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Factors Influencing Participation In Shared Decision Making In The Oncological Setting

Master's thesis

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Tallinn 2022

TALLINNA TEHNIKAÜLIKOOL
Infotehnoloogia teaduskond

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Tegurid, mis mõjutavad valmisolekut osalemaks jagatud otsuste tegemisel onkoloogilise seisundi korral

Magistritöö

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Tallinn 2022

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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09.05.2022

Abstract

Background: Ageing population, growing prevalence of cancer and decline of oncology specialists in Europe’s workforce has brought forth necessity for patients to self-manage their conditions with the help of a health care professional. Patient engagement is widely recognized as a feature of good quality health care and an elementary part of patient management. Ensuring cancer patients’ good understanding of molecular profiling data is crucial for their active participation in illness-related decisions. Although shared decision making (SDM) improves patients’ knowledge and consideration of patients’ needs, several difficulties remain in implementing SDM in cancer care. **Aim**: This research aims to examine the causality between sociodemographic aspects and knowledge of cancer related topics and participation willingness in cancer care. **Methods**: A cross-sectional study using a web-based questionnaire was conducted including 1066 respondents among the population of Estonia. Descriptive statistics are provided to summarize the characteristics of the data set and logistic regression was used to answer research question. **Results**: From patients’ and their relatives’ side, there is a lack of knowledge and willingness to participate in SDM. Unlike previous studies, higher readiness for SDM was observed among ethnic minority and rural citizens. **Conclusions**: In addition to the previously identified factors, there is a need to consider a potential role of cultural and historical background of healthcare system in determining the willingness and readiness of the general public to participate in SDM. Also, a role of ethnicity and location of a patient is crucial in it. These results show the potential uniqueness of societies, where paternalistic and autonomous approach in patient management collide and similar findings may be present in many countries of similar Soviet heritage. If there is a lack of readiness or willingness of a patient to participate in SDM, a physician should be ready to accept the situation and provide alternative options to support their patients.

This thesis is written in English and is 62 pages long, including 6 chapters and 12 tables.

Annotatsioon

Tegurid, mis mõjutavad valmisolekut osalemaks jagatud otsuste tegemisel onkoloogilise seisundi korral

Taust: Vananev elanikkond, kasvav vähkkasvajate levimus ja onkoloogiaspetsialistide arvu vähenemine Euroopas on kaasa toonud olukorra, kus patsient peab ravimeeskonna toetusel oma seisundi haldamisse kaasatud olema. Patsiendi kaasamist raviotsuste tegemisse peetakse üheks kvaliteetse tervishoiu tunnuseks ning on enesehoole üks lahutamatu osa. Vähipatsientide teadlikkus oma haigusest ning selle ravist on nende aktiivseks osalemiseks haigustega seotud otsustes väga oluline. Kuigi jagatud otsustes osalemine (SDM) suurendab patsientide teadlikkust ja patsiendi vajadustega arvestamist, esineb vähiravis mitmeid raskusi patsiendi kaasamises. **Töö eesmärk**: Selle uuringu eesmärk on analüüsida kas esineb põhjuslik seos sotsiaaldemograafiliste tunnuste ning teadlikkuse ja valmisoleku vahel osaleda SDMis. **Meetod:** Veebipõhine läbilõikeuuring, milles osales 1066 vastajat Eesti elanikkonnast. Valimi kirjeldamiseks ning vastajate hinnangute esitamiseks kasutati risttabeleid. Logistilist regressiooni kasutati uuringuküsimusele vastamiseks. **Tulemused:** Patsientidel ja nende lähedastel napib teadmisi ja tahet osaleda SDMis. Erinevalt varasematest uuringutest täheldati rahvusvähemuse ja maakohas elavate inimeste seas kõrgemat valmisolekut osalemaks SDMis. **Järeldused:** Lisaks eelnevalt mainitud teguritele tuleb arvestada tervishoiusüsteemi kultuurilist ja ajaloolist tausta. Samuti mõjutab SDMis osalemise valmisolekut patsiendi etniline päritolu ja elukoht. Tulemused toovad esile selliste ühiskondade unikaalsust, kus paternalistlik ja individualistlik patsiendi käsitlus on põimunud, sarnased tulemused võivad esineda ka teistes Ida-Euroopa riikides. Kui patsiendil puudub valmisolek või soov SDMis osaleda, peaks arst olema valmis olukorraga leppima ja pakkuma muid võimalusi patsiendi toetamiseks.

Lõputöö on kirjutatud inglise keeles ning sisaldab teksti 62 leheküljel, 6 peatükki ja 12 tabelit.

List of abbreviations and terms

CAP	Cancer Action Plan
OR	Odds ratio
SAMPL	Statistical Analyses and Methods in the Published Literature Guidelines
SDM	Shared decision making
SPSS	Statistical Package for the Social Sciences

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1 Introduction

Cancer is one of the leading causes of death in the world. In 2020 the burden of cancer in the EU-27 rose to 2.7 million new cases with 1.3 million deaths and the risk of developing cancer before the age of 75 is estimated to be 30% [1]. The incidence of cancer in Europe is prognosed to grow by 21% and mortality to rise 29% by the year 2040 [2]. In Estonia during the last 5 years cancer diagnosis was confirmed yearly for approximately 8900 patients [3] and approximately 3800 patients die from cancer each year [4]. Ultimately cancer is becoming more widespread and important as cases rise.

Personalized medicine, also referred to as precision medicine, means that information about a patient's specific characteristics such as genes or proteins are used to understand and treat a disease [5]. Implementation of personalized medicine is a move away from a 'one-size-fits-all' conventional medicine approach [6]. In oncology implementation of precision medicine is widely touted as a standard of care, because cancer is a heterogeneous condition and thus has to be treated based on the specifics of the tumor and the patient [7]. As science is evolving researchers have identified several predispositions of cancer as well as genomic differences in tumors [7]. These finding have ultimately brought a more personalized approach in treating cancer [7]. Precision oncology, which is a process of molecular profiling of a tumor to find targeted treatment [8], plays an instrumental role in assisting oncologists with diagnosis, prognosis, and treatment of cancer [9]. Research has highlighted the importance of ensuring cancer patient's good understanding on molecular profiling data for their active participation in illness-related shared decision making (SDM) [10, 11]. Patients understand more clearly the risks and benefits of treatment, are able to vocalize their preference and thus are more satisfied with their physician as well as treatment decisions [12]. Since the patient's viewpoint is paramount in the execution of implementing tumor genomics to guide cancer treatment decisions, it follows logically that an evaluation of the knowledge of such tests is vital.

Patient engagement in SDM is widely recognized as a feature of good quality health care [13, 14]. SDM has been highlighted as a quality indicator of oncology care in numerous treatment guidelines. A systematic review found that during the years 2010-2019 40% of breast cancer oncology guidelines supported use of SDM in care setting [15]. Estonia has a Cancer Action Plan (CAP) for 2021-2030. CAP provides overview of effective patient-provider communication and sets goals to measure quality of life as well as patient satisfaction during the cancer pathway and highlights the need of involving the patient in treatment decisions [16]. Thus SDM implementation in Estonia is considered important in order to provide quality health care.

Although SDM improves patients' knowledge, satisfaction of clinical encounter, accommodating to patients' needs and in some cases even treatment outcomes [17–19], research studies have also shown difficulties in implementing SDM in cancer care, especially in terms of time and structural constraints in clinical practice [18–21], problems with the patients' ability to participate in SDM due to lack of knowledge [11, 22–24] and even unwillingness [11, 25, 26]. Patient characteristics and cultural aspects shape the willingness to participate in SDM as well [24]. Previous research has highlighted several socio-demographic groups, which are less susceptible to information about cancer as well as lack willingness to participate in SDM: people with lower level of education [18, 24, 27, 28], living in rural residence [29], being amongst ethnic minority [30, 31], with lower economic status [11], being male and of older age [28]. SDM is not self-evident; patients need to be assisted to achieve SDM and one of the options is to improve knowledge and willingness to participate [24], especially with an emphasize on groups which are by nature less susceptible to information and less willing to participate.

The cultural landscape of a countries healthcare system affects the use of SDM as well. Paternalistic or autonomous approaches to patient management affect whether SDM is implemented and expected [32]. If paternalism is the dominant approach then patients are not accustomed to raising their opinions about treatment and care, this makes SDM not implementable and if autonomous approach is expected then the situation is vice versa [32]. Understanding cultural and patient socio-demographic differences provide great value in clinical practice and help to shape SDM process.

