

## **Dementia care in the Danube Region. A multi-national expert survey**

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## **ABSTRACT**

**Background:** Dementia is a particularly severe societal challenge in several countries of the Danube Region due to higher-than-average increment in population longevity, disproportionate increase of the old-age dependency ratio, and selective outward migration of healthcare professionals. A survey was conducted among dementia experts to obtain a deeper understanding of the dementia care structures and services in this geographical area, and to identify the educational needs of healthcare professionals, and the availability of assistive technology.

**Subjects and methods:** A standardised questionnaire was sent out to 15 leading dementia experts/clinicians in 10 Danube Region countries inquiring about professional groups involved in dementia care, availability and reimbursement of services, inclusion of dementia in professional education and training, acceptability of internet-based education, and availability of assistive technology. The authors are the survey respondents.

**Results:** The majority of individuals with dementia receive care in the community rather than in institutions. The roles of medical specialties are disparate. General practitioners usually identify dementia symptoms while specialists contribute most to clinical diagnosis and treatment. Healthcare professionals, particularly those who work closely with patients and carers, have limited access to dementia-specific education and training. The greatest need for dementia-specific education is seen for general practitioners and nurses. An internet-based education and skill-building program is considered to be equivalent to traditional face-to-face but offer advantages in terms of convenience of access. Assistive technology is available in countries of the Danube Region but is significantly underused.

**Conclusions:** Dementia care in the Danube Region can be improved by an educational and skill-building program for healthcare professionals who work in the frontline of dementia care. Such a program should also attempt to enhance interdisciplinary and intersectorial

collaboration, to intensify the interaction between primary care and specialists, and to promote the implementation of assistive technology.

**Key words**

Dementia, Danube Region, expert survey, dementia care structures, education, assistive technology

## INTRODUCTION

The Danube Region is a functional area defined by its river basin. It extends over 14 states, among them nine EU-member states (Germany, Austria, the Czech Republic, Slovakia, Hungary, Slovenia, Croatia, Bulgaria and Romania) and five countries which are not presently EU-members (Serbia, Montenegro, Bosnia and Herzegovina, the Ukraine and Moldova). The Danube Region has a total population of 150 million. In socio-economic regard, the region shows disparity since it includes some of the most affluent but also some of the poorest regions in the European Union.<sup>1</sup> The prevalence of dementia among people aged 60 years and older is not uniform across the area. Rates of about 5 % have been reported in Slovakia and Romania, whereas prevalence is as high as 7 % in Austria, Germany, and Bulgaria.<sup>2,3,4,5</sup> An even higher prevalence of dementia (10%) has been found in the Ukraine but the validity of this data is questionable.<sup>6</sup> Taken together, at least 3 million older adults are affected with dementia in the countries of the Danube Region.<sup>7,8</sup> (Table 1).

Due to increasing life expectancy the number of people affected with dementia is predicted to rise by 50 % from 2015 to 2030 in eastern and southern Europe,<sup>9</sup> and the dependency ratio (the ratio of people aged 65 or above relative to the working-age population) is expected to increase.<sup>10</sup> An additional challenge in the Danube Region is the migration of health workers, predominantly Eastern part, („care drain“)<sup>11</sup> and has resulted in a lack of qualified health personnel and reduced family support in the sending countries.<sup>12</sup> The improvement and sustainability of dementia care and access to dementia-related knowledge has to be placed high on public and political agendas in the Danube Region. Here we report the results of a multi-national survey which was carried out by the DANDEC consortium (for Details see subjects and methods) in order to obtain a deeper understanding of dementia care and dementia-specific education in the Danube Region.

