

TALLINN UNIVERSITY OF TECHNOLOGY

School of Information Technologies

Department of Health Technologies

**IMPROVEMENT OPPORTUNITIES FOR
ALZHEIMER'S DISEASE SCREENING AND
DIAGNOSTICS IN ESTONIA: FAMILY
PHYSICIANS' PERCEPTIONS**

Master's Thesis

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Hereby I declare that this Master's Thesis is my original investigation and achievement submitted for the Master of Science degree of Tallinn University of Technology.

Current work has not been submitted for any other academic degree.

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**VÕIMALUSED ALZHEIMERI TÕVE
SKRIININGU JA DIAGNOSTIKA
PARANDAMISEKS EESTIS: PEREARSTIDE
ARUSAAMAD**

Magistritöö

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Tervishoiutehnoloogia

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ABSTRACT

The aim of the thesis was to find out Estonian family physicians' perceptions about Alzheimer's disease population screening, cognitive screening tools, and diagnostics according to the existing Estonian Dementia Treatment Guide.

A web-based questionnaire and semi-structured interviews were used for gathering the Estonian family physicians' perceptions. A web-based questionnaire was formed based on literature review and previous studies and sent out to 785 family physicians from which 124 (16%) answered. The interview guide was formed keeping in mind the recommendations from the Estonian Dementia Treatment Guide. Six physicians were included in the study with snowball sampling method from two Estonian counties.

The results of two studies show that family physicians value the importance of Alzheimer's disease detection as early as possible, but the majority of them does not support regular screening for people without clinical symptoms. Mini-Mental State Examination was the most used screening test, but several problems were reported, which makes the use of cognitive screening tools difficult in primary care. There are some family physicians supporting computer-based screening tools, creating a possibility for piloting new solutions. Family physicians themselves are not confident in Alzheimer's disease diagnosing, however, all patients with suspected disease might not get the referral for further investigations due to poor access to the specialists in different locations in Estonia.

Eight improvement opportunities for Alzheimer's disease screening and diagnostics are brought out in the thesis, among which are proper training for family physicians, checklist-based treatment guide for primary care usage and a special funded screening program.

The thesis is in English and contains 67 pages of text, two chapters, and three figures.

ANNOTATSIOON

VÕIMALUSED ALZHEIMERI TÕVE SKRIINGU JA DIAGNOSTIKA PARANDAMISEKS EESTIS: PEREARSTIDE ARUSAAMAD

Magistritöö eesmärk oli leida Eesti perearstide arusaamad Alzheimer'i tõve populatsiooniskriiningu, kognitiivsete skriiningtestide ning Eesti Dementsuse Ravijuhendist lähtuvate diagnostikasoovituste kohta.

Eesti perearstide arusaamade uurimiseks kasutati veebipõhist küsimustikku ning semi-struktureeritud intervjuusid. Veebipõhine küsimustik koostati kirjanduse analüüsi ja varasemate uuringute põhjal ning saadeti 785 perearstile, kellest vastasid 124 (16%) arsti. Intervjuu kava koostati tuginedes Eesti Dementsuse Ravijuhendi soovitustele. Lumepalli meetodil kaasati intervjuudesse kuus perearsti kahest Eesti maakonnast.

Uuringute tulemused näitavad, et Eesti perearstid peavad Alzheimer'i tõve võimalikult varajast avastamist tähtsaks, ent enamik neist ei toeta inimeste regulaarset skriinimist kliiniliste sümptomite puudumisel. Enim kasutatud skriiningtest on Mini-Mental Test, kuid välja toodi mitmeid probleeme, mis muudavad esmatasandi arstiabis kognitiivsete skriiningtestide kasutamise keeruliseks. Mõned perearstid toetavad arvutipõhiseid skriiningteste, luues sellega võimaluse uute lahenduste piloteerimiseks. Perearstid ei tunne end Alzheimer'i tõve diagnoosimisel kindlalt, kuid kõiki haiguse kahtlusega patsiente ei suunata edasistele uuringutele, kuna spetsialistide kättesaadavus erinevates Eesti piirkondades on kehv.

Antud magistritöös tuuakse välja kaheksa võimalust Alzheimer'i tõve skriiningu ja diagnostika parandamiseks, mille hulka kuuluvad koolituste korraldamine, checklistipõhise ravijuhendi koostamine esmatasandile ning spetsiaalse rahastatud skriiningprogrammi loomine.

Magistritöö on kirjutatud inglise keeles ning sisaldab teksti 67 leheküljel, kahte peatükki ja kolme joonist.

ABBREVIATIONS

ACE-R – Addenbrooke’s Cognitive Examination–Revised

AD – Alzheimer’s disease

AT – *Alzheimer’i tōbi*

CDT – Clock-Drawing Test

CT – computer tomography

EHR – Electronic Health Record

GP – general practitioner

ICD-10 – tenth revision of the International Statistical Classification of Diseases and Related Health Problems

MCI – Mild cognitive impairment

MMSE – Mini-Mental State Examination, *Mini-Mental Test*

MoCA – Montreal Cognitive Assessment

MRI – magnetic resonance imaging

NINCDS-ADRDA – National Institute of Neurological and Communicative Disorders and Stroke, and the Alzheimer’s Disease and Related Disorders Association

WHO – World Health Organisation

DEFINITIONS

AD – a slowly progressive neurodegenerative disease that causes different cognitive, functional and behavioural problems, and is mostly diagnosed in the eighth or ninth decade of life.

Diagnostics – the practice of diagnosis.

Early AD diagnosis – a diagnosis that is made already in the asymptomatic phase of the disease.

Early-onset AD – an uncommon form of AD that is diagnosed before the age of 65.

Mild cognitive impairment – a condition when the patient has cognitive decline, but not yet functional impairment.

Population screening – offering a screening test systematically to all individuals in the defined target group within a framework of agreed policy, protocols, quality management, monitoring, evaluation and review.

Screening – a preliminary procedure, for example, a test or examination, performed with the aim to find some characteristics of a disease, which requires further investigation.

Timely AD diagnosis – a diagnosis that is made at a time when individuals or their relatives become worried about the condition and are seeking help for the first time, or when the physicians have their first concerns about patients' cognition, behaviour or functioning.

Underdiagnose – to diagnose a disease or a condition less often than it is actually present.

TABLE OF CONTENTS

INTRODUCTION	12
1. LITERATURE REVIEW ON ALZHEIMER’S DISEASE SCREENING AND DIAGNOSTICS.....	14
1.1 Background of the disease.....	14
1.1.1 Etiology and cost	14
1.1.2 Pathological changes and clinical symptoms	15
1.1.3 Treatment and care	17
1.2 Screening and diagnostic recommendations.....	18
1.2.1 Population screening.....	18
1.2.2 Cognitive screening tools	19
1.2.2.1 Paper-based tools.....	19
1.2.2.2 Digitized tools.....	20
1.2.2.3 Self-administered tools	22
1.2.3 Diagnostic recommendations	23
1.2.4 Benefits and concerns of screening and diagnostics	25
1.3 Previous studies and methodology	27
2. STUDIES AMONG ESTONIAN FAMILY PHYSICIANS.....	30
2.1 Materials and methods.....	30
2.1.1 Development of the web-based questionnaire and the interview guide	30
2.1.2 Web-based study participants, procedures and data analyses	31

2.1.3 Interview participants, procedures and data analyses.....	32
2.2 Results	33
2.2.1 Web-based study.....	34
2.2.2 Interviews	38
2.3 Discussion.....	41
2.3.1 Population screening.....	42
2.3.2 Cognitive screening tools	43
2.3.2.1 Paper-based tools.....	43
2.3.2.2 Computer-based tools	44
2.3.3 Diagnostics according to the Guide.....	45
2.3.2.1 Patients' history	45
2.3.2.2 Blood samples, CT and MRI	46
2.3.4 Suggestions and further studies	47
2.3.5 List of improvement opportunities	48
2.3.6 Limitations.....	48
2.4 Conclusion.....	50
REFERENCES	52
APPENDIX 1. Web-based questionnaire in Estonian.....	58
APPENDIX 2. Web-based questionnaire in English.....	61
APPENDIX 3. Interview guide in English.....	64
APPENDIX 4. Interview guide in Estonian	66

LIST OF FIGURES

Figure 1. Distribution of practising counties of the respondents and counties on the full list of participants.	34
Figure 2. Answers to the question “How do you value the importance of regular screening for people aged 65+ to detect AD as early as possible?”	35
Figure 3. Answers to the question “What initiates most often the evaluation of the patient to detect AD?”	36

INTRODUCTION

Alzheimer's disease (hereinafter referred to as AD) is a slowly progressive neurodegenerative disease that causes different cognitive, functional and behavioural problems (Dubois et al., 2016). The most common first clinical symptom of AD is a problem with remembering new information (Alzheimer's Association, 2016). There is no treatment available for AD that would change the course of the disease, but the disease can be eased by symptomatic and supportive treatments (Hugo and Ganguli, 2014).

Population screening for dementia is mostly not recommended, but the newest health care priorities and research suggest that the benefits of routine AD screening outweigh its' potential harms and limitations (Borson et al., 2013; Martin et al., 2015).

There are multiple paper-based screening tools for detecting cognitive impairment, but family physicians have reported several problems which make the usage of these tools complicated (Laske et al., 2015; Stewart et al., 2014). Computer-based cognitive screening tools have multiple benefits when compared with existing paper-based cognitive screening tools. Some computer-based cognitive screening tools have shown comparable or better results in earlier detection of AD (Dougherty et al., 2010; Müller et al., 2017).

Even though the timely diagnosis is preferred in the case of AD, it is often diagnosed in the later stages of the disease, because the recognition of AD in earlier stages is difficult (Eichler et al., 2015). Also, dementia is underdiagnosed worldwide (World Health Organization, 2016).

Different guidelines suggest that the disease should be mostly managed by family physicians (Geldmacher and Kerwin, 2013). Previous studies concerning family physicians' perceptions about dementia screening and diagnostics have shown that family physicians value AD screening as early as possible, but report some limitations during the screening and diagnostic procedures (Bond et al., 2010; Stewart et al., 2014).

The initial interest about the topic derived from the authors' wish to add a self-administered cognitive screening tool to the Estonian dementia web page (www.dementsus.ee), which is created by the voluntarily formed Dementia Workgroup.

Before the addition to the web page, a number of questions were raised about the need and usefulness of the tool. For example, if people are filling the test and go to their family physicians with the test results, then what will happen next? In the process of finding answers to these questions, a brief literature research revealed many issues related to AD screening and diagnostics in primary care. Hence, gaining more knowledge about problems concerning AD screening and diagnostics in Estonia from the perspective of Estonian family physicians was inevitable.

Therefore, the aim of the thesis is to find out Estonian family physicians' perceptions about:

1. AD population screening;
2. Cognitive screening tools:
 - a. Paper-based tools;
 - b. Computer-based tools;
3. AD diagnostics according to the Estonian Dementia Treatment Guide:
 - a. Taking the patients' history;
 - b. Ordering blood samples, computer tomography (hereinafter referred to as CT) and magnetic resonance imaging (hereinafter referred to as MRI).

As a result of this thesis, a list of improvement opportunities is suggested for AD screening and diagnostics in Estonia.

The thesis is divided into two main chapters. The first chapter is a literature review and describes the main features concerning the AD screening and diagnostics.

The second chapter focuses on the methodology and results of the web-based study and the in-depth semi-structured interviews among Estonian family physicians, followed by a discussion and a list of improvement opportunities for AD screening and diagnostics in Estonia.

1. LITERATURE REVIEW ON ALZHEIMER'S DISEASE SCREENING AND DIAGNOSTICS

This chapter is based on a literature review. It focuses on the background of the disease, main recommendations for AD screening and diagnostics, and the usage of computer-based cognitive screening tools.

