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Regional variations in healthcare in people living with dementia in Germany: protocol for a mixed-methods study

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ABSTRACT

Introduction Care for people living with dementia is both important and complex, and there is evidence of large regional variations in the quality of care. This study protocol describes design, methods and objectives of an investigation of regional variations in the utilisation, the quality and the costs of care for people living with dementia in Germany.

Methods and analysis An exploratory, naturalistic, mixed-methods study is being conducted with three modules: *Module A:* A quantitative analysis of claims data of statutory health insurance will be conducted to investigate regional variations in the utilisation and costs of care. *Module B:* In selected regions of interest that deviate significantly from the average in terms of utilisation in Module A, the quality of care and patient characteristics, variations and possible causes of these variations in care will be examined in more detail using quantitative and qualitative assessments. *Module C:* The claims and primary data from modules A and B will be combined, synthesised and evaluated to elicit recommendations for regional healthcare using a participatory consensus method.

Ethics and dissemination The study is overseen by the German Alzheimer's Association. The study's ethics and data protection plan was approved by the data and ethics committee of the leading university, Brandenburg Medical School Theodor Fontane (reference number: 152092023-BO-E) as well as the data committee of the three participating health insurances. Dissemination plans include dissemination of our main results to the general public, people affected, the scientific community and funding-, policy- and decision makers. Study outcomes and conclusions will be published on our own and the funder's websites, through presentations at conferences and in scientific journals. The funder ensures dissemination of main study results and recommendations for action to relevant organisations and institutions. Publication of the study's main results is planned within 6 months of the study's conclusion.

Trial registration number DRKS00031944 (https://trialsearch.who.int/Trial2.aspx?TrialID=DRKS00031944).

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ Using regional comparisons of existing guidelines and standards with the actual care of people living with dementia in Germany, the study contributes to the identification of misuse and misallocation as well as successful care and reveals potentials for optimisation.

⇒ The study takes a multi-perspective mixed-methods approach by combining different research methods and data sets, such as claims data, survey data and qualitative data.

⇒ This will enable a comprehensive analysis of the actual healthcare situation of people living with dementia, including its deficits and variations, and the factors influencing healthcare pathways.

⇒ Within the study, measures are taken to involve people living with dementia, their families and caregivers, both through the use of qualitative research methods and through participation in the research process.

⇒ The study's key limitation is that survey data about advanced dementia cases come exclusively from proxy respondents, due to ethical constraints and constraints in questionnaire construction.

INTRODUCTION

Dementia is a major global health concern with approximately 55 million people living with dementia (PlwD) worldwide and 10 million new cases of PlwD emerging annually.[1 2] Various projections indicate a rising trend in the prevalence of dementia.[3 4] In a systematic review, researchers estimated that the total annual cost per person with dementia in Europe was on average €32 506.73 and €42 898.65 in the USA.[5] This poses significant social and economic challenges worldwide.[6]

In Germany, the number of PlwD is currently estimated at 1.8 million.[7] Many PlwD have several coexisting diseases (multimorbidity), take several medications (polypharmacy) and need complex and interprofessional care.[8 9] There is evidence that people with dementia are more frequently admitted to hospitals than those without dementia, independent of physical comorbidities.[10] At the same time, studies estimate that only a small portion of those affected receive evidence-based healthcare as recommended by clinical guidelines,[11 12] such as timely and sufficient diagnostics, specific diagnosis, prescription of appropriate medication and no prescription of potentially harmful medication.[13–15] Several studies found delayed diagnosis in routine primary care[16 17] and 90% of PlwD had three or more unmet medical care needs.[18]

A particular challenge in optimising care is the wide regional variation in both the number of PlwD diagnosed and the use of recommended healthcare services.[4 19–24] Availability and quality of healthcare services may be two important influencing factors. These factors are particularly important in complex care situations, as care provision is very sensitive to preference and supply.[25] In addition, regional differences in demographics, socioeconomic conditions and lifestyles are likely to influence the healthcare provision and utilisation at both individual and regional levels.[26–30] In an international systematic review on rural and urban differences in the quality of dementia care, researchers found that PlwD living in rural areas had higher mortality rates, lower visits to physicians, more hospitalisations but shorter stays, higher antipsychotic medications, lower use of home care services and higher use of nursing home compared with PlwD living in urban areas.[31]