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Table 1 about here

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## **SUBJECTS AND METHODS**

In 2013 a consortium of 10 academic centres, 2 patient and carer organisations and 2 enterprises from 10 countries in the Danube Region formed the Danubian Network for Dementia Education and Care (DANDEC). The DANDEC project was supported by the German Ministry for Education and Research with grant number 01DS13011. The partners are active in dementia research, patient and carer advocacy, medical engineering and software development. The aim of the group is to contribute to the improvement of dementia care in the Danube Region by providing a web-based education and skill-building program for healthcare professionals. This aim is consistent with national European action plans for dementia.<sup>13</sup>

### **Data collection**

The survey was conducted using a standardized questionnaire which was completed by 15 leading experts/clinicians with research activities and outstanding expertise in dementia care in ten countries of the Danube Region (Austria, Bulgaria, Croatia, the Czech Republic, Germany, Romania, Serbia, Slovenia, Hungary, the Ukraine) from August 2014 to September 2014. The authors are the survey respondents. All these clinicians/experts are medical doctors or neuropsychologists with specialty in neurology, psychiatry and clinical psychology. Most of the participants are National Dementia experts and members of European Alzheimer's Disease Consortium from where they have been selected and contacted. The questionnaire was designed by the experts from Germany and Bulgaria. All authors approved the final version of the questionnaire. Since terminology of healthcare settings and services varies across countries definitions were provided.

The clinicians/experts responded to the questionnaire according their perceptions/claims and at the same time collected information from the main national stakeholders and national research studies.

In its first part, the questionnaire inquired about existing infrastructures of dementia care. It considered 1) care setting (home care vs. institutional care) 2) integration of different medical specialties in dementia management; 3) availability of services for people with dementia and their carers, 4) corresponding reimbursement mechanisms 5) relevance of dementia as a part of vocational education and training, 6) access to dementia-specific postgraduate professional education; 7) availability and financing of assistive technology.

Information on those infra-structural framework conditions were stratified by country to highlight the heterogeneity of dementia care in the Danube Region.

In the second part, the questionnaire assessed expert opinion on professional groups considered most important for dementia care; professional groups most in need of dementia-specific education and training, and acceptability of an internet-based educational program. These ratings were pooled across countries by calculating the mean ( $\pm$ SD) of available responses. Items and scoring of the questionnaire are shown on Table 2.

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Table 2 about here

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## **RESULTS**

### **Part I.**

#### *Home care and institutional care*

The majority of people with dementia are being looked after in their own homes and not in institutions. However, the share of home care and institutional care varies across countries. The proportion of patients receiving care in their own homes is lowest in Germany (~ 60%) and highest in Bulgaria (>90 %). On average about 80% of people with dementia are cared for at home.

#### *Contribution of medical specialties to the management of dementia*

In all countries, general practitioners (GPs) are the entry point to the medical management of dementia. Their role is to identify older adults with cognitive and functional decline and refer them to specialists. Only in Germany the medical care of people with dementia is largely in the hands of GPs. In all other countries, GPs play a minor role in dementia diagnosis (Figure 1), and are even less involved in dementia treatment. In all countries neurologists and psychiatrists play an essential role in dementia diagnosis and treatment with different involvement rate (Figure 1,2). Geriatricians are not available as a medical specialty in Austria, Bulgaria, Serbia, Hungary and Slovenia.

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Figure 1 about here

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Figure 2 about here

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#### *Availability of services for people with dementia and their family carers*

Nursing home care and caregiver counseling and support are available in all countries. Day care facilities and respite care are lacking in Romania, Serbia and the Ukraine. Respite care is available only in Austria, the Czech Republic and Germany. Assistance with activities of daily living, e. g. by home helpers is not provided in Romania. Other services such as meals

on wheels are not available in Romania and Serbia (Figure 3). In almost all countries there is a considerable gradient regarding the availability of services from urban to rural areas which were defined as geographic areas that are located outside towns and cities.

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Figure 3 about here

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#### *Financing of dementia-related service utilization*

Visits to GPs and medical specialists are free in all countries. Patients are required to make co-payments for neuropsychological evaluations in Bulgaria, Romania and the Ukraine. Different co-payment systems for in-patient hospital treatment are due in Germany, Austria, Croatia and the Ukraine. In most countries, patients are required to contribute to the cost of medications and other medical treatments. Exceptions are Romania and Slovenia, where antidementia drugs are available for free. Medical treatment is paid completely out of pocket in the Ukraine. Occupational therapy for people with dementia is not available in Bulgaria, the Czech Republic, Romania and Serbia. It is free in Croatia, but different patient co-payments are due in Germany, Austria, Slovenia and the Ukraine. Non-pharmacological interventions such as cognitive training and rehabilitation are free in most countries, but part-payment is required in Austria, Slovenia, Hungary and the Ukraine, and full payment is required in Bulgaria.