Derived from everything above the **research problem of the thesis** is that patient socio-demographic factors [24] as well as previous knowledge of cancer related topics [11, 22–

24] and willingness to participate in SDM [11, 25, 26] have been highlighted to affect the implementation of SDM, but a thorough search of the relevant Estonian literature yielded no results, thus knowledge of the situation in Estonia remains unknown. This **research aims** to examine the causality between sociodemographic aspects and knowledge of cancer related topics and participation willingness in cancer care. This research might indicate the challenges behind SDM implementation in societies where paternalistic and autonomous approach collide, thus contributing to international research on this topic. **Research question**: In what ways does the knowledge of cancer related topics and willingness to participate in shared decisions differ between socio-demographic groups and between groups with different exposure to cancer within social sphere in Estonia? Hypothesis of the research is provided in chapter 3.2.

2 Theoretical framework

2.1 Cancer epidemiology and cancer treatment in Estonia

8 907 patients received a cancer diagnosis in Estonia according to the latest statistic from 2019 [3]. The incidence of cancer in Estonia is prognosed to rise and reach 11 000 new cases per year by 2030 [16]. Incidence rates for men are 15% higher than the European average [33]. Cancer survival rates continue to rise in Estonia, but effectively lag behind Northern European countries [34]. Late detection seriously affects life expectancy of patients [35] and even though population based screenings are in place in Estonia, in 2018 only 29% of cervical cancers, 35% of colon cancers and 49% of breast cancers were detected in the early stages of the disease [35]. People live longer after being diagnosed with cancer [36]. In the Estonian population 4% have had cancer within their lifetime [37] and according to the latest data from 2012-2016, more than 60% of people who have been diagnosed with cancer are still alive five years after being diagnosed [36]. Thus meaning the rise of number of people who are living with cancer for many years. To conclude cancer is becoming more widespread in Estonia.

In Estonia cancer is treated mainly in three hospitals: the North Estonia Medical Centre, the Tartu University Hospital, East Tallinn Central Hospital [38]. Support is provided from these main hospitals to three smaller sites: Pärnu Hospital, East-Viru Central Hospital and Kuressaare hospital [38]. Derived from CAP, the ultimate goal is to provide treatment to the patient nearer to home, thus supporting continuance of the patients day-to-day life [16].

Cancer treatment is divided into two parts: local therapies and systemic therapy [16]. Decisions about treatment are made in a multidisciplinary team, which consists of specialists from the two aforementioned treatment modalities as well as tumor diagnosticians (radiologists and pathologists) [16]. Each patient has an assigned oncologist who as well is the leader of the multidisciplinary team [16]. The treatment team also includes other professionals such as nurses, psychologists, social workers, etc, who support patient's quality of life [16]. For each patient a treatment plan is prepared

[39]. Treatment plan takes into account the type, location, size and spread of the tumor, which is based on previous examination and tests [39]. Separate discussions about the treatment type, purpose of the treatment as well as side effects are communicated and discussed with the patient and the treatment plan is executed only upon patient's consent [39]. Discussions with the patient about the treatment plan are important because decisions affect the patient's day-to-day life and it is therefore important that the patient is knowledgeable enough to make the right choices for themselves.

2.2 Personalized medicine and precision oncology

Personalized medicine or precision medicine is when information about a patient's specific characteristics such as genes or proteins are used to understand and treat a disease [5, 6]. Precision medicine enables individualized treatment strategies to be implemented based on the characteristics found [6]. Use of tumor genomics to guide cancer treatment is a cornerstone of precision oncology [20]; these developments are expected to bring forth a more personalized approach to clinical care [40] and offer an opportunity to use anti-tumor systemic therapies more effectively with better response and cost-effectiveness with minimum side effects [16]. This supports the continuation of patients' self-management and day-to-day life.

Cancer patients have expressed high interest in implementing cancer genomic testing during their treatment [27, 41]. Increased awareness of cancer types [41, 42], improved disease management decisions with higher patient satisfaction [27, 41, 42] and an active participation of patients in cancer care decision making [42] are considered as key motivations for pursuing cancer genomic testing. Patients believed that if testing was implemented, it would lead to a better understanding of cancer in general, it's cause and condition [41]. Due to testing patients hypothesized that they may have better outcomes which would prolong their life [41, 42].

Previous research has found several barriers of implementing cancer genomic testing, wherein cost [40, 41, 43], privacy and confidentiality of results [27, 40, 41, 43] as well as clinical utility [40, 41] have been seen as key issues. Patients concerns about cost and privacy were mainly prevalent in studies conducted in the United States, since the test was either paid out of pocket by the patient or remained concerns whether insurance would compensate the cost of the test [41, 43]. Patients voiced concerns of clinical utility, whether the results of the cancer genomic test actually have any value to the treatment options [40, 41]. Anxiety of patients caused by waiting time and uncertainty of consequences to receiving test results have been widely studied [27, 41–44]. There have been opposing results, where some studies reported negative psychological impact (anxiety, distress and depression) on the patient [27, 41, 43] and some studies reported no impact [42, 44]. Physicians have been mainly concerned about their insufficient knowledge and comfort of interpreting results and patient access to relevant treatment [43, 45].

Tumor genomics and anti-tumor systemic therapies are gaining popularity in Estonia [16]. Tumor genome sequencing is covered by Estonian Health Insurance Fund since 2014 [46], which is important in order to find genetic changes in tumors and thus assess whether targeted treatment can be used [33]. Ultimately Estonian patients may derive similar benefits as listed in previous studies [41, 42] like more knowledge of the disease and higher satisfaction with disease management, but active participation can be achieved only with the willingness of the patient.

Personalized medicine in Estonia has been mainly promoted by the Estonian Genome Project Foundation, which was set up in 2001 followed by extensive campaign in 2018 [47] to enable the access to genome data for 1/5th of Estonia's population [48]. Project "Implementation of Personalized Medicine in Estonia (2019-2022)" lead by National Institute for Health Development is preparing the availability for genetic risk assessments to be accessible for health care providers as well as the patients [49]. The risk assessments are based on the genome data already gathered by Estonian Genome Foundation and include assessment of genetic predisposition of breast cancer [49]. Ultimately the project is providing patients personal health and treatment recommendations based on their genetical data. One can conclude, that on the national level in Estonia awareness-raising of personalized medicine is being pursued and is a priority.

2.3 Approaches in patient management

Patient management can be categorized into two opposing models based on interaction style: paternalism and autonomy [50, 51]. Differences lie in the decision making process, where in paternalistic approach the physician makes the decision themselves and patient remains passive in this process and during the autonomous approach the physician informs the patient of a broad range of choices and the patient has an active role in deciding what is best for him/her [32, 51]. Table 1 provides a comparison of paternalism and autonomy in patient management.

Table 1 Paternalism and autonomy comparison overview, adapted from [32, 50–52]

	Paternalism	**Autonomy**
Patient's role	Sick role, to abide by the rules of the physician	Active participator in care decisions
Physician's role	Authority	Partner
Treatment decision	Unilateral decision made by the physician	Physician presents the options and patient provides input of preferences and based on the information the decision is made
Patient engagement	No engagement, patient obeys to the physician's rules	Patient is engaged in every step of the care process
Involvement and role of other professionals	Physician is the single decision maker and other professionals' role is to abide by the rules of the physician	Multidisciplinary team making joint decisions
Treatment of the disease	Best available clinical treatment	

Since the second half of the 20th century patient management has shifted from paternalistic approach towards autonomous approach [53, 54]. During this transition the medical process moved from doctor-centric to patient-centric and the doctor's exclusive authority has been replaced by an interdisciplinary team.

2.3.1 Paternalistic and autonomous approach in patient management

Paternalism in healthcare has been extensively covered by Talcott Parsons who in his book (1951) elaborated on the sick role and doctor role [52]. According to Parsons' theory sickness in society is considered as a deviant behavior and thus the sick person should be motivated to gain their health as quick as possible [52]. One of the obligations of the sick person is to seek medical attention as to be treated from their illness [52]. Doctors have position of authority over the sick person and thus can make decisions, that they consider best for the patient [52]. In this instance the patient does not need to be knowledgeable nor active in decision making process [52]. The patient has to abide by the rules of the doctor as to regain health and to move away from deviant behavior [52]. Once health is gained, the patient regains their normal social role and returns to their social obligations [52].

Parson's theory of the sick role has been mainly criticized due to it not being able to explain situations where the patient did not want to relinquish their normal roles and accept the sick role [55]. An example being a cancer patient who remains in the sick role but fulfills their social responsibilities as going to work and taking care of their family, thus not affecting their performance of their normal social roles. Cancer patients can have several phases of good and poor health, which affect in what extent they are able to operate within their normal roles. Ultimately Parsons' theory may not describe sufficiently enough a cancer patient's situation [56].

Parson's work was expanded by Suchman (1965) who defined stages which sick person went through [57]. Table 2 describes the defined stages and sick person actions by Suchman.

