

Lay Knowledge About Dementia in Iceland: Symptoms and Risk and Protective Factors

Gerontology & Geriatric Medicine
Volume 8: 1–10
© The Author(s) 2022
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/23337214221142937
journals.sagepub.com/home/ggm



María K. Jónsdóttir PhD,^{1,2} , Elva Björk Pálsdóttir BS,^{1*},
Stefanía Ýr Hannesdóttir BS,^{1*}, and Thorlakur Karlsson PhD,¹

Abstract

No studies are available on the lay knowledge about dementia in Nordic countries. A survey was sent to 829 Icelanders aged 25 to 65 (61.2% female). 60.8% resided in the capital area of Reykjavik. About 90% or more recognized eight of eleven dementia symptoms, with females recognizing them proportionally more often than males. About 50% believed that an individual's risk of developing dementia could be modified. For individual risk factors, agreement ranged from 4% (hearing loss) to 75.1% (history of brain injury). Knowledge about cardiovascular risk factors ranged from 24.8% (obese) to 43.6% (high blood pressure). Participants acknowledged the importance of a healthy diet and an active lifestyle, but only 8% identified a low education level as a risk factor. Public health campaigns and educational efforts about dementia should focus on the whole lifespan targeting all risk and protective factors operating throughout the lifespan.

Keywords

dementia, health literacy, health promotion, prevention

Manuscript received: September 16, 2022; **accepted:** November 15, 2022.

What This Paper Adds

- As in English-speaking countries and Asia, the knowledge of risk and protective factors of dementia is lacking in Iceland, while symptom knowledge is adequate.
- Knowing that education acts as a protective factor is, in particular, lacking.
- Only about 50% of participants know that dementia risk can be modified.

Applications of Study Findings

- Public health campaigns must address that education is one of the pillars of brain health.
- Brain health knowledge among adolescents has to be studied and subsequent educational campaigns implemented.
- Further studies in Iceland have to address if ageism possibly affects the fatalistic view of cognitive impairment in aging.

In the early 1900s, Frederick Tilney presented a modern view of the relationship between lifestyle, disease, and brain health when stating that “I should prefer to

consider the so-called aged brain as one which has been diseased, abused or neglected” (Tilney, 1928, p. 1127). Further, he proposed that “mental old age” reflects underlying pathology, which can be “combated or corrected.” Tilney proved correct in that cognitive impairment is not an unavoidable consequence of aging. Further, studies have shown that appropriate lifestyle choices throughout the life span can reduce dementia risk (Barnett et al., 2013; Livingston et al., 2020), although it has also been argued that the evidence for the association between modifiable risk factors and Alzheimer's disease is relatively weak (Daviglius, 2011). While scientific knowledge about dementia risk factors has dramatically increased in the past decades, lay knowledge about risk factors is not optimal (Heger et al., 2019). In fact, it is a frequent assumption, both in

¹Reykjavik University, Iceland

²Landspítali—The National University Hospital of Iceland (Memory Clinic), Reykjavik, Iceland

*These authors contributed equally to this work.

Corresponding Author:

María K. Jónsdóttir, Department of Psychology, Reykjavik University, Menntavegur 1, 102 Reykjavik, Iceland.
Email: mariakj@ru.is



Western and non-Western cultures, that dementia is a normal part of aging (Cahill et al., 2015; Cations et al., 2018; Li et al., 2011).

As would be expected with increased theoretical knowledge and dementia awareness, dementia diagnosis is on the rise (Phung et al., 2010). However, dementia remains underdiagnosed (Amjad et al., 2018; Bradford et al., 2009; Lang et al., 2017). In some cases, the diagnosis comes too late, as was shown by a median Mini-Mental State Exam (MMSE) score of 22 (Fereshtehnejad et al., 2015; Garcia-Ptacek et al., 2016) and an average MMSE score of 17.9 (Grimmer et al., 2015) at diagnosis in recent studies. Lack of general lay knowledge about dementia may contribute to this state of affairs and thus be a barrier to diagnosis (Garcia-Ptacek et al., 2016). Moreover, if the general public had a less fatalistic view of cognitive health and were aware that dementia is not a normal part of aging, healthy lifestyle choices would hopefully increase, possibly resulting in a further decrease in the prevalence of dementia than has already been documented in Western countries (Lopez & Kuller, 2019; Serrano-Pozo & Growdon, 2019).

There is no curative treatment for degenerative dementia (Tisher & Salardini, 2019), and increasing age and genotype represent the most significant non-modifiable risk factors (Yin & Wang, 2018). Female sex is the third major risk factor in Alzheimer's disease (Riedel et al., 2016; Sacuiu, 2016). However, dementia could possibly be delayed or prevented if appropriate lifestyle measures are taken (Fratiglioni & Qiu, 2011; Livingston et al., 2020; Serrano-Pozo & Growdon, 2019). For example, maintaining social and mental activity and health-promoting behaviors (i.e., diet, cardiovascular risk factors, exercise) decreases dementia risk, as does education (Barnett et al., 2013; Livingston et al., 2020). Therefore, studying lay knowledge about modifiable risk factors is essential as this will reveal knowledge gaps, which could guide public health education campaigns (Friedman et al., 2015). Examining general dementia knowledge and knowledge about cognitive aging is also important because if the general public's threshold for seeking medical advice for cognitive changes is too high, dementia diagnosis will be less timely.

