

Structures for the care of people with dementia: A European comparison

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Research Article

Keywords: Dementia, Care, Structures, Services, Models of good practise, Gaps, Europe, Expert interviews

Posted Date: March 10th, 2022

DOI: <https://doi.org/10.21203/rs.3.rs-1253889/v1>

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Abstract

Background

Dementia is a disease that impacts people with dementia, their families, and the health care system. In 2018, the number of people with dementia in the EU, the European Free Trade Association (EFTA), and the UK was estimated to be 9.1 million. National dementia strategies and publications by organisations such as Alzheimer Europe outline how dementia-specific care should be organised and designed. This study aims to provide a systematic overview of existing formal support and care structures, models of good practise, and gaps in dementia-specific care for people with dementia in 17 European countries.

Methods

The research is based on guided qualitative interviews with country-specific care experts. All interviews were recorded and transcribed verbatim based on the transcription rules of Kuckarts (2010). For data evaluation, the qualitative content analysis model of Mayring (2014) was used. The content was structured with a combination of deductive and inductive categorisation, summarised, and presented descriptively.

Results

In all 17 countries, efforts for dementia-friendly care and models of good care practise exist. However, there are large differences between European countries regarding the spread of dementia-specific services. In some countries (Finland, Liechtenstein, Luxembourg, the Netherlands, Norway, Sweden, the UK), there are already nationwide structures, while in other countries (Belgium, Greece, Ireland, Portugal, Romania), services are only available in certain regions. Simultaneously, in all countries, areas with major care gaps exist. Several European states have an urgent need for action concerning the expansion of the provision of dementia-specific services in outpatient and inpatient care, the reduction of regional differences regarding the provision of care, the elimination of barriers to access to care, the dementia-friendliness of services, and the participation of people with dementia and their relatives in care and research.

Conclusions

To reduce the existing structural inequalities in care between and within European countries, and to establish quality-related minimum standards in the care of people with dementia, transnational concepts are needed. The EU, in cooperation with the parliaments of its member states, care planners, research institutions, care providers, and patient organisations, should develop European care guidelines or dementia plans that contain concrete measures, schedules, and budgets.

Background

Dementia is a disease with a comprehensive impact on people with dementia (PwD), (caring) relatives, and the health care system. PwD may experience limitations not only in cognitive abilities and behaviour [1] but also, for example, depression and anxiety [2]. The severity of dementia, behavioural problems, or psychological symptoms of PwD can be a cause of depression and a great burden on caregivers [3]. Furthermore, a number of unmet care needs in various areas, such as physical and mental health or quality of life (QoL), also emerge among those caring for PwD. A high number of unmet needs can further contribute to caregiver burden [4, 5].

Alzheimer Europe estimates in its 'Dementia in Europe Yearbook 2019' the number of PwD at approximately 9.1 million in 2018 for the EU^[1], the EFTA^[2], and the UK^[3]. By 2050, this number is estimated to rise to approximately 16.8 million [6]. In 2015, this high number of people affected outcomes in annual costs for the treatment and care of Alzheimer's disease in the EU-28 of €119.6 billion (for mild stages of the disease), €66.8 billion (moderate), and €45.6 billion (severe). These costs are estimated to increase to €330.4 billion (mild), €180.8 billion (moderate), and €121.3 billion (severe) by 2050 [7].

On a policy level, European countries are increasingly publishing national dementia plans (NDPs) in which they outline various areas that are relevant for the dementia-specific care of PwD and their caregivers [8]. There are also reports from organisations such as Alzheimer Europe, Alzheimer's Disease International, and Alzheimer societies on how best to provide dementia-specific care. However, in practise, the care situation of PwD and their caregivers may be different from what is required and desired in NDPs and reports from these organisations.

Although the organisation of health care in the EU is the responsibility of individual countries, the European Commission's objectives include protecting and improving the health of Europe's inhabitants, making health systems more resilient, and supporting health care systems to modernise and digitalise. To implement these goals and make countries' health care systems accessible, resilient, and effective, the European Commission's Directorate-General for Health and Food Safety provides aid in the form of funding, coordinating exchanges between EU countries and health experts, or through health promotion activities. On this basis, it makes sense to develop an EU strategy to support PwD and their families, which individual states can use as a guideline [9].

The aim of this study is therefore to provide national and international care planners with an overview of the extent to which formal support and care structures are available to PwD and their relatives in different European countries, which models of good care practise exist in Europe, and in which areas of dementia-specific care there are gaps that create a particular need for action. By systematically presenting existing structures, models of good practise, and gaps in dementia care at the national and European levels, care planners will be shown fields of action as well as potential solutions and networking opportunities.

[1] European Union

[2] European Free Trade Association

[3] United Kingdom

Methods

The analysis was conducted within the framework of the project 'EU Atlas: Dementia & Migration' funded by the Robert Bosch Foundation. Experts in the fields of health and dementia care, as well as migration, were interviewed in n=17 European countries using guided qualitative interviews. The participants were researchers, care planners, care providers, or representatives of dementia associations or Alzheimer societies and thus general experts in the field. They were asked questions about formal care of PwD and the support of their family members, some specific to the care of people with a migratory background, and some aiming at the general population. While largely comprehensive responses to migration-specific items have been published, general population data are systematically published for the first time in this article.

