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Dementia and migration in Germany.

An estimate of the number of people with a migration background with dementia and an analysis of the caregiving situation, current information and healthcare services and measures to improve the healthcare situation of those affected.

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1. INTRODUCTION

People with a migration background (PwM) are at a disadvantage in terms of healthcare, and PwM with dementia are an especially vulnerable subgroup within this population. Although it is becoming increasingly clear that this group needs more support and awareness than they are currently receiving, healthcare, society, and politics are not providing the necessary attention. This may be partially due to a lack of visibility of and knowledge about PwM with dementia. Researchers are attempting to change this situation, and ‘dementia and migration’ is a topic that is currently receiving more attention, and the amount of knowledge about PwM with dementia, their care situations, and their utilisation of the healthcare services is growing. This dissertation studies this topic from a German perspective. The aim is to a) generate knowledge about PwM with dementia, their family caregivers, and their individual care situations; b) derive a potential model for PwM (with dementia) to navigate the healthcare system; and c) investigate the availability of culturally sensitive healthcare services. This will serve to raise awareness of a topic that is still under-researched and lacks the attention it deserves from healthcare providers and lawmakers and to provide knowledge to affected PwM and people working in the German healthcare system. First, definitions and information on dementia, migration, and challenges in dementia care for non-migrants and PwM is discussed. After the presentation of the quantitative and qualitative methodological approaches undertaken in this study, the results and the implications of these findings for the healthcare system and for research will be described and discussed in terms of cultural sensitivity, education, expansion of healthcare structures, and networking and cooperation.

1.1 Dementia and challenges in healthcare

Dementia is an umbrella term for a range of diseases that affect cognitive abilities and behaviour. According to the ICD-10 (International Statistical Classification of Diseases and Related Health Problems), dementia results from a chronic brain disease. It affects a number of cortical functions, for instance, memory, orientation, language, learning abilities, and thinking, among others. Changes in emotion control, social behaviour, or motivation can occur [1]. The DSM-V (Diagnostic and Statistical Manual of Mental Disorders) describes neurocognitive disorders with impairments in at least one of the following six domains: attention, memory, language, executive functions, social cognition, or perceptual motor skills. Dementia (e.g. Alzheimer’s disease or dementia with Lewy bodies) is cited as one possible cause of these neurocognitive disorders [2]. There are different types of dementia with many underlying causes, and there is primary as well as secondary dementia. Primary dementia results from

physical changes in the brain, while secondary dementias are caused by events or diseases such as head injuries, multiple sclerosis, or HIV. Alzheimer's disease, dementia with Lewy bodies, frontotemporal dementia, and vascular dementia fall into the primary dementia group. The most common types are Alzheimer's disease (60–80% of all dementia cases), vascular dementia (5–10%), and dementia with Lewy bodies (5–10%). Mixed forms of dementia are also possible [3, 4]. There are many risk factors for dementia, some of which are old age, lower education, little cognitive stimulation, physical inactivity, smoking, or depression [5, 6]. The prevalence of dementia is increasing worldwide. The World Alzheimer Report 2015 [6] states that, in 2015, there were 46.8 million people living with dementia, and it estimates that, by 2050, there will be 131.5 million people living with this disease. In Germany, the numbers are also expected to increase. In 2019, there were approximately 17.15 million people aged 65 or older living in Germany [7], of which 1.5 million had a form of dementia. It is estimated that this number will increase to 2.3–2.8 million by 2050 [8]. However, it is also thought that there are high numbers of undetected cases since dementia is underdiagnosed [9]. In Germany, although the rate for formal dementia diagnosis (40% of people who screened positive for dementia receive a formal dementia diagnosis) lies within the range of international reference data (20–50%), dementia recognition should be improved. A dementia diagnosis paves the way to evidence-based treatment, support, and care, thereby providing people with dementia and their families the opportunity to prepare themselves and plan for the future [10, 11]. The timely diagnosis of dementia is not the only challenge; healthcare systems have difficulties with delivering appropriate care. Care is in many cases 'fragmented, uncoordinated, and unresponsive to the needs of people with dementia and their families' [9]. Examples of these problems are managing the caregiver burden and the patients' problematic behaviour, supporting people with dementia and their families, referral to a specialist, or adequate pharmaceutical treatment [12, 13]. The increasing numbers of people with dementia and the challenges in their care illustrate that dementia is a topic that should concern every member of society, because anyone can be affected by it in one way or another and will then need support.

A subgroup that is especially vulnerable in the group of people with dementia are PwM, which is discussed in the following sections.

1.2 People with a migration background with dementia

1.2.1 MIGRATION: DEFINITION, HISTORY AND NUMBERS

While PwM is a common classification, it poses a challenge to determine who qualifies as PwM as there is no set term or definition for this population that is used consistently across the world;

different countries use different terms. The United Nations Migration Agency (2019) defines PwM as people who are not living in their habitual place of residence but have moved, either within a state or across borders. In Germany, the definition of the Federal Statistical Office (2020) states that persons not born with German citizenship, or if at least one of the parents was not born with German citizenship, have a migration background. Immigrant and non-immigrant foreigners, German re-settlers, immigrant and non-immigrant naturalized citizens, and descendants of the former groups born with German citizenship fall within that definition. Gove et al. (2018) offers a comprehensive examination of this topic, with the different terms used and the challenges originating from it.

The recent history of immigration in Germany is characterized by different phases, namely recruitment of workers from countries such as Italy, Turkey, Portugal, former Yugoslavia, and Tunisia between 1955 and 1973, the collapse of the Soviet Union in the 1990s, the introduction of dual citizenship in 2000, the Immigration Act from 2005, high youth unemployment in southern regions of Europe, and the conflict in Syria [16, 17]. All of this has resulted in the presence of approximately 21 million PwM in Germany by 2019, and, of this group, 2.07 million were aged 65 or older [7]. The number of older PwM is expected to rise, resulting in a growing cultural and ethnic diversity among the older population in Germany [18].

1.2.2 MIGRATION AND HEALTH

The data on migration and health on a global, European, and German level varies in availability and quality. However, it is possible to make some statements on the matter [19-21], such as state of health, mortality, and health-related behaviour of PwM are influenced by the different phases of migration (pre, peri, and post) and by the conditions of these phases. Some might have encountered certain experiences or illnesses in their country of origin or during migration that will have a lasting impact on their life-long health [22]. The data also reveals that, generally, PwM do not differ significantly from the autochthonous population (population without a migration background) in terms of mortality and morbidity, but there are differences in age of onset, gravity, and significance [20]. Although, often a healthy migrant effect is first observed (people migrating to another country are initially healthier and mortality in younger and middle-aged cohorts is lower), but this can change with longer stays in the destination country and state of health can worsen due to poor post-migration conditions [20, 22]. For example, an increase in mortality and low self-rated health can be observed. Furthermore, it is evident that multimorbidity and unmet healthcare needs in PwM are as prevalent as they are in the host population across European countries [19, 22]. Mental and dental health are particularly

affected [19]. For example, PwM can have a higher rate of mental health conditions overall, such as depression, and there can be a higher prevalence of dementia among some PwM [22]. However, according to the data, PwM utilise healthcare services to a lower extent than non-migrants and hesitate to seek help. Data for Germany shows that, depending on the healthcare area and migration background, PwM utilise healthcare services less than the autochthonous population. For example, there is a lower utilisation of prevention, rehabilitation, and therapy services by PwM. This is especially true for the first generation PwM, women, children/adolescents, and PwM whose migration background is two-sided [23]. There are many reasons for this, such as a lack of health literacy, issues with communication, financial and cultural barriers, discrimination and racism, legal barriers, differing cultural viewpoints on health and healthcare services, the stigma associated with certain diseases, a lack in the intercultural opening of healthcare services, poor coordination of all parties involved, or a lack of resources in services to appropriately care for PwM [20, 22].

1.2.3 MIGRATION AND DEMENTIA: NUMBERS AND CHALLENGES

The number of older PwM is increasing, which leads to a growing probability of age-associated and chronic diseases such as dementia [6, 24]. There is a scarcity of data on the number of PwM in Germany who may have dementia. Estimated numbers range between 37,000 and 106,000 [25, 26]. An analysis from the year 2014, based on data from the German Federal Statistical Office and the Central Register of Foreigners, estimates the number of PwM with dementia in Germany to be approximately 106,000 [26]. A more recent analysis, based on data from Eurostat, proposes the number of PwM with dementia at approximately 37,000 in Germany. This analysis provides an overview of all EU- and EFTA member states and provides the number of affected people in different age groups [25]. Both of these analyses do not disclose where the PwM with dementia actually live in Germany. Drewniok (2014) has shown the number of affected people for a few selected groups in the whole of Germany (PwM, resettlers, people with a Turkish migration background, foreigners, and non-migrants), while Canevelli et al. (2019) provided the number of affected people in the entire country. The migration background for the PwM with dementia is not provided in either analysis. A closer look into the geographical distribution of PwM with dementia in the regions of Germany and information on their country of origin could assist in individual healthcare planning tailored for PwM with dementia and their families. Individual planning would then also be possible for migrant organisations and other organisations working in this field. They can adapt their policy-making to the regional characteristics and learn more about the population they strive to support. Furthermore, this presents an opportunity to network. It would also be helpful for those affected

to obtain this knowledge, so that they will be in a better position to access the support they might need.

This clear lack of quantitative data on PwM with dementia is not the only problem. In addition, there have been reports of additional or increased challenges in terms of dementia and migration background or culture, such as a lack of access to appropriate care. There are various possible reasons that can be cited for these circumstances, for example, language barriers [27-32] that impede communicating needs and symptoms and hinders care-seeking and the utilisation of healthcare services [33]; financial [30, 34] or transportation issues [35, 36]; a lack of knowledge of dementia [27-30, 36-39] and how to utilise the available healthcare services for support [27, 29, 30, 32, 34, 40-43]; or fear of gossip and disapproval from people in their community when seeking formal help [27, 42]. Furthermore, healthcare professionals sometimes lack cultural sensitivity and do not know how to interact with PwM with dementia and their family members [34, 38, 44, 45]. In addition, there is also a lack of culturally sensitive and suitable information and healthcare services to educate and appropriately care for PwM with dementia [27-29, 34, 35, 41-44, 46, 47]. The scarcity of research on this topic in Germany aggravates the lack of cultural sensitivity in the healthcare system and in healthcare professionals. There are studies available on PwM with dementia and how to properly care for them but, compared to other research fields, this is still a niche topic that deserves and requires more attention and action. Therefore, generating knowledge about how the healthcare system can be more culturally sensitive towards PwM with dementia is imperative and could support the healthcare system and healthcare professionals in providing adequate care for this group. Moreover, it is important to note that, according to the literature, it is not only important to generate this knowledge but also that the information should originate from the affected people since they are the experts on their own situations [48]. The Federal Ministry for Family Affairs, Senior Citizens, Women and Youth and the Federal Ministry of Health acknowledge the described lack of access to healthcare for PwM (with dementia) and the lack of culturally sensitive healthcare services for this population in Germany's first National Dementia Strategy [49]. As a first step, different goals have been formulated to provide PwM (with dementia) with low-threshold, culturally sensitive care and information. Two of the measures to achieve this are to raise awareness about existing services and to establish more culturally sensitive information and counselling services throughout Germany. However, thus far, there seems to have been little effort to systematically showcase the scope of available culturally sensitive healthcare services throughout Germany and to pinpoint the gaps in the provision of services.

2. CONCLUSIONS AND RESEARCH FOCUS

The situation of PwM with dementia and their family members and the challenges in healthcare indicate the following:

- a) PwM with dementia and their families are not part of the healthcare landscape. They are not optimally educated about dementia, the healthcare system, its services, and the support it can provide, which means that they do not receive support that is tailored towards them and their needs.
- b) The healthcare system and the healthcare professionals and service providers seem to lack awareness of cultural sensitivity and how to approach and provide optimal care for PwM with dementia.
- c) There are some efforts towards providing PwM with dementia and their families with culturally sensitive care tailored for them, but there is no systematic overview on what is available and where action is required.

More knowledge about this vulnerable population is needed to address these issues. For example, in Germany, there is little data available on how many people of different migration backgrounds are possibly affected by dementia and their locations, as mentioned before. There is also a need to learn how to design healthcare services and about what other measures are required to increase the utilisation of healthcare by PwM with dementia and their families. It is essential that data on culturally sensitive healthcare services and the needs, situations, and experiences of PwM with dementia and their families should be generated in cooperation with PwM. If more direct knowledge on their unique experiences with care, diagnostics, and treatment is available, healthcare professionals and service providers will be better able to tailor their services with more culturally sensitive care. This and culturally sensitive information could assist in formulating plans to support those affected to utilise the healthcare system and to help them to obtain the support they require [19, 21, 48]. This is especially important since PwM are not one homogenous group who can all be treated the same. Similar to non-migrants, some characteristics are shared but not others, and the subgroups should be identified. Knowledge of the subgroups and where PwM with dementia live is helpful for service providers to tailor their services for this population. Furthermore, PwM with dementia and their family members have to be educated about dementia, the healthcare system, and the available healthcare services. An overview of existing culturally sensitive services and projects targeting dementia and migration would be useful to raise awareness and make these initiatives known

among the public, those affected, and service providers, as formulated in the German National Dementia Strategy. This can encourage help-seeking behaviour in those affected and networking among service providers.

Therefore, this dissertation focuses on the following research questions:

1. What is the number of PwM in Germany by migration background and geographical region?
2. What are barriers or facilitators to healthcare utilisation for PwM in Germany? What are strategies to increase utilisation? What is the experience of family caregivers of PwM and dementia, specifically for people with a Turkish migration background?
3. How systematically available are culturally sensitive projects, information, and healthcare services for PwM with dementia and their family caregivers in Germany?

To the best of the author's knowledge, this will be the first study that breaks down the number of PwM with dementia by migration background and federal states. Furthermore, it attempts to illustrate measures that can be implemented to improve utilisation of healthcare services by PwM from the perspective of family caregivers for PwM with dementia. Therefore, this study aimed to find solutions by approaching the people affected and talking to them about their situation instead of talking about them without their input, which has been advised in previous studies [48]. This information is used to derive a first model for easier navigation of the healthcare system for PwM with dementia and their family members. Furthermore, also to the best knowledge of the author, this is the first study that depicts the scope of culturally sensitive information and healthcare services for PwM with dementia and their families and projects on dementia and migration. This reveals the current efforts of healthcare service providers and the gaps in this area, and, therefore, identifies where further action is required to provide PwM (with dementia) with optimal care and information.

These research questions guided the scientific work during the PhD phase, and a variety of articles have been published in peer-reviewed international journals and books [50-56]. A selection of these analyses and results that serve as the basis of this dissertation are presented in the following sections, along with unpublished results [57-59].

3. METHOD

A variety of methodological approaches were applied to answer the research questions. A review as well as quantitative and qualitative methods were used to investigate the different aspects of this topic.

3.1 Research question 1: Estimated number of people with a migration background with dementia

In this section, the number of PwM with possible dementia estimated to live in Germany are presented, according to different migration backgrounds and regions in Germany.

A quantitative approach was used to estimate the number of PwM possibly affected by dementia. In this approach, the dementia prevalence rates for all the countries of origin were applied to the number of PwM aged 65 or older in the respective migration groups in Germany. The prevalence rates were obtained from Alzheimer Europe's 'Dementia in Europe Yearbook 2013' and the 'World Alzheimer Report 2015' from Alzheimer's Disease International. The number of PwM aged 65 or older in Germany was provided by the German Statistical Office. This data is for Germany as a whole and additionally shows how many people aged 65 or older from different countries of birth are living in the federal states. The prevalence rates as well as the data on the numbers of PwM are publicly available. The results from the calculations show the estimated number of PwM with dementia in every federal state and in the whole of Germany, as well as the countries and continents that most of the affected people originate from on a national and federal state level. Details of the methodological procedures can be found at Monsees, Hoffmann, and Thyrian (2019).

3.2 Research question 2: Experiences and healthcare utilisation of people with a Turkish migration background

In this section, the experiences of family caregivers with a Turkish migration background in caring for a person with dementia are discussed. Furthermore, their utilisation and evaluation of the available healthcare and information services and their recommendations for improvement is investigated.

A qualitative design was chosen to obtain individual views on the topic of interest and in-depth responses from participants on their experience of caregiving, why they choose (or not) to utilise healthcare services, and what can be done to increase utilisation. Eight persons with a Turkish migration background who are currently or were in the past caring for a relative with dementia were interviewed. Characteristics of the interview participants are provided in Table 1

(appendix). The participants were recruited via stakeholders from the same cultural background in the field of dementia and migration in a snowball sampling method to obtain access to a ‘difficult-to-reach’ population. The interview followed a semi-structured guide that was developed in cooperation with the University of Wisconsin. A wide range of topics were included, such as the caregiving experiences and the care situation at home, formal and informal help, and recommendations on improvements for healthcare services. Examples from the interview guide are available in the appendix (Table 2). The interviews were conducted between June 2018 and March 2019 at venues most convenient for the participants. Qualitative content analysis according to Mayring was used, with a combination of deductive and inductive coding. For more details on the participants, the interview guide, data collection, and analysis, see Monsees et al. (2020).

3.2.1 ORIGINALLY INTENDED PROCEDURE

The actual process in this study differed from what was originally planned. The initial intention was to interview people with Turkish, Russian, and Japanese migration backgrounds for this study. Those from Turkey and Russia were selected because these are two of the largest migrant groups in Germany, and people from Japan were considered because there was already contact with a stakeholder (convenience sampling). However, despite a significant effort to recruit participants and extremely motivated contact persons, it was extremely difficult to recruit any interview participants. Eventually, only three people with a Russian migration background participated in the interviews and none with a Japanese migration background. As previously mentioned, the contact persons were extremely motivated and it was not difficult to find them, and they would have been in a position to talk about people with a Russian or Japanese migration background. However, the aim was to talk to the actual PwM to obtain their point of view, not to have an external assessment. The contact persons reported that the PwM are sceptical about and/or afraid of research and the extent of the consent forms was too daunting, which were cited as the main reasons why the PwM did not want to participate in the study. Therefore, it was decided to only use the interviews with the people with a Turkish migration background for the analysis. PwM are a ‘difficult-to-reach’ population for research, and, as a result, studies often have a small number of participants with a migration background [44, 47, 60, 61]. A systematic study by George et al. (2014) cited stigma, mistrust, and fear of participating as some of the reasons for the low participation in research of PwM [62].

