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OVERVIEW

What elements are important in current treatment and care guidelines to provide culturally sensitive care for people with a migration background and dementia? A systematic analysis

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Introduction

Throughout Europe, the care of people with a migration background with dementia (PwM) poses a major challenge. In the EU, the number of PwM over 64 years of age rose considerably from 4.73 million in 2000 to 7.37 million in 2017 (United Nations Department of Economic and Social Affairs 2017) and will continue to grow. There is limited data on how many PwM are affected by dementia in Europe. Estimates are available for some countries, such as Germany (Monsees et al. 2018), but these have severe limitations for a European perspective. One key problem is the absence of a common definition of the term "migrant". While the United Nations defines PwM based on their country of birth [PwM are living in countries other than their country of birth, (United Nations Department of Economic and Social Affairs 2016)], in Germany, the status is based on their own and their parents' citizenship (PwM are those not born with German citizenship or who have at least one parent who was not born with German citizenship (Statistisches Bundesamt 2017)). The subject matter encounters definitional problems on many levels. In this study, we focus on people with a migration background (PwM) or synonymously migrants. We do not use the term "minority ethnic groups" as used in many international studies and reports. Our emphasis is on measures to improve the care situation of people who have immigrated to the country they currently live in. This specificity is associated with specific challenges that differ from the challenges faced by people from minority ethnic groups who might already have been living in the respective country for generations. While there are many similarities and intersections between these groups, not every member of a minority ethnic group is a migrant (Alzheimer Europe 2018). In some European countries, certain minority ethnic groups have specific rights (for example, concerning linguistic and culturally sensitive information) that PwM currently do not have in most countries. For these reasons, the authors believe that specific consideration of PwM in the context of dementia care is indicated. A detailed discussion on the definition of the term "migrant" and common concepts such as a "minority ethnic group" can be found in the Alzheimer Europe report "The development of intercultural care and support for people with dementia from minority ethnic groups" (Alzheimer Europe 2018). Another key problem is diagnosis. On top of the general problem of diagnosing dementia in the general population, underdiagnosis and late diagnosis of dementia are more widespread among PwM than in people without a migration background (Seven 2015). Particularly due to the lack of language- and culture-sensitive diagnostic tools, early and valid diagnosis of dementia is a major challenge for general practitioners (GPs) and specialists (Alzheimer Europe 2018).

However, PwM with dementia are a group facing specific problems. There are reports that age-associated diseases such as dementia occur at a younger age and require care at an earlier stage (Gronemeyer et al. 2017; Kaiser 2009). In addition, dementia is often associated with an early loss of the language of the country of residence (Bundesministerium für Gesundheit 2011). While families and social networks have been described as important resources for PwM with dementia, the psychological burden on their families is often higher than that on families without a migration background (Kücük 2010; Montoro-Rodriguez and Gallagher-Thompson 2009; Piechotta-Henze and Matter 2008). This constitutes a high demand for support services (Jutla 2015), and there is an evident need for sensitization, information, and networking among migrant communities and care providers. For example, dementia is considered to be a

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part of normal aging or attributed to religious or spiritual elements in some migrant communities (Chaouni et al. 2020; Deutsche Alzheimer Gesellschaft 2019; Xiao et al. 2015). Simultaneously, many service providers have limited knowledge about the specific care situation of PwM (Höfler et al. 2015).

There is growing evidence that PwM with dementia are underrepresented in dementia-specific healthcare services (Giebel et al. 2015; Mukadam et al. 2011; Mukadam et al. 2015; Parveen and Oyebode 2018) and that family caregivers use fewer formal support services than people without a migration background (Dilworth-Anderson et al. 2002; Dunlop et al. 2003). This has been explained as resulting from language problems, cultural beliefs about dementia and care, stigma and shame, lack of information about available healthcare services, and lack of culturally, religiously, and linguistically appropriate services (Alzheimer Europe 2018; Bermejo et al. 2012; Bowes and Wilkinson 2003; Braun et al. 1996; Chaouni et al. 2020; Greenwood et al. 2015; Jett 2006; Mogar and von Kutzleben 2015). These factors lead to care inequalities, which should be addressed in treatment guidelines. However, a recent analysis of national guidelines on dementia care in the EU and EFTA (European Free Trade Association) countries has shown that the topic of migration plays a subordinate role in these guidelines. Moreover, no European country provides a separate, specific guideline for culturally sensitive care (Schmachtenberg et al. 2020b).

Therefore, this study aims to provide a systematic overview of the key elements and measures with regard to culturally sensitive care referred to in scientific articles and statements, political documents, and medical guidelines. First, we identify which thematic and content-related priorities are set in the documents and statements examined. Subsequently, we describe some measures recommended to improve the care situation of PwM with dementia. These are not necessarily specific to migrant groups, and have a general and transnational character. This article is addressed to policymakers, health system leaders, and further decision-makers and care planners at national and international levels. It is intended to show them which elements are important for the holistic orientation of healthcare systems and structures towards culturally sensitive care. In a further paper by Monsees et al. (submitted but not published), intercultural care as a model for the implementation of culturally sensitive care by healthcare professionals and providers of healthcare services is described in detail (Monsees et al. 2021).