Nursing home care is completely free for people with dementia and their families in Serbia, but requires different co-payments in all other countries. The persons with dementia and their carers need to make a financial contribution to day care in Austria, Croatia, the Czech Republic, Hungary and Slovenia. In Bulgaria, day care needs to be paid completely out of pocket, and is only free in Germany.

#### *Dementia in the education for healthcare and allied professionals*



Dementia is part of the education curriculum for specialist physicians (neurologists, psychiatrists, geriatricians) in all countries. However, dementia is not included in education and training for GPs in Austria, Romania and Slovenia. Whereas dementia is part of the training for nurses in all countries with the exception of Austria, social workers do not learn about dementia in Austria, the Czech Republic, Croatia and the Ukraine. Dementia is not included in the education of psychologists in Romania.

There is also a lack of dementia-specific education for occupational therapists in Austria and Romania (Figure 4).

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Figure 4 about here

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Postgraduate professional education includes dementia for all healthcare professionals in Austria, the Czech Republic and Germany. In Slovenia, dementia-specific postgraduate education is only available for GPs whereas in Romania it is only provided for medical specialists. In Bulgaria, social workers and allied professionals have no access to this kind of education. Non-medical healthcare professionals cannot engage in postgraduate dementia-specific training in Croatia, Romania, Serbia and the Ukraine.

#### *Availability of assistive technology*

Technology-based assistive devices are deemed useful in dementia care in most countries of the Danube Region, with sensors (e.g. smoke, fire, gas, water) and communication solutions (e.g. senior mobile phone, senior phones being fixed lines), are used most frequently, while prompts and reminders (e.g. for keys and medication) are less used. Although in most countries people with dementia and their carers have access to a broad variety of devices, utilisation rates are generally very low.

## **Part II.**

### *Need for dementia-specific education and training*

Across countries, the greatest need for post-graduate dementia-specific education and training was seen for GPs, nurses, allied professionals, social workers and occupational therapists, i. e. for those who are involved in the front-line work with people with dementia and their family members. A lesser need was seen for specialist physicians and psychologists

### *Usefulness of an internet-based educational program*

The groups of healthcare professionals who work in the frontline of dementia care, i. e. nurses, social workers, occupational therapists, GPs and allied professionals are also those for whom a web-based educational program on dementia is considered to be most beneficial. This educational format is seen less useful for specialist physicians and psychologists (Figure 5).

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Figure 5 about here

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## **DISCUSSION**

The prevalence rates of dementia in the countries of the Danube Region are probably similar to those in western Europe.<sup>14</sup> Differences across countries, with some showing prevalence rates below the European average<sup>7</sup> of 7 % are likely due to methodological difficulty and heterogeneity as the identified studies were characterized by an immense diversity with a considerable degree of clinical and methodological variations.

The Danube Region has higher-than-average increment in population longevity, disproportionate increase of the old-age dependency ratio<sup>10</sup>, and selective outward migration of healthcare professionals.<sup>11</sup> For these reasons, dementia is a particularly severe societal

challenge in the Danube Region and appropriate strategies need to be developed and implemented to tackle it.

In Europe the majority of people with dementia are being cared for in their homes by family members.<sup>15</sup> The share of community care is particularly large in some countries of the Danube Region. This may be due to cultural traditions which consider within-family care as a kind of social duty of the younger generation, but also to lack of appropriate long-term care facilities and limited affordability of nursing homes. Hence, strengthening community care and supporting family carers is a logical priority in improving the management of dementia in this geographical area.