However, regional variations in healthcare provision and utilisation of PlwD have not been sufficiently examined, especially for the German healthcare setting. A previous study observed significant differences in the prevalence of dementia in different regions of Germany.[32] Three studies found regional differences in the frequency of diagnostic and therapeutic services for newly diagnosed PlwD and in the prescription of anti-dementia drugs.[33–35] One study observed that more than half of PlwD did not consult a neurologist or psychiatrist and this proportion varied widely by region.[29] In another study, it was shown that the consultation of specialists depended on the degree of urbanisation, with urban patients being more likely to consult neurologists or psychiatrists than rural patients.[19] However, these studies did not analyse patient pathways nor evaluate other determinants of regional variations, such as variations in sociodemographic structures.

To address this research gap, the planned study aims to investigate regional variations in the utilisation, quality and costs of care for PlwD. For this purpose, nationwide claims data of statutory health insurance funds, quantitative data derived from a survey and qualitative methods will be used to identify determinants of regional variations in healthcare and healthcare costs of PlwD in Germany, as well as the consequences of these differences.

METHODS AND ANALYSIS

Design

The present study has three consecutive modules, evaluating regional variations in healthcare and healthcare costs of PlwD from different perspectives and deriving recommendations for optimising regional healthcare (see figure 1). A mixed-methods design is used to enable the triangulation and contextualisation of data and results to increase the generalisability and depth of findings.[36] The study is registered at the German Clinical Trials Register, and therefore part of the WHO register.

Patient and public involvement

Various measures are being taken to ensure patient engagement in the project and to anchor the procedures, interpretations and dissemination strategies in their specific needs and perspectives.

A project advisory board consisting of the German interest group of PlwD and their relatives (‘German Alzheimer’s Society’, DAlzG) and representatives of the German professional associations (‘German Association for Psychiatry, Psychotherapy and Psychosomatics’, DGPPN and ‘German Association for Gerontopsychiatry and Psychotherapy’, DGGPP) has been set up to accompany the study and ensuring patient engagement. Their tasks include selecting the criteria for regions of interest, participating in the development of the survey and interview guidelines and defining recommendations for care provision.[37] For these research decisions, approval from the German Alzheimer’s Society is mandatory. The project advisory board is involved in dissemination of the study’s results. These tasks and rights are contractually regulated in a cooperation agreement.

A working group of PlwD from the Alzheimer’s Society is involved in the development of the questionnaire and interview guidelines. Additionally, the questionnaires and interviews will be piloted with a group of patients and relatives. Both the working group of PlwD and the piloted patients and relatives group will be explicitly asked to assess the burden of the questionnaires and interviews and the time required to participate in the research.

We took measures to include experiences of people with severe dementia in the surveys and qualitative interviews, even though their inclusion remains, unfortunately, limited. In the questionnaire, we deliberately include instructions that relatives or caregivers could also help or fill out the questionnaire in case the person affected is not able to answer the questions on their own. In the interviews, a prerequisite for obtaining the ethics vote in Germany was that people were able to give informed consent, which is why severely affected people are excluded from participating as interview partners. However, relatives of people with severe dementia are explicitly sampled and asked to participate in the problem-centred interviews and focus groups.

One limitation of the involvement of patients and caregivers is that they were not involved in the development of recommendations for action. This was not feasible in this study due to constraints of time and resources, as outlined elsewhere.[37] We have, however, included a discussion of recommendations for action in the focus groups. Furthermore, a participatory expert panel,

