Understanding Patient Choice: A Study of Women’s Choice in Prenatal Screening and Testing

An Chen
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Abstract
With the megatrends of autonomy and individual empowerment in health care, patient choice becomes an essential part of improving health care quality and appears as a health care policy in many developed countries. Patients are endowed with increased opportunities to choose and decide according to their own preferences. However, patient choice comes with controversy and complexity. A large amount of evidence has shown that patient choice does not always produce positive effects. The big problem we have to face and address in an urgency is how to manage patient choice in an optimal way. Over the recent decades, a great effort has been made to understand patient choice and design appropriate choice interventions to achieve desired outcomes. However, there is a lack of contextual awareness in the existed research and little attention has been paid to the patient’s experience in choice-making process. This dissertation advances the understanding on patient choice by contextualizing patient choice and exploring patient experience in choice-making processes within certain contexts. It aims to provide possible solutions for optimizing patient choice and improving patient satisfaction with the choice.

This dissertation based on four articles took a pragmatic view and applied a mixed-method case study approach. The study undertook an in-depth investigation on women’s choice in the prenatal screening and testing implemented in the Hospital District of Helsinki and Uusimaa (HUS) in Finland. Qualitative data were collected by reading relevant documents and interviewing pregnant women and the medical staff from maternal clinics, delivery hospitals, and the Fetal Medical Center (FMC). Quantitative data were obtained by accessing the prenatal testing choice database at FMC and conducting a cross-sectional self-completion survey.

This study found that contextual factors, e.g. service schedules and arrangement, were important for patients to make choices. It applied Demand-Supply based Operating logic to contextualize patient choice and showed that at different contexts patients have different choice-making processes in terms of activeness, preferences or considerations, information needs and sources, social influence, emotion status and choice-making difficulty. This dissertation also developed a set of measurements to quantify and evaluate patient experience in choice-making processes and identified experiential factors that significantly influence patient satisfaction with the choices the patient made.

The combination of the four articles can provides an insight into how to systematically construct possible choice architectures and design appropriate choice aids. Especially, it highlights the role of context in organizing health services and studying patient choices. It also contributes to the practices of communicating with patients who are suffered from unexpected situations and assisting them in arriving at a satisfying choice.

Keywords
Patient choice, contextualization, experience, management, choice architecture

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I owe a great debt of gratitude to my advisor and co-author, Professor Vedran Stefanovic, who was the Head of the Fetomaternal Medical Center (FMC) in the Hospital District of Helsinki and Uusimma (HUS) at the time I commenced the empirical part of this research. His unique combination of academic experience and medical expertise in maternal and fetal care greatly contributed to this work. Even though his schedule was very full, he contributed to every step of this research, from designing the study to publishing the results. His comments
were always very constructive, which made this work convincing and professional. I also want to thank Professor Seppo Heinonen, the Director of the Department of Gynecology and Obstetrics at HUS, for his invaluable support. Without him, I would not have had the opportunity to engage in study of gynecology and obstetrics. He suggested that I focus on prenatal screening and testing, introduced me to Dr. Vedran Stefanovic, and helped resolve numerous administrative issues. He contributed to all the articles included in this dissertation.

I owe much gratitude to my brilliant colleague, research peer, coauthor, and friend, Henni Tenhunen. I feel privileged to have traveled this road with Henni. I remember clearly how we wrote and refined all kinds of applications together, overcame many difficulties in collecting the data we needed, and met challenges in publishing our papers. I will never forget all the frustration, confusion, joy, and cheerfulness we experienced together in this process. Without Henni’s collaboration, I would not have managed to complete this research.

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I wish to sincerely thank the pre-examiners of this thesis, Professor Emeritus Anders Möller from Ersta Sköndal Bräcke University College and Professor Katri Vehviläinen-Julkunen from University of Eastern Finland, for their time and effort in thoroughly examining my dissertation and for their supportive comments and constructive suggestions on improving it. I feel truly honored to have Associate Professor Louise Bryant from Leeds University as my opponent, as her work is exemplary in the field this dissertation covers. I would like to thank Professor Bryant for kindly agreeing to act as the opponent and being flexible with her schedule to accommodate my defense. I also would like to thank her in advance for commenting my work, sharing her wisdom, and opening a new chapter for this study.

The empirical study described in this dissertation was defined as a project and approved by HUS. Dr. Vedran Stefanovic was the principle investigator. Henni and I were the two main researchers. Many individuals made important contributions to planning and executing this project. My sincere gratitude goes to all the people that have been involved. I want to thank Dr. Anna-Maija Tapper, a senior expert in obstetrics and gynecology, for being the project advisor. I thank Ms. Eija Raussi-Lehto and Mr. Antti Niemi from Helsinki Metropolia University of Applied Sciences for organizing students to help conduct interviews. I thank Ms. Maaria Puupponen from HUS for helping solve administrative issues related to this project. I thank Ms. Minna Richards from Kätilöopisto for helping draw the roadmap and patient flow of prenatal screening and testing service
implemented at HUS. I thank midwives from FMC and screening units for working hard to recruit interviewees and survey respondents. I especially thank Ms. Satu Leminen for kindly arranging the data collection at FMC, providing relevant documents, responding to all my requests, and being open to discuss and facilitate execution of the project. I am also thankful for the women who voluntarily participated in interviews or the survey for sharing their ideas, knowledge, and experiences.

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I am also deeply indebted to my family. I thank Mr. Goran Nummelin and Mrs. Brita Nummelin for treating me like their daughter and giving me family
warmth in Finland. I thank my parents-in-law for believing in me and supporting me. I thank my parents for unconditionally loving me, instilling me with a strong passion for learning and giving me the best gift of all the world—education. Particularly, I owe a great debt of gratitude to my mother-in-law and my father for coming to Finland and helping to take care of Leo so that I could have time to work on my dissertation.

My deepest gratitude goes to my husband Johan Li. In 2014, he moved to Finland to support and accompany me along the journey of pursuing this goal. I am so thankful for his companionship, the sacrifices he made for me, and the most precious love he gave me. He makes me better. In 2015, I got pregnant. I would say that not many researchers get such luck to combine the research with life so perfectly. The new life growing inside of me gave me inspirations, passions and strength to go ahead in this journey. Lastly, and most importantly, I thank my amazing boy: Ye Leo Li.

One big step of my life come to the end, but it has opened a new avenue. I still keep my curiosity and motivation to explore the world. I think I am ready to move on to the next adventures.

Espoo, October 2017

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## Definitions of Concepts

<table>
<thead>
<tr>
<th>Concept or abbreviation</th>
<th>Definition in this dissertation</th>
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<tr>
<td>Amniocentesis</td>
<td>A method of invasive prenatal testing of chromosomal abnormalities, in which a small amount of amniotic fluid containing fetal tissues is obtained from the amniotic sac surrounding a fetus</td>
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<tr>
<td>Aneuploidy</td>
<td>The presence of an abnormal number of chromosomes in a cell</td>
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<td>Bounded rationality</td>
<td>An idea that human rationality is bounded by one’s cognitive capabilities and that people frequently violate the principles of rationality and utility maximization in the decision-making</td>
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<tr>
<td>Choice</td>
<td>An act of choosing between two or more possibilities; An option which is chosen</td>
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<tr>
<td>Choice architect</td>
<td>Anyone who presents people with choices</td>
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<tr>
<td>Choice architecture</td>
<td>A choice environment, structure, or platform in which choices are presented</td>
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<tr>
<td>Choice-making</td>
<td>A process by which individuals arrive at a choice</td>
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<tr>
<td>Chorionic villus sampling (CVS)</td>
<td>A method of invasive prenatal testing, in which a sample of chorionic villi is removed from the placenta for testing</td>
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<tr>
<td>Context</td>
<td>A set of external factors that is choice-related but cannot be momentarily changed via the effort or control of the focal object (i.e., patient who is making a choice)</td>
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<tr>
<td>Default choice</td>
<td>An option that will be obtained if the chooser does nothing; it usually represents a recommendation given by authorities or organizations</td>
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<tr>
<td>Demand-supply based operating (DSO) modes</td>
<td>A framework to segment health care contexts by combining what needs to be done (demand) with what can be provided (supply). The seven demand-supply-based operating (DSO) modes are “Prevention,” “Emergency,” “One-visit,” “Electives,” “Cure process,” “Care process,” and “Project”</td>
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<tr>
<td>Discrete choice model</td>
<td>A model that explains or predicts the choices between two or more discrete alternatives</td>
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<td>First trimester combined screening (FTS)</td>
<td>A screening method that takes into account the mother’s age, results of the fetal anatomy and nuchal translucency measurement by ultrasound, and results from maternal serum biomarkers (free β-human chorionic gonadotropin (β-hCG), pregnancy-associated plasma protein-A (PAPP-A))</td>
</tr>
<tr>
<td>FMC</td>
<td>Fetomaternal Medical Center of Helsinki University Hospital</td>
</tr>
<tr>
<td>HUS</td>
<td>Helsinki and Uusimaa Hospital District, Finland</td>
</tr>
<tr>
<td>Informed choice</td>
<td>A choice made by a reasonable individual with autonomy, based on relevant knowledge, consistent with the decision maker’s values, and behaviorally implemented</td>
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<tr>
<td>Invasive prenatal testing</td>
<td>Methods for prenatal testing, e.g., amniocentesis and CVS, that involve probes or needles being inserted into the uterus, use fetal tissues to provide an accurate diagnosis, and carry a miscarriage risk</td>
</tr>
<tr>
<td>Libertarian paternalism</td>
<td>An idea that changes in the decision environment can affect individual decision-making behavior and implicitly alter people’s behavior in a predictable way while preserving freedom of choice</td>
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<tr>
<td>Maternal serum screening</td>
<td>A blood test in prenatal screening available to pregnant women to help evaluate the risk of carrying a baby with chromosome disorders</td>
</tr>
<tr>
<td>Multidimensional Measure of Informed Choice (MMIC)</td>
<td>A instrument to assess informed choice, consisting of a knowledge scale (scored as good or poor knowledge), an attitude scale (scored as positive or negative attitude), and behavior implementation scale (scored as taking or not taking)</td>
</tr>
<tr>
<td><strong>Neuvola</strong></td>
<td>Finnish community-based maternity care unit</td>
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<td><strong>Non-invasive prenatal testing (NIPT)</strong></td>
<td>A method for prenatal testing that is based on next-generation sequencing of cell-free fetal DNA in maternal plasma to assess the most common fetal aneuploidies; it only uses maternal blood samples and has no miscarriage risk</td>
</tr>
<tr>
<td><strong>Nudge</strong></td>
<td>A behavior change intervention, mechanism, technique, or device that addresses or utilizes human biases and cognitive limitations, intervenes in the decision-making process, and modifies people’s behaviors and decisions in a subtle way, usually nudging people toward a socially desirable direction</td>
</tr>
<tr>
<td><strong>Patient decision aids (PtDAs)</strong></td>
<td>Standardized, evidence-based tools embedded in and enabling the SDM process that are supposed to provide information about the available options and the outcomes relevant to a person's health status, assist patients in personalizing this information, help them clarify their values and preferences regarding the benefits and risks of the options, structure the decision process, empower patients to actively participate in the choice-making process, and ultimately facilitate an informed, deliberative, values-based, preference-sensitive choice where there is no “best” option</td>
</tr>
<tr>
<td><strong>Prenatal screening</strong></td>
<td>A screening program to identify a subgroup with increased risk for Down syndrome and other common chromosomal anomalies</td>
</tr>
<tr>
<td><strong>Prenatal testing</strong></td>
<td>A testing program to pursue further information once the individual risk of chromosomal anomalies has been revealed by screening</td>
</tr>
<tr>
<td><strong>Prospect theory</strong></td>
<td>A behavioral economic theory stating that people make decisions based on the potential value of losses and gains perceived by themselves rather than the final outcome</td>
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<tr>
<td>Term</td>
<td>Definition</td>
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<tr>
<td>Rational choice</td>
<td>A theory for understanding economic behaviors, with the main assumption that people are logical and rational decision makers who are motivated by goals, have consistent values and preferences, possess complete information, weigh the various options with good computation skills, and choose a course of action that they believe will maximize the benefits and minimize the risks.</td>
</tr>
<tr>
<td>Second trimester serum screening (STS)</td>
<td>A screening method that is based on maternal serum β-hCG and alpha fetoprotein (AFP) adjusted for the gestational age; it does not involve ultrasound.</td>
</tr>
<tr>
<td>Shared decision-making (SDM)</td>
<td>An interactive and collaborative process in which both parties (patient and doctor) equally and actively go through all phases of the decision-making process together, exchange information, share treatment preferences, reach an agreement on a choice, and jointly take the responsibility.</td>
</tr>
<tr>
<td>Theory of Planned Behavior (TPB)</td>
<td>A theory that links beliefs and behaviors and assumes that a choice is consistent with the choice maker’s goals, expectations, and values. It analyzes and predicts individual’s choice with three constructs: behavioral beliefs, subjective norms and perceived behavioral control.</td>
</tr>
<tr>
<td>Utility</td>
<td>A measurement of relative liking, preference for particular outcomes, or the value that people place on the outcomes of different alternatives or actions.</td>
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List of Publications