3.3 Research question 3: Scoping review on culturally sensitive healthcare services and projects for people with a migration background with dementia

In this section, healthcare services that are culturally sensitive for PwM (with dementia) and projects on dementia and migration in Germany are systematically analysed. The identified services and projects are described in relation to the target population, the type, and the region where they are available. It is assessed whether the distribution of these services mirror the distribution of PwM with dementia in Germany and where there are gaps.

A scoping review was chosen to find and analyse the data. This type of review provides the opportunity to include information on a topic for which not much scientific research is available. It aids in the determination of the amount of information available, or more specifically in this case, the scope/spectrum of available healthcare services and projects, and to identify gaps in service provision. Available intercultural and culturally sensitive healthcare services were detected and located with the ‘Netzwerkkarte’ created by Demenz Support Stuttgart. The ‘Netzwerkkarte’ was chosen because it is the only source that provides an overview of existing healthcare and information services and projects for PwM (with dementia) in Germany. The ‘Netzwerkkarte’ is on the website www.demenz-und-migration.de, which was launched in September 2019; is funded by the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth and the Robert Bosch Stiftung and is regularly kept up-to-date. Further projects were searched for in a systematic search: 1) websites of the following research funders: BMBF, BMG, DFG, and DLR; 2) the databases PsycInfo, PsycArticles and Psychology & Behavioral Sciences Collection; and 3) Google Search, because the search in the databases and the websites of research funders yielded no results. In addition, the German Alzheimer Society was approached about projects for dementia and migration. To read more about the methods used, see Monsees, Öztürk and Thyrian (2022).

4. RESULTS

The quantitative analyses, qualitative interviews, and scoping review yielded interesting results with important information and possible implications for affected PwM, healthcare service providers, and healthcare professionals. A selection of the results from all the analyses and their limitations are described in the following paragraphs.

4.1 Research question 1: Estimated number of people with a migration background with dementia

The analyses show that of 18.6 million PwM in Germany, 1.9 million are aged 65 or older. In this population, an estimated 96,500 people probably have dementia. Table 3 illustrates that the most frequently affected PwM presumably originate mainly from Poland (14,000), Italy (8,900), Turkey (8,800), Romania (6,400), and the Russian Federation (6,300). This is reflected on the continents of origin in Figure 1 and Table 4 (see appendix), where it is evident that PwM

Table 3 Most frequently affected groups of people with a migration background in Germany			
Country	Prevalence	Number of people > 64	Number of people with dementia
Poland	7.27%	192,000	13,960
1. Generation		187,000	13,600
Italy	8.92%	100,000	8,920
1. Generation		98,000	8,740
Turkey	4.25%	208,000	8,840
1. Generation		207,000	8,800
Romania	7.14%	90,000	6,430
1. Generation		89,000	6,360
Russian Federation	4.60%	137,000	6,300
1. Generation		136,000	6,260
Austria	8.24%	75,000	6,180
1. Generation		69,000	5,690
Croatia	7.65%	73,000	5,590
1. Generation		73,000	5,590
Kazakhstan	4.20%	96,000	4,030
1. Generation		96,000	4,030
Ukraine	4.60%	47,000	2,160
1. Generation		46,000	2,120
Serbia	4.60%	34,000	1,560
1. Generation		33,000	1,520
USA	6.40%	16,000	1,020
1. Generation		13,000	830
Iran	4.70%	16,000	750
1. Generation		16,000	750
Morocco	6.00%	11,000	660
1. Generation		11,000	660
Egypt, Algeria, Lybia, Tunisia	6.00%	8,000	480
1. Generation		8,000	480
Syria	4.70%	8,000	380
1. Generation		8,000	380

with dementia presumably mostly originate from Europe (84,500), mainly from other European countries (50,600), Asia (9,000), and America (1,900). Unpublished data from this study indicates that people with dementia originating a) from Poland mostly reside in North Rhine-Westphalia (6,000), Bavaria (1,400) and Lower Saxony (1,200); b) those from Italy mostly dwell in Baden-Württemberg (2,900) and North Rhine-Westphalia (2,400); and c) those from Turkey mostly live in North Rhine-Westphalia (3,200) and Baden-Württemberg (1,300) (Table 5, in appendix). Overall, the majority of PwM with dementia live in North Rhine-Westphalia (26,000), Baden-Württemberg (18,100), and Bavaria (16,700). Federal states that house the smallest number of PwM with dementia are Brandenburg and Saxony-Anhalt (650 respectively), Thuringia (530), and Mecklenburg-Western Pomerania (470) (Table 6, in appendix & Figure 2). Figure 1 also shows the distribution of PwM with dementia in Germany. It is possible that the validity of these calculations is limited because the two sets of prevalence rates are based on a systematic review or a meta-analysis. The differences in the underlying

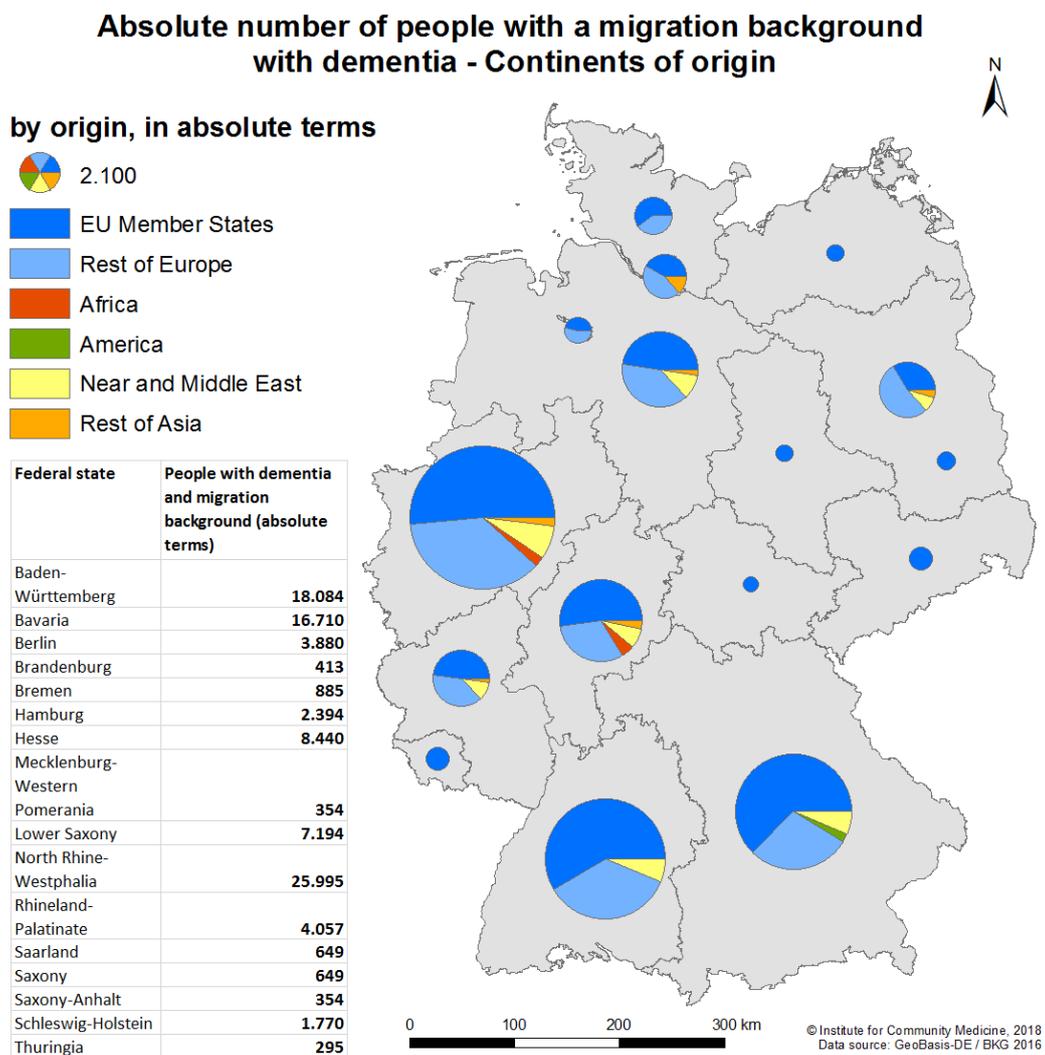


Figure 1 Absolute number of people with a migration background with dementia in the federal states - Continents of origin

Absolute number of people with a migration background with dementia

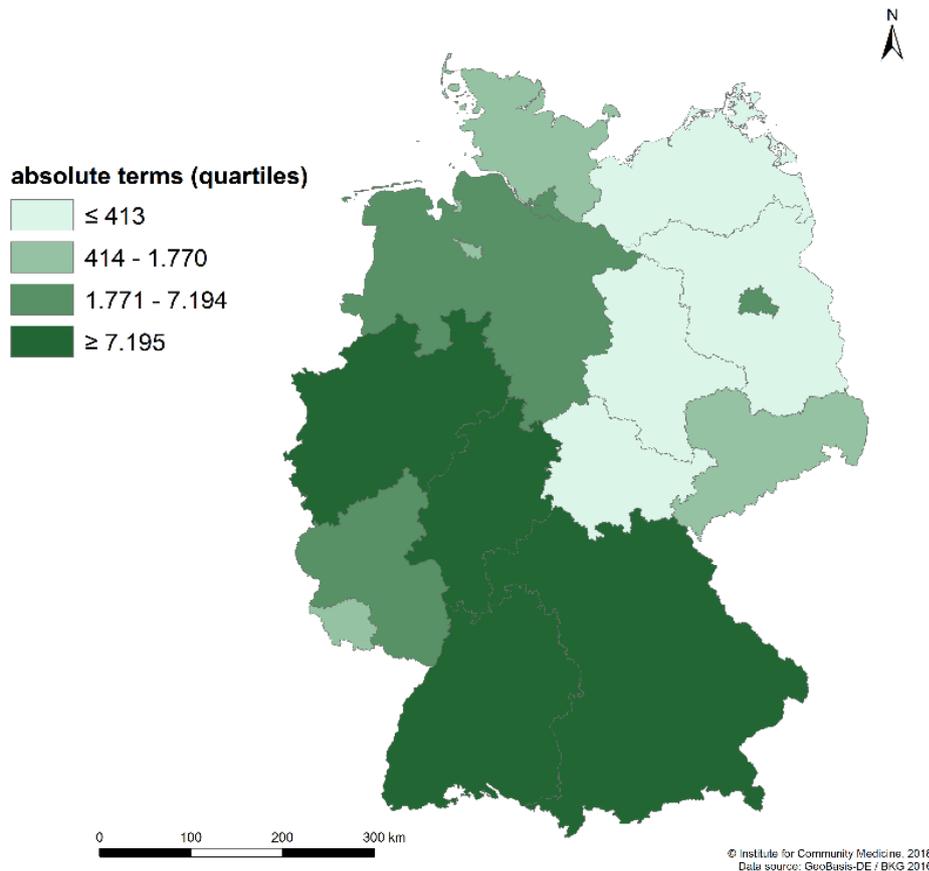


Figure 2 Absolute number of people with a migration background with dementia in the federal states

calculations in this study. Therefore, interpretations of the results have to be made carefully [57].

4.2 Research question 2: Experiences and healthcare utilisation of people with a Turkish migration background

The interviews with family caregivers of PwM with dementia yielded multi-faceted results and showed that, while there are similarities in the care of persons with dementia between people with and without a migration background, there are divergent characteristics that are equally important and have to be considered in the care of PwM with dementia and their families. The findings were grouped into five categories, namely care situation, prior knowledge, challenges, utilisation of healthcare services, and recommendations [58].

4.2.1 CARE SITUATION

Participants reported that care within the family is a matter of course and the deciding factor in the care is a family member requiring assistance. One person, who is supported by other family

studies of the systematic review and the meta-analysis in terms of methodology, quality, or the number of studies on dementia prevalence, which differs from country to country, can all have an impact on the dementia prevalence rates derived from the studies. In turn,

this could have influenced the

members and neighbours, is mainly responsible for the care. The majority of the interviewees shared that there are negatives associated with caring, such as stress and challenges [58].

4.2.2 PRIOR KNOWLEDGE

Before the family member developed dementia, the participants had only limited knowledge of this condition and did not know where to find information or what healthcare services are available. In some cases, existing knowledge was not correct. To close this knowledge gap, the participants consulted general practitioners, people working in the field of dementia, health and nursing care insurance companies, courses and literature on dementia, and had conversations with other people who have experienced this condition [58].

4.2.3 CHALLENGES

The greatest challenges experienced by the interviewees are night-time activity of the person with dementia, the fact that a family member is changing, the need to watch the person with dementia at all times, lack of time for oneself, aggressiveness, forgetfulness, refusal of help, and attempts to run away by the person with dementia. As a consequence, they report lack of sleep, exhaustion, depression, constraints in their personal lives and livelihoods, headaches and other physical pain, stress, and feelings of sadness regarding the irreversibility of the disease. One positive outcome that was experienced by one participant is the wish to care for other people with dementia once the family member with dementia passes. Coping mechanisms to deal with the consequences include being patient, paying close attention to the PwM with dementia, explaining everything to the family member, seeking help from professionals, reminding oneself that dementia is a disease, taking things lightly, providing love, seemingly capitulating to the wishes of the affected person, and treating the person with dementia like a child [58].

4.2.4 UTILISATION OF HEALTHCARE SERVICES

A lack of knowledge about healthcare services, regardless of whether nonculture-specific or culture-specific, no proper information on the available services, difficulties in obtaining information, fear of what other people would think about the utilisation, refusal of the services by the person with dementia, concerns about financial constraints, and a lack of available places in the care services were reasons cited for low or non-utilisation of the healthcare services. Transferring the family member into a nursing home was strictly not an option for the interviewees, as that would mean that the person with dementia did not raise their children

properly and that the children are ‘bad people’. Moreover, it is a tradition that children want to show the same love and affection that they received from their parents [58].

4.2.5 RECOMMENDATIONS

Two areas for improvement were identified, namely in the availability of information and in the actual healthcare services. The interviewees want information on dementia and the healthcare services, and the healthcare system should be easier to access. One way to achieve that could be through culture-specific consultants who could visit the affected people at home and provide them with personalized/contextualized information on what can be done in each individual situation. Another suggestion was that younger people should be educated and receive appropriate information, for example, by offering courses on dementia at school. The participants also suggested that healthcare services could be more culture- or language-specific, for example, by employing staff from a Turkish migration background. This would aid potential users in identifying with the services and feeling enabled to engage, especially since language is an important factor in culture and connection.

With these results, it was possible to devise a model that allows for easier navigation in the healthcare system for people with dementia and their families from Turkish migration backgrounds by implementing current concepts (Figure 3). A key component in this model is a navigator on the community level who provides information and support in accessing the healthcare system and formal healthcare services. These navigators should be either from the same culture or at least have a thorough knowledge of and familiarity with Turkish culture. On the healthcare system level, institutions and healthcare professionals should be culturally sensitive. Gatekeepers are specialized options and could serve as an additional way to support affected people to access to the healthcare system.

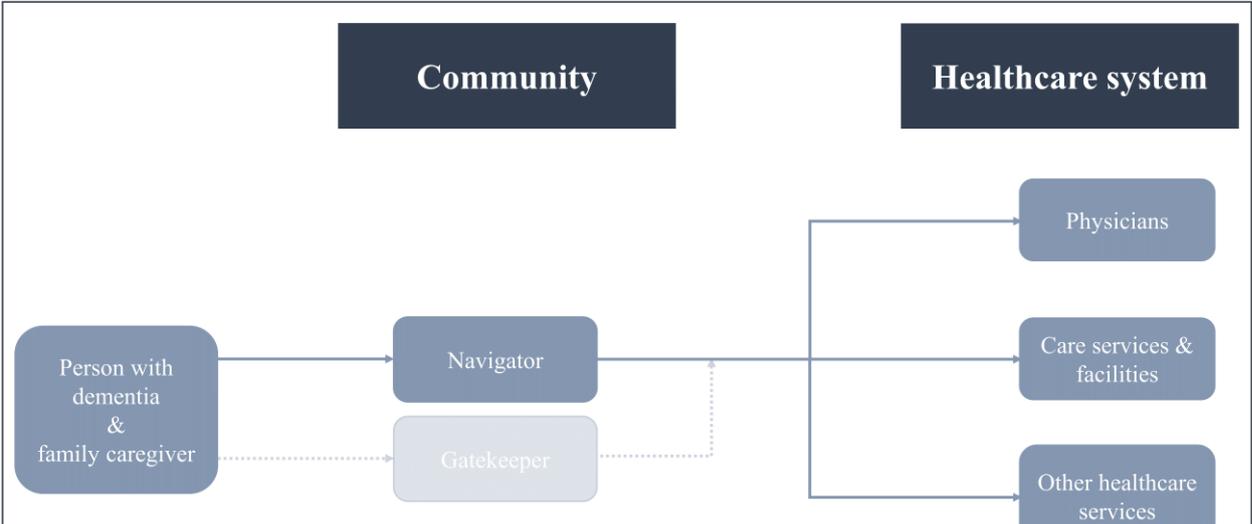


Figure 3 Proposed approach for navigation in the healthcare system

The limitations to the findings are a result of the difficulties in recruiting. Finding interview partners from a migration background who were willing to talk about their experiences was a difficult and tedious task that resulted in a small and selective sample. Hence, a selection bias might be present in this study. This sample might not be representative for the entire population from a Turkish migration background since a majority of the participants could be considered to be integrated into the healthcare system and quite pro-active in seeking help. If PwM who are not integrated into the healthcare system were interviewed, there might have been more findings and/or the findings might have been different [58].