Given the high societal costs that dementia entails, increasing general knowledge and awareness of dementia is a significant public health issue (Wimo et al., 2017). While the general public's recognition of the symptoms of impending dementia is essential, one could argue that awareness of the modifiable and manageable risk factors of neurodegenerative disorders that operate during the whole lifespan is even more critical (Barnett et al., 2013). However, recent studies of lay knowledge about dementia have shown that although knowledge about symptoms of dementia may be adequate, awareness of modifiable risk factors and preventative measures is generally poor (Cahill et al., 2015; Cations et al., 2018; Low & Anstey, 2007; Nagel et al., 2021). In a

recent study in the Netherlands (Heger et al., 2019), 56% of a well-educated community-dwelling sample (aged 40–75 years) did not associate dementia risk with lifestyle, and only 8% to 30% of the participants correctly identified the various vascular risk factors of dementia. This relative lack of public knowledge about vascular risk factors for dementia is a common theme and is even seen in groups with otherwise good knowledge about dementia symptoms (Hudson et al., 2012). It is of note that a relative lack of knowledge about risk factors for dementia is also seen in health professionals (Annear, 2020; Nordhus et al., 2012). As with lay knowledge about other diseases (Tedesco et al., 2015), education level generally predicts general dementia knowledge (Annear, 2020; Heger et al., 2019; Seo et al., 2015). Women are often better informed about dementia than men (Cahill et al., 2015) although this is not consistently found (Seo et al., 2015) and age is frequently negatively associated with dementia literacy (Hudson et al., 2012; Park et al., 2008; Seo et al., 2015). Other variables that have been negatively related to dementia knowledge are living in rural areas (Annear, 2020) and being of racial or ethnic minority (Cahill et al., 2015). Although one of the most substantial risk factors for dementia is lack of formal education (Livingston et al., 2020), only a small percentage of people associate having little education with increased dementia risk (Friedman et al., 2015; Park et al., 2008). Having had personal experience with someone with dementia is associated with better knowledge (Smith et al., 2014).

This study aimed to examine knowledge about dementia and its risk and protective factors, including the overall awareness of whether anything can be done to prevent dementia, among Icelanders aged 25 to 65 living in rural and urban areas. There are no published studies on this topic we know of in Nordic countries. This represents a knowledge gap. One cannot generalize findings on lay dementia knowledge across cultures. For example, education levels, which influence dementia knowledge (Cahill et al., 2015), differ between countries. In Iceland, 40.6% of those 25 to 64 years of age have a tertiary education, whereas 49.3% of Australians have a tertiary education (OECD, 2021). In addition, more Icelanders in this age range only have below upper secondary level education (24%), whereas the corresponding proportion is 19% and 16% for the Netherlands and Australia (OECD, 2021). Moreover, Iceland is a small country with only around 370,000 inhabitants, of whom 64% live in the Reykjavik metropolitan area (*Statistics Iceland*, 2021) and has a relatively ethnically homogenous population. It is not unreasonable to assume that this would facilitate the dispersion of knowledge about dementia among the general public, both because of the sparse population and the ethnic homogeneity (Cahill et al., 2015). On the other hand, a national dementia policy was not implemented in Iceland until 2020 and is only in its very early stages

Table 1. Number (N) and Percentage (%) of Participants by Gender, Age, Residence, Education, Health-Related Studies, and Knowing People With Dementia Compared With Population Percentages.

Background variables	N	Sample %	Population %
Gender			
Female	507	61.2	47.8
Male	322	38.8	52.2
Age			
25–34 years old	171	20.6	29.2
35–44 years old	164	19.8	25.2
45–54 years old	212	25.6	22.5
55–65 years old	282	34.0	23.1
Residence			
Capital area of Reykjavik	504	60.8	64.9
Other areas	325	39.2	35.1
Education			
Primary school	115	15.9	24.1
High school	207	28.6	35.3
University, bachelor	216	29.9	40.6 ^a
University, master/PhD	185	25.6	
Health-related studies?			
No	587	81.2	
Yes	136	18.8	
Know people with dementia?			
None	238	29.4	
1–7 people	572	70.6	

^aAll university degrees.

(Ministry of Health, 2020), possibly contributing to less than optimal knowledge about dementia and its risk factors in Iceland. Knowing the current status of dementia knowledge is vital in order to later assess the possible increased lay dementia literacy in the wake of the newly established governmental dementia strategies. Also, the current status of lay knowledge will demonstrate where further education is needed when future awareness campaigns are designed. In accordance with previous studies in the field, it was hypothesized that well-educated participants in urban areas would have better knowledge about dementia and its risk factors than those that are less educated and living rurally but that knowledge would also depend on gender and age, and whether the participants had a health-related background and had known someone with dementia.

Method

Participants

The survey was sent to 2,500 randomly chosen members of a panel of *Maskina Research*, which conducts survey research in Iceland (maskina.is). There are about 20,000 members in Maskina's panel and they were recruited randomly from the National Registry in Iceland. They were originally contacted by telephone and asked to join the

panel. In the present study, there were 829 participants aged 25 to 65, yielding about a 33% response rate. Information on the background of the sample and the dispersion of background groups in the population according to the National Registry is presented in Table 1. More females (61.2%) than males (38.8%) responded. Also, the participants were somewhat older on average than the population of 25 to 65 years old Icelanders and had more formal education. Over 60% of the sample resided in the capital of Reykjavik and surrounding towns and 18.8% had studied some health-related subjects.