Thus, the article aims to provide an answer to the following question: what elements play key roles in ensuring culturally sensitive care for PwM with dementia?

Methods

This study is a systematic analysis of the special discourses held in articles from peer-reviewed scientific journals, in scientifically oriented oral statements from conference presentations, in politically determined dementia plans and international reports, and in medically oriented guidelines on the care of PwM with dementia. Thereby, three models were combined (triangulation): (1) for the collection of statements from scientific articles, the systematic literature analysis by Becker (2018) was used, (2) for the analysis of the data, the discourse analysis by Keller (2011) was implemented, and (3) for the coding, the qualitative content analysis model proposed by Mayring (2014) was applied.

Data collection

1. To identify relevant articles in scientific journals, the databases PsycARTICLES, Psychology and Behavioral Sciences Collection, and PsycINFO on the platform EBSCOhost and the PubMed database were screened. In doing this, the key terms 'care', 'Versorgung', 'dementia', 'Demenz', 'migration', and 'Migration' were used. These terms were chosen because they represent the key elements of the research question of this study, and in previous research, these terms have generated the most hits for articles that explicitly report results from studies on the care of PwM with dementia. For example, analyses of national dementia plans and care guidelines have shown that entering the term 'migration/Migration' in the search function of the documents generates a significantly higher number of hits regarding the reference to PwM than other search terms such as 'minority', 'culture', or 'ethnic'. In this study, only articles in German and English were considered, as these represent the mother tongue and second language, respectively, of the authors. Most of the studies were published in English, but there are also relevant articles on the care of PwM with dementia that were published exclusively in German. For a qualitative content analysis of articles in other languages, the language skills of the authors are insufficient. The study covers the period from 1 January 2009 to 1 November 2019. This period is based on the validity of recommendations for action from guidelines and dementia plans of various European countries. In most EU and EFTA countries, the validity of guidelines and dementia plans is 5 years. Since the recommendations for action in two successive documents often differ only slightly, and since clear discrepancies only occur between recommendations from guidelines or dementia plans whose publication is more than 10 years apart, this period was used as a basis for this analysis. The database search was limited to abstracts and titles because the study should only consider articles that focus on the care of PwM with dementia.

The formal search criteria were as follows: language: German and English, publication date: 1 January 2009–1 November 2019, publication type: Open Access, and search date: 1 November 2019. The search terms and results were as follows: PubMed: (((Versorgung [Title/Abstract] OR care

[Title/Abstract])) AND (Demenz [Title/Abstract] OR dementia [Title/Abstract])) AND (Migration [Title/Abstract] OR migration [Title/Abstract]): 17 hits; EBSCOhost: database: PsycARTICLES, Psychology and Behavioral Sciences Collection, PsycINFO: (((Versorgung or care [Abstract])) AND (Demenz or dementia [Abstract])) AND (Migration or migration [Abstract]): 21 hits. Thus, the total number of articles after excluding duplicates was 25.

After excluding four articles due to the date of publication (before 11 November 2009) and four articles due to the implementation of material quality criteria (inclusion of elements/measures on the care of PwM with dementia), the corpus comprised $n = 17$ articles.

2. Afterwards, the following documents were integrated into the corpus: the dementia plans of the EU and EFTA countries, which were available via the website of Alzheimer Europe or the search engine Google on 1 November 2019; the dementia care guidelines, which were sent after a mail request (between 2 May and 11 July 2019) until 1 November 2019 by the national Alzheimer societies, health ministries, and professional societies (for geriatrics, gerontology, and neurology) of the EU and EFTA countries; articles referenced in the systematically derived articles; and international reports, books, databases, and websites that were available online on 1 November 2019, and where elements or measures regarding the care of PwM with dementia could be derived. For this purpose, a Google search was carried out. The search engine was searched for several keywords such as report/book/database/website and dementia and migration, dementia care, or migrants and health.

3. Finally, oral statements were derived from conference presentations, workshops, and discussion panels in EU countries on the topic of dementia and migration. Only contributions from events attended by the authors were considered. The authors evaluated the programs of various events organized at the EU level, and attended those that highlighted topics that the authors identified as relevant in the context of caring for PwM with dementia. In addition, an event of the German Alzheimer Society with contributions from scientists, practitioners, and family caregivers on the topic of dementia and migration was considered.

Basis of the data

The search resulted in the following hits: $N = 113$ documents, books, databases, and websites, and $n = 4$ events. After screening the content of these texts and events, the following discourse fragments remained: $N = 64$ documents, books, databases, and websites ,and $n = 4$ events. These are divided as follows: 28 scientific articles, 15 national guidelines, 11 national dementia plans, six international reports on dementia, health, and migration, two books on dementia and migration, one database with initiatives on intercultural care, one website on health and migration, the North Sea Dementia Group Meeting 2019, the Alzheimer Europe Conference 2019, the European Public Health Conference 2019, and the Symposium Dementia and Migration of the German Alzheimer Society 2019. These texts, publications, and events represent the database for the results of this study.

