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Rarer dementia subtypes – what does the general public know? A survey across five European language groups

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Abstract

Background There is a lack of understanding about dementia in the general population. However, dementia comprises of various different subtypes, with different symptom profiles. To date, it is unclear how much the general public knows about rarer dementia subtypes, including frontotemporal and Lewy Body dementia and primary progressive aphasia. Therefore, the aim of this five-country survey was to explore the knowledge of the general public about different dementia subtypes in Germany, Lithuania, the Netherlands, Poland, and the United Kingdom.

Methods An online survey was developed with researchers from the UK, Germany, and Lithuania. The survey was then also adapted to Poland and the Netherlands. The survey was shared via multiple networks in each country, including social media. German, English, Dutch, Polish, and Lithuanian speakers across Europe were able to complete the survey. Data were analysed using multivariate logistic regressions in R.

Findings Whilst over 1000 participants provided data, a total of 681 people aged 18 + speaking English ($n = 202$), Lithuanian ($n = 143$), German ($n = 141$), Polish ($n = 118$), or Dutch ($n = 77$) fully completed the survey between May 2025 and April 2026. Awareness of dementia subtypes and related knowledge varied by language of response, with Dutch, German, Lithuanian, and Polish participants showing lower awareness of dementia subtypes, being more likely to select a non-Alzheimer's dementia subtype as the most common, and less likely to endorse that different dementia subtypes have distinct symptoms compared with English participants.

Interpretation This is the first international comparative evidence on general public's awareness of rarer dementia subtypes. Findings can be used to develop targeted awareness campaigns in and across different countries, as greater knowledge about rarer dementias can help improve diagnosis rates and plan better care.

Background

Dementia affects more than 57 million people worldwide and poses significant challenges to healthcare systems, families, and communities [30]. Understanding what dementia is and how to spot the early signs of the conditions are vital to facilitate more timely diagnosis. Whilst diagnosis does not always equate to equitable and improved

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access to post-diagnostic care [14], receiving a clinical diagnosis is a necessary requirement to accessing medical (if applicable) and non-medical care.

The most common form is late-onset Alzheimer's disease dementia, with rarer subtypes including Lewy body, Parkinson's disease, vascular, behavioural-variant fronto-temporal dementias as well as posterior cortical atrophy for example presenting differently or with different variations in symptomatology [4]. These include behavioural challenges, cognitive and everyday functioning, motor and speech difficulties [7, 11, 31]. Without adequate knowledge, it can be difficult to spot the signs of different dementia subtypes. Therefore, raising awareness in the general population can potentially aid recognition of symptoms and contacting a health care professional to refer for a diagnostic assessment. However, understanding the symptoms of rarer dementia subtypes in health care professionals is similarly important, with frequent delays and diagnosis and misdiagnosis of subtypes [9, 13].

Research has demonstrated that the general population has limited knowledge of dementia and its associated risk factors. Moreover, the level of awareness of dementia and knowledge surrounding the condition varies across the global population [5, 19, 21, 23]. For example, a review conducted by [6] which included 33 studies from Europe, the USA, Israel, Eastern Asia and Australia found that half of the respondents reported that dementia was not preventable and is a normal part of ageing.

Findings from across Europe and further afield support the lack of awareness about dementia. Surveying over 1200 members of the general public in Ireland, [16] reported that less than 40% were confident in spotting the early signs of dementia. Where demographic factors such as social class and areas of residence were considered, substantial gaps in knowledge remained regardless of demographic background. This was corroborated in a survey among over 1500 Swiss and Italian young adults [22]. Being asked to complete the Dementia Knowledge Assessment Survey [1], young adults showed a general lack of understanding about dementia symptoms, characteristics, and risk factors, as well as how to communicate with someone with dementia. Women, higher educational level, and those who knew someone with dementia had statistically higher levels of knowledge than men, those with lower educational backgrounds and without an acquaintance with dementia. Similarly, in the Netherlands, only about half the sample considered their knowledge about dementia as 'fair' [19]. A recent nationally representative survey in the UK found that ethnic disparities in dementia knowledge are evident even before a dementia diagnosis or direct involvement in care, and that disclosure-related stigma is higher among minoritised ethnic groups [2].

Focusing on the different subtypes of dementia in particular, Alzheimer's disease is the most common and widely recognised form. However, dementia includes multiple subtypes including vascular dementia, Lewy Body dementia, primary progressive aphasia, and frontotemporal dementias, each with distinct symptoms and underlying causes [4, 10, 20]. Public knowledge and awareness of not only dementia but also subtypes and associated symptoms are critical for early and accurate diagnosis. Research conducted in the UK on public knowledge of dementia and its subtypes found that almost all participants had heard of Alzheimer's disease (98%) and more than half of vascular dementia (57%), whilst less than a quarter had heard of frontotemporal dementia (23%) or Lewy bodies dementia (17%) [26]. Overall participant accuracy of dementia knowledge was low for rarer subtypes of dementia [26], indicating a need to improve public awareness of dementia subtypes and their associated symptoms in the UK.

To date, no research has yet compared public awareness of rarer dementia subtypes across European countries, despite substantial differences in care systems, cultural context and education representation [15]. These variations may influence how symptoms are recognised, interpreted and acted upon, while poor awareness can delay diagnosis, contribute to inappropriate symptom management and limit access to timely support [24, 25]. This leads to inequalities in access to diagnosis and care [12]. Therefore, understanding possible variations in knowledge across countries and nationalities could inform European-wide programmes to reduce health inequalities.