This doctoral dissertation consists of a summary and of the following four articles which are referred to in the text by their numerals:


Author’s Contribution

Article 1: Women's choices for invasive or non-invasive testing: influence of gestational age and service delivery.

This is a coauthored article. The first author of this paper, Chen, was responsible for defining the topic, designing the study, and implementing the research. She collected and analyzed the data, interpreted the results, and drafted the paper. Tenhunen participated in collecting data, interpreting the results, and drafting the paper. Stefanovic guided the empirical research, helped access the relevant medical data, provided medical expert comments, and revised the paper often throughout the drafting process. Torkki gave advice for study’s design, data analysis, and interpretation of the results. Heinonen provided insights into the research plan and implementation as a medical expert and institution manager. Lillrank supervised the whole research. The development of the paper for publication depended on the collective effort of all the authors.

Article 2: Considering medical risk information and communicating values: A mixed-method study of women’s choice in prenatal testing.

This is a coauthored article. The first author of this paper, Chen, was responsible for defining the topic, designing the study, and implementing the research. She designed the interviews, collected and analyzed the data, interpreted the results, and drafted the paper. Tenhunen performed the interviews for the study, translated the data, and participated in analyzing the interview data and interpreting the results; she participated in collecting quantitative data, interpreting the findings, and revising the paper during the drafting process. Stefanovic guided the empirical research, helped to recruit the interview participants and access the relevant medical database, provided medical expert comments, and revised the paper often throughout the drafting process. Torkki gave advice for the study’s design, data analysis, and interpretation of the results. Heinonen provided insights into the research plan and implementation as a medical expert and institution manager. Lillrank supervised the whole research. The development of the paper for publication depended on the collective effort of all the authors.

Article 3: Facilitating autonomous, confident and satisfying choices: A mixed-method study of women’s choice-making in prenatal screening for common aneuploidies.
This is a coauthored article. The first author of this paper, Chen, was responsible for defining the topic, designing the study, and implementing the research. She designed the interviews and surveys, collected and analyzed the data, interpreted the results, and drafted the paper. Tenhunen performed the interviews for the study, translated the data, and participated in analyzing the interview data and interpreting the results; she participated in translating and refining the survey’s questionnaire, interpreting the findings, and revising the paper throughout the drafting process. Stefanovic guided the empirical research, helped to recruit the interview participants and distribute the questionnaires, provided medical expert comments, and revised the paper often throughout the drafting process. Torkki and Peltokorpi gave advice for the study’s design, data analysis, and interpretation of the results. Heinonen provided insights into the research plan and implementation as a medical expert and institution manager. Lillrank supervised the whole research. The development of the paper for publication depended on the collective effort of all the authors.

**Article 4:** Context-based patient choice management in healthcare.

This is a coauthored article. The first author of this paper, Chen, was responsible for defining the topic, designing the study, and implementing the research. She designed the interview, collected and analyzed the data, interpreted the results, and drafted the paper. Lillrank was responsible for the theoretical part of the study, participated in drafting the paper, developed the structure of the paper, and supervised the whole research. Tenhunen performed the interviews for the study, translated the data, and participated in analyzing the interview data, interpreting the results, and developing the paper. Stefanovic guided the empirical research, helped to recruit the interview participants, provided medical expert comments, and revised the paper often throughout the drafting process. Torkki and Peltokorpi gave advice for the study’s design, data analysis, and interpretation of the results. Heinonen provided insights into the research’s plan and implementation as a medical expert and institution manager. The development of the paper for publication depended on the collective effort of all the authors.
1. Introduction

1.1 Background

This is a freedom-loving era. Freedom is the essence of humanity and is highly valuable. A way to increase individual freedom is to provide a choice, which has been a notion that is deeply embedded in most people's lives. We have “an in-built preference for a choice-rich environment” (Bryant et al., 2007). We celebrate and cheer when we get more opportunities to choose in a political voting, in a commercial promotion or in a matchmaking party. However, some dissenters, such as Barry Schwartz and Cass R. Sunstein, question the value of choice and claim that choice could be an immense burden. The abundance of choice has made us less freer but more paralyzed, less happier but more dissatisfied (Schwartz, 2004). Forced choice is another form of paternalism (Sunstein, 2015). Uncertainty emerges when a controversial choice is introduced into health care. What is happening when patients are allowed to or must make choices? Does choice liberate or shackle the patient? For a patient, is choice a blessing or a curse? For health service providers, should and could patient choice be managed?

Over the recent 25 years, the world has been witnessing an increased wave of patient-centred care, patient empowerment and patient involvement (McGregor, 2006); this emphasizes the importance of health care workers respecting and being sensitive to patients' values, beliefs, preferences, expectations, behaviors and experiences with different social, racial and ethnic backgrounds, and tailoring the service to meet patients’ multilayered needs (Lupton, 2012; Betancourt et al., 2002). Capturing patient perspectives in health care services is a fundamental part of quality improvement in health care (Siriwardena and Gillam, 2014). The culture of medicine is shifting from paternalism to consumerism as the patient changes from having a passive to active role (Betancourt et al., 2002; Elg et al., 2012).

The increased patient activeness and autonomy is embodied in the development of patient involvement in the decision-making process (McGregor, 2006). Choice is inevitable in health care because modern medicine is rapidly developing, and new options of health care are emerging. People should be allowed, and sometimes must, to make choices for their own health and diseases because
there is no obvious one-best-way option that could be offered with certainty; not to mention, all interventions include risks. Patient choice has appeared as health care policy in the United States, UK, and many European countries. Especially with ICT support, patients are equipped with increased opportunities to choose and decide according to their own preferences (Topol, 2015; McGregor, 2006; Honka et al., 2011; Cohen et al., 2010).

Many studies have shown the benefits of patient choice. Patient choice enables competition between providers, which is a main driver of quality (Hester, 2004; Cooper et al., 2011). With choice, health service demand and supply meet more precisely (Appleby et al., 2003). Choice can reduce the wait for elective services because patients can choose the caregiver with the shortest queue (Dawson et al., 2007). By exercising choice, patients can be involved in their own care and satisfy their preferences and needs (Quill and Brody, 1996), which facilitates reassurance, intrinsic motivation, and commitment and brings numerous psychological and physical benefits (Iyengar and Lepper, 1999).

However, many scholars and practitioners argue that patient choice does not always produce positive effects; there are five choice-related problems mainly discussed in health care. The first concern is that patient choice may endanger clinical quality. Information asymmetry means the doctor knows more than the patient and is better able to make the medical choices (Fredriksson, 2013; Fredriksson et al., 2013; Nguyen et al., 2005). Second, choice may hamper the efficiency of health care (Ward and Savulescu, 2006). Doctors hesitate giving up the efficiency induced by paternalism, and they are reluctant to spend time negotiating with over-inquisitive patients (Gafni et al., 1998; McKinstry, 1992). Third, patients’ involvement in choice-making is uncertain. If patients do not want to choose, patient choice is just meaningless and empty rhetoric. Even if patients do want to be involved in the decisions about their health, they generally participate much less than they want to (Fotaki et al., 2008). For patients not willing or capable of choosing, forced choice can be an immense burden, equal to choice-requiring paternalism (Sunstein, 2015). Fourth, the patients’ experiences of exercising choice may not always be satisfactory. Contemporary health care provides a range of alternative treatments, but recent research indicates that an excessive number of alternatives cause cognitive overload, intellectual burden, and decision difficulties (Iyengar and Lepper, 2000; Kim et al., 2014; Scheibehenne et al., 2010; Schwartz, 2004). Finally, choice may compromise the equity of health care. Different patients have different capabilities to choose, which may lead to inequity among social classes. Choice may immorally benefit the advantaged and leave the disadvantaged behind (Fredriksson et al., 2013).

The value of patient choice is still very blurred, and choice in health care is difficult to explicate and manage. The research to understand patient choice and exploring the choice-making experience is far from adequate; there is limited knowledge of optimally managing patient choice to benefit the most from it.
while minimizing its downsides. The current study will address these research issues.

1.2 Research objectives and scopes

The overall aim of the current study is to advance the understanding of patient choice, explore the choice-making process from a patient perspective, and provide possible solutions regarding patient choice for management to optimize patient choice and improve choice satisfaction. The addressed practical challenge “how to manage patient choice,” more specifically, “what could be good behavioral technologies to assist patients in making choices,” will be addressed in the following five research questions:

1. What is patient choice and its characteristics?
2. What is patient preference and its influential factors?
3. How do patients make choices?
4. What does the patient experience in the choice-making process?
5. What are the experiential factors in choice-making that influence choice satisfaction?

The first research question helps characterize patient choice and depict the choice situation in health care. The second question explores patients’ preferences and their considerations when they make choices between options, the characteristics of the options that they base their choices on, and the factors that influence their preferences. The third question investigates the patient choice-making process, i.e. a course of action and cognitive process resulting in the selection between two or more possibilities. The fourth and fifth questions explore patients’ experiences when they make choices, operationalize the choice-making experience, and identify the experiential factors influencing choice satisfaction. Based on the answers to the five questions, we can address the problem of how to manage patient choice, which is a service design and engineering assignment and involves a set of design and engineering principles that can help manage the complexity of patient choice, facilitate healthy choice-making, improve the patient choice-making experience, and increase the choice satisfaction.