Recruitment of study participants

Experts were recruited through professional events such as the Alzheimer Europe Conference 2019 or the Public Health Conference 2019. In addition, authors of dementia-specific articles identified via databases such as PubMed, editors, and authors of NDPs and care guidelines, as well as representatives of national ministries of health, professional societies, and Alzheimer societies, were contacted and invited to participate in the interviews. Overall, recruitment was a challenge exacerbated by the COVID-19 pandemic. Correspondence with some experts broke off temporarily or permanently during the pandemic. Furthermore, no experts could be recruited from several countries [10].

Interview setting and study participants

The first interview took place in a face-to-face setting at the institution of the expert, while the remaining interviews were conducted via the Zoom video conferencing platform due to increased health risks and travel restrictions in the wake of the COVID-19 pandemic. The period over which the interviews were conducted was twelve months (early 2020 to early 2021). A total of 25 experts from 17 countries were interviewed: Austria, Belgium, Bulgaria, Denmark, Finland, Germany, Greece, Ireland, Italy, Liechtenstein, Luxembourg, the Netherlands, Norway, Portugal, Romania, Sweden, and the UK. Except for Sweden, whose expert provided written answers, all interviews were conducted orally. Almost all interviews were held in English. Exceptions are interviews with experts from Germany, Liechtenstein, and Luxembourg, which were carried out in German [10].

Interview guide

The questions for the interviews were derived from scientific articles, national and international reports, and an analysis of NDPs. The primary source was the Alzheimer Europe report 'The development of

intercultural care and support for people with dementia from minority ethnic groups' from 2018. The questions considered in this article were:

1) Please estimate to what extent are services for outpatient care of people with dementia widespread in your country?

- Nationwide
- Almost nationwide
- In several regions (areas)
- In single regions
- Not available

a) Could you explain this in more detail?

2) Please estimate how widely available services for inpatient care of people with dementia are in your country?

- Nationwide
- Almost nationwide
- In several regions (areas)
- In single regions
- Not available

a) Could you explain this in more detail?

3) According to your opinion, are existing services suitable for the adequate care of people with dementia?

- Yes, for people with and without a migratory background
- Yes, but only for people without a migratory background
- Yes, but only for people with a migratory background
- No, neither for people without nor for people with a migratory background

a) Could you explain this in more detail?

4) Could you please estimate the level of inclusion of people with dementia into health care in your country?

- Completely
- Almost completely
- Partly
- Slightly
- Not at all

a) Are there any models of good practise?

5) According to your opinion, how widely available are informational services for people with dementia and their family members in your country?

- Nationwide
- Almost nationwide
- In several regions (areas)
- In single regions
- Not existent/available

a) Could you explain this in more detail?

6) According to your opinion, are people with dementia and/or their family members participating in the development of health care services, the design of informational material, or the design of residential and care facilities?

- Always
- Often
- Sometimes
- Rarely
- Never

a) Could you explain this in more detail?

Before the interviews took place, the experts were sent the interview guide with these and other questions on care, inclusion, and information of PwD with and without a migratory background, professional care, and support for family caregivers, together with a document containing definitions of key terms and the research proposal of this project. This enabled the experts to prepare specifically for the interview and the individual questions, and to obtain knowledge from other experts that they did not have themselves. Experts were also offered an honourarium of €400 for their participation [10]. The document with the key terms can be found in the chapter 'Supplementary information' at the end of this article.

Transcription and analysis of the data

The interviews, which had an average duration of 90 minutes, were recorded and then transcribed. Therefore, the transcription rules of qualitative content analysis by Kuckartz (2010) were applied, and verbatim transcription was carried out [11]. The evaluation of the interviews was based on the method of qualitative content analysis by Mayring (2014). A combination of deductive and inductive categorisation was used to structure the content [12]. First, two categories were deductively derived from the categories of the interview guide: (1) care services for PwD; and (2) inclusion and information of PwD and their family members. The text passages that directly referred to one of these two topics were assigned to the categories and extracted. Then, subcategories were inductively derived from the data. The next steps included the formation of a category system, sorting and summarising the material, and tabulating the data. Finally, the results were presented in the form of country profiles. For a comparative analysis of the European countries involved, the country-specific results were first summarised in a table. The data were coded again (inductively), organised within the framework of a category system, and quantitatively processed and sorted. Subsequently, the similarities and differences regarding the country-specific results were described.

Results

The results are first presented separately based on profiles for each of the 17 European countries considered before a comparison was made, and the situation at the European level is described. The following country profiles are in alphabetical order.

Country profiles: the EU, the EFTA, and the UK

Austria (population/area 2021: 8.9 million [13]/83,900 km² [14])

The expert interviewed stated that in Austria, there are nationwide services for the outpatient care of PwD, although the offer is greater in urban areas than in rural areas. Larger cities such as Vienna and Graz have geriatric centres, memory clinics, and other facilities that focus on early detection, diagnosis, and preventive measures regarding dementia. However, there are also gerontopsychiatric centres in rural areas and dementia self-help groups at the municipal level. As for inpatient care, the urban-rural disparity is much greater. Inpatient services are hardly available in rural areas. The responsible district hospitals are poorly equipped in terms of dementia care, as they have no specialists or psychiatry services. According

to the expert, a number of specialised facilities offer high-quality dementia care. However, these services are not sufficient to meet existing needs. The structures are insufficiently developed, while the need for dementia-specific care is growing due to demographic change. Models of good practise are the nationwide availability of multilingual information on dementia, the system of outreach by home care nurses, and the legal possibility of professionalising the role of a family caregiver, including the associated entitlement to a salary, holidays, and paid rehabilitation.

