

TALLINN UNIVERSITY OF TECHNOLOGY
School of Information Technologies

Ülle Rohtla 163137YVEM

**PERSON-CENTRED AND INTEGRATED
HEALTHCARE IN ESTONIA: EXPLORING
NECESSITY AND FUNCTIONS OF THE
CARE COORDINATOR FOR ESTONIAN
HOSPITALS**

Master's thesis

Supervisors: Katrin Gross-Paju
MD, PhD
Tiina Sats
MA

Tallinn 2020

TALLINNA TEHNIKAÜLIKOOL
Infotehnoloogia teaduskond

Ülle Rohtla 163137YVEM

**INIMKESKNE JA INTEGREERITUD
TERVISHOID EESTIS: KOORDINAATORI
VAJALIKKUS JA FUNKTSIOONID EESTI
HAIGLATES**

magistritöö

Juhendajad: Katrin Gross-Paju
MD, PhD
Tiina Sats
MA

Tallinn 2020

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.

Author: Ülle Rohtla

20.05.2020

Abstract

The aim of this thesis was to explore necessity and functions of the care coordinator for Estonian hospitals.

In-depth semi-structured interviews were conducted with representatives of all patient-centred and integrated care pilot programs initiated in Estonian hospitals as of the 1st of February 2020. Altogether, five individual and two focus group interviews were carried out totally with 12 program representatives – six program managers, one nursing manager, one social worker and four coordinators. The interview guide was formed based on the literature overview and validated by the test participant.

All interviewees emphasised the need for the full-time care coordinator in hospitals to ensure services delivery to patient in right place, in right time and in needed capacity, and to deliver the promise of person-centredness. The care coordinator is a member of a multidisciplinary care team and a nominated single-point of contact for the person and family. In hospitals the care coordinator services are needed by patients who have medical condition and chronic illness(es) that require complex, extensive and long-term acute care, follow-up care and rehabilitation services between different departments, clinics and organisations on secondary care level. Based on the needs of the target patients and structure of the multidisciplinary care team, some of the functions or sub-functions of the care coordinator in hospital may be managed by other members of the care team. Requirements for the qualification and skills of the care coordinator in hospitals depend on the content of provided functions.

Six functions of the care coordinator in hospitals were identified by interviewees: a) assessment of patient needs and contribution to the individualised care plan, b) coordination of care, c) navigation through services, d) case monitoring, e) patient education, f) emotional support and reduction of barriers.

This thesis is written in English and is 51 pages long, including six chapters and eight figures.

Annotatsioon

Inimkeskne ja integreeritud tervishoid Eestis: koordinaatori vajalikkus ja funktsioonid Eesti haiglates

Magistritöö eesmärgiks oli hinnata koordinaatori vajalikkust ja funktsioone Eesti haiglates. Koordinaatori vajalikkuse ja funktsioonide välja selgitamiseks Eesti haiglates kasutati semistruktureeritud intervjuusid. Intervjuud viidi läbi kõigi Eesti haiglates 1. veebruari 2020 seisuga algatatud patsiendikeskse ja integreeritud ravi pilootprogrammi töötajatega. Kokku viidi läbi viis individuaal- ja kaks fookusgruppiintervjuud, milles osales kokku 12 haiglatöötajat – 6 programmijuhti, ühe õendusjuht, ühe sotsiaaltöötaja ja neli koordinaatorit. Intervjuude küsimustik koostati kirjanduse ülevaate põhjal ja valideeriti eelnevalt ühe testosalejaga.

Kõik intervjuueeritavad kinnitasid täiskohaga koordinaatori vajalikkust haiglates, et tagada patsiendikesksus ning patsientidele vajalike teenuste osutamine õigel ajal ja õiges kohas. Koordinaator on patsiendile ja tema omastele esmaseks kontaktiks ning multi-distsiplinaarse ravimeeskonna liige. Koordinaatori teenust vajavad haiglates patsiendid, kelle haigusseisund(id) nõuavad kompleksset ja pikaajalist eriarstiabi teenust erinevate akuut-, järel- ja taastusravi osakondade, kliinikute ja haiglate vahel. Sõltuvalt patsientide vajadustest ja multi-distsiplinaarse meeskonna ülesehitusest, võib osa koordinaatori funktsioone olla täidetud teiste meeskonnaliikmete poolt. Nõudmised koordinaatori kvalifikatsioonile ja oskustele sõltuvad tema poolt osutatavate teenuste paketest.

Intervjuueeritavate hinnangul on koordinaatori funktsioonideks haiglas: a) patsiendi vajaduste hindamine ja raviplaani koostamisel osalemine, b) ravi koordineerimine, c) teenustes navigeerimine, d) raviplaani jälgimine, e) patsiendi õpetamine, f) emotsionaalne tugi ja barjääride vähendamine.

Lõputöö on kirjutatud inglise keeles ning sisaldab teksti 51 leheküljel, kuute peatükki ja kaheksat joonist.

List of abbreviations and terms

EHIF	Estonian Health Insurance Fund
EU	European Union
GDP	Gross domestic product
MoSA	Ministry of Social affairs
WHO	World Health Organisation

Table of contents

1 Introduction	10
2 Background.....	13
2.1 Functions of the care coordinator	15
2.1.1 Function of needs assessment and development of the individualised care plan	16
2.1.2 Function of care coordination.....	16
2.1.3 Function of navigation through services	17
2.1.4 Function of case monitoring.....	17
2.1.5 Function of patient education	17
2.1.6 Function of emotional support and reduction of barriers	17
3 Methodology and methods	19
3.1 Setting identification and participant recruitment	19
3.2 Data collection	21
3.2.1 Development of interview guide and interview procedure	21
3.3 Data analysis method.....	22
3.4 Method quality control	23
3.5 Ethical considerations.....	23
4 Results	25
4.1 Need for the care coordinator role in hospitals.....	26
4.2 Functions of the care coordinator in Estonian hospitals.....	28
4.2.1 Assessment of patient needs and contribution to the individualised care plan	29
4.2.2 Coordination of care	30
4.2.3 Navigation through services	32
4.2.4 Case monitoring.....	33
4.2.5 Patient education	34
4.2.6 Emotional support and reduction of barriers	35
5 Discussion.....	37
5.1 Limitations.....	43

5.2 Suggestions and further studies	43
6 Conclusions	44
Acknowledgement	45
References	46
Appendix 1 – Interview guide in Estonian	51

List of figures

Figure 1. Research process map. Source: author.....	19
Figure 2. Functions of the care coordinator in the Estonian hospitals. Source: author. .	29
Figure 3. Function of needs assessment and contribution to care plan. Source: author.	30
Figure 4. Function of coordination of care. Source: author.....	32
Figure 5. Function of navigation through services. Source: author.....	33
Figure 6. Function of case monitoring. Source: author.	34
Figure 7. Function of patient education. Source: author.	35
Figure 8. Function of emotional support and reduction of barriers. Source: author.	36

1 Introduction

Emerging health challenges are an extensive burden on health systems all over the world [1]-[3]. Between the years 2005 and 2017, the EU's health expenditure per capita has increased faster than the growth rate in GDP per capita [4]. This trend is estimated to continue [5]. European Commission and Economic Policy Committee has estimated that EU countries' public spending on health will increase by one percentage point of GDP by the year 2070 [4] and public spending on long-term care across the EU countries will increase during the next 54 years by more than one percentage point, from 1.6% of GDP in 2016 to 2.7% of GDP in 2070 [6].

In 2015 The World Health Organisation (WHO) introduced a global strategy on people-centred and integrated health services [9], that emphasises that “developing more integrated people-centred care systems has the potential to generate significant benefits to the health and health care of all people, including improved access to care, improved health and clinical outcomes, better health literacy and self-care, increased satisfaction with care, improved job satisfaction, improved efficiency of services, and reduced overall costs.” [9].

The strategy follows the ideas of value-based healthcare concept that was introduced by Porter at al. in 2006 [44]. The concept is based on three fundamental principles that will ensure sustainability in healthcare delivery: a) value delivered for a person must be improved, whereas value is measured as health outcomes mattering to the person divided by costs of delivering these outcomes, b) the organisation of medical practice must be built around holistic approach of person's medical conditions and care pathways, and c) both medical outcomes and costs must be measured at the person's level [44]-[46]. Therefore, in value-based healthcare the processes of healthcare delivery are optimised in a way that leads to better health outcomes of the person with lower costs.

Coordination of care has important part in the people-centred and integrated care strategy [9]. Coordination of care ensures timeliness and continuum of care for people with chronic illnesses and multi-morbidities requiring complex and long-term care [11].

Coordination of care should be carried out by all levels of a care – at hospitals, at primary care and at communities, to avoid fragmentation of care and ensure continuum of care [9]. Care coordinators have integral part in the delivery of value-based, integrated and person-centred care [9], [12].

According to the study [7] conducted by the World Bank, the Estonian health system is fragmented, diagnosis-centred and lacks attention to rehabilitation and follow-up care. The same threats and weaknesses were emphasised by the report of the financial sustainability of the Estonian healthcare [8]. Therefore, new sustainable value-based and integrated healthcare solutions helping to ensure effective use of healthcare resources and improving care outcomes have been strongly on the global, as well as on local, health agenda [3], [8]-[10].

During recent years, the Ministry of Social Affairs and the Estonian Health Insurance Fund have initiated projects promoting the idea of people-centredness and integrated care, including the pilot project to improve cooperation and information flow between the levels of healthcare and social care [13] and the integrated care pilot project of care pathway for ischemic stroke patients [14]. The need to integrate a new role as care coordinator into Estonian healthcare services has been under discussion among Estonian health and social care stakeholders for a while [14]. Currently there is no single and clear understanding about the position's characteristics and functions of the coordinator between the stakeholders [14]. This has made implementation of the care coordinator's role into care pathways and finding most suitable financing schemes for the new role challenging [8], [14].

Although the care coordinator role is new for the Estonian healthcare market, successful care coordinator programs have been implemented in other countries [15]-[20]. Improvements in care outcomes of persons with complex and long-term health conditions and decrease in costs through efficient use of healthcare resources have been reported by the programs [1], [19], [21]-[27].

The current research focuses on the need and functions of care coordinators in Estonian hospitals. Previous personal experience of the author as a nursing student in the oncology and cardiology wards in different hospitals and current experience from the speciality care department of the Estonian Health Insurance Fund has raised the interest of the

author to investigate further the necessity to implement the care coordinators' role in Estonian hospitals. As of knowledge of the author of the research, there is not previous researches on the role and functions of the care coordinator in Estonian hospitals.

The aim of the research is to explore necessity and functions of the care coordinator for Estonian hospitals.

Objective 1: to explore the need for the care coordinator in Estonian hospitals.

Research question 1: Is there need for the care coordinator services in Estonian hospitals?

Research question 2: What medical conditions need care coordinator services in hospital?

Research question 3: What should be professional background of the hospital care coordinator?