The aim of this European online survey was to establish the level of knowledge about rarer dementia subtypes in the general population across Europe, using survey versions administered in German, Lithuanian, the Dutch, Polish, and the English. To existing knowledge, no other survey exists that has specifically focused on the general

public's awareness of rarer dementias and dementia subtypes across different European languages. Findings can help identify recommendations for public health messaging to increase awareness of specific subtypes in different languages, to improve help seeking and understanding of how best to support people with a rarer dementia, including Lewy Body dementia and frontotemporal dementias.

Methods

Participants and recruitment

Participants were eligible to participate if they were aged ≥ 18 years, a British, German, Dutch, Polish, Lithuanian national (either residing in the country or living in Europe) or resident and had the capability to complete an online survey (i.e. access to sufficient IT). Age was self-reported and was not independently verified. Language proficiency was not formally assessed; completion of the questionnaire was taken to indicate sufficient proficiency to participate.

Participants were recruited via social media advertisements and email adverts to established local and regional research networks. The survey was accessed through an online link and participation was self-selected. A priori power analysis for multiple regression was conducted using the pwr package in R. Assuming a small effect size ($f^2 = 0.02$), $\alpha = 0.05$, power = 0.80, and six predictors, the required minimum sample size was 647 participants.

Survey development

The survey was iteratively developed through consultation with members of the research team. Development followed a three-step process. (1) A skeleton survey was developed by the lead authors based on the gaps identified in the literature (CG, MRR), (2) the wider research team in the UK, Germany, and Lithuania reviewed the draft survey and provided feedback on the content and structure, and (3) the survey was revised accordingly. The survey was translated by the research team members into German (AEZ) and Lithuanian (JM, AP). The Netherlands and Poland also joined the survey after it had launched in the three previous languages and translated the survey into the respective national languages (GA, JR). No formal pilot testing, usability assessment, or questionnaire acceptability assessment was undertaken prior to data collection.

Survey measures

Demographics

Demographic variables included language the response was collected in, current country of residence, whether the participant has always resided in this country, age, self-identified gender, ethnicity, religion, current employment status, highest level of educational attainment, years of formal education, and annual household income. Participants were also asked whether they currently or previously have known anyone living with dementia and how they currently or have previously engaged with people living with dementia outside of a professional capacity (see supplemental table S1 for full questions and response options).

Knowledge and awareness of dementia subtypes and associated symptoms

To assess knowledge of dementia subtypes, participants were asked to indicate whether they believe dementia encompasses multiple conditions, and if Alzheimer's disease is one specific subtype of dementia. Participants were also asked to estimate the number of dementia subtypes and to identify any dementia subtypes they were aware of from a pre-specified list. Separately, participants were asked via a free-text question which subtype of

dementia they believed to be the most common. Full question wording and response options, where applicable, are provided in Supplementary Table S1.

Data collection

The survey was completed online only using Qualtrics. All data were collected between May 2025 and April 2026, with the survey taking between 25–30 min to complete. The survey was designed to be completed within a single session. On following the online survey link, participants were directed to the study information sheet clearly detailing the aims of the study and associated tasks. If participants elected to proceed, they then provided digitalised informed consent by completing the online consent form. On attainment of informed consent, participants were presented the main survey. All participants provided consent for their anonymised data to be included in the present publication and other outputs relating to this study. Eligibility was determined from self-reported participant information, with no additional automated eligibility screening procedures applied. No specific procedures were implemented to identify or prevent duplicate responses.

Data analysis

Data transformations

For Questions 1 and 7, four level responses ("Yes", "No", "I don't know", "Prefer not to say") were dichotomised according to whether they demonstrated awareness of the relevant aspect of dementia. Correct responses were coded as demonstrating awareness, while incorrect and "I don't know" responses were coded as not demonstrating awareness. This categorisation distinguished demonstrated knowledge from an absence of demonstrated knowledge and does not imply that uncertainty was equivalent to holding an incorrect belief. "I don't know" responses were retained as a separate category in descriptive analyses, while "Prefer not to say" responses were treated as missing.

Due to sparse data across several responses to the free-text question "Which subtype of dementia do you think is the most common?", responses were categorised into three groups for analysis: Alzheimer's disease dementia (correct identification), non-Alzheimer's dementia (identification of another dementia subtype), and unsure. This categorisation reduced sparse outcome cells to enable reliable estimation of the multinomial logistic regression model.

Primary analysis

Descriptive statistics were used to describe the study population. Categorical variables were reported as frequencies and percentages, while continuous variables were summarised using means and standard deviations. Responses of "prefer not to say" were treated as missing. Responses of "I don't know" were retained as valid response categories in descriptive analyses; for binary regression analyses of demonstrated awareness, incorrect and "I don't know" responses were grouped as not demonstrating awareness. Missing data were handled using available-case analysis, whereby participants were excluded only from analyses for which the required data were missing. Consequently, sample sizes could between analyses according to the availability of data for the variables included.

Regression analyses were conducted to examine whether responses were associated with demographic characteristics. Given the breadth of survey items, analyses focused on a subset of key questions (Q1: "Is this statement true or false: There is more than one type of dementia."; Q6: "Which subtype of dementia do you think is the most common?"; Q7: "Is this statement true or false: Different types of dementia have different symptoms?" (Full questions and response options can be found in Supplemental materials Table S1)), selected a priori as most relevant to awareness and understanding of rarer dementia subtypes. Country, age, gender, and highest education

level were included as predictor variables in all models, and the respective survey responses was the outcome variable. Binary outcomes (Questions 1 and 7) were analysed using multivariable logistic regression models including these variables, with results presented as odds ratios (ORs) with 95% confidence intervals (CIs) and p values. The non-ordinal categorical outcome (Question 6) was analysed using multinomial logistic regression models including these variables, with results presented as odds ratios (ORs) with 95% confidence intervals (CIs) and p values. To account for multiple comparisons and reduce the likelihood of type I error, a Bonferroni correction was applied across the three primary related hypothesis tests, with a corrected significance threshold of $p<0.017$.

