects for specific dementia care counselling from the perspective of people living with dementia, their care partners and healthcare professionals. For this reason, we are planning a scoping review¹⁵ to provide a comprehensive overview of various quality aspects related to care counselling for those various perspectives.

METHODS AND ANALYSIS

Within the scope of our planned scoping review (October 2025–December 2026) in our B-DEM II project, we have developed the following research question:

1. Which aspects of quality are discussed in the literature regarding care counselling from the perspective of people living with dementia, their care partners and healthcare professionals?

For our planned scoping review, we will adopt the framework proposed by Arksey and O'Malley,¹⁶ further refined by Levac *et al*¹⁷ and Peters *et al*¹⁵ and The Joanna Briggs Institute.¹⁸ Accordingly, the review will follow these steps: (1) defining and aligning the objectives and research questions; (2) developing and aligning the inclusion criteria with its objectives and questions; (3) outlining the approach to evidence searching, selection, data extraction and presentation; (4) searching for the evidence; (5) selecting relevant studies; (6) extracting the data; (7) analysing the evidence; (8) presenting the results and (9) summarising the findings in relation to the review's purpose, drawing conclusions and identifying implications.¹⁶

Where applicable, this protocol will be reported in accordance with the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRIS-MA-P) guidelines¹⁹ (see online supplemental table 1).

Table 1 Inclusion and exclusion criteria

Criteria	Definition
Population	▶ People living with symptoms of dementia (with or without a dementia diagnosis) ▶ Care partners of people living with symptoms of dementia (with or without a (medical approved) dementia diagnosis) ▶ Healthcare professionals in the context of dementia care counselling (eg, nurses, social workers)
Concept of Interest	▶ Counselling related to the care of people living with dementia (with or without a dementia diagnosis) ▶ Consulting about care that is not part of or embedded in the nursing process (eg, conducted in dementia service centres)
Context	▶ International
Types of evidence sources	▶ Focus on literature published in peer-reviewed journals ▶ Grey literature in the form of (evaluation) reports, magazine articles and theses
Others	▶ Languages: German or English

We have published a review protocol and a grey-shaded scoping review for our completed B-DEM-I project, which at the time focused on dementia care counselling in accordance with Section 7a Paragraph 11 German Social Law.^{14 20} In line with the publication and commentary by Pieper *et al*,²¹ we reused and rephrased the text from our B-DEM I review protocol and grey-shaded scoping review for the methods section of this publication with ChatGPT and revised it where the actual methodological process in B-DEM II differed from the conducted approach in B-DEM I.

Inclusion criteria

For reporting the inclusion and exclusion criteria of our scoping review, we apply the 'PCC' (Population, Concept of Interest and Context) mnemonic as outlined by The Joanna Briggs Institute,¹⁸ supplemented by the additional categories 'Types of evidence sources' and 'Other' (table 1).

Search strategies and participatory approach

Given the aims of our scoping review, we will search for literature published in peer-reviewed journals that focuses on the analysis and evaluation of quality aspects of dementia care counselling from the perspectives of people living with dementia, their care partners and healthcare professionals (search strategy 1). In addition, we will conduct a search for grey literature following the approach described by Rommerskirch-Manietta *et al*¹⁴ (search strategy 2). Furthermore, a participatory approach will be adopted by actively involving people living with dementia, their care partners and healthcare professionals at both the beginning and the end of the

review to discuss, for example, the research aims, questions and findings.^{22 23}

Strategy 1: search in academic electronic databases

For the search in academic electronic databases, we will use MEDLINE (via PubMed), CINAHL (via EBSCO) and PsycInfo (via EBSCO). The search terms are derived from our research questions and supplemented with additional free-text terms and indexing terms identified through an initial exploratory search. These terms were organised according to the 'PCC' framework and combined into a comprehensive search string. The search string was developed by two reviewers (MR-M and CM) and subsequently peer-reviewed by a third reviewer (MR) using the Peer Review of Electronic Search Strategies guideline.²⁴ It was initially created for MEDLINE (via PubMed) (see online supplemental table 2) and then adapted for CINAHL (via EBSCO) following RefHunter.²⁵

Strategy 2: search in grey literature databases

To identify relevant electronic databases for grey literature, we referred to the descriptions provided by Nordhausen and Hirt.²⁵ Based on this, the following databases will be included: Livivo, GeroLit (via GBV) and SSOAR (via GESIS). For these searches, we will apply simplified versions of the search strings developed for the academic electronic databases (eg, using fewer term combinations and a reduced set of search terms). The specific search strings for each of the three databases are provided in online supplemental table 3. All searches will be conducted by one reviewer (MRM).

