



Public Knowledge and Understanding of Alzheimer's Disease in Iceland

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Foreword

Submitted in partial fulfillment of the requirements of the BSc Psychology degree, Reykjavik University, this thesis is presented in the style of an article for submission to a peer-reviewed journal.

Abstract – English

Public knowledge of Alzheimer's Disease (AD) is vital. With research and increased awareness of AD it is effectively possible to reduce the discomfort of patients and their families and improve services to patients within the health care system. The aim of this study was assess general public knowledge in Iceland about AD and to examine factors that affect this knowledge. The sample was 1,002 Icelanders from 18-80 years old. General knowledge levels of AD were assessed via the Alzheimer's Disease Knowledge Scale (ADKS). Results of the study revealed that: 1) females scored higher on the ADKS than males 2) having had information on AD had a stronger impact on knowledge of AD than having had a personal experience of knowing someone who has/had AD; and 3) persons with a university degree did better on the ADKS than those who had secondary education or less.

Keywords: Alzheimer's disease, public awareness, education, experience

Abstract – Icelandic

Þekking á Alzheimer sjúkdómnum er mikilvæg. Með rannsóknum og aukinni vitund á Alzheimer er á árangursríkan hátt hægt að draga úr vanlíðan sjúklinga og aðstandenda ásamt því að bæta þjónustu við sjúklinga innan heilbrigðiskerfisins. Markmið þessarar rannsóknar var að meta almenna þekkingu Íslendinga á Alzheimer sjúkdómnum og að skoða þá þætti sem hafa áhrif á þekkinguna. Þýðið samanstóð af 1002 Íslendingum á aldrinum 18-80 ára. Þekking almennings var metin með Alzheimer's Disease Knowledge Scale (ADKS). Niðurstöður rannsóknarinnar leiddu í ljós að: 1) konur skorðu hærra á ADKS heldur en karlar 2) það að hafa fengið fræðslu um Alzheimer hafði meiri áhrif á þekkingu á sjúkdómnum heldur en að hafa persónulega þekkt einhvern sem er eða var með Alzheimer; og 3) einstaklingar með háskólagráðu gekk betur á ADKS en þeir sem voru með framhaldsskóla menntun eða minna.

Lykilorð: Alzheimer sjúkdómur, almenn þekking, menntun, reynsla

Public Knowledge and Understanding of Alzheimer's Disease in Iceland

Dementia is a progressive illness of the brain that affects cognition, and/or behavior to such an extent that daily function is impaired (Lipton & Marshall, 2013). It is a public health concern that is growing in both developed and developing countries (Fratiglioni, De Ronchi, & Agüero-Torres, 1999; Smith, Ali, & Quach, 2014). In 2013 Prince et al estimated that, globally, 35.6 million people were living with dementia, expecting numbers to double every 20 years to 65.7 million in 2030 and 115.4 million in 2050 (Prince et al., 2013). Dementia is an umbrella term covering many disorders that have different causes including Alzheimer's disease (AD), front temporal dementia, vascular dementia and many others (Blazer, 2013).

AD is the most common type of dementia and is thought to make up about 75% of all cases (Qiu, Kivipelto, & von Strauss, 2009). AD is a progressive disease where nerve cells in the brain deteriorate gradually, they then die one-by-one causing symptoms that gradually worsen over time. The most common early symptom of AD is difficulty in remembering newly learned information (Förstl & Kurz, 1999). Other common symptoms are forgetting appointments, difficulties with completing sentences or finding the right words to say and repeating questions or stories regularly. Other symptoms such as depression are not infrequent. People usually manage to live and support themselves, however, in the early stages of the disease. Persons afflicted with AD may get lost in familiar environments, can become confused about time and events and sometimes have unfounded suspicion about professional caregivers, friends and family. As the disease advances in the brain it leads to increasingly severe symptoms including disorientation, mood swings, behavior, and personality changes. In some cases, people develop

hallucinations at which point full supervision by caregivers is needed (Förstl & Kurz, 1999).

Like other progressive degenerative disorders AD is incurable, but there are treatments available which slow down the progression of the disease (De la Torre, 2010). Due to the non-existence of any permanent interventions for the disease, and due to growing awareness with respect to the incremental progression of its symptoms over time, clinical focus has shifted towards recognizing and detecting preventive measures against AD (Murray et al., 2012; Spector, Orrell, Schepers, & Shanahan, 2012). It has been shown that successful implementation of preventive measures that would delay symptom onset for up to one year could dramatically decrease the prevalence of AD over the decades to come (Murray et al., 2012).

Considering the increased prevalence of AD globally and the burden it places on patients and their families as well as health care systems, strategies that aim at population risk reduction and preventive measures have been gathering interest (Smith et al., 2014). The challenge in this respect is to raise public awareness of the disease and its causes and to refute the popular belief that symptoms of dementia are just an unavoidable part of aging (Smith et al., 2014).