1.3 Research context

Victoor et al. (2012) points out “there is no such thing as the typical patient: different patients make different choices in different situations.” It is wise to set the study of patient choice within a certain medical situation. The current study applies a case study approach and takes the prenatal screening and testing implemented in the Hospital District of Helsinki and Uusimaa (HUS) in Finland as the research context.
Women’s reproductive rights have been increasingly recognized since the early 1990s (Levy, 1999), and the importance of childbearing women making autonomous and informed choices has been highly emphasized (Kirkham, 2004). Silcock et al. (2014) agree that only through the provision of choice can women take responsibility for their own reproductive decisions. Women’s choice has been characterized as an essential quality-enhancing part of women-centered care in maternal services (Kirkham, 2004). One important choice for pregnant women, especially for those with potential high-risk pregnancies, is whether to undergo prenatal screening and testing and which test methods to utilize. In many countries, autonomous and informed choice has been highly recognized in prenatal screening and testing programs (Crombag et al., 2014; Ahmed et al., 2014; Ahmed et al., 2013b). The current study provides insight into women’s choice and choice-making in prenatal screening within the public maternal service system in Finland, where all the tests are offered free of charge.

1.4 Dissertation structure

This dissertation consists of four articles and a summary. Article 1 is a study of women’s preferences of prenatal testing methods and examines the factors influencing women’s choice between non-invasive prenatal testing (NIPT) and invasive prenatal diagnosis in pregnancies with elevated risk of fetal aneuploidy. Article 2 quantitatively studies the factors influencing women’s choices between NIPT and invasive prenatal diagnoses, with the abnormal result revealed by maternal serum screening; this study qualitatively explores how women make choices and the reasons behind their selection. Article 3 explores women’s experiences when they make choices for screening tests (the first trimester combined screening and the second trimester serum screening), operationalizes the choice-making experience, and identifies the experiential factors influencing choice satisfaction. Article 4 contextualizes the choices women face in prenatal screening and testing and characterizes patient choice in different contexts. Table 1 illustrates the focus of each article, linking each focus to the research questions.

Table 1. The focus of each article and its connections to the research questions

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The summary part of this thesis presents a review of the current knowledge of patient choice, as well as the methods, results, and contributions of the four papers. In chapter 2, the ontological, epistemological, and dynamic knowledge about patient choice is reviewed, and research gaps are identified. Chapter 3 describes the research design, empirical contexts, and research methods. Chapter 4 synthesizes the findings of the study. Chapter 5 discusses the contributions, practical implications, limitations, and proposals for future research. Chapter 6 concludes the dissertation.
The current study looks for possible behavioral technologies that could help assist patients in making choices and manage the complexity of patient choice. Technology is a systematic attempt to accomplish something. It can be based on observed empirical regularities exploited for a purpose, and more fully, based on knowledge about the underlying phenomena and associated mechanisms (Arthur, 2009; Lillrank, 2015). The knowledge used to solve the problem can be built and developed on three dimensions: epistemology, ontology, and dynamics. Epistemology that literally means “knowledge’s knowledge” inquires into how things can be studied, evaluated, and known. It is concerned with what constitutes the knowledge and provides methodological and theoretical foundations with which people can construct the knowledge (Saunders et al., 2011; Johnson and Duberley, 2000). Ontology explores the essence of things and asks what is reality (Saunders et al., 2011). Dynamics inquires into the changes and mechanisms of the phenomenon, e.g., how it works or what happens after an intervention.

The focal phenomenon of this study is patient choice. Knowing patient choice means being able to access this phenomenon, to understand what patient choice is and in what sense it is real, to evaluate the quality (good choice and bad choice), to investigate the factors that influence the choice, and to portray the effectiveness of interventions. The boundaries of the ontological, epistemological, and dynamic elements of knowledge regarding patient choice seems dull, and neither do they appear in a given order. Thus, the knowledge reviewed for this study is organized by themes, including the analytic models of human choice (epistemology and ontology), the elements and characteristics of patient choice (ontology and dynamic), patient choice measurements (epistemology), and patient choice management (dynamic). This chapter identifies the concepts, models, and theories that are useful in addressing the focal problem, and defines the lack of knowledge regarding patient choice.

2.1 Choice theory

According to the Oxford English Dictionary, choice can be understood as “an act of choosing between two or more possibilities” or “the person or thing chosen”
The terms “choice” and “decision” are often used interchangeably in the literature (Bryant *et al.*, 2007; Jepson *et al.*, 2005). For over 40 years, choice theory has developed in a wide range of disciplines, including economics, psychology, and behavior science, and the concept has been framed by different theories and perspectives (Bekker, 1999; Bhogal, 2016). This section elaborates the three analytic models of human choice, i.e., the rational choice model, bounded rational choice model, and synthetic model. The arguments, applications, and accompanying limitations of these models are discussed. These three models provide the foundations and approaches with which to study patient choice.

### 2.1.1 Rational choice model

Rational choice is the core theory when it comes to understanding economic behaviors. The main assumption is that people are logical and rational decision makers who are motivated by goals, have consistent values and preferences, possess complete information, weigh the various options with good computational skills, and choose something that they believe will maximize the benefits and minimize the risks (Simon, 1955). The foundation of the rational choice model is Von Neumann and Morgenstern’s expected-utility (EU) theory (Von Neumann and Morgenstern, 2007), the major paradigm of individual rational decision making under uncertainty since the Second World War (Schoemaker, 1982). In choice theory, utility refers to a measurement of relative liking or preference for particular outcomes (Baird, 1989). In the EU model, people’s choices depend on the utility (value) they place on the outcomes of different alternatives or actions and the probability that each outcome will occur. A EU figure is the product of probability and value; the value pertaining to one action or alternative is the sum of the EU figures of all the consequences of the action or alternative. The choice maker compares the EU value for different actions. Based on the principle of EU maximization, the optimal (or most rational) choice is the action with the maximum expected utility value, namely the highest benefits and lowest costs. Chai (2005) concludes that rational choice has been explored through three different perspectives: normative, positive, and interpretive. Different perspectives use the rational choice model in different ways. Considered as a normative model, rational choice is defined by the characteristics that are necessary to make the most appropriate choice under uncertainty in an “ideal world” (Bekker, 1999; Bell *et al.*, 1988; van der Pligt, 1998). Normative rational choice articulates what people should do to be rational (Hands, 2015; Bhogal, 2016). Considered as a positive scientific theory, rational choice is a powerful approach for predicting the economic agent’s choice (Chai, 2005; Hands, 2015). In an interpretive manner, the rational choice theory takes the information of choice pattern and infers the agent’s preferences that are driving the choice (Chai, 2005).

Normative, positive and interpretive perspectives on choice give the subject credit for possessing logical thinking and human intentionality, and the perspectives agree that preferences drive choices (Chai, 2005). The rational choice
model reflects the philosophy of positivism and regards the chooser as an economic actor (Saunders et al., 2011). With these premises, it is possible to objectively and quantitatively analyze the choices and specify the preferences. The nature of choice is presented in statistical figures. The discrete choice model (Ben-Akiva and Lerman, 1985) examines “which option” is taken and explains or predicts the choices between two or more discrete alternatives. It specifies the probability that an individual chooses an option among a set of alternatives, statistically links the choice to the attributes of the choice maker or the attributes of the options available, and identifies the influential factors. The multinomial logic model is the most commonly used model for analyzing discrete choice (Hosmer Jr et al., 2013).

The rational choice theory is a productive instrument, but it has been heavily criticized because it fails to capture the complex nature of human choice-making (Cohen, 1993). Behavioral and psychological scientists criticize that the postulation of a rational, economic man with invariant and transitive preferences, super computational skills, and complete information is unrealistic, and the definition of rationality is too narrow (Simon, 1955; Tversky, 1969; Hands, 2015). The rational choice model is not suitable for empirically describing or characterizing the choice-making processes of a real economic agent (Hands, 2015).

### 2.1.2 Bounded rational choice model

Bounded rationality, initially proposed by Herbert Simon, is the idea that human rationality is bounded by cognitive capabilities and that people frequently violate the principles of utility maximization in the decision-making process (Kahneman, 2011; Simon, 1957; Simon, 1982; Simon, 1997). The lack of full rationality does not necessarily end with bad choices, and some human’s decision strategies, such as heuristics and satisficing (Nease et al., 2013), may lead to acceptable choices. Bounded rationality modifies the assumptions of the rational choice theory, responds to the rational choice theory’s apparent lack of realism, and creates the possibility of describing actual human decision making. Kahneman and Tversky (1979) observe and analyze people’s behavior in a lottery and propose the prospect theory, stating that people make decisions based on the potential value of losses and gains perceived by themselves rather than the final outcome. The utility function of the rational choice model is replaced by a value function that emphasizes people’s different perceptions on the gains and losses, i.e., gains of a certain amount generate less value than the losses of the same amount do (Hough, 2014).

The bounded rational choice model reflects the philosophy of realism, or more precisely, “direct realism.” Direct realism means that the world is portrayed through human observation and experience (Saunders et al., 2011). Choice theories in the stream of bounded rationality are primarily constructed from the observations made in real-world settings (Bhogal, 2016). Many pervasive effects in the human choice-making process have been revealed (Kahneman and
such as the following:

1. Certainty effect, referring to the risk aversion in choices involving sure gains and risk seeking in choices involving sure losses;
2. Isolation effect, referring to the inconsistent preferences when the same choice is presented in different forms;
3. Anchoring effect, referring to the tendency to place a greater weight on the first piece of information (the “anchor”) when making decisions; and
4. Framing effect, referring to the phenomenon that people’s choices are influenced by how the information is presented.

The bounded rational choice model has an interpretive stance as well. Bounded rationality calls for descriptive models to understand what people actually do (Bhogal, 2016) and characterize the real choice-making process and human cognition with a set of meanings (Saunders et al., 2011). Because cognition cannot be measured directly, special techniques have been developed to trace people’s thoughts or reasoning, such as process-tracing techniques (Collier, 2011) and narrative techniques (O’Connor, 1997). One useful framework with which to investigate the choice-making process is the theory of planned behavior (TPB), which was proposed by Icek Ajzen (1985). This theory retains the assumption that a choice is consistent with the choice maker’s goals, expectations, and values (van der Pligt, 1998); TPB was originally used to predict an individual’s choice by looking at the choice through three constructs: behavioral beliefs, subjective norms, and perceived behavioral control. In modern research, TPB has been widely used as a descriptive model (Batchelor et al., 2015; Chen et al., 2017; Lohr et al., 2017; Mohammad Mosadeghrad, 2014; Oosterhoff et al., 2014; Rahnama et al., 2016; Walsh et al., 2015; Zoellner et al., 2012) because it plays an important role in exploring and interpreting the psychological processes associated with an individual’s choice-making (Bekker, 1999).

However, both the rational choice theory and bounded rational choice theory are criticized for their overestimations of individual issues. An individual’s choice and choice-making cannot be fully understood by simply focusing on the individualistic level. One famous experiment, the ultimatum game, reveals the limitations of the standard economic models of human decision-making (Sanfey et al., 2003; Thaler, 1988). In the game, social justice and fairness override the economic elements in human’s decision making. In some real-life situations, e.g., pregnancy and childbirth, people’s choices may be determined by societal norms and values or social policies, rather than based on individualistic utilitarianism (Lawson and Pierson, 2007). Bekker (1999) states that the strategies and processes individuals employ in decision making are a function of the demands of the decision and the factors associated with decision context, such as knowledge of the context, time pressure, the seriousness of the choice situation,
2.1.3 Synthetic model

Because the individual focus of choice models is too narrow to encompass the circumstances relevant to the choices, an integrative perspective is called for. Literature of organizational study shows that people’s behavior is a function of the interactions between the person and the organization (Verbeke et al., 1996). In light of this, Verbeke et al. (1996) study organizational structure theories and propose a structural model identifying the effects of the organizational environment, ethical climate, and personal traits on people’s ethical decision making; the study confirms that organizational context can affect an individual’s choice-making. Papadakis et al. (1998) follow the contextual thinking and empirically study the role of management factors, contextual factors, and decision-specific characteristics in the actual strategic decision-making processes. The major studies with a contextual and systematic view have a positive or realistic stance, analyzing the choice circumstances by observation and reducing the phenomena to their simplest elements (Saunders et al., 2011).