According to our survey there is a discrepancy in most countries of the Danube Region between the key importance that is assigned to general physicians (GPs) for the identification of dementia and as entry points to dementia care, and the minor contribution which this group of physicians makes to the diagnosis and management of dementia. We also found that dementia is not included in the education of GPs in several countries. It is known that the management of dementia in primary care is a challenge due to inadequate knowledge, inadequate skills set, fear of making a wrong diagnosis and lack of coordination between physicians and community services, among other reasons.<sup>16</sup>

Our survey also showed that nurses, social workers, occupational therapists and allied health workers are important professional groups involved in the management of dementia. However, dementia often is not included in their regular education curriculum and they have limited access to postgraduate dementia-specific education. Other studies have also found that healthcare professionals who work closely with people with dementia and their family carers have limited access to specialised education.<sup>17</sup>

Therefore, we strongly believe that it is important to develop and evaluate educational programs that enhance the knowledge and skills of the professional groups who are active in the frontline of dementia care including educational programs for GPs. Such programs might

also increase the collaboration between different groups of healthcare professionals.<sup>18</sup> This has been shown to improve the quality of dementia care.<sup>19</sup>

Web-based learning has been shown to be an effective and economical format of postgraduate training among healthcare professionals.<sup>20</sup> It may be particularly useful in countries of the Danube Region which are culturally, economically and geographically highly diverse. Also, such innovative learning formats are particularly needed in rural areas where other forms of postgraduate professional education are difficult to access. The survey demonstrates that an internet-based educational program is viewed as useful for all healthcare professionals. Additional face-to-face education and training may be appropriate for healthcare professionals involved in the frontline of dementia care.

Web-based information and education programs for healthcare professionals have been found to be as effective as face-to-face interventions in improving knowledge and skills, and can overcome geographical and mobility related barriers.<sup>21,22,23</sup> Assistive technology, defined as any device that supports a person in retaining or improving their independence, safety, security and dignity, can take many forms. These include safety alarms, monitoring of vital signs, fall detectors, flood sensors, and automated shut-offs for household appliances. For people with mild to moderate dementia reminders and prompts, communication devices, and person tracking systems may particularly useful.<sup>24,25</sup> The use of assistive technology devices might also be a part of such educational efforts, including ethical and data protection aspects. A literature review described frequent ethical dilemmas of which 2 are notable. The first is about privacy and respect for autonomy versus safety and minimizing risks. The more safety a person with dementia wishes to have, the more it may be necessary for them (or others on their behalf) to accept some loss of privacy or autonomy and with various possible negative consequences (eg, safety at the expense of reduced quality of life, some risk but possibility to delay entry into residential care, deterioration of carer's quality of life or health). The second ethical dilemma is about obtaining informed consent from persons with dementia due to

possible difficulties understanding complex technology and loss of awareness over time of the presence or purpose of assistive technology, or that data is being collected on them. The characteristics of home telecare should be made clear so that users have a thorough understanding of the limitations as well as the capabilities involved in this technology. Moreover, it is necessary to develop specific guidelines for the delivery of these services to the cognitively impaired elderly population.<sup>26,27</sup>

Non-pharmacological interventions such as cognitive training, behavioural management or occupational therapy are considered an essential part of the management of dementia by European guidelines.<sup>28,29</sup> However, the survey shows that access to these forms of treatment is limited in several countries of the Danube region. Another important gap in dementia care in the Danube Region that was identified by the survey is the lack of day care and respite care facilities. These services are important to support family carers and enhance their resilience.<sup>30</sup> Given this shortage, education of professionals on which interventions and services are available and information about their indication and effectiveness are even more important for the improvement of dementia care. This could also increase the awareness of people with dementia and their carers for already available health and social services and how to access them.

In conclusion, we suggest that dementia care in the Danube Region can be improved by an educational and skill-building program for healthcare professionals who work in the frontline of dementia care. Such a program should also attempt to enhance interdisciplinary and intersectorial collaboration, to intensify the interaction between primary care and specialists, and to promote the implementation of assistive technology. Additionally, due to limited services in Danube region, it is essential to develop national plans for funding services for people with dementia and their carers.

## **Acknowledgments**

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## **Conflict of Interest**

The authors are the survey respondents.