Studies have shown that physical inactivity and other lifestyle factors account for the major proportion of AD cases in the USA and have been identified as a major cause for AD worldwide (Barnes & Yaffe, 2011). Since the lack of physical activity is linked to major AD risk factors, such as depression, midlife hypertension, midlife obesity and diabetes, policies which promote a healthy lifestyle such as exercise may have a considerable impact on AD population risk and prevalence over time. Further, initiatives

that increase public awareness of AD risk factors and causes, are likely to lower population risk as well (Barnes & Yaffe, 2011).

Different levels of knowledge of AD among patients, relatives of patients and/or caregivers has been shown to impact outcomes in the treatment of the disease (Low & Anstey, 2009; Millard, Kennedy, & Baune, 2011). Greater knowledge of AD is predicted by higher levels of education (Jang, Kim, & Chiriboga, 2010). Those with higher levels of education generally have better knowledge of AD, which can result in earlier detection of the disease. In the case of little or no general insight into AD, a late diagnosis of the disorder is more likely, with relatives, health professionals or patients themselves not equipped to seek advice or recognize symptoms in a timely manner (Low & Anstey, 2009; Millard et al., 2011). It has been shown that symptoms will normally go undetected for a shorter amount of time, the higher the general and specialized knowledge of AD is in the affected patient and in his surroundings. Opportunities and preferences with respect to treatment tend to be higher as well (Spector et al., 2012; Sullivan & O'Connor, 2001).

On the contrary, where patients are being treated for AD within a context of poor general AD knowledge they are often affected by a delayed diagnosis which aggravates their symptoms further through belated treatment (Bailey, 2000). Follow-up and treatment can also worsen outcomes for the patients by the underutilization of the best available options with respect to treatment and support. Caregivers, both professional and relatives of the patient, who are uninformed about AD, are more likely to misinterpret patient behaviors and come under stress due to failure to provide appropriate care, resulting in inadequate treatment (Smyth et al., 2013).

The Harvard School of Public Health conducted a survey in association with

Alzheimer Europe in four European countries (Spain, Germany, France and Poland) and in the US (Alzheimer Europe, 2011). The purpose of the study was to identify in what way the public perceived AD, what level of understanding it had of the disease and their expectations with respect to diagnosis and treatment. It showed that recognition of AD symptoms was considerable but a minority of respondents were aware that the disease could lead to fatality. Most people in the concerned countries had known or knew someone afflicted with AD, which probably explains the general awareness of usual symptoms. Results in general pointed to a high degree of awareness of AD, which was attributed to the achievements of coordinated awareness campaigns (Alzheimer Europe, 2011).

Þórhallsson and Línadóttir (2013) studied public awareness of AD in Iceland by using the Alzheimer's disease knowledge scale (ADKS) as a unit of measure. The results showed that participants answered an average of 20 questions correctly out of 30, or 67%. They also looked at AD awareness at different levels of education and the results showed that participants with university degrees scored higher on the ADKS than those with secondary education or lower. They observed a significant difference in gender on the ADKS, with respondents identifying as female generally scoring higher than those identifying as male (Þórhallsson & Línadóttir, 2013).

Carpenter et al (2009) questioned people on the ADKS who had been in support groups for dementia, people who had received training or attended courses on dementia, people who had worked with dementia patients and people who had tended to patients with dementia on a voluntary basis. The questionnaire was also given to a control group consisting of people who did not have experience with any of the above. Results showed

that general knowledge was better if people had been in support groups, received training or had worked with patients with dementia, irrespective of whether it was paid or on a voluntary basis (Carpenter et al., 2009). In a similar study in 2011 results revealed that respondents were mostly aware about assessment, treatment, and management of AD and knew less about risk factors and prevention (Carpenter, Zoller, Balsis, Otilingam, & Gatz, 2011).

Hudson et al (2012) used the ADKS to examine public awareness of Alzheimer's disease in the UK. A discrepancy was found between knowledge of AD progression, knowledge of the risk factors of AD and knowledge of the symptoms that resemble symptoms of AD and other diseases. About 75% did not recognize, however, that high cholesterol could increase the risk of AD (Hudson et al., 2012).

The aim of this study was to assess general public knowledge in Iceland about AD and to examine factors that affect this knowledge. The study is put forward with the prospect that it may lead to further research on knowledge of AD in Iceland and to present the public with information on the dissemination of awareness about the disease and its effects. The results of the study will be analyzed from the perspective of age, gender and education levels of respondents in a survey on general knowledge of AD. The first hypothesis put forward is that women have better general knowledge of AD than men in Iceland. Whereas knowing someone with AD and to have received information or training on AD are common factors that lead to increased knowledge of AD, it raises the question whether they affect awareness equally? Can it be that education on AD leads to better AD knowledge? The second hypothesis is thus that having had information or training on AD has a stronger impact on knowledge of AD than the personal experience

of knowing someone who has/has had AD. The third hypothesis that will be tested is that people with a higher level of education will do better on the ADKS than those who have secondary education or less.