4.3 Research question 3: Scoping review on culturally sensitive healthcare services and projects for people with a migration background with dementia

In the scoping review, 48 projects and culturally sensitive healthcare and information services for PwM with dementia in Germany were identified (see Table 7). These are largely located in North Rhine-Westphalia (12 services), Baden-Württemberg (7), Bavaria, and Hesse (5 each), which mirrors the fact that a large majority of PwM and PwM with dementia live in these federal states. Brandenburg, Mecklenburg-Western Pomerania, Rhineland-Palatinate, and Saxony-Anhalt do not seem to offer any services or projects, while up to four services could be found for each of the other six federal states. Although the findings range from information and consultation in different languages, inpatient and outpatient care, residential communities and training people of different cultures to be able to provide information on dementia, to efforts to connect stakeholders with one another to implement culturally sensitive information and healthcare services, most of the findings involve counselling in different languages. The findings show that there is effort in educating and taking care of PwM with dementia and their families. However, the results also reveal a gap in healthcare services that should be further investigated. Information and healthcare services should not only be available in every region but also adapted to the needs of people of different migration backgrounds.

There has to be some caution regarding these findings. The search strategy led to a selective sample that probably cannot provide a conclusive overview. There are many people engaging in or improving care for PwM, but this is often not made public or made known to a broader audience. Hence, there might be a selection bias in the sample and the ‘Netzwerkkarte’ on culturally sensitive information and healthcare services, initiatives, or projects involving dementia and migration [59].

Table 7 Overview of services, information, and projects

Location	Number	Type	Language(s)
Germany	4 (1 ended in 2019)	Counselling Support services Care services Information Networking	Turkish, Russian, Italian, Greek, Serbo-Croat, Polish, Spanish, Arabic, Vietnamese
North Rhine- Westphalia	12	Counselling Care services Training	Turkish, Greek, Russian, multi- lingual
Baden-Württemberg	7	Counselling Information Care services Support services	Turkish, Russian, Polish, Greek, Arabic, Croatian, Italian
Bavaria	5	Counselling Support services Training	Turkish, Russian, Arabic, Italian, Greek, Serbo-Croat, Polish, Spanish, Vietnamese
Hesse	5	Counselling Care services Support services	Turkish, Russian
Berlin	4	Counselling Support services	Turkish, Serbo- Croat, Spanish, Russian, Arabic, Vietnamese
Saxony	3	Counselling Care services	Russian, Vietnamese
Hamburg	2	Care services Counseling	Turkish, multilingual
Lower Saxony	2	Counselling	Turkish, Russian, Italian
Bremen	1	Counselling Support service	Turkish
Saarland	1	Information	Turkish, Arabic, Russian, English, Italian
Schleswig-Holstein	1	Counselling	Turkish, Russian, Polish
Thuringia	1	Counselling	Russian, Arabic
Brandenburg, Mecklenburg- Western Pomerania, Rhineland- Palatinate, Saxony- Anhalt	/	/	/

5. DISCUSSION

As is discussed in the following sections, this study revealed a) the number of PwM with dementia, the differences in terms of how many of them live in each of the federal states, and from which migration background they come; b) the challenges PwM with dementia and their families encounter in accessing and utilising the healthcare system; and c) the clear lack of culturally sensitive services adapted to individual situations in the respective regions in terms of healthcare structures and the numbers of PwM with dementia and their migration backgrounds. These results align with previous findings in the literature but also reveal new insights.

5.1 Research question 1: Estimated number of people with a migration background with dementia

To better serve PwM with dementia and their families and to support the healthcare system, the service providers and healthcare professionals in resource planning and building a culturally sensitive focus, it is important to know the numbers of affected PwM. To the author's best knowledge, this is the first time that estimated numbers of PwM with dementia in Germany has been broken down by migration backgrounds and by the federal states where those affected are living. The determinations on a federal state level can enhance state-specific healthcare planning, which is imperative since the states differ considerably in terms of the numbers of affected PwM and their migration backgrounds. This means that each region has to find individual solutions since a 'one-size-fits-all' solution cannot be applied.

5.2 Research question 2: Experiences and healthcare utilisation of people with a Turkish migration background

The results from the participants with Turkish migration backgrounds in this study align with other findings on PwM in the literature. Therefore, based on the empirical results, it was possible to design a model to aid PwM (with dementia) to navigate the healthcare system by implementing certain existing healthcare structures nationwide. The results also support previous findings on PwM with dementia being at special risk of incorrect diagnoses and less utilisation of healthcare services, so they should be flagged as a vulnerable group by the healthcare system.

5.3 Research question 3: Scoping review on culturally sensitive healthcare services and projects for people with a migration background with dementia

Furthermore, this dissertation provides an overview of culturally sensitive healthcare services and projects and reveals gaps in terms of geography and type of information and available healthcare services. These findings show that more research, transfer of knowledge, and systematic access to and availability of culturally sensitive information and healthcare services are needed, as well as more funding for and projects on dementia and migration. In addition, this study supports raising awareness of existing services, which is regarded as an important measure to support PwM with dementia and their families in the German National Dementia Strategy [49].

This is important information for the healthcare system and healthcare service providers to tailor their services to the needs of PwM, and it also shows where culturally sensitive services are required. As shown further along in this dissertation, the project ‘EU-Atlas: Dementia & Migration’ examines similar research questions on a European level, and comparable results have emerged [54]. This emphasises the fact that dementia and migration is not just an issue in Germany but a topic of international importance.

5.4 Challenges in the field of dementia and migration

Working in the field of dementia and migration is challenging. One of these challenges is that there is no consensus on a term and definition for PwM that is used globally. There are different terms, such as PwM, migrant/immigrant, or ethnic minority. Migrant and immigrant are terms with no conclusive definitions. These can be people who were born in a different country, have migrated to permanently/temporarily live in another country, or have a different nationality. People from ethnic minorities have cultural identities that differ from that of the majority ethnic group [15]. The United Nations Migration Agency uses the term migrants and defines it as persons who are not living in their habitual place of residence [14]. The Federal Statistical Office in Germany uses the term PwM, while Ireland uses ethnic minorities and Sweden uses the term people born abroad [53]. Therefore, one has to decide on a definition to use in a study and be mindful of the limitations of the definition, which is important to consider when analysing and interpreting results. This has an influence on studies on dementia and migration in general and, therefore, also on this study.

The numbers established on the prevalence of dementia in PwM in this dissertation have to be interpreted with caution since they can differ with a different definition. For example, if a

definition of PwM establishes that a person has a migration background if they live in a different country from where they were born, the numbers would be somewhat different since only the first generation of PwM would be included in the calculations (see Table 6, in appendix). Moreover, the prevalence is also influenced by other factors, such as the prevalence rates used. There is an option to apply the prevalence rate of the country where PwM are living, and there is an option to use the prevalence rate of the country PwM originate from. It is important to know that the validity of these prevalence rates differ from country to country, since studies on this topic have not been conducted in every country, so some countries may have a plethora of studies while others only have a few or none. In addition, the methodology of the conducted studies differ [6]. Moreover, the conditions in which PwM live also have an impact on the prevalence rates. For example, risk factors in the countries where they are residing, such as difficulties with access to healthcare services (e.g. social exclusion and racism can prevent access), poor living conditions, or ongoing violence can have negative impacts on their health outcomes [19, 21]. These are just some of the factors that make it difficult to pinpoint the exact number of PwM with dementia. Nevertheless, the analyses in this study still provide valuable and useful information for the healthcare system, healthcare services, and healthcare professionals among others.

Another challenge in this field is the provision of culturally sensitive healthcare to PwM with dementia. An estimate of the number of PwM with dementia is, therefore, one step towards adapting to culturally sensitive healthcare services in the different regions in Germany. Currently, North Rhine-Westphalia, Baden-Württemberg, and Bavaria have the highest number of healthcare services available. This is reflected in the number of PwM with dementia living there since these are the federal states where most PwM and PwM with dementia reside. The services consider the linguistic backgrounds of the groups of PwM who live in the respective federal states to a large extent. Federal states with a lower number of PwM with dementia seem to either have no services at all, for example, Mecklenburg-Western Pomerania and Saxony-Anhalt, or only a small number of services, such as in Thuringia or Saarland. There are exceptions, such as Lower Saxony that seemingly offers only two services in spite of housing a relatively high number of PwM with dementia [59]. This shows that, although the federal states each house a significant number of PwM with dementia to varying degrees, there seems to be an insufficient quantity of a) culturally sensitive healthcare services in the federal states and b) services that consider the different groups of PwM.

5.5 Education of people with a migration background

The shortage of culturally sensitive healthcare services is only part of the reason why PwM with dementia and their families are a vulnerable population in healthcare. The lack of knowledge about dementia, the healthcare system, and the services with potential benefits for affected people also plays an important role [29, 41]. The interviews done for this study confirmed this circumstance [58]. An important aspect of support to PwM with dementia and their families is to educate and inform them and also the healthcare professionals and service providers. Thorough education can help to reduce stigma, increase skills and knowledge to deal with dementia and increase the utilisation of healthcare services and help-seeking behaviour [32, 37]. PwM have to be educated about dementia, the services in the healthcare system, how they can potentially benefit from those services [27, 28, 32, 36, 37, 45], and the importance of timely diagnosis and adequate and person-centred care [28, 32]. Furthermore, cultural beliefs that might aggravate their situation should be discussed, such as the belief that accepting formal help is shameful or means deserting the person with dementia and that dementia is a taboo subject [44, 45]. In addition, it is important to stress that formal healthcare services do not replace the care provided by the family but supports and complements the family in providing care [15, 44]. The education has to be culturally and linguistically appropriate [32], and it would be best if it is designed as targeted awareness and public education programmes for all ages, with active outreach [27, 30, 44, 45] and information in different languages and formats, phrased in simple and familiar words in a culturally appropriate context [29, 31, 45]. Boughtwood et al. (2011) and Xiao et al. (2015) noted that bilingual/bicultural health professionals are essential to help with providing information. To further decrease the stigma associated with dementia, it could be helpful to involve influential (religious) leaders of the community. For instance, they could help to facilitate educational courses in religious buildings [36]. Developing and using existing culturally specific radio programmes and newspapers could be another way to approach PwM [15, 32]. In some countries, there are or have been efforts to inform PwM about dementia and to provide support via education programmes, such as community-based health education workshops [64], an internet-based caregiver support service [65], or a computer- and smartphone-based dementia care education programme for Asian American family caregivers [66]. These are initiatives for informing PwM about dementia and possible support measures in a culturally sensitive way that should be widely available.

5.6 Education of healthcare professionals

Moreover, it is not enough to just inform and educate PwM; it is essential to provide education and training opportunities to healthcare service providers and healthcare professionals regarding intercultural care, cultural sensitivity, and the healthcare needs of PwM with dementia and their families to ensure timely diagnosis and adequate care [32, 36]. The healthcare system and services can be adapted to provide adequate care and to interact with the affected people in a non-discriminatory and supportive way. For instance, studies involving general practitioners revealed that they want information on how to care for PwM with dementia, specifically regarding communication, specific diagnostic instruments, culturally sensitive care, and specialised healthcare services for PwM with dementia, and how to address cultural differences [31, 45]. They require further education on the health beliefs of PwM and how that influences health behaviour [29]. Awareness of the possible influence of cultural and traditional beliefs on the caregiving situation is important. In some cultures, it is expected that female family members will exclusively provide caregiving [28, 48]. In some PwM families, caregiving is done within the family because of a sense of filial piety and because children want to give back to their parents for the care they received during their childhoods [28, 29, 32, 33, 42, 44, 47, 58]. In other cultures, the community would disapprove and it would mean to fail in the caretaking duty if the formal healthcare services are utilised to help with the care [27, 33, 42, 47, 58]. Addressing false beliefs among healthcare professionals regarding PwM, such as assuming that PwM who care for a family member with dementia would not want or accept formal help is another important aspect in educating them [34, 42, 46]. Many PwM have met with negative experiences, such as racism and discrimination, in the healthcare system [27, 34, 46], and studies have shown that healthcare professionals are sometimes concerned about being accused of racism and unsure on how to interact with PwM [34, 38]. Educating healthcare professionals would help to decrease their concerns and build cultural sensitivity and confidence [38]. This would enable healthcare professionals to avoid discriminatory and potentially racist behaviour and to build fruitful relationships with PwM with dementia and their families.

5.7 Cultural sensitivity of healthcare services

As described in the following section, some of the challenges that people with a Turkish migration background encounter regarding dementia are also encountered by people with other migration backgrounds. A recommendation on how to deal with these challenges has recently been published [51]. It states that not enough has been done to integrate this population into the

healthcare landscape, which is why culturally sensitive solutions, such as the proposed model to navigate the healthcare system in this study (see Figure 3), are necessary. Some PwM might be hesitant to utilise healthcare services since there are concerns that a focus on Western cultures would be prevalent, and healthcare providers might not be sensitive to their religions or cultures [27, 44, 46, 47, 58]. This concern, coupled with a lack of culturally sensitive services [27-29, 34, 35, 44, 47, 59], can lead to PwM not seeking healthcare. A more focused approach to diversity sensitivity in healthcare services and among healthcare professionals, together with a person-centred approach, can improve the care for a diverse society [39]. It is also important to be inclusive, supportive, and non-discriminatory of age, cognitive competence, and migration background [46]. In addition, healthcare professionals have to be cautious to not stereotype PwM based on their migration backgrounds [38, 46]. Therefore, it is essential to invest in the cultural sensitivity and competence of healthcare professionals and healthcare services [27, 63] to provide adequate intercultural care to PwM with dementia and their families [28]. Incorporating cultural elements and employing staff who share the cultural background of PwM with dementia can help to form a common bond and to deliver culturally sensitive care [28, 67]. For example, low-threshold information and consulting services should be available in the mother tongues of PwM [30]. In general, bilingual/bicultural healthcare professionals can act as a link between healthcare services and PwM and provide information, support the utilisation of healthcare services, and interact with services on behalf of the PwM with dementia and their families [63]. As pointed out in Monsees et al. (2020), some of the challenges that PwM with dementia and their families encounter are also encountered by people with dementia who do not have a migration background. Therefore, it might be worth considering adapting existing programmes and healthcare services that have been proven to be beneficial to people with dementia, so that these programmes will be more culturally sensitive to meet the needs of PwM with dementia. The interviewees noted that they do not necessarily want services that are specifically geared to PwM only, but that the services should be more inclusive of other cultures. Therefore, adapting a programme such as the dementia care management (DCM) approach to be more culturally sensitive might be useful [58]. The DCM programme was successfully implemented in Mecklenburg-Western Pomerania by the ‘Deutsches Zentrum für Neurodegenerative Erkrankungen (DZNE)’ Rostock/Greifswald. Specifically trained dementia care managers provide support and advice to people with dementia and their families and do home-visits to examine individual situations on site [68].

As previously mentioned, intercultural care for PwM with dementia is a complex issue, and different measures and approaches have to be considered. Alzheimer Europe (2018) published

a report titled 'The development of intercultural care and support for people with dementia from minority ethnic groups'. This report describes challenges in the diagnosis and care of PwM with dementia as well as the important aspects of intercultural care. A person- and relationship-centred approach to care and support should be implemented in specialised as well as mainstream services [15]. Just as pointed out in the author's study [59] the Alzheimer Europe report also stresses that these culturally sensitive healthcare services should be widely available. PwM with dementia and family caregivers should be included in the design of culturally sensitive information and healthcare services and provide input into how the services can best facilitate opportunities for PwM to practise their religion or to guarantee that PwM can continue with their traditions and be provided with food and activities that are culturally sensitive. To guarantee that the culturally sensitive services and information are adequate, it is important to obtain feedback from PwM and to adapt services and information accordingly [15].

Another important factor is the training healthcare professionals should receive regarding intercultural care. They can build trusting and respectful relationships when they are aware of differences in cultures and are culturally competent [15, 29, 58]. As a supporting measure, Alzheimer Europe published a guide titled 'Intercultural dementia care: A guide to raise awareness amongst health and social care workers' to aid those working in health and social care in their understanding of and interactions with PwM with dementia and their families. The topics include information about 'minority ethnic groups and dementia'; 'different cultural approaches to dementia care'; 'intercultural care and support'; and 'language and communication'. Healthcare professionals learn about dementia, PwM, and how PwM possibly understand dementia, and how they can care for a family member with dementia. They are also taught about cultural characteristics such as, for example, appearance, religious customs, and food; how to communicate verbally and non-verbally; the significance of multilingual staff; how to include the family in care; and how working with the families can facilitate the development of intercultural services [55].

5.8 Key measures on an administrative and political level to ensure intercultural care

Ensuring nationwide availability of low-threshold intercultural information and healthcare services should be a priority, not only for healthcare professionals and healthcare service providers but also for law- and decision-makers. Motivated healthcare professionals and service providers are needed, but their work should be facilitated from a higher level. This means that administrators should support the healthcare professionals in the decision-making processes and allow them the time and freedom to act flexibly to adequately meet the needs of PwM with

dementia and their families [34]. Further, stability in care is essential [33, 38, 67], because this ensures that healthcare professionals have adequate knowledge of the PwM with dementia [67] and avoids any confusion on the part of the patients and their families [33]. In addition, decision-makers on administrative and political levels must aid and enable PwM to access services. PwM might be concerned about the high costs of healthcare services or have other financial barriers [30, 34] or transportation issues, which also has to be addressed. Healthcare services should be easily accessible. If the services are not available everywhere, guaranteed transportation options must be available to facilitate access to the services [35, 36].