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**Figure legends:**

Figure 1. Contribution of medical specialties to dementia diagnosis

Figure 2. Contribution of medical specialties to dementia treatment

Figure 3. Availability of services for people with dementia and family carers

Figure 4. Dementia as a topic of education for healthcare and allied professionals

Figure 5. Usefulness of a web-based educational program

Table 1: Population size and numbers of people with dementia in the Danube Region

Country	Total population <sup>1</sup>	Population over 65 years [%] <sup>1</sup>	Prevalence of dementia in people over 60 years <sup>2</sup> [%]	Estimated number of people with dementia
Austria	8,576,000	18.3	7.1	145,000
Bosnia-Herzegovina	3,825,000	-	-	-
Bulgaria	7,202,000	19.6	7.2*	110,000
Croatia	4,390,000	18.4	6.2	80,000
The Czech Republic	10,538,000	17.4	6.9	143,000
Germany	81,198,000	20.8	7.0	1,572,000
Hungary	9,856,000	17.5	6.2	149,000
Moldova	4,066,000	11.1	-	-
Montenegro	622,000	13.3	4.3	3,700
Romania	19,871,000	16.5	5.7	270,000
Serbia	7,114,000	18.4	6.7	88,000
Slovakia	5,472,000	13.5	5.5	59,000
Slovenia	2,036,000	17.5	6.5	32,000
The Ukraine	45,246,000	15.6	10.4	880,000

<sup>1</sup> eurostat (ec.europa.eu); <sup>2</sup> (Alzheimer-Europe 2014); \*Dimitrov et al. 2012

Table 2: Items and scoring of the questionnaire

Item	Scoring
Proportion of people with dementia receiving care at home vs. receiving care in institutions	% estimate
Contribution of medical specialists to dementia diagnosis	% estimate
Contribution of medical specialists to dementia treatment	% estimate
Patient payment for healthcare and allied professionals	0 = none, 1 = partly, 2 = completely
Availability of services for people with dementia	0 = not at all, 1 = in large cities, 2 = countrywide
Patient payment for services	0 = none, 1 = partly, 2 = completely
Dementia as part of educational training	0 = no, 1 = yes
Access to dementia-specific postgraduate professional education	0 = no, 1 = yes
Availability of assistive technology for people with dementia	0 = not at all, 1 = in large cities, 2 = countrywide
Patient payment for assistive technology	0 = none, 1 = partly, 2 = completely
Importance of healthcare and allied professionals in dementia care	0 = none, 1 = somewhat important, 2 = moderately important, 3 = important, 4 = extremely important
Usefulness of an internet-based educational program	0 = not useful, 1 = somewhat useful, 2=useful, 3 = very useful
Need for a face-to-face educational program	0 = not necessary, 1 = somewhat necessary; 2 = necessary, 3 = highly necessary