Also, as an introduction to the next chapter about the study among Estonian family physicians, previous similar studies carried out in different countries, and methodologies used among Estonian family physicians are described.

1.1 Background of the disease

AD is a slowly progressive neurodegenerative disease that causes different cognitive, functional and behavioural problems (Dubois *et al.*, 2016).

To create a better understanding of the complexity of AD screening and diagnostics, the etiology and cost, main pathological changes and clinical symptoms, as well as treatment and care of AD are described briefly in the following section.

1.1.1 Etiology and cost

60 to 80 percent of dementia cases are associated with AD, making it the most common cause of dementia. Around half of these cases are associated with AD only, other half of the cases have in addition pathologic changes related to other dementias. These cases are called mixed dementia (Alzheimer's Association, 2016).

AD is mostly diagnosed in later stages of life, in the eighth or ninth decade, but the early-onset AD might get diagnosed already before the age of 65 (Hugo and Ganguli, 2014; Mayo Clinic, 2017). The early-onset AD is an uncommon form of AD, which constitutes around 5% of the cases (Mayo Clinic, 2017). For diagnosing AD, the presence of dementia syndrome is essential. Dementia syndrome is diagnosed based on the tenth revision of the International Statistical Classification of Diseases and Related Health Problems (hereinafter referred to as ICD-10) criteria. The dementia syndrome diagnosis relies on the description of the symptoms and thorough patients' history that

is taken preferably from a close relative. Neuropsychological tests and evaluation of the capability to perform activities of daily living could be done for objective diagnosis. The stage of dementia is determined by descriptive evaluation (Linnamägi et al., 2006). The specified diagnosis of AD should be made based on the National Institute of Neurological and Communicative Disorders and Stroke, and the Alzheimer's Disease and Related Disorders Association (hereinafter referred to as NINCDS-ADRDA) AD diagnosing criteria. NINCDS-ADRDA criteria allow differentiation in between probable, possible and definite AD (Linnamägi et al., 2006; McKhann et al., 1984).

After the AD onset, average survival duration is around 10 years. The survival duration is influenced by the age of a person, the severity of cognitive problems, the occurrence of comorbid diseases, and other factors (Hugo and Ganguli, 2014). The prevalence of AD is high and continuously growing due to population ageing. The main risk factors for AD are age and genetics. Other risk factors include, for example, cardiovascular disease, inflammation and alterations in inflammatory markers, head injury, and depression (Hugo and Ganguli, 2014).

There were approximately 46.8 million people living with dementia in 2015. The estimated number of dementia cases by 2030 is 74.7 million. By 2050, the number of current dementia cases has tripled due to population growth and population ageing, rising up to 131.5 million (Alzheimer's Disease International, 2015). By the estimation of Alzheimer Europe, there were 21,721 people with dementia in Estonia in 2012, representing 1.62 percent of the Estonian population (Alzheimer Europe, 2013).

Dementia is a burden for both, the medical and the social sphere. In addition to direct medical and social expenses, around 40% of the dementia cost comes from informal care – the money that family members of the dementia patients are spending. The total estimated worldwide cost of dementia will reach 1 trillion US dollars by 2018 and 2 trillion by 2030 (Alzheimer's Disease International, 2015).

1.1.2 Pathological changes and clinical symptoms

The course of AD could be divided into asymptomatic and symptomatic phases. Duration of the asymptomatic phase is relatively long, varying from many years to decades, and despite the occurring pathophysiological changes, there is neither noticeable cognitive decline nor clinical symptoms. The asymptomatic phase is

followed by a progressive cognitive decline – the symptomatic phase (Dubois et al., 2016; Jack and Holzman, 2013). Symptoms advance in at different pace from mild to moderate and severe (Alzheimer’s Association, 2016).

There are several pathophysiological changes that might predict the development of AD before the occurrence of clinical symptoms and cognitive decline. One of the novel diagnostic tools proposed to detect and monitor neurodegenerative diseases is eye testing. Changes in retina and pupil reactions to light, as well as reduced visual performance, are associated with AD (Laske et al., 2015).

Searching certain biomarkers from biological fluids is another promising tool for early dementia detection in the future. So far, it is clear that molecular changes taking place in case of AD could appear already up to 20 years before the onset of clinical symptoms. Some blood-based biomarker dementia panels for AD detection have been developed and studied, but these are not yet ready for regular clinical use (Laske et al., 2015).

The most prominent pathophysiological changes take place in the brain. AD is characterized by a progressive loss of synapses and nerve cells, cholinergic deficits, and accumulation of plaques and neurofibrillary tangles (Hugo and Ganguli, 2014). It has been found that the changes in the brain may occur 10-15 years before the onset of clinical symptoms (Bateman et al., 2012).

Usually, the destruction and damaging of brain cells start in the brain regions that are responsible for forming new memories, therefore, the most common first clinical symptom of AD is a problem with remembering new information. As the disease progresses, brain cells from other areas get involved, causing a number of different symptoms (Alzheimer’s Association, 2016).

Besides memory problems that disrupt everyday life, AD causes challenges in problem planning and solving, and completing familiar tasks. People with AD have trouble with perception, understanding visual images and spatial relationships, and are confused with time and place. It might be difficult for them to find correct words when speaking and writing, and their judgment might be poor. People with AD tend to misplace things and have trouble with retracing their steps. Common problems are apathy, anxiety, agitation and depression, but other changes in mood and personality might also occur. This all

leads to a withdrawal from social life – work and other social activities (Alzheimer’s Association, 2016).

The more disease progresses, the more help is needed in activities of daily living, such as bathing, eating and dressing. In the later stages of the disease, people with AD fail to recognize their family members and lose the ability to communicate. Eventually, they become bed-bound and need 24-hour care, as the brain cells responsible for basic bodily functions, for example walking and swallowing, are also affected. It makes people more vulnerable to infections, and AD-related pneumonia is often a contributing factor to their death (Alzheimer’s Association, 2016).

1.1.3 Treatment and care

There is no treatment available for AD that would change the course of the disease, but the disease can be eased by symptomatic and supportive treatments (Hugo and Ganguli, 2014). There are some pharmacologic and non-pharmacologic therapies available that are often used in the AD care process (Alzheimer’s Association, 2016).

The AD pharmacologic treatment includes using drugs that can temporarily improve some symptoms of AD by influencing the amount of certain neurotransmitters in the brain (Alzheimer’s Association, 2016). Cholinesterase inhibitors (donepezil, rivastigmine, galantamine) and memantine are approved drugs for AD treatment (Wong, 2015). The goal of non-pharmacologic treatment is maintaining and improving cognitive function, as well as the ability to perform activities of daily living. Non-pharmacologic interventions are also used to reduce behavioural symptoms – depression, apathy, wandering, sleep problems, agitation and aggression. For instance, memory training is one of the examples of non-pharmacologic treatments (Alzheimer’s Association, 2016).

The need for assistance and care is growing in parallel with the deterioration of the disease (Alzheimer’s Association, 2016). While the main burden of care lies on the relatives of the people with dementia, attending day care that is specialized for dementia could improve the quality of life of the people with the disease (Rokstad et al., 2017).

In the later stages of the disease, people with AD get often admitted to care homes. Still, most people with AD prefer living in their own home as long as possible. Although

taking care of people with AD is burdensome, staying at home is also usually the preference of their relatives. Poor living circumstances, living alone and functional impairments increase the care home admission rates (Knapp et al., 2016).

1.2 Screening and diagnostic recommendations

This section focuses on current Estonian screening and diagnostic recommendations, including the background about population screening.

Moreover, paper-based and computer-based cognitive screening tools are introduced, and the main benefits and concerns of screening and diagnostics are explained in detail.

1.2.1 Population screening

In this thesis, the concept of screening is used as a preliminary procedure, for example, a test or examination, performed with the aim to find some characteristics of a disease, which requires further investigation (Mosby's Medical Dictionary, 2009). AD population screening means offering a screening test systematically to all individuals in the defined target group within a framework of agreed policy, protocols, quality management, monitoring, evaluation and review (Community Care and Population Health Principal Committee, 2016).

The World Health Organisation (hereinafter referred to as WHO) has published four main criteria for population screening. Based on these, the screened disease has to be an important health problem with high prevalence and easily recognizable in an early symptomatic stage; there has to be a safe and accepted diagnostic tool to detect the disease; there should be a treatment available; and the cost of the case finding should be balanced with the whole possible medical expenditure (Holland et al., 2006).

It is clear, that in the case of AD, many of these WHO criteria do not match with the current possibilities in AD care. For instance, although AD is an important health problem with high prevalence, it is difficult to recognize it in the early stages (Eichler et al., 2015; Geldmacher and Kerwin, 2013). On the other hand, there are several safe and accepted screening tools for AD and it has been found, that certain cognitive screening tools can help to detect the disease in early stages (Laske et al., 2015; Tong et al., 2016). Moreover, if an early access to medication is given to patients, it increases savings in

health care, social and informal care, but in spite of that, there is still no treatment to actually cure AD (Kumar et al., 2015; Tong et al., 2016). Therefore, population screening for dementia is mostly not recommended (Martin et al., 2015). Although, Borson et al. have concluded that newest health care priorities and research suggest that the benefits of routine AD screening outweigh its' potential harms and limitations (Borson et al., 2013).

The latest publicly available Estonian Dementia Treatment Guide (*Eesti Dementsuse Ravijuhend*) from 2006 is not supporting population screening for people without any complaints. The only exception is when the relatives of the patients are addressing their concerns about cognitive deficits.

1.2.2 Cognitive screening tools

There are many paper-based cognitive screening tools for dementia and AD, and it has been found, that cognitive impairment might not be recognized without a proper cognitive test (Eichler et al., 2015; Tsoi et al., 2015).

To get a glimpse of the future in AD screening, this section involves also a brief introduction to computer-based cognitive screening tools. The focus will be on finding the possible benefits in digitization of existing paper-based cognitive screening tools, and self-administered cognitive screening tools.

1.2.2.1 Paper-based tools

Mini-Mental State Examination (hereinafter referred to as MMSE) is the most widely used test for dementia screening (Tsoi et al., 2015). It was originally created in 1975 and since then, it has been slightly modified. MMSE is a 30-point questionnaire, which takes around 5-10 minutes to complete, and has to be administered by a specialist. It has tests of orientation in time and place, concentration, attention, verbal memory, naming and visuospatial skills (Alevares-Rodriguez et al., 2015; Folstein et al., 1975). The evidence suggests that MMSE is not an ideal tool for diagnosing dementia, but it could be successfully used as a first screening tool in dementia detection (Larner, 2016).

The second popular screening test, the Clock-Drawing Test (hereinafter referred to as CDT), is a widely used brief test for screening cognitive impairment that is frequently used by family physicians. Clock drawing requires many cognitive skills that are

typically impaired with AD – verbal and visuoconstructional skills, memory, spatial knowledge, abstract thinking, planning and concentration (Aprahamian et al., 2010; Shulman, 2000). CDT is an accurate screening tool to detect AD in an elderly population with heterogeneous backgrounds (Aprahamian et al., 2010).

There are several other cognitive tests besides MMSE and CDT with comparable results in cognitive impairment screening (Tsoi et al., 2015). For example, Montreal Cognitive Assessment (hereinafter referred to as MoCA) is used quite frequently. Tsai et al. have found that both, MoCA and MMSE can be used for fast and accurate cognitive impairment screening. It has been proved that in case of the Chinese population, MoCA is more efficient for screening Mild cognitive impairment (hereinafter referred to as MCI), a condition with cognitive decline and without yet functional impairment, than for dementia screening (Geldmacher and Kerwin, 2013; Tsai et al., 2016). MMSE is more efficient for dementia screening than for MCI screening (Tsai et al., 2016).

