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Intersectional research on dementia care for people from culturally and linguistically diverse backgrounds: a protocol for a scoping review

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ABSTRACT

Introduction The specific preferences that shape the daily lives of people with dementia serve as the basis for the concept of person-centred care. However, information on the complex experiences of culturally and linguistically diverse people with dementia (CALDPwD), which determine their multifaceted preferences, is lacking. Therefore, the objective of this scoping review is to identify the range, extent and nature of evidence available in peer-reviewed and grey literature examining how the multilayered experiences of CALDPwD influence everyday living preferences.

Methods We aim to conduct a scoping review to explore the multilayered experiences of CALDPwD and the intersectional determinants of their everyday living preferences. Using PubMed, MEDLINE (via Ovid for precision and controlled searching), CINAHL (via EBSCO), Scopus and the Cochrane Library, as well as grey literature, we will systematically search for literature in English, German and Turkish without any publication date restrictions. The titles/abstracts and full texts of the identified records will be independently screened by two reviewers. Data extraction will be performed by one researcher and verified by another. All the authors will discuss the conflicts. We will analyse the identified intersectional determinants of preferences using inductive content analysis.

Ethics and dissemination There are no ethical concerns related to conducting this study. We will share our findings with nursing care practitioners. The results will be presented at conferences and disseminated through peer-reviewed articles and practical publications.

Discussion The findings of the study will address the important gaps in knowledge on the complex intersecting factors that influence the preferences of CALDPwD. A key strength of this study is its comprehensive search strategy, which includes multiple databases and citation tracking to capture diverse, intersectional perspectives of CALDPwD. However, excluding the studies focused on caregiver's burden may limit insights into how care systems shape the needs and expectations of this population.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This study uses a systematic approach that integrates an intersectional lens to examine the determinants of everyday living preferences, enhancing the depth and breadth of the scoping review.

⇒ The inclusion criteria involve publications in the English, German and Turkish languages, as well as peer-reviewed and grey literature. This approach aims to enhance the breadth and comprehensiveness of the review.

⇒ Expectations include the identification of the unique everyday-living preferences in respective settings of diverse populations with culturally and linguistically different backgrounds.

⇒ A primary limitation of the planned scoping review is the lack of uniform usage of the term 'preferences' among culturally and linguistically diverse people with dementia, which leads to a broad array of terms and synonyms.

INTRODUCTION

Dementia is one of the top priorities in global health because of the high prevalence of neurodegenerative and neurovascular conditions among the older population.[1] Providing care to culturally and linguistically diverse people living with dementia (CALDPwD) is still a crucial challenge for public health, not only in Germany but also in Europe.[2] In 2020, 1.6 million people were living with dementia in Germany, and these figures are expected to reach 2.8 million by 2050.[3] However, precise numbers of the diverse population experiencing dementia and requiring special care are still lacking.[4] In global reports, despite their widespread dissemination, the lived realities and associated challenges of CALDPwD are either inadequately addressed or not at all addressed.[5] Even when reports specifically focus on dementia care among ethnic minority groups, there remains a lack of coverage and attention given to this critical area.[6] This stresses the urgent need for a more nuanced perspective on promoting awareness through information and education

and incorporating the diverse perspectives of various social groups into reports.[7] The failure to implement this nuanced approach could perpetuate the marginalisation of specific social groups within the realms of nursing and dementia research.

To maintain the well-being of CALDPwD, person-centred care considering their individual needs and preferences becomes important since experiences with dementia vary widely from person to person.[8] This approach has the potential to enhance the overall care of and maintain quality of life for individuals with dementia while promoting a comprehensive, equitable and diverse understanding of healthcare requirements.[9] Person-centred care, which is characterised by responsiveness to individual preferences, needs and values, can significantly impact the well-being and satisfaction of the individual receiving care.[10] For individuals living with dementia, especially considering the diversity of language and/or culture, a sense of connection, familiarity, and fulfillment is connected to the person-centred care, which is significant for an inclusive healthcare system.[9]

Person-centred care serves as a basis for addressing specific preferences that shape the daily lives of people with dementia. According to Van Haitsma *et al*, a stated preference is an expression of the desirability of an option that fulfills a person's needs, aligns with their values and guides behaviors towards achieving goals.[11] Acknowledging and considering personal preferences allows individuals to make decisions in alignment with their own values, promoting autonomy and a sense of control over their lives.