Objective 2: to classify functions of the care coordinator in Estonian hospitals.

Research question 4: What should be functions of the care coordinator in Estonian hospitals?

2 Background

Coordination of care is an important cornerstone of the people-centred and integrated care paradigm [9], [16], [28]. The people-centred integrated care paradigm foresees health services, that are [9]:

- organised according to the health needs and expectations of people,
- designed and delivered at all levels of care within the health system and beyond,
- provided in a manner that ensures ongoing disease prevention, health promotion, diagnosis, treatment, disease management, rehabilitation and palliative care during the entire lifetime of people.

Coordination of care is defined as “a person-centred, assessment-based, interdisciplinary approach to integrating healthcare and social support services in a cost-effective manner in which an individual’s needs and preferences are assessed, a comprehensive care plan is developed, and services are managed and monitored by an evidence-based process which typically involves a designated lead care coordinator” [12].

Coordination of care fights against fragmentation of care caused by poor communication, lack of collaboration and insufficient provision or loss of information [9]. Fragmentation of care hinders delivery of holistic, high-quality, safe and accessible care [1], [9], [21]-[27]. Coordination of care helps to avoid unwanted outcomes of care, such as defaulted follow-up, re-hospitalisation and medication errors [9]. Therefore, coordination of care ensures continuum of care [9], [11] in all three dimensions of care continuity [11]: informational continuity (defined as “use of information on past events and personal circumstances to make current care appropriate for each individual”; interpersonal continuity (defined as “ongoing therapeutic relationship between a patient and one or more clinicians”, and management continuity, defines as “consistent and coherent approach to management of a health condition that is responsive to patient’s changing needs” [11]. Coordination of care does not automatically urge merging different organisations, services or workflows, but rather concentrates on reforming the care delivery through adjustment of processes of different providers and services to deliver the

patient-centredness and continuum of care [9], for example through multi-disciplinary care teams led by the dedicated care coordinators [12].

Implementation of patient-centred and integrated care programmes has increased the importance of roles dedicated to care coordination. Literature overview revealed, that care coordinator roles have great variety in terms of job titles – a care coordinator, a case manager, a patient navigator, a care manager, a clinical care coordinator, a post-acute care coordinator, a guided care nurse, a transition coach, a transitional care nurse, etc [15], [20]. In the literature these terms are used interchangeably and the evidence from different studies show, that these roles have overlapping functions and responsibilities [15], [17]-[20], [29], [30]. The main goal for all the roles is to overcome barriers in care delivery and to improve coordination of care [9], [15], [17].

Dedicated care coordinators work in different settings: hospitals, primary care centres, rehabilitation centres, long-care facilities and community-based organisations [15], [19]. Care coordinators are persons with or without a healthcare-related background or clinical expertise. Care coordinators are usually nurses or social workers, but in some cases also individuals with lived expertise [15].

Care coordinators work with specific patient populations, that have complex and long-term health conditions, such as chronically ill patients with one or multiple diseases. The results of the systematic review by McBrien et al. [20] indicated that about 65% of the identified studies took place in the oncology setting (breast cancer, cervical cancer, colorectal cancer, gastrointestinal cancers etc), 12% with the diabetes patients, 10% with the HIV/AIDS patients and 6% with cardiovascular disease patients (stroke). The study by Conway et al. [19] lists also congestive heart failure, coronary artery disease, cardiac arrhythmias and COPD as medical conditions where hospital-based care coordinator was included to the patient care pathway

Also, chronic kidney disease, dementia and multiple chronic diseases were mentioned. In hospitals dedicated care coordinators are with patients with stroke, congestive heart failure, coronary artery disease, cardiac arrhythmias, COPD, diabetes mellitus, spinal stenosis, hip fracture, peripheral vascular disease, deep venous thrombosis and pulmonary embolism patients. dementia and mental disorders [19].

2.1 Functions of the care coordinator

In 2019, Desveaux et al. introduced a program theory for the care coordinators (defined as patient navigator) for people with chronic diseases [31]. The theory constructs a model defining 13 care coordinator activities helping people to overcome barriers hindering them to access the care and to follow the recommended care guidelines. The model groups activities of care coordinator into five categories: a) activities improving patient communication with health care providers (providing information to healthcare providers for patient, providing translation), b) activities enabling patient to understand (providing education), c) providing social and emotional support (connecting patient and family with resources, advocating for patient, showing empathy), d) supporting self-management (supporting adherence to care plan, motivating patient and family, reinforcing goals), and e) improving coordination and navigation (arranging referrals, scheduling appointments, monitoring attendance and follow up after missed appointment, liaising with employer, facilitating transportation). The complete model of program theory can be found in Appendix X. The theory was constructed based on the results of a systematic literature review including 19 different care coordinator programmes. The authors used the capability-opportunity-motivation model of the behaviour change theory Behaviour Change Wheel (COM-B) to build an evidence-based patient navigator intervention strategy. All together the authors identified 17 care coordinator activities and 20 different personal, external or system barriers. Activities most frequently implemented by the programmes were promotion of skills and education of the person and family, coordination of specialist referrals, provision of emotional and social support and support of self-management. Majority of the care coordinator activities were addressed to remove barriers related to patients' physical abilities, as helping with paper-work, scheduling appointments and arranging transportation. Most of the programs reporting positive patients care outcomes concentrated on educating the person and family, scheduling the specialist appointments, re-scheduling appointments for the person if they had missed them and solving the problems with insurance companies.

Comprehensive systematic review by Conway et al. [19] showed that if the care coordinator's role was performed by a nurse, the assessment of the person's physical, emotional and social needs and development of the individualised care plan was an important function of the care coordinator. The same result was reported in the scoping

review study by Kelly et al. [15]. The authors found that initial needs assessment of the person's overall emotional, physical, social and financial status that leads to development of an individualised care plan (together with nominated multidisciplinary team and in cooperation with all care providers), is an essential function of the care coordinator.

Based on the introduced program theory and empirical evidence from the literature, the functions of the care coordinator may be categorized as: a) needs assessment and development of the individualised care plan, b) coordination of services and navigation, c) case monitoring, d) self-management support, and e) emotional support and reduction of barriers.

2.1.1 Function of needs assessment and development of the individualised care plan

Patient needs assessment includes holistic and comprehensive assessment of person's physical, mental and social needs by the care coordinator. Special attention is paid to identifying the person's own wishes and goals. The assessment of needs will lead to development of person's individual care plan together with the patient, family and members of a multidisciplinary team. The care plan includes list of identified needs, objectives together with patient's own goals, activities, deadlines and a responsible party [15], [16], [19].

2.1.2 Function of care coordination

The care coordinator is responsible for coordination of services during person's transitions, hospital discharge and rehabilitation. The care coordinator ensures continuous information flow, networking and collaboration between individuals, services and organisations across diverse care settings to ensure timeliness and continuity of care [15], [16], [19], [20]. The care coordinator helps to improve patient communication with health care providers through providing information to care providers for patient [20]. The care coordinator is a nominated single-point of contact for the person and family. The care coordinator arranges referrals, schedules appointments, sends appointment reminders, monitors attendance, arranges follow up after missed appointment, liaises with employer, facilitates transportation etc. [15], [16], [19], [20] [31].

2.1.3 Function of navigation through services

The care coordinator assists the person and family to navigate through the heterogeneous and complex systems of healthcare, social care and community. Navigation of services helps the person to access the needed care. The care coordinator signposts the person and family to different services and service providers, so the person will know where to go and whom to ask. The care coordinator advocates the person for available services, arranges logistical support (transportation), translation etc [11], [15], [20], [32].

2.1.4 Function of case monitoring

The care coordinator monitors the patient, the care and the patient's individual care plan. The care coordinator collects opinions and experiences of the patient and family, evaluates used strategies and interventions against outcomes and adjusts the individualised care plan according to the changed needs of the person. The care coordinator helps the patient and family to achieve the set goals of care [15], [19], [20].

2.1.5 Function of patient education

The care coordinator engages and empowers the person through providing education and knowledge about the disease, risk-factors, lifestyle changes, treatment options, possible complications, available resources and healthcare system [15], [19], [20]. The care coordinator promotes health literacy, practices of health maintenance and encourages care adherence [19], [20]. It is important, that care coordinator provides knowledge and skills with patient and patient's family how to cope with the illness with the disease and supports patient's self-management: supports adherence to care plan, motivates patient and family, reinforcing goals [20], [31].

2.1.6 Function of emotional support and reduction of barriers

The care coordinator provides emotional support to the patient and family to reduce distress and anxiety [15]. The care coordinator understands the patient's fears and hopes, removes barriers to effective care [11]. Addresses attitudes and beliefs [20], provides emotional support to patients and their caregivers, aims to reduce patient's anxiety and distress while interacting with care system, build and maintain relationship with patients, caregivers and their providers, works to proactively reduce barriers to care [15].

3 Methodology and Methods

The aim of the research is to explore necessity and functions of the care coordinator for Estonian hospitals. A qualitative study design including in-depth interviews and focus group discussions with representatives of the person-centred and integrated care projects in Estonian hospitals was selected. Creswell [33] defines the purpose of qualitative research as “to gain a better understanding of phenomenon through the experiences of those who have directly experienced the phenomenon, recognizing the value of participants’ unique viewpoints that can only be fully understood within the context of their experience and worldview” [33]. Specialist interviews are a reasonable choice if the researcher needs initial orientation in a field that is either substantively new or poorly defined [39].

The qualitative content analysis is a method that follows naturalistic paradigm [34], and is used to interpret the content of written data through a systematic structuring and coding that allows to identify main ideas, themes or patterns of the text [35, 36]. It follows step by step stages and rules of content analysis when interpreting the qualitative material to ensure reliability and validity of the research [36]. In the manifest approach of the qualitative content analysis the researcher describes what the research participants really say, stays as close to the text as possible and describes the obvious and visible in the text [34].

Other possibilities for research design were to use open-ended questionnaires as the data collection method and the thematic analysis instead of the qualitative content analysis as the data analysis method. Questionnaires were considered, as the research participants were located at different settings all over Estonia. Questionnaires would have been less costly and time-consuming alternative to interviews. Nevertheless, as the open-ended written questions cannot provide the same depth of the analysis as face-to-face interviews, the interviews were preferred [34]. The qualitative content analysis approach was selected over the thematic analysis, as it allows to measure the frequency of different categories and themes [37].

As the research uses empirical knowledge from previous studies about the role and functions of the care coordinator to classify the functions of the care coordinator identified in Estonian hospitals, a deductive approach of content analysis was used. Deductive

content analysis is used when the existing data is wished to be retested in a new context [38].