Table 2 Suchman's stages of sick person [57]

Stage	Action
Symptom experience	Something is wrong
Assumption of the sick role	Relinquish normal roles
Medical care contact	Seek professional advice
Dependent patient role	Accept professional treatment
Recovery and rehabilitation	Resume normal roles

As seen from Table 2, similarly to Parsons, Suchman described the stages of sick person linearly, where control was given over to the professional and once regained health then normal roles were resumed. A criticism of patient dependent role was provided by Bury [58]. Bury argues that due to extensive patient empowerment, even though patients usually accept professional treatment, then obeying by the rules of the physician without voicing their own concerns or opinions about the treatment did not seem realistic [58]. Suggesting, that cancer patients may not want to obey by the rules of the physician and wish to be active stakeholders in the treatment decisions.

Paternalistic approach was considered as the optimal way of clinical decision making in most countries of the developed Western societies until the second half of the 20th century [53, 54]. This shift from paternalism to patient autonomy has been explained by medical ethics guidelines such as the American Medical Association and The Principles of Biomedical Ethics by Beauchamp and Childress highlighting patient autonomy as well as scholars like Balint [59], Szasz and Hollender [60] starting to rule in favor of patient autonomy. Balint in his work (1964) argued, that illness is about symptoms as it is about individual psychological and social context [59]. He advocated for mutual participation of the physician as well as the patient in the decision making process [59]. Szasz and Hollender (1956) discussed three patient-provider communication models, where two models described the patient being either unresponsive or obeying recipient of the treatment and the third model being mutual participation where patient and provider are in a partnership [60]. Szasz and Hollender argued that even though communication model depends on the situation, it is clear that during chronic illness management the patient-provider partnership model is of best fit to the patient [60]. Byrne and Long (1976) advocated for encouraging patients to voice their needs and preferences [61]. In addition Mead and Bower (2000) found several barriers to implement patient-centeredness: patient's and doctor's background and attitudes, personal experience, communication and physical barriers, norms and time limitations [62]. Table 3 provides an overview of the theories discussed in chronological order.

Table 3 Timeline of paternalistic and autonomous patient management theories, adapted from [52, 57, 59–64]

Year	Event
1951	Parsons introduces the sick role
1956	Szasz and Hollender introduce three patient provider communication models
1964	Balint advocates for mutual participation of the physician and the patient
1965	Suchman complements Parsons' theory
1976	Byrne and Long encourage patients to voice their needs
2000	Mead and Bower find barriers in implementing patient centeredness

As depicted in Table 3 the process from paternalistic to autonomous approach took several decades. Ultimately, as seen from Table 3, several scholars found shortcomings of paternalistic approach of patient management and highlighted this in their work. Even though there are several shortcomings in paternalistic approach, then the decision line is easily understandable, ultimately the doctor decides based on their best knowledge. In autonomous approach there are several stakeholders: patient with family members and the interdisciplinary team consisting of the main treating physician as well as nurses and other members. Even though decisions are made jointly, the process itself is much more complex as compared to paternalistic approach.

In Eastern Europe, as well as in Estonia, change from paternalistic to autonomous approach started in the 1990s [48, 51, 65]. Due to this change happening much later than in Western European countries, patients in Estonia may not be accustomed to participate in decision making about their health and treatment [65, 66], although a trend towards patient involvement has been a central topic in Estonian healthcare system [48]. In Estonia patients' involvement in decision making regarding their own health is required by law [67].

Estonia has a CAP for 2021-2030, which sets national goals to improve the quality of life of cancer patients [16]. CAP provides overview of effective patient-provider communication and sets goals to measure quality of life as well as patient satisfaction during the cancer pathway and highlights the need of involving the patient in treatment decisions [16]. In CAP the goal is to ensure that by the year 2024 95% of cancer patients will have filled in a satisfaction questionnaire [16]. Thus highlighting that cancer patients have a say in their care process, which is the goal of SDM as well. In CAP an overview of how effective patient-provider communication needs to take place is highlighted [16]. During treatment plan development physician provides personalized information, identifies psychosocial need strategies, provides emotional support, helps the patient cope with their disease and supports patients health and if needed connects the patient with the services they need and coordinates psychosocial support and treatment [16]. One can conclude, that patient centeredness is an important topic in Estonia.

2.3.2 Shared decision making

The term "SDM" came to the forefront in the late 1980s as a part of patient-centered care [68]. SDM has been defined in numerous articles [68–70] and can be concluded as a process during which physician and patient discuss the medical evidence and patient preferences to decide the best treatment process. Cancer treatment may have a serious impact on patient's quality of life thus making patient's opinion which treatment to choose very important [71]. During the SDM process different options are provided to the patient [68–70]. The patient takes the responsibility to familiarize with the various treatment options and participates in decision making [68–70]. Decisions are made in cooperation between the physician and the patient [68–70].

Charles and colleagues (1999) described the steps in shared decision making [72]. They identified three steps in SDM: information exchange, deliberation and making a decision [72]. The three steps may change places since the patient-provider relationship is ever evolving [72]. Stiggelbout and colleagues (2015) furthered Charles and colleagues theory [73]. They provided four steps of SDM: professional informs that decision has to be made and the patient's opinion is important, professional explains pros and cons of the relevant options, patient's preferences are discussed, decisional role preference is identified and follow-up is discussed [73]. As compared to Stiggelbout and colleagues theory the Charles and colleagues' theory was lacking the discussion of role preference as well as follow-up [72, 73]. In a more practical example, the oncologist must provide the cancer patient all relevant options, after that patient preferences of care and treatment as well as the extent of the patient's role and physician's role in the decision making process are discussed and decisions are made. These discussions are continued in follow-ups making SDM an ongoing process throughout the care pathway.

Based on the theory of Cribb and Entwistle SDM can be divided into broad and narrow concept [74]. Narrow concept of SDM entitles that patients may have preferences and physicians should take them into account, because in doing so patient's autonomy is considered and there is much clearer understanding of what substitutes as good care for the patient [74]. In this concept physician only asks for the patient's preference and does not debate on the reasons of the preference [74]. Broad concept of SDM is when the physician helps the patient to voice preferences and reflect upon them, as well as challenge patient's preferences in a manner of concern [74]. The relevance of broader or narrower concept depends on the length of the encounters between physician and patient, the flexibility of physician's role, the depth of discussions and what is at stake due to the decision [74]. Cribb and Entwistle argued that chronic conditions would much benefit from a broader concept of SDM and acute conditions can be treated using narrow SDM [74]. In oncology the situation is further complicated by the patients progression of illness, some patients require urgent solutions due to deteriorating health, others illness does not progress and patient management is more similar to chronic illness. This complicates the situation, because the treatment team must adapt on a case-by-case basis.

Paternalistic or autonomous approaches to patient management affect whether SDM is implemented and expected [32]. If paternalism is the dominant approach then patients are not accustomed to raising their opinions about treatment and care, this makes SDM not implementable and if autonomous approach is expected then the situation is vice versa [32]. Previous research has highlighted that patient characteristics and cultural aspects shape the willingness to participate in SDM [24]. People with lower level of education [18, 24, 27, 28], living in rural residence [29], being amongst ethnic minority [30, 31], with lower economic status [11], male and of older age [28] are less susceptible to information and may lack willingness to participate in SDM. Rural residence was highlighted as a problematic factor due to access and speed of internet being low compared to urban residences [29]. In Estonia there is not immanent difference between families in rural and urban setting according to Internet access at home [75] and thus it may mean that for Estonia rural residence does not impact information susceptibility. Ethnic minorities in Estonia lack trust towards the health care system and its' providers [69, 76, 77] and ultimately this might affect SDM process. Russians in Estonia were found to be more prone to leave full responsibility of health matters to the doctor and the medical system as well as denying the need to search for health information and to be aware of one's own health condition [78]. This might indicate that Russians are less prone to be a part of SDM process. In Estonia females are more active in seeking health information and developing new healthier habits than men [78]. Thus the author argues that women are more active information seekers and are more willing to participate in SDM. SDM is not self-evident; patients need to be assisted to achieve SDM [24], especially with an emphasize on groups which are by nature less susceptible to information and less willing to participate.

3 Materials and methods

A cross-sectional study was conducted in February 2021 among the Estonian population. A web-based survey was used which included questions about socio-demographic characteristics of participants and their exposure to cancer, cancer-related information search, attainable knowledge and recognition of terms. Logistic regression and descriptive analyses of the data was used to answer research question.

Data collection was conducted by market research company RAIT Faktum&Ariko at the request of biotechnology company Roche Estonia. The author was working for the market research company and was the project lead of the research for Roche Estonia, in addition the author worked as an intern in Roche Estonia during that time. The author received consent from Roche Estonia to use this data in this thesis. The questionnaire was originally not designed to collect data for this thesis even though the author of this thesis was involved in the making of the questionnaire, data collection and report writing for the client.

3.1 Study design

This paragraph is divided into five sections addressing sample design, questionnaire, data gathering design, study method and weighting of the sample. An overview of the process is provided in Table 4 (chapter 3.1.3).