Measures

The study was a cross-sectional survey based on a questionnaire used in a recent dementia awareness study in the British Social Attitudes Survey (Marcinkiewicz & Reid, 2016) and in the Netherlands (Heger et al., 2019). Further questions were added to incorporate all of the most recently listed modifiable risk factors for dementia (Livingston et al., 2020), resulting in a total of 47 items in three parts. The first part consisted of six background questions, a question on the respondents' subjective general knowledge about dementia, and the statement: *There is nothing anyone can do to reduce their risks of getting dementia*. The knowledge questions were answered on a Likert-response scale ranging from Very much (5) to Very little/None (1), and the statement also had a Likert-response scale ranging from Agree strongly (5) to Disagree strongly (1).

In the second part of the survey, respondents were asked about their knowledge about specific dementia symptoms—items shown in Table 2. There were 11 known symptoms and five distractors, and for each of them the respondent was required to indicate whether it was a symptom (Yes) or not a symptom (No). In the third and final part of the questionnaire, there were 23 questions about knowledge about modifiable risk (17) and protective (6) factors of dementia, all measured on a five-point Likert scale from Totally agree (5) to Totally disagree (1) (see the 23 items in Tables 3 and 4). Of the 17 risk factors, four were distractors and one distractor was among the six protective factors. The questionnaire was administered in Icelandic. Following the translation and adaptation, 19 native Icelandic speakers in the same age range as the sample read the questionnaire in order to detect potential problems with the Icelandic versions of the questions. None were noted.

Procedure

On February 26, 2021, a link to a web-based survey was sent to the participants via e-mail. Two reminders were sent to those who had not responded within 5 days of receiving the survey link or the first reminder. The data collection was terminated on March 10, 2021. The e-mail to the participants contained an introduction

about the survey; people were promised anonymity and told that their identity would in no way be linked to their answers. Also, the participants were told that they were neither obliged to answer any specific questions nor the questionnaire as a whole and that answering the questionnaire was equivalent to informed consent. One randomly chosen respondent received 20,000 ISK (about 150 USD) for participation.

Data Analysis

Descriptive statistics were calculated for each dementia symptom item, as well as risk and protective factors. An exploratory factor analysis (EFA) of the symptoms on the one hand and risk and protective factors on the other was performed. Using the symptoms with the distractors, the EFA did not yield an interpretable solution. However, leaving the distractors out, the EFA suggested that the data could be described as one factor, with factor loadings ranging from .32 to .65 (Cronbach's $\alpha = .70$). In the case of risk and protective factors, including the distractors, the EFA yielded an interpretable one-factor solution with loadings ranging from .58 to .82 (Cronbach's $\alpha = .84$). Therefore, in each case, the items were added together, 11 symptoms of dementia on the one hand and 23 risk and protective items with distractors on the other, producing two dependent variables: (1) Knowledge about dementia symptoms (scale 0–11 representing the number of symptoms identified), and (2) Knowledge about dementia risk/protective factors (scale of 1–5 as the sum of the 23 risk and protective items were divided by 23 so the resulting scale would be the same as for

each item; from Totally agree (5) to Totally disagree (1)). Finally, a regression analysis was performed on the two dependent variables of knowledge, with respondents' background, whether respondents had studied health-related subjects, and whether they knew people with dementia as predictors. The significance level was set at $\leq .05$.

Results

About 70% of the respondents said they knew one or more individuals with dementia, whereas almost 30% claimed to know none. Over 18% said they knew very much (3.8%) or rather much (14.4%) about dementia, while over 40% said they had rather little (33.5%) or very little/no (7.1%) knowledge about dementia. The remaining 41.3% maintained an average knowledge about dementia. The Pearson's correlation coefficient between the subjective general knowledge about dementia on the one hand and knowledge about dementia symptoms and knowledge about dementia risk/protective factors on the other was very low, $r = .07$ and $r = .05$, respectively. The correlation between the two dependent variables, knowledge about symptoms and risk/protective factors, was $r = .17$ ($p = .015$, one-tailed test).

Knowledge About Symptoms of Dementia

In Table 2, the results for the question about symptoms of dementia are presented by gender. About and over 90% recognized eight of the eleven symptoms, where 97% to 98% selected *personality changes* and 97% *difficulty*

Table 2. Number (N) and Percentage (%) of Those Who Identified Dementia Symptoms and Distractors (Knowledge About Dementia Symptoms) by Gender.

Symptoms/distractors	All		Females		Males	
	N	%	N	%	N	%
Symptoms						
Personality changes	775	97.5	475	98.1	300	96.5
Difficulty recognizing people	764	97.0	465	97.5	299	96.1
Behaving inappropriately	716	93.7	440	95.0	276	91.7*
Losing track of time	700	92.6	437	95.6	263	88.0***
Putting things in the wrong place	717	92.2	443	93.7	274	89.8*
Feeling lost in new places	713	91.5	440	92.6	273	89.8
Slower thinking	684	89.6	432	93.1	252	84.3***
Feeling low	673	89.1	430	92.5	243	83.8***
Paranoia	594	81.7	364	82.4	230	80.7
Losing distance and depth perception	520	74.6	317	75.7	203	73.0
Feeling extremely tired	425	61.8	273	65.8	152	55.7**
Distractors						
Dizziness	393	57.0	235	57.2	158	56.8
Weight loss	369	53.5	251	59.9	153	43.5***
Numbness in hands	264	40.2	160	40.4	157	39.8
Hearing loss	204	30.7	118	30.0	86	31.7
Hair loss	88	13.5	57	14.7	31	11.7

* $p < .05$. ** $p < .01$. *** $p < .001$, between females and males on the Chi-square test of independence.

Table 3. Number (N), Mean (M), Standard Deviation (SD), and Percentage (%) for Risk Factors for Dementia and Distractors.