This is a qualitative research including in-depth semi-structured interviews and focus group discussions. A qualitative content analysis approach was used to analyse collected data - transcripts of interviews. The process map of the research is presented in the following figure:

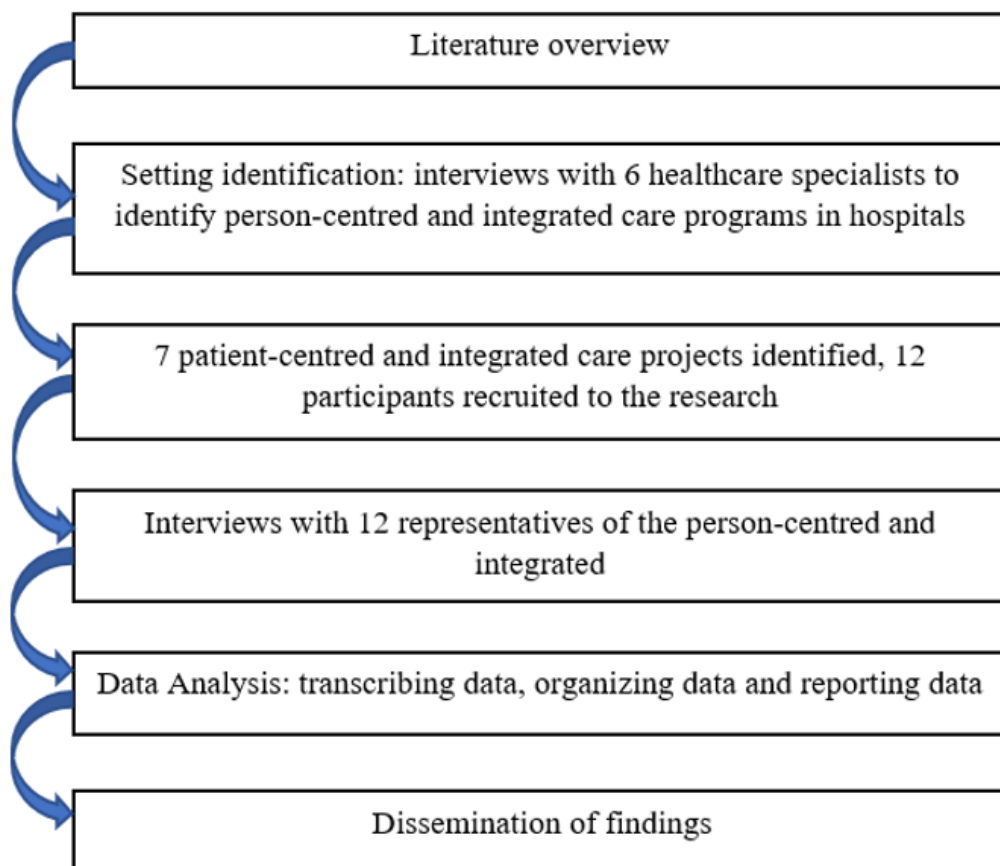


Figure 1. Research process map. Source: author.

3.1 Setting identification and participant recruitment

To identify participants to the research, one specialist from the Ministry of Social Affairs, four specialists from the Estonian Health Insurance Fund and one specialist from the North-Estonian Medical Centre responsible for the implementation of the person-centred and integrated care programs into Estonian healthcare were approached and asked information about the implemented person-centred and integrated care programs in

Estonian hospitals. Exponential non-discriminative snowball sampling was used. As no new information about the person-centred and integrated care programs in Estonian hospitals was received after the sixth specialist, the data had received its saturation and no new specialists were approached.

As the 1st of February 2020, seven person-centred and integrated care programs in Estonian hospitals were identified:

- the PAIK pilot program in the Viljandi Hospital,
- four person-centred and integrated care pilot programs for stroke patients in four hospitals: the Tartu University Hospital, the North Estonia Medical Centre, the Ida-Viru Central Hospital and the West-Tallinn Central Hospital,
- one oncology patients' care coordinator pilot program in the North Estonia Medical Centre,
- one person-centred and integrated care pilot program of East-Tallinn Central Hospital.

Representatives from all seven identified person-centred and integrated care programs in Estonian hospitals were contacted by phone or e-mail and invited to participate to the research. All invited participants agreed to participate in the study. In case of four programs (the stroke program of the Tartu University Hospital, the stroke program of the North Estonia Medical Centre, the stroke program of the Ida-Viru Central Hospital and the program of East-Tallinn Central Hospital), the program manager was included to the sample as the programs were in implementation phase and the programs did not have any other members. The stroke program of the West-Tallinn Central Hospital was represented by the program social worker, the oncology program of the North Estonia Medical Centre was represented by the program manager and the nurse manager responsible for the program and the PAIK program in the Viljandi Hospital was represented by all four care coordinators together with the program manager. The final sample size was 12 participants.

3.2 Data collection

Data collection took place from February 2020 – March 2020. In-depth semi-structured interviews were conducted with representatives of all patient-centred and integrated care pilot programs initiated in Estonian hospitals as the 1st of February 2020.

In case of five programs with one representative (the stroke program of the Tartu University Hospital, the stroke program of the North Estonia Medical Centre, the stroke program of the Ida-Viru Central Hospital, the stroke program of the West-Tallinn Central Hospital and the program of East-Tallinn Central Hospital), one-to-one face-to-face interview approach was used. In case of two programs (the PAIK program of the Viljandi Hospital and the oncology program of the North Estonia Medical Centre), where more than one participant participated in the research, a focus group interview approach was used. In-depth semi-structured interviews and focus group interviews took place in hospitals. In case of two programs (the oncology program of the North Estonia Medical centre and the program of the East-Tallinn Central Hospital), where the interview time was agreed after the 13th of March, the interview was done via Skype or by phone due to emergency situation in Estonian hospitals. Five hospitals were visited by the researcher: the Tartu University Hospital, the North Estonia Medical Centre, the Ida-Viru Central Hospital, the West Tallinn Central Hospital and the Viljandi hospital.

3.2.1 Development of interview guide and interview procedure

The interview guide in Estonian with semi-structured open-ended questions as a guide to allow discussion and explore opinions of the participants about the research topic was developed (Appendix 1). The interview guide was divided into two main topics reflecting the research objectives. The questions of the first part of the interview concentrated on the need for of the care coordinator in Estonian hospitals – objectives of the position, target patients and professional background of the care coordinator. The second part of the interview concentrated on the identification of the functions of the care coordinators in Estonian hospitals. Sub-themes reflecting categories derived from the literature overview were added to the main theme. At the end of the interview, the interviewees were encouraged to raise additional topics they considered relevant and important in connection with the care coordinators role in the hospitals.

To confirm the suitability of the interview guide to explore the phenomenon and test duration of the interview, one pilot interview was conducted. Some amendments, as sub-themes under the second theme about the functions of the care coordinators in hospitals were added.

The interviews took place from the 20 February 2020 – 20 March 2020. Practical issues of the interviews (time, location) were agreed with the participants via an e-mail or by phone. Face-to-face interviews, both individual and focus group, were organised in hospital premises of each program. A separate room, where the interviewee(s) and the interviewer could talk in privacy was arranged. Two interviews initially agreed to take place in hospital premises were organised as a Skype meeting and by phone. The reason was nationally set regulations as of 13 March 2020 prohibiting hospital visits and face-to-face meetings due to global pandemic crises.

Focus group interview approach was selected, if more than one participant from the program participated in the interview. All interviews were digitally recorded and transcribed afterward. Permission to record the interview was asked from the participants of the interview beforehand. At the beginning of each interview, the researcher introduced herself, the purpose of the research, ethical principles of the research and asked consent from participants to participate in the research. At the end of each interview the researcher asked permission to contact the interviewee if there would be any additional questions. Average length of the interview was 58 minutes.

3.3 Data analysis method

A qualitative content analysis method was used to analyse interview transcripts. This method enables to obtain a thorough and broad description of the phenomenon, helps to formulate categories describing the phenomenon based on the obtained data and allows the researcher to build up a model, conceptual system or categories [38]. A deductive approach of the content analysis was selected, as it enables to model the functions of the care coordinator in Estonian hospital based on the theory and empirical evidence from the previous studies.

Three phases of the content analysis process defined by Elo et al. [38] were followed by the researcher during the data analysis process. During the preparation phase, individual

and the focus group interviews were transcribed. Before the transcription of each interview, the full recording of the interview was listened to by the author to get the general overview of the interview. Then, the interview was transcribed word-by-word. Finally, the proofreading of the transcript was done while listening the recording of the interview. The identity of participants and their employer was coded in the transcripts to ensure anonymity of the participants. One whole interview was selected as a unit of analysis. All transcribed interviews were read through several times before starting to organise the data to get a sense of whole before starting to organise the data. A manifest analysis approach was used to analyse the content of each interview.

In the organising phase a structured categorisation matrix of analysis was developed based on earlier theories and literature reviews covered in the literature overview chapter. Thereafter, the written data was reviewed for content and coded according to the categories. In the transcribed text the meaning units were coloured with different colours to distinguish different codes and categories and to identify unmarked text. If the unmarked text included information important in respect of the research question, it was included to the analysis.

In the reporting phase the results were presented through the conceptual categories and story line. The analysing process was described as detailed as possible to increase the reliability of the research.

3.4 Method quality control

Detailed overview of each steps of the research process, including the design, participants, data collection and analysis, is describes to ensure rigor of the research. Deductively created list of categories and codes for analysing the material help to obtain reliability [34]. The Standards for Reporting Qualitative Research [40] were followed to improve transparency of the research and to assist readers to critically apprise, apply and synthesize the research findings.

3.5 Ethical considerations

The research was conducted in compliance with the European Commission's ethical principles for the research in social science and humanities [41]. The privacy and

confidentiality of participants was ensured through data coding. Recognizable information about the identities of the participants or their employer was anonymized in the transcripts and in this research. Participation in the study was voluntary. All participants had the right to withdraw from the research at any stage of the research. At the beginning of each interview a briefing of the research was conducted by the researcher and informed consent was asked.

4 Results

Totally 12 participants representing all patient-centred and integrated care pilot programs initiated in Estonian hospitals as of 1st of February 2020 participated in the research. Participants represented the following patient-centred and integrated care pilot programs:

- care coordinator program for the stroke patients in the North Estonia Medical Centre,
- care coordinator program for the stroke patients in the Tartu University Clinic,
- care coordinator program for the stroke patients in the East-Viru Central Hospital,
- care coordinator program for the stroke patients in the West-Tallinn Central Hospital,
- care coordinator program for the stroke patients in the East-Tallinn Central Hospital,
- care coordinator program for the oncology patients in the North Estonia Medical Centre,
- care coordinator program for elderly people (60 years and older) with multiple chronic diseases in Viljandi County Hospital.

4/7 of identified programs were represented by the program manager, 1/7 program by the program manager and the nurse manager, 1/7 program by the program social worker and 1/7 program by the program manager and four program care coordinators.