3.1.1 Sample

Sample size consisted of 1066 respondents in the age range of 20 to 75 years. For sample size determination Cochran formula was used with a margin of error of 3% and 95% confidence interval. The respondents were recruited according to the Estonian population proportions by age, sex, language, region of residence and settlement type characteristics. Demographic quotas were applied to ensure that the profile of achieved interviews in each sample point reflects the actual population of Estonia. Population proportions were received from Statistics Estonia upon request by the author. See Appendix 1 for received population proportions.

Data was weighted according to the socio-demographic profile of the population of Estonia aged 20-75 years. Data was weighted by sex, language, age and place of residence. Weighting was not performed if the difference between sample and data provided by Statistics Estonia was less than 3%.

3.1.2 Questionnaire

The questionnaire included 18 questions (English translation of questionnaire in Appendix 2). Questions were divided into four blocks: socio-demographic characteristics of participants and their exposure to cancer, cancer-related information search, attainable knowledge and recognition of terms. Exposure to cancer was defined by the respondent knowing a person within their social sphere who has had cancer within the last 5 years. Questions were either in the form of multiple-choice questions or open-ended questions. Roche Estonia defined the content of the Estonian questionnaire with the author. Data was gathered in Estonian and Russian language, as ethnic Russians make up 25% of Estonia's population [79]. The questionnaire is originally in Estonian language. A translation bureau conducted translation of the questionnaire from Estonian to Russian. The questionnaire was created for and with the market research company client Roche Estonia. This questionnaire was based on the needs of the client and was originally not designed to collect data for this thesis.

3.1.3 Data collection method

Quantitative method was used due to the author having permission of the client to access the dataset and means to re-use already gathered quantitative data. Re-using data saves time and does not inflict extra burden on the respondents [80]. Quantitative method enables to generalize results to a wider population and to find patterns and averages within the population [80]. As an advantage compared to qualitative research, quantitative research results are representative of the given population [80].

Cross-sectional study method was used to conduct this research. It is a type of quantitative observational method where outcomes and exposures are measured at the same time [81]. Cross-sectional study method was used because it suited the purpose of the study to prove or disprove assumptions about a bigger population. This method is typically used for population based surveys [81]. Cross-sectional studies are less expensive compared to longitude studies and do not require previous data to be gathered [80]. Cross-sectional study method does not allow to analyze behavior over a period of time and typically the reasoning behind answers are not known [81].

Data collection was conducted in February 2021 using a web-based panel of 54 000 members (4% of the population of Estonia). A survey panel is a centralized database of respondents who have agreed to provide feedback in surveys [80]. Respondents participation is typically compensated by the opportunity to collect points and if a number of points are gathered then the respondents can choose from a variety of gifts or participate in lotteries. Respondent panels are timelier and more cost-effective with higher response rate, but panels are an extract of the actual population, where a participation bias may occur [80]. Data was collected with an online questionnaire. Alchemer platform [82] was used to create the online survey. The members of the panel received a link to the online questionnaire via e-mail. Web-based questionnaire was used because of increased response rate, timeliness, lower cost and no interviewer bias [80], but population not using the Internet were unable to participate (see 5.3 Limitations). Table 4 provides an overview of the study preparation process, data collection and data processing.

Table 4 Study preparation process

Time	Stage	Actions
January 2021	Preparation of questionnaire and method	Consultations with Roche Estonia about topics and method based on research questions Specification of question types to be used to achieve relevant answers Entering survey to Alchemer platform
January 2021	Preparation of population proportions	Proportions by age, sex, language, region of residence and settlement type characteristics asked from Statistics Estonia by the author Proportions of the sample were entered to the Alchemer platform to ensure gathering data according to the population proportions
February 2021	Data collection	E-mail invitations to participate in the survey were sent to the panel members If respondents from each sample point exceeded the number of needed respondents then data from such groups were not gathered anymore, meaning that they could not respond to the questionnaire

Time	Stage	Actions
February 2021	Data cleaning	Quality check of responses. If answers are provided in a manner where there is a pattern of answers then such responses are graded as low quality and are excluded Weighting sample according to sample characteristics provided by Statistics Estonia Coding open answers
February 2021 - February 2022	Data processing	Analyses of results was conducted (see 3.2 Quantitative variables and statistical methods)

As seen from Table 4 the preparation process started with specifying questions of the survey followed by online survey construction. Continued by data gathering, cleaning and processing. The author was a part of the whole process.

3.2 Quantitative variables and statistical methods

Statistical analyses were conducted in line with the Statistical Analyses and Methods in the Published Literature (SAMPL) Guidelines. SAMPL highlights the importance of specifying the purpose, description, assumptions, results and quality measurements of the analyses [83]. Purpose of this analyses was to examine various aspects influencing cancer related information search, willingness to contribute to cancer care and knowledge of personalized medicine and cancer genomic testing. Description, results and quality measurements are provided in this paragraph in the following sections. Analyses were conducted using Statistical Package for the Social Sciences (SPSS) software version 23.

Participants' characteristics were sex, age, language, education, settlement type, income per family member, field of work and knowing someone with cancer. Dependent variables were information search of cancer treatment, contribution to cancer care, knowledge of personalized medicine and cancer genomic testing. Descriptive analyses of participants' characteristics and dependent variables were conducted as cross-tabulation and presented in absolute numbers and percentages. Logistic regression was used to explain information search of cancer treatment, contribution to cancer care, knowledge of personalized medicine and cancer genomic testing with the socio-demographic independent variables that were considered to be potentially relevant according to previous literature [11, 18, 24, 27–31]. The author used logistic regression because of dichotomous nature of the dependent variables. Dichotomous means that answers to questions were provided as yes or no answers. A *p* value <0.05 was considered as statistically significant. Odds ratio (OR), confidence interval and R^2 (Cox&Snell and Nagelkerke) values are presented in the results. The hypotheses are as follows:

Null hypothesis: There is no statistically significant relationship between knowledge of cancer related topics and willingness to participate in shared decision making with socio-demographic groups and groups with different exposure to cancer within social sphere.

Alternative hypothesis: There is a statistically significant relationship between knowledge of cancer related topics and willingness to participate in shared decision making with socio-demographic groups and groups with different exposure to cancer within social sphere.

To avoid misleading results in the logistic regression model, the author revised crosstabs between dependent and independent variables to evaluate that each group contained at least a few respondents (see Appendix 3), and used Cramer's V to assess, how strongly two independent variables are associated with each other to avoid a strong link between independent variables in the logistic regression model. In Cramer's V analyses if V>0.5 then it is considered as a strong association between variables [84]. Cramer's V analyses results are provided in Table 5. As seen from Table 5 Cramer's V analyses showed an association higher than 0.5 for region of residence between settlement type and language, due to this the region of residence variable was excluded from the analyses.

Table 5 Association analyses of independent variables, performed using Cramer's V

	Sex	Age	Language	Education	Settlement type	Region of residence	Income per family member	Field of work (healthcare/ social care vs not)	Cancer diagnosis
Sex	1.00	0.25	0.10	0.09	0.11	0.06	0.09	0.18	0.10
Age	0.25	1.00	0.28	0.39	0.41	0.46	0.43	0.23	0.30
Language	0.10	0.28	1.00	0.09	0.42	**0.53**	0.14	0.01	0.04
Education	0.09	0.39	0.09	1.00	0.13	0.20	0.20	0.05	0.10
Settlement type	0.11	0.41	0.42	0.13	1.00	**0.90**	0.14	0.04	0.05
Region of residence	0.06	0.46	**0.53**	0.20	**0.90**	1.00	0.20	0.03	0.10
Income per family member	0.09	0.43	0.14	0.20	0.14	0.20	1.00	0.08	0.08
Field of work (healthcare/ social care vs not)	0.18	0.23	0.01	0.05	0.04	0.03	0.08	1.00	0.02
Cancer diagnosis	0.10	0.30	0.04	0.10	0.05	0.10	0.08	0.02	1.00

3.3 Ethical considerations

The author, during the data collection process, was working for market research company RAIT Faktum&Ariko, which was hired to conduct market research by biotechnology company Roche Estonia. Roche Estonia defined the content of the questionnaire together with the author. The funder had no role in the data collection, the statistical analysis nor writing the report. The report for Roche Estonia was written by the author in Estonian and is accessible on their webpage [85]. The funder did not receive access to personal data gathered. The report provided to the client uses the same dataset as this research, but the theoretical framework is different and analyses in this research further into the topic of SDM and willingness to participate in cancer care. Author has been provided verbal consent by Roche Estonia to use this dataset in the making of this thesis.

RAIT Faktum & Ariko is a member of the European Society for Opinion and Marketing Research (ESOMAR) and the research was conducted in accordance with the ESOMAR Code of Conduct [86]. In compliance with ESOMAR standards [86]: data was gathered only for the purpose of research, respondents' anonymity was ensured such that they were not identified by name or any other personal identifier and personal data cannot be traced via deduction, meaning that cross-analyses are done in a manner where the groups of the respondents are large enough that it does not allow to identify the respondent. Permission to analyze data was given by the respondents to the market research company and participation in research was voluntary, the respondents could decline participation in the research at any point and the aim of the research was clearly stated to the participants.