Belgium (population/area 2021: 11.6 million [15]/30,500 km² [16])

According to the two experts, outpatient care services for PwD are widespread in Belgium and available in every municipality. In the inpatient context, there are differences in terms of region and type of service. Concerning state and private nursing homes, the offer is very large, while the availability of other types of inpatient care, such as day-care facilities, is significantly lower. This is related to the low level of state support in this area and the focus of care policy on nursing homes. The experts stated that whether dementia-sensitive care is offered to PwD depends on individual organisations. Some organisations try to provide person-centred care and offer dementia-specific services, while some organisations do not. GPs and diagnostic centres are often dementia-sensitive, but this is not the norm in general hospitals. Among care providers and professional caregivers, there are often large knowledge gaps in terms of dealing with PwD. Another problem is access to information, which is a major challenge for PwD and their relatives due to the distribution of services among different organisations and websites. Overall, the two experts concluded that there is a lack of a minimum standard for the care of PwD in Belgium. Models of good practise are projects of individual organisations such as dementia-friendly hospitals or nursing homes.

Bulgaria (population/area 2021: 6.9 million [17]/110,879 km² [18])

In Bulgaria, services for outpatient and inpatient care for PwD are available almost nationwide. For example, doctors, psychiatrists, neurologists, hospitals, and medical centres can be found in every region. Regarding inpatient care, there are nursing homes provided by the state and municipalities, in addition to private homes and hospices. Even if these offers exist and are suitable for the care of PwD, they are nevertheless not available in sufficient quantity, as their accessibility remains limited for people from rural regions, for example. The possibility of obtaining information about dementia and care services also occurs nearly nationwide through the offer of an Alzheimer café, the online consultation website, and the Facebook page of the 'Foundation Compassion Alzheimer Bulgaria', as well as the availability of written informational materials. According to the experts, the inclusion of PwD in the country's health care system is fully successful. The Alzheimer café and the possibility of online consultation through the 'Foundation Compassion Alzheimer Bulgaria' were cited as models of good practise.

Denmark (population/area 2021: 5.8 million [17]/43,100 km² [18])

According to the expert interviewed, outpatient care for PwD is possible nationwide. Memory and outpatient clinics specialising in dementia are available in each of the five Danish regions. The responsibility for diagnosis and assessment is with the memory clinics. After a diagnosis of dementia

has been given, the person is transferred over to public care. This means a dementia coordinator (there is one in every municipality) receives information about the patient and, if desired, makes contact to determine where there is a possible need for help. This also means that PwD are almost completely integrated into the health care system. In Denmark, there are no specialised services for PwD in inpatient care. This is due to the focus on making hospitals and similar facilities dementia-friendly instead of creating separate services. These dementia-friendly hospitals are also mentioned as a model of good practise, similar to the type of care for PwD described above. Memory clinics and the Alzheimer Society provide people in Denmark with information about dementia in different languages nationwide. Furthermore, PPIs^[4] have been increasingly used for several years. For example, the Alzheimer's Society has set up a panel with PwD that serves as an advisory body to many projects on dementia.

Finland (population/area 2021: 5.5 million [19]/338,100 km² [18])

According to expert assessment, outpatient and inpatient services for PwD are available nationwide. Home care is the most common form of treatment for PwD in Finland. There are regional and individual differences in the implementation of treatment. This entails, for example, care in the capital, outpatient treatment, and rehabilitation plans. Furthermore, hospitals with specialised care services and special care partners for university hospitals exist nationwide. However, regional hospitals and university hospitals offering specialised care for PwD can be far away. As dementia is a topic with very high nationwide attention in Finland, there is a large amount of information and materials about it. Consequently, dementia-specific knowledge about dementia in the general population is quite high. The strong involvement of family members of PwD in the assessment of services represents another model of good practise in Finland. The expert concluded that existing services are suitable for adequate care of the autochthonous population with dementia, and that PwD are almost fully included in health care.

Germany (population/area 2021: 83.1 million [20]/357,000 km² [18])

Based on expert experience, outpatient care services for PwD are available all over the country. Outpatient nursing services, in particular, are very widespread, while outpatient GP and geriatric, psychotherapeutic, and rehabilitative care for PwD in rural areas is critical. Inpatient services for PwD exist in several regions. However, facilities such as dementia units or structures such as dementia files are not yet available in all hospitals. As general somatic units often lack geriatric knowledge, care for PwD in hospitals is often inadequate. Furthermore, the number of dementia-friendly specialists and general practitioners is far too low. Overall, services for PwD often lack sensitivity to the specific needs of these people. A further structural problem is that too many PwD drop out of the informational and counselling system due to a lack of specific information for people with other diversity characteristics such as early-onset dementia, a migratory background, or homosexual orientation. In addition, participatory care and research with PwD and their relatives rarely occur. The expert concluded that there are good offers, but that a different structuring of the care system is needed. Models of good practise include the concept of dementia-friendly hospitals, the high activity of Alzheimer societies at the national and regional levels, and the almost nationwide availability of comprehensive information for PwD.