Data evaluation

The relevant text sections and oral contributions were paraphrased, memos and comments were added, and the text was coded (Keller 2011). A combination of deductive and inductive categorization was used. First, categories were derived from other guidelines on dementia care (DGPPN and DGN 2016; Dorner et al. 2011; Fröschl et al. 2015; Schweizerische Akademie der Medizinischen Wissenschaften 2017; Schweizerische Alzheimervereinigung 2014). These categories were assigned to the individual text sections. From data material that could not be coded in this way, content categories were aggregated. Then, the category set shown in Table 1 was structured by formulating main categories. Afterward, a rough structure was generated from the main categories, and the content was placed in order (Mayring 2014). A consensus was built, central statements were derived, and deviating or singular statements were excluded (Becker 2018). Subsequently, the central statements were summarized into a catalog of measures and finally structured.

Results

In developing guidelines for culturally sensitive care of PwM with dementia, the following topics should be considered: 1. definition of the term “migrant”, 2. raising awareness in migrant communities, 3. healthcare structures, 4. cooperation/networking of central stakeholders regarding dementia and migration, 5. diagnostics, 6. support for family caregivers, 7. support for care providers, 8. communication between care providers and care recipients, 9. access to healthcare, 10. culturally sensitive care, and 11. research.

In the following section, the key elements are described for each topic:

1. Definition of the term “migrant”

The term “migrant” needs to be clearly defined, and clear criteria must be established to determine which persons this term includes. In addition to government institutions and migration experts, migrants should play an active role in the definition process (Alzheimer Europe 2018).

2. Raising awareness in migrant communities

Table 1 Category set after coding of the data material

Main category	Subcategories
Definition of the term "migrant"	1. General recommendation 2. Specific options for action
Raising awareness in migrant communities	1. Confidence building 2. Dementia-specific campaigns 3. Design/publication of information material 4. Culturally sensitive projects 5. Multiplier training 6. Prominent speakers 7. Rights regarding care 8. Audiovisual services
Healthcare structures	1. Migrant health centers 2. Dementia service centers 3. Building/modernization of care facilities
Systematic knowledge generation/data collection	1. Networking of knowledge-generating organizations 2. Participation in mainstream care/utilization of care
Government support/funding	1. Training 2. Interpreters 3. Support for general practitioners
Cooperation/networking of central stakeholders regarding dementia and migration	1. Care providers 2. Care providers — care recipients 3. Dementia specialists — migration experts
Support migrant organizations/multiplier training	1. Recognition, involvement, support 2. Staff training 3. Information/education migrant advice centers
Diagnostics	1. Diagnosis 2. Diagnostic tools/dementia screening tests 3. Diagnostic evaluation 4. Interpreter 5. Training of care providers
Support for family caregivers	1. Identification of needs/challenges/problems/stress factors 2. Information/education/counselling 3. Training 4. Interventions/services
Raising awareness/training/providing further education/support for care providers	1. Service providers 2. Professional caregivers/healthcare professionals
Communication between care providers and care recipients	1. Language-bridging instruments 2. Interpreter
Access to healthcare	1. Barriers to access 2. Improving access to care 3. Reducing health inequalities 4. Evaluating access to care
Culturally sensitive care	1. Organization/structures/culture of care providers 2. Raising awareness of inequalities 3. Identification/consideration of needs 4. Care team 5. Intercultural mediator 6. Connection specialist 7. Bridge builder 8. Psychosocial caregiver 9. Cultural/linguistic background professional caregiver 10. Integration of a caregiver with a migration background 11. Inclusion of a family caregiver in professional care 12. Social inclusion of people with a migration background with dementia 13. Inclusion of people with a migration background in the development of care services 14. Prevention 15. Care concept/service design 16. Living space 17. Validation of care services by people with a migration background
Research	1. Inclusion of researchers with a migration background 2. Needs of people with dementia/family caregivers 3. Level of knowledge in migrant communities 4. Diagnostics 5. Dementia prevalence 6. Care situation/practice 7. Identification of service gaps 8. Access to care/barriers 9. Development of care services 10. Cultural sensitivity of care services 11. Use of care services 12. Dealing with dementia 13. Effects of dementia 14. Target group 15. Access to studies

In many migrant communities, there is a high demand for information about living with dementia, symptoms of dementia, possible disease progression, diagnosis, dementia-specific care, and available services. Nationwide initiatives with language and culturally sensitive information events, information portals, and information materials can be useful tools to meet this need. Daily structures such as migrant facilities, places of worship, cultural centers, schools, or youth leisure facilities are particularly suitable for personal contact (Alzheimer Europe 2019; Alzheimer's Disease International 2019; Berdai Chaouni and De Donder 2019; Bermejo et al. 2012; Blümel 2015; Giebel et al. 2015; Jutlla and Moreland 2009; Matter and Piechotta-Henze 2009; Mukadam et al. 2015; World Health Organization 2018a).