5.9 Outlook

This dissertation has shown that PwM (with dementia) are not only a vulnerable group but also lack healthcare services and information tailored to their needs. These results should be regarded as a starting point to delve deeper into this topic and can provide recommendations on how this could be done. Although there are efforts towards providing culturally sensitive information and healthcare services in Germany, more can be done, and the information in this study can aid the healthcare system and healthcare professionals to tailor their services to the needs of these groups. However, ensuring access to information and healthcare services also involves the expansion of healthcare services in the future. Low-threshold intercultural healthcare services have to be implemented in every region [30, 59]. However, this might not be feasible everywhere. A possible alternative solution might be to employ professional caregivers of various migration backgrounds to work flexibly, depending on where they are needed [67]. Another measure is to expand existing structures. For example, in some regions in Germany, there are so-called ‘intercultural dementia navigators’. These navigators are PwM who have been trained to inform PwM with dementia and their families about dementia, the services of the healthcare system, the healthcare system itself, and the steps required to obtain help [69, 70]. These are useful measures to integrate PwM who find it difficult to obtain the right information regarding the healthcare system, and these measures should be implemented nationwide, free of charge [15, 58]. Interdisciplinary cooperation and networking of all parties involved in healthcare is required to provide information and healthcare services. This includes healthcare professionals [15, 32, 34, 38, 45], mainstream and specialised healthcare services, [15, 38, 45], interpreters [38], policy makers, politicians, and other stakeholders [71]. Germany’s first National Dementia Strategy not only calls for the implementation of low-threshold counselling services but also that the services interact with other culturally sensitive establishments and migrant organisations [49], for example, the ‘DeMigranz’ project in Germany. On the one hand, DeMigranz aims to educate PwM with dementia and their families

about dementia and to lend support in accessing healthcare services. On the other hand, the nationwide initiative aims to establish culturally sensitive information and healthcare services and networks in every federal state that will connect stakeholders and representatives from migrant organisations, the healthcare system, communities, and politics. The goal is to encourage networking and collaboration among interested parties in this field and to strengthen existing care structures [71].

Cooperation is required on a national level as well as an international level. The main findings from this study are not only a phenomenon in Germany but also in other European countries. Germany is not the only country with a significant number of PwM with dementia. Canevelli et al. (2019) showed that, in the EU and EFTA countries, there are an estimated 476,500 PwM with probable dementia. These numbers range from 108 (Iceland) to 119,161 (France), and in most countries there are relevant estimated numbers of PwM with dementia. This emphasises the significant amount of PwM with dementia and, therefore, the need for culturally sensitive care for this population. However, there is a need for more analyses on the estimated number of PwM with dementia in Europe, which is provided in the EU-atlas on dementia and migration [54] and is described in the next section. Furthermore, the literature shows that, also in other countries than Germany, dementia-related services are often not culturally sensitive, sufficient in number, and/or available everywhere. For instance, Nielsen et al. (2015) noted these circumstances in the Nordic European countries, and Parveen and Oyeboode (2018) found the same situation in the UK. Altogether, these results emphasise the need for action on a European level.

This reveals that caring for PwM with dementia and their families is not only a national matter but a universal challenge, and that achieving the goal of providing support for PwM with dementia and their families in their unique situations requires cooperation. The Alzheimer Europe report (2018) on intercultural care highlights the need for a system that facilitates the exchange of information on healthcare services and support between healthcare professionals and healthcare services. One important key element for this is the generation and collection of data on PwM with dementia. Every country should generate data on this topic on a national level. Providing data and information to the healthcare system, healthcare professionals, stakeholders working in dementia and/or migration, and politicians is important to create a basis for them to provide culturally sensitive care and deal with the challenges of PwM with dementia. Therefore, a thorough overview of this topic on a European level is needed. The project 'EU-Atlas: Dementia & Migration' does exactly that and provides estimates on the numbers of PwM with dementia in the EU, EFTA, and UK countries, with graphical

presentation as well as analyses of national dementia plans and national guidelines on diagnosis, treatment, and care of patients with dementia, and if they focus on PwM. Furthermore, analyses of services and support from healthcare systems are provided. With this information, the atlas aims to support organisations and healthcare professionals working with PwM but also serves to support ‘strategically developing healthcare systems and its services on a political level in laws, policies, strategies, and action plans’ [54] and it could support efforts to find an international solution. This international solution can then serve as a base for European-wide cooperation between researchers, healthcare professionals, healthcare service providers, representatives of healthcare systems, law-makers, and other stakeholders in the field of dementia and migration to coordinate, exchange information and experiences, and develop ideas and solutions to support PwM with dementia and their families. Of course, healthcare systems, the organisation of healthcare, and laws regulating healthcare differ from country to country. However, cooperation on this matter still provides opportunities to learn from other countries and the way they address this issue. An example of networking between researchers and people working with PwM (with dementia) is the INTERDEM taskforce on intercultural care. The members of this taskforce are working together to raise awareness of and generate more knowledge on this topic. This is a great first step in raising awareness on this topic on a European level and support European-wide networking and cooperation. Furthermore, European-wide conferences should be conducted to further encourage networking, exchanging knowledge and experiences, and learning from one another.

6. SUMMARY

Literature shows that people with a migration background (PwM) with dementia are an especially vulnerable group. Data on the number of PwM with dementia in Germany is scarce meaning the healthcare system faces a challenge of an unknown magnitude. They are mostly not part of the healthcare landscape and lack knowledge about dementia and healthcare services. Healthcare professionals and services do not seem to be culturally sensitive enough and not adequately equipped to take care of PwM with dementia. Therefore, this work focuses on a) estimating the number of PwM with dementia broken down by country of origin and federal state; b) exploring the caregiving experience, barriers of healthcare utilisation and measures to increase utilisation; and c) determining the scope of culturally sensitive information and healthcare services as well as projects on dementia and migration in Germany. A combination of quantitative and qualitative research methods as well as a scoping review are applied to examine the research focus.

Calculations show that an estimated 96,500 PwM have dementia, presumably mostly originating from Poland, Italy, Turkey, Romania, and the Russian Federation. The majority of affected PwM live in North Rhine-Westphalia, Baden-Württemberg, and Bavaria. Family members experience similar challenges and consequences as non-migrants in the care of a person with dementia. PwM lack sufficient knowledge of dementia and information regarding the available healthcare services. These are only two of the reasons why the healthcare system is not utilised. To increase utilisation, services should be culturally sensitive and information easily accessible. In addition, easier navigation and the expansion of existing healthcare structures is needed. The scoping review identified 48 culturally sensitive healthcare and information services and projects for PwM with dementia. The majority are located in North Rhine-Westphalia, Baden-Württemberg, Bavaria, and Hesse, which mirrors the distribution of PwM with dementia in Germany. For the most part, these services offer counselling in different languages. These results confirm that PwM (with dementia) and healthcare professionals need in-depth education on this topic. There should be a focus on the design of information and healthcare services that are tailored in a culturally sensitive way. This dissertation further indicates that culturally sensitive healthcare services, personalised for individual situations on site, should be expanded and also facilitated by not only healthcare professionals and service providers but also by law- and decision-makers. Furthermore, there is a need for cooperation between researchers, healthcare professionals, service providers, healthcare systems, law-makers, and other stakeholders in the field on a national and an international level.

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8. APPENDIX

Table 1 Characteristics of participants and the care situation

Partici- pant	Age, sex	Who is cared for	Main caregiver	Duration of caregiving	Living arrangement	Formal help or services
T1	Female, 38	Father	Brother of T1	/	Father lives with brother of T1	No
T2	Female, 52	Father	T2	1 year	Multigenerational house	No
T3	Female, 57	Father & mother	T3	13.5 years (3.5 years at T3's home)	Father lived with T3 Mother lives with T3	Yes
T4	Female, 52	Mother	T4	8 years	Mother lives with T4	Not anymore
T5	Female, 31	Grandmother	Mother of T5	/	Grandmother lives with daughter (T4)	Not anymore
T6	Female, 36	Mother	Brother of T6	/	Mother lives with brother of T6	Yes
T7	Female, 56	Mother	Son of T7	/	Mother lives on her own	Yes
T8	Male, 49	Mother	Wife of T8	4 years	Mother lives on her own	Yes

Table 2 Question guide – Examples

Category	Question
Background	Can you tell me a bit about [person with dementia]? What is your relationship to [person with dementia]? How long have you been caring for [person with dementia]? Before you started taking care of [person with dementia] did you have any other caregiving experience?
Caregiving experience	How has it been caring for [person with dementia]? What are the hardest things about caregiving for [person with dementia]? What are the most rewarding things about caregiving for [person with dementia]? Can you describe a time when you needed to get support or information to take care of [person with dementia]?
Informal resources	Are other family members or friends involved in taking care of [person with dementia]? What things make it difficult to involve family/friends in [person with dementia]'s care?
Formal resources	Are there any services you are using to help with [person with dementia]'s care? How did you find this service? How often do you use this service? How has this service been meeting [person with dementia]'s and your needs? What is working well with this service? What kinds of problems do you find with this service? Would you say your interactions with people from this service are generally positive or negative? How could this service be improved for people in the future?
Differences in healthcare systems	What differences exist in the healthcare system between [country of origin] and Germany? Are there dementia-specific healthcare services in [country of origin]?

Table 4 Frequency of dementia among people with a migration background, broken down by continent

Continent	Prevalence	Number of people > 64	Number of people with dementia
Europe	5.90%	1,432,000	84,490
1. Generation		1,384,000	81,660
<i>EU</i>	5.90%	857,000	50,560
1. Generation		826,000	48,730
Asia	4.70%	191,000	8,980
1. Generation		190,000	8,930
America	6.40%	30,000	1,920
1. Generation		25,000	1,600
<i>North America</i>	6.40%	18,000	1,150
1. Generation		13,000	830
<i>Central and South America</i>	6.40%	12,000	770
1. Generation		12,000	770
Africa	6.00%	27,000	1,620
1. Generation		27,000	1,620
Australia	6.70%	-	-
1. Generation		-	-

Table 5 The 5 most frequently affected groups of people with a migration background in the federal states

	1. Country of origin	2. Country of origin	3. Country of origin	4. Country of origin	5. Country of origin
Baden-Württemberg	Italy 2,850	Romania 2,140	Croatia 1,840	Turkey 1,280	Poland 1,160
Bavaria	Austria 2,720	Romania 2,500	Croatia 1,530	Poland 1,380	Greece 1,100
Berlin	The Russian Federation 320	Turkey 850	/	/	/
Brandenburg	/	/	/	/	/
Bremen	/	/	/	/	/
Hesse	Italy 980	Poland 950	Turkey 810	Croatia 610	Austria 580
Hamburg	Turkey 380	Poland 360	/	/	/
Lower Saxony	Poland 1,240	The Russian Federation 880	The Netherlands 720	Turkey 640	Italy 620
Mecklenburg-Western Pomerania	/	/	/	/	/
North Rhine-Westphalia	Poland 5,960	Turkey 3,150	Italy 2,410	Greece 1,940	The Russian Federation 1,660
Rhineland Palatinate	Poland 510	The Russian Federation 410	Turkey 340	Kazakhstan 290	/
Saarland	/	/	/	/	/
Saxony	/	/	/	/	/
Saxony-Anhalt	/	/	/	/	/
Schleswig-Holstein	/	/	/	/	/
Thuringia	/	/	/	/	/

Table 6 People with a migration background (PwM) with dementia in Germany

	PwM	Number of people > 64	Number of people with dementia
Total	18,576,000	1,862,000	96,470 (5.18%)
1. Generation		1,814,000	
Baden-Württemberg	3,251,000	357,000	18,080 (5.07%)
1. Generation		349,000	
Bavaria	2,956,000	317,000	16,710 (5.27%)
1. Generation		310,000	
Berlin	991,000	79,000	3,940 (4.99%)
1. Generation		78,000	
Brandenburg	162,000	15,000	650 (4.33%)
1. Generation		14,000	
Bremen	205,000	20,000	940 (4.72%)
1. Generation		19,000	
Hamburg	538,000	46,000	2,390 (5.20%)
1. Generation		45,000	
Hesse	1,870,000	171,000	8,440 (4.94%)
1. Generation		168,000	
Lower Saxony	1,557,000	150,000	7,190 (4.80%)
1. Generation		147,000	
Mecklenburg-Western Pomerania	102,000	11,000	470 (4.29%)
1. Generation		10,000	
North Rhine-Westphalia	4,873,000	500,000	26,000 (5.20%)
1. Generation		482,000	
Rhineland Palatinate	920,000	86,000	4,060 (4.72%)
1. Generation		83,000	
Saarland	199,000	19,000	830 (4.35%)
1. Generation		19,000	
Saxony	267,000	23,000	940 (4.10%)
1. Generation		22,000	
Saxony-Anhalt	140,000	15,000	650 (4.33%)
1. Generation		15,000	
Schleswig-Holstein	414,000	42,000	1,770 (4.21%)
1. Generation		40,000	
Thuringia	131,000	12,000	530 (4.43%)
1. Generation		12,000	

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Prävalenz von Demenz bei Menschen mit Migrationshintergrund in Deutschland

Im Jahr 2013 lebten 16,5 Mio. Menschen mit einem Migrationshintergrund in Deutschland, wovon ca. 1,5 Mio. älter sind als 65 Jahre. Für diese Population existieren bisher keine systematischen Angaben zur Anzahl Demenzerkrankter, was das Gesundheitssystem vor eine Herausforderung stellt, deren Dimension kaum einzuschätzen ist. In diesem Beitrag wird daher anhand verschiedener frei zugänglicher Datensätze die Prävalenz von Demenz für verschiedene Ethnien in Deutschland und deren Verteilung auf die einzelnen Bundesländer geschätzt.

Hintergrund

In Deutschland wird die Prävalenz an Demenz erkrankter Menschen auf ca. 1,5 Mio. Menschen geschätzt, wobei die Prävalenz jährlich steigt. Die Inzidenz wird mit 300.000 Neuerkrankungen/Jahr angegeben. Aktuelle Prognosen zufolge wird sich die Anzahl der Erkrankten bis 2050 auf 3 Mio. Menschen erhöhen [5]. Die hohe Inzidenz und Prävalenz stellen eine Herausforderung für das Gesundheitssystem und die Gesellschaft als Ganzes dar [7, 26]. Aus diesem Grund wurde am 19. September 2012 die „Allianz für Menschen mit Demenz“ durch die Bundesfamilienministerin und den Bundesgesundheitsminister gegründet [6]. Ziele der Allianz sind die Weiterentwicklung von Hilfen und Unterstützung für Betroffene sowie die Förderung von Verständnis und Sensibilität für Men-

schen mit Demenz und ihre pflegenden Angehörigen. Beim Umgang mit der Demenz sind nicht nur medizinische und pflegerische Aspekte zu beachten. Genauso wichtig ist ein biografischer, sozialer, kultureller und spiritueller Zugang zu den betroffenen Menschen, ihren Familien und ihren pflegenden Angehörigen [18, 22]. Demenzversorgung muss kultursensibel sein!

Eine Handlungsempfehlung der Allianz besagt deshalb: „Das Versorgungssystem muss daher individuell ausgerichtet sein und passende Unterstützungsangebote [...] bieten [...] für Menschen mit Migrationshintergrund [...]“ [8]. In Deutschland lebten im Jahr 2013 16,5 Mio. Menschen mit Migrationshintergrund. Das waren 20,5% der Gesamtbevölkerung [9]. Bei geschätzten 1,5 Mio. Menschen mit Migrationshintergrund, die älter als 65 Jahre sind, wird die Gruppe der Demenzerkrankten eine relevante Größe in der Versorgung darstellen. Der Wissensstand über diese Gruppe ist jedoch derzeit unzureichend. Migrationshintergrund stellt einen Risikofaktor für die Gesundheit dar [4]. Besondere Gruppen von Migranten nehmen verfügbare Gesundheitsleistungen [16], darunter auch Pflegeleistungen [25], kaum in Anspruch. Da die Demenz in Deutschland unterdiagnostiziert ist [13], ist davon auszugehen, dass dies bei der Gruppe der Migranten eher noch ausgeprägter der Fall ist. Gründe für die geringere Inanspruchnahme werden auf Sprachbarrieren/Analphabetismus [2], kulturelle Unterschiede im Verständ-

nis von Krankheit/Gesundheit oder im Umgang damit [3, 17, 18] oder das Fehlen kulturspezifischer Informationen und Angebote [2] zurückgeführt. Ein erheblicher Anteil von Personen mit Migrationshintergrund wird nur schwer vom Gesundheitssystem erreicht, und, wo dies gelingt, kommt es häufig zu Problemen in der Verständigung [2, 21]. Eine differenzierte Schätzung der Anzahl an Demenz erkrankter Menschen mit verschiedenem Migrationshintergrund ist notwendig, um die Größe und Art der Herausforderung auf das Gesundheitssystem abschätzen und ihr durch differenzierte Planung begegnen zu können. Eine Studie aus dem Jahre 2014 schätzte die Zahl der Menschen mit Migrationshintergrund mit einer demenziellen Erkrankung auf 105.543 [11]. Jedoch beruht diese Schätzung nicht auf länderspezifische Prävalenzen. Stattdessen wurden die für Deutschland geltenden Prävalenzzahlen auf die verschiedenen Gruppen angewandt. Zudem wurde für die Analyse nicht nach einzelnen Ethnien unterschieden, sondern generell nach Menschen mit Migrationshintergrund, Ausländern und (Spät-)Aussiedlern.

Das Ziel der vorliegenden Analyse ist eine nach Bundesländern und Prävalenzen in den Heimatländern der verschiedenen Ethnien differenzierte Schätzung der Zahl an Demenz erkrankter Menschen mit Migrationshintergrund in Deutschland.

Tab. 1 Menschen mit Migrationshintergrund (MmM) und Demenz in Deutschland

	MmM n	>65 n	Mit Demenz n (%)
<i>Total</i>	18.576.000	1.862.000	96.474 (5,18)
1. Generation	–	1.814.000	–
<i>Brandenburg</i>	162.000	15.000	649 (4,33)
1. Generation	–	14.000	–
<i>Berlin</i>	991.000	79.000	3939 (4,99)
1. Generation	–	78.000	–
<i>Baden-Württemberg</i>	3.251.000	357.000	18.084 (5,07)
1. Generation	–	349.000	–
<i>Bayern</i>	2.956.000	317.000	16.710 (5,27)
1. Generation	–	310.000	–
<i>Bremen</i>	205.000	20.000	944 (4,72)
1. Generation	–	19.000	–
<i>Hessen</i>	1.870.000	171.000	8440 (4,94)
1. Generation	–	168.000	–
<i>Hamburg</i>	538.000	46.000	2394 (5,20)
1. Generation	–	45.000	–
<i>Mecklenburg-Vorpommern</i>	102.000	11.000	472 (4,29)
1. Generation	–	10.000	–
<i>Niedersachsen</i>	1.557.000	150.000	7194 (4,80)
1. Generation	–	147.000	–
<i>Nordrhein-Westfalen</i>	4.873.000	500.000	25.995 (5,20)
1. Generation	–	482.000	–
<i>Rheinland-Pfalz</i>	920.000	86.000	4057 (4,72)
1. Generation	–	83.000	–
<i>Schleswig-Holstein</i>	414.000	42.000	1770 (4,21)
1. Generation	–	40.000	–
<i>Saarland</i>	199.000	19.000	826 (4,35)
1. Generation	–	19.000	–
<i>Sachsen</i>	267.000	23.000	944 (4,10)
1. Generation	–	22.000	–
<i>Sachsen-Anhalt</i>	140.000	15.000	649 (4,33)
1. Generation	–	15.000	–
<i>Thüringen</i>	131.000	12.000	531 (4,43)
1. Generation	–	12.000	–

Methode

Die Analyse basiert auf der Zusammenführung verschiedener, öffentlich verfügbarer Datensätze zur Prävalenz von Demenz und zu Bevölkerungszahlen von Menschen mit Migrationshintergrund.