Greece (population/area 2021: 10.7 million [17]/131,957 km² [18])

Services for outpatient care of PwD are available in some regions. People who have financial resources use services from the private sector or hire a person—usually with a migratory background—to live with and care for PwD. The private sector offers many options for residential care for PwD, but there are hardly any alternatives outside these offers. As a result, PwD are only integrated to a certain extent into the health care system in Greece. When people receive a dementia diagnosis, they have to determine for themselves which services exist and what they can use. This process can be facilitated by the nationwide availability of information for PwD and family members, which is promoted through different communication channels in different campaigns. PwD and their families are rarely involved in the creation of information, care, and support services. Although the National Dementia Action Plan calls for participation of this group in everything related to dementia, few PwD and/or family members are involved.

Ireland (population/area 2021: 5 million [17]/70,273 km² [18])

According to expert, in some regions of Ireland, there are offers for outpatient care of PwD. However, these services are mainly provided in urban areas, whereas rural areas do not offer services in this field. However, due to the COVID-19 pandemic, some memory cafés have virtualised their services so that people from rural areas can also access them. The expert estimated that existing services are not suitable to adequately care for PwD, as there is a lack of dementia-specific services and existing ones are often not dementia-friendly. Due to the difficulty in obtaining a dementia diagnosis and the dependence of access to care services on one's place of residence, PwD are only partially integrated into the health care system. GPs, community nurses, and 'The Alzheimer Society of Ireland' provide information about dementia to PwD and their families. The Alzheimer Society offers both written informational packages and a telephone counselling service.

Italy (population/area 2021: 59.3 million [17]/301,340 km² [18])

The availability of outpatient and inpatient care for PwD was indicated by the expert to be nationwide, since in Italy, for example, there are over 600 memory clinics. On this basis, the integration of PwD into the health system can be described as almost complete. Information for PwD and their family members is also available nearly nationwide. However, there is a north-south difference in the sense that there may still be a lack of services and information in the south, and that the organisation of services is not yet optimally set up. According to the expert, existing services are generally adequate for the care of PwD. As a model of good practise in this area, it was mentioned that a working group should be established that includes associations for patients and family caregivers.

Liechtenstein (population/area 2019: 39,000/160 km² [21])

The two interviewed experts stated that both outpatient and inpatient care services for PwD are available nationwide. The 'Familienhilfe Liechtenstein e.V.' is responsible for outpatient care and the

'Liechtensteinische Alters und Krankenhilfe' (LAK) for inpatient care. For 10 of the 11 municipalities, the 'Familienhilfe' provides nursing and care services as well as meal services. The 'LAK' operates 6 nursing homes at 5 locations and provides holiday, day, night, rehabilitative, and inpatient long-term care for these 10 municipalities. In one municipality, there is separate follow-up care and support infrastructure, as well as a day-care service for PwD by the 'Lebenshilfe Balzers e.V.'. The association 'Dementia Liechtenstein' ensures that information on dementia is available nationwide (e.g. through various media appearances, the biannual mailing of information brochures to all households, and digital services). According to the experts, existing care services are suitable for adequate care of PwD, who are almost completely included in the health care system. While outpatient and inpatient services are well accepted, day-structured and night-time services for PwD to relieve the burden of family caregivers are not yet fully utilised. Furthermore, there is a need to improve the participation of PwD and their relatives in the development of services. Models of good practise are the awareness-raising and training efforts of 'Dementia Liechtenstein', the care and support services of the 'Familienhilfe', and the nationwide programme for activating people with cognitive impairment.

Luxembourg (population/area 2021: 635,000 [17]/2,600 km² [18])

According to the expert, outpatient and inpatient care for PwD is widespread throughout the country. In Luxembourg, a new law was passed that requires at least 40% of staff in inpatient and outpatient settings to receive 40 hours of psychogeriatric training. This measure enables the majority of staff to work adequately with PwD. At the same time, dementia-specific informational services are also available nationwide. In addition to the work of the 'Info-Zenter Demenz' and the high presence of the 'Association Luxembourg Alzheimer', this is due to the efforts of the government, which emphasises in the design of training that its employees receive information about dementia that they can pass on to PwD and their relatives. The expert stated that existing care services are adequate to provide appropriate care for PwD from all population groups. PwD and their relatives only sometimes participate in the development of services, but overall, they are almost fully included in health care. A model of good practise is the educational work of the 'Info-Zenter Demenz', which provides information about dementia in seven languages.

Netherlands (population/area 2021: 17.5 million [17]/41,500 km² [18])

The two experts stated that services for outpatient and inpatient care for PwD are available nationwide. Almost every hospital has a neurologist or geriatrician to contact in case of dementia symptoms. Furthermore, there are almost 100 memory clinics in the Netherlands. The larger cities also all have inpatient care facilities. In rural areas, the distances to such facilities can sometimes be slightly longer. Dementia-specific informational services are also available throughout the country. Since most of the information provided mainly by 'Alzheimer Netherlands' and 'Pharos' is available online, access is difficult for many older people. According to experts, there is a need for different forms of informational services. Overall, existing care services are suitable for adequate care of PwD. However, this does not apply equally to all population groups. Since services are usually developed by people without a migratory background,

they are more suitable for the autochthonous population than for people with a migratory background. Currently, PwD and their relatives are rarely involved in the development of care services. One reason for this is that GPs, who play a key role in the Dutch care system, have difficulties in diagnosing dementia. In the opinion of the experts, PwD are partly included in health care, as the design of dementia care is strongly determined by professionals. A model of good practise is the concept of the 'dementia-friendly community', which includes a quality label and staff training for supermarkets and communities, as well as needs assessment through biography work with PwD.