2/7 programs were running for over one year – the care coordinator program for elderly people with multiple chronic diseases in Viljandi County Hospital and the care coordinator program for oncology patients in the North Estonia Medical Centre. The Viljandi program employs four care coordinators: two with nursing background and two with the background of social work. The oncology program of the North Estonia Medical centre employs one care coordinator with nursing background.

5/7 programs were in the implementation phase and employed program managers only as the mid of March 2020. These are the care coordinator programs for stroke patients in the North Estonia Medical Centre, Tartu University Hospital, East-Viru Central Hospital, West-Tallinn Central Hospital and East-Tallinn Central Hospital. In these programs the recruitment process of care coordinators was still in process.

4.1 Need for the care coordinator role in hospitals

All interviewees (100%) pointed out the need for the care coordinator in hospitals. All interviewees said the care coordinators role should be a full-time position. Two respondents said the need for the position will grow in the future. In one respondent's opinion the position of the care coordinator is needed today so urgently because there have not been enough social workers in hospitals:

“In my opinion, in create deal the reason why the need for care coordinators in hospitals has developed as urgent as it is today is the fact, that the service of hospital social worker is not in the list of healthcare services reimbursed by the EHIF. Importance of this side has been underestimated. I mean, to ensure that results of expensive and high-quality care will remain” (IP3).

Two objectives of the care coordinator role were indicated by the interviewees: ensuring continuity of care and patient-centredness. In long-term, integrating the role of the care coordinator into hospitals processes will help to improve health outcomes of patients (less complications, care adherence increased, quality of life increased) and lower costs (number of avoidable ambulance calls, ER department and specialist doctor visits will decrease, duplication of services will decrease):

“The main objective of this new specialist (care coordinator in hospital) is to ensure that needed services are provided to the patient at right time and in needed capacity. In general, to ensure the continuity of needed services. And to make sure interests and wishes of the patient are not left without attention. /.../ The long-term outcome will be that patients have less complications, number of avoidable and unjustified visits to specialist doctors and acute re-hospitalisations will decrease. Also, ambulance calls and ER department visits (will fall)” (IP6).

“The aim is to make the care pathway to the patient as smooth as possible and to ensure that the patient will manage with her/his life.” (IP2).

According to interviewees, in hospitals the care coordinator services are needed by patients who have medical condition and chronic illness(es) that require complex, extensive and long-term acute care, follow-up care and rehabilitation services between

different departments, clinics and organisations on secondary care level. One such patient segment mentioned by all interviewees are the cancer patients:

“Cancer care is much more specific. In acute period of illness, cancer patients visit cancer clinic continuously – chemotherapy, surgery, radiation therapy.... In this case coordinating role is needed in the clinic.” (IP5).

Two-third of the interviewees mentioned amputation, both as a result of extensive traumas or diabetes, as one medical condition that needs care coordinator in hospitals. In case of stroke, the interviewees had different opinions about the need for the care coordinator in hospital level, especially at acute care level. About half of the interviewees found the care coordinator is needed in hospital level also for stroke patients. In opinion of three interviewees the care coordinator for the stroke patients should be at the primary care level:

“If we talk about the stroke, then I am not sure if the care coordinator should be in the hospital level, especially at acute care level. Patients are there (at acute care) only maximum 5 days. In this case, maybe the care coordinator should be someone in the primary care level – a family nurse or maybe someone else.” (IP5)

Also, patients with mental diseases (schizophrenia), ischemic heart disease and complex multiple chronic diseases were mentioned as segment needing care coordinator services at hospital.

More than half (58%) of the interviewees found the professional background of the care coordinator should either be a nurse or a social worker, one-fourth (25%) found the care coordinator should be only a nurse and the rest (17%) said the care coordinator should be a social worker. None of the interviewees said the care coordinator should be a ‘person from the street’. One interviewee pointed out that responsibilities of the care coordinator should not be transferred as extra duties to the department nurses delivering also daily nursing care. To avoid the situation where the care coordinator with nursing background is used by the department nurse manager as substitute for the department nurses in their daily nursing care, the care coordinators should work under the authority of the nursing manager of the clinic and not under the authority of the department nursing manager.

Five interviewees representing two programs said functions of the care coordinators in hospital must be divided between two care coordinators, one with nursing background and the other with background in social work:

“For one person this (all functions) is enormous responsibility and burden to carry. Two persons in cooperation...well, they work in tandem, there is cohesion..., it’s important, that the person (care coordinator) is not alone.” (IP10).

More than half of the interviewees mentioned also the importance of funding issue in the success of implementing the new coordinating role into the hospital processes. They found that services of care coordinator in hospitals should be financed by the EHIF to ensure continuity of current programs and implementation of new programs into hospitals. One interviewee also pointed out that the payment for the care coordinator services should be clearly distinguished as for developing the role of the care coordinator:

“This position has to be financed by the state (the EHIF). /.../ And not that the general funding of hospital is increased, but the payment should be clearly dedicated to developing the idea of care coordination and care coordinators.” (IP4).

4.2 Functions of the care coordinator in Estonian hospitals

All specific functions of the hospital care coordinator identified by the interviewees were classified under categories six categories: 1) needs assessment and development of the individualised care plan, 2) coordination of care, 3) navigation through services, 4) case monitoring, 5) patient education, 6) emotional support and reduction of barriers.

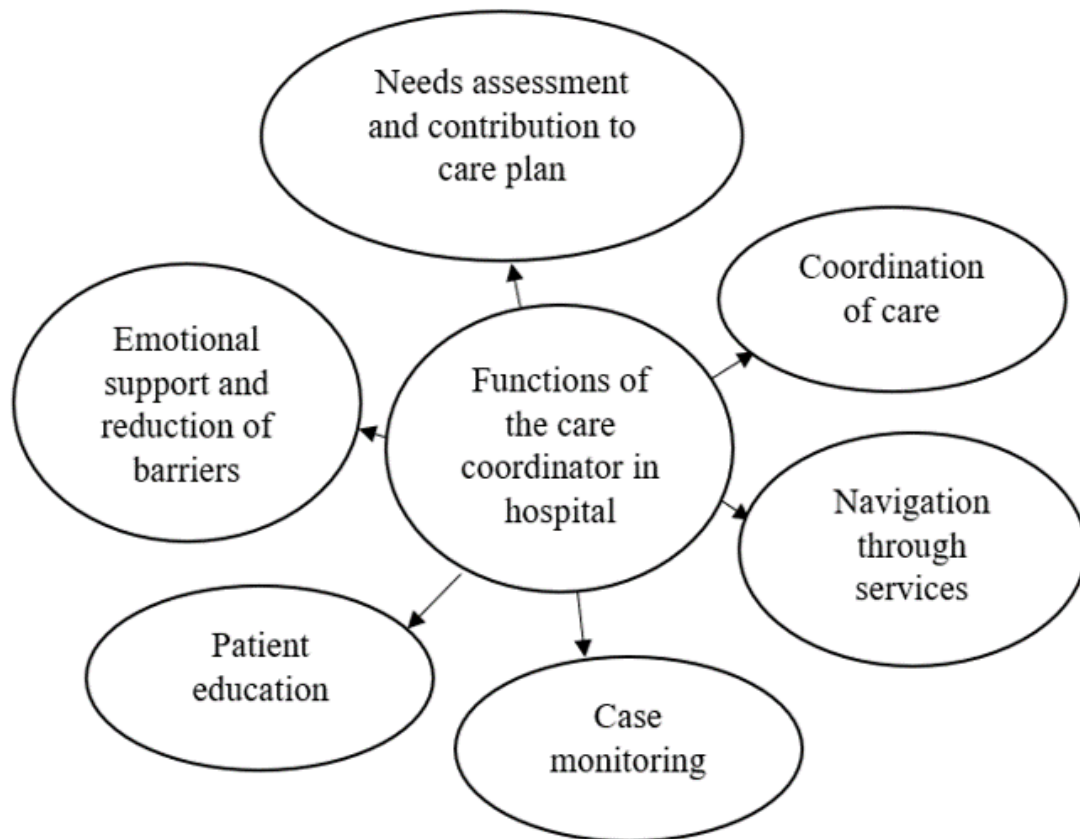


Figure 2. Functions of the care coordinator in the Estonian hospitals. Source: author.

4.2.1 Assessment of patient needs and contribution to the individualised care plan

Interviewees emphasised the needs assessment of the patient to be one primary functions of the care coordinator. The care coordinator conducts comprehensive needs assessment of the patients' emotional, physical and social state. There was difference in the extent and depth of delivered needs assessment between programs. All interviewees said the care coordinator conducts continuous needs assessment while monitoring the case and if needed, adjusts the care plan or informs the responsible specialist for the need. Four interviewees said the care coordinator, as member of the multidisciplinary care team, contributes also to the initial comprehensive assessment of the patient's needs at the beginning of the patient's care and participates in development of the individualised patient care plan together with the patient, family and multidisciplinary team. In these cases, the care coordinator was confirmed to have nursing background. Interviewees emphasised that the care coordinator must pay special attention identifying the person's own wishes and goals during both the development and monitoring phase of the care plan.

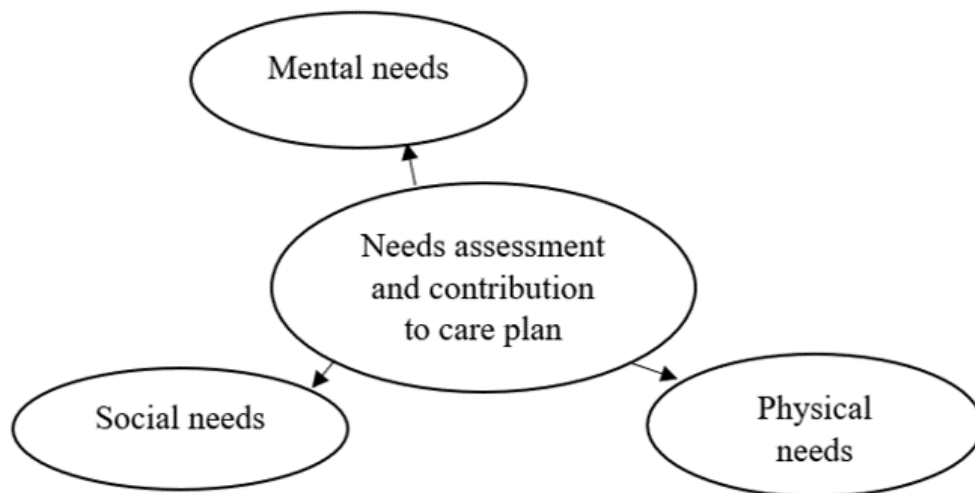


Figure 3. Function of needs assessment and contribution to care plan. Source: author.

4.2.2 Coordination of care

All interviewees said the coordination of care is the central function of the care coordinator in hospital. The hospital care coordinator coordinates services during the patient’s transfers between the departments and clinics of hospital, during the hospital discharge and, also during the follow-up care and rehabilitation services with other service providers. It requires constant information flow and collaboration between the care team members inside the hospital but also outside the hospital.