Based on Tsoi et al. literature research, the best alternatives for MMSE that give comparable results in dementia screening are Mini-Cog and Addenbrooke's Cognitive Examination–Revised (hereinafter referred to as ACE-R) test. The best substitution for MMSE in MCI screening is the MoCA (Tsoi et al., 2015). Both MoCA and ACE-R include also the CDT as one part of the complex test (Mioshi et al., 2006; Nasreddine et al., 2005).

1.2.2.2 Digitized tools

Digitization of existing paper-based cognitive screening tools is seen as a necessary, but not yet widely accepted shift from traditional interview-based cognitive examination to more modern ways of cognitive screening. Using the digitized screening tools that rely greatly on interviewing and complex analyses of the patients' cognitive skills, still require some participation by the clinician, either when carrying out the testing or evaluating the results. Although, it is believed that opposite to screening test grading done by humans, the grading done by computers is free from subjectivity and personal biases (Jurica et al., 2015).

There are numerous different paper-based cognitive screening tools, but they are not all applicable for digitization, as there might be some difficulties with the copyright issues, like in case of the MMSE (Newman, 2015; Tsoi et al., 2015). Hence, the CDT is looked

at more closely, as it is reported to be very common in AD screening besides MMSE (Arahamian et al., 2010; Shulman, 2000).

To perform the CDT, a handwriting task is required from the patient (Müller et al., 2017). Tasks that need pen input could be adapted to different kind of tablets. For example, there are tablets that allow digitization of handwriting done on paper, when a special ball pen, equipped with sensors, is used for writing or drawing. Other types of tablets are typical computers which are portable and do not require any extra equipment for digitization. Although tablets, which allow digitization of writings and drawings done on paper might be more precise in their recordings, other type of tablets are more reachable for consumers, allowing remote data collection from a larger amount of people (Jurica et al., 2015).

Handwriting digitization creates new possibilities for evaluating cognitive impairment. For instance, it is possible to measure precisely the time when the pen is in the air, the time when the pen is drawing lines, and the complete time of performing the task. Müller et al. made a study of people with early stage of AD, people with MCI and a healthy control group, by comparing their results in digitized CDT. They found that the time when the pen was in the air was longest in the group of people with early AD, and shortest in the group of healthy participants. Comparing the time-in-air allows discriminating people with MCI from healthy people with clinically relevant sensitivity and specificity. It means that even if the physician evaluates the traditional paper-based CDT to be “normal”, usage of digitized CDT could show already a cognitive decline (Müller et al., 2017). On the other hand, in the area of mental health evaluation, automated analyses of pen input is quite new and untested (Jurica et al., 2015).

Quest Diagnostics has also launched a digitized CDT as part of their digitized cognitive assessment tool CogniSense. The tool is an iPad application meant for detecting early signs of dementia or AD. Completing the test takes around 15 minutes and the application allows integration with most of the Electronic Health Records (hereinafter referred to as EHR) (Quest Diagnostics, 2017).

The integration of computer-based cognitive screening tools with EHRs brings along a range of potential benefits that could be achieved through the secondary use of data. Computerized screening tools promise to collect and store data in large quantities for

future analyses either from the populations' or individuals' perspective. For instance, it is possible to make retrospective analyses of the persons' data that is collected through repeated testing and make conclusions about the progression of the disease (Jurica et al., 2015; Quest Diagnostics, 2017). If the data is integrated to EHRs, it is easy for physicians to track patients' results over time (Quest Diagnostics, 2017).

Many other cognitive tests have high emphasis on oral tasks and performing cognitive screening requires some verbal exchange. There are not many opportunities to digitize these tasks. The data could be collected through questionnaires or alternative tasks could be developed. Otherwise, carrying out the test still needs the assistance of the clinician (Jurica et al., 2015).

1.2.2.3 Self-administered tools

To assess cognitive impairment and primarily memory problems without the need for clinicians' administration, computer-based self-administered cognitive screening tools could be used. These tests can be anonymous and easily accessible from a private home environment. Self-administered cognitive screening tools are not diagnostic instruments, and they have two main goals. Firstly, to refer people to family physicians in case of cognitive decline and secondly, to reduce the anxiety level of the people who are unnecessarily worried about their memory (Van Mierlo et al., 2017). It can be argued, that self-administered cognitive screening tools are not suitable for people with AD, as they have low awareness about their condition and therefore taking the test on their own initiation is highly questionable (Lehrner et al., 2015). Still, these tests could be useful in case of MCI (Kluger et al., 2009; Lehrner et al., 2015).

Kluger et al. have developed a brief self-administered cognitive screening test for dementia detection that consists of multiple measures of cognitive status. The test is correlating significantly with accepted standard cognitive tests and distinguishes between healthy individuals, people with MCI, AD, and other dementias. The screening test requires custom software and is performed on a laptop computer. In addition to the cognitive screening itself, the test includes a short assessment of the persons' computer skills, to be clear if the person can perform following cognitive tasks. Answers to this test are recorded via keyboard. Completing the test takes around 12 to 15 minutes on

average and it has been found that the majority of elderly, including people with dementia, can perform the test without any assistance (Kluger et al., 2009).

Dougherty et al. developed a web-based self-administered cognitive test, the COGselftest, for early dementia detection. Among some other cognitive skills, it measures verbal fluency, working memory, and attention. A computer screen displays the stimuli and both, oral and written instructions are given. Answers are recorded via keyboard or mouse and completing the test takes around 15 minutes. Feedback is given to the patient after completing the test, but the feedback is not referring to any diagnosis. The test is distinguishing very well in between healthy individuals and people with a cognitive decline, and in between different stages of cognitive impairment. Moreover, the test has shown better results in the mentioned occasions than the MMSE. This test might help to detect cognitive impairment in primary care settings, as it is interactive, internet-based, and easy to use and interpret (Dougherty et al., 2010).

1.2.3 Diagnostic recommendations

In this thesis, the definition of diagnostics means the practice of diagnosis (Dictionary.com, 2017). In the Estonian Dementia Treatment Guide, family physicians are not seen as the specialists who should be responsible alone for dementia diagnostics. Their role in AD care is described as conducting primary screening using MMSE, evaluating general health of the patient, making additional interventions if necessary, referring patients to other specialists and continuing the treatment that other specialists have ordered (Linnamägi et al., 2006). Although, in the newest guidelines from the world practices, family physicians are thought to be essential in making the dementia diagnosis (Geldmacher and Kerwin, 2013).

The ICD-10 and NINCDS-ADRDA diagnosing protocols should be followed in AD diagnostics, and to determine the existence of the dementia syndrome, a thorough patients' history should be taken preferably from a close relative of the patient. In case of AD suspicion, the MMSE should be performed (Linnamägi et al., 2006).

If MMSE result is indicating memory decline, family physicians should order a range of clinical and biochemical blood samples to rule out other possible conditions. For further diagnostics, the patients should be referred to a neurologist or a psychiatrist for CT or MRI investigation. If the MMSE gives a negative result, it should be repeated after 1-2

years when the symptoms have worsened. If there is a cognitive decline reported by patients' relatives and the MMSE test is negative, a neuropsychological assessment is recommended (Linnamägi et al., 2006).

If the patient does not yet have decline in functional skills but has cognitive impairment, a diagnosis of MCI should be made (Geldmacher and Kerwin, 2013). MCI can be one of the predictors of future AD, but the diagnosis of MCI does not mean, that the person will definitely develop AD (Fox et al., 2013; Lin et al., 2013). The Estonian Dementia Treatment Guide suggests, that in case of MCI suspicion, patient should be referred to specialized centre for neuropsychological assessment. Patients with suspected or diagnosed MCI should be under close observation by their family physicians (Linnamägi et al., 2006).

There are two main concepts describing the time when AD diagnosis is made – “early” and “timely” diagnosis (Dubois et al., 2016). Early diagnosis means that the diagnosis is made already in the asymptomatic phase of the AD. Therefore, a targeted population screening with novel AD screening methods would be required to identify people with AD suspicion (De Lepeleire et al., 2008; Laske et al., 2015).

The timely diagnosis has different definitions. Firstly, it is understood, that it is a diagnosis that is made at a time when individuals or their relatives become worried about the condition and are seeking help for the first time, or when the physicians have their first concerns about patients' cognition, behaviour or functioning. The other way to define timely diagnosis is from the patient's perspective. The timely diagnosis could be seen as a diagnosis that is made at the right time for the patient. This concept is not dependent on the stage of the disease (Prince et al., 2011).

As the targeted population screening for AD with novel screening methods is not yet widely accepted and the usage of these methods is often out of range of the knowledge and possibilities of the family physicians, to indicate AD diagnosis that is made by family physicians as early as possible, the first definition of “timely diagnosis” is used in this thesis (Laske et al., 2015; Martin et al., 2015).

Even though the timely diagnosis is preferred in the case of AD, it is often diagnosed in the later stages of the disease, because the recognition of AD in earlier stages is difficult (Eichler et al., 2015). Also, WHO claims that dementia is underdiagnosed worldwide,

meaning, that it is diagnosed less often than it is actually present (Merriam-Webster, 2017; World Health Organization, 2016). Only 20-50% of the cases are recognized and documented in primary care in case of high income countries, and in Estonia, only 10% of the people with dementia get the diagnosis (Linnamägi et al., 2006; World Health Organization, 2016).

Some reported reasons for not diagnosing AD are following: physicians are uncertain about the diagnosis, lack of time and support systems for families, communication difficulties, fear of causing emotional disturbance, patient or caregiver is against it, lack of treatment, and stigmatization. Furthermore, lack of confidence in AD diagnosing might lead to higher numbers of undiagnosed AD or increase the referrals to other specialists (Alzheimer's Association, 2015).

1.2.4 Benefits and concerns of screening and diagnostics

In literature, there are opposite views about the benefits of AD screening. On one hand, it is believed that early detection of cognitive decline has positive effects on patients, families, caregivers, health care systems and society in general, but on the other hand, some say there is not enough evidence to prove the benefits (Fox et al., 2013).

The widely mentioned benefit of AD early detection is that it gives patients and their relatives possibility to plan for the future care and allows them to make necessary financial decisions (Fox et al., 2013; Geldmacher and Kerwin, 2013). It can be argued that this should not be seen as a benefit of AD screening because planning for future care and finances should apply for all elderly (Fox et al., 2013). Still, living with AD without the diagnosis is believed to limit peoples' access to relevant information, treatment and care (Prince et al., 2011).

For patients, earlier identification of cognitive decline allows prompt AD treatment with medications. Therefore, possible problems with medication compliance and inappropriate medication could be handled earlier. However, there is not enough evidence to support this concept (Fox et al., 2013). It has been found that early education for the relatives of AD patients can reduce caregiver stress and burden. Moreover, applying packages of specialized services after timely diagnosis can improve quality of life and reduce behavioural dementia symptoms, as well as delay moving to care homes (Banerjee et al., 2007; Mittelman et al., 2007). For health care and social

care, early disease detection is thought to offer an opportunity for better planning and patient monitoring, but there is no clear evidence to actually support this view (Fox et al., 2013).

The main concern of earlier screening and diagnostic testing derives from the impact of getting the MCI diagnosis. Detection of MCI is increasing because of the pressure to identify people who are at risk of dementia in earlier stages than before. Population-based longitudinal studies suggest that a higher number of MCI cases return to normal than develop to dementia because some impairments detected as MCI are extremely common in older age. There is no effective treatment for MCI and it is not known, who is going to develop AD after getting the MCI diagnosis and who is not. Therefore, getting the MCI diagnosis can increase the anxiety of the well and coping people for no reason (Fox et al., 2013).