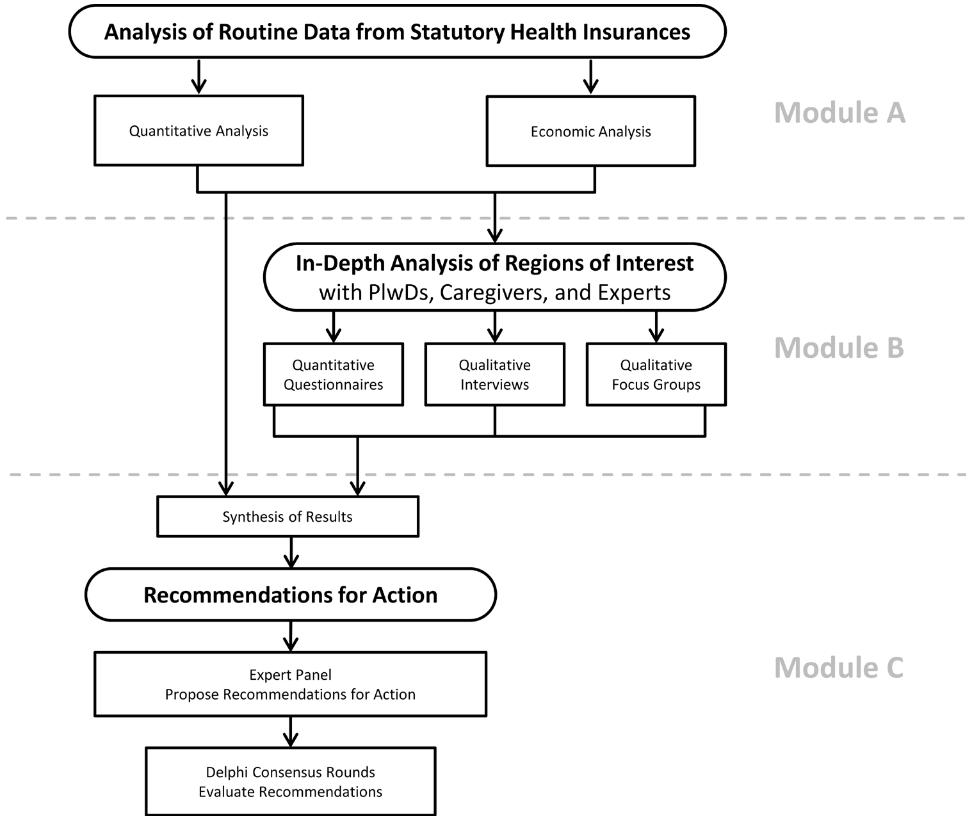

Figure 1 Depiction of the three study modules. PlwD, people living with dementia.

including patients and caregivers, will be recruited. They will be presented with research results and recommendations for care,which they will then be asked to consent to in an abbreviated Delphi procedure.[38]

Module A: nationwide claims data analyses

Study population

In Module A, claims data of PlwD from three nationwide statutory health insurance funds (Barmer, Deutsche Angestellten Krankenkasse (DAK), Techniker Krankenkasse (TK) will be analysed, covering approximately 25 million insured people in Germany. The data comprise individuals of 18 years or older who received at least one diagnosis of dementia (according to the tenth revision of the International Classification of Diseases: diagnoses F00, F01, F02, F03, F05.1, G30, G31) or mild cognitive impairment (F06.7) in the period 2019–2022.

Regionalisation

To identify potential regional variations in the care of PlwD, all outcomes will be analysed at a regional level. The regional unit is based on the first three digits of the German postal code (n=671). These units are further stratified by cross-combinations of the degree of urbanisation[39] (three categories) and the German Index of Socio-economic Deprivation[40] (five categories). Regional variation will be visualised and analysed using Geographical Information Systems. Further factors may be added at the district level (eg, demographic information, physician density).

Outcomes and covariates

Regional variations of healthcare provision and utilisation of PlwD will be analysed according to age at diagnosis relative to the age distribution of the region, frequency of physician consultations in primary and specialist ambulatory care, frequency of appropriate and inappropriate prescribed medication (PRISCUS[14]) and frequency of therapies (including occupational therapy, speech therapy, physiotherapy). Primary outcome characteristics are hospitalisation, need for long-term care, institutionalisation and mortality. Secondary outcome characteristics are direct healthcare costs. Outcome characteristics will be analysed separately for prevalent and incident cases of PlwD. Incident cases of PlwD are defined as individuals at risk without a prior diagnosis of dementia in a predefined observation period.

