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HEALTH LITERACY AND DIABETES: CHALLENGES IN COMMUNICATING DIABETES-RELATED INFORMATION REPORTED BY THE DIABETES NURSES

Master's thesis

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TERVISEKIRJAOSKUS JA DIABEET: DIABEEDIÕDEDE VÄLJAKUTSED DIABEEDIALASE INFORMATSIOONI KOMMUNIKEERIMISEL

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Author’s declaration of originality

I hereby certify that I am the sole author of this thesis. All the used materials, references to the literature and the work of others have been referred to. This thesis has not been presented for examination anywhere else.

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Abstract

The focus of this thesis is to describe the challenges that diabetes nurses are facing in communicating diabetes-related information to patients and suggest improvements to enhance patient-provider communication.

For the research, explorative in-depth semi-structured interviews were used to gain insight on diabetes nurses views and perceptions about the topic. There were 10 diabetes nurses interviewed using the snowball sampling method. The interview guide was developed based on literature findings and modified accordingly after the pilot interview.

The results of this study show that patients tend to not read diabetes-related materials in between their appointments. Most of the diabetes nurses rate the quality of diabetes patient education materials to be poor. Nurses are not assessing patients' health literacy levels in clinical settings in general, or with specific instruments. Many nurses found different technological patient education solutions to be advantageous, but they rather find these to be suitable for younger generations.

There were several communication improvement possibilities brought out in the discussion. Three main suggestions include offering regular trainings for diabetes nurses on how to communicate with the patients, while setting an emphasis on health literacy; forming a workgroup which would produce comprehensive and up-to-date diabetes-related materials; raising discussing in between involved parties on how to enhance interdisciplinary teamwork to improve patients' referral to diabetes nurse's appointment.

This thesis is in English and contains 56 pages of text, 3 chapters, 2 figures, 1 table.

Annotatsioon

Tervisekirjaoskus ja diabeet: diabeediõdede väljakutsed diabeedialase informatsiooni kommunikeerimisel

Uuringu eesmärk on kirjeldada diabeediõdede väljakutseid diabeedi-alase informatsiooni kommunikeerimisel ning anda soovitusi selle tõhustamiseks.

Diabeediõdede arvamuse uurimiseks kasutati poolstruktureeritud süvaintervjuusid. Intervjuudel osales 10 diabeediõde. Intervjuude läbiviimiseks kasutati lumepallimeetodit. Kirjanduse ülevaate põhjal koostati intervjuu kava, milles tehti muudatusi pärast pilootintervjuu läbiviimist.

Uuringutulemused näitavad, et patsiendid pigem ei loe diabeedi-alaseid materjale visiidivälisel ajal. Enamiku diabeediõdede arvates on diabeedi-alaste materjalide kvaliteet kehv. Õed ei ole teadlikud tervisekirjaoskuse mõõtmise instrumentidest ning ei kasuta neid patsientide tervisekirjaoskuse hindamisel kliinilises keskkonnas. Paljud diabeediõed usuvad erinevate tehnoloogiliste vahendite kasulikkusesse, kuid peavad neid sobivaks pigem noorematele generatsioonidele.

Töö diskussioonis toodi välja erinevaid soovitusi kommunikatsiooni tõhustamiseks. Kolme tähtsama soovituse hulka kuuluvad regulaarsete kommunikatsioonialaste koolitusvõimaluste pakkumine diabeediõdedele, pannes erilist rõhku tervisekirjaoskusele; moodustada töögrupp sisukate ja ajakohaste diabeedi-alaste materjalide loomiseks; diskussiooni tekitamine erinevate seotud osapoolte vahel eesmärgiga parandada interdistsiplinaarset meeskonnatööd, et patsiente suunataks diabeediõdede visiidile.

Lõputöö on kirjutatud inglise keeles ning sisaldab teksti 56 leheküljel, 3 peatükki, 2 joonist, 1 tabelit.

List of abbreviations and terms

DNT	The Diabetes Numeracy Test
eHealth	electronic health
EHIF	Estonian Health Insurance Fund
EHR	electronic health record
HLS-EU	The European Health Literacy Survey
IDF	The International Diabetes Federation
mHealth	mobile health
NVS	The Newest Vital Sign
REALM	The Rapid Estimate of Adult Literacy in Medicine
TOFHLA	The Functional Health Literacy in Adults
WHO	World Health Organization

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1 INTRODUCTION

Diabetes describes a group of metabolic disorders, which are causing elevated blood glucose levels [1]. Regular visits to health care providers help to maintain a good level of control over the disease and prevent and manage possible complications [2]. As diabetes prevalence is rising rapidly, it will pose a serious challenge to the health care systems in the coming years, including in Estonia [3].

Health literacy is an essential skill for an individual – to be able to read and understand health information, discuss their test results with the provider and make right decisions based on the collected information [4]. Studies in the United States showed that around 30% of patients had inadequate health literacy [5][6]. One study in Europe found that 12,4% of study participants had inadequate health literacy. Nearly one-third of participants (35,2%) had problematic health literacy [7].

Identifying individuals with poor health literacy is essential in health care settings. Not only can poor health literacy levels impact the patient's health, but people with lack of interest, knowledge, understanding and self-care skills can burden the system financially and increase the workload for doctors [8][9]. There are various general measurements to assess health literacy [10][11][12] and also some specific to measure diabetes-related health literacy [13][14][15].

Improving an individual's health literacy level could help to raise one's motivation and knowledge to manage their health throughout the lifetime [16]. Effective communication between the patient and provider leads to enhanced patient satisfaction and adherence to disease management plan [17].

eHealth and mHealth solutions hold great potential in supporting the patient-provider communication, as these are widely spreading among younger generations [18].

Diabetes nurse performs an important role in diabetes patient care, where the main role is to counsel, support and motivate the patient [19].

The aim of this thesis is to describe the challenges that diabetes nurses are facing in communicating diabetes-related information to patients and suggest improvements to enhance patient-provider communication.

Research questions:

How is diabetes-related health information communicated to patients in Estonia, in which formats?

How do diabetes nurses evaluate the quality and purposefulness of supplementary diabetes materials that are shared with the patient?

How do diabetes nurses evaluate their patients' understanding of diabetes-related health information?

What could be technological solutions diabetes nurses see that would enhance diabetes-related health literacy?

2 LITERATURE OVERVIEW

This chapter is based on a literature review. The following section gives an overview about diabetes, health literacy and patient-provider communication.

The methodology of health literacy and diabetes study made among Estonian diabetes nurses is also brought out in the final section of the literature review.

2.1 Diabetes

Diabetes is a very complex chronic disease that demands education, management and comprehensive self-care skills from an individual with the diagnosis [8].

Diabetes is mostly diagnosed by primary health care practitioners and treated by endocrinologists in secondary care, but diabetes nurses are the specialists who help diabetics to manage their disease [20].

2.1.1 Diabetes definition, statistics and prevention

Diabetes describes a group of metabolic diseases, which are causing elevated glucose levels. Main forms of diabetes are type 1 diabetes, in which case pancreas does not produce insulin (mostly younger people affected) and type 2 diabetes – the body does not respond properly to the insulin production by pancreas (mostly adults affected) [1].

Of all the people with a diabetes diagnosis, around 90-95% have adult-onset diabetes or known as type 2 diabetes. This form of diabetes is often under-diagnosed in earlier development years because the symptoms develop gradually and might not be so severe [1]. It has been evaluated that every second adult with diabetes is undiagnosed [8]. Most patients with type 2 diagnosis are overweight, which already causes some level of insulin resistance [1]. People who are overweight and also physically inactive are estimated to constitute the main proportion of diabetes burden globally [21].

Due to obesity and sedentary lifestyle, type 2 diabetes occurrence is rapidly increasing among adolescents and young adults [22]. Mostly it is effectively possible to delay or prevent type 2 diabetes with proper nutrition and regular physical activity [21].

Diabetes prevalence is a rapidly increasing problem in the world. According to the report by the World Health Organization (WHO), there were an estimated 422 million people globally with a diabetes diagnosis in 2014, which is 8,5% of the adult population [21]. In 2017, there were 55,300 diabetes cases in Estonia, the prevalence of occurrence in adults was 5,7% [8]. It is estimated that by the year 2045, there will be 629 million people worldwide with diabetes [23].

Due to chronic diseases, also known as noncommunicable diseases, 41 million people die every year globally, which marks 71% of all deaths [24]. Diabetes was the 7th cause of death to 1.6 million people in 2016, which made it 7th cause of death in the world [25].

Healthy lifestyle, like consuming healthy foods, regular activity and weight management can prevent onset of type 2 diabetes. Regular screenings are recommended for risk groups [26].

2.1.2 Diabetes diagnostics, treatment and care

To manage one's health and have a good quality of life with diabetes, it is essential to diagnose and start treating the person with diabetes diagnosis as early as possible [21]. Type 2 diabetes is usually diagnosed with glycated haemoglobin (HbA1c) test that shows a person's average glucose level for the past few months. For the glycated haemoglobin test, patient does not need to be in a fasting condition, but this measurement is more costly than blood glucose measurement. Type 2 diabetes patients should have their glucose level monitored two times a year and type 1 patients more often [21]. Other possible tests to detect signs of diabetes include random or fasting blood glucose tests or oral glucose tolerance test [26].

In Estonia, diabetes is mostly diagnosed by primary health care practitioners. An endocrinologist is a specialist who diagnoses and treats diabetes patients in secondary care level. Education about the disease and management guidelines are provided by a diabetes nurse or specially trained family nurse [19]. Regular visits to health care

providers help to maintain a good level of control over the disease. Complete health checks are conducted annually to prevent and manage possible complications due to diabetes disease [2]. Diabetes patients visited providers on average 10,3 times in the year 2013, where 42% of the visits were made in secondary care. The greater proportion of diabetes treatment cases are managed in secondary care. On primary care level, the diabetes care tends to be regionally inconsistent [3].

According to the Estonian type 2 diabetes treatment guide, treatment is commenced right after diagnosing the disease, if tested blood glucose levels are elevated. A patient gets an education about a suitable diet, recommendations for lifestyle and self-care from the health care personnel. The patient also needs assistance and training on how to properly use the glucometer and injection device. Disease management effectiveness is being monitored over time and adjusted according to the needs [20].

Monitoring blood glucose levels regularly is essential to prevent any complications from developing and progressing. Patients who are receiving insulin need to self-monitor their blood glucose levels daily. Poorly managed diabetes can cause some serious complications in many parts of the body and affect blood vessels, heart, kidneys, eyes, and nerves. Acute complications of diabetes disease are a large cause of mortality, poor life quality and high costs [21]. There are several risk factors contributing to the occurrence of cardiovascular diseases, like elevated glycated haemoglobin level, low-density lipoprotein (LDL) level, systolic blood pressure, also albuminuria and smoking. According to the Rawshani et al. research, if these risk factors are in the normal range, it has no marginal risk of death, stroke and myocardial infarction for the diabetes patient compared to the general population [27].