This research followed all relevant Personal Data Protection Act rules [87]. §6 of the Personal Data Protection Act stipulates that processing special categories of personal data for scientific research without the consent of the data subject requires verification by an ethics committee [87]. However, as participation in research was voluntary and the respondents willingly consented to take part in the study, this study does not require the verification of the ethics committee [87].

4 Results

This chapter provides information about descriptive and regression analyses results. Sample characteristics, dependent variables of logistic regression as well as overview of dependent variables comparison according to cancer within social sphere and the characteristics of respondents who would let the doctor make decisions themselves are provided in the first paragraph. The second paragraph provides an overview of logistic regression models of the dependent variables: information search of cancer treatment, contribution to cancer care and knowledge of personalized medicine and cancer genomic testing.

4.1 Results of descriptive statistics

Table 6 provides an overview of the descriptive results of the sample. The sample corresponds to the Estonian population according to the proportions by age (20-75), sex, language, region of residence and settlement type characteristics.

Table 6 The study sample characteristics (N=1066)

		Proportion (%)	n
Sex	Male	48	512
	Female	52	554
Mother tongue	Estonian	68	727
	Russian or other	32	339
Income per family member per month	Under 500 EUR	20	217
	500-1000 EUR	42	447
	1000-1500 EUR	23	246
	Over 1500 EUR	15	156
Education	Primary education	7	70
	Secondary education	53	566
	Higher education	40	430
Settlement type	Tallinn	36	380
	Other cities	31	330
	Borough or village	33	356

		Proportion (%)	n
County	Harjumaa	47	499
	Ida-Virumaa	12	127
	Tartumaa	10	112
	Pärnumaa	6	63
	Lääne-Virumaa	4	46
	Viljandimaa	3	34
	Võrumaa	3	27
	Raplamaa	2	25
	Saaremaa	2	25
	Järvamaa	2	24
	Jõgevamaa	2	22
	Valgamaa	2	21
	Põlvamaa	2	20
	Läänemaa	1	15
	Hiiumaa	1	8
Field of work	Healthcare or social care	5	56
	Other	95	1010
Have you or people you know been diagnosed with cancer in the last 5 years?	Myself	3	34
	In my family	14	145
	Among relatives	25	263
	Among friends or colleagues	23	248
	None of the above	44	472
Total		100	1066

As seen in Table 6, majority of respondents were females with Estonian ethnicity (52% and 68% respectively), with secondary education (53%), and having income lower than 1000 euros per month per family member (62%). The latter corresponds to the general income level, where average income per family member is 814 Euros [88]. The mean and median age of the respondents was 47 years and standard deviation 15. Type of settlement, where the respondents lived was almost equally distributed with 36% living in the capital city, 31% in other cities and 33% in rural areas. The sample corresponds to the national average provided by Statistics Estonia.

During the last 5 years, only 44% reported for not having known anyone with cancer. 14% of the respondents had cancer within their family and 3% themselves were cancer patients. These results correspond to national statistics, according to which, 4% have had cancer within their lifetime and 2% within the last 12 months [37].

Table 7 describes the distribution of dependent variables: information search of cancer treatment, contribution to cancer care, knowledge of personalized medicine and cancer genomic testing.

Table 7 Descriptive statistics of dependent variables

		Proportion (%)	n
Searched for cancer treatment related information within past 5 years	No	77	821
	Yes	23	245
Would ask the doctor what they could do themselves when diagnosed with cancer	No	88	933
	Yes	12	133
Know what personalized medicine means	No	80	858
	Yes	20	208
Know what cancer genomic testing means	No	86	919
	Yes	14	147
Total		100	1066

As seen from Table 7 knowledge about personalized medicine still remains as low as 20% even though there has been an extensive discussion on personalized medicine due to Geenivaramu project [47]. A similar knowledge gap is present with cancer genomic testing, where only 14% of the population knew what it is. These results suggest, that more extensive educational campaigns may be needed.

Even though 56% of respondents knew someone with cancer (refer to Table 6), only 23% have searched for cancer related information individually and 12% would have asked what they themselves could do, when diagnosed with cancer. These results indicate, that even though people may have experience with cancer, then active participation is on the minds of only few respondents, ultimately indicating that once they become patients, they may remain passive treatment recipients. These results suggest lack of interest in shared decision making in cancer care.

Table 8 describes how dependent variables, information search of cancer treatment, contribution to cancer care, knowledge of personalized medicine and cancer genomic testing, are distributed according to cancer within social sphere.

Table 8 Dependent variables according to cancer within social sphere

		Has cancer diagnosis themselves or within family (%)	Cancer diagnosis among friends or relatives (%)	No cancer diagnosis within social sphere (%)
Searched for cancer treatment related information within past 5 years	No	59	74	87
	Yes	41	26	13
Would ask the doctor what they could do themselves when diagnosed with cancer	No	87	85	90
	Yes	13	15	10
Know what personalized medicine means	No	81	76	84
	Yes	19	24	16
Know what cancer genomic testing means	No	87	83	89
	Yes	13	17	11
Total		17	39	44

As described in Table 8, 41% of the respondents with cancer diagnosis in the family have searched for cancer related information and the amount is 3 times higher compared to respondents who do not know anyone with cancer (13%). These results show that cancer is not a topic of interest unless there is someone within the respondents' social sphere dealing with cancer, which may as well explain the finding of low knowledge about cancer related topics such as personalized medicine and cancer genomic testing (see Table 7).

The proportion of respondents who would ask what they could do themselves when diagnosed with cancer does not differ between people who know someone with cancer (13% and 15%) compared to people who do not know anyone with cancer (10%). These results suggest that patients and their family members may not be ready for active participation in cancer care and may remain passive bystanders while physician makes the treatment decisions.

Knowledge of personalized medicine remains higher than cancer genomic testing in each group, suggesting that cancer genomic testing may be hard for patients and their family members to understand and thus may need extensive clarification from the physicians side. Knowledge of personalized medicine and cancer genomic testing was higher among respondents who knew a friend or a relative with cancer (24% and 17%) compared to respondents who have cancer within family (19% and 13%) and respondents who do not know anyone with cancer (16% and 11%). Even though the proportions of respondents who have cancer within family show higher knowledge (19% and 13%) than respondents who do not know anyone with cancer (16% and 11%), the difference is relatively small and ultimately supports the assumption that cancer patients' family members are lacking knowledge.

Table 9 describes the socio-demographical differences in respondents who would prefer that the doctor made decisions in case of a cancer diagnosis.

Table 9 Sociodemographic factors of respondents who would let the doctor decide in case of cancer

		Would not know what to ask from the doctor, would let the doctors decide	
		No (%)	Yes (%)
Sex	Male	88	12
	Female	94	6
Mother tongue	Estonian	93	7
	Russian or other	89	11
Age	20-34	94	6
	35-49	88	12
	50-64	93	7
	65+	88	12
Income per family member per month	Under 500 EUR	83	17
	500-1000 EUR	93	7
	1000-1500 EUR	93	7
	Over 1500 EUR	94	6

		Would not know what to ask from the doctor, would let the doctors decide	
		No (%)	Yes (%)
Settlement type	Tallinn	92	8
	Other cities	91	9
	Borough or village	91	9
Education	Primary education	85	15
	Secondary education	91	9
	Higher education	93	7
Have you or people you know been diagnosed with cancer in the last 5 years?	Myself or in the family	93	7
	Among friends or relatives	93	7
	None of the above	89	11
Total		91	9

If the respondent themselves or a family member would be diagnosed with cancer, then 9% of respondents would not know what to ask the doctor and would let the doctors decide on their own, as seen from Table 9. These results highlight the importance of asking a patient if they are ready to be a part of shared decision making, since some patients may not want to. Females are more interested in having a voice in treatment decisions compared to males, this is supported by previous research [28, 78]. Respondents with lower income and lower education are more interested in letting the doctor decide on their own compared to respondents with higher income and higher education. These results suggest that among those who are not willing to be a part of shared decision making are probably rather men, people with lower education and lower levels of income.

To conclude cancer is a topic affecting many respondents – 56% knew at least someone with cancer. Cancer treatment related information was searched by 23% of respondents, even though exposure to cancer remain relatively high (56%). Respondents were not very knowledgeable of cancer genomic testing nor personalized medicine. 12% would ask what they could do when diagnosed with cancer and 9% would let the physician completely decide for themselves. Willingness to contribute to care was higher among females, respondents with higher education and income.

4.2 Results of logistic regressions

Table 10 summarizes the results of four logistic regression models. Results of the logistic regression are presented with OR and corresponding 95% confidence intervals regarding information search of cancer treatment related topics (Model 1), willingness to contribute to cancer care (Model 2) and knowledge of cancer related terminology (Model 3 and Model 4). All the models predict the odds of a positive outcome, meaning that Model 1 predicts the odds of having searched for information, Model 2 predicts the odds of having willingness to contribute to cancer care, Model 3 predicts the odds of knowing what personalized medicine is, Model 4 predicts the odds of knowing what cancer genomic testing is.