Analysis of patient trajectories and outcome parameters

Patient trajectories within the healthcare system will be described and visualised including intrasectoral and intersectoral journeys. The use of healthcare services reflected in a large number of available patient trajectories will be analysed by operationalising the trajectories into indicators of guideline-conform treatment. Guideline-conform treatment includes, for example, timely and sufficient diagnostic,[13] specific diagnosis,[13 15] prescription of appropriate medication[13] and no prescription of potentially harmful medication.[14] State sequence analysis[41] will be used to identify clusters of similar utilisation and their determinants using polytomous regression.

The identified trajectory groups will then be used in further analyses, identifying their associations with potential outcomes. Associations are calculated using (hierarchical) linear, logistic or Cox regression, depending on the endpoint.

Health economic analyses

Health economic analyses aim to evaluate the variations in healthcare costs of PlwD by regions and to identify associated factors that influence these costs (cost drivers) using an incident-based cost-of-illness design.[42] Based on the indicators described above, different treatment pathways will be mapped, and the costs of the respective pathways' will be calculated. Differences in regional healthcare pathway costs as well as their cost drivers will be analysed using univariate and multivariate statistics. In subsequent analyses, regions with high or sharply increased healthcare costs as well as regions with low or constant healthcare costs will be examined in more detail.

Module B: in-depth analysis of selected regions of interest using quantitative surveys and qualitative interviews and focus groups

The results of Module A will be discussed with the project advisory board, and the criteria for the selection of eight regions of interest will be defined. Criteria for the definition of healthcare provision and utilisation could be, for example, guideline-compliant versus less guideline-incompliant care. The sizes of the potential regions of interest are further determined by the number of PlwD within the regions. If necessary for data protection purposes, multiple regions will be aggregated.

After selecting the regions of interest, the healthcare of PlwD within these regions will be examined in more detail. The aim is to enrich the claims data with patient-reported experience and outcome measures, using a mixed-methods approach.

Part 1: quantitative survey (questionnaire)

A postal survey will be conducted via the participating health insurances (Barmer, DAK, TK), which will send the questionnaire by mail to insured PlwD in the eight regions of interest (inclusion criteria=inclusion criteria for claims data analysis of prevalent PlwD). The completed questionnaires, not containing any identifying information, are returned via pre-paid postal mail to the research institute. Stratified by sex and age, n=1340 questionnaires will be sent out per region.

The questionnaire is intended to capture specific aspects of the quality of care that cannot be covered by the claims data analysis (eg, duration from noticing the first symptoms to diagnosis), factors that could have an influence on patient-relevant and care-relevant outcomes of PlwD (eg, family constellation and support from social networks, eg, OSLO Social Support Scale[43]) and patient-reported experience and outcome measures (eg, quality of life, using the EQ-5D-5L,[44] satisfaction with healthcare, caregiver burden, using items from the Zarit burden interview[45]).

Their operationalisations will be developed in a participatory manner during the research project, in cooperation with the project advisory board and the working group of the DAlzG. In collaboration with the project advisory board, relevant aspects will be selected. In parallel, a literature review of existing surveys that assess those specific aspects will be conducted. Already established and standardised survey instruments as well as, if necessary, novel items will be integrated into the first draft of the questionnaire. This draft will be presented to the project advisory board and the working group of the DAlzG and discussed until a final version of the questionnaire is agreed on.

Statistical analysis and power calculations

With an expected response rate of 10%, the number of responders (n=134 per region) is sufficient to demonstrate factors with medium effect sizes on the patient-related outcomes with sufficient statistical power within the regions. Factors influencing care satisfaction and patient-relevant and care-relevant outcomes such as cumulative length of hospital stay or early nursing home admission are identified using hierarchical linear regression models with simultaneous adjustment for confounders such as age, sex and other patient characteristics.

Part 2: qualitative methods

Qualitative methods are suitable for contextualising and appropriately interpreting data obtained through standardised surveys. In the context of our study, possible inconsistencies within the results of the standardised surveys and/or the claims data analysis may be explained or better understood additionally employing qualitative methods. The data obtained through these different methodological approaches may be triangulated and validated to increase the creditability and generalisability of the results.[46 47] In the planned study, problem-centred interviews, focus groups and expert interviews will be carried out for these purposes. In each of the selected regions of interest, the recruitment will take place in a stepwise procedure via our networks, regional self-help organisations and, if necessary, by approaching care networks and providers directly.