Additional citation tracking

For the identified literature through our academic electronic database searches, we will provide a backward and forward citation tracking via reference lists and Google Scholar. For the identified grey literature, we will provide a backward citation tracking via reference lists.

Participatory approach

For the active involvement of people living with dementia, their care partners and healthcare professionals, we collaborated with co-researchers from our practice partners (eg, acute and long-term care setting, care counselling agencies) and the DZNE Witten Co-Research Council (Project *Mitforschen*). To this end, we sent an informational email and additional details to all potential co-researchers and presented the project at a kick-off meeting. As a result, six people (one person living with dementia, two care partners of people living with dementia, one person from the Alzheimer Association, one person from a dementia care counselling agency and one person with the focus on quality management in long-term care setting) have agreed to actively participate in the B-DEM II project as co-researchers.

Three meetings with the co-researchers are planned as part of the project, which will be facilitated by the researcher of the DZNE B-DEM II project group. In the first meeting, the concept of quality in dementia care

counselling was discussed, and each co-researcher determined their level of involvement in the review using the DECIDE-SR framework.^{22 23} All the co-researchers voted that the research objective and review question were to be developed together during the first meeting, and that the review results would be jointly discussed and classified during the second meeting. In a final workshop, to be jointly organised and conducted at the end of the project, the results will be revisited with a broader audience of people living with dementia, their care partners and healthcare professionals and translated into recommendations for key stakeholders (eg, policymakers, counselling service providers and healthcare practitioners).

Source of evidence selection

Records identified through our electronic database searches (strategies 1 and 2) will be imported into Rayyan,²⁶ where duplicates will be automatically removed. Two reviewers will independently screen titles and abstracts against the inclusion criteria. Full-text articles will be assessed independently by both reviewers, with reasons for exclusion documented. Any disagreements between reviewers will be resolved through discussion, or, if necessary, by involving all co-authors to reach consensus. The inclusion criteria will be pilot-tested on the first 25 records and refined if needed. Revisions will be considered if discrepancies between reviewers exceed 25%.²⁷ Any changes made to the inclusion criteria during screening will be transparently reported in subsequent publications. The study selection process will be presented using a PRISMA flowchart.²⁸

Data extraction

For data extraction, we will use The Joanna Briggs Institute¹⁸ template (table 2). One researcher will carry out the data extraction, and a second researcher will perform random checks to ensure accuracy. The process will be iterative, following Joanna Briggs Institute guidance,²⁷ meaning that after every two studies are extracted, the template will be reviewed to confirm that all relevant data

Table 2 Data charting framework

Domains	Description (content)
General information	▶ Author ▶ Year ▶ Publication type (eg, report) ▶ Aim of the publication (eg, evaluation) ▶ Study design (eg, process evaluation)
Participants	▶ Characteristics of the participants (eg, population, age, care arrangement)
Intervention	▶ Dementia care consulting (eg, concept, content, target population, structures and delivery)
Results	▶ Effectiveness (eg, consultation outcomes) ▶ Experiences (eg, of people living with dementia and their care partners)

are captured or to determine whether any modifications are necessary.

Analysis and presentation of the results

To analyse the various aspects of quality in dementia care counselling from the perspective of people living with dementia, their care partners and healthcare professionals as presented in the studies, we will use the RE-AIM framework.²⁹ The RE-AIM framework is divided into the following components: Reach (eg, accessibility, equality and equity of dementia care counselling services), Effectiveness, Adoption (eg, structure and embedding of dementia care counselling services), Implementation (eg, dementia-sensitive adaptations/components of counselling interventions) and Maintenance (eg, duration of counselling, timing of termination and sustainability).^{29,30} In this process, we will use the individual components of the RE-AIM frameworks as deductive categories to categorise the identified quality aspects using MAXQDA 2025.³¹ This analysis process will be conducted by one researcher, and the result will be discussed with all researchers.

The extracted and analysed data will be presented and described in the form of a table and descriptively based on the question.¹⁸

Patient and public involvement

We will actively involve people living with dementia, their care partners and healthcare professionals to discuss our research aims, questions and findings using the DECIDE-SR framework reported above (see 'Participatory approach').^{22,23}

ETHICS AND DISSEMINATION

No ethical concerns are associated with this review. The findings will be disseminated to a range of stakeholders involved in care counselling in Germany. In addition, the results will be presented at national and international conferences and published in both practitioner-oriented and peer-reviewed journals.

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Contributors MR-M and AF wrote the initial draft of the protocol. CM and MR revised the manuscript. All authors read and approved the final manuscript. MR is the guarantor. ChatGPT was used to rephrase sentences in the 'Methods and analysis' section.

Funding This review is part of an activity described in the National German Dementia Strategy 2020. We did not receive any funding, neither from the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth nor from the Federal Ministry of Health.

Competing interests None declared.

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

Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

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