The Estonian Health Insurance Fund (EHIF) has contracts with 17 providers all over Estonia, who are offering various endocrinological services [28]. There are 22 regional associations supporting local diabetes care [29]. The International Diabetes Federation (IDF) is an organization that provides support and resources for people and health care providers dealing with diabetes care and management. The IDF is uniting different national diabetes institutions from all around the world and in Estonia it’s an official member is Estonian Diabetes Association [8].

2.2 Diabetes care and health literacy

Various sets of skills form a person's health literacy level – besides reading and writing, listening, the basic level of numeracy, knowledge, and speaking are important for understanding health information [4]. Limitations in health literacy lead to poor knowledge about health issues, inferior health status, higher rates of hospital admissions and more costly health care [30].

Numeracy is part of literacy which basically means the ability to daily use and understand numbers [15]. Numeracy is an essential factor affecting diabetes patient's care and treatment process. Numeracy plays an important role in effective diabetes care – person daily needs to calculate the number of calories, read food labels, interpret glucose readings and make decisions based on the results. A number of studies indicate that numeracy is a great issue in diabetes self-management [31][32][33]. A study that analysed diabetic patients medication costs over 2 years concluded that patients with limited health literacy had created higher medical costs [34].

A cross-sectional survey about diabetes-related numeracy relations with glycemic control concluded that low numeracy skills were associated with diabetes patients. Most common errors patients made were related to miscalculating the medication doses and necessary carbohydrate intake, also misinterpreting their glucose measuring device's readings [35].

A literature overview study found that low literacy is associated with many poor health outcomes, like knowledge about health services and outcomes, general health status and also the use of health resources [36]. Specifically, health literacy has shown to be a more effective indicator of health outcomes than for example a person's age, earnings, education level, race, an occupation status, or ethnicity [37].

2.2.1 Health literacy definitions

Health literacy has had many different definitions. Earlier definitions focused on patients only in the health care system and their understanding of medical data presented by the doctor. Newer specifications include health promotion and preventive aspects outside the clinical environment [16]. WHO defines health literacy as follows: 'Health literacy represents the cognitive and social skills which determine the

motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health' [38].

Nutbeam describes health literacy in three levels: (1) functional health literacy, which focuses on the individual's basic knowledge; (2) interactive health literacy, which emphasises on the development of personal skills; (3) critical health literacy includes advanced skills to critically analyse given information and apply them to life. According to this classification, individual and society both have benefits in all these three levels. Individuals' benefits include healthier lifestyle choices and improved ability to make independently better health-related decisions. Social benefits include improved interaction with social groups and improved empowerment of the community [39].

Sorensen et al. developed an integrated definition for health literacy concept based on 17 previously described definitions: 'Health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgements and take decisions in everyday life concerning health care, disease prevention and health promotion to maintain or improve quality of life during the life course' [40].

2.2.2 Health literacy statistics

According to the UNESCO Institute for Statistics data, the global literacy rate in the year 2016 among adults (15 years and older) was 86%. For young people, aged 15-24 years, this rate in the same year was 91%. There are still around 750 million people globally, who are illiterate and almost two-thirds of them are women [41].

The European Health Literacy Survey (HLS-EU) was the first comparative project for health literacy in the EU. The survey was conducted in 8 European countries. Aim for the HLS-EU was to develop a measurement instrument and analyse health literacy across diverse nations in the European Union. For the HLS-EU survey, the European Health Literacy Survey Questionnaire (HLS-EU-Q86) was developed [7].

In the United States, studies showed that around 30% of English-speaking patients had inadequate health literacy [5][6]. Available population data about European health literacy status has remained poor [40]. The HLS-EU found that 12,4% of study

participants had inadequate health literacy, this rate varied from 1,8 to 26,9% by country (Figure 1). Nearly one third of participants (35,2%) had problematic health literacy [7].

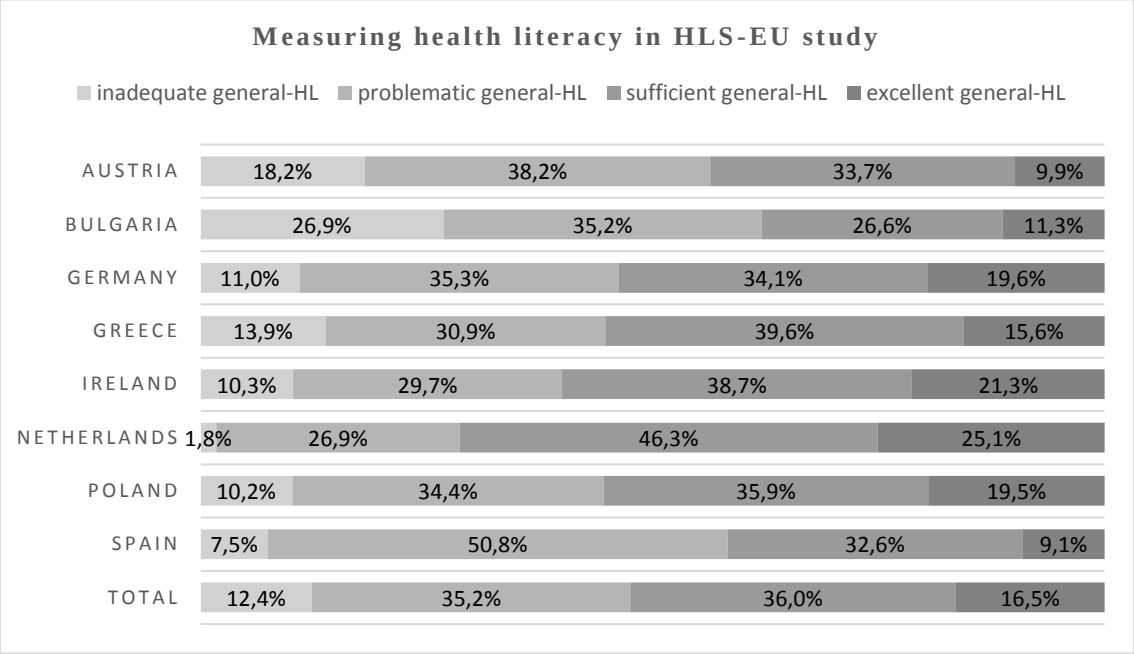

Figure 1. Health literacy indexes from HLS-EU.

European Commission's report concluded that in Estonia some national policies and programs might connect with health literacy, but no actions specifically towards improving population health literacy levels were found [42]. The EHIF has set a goal to assess the population's health literacy levels from the year 2018. Health literacy instrument will be designed based on validated tools from earlier studies conducted in the EU and international levels. The EHIF's development plan 2018-2021 states the need to enhance health literacy to raise people awareness on health topics and find ways to promote science-based medical information distribution [43].

2.2.3 Identifying patient's health literacy level

Low health literacy level affects heavily patient's own care processes and health status, but also increases providers' workload and will have an effect on the health care system financially [8][9]. However, measuring and assessing individuals' capabilities in health care settings can be a difficult task for the providers as lacking skills might not be that obviously detectable. Bass et al. study indicated that in everyday clinical settings, health care workers might overestimate the patient's literacy level. Residents believed that

10% of studied individuals might have low health literacy, but actually, the proportion was 36% [44]. Some patients with low literacy level tend to overestimate their skills [45].

Providers might avoid screening patients' health literacy because they are afraid to offend the patient with the request. Also, they tend to assume patient's literacy levels by the appearance or on school education level. Individuals, on the other hand, might overestimate their health literacy levels, because they are ashamed to admit reading problems [45] and try to mask those impairments from health care workers [46]. There are many aspects that could influence a person's mindset during the assessment test, like current health issues and test anxiety [11]. The contrary conclusion was made in a study published in Health Education Research Journal, finding that literacy assessments did not decrease patient satisfaction with the health care service [30].

A study investigating patients' views on documenting literacy levels in medical records stated that more than 90% of patients found it to be little, somewhat, or very useful information for medical personnel [47]. Seligman et al. investigated the outcomes of informing physicians about diabetes patient's limited health literacy. 64% of physicians and 96% of studied patients admitted health literacy screening to be useful [48].

2.2.4 Health literacy measurements

Numerous measurements for health literacy have been developed, though no unison tool has been described to measure literacy in clinical settings. There are two main tools to assess health literacy: The Rapid Estimate of Adult Literacy in Medicine (REALM) and the Functional Health Literacy in Adults (TOFHLA) [11]. The REALM is the first screening instrument to evaluate individuals' ability to read common medical terms and help physicians to identify patients with poor reading skills so that the most efficient approach can be used [10]. This recognition tool consists of 125 medical words commonly used in the primary care level, though it is not evaluating persons' knowledge of those words [37]. The TOFHLA instrument consists of health-related tasks to evaluate individuals reading as well as numerical skills [49]. The reading part is structured as passages from actual medical materials, where the reader needs to fill in the blank spaces with suitable answers, where each space has four possible choices with similar context or grammar. Numeracy part evaluates a person's skills to understand and use simple numerical concepts [11].

Weiss et al. have developed a health literacy measurement tool Newest Vital Sign (NVS). An ice cream container's nutritional label is shared with the patient and then six questions about the label is asked from the patient with possible response options (correct or incorrect). Based on the scoring outcome provider can adjust their communication practices, so the patient has a better understanding of shared medical information and follow instructions. The nutritional label was chosen for the instrument as it requires similar reading and analysing skills a person needs to have in the clinical settings [12].

An online database has collected 172 instruments that measure health literacy into one tool shed, from which 9 measures are specifically designed for diabetes health literacy [50]. The Literacy Assessment for Diabetes instrument was specifically developed for diabetes and measured an individual's ability to pronounce words that they would likely encounter during their disease management [14]. A specific tool to assess individuals' diabetes-related numeracy was developed in 2008 called the Diabetes Numeracy Test (DNT). The DNT assesses a variety of skills that diabetes patient may need during everyday care, like glucose monitoring, nutrition, exercise, medication administration. [15]. Patients who had completed formal diabetes education had better DNT scores than patients without the education [31].

The Diabetes Literacy and Numeracy Education Toolkit is a tool that was developed for patients to help them understand diabetes education and management materials [13]. The toolkit consists of modules about insulin administration and dosing, base information about exercising and nutrition. Although toolkit was specifically designed for patients with lower literacy and numeracy skills, it is beneficial educational material for all diabetes patients [51].

A study that used the NVS instrument to assess diabetes patients' health literacy found that 65% of the participants had limited health literacy. Results did find a positive correlation between lower educational level, though the correlation between age and health literacy was not found [37]. Another study in Japan indicates that besides the lower educational level, advanced age and low economic status are connected with poor health literacy [52]. Schillinger et al. study among patients with type 2 diabetes found that deficient health literacy was related to poor glycaemic management and higher

occurrence of retinopathy [53]. Smaller scale study similarly noted a trend in insufficient health literacy and weak blood glucose management [54].