Problem-centered interviews and focus groups

In the first step, five PlwD, caregivers or dyads per region will be recruited to conduct problem-centred interviews.[48] In a second step, 5–8 PlwD or caregivers per region, who have not yet participated in problem-centred interviews, will be recruited for a focus group. All participants have to be able to give informed consent to participate. To ensure the inclusion of experiences of people with severe dementia, caregivers of people with severe dementia are explicitly sampled. Recruitment takes place via recruitment centres, via trained regional recruiters in the eight regions of interest.

Problem-centred interviews are a qualitative social research method, that focuses on the experiences, perceptions and reflections of the interviewees on a specific problem (topic). The method was introduced by Witzel.[49] This research method has been selected because it is a pragmatic and reliable tool for collecting information and can be adapted to diverse situations and purposes. Interviews follow the so-called patient journeys and are transferred to an individualised process map[50 51] during the interviews. The aim is to narratively reconstruct the illness and treatment experiences of PlwD and to follow-up with questions about personal needs and structural barriers to care at each of these stages. The semistructured interview guideline developed for this purpose provides flexibility for individual accounts and ensures that key information is captured. In interviews with dyads, both perspectives are recorded separately and where possible integrated into one process map, while discrepancies between both perspectives are also discussed. The categories and questions of this interview guideline are agreed and tested in advance in collaboration with members of the advisory board and the working group of the DAlzG. Example themes that the questions will cover are: sticking points and barriers in the health system, regional infrastructure and quality of life. Preliminary results from these interviews will be used as input for the focus groups.

The focus group method is a moderated group discussion between several participants, which is usually based on a guideline with open questions, and is often used in qualitative social research. In this research project, its purpose is to clarify the perspective of those affected and their relatives and reflect the variance in viewpoints. The discussion will be moderated by a research assistant and will be directed towards the research question and research subject, dementia-related healthcare services. The focus groups with new participants can be used as member checking, a frequently used strategy in which the investigator takes summaries of the findings back to key participants in the study and asks them whether the findings are an accurate reflection of their experiences. This procedure serves to examine the results of the individual interviews together and to diversify and generalise them.[52] In addition, at the end of each focus group discussion, participants are invited to formulate potential solutions or recommendations for action.

Expert interviews

Three experts per region of interest will be recruited via our local recruitment centres and interviewed. Experts are defined as people with extensive knowledge of the regional healthcare structures and the regional care situation for PlwD and therefore have specific regional expertise.[53] In contrast to the problem-centred interviews and focus groups, the expert interviews do not focus on patient journeys, but instead on the structural peculiarities of the regions of interest. The expert interviews are intended to add additional, potentially broader perspectives, and to highlight barriers or facilitators of local healthcare which cannot be observed through quantitative data alone. Examples of such barriers or facilitators could include, for example, difficulties in filling an important vacant position at a dementia advice centre, or a highly motivated healthcare professional with a special expertise in dementia diagnosis.

Qualitative content analyses

The transcribed interviews and the process maps are analysed using qualitative content analysis, which is characterised by the process of summarising, explicating and structuring.[54] In each region, the results of the interviews and focus groups will be interpreted by using a category system. The results will be embedded in the scientific consensus and will be put into perspective at the discussion level.[36]

Module C: synthesis of results and recommendations for action

Synthesis of results

Results of regional analyses of claims data will be compared with primary data from the quantitative surveys.[55] The expected age-related prevalence of dementia, the morbidity structure derived from the claims data and the care structures are taken into account on a regional basis. Furthermore, we will investigate whether regional levels of care quality correlate with satisfaction with healthcare provision and utilisation of survey participants.

In the second step, the aggregated results will be integrated with the qualitative data using a mixed-methods approach[36] to validate (triangulate), deepen (qualify) and broaden (add new aspects) the evidence.[56] In our synthesis of results, we will follow the seven steps suggested by Creswell[36] (page 219, data reduction, data display, data transformation, data correlation, data consolidation, data comparison, data integration). The results of the qualitative and quantitative databases will be merged in a convergent design. The convergent design is characterised by parallel action, in which qualitative research and quantitative research take place simultaneously. No emphasis is placed on one research strand, but both qualitative and quantitative data are equally important in the processing, evaluation, interpretation and joint display on the data.[36] Afterwards, those results will be compared and discussed.