The problem with AD timely diagnosis for patients has been the fear of being stigmatized by others when they hear about the AD diagnosis. Tang et al. found in their study, that 66% out of 4,033 participants were worried that sharing the AD diagnosis with others will change the way, how others think and feel about them (Tang et al., 2017). Moreover, the fear of telling others about their condition might prevent people with AD from seeking proper help (Toms et al., 2015).

Despite the controversial opinions, in general, people welcome the idea of AD screening and are positively minded about it. For instance, Tang et al. studied peoples' concern about developing AD and their intention to be screened. Out of 4,033 adults, around 55% of participants were "very worried", "worried" or "somewhat worried" about developing AD. The more worried they were, the more likely they agreed that they will get screened and tested for AD if they experience changes in memory and thinking ability (Tang et al., 2017).

In long term, there is hope that AD treatment is found, as continuous efforts are being made towards it (Alzheimer's Association, 2017). Hence, in the opinion of the author, the question of AD screening should be under a discussion already today.

1.3 Previous studies and methodology

Family physicians are the key persons in AD management, as suggested by many guidelines (Geldmacher and Kerwin, 2013). Therefore, a number of qualitative and quantitative studies have been made to seek physicians' perceptions about the AD screening and diagnostic processes.

For example, the IMPACT survey studied the opinions of physicians, general public, payors and caregivers about cognitive impairment, AD and other dementia screening. They collected altogether 1,800 opinions, of which 500 were from physicians, from five European countries – the United Kingdom, Germany, Italy, Spain and France. Respondents were asked about the importance of a routine screening for AD for people aged 65 and over, and if everyone who has turned 65 should be routinely screened for AD. If the respondents answered “no” to the last question, they were asked for an explanation (Bond et al., 2010).

83% of the physicians evaluated the importance of routine screening for AD as being “extremely”, “very” or “somewhat important”. 56% of the physicians thought, that the screening is “extremely” or “very” important and 27% that it is “somewhat” important. Others thought it was “not very important” or “not important at all” (Bond et al., 2010).

Only 42% of the physicians thought that routine screening should be carried out regularly after people turn 65. Main reasons for opposing to regular screening were screening inaccuracy (44%), high cost (33%) and lack of treatment (24%) (Bond et al., 2010).

In the USA, a qualitative study about dementia care processes was made with the members of the American Academy of Family Physicians. Out of the 1,500 surveys that were sent to the randomly chosen members of the Academy, 851 (60%) were completed and analysed. The survey included questions about the screening and diagnosing processes in primary care settings (Stewart et al., 2014).

56% of the physicians said that “at least some of the time” they screen asymptomatic patients for dementia. 52% of the physicians screen as well as conduct diagnostic evaluation, whereas 4% only screen. The main triggers to screen are age, family history and cerebrovascular risk factors. Moreover, 37% of the respondents do only diagnostic

evaluations and 7% of the physicians said that they do not evaluate nor screen. 80% of the screening physicians reported that they use a certain screening tool. Most frequently, the MMSE and the CDT were mentioned. 90% of the respondents evaluate patients for dementia if they have early signs or symptoms or if the patient or caregiver address their concerns (Stewart et al., 2014).

The family physicians reported also barriers to diagnosing and caring for patients with dementia. The biggest barrier, reported by 78% of the physicians, was inadequate clinician time. 51% listed the length of administering screening tools as a barrier and 48% brought out limited treatment possibilities. 62% of the physicians thought that they need better assessment tools, 48% needed better access to diagnostic tools and 40% to screening tools (Stewart et al., 2014).

40% of the family physicians that reported to screen, diagnose and/or care for dementia patients refer them to other specialists mainly for diagnosis verification and long-term disease co-management. 78% of these patients were referred to neurologists, 17% to psychiatrists and 16% to geriatricians. The main reason for not referring patients to other specialists was that the physicians feel comfortable in dementia diagnosing and treatment process. This reason was reported by 85% of the physicians that were not referring their patients (Stewart et al., 2014).

Prins et al. made a qualitative study in Netherlands among 18 general practitioners (hereinafter referred to as GP). They used semi-structured interviews to learn about GPs' practices and views on dementia diagnostics. The participants said that their role in the dementia diagnostics was to detect the patients' cognitive decline and to make a decision if the patient should be referred to other specialists for further investigation and diagnosis or it would be possible to organize appropriate care without the specialist diagnosis (Prins et al., 2016).

GPs thought it is more important to refer younger patients with rapid disease development for further investigations than very old patients with slow cognitive decline. They viewed that giving specific dementia diagnosis to younger people would help them to prepare better for their future care and end-of-life decisions. In opposite, they felt that the impact of dementia treatment and care for older patients is not so apparent (Prins et al., 2016). Finally, Dutch GPs were more likely to refer patients for

further investigation if the patients, their caregivers or dementia case managers specifically requested it (Prins et al., 2016).

In this thesis, family physicians' perceptions were gathered with quantitative and qualitative methods, a web-based questionnaire and in-depth semi-structured interviews were used.

Using a web-based questionnaire has multiple benefits - the method is cheap, fast and easy to administer (Fox et al., 2003). It allows approaching physicians from every corner of the country that might have a great influence in studying dementia – living in rural areas is associated with a higher risk of developing AD (Russ et al., 2012). Also, family physicians are known to have busy working hours, but the web-based questionnaire could be answered at any time of the day and even on weekends. Finally, as every family physician has to orientate in digital environments used for documentation, they are all at least somewhat familiar with computers.

For the interviews, the exponential discriminative snowball sampling was used. The method is beneficial for studying populations that are hard to reach, as it relies on chain-referral (Etikan et al., 2015; Research Methodology, 2017). The exponential discriminative snowball sampling allows researcher to choose new participants from the multiple recommendations of the previous participant, based on the aim and objectives of the research (Research Methodology, 2017). For conducting the interviews, an interview guide was developed. An interview guide is a crucial tool for interviewing, as it lists the most important issues to be targeted and questions to be asked (Bryman, 2016).

2. STUDIES AMONG ESTONIAN FAMILY PHYSICIANS

This chapter describes a web-based study among Estonian family physicians in April 2017, and in-depth semi-structured interviews with family physicians in July and August 2017.

The chapter divides into a description of research methodologies, results, discussion, and conclusions.

2.1 Materials and methods

Family physicians' perceptions in AD screening and diagnostics were gathered by using two different methods – a quantitative web-based study and qualitative semi-structured interviews.

Firstly, a web-based questionnaire was formed and sent out to 785 family physicians, to seek their perceptions about the widely mentioned problems with AD screening and diagnostics, that came up from the literature research and previous studies. Secondly, six family physicians were interviewed to confirm the findings from the questionnaire and discuss thoroughly the family physicians role in AD screening and diagnostics.

2.1.1 Development of the web-based questionnaire and the interview guide

The questionnaire was formed in Estonian and consisted of demographic information, and nine closed and open-ended questions (Appendix 1, 2). The demographic information included family physicians' gender, age, length of working experience and county of practice. There were six questions concerning the screening processes and three questions about making the diagnosis that were formed by keeping in mind the findings from the literature and previous studies among family physicians.

In addition to the web-based study, interviews were held with six family physicians, and an interview guide was developed (Appendix 3, 4). Interview questions were open-ended and the interview was in semi-structured form. It allowed for flexibility in the order of the questions and asking questions that were not included in the original interview guide when the interviewer picked up some interesting ideas based on the interviewee's answers.

The main part of the interview was divided into four topics. The first topic included questions about family physicians' opinion about population screening and possible usage of technology in the screening process. It was possible to add the questions about self-administered and digitized screening tools to the interviews and not to the web-based study, as during the interviews, the explanation about these questions was given based on each participant's knowledge and need.

The second topic concentrated on a patient with AD suspicion and included the steps of determining the need for screening until taking the cognitive screening test. The third topic was about concrete AD suspicion and physicians' actions in referring the patient to further diagnostics and to other specialists. The final topic included questions about taking the blood tests and evaluating the AD Treatment Guide's recommendations.

2.1.2 Web-based study participants, procedures and data analyses

Since web-based questionnaires are cheap to administer, sending e-mails is a fast procedure and the number of Estonian family physicians is known, it was decided to approach all practicing family physicians who were listed as contract partners of the Estonian Health Insurance Fund (*Eesti Haigekassa*) on 1st April 2017, and who owned an official valid and accessible email address (Eesti Haigekassa, 2017).

The original list consisted of 829 names but included several data duplications. 792 family physicians remained to the list after removing the duplications. Three of these physicians did not have an official email address, three had an invalid email address and one physician's email was not accessible. In total, 785 family physicians received an email and were included in the study. That is approximately 99% of the practising Estonian family physicians according to the information provided by the Estonian Health Insurance Fund. From 785 physicians, 68 (9%) were men and 717 (91%) women. 43% of these physicians practice in the Harju County, 12% in Ida-Viru and 11% in Tartu County (Eesti Haigekassa, 2017).

The study was carried out from the 10th of April to 28th of April 2017. On the first day of the study, all the participants received a personalized email to their official email address. The email contained introduction of the author of the thesis, the topic and the aim of the study, short description of the questionnaire, and a clarification that participating in the study is anonymous.

The link with the web-based questionnaire was attached to the email. Every physician with the link could access the questionnaire without providing any sensitive personal information. A reminder email was sent five days prior the end of the study, as sending reminders has proven to increase the response rates in web-based surveys (Sills and Song, 2002). The contact information of the author of the thesis was provided in the email and after submitting the questionnaire, in case there are any additional comments or questions about the study.

Google Forms application was used for administering the web-based questionnaire (Google, 2017). Data from the questionnaire was automatically saved to an MS Excel file. The program's functions were also used for data analyses. In case of open-ended questions, the answers of Estonian family physicians were translated to English, grouped into themes and a matrix was formed. The frequency and proportion of the occurrence of these themes were calculated.

2.1.3 Interview participants, procedures and data analyses

Two geographically different locations were chosen for finding the interview participants. Firstly, Hiiu County was chosen, because it is relatively distant from the well-equipped medical centres that are specialized for AD diagnostics. Although there is a hospital with the CT possibility, there is a neurologist available only on certain days of the month, so the services are not easily accessible (Hiiumaa Haigla, 2017). For specialized AD diagnostics, people should travel over the sea, which might create difficulties for the whole family, as the patients are usually elderly and need assistance. In contrary, Harju County was chosen to be the other location, with its' well-equipped hospitals and higher number of specialists. It was assumed, that the accessibility issues could create differences in between family physicians' perceptions in AD screening and diagnostics.

In both locations, an exponential discriminative snowball sampling was used to recruit participants and determine the final number of interviews. The interviews were stopped after there was no substantive new information coming in addition to the previous findings (Research Methodology, 2017). Altogether, three family physicians were interviewed in Hiiu, and three in Harju County.

In Hiiu County, two family physicians were from the town Kärkla, and one from Käina. These physicians had not been involved in any other specific AD or memory-related activity than their own experience as family physicians. In opposite to Hiiu physicians, the first interviewee from Harju County had broader experience as a member of the working group, which is currently developing the new Estonian AD Treatment Guide (Ravijuhend, 2016). The second interviewee had long working experience from Finland, and the interviewee's practice was listed as one of the high-ranking primary care centres in Estonia. The third interviewee was a member of the board of Family Physicians Association of Estonia (*Eesti Perearstide Selts*) (Eesti Perearstide Selts, 2016). All the physicians of Harju County were practising in the Estonian capital, Tallinn.