Norway (population/area 2021: 5.4 million [17]/385,200 km² [22])

Norway was one of the first countries to establish a dementia action plan. Since then, the government has published three NDPs. As a result of the NDPs, many municipalities have installed special dementia teams and dementia coordinators. According to the expert, services for outpatient and inpatient care for PwD are available nationwide. In contrast to countries such as Germany, Norway has a unified health care system and provides universal health care. As a result, home care is available to all people living in Norwegian communities. These services are almost exclusively offered by public service providers. Informational services for PwD and their family members are also widespread. Through the NDPs, as well as the work of the 'Norwegian Centre for Ageing and Health' and the 'Centres for Care Research', there has been a strong focus on dementia at the national, regional, and local levels. While it is very easy for the autochthonous population to access information about dementia, access for people with a migratory background is a challenge. The expert stated that existing care services are suitable for adequate care of PwD. However, this does not apply to people with a migratory background, and the services are not perfect for the autochthonous population either, as the pressure on the care system is growing due to the increasing number of older people. Moreover, since the system is bureaucratic and has precise requirements on how to articulate needs, relatives often have to be resourceful to obtain the services they are entitled to. Overall, relatives need more support, for example, in the form of home-based services. Over the past decade, there has been a great focus on the care of PwD with action plans, the funding of research, and the development of initiatives. However, the greatest challenge is the implementation of existing knowledge in practise. Due to the high potential for improvement in this area, the expert estimated the degree of inclusion of PwD in health care to be hardly to partly. Models of good practise are the broad public campaigns on dementia and the relatively high level of state investment in dementia care, the increasing participation of PwD and their relatives in the design of care services, and the establishment of a dementia hotline by an organisation for PwD and their relatives.

Portugal (population/area 2021: 10.3 million [17]/92,090 km² [18])

The interviewed experts stated that both outpatient and inpatient care services for PwD are only available in some regions. The reasons given included a lack of funding and organisation. Furthermore, existing services are only partly suitable to adequately care for PwD. Due to this circumstance and various barriers of access to care services, PwD are only integrated into the health care system to a limited extent. Additionally, it does not seem clear who is responsible for the care of PwD. Currently, neurology,

psychiatry, and mental health teams share this work. Informational services for PwD and their family members exist in some regions. These services are provided by Alzheimer cafés, the website of the 'Association Alzheimer Portugal' and a growing movement at the community level to reach PwD, raise awareness of dementia, and disseminate information. This movement in the municipalities was highlighted by the experts as a model of good practise.

Romania (population/area 2021: 19.2 million [17]/238,400 km² [18])

According to the expert, outpatient services for PwD exist in several regions. In university centres of large cities, there is a special service for PwD. Otherwise, outpatient services are available where PwD can ask for help, but these services are not specialised for their needs. In inpatient care, there are only a few specialised services for PwD. Psychogeriatric facilities do exist in large emergency hospitals. However, the major problem is that there is a lack of staff qualified to treat PwD and specialised facilities such as dementia units. As PwD are often placed together with younger people and cared for by staff that are not trained in dementia care, they do not receive dementia-specific care in most hospitals. In Romania, although there are a few public facilities (especially hospitals), most care homes are operated by private organisations. Due to the high costs of these services, which are in principle available to all, many older PwD do not have access to them. Further, only a few care homes provide specific services for PwD and the organisations that do so rarely take their needs into account. As a result, PwD are only partially included in health care. Information on dementia is available online, but access to it is very unevenly distributed. There are some highly qualified professionals and experts who deal with the topic of dementia in detail, have a great deal of knowledge, and share important information, for example, in lectures. However, this information does not reach the majority of the population and, in particular, not the large number of PwD and their relatives. Many older people (especially in rural areas) do not have any internet skills, have no technical access to the internet, and lack the financial resources to participate in education. The expert stated that the political will to change this does not exist. Overall, a national strategy for dementia care is lacking. Models of good practise are the annual events organised by the 'Societatea Română Alzheimer' with PwD and their family members, as well as some other projects initiated in different regions and by local Alzheimer Societies with self-help groups, educational programmes, theatre and storytelling groups, and other services for PwD. Another positive aspect is that awareness of dementia in the population has increased through large public campaigns.

Sweden (population/area 2020: 10.4 Millionen/407,300 km² [23])

The expert reported that outpatient and inpatient care services for PwD are widespread. There are several nationally available opportunities to access dementia-specific care and support, both in the state, community, and private sectors. Informational services for PwD and their family members are also available nationwide. Overall, care services are suitable for adequate care for PwD, but this does not apply to people with a migratory background. The expert estimated the degree of inclusion of PwD in health care as partly to almost completely. However, PwD and their relatives rarely participate in the development of care services. Although there are associations of relatives that try to influence dementia

care, there are large regional differences. In Sweden, several models of good practise exist concerning information, support, care, and inclusion of PwD. For example, there are websites with information about dementia, care and research, specialised services such as dementia nurses and family support, and a register for people with behavioural and psychological symptoms of dementia (BPSD) that helps staff and relatives to identify different needs or symptoms in patients.

The UK (population 2020/area 2021: 67.1 Millionen [24]/243,600 km² [18])

According to the expert, both outpatient and inpatient care services for PwD are available nationwide, although most care is provided by families. Despite the existence of services for care at the national level, PwD are only partially integrated into health care, depending on the region. Information is available throughout the country for PwD and their family members. However, obtaining the right information at the right time can be a challenge. The expert mentioned, as a model of good practise, an initiative that tries to bring specialists together in one place and to centralise the treatment of PwD. In this way, PwD in GP practises have access to a neurologist, for example.