Development and consensus of recommendations for action

The synthesis serves as the basis for the subsequent evaluation and consensus process. To this end, an expert panel will be set up, consisting of representatives of self-help organisations, the participating health insurances and professional associations, and clinical experts in the healthcare field (n=10). Three meetings are planned for the subsequent coordination process to discuss the material and propose recommendations for action. After the first and second meetings, the (interim) results, including all the main contributions to the discussion,

Table 1 Dissemination plan

Target audience	Objective	Approach
General public	Inform them on project outputs Increase awareness of variations in healthcare for PlwD	Website (own and G-BA* website), open access publications of main research results
Affected group (PlwD and associated, people working in the field)	Inform them on project outputs Engage in discussion about potential for improvement	Website (own and G-BA website), attendance of conferences (eg, of the German Alzheimer's Association)
Scientific community	Increase awareness of variations in healthcare for PlwD Inform about new research methods PlwD	Website, attendance of scientific conferences, publication of research results in scientific journals
Funding-, policy-, and decision makers	Inform them on project output Inform them about recommendations for action Improve healthcare for PlwD	Workshop included in Module C, final report of the project within 6 months after project completion, resulting transfer recommendation by the G-BA (resolutions), publication of the report and the resolutions on the G-BA website, forwarding of the report and the resolutions to relevant organisations and institutions by the G-BA, publication of the feedback from these organisations and institutions also on the G-BA website. By publishing the project results, recommendations and feedback, all stakeholders in the healthcare system can make use of the knowledge gained.

Note. Description of the study's dissemination plan.
*The G-BA consists of four parties: The National Association of Statutory Health Insurance Physicians (KBV), the National Association of Statutory Health Insurance Dentists (KZBV), the German Hospital Federation (DKG) and the National Association of Statutory Health Insurance Funds (GKV-Spitzenverband).
PlwD, people living with dementia.

will be analysed and made available to the panel members for comment. The final recommendations for action will then be evaluated in two abbreviated Delphi rounds by another panel of PlwD, caregivers and new clinical experts who were not involved in developing the recommendations for action. For this Delphi process, n=20 PlwD and their relatives and n=20 experts in the care of PlwD will be recruited through self-help organisations and the researchers' networks. Participants will be surveyed individually by letter. The abbreviated Delphi process, which focuses on consensus on pre-identified recommendations for action, will be carried out in the standard steps of questioning, categorisation and hierarchisation of responses and feedback. At the end of this process, consensus-based recommendations for action will be made available for the region-specific optimisation of healthcare for PlwD in the statutory health insurance system.

Planned start and end dates

The data transfer from the claims data is planned for August 2024. The data evaluation period of the claims data is planned from August 2024 until March 2025. The selection of the regions of interest for the distribution of the surveys and the selection of interview partners and focus groups are planned to be decided by the end of December 2024. The survey is planned to be sent out by March 2025, and there is a planned 3 months period for participants to complete and return the surveys to be completed in the data analysis. The interviews and focus groups are planned to take place between February 2025 and September 2025. The synthesis of results and development of recommendations for action are planned to be executed between September 2025 and August 2026.

ETHICS AND DISSEMINATION

To address ethical and safety considerations, the study design and conduction is overseen by the German Alzheimer's Association. The study's data protection protocol regulates data depositions and curation. The study protocol and the study's data protection protocol were submitted and accepted by the data protection and ethics committee of Brandenburg Medical School Theodor Fontane (reference number: 152092023-BO-E), as well as the data protection committees of the three participating health insurances (Barmer, DAK and TK). The study's data protection protocol of Module A was submitted and accepted by the Federal Office for Social Security.

Data dissemination is planned for the following four target audiences: general public, those affected (PlwD, relatives and professionals), scientific community and funding-, policy and decision makers. An overview of the objectives for each target audiences and the planned approaches can be found in table 1. Besides common approaches such as publication on our own websites, presentation at conferences and in scientific journals, dissemination will take place through our funder, the G-BA (Federal Joint Committee). The G-BA ensures the dissemination of main study results and recommendations for action to relevant organisations and institutions.

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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.

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