3. Healthcare structures

Structures must be created that promote the intercultural opening of healthcare, the inclusion of PwM in the healthcare system, and the participation of this group in the provision of care.

Organization of care An important step could be the establishment of national institutions for the health of PwM with a task force on dementia (Alzheimer Europe 2019). At the local level, the inception of migrant health centers with dementia-specific trained medical staff and dementia-specific services (screening, information, counseling, primary healthcare) or migrant dementia centers can be an opportunity to include PwM in healthcare (Deutsche Alzheimer Gesellschaft 2019; European Public Health Association 2019; North Sea Dementia Group 2019; Tillmann et al. 2019).

Government support Migrant organizations, faith/community groups, and care networks should be given more financial support and assistance in the form of dementia-specific multiplier training (Alzheimer Europe 2019; Höfler et al. 2015; Xiao et al. 2015). Investments are also needed in translation or mediation services as well as culturally sensitive education and training for health and care professionals (Alzheimer Europe 2018; Chaouni et al. 2020; Regan 2014).

Cooperation/networking of central stakeholders regarding dementia and migration

A further focus should be on the development of care networks and local, national, or international cooperation between government representatives, care providers, care recipients, organizations, initiatives, and researchers in the field of dementia and migration (European Public Health Association 2019).

Care providers and experts Cooperation and knowledge transfer between care providers and experts with expertise in the healthcare systems of the countries of origin and the host countries, dementia care, and the needs of PwM should be supported (Alzheimer Europe 2019). The establishment of networks between doctors and other care providers from the respective countries of origin and host countries (e.g., through student exchange programs) can be particularly useful (European Public Health Association 2019).

Care providers and care recipients Internet portals are an adequate networking instrument for PwM with dementia, family members, and healthcare professionals. Network maps with healthcare services and relevant organizations, videos with multilingual and culturally sensitive information on dementia, text-to-speech functions, and blogs for the interaction of relatives, migrant organizations, and care providers should be integrated into the websites (Alzheimer Europe 2019; World Health Organization 2018a).

Diagnostics Particularly important is the initiation of actions to ensure the early and valid diagnosis of dementia in PwM (Alzheimer Europe 2018). Increased investment in linguistically and culturally sensitive diagnostics is needed (Berdai Chaouni and De Donder 2019; Nielsen and Waldemar 2016).

Diagnostic tools When selecting diagnostic tests, whether these tests are appropriate for the cultural and linguistic background of the person should be considered (Alzheimer Europe 2018; Berdai Chaouni and De Donder 2019; Deutsche Alzheimer Gesellschaft 2019; National Institute for Health and Care Excellence 2018). The intercultural dementia screening tool RUDAS (Rowland Universal Dementia Assessment Scale) can be an adequate instrument for the diagnosis of dementia in PwM, ideally combined with other tests (Alzheimer Europe 2018; Helsedirektoratet 2017; Sundhedsstyrelsen 2018). For oral tests, it may be appropriate to use standardized versions in the mother tongue of the person (Helsedirektoratet 2017). Therefore, diagnostic tools need to be available in a variety of languages (Llywodraeth Cymru Welsh Government 2018). In the case of language barriers, a professional interpreter should be consulted (Helsedirektoratet 2017; National Collaborating Center for Mental Health 2007). In the future, efforts must be made to develop diagnostic tools that are linguistically and culturally independent (Kaiser 2009; Tillmann et al. 2019).

Support for family caregivers

To improve the care situation of people with dementia (PwD) and reduce the burden on their relatives, family caregivers should be offered support services that are oriented towards their individual and cultural needs (Herat-Gunaratne et al. 2019; Kaiser 2009; Mogar and von Kutzleben 2015; National Institute for Health and Care Excellence 2018). Emphasis should be set on information and counseling services (Kaiser 2009), help with household and nursing activities, and emotional and mental support (Johl et al. 2016; Jutla and Moreland 2009).

Education and counseling First, PwM with dementia and their relatives must be informed in a culturally appropriate manner and in their mother tongue about dementia, care dependency, and available treatment and support services (Alzheimer Europe 2018; Department of Health 2009; Mogar and von Kutzleben 2015; Tillmann et al. 2019). In addition to personal contact in accessible counseling centers, information material in the mother tongue, and education via culture-specific mass media (Kaiser 2009), intercultural telephone counseling can be an adequate communication method. The establishment of a dementia hotline for PwM could be very important (Deutsche Alzheimer Gesellschaft 2019; Sagbakken et al. 2018; World Health Organization 2018a; World Health Organization 2018b). Inviting PwM with dementia and their relatives to information events in nursing homes (World Health Organization 2018b) or congresses on dementia and migration can be another useful measure (Kaiser 2009).