A comparative analysis of European countries

In this section, the results of the country-specific interviews with experts from 17 European countries are brought together, and an attempt is made to draw a picture regarding the existing care structures and gaps at the European level.

Existing structures in dementia care

As shown in Figure 1, the expert interviews indicated that in 13 of the 17 European countries considered, outpatient health care services for PwD are available nationwide or almost nationwide. While these services are available in several regions in Ireland and Romania, outpatient care for PwD is limited to individual regions in Greece and Portugal. Inpatient health care services are only available nationwide or almost nationwide in just over half of the countries (see Figure 2). In Belgium, Germany, and Austria, such services exist in several regions and in Portugal and Romania in individual regions. In Greece, there are some inpatient services in the private sector but hardly any in the public sector. No specialised inpatient services for PwD are available in Denmark, where a different approach is taken, as well as in Ireland.

According to country-specific experts, in 11 of the 17 countries, existing care services are suitable for adequate care of PwD (Figure 3), although in four countries, this is not the case (Finland, Norway, Sweden) or not to the same extent (the Netherlands) for people with a migratory background. While the expert from England could not give a clear answer for the UK due to the constantly changing situation, the experts from Belgium and Portugal indicated that this is partly the case in their country. In Romania, dementia-friendly services are only available in a few regions, and in Germany and Ireland, existing care services overall are not suitable for adequate care of PwD.

Informational services for PwD and their family members are available nationwide or almost nationwide in 15 countries, as shown in Figure 4. In Belgium and Portugal, such services are only provided in some

regions.

Figure 5 and Figure 6 illustrate that the situation is different for the topics of participation and inclusion. According to the experts, PwD are fully (Bulgaria) or almost fully (Denmark, Finland, Italy, Liechtenstein, Luxembourg) included in health care in six countries. While this is still partially the case in eight countries, inclusion hardly happens in Belgium, Germany, and Norway. The only country where PwD or their family members are often involved in the development of care services is Finland. Such a participatory approach is sometimes adopted in Austria, Bulgaria, Ireland, Luxembourg, and the Netherlands and increasingly in Denmark and Norway. Based on expert interviews, this is rarely the case in Germany, Greece, Italy, Liechtenstein, Sweden, and the UK, and not at all in Portugal.

Models of good practise and existing care gaps

Although there are considerable country-specific differences with regard to the availability and spread of dementia-specific care and informational services, as well as the inclusion and participation of PwD and their family members, all experts cited models of good practise in one or more of these areas (see Figure 7). Such models were most frequently identified in the field of care services for PwD (eight times). For example, experts from Italy and the Netherlands referred to a high number of memory clinics, while other interviewees highlighted outreach services such as home care nurses (Austria), care, and support services (Liechtenstein), as well as dementia nurses and family support (Sweden). In Bulgaria, the concept of Alzheimer cafés is partly implemented. Another focus is on raising awareness in society and the care system (seven models of good practise). In Norway and Romania, for example, there are broad public campaigns on the topic of dementia. The Netherlands is focusing on the concept of a dementia-friendly community, and in Belgium, Denmark, and Germany, there are projects on dementia-friendly hospitals/nursing homes. Five models of good practise were cited by experts related to support services for family members. The focus here is on education, counselling, and training for family members of PwD (Bulgaria, Ireland, Liechtenstein, Norway). Experts from each of the three countries underscored models of good practise in the areas of dementia-specific information (Austria, Luxembourg, Sweden) and care structures (Denmark, Norway, Sweden). Especially in Denmark and Norway, there seem to be great efforts at the government level to establish nationwide standards in dementia care. Experts from Germany (where there is high activity among Alzheimer societies) and the UK (where there is an initiative to bring together GPs and specialists for dementia care) also cited models of good practise that can be assigned to the area of networking among stakeholders regarding dementia.

Simultaneously, all experts pointed to structural problems and gaps regarding the health care of PwD and their relatives (the main areas are shown in Figure 8). However, these problems and gaps seem significantly larger in some countries (Belgium, Greece, Ireland, Portugal, Romania) than in others (Finland, Liechtenstein, Luxembourg, the Netherlands, Norway, Sweden, the UK), indicating the existence of major care inequalities within Europe and the EU.

Most frequently, the interviewed experts referred to gaps in service provision for PwD (24 identified problems). The interviewees from Austria, Bulgaria, Germany, Portugal, and Romania emphasised that