Risk factors	N ^a	M ^b	SD	% agree ^c	% don't knows ^d
History of brain injury	522	3.9	0.9	75.1	27.1
Parents with dementia	565	3.6	0.9	65.0	26.8
High blood pressure	422	3.2	1.0	43.6	43.9
Smoking	487	3.1	1.2	42.9	36.2
Living in highly polluted area	422	2.9	1.1	34.1	39.2
Diabetes	432	2.9	1.1	34.0	40.8
Depression	457	2.9	1.1	31.1	37.6
High cholesterol	420	2.8	1.1	29.5	39.4
Being obese	452	2.7	1.1	24.8	38.1
Heart disease	444	2.7	1.1	24.8	39.0
Kidney disease	410	2.3	1.0	10.2	42.5
Hearing loss	500	1.8	0.9	4.0	29.6
Little education	574	1.7	1.0	8.0	20.9
Working in noisy environment (distractor)	437	2.5	1.0	16.2	42.1
Use of painkillers (distractor)	435	2.3	1.0	9.2	42.3
Poor personal hygiene (distractor)	532	1.8	0.9	3.9	28.2
Having children (distractor)	546	1.7	0.9	3.5	26.8

^aNumber of those who had an opinion in each question of the 829 total respondents.

^bThe mean of those who had an opinion on the scale of 1 to 5, where 1 denotes disagrees strongly and 5 agrees strongly.

^c% agreeing (strongly and rather agree) of those who had an opinion.

^d% of those who did not know of the 829 total respondents.

Table 4. Number (N), Mean (M), Standard Deviation (SD), and Percentage (%) for Protective Factors of Dementia and a Distractor.

Protective factors	N ^a	M ^b	SD	% agree ^c	% don't knows ^d
Regular physical activity	603	3.8	0.9	74.3	22.3
Mentally active lifestyle	563	3.6	1.0	64.3	24.5
Healthy diet	530	3.5	1.0	60.4	26.1
No or moderate alcohol use	522	3.1	1.1	37.7	31.7
High level of social engagement	541	3.0	1.2	44.4	24.8
Living in a rural area (distractor, opposite)	488	2.0	1.0	7.2	31.2

^aNumber of those who had an opinion in each question of the 829 total respondents.

^bThe mean of those who had an opinion on the scale of 1 to 5, where 1 denotes disagrees strongly and 5 agrees strongly.

^c% agreeing (strongly and rather agree) of those who had an opinion.

^d% of those who didn't know of the total 829 respondents.

recognizing people. A somewhat lower proportion checked *paranoia* (81.7%), *losing distance and depth perception* (74.6), and *feeling extremely tired* (61.8%). More than half thought that the distractors *dizziness* (57.0%) and *weight loss* (53.5%) were symptoms of dementia.

In all eleven cases of the symptoms (Table 2), females recognized them proportionally more often than males, and in six cases the difference was significant ($p \leq .05$). Also, in four out of five distractors, females selected them rather than males as symptoms although with a narrow margin except for *weight loss*, where over 16% more females than males chose it as a symptom.

Knowledge About Risk and Protective Factors of Dementia

Slightly over 50% believed that an individual's risk of developing dementia could be modified, that is, disagreed with the statement that there is nothing anyone can do to reduce their risk of getting dementia. About 21% agreed with the statement, whereas about 28% said "Neither nor." No difference was found between women and men or between age groups. However, higher education and residing in the capital area of Reykjavik were associated with more likelihood of disagreeing with the statement, that is, believing that dementia risk could be modified.

Table 5. Mean (*M*) and Standard Deviation (*SD*) of the Symptoms and Risk and Protective (R/P) Factors of Dementia by Background Variables.

Background variables	Knowledge of dementia					
	Symptoms			R/P factors		
	<i>M</i>	<i>SD</i>	<i>p</i> *	<i>M</i>	<i>SD</i>	<i>p</i> *
Total	9.5	1.8		3.1	0.5	
Gender			<.001			.526
Female	9.7	1.6		3.0	0.5	
Male	9.2	2.0		3.1	0.4	
Age			<.001			.691
25–34 years old	10.0	1.4		3.1	0.5	
35–44 years old	9.8	1.7		3.1	0.5	
45–54 years old	9.4	1.7		3.0	0.5	
55–65 years old	9.0	2.1		3.1	0.4	
Residence			.663			.263
Capital area of Reykjavik	9.5	1.8		3.1	0.5	
Other areas	9.5	1.8		3.0	0.4	
Education			.003			.481
Primary school	9.0	2.1		3.0	0.5	
High school	9.2	1.9		3.0	0.4	
University, bachelor	9.7	1.7		3.1	0.4	
University, master/PhD	9.7	1.6		3.1	0.5	
Health-related studies?			<.001			.031
No	9.3	1.9		3.0	0.4	
Yes	10.1	1.4		3.2	0.6	
Know people with dementia?			.245			.341
None	9.4	1.9		3.0	0.3	
1–7 people	9.6	1.8		3.1	0.5	

*The *p*-value is based on One-way ANOVA and shows whether the difference between background groups is significant.

The individual risk and protective factors with distractors can be seen in Tables 3 and 4 with means on the ordinal scale of 1 to 5, where higher means denote more agreement. The proportion of those who agreed or did not know is also shown. *History of brain injury* had the highest agreement proportion (75.1%) of all the risk factors (Table 3), with a mean of 3.9 on the 1 to 5 Likert scale. This was followed by *parents with dementia* (65.0%, *M*=3.6). The lowest agreement among the risk factors was *hearing loss* (4.0%) and *little education* (8.0%), with a mean of 1.8 and 1.7, respectively. All four distractors had a low agreement ratio, ranging from 3.5% to 16.2%.