Method

Participants

This study was conducted on a convenience sample. Participants were collected through public sharing on Facebook using the free survey website www.surveymonkey.com. In total there were 1,002 Icelandic respondents, 746 of these identified as female, 249 identified as male and 7 did not disclose their gender. The age of the respondents ranged from 18 to 80 years, divided into 5 age groups (see Table 1) and further divided into two groups depending on the level of education they had completed, whether they had a university degree (65.8%) or secondary education or lower (35.2%). An information sheet about the study along with contact information was posted on Facebook before participants responded to the questionnaire. Therein, participants' right to withdraw their consent at any time was emphasized. Participants were volunteers and no incentives were offered for participation in the study.

Table 1

Frequency and Percentage of People in each Age Group

Age	Frequency (Male/Female)	%
18-25	255 (139/116)	25.6
26-35	156 (29/127)	15.6
36-45	143 (12/131)	14.3
46-55	203 (32/171)	20.4
56 and older	240 (40/200)	24.1

Instruments and measures

The survey was presented using the title "What do you know about Alzheimer's

disease”? The questionnaire consisted of 50 questions that were divided into two main parts. The first 20 questions concerned demographic information, which was assessed with questions considering basic information (i.e. gender, age, educational level). In addition to the background variables, in this part, participants were asked to answer selected questions from a questionnaire that the Harvard School of Public Health and Alzheimer Europe put before respondents in five other countries (Alzheimer Europe, 2011). Those questions related to whether they had received special education on AD and if they knew someone / had known someone with AD. There were also questions in this part concerning whether participants were concerned about developing the disease, whether they were aware of AD risk factors and if they thought that anything could be done to reduce the risk of developing dementia and if so, what would that be? (see Appendix A). Although these latter type questions in themselves are relevant, they constituted a deviation from the studies stated scope and purpose and were not used to any extent in the analysis of the results. Questions in this first part were either multiple choice or in the form where participants were asked to indicate the extent of their agreement to each statement with a ‘yes, no or I don’t know’ answer. Examples of items are: ‘Do you know anyone currently who has Alzheimer’s disease?’ (see Appendix A).

The second part of the questionnaire, consisting of 30 questions, was made up of the set of standardized questions that constitute the Alzheimer’s Disease Knowledge Scale (ADKS) (see Appendix B). General knowledge levels of AD are assessed via the ADKS by looking at responses to 30 true or false statements pertaining to risk factors, assessment and diagnosis, symptoms, course, life impact, caregiving and treatment and management of AD. The ADKS is designed for use in both an applied and academic

context, capable of assessing knowledge about AD among lay people, patients, caregivers and professionals. The ADKS has adequate reliability (test-retest correlation = .81 and internal consistency reliability = .71) and validity (content, predictive = .50, concurrent and convergent = .65) (Carpenter et al., 2009). The scale was translated into Icelandic by Brynhildur Jónsdóttir and María K. Jónsdóttir with permission from the authors.

Since each of the 30 questions on the ADKS scale are considered to have a correct answer, the respondent's AD knowledge levels are assessed by identifying the proportion of correct answers. The higher the proportion of correctly answered questions is across the sample, the higher the AD knowledge level can be assumed to be. In this study reference will be made to the average amount of correctly answered questions across the sample with the term "score".

Procedure

The survey was made available on Facebook from March 13th - March 15th 2016. It was published by the researcher. Complete anonymity was ensured by the researchers and no information could be traced back to particular individuals.

Data Analysis

Knowledge of AD, which is measured by average scores on the ADKS, was compared across gender, age, educational level with factorial ANOVA. In addition, the impact of personal experience on AD knowledge was assessed by looking at whether respondents knew or had known someone with AD and in addition, whether the respondents had received any information or training on AD. These variables were regressed on the ADKS scores across the sample in order to find their respective impacts. Averages, distributions and standard deviations were calculated where relevant.

Results

Table 2 below shows the percentages of correct responses per item of the ADKS. Possible range was from 0 to 30, the minimum value obtained was 1, the maximum was 29 and the mean value was 21.17 (SD = 4.37). Cronbach's alpha was used to calculate the internal consistency reliability of the scale, $\alpha = 0.558$.