not enough specific services are available for PwD in both the outpatient and inpatient sectors. In Belgium, Bulgaria, Norway, and Portugal, there are significant regional differences (including a strong urban-rural contrast) in the provision of inpatient care, and in Bulgaria, Norway, Portugal, and Romania, there are large disparities in the outpatient context. Further, the experts from Germany and Romania stated that care for PwD in hospitals is often insufficient. In Belgium and Bulgaria, a key problem seems to be the low availability of daycare facilities. Seven of the problems described can be assigned to the area of care access. Experts from Bulgaria, Finland, and the Netherlands reported that in some parts of their country (especially in rural areas), access to care is limited. For Finland, Greece, Norway, and Portugal, the experts identified fundamental barriers to accessing health care for PwD and their families, such as bureaucratic obstacles (Norway), the high cost of services (Greece), and a lack of support (Finland). Seven of the structural gaps cited by the experts were related to the adequacy and dementia-friendliness of care services. In Belgium, Germany, and Ireland, there seems to be a lack of sensitivity of services tailored to the specific needs of PwD. Another area where a great need for action exists is the participation of PwD and their relatives in care. According to the experts, such patient and family involvement either does not happen at all or hardly takes place in Germany, Greece, Italy, Liechtenstein, Portugal, Sweden, and the UK. Six points of criticism relate to the organisation and structuring of the care system. The experts from Belgium and Portugal stated that there is a lack of financial and government support for the establishment of comprehensive care standards. The Dutch experts criticised the one-sided design of dementia care, which is determined by experts, and the Norwegian interviewee considered the implementation of existing dementia-specific knowledge in practise to require improvement. While the availability of dementia-specific information is nearly nationwide in almost all countries included, the lack of accessibility of these services is a problem in several states. For Belgium, Germany, Ireland, and Romania, the experts identified structural deficiencies in the organisation and accessibility of informational services. Two experts each pointed to difficulties in dementia diagnosis (Ireland, the Netherlands) and a major lack of dementia-specific trained staff in hospitals (Romania) or care (Belgium).

Summary

Overall, efforts for dementia-friendly care and models of good care practise exist in all 17 countries. However, there are great differences between individual European countries regarding the spread of dementia-specific services and the development of structures for the care of PwD and their relatives. In some countries, comprehensive care structures already exist, while in other ones, care services are only available sporadically, efforts are made exclusively at the level of individual service providers or professionals, and there is a lack of political will to establish care standards. Simultaneously, in all countries, there are areas where there are major gaps in care and an urgent need for action. While salient differences are evident in the extent of the gaps, there is also some overlap in the thematic priorities between different European nations. Several experts called for restructuring measures in their country, such as a consistent national strategy for dementia care (Romania), a different structuring of the care system (Germany), or an expansion of existing structures (Austria). This could be used as a starting point

for transnational networking of dementia care and the development of European strategies to establish minimum standards in the care of PwD and their relatives.

[4] Patient and Public Involvement

Discussion

The aim of this analysis was to provide an overview of existing care structures, gaps, and models of good practise in dementia-specific care based on interviews with dementia care experts from 17 European countries.

Despite some positive results in this analysis (such as the organisation of dementia care in Denmark), there are nevertheless deficits that can overlap across states. One area that was often criticised by the experts was the provision of health care services for PwD. This is reflected in the literature [25-27]. Therefore, dementia-specific care needs to be adapted accordingly. In its Alzheimer's Innovation Readiness Index of 2021, 'Alzheimer's Disease International' emphasised that care for PwD 'will require a more comprehensive infrastructure for detection, monitoring, diagnosis, treatment, and care, along with more advanced legislation and policies for effectively protecting informal carers and the rights of persons living with dementia, and facilitating greater access to services and treatments', and that both informal and professional caregivers need more dementia-specific training. However, the reality shows that corresponding initiatives can be underfunded and in part not optimally executed [25]. Broda et al. (2017) indicated that there are different components for optimised dementia care, e.g. multidisciplinary, person-centred care services, the need to ease the dementia care pathway, and the networking of formal and informal care [28]. Alzheimer Europe highlighted the importance of dementia friendliness and the need to build a model for dementia-friendly communities that could be implemented on a European basis. This model should integrate existing efforts at the national level but leave room for individual adaptation to local circumstances [29].

Another area where significant deficits are evident is the participation of PwD and family carers in the development of health care services and information. Although greater awareness and understanding of the importance of the participation of PwD in health care services, research, and support have emerged in recent decades [30], the present analysis revealed a need for improvement. It is of immense relevance to involve PwD in the creation of health care services (as well as research and policy) for the following reasons: (1) PwD are experts in dementia and involving them leads to better outcomes; (2) involving them has advantages for PwD themselves, but also for (health care) professionals; and (3) PwD have the right to be involved. Thus, the participation of PwD and their family carers in the design and evaluation of health care services leads to services that are better tailored to their needs [30].

A further important aspect is the role of governments in the care of PwD and family carers. First, it is vital that they recognise dementia as a public health priority, which is not yet the case in all European

countries [31]. In addition, they have a special responsibility to improve access to and quality of care, to help (in)formal caregivers, and to ease care pathways for those affected [25].

These are only a few relevant aspects regarding the care of PwD. Coordinating, repositioning, and optimising care for PwD and family carers requires a combination of actions among key stakeholders such as care providers, care planners, patient organisations, research, and governments.

Limitations

A limitation regarding the generalisability of this study's findings is that the group of interview participants must be described as selective and not representative of experts in dementia care in European countries. Despite an extensive search, it was not possible to include an expert for every EU, EFTA, and UK country. While several experts were identified and interviewed in a few states, only one expert could be recruited in most of the countries studied. Moreover, according to self-assessment, not all interview participants were primarily experts in the field of dementia. Some participants focused on general health care or the topic of migration (e.g. Greece), which is partly because experts in the area of dementia and migration were originally searched for. Hence, the findings do not provide a complete picture of the care situation in individual European countries, although that was not the aim. Rather, this paper is intended to draw attention to specific country-specific and cross-country care areas where there is a particular need for action. This study can and should be used as a starting point for further, more in-depth analyses with experts from different areas of formal and informal care in as many European states as possible. For a valid description of the situation regarding the formal care of PwD and their relatives, as well as existing specific care services for this population in individual European countries, more research is necessary using different methods, such as country-specific literature analyses and large-scale surveys among care experts, planners, and providers in the respective countries. To control the outcomes of these expert interviews, country-specific literature such as NDPs, national care guidelines, and national dementia reports were screened.