Model 1 indicated that the odds of searching for cancer treatment related information was significantly lower for the people, who had a cancer diagnosis among friends or relatives (OR=0.48, *p*=0.000) or no cancer diagnosis within social sphere (OR=0.22, *p*=0.000) as compared to respondents who had cancer diagnosis in the family. No differences were found between sex, age, education nor income levels. This result showed that people are not interested in cancer information search unless the topic is relevant for them personally.

Model 2 showed the willingness to contribute to cancer care. Females (OR=1.56, *p*=0.029) were significantly more willing to contribute than males. Respondents from ethnic minority (OR=2.10, *p*=0.002) were more interested in contributing to their own cancer care than the ethnic majority population in Estonia. Interest to contribute to cancer care did not differ between the groups, where cancer was in the family as compared to the participants, who did not know anyone with cancer (OR=0.93, *p*=0.502). Apparently, after facing a challenge of such life-threatening disease, active participation is not something that people are willing to engage in. No differences were found between age, income levels and settlement type.

Model 3 and Model 4 results were assessed to understand the participants' general level of knowledge about cancer related issues. Analyses evaluated the knowledge of personalized medicine and cancer genomic testing. For both the topics, education was an aspect influencing the level of knowledge. The respondents with tertiary education were 3 times more likely (OR=3.17, *p*=0.011) to know what personalized medicine is and 9 times more likely (OR=9.42, *p*=0.005) to know what cancer genomic testing is as compared to the respondents with primary education.

Model 3 indicated that the odds of knowing what personalized medicine is, became more probable with increasing age (OR 1.01, *p*=0.039). The respondents living in rural area (OR=1.04, *p*=0.033) were more likely to know about personalized medicine than people living in the capital city. Regarding knowledge of personalized medicine and cancer genomic testing, there were no differences between the people who had cancer in their family as compared to the people who did not know anyone with a cancer diagnosis (OR=0.84, *p*=0.453, OR=0.84, *p*=0.530). No apparent difference of knowledge indicates an information gap that is present in cancer patients and their immediate family. No differences were found between sex, native language and income levels.

Table 10 Information search of cancer treatment, contribution to cancer care and knowledge of personalized medicine and cancer genomic testing

	Model 1			**Model 2**			**Model 3**			**Model 4**		
	OR	**95% CI**		**OR**	**95% CI**		**OR**	**95% CI**		**OR**	**95% CI**	
Female (ref. male)	0.99	0.72	1.35	**1.56**	**1.05**	**2.32**	0.99	0.72	1.38	0.81	0.55	1.18
Age (20-75)	1.00	0.99	1.01	1.01	0.99	1.02	**1.01**	**1.00**	**1.02**	1.00	0.99	1.02
Other language (ref. Estonian)	1.27	0.89	1.82	**2.10**	**1.33**	**3.34**	1.13	0.77	1.66	0.74	0.47	1.15
Secondary education (ref. primary education)	1.70	0.79	3.66	**4.34**	**1.09**	**17.26**	2.02	0.84	4.87	**4.68**	**1.00**	**21.88**
Tertiary education (ref. primary education)	2.13	0.98	4.66	3.92	0.97	15.86	**3.17**	**1.30**	**7.75**	**9.42**	**2.00**	**44.32**
Other cities (ref. Tallinn)	0.90	0.62	1.30	0.82	0.50	1.34	1.20	0.80	1.80	0.98	0.61	1.56
Rural area (ref. Tallinn)	1.06	0.70	1.60	1.61	0.95	2.74	**1.60**	**1.04**	**2.47**	1.24	0.76	2.01
501-1000 EUR (ref. up to 500 EUR)	0.88	0.58	1.32	1.09	0.67	1.80	1.46	0.94	2.27	1.66	0.96	2.86
1001-1500 EUR (ref. up to 500 EUR)	1.15	0.73	1.81	1.13	0.63	2.00	0.98	0.58	1.63	1.55	0.85	2.81
Over 1500 EUR (ref. up to 500 EUR)	0.83	0.48	1.42	0.54	0.24	1.19	1.28	0.73	2.26	0.98	0.48	2.00
Field of work (ref. medical or social worker)	0.89	0.47	1.69	1.67	0.66	4.20	0.93	0.47	1.83	0.61	0.30	1.24
Cancer diagnosis within friends or relatives (ref. myself or within family)	**0.48**	**0.33**	**0.70**	1.18	0.69	2.00	1.34	0.85	2.09	1.22	0.73	2.05
No cancer diagnosis within social sphere (ref. myself or within family)	**0.22**	**0.15**	**0.33**	0.83	0.48	1.43	0.84	0.53	1.33	0.84	0.50	1.43

P-values that are significant ($p < 0.05$) are in bold. *Cox&Snell R Square is 0.064 and Nagelkerke R Square is 0.097; **Cox&Snell R Square is 0.039 and Nagelkerke R Square is 0.075; ***Cox&Snell R Square is 0.038 and Nagelkerke R Square is 0.061.****Cox&Snell R Square is 0.040 and Nagelkerke R Square is 0.073

To conclude Model 1 showed that interest in information about cancer is relevant when a family member is diagnosed with cancer, respondents did not tend to search for cancer related information if they did not know anyone with cancer. As seen from Model 2 active participation in cancer care is not self-evident, respondents with cancer in their family were not more eager to contribute than any other group. An unexpected finding was that ethnic minority was more eager to contribute to cancer care than ethnic majority. Interestingly Model 3 and Model 4 showed that respondents with cancer in their family were not more knowledgeable than any other groups. Knowledge of cancer genomic testing and personalized medicine was seen in respondents with higher education and interestingly as well in people living in rural areas.

In order to answer the research question, in what ways does the knowledge of cancer related topics and willingness to participate in shared decisions differ between socio-demographic groups and between groups with different exposure to cancer within social sphere in Estonia, it may be concluded that knowledge and willingness did not differ between groups with different exposure to cancer within social sphere. Some socio-demographic groups, such as females and ethnic minority groups stood out with more intent to participate in cancer care and respondents with higher education and living in rural area were more knowledgeable.

5 Discussion

Whereas SDM has been highlighted to improve patients' knowledge, satisfaction of clinical encounter, accommodating to patients' needs and in some cases even treatment outcomes [17–19], little work to date has examined how socio-demographics, knowledge of cancer related topics and willingness to participate in SDM affects the implementation of SDM. It is necessary to understand public perceptions to develop appropriate practices of SDM in oncology. Successful SDM is accompanied by a knowledgeable patient who should participate willingly and be equipped for participation. The analyses showed that in Estonian context people might not be either.

5.1 Knowledge of cancer related topics and willingness to participate in cancer care of cancer patients and their family

Research findings show that knowledge levels remain low for cancer related topics in the public and do not differ between the people who have cancer in their family as compared to the people who do not know anyone with cancer. This result highlights one of three aspects. Firstly either cancer patients and their immediate family have not been informed of general cancer topics like personalized medicine and cancer genomic testing. This finding is supported by previous research highlighting time and structural constraints in cancer care [18–21], due to which there is no time in the clinical setting to deal with patient education on general cancer topics. Secondly lower levels of knowledge may be because during such a life-threatening diagnosis people are not receptive to information on such topics. Thirdly, cancer patients and their immediate family may not be willing to acquire such knowledge. This has been highlighted in previous research as well stating cancer patients' lack of ability to acquire information [11, 22–24] and unwillingness to acquire information on cancer topics during disease [11, 25, 26]. Thus keeping a close and ongoing communication between the physician and patient is needed, in order for the patient to attain reasonable level of knowledge so that the patient can have an active role in SDM. This will require the support from the treating physician as well as other members of the care team, for example oncology nurses. Their contribution to patient education can have a positive effect on patient satisfaction on treatment decisions.

Even though information about cancer treatment is widely accessible [48], present research outlines that such information search is only widespread among the people who already are affected by cancer and between other socio-demographic groups information search did not differ. Thus supporting cancer patients with relevant information throughout the care pathway is an important task for the healthcare professionals. Providing relevant information to the patient may help them in becoming more active participators in the SDM process.