The interviews were held 24.07, 27.07, 28.07 and 03.08 in 2017. The meetings with family physicians started with an introduction, where the purpose of the interview and the interviewer were introduced. Also, general information about the interviewee was asked. Further on, the interview guide was followed during the interviewing process. All the interviews took around 25-30 minutes. In case of Hiiu County, because of physicians' strict time limitations, they were interviewed as a focus group. For this reason, there were also two persons conducting the interviews, one person was leading the interview, and the other was transcribing. Although the interview was held in a focus group, each participant was separately answering to each question. In Harju County, the interviews were individual and held by one interviewer.

All the interviewees' answers were transcribed during the interview. For analyses, the answers were translated to English and grouped together under the discussed topics based on the interview guide. The frequency of the occurrence of each opinion for each question was calculated.

2.2 Results

The results of the web-based study and interviews are complementary to each other. If the web-based study was anonymous and more broad-based, the interviews were in-depth and concentrating on specific steps in the AD screening and diagnostics.

Combining the web-based study results with the qualitative study allows better characterization of the family physicians' attitudes.

2.2.1 Web-based study

Out of the 785 family physicians, 124 answered the web-based questionnaire. The response rate was 16%.

72% (89) of these answers came after the first mention of the questionnaire, and 28% (35) answers after sending out the reminder-email. 53% of the answers came on regular working days during the working-hours (from 8 to 17). 47% of the answers were received outside working-hours and on weekends. All of the received questionnaires were fully completed and considered in analyses.

94% (117) of the respondents were women and 6% (7) men. The proportion of men from respondents was slightly lower than from the whole list of participants (9%). The mean age of respondents was 52.8 years. The mean age for men was 44, and mean age for women was 53.3 years. The mean length of working experience was 26.3 years. For men, the number was 17.4 and for women, 26.8 years.

All 15 Estonian counties were represented (Figure 1). The greatest number of responses came from Harju County, forming 34% (42) of all answers.

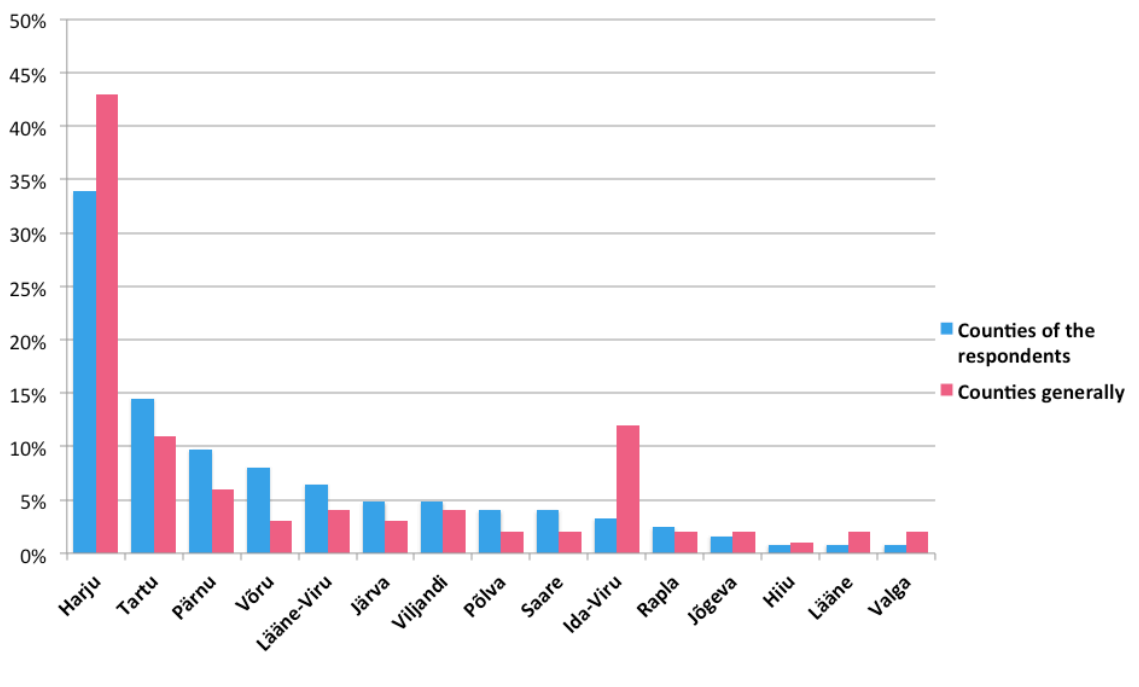


Figure 1. Distribution of practising counties of the respondents and counties on the full list of participants.

The importance of regular screening for people aged 65 and over to detect AD as early as possible was assessed on a 5-point scale. Approximately 41% of respondents valued the importance as “somewhat important”, 40% as “very important”, 11% as “not very important” and 8% as “extremely important” (Figure 2). The option of “not at all important” was not chosen. So, 89% of physicians thought that regular screening is at least somewhat important and 11% did not consider it to be important.

43% of the respondents answered “yes” to the question about the need for screening regularly every person aged 65 and over to detect AD as early as possible. 57% of the physicians answered “no”. From 71 physicians who answered “no” to the second question, 89% brought out one or multiple reasons why they think regular screening for every individual over 65 is not necessary, and 11% chose to not give an explanation.

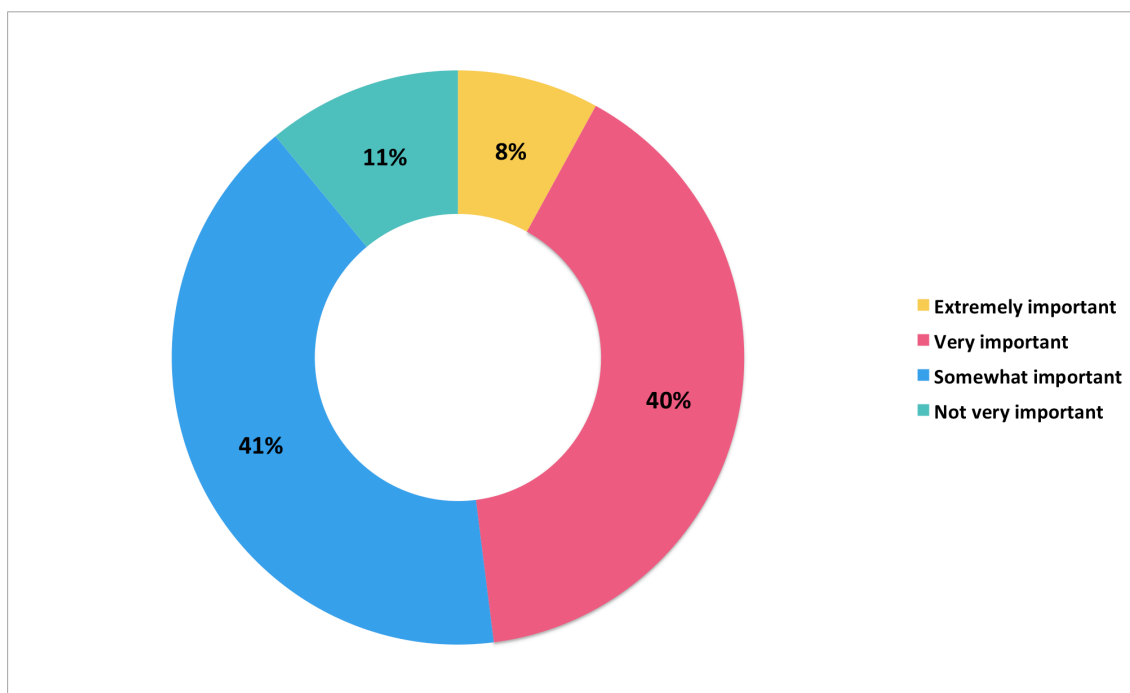


Figure 2. Answers to the question “How do you value the importance of regular screening for people aged 65+ to detect AD as early as possible?”

From 63 persons naming the reasons, the most popular reason was that AD screening should be done only based on clinical symptoms and AD suspicion (37%). In this question, three physicians added, that they know their patients well, and therefore they know when to screen. Other answers were lack of time (22%), 65 is not a proper age to screen (14%), there is no effective treatment (11%), lack of specialized personnel and treatment/rehabilitation facilities (11%), screening is not effective, realistic and needed

(11%), AD has low prevalence and screening some other diseases is more important (10%), lack of resources in general (10%), resistance of patients (8%), and there should be effective screening tests available (2%).

In addition, six people made general remarks about the screening procedure. Three physicians were worried about who should be the right specialist for screening, two physicians thought that family physicians should not be the ones who screen, and one person thought that inviting people for screening should not be done through the post, but screening could be done when people visit medical centres.

From all respondents, 36% said that patients' evaluation for AD is most often initiated when a patient's relative addresses the concern, 35% after the family physician notices a problem, 7% when the patient is concerned and 3% based on the patients' family history. No one said that the evaluation should be initiated by the age alone. 19% chose the option "other" (Figure 3). From these 24 physicians, 83% mentioned that the evaluation is most often initiated based on simultaneous occurrence of multiple previously mentioned reasons, 8% said that they do not know the answer, and 8% brought out also the occurrence of objective findings and thorough history from the patient.

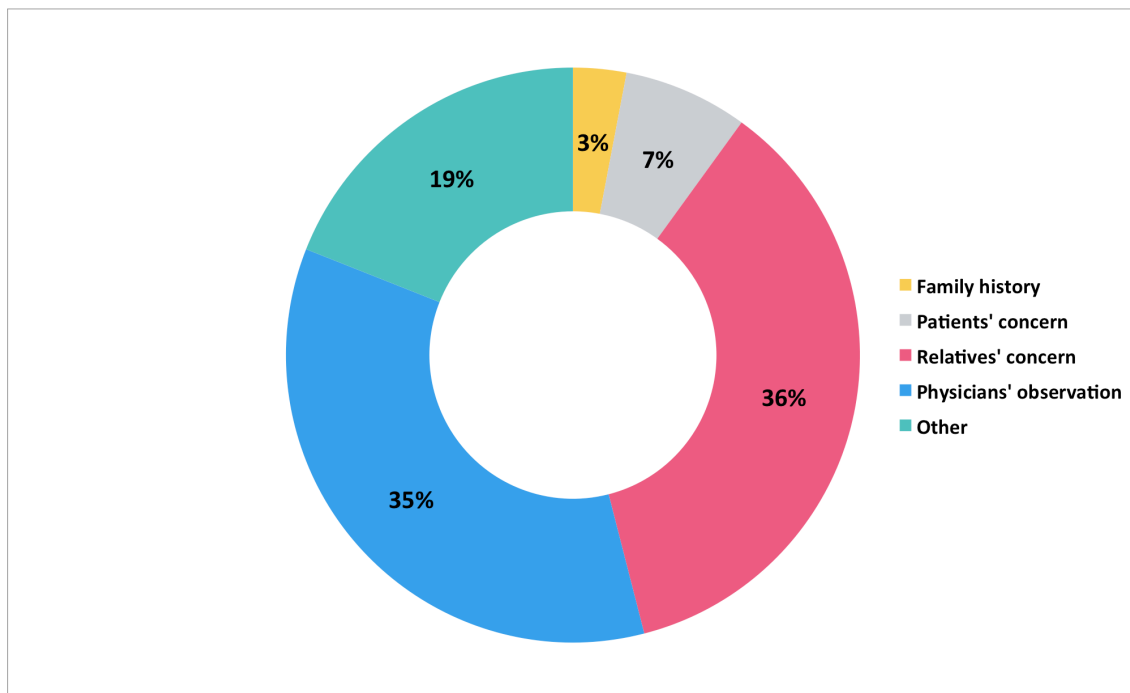


Figure 3. Answers to the question "What initiates most often the evaluation of the patient to detect AD?"