Regular physical activity got the highest support as a protective factor with over 74% agreement and a mean of 3.8 (Table 4). This was followed by *mentally active lifestyle* with over 64% agreement and a mean of 3.6. *High level of social engagement* obtained the least support of the five protective factors, with over 44% to 45% agreement and a mean of 3.0. The distractor *living in a rural area* was agreed to by fewer than 10%.

The Effects of Respondents' Background on the Knowledge About Dementia

The means and standard deviations of the knowledge about symptoms and risk and protective factors by background variables are shown in Table 5. The total mean for the symptoms was 9.5 correctly identified symptoms out of 11. The total mean for the risk and protective factors was 3.1 on a scale of 1 to 5. In general, there was not much difference in knowledge according to background variables. The difference was significant in four background variables out of six in terms of the number of identified symptoms, where females obtained a higher score than males, and younger respondents had a higher score than older respondents. More education was associated with a higher mean, as was having a background in health-related studies. Only this last background variable showed a significant difference in knowledge about risk and protective factors, that is, having been in health-related studies was associated with a slightly higher mean, indicating more knowledge.

Table 6 shows the results of a regression analysis on the knowledge about symptoms and knowledge about risk and protective factors. In general, the six background factors did not statistically explain much in this twofold knowledge, or 9% in the symptoms of dementia and 4% in risk and protective factors of dementia, with the latter R^2 not being significant. Age was the strongest predictor of knowledge about symptoms of dementia ($\beta = -.17$), where younger people, on average, knew more about the symptoms than older people. This was followed by gender ($\beta = .12$), with females knowing more than males. Standardized betas for other predictors were weak.

Discussion

In line with results from some studies conducted in other cultures, female gender and younger age (e.g., Heger et al., 2019; Seo et al., 2015) were associated with better knowledge about symptoms of dementia. We did not, however, find as strong a relationship between dementia knowledge and education and health-related educational background as was expected. The background variables (gender, age, education, residence, and knowing someone with dementia) explained only 9% of the knowledge about symptoms and 4% of the knowledge about risk and protective factors of dementia. In line with other studies (Annear, 2020; Glynn et al., 2017; Hudson et al., 2012; Low & Anstey, 2007), the knowledge about individual risk and protective factors of dementia was proportionally worse than knowledge about clinical symptoms. A large percentage of the sample, or about 70%, which is relatively large compared to other studies (Glynn et al., 2017; Hudson et al., 2012; Low & Anstey, 2007), reported knowing someone with dementia. Thus, it may not be surprising that knowledge about the most common symptoms of dementia was generally good, regardless of education or health-related background. About 50% of the participants believed that overall dementia risk could not be modified. Similar but slightly lower percentages were reported by Glynn et al. (2017) and Smith et al. (2014), or 46.0% and 41.5%, respectively. It is of concern that education, which is one of the significant single contributors to dementia risk, and comes into play early in life, both directly (Viner et al., 2012; WHO, 2008) and indirectly, through parental education and socioeconomic status (Katsnelson, 2015; Noble et al., 2015), was recognized as a risk factor by only 8% of the participants. This is in line with other studies in this field (e.g., Friedman et al., 2015).

It is crucial for the general public to understand that although age is the greatest risk factor for cognitive impairment and dementia, dementia is not a normal part of aging. Studies have shown that up to 75% of people (range 39%–75%) believe this to be the case (Cations et al., 2018; Vrijnsen et al., 2021). This issue was not addressed in this study, but it is likely that this false belief is as common in Iceland as in other Western cultures.

Lack of knowledge about risk factors is not unique to dementia. For example, an Italian study among females showed that knowledge about cardiovascular risk factors was less than adequate (Tedesco et al., 2015). It cannot be expected that the general public has expert knowledge about diseases and their risk factors and a full grasp of the medical concept of risk. However, the current findings show that public education campaigns need to focus on risk and protective factors and aim their education at young people in addition to informing people who have reached mid-life about symptoms of dementia.

The current study has some strengths. The sample is large and randomly drawn from both rural and metropolitan areas, with the relative proportions in each group being similar to the population. It is also a strength that we asked about health-related education in the sample. This is also the first large-scale study on the topic in a Nordic country. Most of the existing studies in the field have been conducted in Australia, the US, the UK, and Asia.

A limitation of our study is that the number of males that participated in our study was only 38.8% which is lower than the population proportion of 52.2%. This is quite commonly seen in studies in this field which rely on voluntary participation and may reflect gender-related interests. However, as there was not much difference between the genders, this should have a small effect on the overall results. The second limitation relates to ageism and dementia-related stigma, which might influence knowledge and knowledge-seeking and was not addressed in this study. The third limitation of our study is that our sample did not include ethnic minorities, which often have worse dementia literacy than non-minorities (Cahill et al., 2015). Although Iceland has long been considered an ethnically homogeneous country, this has changed somewhat in recent years. In January 2020, immigrants constituted 15.2% of the population in Iceland, 37.0% of those being Polish (*Statistics Iceland*, 2021).