To better represent the diversity among CALDPwD, it is essential to acknowledge and appropriately consider the unique and varied characteristics of each person.[12] To address the complexities within a population subjected to multiple intertwined forces of inequality, intersectionality has emerged as a critical feminist perspective. Intersectionality discourse was introduced by Crenshaw in 1989 to analyse inequities within axes of racism and sexism to understand the experiences of black and indigenous women who were oppressed.[13] The discourse emphasises interconnectedness, focusing on the interplay of constructs such as race, class and gender as interdependent systems of power.[13]

Intersectionality encompasses various aspects, including personality characteristics, life history and sociocultural context, in addition to structural determinants such as race, gender, class, education, citizenship or geographical location.[12 13] This diversity is linked to different needs, especially for people with a history of migration.[14] Different lived experiences also become more nuanced when the perspectives, attitudes and circumstances of the caregivers are taken into account. It is known that family caregivers who assume responsibility for a family member with dementia face high levels of perceived stress and depression, as caregiving tasks can be emotionally and physically demanding tasks.[15] In addition, caregivers who are culturally and linguistically diverse may face additional challenges and stressors compared with those who are not.

Studies of the experiences of people with a migration history living with dementia have focused mostly on the need for culture-specific offers.[16–18] Although these studies are important in making underrepresented groups more visible by highlighting the care needs and wishes of culturally and linguistically diverse groups,[17 18] they tend to overlook the complex experiences of this population, especially the self-expressed experiences of people living with dementia, due to the one-sided focus. Since culture is not homogeneous, it is important to embrace a perspective considering multiple identities of individuals, such as ethnicity, religion, class, gender and education, intersecting with the structural inequalities in the health system.[19–21] The lack of systematic understanding of the nuanced everyday-living preferences of these diverse groups with dementia may hinder the development of comprehensive and inclusive care practices and overall progress in dementia care and support.[22] CALDPwD are confronted with many barriers when accessing healthcare, including different lifestyles, language challenges, certain attitudes and cultural differences or values,[23–26] which often leads to unmet needs and an inadequate quality of care.[27 28] It is clear that neither culturally sensitive medical and nursing care materials nor multilingual information materials have been standardised as of yet.[3] Limited communication options increase the risk of misunderstandings, social isolation and discrimination by nursing staff.[29] Therefore, the complex preferences of CALDPwD should be taken into consideration, along with their multilayered experiences. Incorporating an intersectional perspective places a large emphasis on complex expectations, desires or goals to meet the everyday preferences of diverse populations. Enhancing the integration of this underrepresented group into the healthcare system requires prioritising both the acknowledgment of the preferences of CALDPwD and their caregivers and understanding the multilayered factors influencing these preferences.[7 9 11 22 30] This is essential for ensuring the availability and accessibility of personalised care within healthcare facilities.

Study objectives
The objective of this scoping review on the intersectional determinants of everyday-living preferences is outlined as follows:

▶ To categorise the range, extent and nature of the evidence available in peer-reviewed and grey literature that examines the multilayered experiences of people from culturally and linguistically diverse backgrounds living with dementia that affect their everyday living preferences.

METHODS AND ANALYSIS
In this review, the scoping method is chosen to offer the first comprehensive and systematically structured overview of the everyday living preferences of CALDPwD patients. This approach allows for the inclusion of various study designs and facilitates a broad understanding of the research on this topic.

Table 1 Eligibility criteria

Criteria	Definition
Population	We will include studies involving individuals from culturally and linguistically diverse groups such as people with a migration history and individuals from ethnic minority groups with diverse care needs across various care settings, without specific country restrictions. We will include studies where caregivers, healthcare professionals or family members provide proxy reports on the preferences of people with a migration history living with dementia. However, we will exclude studies focusing on individuals receiving palliative care or those centred on end-of-life preferences.
Concept of interest	We will examine studies detailing everyday-living preferences of CALDPwD. We will broaden our search to include related terms and synonyms for 'preferences' to ensure that we capture relevant literature, even if the term is not explicitly used in titles or abstracts. During full-text screening, multiple terms will be considered for inclusion or exclusion, not just 'preferences'. The following terms will all be used: ▶ Preferences ▶ Expectations ▶ Wishes ▶ Needs ▶ Values ▶ Demands ▶ Goals ▶ Attitudes
Context	Intersectional determinants of everyday-living preferences will be the focus. This will encompass a wide range of aspects, including personality traits, life experiences, overall health and sociocultural background, alongside structural determinants like race, gender, socioeconomic status, education, citizenship and geographical location.[12 13]
Types of evidence sources	The searches will prioritise peer-reviewed scientific empirical research papers. All types of studies will be considered, while discussion papers, conference abstracts and editorials will be excluded. The focus will be on grey literature, particularly in the form of evaluation reports.
Others	We will encompass studies published in either English, German or Turkish since these are the spoken languages of the authors. There will be no restrictions on publication status or date. However, e-preprints will be excluded.