The category 'symptoms' received the highest mean percentage of correct responses (82.4%) followed by 'treatment and management' (80.2%), 'course' of AD (76.6%), 'assessment and diagnosis' (74.7%), 'caregiving' (70.6%). Significantly less is known about associated 'risk factors' (61.5%) and 'life-impact' (55.0%). Of the 30 questions, there were three questions where a minority of participants, or between 24 and 40 percent, failed to give a correct answer. These questions referred to high blood pressure (item 18) and high cholesterol (item 26) as potential risk factors for developing AD as well as to caregiving for Alzheimer's patients (item 6). Two questions were answered correctly by a large majority of the respondents, between 98 and 96 percent. The questions, stating that AD is one type of dementia (item 21) and that AD cannot be cured (item 29), thus had the highest percentage of correct answers given by respondents in the sample.

Table 2

ADKS Items: Including the Correct Answers, Question Domains, Percentage of Correct Responses and Lower and Upper Bound. LI = Life-Impact, RF = Risk Factors, CO = Course, C = Care-Giving, TM = Treatment and Management, SY = Symptoms, AD = Assessment and Diagnosis

Item	Correct	Domain	% Correct	Lower bound	Upper bound
21. Alzheimer's disease is one type of dementia	T	AD	98.3%	97.4%	99.2%
4. When a person with Alzheimer's disease becomes agitated, a medical examination might reveal other health problems that caused the agitation	T	AD	81.5%	78.9%	84.1%
10. If trouble with memory and confused thinking appears suddenly, it is likely due to Alzheimer's disease	F	AD	66.7%	63.5%	69.8%
20. Symptoms of severe depression can be mistaken for symptoms of Alzheimer's disease	T	AD	61.4%	58.2%	64.7%
5. People with Alzheimer's disease become agitated, a medical examination might reveal other health problems that caused the agitation	T	C	93.7%	92.0%	95.3%
6. When people with Alzheimer's disease begin to have difficulty taking care of themselves, caregivers should take over right away	F	C	40.7%	37.4%	44.0%
7. If a person with Alzheimer's disease becomes alert and agitated at night, a good strategy is to try to make sure that the person gets plenty of physical activity during the day	T	C	85.1%	82.7%	87.5%
15. When people with Alzheimer's disease repeat the same question or story several times, it is helpful to remind them that they are repeating themselves	F	C	84.7%	82.2%	87.1%
16. Once people have Alzheimer's disease, they are no longer capable of making informed decisions about their own care	F	C	56.8%	53.5%	60.2%
3. After symptoms of Alzheimer's disease appear, the average life expectancy is 6 to 12 years	T	CO	62.5%	59.2%	65.7%
8. In rare cases, people have recovered from Alzheimer's disease	F	CO	90.8%	88.9%	92.7%
14. A person with Alzheimer's disease becomes increasingly likely to fall down as the disease gets worse	T	CO	72.4%	69.3%	75.4%
17. Eventually, a person with Alzheimer's disease will need 24 hour supervision	T	CO	91.5%	89.6%	93.4%
1. People with Alzheimer's disease are particularly prone to depression	T	LI	79.4%	76.7%	82.1%

11. Most people with Alzheimer's disease live in nursing homes	F	LI	76.7%	73.8%	79.6%
28. It is safe for people with Alzheimer's disease to drive, as long as they have a companion in the car at all times	F	LI	90.9%	88.9%	92.8%
2. It has been scientifically proven that mental exercise can prevent a person from getting Alzheimer's disease	F	RF	55.6%	52.2%	58.9%
13. People in their 30s can have Alzheimer's disease	T	RF	87.5%	85.3%	89.3%
18. Having high cholesterol may increase a person's risk of developing Alzheimer's disease	T	RF	24.4%	21.5%	27.4%
25. Prescription drugs that prevent Alzheimer's disease are available	F	RF	93.7%	92.0%	95.3%
26. Having high blood pressure may increase person's risk of developing Alzheimer's disease	T	RF	31.6%	28.4%	34.8%
27. Genes can only partially account for the development of Alzheimer's disease	T	RF	92.9%	91.2%	94.7%
19. Tremor or shaking of the hands or arms is a common symptom in people with Alzheimer's disease	F	SY	79.1%	76.3%	81.9%
22. Trouble handling money or paying bills is a common early symptom of Alzheimer's disease	T	SY	81.2%	78.5%	83.8%
23. One symptom that can occur with Alzheimer's disease is believing that other people are stealing one's things	T	SY	83.4%	80.9%	86.0%
30. Most people with Alzheimer's disease remember recent events better than things that happened in the past	F	SY	90.5%	88.5%	92.5%
9. People whose Alzheimer's disease is not yet severe can benefit from psychotherapy for depression and anxiety	T	TM	87.0%	84.7%	89.3%
12. Poor nutrition can make the symptoms of Alzheimer's disease worse	T	TM	79.1%	76.4%	81.9%
24. When a person has Alzheimer's disease, using reminder notes is a crutch that can contribute to decline	F	TM	70.0%	66.8%	73.2%
29. Alzheimer's disease cannot be cured	T	TM	96.5%	95.2%	97.7%