2.2.5 Importance of health literacy in health care

Health literacy is an important skill for a person to have – to be able to read and understand health information, discuss his/her test results with the doctor and make right decisions based on the collected information [4]. Furthermore, with the Internet and rapid expansion of media over the last two decades, people have access to countless health information sources that are not overviewed and confirmed by health care personnel [55].

People with low health literacy might find filling in clinical forms challenging and embarrassing if failing to succeed. Understanding and recalling correct medication administration instructions is especially problematic for patients with several prescriptions. Also, patients often find hard to communicate with doctors and nurses as medical vocabulary is technical and medical staff does not seem to have time to explain things over in plain language [56]. Several studies show that individuals with poor health literacy are more likely to deviate from prescribed treatment and mistreat medical instructions from their health care provider [57][58][5].

Improving an individual's health literacy skills could raise one's motivation and knowledge to promote a healthy lifestyle and manage their own health behaviour throughout life [16]. Engaging and activating a person in their own health improves an individual's willingness and desire to manage their own well-being and health. Focusing on engagement and activation rather than compliance is important as a person needs to manage their health mostly out of health care settings and make independent decisions daily on their own [59]. Though, Graffigna and Barello's study concluded that patients do not necessarily need more engagement to their care processes, but rather more individual approaches in different settings [60].

Patient adherence is described as a level to which an individual follows the health care worker's recommendations. On average 25% of patients fail to follow their health care management and prevention plans [61], for chronic patients this rate is even nearly 50%. Health literacy has been strongly associated with compliance [62]. Health literacy

interventions are studied to be effective in improving individuals' health literacy and compliance with treatment [63].

2.3 Patient-provider communication

Effective patient-provider communication is a key point to enhanced patient satisfaction and adherence to disease management plan [17]. Patients tend to be able to recall only 50% of the information that the provider shares with them. Also, patients find it uncomfortable to ask clarifications [64]. Health care providers tend to notice the patient's problems to understand their instructions but hope that paper handouts will solve the patient's confusion and answer remained questions. Though, several studies demonstrate that health care materials are often written in too complicated ways for an average person to understand [65][66].

When providing management and direction information to the patient, it is recommended to use simple and clear instructions, limit the amount of info and let patient reflect back received information [17].

Many strategies are used to make patients' feel more comfortable and shame-free in clinical settings, like introducing yourself, offering assistance with paperwork, ensuring the private environment, and being kind and respectful towards the patient [17].

Rudd concludes that if addressing literacy and health outcomes in the same settings, it is necessary to evaluate different perspectives. When evaluating a person's literacy, the evaluation of providers' communication skills is also needed. Furthermore, practice's policies should be assessed together with the providers' communicative skills. [67].

Across the world, health care costs are rising each year. To manage the number and costs of hospitalisations, re-admissions and follow-up care, it is important to engage people in medical decision making, as it may support the patient's self-care alongside medical interventions. Patient-centred care focuses on the individual's needs and engagement level to achieve better health outcomes. To achieve effective patient-centeredness, it is essential for the patient to understand her/his health care information and current health status. If a person can express their own opinion and discuss their ideas about lifestyle or condition management, they might be more interested to

cooperate with health care practitioners and take actions to maintain or improve their health [68][59][69].

Simmons et al. systematic literature overview about patient involvement in personalised health care indicated patient's engagement improvement in 9 out of 10 studies, from which all 5 trials investigating interventions for diabetes reported upgrades. Diabetes studies also reported improvements in glycated haemoglobin (HbA1c) reduction, lipid ratios, blood pressure and in lifestyle behaviours [70].

Ten features are characterising health literate patient care in an organization containing easy access to medical information and spreading clear and simple print and audio-visual materials. Navigational tasks include finding a correct health care building, connecting with the needed provider and finding health information [71]. Methods of health information presentation play an important role in individuals' capability to understand and apply medical information shared with them [72]. Educational materials should not replace in-person lessons, the information should be presented in simplified ways [71].

There are several methods to communicate health information to patients. The most common is paper materials, like different forms, medication labels, brochures, and fact sheets. Using visuals is especially beneficial for patients with lower literacy, but also simplifying materials for every person. More and more, individuals turn to the Internet to obtain information from websites, blogs, via email and patient portals. Also, some people prefer direct communication with medical staff [17].

2.3.1 Technological interventions for communication

Electronic health (eHealth) term combines health-related information and services that are processed through different technological solutions and the Internet, like electronic medical records, patient portals, online communication solutions with providers. As eHealth services are widely spreading, people are assumed to have sufficient health literacy levels to use the features [18]. In 2012, it was reported that 77% in the age group of 50-64 and 53% of elderly Americans (aged over 65) used Internet services occasionally. Main reported reasons for elderly people not to use the services are anxiety about computer usage, health issues and disbelief to technology capabilities [73]. Though, in a survey, 83% of low literate diabetes patients' reported that they

would learn or enhance their computer skills to know more about diabetes [74]. According to Eurostat, around 45% of elderly (aged 65-74) in the European Union and around 47% of elderly people in Estonia used the Internet at least once a week in 2016 [75].

Patient portals are web-based platforms, where patients can view their medical information provided from health care organisations' electronic health record (EHR). From the portal, a patient can find laboratory results, visit comments/summaries, manage their appointments and communicate with health care providers [76]. Some EHRs have functionality to send educational materials via patient portal to the patient. The individual receives a notification to the portal and can access the materials and complete them for the next visit. The provider has the possibility to track the completion process. This process helps the patient prepare for upcoming visits and helps the provider educate patients about their diagnose with scientific materials [77]. Portals that are directed to diabetes disease, provide several features for patients. The patient could upload their blood glucose monitor results and lifestyle information to the EHR, and get educational materials about the disease [76].

Web-based intervention solutions for patients' communication and education purposes tend to lose their users over time. There need to be some changing or motivational parts during the process, so individuals would not lose their interest [78]. Interactive multimedia content, like educational videos, is shown to be an effective method to present health information to individuals from various generations [18].

As people increasingly use their mobile phones for everyday errands - mobile applications show great potential in making health services more accessible for a wider range of patients and support their disease management processes. Mobile health (mHealth) technologies combine health care solutions via person's mobile phones, like disease tracking, lifestyle management, remote monitoring and communication [18]. Limitations for described intervention includes older adults not being engaged with mobile phone usage overall and that engagement greatly depends on the person's own motivational level [78].

2.3.2 Diabetes nurses and communication

According to the Estonian diabetes treatment guideline – a family nurse, who is specially trained in diabetes care or a diabetes nurse, gives diabetes-related education to the diagnosed patient. Patients are directed to the diabetes nurse appointment by the family doctor or endocrinologist [19]. Nurses have an important role in patients' disease management and treatment path inside health care settings and beyond [45]. Diabetes nurse provides counselling and care in various topics related to diabetes, like explaining the disease (the nature of the disease, symptoms of blood glycose derivation, possible complications, etc); gives information about the disease management; educates about healthy nutrition; supports and motivates the patient [19]. Patients find nurses to be more approachable if they have any issues with the care [79].

Patients with chronic disease and low health literacy are especially difficult to manage in health care settings, as they need special attention from the provider to ensure that management instructions and medication schemes were understood [17]. Study about nurses' assessment of patients' health literacy levels demonstrated that nurses are overestimating individuals' health literacy [80].

For diabetes patients, it is extremely important to know when they are about to experience symptoms of too low or too high blood glucose levels and how to act when it happens. A study showed that even when diabetes patients got the education, half of them did not recognise the symptoms of hypoglycaemia and two third of individuals did not report eating something as an emergency self-care [54]. Another study found diabetes-related education to show effect for patients with limited health literacy as they committed more to self-care reporting [81].

In a Brief Health Literacy Screen (BHLS) study, several nurses pointed out that they would like to have more training on how to communicate with patients who have identified with low literacy [82].

Interim evaluation report on Estonian National Health Plan 2009-2020 suggests improving medical support services availability, like nutrition advising and diabetes nurse services. Also, it is advised to increase the number of service providers and regional coverage [3].

2.4 Methodology

In this study, diabetes nurses' challenges in communicating diabetes-related information were investigated by using qualitative semi-structured in-depth interviews. A qualitative method was chosen for this study to gain diabetes nurses' experiences and personal perspectives regarding the topic. Semi-structured interview method provides more personalisation for each interview and helps to keep the discussion's focus. In-depth interviews allow interviewees to express their deep thoughts on the matter [83].

The study is exploratory, meaning that it concentrates solely on exploring research questions and helps to gain a better understanding of the problem [84]. According to the author's knowledge, there has not been conducted any studies about the topic in Estonia and this method is suitable for gathering primary base information for further studies.

As there were no direct sources to approach diabetes nurses for this study, the exponential non-discriminative snowball sampling method was used to take advantage of this small community's people-to-people contacts [85]. Snowball sampling bases on the advantage to use first interviewees to contact with the following ones. This chain process continues until no additional relevant information is gathered [86].

Interviews were combined from face-to-face and phone interviews. Though, face-to-face interviews are being preferred while conducting in-depth interviews, interviewing participants over the phone offers great potential for the researchers [87]. Interviews were voice recorded to help the interviewer to focus on the discussion with the participant and to collect interviewees' verbatim thoughts for data transcription [88]. To process the data collected from interviews, thematic analysis principles were implemented [89].

3 HEALTH LITERACY STUDY AMONG DIABETES NURSES

The following chapter describes how in-depth semi-structured interviews were conducted with diabetes nurses in April 2019.

This chapter consists of detailed description about study materials and methods, results, discussion section and conclusions.

3.1 Materials and methods

Diabetes nurses' challenges communicating diabetes-related information were investigated in this explorative study by using qualitative semi-structured interviews.

Interviewees were approached using the snowball method. A semi-structured interview guide was used to keep the discussions focused and to ensure that all the questions of interest were discussed.

To the author's knowledge, no research about health literacy in diabetes care has been done in Estonia.

3.1.1 Development of the guide for interviews

An interview guide with semi-structured questions (in appendix 1 and 2) was developed to explore diabetes nurses' perspectives about (1) communicating diabetes-related information and materials; (2) quality of the materials; (3) health literacy assessment; and (4) technological support solutions.

The demographical information collected about the nurse was age, years worked as a diabetes nurse and county of practice.

The interview guide was developed based on the findings from the literature. Before the interviews, the guide was pretested with one family nurse, who had had some experience with counselling diabetes patients. The goal was to figure out the interview's

approximate length, understand if the questions and terms were understandable and content suitable. One question was added to the interview guide after pretesting with the nurse. The responses of the family nurse were not included to the study.