Training of family caregivers Furthermore, linguistically and culturally sensitive training series regarding dementia and care should be developed (Höfler et al. 2015; Kaiser 2009; Piechotta-Henze and Matter 2008; Xiao et al. 2015). Another key element is the development of guidelines and brochures on culturally sensitive dementia care, with recommendations on specific services and activities (Alzheimer Europe 2019).

Interventions for caring relatives Measures should be taken to strengthen the exchange between family caregivers to overcome possible taboos and feelings of shame and guilt, and to allow free space from homecare (Kaiser 2009). Proven instruments are support and self-help groups (Deutsche Alzheimer Gesellschaft 2019; Giebel et al. 2015; Kaiser 2009; Piechotta-Henze and Matter 2008) as well as interactive workshops and webinars (European Public Health Association 2019; World Health Organization 2018a).

Support for care providers

Providers of dementia care services must be supported in gaining awareness and knowledge about the importance of migration-specific, cultural, and religious elements in dementia care (Chaouni et al. 2020).

Raising awareness of care providers Intercultural training courses, handbooks on cultural sensitivity, and guidelines with recommendations for measures to convey cultural sensitivity in the education and training of professionals should be developed. Also very important is the information for care providers in workshops about the rights and needs of PwM and the available healthcare services (Alzheimer Europe 2019; World Health Organization 2018b).

Training of care/health professionals Care and health professionals should be trained regarding cultural sensitivity, the needs and treatment of PwM with dementia, dealing with barriers, and using community resources (Alzheimer Europe 2018; Deutsche Alzheimer Gesellschaft 2019; Giezendanner et al. 2018; Llywodraeth Cymru Welsh Government 2018; Tillmann et al. 2019; World Health Organization 2018b; Xiao et al. 2015). In addition to the organization of seminars and conferences (Alzheimer Europe 2019), the development of virtual and Internet-based training programs could be a key element in this regard (Alzheimer's Disease International 2019; Mehrabian et al. 2019; World Health Organization 2018a). Curricula for initial education of health and care professionals should also increasingly focus on broadening skills in the care of PwM with dementia (Department of Health 2009; Herat-Gunaratne et al. 2019; Ministry of Health and Care Services 2016).

Communication between care providers and care recipients

Measures must be taken to overcome communication barriers between care providers and PwM with dementia (World Health Organization 2018b). Professionals who care for PwM with dementia should have access to special publications (Adamson 2001; National Collaborating Center for Mental Health 2007) such as guidelines for culturally sensitive care (World Health Organization 2018a) or handbooks for linguistically and culturally sensitive patient conversations (Deutsche Alzheimer Gesellschaft 2019). If language barriers are an obstacle to care, a professional interpreter should be consulted (Deutsche Alzheimer Gesellschaft 2019; Giebel et al. 2015; National Collaborating Center for Mental Health 2007). For this purpose, it would be beneficial if care providers set up professional interpreter pools (Deutsche Alzheimer Gesellschaft 2019; Tillmann et al. 2019). As a supplement or in emergencies, telephone and video interpreting services, translation apps, or computer-aided translation programs can be useful (World Health Organization 2018a). Interpreting services should be government-funded, and clear standards for the training, accreditation, and use of interpreters are needed (Deutsche Alzheimer Gesellschaft 2019).

Access to healthcare

PwM should have the same access to the health system and be offered the same level of care as people without a migration background (Institut für Migrationsforschung und Interkulturelle Studien and Bundeszentrale für politische Bildung 2015; World Health Organization 2018a). One way to ensure this is to provide health cards for all migrant groups. Irregular migrants could anonymously receive a code for access to primary healthcare (World Health Organization 2018b). Simultaneously, it should be ensured that culturally sensitive care and support for dementia are generally accessible, and that multilingual information and mother-tongue services are comprehensively available (Alzheimer Europe 2018; Tillmann et al. 2019). The utilization of formal healthcare services can be improved through technical support for registration and appointment (World Health Organization 2018b) and early confidence-building (e.g., through visiting, mother-tongue care counseling) (Tezcan-Güntekin 2018). The implementation of tools for assessing access to care can also be useful (World Health Organization 2018b).

Culturally sensitive care

PwM with dementia should receive culturally sensitive post-diagnostic support, care, and treatment, preferably from a person who speaks their mother tongue (Alzheimer Europe 2018;

Alzheimer Europe 2019; Llywodraeth Cymru Welsh Government 2018). In this context, a person-centered approach has proved to be appropriate (Deutsche Alzheimer Gesellschaft 2019; Jutlla and Moreland 2009).

Culture care providers Service providers should create an inclusive environment (Jutlla 2015) and ensure that their policies, procedures, and staff are sensitized to different cultural needs (The Mental Welfare Commission for Scotland 2011). Specifically, it is useful to create internal folders with guides regarding culturally and linguistically sensitive diagnostics and care as well as available services (Deutsche Alzheimer Gesellschaft 2019).