All interviewees said the care coordinator in hospital should be the member of multi or interdisciplinary team. Two respondents said the care coordinator should manage the work of multidisciplinary team:

“In our speciality, she/he (the care coordinator) should not be only the member of the multidisciplinary team but also to lead the multidisciplinary teams work: to manage team meetings, involve needed specialists, as psychologist, social worker, speciality nurse, etc.” (IP4).

All interviewees said the care coordinator must be a nominated single-point of contact for the person and family. Interviewees had different views on the issue about the length of the period the care coordinators in hospitals should be a single-point of contact responsible for the care coordination of the patient. Seven out of 12 interviewees said the

hospital care coordinator should be the first and single point of contact for the patient even when the patient is moving between organisations and level of care.

“If we take patient point of view, then to have one person (as your contact) is much friendlier and human than to have after every week or two a new contact person. Especially in case of older people.” (IP2).

“One issue that strongly came out from the results of interviews with our oncology patients was the fact that they missed this one dedicated person (care coordinator). Their journey of care may be very long. We may talk about years. Different treatments, operations, rehabilitation, again treatments.” (IP4).

Time of transfer of coordination responsibility to the primary care level need to be fixed by predefined care pathways and treatment guides. Such long-term relationship allows to develop a trustful and therapeutic relationship between the coordinator and the patient.

In current pilot programs the care coordinator in hospital is responsible for the coordination of patient’s care for defined time period. In case of pilot programs for stroke patients the defined time period is one year, in the pilot program for elderly with chronic diseases the hospital care coordinator is responsible for care coordination of the patient until the end of the patient’s life.

Five out of twelve interviewees said the responsibility of care coordination should be transferred from the hospital care coordinator to the next care coordinator in partner organisation or in next level of care (primary care) when the patient is dismissed from the hospital.

The care coordinator helps the patient to communicate and interact with health care providers – if needed, arranges referrals, schedules appointments, arranges follow up appointment after missed appointment. In cases, where the patient needs transportation to attend the procedure or a specialist doctor visit, the care coordinator helps the patient to communicate with the community social worker or family members to arrange transportation.

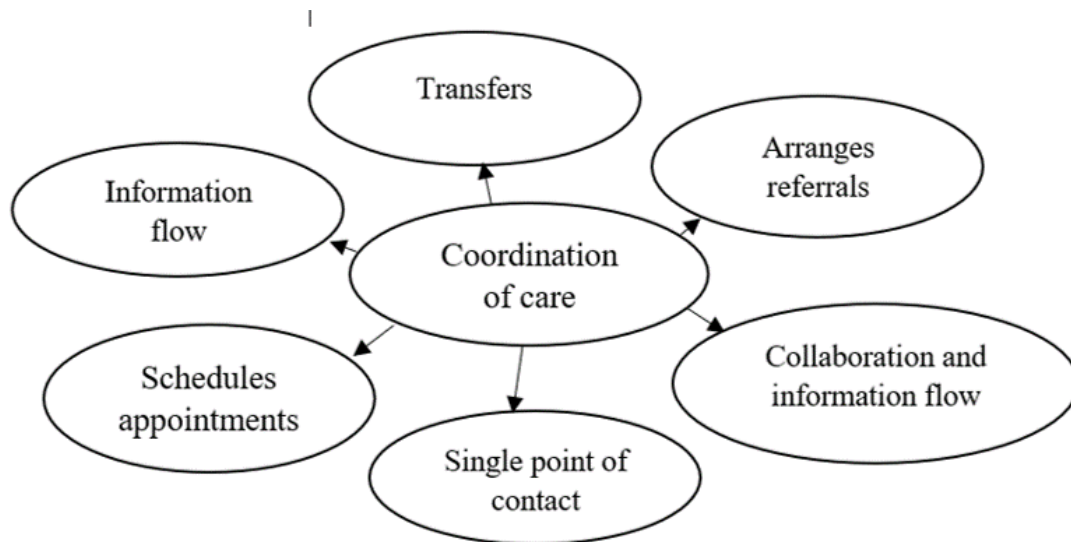


Figure 4. Function of coordination of care. Source: author.

4.2.3 Navigation through services

The interviewees pointed out that the care coordinator in hospital advocates the patient and family about the available services and explains preconditions to be eligible for the service or resource. 11 interviewees brought out rehabilitation services, social services, health insurance coverage and disability evaluation issues. The care coordinator explains to the patient or family member(s) where to go and whom to contact to get a service, for example transportation services. The interviewees pointed out that sometimes it is needed to make the calls or fill in papers for the patient:

“In case of some patients, they need to apply for disability. A lot of papers and forms they need to fill-in...and they are completely lost. Where to go? What to do? They do not know. /.../ In some cases, we have even visited the Unemployment Insurance Fund office to bring the papers (documents) for the patient.” (IP11).

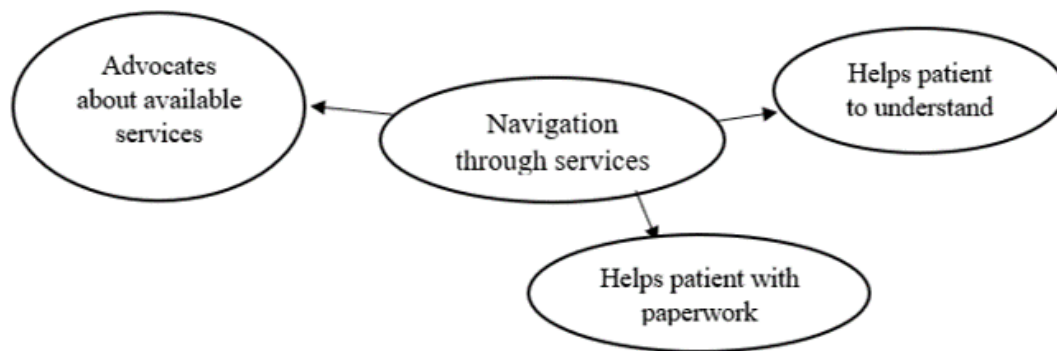


Figure 5. Function of navigation through services. Source: author.

4.2.4 Case monitoring

All interviewees confirmed the care coordinator monitors whether all analysis, procedures and services agreed in the patients' individual care plan are delivered by the service providers in agreed capacity and in time. The care coordinator monitors patient's attendance at visits. If needed, the care coordinator contacts either the service provider or the patient and asks for the reason the service is not delivered or appointment missed:

"She (care coordinator) has to monitor, how the patient is doing. For example, calls and asks whether all services in plan are delivered as agreed. If not, then finds out reasons. And makes sure that everything will be done as planned." (IP7).

In case patient needs help in rescheduling the appointment, the care coordinator reschedules the appointment for patient. The care coordinator monitors changing needs of the patient and informs the care team about it or adjusts the care plan herself/himself. According to interviewees, the depth and extent of the needs evaluation the care coordinator executes depends on the qualifications of the care coordinator. One interviewee said the care coordinators with medical background (nurses) evaluates also analyses and medication side-effects.

All interviewees agreed that care coordinators collect opinions and experiences of the patient and family about the care and evaluate used strategies and interventions against the outcomes.

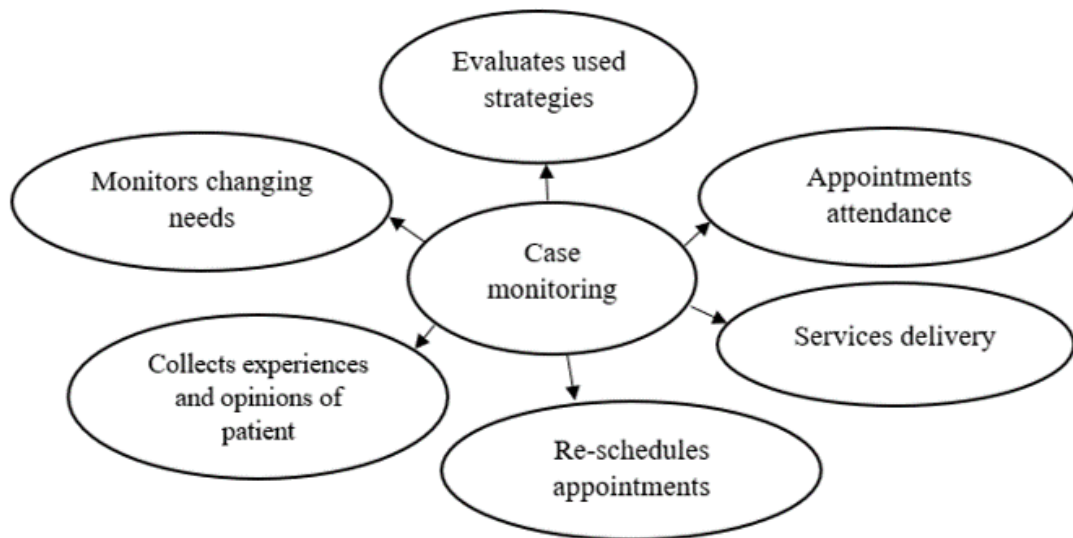


Figure 6. Function of case monitoring. Source: author.

4.2.5 Patient education

According to interviewees, educating the patient and family members is an essential part of the care coordinator. The care coordinator educates the patient about the disease, risk-factors, needed lifestyle changes, different options for treatment(s), possible complications and side-effects of the treatments, available resources, as mobility and disability aids, and how to manage daily tasks. It was emphasised by the interviewees that health counselling activities, as counselling about risk factors, life-style changes, side-effects of treatment, etc, should be done by the care coordinator only in case the care coordinator has medical background (nurse).

“In case of health counselling, as if the patient asks about risk-factors or life-style counselling, it’s important the care coordinator has nursing background. In hospital we cannot allow that someone who has just read from internet about the risk-factors and life-style..., to allow this person to counsel the patient as a hospital employee.” (IP2).

One interviewee said that health counselling should not be part of the care coordinators functions at all:

“Health counselling of the patient should not be the responsibility of the care coordinator. In acute care level it is done by the care team members, as specialised nurse

and other specialists. Especially, at the beginning, the empowerment and education of the patient should be done by the medical team.” (IP6).

The care coordinator promotes health literacy and helps the patient and family to understand information provided by care providers. The care coordinator promotes to the patient practices of health maintenance and explains the importance of self-management and taking responsibility for own health.