The results of this study suggest that people may be ready and looking for information during a family member's cancer treatment, but their own contribution to cancer care is not in their minds during that time. As current research shows only 12% of the population would ask what they themselves could do if diagnosed with cancer, indicating a lack of willingness to take part in SDM or bear individual responsibility in wider terms than pure obedience to medical instructions. 9% of the population would not know what to ask the doctor and would let the doctors entirely decide themselves. These results highlight the need for physicians to use SDM models such as Stiggelbout and colleagues model [73] in daily practice. According to the Stiggelbout and colleagues model if the patient is not willing to participate or does not know how to participate, then the physician has to provide all relevant information, ask about patient preference and if there is no preference, then physician can inform the patient, that the patient's opinion is important in order to make a decision [73]. If the patient voices their preference for a more paternalistic approach, then the physician has to accept the situation and lead the treatment decisions themselves [73]. These discussions between the physician and patient about patient preference are continued in follow-ups making SDM an ongoing process throughout the care pathway [73]. The physicians' role in SDM implementation is very important, because creating an environment for the patient where it is easy to be a part of treatment decisions shapes future encounters between the patient and the physician [60]. Ultimately patients will start to expect that they need to contribute in treatment decisions about their health [60].

The findings of this study align with previous research demonstrating a lack of interest of cancer patients to participate in cancer care [11, 25, 26]. Cultural aspects, including approaches to patient management, might remain influenced by a paternalistic approach more in societies of Soviet heritage, even if extensive actions are taken to implement change towards SDM [65, 66], as it has been done in Estonia [48]. In a culture of paternalistic heritage during cancer treatment patients are likely to remain passive bystanders, for whom decisions are made by physician. It could be fruitful in the oncological setting to empower patients to ask questions and express their preferences for their role of participation [19, 24], since as seen from the analyses the majority (88%) would not consider having any role in cancer care on their own. In a culture of Soviet heritage the change towards less paternalistic and more autonomous approach in patient management has not happened overnight and will continue to need more time and effort [48]. Thus suggesting that resources should be allocated for activities which help speed up this transition. The author of this research suggests that educating physicians and patients about the importance of patient autonomy will make a difference in the long run.

5.2 Socio-demographics affecting knowledge of cancer treatment related topics and willingness to contribute to care

Present research outlines that in Estonia, knowledge of cancer genomic testing and personalized medicine is quite low – 14% of the population know what genomic testing is and 20% know the meaning of personalized medicine. Expectation of the patient having demands and being able to make decisions in cancer care is unlikely due to low awareness [24]. Ultimately, it is expected that the decisions will be made by the doctor. In this context of low knowledge educating patients about general cancer topics may be fruitful for their more active participation in SDM process. More educated patients have a greater ability to understand the physicians explanations, ask consecutive questions and have more fruitful discussions about treatment decisions [24].

Previous research has highlighted that people living in the country side are subjected to lack of access to high-speed internet, which challenges education, e-learning and e-health programs [29]; however, in Estonia difference of families having internet access at home does not differ between rural and urban settings [75]. Present research findings show that rural families are even more receptive to cancer related information as compared to urban families which indicate a more extensive role of internet in rural families. This finding may suggest that patients from rural setting are more ready to be a part of SDM. The difference between rural and urban citizens may derive from their situation – a rural citizen does not have access to a doctor at all times and is forced to be more independent and active in the context of their treatment, while urban citizen's access to treatment may be much closer to home and thus easier. Patients from urban setting may need more support from the physician in attaining knowledge of cancer related topics, thus ultimately supporting their participation in SDM.

Another differentiator, which has been extensively highlighted in previous research [18, 24, 27], is education; analyses of this research indicate that higher levels of education support awareness of cancer topics. This means that patients with higher education are more ready for SDM than those of lower level education. Participation in SDM may be harder for patients with lower levels of education, due to their lower ability to understand physicians explanations. Physicians and oncology nurses may need to support patients with lower level education more.

Previous research has highlighted that females are more interested in having a voice in treatment decisions compared to males [28]. Analyses of this research shows that compared to males females are more willing to contribute to cancer care than men. Thus it might be fruitful to involve a female family member in the process of SDM.

Present research outlines that socio-demographic aspects do not affect cancer information search. Thus meaning that supporting patients with attaining relevant information about cancer treatment would be fruitful for all counterparts. Also, there is no correlation between information-seeking attitude and ethnicity, although previous research studies have suggested, that in Estonia Russian-speaking minority was less likely to know about proper information sources to update themselves on health related topics [30, 31]. In this study, a contradictory finding appears in a matter, where the ethnic minority is more willing to participate in cancer care than the ethnic majority. Previous research has highlighted that Russian minority in Estonia was not as contempt with health care management [31] and fewer of them felt that health care provider showed them care and consideration during the visit [30]. This may be a trust issue towards the health care system and its providers which was noted in previous research [69, 76, 77] and due to this ethnic minority maybe more interested in contributing on their own. Thus winning the trust of ethnic minority patients will require building long-term relationship. Using the broader SDM approach the physician can help the patient voice their preference and reflect upon these preferences in a manner of concern, thus building trust between the patient and physician. It can be argued as well that patients from ethnic minority in

Estonia are more ready and eager to be a part of SDM process and Estonians prefer a more paternalistic approach to the treatment process, even though previous research has suggested otherwise [78]. Ethnic minority in Estonia, who in this research consisted mainly of Russian speaking respondents may have more information sources about cancer treatment via Russian media, but for Estonian speaking population access to materials in Estonian are limited. This access to more information may result in Russian speaking respondents having more questions and concerns about their treatment options and in result being more active participants in treatment decisions.

To summarize, the ethnic minority is more interested to contribute to cancer care than the ethnic majority. Moreover, the people living in rural areas are more knowledgeable about cancer related topics. These results show the potential uniqueness of societies where paternalistic and autonomous approach to patient management collide, which may be present in many countries of Soviet heritage. These results will help the treatment team to understand which SDM approaches are suitable for which patients. In all cases using Stigglebout and colleagues SDM model [73] to understand patient preference of their decisional role in each treatment decision is a reasonable step towards a more satisfied patient. Adequate counseling, which is a prerequisite for the patient to make an individual decision, means additional effort for doctors and a burden on the medical system. The physicians role in the SDM process is to create an environment for the patient where it is easy to be a part of treatment decisions, this will shape future encounters between the patient and the physician into a more partnership than paternalistic model [60].

Patient involvement and a more patient-centered approach has been a central topic in Estonian healthcare [39, 48, 67]. The results of the study show that there is a lack of patient interest, so the healthcare system as a whole should intervene because the system expects and needs people to be active in making treatment decisions. In addition, because people are not ready for SDM at the moment, cultural and background factors are as well not taken into account by the treating physician.

Females and the ethnic minority who are more eager to take individual responsibility are more likely to be more demanding of the physician and expect accurate explanations from him or her. Failure to listen to the patient's concerns and answer questions due to time constraints may leave the patient with questions and frustration with the medical system. These results point to the following needs: education and adequate information channels as well as supportive environment. Patients, physicians and other healthcare professionals should be educated about SDM implementation. The physician may not have time for these discussions about patient preferences, so this time should be allocated for the physician and the patient. Implementing SDM must be an easy option and environment should support it.

5.3 Limitations

The study has some limitations. Cross-sectional study design is susceptible to misclassification due to a recall bias. Population based panels are an extract of the actual population, where a participation bias may occur. This research was conducted as an online study, thus, population not using the Internet or do not have access to it, could not participate. Since prevalence of cancer is higher among the age group 65+ [3] and the proportion of Internet users among 65+ age group is lower (65%) compared to younger age groups (usage varies from 86%-99%) [89], then this might mean that the sample is over represented of respondents who are not personally affected by the topic. Finally, this research examined socio-demographic characteristics as influential factors to knowledge, but the model showed low explanatory power, suggesting that knowledge and willingness to participate in cancer care are affected by other characteristics that are not studied in this research. Despite of these limitations, the author believes that this study provides valuable insights for the possible reasons of SDM failure in the countries, where paternalistic heritage has shaped the patient-doctor relationship.

5.4 Future research

Healthcare providers are key executors of SDM [73]. Further research should focus on exploring their attitudes about SDM as well as barriers and facilitators in the clinical setting. If barriers are addressed then implementation of SDM may become more widespread. Monitoring implementation of SDM will help define shortcomings of SDM implementation in hospitals and ultimately help diminish such shortcomings. The topic of genome testing could also be explored, including doctors' own awareness of the topic and their willingness to discuss these issues with patients. Cancer genome testing can help broaden treatment options [16] and thus is an important topic to be discussed with the patient.

The model of logistic regression showed a rather small explanatory power, meaning that besides socio-demographic and economic aspects there are other influencers of willingness to participate in SDM. Thus investigation of other aspects would provide additional information. Previous literature has highlighted that socio-cultural conditions of the country affect attitudes towards SDM [32] and these attitudes should be researched.