Die Definition des Statistischen Bundesamtes beschreibt, dass „einen Migrationshintergrund hat, wer durch Geburt nicht die deutsche Staatsangehörigkeit besitzt oder wer mindestens einen Elternteil hat, der durch Geburt nicht die deutsche Staatsangehörigkeit besitzt“.

Dazu zählen in erster Linie Ausländer, (Spät-)Aussiedler und Eingebürgerte, aber auch deren Kinder [9]. Soweit möglich wird diese Differenzierung in den Analysen berücksichtigt. Die Daten des Statistischen Bundesamtes werden nach Geschlecht und Bundesland getrennt aufgeführt.

Die Konzeptualisierung von Demenz orientiert sich an den Vorgaben, die Alzheimer's Disease International und Alzheimer Europe für ihre Berechnungen zugrunde gelegt haben. Diese schließen Menschen ein, die 60 bzw. 65 Jahre alt

sind und eine diagnostizierte Demenz aufweisen, die nach klinischen Kriterien festgestellt wurde [1, 19].

Für die Analysen wurden folgende Datensätze verwendet:

1. *Dementia in Europe. Yearbook 2013* der Alzheimer Europe. Alzheimer Europe listet hier für verschiedene europäische Länder die Anzahl der Demenzerkrankten in verschiedenen Alterskategorien auf [1].
2. *World Population Prospects. Key findings & advance tables* der United Nations (2017) führt für verschiedene Länder die Gesamtpopulation auf [27].
3. *World Population Prospects Volume II: Demographic Profiles* der United Nations (2017). Die United Nations geben hier an, wie hoch der prozentuale Anteil der über 65-Jährigen an der jeweiligen Population eines Landes ausfällt [28].
4. *World Alzheimer Report 2015* der Alzheimer's Disease International. Hier werden Prävalenzzahlen für Personen ab 60 Jahren verschiedener Weltregionen, wie Europa, Asien oder Afrika und deren Subregionen, angegeben [19].
5. *Bevölkerung und Erwerbstätigkeit. Bevölkerung mit Migrationshintergrund – Ergebnisse des Mikrozensus 2016* des Statistischen Bundesamtes (2017). Im Mikrozensus wurden im Rahmen einer Zufallsstichprobe 365.700 Haushalte mit 744.000 Personen u. a. zu verschiedenen demografischen und soziodemografischen Merkmalen befragt. Die hier genutzte Fassung fokussiert dabei auf die Lage der Menschen mit Migrationshintergrund [9].

Um angeben zu können, wie viele Menschen mit einem Migrationshintergrund in Deutschland schätzungsweise eine demenzielle Erkrankung aufweisen, wurden im ersten Schritt Prävalenzen für Demenz der verschiedenen Herkunftsländer ermittelt. Dafür wurden für Bulgarien, Frankreich, Griechenland, Italien, Kroatien, Niederlande, Österreich, Polen, Portugal, Rumänien, Spanien, die Türkei und das Vereinigte Königreich diese Prävalenzen anhand des

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Prävalenz von Demenz bei Menschen mit Migrationshintergrund in Deutschland

Zusammenfassung

Hintergrund. In Deutschland lebten 2013 16,5 Mio. Menschen mit Migrationshintergrund, wovon schätzungsweise 9 % älter als 65 Jahre sind. Sie zeigen häufig schlechtere Gesundheitsoutcomes als Menschen ohne Migrationshintergrund, aber aus verschiedenen Gründen werden Gesundheits- und Pflegeleistungen kaum genutzt. Für diese Population gibt es keine systematischen Angaben zur Anzahl Demenzerkrankter. Dies hat zur Folge, dass das Gesundheitssystem vor einer Herausforderung steht, dessen Dimension kaum einzuschätzen ist.

Ziel. Darstellung der Prävalenz von Demenz bei Menschen mit Migrationshintergrund für Deutschland und die einzelnen Bundesländer.

Methode. Länderspezifische Daten zu Bevölkerung, Demenzerkrankten und altersspezifischen Prävalenzen wurden genutzt, um länderspezifische Prävalenzen für verschiedene Ethnien zu berechnen. Daraus wurde die Anzahl von Menschen mit Migrationshintergrund und Demenz in Deutschland geschätzt, und wie diese sich auf die Bundesländer verteilen.

Ergebnisse. Von 1,86 Mio. Menschen mit Migrationshintergrund in Deutschland, die 65 Jahre oder älter sind, sind schätzungsweise 96.500 Personen (5,2 %) an Demenz erkrankt. Der Großteil entfällt auf Menschen mit polnischem (13.960), italienischem (8920) und türkischem (8840) bzw. europäischem Hintergrund (84.490). Die vermutlich höchsten

Erkrankungszahlen zeigen Nordrhein-Westfalen (26.000), Baden-Württemberg (18.080) und Bayern (16.710).

Diskussion. Unsere Analysen zeigen die Anzahl an Demenz erkrankter Menschen mit Migrationshintergrund separat für ausgewählte Herkunftsländer als auch die deutschen Bundesländer. Dies bildet eine erste Grundlage für eine länderspezifische Handlungssteuerung und die Planung kultursensibler Angebote zur Versorgungsverbesserung der an Demenz erkrankten Menschen mit Migrationshintergrund.

Schlüsselwörter

Demenz · Migration · Prävalenz · Versorgung · Deutschland

Prevalence of dementia in people with a migration background in Germany

Abstract

Background. In Germany the number of people with a migration background was 16.5 million people in 2013 with 9% being older than 65 years. In this population utilization of health services is low, especially in older people, although they often display worse health outcomes. Little is known about the number of people with dementia and migration background in Germany and their distribution on the state level, resulting in a challenge that is barely assessable for the healthcare system.

Objective. The depiction of the prevalence of dementia in people with a migration background for Germany and the individual federal states.

Method. The number of people with a migration background and dementia living in Germany and the individual federal states was estimated for different ethnic groups using country and state-specific data on the population, dementia frequency and age-specific prevalence.

Results. Out of 1.86 million people with a migration background who are 65 years or older, approximately 96,500 persons (5.2%) have dementia. The majority are of European (84,490), more specifically Polish (13,960), Italian (8920) and Turkish (8840) heritage. North Rhine-Westphalia (26,000), Baden-Wuerttemberg (18,080) and Bavaria (16,710)

are presumed to show the highest rates of people affected.

Conclusion. In Germany people with a migration background and dementia represent a large target group for health care; however, the numbers and ethnic populations affected differ considerably between states. These analyses can be used for state-specific healthcare planning of culture-specific and culture-sensitive services and care so that specific healthcare improvements can be achieved.

Keywords

Dementia · Migration · Prevalence · Health care · Germany

Dementia in Europe. Yearbook 2013, des World Population Prospects. Key findings & advance tables und des World Population Prospects Volume II: Demographic Profiles geschätzt, indem der prozentuale Anteil der Demenzerkrankten aus einem Land an dessen Population der über 65-Jährigen bestimmt wurde. Für Bosnien, Kosovo, die Russische Föderation, Serbien, die Ukraine, Marokko, Ägypten, Algerien, Libyen, Tunesien, die Vereinigten Staaten, Irak, Iran, Kasachstan, Syrien, Afghanistan, China, Indien, Pakistan, Vietnam, Australien

und Ozeanien wurden die Prävalenzzahlen des „World Alzheimer Report 2015“ verwendet. Diese länderspezifischen Prävalenzen für Demenz wurden angewandt auf die jeweiligen Gruppen von Menschen mit Migrationshintergrund, die in Deutschland leben und über 65 Jahre alt sind. Die Angaben zu den hier lebenden Menschen mit Migrationshintergrund wurden aus *Bevölkerung und Erwerbstätigkeit. Bevölkerung mit Migrationshintergrund – Ergebnisse des Mikrozensus 2016* entnommen. Das Produkt aus der Anzahl von Menschen

mit Migrationshintergrund über 65 Jahre einer Ethnie und der entsprechenden Herkunftslandprävalenz stellt die Anzahl derer dar, die in dieser Gruppe eine demenzielle Erkrankung aufweisen.

Die Anzahl an Menschen mit einem Migrationshintergrund und einer Demenz wurde für jedes Herkunftsland bestimmt und daraufhin für die einzelnen Bundesländer und für ganz Deutschland aufaddiert. Anschließend wurde der prozentuale Anteil der Erkrankten an der Population der Menschen mit

Tab. 2 Ethnien mit den häufigsten Demenzerkrankungen in Deutschland

Nationalität	Prävalenz %	Anzahl der Menschen >65 n	Anzahl der Menschen mit Demenz n
<i>Polen</i>	7,27	192.000	13.959
1. Generation	–	187.000	13.595
<i>Italien</i>	8,92	100.000	8920
1. Generation	–	98.000	8742
<i>Türkei</i>	4,25	208.000	8840
1. Generation	–	207.000	8798
<i>Rumänien</i>	7,14	90.000	6426
1. Generation	–	89.000	6355
<i>Russische Föderation</i>	4,60	137.000	6302
1. Generation	–	136.000	6256
<i>Österreich</i>	8,24	75.000	6180
1. Generation	–	69.000	5686
<i>Kroatien</i>	7,65	73.000	5585
1. Generation	–	73.000	5585
<i>Kasachstan</i>	4,20	96.000	4032
1. Generation	–	96.000	4032
<i>Ukraine</i>	4,60	47.000	2162
1. Generation	–	46.000	2116
<i>Serbien</i>	4,60	34.000	1564
1. Generation	–	33.000	1518
<i>Vereinigte Staaten</i>	6,40	16.000	1024
1. Generation	–	13.000	832
<i>Iran</i>	4,70	16.000	752
1. Generation	–	16.000	752
<i>Marokko</i>	6,00	11.000	660
1. Generation	–	11.000	660
<i>Ägypten, Algerien, Libyen, Tunesien</i>	6,00	8000	480
1. Generation	–	8000	480
<i>Syrien</i>	4,70	8000	376
1. Generation	–	8000	376

Migrationshintergrund über 65 Jahre errechnet.

Im nächsten Schritt wurde aus diesen Angaben eine Auflistung der 15 Ethnien mit den höchsten geschätzten Erkrankungszahlen in Deutschland zusammengestellt.

Schließlich wurde eine kontinent-spezifische Aufschlüsselung der Häufigkeit von Demenzerkrankungen bei Menschen mit Migrationshintergrund erstellt. Hierfür wurden aus dem *World Alzheimer Report 2015* die kontinent-spezifischen Prävalenzen von Asien, Europa, Amerika, Afrika und Australien übernommen und multipliziert mit der

Anzahl von Menschen aus den jeweiligen Kontinenten, die in Deutschland leben und älter als 65 Jahre sind.

Alle Angaben wurden sowohl für die Gesamtgruppe der Menschen mit Migrationshintergrund als auch für die Gruppe der Personen mit eigener Migrationserfahrung (Personen mit Migrationshintergrund der 1. Generation) berechnet.

Ergebnisse

Wie in [Tab. 1](#) zu sehen ist, lebten in Deutschland im Jahr 2016 18.576.000 Menschen mit einem Migrationshintergrund, von denen 1.862.000 Menschen

älter als 65 Jahre sind. Von diesen entfällt ein Großteil auf die 1. Generation der hier lebenden Personen mit Migrationshintergrund. In dieser Alterskohorte leiden schätzungsweise 96.480 Menschen an einer Demenzerkrankung. Die meisten Erkrankten finden sich mit ca. 93.800 Erkrankten ebenfalls in der 1. Generation. Die größere Anzahl an Personen mit einer demenziellen Erkrankung findet sich im Westen Deutschlands mit ca. 39.300 Erkrankten (in den Neuen Bundesländern ca. 7200 Erkrankte). In Nordrhein-Westfalen (ca. 26.000 Erkrankte), Baden-Württemberg (ca. 18.000 Erkrankte) und Bayern (ca. 16.700 Erkrankte) leben die meisten Betroffenen. Die wenigsten in Brandenburg und Sachsen-Anhalt (je ca. 650 Erkrankte), Thüringen (ca. 530 Erkrankte) und Mecklenburg-Vorpommern (ca. 470 Erkrankte) ([Tab. 1](#)). Nach Herkunftsland stammt die größte Gruppe von Menschen mit einer demenziellen Erkrankung aus Polen (ca. 14.000 Erkrankte), gefolgt von Italien (ca. 8920 Erkrankte), Türkei (ca. 8840 Erkrankte), Rumänien (ca. 6430 Erkrankte) und der Russischen Föderation (ca. 6300 Erkrankte) ([Tab. 2](#)). Aus anderen Kontinenten (Asien, Amerika, Afrika und Australien) stammen 12,97% der an Demenz erkrankten Menschen mit Migrationshintergrund in Deutschland ([Tab. 3](#)).

Diskussion

Die vorliegenden Analysen zeigen die Anzahl der an Demenz erkrankten Menschen mit Migrationshintergrund auf Basis länderspezifischer Prävalenzzahlen separat nach ausgewählten Herkunftsländern sowie summarisch für alle deutschen Bundesländer. Im Ergebnis leben in Deutschland annähernd 96.500 (ca. 5,2%) der 1,86 Mio. Menschen mit Migrationshintergrund mit einer demenziellen Erkrankung. Die Schätzung der Gesamtzahl liegt dabei in einem ähnlichen Bereich wie die Schätzung von Drewniok [11]. Es ist jedoch davon auszugehen, dass die tatsächliche Anzahl der Demenzerkrankten höher liegt, da die Demenz unterdiagnostiziert ist [12, 13] und daher die Verwendung

Tab. 3 Häufigkeit von Demenzerkrankungen von MmM in Deutschland, aufgeschlüsselt nach Kontinenten

Kontinent	Prävalenz %	Anzahl der Menschen >65 n	Anzahl der Menschen mit Demenz n
Europa	5,90	1.432.000	84.488
1. Generation	–	1.384.000	81.656
<i>EU</i>	<i>5,90</i>	<i>857.000</i>	<i>50.563</i>
1. Generation	–	826.000	48.734
Asien	4,70	191.000	8977
1. Generation	–	190.000	8930
Amerika	6,40	30.000	1920
1. Generation	–	25.000	1600
<i>Nordamerika</i>	<i>6,40</i>	<i>18.000</i>	<i>1152</i>
1. Generation	–	13.000	832
<i>Mittel- und Südamerika</i>	<i>6,40</i>	<i>12.000</i>	<i>768</i>
1. Generation	–	12.000	768
Afrika	6,00	27.000	1620
1. Generation	–	27.000	1620
Australien	6,70	–	–
1. Generation	–	–	–

der publizierten Prävalenzrate zu einer konservativen Schätzung führt.

Trotz dieser Limitation ist mit diesen Zahlen eine Aussage zu Demenzerkrankten unter den Menschen mit Migrationshintergrund möglich. Bisher gab es nach bestem Wissen der Autoren keine Analyse, die die Prävalenz von Demenz bei Menschen mit Migrationshintergrund in Deutschland ethnien- bzw. kontinentspezifisch dargelegt hat. Die vorliegenden Zahlen können Einrichtungen und Vertretern des Gesundheits- und Versorgungssystems helfen, die Größenordnung der auf sie zukommenden Herausforderung einzuschätzen und bei der Ressourcenplanung, aber auch bei der kultursensiblen Ausrichtung der Angebote helfen. So kann auf Länderebene die Handlungssteuerung verbessert werden, was relevant ist, da die Bundesländer unterschiedliche Verteilungen hinsichtlich der Menschen mit Migrationshintergrund aufweisen (Tab. 1). Diese Tatsache spiegelt sich entsprechend auch in der Anzahl von Menschen mit einem Migrationshintergrund und einer demenziellen Erkrankung wider, wobei besonders Nordrhein-Westfalen, Baden-Württemberg und Bayern in den kommenden Jahren mit einer deutlich ansteigenden Anzahl an Demenz erkrankter

Menschen mit Migrationshintergrund konfrontiert werden.

Die Allianz für Menschen mit Demenz hat diesbezüglich in einer Handlungsempfehlung angegeben, dass das Versorgungssystem besser auf Menschen mit Migrationshintergrund eingehen muss [8]. Eine notwendige Voraussetzung für die Umsetzung dieser Empfehlung ist die Kenntnis darüber, wie viele Personen mit welchem Migrationshintergrund betroffen sind. Hier soll die vorliegende Analyse eine Lücke schließen.