3.1.2 Interview participants

The number of diabetes nurses in Estonia is varying and there is no unison source for the exact number of diabetes nurses practicing. According to one study, there are around 45 nurses in Estonia, who are providing diabetes-related services [90]. In the Health Board's National Register of Health Care Professionals, there are 12 nurses listed as specialised to diabetes nursing. From which, working position information is missing for 3 of the listed nurses [91]. No accurate database exists.

Although several specialists are involved in diabetes management [19], in this research, only nurses whose occupation is specifically "diabetes nurse" were included to the study.

3.1.3 Interview procedure

The community of diabetes nurses is difficult to reach as there are limited numbers of nurses who provide diabetes counselling in Estonia, there is no database with their working locations, they are not easily tracked without other nurses' recommendations and they have a limited amount of time during a workday. There were no location restraints set for the interviewees. It was done so to gain possibly valuable information from both - nurses from the bigger Estonian cities as well as nurses from the more remote areas.

In-depth interviews with diabetes nurses were conducted during April in the year 2019. To find interview participants, snowball sampling was used. An informational email about the study was shared with the Estonian Diabetes Association - consisting of a short description, the purpose of the interview and declaration of their anonymity regards of the participation. From where the first contact with a diabetes nurse was established. The email address of a new contact suggestion for the next interview was received from previous participants. An email with the study's aim and short introduction was sent to the new contact suggestion. Possible interview's place and time were agreed over the phone or by email.

Interviews were mainly done face-to-face, but to overcome locational and time-restraints in case of three interview participants, an option of Skype and phone-interviews were offered. So, 7 interviews were held face-to-face, 2 by Skype and 1 by phone.

Before each interview, interviewer and study aims were introduced to the interviewee. Also, the anonymity of their responses was declared by the interviewer. Consent was asked to record the interviews with the voice recorder with the purpose not to lose any important information, to use some highlighting quotes in the final paper and to help transcribe the interview.

During the interviews, questions were left open-ended. Some questions were added when the interviewer saw that some answers were leading to the interesting direction and to receive interviewees' deeper insight about the subject. After each interview, the interviewee was thanked for contributing to the research.

Interviewing process was stopped after there was no new information received [86]. In total, ten individual interviews were conducted for this study with diabetes nurses.

Data was directly transcribed from recorded voice files into the excel table in the Estonian language. Direct data transcription enables to use some interesting quotes in the final paper [88]. Each interviewee was signed with the characteristic to ensure their anonymity in the conducted study. As there were 10 diabetes nurses interviewed, each of them received a notation from 'DB1' to 'DB10'.

Thematic analysis principles were used to organise the received data to themes and categories [89]. After the interviews' transcription to Word file, data was coded and themed according to the research and interview's structure questions to Excel file. Supplementary comments from diabetes nurses were also transcribed and themed during the analysis. After the transcription, all the voice recording files were deleted. All the participants agreed.

3.2 Results

The study included in-depth semi-structured interviews with diabetes nurses. Interviews' discussion points were focusing on the challenges that diabetes nurses are facing in communicating diabetes-related information to patients.

Interviews were conducted individually with nurses to gain personal insight and perspectives about the topic.

3.2.1 Demographics

The study included 10 individual interviews with diabetes nurses who regularly work with diabetes patients. All the interviewed diabetes nurses were women. The mean age for the nurses was 47,3 years. The youngest interviewee was 24 years old and eldest 74 years old. Nurses had average working experience for 10,65 years as diabetes nurse.

Seven nurses mainly offered counselling service to type 2 diabetes patients, 1 was working with both (type 1 and 2 patients), 1 diabetes nurse was specialised on children, young adults and pregnant women, and one nurse was specialised on children and young adults.

Nurses presented 6 counties all over Estonia (table 1). The shortest interview duration was 18 minutes and the longest 2 hours. The mean duration for the interviews was 56 minutes.

Table 1. County of practice by the interviewees.

County of practice	**Number of diabetes nurses interviewed**
Rapla county	1
Tartu county	1
Viljandi county	1
Harju county	4
Võru county	1
Pärnu county	2
No. of diabetes nurses in total	**10**

3.2.2 Diabetes-related information to the patient

When asking in which format the diabetes-related information is communicated to the patient in the current settings, nurses used various possibilities. As shown in figure 2, besides oral and exemplary education, 10 diabetes nurses were showing paper materials during the visit and gave additional brochures for patients to study at home. One nurse added that she had put together her own materials, which included information about foods that are better to restrict/avoid; another nurse made a scheme about carbohydrates evaluation, third nurse had one A4 paper with the list of foods that definitely need carbohydrates calculation and another page with foods that do not need the calculation. One diabetes nurse also made 4 or 7-days sample menus for patients.

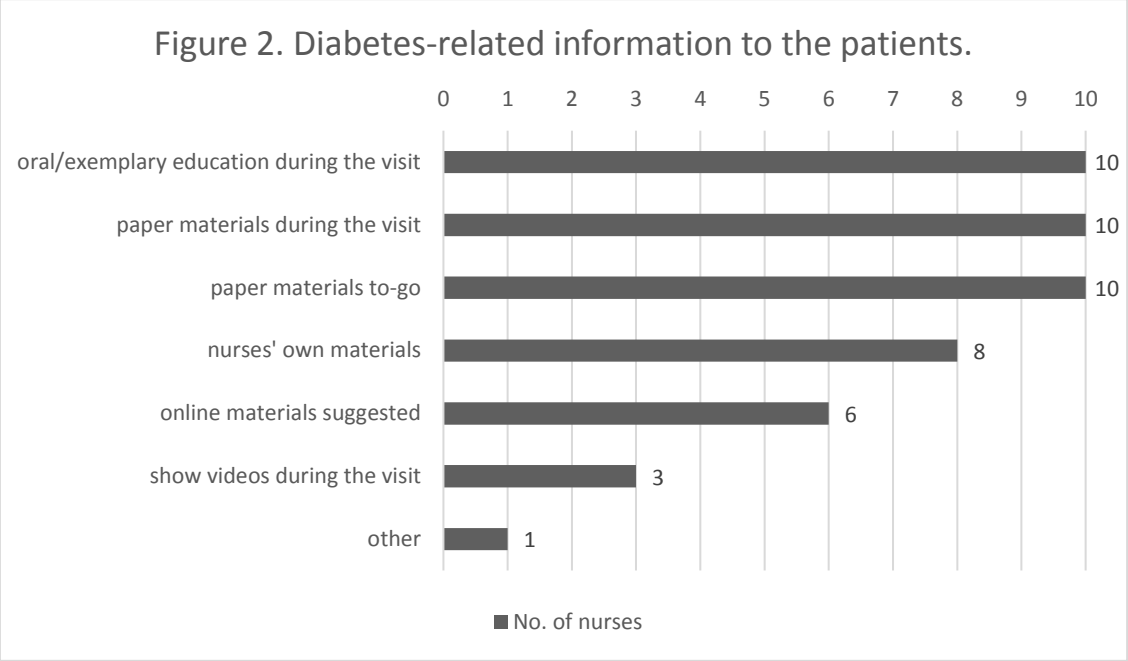

Figure 2. Form of diabetes-related information shared to the patient.

Three diabetes nurses recommend patients to try out different nutrition programs on the Internet (Nutridata, Ampser). Also, some specific webpages were suggested, like toitumine.ee, diabeet.ee, lastediabeet.ee, and the hospital's materials. 3 nurses are showing video materials during the appointment. One nurse also mentioned directing diabetes patients to local diabetes association. Some additional comments were made about sending patients to look for additional information.

"Nutridata, if a person is familiar with computers." DB2

"We cannot suggest much for older people." DB5

"There are possibilities, but it really depends on a person." DB4

Three nurses stated that they do not suggest any additional information sources, like online pages to patients.

"Do not know, where to direct the patients." DB1

"Do not direct usually – we will talk things through during the appointment." DB8

Two nurses additionally commented that the patients rather do not seek any additional information between the appointments. They also mentioned that there are heaps of information and people struggle to find quality information.

In addition to oral communication during the visit, eight diabetes nurses communicate with patients also via phone and two via email, none of the nurses used video solutions to communicate with patients. The main issues patients have for contacting with nurse: too low or high blood sugar levels (3), in case of viral diseases (2), questions about injection (2), daily situations (2), and questions about insulin pumps (1).

When talking specifically about the brochures that diabetes nurses are handing out to the patients, 7 nurses stated that in their experience people do not read them. One nurse commented that maybe 1/3 of patients read the brochures that they receive from the visits. When asked about the brochures' sources, materials developed by pharmaceutical companies, the National Institute for Health Development, and hospitals were mentioned.

"If I am offering brochures to the patient, they just say that they have enough of those at home". DB1

"Patients are telling about the brochures that "I had so many of them and did not have time to read them all through"". DB2

3.2.3 Quality of shared materials

When asking from diabetes nurses how would they rate the quality of the brochures then 7 nurses stated that they are not satisfied with the quality of the materials. The most

mentioned reasons were that different materials do not have unity and sometimes might be controversial and that materials are often outdated.

"A lot of materials are considering that people are very active, but actually this is not the case anymore." DB7

"Materials tend to be uneven. The patient says, "but the picture is showing it like this." A lot of materials need to be explained." DB4

When discussing what type of materials would be most beneficial for patients, four diabetes nurses find that materials need to be very simple and unified, so people would not get confused. Six nurses stated that direct contact, talking and explaining is very important for chronic patients. Three nurses noted that group sessions could be beneficial. Two nurses emphasised that it is very important to stay calm and kind during the appointment, diabetes patients need a lot of motivating too.

"There is no universal material as people are so different." DB8

"Patient's engagement level depends greatly on motivation. If I already see that motivation is low and the patient does not care…then it is difficult". DB3

"Diabetes patients just do not know what disease they have. A lot of explanation and justification needs to be done, the patient's interest grows and there is a bigger chance that they will do what they are told". DB8

"Some people say that they understood, but actually they did not. It comes out in further discussions." DB2

3.2.4 Identifying patient's health literacy level

Five nurses stated that patients rather tell them than the doctor, when they have not understood something that the doctor said, or they have problems with the treatment plan. Three nurses suggested that the reason might be that patients do not want to give a bad impression to the doctor or to "waste doctor's precious time". *"The story for the doctor, the story for the nurse and actual home care are three totally different things – it is really important to listen to the patient. Very good, if those things are coming out." DB8*

"They (patients) do not dare to ask if something was unclear for them." DB1

The most complicated topics for patients to understand according to diabetes nurses are carbohydrates consumption (mentioned by 7 nurses) with short-term insulin (2) and the essence of diabetes as a chronic disease (4).