2.2 Patient choice: concepts, elements and characteristics

2.2.1 The concepts and elements of patient choice

The three analytic models provide different ontological knowledge of patient choice. The rational choice model regards choice as an end product of rational calculation based on available information in the attempt to maximize utility. In the bounded rational choice model choice is a process that involves subjective thinking and reasoning. The synthetic model broadens the focus from individual to circumstance and views the choice as the center of a network.

Patient choice as the outcome of an act of choosing reflects patient preference on the attributes of alternatives. The dominant investigations of patient choice using choice modeling (Adams et al., 1996; Crivelli and Zweifel, 1998; Matejka and McKay, 2014), such as the discrete choice experiment (Lancsar and Louviere, 2008) and conjoint analysis (Ryan and Farrar, 2000), are guided by the rational choice theory, which assumes that patients are autonomous decision makers and that they weigh the various options and choose the ones with the maximum expected utility value (Lawson and Pierson, 2007). A large amount of research on patient preferences and choice takes the positivist approach (Albada and Triemstra, 2009; Al-Doghaith et al., 2003; Janssen and Lagro-Janssen, 2012; Jing et al., 2015; Mohammad Mosadeghrad, 2014; Santos et al., 2016; Victoor et al., 2012; Yassini et al., 2010).

Research on patient preferences has been growing (Chan et al., 2009; Harrison et al., 2017; Higginson and Sen-Gupta, 2000; Janssen and Lagro-Janssen,
but a little in the way of consensus exists. Even conflicts appear in some studies. For example, the resemblance effect in Godager (2012) study shows that patients prefer doctors who resemble the patients’ observable characteristics, but Delgado et al. (2011) report that patient gender and general practitioner (GP) gender has no interactive effect on preferences. Most conflicting results can be attributed to the fact that patient choice studies are conducted in various contexts with different populations, health service systems, medical situations and so forth. Because it is impossible to generalize and cross-transfer the results, a context-based or case-based patient choice study is more appropriate for developing knowledge on patient choice.

Applying the bounded rational choice model, the current research on patient choice has paid more attention to the choice-making process (Dixon et al., 2010; Elwyn et al., 2001; Entwistle and Watt, 2006; Fischer et al., 2015a; Groenewoud, 2008), being particularly interested in patient awareness and attitudes toward the choice (Dixon et al., 2010), patient involvement or participation (Mansell et al., 2000; Rademakers et al., 2014; Say et al., 2006), information need (Laverty et al., 2015), capability (Dixon and Le Grand, 2006; Rademakers et al., 2014), decision-making style or strategy (Fischer et al., 2015b; Scott and Bruce, 1995), emotions (Baxter and Glendinning, 2013), and behavior (Fischer et al., 2015a; Groenewoud, 2008; Scott and Bruce, 1995). However, patient choice-making experience is not granted enough attention. Aiming to deliver patient-centered health services, it is crucial to understand patient experience in the medical process (Merkouris et al., 1999), including the process of making medical choices, and explore how the experience affect the patient satisfaction with the outcome. However, only a few studies attempt to build an understanding on patient choice-making process from the patient’s perspective when making choices (Kelly-Powell, 1997). From a service perspective, experience can be understood as a phenomenological product of sense making, a service value determinant, a perceived value process, or a holistic phenomenon that is individually, socially, and contextually constructed (Helkkula et al., 2012b; Helkkula, 2011; Helkkula and Kelleher, 2010). In a health service context, the patient as a social actor perceives the phenomena, makes sense of the events, and constructs the experience. The few studies on the patient choice-making process and experience have a narrow focus on wishes, preferences, and ethical views (Garcia et al., 2009), anxiety and depression affecting choice-making (Brondino et al., 2013), the difficulty of making choices (Aune and Möller, 2012), or information needs (Ternby et al., 2015). There is no comprehensive study that explores and operationalizes the choice-making experience and identifies the experiential factors that influence choice satisfaction.

In the synthetic model, patient choice is the integration of multiple factors, e.g., demographic factors (Farfan-Portet et al., 2012), psychological factors (Pieterse et al., 2013), emotional factors (Baxter and Glendinning, 2013), cultural factors
(Khairullah and Khairullah, 2013), social factors (Deri, 2005), and contextual factors (Dixon et al., 2010). The synthetic model pays special attention to the choice network. Lawson and Pierson (2007) propose a contextual framework with which to conceptualize the choice and choice-making in the case of prenatal diagnosis. They suggest a choice study should expand the scope and consider the contextual factors, such as societal norms and values, media portrayals, governmental and medical policies, and legislations. One big challenge of applying the synthetic approach to a patient choice study is the complexity of the choice network or circumstances. The complexity of the contextual information used to study the patient and provide individualized service has not been well addressed (Devantier et al., 2009; Weiner, 2004). Context, at least in health care, is still loosely conceptualized. There is no solid ground to segment or classify the context. Operating contextual factors lacks of systematic views (Weiner, 2004).

2.2.2 Distinguishing patient choice from other human choice

In health care, choice emerges as modern medicine is rapidly developing, and new options are springing up. Individual choice is a widely celebrated idea in its market form (Mol, 2008) as freedom and autonomy are the most valued principles in the modern society (Schwartz and Ward, 2004). When it comes to health care, people should have the right to make choices for their own health. Patient choice, first introduced as a policy in the NHS in England in the 1990s, signals the marketization and consumerism of health care (Bhogal, 2016). In the past decade, many countries have encouraged patients to make choices with the aim of improving health care (Sheiman et al., 2014). Woolf et al. (2005) conclude that the drivers of increased patient choice are increased patient autonomy, broader access to information, expanding clinical options, rising costs, the increase of chronic illness, complex trade-offs, and greater accommodations of personal values. According to Dixon et al. (2010), there are four types of patient choice in health care: choice of treatment (what), choice of individual health professional (who), choice of which provider (where), and choice of appointment time and date (when). Choices of what and who have received the most academic attention.

Characterizing patient choice and comparing it with consumer choice in the normal market, Mol (2008) suggests two things: the distinction between patients and normal consumers and the distinction between care and normal commercial goods or service. First, patients are special customers. When they are suffering from diseases or medical risks that are usually unpredictable and uncontrollable, the patients are physically and mentally fragile (Mol, 2008). The physical environment, where a medical service process takes place, e.g., a hospital, is usually frightening and causes patients “to be far more emotional, demanding, sensitive, and/or dependent than they would normally be as consumers” (Berry and Bendapudi, 2007). Even though they could be called “customers” in careland (Mol, 2008), it is over-idealistic and unjustified to expect that patients can act as normal customers who have the ability to make choices actively and assuredly. Second, the health services that patients are supposed to choose are
different from nonmedical services. Attractiveness is one condition on which customers in a nonmedical market make choices. But in health care, the services rarely fit this criterion (Mol, 2008). Health care services are unattractive, sometimes dreaded, and are used for passive consumption, carrying pain and even harm. Distance or conflict exists between what patients want and their needs (Berry and Bendapudi, 2007). Undoubtedly, choosing something unattractive and undesired limits activism. In addition, getting to know a service in health care is different from getting to know a normal good or service. Care always involves abstruse medicine science and other complex issues. How can a lay patient learn about the health care service deeply only in a couple of days while the doctor must study hard for many years to become a specialist? Furthermore, in health care, uncertainty exists between what is done and what happens. It is hard to define the responsibility if a choice leads to a bad outcome. To summarize, facing medical choices is a demanding situation. Thus, Mol (2008) encourages the study on patient choice to take a step back and consider the “situation of choice” instead of the choice itself.

2.3 Patient choice measurement

2.3.1 Informed choice

Jepson et al. (2005) state “the fundamental goal in enhancing patient choice is to enable patients to make an autonomous decision which reflects their personal preferences.” This statement shows an important part of today’s healthcare provision: informed patient choice (Van den Heuvel et al., 2009). The concept of informed choice is based on, yet is broader than, the concept of informed consent that is a only legal construct referring to consent based on an understanding of an action before proceeding (Marteau, 2009; Jepson et al., 2005). Informed choice is generally understood as a choice made by a reasonable individual with autonomy, based on relevant knowledge, consistent with the decision maker’s values, and behaviorally implemented (Hibbard et al., 2001; Jepson et al., 2005; Marteau et al., 2001; O’Connor and O’Brien-Pallas, 1989; van den Berg et al., 2006; van den Berg et al., 2005). Informed choice, characterized as an ethical feature of healthcare, a key objective of individual autonomy, and an evaluation of individual choice, has received high amounts of recognition in many medical areas, for instance, in the area of antenatal screening and testing (Ahmed et al., 2014; Ahmed et al., 2013b; Ahmed et al., 2012; Bryant et al., 2010).

Based on the key features of informed choice (i.e., made with sufficient knowledge, in line with the person’s values and attitudes, and behaviorally implemented), Marteau et al (2001) develop a measure framework of informed choice—the Multidimensional Measure of Informed Choice (MMIC) (Marteau et al., 2001; Lewis et al., 2016), which has been widely used in health care research. The MMIC consists of a knowledge scale (scored as good or poor knowledge) based on the itemized medical information of specific conditions,
an attitude scale developed from the theory of planned behavior (Ajzen, 1991) (scored as a positive or negative attitude), and a behavior implementation scale (scored as taking or not taking) (Ames et al., 2015a; Marteau et al., 2001). A choice is categorized as an informed choice if it is made with good knowledge and values-behavior consistent (Ames et al., 2015b; Marteau et al., 2001). The choice is uninformed if the knowledge level is low or the behavior and attitude are not consistent (Dormandy et al., 2002).

Although the MMIC has proved to be a robust measure with high reliability and validity (Michie et al., 2002), it is still criticized as a problematic measure. First, regarding the knowledge measurement, it is difficult to decide what questions to ask in order to evaluate the knowledge level, and the case-based knowledge measurement lacks guidelines (Ames et al., 2015a). Second, dichotomizing a continuous knowledge scale and defining “good” knowledge are quite complex and sometimes groundless (Ames et al., 2015a). Third, the definition and operationalization of informed choice lack a patient’s perspective, and the perception of an informed choice varies by the individual (Ahmed et al., 2012; Jepson et al., 2005; Woolf et al., 2005). Fourth, the MMIC fails to capture the choice-making process, e.g., deliberation and information perception (van den Berg et al., 2005; Ames et al., 2015a).

2.3.2 Choice satisfaction and regret

Understood as the end product of a decision-making process, patient choice is sometimes measured by choice satisfaction and decision regret (Ames et al., 2015b), which are two relevant measures that both take the patient’s perspective when measuring the outcome. Brehaut et al. (2003) define decision regret as remorse or distress over a decision that is associated with “self-recrimination around having made a bad decision” or stemming from “the knowledge that another choice would have resulted in a better outcome.” Brehaut et al. (2003) focus on the aspect of regret stemming from the knowledge that the choice made was non-optimal, and develop a 5-item decision regret scale within a health care setting. To measure the decision satisfaction, patients are usually asked to rate their satisfaction with a single-item measurement, scaling from “not at all satisfied” to “extremely satisfied.”