To carry out this scoping review, which began in December 2023 and will end by November 2024, we are following the step-by-step framework for scoping studies suggested by Arksey and O'Malley,[31] which has been further refined by Levac *et al*.[32] This framework involves six main stages: (1) defining the research question, (2) finding relevant studies, (3) selecting studies, (4) organising the collected data, (5) summarising and presenting the findings and (6) seeking input from others. Additionally, we are adhering to the preferred reporting criteria for systematic reviews and meta-analyses.[33] When reporting our inclusion and exclusion criteria for our scoping review, we will consider the population, concept of interest and context (PCC) mnemonic (table 1).[34] The outcomes of the search and the study inclusion process will be comprehensively detailed in the final scoping review and depicted through a flow diagram adhering to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Review guidelines.[35]

Stage 1: identifying the research question
During a pilot study aimed at translating and psychometrically testing an instrument to evaluate the everyday living preferences of older individuals across different care environments, it became evident that the viewpoints of people with a migration history and individuals from an ethnic minority group have been disregarded.[22] Our research team extensively discussed the importance of including diverse groups, with a specific emphasis on CALDPwD and their unique everyday-living preferences.[22] However, we realised that there has been no focus on the intersectional determinants of everyday living preferences within these groups. Consequently, we formulated the following research question for our scoping review: 'What are the multilayered experiences of people from culturally and linguistically diverse backgrounds living with dementia and their caregivers influencing their preferences in dementia care?'

Stage 2: identifying relevant studies
Our literature search is expected to conclude in November 2024. We are conducting searches across electronic databases, including PubMed, MEDLINE (via Ovid for precision and controlled searching), CINAHL (via EBSCO), Scopus and the Cochrane Library to identify the everyday living preferences of CALDPwD. We applied a preliminary search (December 2023/January 2024) and key publications to identify relevant search terms and indexing words. These terms are organised according to the 'PCC' mnemonic (table 1) and lead to the creation of distinct search strings.[36] The detailed search strategy, including the key terms and search strings used across databases, is presented in table 2. Moreover, we will

Table 2 Search strategy

Keywords and search strings		
Population: alzheimer* OR dementia* OR elderly* OR older* OR senior* OR "dementia" OR "cognitive impairment" OR "cognitive dysfunction" OR "cognitive decline" AND immigrant* OR origin* OR migrant* OR migration OR background OR ancest* OR diaspor* OR ethnic* OR Ethnoc* OR Ethnog* OR "identity politics" OR ingroup* OR outgroup* OR kinship OR minority group* OR "minority population" OR minorities OR multicultu* OR intercultu* OR polyethnic* OR "population genetics" OR tribe* OR polyethnic* OR "afro american" OR black OR latin* OR roma OR romani OR refugee* OR "displaced person" OR "displaced persons" OR "latin population" OR "latin group" OR "people of color" OR "people of colour" OR native OR enslaved	Cochrane Library	942
	PubMed	307
	CINAHL	75
	MEDLINE via Ovid	12
Context: preference OR expectation OR wish OR need OR value OR demand OR goal OR attitude	Web of Science	131
Concept: gender OR caste OR sex OR race OR racial OR ethnicity OR cultur* OR norm OR class OR religion OR disability OR weight OR "physical appearance" OR education OR intersection* OR intersecting OR multilayered OR colour OR color OR aboriginality OR "refugee background" OR "asylum seeker background" OR "migration status" OR "visa status" OR language OR ability OR age OR "mental health" OR "socioeconomic status" OR "housing status" OR "geographic location" OR "medical record" OR "criminal record" OR biological OR biology OR body OR BAME* OR sociocultural OR "health status" OR "health issues" OR stigma OR discrimination OR history OR location OR place OR divers* OR difference OR inequalit* OR community OR underrepresented OR disparit*	Scopus	41

conduct backward and forward citation tracking by examining reference lists and using Google Scholar.

Stage 3: study selection

Records identified through electronic database searches will be imported into Covidence[37] and automatically scanned for duplicates. Two reviewers (KA and SG) will independently screen titles and abstracts and review full texts for inclusion. The explanations and reasons for exclusion will be documented. Discrepancies will be resolved through discussion or consultation with all coauthors if needed.

We will conduct a pilot test of our inclusion criteria using the first 25 records and make necessary adjustments if discrepancies between the two reviewers exceed 25%.[38] Any modifications to the inclusion criteria during the screening process will be documented in subsequent publications. The process of selection will be reported using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow chart.[35] Reviewer disagreements will be resolved through consensus or discussion involving all authors. The eligibility criteria will be refined through team discussion, with changes being documented in subsequent publications.