Die vorliegenden Hochrechnungen weisen mehrere Einschränkungen auf. Zunächst ist unklar, ob es angemessen ist, für die verschiedenen Ethnien die jeweiligen Prävalenzen der Herkunftsländer zu verwenden. Zudem weisen die Angaben zur Prävalenz z. T. große Unterschiede auf, z. B. sind die Prävalenzen von Italien (8,92 %), Österreich (8,24 %) und Kroatien (7,65 %) wesentlich größer als die Prävalenzen von Kasachstan (4,20 %), der Türkei (4,25 %) und der Ukraine und Serbien (je 4,6 %) (Tab. 2). Für diese deutlichen Unterschiede besteht kein berechtigter Grund. Sie könnten aber zum einen durch die angewandte Methodik der Studien erklärt werden. Die Prävalenzraten, die für die Berechnungen herangezogen wurden, beruhen

auf Metaanalysen bzw. einem systematischen Review. Die zugrunde liegenden Studien weisen einige Schwächen auf, z. B. in der Qualität oder aufgrund der Tatsache, dass für einige Länder bzw. Regionen mehr Studien bezüglich Prävalenz vorliegen als für andere Länder. Auch Unterschiede im diagnostischen Prozedere der zugrunde liegenden Studien können zu Unterschieden in den resultierenden Prävalenzangaben führen [19]. Zum anderen kann die Erkrankungsrate von Demenz abhängig sein von der ethnischen Zugehörigkeit, was in einem unterschiedlichen Demenzrisiko resultiert. So konnten Studien in den USA aufzeigen, dass Afroamerikaner und Hispanoamerikaner mit 10,5 % bzw. 7,6 % anstelle von 3,4 % ein höheres Risiko für eine Demenz vom Alzheimer-Typ aufweisen. Dabei ist die Zugehörigkeit zur afroamerikanischen bzw. hispanoamerikanischen ethnischen Gruppe direkt und unabhängig mit der Prävalenz von Alzheimer assoziiert [10, 23]. Darüber hinaus ist ein Großteil der Differenz in der Prävalenz von Demenz noch nicht zu erklären.

Durch die Anwendung dieser Prävalenzen auf der Bundeslandebene wird eine Clusterung von Migration nicht berücksichtigt. Demnach könnten durch die Anwendung vorhandene regionale oder lokale Cluster nicht erfasst werden, oder im Gegensatz werden künstliche Cluster gebildet, die nicht vorhanden sind. Nichtsdestotrotz stellt der hier gewählte Ansatz den mit den zurzeit verfügbaren Daten bestmöglichen Ansatz dar.

Eine weitere Limitation betrifft die nicht immer deckungsgleichen Alterskategorien der herangezogenen Datenquellen. So werden die Prävalenzen der Alzheimer's Disease International auf die Gruppe der Personen ab 60 Jahren bezogen, während in der vorliegenden Hochrechnung diese auf die Altersgruppe der über 65-Jährigen angewandt wurde. Dies bedeutet, dass die entsprechenden resultierenden Zahlen von Erkrankten unterschätzt werden. Weiterhin ist anzumerken, dass die Zahlen des Statistischen Bundesamtes auf Hochrechnungen basieren, die gerundet werden, wobei auch widersprüchliche Zahlen resultieren können. Für das Saarland weisen die

Angaben beispielsweise darauf hin, dass unter den 19.000 Menschen mit Migrationshintergrund, die 65 Jahre oder älter sind, alle über eigene Migrationserfahrungen verfügen, was bedeuten würde, dass es keine Menschen mit Migrationshintergrund in der zweiten Generation gäbe. Genauere Zahlen würden primäre Erhebungen in prospektiven Designs erfordern, die in den betroffenen Gruppen mit erheblichen methodischen Herausforderungen verbunden sind. Jedoch ist es aufgrund vielfältiger Gründe, wie Sprachbarrieren, Angst und Misstrauen, eine Herausforderung, Menschen mit Migrationshintergrund zur Teilnahme an Studien zu bewegen [14, 20]. Zudem besteht die Möglichkeit, dass die hier verwendeten Anzahlen von Personen mit Migrationshintergrund, aber ohne eigene Migrationserfahrung, unterschätzt werden, da diese sich ausschließlich auf Kinder beziehen, die im Haushalt der Eltern leben.

Die hier vorgestellten Hochrechnungen beziehen sich auf das Jahr 2016 und stellen somit nur eine Momentaufnahme dar. Tatsächlich wird der Anteil älterer Menschen mit einem Migrationshintergrund ebenso wie in der deutschstämmigen Bevölkerung ansteigen und damit auch die Prävalenz der demenziellen Erkrankungen. Völlig unklar ist, wie sich die Lage der Menschen der 2. Generation mit einer Demenz darstellen wird. Diese Menschen mit Migrationshintergrund sind in Deutschland geboren und aufgewachsen, deshalb ist anzunehmen, dass sich bei ihnen sowohl Versorgungsbedarfe als auch die Inanspruchnahme von den Personen der 1. Generation unterscheiden. Dies wird in besonderem Maße auf verschiedene Kulturen zutreffen, wobei auch der Erfolg der Integration eine wichtige Rolle spielen wird. Obwohl dies schwer quantitativ belegt werden kann, gehen wir davon aus, dass die Verfügbarkeit von kulturspezifischen Einrichtungen und Angeboten in Deutschland bei Weitem noch nicht ausreicht und in den kommenden Jahren verstärkt auf- und ausgebaut werden muss. Gleichzeitig müssen die Bemühungen zur Erfassung von Primärdaten sowohl zur Morbidität als auch zur Versorgungssituation von Menschen mit Migrationshinter-

grund fortgesetzt und, wo erforderlich, weiter intensiviert werden [15, 20, 24].

Fazit für die Praxis

- Die Gruppe der Menschen mit Demenz und Migrationshintergrund stellt allein von ihrer Anzahl her eine relevante Größe in der Versorgungslandschaft dar. Es besteht Handlungsbedarf bei der Erforschung und kultursensiblen Versorgung der Betroffenen.
- Die Bundesländer sind verschieden stark betroffen. Zum einen, was die Anzahl der Menschen mit Demenz und Migrationshintergrund angeht. Zum anderen, was den Migrationshintergrund angeht. Strategien zum Umgang und zur besseren Versorgung müssen kultursensibel und regional angepasst entwickelt und umgesetzt werden.

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Einhaltung ethischer Richtlinien

Interessenkonflikt. J. Monsees, W. Hoffmann und J.R. Thyrian geben an, dass kein Interessenkonflikt besteht.

Dieser Beitrag beinhaltet keine Studien an Menschen oder Tieren.

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Dementia in People with a Turkish Migration Background: Experiences and Utilization of Healthcare Services

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Abstract.

Background: As the proportion of older people with migration background (PwM) increases, the proportion of older PwM with dementia might also increase. Dementia is underdiagnosed in this group and a large proportion of PwM with dementia and family caregivers are not properly supported. Healthcare utilization is lower among older migrant populations. Thus, a better understanding of how PwM and family caregivers perceive their situation and how they experience healthcare services is needed to improve utilization of the healthcare system.

Objective: Analyze how family caregivers of PwM with dementia experience their situation, why healthcare services are utilized less often, and what can be done to reverse this.

Methods: Eight semi-structured interviews were conducted with people with Turkish migration background caring for PwM with dementia. Qualitative content analysis was used for data analysis.

Results: Daily care was performed by one family member with the support of others. Healthcare services were used by most participants. Participants identified a need for better access to relevant information and incorporation of Turkish culture into healthcare services.

Conclusion: PwM face similar challenges in taking care of persons with dementia as those without migration background. There is a willingness to use services, and services embracing Turkish culture would help to reduce hesitance and make affected people feel more comfortable, thereby increasing utilization and satisfaction. A limitation of this study is that participants were already connected to health services, which may not reflect the help-seeking behavior of those in the Turkish community who are not involved in healthcare.

Keywords: Dementia, healthcare, healthcare services, migration, Turkish migration background, utilization

INTRODUCTION

Germany, like many other European and western societies, faces increasing numbers of people with migration background (PwM) and health problems.

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The Federal Statistical Office of Germany defines migration background as not having German citizenship from birth or having at least one parent who does not have German citizenship from birth. This includes immigrant and nonimmigrant foreigners, immigrant and nonimmigrant naturalized citizens, German resettlers, and descendants born with German citizenship from the former groups [1]. According to census data, the number of PwM amounts to 18.6 million people, accounting for 23% of the population in Germany. In Germany, PwM often experience adverse health-related outcomes [2, 3]. However, they often do not utilize healthcare services to the same extent as those without a migration background, potentially exacerbating health related disparities in this population [2, 4, 5].

Older adults represent a subgroup of special interest in this population. According to census data, 1.99 million PwM are older than 64 years, representing 2.44% of the entire population of Germany and 11.52% of the population 65 years and older [1]. With increasing age, there is a growing probability of chronic and age-associated diseases including dementia [6, 7]. Dementia among people with migration background leads to different challenges for those affected as well as for professionals. For example, if the people affected have limited German language skills, it is problematic for them to communicate their symptoms to professionals; in turn, it is difficult for professionals to administer cognitive tests and interpret the results due to the lack of culturally sensitive cognitive tests and screening instruments, which may contribute to over- and underdiagnosis of dementia [8–11]. Provided both increasing numbers of persons with a migration background and growth in the older adult population and dementia cases, there is a need to better understand the specific problems facing this subpopulation and the healthcare system.

A major barrier to progress in this area is the lack of general research knowledge regarding people with migration background and dementia. For example, if more knowledge was available regarding their unique experiences with treatment and care directly from this population this would aid healthcare and service providers in tailoring their services to this population through more culturally responsive care. This is also critical to helping people with dementia and their family caregivers to engage support and resources to manage their situation. This is even more important when considering that PwM do not comprise one large homogeneous group where everyone with dementia can be treated the same. Similar to

people without migration background, some characteristics are shared by some people but not others; thus, subgroups exist in this population and need to be identified. Recent analyses, for example, have highlighted the country of origin as a subgrouping factor. According to this estimation, approximately 96,500 PwM older than 64 years live with dementia in Germany. The most frequent migration backgrounds are as follows: Asian, Turkish, Polish, Russian, and Italian [12]. While there is little research focusing on Asian, Russian, or Italian countries of origin, there has been some research focusing on people from Turkey [13–16].

The number of people with Turkey as the country of origin in people 65 years and older is approximately 208,000, and the number of people with dementia in this group adds up to approximately 8,900 [12]. Thus, people from Turkey are not only one of the largest groups in the population of PwM in Germany but also in the group of PwM with dementia. Additionally, more research is needed on how to properly include PwM of Turkish background into the healthcare landscape. One previous study has identified challenges in treating and caring for this group. Based on personal interviews ($n=7$) with people of Turkish background, the authors described that participants experienced a lack of knowledge about healthcare services and the fear of violating cultural norms when using professional help and formal services among others. Providing informal support is not guided by the diagnosis but rather that he or she needs help. These results are in line with other research in this field [13, 17, 18].

For the reasons cited above, we assume that dementia is even more underdiagnosed in PwM than in the population in Germany as a whole [19, 20]. This also results in a high unidentified proportion of family caregivers meaning a larger proportion of people in the group of PwM with dementia and their family caregivers are not being optimally supported by the healthcare system. In investigating how to optimally support this population, a practice-oriented approach is needed and it is important to analyze what is required in collaboration with the people affected. Generating such knowledge and using that approach could also help to ensure that cultural sensitivity will not be understood as a stereotyped concept but as a concept with different nuances that considers special characteristics without painting everyone with the same brush [18]. Considering the existing evidence, a need exists for action to determine the reasons for lower utilization of healthcare services and needed

culturally responsive supports specific to dementia and caregiving. Due to a lack of culturally responsive healthcare services, it is important to determine what can be done to design healthcare services that are suitable for people with migration background, thereby increasing the utilization of healthcare services.

The present study focuses on PwM with dementia from Turkey and aims to: 1) examine the caregiving experience of family caregivers; 2) identify barriers to using information and healthcare services for people with dementia (PwD) by people with Turkish migration background; and 3) assess recommendations from the caregivers of PwM with dementia to increase healthcare utilization. The results are important to provide assistance to the healthcare system for a culturally sensitive approach in providing their healthcare services.

METHODS

The study was approved by the University Medicine Greifswald’s ethics committee. A qualitative design was chosen to obtain individual views on the topic of interest and in-depth responses on how participants experience caregiving, why they chose (or not) to utilize healthcare services, and what can be done to increase utilization [21]. The interviews were conducted in German, and quotes for this article were translated.

Participants

To be eligible for the study, the participants had to have a Turkish migration background and be involved in the care of a family member (also with a Turkish migration background) with dementia. Recruiting was performed via snowball sampling to obtain access to a population that is hard to reach [22, 23]. Stakeholders from the field of demen-

tia and migration were contacted via phone or e-mail or at symposia and were asked to help find suitable interview partners. In doing so, Deutsche Alzheimer Gesellschaft, Demenz-Support Stuttgart, Demenz-Servicezentrum Gelsenkirchen, Landesverband der Alzheimer Gesellschaften NRW e. V. and freelance/self-employed individuals, among others, offering culture-specific services for the family members of PwD, were contacted. Additionally, two participants arranged contact for further interviews. The participants lived in North Rhine-Westphalia or Hessen and provided informed consent to participate in the study. The characteristics of the eight participants and their care situation can be found in Table 1.

The interview

The interviews followed a semi-structured question guide that covered a range of topics, including the care situation at home, the experience of caring, help from family and friends, the utilization of healthcare services, preferences regarding healthcare services, and differences in the healthcare systems between the country of origin and Germany (see Table 2).

The question guide was developed in collaboration with the University of Wisconsin-Madison, where it has been applied in investigations of the needs of underserved dementia caregivers living in sociocontextually disadvantaged areas.

Data collection

To obtain data for this study, interviews with informal caregivers with a Turkish migration background were conducted. Despite a long recruiting phase and intensive attempts at recruiting, it was only possible to find $n = 8$ participants who were willing to be interviewed. The first author, a trained psychologist with acquired expertise in qualitative research, con-

Table 1
Characteristics of the participants and the care situation

Participant	Age, sex	Who is cared for	Who is the main caregiver	Duration of caregiving	Living arrangement	Formal help or services
T1	Female, 38	Father	Brother of T1	X	Father is living with brother of T1	No
T2	Female, 52	Father	T2	1 y	Multigenerational house	No
T3	Female, 57	Father & mother	T3	13.5 y (3.5 y at T3’s home)	Father lived with T3 Mother is living with T3	Yes
T4	Female, 52	Mother	T4	8 y	Mother is living with T4	Not anymore
T5	Female, 31	Grandmother	Mother of T5	X	Grandmother is living with daughter (T4)	Not anymore
T6	Female, 36	Mother	Brother of T6	X	Mother is living with brother of T6	Yes
T7	Female, 56	Mother	Son of T7	X	Mother is living on her own	Yes
T8	Male, 49	Mother	Wife of T8	4 y	Mother is living on her own	Yes

Table 2
Question guide—examples

Category	Question
Background	Can you tell me a bit about [person with dementia]? What is your relationship to [person with dementia]? How long have you been caring for [person with dementia]? Before you started taking care of [person with dementia], did you have any other caregiving experience?
Caregiving experience	How has it been caring for [person with dementia]? What are the hardest things about caregiving for [person with dementia]? What are the most rewarding things about caregiving for [person with dementia]? Can you describe a time when you needed to get support or information to take care of [person with dementia]?
Informal resources	Are other family members or friends involved in taking care of [person with dementia]? What things make it difficult to involve family/friends in [person with dementia]'s care?
Formal resources	Are there any services you are using to help with [person with dementia]'s care? How did you find this service? How often do you use this service? How has this service been meeting [person with dementia] and your needs? What is working well with this service? What kinds of problems do you find with this service? Would you say your interactions with people from this service are generally positive or negative? How could this service be improved for people in the future?
Differences in healthcare systems	What differences exist in the healthcare system between [country of origin] and Germany? Are there dementia-specific healthcare services in [country of origin]?

ducted the interviews, which occurred between June 2018 and March 2019 and lasted, on average, 72 minutes. All interviews were recorded and transcribed verbatim. The interviews followed a qualitative semi-structured question guide covering topics such as the care situation at home, utilization of healthcare services, inhibiting and supporting factors of this utilization, and preferences regarding healthcare services. For the interviews, an effort was made to make it as convenient as possible for the participants. It was offered to visit the interview partners at home or another place they wished, the participants could pick a weekday and time that suited them best, and, if desired, it was possible to have a translator present during the interview (either one of the stakeholders, or a family member, or a professional translator).

Analysis

The data were analyzed by the first author using qualitative content analysis [24]. A combination of deductive and inductive category formation was chosen to create the coding framework. Deductive categories were derived from the semi-structured question guide, and inductive subcategories emerged from the conducted interviews. Half of the interviews were utilized to identify additional subcategories that would be of interest for further analysis. These interviews were reviewed in their entirety and were

performed more than once to ensure the coding framework will be encompassing. When no new categories could be derived from the interview material, the coding framework was used to interpret all the conducted interviews line-by-line.

RESULTS

The main findings of the interviews can be classified into five main categories: care situation, prior knowledge, challenges, utilization of healthcare services, and recommendations.

Care situation

The main care was usually provided by one family member. In this study, other family members, such as the husband, children, and neighbors, supported the main caregivers. The people involved in care considered it a matter of course that care was being handled within the family:

'It is natural to me that I take care of my mom.'
(ref. T3, personal translation J. M.).

'This is our mother, this is our father, we have to watch them. They have done so much for us, so we have to take care of them now.' (ref. T4, personal translation J. M.).

The deciding factor in family care was that a family member needs help:

'This is natural, also for my daughter.' (ref. T3, personal translation J. M.).

This view was also shared by one interviewed grandchild:

'Everybody has to help [...] if this happens to my parents, I am not going to let other people take care of them. I will take care of them.' (ref. T5, personal translation J. M.).

Most families reported having no previous experiences with dementia care and PwD. Participants perceived the care situation differently. For most, it was associated with challenges and stress, while one participant reported that taking care of a family member with dementia is fulfilling and being very thankful for the professional help she is getting:

'... it is nice taking care of a family member. It is nicer than taking care of a stranger, isn't it?' (ref. T3, personal translation J. M.).

Prior knowledge

There was only very limited knowledge about dementia beforehand:

'Like, only this online knowledge. What you can read on the internet, just that and nothing more.' (ref. T1, personal translation J. M.).

'I only knew that one forgets, forgets everything.' (ref. T2, personal translation J. M.).

In some cases, this knowledge was not correct:

'Alzheimer's, they are forgetful [...] and dementia is even more extreme.' (ref. T6, personal translation J. M.).

There was no prior knowledge about information and healthcare services for PwD and their caregivers. The reason cited for this was that they did not experience dementia before so they did not occupy themselves with dementia and these kinds of services:

'We experience these things for the first time. We don't have someone in the family with it, so you don't know that.' (ref. T2, personal translation J. M.).

'... maybe I don't have so many friends, that are familiar with this.' (ref. T1, personal translation J. M.).