Note: The bold values are the questions with the highest and lowest percentage

Table 3 below illustrates that with respect to gender, those respondents that identified with being female scored higher on the ADKS than those who identified with being male. It also shows the impact of education levels on the correct answers average, according to the ADKS. Individuals with a university degree scored higher on the ADKS in general, thus indicating higher general AD knowledge, than those who did not have a university degree (secondary education). A Bonferroni post hoc test revealed that the

youngest age group, 18-25 years, scored lower on average than those in the 46-55 years age bracket ($p = .004$) and those who are 56 and older ($p = .003$). Furthermore, those who were 36-45 years of age scored lower on general knowledge than those who were 46-55 years ($p = .012$) and 56 years and older ($p = .014$)

Table 3

The Mean, Standard deviation and Minimum and Maximum of ADKS Scores with respect to Age, Education Level and Gender

		Mean	Standard Deviation	Minimum	Maximum
Gender	Female	22.5	4.01	2	30
	Male	19.99	5.28	1	29
Age	18-25	19.9	5.34	1	27
	26-35	22.43	4.47	2	30
	36-45	22.67	4.98	5	30
	46-55	22.51	3.89	6	30
	56 +	22.39	3.14	3	29
Education	Secondary education and less	20.46	4.58	1	28
	University degree	22.69	4.15	2	30

Table 4 shows the impact of age, gender and education level on the ADKS score across the sample. There were significant differences between the three demographic groups with age being the most significant determinant on the level of general knowledge about AD in the sample.

Table 4

Impact of Age, Gender and Education Level on the ADKS Score

Source	Type III Sum of Squares	<i>df</i>	Mean Square	<i>F</i>	Sig.	Partial Eta Squared
Corrected Model	2367.072a	19	124.583	7.378	.000	.144
Intercept	129373.018	1	129373.018	766.429	.000	.902
Age	418.585	4	104.646	6.197	.000	.290
Education	358.433	1	358.433	21.226	.000	.025
Gender	306.329	1	306.320	18.141	.000	.021
Age*Education	113.077	4	28.269	1.674	.154	.008
Age*Gender	110.422	4	27.606	1.635	.163	.008
Education*Gender	7.07	1	7.807	0.462	.497	.001
Age*Education*Gender	75.566	4	18.892	1.119	.346	.005
Error	14116.928	836	16.886			
Total	430788	856				
Corrected Total	16484	855				

Making further inferences on the results highlights that there is an association between having received education about AD and to have known someone with AD on the ADKS score. Looking at the two variables together shows that they explain 7.7% of the variance of the ADKS score with $F(2,853) = 35,776$, ($p < .001$). However, it turns out that having had information about AD has a stronger impact on the ADKS score compared to have had the experience of knowing someone who has/had AD. Table 5 shows the results from a multivariate linear regression analysis made to identify the impact of the two variables on the average ADKS score. It shows that having received information or training on AD alone will on average have a higher impact on the average ADKS score of a respondent than if he/she has known someone with AD.

Table 5

AD Experience and AD Education and impact on ADKS Average Score

	Male/Female %	Coefficients	<i>t</i>	Sig.
		Beta		
Constant		20.683	63.734	<.001
Experience w. AD	64.3/80.9	0.63	1.764	.078
Received AD information/ training	16.1/33.8	2.576	8.109	.000

Discussion

The aim of this study was to assess general public knowledge in Iceland about AD and to examine factors that affect this knowledge. The results of the study supported the primary hypothesis revealing significant gender differences when measuring the ADKS score, showing that females scored higher on the ADKS than males. These findings are consistent with a previous study on public awareness of AD in Iceland (Þórhallsson & Línadóttir, 2013).

From the results it is also clear that having had information on AD had a stronger impact on knowledge of AD than having had the personal experience of knowing someone who has/had AD. These findings confirm the second hypothesis where having had information on AD had a stronger impact on knowledge of AD. These findings are also consistent with previous studies that have shown that dissemination of information and training on AD plays a major role in the awareness level of AD, something which can benefit both patients and caregivers in managing the progression and the prevalence of the disease (Barnes & Yaffe, 2011; Carpenter et al., 2009; Low &

Anstey, 2009; Millard et al., 2011; Smith et al., 2014; Spector et al., 2012; Sullivan & O'Connor, 2001).

The lower impact on awareness associated with the variables concerned with personal experience could be explained with the existence of an information bias. The general awareness of usual symptoms gained from knowing someone afflicted with AD may only be specific to that patients or patients, but the disease manifests itself in many different forms. It may therefore be expected that receiving information or training on AD is probably more reliable and valuable in general terms and would contribute to a broader awareness of the disease.