Stage 4: analysing and charting the data

The data extraction process from the included studies will be conducted by the primary researchers (KA and SG) and cross-verified by the other authors (BY, OR and MR). Following the completion of the extraction, the same primary authors (KA and SG) will review each extracted data item for consistency. In cases where discrepancies arise, discussions will be initiated to reach a consensus. If no agreement is reached, the other authors (OR and MR) will be consulted. The articles included in the study will undergo qualitative content analysis adopting an inductive approach.[39] This analysis will encompass a blend of in vivo coding (verbatim representation) and descriptive coding (summarising the meaning of extracted text into words or concise phrases) to comprehensively assess the included studies.[40]

Stage 5: collating, summarising and reporting the results

We will present the extracted data (table 3) in tabular formats, summarising and reporting general aspects of identified determinants, such as type and referred topics. The tables will provide an overview of the intersectional determinants of the preferences. Additionally, more detailed information about the identified determinants will be presented through a descriptive narrative summary and data visualisation.[41] To achieve this, we will summarise the identified terms based on the type of preferences.

Stage 6: consultation

The development of a scoping review will involve an interactive process, ensuring that all authors are consulted at each stage. The research team will convene after each stage to assess the current approach, the results and the necessity for further procedural adjustments. We plan to engage practitioners in the nursing care field and family caregivers, focusing on CALDPwD. Furthermore, during the discussion of our findings, we will include health professionals, family caregivers and people with dementia in online workshops. We plan to include 5–10 people. Depending on the recruitment process and the participant's language requirement, we plan to do two workshops, one in German and the other in Turkish. During the workshop, we aim to gather their feedback and obtain real-world experiences, which may add different interpretations and/or conclusions. These discussions will address identified preferences, gaps in research and any underrepresented preferences.

Patient and public involvement

Patients and/or the public were not involved in the design, conduct, reporting or dissemination plans of this

Table 3 Data extraction framework

Domains	Description (coding)
Study characteristics	► Name ► Publication date ► Year of the study ► Geographical location (country) ► Language (of the study) ► Aim (of the study) ► Study design and methods of data collection ► Publication type (peer-reviewed or grey literature) ► Population ► Setting (e.g. nursing or care homes, home care or adult day care)
Author details	► Name (first author) ► Institution (e.g. university or research institute of the first developer)
Intersectional determinants of preferences of people from culturally and linguistically diverse background with dementia/results of the study	► Main findings of the determinants: Identification of everyday living preferences in relation to different intersecting factors, like personality traits, life experiences, overall health, sociocultural surroundings, as well as structural elements such as race, gender, class, education, citizenship or location, contribute to the circumstances of CALDPwD. ► Main findings of the evaluation of the determinants: Structural determinants and multilayered experiences influencing everyday living preferences including leisure activities, care and support, social engagement and routine daily activities.

CALDPwD, culturally and linguistically diverse people with dementia.

research. However, for the upcoming scoping review, we plan to engage health professionals, family caregivers and people with dementia. These stakeholders will be consulted during stage 6 of the scoping review.

ETHICS AND DISSEMINATION

There are no ethical concerns related to conducting this study. The protocol does not raise ethical concerns since it does not involve human participants in the design, conduct, reporting or dissemination plans of this research. The results will be disseminated through presentations given at both national and international conferences and publication in journals aimed at practitioners and peer-reviewed publications. Furthermore, we intend to identify potential research gaps in the current landscape and consider them for future projects.

DISCUSSION

This study will address critical gaps with regard to knowledge on the complex intersecting factors that influence the preferences, wishes, needs, attitudes and expectations of CALDPwD. To our knowledge, no qualitative scoping review has studied this topic. This work will carefully identify the studies bringing an intersectional perspective to the complex experiences of diverse minority groups around the world living with dementia. One of the strengths will be the inclusion of several literature databases and relevant studies with an additional forward and backward citation tracking. It is expected that the included studies from several countries representing various communities will allow us to gather information about underrepresented groups. However, this diversity also brings the limitation of the generalisability of some findings. Another limitation of the study will be related to our specific attention to the experiences, wishes, needs and expectations of the diverse groups to emphasise empowerment and autonomy. Therefore, we will exclude the studies having a primary focus on the burden of caregiving. From an alternative interpretative perspective, these studies may provide valuable insights into the interpretation of needs and expectations by examining the challenges this population faces within the health system.

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