Delaying or preventing dementia is a pressing public health priority (Friedman et al., 2015). While dementia is generally a disease of older people, the development of the disease can start at a relatively young age. Thus, dementia prevention is a lifelong pursuit (Barnett et al., 2013; Livingston et al., 2020). Motivating young people to commit to a healthy lifestyle in order to ensure brain health in the distant future is an important challenge. Young people may think that there is not much one can do to delay or prevent cognitive decline and dementia (Friedman et al., 2015). Also, because dementia might not afflict them until another 50 years or so, motivation may be less than among those who are older and who see the immediate benefits of good health (Friedman et al., 2015). Thus, for young people, it is possible that emphasizing cognitive and brain health rather than dementia prevention may be a more successful strategy.

Table 6. Regression Analysis for Background Variables and Knowing People with Dementia Predicting Knowledge about Symptoms and Knowledge about Risk and Protective (R/P) Factors for Dementia.

Predictors	Knowledge of . . .							
	Symptoms for dementia				R/P factors for dementia			
	B ^a	β ^b	t	p Value	B	β	t	p Value
Gender (male = 1, female = 2)	0.43	.12	2.72	.007	-0.06	-.07	-0.89	.376
Age	-0.27	-.17	-3.98	<.001	-0.02	-.04	-0.51	.611
Residence (capital = 1, other = 2)	0.10	.03	0.61	.543	-0.08	-.09	-1.22	.226
Education	0.24	.10	2.27	.024	0.03	.05	0.64	.526
Health-related studies	0.32	.07	1.58	.057 ^c	0.09	.08	1.11	.135 ^c
Knowing people with dementia	0.17	.08	1.80	.036 ^c	0.06	.12	1.61	.055 ^c
	R ² = .09		F = 9.25*		R ² = .04		F = 1.51	

^aUnstandardized coefficient.

^bStandardized coefficient.

^cOne-tailed test.

*p < .001.

A recent dementia prevention report listed the various risk factors according to life stages (Livingston et al., 2020). In line with this, the lack of lay knowledge about the different risk factors of dementia needs to be addressed and improved at various stages of life. For example, equal opportunity for all children in access to the best possible education is one of the first steps in maintaining brain health throughout the lifespan. Policymakers, educators, young people, and their parents should be informed about the importance of education as one of the pillars of long-term cognitive health. As people advance in age, other factors may become more important, such as addressing hearing loss, sleep problems, and high blood pressure (Livingston et al., 2020). Thus, education about brain health needs to be age-specific.

Further studies are needed to plan a public health education that could meet the need for more knowledge about risk factors of dementia among the Icelandic population. First, a similar study to the one presented here should be conducted among adolescents and ethnic minorities. Secondly, studying the attitude toward dementia and the older population among all age groups should be conducted. Such a study could inform us about the best way to educate the population of all ages about dementia and lifelong brain health.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Landspítali-The National Hospital of Iceland, Alzheimer Iceland, Hrafnista Science Fund.

Ethics Statement

Maskina (<https://maskina.is/>), the company which conducted the survey and collected the data, is a member of the European Society for Opinion and Marketing Research (ESOMAR) and complies with its code of ethics. Further, Maskina is in full compliance with Icelandic laws and rules on data protection and provides data with no personally identifiable information. The participants, as members of Maskina's panel, voluntarily participate in their surveys. The Icelandic Bioethics Committee does not require permission for a study such as this one where participants do not provide sensitive personal information on health-related issues. All authors have duly contributed to this manuscript.

ORCID iD

María K. Jónsdóttir  <https://orcid.org/0000-0003-0383-007X>

References

- Amjad, H., Roth, D. L., Sheehan, O. C., Lyketsos, C. G., Wolff, J. L., & Samus, Q. M. (2018). Underdiagnosis of dementia: An observational study of patterns in diagnosis and awareness in US older adults. *Journal of General Internal Medicine, 33*(7), 1131–1138. <https://doi.org/10.1007/s11606-018-4377-y>
- Annear, M. J. (2020). Knowledge of dementia among the Australian health workforce: A national online survey. *Journal of Applied Gerontology, 39*(1), 62–73. <https://doi.org/10.1177/0733464817752085>
- Barnett, J. H., Hachinski, V., & Blackwell, A. D. (2013). Cognitive health begins at conception: Addressing dementia as a lifelong and preventable condition. *BMC Medicine, 11*(1), 246. <https://doi.org/10.1186/1741-7015-11-246>
- Bradford, A., Kunik, M. E., Schulz, P., Williams, S. P., & Singh, H. (2009). Missed and delayed diagnosis of dementia in primary care: Prevalence and contributing factors. *Alzheimer Disease & Associated Disorders, 23*(4), 306–314. <https://doi.org/10.1097/WAD.0b013e3181a6bebc>