Looking at the third and last hypothesis presented in this study; that persons with a higher level of education will do better on the ADKS than those who have a secondary education or less, the results indicate that it holds true. This outcome is in line with a previous study in Iceland on public knowledge about AD, where results showed the same outcome, that participants with a university degree scored higher on ADKS than those with secondary education or lower (Þórhallsson & Línadóttir, 2013). They are also in line with a previous study showing that greater knowledge of AD is predicted by higher levels of education (Jang, Kim, & Chiriboga, 2010).

Regarding the general ADKS score, participants in this study answered an average of 21.17 questions correctly out of 30. That is a higher average (by one question) than the results of previous study on the topic in Iceland (Þórhallsson & Línadóttir, 2013).

Looking instead at the questions respondents did not answer correctly, about 76% did not know that high cholesterol could increase the risk of AD. That is almost entirely in accordance with the results of the study, Hudson et al (2012), on the ADKS.

When respondent's scores in different domains of the ADKS are examined, it shows that the category 'symptoms' received the highest mean percentage of correct responses in the sample. That is not in line with Carpenter et al (2011) where respondents scored the highest on the domain related to assessment, treatment, and management of AD. The results of this study also show that respondents knew less on average about 'risk factors' and 'life-impact', which on the other hand is consistent with Carpenter et al (2011).

These are interesting and no less important results. If knowledge of risk factors and impact on daily life is bad it may well be that people ignore these aspects in relation to themselves or others close to them when confronted with the possibility of AD. Building further on this assumption one could suggest ways to improve training material concerned with these facets of the disease.

Overall knowledge of AD, according to the ADKS, in this sample is good. Having received training or information on AD seems to be of great importance in the opinion of the authors of previous studies and it is important that it is increased in Iceland.

The study presented here is not without its limitations. Since women received higher scores on the ADKS than men on average, it was also tested whether women, in general, had received information about the disease to a higher degree. This turned out to be true for the sample with 33.8% of the women but only 16.1% of the men having received AD information. There are things that could have been done better with the implementation of this study. Women were overrepresented in the sample and it could be beneficial for the validity of the results to repeat the study using methods to ensure a more even gender balance. The sample is also disproportionately high in respondents with

university degrees or in the process of obtaining them. Although a more even distribution in educational levels would not be expected to produce different results, it would likely affect their robustness. Further, the study was conducted on a convenience sample and conversely, it would be interesting to carry out a similar study on a randomized sample to more reliably reflect public knowledge in the country.

Although AD is incurable, early diagnosis is nonetheless important. Those who end up taking patients to be diagnosed are in many cases family members. Patients themselves rarely seek diagnosis due to lack of insight and perspective of their own situation. That is why public knowledge of AD is vital. It is essential that people reconsider traditional reactions to memory loss and other AD symptoms as just a normal part of the aging process. In this respect, health authorities must create initiatives for enhancing and linking discussions between those who are diagnosing and treating patients and the general public. With research and increased awareness of AD it is effectively possible to reduce the discomfort of patients and their families and improve services to patients within the health care system. Increased AD awareness could thus work for the benefit of patients, families and health care professionals and ensure that patients get early diagnosis, appropriate care and good quality of life.

It would be interesting to follow up initiatives aimed at increasing public knowledge of AD in Iceland and investigate the same parameters presented in this study again after that. Possibly, it would also be beneficial to examine public knowledge in Iceland of other diseases, in comparison to the knowledge of the public of Alzheimer's disease, to determine if public knowledge of Alzheimer's disease is consistent with a general knowledge of other diseases.

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*Appendix A**HLUTI I: Fjölvalsspurningar***Hvað veist þú um Alzheimer sjúkdóminn?**

Kæri viðtakandi

Eftirfarandi könnun er liður í rannsókn á þekkingu almennings á Alzheimer sjúkdómnum, áhættuþáttum og áhrifum heilbrigðs lífsstíls á sjúkdómnum. Ætla má að það taki um 5-10 mínútur að svara könnuninni. Ég bið þig um að svara spurningunum eftir bestu getu en þér ber þó hvorki skylda til að svara einstökum spurningum eða listanum í heild. Þér er frjálst að hætta hvenær sem þú vilt. Þátttaka þín er nafnlaus og því ekki hægt að rekja svör til einstaka þátttakenda.

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1) Hvert er kyn þitt?

Kk

Kvk

Annað

2) Hver er aldur þinn?