5.5 Final conclusions

Following conclusions based on study findings can be drawn:

1. Findings of this research show that knowledge levels remain low for cancer related topics in the public and do not differ between the people who have cancer in their family as compared to the people who do not know anyone with cancer. Indicating that there may be no time in the clinical setting to deal with patient education and patients may not be receptive to or even unwilling to acquire information on such topics. Thus keeping a close and ongoing communication between the physician and patient is needed, in order for the patient to attain reasonable level of knowledge so that the patient can have a more active role in SDM. This will require the support from the treating physician as well as other members of the care team, for example oncology nurses.
2. People living in rural areas are more knowledgeable about cancer related topics than people living in urban setting, which may indicate a more extensive role of internet in rural families. The difference between rural and urban citizens may derive from their situation – a rural citizen does not have access to a doctor at all times and is forced to be more independent and active in the context of their treatment.
3. Higher education is linked to better knowledge of cancer related topics. Participation in SDM may be harder for patients with lower levels of education, due to their lower ability to understand physician’s explanations. Physicians and oncology nurses may need to support patients with lower level education more.
4. Females compared to males are more willing to contribute to cancer care. Thus it might be fruitful to involve a female family member in the process of SDM.
5. The ethnic minority is more willing to contribute to cancer care than the ethnic majority. This may be a trust issue towards the health care system and its

providers. It can be argued as well that ethnic minority may have more information sources about cancer treatment via Russian media and this access to more information may result in Russian speaking respondents having more questions and concerns about their treatment options and in result being more active participants in treatment decisions.

6. Research findings align with previous research demonstrating a lack of interest to participate in cancer care, suggesting a more paternalistic approach in patient care being prevalent. These research results point out the following needs: education of treatment team and patient about SDM implementation and providing supportive environment for the physician and patient to have the ability to discuss patient preferences.

6 Summary

The aim of the research was to examine the causality between sociodemographic aspects and patient knowledge of cancer related topics and participation willingness in cancer care. The author of the thesis conducted statistical analyses to understand socio-demographic aspects that influence knowledge and willingness to participate in SDM.

Firstly the analyses of this data gave valuable insights into knowledge of cancer related topics. Lack of knowledge is evident and knowledge is influenced by the respondents education as well as living in a rural area.

Secondly patients' willingness to contribute to SDM in oncological context was relatively low and participants mainly did not see that they had a role in SDM. Given a possible misinterpretation of patients' willingness to be a part of SDM, it is imperative that more attention should be paid to support and highlight its importance to general public. In the oncological context, patients may not be ready and not willing to be a part of the decision making process. Thus extensive support from physician may be needed.

Thirdly cultural and socio-demographic context needs an extensive consideration in SDM in the oncological care setting. Especially, this is relevant in the countries, where a paternalistic approach to medicine is still very much a norm. In oncological setting doctors need to consider patients' historical and cultural background while looking at SDM models and professionals need to provide alternative solutions to SDM.

To sum up, this thesis assessed socio-demographic factors as influencing SDM, but there are several aspects affecting SDM implementation. Therefore, to increase SDM implementation, a set of different aspects should be assessed: physician preferences, barriers of implementation in oncology clinic setting and cultural setting of the country.

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Appendix 1 – Estonian population proportions

Table 11 Estonian population proportions received from Statistics Estonia

		Proportion (%)
Sex	Male	49
	Female	51
Age	20-29	16
	30-39	21
	40-49	20
	50-59	18
	60-75	25
County	Harju (without Tallinn)	12
	Tallinn	34
	Hiiu	1
	Ida-Viru	10
	Jõgeva	2
	Järva	2
	Lääne	2
	Lääne-Viru	4
	Põlva	2
	Pärnu	6
	Rapla	2
	Saare	3
	Tartu	11
	Valga	2
	Viljandi	3
	Võru	3
Settlement type	City	69
	Rural	31
Mother tongue	Estonian	67
	Russian and other	33
Total		100

Appendix 2 – Questionnaire translated into English

1. Sex
    1. Male
    2. Female

2. Age

_____ years

3. What is your main language of communication?

    1. Estonian

    2. Russian

    3. Other

4. Where do you live?

    1. Tallinn

    2. Harju county

    3. Tartu County

    4. Ida-Viru County

    5. Pärnu County

    6. Lääne-Viru County

    7. Viljandi County

    8. Rapla County

    9. Võru County

    10. Saare County

    11. Jõgeva County

    12. Järva county

    13. Valga County

    14. Põlva County

15. Lääne County

16. Hiiu County

4a. What type of settlement is your place of residence?

1. City
2. Town / town
3. The village

5. What is a monthly income of your household per family member (net, ie after state taxes)?

1. Under 500
2. 500-1000
3. 1000-1500
4. 1500-2000
5. Over 2000
6. Don't want to answer

6. In what field do you work / operate? Tick only one, closest

1. Industry / Construction / Energy / Transport and logistics
2. IT and telecommunications
3. Business services
4. Private sector services
5. Trade
6. Culture / Entertainment / Sports / Media
7. Agriculture / Fisheries / Maritime
8. State and public administration
9. Social work

10. Healthcare / Medicine ->

a. if so, what specialty___________________

11. Education / Science

12. Not working, I'm retired

13. Not working, I'm learning

14. On parental leave or at home

15. Other, please specify ___________________________________

7. What is your level of education?

1. Primary education or less (incl. vocational education without secondary education)

2. Secondary education (incl. vocational education with secondary education)

3. Completed higher education

8. Have you or your vicinity had / been diagnosed with cancer in the last 5 years?

1. Yes, among friends or colleagues

2. Yes, among relatives

3. Yes, in the family

4. Yes, myself

5. No, not in any of them

9. During these 5 years, have you independently researched cancer treatment issues and treatment options?

1. yes

2. no

10. From what sources have you researched this?

1. From general Internet sites or the general press (including print, radio and television). Specify which source was last

2. professional (medical) websites or professional press. Please specify which source last

3. from doctors / medical professionals

4. from friends, acquaintances, relatives

5. Elsewhere, specify

11. Where do you prefer to search / get information on cancer treatment?

12. If you or a member of your family were diagnosed with cancer, what would you ask your doctor in particular? Try to think of as many questions as you may have in this situation.

13. The following are some typical questions that arise in such a situation. Please indicate what questions you would ask your doctor if you or a member of your family were diagnosed with cancer.

1. What are the possible treatment options (chemotherapy, targeted treatment, etc.)

2. What are the options for surgical treatment

3. Need and possibilities for further research and diagnostics

4. The need and possibilities of cancer genomic testing

5. Expanding the range of treatment and diagnostics with paid services

6. Opportunity to participate in clinical trials

7. Prognosis of the disease

8. Counseling for organizing everyday life

9. Other, please specify

10. Don't know, leave it entirely up to the doctors to decide

14. Please specify in your own words what is personal medicine?

1. WRITE IN
2. not sure, can't explain
3. have never heard of the concept of personal medicine

15. Do you think that genetic testing and cancer genomic testing are different and how?

1. WRITE IN
2. not sure, can't explain
3. have never heard of the concept

16. What do you think is cancer genomic testing?

1. WRITE IN
2. not sure, can't explain

17. Cancer genomic testing allows the identification of a patient's type of cancer before starting treatment to specify the choice of treatments. How important do you think cancer genomic testing and profiling is for further treatment? I think that….

1. It is very important and definitely necessary
2. It may be useful to know
3. Don't think it will change anything
4. Can't say

18. Would you be willing to pay for a cancer genomic test yourself if you or a member of your family were diagnosed with cancer? The price of the cancer genomic test is in the range of 1500-2000 euros and is not covered by health insurance.

1. Yes
2. No
3. Don’t know

Appendix 3 – Crosstabulation of dependent and independent variables

Table 12 Crosstabulation of dependent and independent variables, number of respondents

		Searched for cancer treatment related info (N)		Contribute to cancer care oneself (N)		Know what personalized medicine is (N)		Know what cancer genomic test is (N)	
		No	Yes	No	Yes	No	Yes	No	Yes
Sex	Male	401	110	464	48	418	94	440	71
	Female	420	135	470	85	440	114	479	76
Language	Estonian	571	157	652	75	585	143	619	108
	Other	250	88	281	57	273	66	300	39
Education	Primary	62	9	68	2	64	6	69	2
	Secondary	443	122	491	74	469	97	504	61
	Higher	316	114	374	56	324	106	346	84
Settlement type	Tallinn	289	91	332	48	316	64	330	50
	Other city	257	72	297	33	269	61	289	40
	Rural area	274	82	304	52	273	83	299	57
Income per family member	Under 500	167	51	190	27	183	35	198	20
	500-1000	349	97	384	63	346	101	378	68
	1000-1500	180	65	213	32	204	42	204	41
	1500 and more	124	32	147	10	125	31	138	18

		Searched for cancer treatment related info (N)		Contribute to cancer care oneself (N)		Know what personalized medicine is (N)		Know what cancer genomic test is (N)	
		No	Yes	No	Yes	No	Yes	No	Yes
Occupation	Health or social care	41	15	51	6	44	12	45	12
	Other	780	230	883	127	814	196	874	136
Cancer diagnosis	In my family	104	73	154	22	143	34	153	24
	Among relatives, friends or colleagues	308	109	354	63	316	101	347	70
	None of the above	409	63	425	47	399	74	419	54

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