The interview guide designed for the project 'EU-Atlas - Prevalence of dementia in people with a migration background' contains specific questions on the care of PwD with a migratory background [10]. According to the authors, the general questions on dementia-specific care structures are sufficient to give an initial overview of basic inequalities and gaps in the care systems and to identify individual models of good care practise, but an objective and comprehensive representation of care services cannot be provided. The interview guide and the results were shaped by the experts' points of view. To reduce the influence of the individual's personal opinion and to improve the quality of the answers, the guide was sent to the experts some time before the interviews were held. Another limitation concerns the predefined answer categories, which improved the comparability of the data but distorted the experts' documented views on the care situation in their respective countries, and led to an underestimation of complexities in individual nations. To counteract this limitation, open questions were asked after almost every closed question. In the evaluation of some answers, interpretations were necessary to ensure the comparability of the data. Certain methodological models were applied for this purpose. However, the results do not represent a

verbatim reproduction of the experts' statements, but are instead summaries of the interviews by the authors. Despite these limitations, the study provides useful information for care planners at the national and European levels regarding current problems in formal dementia care, existing gaps in European health systems, important dementia-specific fields of action, and models already established in individual countries to address the problems described. This study is a valuable addition to the current literature on existing structures for the care of PwD in Europe, as its qualitative approach and the consultation of experts in care practise from individual countries provide more in-depth, country-specific information and first-hand conclusions, and can thus be used as a reference point for comparisons between care planning written down in documents and the actual circumstances in care practise.

Conclusions

The considerable inequalities in dementia care within and between many European countries, as well as the structural deficiencies in key areas of care that exist to varying degrees in all countries and partly show large overlaps (according to interviews with country-specific experts from 17 EU, EFTA, and UK countries), illustrate the need for major restructuring measures and paradigm shifts. To initiate such extensive systemic transformations and to establish quality-related minimum standards in the care of PwD—which is often marginalised and has specific needs—supraregional and (ideally) transnational strategies are required. Since the EU was originally a community of values and its institutions are committed to the goal of achieving equal living conditions for all population groups living in its member states, it should be the EU's task to develop such concepts at the European level together with cooperation partners, such as the parliaments and ministries of their member states, care planners and experts, research institutions, care providers, and organisations of PwD and their relatives. Within the framework of EU programmes such as European care guidelines or dementia plans, which must receive binding budgeting in addition to concrete time schedules, special attention should be given to the European networking of key stakeholders in dementia care; the sensitisation of European societies and care systems to the topic of dementia; the development of Europe-wide care structures for PwD and their relatives in both outpatient and inpatient contexts; the validation of the dementia-friendliness of these services with PwD and their relatives; the elimination of barriers for the access of PwD and their relatives to information, support, and care services; the dementia-specific education and training of health and care professionals; and the participation of PwD and their relatives in all areas of dementia-specific care and research. In particular, the inclusion of PwD and their relatives in European societies and care systems should be given greater priority in future dementia care strategies. In addition to a fundamentally open attitude toward the needs of other people, adopting a supraregional and transnational perspective can be helpful in this regard.

Abbreviations

EFTA

European Free Trade Association

EU

European Union

NDPs

National dementia plans

PwD

People with dementia

QoL

Quality of life

UK

United Kingdom

Declarations

Ethics approval and consent to participate

The data on which this paper is based were collected and evaluated as part of the study 'EU-Atlas - Prevalence of dementia in people with a migration background'. The Ethics Committee at the University Medicine Greifswald has reviewed the documents submitted for the research plan of the study mentioned above (internal registration number: BB 026/22). The Ethics Committee at the University Medicine Greifswald has exempted this study and waived consent. All methods were carried out in accordance with relevant guidelines and regulations.

Consent for publication

Not applicable

Availability of data and materials

The data are not publicly available because the answers to the questions asked are personal assessments of experts working in the care or research system of the respective countries, which have been anonymised in this article. For data, please contact Jessica Monsees (jessica.monsees@dzne.de).

Competing interests

The authors declare that they have no competing interests.

Funding

The project 'EU-Atlas - Prevalence of dementia in people with a migration background' was funded by the Robert Bosch Stiftung. Robert Bosch Stiftung did not influence the design of this study, the analysis of the data, or the process of writing the manuscript.

Authors' contributions

TS and JM prepared the first draft. TS, JM, and JRT participated in the study's design and analysis. TS, JM, and JRT revised the manuscript and provided further contributions and suggestions. All authors read and approved the final manuscript.

Acknowledgements

The authors would like to thank the Robert Bosch Stiftung for funding this project and all the experts for their valuable insights and contributions.

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Figures

Figure 1

Availability of outpatient health care services for people with dementia

Figure 2

Availability of inpatient health care services for people with dementia

Figure 3

Suitability of existing services for adequate care of people with dementia

Figure 4

Availability of informational services for people with dementia

Figure 5

Inclusion of people with dementia into health care

Figure 6

Participation of people with dementia in the development of care services

Figure 7

Models of good practice

Figure 8

Gaps in the health care of people with dementia

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