Sensitivity analyses

Given the presence of low-frequency categorical responses and evidence of quasi-complete separation in the data (i.e., instances where some predictor categories were associated with near-uniform outcome responses), standard maximum likelihood logistic regression produced unstable estimates with inflated standard errors and, in some cases, non-finite confidence intervals. To address this, Firth's penalised likelihood logistic regression was used as a sensitivity analysis.

Ethical approval

This study was first approved in the UK via the University of Liverpool ethics committee [ID: 16034]. The ethics application was translated into Polish, German, Lithuanian, and Dutch and submitted with the University of Liverpool ethics committee letter of approval to Research Ethics Committee of Wrocław University of Science and Technology in Poland; to Ethics Committee of the Medical Faculty of Leipzig University [224/25-ek] and University Medicine Greifswald [BB 192/5] in Germany; to the Lithuanian University of Health Sciences Research Ethics Compliance Committee in Social Sciences and Humanities [No 2025-BEC3-T-066] in Lithuania; and to Radboud University Medical Centre (METC Oost-Nederland) [2025–18574] in the Netherlands. The study was conducted in accordance with the Declaration of Helsinki.

Results

Overview of sample

More than 1,000 individuals accessed the survey link; however, many did not proceed beyond initial access and were therefore not considered participants. The analysed sample comprised 681 participants who proceeded beyond consent and provided survey data. People from twelve European countries (and five European languages (German, Lithuanian, Polish, Dutch, and British) completed the survey (Austria $n=5$; Belgium $n=2$; France $n=2$; Germany $n=129$; Ireland $n=2$; Lithuania $n=140$; Luxemburg $n=1$; Poland $n=116$; Switzerland $n=3$; The Netherlands $n=73$; UK $n=201$; Ukraine $n=1$ (note: country of residence was not reported by 6 participants)). The survey was distributed in five key languages with most responses being obtained in English ($n=202$ (29.7%)), followed by Lithuanian ($n=143$ (21.0%)), German ($n=141$ (20.7%)), Polish ($n=118$ (17.3%)) and then Dutch ($n=77$ (11.3%)). Participants were predominantly aged between 45–54 years of age ($n=145$; 21.3%), female ($n=530$; 77.8%), self-identified as white ethnicity ($n=641$; 94.1%), in full-time employment ($n=391$; 57.4%), and educated to degree level or above ($n=531$; 77.9%).

The demographic distribution significantly differed across language groups (age: $\chi^2(32)=130.27$, $p<0.001$; gender: $\chi^2(12)=35.30$, $p<0.001$; ethnicity: $\chi^2(20)=53.13$, $p<0.001$; employment: $\chi^2(28)=203.72$, $p<0.001$). Lithuanian participants concentrated in the older age ranges (45+) and German participants concentrated in the younger age ranges (18–44). Overall participants were predominantly female and White across all groups, with