Identification of needs Care providers should interview people in need of care about their individual, linguistic, cultural, spiritual, and religious needs, as well as their priorities with regard to illness, health, and care (Alzheimer Europe 2018; Llywodraeth Cymru Welsh Government 2018; Ministry of Health Social services and Equality 2010; The Mental Welfare Commission for Scotland 2011; World Health Organization 2018b), and incorporate these needs into care plans (National Collaborating Center for Mental Health 2007).

Healthcare team The healthcare team for PwM with dementia should include family members (if available), GPs and specialists (neurologist/psychiatrist), a psychologist/psychosocial caregiver, and if needed, professional caregivers and/or supportive care providers. In addition, the services of a cultural mediator and a connection specialist can be very important (Deutsche Alzheimer Gesellschaft 2019).

Cultural mediator She/he should mediate culture-specific information to care providers (European Public Health Association 2019; World Health Organization 2018a) and be available on an on-call basis to GPs, hospitals, specialists, and staff in nursing services and be stationed in nursing homes (Chaouni et al. 2020; Ministry of Health Social services and Equality 2010; World Health Organization 2018a).

Connecting specialist She/he should communicate the needs of PwD to care providers, doctors, and nurses, provide PwD and their relatives with information on dementia and available healthcare services, and support them in dealing with bureaucratic challenges. The connecting specialist should be available on an on-call basis to PwM with dementia and their families (European Public Health Association 2019; Xiao et al. 2015). This service could be provided by government-funded social workers who have received dementia-specific training as well as culture-specific and language skills.

Cultural background of professional caregivers When recruiting their staff, service providers should ensure that caregivers have different cultural backgrounds and language skills. The recruitment of multicultural staff with intercultural experience can serve as a prevention measure with regard to language and cultural barriers in the care of PwM (Deutsche Alzheimer Gesellschaft 2019; Giebel et al. 2015; Gronemeyer et al. 2017; Höfler et al. 2015; Johl et al. 2016; Kaiser 2009; Ministry of Health and Care Services 2016).

Inclusion of people with a migration background:

1. **Inclusion of professional caregivers:** to meet the need for care and health professionals with a migration background, programs are required to integrate this group into the health system. Such programs should include standardized procedures for the recognition of educational qualifications acquired abroad and adaptation training for doctors and professional caregivers from different countries of origin (World Health Organization 2018a).
2. **Integration of family caregivers into formal care:** The integration of relatives into professional care and increased cooperation between professional caregivers and relatives can improve the care situation of PwM with dementia (Chaouni et al. 2020; Rosendahl et al. 2016; Wittenberg et al. 2018). Nursing homes should provide opportunities for family members to live in close proximity (Sagbakken et al. 2018).
3. **Social inclusion of people with dementia:** It is important that PwD still have access to daily community activities (leisure facilities, churches, and faith groups, culture-specific facilities). They should be allowed to become actively involved (e.g., through volunteering, activities in sports clubs) (Williamson 2016).
4. **Participation in the development of healthcare services:** PwM with dementia and their relatives should be integrated into the development of culturally sensitive dementia-specific care services (e.g., by giving presentations, carrying out planning activities, communicating with the media, evaluating the cultural sensitivity of care services) (Alzheimer Europe 2018; European Public Health Association 2019; Williamson 2016; World Health Organization 2019).

Care concept The first question arising in the conception of care is whether PwM with dementia should be integrated into the established care system (integration model) or if specific offers should be developed for different migrant groups (segregation model) (Kaiser 2009). Since this question cannot be answered in general terms and only in consideration of the respective care situation, both integrative and segregative care services should be developed. Context-specific service design is the most promising concept (Alzheimer Europe 2018; Giebel et al. 2015).

Integrative care services Existing dementia-specific care services and general services for elderly people must be adapted to the individual, linguistic, cultural, religious, and migration-specific needs of PwM (Alzheimer Europe 2019; Johl et al. 2016; Kaiser 2009; Mogar and von Kutzleben 2015; Psota 2015). Care providers have to create a framework that allows PwM with dementia to celebrate religious or cultural festivals, practice traditions, customs, and religious rituals, and eat culturally appropriate food (Alzheimer Europe 2019; Berdai Chaouni and De Donder 2019; Mogar and von Kutzleben 2015; Socialstyrelsen 2017). The staff of nursing homes should gather information about the cultural background of their potential residents, identify the culture-specific needs in personal interviews, and take measures to ensure that these needs are taken into account. These measures may include the establishment of a list of common sentences in the native language for staff, culturally sensitive design of the home environment, or cooking of country-specific meals (National Collaborating Center for Mental Health 2007; Socialstyrelsen 2017; The Mental Welfare Commission for Scotland 2011). Suitable alternatives to full inpatient care could be intercultural daycare for elderly people (Deutsche Alzheimer Gesellschaft 2019) or 24-h care in the household of PwD (Alzheimer Europe 2018).