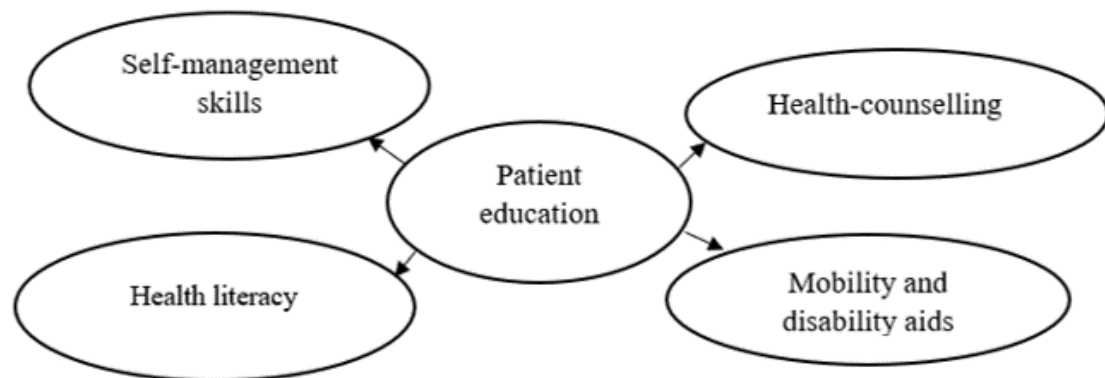


Figure 7. Function of patient education. Source: author.

4.2.6 Emotional support and reduction of barriers

Functions as listening and understanding patients and family members fears and worries, showing empathy, addressing negative attitudes and beliefs about the care providers or care, reducing patients anxiety and distress and building and maintaining trustful relationship with patient and family member were mentioned by majority of interviewees.

“Providing emotional support to patient and family members is important. It is especially important in case of family members. Sometimes they are even more in panic and worried than the patient. For them it all comes so suddenly.” (IP1).

“It’s very important that there is trustful relationship between the patient and the care coordinator. They (patients) are used to talk to me about their worries. I do not know why, but it seems that sometimes people are trusting the coordinator (in hospital) more than the local community social worker.” (IP9).

Three interviewees pointed out, that encouraging patient’s and family members self-confidence is something the care coordinator should pay extra attention.

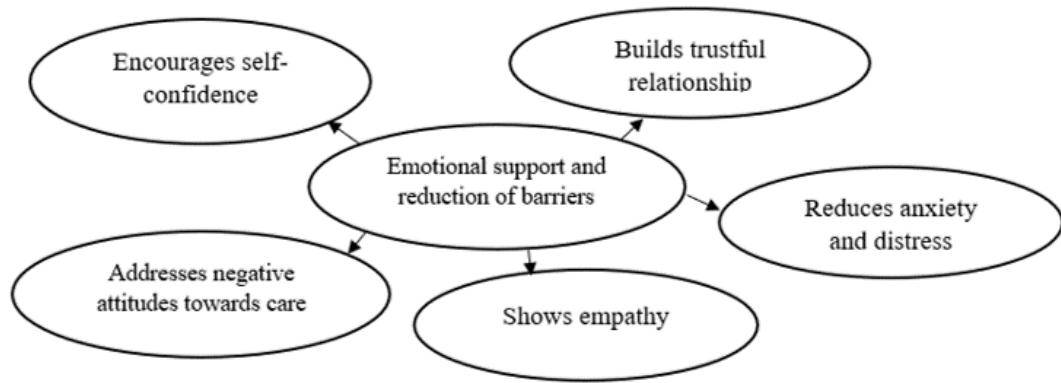


Figure 8. Function of emotional support and reduction of barriers. Source: author.

5 Discussion

Improving persons' quality of life is the fundamental goal of healthcare. Current volume-based, diagnose-centred and fragmented healthcare system in Estonia, that lacks attention to rehabilitation and follow-up care has negative impact on persons' health outcomes causing poorer quality of life and has caused unsustainable increase in Estonian healthcare costs [3], [7]-[8]. For example, although mortality rates for both men and women have decreased since the millennium, they remain above the European average [3]. Improving persons' quality of life is the fundamental goal of the healthcare. Therefore, new sustainable healthcare solutions that improve health outcomes of people and help to ensure effective use of healthcare resources, such as value-based, person-centred and integrated healthcare, have been strongly on Estonian's health agenda [3], [8].

The concept of value-based healthcare was introduced by Porter et al in 2006. In value-based healthcare work processes of healthcare organisations are optimised to deliver better health outcomes with lower costs. It includes improving value for person, restructuring healthcare services to support person's medical conditions as a whole and along entire care pathway, measuring both outcomes and costs at the person's level, considering the person's own will and wishes about her/his health etc. In value-based healthcare, the quality of healthcare service is not measured any more by the volume or range of service(s) delivered to the person but based on the impact of delivered service(s) on health and clinical outcomes mattering most to the person. The principles of value-based, person-centred and integrated care are followed also in the *Global Strategy for People-Centred and Integrated Healthcare Services* introduced by the WHO in 2015 [9]. The aim of the strategy is to improve persons' health outcomes, access to care, health literacy and self-management skills, satisfaction with care, efficiency of services and to reduce healthcare costs. The strategy emphasizes the importance of co-production of care by individuals, health-workers and communities. Coordination of care plays central role in the value-based person-centred and integrated care services. It ensures timeliness and

continuum of care and increases persons' satisfaction with care during the entire care cycle.

Transforming Estonian health system from volume-based into value-based patient-centred and integrated healthcare system requires contribution and effort from all healthcare stakeholders and at all levels of a care, as secondary and primary care, but also beyond the sectors – between healthcare and social care. Need to integrate a new care coordination specialist role to patient care pathways to ensure successful implementation of person-centred and integrated care has been recognised by the stakeholders for a while [14]. Although the care coordinator role is new for the Estonian healthcare market, there has been examples of many successful care coordinator programs from other countries, showing that implementing the care coordinator role into service providers processes, including hospitals, increases persons' satisfaction with the care and improve care outcomes [19], [23], [26], [27]. For example, the results of the systematic review study by Conway et al. [19] about the effectiveness of the care coordinator's role on patient-reported and health service outcomes showed that the care coordinator's role has positive impact both on a) patient-reported outcomes, such as increase in quality of life, less psychological morbidity (depression), less physical symptoms (sleeping disorders, pain), higher satisfaction with care; and b) health service outcomes, such as decreased hospitalizations, emergency department visits, increased treatment adherence, decreased use of health services and decreased health service costs. Therefore, the care coordinator helps to achieve the fundamental goal of the value-based healthcare – to increase patient value [42, 43, 44].

To explore the need for the nominated care coordination role for hospitals and to identify functions the role must fulfil, interviews with hospital representatives working in hospitals' person-centred and integrated care pilot programs were conducted. All respondents emphasised the need for the full-time nominated care coordinator role in hospitals in order to ensure services delivery to patient in right place, in right time and in needed capacity, and to deliver the promise of person-centredness.

Currently different functions of care coordination are carried out by the medical staff, such as doctors and nurses, who often help patients and their family to solve social problems, share information about available non-medical services, help to solve insurance issues of patients etc. Such inefficient use of clinical resources causes longer waiting lists

and overloaded clinicians. At the same time patients and family feel they are left alone with their questions and worries as usually doctors and nurses are busy with their other duties and have time only for short ‘corridor talks’.

In hospitals the care coordinator services are needed by patients who have medical condition and chronic illness(es) that require complex, extensive and long-term acute care, follow-up care and rehabilitation services between different departments, clinics and organisations on secondary care level. Cancer was mentioned by all hospital representatives as one medical condition that needs care coordinator services urgently at hospital level. Also, amputation, both as a result of extensive traumas or diabetes, stroke, mental diseases (schizophrenia), ischemic heart disease and complex chronic diseases were mentioned as medical conditions needing care coordinator services at hospital level. In the study by Conway et al, chronic diseases such as congestive heart failure, coronary artery disease, cardiac arrhythmias and COPD were also mentioned as medical conditions where hospital-based care coordinator interventions were used [19].

Most often the care coordinators in hospitals have the professional background in nursing or social work. To avoid situations where the care coordinator with nursing background is used by the department nurse manager as substitute for the department nurses in their daily nursing duties, the care coordinators must work under the authority of the clinic’s nursing manager and not under the authority of the department nursing manager.

To ensure successful integration and patient-centredness of care for the patients with the abovementioned complex and long-term medical conditions, the hospital representatives listed six functions that need to be fulfilled by the hospital care coordinator: a) assessment of patient needs and contribution to the individualised care plan, b) coordination of care, c) navigation through services, d) case monitoring, e) patient education, f) emotional support and reduction of barriers.

It is important, that the care coordinator is a member of a multi- or interdisciplinary team to have up to date information about the patient’s medical condition, needs and changes in care plan. By some hospital representatives, the care coordinator is seen as the leader of the multidisciplinary team. The study by Kelly et al. [15] indicates that the care coordinator must represent the ‘voice of patient’ in the team of professionals and to take patient’s interests and wishes to the multi- or interdisciplinary team. The care coordinator

conducts continuous needs assessment of patient while monitoring the case and, if needed, adjusts the care plan or informs the responsible specialist for the need. If the care coordinator has medical background (nurse) then initial comprehensive assessment of the patient's needs at the beginning of the patient's care is also done by the care coordinator together with the patient, family and multidisciplinary team.

The care coordinator is a nominated single-point of contact for the person and family while they need specialist care. The hospital care coordinator coordinates services during the patient's transfers between the departments and clinics of hospital, during the hospital discharge and, also during the follow-up care and rehabilitation services with other service providers. It requires constant information flow and collaboration between the care team members inside the hospital but also outside the hospital. The care coordinator helps the patient to communicate and interact with health care providers – if needed, arranges referrals, schedules appointments, arranges follow up appointment after missed appointment. In cases, where the patient needs transportation to attend the procedure or a specialist doctor visit, the care coordinator helps the patient to communicate with the community social worker or family members to arrange transportation.

Today, there is no single understanding among the hospital representatives, when should the responsibilities of the hospital care coordinator be transferred to the next level of care – to the family doctor. According to one opinion, the responsibilities of the care coordinator should be transferred to the next level coordinator immediately after the person is discharged from the hospital. The opposing opinion is, that the hospital care coordinator should stay as the first and single point of contact for the patient and family and be responsible for the coordination of care, even when the patient is discharged from the hospital but she/he still needs constant supervision by the specialist doctor. Such long-term relationship allows to develop a trustful and reliable relationship between the coordinator and the patient, that will give the person the sense of confidence. Also, from perspective of the coordinator, such long-term relationship is useful as he/she knows thoroughly patient's background, personality and medical condition from the very beginning, which allows her/him to anticipate and eliminate barriers, that may otherwise remain unnoticed. In identified Estonian pilot programs, the care coordinator is responsible for the coordination of patient's care for the defined time period. In case of stroke patients, the defined time period is one year, in case of high-risk elderly people with multiple chronic diseases the hospital care coordinator is responsible for the care

coordination of the patient until the end of the patient's life. In case of cancer patients, the need for the hospital care coordinator services for the longer period of time, even up to five years, was emphasised as majority of treatments and procedures, as chemotherapy, radiation therapy and surgery, take place in oncology clinic and may last for years.

To have clarity in this issue, the criteria and standards for the point of transfer of coordination responsibility from the hospital coordinator to the primary care level need to be fixed for each medical condition by predefined care pathways and in treatment guides, so it would be clear to all who and when is responsible for the patient's care coordination.