- Cahill, S., Pierce, M., Werner, P., Darley, A., & Bobersky, A. (2015). A systematic review of the public's knowledge and understanding of Alzheimer's disease and dementia. *Alzheimer Disease & Associated Disorders*, 29(3), 255–275. <https://doi.org/10.1097/WAD.0000000000000102>
- Cations, M., Radisic, G., Crotty, M., & Laver, K. E. (2018). What does the general public understand about prevention and treatment of dementia? A systematic review of population-based surveys. *PLoS One*, 13(4), e0196085. <https://doi.org/10.1371/journal.pone.0196085>
- Daviglius, M. L. (2011). Risk factors and preventive interventions for Alzheimer disease: State of the science. *Archives of Neurology*, 68(9), 1185. <https://doi.org/10.1001/archneurol.2011.100>
- Fereshtehnejad, S.-M., Johannsen, P., Waldemar, G., & Eriksdotter, M. (2015). Dementia diagnosis, treatment, and care in specialist clinics in two Scandinavian countries: A data comparison between the Swedish Dementia Registry (SveDem) and the Danish Dementia Registry. *Journal of Alzheimer's Disease*, 48(1), 229–239. <https://doi.org/10.3233/JAD-150144>
- Fratiglioni, L., & Qiu, C. (2011). Prevention of cognitive decline in ageing: Dementia as the target, delayed onset as the goal. *The Lancet Neurology*, 10(9), 778–779. [https://doi.org/10.1016/S1474-4422\(11\)70145-4](https://doi.org/10.1016/S1474-4422(11)70145-4)
- Friedman, D. B., Becofsky, K., Anderson, L. A., Bryant, L. L., Hunter, R. H., Ivey, S. L., Belza, B., Logsdon, R. G., Brannon, S., Vandenberg, A. E., & Lin, S.-Y. (2015). Public perceptions about risk and protective factors for cognitive health and impairment: A review of the literature. *International Psychogeriatrics*, 27(8), 1263–1275. <https://doi.org/10.1017/S1041610214002877>
- Garcia-Ptacek, S., Modéer, I. N., Kåreholt, I., Fereshtehnejad, S.-M., Farahmand, B., Religa, D., & Eriksdotter, M. (2016). Differences in diagnostic process, treatment and social support for Alzheimer's dementia between primary and specialist care: Results from the Swedish Dementia Registry. *Age and Ageing*, 46(2), 314–319. <https://doi.org/10.1093/ageing/afw189>
- Glynn, R. W., Shelley, E., & Lawlor, B. A. (2017). Public knowledge and understanding of dementia-evidence from a national survey in Ireland. *Age and Ageing*, 46(5), 865–869. <https://doi.org/10.1093/ageing/afx082>
- Grimmer, T., Beringer, S., Kehl, V., Alexopoulos, P., Busche, A., Förstl, H., Goldhardt, O., Natale, B., Ortner, M., Peters, H., Riedl, L., Roßmeier, C., Valentin, W., Diehl-Schmid, J., & Kurz, A. (2015). Trends of patient referral to a memory clinic and towards earlier diagnosis from 1985–2009. *International Psychogeriatrics*, 27(12), 1939–1944. <https://doi.org/10.1017/S104161021500157X>
- Heger, I., Deckers, K., van Boxtel, M., de Vugt, M., Hajema, K., Verhey, F., & Köhler, S. (2019). Dementia awareness and risk perception in middle-aged and older individuals: Baseline results of the MijBreincoach survey on the association between lifestyle and brain health. *BMC Public Health*, 19(1), 678. <https://doi.org/10.1186/s12889-019-7010-z>
- Hudson, J. M., Pollux, P. M. J., Mistry, B., & Hobson, S. (2012). Beliefs about Alzheimer's disease in Britain. *Ageing & Mental Health*, 16(7), 828–835. <https://doi.org/10.1080/13607863.2012.660620>
- Katsnelson, A. (2015). The neuroscience of poverty. *Proceedings of the National Academy of Sciences of the United States of America*, 112(51), 15530–15532. <https://doi.org/10.1073/pnas.1522683112>
- Lang, L., Clifford, A., Wei, L., Zhang, D., Leung, D., Augustine, G., Danat, I. M., Zhou, W., Copeland, J. R., Anstey, K. J., & Chen, R. (2017). Prevalence and determinants of undetected dementia in the community: A systematic literature review and a meta-analysis. *BMJ Open*, 7(2), e011146. <https://doi.org/10.1136/bmjopen-2016-011146>
- Li, X., Fang, W., Su, N., Liu, Y., Xiao, S., & Xiao, Z. (2011). Survey in Shanghai communities: The public awareness of and attitude towards dementia: Survey in Shanghai about dementia. *Psychogeriatrics*, 11(2), 83–89. <https://doi.org/10.1111/j.1479-8301.2010.00349.x>
- Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., Brayne, C., Burns, A., Cohen-Mansfield, J., Cooper, C., Costafreda, S. G., Dias, A., Fox, N., Gitlin, L. N., Howard, R., Kales, H. C., Kivimäki, M., Larson, E. B., Ogunniyi, A., . . . Mukadam, N. (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *The Lancet*, 396(10248), 413–446. [https://doi.org/10.1016/S0140-6736\(20\)30367-6](https://doi.org/10.1016/S0140-6736(20)30367-6)
- Lopez, O. L., & Kuller, L. H. (2019). Epidemiology of aging and associated cognitive disorders: Prevalence and incidence of Alzheimer's disease and other dementias. *Handbook of Clinical Neurology*, 167, 139–148. <https://doi.org/10.1016/B978-0-12-804766-8.00009-1>
- Low, L.-F., & Anstey, K. J. (2007). The public's perception of the plausibility of dementia risk factors is not influenced by scientific evidence. *Dementia and Geriatric Cognitive Disorders*, 23(3), 202–206. <https://doi.org/10.1159/000099038>
- Marcinkiewicz, A., & Reid, S. (2016). *Attitudes to dementia: findings from the 2016 British social attitudes survey*. NatCen Social Research. https://www.basw.co.uk/system/files/resources/basw_60440-1_0.pdf
- Ministry of Health. (2020). *Aðgerðaaætlun um þjónustu við einstaklinga með heilabilun [Action plan: For services for people with dementia]*. <https://www.stjornarradid.is/gogn/rit-og-skyrslur/stakt-rit/2020/04/14/Adgerdaaaetlun-um-thjonustu-vid-einstaklinga-med-heilabilun/>
- Nagel, A. K., Loetscher, T., Smith, A. E., & Keage, H. A. (2021). What do the public really know about dementia and its risk factors? *Dementia*, 20(7), 2424–2440. <https://doi.org/10.1177/1471301221997301>
- Noble, K., Houston, S., Brito, N., Bartsch, H., Kan, E., Kuperman, J., Akshoomoff, N., Amaral, D., Bloss, C., Libiger, O., Schork, N., Murray, S., Casey, B., Chang, L., Ernst, T., Frazier, J., Gruen, J., Kennedy, D., & van zijl, P. (2015). Family income, parental education and brain structure in children and adolescents. *Nature Neuroscience*, 18, 773–778. <https://doi.org/10.1038/nn.3983>
- Nordhus, I. H., Sivertsen, B., & Pallesen, S. (2012). Knowledge about Alzheimer's disease among Norwegian psychologists: The Alzheimer's disease knowledge scale. *Ageing & Mental Health*, 16(4), 521–528. <https://doi.org/10.1080/13607863.2011.628973>
- OECD. (2021). *Education at a glance 2021: OECD indicators*. Author. <https://doi.org/10.1787/b35a14e5-en>