Table 1 Demographic characteristics of the analysed sample

	Full Sample (*n* = 681)	English (*n* = 202)	Dutch (*n* = 77)	German (*n* = 141)	Polish (*n* = 118)	Lithuanian (*n* = 143)	$\chi 2, p$ [a]
Age							$\chi^2(32, N=681)=130.27, p<.001$
18–24	53 (7.8)	8 (4.0)	3 (3.9)	18 (12.8)	17 (14.4)	7 (4.9)	
25–34	128 (18.8)	34 (16.8)	17 (22.1)	44 (31.2)	21 (17.8)	12 (8.4)	
35–44	128 (18.8)	33 (16.3)	18 (23.4)	30 (21.3)	24 (20.3)	23 (16.1)	
45–54	145 (21.3)	35 (17.3)	11 (14.3)	26 (18.4)	26 (22.0)	47 (32.9)	
55–64	144 (21.1)	47 (23.3)	13 (16.9)	11 (7.8)	25 (21.2)	48 (33.6)	
65–74	58 (8.5)	34 (16.8)	8 (10.4)	7 (5.0)	3 (2.5)	6 (4.2)	
75–84	21 (3.1)	10 (5.0)	7 (9.1)	4 (2.8)			
85+	3 (0.4)	1 (0.5)		1 (0.7)	1 (0.8)		
Prefer not to say	1 (0.1)				1 (0.8)		
Gender							$\chi^2(12, N=681)=35.30, p<.001$
Female	530 (77.8)	161 (79.7)	63 (81.8)	92 (65.2)	87 (73.7)	127 (88.8)	
Male	136 (20)	34 (16.8)	14 (18.2)	44 (31.2)	29 (24.6)	15 (10.5)	
Non-binary	12 (1.8)	4 (2.0)		5 (3.5)	2 (1.7)	1 (0.7)	
Prefer not to say	3 (0.4)	3 (1.5)					
Ethnicity							$\chi^2(20, N=681)=53.13, p<.001$
White	641 (94.1)	190 (94.1)	63 (81.8)	129 (91.5)	118 (100)	142 (99.3)	
Black	1 (0.1)	1 (0.5)					
Asian	9 (1.3)	4 (2.0)	4 (5.2)	1 (0.7)			
Mixed	13 (1.9)	5 (2.5)	3 (3.9)	4 (2.8)		1 (0.7)	
Other	11 (1.6)	1 (0.5)	6 (7.8)	4 (2.8)			
No response	6 (0.9)	1 (0.5)	1 (1.3)	3 (2.1)			
Employment							$\chi^2(28, N=681)=203.72, p<.001$
Full time	391 (57.4)	96 (47.5)	30 (39.0)	59 (41.8)	90 (76.3)	116 (81.1)	
Full time, and student	11 (1.6)	2 (1.0)		3 (2.1)	5 (4.2)	1 (0.7)	
Part time	94 (13.8)	36 (17.8)	25 (32.5)	26 (18.4)		7 (4.9)	
Part time, and student	14 (2.1)	1 (0.5)		12 (8.5)		1 (0.7)	
Student	62 (9.1)	11 (5.4)	2 (2.6)	24 (17.0)	17 (14.4)	8 (5.6)	
Retired	83 (12.2)	49 (24.3)	15 (19.5)	10 (7.1)	5 (4.2)	4 (2.8)	
Out of work	16 (2.3)	6 (3.0)	3 (3.9)	4 (2.8)		3 (2.1)	
Prefer not to say	10 (1.5)	1 (0.5)	2 (2.6)	3 (2.1)	1 (0.8)	3 (2.1)	
Number of years of formal Education	Range: 0–35 Mean: 14.34 SD: 6.18	Range: 4–30 Mean: 15.76 SD: 4.93	Range: 3–24 Mean: 15.89 SD: 4.77	Range: 0–28 Mean: 14.53 SD: 6.43	Range: 1–35 Mean: 17.39 SD: 4.39	Range: 1–30 Mean: 9.09 SD: 6.14	$F(12, 625)=14.58, p<.001$
Highest Level of Educational Attainment		*Degree level or above:* 139 (68.8) *AS/A levels or equivalent:* 32 (15.8) *GCSE or equivalent:* 28 (13.9) *No qualifications*: 2 (1.0) *Prefer not to* say: 1 (0.5)	*Degree level or above:* 66 (85.7) *Secondary education:* 4 (5.2) *Secondary of preparatory higher education:* 6 (7.8) *Prefer not to say*: 1 (1.3)	*General/subject-specific university entrance qualification:* 101 (71.6) *10th Grade:* 1 (0.7) *Left school without a secondary school leaving certificate*: 1 (0.7) *Lower secondary school leaving certificate:* 6 (4.3) *Secondary school leaving certificate:* 10 (7.1) *Still a student without a diploma:* 1 (0.7) *University entrance qualification, completion of vocational upper secondary school*: 17 (12.1) *Prefer not to say:* 4 (2.8)	*Degree level or above:* 100 (84.7) *Post-secondary:* 3 (2.5) *Secondary or less:* 14 (11.9) *Prefer not to say:* 1 (0.8)	*Degree level or above:* 125 (87.4) *Second-ary or specialised secondary:* 17 (11.9) *Basic:* 1 (0.7)	

Table 1 (continued)

	Full Sample (*n* = 681)	English (*n* = 202)	Dutch (*n* = 77)	German (*n* = 141)	Polish (*n* = 118)	Lithuanian (*n* = 143)	*χ2, p* [a]
Relationship to people living with dementia							$\chi^2(20, N=681)=57.82$, p<.001
I have dementia myself	2 (0.3)	1 (0.5)		1 (0.7)			
I work with people with dementia	181 (26.6)	61 (30.2)	31 (40.3)	37 (26.2)	13 (11.0)	39 (27.3)	
Someone I know has dementia	361 (53.0)	121 (59.9)	37 (48.1)	74 (52.5)	68 (57.6)	61 (42.7)	
I don't know anyone with dementia	105 (15.4)	15 (7.4)	7 (9.1)	22 (15.6)	27 (23.9)	34 (23.8)	
I am not sure	25 (3.7)	4 (2.0)	1 (1.3)	5 (3.5)	9 (7.6)	6 (4.2)	
Prefer not to say	7 (1.0)		1 (1.3)	2 (1.4)	1 (0.8)	3 (2.1)	

[a]The *p*-values and χ2 documented here were obtained from chi-squared tests of independence and an independent samples ANOVA which examined whether demographic characteristics significantly differ between language in which the survey was complete. To account for multiple comparisons a Bonferroni correction was applied to the desired significance level (α) of 0.05. Given that 5 comparisons were conducted (across both this analysis and the analysis grouped by hearing impairment category), a required significance level of.01 was applied

this distinction being particularly evident among Lithuanian and Polish participants. Employment patterns also differed, with higher proportions of full-time employment observed in Lithuanian and Polish participants, while more varied employment distributions were seen in other groups.

A majority of participants indicated that they knew/previously knew someone living with dementia ($n=363$; 53%). Additionally, 181 participants indicated that they currently work with/previously worked with people living with dementia ($n=181$; 26.6%), and a small proportion of participants indicated that they themselves are living with dementia ($n=2$; 0.3%). The level of contact with people living with dementia significantly differed across language groups ($\chi^2(20)=58.83$, $p<0.001$). Dutch participants were more likely to report professional contact with people living with dementia ($n=31$; 40.3%), whereas English and Polish participants were more likely to report knowing someone with dementia (English $n=121$; 59.9%; Polish $n=68$; 57.6%).

Table 1 provides an overview of the demographic characteristics by country and for the total sample.