The care coordinator in hospital advocates the patient and family about the available services and explains preconditions to be eligible for the service or resource (rehabilitation services, social services, health insurance coverage or disability evaluation issues). Also, she/he explains to the patient or family member(s) where to go and whom to contact to get a service. If necessary, the care coordinator helps the patient to make the calls or fill in papers for the patient.

The care coordinator contacts the person and/or family members regularly to ask their feedback and opinions about the care process. She/he monitors whether all analysis, procedures and services agreed in the patients' individual care plan are delivered by the service providers in agreed capacity and in time. The care coordinator monitors patient's attendance at visits. If needed, the care coordinator contacts either the service provider or the patient and asks for the reason the service is not delivered or appointment missed. In case patient needs help in rescheduling the appointment, the care coordinator reschedules the appointment for the patient. The care coordinator monitors changing needs of the patient and informs the care team about it or adjusts the care plan herself/himself. The depth and extent of the needs evaluation the care coordinator executes depends on the qualifications of the care coordinator. In case of medical background (nurses), the care coordinator evaluates also analyses, medication side-effects and evaluate used strategies and interventions against the outcomes.

Educating the patient and family members is an essential function of the care coordinator. She/he educates the patient about the disease, risk-factors, needed lifestyle changes, different options for treatment(s), possible complications and side-effects of the

treatments, available resources, as mobility and disability aids, and how to manage daily tasks. In case of health counselling activities, as counselling about risk factors, life-style changes, side-effects of treatment, etc, the care coordinator must have a nursing background. The care coordinator promotes health literacy, helps the patient and family to understand information provided by care providers and improves self-management skills of the patient.

One important function of the care coordinator in hospital is to offer emotional support for the patient and family. The care coordinator listens to their fears and worries, reduces anxiety and distress, builds trustful relationship and encourages for self-confidence. She/he addresses negative attitudes and beliefs the patient may have about the care providers or care in order to increase care adherence.

All above-mentioned six functions of the care coordinator in hospital are essential to ensure the delivery of successful care coordination and patient-centredness. On other hand, the scope and depth of the identified functions is comprehensive. Therefore, it can be challenging to handle by one person, whether with medical or non-medical background. It may cause burnout of the care coordinators and the quality of the care may be jeopardised. Thus, while planning implementation of the care coordinator position into the hospital processes, program management should consider, based on needs of the target patients and structure of the multidisciplinary care team, whether some of the listed functions or sub-functions can be delivered by other members of the care team. For example, patient education, self-management and health counselling of the patient may be delivered by the specialist nurse among other counselling interventions. Functions as coordination of services, navigation through services, monitoring the care plan and providing emotional support, as listening and understanding worries of the patient and family members, does not need medical competence and can be delivered by the care coordinator without medical background, as social worker. Other possibility is to implement multiple care coordinators with different functionalities. Noteworthy solution was implemented by one hospital program, where two care coordinators, one with nursing background and the other with social work background, were working in tandem, while each having their dedicated functions. Depending on the patient needs, whether she/he needed more medical or social support, one care coordinator was nominated single point of contact for the patient and family members.

For the successful and universal implementation of the care coordinator service into all hospitals processes to ensure high-quality care equally for all persons in Estonia, the position of the care coordinator should be financed by the EHIF as it is done in case of pilot programs.

5.1 Limitations

A major limitation of the research is that the number of person-centred and integrated care programs piloted in hospitals is small. Therefore, although all members of the pilot programs agreed to participate in the study, the number of study participants was limited to twelve persons.

Additionally, due to the emergency situation, hospitals were closed for visitors as of 13 March 2020, and two interviews – one individual interview and one focus group interview, were conducted via telecommunication equipment. The first interview was arranged via the phone and the second interview was arranged via the Skype.

5.2 Suggestions and further studies

The subject of care coordinator, both in hospital and in primary care level, needs further investigation. Hospital representatives from the stroke pilot programs emphasised the need to investigate at the end of pilots in 2022 if the objectives of implemented care coordinator programs were achieved. The research is needed both on clinical outcomes of patients and patient reported outcomes.

Additionally, criteria and standards for the point of transfer of coordination responsibility from the hospital coordinator to the primary care level should be mapped for each medical condition by predefined care pathways, so it would be clear to all who and when is responsible for the patient's care coordination.

Different remuneration schemes for hospitals for the care coordinator services, as monthly payment for care coordination or bundled payment, need to be evaluated together with the EHIF.

6 Conclusions

The care coordinators are needed in hospitals to ensure person-centredness of care and delivery of services to patient in right place, at right time and in needed capacity. They must be the member of a multidisciplinary care team and a nominated single-point of contact for the patient and family.

In hospitals the care coordinator services are needed by patients who have medical condition that require complex, extensive and long-term acute care, follow-up care and rehabilitation services between different departments, clinics and organisations on secondary care level, as cancer, amputation (both as a result of extensive traumas or diabetes), stroke, mental diseases (schizophrenia), ischemic heart disease and other complex chronic diseases.

The position of the care coordinator in hospital must be a full-time job with its own dedicated duties. Care coordinators in hospitals must have the professional background in nursing or social work. Whether the care coordinators in hospitals need medical background or not, depends on the final scope of functions.

Functions of the care coordinator in hospitals are: a) assessment of patient needs and contribution to the individualised care plan, b) coordination of care, c) navigation through services, d) case monitoring, e) patient education, f) emotional support and reduction of barriers.

As the full scope of functions is comprehensive and, therefore, challenging to deliver by one person, then based on the needs of the target patients and structure of the multidisciplinary care team, it is recommended that some of the functions or sub-functions of the care coordinator in hospital could be managed by other members of the care team or divided between different care coordinators. Patient education, self-management and health counselling of the patient may be delivered by the specialist nurse among other counselling interventions. Functions as coordination of services, navigation through services, monitoring the care plan and providing emotional support, as listening and understanding worries of the patient and family members, can be delivered by the care coordinator without medical background, as social worker.

Acknowledgement

I would like to express my sincere gratitude to my supervisors Tiina Sats and Katrin Gross-Paju, for their guidance and support throughout the process of thesis writing.

Also, I would like to thank all participants of the research for their time and contribution.

Additionally, special thanks to my family and friends to their endless understanding, encouragement and support.

References

- [1] Leach MJ, Eaton H, Agnew T, Thakkar M, Wiese M. The effectiveness of integrative healthcare for chronic disease: A systematic review. *Int J Clin Pract.* 2019 Apr;73(4): e13321. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/30721565> (Accessed on 21 Jan 2020).
- [2] Lê, G., Morgan, R., Bestall, J., Featherstone, I., Veale, T., Ensor, T. Can service integration work for universal health coverage? Evidence from around the globe. *Health Policy*, 2016, 120(4), 406-419.
- [3] Habicht, T., Reinap, M., Kasekamp, K., Sikkut, R., Aaben, L., van Ginneken, E. Estonia: Health system review. *Health Systems in Transition*, 2018; 20(1): 1 – 193. Available at: https://www.sm.ee/sites/default/files/content-editors/Tervishoid/hit_-_estonia_-_web_version_01.06.2018.pdf (Accessed on 11 Jan 2019).
- [4] OECD/EU (2018), *Health at a Glance: Europe 2018: State of Health in the EU Cycle*, OECD Publishing, Paris. Available at: https://doi.org/10.1787/health_glance_eur-2018-en (Accessed on 15 Jan 2020).
- [5] Lorenzoni L., Marino, A., Morgan, D., James, C. (2019). *Health Spending Projections to 2030*. OECD Health Working Paper No. 110, 1 – 45. Available at: [http://www.oecd.org/officialdocuments/publicdisplaydocumentpdf/?cote=DELSA/HEA/W D/HWP\(2019\)3&docLanguage=En](http://www.oecd.org/officialdocuments/publicdisplaydocumentpdf/?cote=DELSA/HEA/W D/HWP(2019)3&docLanguage=En) (Accessed on 3 Oct 2019).
- [6] European Commission (DG ECFIN) and Economic Policy Committee (Aging Working Group) (2018), *The 2018 Aging Report: Economic and Budgetary Projections for the 28 EU Member States /2016-2070*, European Economy, No 79/2018, Brussels. Available at: https://ec.europa.eu/info/sites/info/files/economy-finance/ip079_en.pdf (Accessed on 15 Jan 2020).
- [7] Maailmapank (2015). *Ravi terviklik käsitlus ja osapoolte koostöö Eesti tervishoiusüsteemis*. Available at: https://www.haigekassa.ee/sites/default/files/Maailmapanga-uuring/veeb_est_summary_report_hk_2015_mai.pdf (Accessed on 20 Jan 2020).
- [8] Sotsiaalministeerium. *Analüüs ja Ettepanekud tervisesüsteemi rahastamise jätkusuutlikuse tagamiseks*. 2017. Available at: https://www.sm.ee/sites/default/files/content-editors/Tervishoid/th_rahastamise_analuus.pdf (Accessed on 2 Oct 2019).
- [9] WHO (2015). *WHO global strategy on people-centred and integrated health services, interim report Geneva*. Available at: http://apps.who.int/iris/bitstream/10665/155002/1/WHO_HIS_SDS_2015.6_eng.pdf (Accessed on 2 Oct 2019).