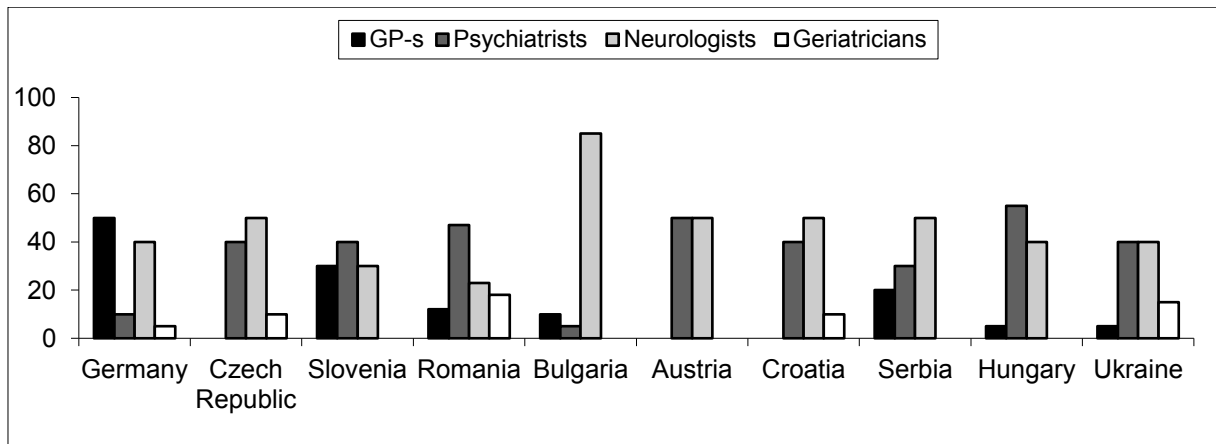


Figure 1. Contribution of medical specialties to dementia diagnosis

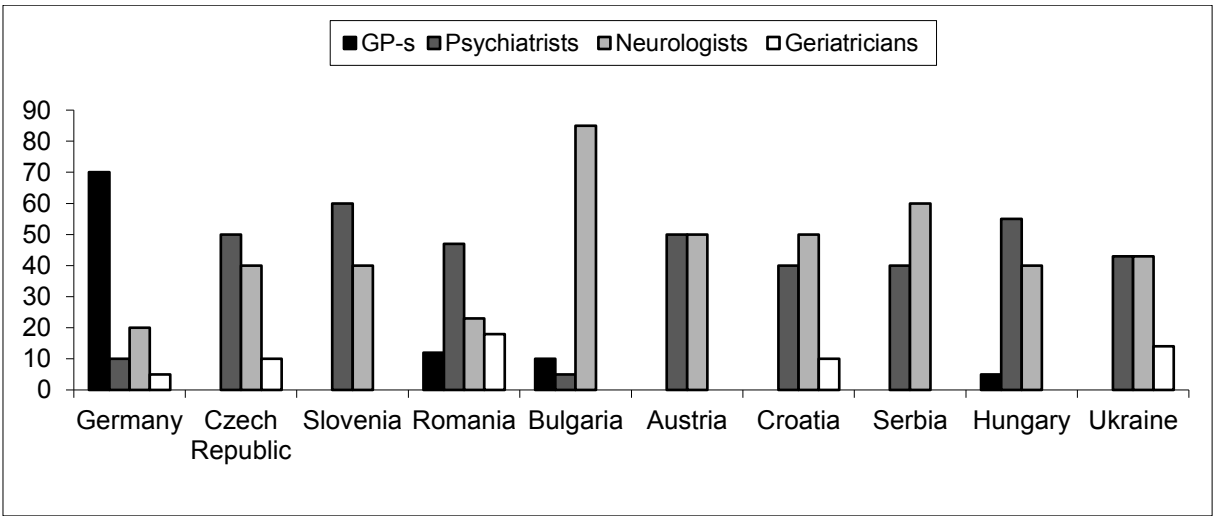


Figure 2. Contribution of medical specialties to demnetia treatment

	Nursing home	Day care	Respite care	carer support	Home helpers	Other services
<b>Germany</b>	Country wide	Country wide	Country wide	Country wide	Country wide	Country wide
<b>Czech Republic</b>	Country wide	Only in large cities	Only in large cities	Only in large cities	Country wide	Country wide
<b>Slovenia</b>	Country wide	Only in large cities	Not available	Only in large cities	Only in large cities	Only in large cities
<b>Romania</b>	Country wide	Not available	Not available	Only in large cities	Not available	Not available
<b>Bulgaria</b>	Country wide	Only in large cities	Not available	Only in large cities	Country wide	Country wide
<b>Austria</b>	Country wide	Only in large cities	Only in large cities	Country wide	Country wide	Country wide
<b>Croatia</b>	Only in large cities	Only in large cities	Not available	Only in large cities	Only in large cities	Only in large cities
<b>Serbia</b>	Only in large cities	Not available	Not available	Only in large cities	Only in large cities	Not available
<b>Ukraine</b>	Country wide	Not available	Not available	Only in large cities	Country wide	Country wide
<b>Hungary</b>	Country wide	Country wide	Not available	Only in large cities	Country wide	Country wide