Sources that were consulted to compensate these knowledge gaps were general practitioners, courses related to dementia, literature regarding dementia, people working in the field of dementia, health and nursing care insurance, and communication with other people in the same situation:

'That is what I learned in the course. This did a lot for me and I won't forget that.' (ref. T2, personal translation J. M.).

'We read a lot of specialized literature [...] watched documentaries [...] talked to people, who are working in that field.' (ref. T5, personal translation J. M.).

Most of the participants were also very proactive in obtaining these information, e.g., calling institutions to learn what one can do, what services one can use, and what help is available:

'I demand from the city. I always call someone. I go to the health insurance and the doctor.' (ref. T2, personal translation J. M.).

'I can talk to the doctor. I can coordinate very well with the doctors.' (ref. T3, personal translation J. M.).

'I called everyone. I searched for help.' (ref. T3, personal translation J. M.).

Challenges

The main challenges reported were the aggressiveness of the family member with dementia, activity at night, forgetfulness, the need to watch the affected person at all times and to accept that the family member is changing:

'She was a "power woman" and that [...] she declined so much was hard to accept.' (ref. T5, personal translation J. M.).

Not having time for oneself and the PwD running away and refusing to accept help were also challenges reported:

'I don't have time for myself or my children or my home.' (ref. T8, personal translation J. M.).

'I would like to, but my mother would never do that.' (ref. T8, personal translation J. M.).

These situations led to several consequences for caregivers. The participants described physical as

well as mental problems. They revealed experiencing stress, headaches and other physical pains, lack of sleep, desperation, exhaustion, a painful feeling due to the recognition of the irreversibility of the disease, depression, and constraints in personal life:

'I took three years off because of my father [...] and I haven't gone anywhere [...] it wasn't possible with my father.' (ref. T3, personal translation J. M.)

Caregivers also reported consequences for their livelihoods:

'Until January he was working and now we closed our shop because we have to watch my mother.' (ref. T4, personal translation J. M.)

Participants also described being hurt by comments made by the PwD.

However, there were also positive outcomes, such as developing the wish to care for other PwD in nursing homes or daycare facilities after their family member will be gone:

'I could imagine myself working as a nurse in a daycare facility.' (ref. T3, personal translation J. M.)

The participants developed several coping mechanisms to deal with their family member and his/her behavior. These were, for example, taking things lightly, explaining everything to the affected person, giving love, seeking help by professionals, treating the PwD like a child, reminding oneself that the family member has a disease:

'She is ill, therefore I can't be mad, it's not her fault.' (ref. T3, personal translation J. M.),

paying close attention to what the family member is doing at all times, being patient, and seemingly giving in to the wishes of the PwD.

Utilization of healthcare services

There was a general willingness to utilize healthcare services, and more than half of the participants are or were using these services, e.g., daycare, prevention care, dementia workshops, nursing service, intercultural "dementia guides," and Turkish dementia cafés. However, reasons for not utilizing these services were a lack of knowledge (regarding culture-specific services as well as nonculture-specific services) and not being properly educated about services:

'There is a pamphlet and other stuff, but if no one explains you everything and if you have never experienced it, then you just don't know. Nobody tells you exactly how it's done and then you don't know.' (ref. T2, personal translation J. M.),

a lack of available places in the care services:

'Right now I don't, because there is no place.' (ref. T2, personal translation J. M.),

difficulty obtaining information about the services, worry about shortage of monetary reimbursement, and fear of what other people might think about someone using these services.

The fact that the PwD would refuse to use services was also mentioned:

'I wanted care, help from the health insurance, but my father would never [...] He would never get showered by a nurse.' (ref. T2, personal translation J. M.)

The option of a nursing home for the PwD was rigorously refused by participants. Participants cited tradition of giving back to parents what parents gave to them:

'Always giving back. That is our tradition. What you got, you want to give back.' (ref. T3, personal translation J. M.)

Participants also noted it is shameful to transfer the parents to a nursing home because it would mean that the parents did not raise their children well and that the children are uncaring:

'It is a shame, if you are put into a nursing home, then this person doesn't have good children, they don't have a good heart, they aren't well-raised people.' (ref. T3, personal translation J. M.)

'This is our tradition, our culture, 99% of Turkish people think like that.' (ref. T3, personal translation J. M.)

The fear of what other people might think is also a major factor of hindering service utilization:

'Well, what would others think? [...] my brother didn't want to, for him it is still, others would think that the children left the mother alone.' (ref. T6, personal translation J. M.)

Recommendations

Participants generally would like to use healthcare services, and most are or were using services. They also voiced limitations in existing services and noted room for improvement but were not sure how services could best be improved. However, participants offered several suggestions regarding dementia and healthcare services, which can be divided into two areas. One area is information. The participants wished for an easier way to obtain information about dementia, the healthcare system and healthcare services—for example, through culture-specific consultants who are employed by health and nursing care insurance. These consultants could visit the PwD at home and provide personalized/contextualized recommendations about what can be done in each individual's situation. Furthermore, information should already be distributed to people at a younger age, e.g., by teaching dementia courses in schools.

The second area concerns the healthcare services themselves. Considering the rising numbers of PwM, the participants would like healthcare services to be more culture-specific so potential users could identify with them and feel enabled to engage:

'Well, I think it is important, so that they can identify themselves with it [...] that's why it is important that there are services that consider the culture or language. So one feels more understood, also as a family member.' (ref. T5, personal translation J. M.).

A big help in achieving this would be employment of staff with a Turkish migration background at healthcare institutions because language is an important aspect of culture and connection. PwM with dementia forget their German language skills, and it is easier for them and their family members to express what they are meaning and (especially) feeling in Turkish.

'... same language would be important, although my grandmother can speak German [...] but not in a way that she can express emotions...' (ref. T5, personal translation J. M.).

DISCUSSION

The primary goals of this study were to depict the experiences of caregivers of people with dementia and a Turkish migration background, determine the

reasons for the lower utilization of healthcare services by people with a Turkish migration background diagnosed with dementia and their family, and assess what can be done to reverse this circumstance from their point of view.

Our analyses revealed that PwM face similar challenges in taking care of PwD as people without migration background, e.g., difficulties with increased night activity, aggressiveness, the need to be alert at all times, and being stressed or facing job constraints [25–27]. To deal with these challenges, different coping mechanisms and measures are undertaken, e.g., reminding oneself that dementia is a disease and the PwD is not at fault, explaining everything to the PwD, and being patient with him/her.

Importantly, when the present participants were asked what they would like to have regarding services and if they wanted culture-specific services, most did not wish for services that are solely for people with a Turkish migration background. Instead, participants requested that existing services are more open to Turkish culture. Most Turkish participants experienced pronounced difficulties in obtaining information and/or a lack of information. One participant complained about not getting help and having to inform herself about everything related to dementia. Therefore, it seems to be a challenge to disseminate existing information to people with a Turkish migration background. These findings are in line with the "Allianz für Menschen mit Demenz" that illustrated the need for an approach that is specifically tailored to the needs of PwM concerning support services for PwM in their report. It is important to consider the differences in traditions, language, religion, and customs when taking care of this population [28, 29]. An example of this approach is "Diversity Management." In the German healthcare system, a culturally sensitive and appropriate needs-based care is scarce; therefore, specific information about PwM cannot be fully considered. However, demographic and socioeconomic factors also play roles in the healthcare of PwM and should not be neglected. In optimizing care for PwM, diversity management suggests frameworks that should be implemented in the facilities of healthcare that not only allows for culturally sensitive responses to the needs of PwM but also promotes an open approach toward PwM [30].

As recommended by participants, to gain knowledge not only about available services but also other helpful measures, it would be useful to employ a consultant with a Turkish migration background to

visit PwD and families at home. The consultant could take a close look at the situation and provide recommendations, serving as a navigator for healthcare utilization and other services. In connecting people of Turkish background to pertinent information, personal contact is important and desired. Additionally, the contact person must be someone who has good knowledge of Turkish culture because this helps people open up and feel understood; preferably, the contact perhaps also speaks Turkish as it is sometimes easier to share emotions in one's native language. One illustration of the importance of being familiar with culture in the present study is the observation that nursing homes were not considered an option. The participants talked about how that is something that is just not done in Turkish culture because it means parents have not raised their children well, further supporting results by Mogar and von Kutzleben [13] suggesting that taking care of a family member is a matter of course and the deciding factor is that a family member needs help. This type of culture-specific information is important in forming trustworthy connections between consultants and the people of Turkish background looking for services.

It was evident that information on healthcare services is difficult to obtain and should be made easier for the people affected; another option would be to spread information about services where people with migration background are spending time, e.g., culture-specific community centers or mosques. To accomplish this, it is important to cooperate with people working there to spread the information. If the providers of healthcare systems could work more with these places, it may better inform them about people with migration background. From our experience in conducting the interviews and in trying to find interview partners, we found it was important to work with professionals of the same culture to contact the desired population. Another way to reach PwM may be to use media (e.g., radio, TV, and newspaper) relevant to that culture to disseminate information about dementia and available services. Because there are differences between and within cultures, it is important to engage the people affected themselves in the design of services and obtain their opinion directly [31].

Based on this research, we propose an approach to navigate the healthcare system that supports systematic implementation of current concepts (Fig. 1).

On the community level, navigators should be available to people with Turkish migration

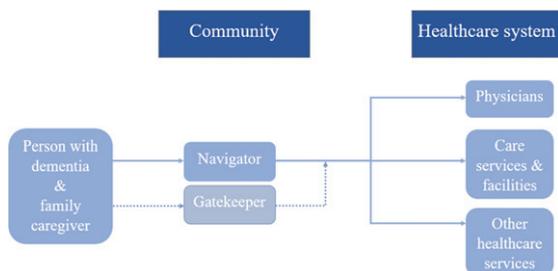


Fig. 1. Proposed approach for navigation in the healthcare system.

background and dementia as well as their family members. These navigators would specifically provide them with information on dementia and help them access the healthcare system and formal healthcare services, e.g., which doctors to consult and where they can obtain caregiving help. In a best-case scenario, these navigators should be of the same culture, or at least have knowledge of and familiarity with Turkish culture, so they know what is valued when providing information to affected people [32, 33].

In Germany, certain cities and communities (e.g., Herne) offer “intercultural dementia guides” to help people in dealing with dementia. These types of useful services should be implemented nationwide. On the healthcare system level, people and institutions should be culturally sensitive in their approaches and services. From the perspectives of current participants, no unique and targeted services were needed for people with Turkish background. Rather, they wanted an awareness, knowledge, and a few alterations to the current system to embrace the Turkish culture. This is aligned with the basic principle of person-centered care. An optional step in this model are the gatekeepers. These are specialized options such as support groups for family members in the native language if needed. Gatekeepers can also serve as a way to help the people affected find their way into the healthcare system.

Of course, this proposal leaves room for discussion. For example, the intercultural dementia guides could also be a form of dementia care manager (DCM), a successful concept that was implemented by the German Center for Neurodegenerative Diseases Rostock/Greifswald in Mecklenburg-Western Pomerania. In this model, specially-trained DCMs visit PwD and their family caregivers at home and offer help and advice regarding their situation [34]. In terms of gatekeeper services, a suggestion would be to build intercultural dementia networks where people affected can be educated, obtain support from people

in the same situation and be easily integrated into the healthcare system.

One might expect different outcomes from this study because PwM with dementia not only face challenges associated with dementia but also may face cultural barriers reported in previous research such as language barriers, different conceptualizations of health and disease, fear of stigmatization or a different organization of healthcare systems in the countries of origin [35, 36]. That situation is not the case in this study. The participants faced similar challenges as the population without migration background. However, the small and selective sample of eight participants needs to be considered when interpreting the results. If more people were interviewed, the analyses might have shown more and/or different experiences from those reported in this study. Furthermore, this population might be considered integrated in the healthcare landscape with better knowledge about the healthcare system and its available services. Hence, they could only report about the non-utilization of healthcare services retrospectively. Furthermore, most participants were proactive regarding help-seeking, e.g., visiting and telephoning offices. Therefore, they may not be representative of populations that are less or not integrated with healthcare systems and less likely to actively seek and accept help. Additionally, most participants wished for a translator to be present during the interviews. The translators were of the same culture and were working in the field of migration and health or, in one case, was a friend of the participant. This could have influenced the response behavior of the interviewed persons.

Although a translator was present during most of the interviews, the participants had good German language skills. This is another factor to consider when interpreting these results. Possessing good German language skills can make it easier to reach out to professionals and communicate with them, as well as obtain help and support. These are factors that distinguish them from people who lack knowledge of the healthcare system and language skills and, therefore, do not appear in the healthcare landscape. Including those people in research might lead to different results.

However, accessing this population is complicated. Recruiting proved to be difficult and tedious despite having approximately 40 stakeholder contacts either of the same culture working in the field of dementia and migration or at least working with our target group, who were more than willing to help find suitable interview partners. One reason for the lack of

willingness to participate is that potential participants are very hesitant to participate in research. Of note, the mandatory signatures for informed consent forms and the length of study information sheets were cited as deterring factors.

Future research should explore how information could best be provided to communities of PwM. However, even more important is identifying measures to reach a population that is excluded from the healthcare landscape and, therefore, cannot be reached by stakeholders in the field of dementia and migration. In this regard, the future aim will be to present that PwM with dementia are not only underserved but also under-researched.

The challenge of a growing population of older Turkish migrants is shared between many countries. There are 6–9 million Turks living outside Turkey, who settled in countries such as Azerbaijan, Kazakhstan, Russia, and Ukraine [37]. Turkish “guest workers” also went to countries such as Germany, the Netherlands, Belgium, France, Austria, and Sweden in the 1960s [38]. An estimated 500,000 Turkish people live in the United States. Even though differences in healthcare systems exist, migration-specific challenges might be of interest to others as well. We hope that our analysis encourages international research on people with Turkish migration background.

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Dementia and migration: culturally sensitive healthcare services and projects in Germany

A scoping review

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In this article

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- Results
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- Discussion
- Practical conclusion

Abstract

Background: There are approximately 96,500 people with a migration background (PwM) with dementia in Germany. They and their families face not only dementia-related challenges but also the challenge of having little knowledge about the healthcare system and its services and thus more difficulty in accessing support. Germany's national dementia strategy recognises these individuals as a risk group and thus aims to expand the provision of culturally sensitive information and healthcare services.

Objective: To determine the amount of culturally sensitive information and healthcare services as well as projects on dementia and migration.

Method: With a scoping review the PsycInfo, PsycArticles and Psychology & Behavioral Sciences Collection databases, Google Search, the network map (*Netzwerkkarte* on the website www.demenz-und-migration.de) and the websites of various research funding bodies were used to find culturally sensitive information and healthcare services as well as current projects on dementia and migration.

Results: Listed are 45 care services as well as 3 additional projects that deal with dementia and migration at the local level. The geographical distribution of the offers shows that most of the services can be found in federal states where most PwM with dementia live.

Discussion: It is necessary to provide information and healthcare services in all regions and to adapt them to PwM. Different aspects and culturally sensitive measures are important when informing PwM with dementia, as such information can enable these individuals to access the healthcare system and help to provide them with care. It is important to bring together relevant stakeholders to provide access and services that improve the situation of PwM with dementia and their families.

Keywords

Healthcare · Vulnerable Populations · Support · Federal States · Access



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In Germany, 1.99 million people with a migration background (PwM) are older than 64 years and approximately 96,500 are estimated to be living with dementia. The PwM with dementia and their families face not only dementia but also challenges related to accessing information and the healthcare system. For them to utilize services that provide information, care and support, these services have

to be low-threshold, culturally sensitive and adapted to their needs. To help with that, projects on the topic are needed to gain knowledge about PwM with dementia and their needs in healthcare.

Background

Over the course of its history, Germany has turned from an emigration country into

an immigration country. The recruitment of guest workers from abroad in the mid-1900s, the collapse of the Soviet Union, the development of high levels of youth unemployment in southern Europe and the Syrian conflict have all contributed to a rise in Germany's migrant population [10, 23]. According to census data, the number of PwM amounts to 18.6 million people, which accounted for 23% of the population in Germany in 2018 [27]. In Germany, as in many other countries of Europe, the number of PwM aged 65 years or older is increasing. A total of 1.99 million PwM are older than 64 years, which represents 11.52% of the German population who are older than 65 years. A growing probability of age-associated and chronic diseases such as dementia is a consequence of increasing age [17, 25]. An analysis from 2019 showed that there were approximately 96,500 PwM with dementia living in Germany at that time, with distinct regional differences regarding the number of PwM and their origin of migration. Most PwM with dementia reside in North-Rhine Westphalia (26,000), Baden-Wuerttemberg (18,100) and Bavaria (16,700), which is not surprising as they are the federal states where the greatest numbers of PwM can generally be found. Fewer PwM with dementia live in Mecklenburg-Western Pomerania (500), Thuringia (500), Saxony-Anhalt (650) and Brandenburg (650). The place of origin of most PwM with dementia (84,500) are other European countries, with most originating from Poland (14,000), Italy (8900), Turkey (8800), Romania (6400) and the Russian Federation (6300). Unpublished results from the abovementioned analysis reveal an uneven distribution across regions. Most people with dementia who originate from (a) Poland are found in North Rhine-Westphalia (6000) and Bavaria (1400), while (b) those from Italy reside in Baden-Wuerttemberg (2900) and North Rhine-Westphalia (2400), (c) those from Turkey live in North Rhine-Westphalia (3100) and Baden-Wuerttemberg (1300), (d) those from Russia live in North Rhine-Westphalia (1700) and Baden-Wuerttemberg (1000) and (e) those from Romania live in Bavaria (2500) and Baden-Wuerttemberg (2100) [19]. Despite the diversity of the group of PwM with dementia, there

have been common challenges identified for this group and their families. It has been reported that there is a lack of culturally sensitive diagnostic and screening tools, which results in difficulties in diagnosing dementia [2, 22]. Additionally, culturally sensitive information and healthcare services are also missing for this population [4, 10, 16, 18]. The PwM show a lack of awareness and knowledge about the healthcare system, its services and support and how to utilize them [4, 16, 18]. Further complicating this situation are language problems that can arise in communication with healthcare professionals, service providers and others [4, 16] or false beliefs, such as thinking that dementia is a regular part of ageing [2, 24]. The PwM can be distrustful of the healthcare system and healthcare professionals or fear facing stigma or judgement from other people when utilizing formal help [10, 16, 18]. These factors are only just a few that play an important role in healthcare for PwM with dementia and their families. These circumstances are associated with worsened access to the healthcare system; thus, services have to be low-threshold, culturally sensitive and adapted to their needs [13, 29]. A more detailed overview of this topic is provided by Alzheimer Europe (2018) [1]. This identifies PwM with dementia as a group at special risk that needs appropriate care with culturally sensitive healthcare services and information that are adapted to their needs. However, the regional differences in areas where PwM with dementia live make it hard to implement a nationwide solution. Therefore, regional and local initiatives that are adapted to the situation on site also have to be established. Germany's first national dementia strategy acknowledges PwM with dementia as a risk group and is committed to providing support and care for them. Therefore, the national dementia strategy aims to implement measures to support PwM with dementia. One measure is to expand the availability of culturally sensitive information and counselling services [14].