56% of respondents use MMSE most often as a screening tool for AD, 12% use CDT, and 2% use MoCA. 6% chose the option “other” and from these people, two admitted that they do not have any screening tests, two said that they refer patients to other specialists for screening, and three people decide which test to use based on the situation.

25% of the physicians do not usually use any screening tests. From those physicians, 39% explained not using any tests because of lack of time, 32% reported not having any knowledge and experience, 13% are referring patients to other specialists for screening, 10% said there is no suitable test available, and 10% did not give an explanation. One physician claimed to have trouble with remembering to do the test, one is not used to the tests, one does not like tests in general, one has not had the need yet, one thinks that family nurses should be educated to screen, and one did not know the answer.

17% of the respondents said “yes” to the question “Do you feel confident in AD diagnosing?” 76% said “no”, and 10% “I do not know”.

55% of all respondents offered appropriate training as a solution how to make family physicians more confident in AD diagnosing. 13% mentioned that there should be a concrete treatment guide for family physicians, 12% thought there should be better screening tests, and 8% said that other specialists should do diagnostics. Gaining more experience was mentioned by 7% of the physicians, and the possibility for quick consultation and cooperation with other specialists was brought out by 6% of the respondents. 4% of the physicians did not know the answer. Extra funding, extra time, extra personnel, patients’ and their relatives’ better knowledge, and creating possibilities for family physicians to order other tests, were all mentioned equally by 2% of the respondents. One person said it is not possible to feel confident because of the characteristics of the disease, patients’ resistance and lack of treatment options. One physician answered that being not confident is normal because there are no accurate options for diagnostic procedures. Also, bigger courage was mentioned once.

The final question asked family physicians opinions about what is causing the underdiagnosed AD in Estonia. All the respondents gave one or multiple answers. The most frequent answers were lack of knowledge and experience (35%), lack of time (19%), poor access to other specialists (10%), and the patients’ and their relatives’ lack

of knowledge (10%). The other responses were too high workload for family physicians (6%), attitude problems and blaming the “old age” (5%), lack of treatment for AD (5%), screening tests are not accessible (5%), problems with general health care system (4%), higher importance of other diseases (3%), formal diagnosis is not always justified (3%), stigmatization (2%), lack of confidence (2%), and patients have no social networks (2%).

Following responses were all mentioned once: AD is not much underdiagnosed; patients do not use their referrals to other specialists; there are no concrete criteria for making a diagnosis; there is no habit to screen; lack of regular geriatric evaluation while cooperating with social workers; not especially seeking for AD; it is mixed with other diseases. Also, an answer “I do not know” was given in 9% of the cases.

2.2.2 Interviews

From six physicians interviewed, five were women and one man. The mean age of the participants from Hiiu County was 61.7 years, and Harju County 47 years. The mean age of all interviewees was 54.3 years. All family physicians from Hiiu County had over 30 years of working experience as family physicians. The working experience of Harju County physicians ranged from 10 to 20 years, with the mean of 16.7 years.

Five out of six physicians did not support population screening for AD. The mentioned reasons behind it were lack of time and money, lack of treatment, and difficulties in detecting AD in early stages. Three physicians found that the population screening is not rational and important. Furthermore, one participant said: “I am doubtful and rather not supportive about the population screening, as it may raise the anxiety level of the patients and waste their time.” The other added, that the screening and cognitive evaluation should be a part of the health check for driver’s licence renewal among elderly patients.

Four out of six family physicians did not support self-administered tests on the web, because “people over 50 cannot handle computers”, and “screening itself has no point”. One physician added an explanation: “Internet and medicine do not work well together. People cannot understand what they read from the web”. Two interviewees were supportive of technology. They saw self-administered and digitized screening tests as beneficial in the future AD screening processes, but added, that usage of these tests

needs raising the knowledge of physicians and patients, and probably these would work with younger generations, not the current elderly population. One of the physicians said that they already use some digitized evaluation tools, and digitization of AD screening tools would be normal. The other noted, that digitized screening tools should all be collected to one database, so the tests would be easily found, instead of searching these from pile of papers.

By the experience of five physicians, the suspicion of the disease starts usually when the relatives of the patients are addressing their concerns. Two of these five physicians also said that they notice the problem sometimes themselves. One out of six physicians had experienced three cases equally: the relatives and especially children of elderly patients address the concern, the younger patients report problems themselves, and the physician notices problems herself.

All the physicians take history from the patient, although one physician said, that the patient is not always capable of giving a thorough history. Five out of six physicians thought that it is not always realistic to follow the Guide's suggestion about taking a thorough history from the relatives because of the time issues. Furthermore, three physicians eliminated the possibility of taking the history simultaneously from the patient and relatives. Still, in general, all five agreed that the suggestion is correct in its essence, and two physicians added, that the relatives would like to be involved in the process. One participant explained that it is realistic to take history from both, the patient and the relatives, because the children of elderly patients are frequently visiting physician together with their parents, and are also patients of the same family physician.

All physicians claimed to know the MMSE test, but only one physician said to use it every time in case of AD suspicion. Others discussed that there is usually no time for the test, as the patients turn to them with other problems. One physician thought, that if the patient comes in with only AD suspicion, then there could be enough time for the test. One other said that MMSE is pointless because the mind is made up about the diagnosis based on the history alone. Three physicians agreed, that the workload of physicians and nurses is already big, and there are other and more important things to screen.

In the opinion of two physicians, who admitted not doing the MMSE every time, the test is still important and should be done if possible, because it confirms the physicians' hypothesis. One of them said: "Family physicians might have low belief in MMSE because it is not perfect for detecting AD in early stages". The interviewee added that appropriate training might help family physicians in using the MMSE. The other physician thought that doing MMSE should be added to the Guide as an optional, not as a compulsory action for family physicians. The physician believed that MMSE should be done either by a family physician or a neuropsychologist, depending on the case.

Every family physician agreed that blood analyses should be done every time in case of AD suspicion to eliminate other conditions, and said that they have always done it.

All six physicians claimed that accessibility to other specialists and diagnostic procedures is bad. For this reason, three of them cannot refer every patient for further diagnostics. Still, younger patients with AD suspicion always get the referral. Five physicians said that it would be easier to get necessary CT or MRI procedures when family physicians themselves would have the opportunity to order these. Two physicians refer all their patients to specialized clinic for further diagnostics, but often start the treatment with medicine beforehand.

One physicians' recommendation was to involve other specialists to cooperate in teamwork already after taking the patients' history. Moreover, consulting with other specialists should be done through e-consultation, like it is arranged in the participants' workplace. The participant noted: "E-consultation has definitely improved the accessibility issues with other specialists". It was also said by the participant that the idea of creating better options for family physicians for ordering CT and MRI is currently under a discussion in different involved organizations and governmental institutions.

Three physicians said that they would need more time to follow the instructions from the Guide. It depends also on the number of patients and patients' knowledge. One physician thought the suggestions of the Guide are quite realistic. Other said that the Guide should be presented in a form of checklist, so it would be easy to use in primary care settings. It was added that AD is not so common disease and family physicians are

not using the AD diagnosing criteria very often. One participant said that the new Guide should be introduced well to family physicians, and possibly in form of workshops.

As an extra comment about the topic, an idea was suggested that there should be a special AD screening program, supported by the Estonian Health Insurance Fund (*Eesti Haigekassa*), so the family physicians could deal with most of the AD cases by themselves, and only turn to specialists with more difficult cases. It involves the possibility of ordering CT and MRI. All other interviewees supported the idea. One of them said: “Family physicians are interested in more training about the topic, and the idea about the screening program would be sold to them quite easily”. It was also brought out as an extra comment, that the knowledge about the disease should be raised among physicians and patients, but also among family nurses because they are often the ones making the first contact with the patient. Finally, it was mentioned, that better cooperation in between all parties is needed to solve the issues concerning also the social side of the disease and AD care possibilities.

2.3 Discussion

AD is a slowly progressive neurodegenerative disease that is a burden for both, the medical and the social sphere (Alzheimer’s Disease International, 2015; Dubois et al., 2016). The most prominent clinical symptom of AD is a problem with remembering new information. The changes occurring in case of the AD lead to a withdrawal from social life – work and other social activities (Alzheimer’s Association, 2016). There is no treatment available for AD that would change the course of the disease, but the disease can be eased by symptomatic and supportive treatments (Hugo and Ganguli, 2014).

Family physicians are the key persons in AD management, as suggested by many guidelines (Geldmacher and Kerwin, 2013). Therefore, a number of studies have been made to seek physicians’ perceptions about the AD screening and diagnostic processes (Bond et al., 2010; Prins et al., 2016; Stewart et al., 2014). In this thesis, Estonian family physicians’ perceptions were gathered with a web-based questionnaire and semi-structured interviews.

A web-based questionnaire was sent out to 785 Estonian family physicians, with a 16% response rate. The response rate to the questionnaire was low and many opinions were found to be controversial. Therefore, six interviews were held with family physicians from two Estonian counties to confirm findings from the questionnaire and get the in-depth view about the family physicians' role in AD screening and diagnostics.

2.3.1 Population screening

Population screening for dementia is mostly not recommended, although the newest health care priorities and research suggest that the benefits of routine AD screening outweigh its' potential harms and limitations (Borson et al., 2013; Martin et al., 2015).

In the opinion of 89% of Estonian family physicians participating in the web-based study, regular AD screening for people over 65 to detect the disease as early as possible is important. It is a similar and even slightly higher result than in the IMPACT study, where 83% of the physicians were evaluating the regular screening of people over 65 as being important (Bond et al., 2010). Although the physicians value the importance of screening, still around half of them do not think everyone over 65 should be screened for AD. In the case of Estonian family physicians, 57% do not support screening everyone, and in the case of the IMPACT study 58%, which shows also the similarity of perceptions about AD screening among European family physicians (Bond et al., 2010).

The importance of population screening was thoroughly discussed in the qualitative part of the study. The interviewees were surprisingly rather not supportive about population screening. In the quantitative study, 43% of the respondents supported the idea, but only one of six interviewed participants was positively minded about it. This physician had a clear vision of how the screening could be adapted to everyday work without creating enormous workload for physicians, what was the main fear for many others. It was suggested, that for instance, the cognitive evaluation should be a part of driver's licence renewal process.

The opinions that were shared about population screening were also supported by physicians' answers to the question about what initiates the first evaluation of the patient. According to the web-based study and interview results, first evaluation of the patient in AD suspicion is initiated when the relatives address their concerns about the patient or the family physician notices the problems. Only 3% of the physicians who

filled the web-based questionnaire claimed to evaluate patients based on family history, and none by age. Although, in the study among USA family physicians by Stewart et al., family history was one of the main factors triggering AD screening (Stewart et al., 2014). So, the disease is mainly detected in stages, when patient's cognitive decline is already noticeable to others.

By the author's vision, most of the physicians find AD detection as early as possible important but are not ready to screen patients regularly themselves, because they have already too much work. Furthermore, the screening might not have as much benefit as they wish, because there is no effective treatment for the disease and AD care possibilities are not good. Still, taking in count of the continuous efforts for finding AD treatment, and keeping in mind the general direction where health care should be heading, a shift from treating diseases to prevention and ensuring better quality of life for all AD patients and their relatives, the idea of population screening should be at least under a discussion in Estonia (Alzheimer's Association, 2017).

2.3.2 Cognitive screening tools

There are many paper-based cognitive screening tools, from which the MMSE is most widely used for dementia screening. It has been found, that cognitive impairment might not be recognized by the family physicians without a proper cognitive test (Eichler et al., 2015; Tsoi et al., 2015). The potential benefits of computer-based cognitive screening tools are deriving from better secondary use of data, greater accuracy in distinguishing in between different stages of dementia, and saving up specialists' time in case of self-administered screening tools (Jurica et al., 2015; Dougherty et al., 2010; Kluger et al., 2009; Quest Diagnostics, 2017).