Seven nurses told that when the patient has not understood or followed given instructions the nurse needs to explain things again and again several times or from a different perspective. Also, one nurse mentioned that life-like examples are helpful, and another nurse told that she lets patients prepare questions for the next visit. One nurse also added: *"Care procedures need to be checked as well and to make sure that patients are conducting them correctly."* DB2

When asked how nurses evaluate patients' understanding of diabetes-related information, seven nurses mentioned that they ask for a reflection (patient explaining what they understood in their own words) back from the patient. One nurse told that she does not know how to evaluate if the patient understood the information. Five nurses stated that from a single visit, patients do not take much information with them, because it is too much for them at once. *"Of course, it would help us (nurses) a lot, when patients come to the appointment and they already know something, because we cannot give much information in one session."* DB10

Diabetes nurses mentioned several supportive methods that they were using to evaluate the patient's health literacy levels. Four nurses said that the blood sugar test results and anamnesis give some feedback about the patient's home care level. Two nurses used nutritional diary that the patient fills in and it allows to assess the person's nutritional habits during the visit. Another nurse used checklist besides anamnesis, where she can see what needs to have more concentration. And she also added: *"I find them to be enough, but it is quite time-consuming."* DB5

None of the diabetes nurses used or had heard about health literacy instruments or tools to evaluate a person's health literacy prior to or during the visit. Two nurses felt uncomfortable about the idea to ask health literacy evaluation questions from the patient.

Three diabetes nurses recalled that there has been one training on how to approach persons with low health literacy level and how to motivate them. Two nurses said that there has been some training about the subject. Six nurses said that additional training

on how to communicate with patients who have low health literacy levels would be necessary for doctors and nurses. One nurse added that communication is a key element for them, as they need to know how to support and motivate patients with chronic diseases. Another nurse pointed out that communication skills are necessary so patients would come back and get the help they need. One nurse said that she is looking for some additional materials on how to save herself from burnout when counselling patients. One nurse added that there are not many trainings offered for staff. *"It is really difficult to build trust-relationship with patients in clinical settings and if they have one 'bad' experience, they would not come back."* DB2

3.2.5 Technological interventions for communication

When talking about technological interventions that could support patients' health literacy in diabetes care, nurses found several solutions to be perspective. Four nurses told that glucometers with sensors could be very beneficial to patients to understand their blood sugar levels. Three of them added that according to their knowledge, these devices are not widely available in Estonia because of the small market. One nurse mentioned that an online communication platform could be beneficial for the patient.

None of the nurses had any suggestions for applications (apps) from the mobile application stores. One nurse added that apps might be helpful for the younger generation. Another nurse stated that when people would send information through applications, then nurses would not have time to look at it separately. One nurse told that she heard about an application solution, where a person can take a photo of their food and the app returns carbohydrates' content.

Six nurses said that video solutions could be helpful. Two nurses added that those videos should be made by specialists, who are demonstrating the whole process. Two nurses mentioned food preparation videos to be useful for patients. One of those nurses added that video consultations and videos about food selection from the store could be helpful. One nurse also noted that supportive videos should be in Estonian. Another nurse pointed out that videos about people, who are managing the disease well could be helpful for others. One nurse was not sure that videos would help patients.

About technological interventions, three diabetes nurses commented that for older people it is not a good solution, as they are not so familiar with the Internet and a lot of

them do not have a computer at home. *"Solution is needed for an aging society – not all are familiar with the technology. In addition, some older people cannot hear, and some cannot see."* DB5

3.2.6 Additional findings from interviews

Two nurses told that sometimes it is difficult to get type 2 diabetes patients to come back for a re-appointment. Two nurses noted that sometimes when diabetes patient arrives in their consultation, they already have problems with glycaemic control and complications. Four nurses stated that the patient's referral by family doctors to diabetes nurses' appointment is problematic. *"Family doctors are referring poorly. They say that they do not know how to refer or making the referral takes a long time (3 minutes). After digitalization, it has gone worse."* DB10

"Almost every patient tells me that family doctor does not know how to treat but would not refer to us either." DB10

The same four nurses also commented that patient education from primary level care is insufficient. *"Family doctors do not have time to educate patients about diabetes. They get rather general recommendations from there."* DB3

Four nurses additionally commented that people have generally bad eating habits and they do not understand what healthy food is. Two nurses also commented that trying to change older peoples' eating habits is very difficult. Two other nurses also stated that people were genuinely surprised to hear that they do not have healthy eating habits.

Two nurses suggested that diabetes patients should be more acquainted with well-managed diabetes patients so they could see that the disease is efficiently manageable with good habits. One nurse added: *"There could be an attractive part added to the appointments – so people would not feel that their lifestyle is just being judged and criticised by someone."* DB2

3.3 Discussion

Diabetes prevalence is increasing at a rapid speed all around the world. Serious complications and the high prevalence of diabetes disease are burdening health care financial system heavily [9]. Based on estimation, there will be over 600 million people

with diabetes by the year 2045 [23]. Of all the diabetes diagnoses, around 90% are type 2 diabetes, which is mostly considered to be a lifestyle disease [1].

Everyday nutritional and activity choices are greatly impacting the disease's formulation period and development speed. The level of health literacy is very important, a great proportion of self-management is happening outside of the provider's office where the patient must manage the disease mostly on their own. Patients need to rely on the instructions received from health care providers' appointment and make fitting disease management decisions based on that information [59].

This study focuses on the challenges that diabetes-nurses are facing during the process of communicating diabetes-related information to patients. Semi-structured interviews with 10 practicing diabetes nurses were held to gain their views and perspectives about the topic.

3.3.1 Diabetes-related information to the patient

Most common diabetes-related materials to diabetes patients are paper-based materials, but also there are several information sources available on the Internet (websites, portals, blogs). Although, some people value direct communication with health care providers [17]. It is extremely important that diabetes patients would understand the information about their condition [8].

Every interviewed diabetes nurse stated that they are giving some paper materials for the patient to read at home, but most of the nurses also said that patients do not read these at home. They simply might have too many materials or they might not understand the content. It may induce a problem where the patient does not remember everything that diabetes nurse has said during the visit and without extra materials, there might be misunderstandings about the given instructions and following the correct disease management plan. Also, the literature suggests that patients can recall only half of the information that is shared with them in clinical settings [64].

Paper-based materials are often the only materials that diabetes patients receive from diabetes nurses' appointment. If there is a tendency of not reading paper-based materials or for example, elderly people do not use technological solutions, then they are left alone with their disease management between the appointments.

Additionally, more than half of the nurses told that they find oral communication to be very important. They see the need for talking with the patient repeatedly about the same disease management topics to be the best solution on how to reach the patient. Also, it was mentioned that there should be group counselling available. It would be very beneficial to conduct intensive group education sessions for newly diagnosed patients. That would give patients a good opportunity to learn from others' experience and build supportive networking groups.

In the author's opinion, to rely only on one-to-one oral communication is not sustainable in the current situation, where we do not have enough diabetes nurses to manage all the patients in need in clinical settings. The author of this thesis sees a need to create a better communication path between the patient and the provider. For instance, there are several successful phone-counselling services that are supporting patients remotely. As the prevalence of diabetes in Estonia in adults is 5,7% and rising, there might be a wide client-base for this service [8]. The other solution might be creating an online communication portal for direct counselling, but it would eliminate a lot of elderly and diabetes nurses' views are controversial about its usefulness. Mainly, they are concerned that they would not have enough time and it would affect their workload heavily.

3.3.2 Quality of shared materials

Providers might notice that patients have problems understanding the shared information, but they still tend to rely on the paper handouts to solve the confusion. Though, many studies show that these materials are written using language that is too complicated for the patients to understand [65][66]. Also, it has been found that adequate online health information could be too complicated for individuals with lower health literacy levels [18].

Most of the interviewees were not satisfied with the quality of shared brochures. In their opinion, these materials are controversial and outdated. Only some nurses suggested their patients' educational video materials, as there are only a few in Estonian and their quality is inconsistent. The issue with all mentioned materials is that the information is varying and there is no unity between different forms.

The suggestion is to form an interdisciplinary workgroup consisting members of different diabetes-related organisations and specialties, to produce comprehensive and up-to-date materials, which includes paper-based, web-based materials, including educational videos. These materials should be widely suggested and easily accessible to all parties. Using these materials should be recommended in the Estonian diabetes treatment guide.

3.3.3 Identifying patient's health literacy level

According to previous studies, providers and patients might overestimate patients' health literacy level [45][44]. In the opinion of the author of the thesis, overestimation of the health literacy levels may lead to a situation, where patients have not communicated as much information as they need to manage their disease successfully.

The main strategies used by the interviewees to identify patient's health literacy level were reflecting the information back from the patient, evaluating blood sugar measurements and anamnesis, and nutritional diary. Still, most of the nurses saw the need for extra training about this matter. The suggestion is to offer this kind of training regularly and add this topic to their educational program because it became evident from the literature review and current research that communication is the key element to motivate and support the patient [17].

In Seligman et al. study, it was found that 64% of doctors and 96% of patients found health literacy screenings to be useful [48]. In the current study, some nurses stated their concerns about asking patients health literacy evaluation questions. Author of this thesis finds that identifying patients' health literacy could help providers to assess person's individual needs for the information communication and based on that choose the right methods to approach the patient. In thesis authors' opinion, as providers' appointment duration in clinical settings is fixed, it needs to be very structured and focused from the beginning.

Several validated assessment tools have been developed to measure health literacy in clinical settings [10][11][12]. Understanding patient's health literacy level prior or during the appointment is essential, as in clinical settings the visit duration tends to be limited and assessing patients' health literacy level might help to really focus on the material that is needed to share to the patient.

Although there are so many different measurements, interviewed diabetes nurses were not aware of the existence and possibilities of these tools. The author of this thesis suggests that the short measurement, like ice cream label reading, would be a good indicator of individuals ability to understand diet-related information [12]. It would help to associate information shared in clinical settings with patient's needs and challenges in everyday life. It could be beneficial to develop an Estonian version of the short health literacy measurement to give providers some indication about patients' health literacy levels. The suggestion from the author is that this tool should be digitized to be able to perform the test either individually or to be easily administered when used together with the provider.

3.3.4 Technological interventions for the communication

There are several technological options to enhance management processes and communication solutions [18][76][78]. As most of the care processes take place outside of the clinical settings - technological interventions could offer key-point solutions for patients' disease management. The main question here is that how patients can contribute to their care process remotely using technological possibilities with the aim to ease the workload on health care providers and to achieve the goal for shared decision making. And as few diabetes nurses stated that if people would understand the disease essence and the reason why they need to perform suggested activities, then they are more compliant to the instructions and gain more motivation to manage the disease effectively. The same conclusion was made in the literature review [63].

Maintaining optimal glycaemic control is one of the most important things for a diabetes patient to follow. Self-care adherence among adults with type 2 diabetes is on a low level. Studies show that eHealth solutions could help patients to gain better glycaemic control [78]. Almost half of the interviewees saw the benefit in glucometers with sensors to gain better glycaemic control, but as indicated by the nurses, these are not available in the Estonian market. In the author's opinion, this topic should be more investigated and take into consideration to enhance their availability through partial governmental funding.