2.3.3 Patient choice-making measurements

The focus of patient choice measurement has gradually shifted from assessing behavioral outcomes to evaluating the decision-making process. Although a choice usually refers to the end product of a course of decision action, choice-making specifically refers to the process of choosing between alternatives before arriving at a choice (van den Berg et al., 2006; Ames et al., 2015a), such as weighing the advantages and disadvantages between the options. Empirically, measuring the process by which an individual arrives at a decision and evaluating what occurs "in the patient's head" are no easy tasks (Charles et al., 1997).
Most of the current measurements of patient choice-making have narrow focuses and do not have a broad and systematic view. Considering whether or not knowledge is used in the decision, van den Berg et al. (2006) add a deliberation scale to the MMIC to measure informed decision-making in prenatal screening for Down syndrome. Elwyn et al. (2003) develop the OPTION (observing patient involvement) scale, an item-based instrument completed by raters who assess the records of consultations (audio or video) to measure and evaluate patient involvement in the shared decision-making process. A decisional conflict scale (O'Connor, 2014; O'Connor and O'Brien-Pallas, 1989; O'Connor, 1995) provides a slightly wider measure range with five subscales that measure how an individual feels about the course of choice action in terms of information, values clarity, support, and uncertainty, as well as about the choice outcome in terms of effectiveness.

Another insufficiency of the measurement for choice-making process is that the ground of the instruments is not clear. Creating constructs and items usually depends on how the researchers define the relevant concepts, hence lacking solid empirical evidence. Directly using the measures from other research contexts is very common. Jepson et al. (2005) implicate that the development of valid measurements should rely on individual interviews, expert opinion, group discussion, and guidelines.

2.4 Patient choice management

2.4.1 Decision-making models in health care

In general, there are three models used to manage patient choice: the paternalism model, informed choice model, and shared decision-making model (Charles et al., 1997; Elwyn et al., 1999). Information exchange, preference involvement, and ascription of responsibility are the three main dimensions used to distinguish these decision-making models (Sandman and Munthe, 2010).

The paternalistic model is characterized by doctor dominance in the decision-making process, imposing a passive and dependent role on the patient. The doctor is the expert who makes the medical decisions and takes full responsibility for the decisions (Charles et al., 1997; Coulter, 1997). The credibility and effectiveness of this traditional style of decision-making has been seriously questioned and challenged since the 1980s, when the public started to become increasingly educated and skeptical of a doctor’s judgement and when the patient’s active role in decision-making started to be recognized (Charles et al., 1999; Frosch and Kaplan, 1999).

Contrastingly, in an informed model with patient dominance, the patient takes the main role in the decision-making process. The patient is informed of the alternatives and makes decisions that reflect his or her preferences (Charles et
Meanwhile, respecting a patient’s right of autonomy and self-determination, the doctor provides relevant information to reduce informational asymmetry and communicates the needed knowledge to patients without presenting his or her own preferences (Emanuel and Emanuel, 1992; Charles et al., 1999). However, research indicates that patients want to be informed, but their willingness for participation in decision-making or taking responsibility for making medical decisions may not be strong (Gafni et al., 1998; Charles et al., 1997).

The third is the shared decision-making (SDM) model, a middle ground of the decision-making models, that has been increasingly advocated as an ideal model for medical decision-making (Charles et al., 1997; Bieber et al., 2009; Barry and Edgman-Levitan, 2012). SDM is generally understood as an interactive and collaborative process in which both parties (patient and doctor) equally and actively go through all the phases of the decision-making process together, exchange information, share treatment preferences, reach an agreement on a choice, and jointly take responsibility (Charles et al., 1997; Elwyn et al., 2012; Frosch and Kaplan, 1999; Holmes-Rovner et al., 2000; Joosten et al., 2008; Kriston et al., 2010; Légaré and Witteman, 2013; Moumjid et al., 2007).

Researchers have made an effort to conceptualize and characterize SDM. The understanding of the phenomenon is similar. Charles et al. (1997, 1999) suggest four key characteristics of shared decision-making: (1) at least two participants—physician and patient—are involved; (2) both parties share information; (3) both parties take steps to build a consensus on the preferred option; and (4) an agreement is reached regarding the treatment to be implemented. Later, the authors add that in SDM “each person needs to be willing to engage in the decision-making process” and recognize that “the patient may decide to share any or all of the decision-making steps with persons other than or in addition to the physician.” In their recent overview, Légaré and Witteman (2013) describe three essential elements of SDM: (1) recognizing and acknowledging that a decision is required; (2) knowing and understanding the best available evidence; and (3) incorporating the patient’s values and preferences into the decision. Based on the conceptualization and characterization of SDM, theory-based instruments used to measure SDM and assess the degree of SDM have been developed, e.g., OPTION (Elwyn et al., 2003), SDM-Q (Simon et al., 2006), and SDM-Q-9 (Doherr et al., 2017; Kriston et al., 2010).

SDM has been widely advocated in policy and conceptually linked with desirable health care service and positive health care outcomes, e.g., improved clinical effectiveness and patient satisfaction (Holmes-Rovner et al., 2000; Légaré et al., 2010). However, the claimed effects are not fully supported by empirical studies and experience. Politi et al. (2011) find that communicating scientific uncertainty in the SDM process might cause dissatisfaction for patients facing cancer treatment decisions. Muscat et al. (2016) suggest that participation in SDM may be difficult for people with a lower literacy level. Légaré and Witteman (2013)
point out that there is also a paucity of evidence on the productivity and cost-effectiveness of the large-scale implementation of SDM across diverse clinical settings. It is hard to implement SDM in practice. The reported constraints of implementing SDM include time pressures, uncertainties inherent in medical care, difficulties in expressing uncertainty, cultural barriers, challenges in developing interpersonal skills, the varying preferences, doctors’ unwillingness to share power, doctors’ biases toward options, patients’ inability to engage, and patients’ unwillingness to be involved (Charles et al., 1997; Frosch and Kaplan, 1999; Elwyn et al., 2000; Holmes-Rovner et al., 2000; Coulter, 2001; Hibbard et al., 2001; McNutt, 2004; Woolf et al., 2005; Edwards and Elwyn, 2006; Légaré et al., 2008).

There is a lack of guidance regarding how to implement SDM in routine clinical practice (Edwards and Elwyn, 2006; Elwyn et al., 2012; Jones et al., 2011). Some scholars attempt to fill this gap. For example, Towle (1997) provides a list of competencies that patients and doctors should have and suggests preliminary skills for implementing SDM (Towle, 1997; Towle and Godolphin, 1999). Frosch and Kaplan (1999) conclude there are conditions that must be met for shared decision making to occur: (1) the atmosphere must be conducive to active patient participation; (2) patients should feel that their contributions are valued; (3) patients need to be frank about their preferences and goals; (4) the doctor should help the patient determine how these goals and preferences fit with the available treatment options; (5) a shared decision is reached. Elwyn et al. (2012) propose a simple three-step model to realize SDM in practice: (1) introducing choice, (2) describing the options, often by integrating patient decision aids, and (3) helping patients explore preferences and make decisions. However, as suggested by Elwyn et al. (2012) and Stiggelbout et al. (2012), shared decision-making is complex, and clinician–patient interaction is coupled with multiple changing factors. Thus, the realization of SDM requires contextualized and multifaceted strategies. Until now, no advances in SDM have been successfully translated into practice (Jones et al., 2011). To develop generalized guidelines with invariant steps would not make meaningful contributions in SDM implementation. The importance of flexibility should be emphasized for implementing SDM at different decision contexts (Charles et al., 1997; Charles et al., 1999)

2.4.2 Choice architecture and aids in health care

Choice architecture

The framing effect shows the importance of the information needed to support choice and of how the information is presented (Bhogal, 2016). The choice environment, i.e., the way a choice is structured and presented, influences how and what a decision maker chooses (Johnson et al., 2012). The choice architecture, a term coined by Thaler and Sunstein (2008) and a manifesto for libertarian paternalism (Leonard, 2008), is based on the idea that changes in the decision environment can affect individual decision-making behavior and implicitly alter people’s behavior in a predictable way while preserving freedom of choice (Münscher et al., 2016; Thaler and Sunstein, 2008). The growing field of choice
architecture research applies the cognitive peculiarities of human decision making drawn from psychological and behavioral research (Selinger and Whyte, 2011), investigates how the structure and presentation of choice situations can address one’s mental constraints and cognitive biases, and provides insights into the development of intervention to change or support people’s behaviors and decisions (Münscher et al., 2016; Thaler and Sunstein, 2008). Choice architecture has been applied in many areas, including finance, environmental engineering, education, public health, and so on (Münscher et al., 2016). The core of choice architecture is called nudge, a behavior change intervention, mechanism, technique, or device that addresses or utilizes human’s biases and cognitive limitations, intervenes in the decision-making process, and modifies people’s behaviors and decisions in a subtle way, usually nudging people toward a socially desirable direction (Selinger and Whyte, 2011; Thaler and Sunstein, 2008).

In recent years, in order to provide conclusive remarks and visualize the possible directions for future research, researches have put considerable effort into summarizing the current applicable and testable choice architectures, or nudges, with the addressed psychological phenomena and processes in decision making. According to Dolan et al. (2012), nine categories of psychological phenomena and processes usually serve as a starting point on which to build choice architectures; they include messenger, incentives, norms, defaults, salience, priming, affect, commitments, and ego. Johnson et al. (2012) list the feasible choice architecture techniques linked with targeted decision problems. The tools are categorized into two groups: those used in structuring the choice task, such as reducing the number of alternatives and setting defaults, and those used in describing the choice options, such as partitioning the options and attributes and customizing information. Münscher et al. (2016) suggest three basic categories of choice architecture intervention techniques. The first category is decision information, referring to the presentation of decision-relevant information without altering the options themselves, such as making information visible and setting reference points. The second is the decision structure, referring to the arrangement of options and the decision-making format, such as setting a default choice and changing the order of options. The final one is decision assistance, the technique used to help people make decisions in accord with their intentions, such as providing reminders.

The most prominent and powerful example of choice architecture is default choice. Default choice is an option that will occur if the chooser does nothing (Thaler et al., 2013). It usually represents a recommendation given by authorities or organizations. A commonly used way to set the default is to default the alternative that most people would choose if they make an active choice (Johnson et al., 2012). The default is normally used for some cognitive phenomenon, including loss aversion, implied endorsement and decision inertia (Münscher et al., 2016). It serves individuals who do not take active steps to-
ward making choices (Johnson et al., 2012). Especially, when the choice is complicated and difficult, a required choice becomes a nuisance, and people may greatly appreciate a sensible default (Thaler et al., 2013).

Choice architecture is still subject to critiques. Leonard (2008) criticizes choice architecture as causing ethical problems by potentially exploiting people’s cognition and manipulating the decisions without people’s awareness, and it highly relies on the choice architect’s intuition, judgement, intention, and worldview, giving what the person “should” want but not what he or she truly wants. Furedi (2011) echoes and exposes the nudge’s political pitfall, saying that it is used as a scheme to erode people’s moral independence, nudges people’s thinking and behavior into what the authority believes to be right, and deprives people of making choices based on what they want. The statement of “helping people make a right choice” is controversial. Targeting default choice, Smith et al. (2013) state that choice architects should be mindful of the ethical risks of setting defaults. Defaults might impinge on liberty if consumers provided with default choices are not aware that they have other choices (Johnson et al., 2012). Johnson et al. (2012) challenge the neutrality of choice architecture and point out that there is no neutral architecture, and any means with which a choice is presented can influence people’s decisions.