Overview of knowledge by country

Overall awareness of dementia. Overall awareness of dementia was high, with most participants reporting that they had previously heard of dementia (93.0%). There was no significant association between survey language and awareness ($p=0.081$). Similarly, self-reported knowledge of dementia was moderate to high, with most participants reporting having "some" (38.5%) or "quite a lot" (31.9%) knowledge regarding dementia. Self-reported knowledge level significantly differed by language in which the survey was completed ($\chi^2(28)=63.44$, $p<0.001$), with the highest proportion of highest self-reported knowledge ("a great deal") observed in English participants (11.8%), followed by Dutch (7.8%) and German (7.8%) participants, and lower proportions in Lithuanian (5.6%) and Polish (3.4%) participants Fig. 1.

Awareness of dementia subtypes

Overall awareness that there is more than one type of dementia was high, with most participants correctly indicating that multiple types of dementia exist (77.0%). Participants indicated there to be between 0–350 different subtypes of dementia (mean = 22.61 (SD = 46.94)). The perceived number of dementia types differed significantly across language groups ($F(4, 401)=9.95$, $p<0.001$), with the highest estimates observed in English participants

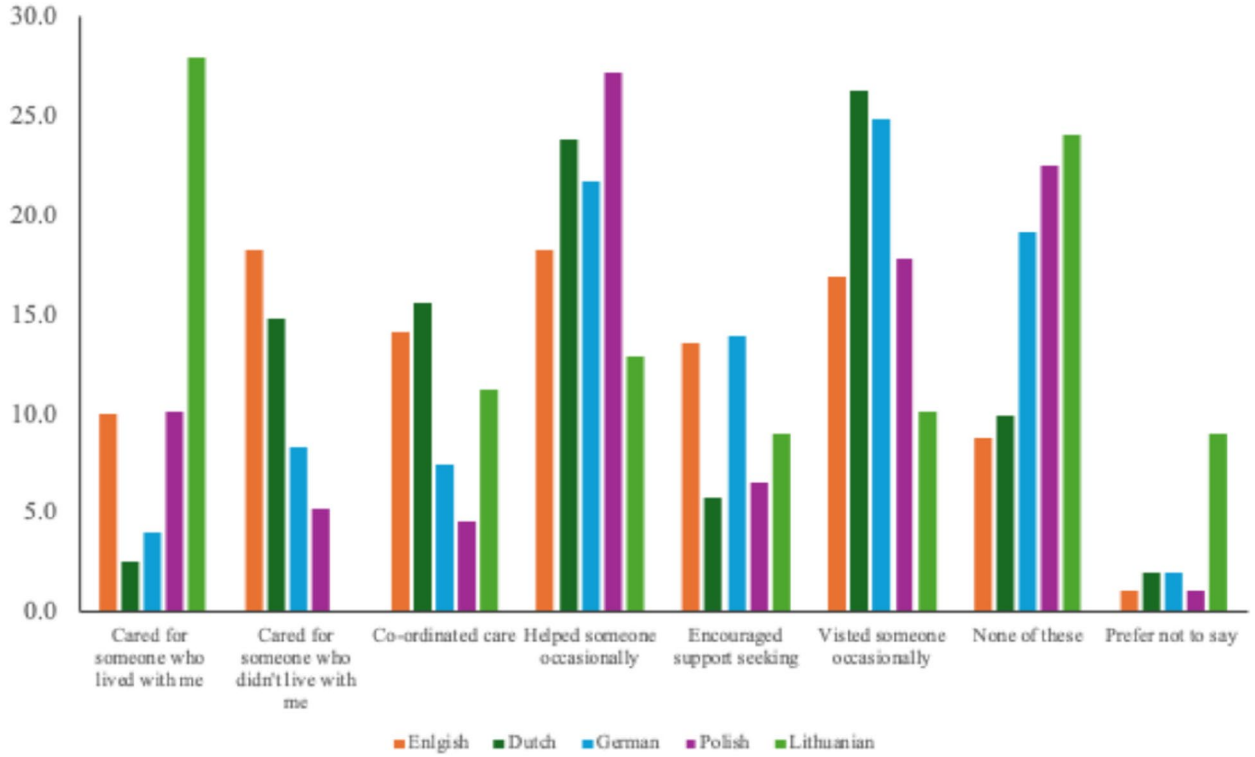


Fig. 1 Support provided to people living with dementia. Note. The y-axis indicates the percentage of respondents who reported having previously provided each type of support to a person living with dementia

(M = 40.43), followed by German (M = 19.24) and Dutch participants (M = 13.80), and lower estimates in Lithuanian (M = 6.77) and Polish participants (M = 5.53).

Identification of most common subtype

Across all participants, Alzheimer's disease was most frequently identified as the most common dementia subtype (45.8%). This was followed by vascular dementia (16.4%) and "not sure" responses (14.1%), indicating a notable level of uncertainty in dementia subtypes. Other subtypes which were less endorsed included mixed dementia (6.3%), early-onset dementia (2.6%), Parkinson's disease dementia (2.2%), frontotemporal dementia (1.4%), and dementia with Lewy bodies (0.6%) (see Fig. 2).

Awareness of symptoms associated with subtypes

Awareness that different dementia subtypes are associated with different symptoms was high across languages, with most participants correctly indicating this to be true (70.3%).