2.3.2.1 Paper-based tools

It occurred that from the respondents to the web-based questionnaire, 56% uses MMSE most often in AD screening, as recommended by the Estonian Dementia Treatment Guide (Linnamägi et al., 2006). The CDT is used quite often as well. One fourth of the web-based questionnaire respondents do not use any screening tests, and the most mentioned reason for it was lack of time, as in the study conducted by Stewart et al. (Stewart et al., 2014).

However, the results of the interviews show, that even though all the interviewees claimed to know the MMSE, only a half of them were using it in case of a need. During the interviews, five out of six physicians expressed their doubts about its' usefulness in detecting dementia in clinical practice. One family physician suggested, that using MMSE should be optional for family physicians in the Guide, and the responsibility of doing it should be shared with neuropsychologists depending on each case. Still, there may be problems with this approach, because the interviewees were evaluating the cooperation in between family physicians and other specialists to be unsatisfying at the moment, and it may lead to a situation, where the test is still left undone.

To sum up, even if family physicians are familiar with some paper-based cognitive screening tools, they are still far from the recommendation of the Guide to use MMSE in case of every patient with AD suspicion (Linnamägi et al., 2006). In conclusion, analysing the situation with knowledge and usage of the MMSE shows that family physicians are in need of appropriate training.

2.3.2.2 Computer-based tools

Estonian computer-based self-administered screening tools could be developed or adapted to health care centres to detect people in need for further evaluation. Using these tools could be a voluntary option for the patient waiting for the appointment in the health care centre, as there are tools developed that are suitable for usage in primary care settings (Dougherty et al., 2010). In long-term, the author welcomes also the idea offered by one of the interviewees, to use digitized cognitive screening tools in AD screening process that are stored in the general tests database. So, each time the physician needs to do the test fast, it is easily found. Beforehand, many studies need to be carried out to develop the tests or determine which existing computer-based tests are suitable for adaption in Estonia, and to prove their usefulness in AD detection.

Most of the interviewed family physicians expressed serious doubts about computer-based screening tools. Still, some physicians are welcoming the idea of using technological solutions in the AD screening processes. In the opinion of the author, there is a ground for piloting these new solutions among Estonian family physicians, but to introduce successfully more technology to the AD screening, many core problems need to be addressed before.

2.3.3 Diagnostics according to the Guide

Even though the timely diagnosis is preferred in the case of AD, it is often diagnosed in the later stages of the disease (Eichler et al., 2015). Also, dementia is underdiagnosed worldwide (World Health Organization, 2016).

The diagnostic recommendations from the Guide in case of AD suspicion are following: taking the patients' history, ordering a range of blood samples after taking the MMSE, and referring the patient for other specialists to CT or MRI investigations (Linnamägi et al., 2006).

2.3.2.1 Patients' history

Based on the Estonian Dementia Treatment Guide, a thorough history should be taken from the patient and the relatives in case of AD suspicion (Linnamägi et al., 2006). Five out of six interviewees said that it is not always realistic to get the history from the relative, and the main issue behind it is the physicians' time. Some physicians pointed out that relatives themselves would be probably interested in being involved in the process. There is no quick fix for solving the problem with family physicians' time or getting the relatives accompanying the patients more often to the physicians' visit.

Raising the knowledge and awareness about AD among the nation could make it more common to join family members in the physicians' appointments and spot their cognitive problems earlier. Raising the knowledge could start from inside the primary care settings that encourage this kind of behaviour with their patients, or it could start from the national level with awareness campaigns. In the authors' opinion, some movement with raising the awareness has already started in Estonia. Issues with dementia have been brought out in several media channels during the last years, and new dementia related organizations have been established, but these activities are not centrally regulated and there is no national strategy in Estonia for dementia. Many European countries have listed dementia as one of their health care priorities and developed national dementia strategies (Alzheimer Europe, 2017). Therefore, the author suggests starting the development of national dementia strategy also in Estonia, with one intention to raise the knowledge and awareness about the disease.

2.3.2.2 Blood samples, CT and MRI

The Dementia Treatment Guide's suggestion about ordering a range of clinical and biochemical blood samples to rule out other possible conditions in case of AD suspicion is well understood by family physicians based on the interview results (Linnamägi et al., 2006). All the interviewees agreed with this suggestion and claimed to order blood samples every time with suspected AD. Although, suggestion of taking the MMSE first is not always followed.

After ordering the blood samples, the patient should be preferably referred to a specialist for further investigations – CT or MRI (Linnamägi et al., 2006). By the experience of the interviewees, accessibility to the specialists is relatively bad, and not every patient in Estonia with AD suspicion is referred to a specialist nor gets necessary interventions. In the opinion of several family physicians, a special funded screening program for AD with the possibility to order CT and MRI by family physicians could help to solve the situation. In this case, family physicians would manage everything from screening to diagnosing and treatment, and refer patients to specialist only in case of early-onset AD or otherwise difficult cases. As one physician explained during the interview, the possibility for family physicians to order CT and MRI is currently under a discussion in Estonia in different involved organizations. Although there is a long way from these discussions to actual process where family physicians can order these investigations, to support the idea of family physicians' greater role in AD diagnostics, the author suggests considering it also in the development of the new Estonian AD Treatment Guide. Otherwise, it may happen, that the suggestions from the new Guide are ageing too quickly and are still not fully met by the physicians.

In conclusion, vast majority of the web-based study respondents do not feel confident in AD diagnosing. It may be linked to the fact that at the moment, the main expectation in AD diagnosing lies rather with neurologists and psychiatrists with their possibilities for CT and MRI investigations. On the other hand, it may also mean that AD screening and diagnosing criteria are not well understood by the family physicians. The physicians claimed to need more training about the topic in general, as well as concrete treatment guide to follow in the process.

2.3.4 Suggestions and further studies

As suggested by a family physician, for improving communication in between family physicians and other specialists, a focus should be turned to implementation of e-consultation to primary care settings. There are not enough specialists in Estonia, and especially in rural areas of Estonia, to meet the actual need. E-consultation could bring them closer to family physicians and their patients.

In the authors' opinion, a great responsibility lies at the moment on the developers of the new Estonian AD Treatment Guide. To learn from the family physicians' perceptions, the usage of MMSE is the most problematic topic in the suggested pathway of AD screening. Some physicians are not seeing any benefit in the test, even if they value the screening in general or support the development of a special AD screening program for primary care. Hence, the recommendations concerning the MMSE should be considered carefully in the new Guide. Also, as an improvement opportunity, a checklist-based version of the Guide should be developed for primary care use, because it would be easier and faster to follow than the full-text document. Moreover, the new Guide should be introduced thoroughly to all family physicians in Estonia, so their understanding of the recommendations would be even.

The author of the thesis thinks that the training, either about MMSE, the new Guide, or the AD in general, should be continuous and accessible anytime and anywhere, and the quality of the information should be the same for all family physicians in Estonia. Therefore, a web-based training could be designed to allow continuous information consumption and replay of training materials whenever needed. Still, as many physicians have expressed their doubts about usage of technology, the web-based training should accompany the face-to-face training, because it could be more acceptable for most of the family physicians.

Even though the thesis concentrates on the perceptions of family physicians about AD screening and diagnostics, involvement of many different health care specialists is required to relieve the problems. So, the future research should find the perceptions of other health care specialists about this matter.

2.3.5 List of improvement opportunities

This list of improvement opportunities in AD screening and diagnostics is put together based on previous findings from the web-based study, interviews, and the authors' formed opinions through the discussion. These suggestions are not only meant for family physicians, but rather to different stakeholders in the health care system to discuss in cooperation.

1. Discuss the possibility of AD screening in form of cognitive evaluation during the driver's licence renewal.
2. Organize appropriate training about the usage of MMSE for family physicians and consider web-based training as one option.
3. Develop/adapt and pilot Estonian self-administered screening tools for voluntary usage in primary care settings/health care centres to detect people in need for further cognitive evaluation.
4. Develop/adapt and pilot Estonian digitized screening tools for the usage in primary care facilities. Develop/adapt a database for different tools and tests used in primary care.
5. Discuss the possibility of creating funded AD screening program for primary care, and support the idea allowing family physicians to order CT and MRI investigations.
6. Enhance the e-consultation possibilities in primary care settings to improve cooperation in between family physicians and other specialists.
7. Develop a checklist-based version of the new Estonian AD Treatment Guide for primary care use and introduce the Guide to all family physicians.
8. Start the development of national dementia strategy in Estonia, with one intention to raise the knowledge and awareness about the disease.

2.3.6 Limitations

Although using a web-based questionnaire in the population of Estonian family physicians has many benefits, there are also some serious limitations.

Firstly, response rate to the questionnaire was typically as low as in other similar studies among family physicians. For example, in a study made in Switzerland and France, it was found that family physicians' response rate to a web-based questionnaire was

10.7%, being around four times lower than the response rate in case of a postal questionnaire (Sebo et al., 2017). The response rate of the study among Estonian family physicians was 16%, so the results of the web-based study were not well representing the whole population of Estonian family physicians, and in-depth interviews were done to complement the study results.

Secondly, family physicians use computers and digital environments in their everyday practice, but they might not be always positively minded about it. So, it might have prevented people who are not keen on working with computers or who are not comfortable with computers in filling the questionnaire.

Thirdly, as with every computerized procedure, technical problems might occur with a web-based study. Because the link to the questionnaire was sent with an email, everyone who could have encountered technical problems while administering the questionnaire had the contact information and the chance to report possible problems. In case of this study, no one reported having any technical issues with administering the questionnaire.

The questionnaire was formed in one language – Estonian. Although by the knowledge of the author of this thesis, there is no official information available about how many family physicians in Estonia speak Russian as their mother tongue, it can be assumed that some physicians prefer Russian as their first language, and might not be comfortable filling in the questionnaire in Estonian. The language problem might have been evident in case of Ida-Viru County that had proportionally much fewer respondents when compared to the number of physicians working in this county. Furthermore, no piloting was done within the population of family physicians. The piloting with family physicians could have possibly generated some further questions for the questionnaire that family physicians themselves are more concerned about.

There were also some limitations concerning the in-depth interviews. It is difficult to decide what is the right amount of interviews when the snowball sampling is used (Research Methodology, 2017). So, the decision of stopping was made after thorough analyses of the existing results and conclusion that there is probably no new information coming that would remarkably change the final results. Furthermore, due to physicians' time constraint, Hiiu County physicians were interviewed in a focus group, that could

have been influencing the interviewees' answers. Still, every person was asked every question separately and although similarly minded, the physicians were not always giving the same answers.

Moreover, using snowball sampling for interviews can lead to bias due to the way the participants are recruited. The participants may be too similar and share some opinions (Etikan et al., 2015; Research Methodology, 2017). In case of the interviews conducted in Estonia, physicians from different counties and with different experience in the field were recruited. Although, the similarity of the interviewees might have existed when compared based on the county alone. Finally, only Estonian-speaking physicians participated in the interviews.

2.4 Conclusion

The aim of the thesis was to find out Estonian family physicians' perceptions about AD population screening, cognitive screening tools, and AD diagnostics according to the existing Estonian Dementia Treatment Guide.

Population screening for AD was supported by 43% of the web-based questionnaire respondents and one of six interviewees. Among some of the reasons for not supporting the population screening, were lack of time and low belief in its' benefits. Still, the possibility of population screening in Estonia should be under discussion.