18-25

26-35

36-45

46-55

56 eða eldri

3) Hver er menntun þín? (Ath.: merkið við núverandi nám, þó að háskólanámi sé ekki lokið skal merkja við það)

Grunnskólapróf

Stúdentspróf/önnur formleg menntun eftir grunnskóla

Háskólapróf

- 4) Hér er listi af sjúkdómum. Ef það á við, merktu við þann sem þú ert hræddust/astur við að fá?
- Sykursýki
 - Heilablóðfall
 - Hjartasjúkdómur
 - Alzheimer sjúkdómur
 - Krabbamein
 - Þunglyndi
 - Flensa
 - Engan af eftirtöldum
 - Veit það ekki
- 5) Hefur þú fengið sérstaka fræðslu um Alzheimer sjúkdóm (t.d. í skóla eða í tengslum við vinnu)
- Já
 - Nei
- 6) Hefur þú þekkt einhvern sem hefur verið með Alzheimer sjúkdóm?
- Já
 - Nei
 - Veit það ekki
- 7) Þekkir þú einhvern sem er með Alzheimer sjúkdóm í dag?
- Já
 - Nei
 - Veit það ekki
- 8) (Ef þú svaraðir já við spurningu 6 eða 7) Er/var sá einstaklingur/ar fjölskyldumeðlimur/ir?
- Já
 - Nei
 - Veit það ekki

9) Hversu miklar áhyggjur hefur þú af því að þú fái Alzheimer sjúkdóm?

Mjög miklar áhyggjur

Talsverðar áhyggjur

Litla áhyggjur

Engar áhyggjur

Veit það ekki

10) Hversu miklar áhyggjur hefur þú af því að einhver í fjölskyldunni þinni fái

Alzheimer sjúkdóm?

Mjög miklar áhyggjur

Talsverðar áhyggjur

Litla áhyggjur

Engar áhyggjur

Veit það ekki

11) Samkvæmt því sem þú veist best, hvað af eftirfarandi telur þú vera algeng einkenni eða merki um Alzheimer sjúkdóm?

	Já	Nei	Veit það ekki
a) Erfiðleikar við að muna hluti úr lífi sínu frá deginum áður			
b) Erfiðleikar við að muna hluti úr lífi sínu frá árum áður			
c) Rugl og óáttun			
d) Ráf og að villast			
e) Erfiðleikar við dagleg verkefni			
f) Reiði og ofbeldi			
g) Ofskynjanir eða að heyra raddir			
h) Verkjavandamál			
i) Erfiðleikar við að fást við og borga reikninga			
j) Lystarleysi			

- 12) Telur þú að Alzheimer sjúkdómurinn sé banvænn sjúkdómur?
Já
Nei
Veit það ekki
- 13) Er til, samkvæmt því sem þú veist best, áhrifarík lækni- eða lyfjameðferð til að hægja á framvindu Alzheimer sjúkdómsins og draga úr einkennum sjúkdómsins?
Já
Nei
Veit það ekki
- 14) (Ef þú telur ekki að meðferðin sé til í dag) Telur þú að það verði til áhrifarík lækni- eða lyfjameðferð fyrir Alzheimer sjúkdóm á næstu fimm árum?
Já
Nei
Veit það ekki
- 15) Telur þú að til sé áreiðanlegt próf sem getur greint hvort að einstaklingur sem þjáist af einhverju rugli og minnistapi sé á byrjunarstigi Alzheimer sjúkdóms?
Já
Nei
Veit það ekki
- 16) Telur þú að það sé hægt að gera eitthvað til að minnka líkurnar á að greinast með heilabilun (þar með talið Alzheimer sjúkdóm)
Já
Nei
Veit það ekki
- 17) Ef þú svaraðir já við spurning 16, hvað telur þú að einstaklingur geti gert til þess að minnka líkurnar á því að þróa með sér heilabilun? (Skrifaðu allt sem þér dettur í hug)

18) Hvert af eftirtöldum atriðum telur þú að geti aukið eða minnkað líkur á að þú fái heilabilun eða hefur engin áhrif á líkur?

	Aukið líkur	Minnkað líkur	Engin áhrif á líkur
Andleg virkni			
Heilbriggt mataræði			
Líkamsrækt			
Félagsleg virkni og tengsl			
Minnkun eiturlyfja/áfengisneyslu			
Lækkun á háum blóðþrýstingi			
Lækkun á háu kólesteróli			

19) Hvern af eftirtölfum heilsuþáttum telur þú vera mikilvægastan fyrir fólk á þínum aldri eða eldra fólki að fá nýjustu upplýsingar um?

Hjartasjúkdómar

Krabbamein

Sykursýki

Hvernig á að sjá um lyf

Alvarleg sjón- og heyrnarskerðing

Heilahreysti

Nýrna eða lifrasjúkdómar

Astmi

20) Hvern af eftirtöldum heilsuþáttum telur þú vera næst mikilvægastan fyrir fólk á þínum aldri eða eldra fólki að fá nýjustu upplýsingar um?