Segregative care services Particularly in the care of PwM who are less well integrated into the health system, segregative care is the more promising approach (European Public Health Association 2019; Kaiser 2009; Tillmann et al. 2019). Therefore, service providers and facilities should increasingly be located within migrant communities (Giebel et al. 2015). Migrant health centers should offer free social and healthcare counseling and interpreting services, as well as transport and accompanying services (World Health Organization 2018a). Furthermore, in several European countries (Netherlands, UK), the concept of dementia cafés/Alzheimer's tea houses for PwM has proved successful. There, PwD, family members, caregivers, and social workers meet in an informal atmosphere and can exchange experiences or information (Alzheimer Europe 2019). Further meaningful measures are the initiation of culture-specific discussion and family groups, the implementation of biography work (Deutsche Alzheimer Gesellschaft 2019), and the use of culturally tailored activity and memory materials (Kaiser 2009).

Housing Another focus should be on the design of innovative intercultural or culture-specific housing and care concepts. The concept of outpatient assisted living communities for PwM with dementia is particularly promising. Central success factors of such projects are the close cooperation with local authorities, social welfare institutions, housing associations, care services, and migrant organizations, connection to public transport and infrastructure of daily needs, and accessibility for relatives as well as native-speaking and culturally trained caregivers (Deutsche Alzheimer Gesellschaft 2019; Kaiser 2009). State subsidies for multigeneration houses could also contribute to improving the care situation of PwD and their relatives (Gronemeyer et al. 2017).

Validation of the cultural sensitivity of care services The implementation of these strategies should be documented and reflected, and the effectiveness of the measures must be evaluated. It should be examined whether the measures are culturally sensitive and to what extent they meet the needs of PwM with dementia. The satisfaction of the service users should be systematically surveyed, and the services should be further developed in cooperation with them (Alzheimer Europe 2018; European Public Health Association 2019).

Research

In the design of studies on the care situation of PwD, more attention must be paid to ensure that PwM have an equal chance of being included (Alzheimer Europe 2018). In addition, separate studies need to be conducted on the needs and care situation of PwM with dementia (Alzheimer Europe 2018; Gronemeyer et al. 2017; Johl et al. 2016). Thereby, researchers with a migration background should be included (Kaiser 2009). A particular need for research exists regarding the resources, experiences, settings, needs, burdens, and knowledge of PwM with dementia and their relatives with regard to dementia care (Alzheimer Europe 2019; Johl et al. 2016; Kaiser 2009; Xiao et al. 2015). Furthermore, studies should be carried out on the use of culturally sensitive diagnostic tools for PwM and the utilization of healthcare services by different migrant groups (Johl et al. 2016; Kaiser 2009; Socialstyrelsen 2018).

The central elements in providing culturally sensitive care for PwM, which have been identified by the conducted discourse analysis and which are described in more detail in this section, are summarized in Table 2.

Discussion

The literature analysis conducted in this study has shown that topics such as raising awareness in migrant communities regarding dementia, building of structures that promote the intercultural opening of healthcare, making an early and valid diagnosis of dementia in PwM, providing support to family caregivers, ensuring culturally sensitive care of PwM with dementia, involving PwM in the development of care services, and improving access of PwM to studies on dementia care, play key roles in developing guidelines. There may be several reasons why these topics play no or only a subordinate role in most of the currently available national dementia plans or care

Table 2 Key elements in providing culturally sensitive care for people with a migration background with dementia

Topic	Measures	Specific options for action
Raising awareness in migrant communities	Nationwide educational initiatives	Information events on dementia and care in migrant institutions, places of worship, and cultural centers
Healthcare structures	Establishment of migrant health centers	Integration of dementia-specific services (screening, information, counseling, primary healthcare)
Cooperation of stakeholders regarding dementia and migration	Establishment of care networks	Cooperation between government representatives, care providers, initiatives, and scientists
Diagnostics	Measures for early and valid dementia diagnosis	Consideration of cultural/linguistic background in selecting test procedures, development of language and culture-independent diagnostic instruments
Support for family caregivers	Development of training programs and interventions	Conception of culturally sensitive training series on dementia care, initiation of self-help groups
Support for care providers	Training of care and health professionals	Integration of culturally sensitive care in curricula for education of professionals, training in treatment of people with a migration background with dementia
Communication between care providers and care recipients	Use of language-bridging instruments and interpreters	Development of special publications (guidelines for culturally sensitive patient conversations and care), establishment of professional interpreter networks
Access to healthcare	Measures to ensure full access to healthcare	Provision of health cards for all migrant groups, comprehensive access to multilingual information and culturally sensitive care/support
Culturally sensitive care	Measures to identify specific needs	Interviewing people with a migration background with dementia with regard to needs/priorities in care
Healthcare team	Development of a pool of cultural mediators, connection specialists, and multilingual care professionals	Provision of cultural mediators for care providers, provision of connection specialists/native-speaking caregivers for people with a migration background with dementia
Inclusion of people with a migration background	Integration of family caregivers into professional care	Development of concepts for accommodating family members in the proximity of nursing homes
Inclusion of people with a migration background	Participation in the development of dementia-specific services	Invitation to presentations regarding and evaluations of the cultural sensitivity of care services
Care concept — integrative care services	Adaptation of existing care services to the needs of people with a migration background	Care providers: create a framework that allows people with a migration background to celebrate culture-specific festivals, practice traditions and rituals, and eat culturally appropriate food
Care concept — segregative care services	Development of specialized services for different migrant groups	Establishment of facilities in migrant communities; implementation of culture-specific dementia cafés, discussion groups, and memory materials
Housing	Design of innovative housing and care concepts	Initiation of projects such as outpatient assisted living communities for people with a migration background with dementia
Culturally sensitive care	Validation of cultural sensitivity	Evaluation of the effectiveness and user satisfaction regarding the measures
Research	Integration of people with a migration background in studies on dementia, performance of separate studies with this group	Research on the care situation of people with a migration background with dementia and their relatives, analysis of the use of culturally sensitive diagnostic instruments and healthcare services