Factors linked to awareness about dementia subtypes

Awareness of dementia subtypes. Awareness that dementia has multiple subtypes varied significantly by the language in which the survey was completed. Compared to English participants (reference group), Dutch (OR = 0.38, 95% CI [0.17–0.84]), German (OR = 0.48, 95% CI [0.23–0.98]), Lithuanian (OR = 0.23, 95% CI [0.11–0.47]), and Polish participants (OR = 0.14, 95% CI [0.07–0.28]) had significantly lower odds of awareness of dementia subtypes. Age was also associated with awareness, with significantly lower odds observed in participants aged

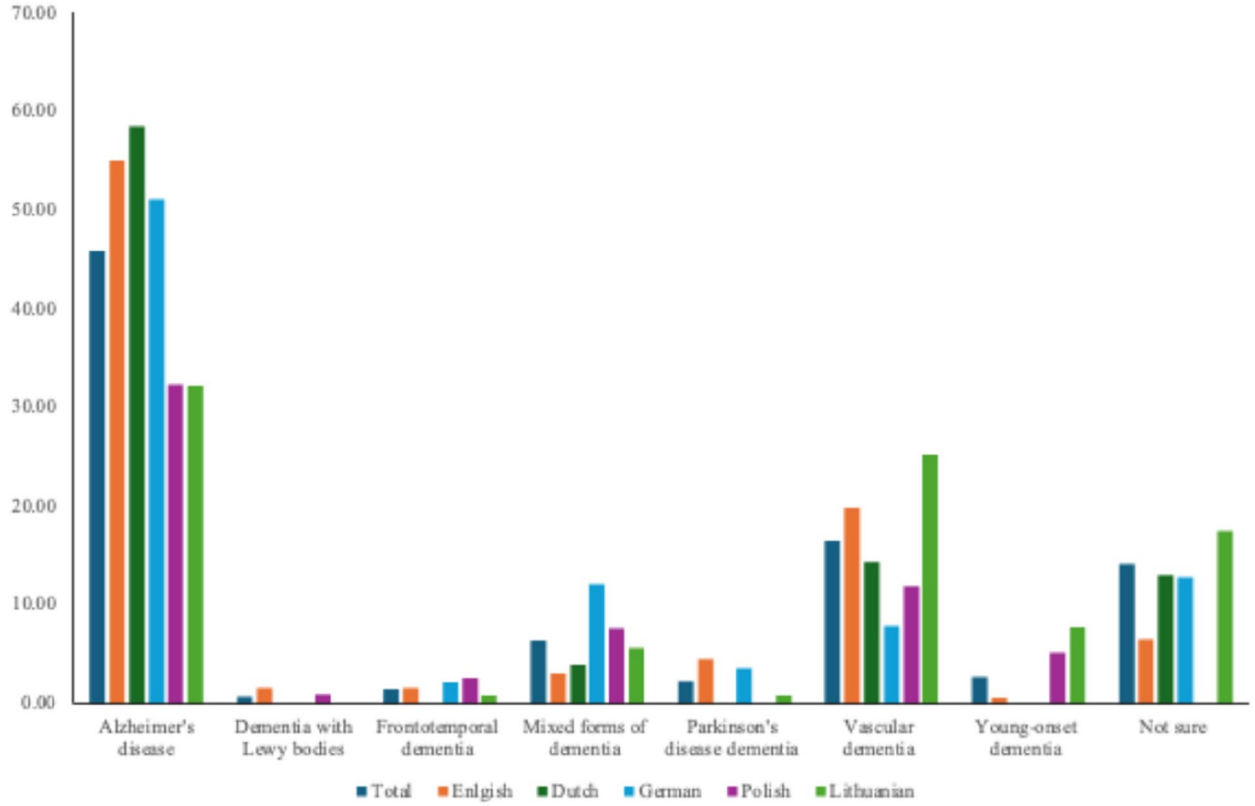


Fig. 2 Identification of the most common subtype of dementia. Note. The y-axis indicates the percentage of respondents who identified each dementia subtype as the most common subtype

35–44 (OR = 0.40, 95% CI [0.16- 1.00]) and 65–74 (OR = 0.26, 95% CI [0.09–0.76]) compared to the 18–24 age group. Men were significantly less likely than women to report awareness (OR = 0.53, 95% CI [0.33–0.87]). Education level was not significantly associated with awareness. Compared with participants who did not know anyone with dementia, those who were unsure whether they knew someone with dementia had significantly lower odds of awareness of dementia subtypes (OR = 0.33, 95% CI [0.12–0.95]). No significant differences in awareness were observed among participants who worked with people with dementia (OR = 0.94, 95% CI [0.50–1.79]), knew someone else with dementia (OR = 1.23, 95% CI [0.70–2.18]), or preferred not to disclose this information (OR = 0.55, 95% CI [0.07–4.46]). The estimate for participants who reported having dementia themselves was unstable because of the very small number of respondents in this category and was therefore not interpreted. Sensitivity analyses using Firth penalised logistic regression produced broadly consistent results, with language of response, age, and gender remaining significant predictors (see Supplementary Material).