- Park, M. H., Jo, S. A., Jo, I., Kim, E., Woo, E. K., Kim, S.-S., Eun, S.-Y., Han, C., & Park, M. K. (2008). Awareness of putative risk factors for Alzheimer's disease among elderly Koreans. *Acta Neuropsychiatrica*, *20*(1), 20–24. <https://doi.org/10.1111/j.1601-5215.2007.00230.x>
- Phung, T. K. T., Waltoft, B. L., Kessing, L. V., Mortensen, P. B., & Waldemar, G. (2010). Time trend in diagnosing dementia in secondary care. *Dementia and Geriatric Cognitive Disorders*, *29*(2), 146–153. <https://doi.org/10.1159/000269933>
- Riedel, B. C., Thompson, P. M., & Brinton, R. D. (2016). Age, Apoe and sex: Triad of risk of Alzheimer's disease. *The Journal of Steroid Biochemistry and Molecular Biology*, *160*, 134–147. <https://doi.org/10.1016/j.jsbmb.2016.03.012>
- Sacuiu, S. F. (2016). Chapter 8—Dementias. In M. J. Aminoff, F. Boller, & D. F. Swaab (Eds.), *Handbook of clinical neurology* (Vol. 138, pp. 123–151). Elsevier. <https://doi.org/10.1016/B978-0-12-802973-2.00008-2>
- Seo, H.-J., Lee, D. Y., & Sung, M. R. (2015). Public knowledge about dementia in South Korea: A community-based cross-sectional survey. *International Psychogeriatrics*, *27*(3), 463–469. <https://doi.org/10.1017/S1041610214001896>
- Serrano-Pozo, A., & Growdon, J. H. (2019). Is Alzheimer's disease risk modifiable? *Journal of Alzheimer's Disease*, *67*(3), 795–819. <https://doi.org/10.3233/JAD181028>
- Smith, B. J., Ali, S., & Quach, H. (2014). Public knowledge and beliefs about dementia risk reduction: A national survey of Australians. *BMC Public Health*, *14*, 661. <https://doi.org/10.1186/1471-2458-14-661>
- Statistics Iceland. (2021). Population and elections. <https://px.hagstofa.is/pxen/pxweb/en/Ibuar/?rxid=bf63cc44-aea4-4feb-a7b6-bb6042e61f6b>
- Tedesco, L. M. R., Di Giuseppe, G., Napolitano, F., & Angelillo, I. F. (2015). Cardiovascular diseases and women: Knowledge, attitudes, and behavior in the general population in Italy. *BioMed Research International*, *2015*, e324692. <https://doi.org/10.1155/2015/324692>
- Tilney, F. (1928). The aging of the human brain. *Bulletin of the New York Academy of Medicine*, *4*(11), 1125–1143.
- Tisher, A., & Salardini, A. (2019). A comprehensive update on treatment of dementia. *Seminars in Neurology*, *39*(2), 167–178. <https://doi.org/10.1055/s-0039-1683408>
- Viner, R. M., Ozer, E. M., Denny, S., Marmot, M., Resnick, M., Fatusi, A., & Currie, C. (2012). Adolescence and the social determinants of health. *The Lancet*, *379*(9826), 1641–1652. [https://doi.org/10.1016/S0140-6736\(12\)60149-4](https://doi.org/10.1016/S0140-6736(12)60149-4)
- Vrijzen, J., Matulesij, T. F., Joxhorst, T., de Rooij, S. E., & Smidt, N. (2021). Knowledge, health beliefs and attitudes towards dementia and dementia risk reduction among the Dutch general population: A cross-sectional study. *BMC Public Health*, *21*(1), 857. <https://doi.org/10.1186/s12889-021-10913-7>
- WHO. (2008). *Closing the gap in a generation: Health equity through action on the social determinants of health. Final report of the Commission on Social Determinants of Health*. <https://www.who.int/publications/i/item/WHO-IER-CSDH-08.1>
- Wimo, A., Guerchet, M., Ali, G.-C., Wu, Y.-T., Prina, A. M., Winblad, B., Jönsson, L., Liu, Z., & Prince, M. (2017). The worldwide costs of dementia 2015 and comparisons with 2010. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, *13*(1), 1–7. <https://doi.org/10.1016/j.jalz.2016.07.150>
- Yin, Y., & Wang, Z. (2018). Apoe and neurodegenerative diseases in aging. *Advances in Experimental Medicine and Biology*, *1086*, 77–92. https://doi.org/10.1007/978-981-13-1117-8_5