Hjartasjúkdómar

Krabbamein

Sykursýki

Hvernig á að sjá um lyf

Alvarleg sjón- og heyrnarskerðing

Heilahreysti

Nýrna eða lifrasjúkdómar

Astmi

*Appendix B**HLUTI II: Satt/ósatt spurningar*

Þekking á Alzheimer sjúkdómnum

Hér að neðan eru nokkrar fullyrðingar um Alzheimer sjúkdóminn. Vinsamlegast lestu hverja fullyrðingu vandlega og hakaðu við það sem þú telur rétt eða rangt. Giskaðu á rétta svarið ef þú ert ekki viss. Það er mikilvægt að haka við svar fyrir hverja fullyrðingu, jafnvel þótt þú sért ekki fullkomlega viss með svarið.

	Satt	Ósatt
1. Fólki með Alzheimer sjúkdóm er sérstaklega hætt við þunglyndi		
2. Það er vísindalega sannað að hugarleikfimi getur komið í veg fyrir að einstaklingur fái Alzheimer sjúkdóm		
3. Eftir að einkenni Alzheimer sjúkdómsins koma í ljós eru meðal lífslíkur 6 til 12 ár		
4. Þegar einstaklingur með Alzheimer sjúkdóm verður órólegur gæti lækni-sskoðun leitt í ljós önnur heilsufarsvandamál sem ollu óróleikanum		
5. Fólki með Alzheimer sjúkdóm gengur best ef fyrirmæli eru einföld og gefin stig af stigi		
6. Þegar fólk með Alzheimer sjúkdóm fer að eiga í erfiðleikum með að annast um sig sjálf tættu umönnunaraðilar að taka strax yfir		
7. Ef einstaklingur með Alzheimer sjúkdóm verður meira vakandi og órólegur að kvöldlagi er gott ráð að reyna að tryggja að hann fái næga hreyfingu að deginum		
8. Í sjaldgæfum tilvikum hefur fólk læknað af Alzheimer sjúkdómi		
9. Fólk með Alzheimer sjúkdóm sem ekki er kominn á alvarlegt stig, getur haft gagn af sálfræðilegri meðferð við þunglyndi og kvíða		

10. Ef erfiðleikar með minni og ruglingslega hugsun koma skyndilega í ljós er líklegt að það sé vegna Alzheimer sjúkdóms		
11. Flestir þeirra sem hafa Alzheimer sjúkdóm búa á hjúkrunarheimilum		
12. Léleg næring getur gert einkenni Alzheimer sjúkdómsins verri		
13. Fólk á fertugsaldri getur fengið Alzheimer sjúkdóm		
14. Eftir því sem sjúkdómurinn versnar verður líklegra að einstaklingur með Alzheimer sjúkdóm detti		
15. Þegar fólk með Alzheimer sjúkdóm endurtekur sömu spurninguna eða söguna aftur og aftur er hjálplegt að minna á að það endurtaki sig		
16. Þegar fólk er komið með Alzheimer sjúkdóm er það ekki lengur fært um að taka upplýstar ákvarðanir um eigin umönnun		
17. Einstaklingur með Alzheimer sjúkdóm mun að lokum þurfa eftirlit allan sólarhringinn		
18. Hátt kólesteról getur aukið áhættu fólks á að þróa með sér Alzheimer sjúkdóm		
19. Skjálfti eða titringur í höndum eða handleggjum er algengt einkenni hjá fólki með Alzheimer sjúkdóm		
20. Hægt er að ruglast á einkennum alvarlegs þunglyndis og einkennum Alzheimer sjúkdóms		
21. Alzheimer sjúkdómur er ein tegund heilabilunar		
22. Erfiðleikar við að sýsla með peninga eða borga reikninga er algengt snemmkomið einkenni Alzheimer sjúkdómsins		
23. Eitt af þeim einkennum sem getur komið fram í Alzheimer sjúkdómnum er að halda að aðrir steli frá manni		

24. Hjá einstaklingi með Alzheimer sjúkdóm getur notkun minnismiða verið hjálpartæki sem stuðlar að hrörnun		
25. Til eru lyfseðilsskyld lyf sem koma í veg fyrir Alzheimer sjúkdóminn		
26. Hár blóðþrýstingur getur aukið áhættu fólks á að fá Alzheimer sjúkdóm		
27. Erfðir skýra þróun Alzheimer sjúkdómsins einungis að hlut		
28. Það er öruggt fyrir fólk með Alzheimers sjúkdóm að aka bíl, svo lengi sem það hefur alltaf fylgdarmann í bílnum		
29. Alzheimer sjúkdómurinn er ólæknandi		
30. Flest fólk með Alzheimer sjúkdóm man nýliðna atburði betur en atburði sem gerðust í fortíðinni		