According to Thaler et al. (2013), a good system of choice architecture helps people improve their ability to map and select options. Just responding to the concerns on nudge’s immorality and unethicality of depriving people of the capability and willingness to make decisions, Thaler and his colleagues’ statement indicates that the more appropriate role that choice architecture plays is to assist people in decision making, rather than modifying their behaviors or decisions based on someone else’s subjectivity.

The challenging issue is defining a methodology and providing a set of principles for an appropriate choice architecture. Thaler and Sunstein initiate the idea of choice architecture and nudge but provide little concrete guidance, paradigms, methods, or techniques to design, construct, and implement a reliable choice architecture (Michie et al., 2008; Münscher et al., 2016; Selinger and Whyte, 2011). Currently, there is a lack of a systematic view on choice architecture and choice architecture design (Münscher et al., 2016). Choice architectures are still limitedly understood and often employed as “widgets” that deal with human cognition and implicitly intervene in people’s choices and decisions. Choice architecture is usually concretized as choice devices, e.g., defaults, framing, salience, pre-commitment, intelligent assignment, predictive shopping, and active choice (Nease et al., 2013; Sunstein, 2015; Thaler and Sunstein, 2008). The purpose of the architecture, who benefits from it, and what the benefits are, e.g., to help the consumer make easy choices, to maximize consumers’ health, or to maximize the business profits, are not always clearly pre-thought or pre-defined in practice (Leonard, 2008). An one-size-fits-all approach to
choice architecture seems impossible, and a cross-context transfer of choice architecture interventions is barely successful (Johnson et al., 2012; Selinger and Whyte, 2011).

It is time for choice architects to extend the vision, view the choice phenomenon contextually and systematically, and design a systematic framework by taking into account the choice situation, constraints and biases in decision making, and the expected outcomes of the interventions (Münscher et al., 2016). Building on the works of Datta and Mullainathan (2014) and Michie et al. (2008), Münscher et al. (2016) propose a systematic approach of developing choice architectures. There are four steps. The first step is to define the behavioral problem(s) and target behavior(s). The second step is to check the applicability of the choice architecture in a certain context and determine the behavior change approach(s) that is applicable to the behavioral context. The next step is to find the reasons why people fail to display the target behavior(s) and identify the “behavioral bottleneck(s)” (Datta and Mullainathan, 2014). Michie et al. (2008) suggest that the analysis could focus on the central determinants of a behavior in the “behavior change wheel,” including capability, opportunity, and motivation, to identify the corresponding biases or constraints, e.g., limits in self-control, attention, cognitive capacity, and understanding (Datta and Mullainathan, 2014). The final step is to build hypotheses on promising-looking choice architectures and choosing potentially effective intervention techniques.

**Choice aids**

In the last 20 years, there has been major growth in the development of patient decision aids (PtDAs) (O’Connor et al., 2007; Stacey et al., 2017), also known as decision support interventions (O’Connor et al., 1999), decision support technologies (DSTs) (Durand et al., 2008), and decision support (Llewellyn-Thomas and Crump, 2013). PtDAs are commonly understood as standardized, evidence-based tools embedded in and enabling the SDM process; they are designed to provide information about the available options, empower patients to actively participate in the choice-making process, assist patients in personalizing this information, help patients clarify their values and preferences, structure the decision process, and ultimately facilitate an informed, deliberative, values-based, preference-sensitive choice when there is no “best” option (Graham et al., 2003; Hibbard and Peters, 2003; Nelson et al., 2007; O’Connor et al., 1999; O’Connor et al., 2005; Stacey et al., 2017). Besides an information provision, values clarification, preferences elicitation, and guidance or coaching in deliberation and communication are the key elements of the full decision-support process (Llewellyn-Thomas and Crump, 2013; O’Connor et al., 2004). PtDAs have been applied and developed in many areas in health care (Stacey et al., 2014), e.g., preventive care (Beulen et al., 2016; Smith et al., 2010; Vlemmix et al., 2013), long-term diseases management (Ghahramani, 2015), acute care (Alexanderson et al., 2014; O’Brien et al., 2009), and surgery (Arterburn et al., 2012). Decision aids are presented in a variety of formats, including leaflets, structured counseling, videos, computer-aided programs, websites, and structured interviews (Bekker, 1999; Kennedy et al., 2002; Woolf et al., 2005; O’Connor et al., 2007).
Since it was first published in 1999, the Cochrane review of PtDAs for people facing health treatment and screening decisions comprehensively reviewed the development of PtDAs and their effectiveness. According to the recent Cochrane review report, PtDAs produce good results, meet the International Patient Decision Aid Standards (IPDAS), and achieve goals across a wide range of medical contexts (Stacey et al., 2017).

Partially because of the context issue, there is no universally applicable support technique or generally accepted guidance for effectively developing and applying PtDAs. Researchers claim that the emphasis of developing PtDAs and evaluating their appropriateness and effectiveness should be placed on understanding the relevant decision-making contexts (Charles et al., 2005; Woolf et al., 2005; Clifford et al., 2017). The decision-making context is multi-dimensional, including the severity and stage of the disease, treatment burden, relevant policies, patient characteristics, and so on (Elwyn et al., 2016; Clifford et al., 2017). The cross-context transferring of PtDAs may be problematic, and the validity of PtDAs without context-based evaluation is questionable. There is a need for research to describe the real decision-making process before money and effort are invested in developing or applying the choice-support techniques (Michie et al., 1997).

2.5 Context approach in health care

The importance of context in service research and management, especially in health service, has been highly recognized (Voss et al., 2016). Bryant et al. (2007) argue that the context of patient choice is important, and healthcare providers should be aware of it. However, no prior attempt has been made to contextualize patient choice. To address context effectively, we must understand what context is and what could be considered as a contextual factor (Dey, 2001).

Context is a multi-dimensional concept and diversely defined in different disciplines. It is often interchangeable with “environment,” “circumstance,” “situation,” “condition,” and “status.” A definition of context for this study is given by Voss et al. (2016): context is a setting within which the phenomenon of interest occurs. However, with this broad definition, it is still difficult to operationalize context for research. In a contingency paradigm (Donaldson, 2001), contextual (or contingent) factors represent the situational characteristics outside the focal entity (Sousa and Voss, 2008), and they are hard to change in a short time (Finne, 2014; Sousa and Voss, 2008). Schilit and Theimer (1994) claim that the important aspects of context are where you are, who you are with, and what resources are nearby. In line with these understandings, the patient choice and choice-making context can be defined as a set of external factors that are choice-related and cannot be momentarily changed via the effort or control of the focal object (i.e., patient who is making a choice), e.g., the medical situation, resources, physical environment, social environment, health insurance, and health care policies. The counterpart of context includes choice-related, internal
factors, e.g., individual’s values, beliefs, preferences, expectations, and willingness.

It is impossible to embrace all contextual factors in one study. The focus must be on a limited number of factors, identifying the possible value of these factors and analyzing the effects from a certain viewpoint. The current study looks at the service context, particularly focusing on the medical context. One inevitable task in a context-related study is to classify or segment the context and enumerate the possible variations of the context.

The tradition of classification in marketing is based on the concept of classifying variables in a meaningful way to group customers or products with similar properties (Christensen et al., 2005). In health care, service is traditionally segmented in a clinical way, e.g., classified by patient demographics (old, young, men, women, etc.), specialized by organ systems (neurology, orthopedics, dentistry, etc.), separated by clinical technologies (surgery, internal medicine, radiation, etc.), or categorized by causes (trauma, infections, tumors, etc.) (Lillrank et al., 2010; Lynn et al., 2007). However, Christensen et al. criticize that this traditional segmentation, considering the variance either in the demand or supply side, possibly fails to guarantee a match between needs and supply (Christensen et al., 2005). To solve the problem, they suggest the segmentation be based on the notion of "jobs-to-be-done," identifying the problems or tasks that the consumers have and counting the available products or services that can help get the jobs done.

Obviously, the clinical segmentation principles for health care service cannot provide a managerial guide for how services should be organized and operated. A basic principle of operations management is managerial homogeneity, which means that tasks organized in one unit should have similar requirements on the resources and operating skills (Lillrank et al., 2010; Skinner, 1974). Although different departments (emergency unit, outpatient department, inpatient department, ICU, etc.) treat patients according to the level of urgency and severity, many other variables affecting health service management and operation are still missing.

**Demand-supply based operating (DSO) modes**

Based on the logic of supply and demand and in line with Christensen et al. (2005), Lillrank et al. (2010) improve the segmentation found in healthcare service. They identify five dividing variables that could effectively segment health care and define the contexts in the combination of what needs to be done (demand) and what can be provided (supply). The five grouping dimensions are urgency, severity, clarity, continuity, and risk. The segmentation is performed by going through a set of dimension-based questions: “Whether the patient is ill” or “whether the risk is being individually revealed” (risk), “whether the case is urgent” (urgency), “whether it is treatable in a connected flow or in one visit” (severity), “whether it is treatable by a process” (severity), "whether the diagnosis is clear and the procedure can be planned and scheduled" (clarity), and
“whether the end point is predictable” (continuity). With these five dimensions, seven demand-supply-based operating (DSO) modes are identified. These are “prevention,” “emergency,” “one-visit,” “electives,” “cure process,” “care process,” and “project.” Figure 1 depicts the seven modes with the algorithm of categorization.

Prevention refers to situations where a person is not yet acutely ill but there is a calculable risk that can be individually revealed by screening and monitoring. Emergency refers to a situation with an urgent and severe health problem that has a limited time window to save and stabilize the patient. One-visit refers to the situation where the problems are not urgent or severe and where the treatment can be administered in one workflow, such as filling a dental cavity. Electives are medical interventions based on a precise diagnosis, such as a hip surgery. They are not urgent and can be planned and scheduled in advance. Cure process is a series of medical interventions that, contrary to electives, cannot be planned from end-to-end, such as early low differentiated adenocarcinoma. In Cure mode, diagnoses are not sufficiently clear and may lead to several alternative pathways that can be planned only a few steps ahead. A desirable end point can be expected. Care process applies to conditions that are chronic or terminal and cannot be cured by available therapies, such as diabetes or Alzheimer’s disease. In contrast to Cure, Care has no end point and the objective is to manage the condition and arrest decline. A project refers to situations where the case is extremely complex and synchronized treatments from several different medical specialties are involved, such as with massive burns. The service network with a case manager and expert team must be quickly built.

Figure 1. DSO mode flowchart (Lillrank et al., 2010)
The DSO classification of medical context is relevant for patient choice and provides a possible solution for how choices could be contextually managed. People have some time to consider their options in Prevention. Health risk recognition, expected life style and the patient’s motivation and capability in changing his or her lifestyle determine the choice. In Emergency, urgency constrains the decision space and paternalism may be applicable for the situation. In One-visit, convenience may be the key factor in choice and choice is made out of a set of accessible standard options. In Electives, patients may shop around and make choices based on providers’ performance records, e.g., complication rate. Cure process includes several decision points with varying risk-benefit constellations, and patient choice-making is path dependent. In Care, choices involve several issues related to a patient’s life-world, requiring broadened and inclusive choice management. In Project, the patient’s ability to make choices is constrained by extreme complexity and the choice may reside in the professionalism of the case manager.

