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

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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 Reykjavík. 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

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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 “combatted 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 (Daviglus, 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

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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.
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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 | Sample N | Sample % | Population N | Population % |
|----------------------|----------|----------|--------------|--------------|
| Gender               |          |          |              |              |
| Female               | 507      | 61.2     | 478          | 47.8         |
| Male                 | 322      | 38.8     | 522          | 52.2         |
| Age                  |          |          |              |              |
| 25–34 years old      | 171      | 20.6     | 292          | 29.2         |
| 35–44 years old      | 164      | 19.8     | 252          | 25.2         |
| 45–54 years old      | 212      | 25.6     | 225          | 22.5         |
| 55–65 years old      | 282      | 34.0     | 231          | 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*        |              |
| 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     |              |              |

*All 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 administrated in Icelandic. Following the translation and adaption, 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 ques-
tionnaire was equivalent to informed consent. One ran-
domly 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 load-
ings ranging from .32 to .65 (Cronbach’s $\alpha = .70$). In
the case of risk and protective factors, including the distrac-
tors, 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 respon-
dents’ 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 demen-
tia 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

| Symptoms/distractors | All  | %   | Females | %   | Males | %   |
|----------------------|------|-----|---------|-----|-------|-----|
| 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.
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 3. Number (N), Mean (M), Standard Deviation (SD), and Percentage (%) for Risk Factors for Dementia and Distractors.

| Risk factors                                      | N | M | SD  | % agree | % don’t know |
|--------------------------------------------------|---|---|-----|---------|--------------|
| 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         |

*Number of those who had an opinion in each question of the 829 total respondents.

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

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

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

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

| Protective factors                                    | N | M | SD  | % agree | % don’t know |
|-------------------------------------------------------|---|---|-----|---------|--------------|
| 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 (distractor, opposite)| 541| 3.0| 1.2 | 44.4    | 24.8         |
| Living in a rural area (distractor)                   | 488| 2.0| 1.0 | 7.2     | 31.2         |

*Number of those who had an opinion in each question of the 829 total respondents.

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

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

% of those who didn’t know of the total 829 respondents.
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 a 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. 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 5. Mean (M) and Standard Deviation (SD) of the Symptoms and Risk and Protective (R/P) Factors of Dementia by Background Variables.

| Background variables          | Symptoms |               | R/P factors |               |
|------------------------------|----------|---------------|-------------|---------------|
|                              | M        | SD            | p*          | M             | SD            | p*          |
| 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.
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; Vrijsen 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.
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.

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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.

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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). 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

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

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                          | Symptoms for dementia | R/P factors for dementia |
|-------------------------------------|-----------------------|--------------------------|
| Gender (male = 1, female = 2)       | 0.43 (0.12)           | -0.06 (-0.07)            |
| Age                                 | -0.27 (-0.17)         | -0.02 (-0.04)            |
| Residence (capital = 1, other = 2) | 0.10 (0.03)           | -0.08 (-0.09)            |
| Education                           | 0.24 (0.10)           | 0.03 (0.05)              |
| Health-related studies              | 0.32 (0.07)           | 0.09 (0.08)              |
| Knowing people with dementia        | 0.17 (0.08)           | 0.06 (0.12)              |

R² = .09  F = 9.25  R² = .04  F = 1.51

*aUnstandardized coefficient.

*bStandardized coefficient.

*cOne-tailed test.

*p < .001.
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.0000000000001012

Cations, M., Radisic, G., Cotty, 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

Davilus, 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/archneur.2011.100

Fereshtehnejad, S.-M., Johannsen, P., Waldemar, G., & Erkisdottir, 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., & Qu, 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

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., Modeer, I. N., Käréholt, I., Fereshtehnejad, S.-M., Farahmand, B., Religa, D., & Erkisdottir, 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/ageage/awf189

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/ageage/afx082

Grimmer, T., Beringer, S., Kehl, V., Alexopoulos, P., Busche, A., Förstl, H., Goldhardt, O., Natale, B., Oertner, M., Peters, H., Riedl, L., Rollmeier, C., Valentin, W., Diehl-Schmid, J., & Kurz, A. (2015). Trends of patient referral to a memory clinic and towards earlier diagnostic 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 MijnBreincoach 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. *Aging & 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*, 12(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., Gittin, L. N., Howard, R., Kales, H. C., Kivimäki, M., Larson, E. B., Ogumiyi, 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

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/10.1159/000099093

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). *Adgerðaáættunum um hínustu 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/adgerdavaetnun-um-hinustu-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/10.1177/14713012191997301

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., 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 in Britain. *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., & Gwondon, 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/lbuar/?xrid=bf63cc44-aea4-4f6b-a7b6-bb6042e61fe6

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

Vrijsen, J., Matulessij, 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