Elderly people are resistant to use computer-based solutions for several reasons [73]. Less than half of people aged 65 to 74 are using Internet services regularly [75]. It was also reported by the interviewees that technological interventions are not good solutions

for the elderly. Currently, there is different technology acceptance between the generations, but future generations are probably more familiar with the presence of technology. Therefore, diabetes nurses suggested several technological solutions that could be helpful to address younger generations. For example, using applications to guide the person while shopping for food to assess products suitability for the assigned diet.

Nurses did not have any good suggestions from mobile application stores, as they were not familiar with validated content. Though, mHealth solutions hold great potential, as people are more and more using their phones for everyday errands. More than half of diabetes nurses found video solutions to be helpful to support patients in their education process. Nurses mentioned that video consultations and food preparation videos with commentaries would be very beneficial for the patients.

Author of this thesis suggests producing more Estonian videos with such content that people can relate with. Also, videos about diabetes patients who are managing their disease effectively could be very motivating to others, so that they can see that people might have a good life quality with the disease and when managing the disease well, they do not have to give up their lives before, but can adjust the disease according to their lifestyle.

Also, one suggestion is that educational materials could be sent to the patient prior to the nurse's visit and web-based materials could allow nurses to send the materials to the patient prior to the visit, so they would have the chance to ask more specific questions and concentrate on problematic topics during the visit. The nurse would see from the EHR system if a patient has downloaded the materials. Rewarding part for the patient could be added, like complimentary care service.

Additionally, online patient-provider communication platforms could be beneficial where the patient can interact with the provider. This solution could ease the workload on patients' counselling over the phone and via email – to channel most of the between-the-visits contacts to the platform. Though, it should be under a discussion, how to finance the service and how to suit it to the nurses everyday working schedule.

3.3.5 Additional findings from interviews

Health care personnel plays an important role in patients' disease management process. Doctors and nurses provide evidence-based information and guidelines to the individual to control one's disease management and health outcomes [17]. Diabetes nurses are supporting diabetes patients' lifestyle management and care processes [19], but patients themselves need to take responsibility and action to maintain good life quality with the disease. Correct diabetes disease management is crucial for a diabetes patient, as properly followed providers' instructions could prevent from developing cardiovascular diseases and early death [27].

As type 2 diabetes is mostly managed in the primary care level, diabetes patients should get sufficient education from the family nurse, according to the Estonian diabetes treatment plan [19]. Though, analysis shows that diabetes care on primary care level tends to be inconsistent regionally [3]. Almost half of the interviewees brought out that family doctors' referral to diabetes specialists is problematic and patients do not get an education on the necessary level that they need to manage their disease effectively. Two diabetes nurses also mentioned that some patients arrive in nurse's visit if they already have developed problems with glucose control or signs of complications. One nurses' statement was especially interesting about the situation that family doctors refer patients to them poorly after referral letters' digitalization. This statement should be investigated more deeply in future studies.

Patients tend to tell more information about their care and disease condition to nurses than to the doctor [79]. Half of the interviewees stated that patients turn to them with questions and problems about the treatment plan rather than to the doctor. The main explanation for that kind of behaviour by the nurses' opinion and as brought out in the literature was, that patients do not want to bother the doctor [56]. More insight is needed about what barriers exist within the doctor-patient relationship. Potential study topics could be quality of communication in different visit settings, within different lengths of visits, doctor-patient relationship dynamic. Moreover, there was a problem that type 2 diabetes patients tend not to come back for diabetes nurses' re-appointments. One diabetes nurse stated that patients might feel like they are judged and criticised during the visit and the other nurse mentioned that it is very difficult to build a trustworthy relationship with the patient in the clinical settings in such a short time.

In the author's opinion, patients should feel comfortable in the clinical settings and understand that correct information about their lifestyle is essential for effective disease management. Patients need all the available support and management instructions right at the beginning of the diagnosis, so they would not feel alone with the disease and could concentrate on avoiding the diabetes-related complications earlier. Author suggestion is to discuss in between involved parties of how to improve interdisciplinary teamwork so the patients would be directed to diabetes nurse appointment at the right time in case of a need. An additional suggestion is to refer patients to focus group meetings to get intense education about the disease and its management as soon as possible.

Four interviewed nurses stated that people tend to have generally bad eating habits and in addition, two nurses said that it is difficult to change older persons nutritional habits. People seem to believe that they have good nutrition, but when the nurse starts asking specifications, it turns out that they have poor knowledge and eating habits. By the author's opinion, this misconception shows how important it is to educate people on good eating habits from an early age on. Recommending health eating without explanation and demonstration is not beneficial. The focus should be on intensive nutritional education starting from the kindergarten level.

3.3.6 Limitations and further studies

Firstly, there were three interview methods used for this study: face-to-face meetings, Skype video calls and a phone call. Face-to-face interviews have some benefits over the Skype interviews, like avoiding technical problems [92] and also benefits over phone interviews, where interviewee's body language is not seen. In the other hand, telephone interviews help participants remain somewhat private and more comfortable if they only focus on the talking. Also, remote solutions are easier to reschedule if needed and conduct over the greater distance [87]. The decision was made accordingly to help nurses to overcome different restraints in their desired participation and to hear their opinions.

Secondly, in the current study, interview structure was piloted with only one family nurse, but future research could proceed with a larger scale pilot to help to focus on the most informative and valuable questions.

Finally, as it was an explorative study without any concrete hypothesis, the results of the study cannot be extended to the wider population [84].

Further studies could focus on diabetes patients' views and opinions about this topic to acquire an integral perspective for both parties. Quantitative study to assess diabetes patients' health literacy levels is needed to compare the results with diabetes nurses' subjective observations.

Based on this study it was brought out that diabetes nurses see some issues with type 2 diabetes patients' counselling quality in primary care settings. So, there is a need to investigate family physicians' and nurses' views and experience about this topic.

3.4 Summary

The aim of the thesis was to describe challenges that diabetes-nurses are facing during the process of communicating diabetes-related information to patients and based on the findings make suggestions to enhance the communication. Semi-structured interviews with 10 practicing diabetes nurses were held to obtain their views and perspectives about the topic.

According to diabetes nurses' observations, patients tend not to read diabetes-related materials outside of the nurse's appointment and nurses' value oral communication during the visit the most. Still, there is a need for creating supplementary communication paths between the patient and the provider.

Diabetes nurses evaluate the quality of diabetes-related materials to be poor. Nurses are not satisfied with the materials' content and unity. The materials should be written in a simple and clear manner.

Nurses are not aware of health literacy instruments in clinical settings. Developing an Estonian version of short health literacy measurement for health care providers could be beneficial.

Nurses found that different technological solutions could be efficient, but they cannot rely only on technology as older generations are not familiar with it. For example, sharing validated web-based materials could raise the knowledge of patients prior to the

nurse's appointment and introducing glucometers with sensors to the Estonian market could help patients to gain better glycaemic control.

Three main suggestions by the author of this thesis are:

1. To offer regular trainings for diabetes nurses on how to communicate with the patients', while setting emphasis on health literacy.

2. To form an interdisciplinary workgroup to produce comprehensive and up-to-date patient education materials.

3. To raise discuss in between involved parties on how to enhance interdisciplinary teamwork to improve patients' referral to diabetes nurse appointment.

Results from this thesis provide valuable insight into challenges that diabetes nurses are facing while supporting diabetes patients' care and lifestyle management. Diabetes care providers and organisations might find the research results to be assistive to enhance diabetes patients' adherence to treatment plans and optimise care management processes. The results of this thesis will be shared with the diabetes nurses' community and support organisations.

References

[1] American Diabetes Association, "Diagnosis and classification of diabetes mellitus," *Diabetes Care*, vol. 27, no. suppl 1, pp. S5–S10, 2004.

[2] "Eesti Diabeediliit. Mis on diabeet?" [Online]. Available: http://www.diabetes.ee/mis-on-diabeet. [Accessed: 20-Mar-2019].

[3] G. Paat-Ahi and Ü.-K. Nurm, "Rahvastiku tervise arengukava 2009-2020 vahehindamine. Diabeedi valdkonna aruanne," Tallinn, 2017.

[4] L. Nilesen-Bohlman, D. A. Kindig, and A. M. Panzer, *Health Literacy: A Prescription to End Confusion*. The National Academies Press, 2004.

[5] M. V Williams *et al.*, "Inadequate functional health literacy among patients at two public hospitals," *JAMA*, vol. 274, no. 21, pp. 1677–82, Dec. 1995.

[6] J. A. Gazmararian *et al.*, "Health literacy among Medicare enrollees in a managed care organization," *JAMA*, vol. 281, no. 6, pp. 545–51, Feb. 1999.

[7] K. Sørensen *et al.*, "Health literacy in Europe: Comparative results of the European health literacy survey (HLS-EU)," *Eur. J. Public Health*, vol. 25, no. 6, 2015.

[8] *IDF Diabetes Atlas*, 8th ed. International Diabetes Federation, 2017.

[9] D. W. Baker *et al.*, "Functional health literacy and the risk of hospital admission among Medicare managed care enrollees," *Am. J. Public Health*, vol. 92, no. 8, pp. 1278–83, Aug. 2002.

[10] T. C. Davis *et al.*, "Rapid assessment of literacy levels of adult primary care patients," *Fam. Med.*, vol. 23, no. 6, pp. 433–5, Aug. 1991.

[11] J. M. Mancuso, "Assessment and measurement of health literacy: An integrative review of the literature," *Nurs. Health Sci.*, vol. 11, no. 1, pp. 77–89, Mar. 2009.

[12] B. D. Weiss *et al.*, "Quick assessment of literacy in primary care: the newest vital sign," *Ann. Fam. Med.*, vol. 3, no. 6, pp. 514–22, Nov. 2005.

[13] R. O. White, K. Wolff, K. L. Cavanaugh, and R. Rothman, "Addressing Health Literacy and Numeracy to Improve Diabetes Education and Care," *Diabetes Spectr.*, vol. 23, no. 4, pp. 238–243, Oct. 2010.

[14] C. R. Nath, S. T. Sylvester, V. Yasek, and E. Gunel, "Development and Validation of a Literacy Assessment Tool for Persons With Diabetes," *Diabetes Educ.*, vol. 27, no. 6, pp. 957–864, 2001.

[15] M. M. Huizinga *et al.*, "Development and validation of the Diabetes Numeracy Test (DNT)," *BMC Health Serv. Res.*, vol. 8, no. 1, p. 96, Dec. 2008.

[16] H. Ishikawa and T. Kiuchi, "Health literacy and health communication," *Biopsychosoc. Med.*, vol. 4, p. 18, Nov. 2010.

[17] T. A. Parnell, *Health Literacy in Nursing. Providing Person-Centered Care*. Springer Publishing Company, 2015.

[18] H. Kim and B. Xie, "Health literacy in the eHealth era: A systematic review of the literature," *Patient Educ. Couns.*, vol. 100, no. 6, pp. 1073–1082, Jun. 2017.