2.6 Summary of literature review

Table 2 summarizes the existing theories and research that lay the foundation for the current study. The table also identifies the gaps of the exiting research and presents how each article included in the dissertation responds to these gaps. The present dissertation is built on choice theory. Three analytic models (the rational choice model, bounded rational choice model, and synthetic model) provide the epistemological foundations for this patient choice study and help conceptualize patient choice. Different frameworks have been developed to evaluate patient choice and the choice-making process. Patient choice could be understood as an outcome of a series of choice-making activities, a process that arrives in a choice, or the core of a network with multiple factors. The patient’s preference and cognitive process in choice-making have obtained the most attention in the current research. Decision-making models, choice aids, and choice architectures are possible approaches to intervening in choice behavior and managing patient choice. There are two main research gaps addressed by this dissertation. First, the issue of context has not been addressed in the development of epistemological, ontological, and dynamic knowledge of patient choice. Most models, frameworks, measures, and approaches of measuring or managing patient choice and choice-making lack context awareness. The studies on the contextual factors of patients lack consistent and systemic views. Particularly, patient choice contextualization has not been studies. Second, little attention has been paid to the patient’s experience in the choice-making process, and the current measurements of patient choice and choice-making lack the patient’s perspective.

The current dissertation pays attention to contextual factors and borrows the DSO logic from health service operation management to contextualize patient choice. This study also addresses the experience issue by investigating the patient’s experience in the choice-making process and developing a measurement
of patient choice-making experience. Thus, based on the research gaps, the empirical questions are further developed. The refined research questions are the following:

1. What are the characteristics of patient choice when considering different contexts?
2. What are the factors, especially contextual factors, influencing patient preference?
3. How do patients make choices when there are different contexts?
4. What does the patient experience in the choice-making process?
5. What are the experiential factors in the choice-making process that influence choice satisfaction?
Table 2. A summary of literature review and the linkage of research gaps to the empirical questions and each article

<table>
<thead>
<tr>
<th>Subjects</th>
<th>Existing theory and research</th>
<th>Gaps</th>
<th>Research questions</th>
<th>Linkage with each article</th>
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<tr>
<td>Contextualizing and characterizing patient choice</td>
<td>The DSO classification of a medical context seems relevant for patient choice. It provides a possible solution for how choices could be contextualized and characterized.</td>
<td>Contextualizing patient choice is rather under-researched. It lacks empirical evidence of how the DSO logic can be applied in patient choice contextualization and how it is useful.</td>
<td><strong>RQ1:</strong> What are the characteristics of patient choice when considering different contexts?</td>
<td><strong>Article 4</strong> applies the DSO model to define the choice contexts and tests the effectiveness of the DSO logic in contextualizing patient choice.</td>
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<td>Models of studying individual choice</td>
<td>(1) The rational choice model helps to quantitatively predict or interpret patient preference. (2) Descriptive models help to understand what people do and characterize the real choice-making process and human cognition. (3) The synthetic model provides an integrative perspective with which to study choice and is concerned with the choice context.</td>
<td>Both the rational choice theory and bounded rational choice theory are criticized for their overestimation of an individual’s economic and psychological factors and for ignoring the effect of contextual factors. The synthetic model pays special attention to the choice context, but it lacks a systematic view to operate contextual factors.</td>
<td><strong>RQ2:</strong> What are the factors, especially contextual factors, influencing patient preference? <strong>RQ3:</strong> How do patients make choices when there are different contexts?</td>
<td><strong>Article 1</strong> studies patient preference and quantitatively examines the factors (including individual factors and contextual factors) that influence patient choices. <strong>Article 2</strong> qualitatively investigates patient choice-making process and explores patients’ thoughts and reasoning. <strong>Article 4</strong> responds to the calls for a context-aware choice study, contextualizing patient choice and investigating and comparing patient choice-making processes in different contexts.</td>
</tr>
<tr>
<td>Patient choice and choice-making evaluation</td>
<td>(1) The current analysis on patient choice and choice-making focuses on two themes: patient preference and the factors that influence patient preference. (2) Informed choice is</td>
<td>Patients’ choice-making experiences have been granted insufficient attention. Most of the current measurements of patient choice-making process?</td>
<td><strong>RQ4:</strong> What does the patient experience in the choice-making process?</td>
<td><strong>Article 3</strong> investigates choice satisfaction from the patient’s perspective, studies the patient choice-making experience, and develops the measurement of</td>
</tr>
<tr>
<td>Patient choice and choice-making management</td>
<td>(1) There are three models used to manage patient choice and choice-making, including paternalism, informed choice, and shared decision-making (SDM). (2) The concept of choice architecture suggests that changes in the decision environment can affect individual decision making and behavior and implicitly alter people’s behavior in a predictable way while preserving freedom of choice. (3) Many patient choice aids have been developed to assist patients in making informed and preference-sensitive choices.</td>
<td>There is no generally accepted guidance regarding how to implement SDM. Cross-context transferring of PtDAs is problematic, and the validity of PtDAs without context-based evaluation is questionable. There is little empirical work that develops or applies choice architectures with context awareness.</td>
<td>The five questions provide empirical evidences for developing the context-based choice architecture and designing the appropriate choice aids.</td>
<td>All four articles provide empirical evidence regarding how to develop and apply choice architectures and choice aids in health care. In particular, Article 4 proposes context-based choice architectures for managing and developing patient choice and suggests that the application of PtDAs should be context-based.</td>
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3. Methodology

3.1 Research approach

3.1.1 Pragmatism

The philosophical fundament of this dissertation is pragmatism, the belief in the possibility of embracing the positivist, realist, and interpretivist perspectives in one study and that the adoption of a philosophical positions relies on the research questions and real practice (Johnson and Onwuegbuzie, 2004; Saunders et al., 2011). The integration of different epistemologies in one study increases the possibility of solving complex problems and helps advance knowledge from different paradigms (Johnson and Onwuegbuzie, 2004). This dissertation applies three analytic models of patient choice and holds multiple views with which to collect and interpret data. The ontological stance of the current study related to patient choice is that choice is a real thing that happens in a certain context, made by humans with bounded rationality, and is affected by the information available, mental capabilities, psychological traits, emotional status, and social and cultural background. Epistemologically, choice can be measured and modeled, the choice-making process is explorable, elicitable, and understandable, and the choice's contexts can be observed, mapped, and categorized.

3.1.2 Case study

A case study is commonly understood as a research approach or an empirical inquiry that can be employed for answering explanatory (why), exploratory (how), and descriptive (what) questions related to a contemporary phenomenon within a real-life context (Eisenhardt, 1989; Saunders et al., 2007; Yin, 1981; Yin, 2013). It plays a useful role in building and testing theories (Eisenhardt, 1989; Yin, 1981). It helps the researcher gain a deep view on events and occurrences, obtain concrete experiences, and deeply understand the complexity of the phenomena, especially when the researcher has little or no control over the events and when the boundaries between the phenomenon and context are blurred (McDermott, 1999; Saunders et al., 2007; Woodside and Wilson, 2003). In a case study, the contextually specific nature of the phenomenon is the focus, and context is the important part being investigated (Yin, 1981; Yin, 2003). Multiple methods, i.e., qualitative, quantitative, and mixed methods, are involved in designing case studies (Eisenhardt, 1989). There are two types of case studies:
a single case study and multiple cases study. A single case study makes an in-depth investigation of a particular phenomenon or tests theories while multiple cases study enables a comparison and produces generalizable conclusions (Aaboen et al., 2012; Darke et al., 1998; Yin, 2009).

A single case study is suitable for the current research. First, it can fulfill the research purposes, which include (1) to deepen the understanding of patient preference and choice, (2) to explore the patient choice-making process, (3) to investigate patient experience when making choices, and (4) to test a framework of contextualizing patient choice. Second, according to Flyvbjerg (2006), case studies investigate real-life and human situations, helping to understand human behavior that is not easily found in theories. Behavior in real situations is exactly what this research is aiming for. Third, in this research, the context is relevant for patients who are making choices, and the context should be defined and investigated to produce valid knowledge, so an in-depth single case study interested in context-dependent phenomenon and building context-dependent knowledge is applicable (Yin, 1981; Yin, 2003). Fourth, case studies are appropriate when the current perspectives fall short of the empirical substantiation (Eisenhardt, 1989), as is the case with patient choice contextualization and choice architecture construction. Fifth, the current research makes contributions to a nearly untouched research topic, patient choice contextualization, and a single case study is appropriate because it is particularly useful in the preliminary stage of understanding the phenomenon and providing an initial experience (Flyvbjerg, 2006). In the current study, no control is put over the event, and the nature of the factors influencing patient choice and choice-making within a certain context will be investigated.

### 3.1.3 Mixed methods study

Pragmatism is the “philosophical partner for mixed methods research” (Johnson and Onwuegbuzie, 2004). In recent years, the mixed methods approach using qualitative data and quantitative data in one study has been used a lot in health care area, particularly combined with a case study (Greenhalgh et al., 2010; Mazzocato et al., 2015; O’Cathain et al., 2007; Oertle and Bal, 2010; Powell et al., 2013). While qualitative research provides an opportunity for researchers to access the complex reality, deeply explore the nature and dynamics of the phenomenon, and understand a social and cultural structure, quantitative research produces objective and generalizable viewpoints by giving concrete numbers (Eisenhardt and Graebner, 2007; Gummesson, 2000; Saunders et al., 2011). The mixed methods approach leads to a more valid and rigorous understanding of the studied phenomenon than either research approach alone (Östlund et al., 2011). It is particularly useful in health care research that requires a broader range of perspectives to view the complex phenomena (Steckler et al., 1992; Foss and Ellefsen, 2002; Clarke and Yaros, 1988).

In this study, two different mixed methods designs are applied. One is the concurrent triangulation design (Creswell and Clark, 2010) in which quantitative
and qualitative studies are conducted simultaneously, and the results are brought together to draw conclusions with. It leads to rigorous arguments by comparing and integrating the results. The other is the sequential exploratory design (Hanson et al., 2005) in which qualitative data are collected and analyzed first, and the design of the quantitative study is based on the results of the qualitative study. It is particularly useful when exploring the underlying constructs of the focal phenomenon and developing new measurements.

### 3.2 Empirical setting

The empirical case of this dissertation is prenatal screening and testing within the public maternal service system implemented in the District of Helsinki and Uusimaa (HUS) in Finland, where all the tests are offered free of charge. Prenatal screening and testing, which helps to detect fetal aneuploidy, an abnormal number of chromosomes such as with Down syndrome, Trisomy 13, and Trisomy 18, involves initial screening and further testing. Because caregivers are usually assigned by the system in Finland, choice of care is more relevant and worth studying.

The initial screening, i.e., population-based prenatal screening, aims to identify a subgroup with increased risk for Down syndrome and other common chromosomal anomalies (Carroll et al., 2013; García et al., 2008; Lou et al., 2015; Santalahti et al., 1998). It provides women and families with a risk figure that estimates the possibility of having a baby with chromosomal abnormalities and allows them to make decisions and preparations timely (Lou et al., 2015; Schoonen et al., 2011; Sutherland et al., 2014). In Finland, prenatal screening is regulated by law and offered to all pregnant women who give informed consent. The Finnish community-based maternity care units (Neuvola), a public-sector activity led by general practitioners providing free maternal care service to all pregnant women, is responsible for informing pregnant women of the prenatal screening program and helps to arrange the tests. All women are registered in Neuvola after confirmation of pregnancy. For screening, women can choose first trimester combined screening (FTS) at 9–13+6 weeks of pregnancy or a second trimester maternal serum screening (STS) carried out at 15–16+6 weeks of pregnancy. The FTS considers the mother’s age, result of the fetal anatomy and nuchal translucency measurement by ultrasound, and the results from maternal serum biomarkers (free β-human chorionic gonadotropin (β-hCG), pregnancy-associated plasma protein-A (PAPP-A)). STS is based on maternal serum biomarkers (β-hCG, alpha fetoprotein (AFP)) adjusted for the gestational age and do not involve ultrasound.