Figure 3. Availability of services for people with dementia and family carers

Not available   
 Only in large cities   
 Country wide

	GP-s	Psychiatrist	Neurologist	Geriatrician	Psychologist	Nurses	Social worker	Occupational therapists	Other allied professionals
<b>Germany</b>	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
<b>Czech Republic</b>	Yes	Yes	Yes	Yes	Yes	Yes	No	Not applicable	Yes
<b>Slovenia</b>	No	Yes	Yes	Not applicable	Yes	Yes	Yes	Yes	No
<b>Romania</b>	No	Yes	Yes	Yes	No	Yes	Yes	No	No
<b>Bulgaria</b>	Yes	Yes	Yes	Not applicable	Yes	Yes	Yes	Not applicable	No
<b>Austria</b>	No	Yes	Yes	Not applicable	Yes	No	No	No	Yes
<b>Croatia</b>	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes
<b>Serbia</b>	Yes	Yes	Yes	Not applicable	Yes	Yes	Yes	Not applicable	Not applicable
<b>Ukraine</b>	Yes	Yes	Yes	Yes	Yes	Yes	No	No	No
<b>Hungary</b>	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No

Figure 4. Dementia as a topic of education for healthcare and allied professionals

No     
 Yes     
 Not applicable



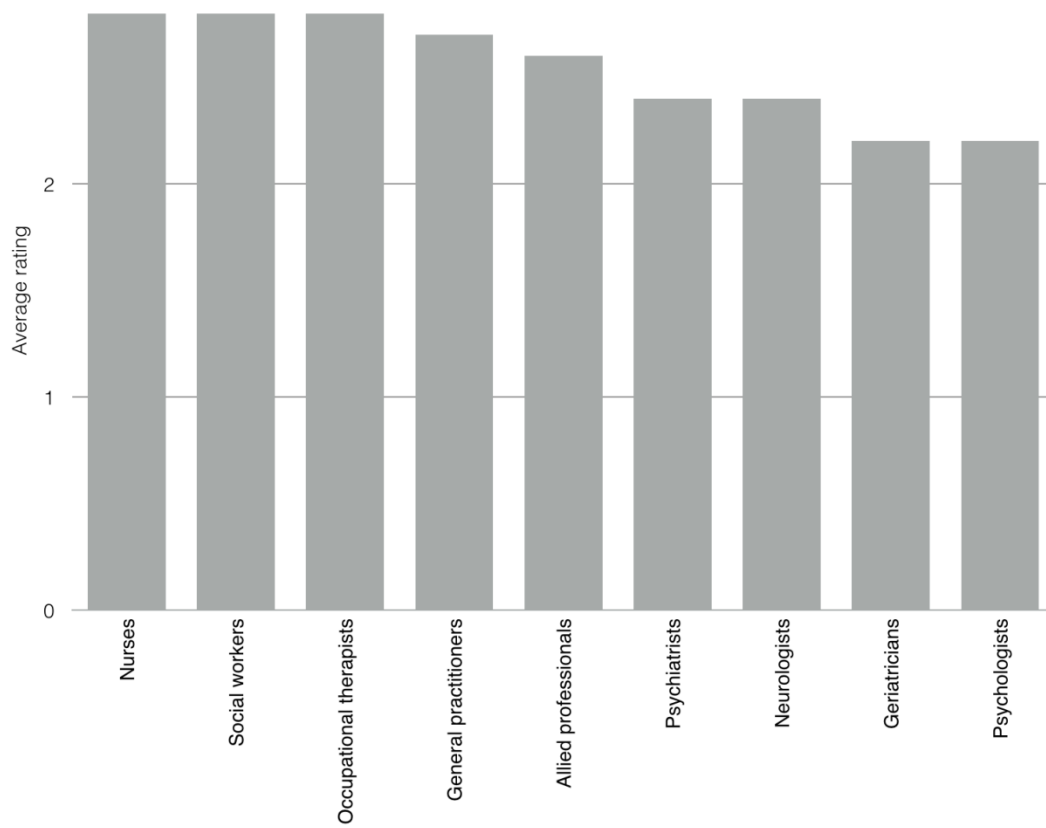


Figure 5. Usefulness of a web-based educational program