[19] A. Ambos *et al.*, "Eesti 2. tüüpi diabeedi juhend 2008," *Eesti Arst*, vol. 87, no. 7–8, pp. 573–585, 2008.

[20] A. Ambos *et al.*, "2. Tüüpi diabeedi Eesti ravijuhend 2016," *Eesti Arst*, vol. 95, no. 7, pp. 465–473, 2016.

[21] "Global Report on Diabetes," World Health Organization, 2016.

[22] N. Lascar, J. Brown, H. Pattison, A. H. Barnett, C. J. Bailey, and S. Bellary, "Type 2 diabetes in adolescents and young adults," *Lancet Diabetes Endocrinol.*, vol. 6, no. 1, pp. 69–80, Jan. 2018.

[23] "IDF diabetes Atlas," *International Diabetes Federation*, 2015. [Online]. Available: http://www.diabetesatlas.org. [Accessed: 11-Mar-2019].

[24] "Noncommunicable diseases," *World Health Organization*, 2018. [Online]. Available: https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases. [Accessed: 06-Mar-2019].

[25] "The top 10 causes of death," *World Health Organization*, 2018. [Online]. Available: https://www.who.int/news-room/fact-sheets/detail/the-top-10-causes-of-death. [Accessed: 06-Mar-2019].

[26] "Mayo Clinic. Type 2 diabetes. Symptoms and causes," 2019. [Online]. Available: https://www.mayoclinic.org/diseases-conditions/type-2-diabetes/symptoms-causes/syc-20351193. [Accessed: 06-Mar-2019].

[27] A. Rawshani *et al.*, "Risk Factors, Mortality, and Cardiovascular Outcomes in Patients with Type 2 Diabetes," *N. Engl. J. Med.*, vol. 379, no. 7, pp. 633–644, Aug. 2018.

[28] "Eesti Haigekassa. Haigekassa lepingupartnerid." [Online]. Available: https://www.haigekassa.ee/inimesele/arsti-ja-oendusabi/haigekassa-lepingupartnerid/eriarstiabi?speciality=697&county=All. [Accessed: 20-Mar-2019].

[29] "Eesti Diabeediliit. Seltsid." [Online]. Available: http://www.diabetes.ee/seltsid. [Accessed: 20-May-2019].

[30] J. G. Ryan *et al.*, "Will patients agree to have their literacy skills assessed in clinical

practice?," *Health Educ. Res.*, vol. 23, no. 4, pp. 603–611, Sep. 2007.

[31] S. D. Zaugg *et al.*, "Diabetes numeracy and blood glucose control: association with type of diabetes and source of care," *Clin. Diabetes*, vol. 32, no. 4, pp. 152–7, Oct. 2014.

[32] C. F. Young, K. Yun, E. Kang, J. H. Shubrook, and J. A. Dugan, "Correlations Between A1C and Diabetes Knowledge, Diabetes Numeracy, and Food Security in a Vulnerable Type 2 Diabetes Population," *Diabetes Spectr.*, vol. 31, no. 2, pp. 177–183, May 2018.

[33] C. Y. Osborn, K. Cavanaugh, K. A. Wallston, R. O. White, and R. L. Rothman, "Diabetes numeracy: an overlooked factor in understanding racial disparities in glycemic control," *Diabetes Care*, vol. 32, no. 9, pp. 1614–9, Sep. 2009.

[34] S. Mantwill and P. J. Schulz, "Low health literacy associated with higher medication costs in patients with type 2 diabetes mellitus: Evidence from matched survey and health insurance data," *Patient Educ. Couns.*, vol. 98, no. 12, pp. 1625–1630, Dec. 2015.

[35] K. Cavanaugh *et al.*, "Association of Numeracy and Diabetes Control," *Ann. Intern. Med.*, vol. 148, no. 10, p. 737, May 2008.

[36] D. A. Dewalt, N. D. Berkman, S. Sheridan, K. N. Lohr, and M. P. Pignone, "Literacy and health outcomes: a systematic review of the literature," *J. Gen. Intern. Med.*, vol. 19, no. 12, pp. 1228–39, Dec. 2004.

[37] C. Heinrich, "Health literacy: The sixth vital sign," *J. Am. Acad. Nurse Pract.*, vol. 24, no. 4, pp. 218–223, Apr. 2012.

[38] D. Nutbeam, "Health promotion glossary," *Health Promot. Int.*, vol. 13, pp. 349–364, 1998.

[39] D. Nutbeam, "Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century," *Health Promot. Int.*, vol. 15, no. 3, pp. 259–267, Sep. 2000.

[40] K. Sørensen *et al.*, "Health literacy and public health: A systematic review and integration of definitions and models," *BMC Public Health*, vol. 12, no. 80, Dec. 2012.

[41] UNESCO Institution of Statistics, "Literacy Rates Continue to Rise from One Generation to the Next," 2017.

[42] M. Heijmans *et al.*, "Study on sound evidence for a better understanding of health literacy in the European Union," 2015.

[43] "Haigekassa kommunikatsiooni ja tervise edenduse arengukava 2018-2021," 2018.

[44] P. F. Bass, J. F. Wilson, C. H. Griffith, and D. R. Barnett, "Residents' ability to identify patients with poor literacy skills," *Acad. Med.*, vol. 77, no. 10, pp. 1039–41, Oct. 2002.

[45] S. Cornett, "Assessing and Addressing Health Literacy," *OJIN Online J. Issues Nurs.*, vol. 14, no. 3, 2009.

[46] N. S. Parikh, R. M. Parker, J. R. Nurss, D. W. Baker, and M. V. Williams, “Shame and health literacy: the unspoken connection,” *Patient Educ. Couns.*, vol. 27, no. 1, pp. 33–39, Jan. 1996.

[47] M. S. Wolf, M. V. Williams, R. M. Parker, N. S. Parikh, A. W. Nowlan, and D. W. Baker, “Patients’ shame and attitudes toward discussing the results of literacy screening,” *J. Health Commun.*, vol. 12, no. 8, pp. 721–732, 2007.

[48] H. K. Seligman *et al.*, “Physician notification of their diabetes patients’ limited health literacy. A randomized, controlled trial,” *J. Gen. Intern. Med.*, vol. 20, no. 11, pp. 1001–7, Nov. 2005.

[49] R. M. Parker, D. W. Baker, M. V Williams, and J. R. Nurss, “The test of functional health literacy in adults: a new instrument for measuring patients’ literacy skills,” *J. Gen. Intern. Med.*, vol. 10, no. 10, pp. 537–41, Oct. 1995.

[50] “Health Literacy Tool Shed.” [Online]. Available: https://healthliteracy.bu.edu/. [Accessed: 24-Mar-2019].

[51] R. R. Wolff K, Cavanaugh K, Malone R, Hawk V, Gregory BP, Davis D, Wallston K, “The Diabetes Literacy and Numeracy Education Toolkit (DLNET): materials to facilitate diabetes education and management in patients with low literacy and numeracy skills,” *Diabetes Educ*, vol. 35, pp. 233–236, 238–241, 244–235, 2009.

[52] H. Ishikawa, T. Takeuchi, M. D. Msc, and E. Yano, “Measuring functional, communicative, and critical health literacy among diabetes patients,” 2008.

[53] D. Schillinger *et al.*, “Association of Health Literacy With Diabetes Outcomes,” *JAMA*, vol. 288, no. 4, p. 475, Jul. 2002.

[54] M. V. Williams, D. W. Baker, R. M. Parker, and J. R. Nurss, “Relationship of Functional Health Literacy to Patients’ Knowledge of Their Chronic Disease,” *Arch. Intern. Med.*, vol. 158, no. 2, p. 166, Jan. 1998.

[55] B. W. Hesse *et al.*, “Trust and Sources of Health Information,” *Arch. Intern. Med.*, vol. 165, no. 22, p. 2618, Dec. 2005.

[56] D. W. Baker *et al.*, “The Health Care Experience of Patients With Low Literacy,” *Arch Fam Med*, vol. 5, pp. 329–334, 1996.

[57] S. C. Kalichman, B. Ramachandran, and S. Catz, “Adherence to combination antiretroviral therapies in HIV patients of low health literacy,” *J. Gen. Intern. Med.*, vol. 14, no. 5, pp. 267–73, May 1999.

[58] P. Quinlan, K. O. Price, S. K. Magid, S. Lyman, L. A. Mandl, and P. W. Stone, “The Relationship Among Health Literacy, Health Knowledge, and Adherence to Treatment in Patients with Rheumatoid Arthritis,” *HSS J.*, vol. 9, no. 1, pp. 42–49, Feb. 2013.

[59] J. H. Hibbard and J. Greene, “What The Evidence Shows About Patient Activation: Better Health Outcomes And Care Experiences; Fewer Data On Costs,” *Health Aff.*, vol. 32, no. 2, pp. 207–214, Feb. 2013.

[60] G. Graffigna and S. Barello, “Spotlight on the Patient Health Engagement model (PHE model): a psychosocial theory to understand people’s meaningful engagement in their own health care,” *Patient Prefer. Adherence*, vol. 12, pp. 1261–1271, 2018.

[61] M. R. Dimatteo, “Social Support and Patient Adherence to Medical Treatment: A Meta-Analysis,” *Heal. Psychol.*, vol. 23, no. 2, pp. 207–218, 2004.

[62] K. B. H. Zolnierek and M. R. Dimatteo, “Physician communication and patient adherence to treatment: a meta-analysis,” *Med. Care*, vol. 47, no. 8, pp. 826–34, Aug. 2009.

[63] T. A. Miller, “Health literacy and adherence to medical treatment in chronic and acute illness: A meta-analysis,” *Patient Educ. Couns.*, vol. 99, no. 7, pp. 1079–1086, Jul. 2016.

[64] D. Schillinger *et al.*, “Closing the loop: Physician communication with diabetic patients who have low health literacy,” *Arch. Intern. Med.*, vol. 163, no. 1, p. 83, Jan. 2003.

[65] R. Parker, “Health literacy: a challenge for American patients and their health care providers,” *Health Promot. Int.*, vol. 15, no. 4, pp. 277–283, Dec. 2000.

[66] F. Hill-Briggs and A. S. Smith, “Evaluation of diabetes and cardiovascular disease print patient education materials for use with low-health literate populations,” *Diabetes Care*, vol. 31, no. 4, pp. 667–71, Apr. 2008.

[67] R. E. Rudd, “The evolving concept of Health literacy: New directions for health literacy studies,” *J. Commun. Healthc.*, vol. 8, no. 1, pp. 7–9, 2015.

[68] S. Barello, G. Graffigna, and E. Vegni, “Patient Engagement as an Emerging Challenge for Healthcare Services: Mapping the Literature,” *Nurs. Res. Pract.*, vol. 2012, pp. 1–7, 2012.