Identification of most common subtype. The most common subtype of dementia identified varied by language in which the response was collected. Compared with English participants, Dutch participants were less likely to select a non-Alzheimer's dementia subtype (OR = 0.45, 95% CI [0.22, 0.96]). German (OR = 1.07, 95% CI [0.61, 1.88]), Lithuanian (OR = 1.84, 95% CI [1.03, 3.31]) and Polish participants (OR = 2.30, 95% CI [1.24, 4.27]) showed higher odds of selecting a non-Alzheimer's dementia subtype compared with Alzheimer's disease, although confidence intervals were large, and non-significant for German participants. Compared with participants aged 18–24 years, those aged 35–44 (OR = 2.85, 95% CI [1.17, 6.96]), 45–54 (OR = 2.85, 95% CI [1.17, 6.92]), 65–74 (OR = 2.89, 95% CI [1.02, 8.13]) and 75–84 (OR = 9.03, 95% CI [2.40, 33.96]) had higher odds of selecting a non-Alzheimer's dementia subtype. No significant differences were observed for participants aged 25–34 and 55–64 years, while estimates for those aged ≥ 85 years were unstable due to the very small sample size. Gender, education, and whether the participant currently or previously have known anyone living with dementia

were not consistently associated with subtype identification, as all corresponding confidence intervals crossed 1 (see Table 2).

Awareness of symptoms associated with subtypes. Compared with English participants, German (OR = 0.55, 95% CI [0.31, 0.97]), Lithuanian (OR = 0.45, 95% CI [0.25, 0.80]) and Polish participants (OR = 0.29, 95% CI [0.16, 0.51]) showed lower odds of endorsing that different dementia subtypes are associated with different symptoms. In contrast, Dutch participants did not differ significantly from English participants (OR = 0.89, 95% CI [0.44, 1.81]). Age, gender, education, and whether the participant currently or has previously known someone living with dementia were not consistently associated with subtype identification, as most corresponding confidence intervals crossed 1. However, education showed a small positive association with awareness (OR = 1.04, 95% CI [1.00, 1.07]) (see Table 3).

Discussion

This is the first study to evidence the general public's knowledge about rarer subtypes of dementia, and across five different European languages. No other study has explored general public's awareness about dementia across five European languages (Germany, Lithuania, Poland, the Netherlands, and the UK), except for [26] in the UK only.

Overall, less than 50% of participants across all languages knew that Alzheimer's disease dementia is the most common subtype. Whilst not asked specifically about the most common subtype, equally fewer than 50% of a localised UK sample in a Southern part of the country were able to name Alzheimer's disease dementia as a subtype [26]. Perhaps to be expected, knowledge of Lewy Body dementia, frontotemporal dementia, and vascular dementia was lower across the 5-linguistic sample, which extends UK-only findings from [26] and provides the first insights into more European-wide levels of a lack of dementia subtype awareness. This clearly highlights the need for greater training and awareness raising campaigns within the general public, which may also influence the health and social care workforce.

Table 2 Identification of most common subtype regression results

	Odds Ratio	95% CI
Age 25–34	1.69	0.69–4.19
Age 35–44	2.85	1.17- 6.96
Age 45–54	2.85	1.17–6.92
Age 55–64	2.38	0.97–5.81
Age 65–74	2.89	1.02- 8.13
Age 75–84	9.03	2.37–33.96
Age 85 +	Not estimable*	-
Gender: Male	0.88	0.54–1.45
Gender: Non-binary	1.01	0.17–5.90
Education	0.96	0.93–1.00
Language Dutch	0.45	0.22–0.96
Language German	1.07	0.61- 1.88
Language Lithuanian	1.84	1.03–3.31
Language Polish	2.30	1.24–4.27
Do you currently/have previously known someone with dementia: I don't know	0.49	0.11–2.15
Do you currently/have previously known someone with dementia: Yes I have dementia myself	Not estimable*	-
Do you currently/have previously known someone with dementia: Prefer not to say	Not estimable*	-
Do you currently/have previously known someone with dementia: Yes I work with people with dementia	1.10	0.58–2.10
Do you currently/have previously known someone with dementia: Yes, someone else	0.92	0.51–1.64

*Cells with not estimable are due to data sparsity and hence should be interpreted with caution

Table 3 Dementia subtypes are associated with different symptoms regression results

	Odds Ratio	95% CI
Age 25–34	0.84	0.37–1.88
Age 35–44	0.58	0.26–1.27
Age 45–54	0.75	0.34–1.67
Age 55–64	0.56	0.25–1.24
Age 65–74	0.46	0.18–1.19
Age 75–84	0.48	0.13–1.73
Age 85 +	Not estimable*	-
Gender: Male	1.34	0.84-2.15
Gender: Non-binary	1.20	0.21–6.77
Education	1.04	1.00–1.07
Language Dutch	0.89	0.44–1.81
Language German	0.55	0.31–0.97
Language Lithuanian	0.45	0.25–0.80
Language Polish	0.29	0.16–0.51
Do you currently/have previously known someone with dementia: I don't know	0.63	0.23-1.72
Do you currently/have previously known someone with dementia: Yes I have dementia myself	Not estimable*	-
Do you currently/have previously known someone with dementia: Prefer not to say	0.19	0.02–2.02
Do you currently/have previously known someone with dementia: Yes I work with people with dementia	0.94	0.52–1.70
Do you currently/have previously known someone with dementia: Yes, someone else	0.99	0.59–1.67

*Cells with not estimable are due to data sparsity and hence should be interpreted with caution

Interestingly, participants from different linguistic backgrounds showed significantly different levels of knowledge about dementia subtypes. Participants responding in English showed the highest levels of knowledge, with substantially lower general public awareness in participants responding in Lithuanian and Polish. Knowledge of participants responding in German and Dutch was in between. This fragmentation of awareness may suggest more advanced public awareness campaigns perhaps in English or Dutch languages, although awareness campaigns and their impacts are not often evidenced. One exception is a reported campaign run in Poland which involved a website, social and traditional media promotions, webinars and social activities [3]. Based on interviews with carers, people with dementia and health and social care professionals, carers reported improved awareness and knowledge of dementia, whilst care professionals identified substantial gaps in the dementia care system. Further explanations might include differences in health literacy, healthcare systems (including diagnostic practices) and cultural perceptions of ageing and dementia across countries [8, 28, 29].