- [10] Zonneveld, N., Driessen, N., Stüssgen, R. A. J., Minkman, M. M. N. Values of Integrated Care. A Systematic Review. *International Journal of Integrated Care*, 2018, 18(4), 9, 1-12. 3
- [11] McDonald KM, Sundaram V, Bravata DM et al. Care Coordination. Vol7 of: Shojania KG, McDonald KM, Wachter RM, Owens DK, editors. Closing the Quality Gap: A Critical Analysis of Quality Improvement Strategies. Technical Review 9 (prepared by the Stranford University-UCSF Evidence-based Practice Center). Rockville, MD: Agency for Healthcare Research and Quality. 2007. Available at: https://www.ncbi.nlm.nih.gov/books/NBK44015/pdf/Bookshelf_NBK44015.pdf (Accessed on 18 Feb 2020).
- [12] National Coalition on Care Coordination. Implementing care coordination in the patient protection and affordable care act. 2011. <https://www.rush.edu/sites/default/files/Implementing%20Care%20Coordination%20in%20the%20Patient%20Protection%20and%20Affordable%20Care%20Act.pdf> (Accessed on 18 Feb 2020).
- [13] Konkursi “Toetuse andmine hoolduse koordinaatsiooni mudeli piloteerimiseks” tingimused ja kord. Sotsiaalministeerium, 2018. Available at: <https://adr.rik.ee/som/dokument/5725564> (Accessed on 22 March 2020).
- [14] Mõtus, M, Pääbo, L, Grigorjan L. Insuldipatsiendi raviteekonna parem korraldus. Teenusedisaini kokkuvõte, sisend patsiendikeskse ja tervikliku raviteekonna juhtprojektile. Eesti Haigekassa: Tallinn 2019. Available at: https://www.haigekassa.ee/sites/default/files/uuringud_aruanded/Insuldipatsiendi_raviteekonna_parem_korraldus_EHK_2019.pdf (Accessed on 20 March 2020)
- [15] Kelly KJ, Doucet S, Luke A. Exploring the roles, functions, and background of patient navigators and case managers: A scoping review. *International Journal of Nursing Studies*. 98 (2019): 27-47. Available at: <https://pubmed.ncbi.nlm.nih.gov/31271977/> (Accessed on 15 Jan 2020).
- [16] Struckmann V, Leijten FRM, van Ginneken E et al. Relevant models and elements of integrated care for multi-morbidity: Results of a scoping review. *Health Policy*. 2018; 122:23-35. Available at: <https://pubmed.ncbi.nlm.nih.gov/29031933/> (Accessed on 13 Feb 2020).
- [17] Lie NEK, Hauken MA, Solvang PK. Providing Coordinated Cancer Care – A Qualitative Study of Norwegian Cancer Coordinators’ Experiences of Their Role. *Cancer Nursing*. 2018; 41(6): 463-472. Available at: <https://pubmed.ncbi.nlm.nih.gov/28537952/> (Accessed on 28 Apr 2020).
- [18] Rijken M, Hujala A, van Ginneken E et al. Managing multimorbidity: Profiles of integrated care approaches targeting people with multiple chronic conditions in Europe. *Health Policy*. 2018; 122: 44-52. Available at: <https://pubmed.ncbi.nlm.nih.gov/29102089/> (Accessed on 2 May 2020).
- [19] Conway A, O’Donnell C, Yates P. The Effectiveness of the Nurse Coordinator Role on Patient-Reported and Health Service Outcomes: A Systematic Review. Evaluation and the

- Health Professions. 2019, 42(3): 263-296. Available at:
<https://pubmed.ncbi.nlm.nih.gov/28974106/> (Accessed on 15 Jan 2020).
- [20] McBrien KA, Ivers N, Barnieh L et al. Patient navigators for people with chronic disease: A systematic review. *PLoS ONE*. 2018,13(2): e0191980. Available at:
<https://doi.org/10.1371/journal.pone.0191980> (Accessed on 14 Feb 2020).
- [21] Berkowitz SA, Parashuram S, Rowan K et al. Association of a Care Coordination Model with Health Care Costs and Utilization: The Johns Hopkins Community Health Partnership (J-CHiP). *JAMA Netw Open*. 2018 Nov 2;1(7). Available at:
<https://www.ncbi.nlm.nih.gov/pubmed/30646347> (Accessed on 17 Jan 2020).
- [22] Murphy SME, Hough DE, Sylvia ML et al. Going Beyond Clinical Care to Reduce Health Care Spending: Findings From the J-CHiP Community-based Population Health Management Program Evaluation. *Med Care*. 2018 Jul; 56(7): 603-609. Available at:
<https://www.ncbi.nlm.nih.gov/pubmed/29781923> (Accessed on 24 Jan 2020).
- [23] Kripalani S, Chen G, Ciampa P et al. A transition care coordinator model reduces hospital readmissions and costs. *Contemp Clin Trials*. 2019 Jun; 81:55-56. Available at:
<https://www.ncbi.nlm.nih.gov/pubmed/31029692> (Accessed on 24 Jan 2020).
- [24] Schelp G. The University of Missouri Health Care approach to Comprehensive Care for Joint Replacement. *Arthroplast Today*. 2018 Nov 30; 5(2): 152-153. Available at:
<https://www.ncbi.nlm.nih.gov/pubmed/31286035> (Accessed on 24 Jan 2020).
- [25] Facchinetti G, A'Angelo D, Piredda M et al. Continuity of care interventions for preventing hospital readmission of older people with chronic diseases: A meta-analysis. *International Journal of Nursing Studies*. 2020; Volume 101, Article 103396. Available at:
<http://www.sciencedirect.com/science/article/pii/S002074891930197X> (Accessed on 3 Feb 2020).
- [26] Talevski J, Sanders KM, Duque G et al. Effect of Clinical Care Pathways on Quality of Life and Physical Function After Fragility Fracture: A Meta-analysis. *Journal of the American Medical Association*. 2019; 20(7), 926.e1-926.e11. Available at:
<https://www.sciencedirect.com/science/article/abs/pii/S1525861019302488> (Accessed on 3 Feb 2020).
- [27] Liljas AEM, Brattström F, Burström B, Schön P, Impact of Integrated Care on Patient-Related Outcomes Among Older People – A Systematic Review. *Int J Integr Care*; 2019; 19(3):6. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6659761/> (Accessed on 4 Feb 2020).
- [28] Goodwin N. Understanding Integrated Care. *International Journal of Integrated Care*. 2016;16(4):6. Available at: <https://www.ijic.org/articles/10.5334/ijic.2530/> (Accessed on 3 Feb 2020).
- [29] Pordes e, Gordon J, Sanders LM, Cohen E. Models of Care Delivery for Children with Medical Complexity. *Pediatrics*. 2018; 141; S212. Available at:
http://pediatrics.aappublications.org/content/141/Supplement_3/S212 (Accessed on 25 Sept 2019).

- [30] Gross AH, Driscoll J, Ma L. The nurse coordinator role: fulfilment of the nursing profession's compact with society. *Israel Journal of Health Policy Research*. 2019; 8:5. Available at: <https://ijhpr.biomedcentral.com/articles/10.1186/s13584-018-0280-6> (Accessed on 23 Apr 2020).
- [31] Desveaux L, McBrien K, Barnieh L, et al. Mapping variation in intervention design: a systematic review to develop a program theory for patient navigator programs. *BMC Systematic Reviews*, 2019, 8:8. Available at: <https://systematicreviewsjournal.biomedcentral.com/articles/10.1186/s13643-018-0920-5> (Accessed on 15 Jan 2020).
- [32] Manderson B, McMurray J, Piraino E, et al. Navigation roles support chronically ill older adults through healthcare transitions: A systematic review of the literature. *Health and Social Care in Community*, 2012; 20, 113-127. Available at: <https://onlinelibrary.wiley.com/doi/full/10.1111/j.1365-2524.2011.01032.x> (Accessed on 15 Feb 2020).
- [33] Creswell J. *Qualitative Inquiry and Research Design: Choosing among Five Approaches*. Thousand Oaks, CA: Sage Publications; 2007.
- [34] Bengtsson M. How to plan and perform a qualitative study using content analysis. *NursingPlus Open*. 2016, volume 2, pages 8-14. Available at: <https://www.sciencedirect.com/science/article/pii/S2352900816000029> (Accessed on 26 Feb 2020).
- [35] Hsieh H-F, Shannon SE. Three Approaches to Qualitative Content Analysis. *Qualitative Health Research*, Vol. 15 No. 9, November 2005. Available at: <https://journals.sagepub.com/doi/10.1177/1049732305276687> (Accessed on 4 Mar 2020).
- [36] Laherand M-L. *Kvalitatiivne uurimisviis*. Tallinn. 2008.
- [37] Vaismoradi M, Turunen H, Bondas T et al. Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing and Health Sciences*. 2013, 15, 398-405. Available at: <https://onlinelibrary.wiley.com/doi/pdf/10.1111/nhs.12048> (Accesses at 18 March 2020).
- [38] Elo S, Kyngäs H. The qualitative content analysis process. *Journal of Advanced Nursing*. 2008; 62(1): 107-115. Available at: <https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1365-2648.2007.04569.x> (Accessed on 17 March 2020).
- [39] Bogner A, Littig B, Menz W. *The SAGE Handbook of Qualitative Data Collection*. London: SAGE Publications Ltd. 2018.
- [40] O'Brien BC, Harris I-B, Beckman TJ et al. Standards for Reporting Qualitative Research: A Synthesis of Recommendations. *Acad Med*. 2014; 89:1245-1251. Available at: https://journals.lww.com/academicmedicine/Fulltext/2014/09000/Standards_for_Reporting_Qualitative_Research__A.21.aspx (Accessed on 17 March 2020).

- [41] Ethics in Social Science and Humanities. European Commission. October 2018. Available at: https://ec.europa.eu/research/participants/data/ref/h2020/other/hi/h2020_ethics-soc-science-humanities_en.pdf (Accessed on 17 March 2020).
- [42] Porter, ME. The Strategy to Transform Health Care and The Role of Outcomes. OECD Policy Forum. January 16, 2017. Available at: <https://www.oecd.org/health/ministerial/policy-forum/Michael-Porter-Presentation-OECD-Health-Forum-2017.pdf> (Accessed on 10 April 2020).
- [43] Mold, J. Goal-Directed Health Care: Redefining Health and Health Care in the Era of value-Based Care. *Cureus*. 2017 Feb; 9(2): e1043. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5360382/> (Accessed on 10 April 2020).
- [44] Porter ME, Teisberg EO. Redefining health care – creating value-based competition, 2006/06/06 edn. Boston: Harvard Business School Press; 2006.
- [45] Kaplan RS, Porter ME. How to solve the cost crisis in health care. *Harv Bus Rev*. 2011;89:46-52, 54, 56-61 passim. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/21939127> (Accessed on 15 April, 2020).
- [46] Porter ME, Teisberg EO. How physicians can change the future of health care. *Jama*. 2007;297:1103-11. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/17356031> (accessed on 15 April 2020).

Appendix 1 – Interview guide in Estonian

SISSEJUHATUS

- Uurija ja uurimuse tutvustamine

INTERVJUU KÜSIMUSTIK

Teema 1: Koordinaatori vajadus haiglates:

- a. Mis on koordinaatori töö peamine eesmärk haiglas?
- b. Milliste haigustega on koordinaatorit haigla kontekstis kõige rohkem vaja?
- c. Milline peab olema koordinaatori hariduslik taust?

Teema 2: Koordinaatori funktsioonid:

- d. Milliseid on koordinaatori funktsioonid haiglas?
 - *Vajaduste hindamine koos patsiendiga*
 - *Individuealse raviplaani koostamine*
 - *Teenuste koordineerimine*
 - *Patsiendi ja tema lähedaste abistamine teenustes orienteerumisel ja navigeerimisel*
 - *Juhtumi ja raviplaani jälgimine*
 - *Patsiendi võimestamine ja motiveerimine ravisoostumuse suurendamiseks läbi koolituste ja teadmise jagamise*
 - *Emotsionaalne tugi*

INTERVJUU LÕPETUS

- Kas Teil on antud teemal veel lisamõtteid või kommentaare, mida sooviksite minuga jagada?
- Kui mul tekib lisaküsimusi intervjuude analüüsimisel, siis kas tohin teiega veel ühendust võtta?
- Täname, Teie vastused on selle teema uurimisel väga olulised.