[69] Susan Dentzer, “Rx For The ‘Blockbuster Drug’ Of Patient Engagement,” *Health Aff.*, vol. 32, no. 2, p. 202, 2013.

[70] L. Simmons, R. Q. Wolever, E. M. Bechard, and R. Snyderman, “Patient engagement as a risk factor in personalized health care: a systematic review of the literature on chronic disease,” *Genome Med.*, vol. 6, no. 2, p. 16, Feb. 2014.

[71] C. Brach *et al.*, “Ten Attributes of Health Literate Health Care Organizations,” 2012.

[72] B. Geboers *et al.*, “The association of health literacy with adherence in older adults, and its role in interventions: a systematic meta-review,” *BMC Public Health*, vol. 15, no. 1, p. 903, Dec. 2015.

[73] N. G. Choi and D. M. Dinitto, “The digital divide among low-income homebound older

adults: Internet use patterns, eHealth literacy, and attitudes toward computer/Internet use," *J. Med. Internet Res.*, vol. 15, no. 5, p. e93, 2013.

[74] L. Samal, H.-C. Yeh, T. L. Gary-Webb, C. L. Jackson, and F. L. Brancati, "Computer and Internet Use of Urban African Americans With Type 2 Diabetes in Relation to Glycemic Control, Emergency Department Use, Diabetes-Related Knowledge, and Health Literacy," *Diabetes Care*, vol. 33, no. 1, p. e9, Jan. 2010.

[75] "Eurostat. A look at the lives of the elderly in the EU today." [Online]. Available: https://ec.europa.eu/eurostat/cache/infographs/elderly/index.html. [Accessed: 13-May-2019].

[76] R. Sun, M. T. Korytkowski, S. M. Sereika, M. I. Saul, D. Li, and L. E. Burke, "Patient Portal Use in Diabetes Management: Literature Review," *JMIR diabetes*, vol. 3, no. 4, p. e11199, 2018.

[77] L. Lenert, R. Dunlea, G. Del Fiol, and L. K. Hall, "A model to support shared decision making in electronic health records systems," *Med. Decis. Making*, vol. 34, no. 8, pp. 987–95, 2014.

[78] L. Nelson, T. Coston, A. Cherrington, and C. Osborn, "Patterns of user engagement with mobile- and web-delivered self-care interventions for adults with T2DM: A review of the literature," *Curr. Diab. Rep.*, vol. 16, no. 7, pp. 66–66, 2016.

[79] S. Rees and A. Williams, "Promoting and supporting self-management for adults living in the community with physical chronic illness: A systematic review of the effectiveness and meaningfulness of the patient-practitioner encounter," *JBI Libr. Syst. Rev.*, vol. 7, no. 13, pp. 492–582, 2009.

[80] C. Dickens, B. L. Lambert, T. Cromwell, and M. R. Piano, "Nurse overestimation of patients' health literacy," *J. Health Commun.*, vol. 18, pp. 62–69, 2013.

[81] S. Kim, F. Love, D. A. Quistberg, and J. A. Shea, "Association of health literacy with self-management behavior in patients with diabetes," *Diabetes Care*, vol. 27, no. 12, pp. 2980–2982, Dec. 2004.

[82] C. Cawthon, L. C. Mion, D. E. Willens, C. L. Roumie, and S. Kripalani, "Implementing routine health literacy assessment in hospital and primary care patients," *Jt. Comm. J. Qual. patient Saf.*, vol. 40, no. 2, pp. 68–76, Feb. 2014.

[83] K. Hammarberg, M. Kirkman, and S. de Lacey, "Qualitative research methods: when to use them and how to judge them," *Hum. Reprod.*, vol. 31, no. 3, pp. 498–501, Mar. 2016.

[84] "Research methodology. Exploratory research," 2019. [Online]. Available: https://research-methodology.net/research-methodology/research-design/exploratory-research/. [Accessed: 19-May-2019].

[85] “Research methodology. Snowball sampling,” 2019. [Online]. Available: https://research-methodology.net/sampling-in-primary-data-collection/snowball-sampling/. [Accessed: 08-May-2019].

[86] Lembit Õunapuu, “Valimid kvantitatiivsetes ja kvalitatiivsetes uurimustes. Lumepallivalim,” 2012.

[87] M. B. Farooq, “Qualitative telephone interviews: Strategies for success,” *18th Annu. Waikato Manag. Sch. Student Res. Conf.*, pp. 1–30, 2015.

[88] S. Jamshed, “Qualitative research method-interviewing and observation,” *J. basic Clin. Pharm.*, vol. 5, no. 4, pp. 87–8, Sep. 2014.

[89] V. Braun and V. Clarke, “Using thematic analysis in psychology,” *Qual. Res. Psychol.*, vol. 3, pp. 77–101, 2006.

[90] M. Randväli, “Diabeediõdede rahulolu töökorraldusega ja töömotivatsiooni mõjutegurid Eesti haiglates,” Tallinna Ülikool, 2017.

[91] “Terviseameti registrid. Otsing.” [Online]. Available: http://mveeb.sm.ee/ctrl/ee/Tervishoiutootajad/index/?kust=&kood=&eesnimi=&perenimi=&kutse=3&eriala=46&otsi=Otsi. [Accessed: 07-May-2019].

[92] P. Hanna, “Using internet technologies (such as Skype) as a research medium: A research note,” *Qual. Res.*, vol. 12, no. 2, pp. 239–242, 2012.

Appendix 1 – Interview guide for diabetes nurses in English

INTRODUCTION

- Giving an overview about the aim of the thesis and introducing interviewer;

Given study focuses on diabetes patients' health literacy. Health literacy is a level of individuals capacity, which defines their ability to understand and process health information and based on that make fitting health decisions.

- Background information (years of experience in field, age and county).

INTERVIEW

Topic: Patients' health literacy

1. In what form do you share diabetes-related information to the patient?
    a. Oral information during the visit/phone counselling/communication via e-mail/communication via video call/paper materials during the visit/paper materials to take home/recommend online materials/other
    b. Do you have any supportive materials that you use during the visit or hand out to the patient? If you have, then how would you rate the quality of the materials?
    c. In your opinion, what type of supportive materials are needed more? In what form would they be most effective?
    d. Where do you direct patient for additional materials/information?
2. In your experience, if and how do patients let you know if they are having trouble understanding the information given to them during the visit?
    a. What type of information seems to be complicated to understand for the patient?

b. What topics do patients seem to ask about more often? What topics need to be discussed several times with one patient?

c. What are the topics patients turn to you most between visit times? What are the channels and how often? How does it affect your workload?

d. Is there a possibility that patient does not follow management guidelines or follows them impartially, because they did not understand instructions? How do you act in this case? How to improve the understanding?

3. If and how do you evaluate patients' understanding of diabetes-related health information?

    e. What, if any, strategies are you using to assess patients' health literacy levels?

    f. Is there any health literacy tool being used to evaluate individual's health literacy prior or during the visit?

    g. Has there been any training how to approach patients with low literacy levels?

    h. Do you think it would be important for nurses and doctors to have additional trainings on how to communicate with patients who have different levels of health literacy?

4. What could be the technological solutions to improve and support diabetes patients' disease management?

    a. Do you have any experiences with good applications in diabetes care?

ENDING THE INTERVIEW

- Do you have any additional comments about the topic you would like to share?
- Asking permission to contact again in case of in need of additional information;
- Thanking nurse for providing time for the interview.

Appendix 2 – Interview guide for diabetes nurses in Estonian

SISSEJUHATUS

- Ülevaade uuringu eesmärkidest ja intervjueerija tutvustamine;

Antud uuring keskendub diabeedipatsiente tervisekirjaoskusele. Tervisekirjaoskus näitab patsiendi võimekust saada aru erinevas vormis esitatud terviseinfost ja selle põhjal teha sobivaid otsuseid oma tervisekäitumises.

- Demograafiline informatsioon (tööstaaži pikkus, vanus, maakond).

INTERVJUU

Teema: Patsiendi tervisekirjaoskus

1. Millises vormis diabeediga seotud infot patsiendile jagate?

    a. suuline seletus visiidi ajal/telefoninõustamine/suhtlus emaili teel/suhtlus video vahendusel/näitan visiidi ajal pabermaterjale/annan pabermaterjalid koju kaasa/soovitan veebikeskkonnas olevaid materjale/muu

    b. Kui Teil on lisamaterjale, mida saab visiidi ajal kasutada või patsiendile välja jagada, siis kuidas hindade lisamaterjalide kvaliteeti?

    c. Millistest lisamaterjalidest on puudu? Millises vormis oleksid need kõige efektiivsemad?

    d. Kuhu Te suunate patsiendi lisaküsimuste/-materjalide saamiseks?

2. Teie kogemuse põhjal, kas ja kuidas patsiendid annavad märku, et neil on raskusi informatsioonist aru saamisega?

    a. Mis tüüpi informatsioonist tundub olevat patsiendil kõige keerulisem aru saada?

b. Mis teemade kohta patsiendid kõige rohkem küsivad? Millised teemad tuleb ühe patsiendiga mitmeid kordi läbi käia?

c. Milliste küsimustega pöörduvad patsiendid kõige enam visiidivälisel aja Teie poole? Millised kanaleid pidi ja kui tihti? Kuidas see mõjutab Teie töökoormust?

d. Kas võib juhtuda, et patsient ei järgi ravisoovitusi või järgib neid valesti, kuna ta ei ole saanud edastatud juhistest korrektselt aru? Kuidas sellisel puhul tavaliselt käitute? Kuidas parandada nende arusaamist juhistest?

3. Kuidas diabeediõed hindavad patsientide arusaamist diabeediga seotud terviseinfost?

   a. Milliseid, kui üldse, strateegiaid diabeediõed kasutavad, et hinnata patsiendi tervisekirjaoskuse taset?

   b. Kas on mõni tervisekirjaoskuse instrument kasutusel, et hinnata diabeetiku tervisekirjaoskuse taset visiidile eelnevalt või selle ajal?

   c. Kas on olnud mõnda koolitust olnud suunatud teemale, et kuidas suhelda inimesega, kellel on madal tervisekirjaoskuse tase?

   d. Kas Teie arust on vaja õdedele ja arstidele lisakoolitusi teemal, et kuidas suhelda erinevatel tervisekirjaoskuse tasemetel olevate patsientidega?

4. Kas ja millistest tehnoloogilistest vahenditest näete võimalikku kasu diabeedipatsiendi harimisel ja toetamisel?

   a. Kas Teil on kogemust mõne hea rakendusega oma töös?

INTERVJUU LÕPETAMINE

- Kas sooviksite mõnda küsimust lisaks kommenteerida või kas jäi mingi oluline teema, millest me ei rääkinud?

- Kui meil tekib lisaküsimusi antud teemal, kas võime Teiega ühendust võtta?

- Täname, et leidsite meie uuringu jaoks aega!