guidelines of European countries (Canevelli et al. 2019b; Schmachtenberg et al. 2020a; Schmachtenberg et al. 2020b), despite the increasing quantitative importance of the topic of dementia and migration (Canevelli et al. 2019a; United Nations Department of Economic and Social Affairs 2017). These could include political backgrounds (e.g., low voter potential within the migrant population, rejection of migrant-friendly policies by larger voter groups, nationalistic/right-wing populist developments), discriminatory structures, low-inclusive (political/medical) discourses, underrepresentation of PwM or their representatives in the relevant working groups, and/or xenophobic attitudes among policymakers. Furthermore, political decisions and care strategies are in general mostly oriented towards the majority population. This is especially the case for a topic such as dementia, which is still highly taboo in many countries and societies and has not (if at all) been on the political agendas for a long time. To break this automatism, the targeted development of guidelines for minorities can be a solution.

Limitations

The results of this study are based exclusively on an analysis of scientific publications and are therefore derived theoretically. In addition, the measures described have a general, cross-national, and cross-group character. Consequently, they need to be adapted to the country-specific context, economic opportunities, structural conditions, and healthcare systems of each country and tailored to the individual migrant groups. It is also necessary to evaluate these measures in practice. Furthermore, the online search for written statements in articles and other documents was limited to the PsycARTICLES, Psychology and Behavioral Sciences Collection, PsycINFO, and PubMed databases, the search engine Google, and the Alzheimer Europe website, and the search for oral statements was limited to events attended by the authors. The screening of the databases was conducted exclusively based on the keywords 'care', 'Versorgung', 'dementia', 'Demenz', 'migration', and 'Migration', and was limited to the abstracts and titles. When compiling the data corpus, only articles in German and English were selected, and the investigation was limited to the period from 1 November 2009 to 1 November 2019. In addition, a filtering procedure with the application of material quality criteria was carried out for the selection of articles for the systematic literature analysis. Due to these limitations, this study represents a selection of the scientific, political, and medical discourses on care for PwM with dementia. Statements about elements or measures related to this topic that were not accessible online, on the determined platforms, or via the attended events, that were included in articles that were not published during the defined investigation period, and that could not be identified by the selected keywords, were not considered. However, due to the systematic approach, this study gives an overview of central elements of culturally sensitive dementia care. In doing this, we did not limit our search on publications with a pure scientific focus, but also integrated publications that aim at improvement of medical practice or comprise a political framework for action.

Conclusions

This study provides a systematic overview of measures recommended in scientific, political, and medical special discourses, to ensure culturally sensitive care of PwM with dementia. These recommendations should be considered in the discussion of national guidelines on dementia care. Due to the specific needs and the particular challenges with regard to the care of PwM with dementia, which require a specific healthcare strategy with a comprehensive set of measures, the development of separate guidelines for the care of PwM with dementia at the national level is also recommended. Furthermore, the development of European guidelines for culturally sensitive care of PwM with dementia can be an instrument for reducing dementia-specific inequalities in care between the various migrant groups in the individual European countries, between the individual migrant groups in the various European countries, and between the European migrant population and the population without a migration background, as well as for establishing European minimum care standards for these people. As a first step, a consensus on the definition of the term "migrant" should be sought at the European level (Alzheimer Europe 2018).

Abbreviations *EFTA,* European Free Trade Association; *GPs,* General practitioners; *PwD,* People with dementia; *PwM,* People with a migration background; *RUDAS,* Rowland Universal Dementia Assessment Scale

Authors' contributions TS prepared the first draft. JRT participated in the study design and analysis. JM and JRT revised the manuscript and provided further contributions and suggestions. TS, JM, and JRT read and approved the final manuscript. All authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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Data and materials availability Most of the data (written statements) analyzed in this study are available on the databases PsycARTICLES, Psychology and Behavioral Sciences Collection, PsycINFO, and PubMed, the search engine Google or the website of Alzheimer Europe (https://www.alzheimer-europe.org/Policy/National-Dementia-Strategies).

Declarations

Ethics approval Not applicable

Consent Not applicable

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