56% of the web-based study respondents use MMSE most often in AD screening, but majority of the interview participants had doubts about its' usefulness in detecting dementia in clinical practice. Family physicians are still far from the recommendation of the Guide to use MMSE in case of every patient with AD suspicion, and need appropriate training. Four of six interviewed physicians did not support computer-based screening tools, but two of the interviewees were welcoming the idea. So, there is a ground for piloting these solutions in primary care.

Five out of six interviewees said that it is not always realistic to get the patients' history from the relative, and the main issue behind it is the physicians' time. Raising the knowledge and awareness about AD among the nation could make it more common to join family members in the physicians' appointments and spot their cognitive problems

earlier. All of the interviewees agreed with the suggestion of the Guide to order blood samples every time with suspected AD. Although, suggestion of taking the MMSE first is not always followed. Also, all of the interviewees claimed that accessibility to the specialists is relatively bad, and not every patient in Estonia with AD suspicion is referred to a specialist nor gets necessary further interventions. In the opinion of several family physicians, a special funded screening program for AD with the possibility to order CT and MRI by family physicians could help to solve the situation.

As a result of reaching the aim, eight improvement opportunities for AD screening and diagnostics were listed.

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APPENDIX 1. Web-based questionnaire in Estonian

Uuring perearstidele: Alzheimer'i tõve skriining ja diagnoosimine

Järgnevate küsimuste vastuseid kasutatakse Tallinna Tehnikaülikooli Tervishoiutehnoloogia õppekava magistritöös, mille eesmärgiks on selgitada välja Eesti perearstide arvamus Alzheimer'i tõve skriinimis- ja diagnoosimisprotsessidest.

Küsimustikule vastamine on anonüümne.

Küsimustikus kasutatavate mõistete täpsustus:

SKRIINING - Patsiendi esmane hindamine võimaliku Alzheimer'i tõve avastamiseks

DIAGNOOSIMINE - Alzheimer'i tõve diagnoosi välja kirjutamine

Sugu:* Mees Naine

Vanus (aastat):* _____

Tööstaaž (aastat):* _____

Praktiseerimise maakond:* _____

1. Kui oluliseks peate 65+ aasta vanuste inimeste regulaarset skriinimist Alzheimer'i tõve võimalikult varajaseks avastamiseks?*

Ülimalt oluline

Väga oluline

Mõnevõrra oluline

Mitte eriti oluline

Mitte üldse oluline

2. Kas kõigile, kes on 65+ aasta vanused, tuleks teostada regulaarset skriinimist Alzheimer'i tõve võimalikult varajaseks avastamiseks?*

Jah

Ei

3. Kui vastasite "Ei", siis mis on selle põhjus?

4. Mille põhjal otsustate enamasti patsienti Alzheimer'i tõve avastamiseks hinnata?*

Patsiendi vanus

Alzheimer'i tõve esinemine perekonnas

Kui mulle tundub, et patsiendil on mäluprobleemid

Kui patsient ise kurdab mäluprobleemide üle

Kui patsiendi lähedane kurdab patsiendi mäluprobleemide üle

Ei oska öelda

Muu: _____

5. Millist skriiningtesti kasutate kõige sagedamini Alzheimer'i tõve kahtlusega patsiendi hindamiseks?*

MMSE (Mini-Mental Test)

MoCA (Montreali kognitiivsete funktsioonide hindamise test)

Kellatest

Ei kasuta enamasti skriiningteste

Muu: _____

6. Kui Te ei kasuta enamasti skriiningteste, siis mis on selle põhjus?

7. Kas tunnete end Alzheimer'i tõve diagnoosimisel üldiselt enesekindlalt?*

Jah

Ei

Ei oska öelda

8. Mis võiks Teie arvates suurendada perearstide enesekindlust Alzheimer'i tõve diagnoosimisel?*

9. Mis põhjustab Teie arvates Eestis Alzheimer'i tõve aladiagnoosimist?*

APPENDIX 2. Web-based questionnaire in English

Questionnaire for family physicians: Alzheimer's disease screening and diagnosing

The answers to the following questions are used in the master's thesis for Healthcare Technology curriculum in the Tallinn University of Technology. The purpose of the thesis is to find out Estonian family physicians' perceptions about Alzheimer's disease screening and diagnosing processes.

The questionnaire is anonymous.

Clarification of the concepts used in the questionnaire:

SCREENING – Preliminary evaluation of the patient for possible detection of Alzheimer's disease

DIAGNOSING – closing the Alzheimer's disease diagnosis

Gender:* Male Female

Age (years):* _____

Length of working experience (years):* _____

County of practicing:* _____

1. How do you value the importance of regular screening for people aged 65+ to detect AD as early as possible?*

Extremely important

Very important

Somewhat important

Not very important

Not important at all

2. Should every person aged 65+ be regularly screened to detect Alzheimer's disease as early as possible?*

Yes

No

3. If you answered "No", then what is the reason behind it?

4. What initiates most often the evaluation of the patient to detect Alzheimer's disease?

Patients' age

Alzheimer's disease in family

If I feel the patient has memory problems

If patient is concerned about memory problems

If patients' relative is concerned about patients' memory problems

I do not know

Other: _____

5. Which screening test do you use most often to evaluate patients with suspected Alzheimer's disease?*

MMSE (Mini-Mental State Examination)

MoCA (Montreal Cognitive Assessment)

Clock-drawing test

I do not use screening tests usually

Other: _____

6. If you do not use screening tests usually, then what is the reason behind it?

7. Do you feel generally confident in Alzheimer's disease diagnosing?*

Yes

No

I do not know

8. In your opinion, what could raise the confidence of family physicians in Alzheimer's disease diagnosing?*

9. In your opinion, what is causing the Alzheimer's disease underdiagnosing in Estonia?*

APPENDIX 3. Interview guide in English

INTRODUCTION

- Introducing the aim of the thesis and the interviewer
- Asking demographic information (age, length of working experience)

INTERVIEW

Topic 1: Population screening and the future use of technology

Background: Based on previous studies, family physicians consider detecting AD as early as possible important, but do not generally support population screening.

1. How do you feel about population screening?
2. How do you feel, if technological solutions like self-testing in the web /digitization of screening tests could be useful in the future AD screening process?

Topic 2: AD suspicion

Background: According to the Estonian Dementia Treatment Guide, a family physician is a key person in the primary evaluation of patients with AD suspicion. The first step in case of AD suspicion according to the Guide is to take a thorough history from patients and the relatives. In case of AD suspicion, everyone should be screened with MMSE.

1. How does the patient management currently work or how it should work in case of AD suspicion?
 - a. When does the physician suspect AD (reported by patient/relative)?
 - b. What is your opinion about the role of family physicians in the management of patients with AD suspicion (concerning screening and diagnostics)?
 - c. Is it possible in reality to get the patients' history from the relatives?
 - d. Have you used cognitive screening tests in practice?
 - i. If yes, then which test do you use most often to evaluate possible AD (MMSE, CDT, MoCA, else)?
 - ii. What is your opinion about the MMSE?

- iii. If you do not use any screening tests, then what is the reason behind it?
- iv. If you do not feel comfortable with the test or not familiar with the test, then would you see the necessity for appropriate training?

Topic 3: Concrete AD suspicion

1. When there is a concrete AD suspicion, what is the usual practice in patient management?
 - a. Do you refer patients to extra investigations? To who? Which investigations (early-onset AD/late AD)? Are these investigations accessible enough for the patients, will the patients agree with these/are patients capable of going to these investigations? If not, then why?
 - b. Do you refer patients to other specialists? To which specialist (psychiatrist, neurologist, geriatrist)? Are their visits accessible enough for the patients, will the patients agree with these/are patients capable of going to these visits? If not, then why?

Topic 4: AD patient management based on the Guide

Background: In case of concrete AD suspicion, every patient must have a set of blood tests and CT or MRI scan.

1. Is taking the blood test in primary care settings reasonable?
2. Is following the recommendations from the Guide feasible?

ENDING

- Asking any extra comments or information that the physician would like to share about the topic.
- Asking the permission for further contact in case there are any questions coming up in analyzing the results.
- Thanking the physician for the participation.

APPENDIX 4. Interview guide in Estonian

SISSEJUHATUS

- Uurija ja uurimuse tutvustamine
- Demograafilise informatsiooni küsimine (vanus, tööstaaž)

INTERVJUU

Teema 1: Populatsiooniskriining ja tehnoloogiliste lahenduste kasutamine tulevikus

Taustinfo: Varasemad uuringud näitavad, et perearstid toetavad AT võimalikult varajast avastamist, kuid ei poolda üldiselt populatsiooniskriiningut.

1. Mida Teie arvate populatsiooniskriiningust?
2. Mis Te arvate, kas erinevad tehnoloogilised lahendused võiksid olla tulevikus AT skriinimisprotsessis kasulikud? Millised lahendused (enesetestimine veebis/digitaliseeritud testid)?

Teema 2: AT kahtlusega patsient

Taustinfo: Vastavalt ravijuhisele on perearst võtmeisik AT kahtluse korral esmasel hindamisel. AT kahtlusel tuleb võtta põhjalik anamnees nii patsiendilt kui ka tema hooldajalt/lähedaselt. AT kahtlusel tuleb kõigil patsientidel läbi viia MMSE.

1. Kuidas AT kahtluse korral edasine haige käsitus praegu toimub ja kuidas see võiks toimuda?
 - a. Millal tekib arstil kahtlus AT-le (kaebused patsiendi/lähedaste poolt)?
 - b. Milline on Teie arvamus perearsti rollist AT kahtlusega patsiendi käsitusel (eeskätt varajane diagnostika)?
 - c. Kas praktikas põhjalik omaste hinnangu saamine võimalik?
 - d. Kas olete praktikas kasutanud sõel- ehk skriiningteste?
 - i. Kui jah, siis millist skriiningtesti kasutate kõige sagedamini Alzheimer'i tõve kahtlusega patsiendi hindamiseks? (MMSE, kella-test, MoCA, muu)?
 - ii. Milline on Teie arvamus MMSE-st?
 - iii. Kui Te ei kasuta enamasti skriiningteste, siis mis on selle põhjus?

- iv. Kui te ei tunne end skriiningtesti kasutamisel kindlalt/pole testidega tuttav, siis kas näeksite vajadust selleteemaliste koolituste järele?

Teema 3: Konkreetne AT kahtlus

1. Milline on praktikas tavaline patsiendi käsitus konkreetse AT kahtluse korral?
 - a. Kas saadate patsiendi lisauuringutele? Kelle juurde? Millistele (varajase/hilise algusega AT)? Kas lisauuringud on teie arvates patsientidele piisavalt kättesaadavad/kas patsiendid nõustuvad/saavad uuringutega? Kui ei, siis miks?
 - b. Kas suunate patsiendi eriarsti juurde? Millise eriarsti (psühhiaater, neuroloog, geriaater) juurde? Kas eriarsti visiidid on teie arvates patsientidele piisavalt kättesaadavad/kas patsiendid nõustuvad/saavad eriarsti visiidil käia? Kui ei, siis miks?

Teema 4: AT-ga patsiendi käsitus vastavalt ravijuhisele

Taustinfo: Kõigile patsientidele, kellel kahtlustatakse AT-d, tuleb teha vereanalüüs ning KT või MRT peaajust.

1. Kas vereproovi võtmine perearstikeskustes on teostatav/mõttekas?
2. Kas Ravijuhendi soovitude järgimine on teostatav?

LÕPETUS

- Kas teil on antud teemal veel lisamõtteid või kommentaare, mida sooviksite meiega jagada?
- Kui meil tekib lisaküsimusi intervjuude analüüsimisel, kas tohime veel teiega ühendust võtta?
- Täname, teie vastused on selle teema uurimisel väga olulised.