Another underpinning variation may be the presence of National Dementia Strategies, which indicate governmental prioritisation of improving dementia diagnosis and care. [27] reported 35 available National Dementia Strategies across Europe, whilst already a few years later in 2026, some of these countries fail to have a continued or renewed strategy – such as a combined one for the UK since 2020.

Besides responding language, gender was also found to be significantly associated with variations in knowledge about dementia subtypes. Specifically, men knew less about different dementia subtypes than women. These appear to be the first international results to show this. One possible reason may be that more women are unpaid carers [18] and therefore have more personal experiences of dementia. It is thus more likely that women come across people with a rarer dementia due to their increased likelihood of being a carer compared to men, although we did not test for the relationship between personal experiences of dementia on awareness of dementia subtypes. This significant difference may suggest that public awareness campaigns may need to target audiences on a variety of ways, with a specific focus on gender. This may include for example targeted sports-related awareness campaigns with major football clubs. Whilst sport-related dementia support is evidenced in the literature (i.e. [17], there are no reported impacts of sport-related awareness campaigns to date.

Strengths and limitations

This study benefitted from having collected data in five European languages with a large sample size, and heterogenous participants characteristics regarding responding language, age, gender, and ethnic groups. Furthermore, the survey development was interdisciplinary and benefitted from a wide range of expertise. It was conceptualised by different research team members from three countries with different levels of expertise of survey design and all with a background in dementia care research.

The most important limitation of this survey is a possible selection bias, which may limit the generalisability of the results. While this is common in online surveys, the specific limitations in this study are as follows. Firstly, the study sought to recruit participants from varied ethnic backgrounds through social media and established local and regional networks. Despite these efforts, 94.1% of respondents identified as White, which limited the statistical power to examine ethnicity as an independent influence on knowledge of rarer dementia subtypes. Secondly, this was an online survey, thereby excluding adults without internet access or limited digital literacy skills. Thirdly, the recruitment procedure aimed at a convenience sample, rather than towards representativeness of the general population in participating languages. While this limits the interpretation of the results and may lead to variations in knowledge based on sample composition in each nationality as opposed to nationality per se, it is the adequate method for a study conducted without major funding. Fourthly, the study was limited to five language groups from pre-selected countries. However, the language groups were in different regions of Europe with varied cultural backgrounds, and this is the first cross-European evidence. It is also important to note that this self-selection bias may explain the high level of dementia awareness in the sample (93%). Study eligibility was based on self-reported participant information, and no procedures were implemented to identify duplicate responses; therefore, eligibility and unique participation could not be independently verified. Finally, the survey was not formally pilot tested, and no formal assessment of usability or questionnaire acceptability was undertaken, which may have limited the opportunity to identify issues with question interpretation or participant burden prior to data collection.

Future research should examine whether the variations in dementia-subtype knowledge identified across these language groups are also evident in Southern Europe and in low- and middle-income countries. This expansion would require careful attention to translation, cultural adaptation, research governance and ethical approval across settings. To support this wider adaptation, it is important to note the need for more in-depth translational processes and testing measures. In this study, we relied on detailed survey translation by the individual national study team members, who are fluent in their first language and English. However, we did not conduct forward–backward translation or pilot testing of the survey in different languages due to time constraints. Future adaptations should consider time commitments to ensure this can be implemented.

Conclusions

Knowledge about different dementia subtypes, especially rarer subtypes, is limited in the general population across Europe – as highlighted by five different European language groups. Limited knowledge in the general population can affect how people with possible symptoms seek out medical advice and a diagnosis, or fail to do so. With a drive to increase (correct) diagnosis rates and thus facilitate improved access to post-diagnostic care, there is an urgent need to increase knowledge and awareness of different dementia subtypes, ensuring that the general public understands that dementia not only affects people over the age of 65 and not only is characterised by memory problems. Public health awareness campaigns may help raise awareness, such as campaigns on dementia risk reduction.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1186/s12889-026-30286-z.

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Authors' contributions CG, MRR, JM, JRT, AZ designed the survey. JR and GA translated the survey into Polish and Dutch. JM translated the survey into Lithuanian. JRT and AZ translated the survey into German. CG led the study and oversaw data collection and drafted the manuscript. MRR run the analysis. All co-authors (MRR, AEZ, JR, JRT, AP, GA, AW, OB, JM) fed back on drafts of the manuscript and approved the final version.

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Data availability Anonymised data may be made available upon reasonable request and after discussion within the research team.

Declarations

Ethics approval and consent to participate This study was first approved in the UK via the University of Liverpool ethics committee [ID: 16034]. The ethics application was translated into Polish, German, Lithuanian, and Dutch and submitted with the University of Liverpool ethics committee letter of approval to Research Ethics Committee of Wrocław University of Science and Technology in Poland; to Ethics Committee of the Medical Faculty of Leipzig University [224/25-ek] and University Medicine Greifswald [BB 192/5] in Germany; to the Lithuanian University of Health Sciences Research Ethics Compliance Committee in Social Sciences and Humanities [No 2025-BEC3-T-066] in Lithuania; and to Radboud University Medical Centre (METC Oost-Nederland) [2025–18574] in the Netherlands.
Participants completed a digital consent form prior to starting the survey.

Consent for publication Not applicable.

Competing interests The authors declare no competing interests.

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