This scoping review provides an overview of existing national, regional and local healthcare services and information on where they are located and where

action needs to be taken. In addition, this article depicts the current projects on dementia and migration present in Germany. This will help (a) affected people to see where they can find support and (b) service providers to initiate and offer new services and get in contact with each other.

Method

For this analysis a scoping review was used. This type of review is designed to a) provide an overview of existing information, b) process information on a topic where not much scientific research is available and c) show gaps in that topic [28]. This approach is used to depict the spectrum of healthcare services and projects on dementia and migration in this analysis.

The websites of the Federal Ministry of Education and Research (BMBF), the Federal Ministry of Health (BMG), the Germany Research Foundation (DFG), and the German Aerospace Center (DLR) were consulted to see if they fund projects on dementia and migration. In addition, PsycInfo, PsycArticles, and Psychology and Behavioral Sciences Collection databases were screened via Ebscohost, which is an online reference tool offering the opportunity to search within a variety of databases. The databases used in this review were selected because they are able to deliver relevant literature on the thematic object of this article. These searches yielded no results and an internet search in Google was conducted on 12 and 13 January 2021. The search included the terms "Projekt" or "Initiative" in combination with "Demenz" or "Alzheimer", "Migration" or "Migrationshintergrund" and "Deutschland" and was limited to websites from Germany in the period from 1 January 2016 to 31 December 2020. The results were in German and were included if a project was ongoing and specifically addressed dementia and migration. The results were excluded if a project had already ended and did not focus on dementia and migration. Projects on migration and health were excluded if they did not solely focus on dementia. Additionally, the German Alzheimer Society was consulted.

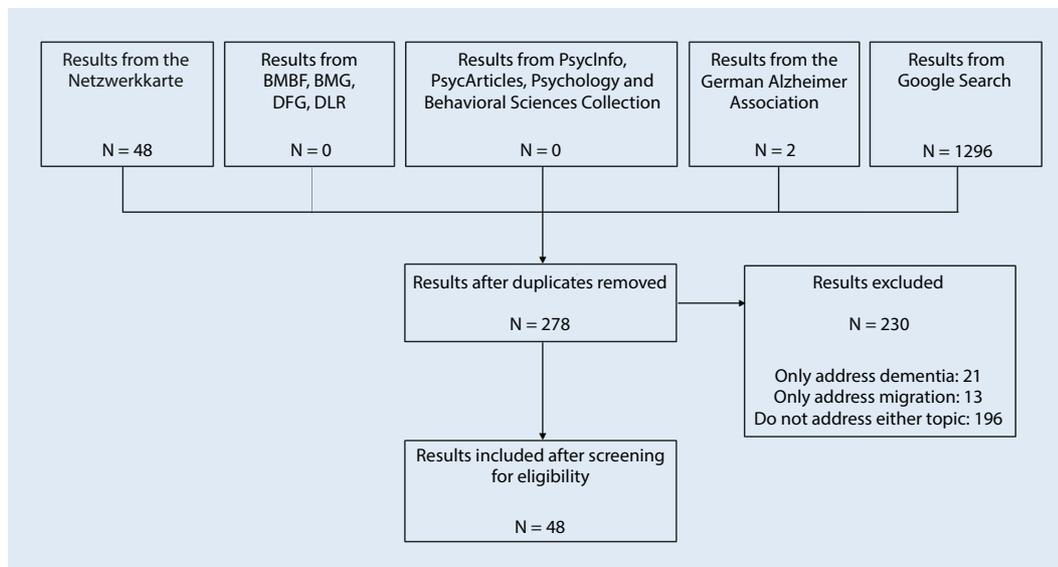


Fig. 1 ◀ Flowchart showing the selection process for culturally sensitive healthcare and information services and projects. BMBF Federal Ministry of Education and Research, BMG Federal Ministry of Health, DFG Germany Research Foundation, DLR German Aerospace Center

The DeMigranz project on dementia and migration connects stakeholders from the healthcare system, communities, migrant organizations and the government ministry to build networks. The aim is to establish culturally sensitive healthcare and information services in the federal states so that PwM with dementia and their families will be informed about dementia and included in the German healthcare system [6]. The “Netzwerkkarte” by DeMigranz lists available dementia-related services, organizations and projects that cater to PwM; it can be found at the following website: www.demenz-und-migration.de. The “Netzwerkkarte” was consulted on 15 October 2020 and 17 March 2021 for potential updates to determine how many services exist, their location and their type. Thus far, this is the only platform that offers an overview of dementia-related services and support for PwM; hence, it was chosen for this scoping review.

Results

The internet search yielded 1296 results, of which 1036 were duplicates. Of the remaining 260 results, 227 were excluded from the analysis because they did not address dementia and migration or only addressed one of these topics. Most of the suitable results ($n = 30$) from the remaining 33 are included in “Netzwerkkarte”. In the end, three additional projects on

a federal state level emerged from the internet search for the analysis. The “Netzwerkkarte” lists 4 results on a national level and 44 on a federal state level. Of these 48 results, 45 are included in the analysis because they are projects, healthcare and information services aimed at PwM. The other three results represent partners of DeMigranz but do not offer services for PwM with dementia and were therefore excluded from the analysis [8]. The German Alzheimer Society reported two projects that operate nationwide and are included in the “Netzwerkkarte”. In the end, 48 culturally sensitive healthcare and information services and projects were included (see ◀ Fig. 1). ◀ Table 1 provides an overview of these services and projects.

Germany

A total of four services were found that offer counselling in Turkish, Russian, Italian, Greek, Serbo-Croat, Polish, Spanish, Arabic, and Vietnamese, with one of them also offering support and care services in Russian.

One project ran until 2019 and aimed to inform PwM about dementia and possible support measures and motivated counsellors to provide more culturally sensitive services. One measure that was implemented was telephone counselling in Turkish, which is still offered. As a follow-up, a website (www.demenz-und-migration.de) was established in cooperation with

DeMigranz to provide information about dementia in different languages (German, Turkish, Polish, Russian, English, Arabic), “Netzwerkkarte” and information to facilitate contact with PwM [7, 9]. Another project is DeMigranz, which is described in the “Method” section.

North Rhine-Westphalia

A total of 12 offers could be identified, 7 provide counselling in Turkish, Greek and Russian and/or care services in Turkish, 2 projects train people who speak different languages to give information about dementia and related services, and 1 is a Russian apartment-sharing community [8]. Another project trains persons with different linguistic backgrounds to act as contact persons for PwM with dementia and their families, inform them about dementia and help them get in contact with healthcare services [11]. Another project qualifies people from different linguistic backgrounds to offer support services and information to PwM with dementia and their families [15].

Baden-Wuerttemberg

A total of six services were detected that provide information, counselling, care services and care facilities in Turkish, Russian, Polish, Greek and Arabic [8]. Another service offers support services and counselling in different languages, such as Rus-

Table 1 Overview on services, information and projects available for PwM with dementia in Germany			
Location	Number	Type	Language(s)
Germany	4 (1 ended in 2019)	Counselling	Turkish, Russian, Italian, Greek, Serbo-Croat, Polish, Spanish, Arabic, Vietnamese
		Support services	
		Care services	
		Information	
		Networking	
North Rhine-Westphalia	12	Counselling	Turkish, Greek, Russian, multilingual
		Care services	
		Training	
Baden-Wuerttemberg	7	Counselling	Turkish, Russian, Polish, Greek, Arabic, Croatian, Italian
		Information	
		Care services	
		Support services	
Bavaria	5	Counselling	Turkish, Russian, Arabic, Italian, Greek, Serbo-Croat, Polish, Spanish, Vietnamese
		Support services	
		Training	
Hesse	5	Counselling	Turkish, Russian
		Care services	
		Support services	
Berlin	4	Counselling	Turkish, Serbo-Croat, Spanish, Russian, Arabic, Vietnamese
		Support services	
Saxony	3	Counselling	Russian, Vietnamese
		Care services	
Hamburg	2	Care services	Turkish, multilingual
		Counselling	
Lower Saxony	2	Counselling	Turkish, Russian, Italian
Bremen	1	Counselling	Turkish
		Support service	
Saarland	1	Information	Turkish, Arabic, Russian, English, Italian
Schleswig-Holstein	1	Counselling	Turkish, Russian, Polish
Thuringia	1	Counselling	Russian, Arabic
Brandenburg, Mecklenburg-Western Pomerania, Rhineland-Palatinate, Saxony-Anhalt	/	/	/

sian, Greek, Croatian, Italian and Turkish [12].

Bavaria

For Bavaria four services were identified as supplying counselling and/or support services and one was found that trains multilingual dementia aides to offer culturally sensitive support services. These services address Turkish, Russian, Arabic, Italian, Greek, Serbo-Croat, Polish, Spanish and Vietnamese speaking people [8].

Hesse

A total of five services that offer counselling and/or support and care services in Turkish or Russian were found [8].

Berlin

In Berlin four services were found that provide counselling and/or support in Turkish, Serbo-Croat, Spanish, Russian, Arabic and Vietnamese [8].

Saxony

A total of three counselling and care services that offer services in Russian and one also in Vietnamese were detected [8].

Hamburg

In Hamburg two services were identified, one is a multilingual care facility that also offers home care and one is a counselling service in Turkish [8].

Lower Saxony

There were two services found that offer counselling in Turkish, Russian and Italian [8].

Bremen, Saarland, Schleswig-Holstein, Thuringia

One counselling (and support) service in different languages such as Turkish, Russian, Italian, Polish, Arabic and English could be found in each of these federal states [8].

Brandenburg, Mecklenburg-Western Pomerania, Rhineland-Palatinate, Saxony-Anhalt

No services could be found [8].

Discussion

The national dementia strategy aims to expand the availability of culturally sensitive information and healthcare services for PwM (with dementia), and this scoping review sets out to determine the number of these services and projects on dementia and migration that are available in Germany. Currently, most services of that kind are found in North Rhine-Westphalia, Baden-Wuerttemberg, and Bavaria and Hesse. Berlin, Bremen, Hamburg, Lower Saxony, Saarland, Saxony, Schleswig-Holstein and Thuringia provide fewer services each, while no services could be identified in Brandenburg, Mecklenburg-Western Pomerania, Rhineland-Palatinate and Saxony-Anhalt. This outcome mirrors in general the distribution of PwM with dementia in Germany, as a majority of the affected PwM live in the federal states

that provide most services. Surprisingly, Rhineland-Palatinate, although the area has quite a large number of PwM with dementia, seems to provide no services, while for Lower Saxony, despite housing 7200 PwM with dementia, only 2 services could be found.

The majority of services for people with dementia from (a) Poland are located in Baden-Wuerttemberg, (b) Turkey are found in North Rhine-Westphalia, Baden-Wuerttemberg and Bavaria, (c) Russia are in Baden-Wuerttemberg, Bavaria, Berlin and Saxony, and (d) Italy are located in Baden-Wuerttemberg, Bavaria, Saarland and Lower Saxony. Although people with dementia from Romania are one of the largest groups of PwM with dementia in Germany, it was not possible to identify services for them.

These results indicate that some efforts have been made to provide information and support to PwM with dementia. Most of these services are located in the federal states where most of the PwM (with dementia) live. It seems to be necessary, however, to establish services in all federal states since every person has a right to person-centered care, which means that information and healthcare services should be available in every region and also be tailored to different ethnicities, as stated in the national dementia strategy [14]. Of the federal states four do not offer services, while six offer only one or two services. This means that a high proportion of PwM with dementia and their families cannot be adequately supported. Furthermore, most of the services offer counselling, and only a few are care facilities and home care services. This reveals a huge gap in care services that needs to be further investigated.

As described, due to the additional challenges PwM face, the usual mainstream services are not entirely suitable to take care of PwM. Different aspects and culturally sensitive measures are important considerations when informing PwM with dementia, as such approaches enable these individuals to gain access to the healthcare system [1, 3, 19, 20, 26]. The national dementia strategy highlights the importance of offering low-threshold services and adapting services to the needs of PwM with dementia; the Alzheimer Europe re-

port on intercultural care (2018) [1], and Schmachtenberg et al. (2021) [26] pointed out how this can be implemented.

The projects that focus on dementia and migration show an effort to inform PwM with dementia and their families about dementia and healthcare services and to connect healthcare providers with one another to expand and improve healthcare for PwM with dementia and their families. Nevertheless, more projects are needed to a) identify PwM with dementia and their needs and demands regarding the healthcare system, its services and information and b) support PwM with dementia and their families in their situation in relation to the healthcare system, service providers and policy makers. When doing so, it is imperative to include the people affected to obtain first-hand information from them on what is needed [5]. Furthermore, it is not enough to have single services and projects that attempt to determine what is needed for this population. It is important to combine these separate services and projects with relevant stakeholders [14], such as people from the healthcare system, service providers, researchers and the people affected, to create access and services that improve the situation of PwM with dementia and their families. This is why initiatives that do exactly that, like DeMigranz, are important.

These results are to be taken with caution. The chosen search strategy resulted in a selective assortment; thus, it does not aim to give a conclusive overview. One should acknowledge that in routine care, there are many people engaged in improved care for PwM, and their efforts are often not published or presented to a broader audience. Therefore, there is the possibility that the “Netzwerkkarte” and the search presented herein may not include every healthcare service and project related to dementia and migration. One attempt to get a more detailed overview could be to set up an initiative similar to DeMigranz at the federal state or even regional level. For example, care providers and staff, healthcare professionals, representatives of local Alzheimer’s societies, dementia networks and psychiatric and medical associations, members of associations for patients and/or relatives could come together and have as a possible goal

to identify the healthcare and information services in the region and to create a comprehensive overview of these services. In this way, it might be possible to look in more detail at what services are available. Another possibility would be to use the approach of the “EU-Atlas: Dementia & Migration”. Here, using various methods, an overview of the topic of dementia and migration, including the current care situation of those affected and available healthcare services, was created at the European level [21], which could be carried out in more detail at the German level. Furthermore, there is the possibility that some migrant groups are considered to be well integrated into society and the healthcare system and therefore no need might be seen to offer specialized services for them. Nevertheless, this review provides valuable information on the current state of culturally sensitive healthcare services and projects in Germany and fosters awareness and exchange.

Practical conclusion

- This scoping review identified 48 culturally sensitive healthcare services and projects on dementia and migration in Germany.
- There are projects aiming at offering support and information to PwM with dementia and their families; however, more research and knowledge transfer is needed.
- Systematic availability and access are needed. Every federal state should offer tailored information and services for PwM with dementia and their families regardless of how many PwM with dementia live in the federal state. In addition, more projects on dementia and migration should be systematically funded, conducted and made available to others.

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Declarations

Conflict of interest. J. Monsees, S. Öztürk and J.R. Thyrian declare that they have no competing interests.

For this article no studies with human participants or animals were performed by any of the authors. All studies performed were in accordance with the ethical standards indicated in each case.

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Demenz und Migration: kultursensible Versorgungsangebote und Projekte in Deutschland. Ein Scoping-Review

Hintergrund: In Deutschland leben etwa 96.500 Menschen mit Migrationshintergrund („people with a migration background“, PwM), die an Demenz erkrankt sind. Sie und ihre Familien stehen nicht nur vor demenzbedingten Herausforderungen, sondern auch vor dem Problem, dass sie wenig über das Gesundheitssystem und seine Angebote wissen und daher Schwierigkeiten haben, Unterstützung zu erhalten. Die nationale Demenzstrategie Deutschlands erkennt sie als Risikogruppe an und hat als Ziel, das Angebot an kultursensiblen Informationen und Versorgungsangeboten zu erweitern. **Ziel:** Ermittlung kultursensibler Informations- und Versorgungsangebote sowie von Projekten zum Thema Demenz und Migration.

Methode: Im Rahmen eines Scoping-Reviews wurden die Datenbanken PsycInfo, PsycArticles und Psychology & Behavioral Sciences Collection, Google Search, die Netzwerkkarte auf der Website www.demenz-und-migration.de sowie die Websites verschiedener Forschungsförderer nach kultursensiblen Informations- und Versorgungsangeboten sowie aktuellen Projekten zu Demenz und Migration durchsucht.

Ergebnisse: Aufgeführt sind 45 Versorgungsangebote sowie 3 weitere Projekte, die sich mit Demenz und Migration beschäftigen. Die geografische Verteilung der Ergebnisse zeigt, dass die Bundesländer, in denen die meisten PwM mit Demenz leben, auch die meisten Angebote bieten.

Schlussfolgerung: Es ist nötig, in allen Regionen Informations- und Versorgungsangebote bereitzustellen und diese an PwM anzupassen. Bei der Aufklärung von PwM mit Demenz sind verschiedene kultursensible Maßnahmen und Aspekte wichtig, da solche Informationen PwM den Zugang zum Gesundheitssystem ermöglichen und bei ihrer Versorgung helfen können. Wichtig ist, relevante Interessenvertreter zu vernetzen, um den Zugang zu Angeboten zu arrangieren, die die Situation von PwM mit Demenz und ihren Familien verbessern.

Schlüsselwörter

Gesundheitsversorgung · Vulnerable Bevölkerungsgruppen · Unterstützung · Bundesländer · Zugang

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