After the initial screening, the screen-positive women with an elevated risk of fetal aneuploidy are offered further testing to diagnose or confirm aneuploidy (Engels et al., 2014; Schoonen et al., 2012). Screen-positive women living in the HUS area are informed of the abnormal screening results by phone and are invited to the pre-test screening at the Fetomaternal Medical Center (FMC) of
Helsinki University Hospital, which serves as a tertiary center for fetal medicine and organizes prenatal testing. Started in 2015, the FMC provides non-invasive prenatal testing (NIPT) and invasive fetal diagnostics (amniocentesis and chorionic villus sampling (CVS) ) for women with a high risk of fetal aneuploidy either a priori (maternal age>40 years and first trimester combined screening not performed for any reason and those with a common aneuploidy in the previous pregnancy), an abnormal result in the first trimester combined screening (risk for 21-trisomy $\geq 1:250$, fetal nuchal translucency 3–3.9 mm), or an abnormal second trimester screening. Invasive procedures, amniocentesis, and CVS involve probes or needles being inserted into the uterus, use fetal tissue to provide an accurate diagnosis, and carry a miscarriage risk. NIPT, based on next-generation sequencing of cell-free fetal DNA in maternal plasma, uses maternal blood samples to assess the most common fetal aneuploidies and has little miscarriage risk (Silcock et al., 2014). NIPT has false positive rates, which are very small but require confirmation using invasive procedures (Allahbadia et al., 2015). The timing of the tests is different. NIPT is feasible for women with gestational age $\geq 10^{+0}$ weeks, CVS is only feasible during pregnancy weeks $10^{+0} – 14^{+6}$, and amniocentesis is feasible if the gestational age exceeds 15 weeks. A crucial service availability issue during the period of the present study was that the NIPT sample drawing service (blood test) was only offered on Mondays and Tuesdays while invasive tests and counseling services were available all business days. This means that if the woman had the counseling on Wednesday, Thursday or Friday and chose NIPT, she had to come back for the blood test the following Monday or Tuesday. On average, it took two weeks to get the NIPT result while the results of invasive tests were available within one week. Blood samples for NIPT (The Harmony Prenatal Test by Ariosa Diagnostics) were sent abroad (the United States) for analysis.

Advances in genomic technology increase the screening and testing options (Skirton et al., 2014), and each test technique has its own strengths and weaknesses. There is no best option, and the women have to make choices (de Jong et al., 2013). The women face a series of choice points in the prenatal screening and testing program. Personal, social, cultural, and religious issues are as important as the biomedical issues involved in this situation (Ahmed et al., 2013a). It is commonly agreed on that the choice for prenatal screening and testing must be voluntary, well-informed, and congruent with the women’s values and preferences (Portocarrero et al., 2015). Supporting the women’s informed and autonomous choice in prenatal screening and testing is an inevitable part of a good maternal care (Skirton et al., 2014). Designing and developing women-centered choice aids in prenatal screening and testing requires studies on women’s choice and choice-making (Portocarrero et al., 2015; Farrell et al., 2014). Thus, prenatal screening and testing is an appropriate empirical context for a study with the theme of patient choice and choice-making.

The case of prenatal screening and testing in HUS is a near-perfect setting, almost like a laboratory where a lot of ordinary variability is not present. First, the
service providers, Neuvola (Finnish community-based maternity care unit), screening units in the delivery hospitals, and Fetomaternal Medical Center (FMC), are respected institutions, where almost anyone can go without selection bias. Second, all the services are free, so there is no problem with economic access. Third, this is a clearly formatted medical situation, and pregnant women face a narrow set of choices. The ethical approval and research permission were granted by HUS.

3.3 Data collection and analysis

Data were collected from multiple sources. First, relevant professionals (gynecologists, obstetrics, primatologists, geneticists, midwives, and public health nurses of Neuvola) were interviewed and consulted. They provided information about the medical, procedural, and practical issues of prenatal screening and testing implemented in HUS, e.g., how the service is organized. Second-hand materials, primarily from Neuvola and HUS, were read and analyzed. It helped with drawing the flowchart of screening and testing services, outlining the service context, and mapping the choice points women may face. A snowballing strategy was used to find the informants and enrich the second-hand data. The choices in the episode were contextualized by using DSO logic.

Second, the FMC test choice database (between January 1, 2015 and December 31, 2015) containing data about women who participated in further testing was used. It included information about women’s choices on further prenatal tests, medical indications and corresponding risk scores, maternal age, gestational age at the counseling session, and the counseling date. Using this database, the significant factors that influenced the women’s choices among testing methods were identified. A chi-square test, ANOVA test, and multinomial logistic regressions were employed to analyze the data. Statistical analysis was performed in STATA 13. A p-value of <0.05 shows statistical significance.

Third, the details of the women’s choice-making in prenatal screening and testing were inquired about through semi-structured interviews. Midwives at the FMC helped to recruit the most interviewees, i.e., the women who went through initial screening and participated in further testing because of the revealed high risk. Two of the women participating in the initial screening were recruited by midwives at screening units when the ultrasound scan for pregnancy was provided. All the informants voluntarily participating in the interviews were informed of the research and signed the written informed consent. The interview lasted six months, from December 2015 to May 2016, and 28 women were interviewed. Semi-structured interviews had open-ended questions to inquire how the women made choices in prenatal screening and testing, the reasons behind the choices, and women’s experiences in the choice-making process. Storytelling or narrative inquiry as a way of making sense of an experience (Mishler, 1986) produced remarkable contributions when delving into the
women’s “lifeworld” (Bury, 2001; Gill et al., 2010; Pottie et al., 2008). The inquired modes of experience were quite broad, including individual’s feeling, seeing, hearing, thinking, reflecting, expecting, imaging, acting, and all other kinds of emotional, mental, and physical activities. The concrete questions were developed from the theory of planned behavior (TPB) (Godin and Kok, 1996; Ajzen, 1991), which helps to explore the choice-making process and identify the factors influencing women’s choice using three main constructs: behavioral beliefs, subjective norms, and perceived behavioral control. Most of the interviews were conducted in Finnish, and two were conducted in English. Interviews were tape recorded, transcribed, translated into English, and imported into the Atlas.ti qualitative data analysis software. Two researchers (including the author of this dissertation) first independently read the transcriptions, coded the interview data, and identified the items that can delineate the women’s choice-making processes, experiences, and the influential factors. Then, the researchers discussed, reached an agreement on the coding, and categorized the codes into themes.

Fourth, a cross-sectional self-completion survey on a retrospective basis was carried out, asking the women to recall their experiences of making prenatal screening and testing choices. The main purpose of the survey was to evaluate the women’s choice-making experiences. The design of the measures was based on the results of the qualitative study, group discussions, and some validated measures, including the Decisional Conflict Scale (O’Connor, 2014; O’Connor, 1995) and six-item short-form of the state scale of the Spielberger State-Trait Anxiety Inventory (Marteau and Bekker, 1992). A factor analysis (DeVellis, 2016) helped to further determine the number of latent variables behind a set of measurement items and refined the inclusion of items for each latent variable of choice-making experiences. Most items were made in a statement format with a 5-point Likert scale ranging from “strongly disagree” to “strongly agree.” Questions were made in English and then translated into Finnish and Swedish. A translation service agency, researchers on the project team, and medical professionals worked together on the translation and back-translation. Midwives in the screening units and FMC helped to hand out the anonymous questionnaires. The survey lasted 10 months, from June 2016 to March 2017. There were 940 questionnaires distributed, and 185 were returned by March 2017, with an overall response rate of 19.7%. A regression analysis was employed to identify the significant experiential factors in the choice-making process that influence choice satisfaction. A p-value of <0.05 shows statistical significance.

3.4 Summary of the methods for each article

Article 1 examines the women’s preferences in further testing and investigates the influential factors of the choices. It uses the data in the FMC test choice database and focuses on the women with a gestational age of less than 15 weeks. A chi-square test, ANOVA test, and multinomial logistic regressions are adopted to explore the significant factors affecting women’s choice.
Article 2 furthers the investigation of women’s preferences and choices by utilizing a mixed methods study. It focuses on the group of women with a high risk detected in the first or second trimester serum screening. For the quantitative study, it uses the data in the FMC test choice database and employs chi-square tests, ANOVA, and multinomial logistic regressions to disclose the significant factors influencing the women’s choice. Meanwhile, for the qualitative study, it uses the semi-structured interview data, focusing on the women’s choice-making in prenatal testing and exploring the underlying values, beliefs, attitudes, and other psychosocial factors that affect the women’s choice.

Article 3 is a mixed methods research and focuses on the women’s choice-making in prenatal screening. First, it uses semi-structured interviews to deeply explore the women’s choice-making experiences in prenatal screening. Second, it analyzes the survey data to quantitatively assesses the women’s experiences in the choice-making process and identify the influencing factors of choice satisfaction. A multiple linear regression analysis is used to find the influential factors of choice satisfaction.

Article 4 studies choice contexts in prenatal screening and testing and investigates the women’s choice-making in the presence of different contexts. It first uses the information provided by the professionals and the second-hand documents to draw a flowchart of the screening and testing services, depict the choice points women may face, and segment the service contexts by applying the DSO framework. Then, it analyzes the interview data about the women’s choice-making in prenatal screening and testing and compares the women’s choice-making processes and experiences among different choice contexts.
Table 3. Summary of the research methods in the four articles.

<table>
<thead>
<tr>
<th></th>
<th><strong>Article 1</strong></th>
<th><strong>Article 2</strong></th>
<th><strong>Article 3</strong></th>
<th><strong>Article 4</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Title</strong></td>
<td>Women’s choices for invasive or non-invasive testing: influence of gestational age and service delivery</td>
<td>Considering medical risk information and communicating values: A mixed-method study of women’s choice in prenatal testing</td>
<td>Facilitating autonomous, confident and satisfying choices: A mixed-method study of women’s choice-making in prenatal screening for common aneuploidies</td>
<td>Context-based patient choice management in healthcare</td>
</tr>
<tr>
<td><strong>Objectives</strong></td>
<td>To examine the women’s preferences regarding further testing and investigate the influential factors</td>
<td>To explore women’s choice-making processes in prenatal testing and investigate women’s preferences and their influential factors.</td>
<td>To understand women’s experiences when they make choices for screening tests, operationalize the choice-making experience, and identify the factors influencing choice satisfaction.</td>
<td>To apply DSO logic in segmenting choice contexts in prenatal screening and testing and investigate women’s choice-making at different contexts</td>
</tr>
<tr>
<td><strong>Philosophical position</strong></td>
<td>Positivism</td>
<td>Positivism, realism, interpretivism</td>
<td>Interpretivism, positivism, realism</td>
<td>Realism, interpretivism</td>
</tr>
<tr>
<td><strong>Research design</strong></td>
<td>Case study</td>
<td>Mixed methods case study with a concurrent triangulation design</td>
<td>Mixed methods case study with a sequential exploratory design</td>
<td>Mixed methods case study with a sequential exploratory design</td>
</tr>
<tr>
<td><strong>Main data source</strong></td>
<td>Test choice database at FMC</td>
<td>Test choice database at FMC; semi-structured interview data</td>
<td>Semi-structured interview data; survey data</td>
<td>Information provided by professionals; second-hand data; semi-structured interview data</td>
</tr>
<tr>
<td><strong>Study cohort</strong></td>
<td>Women with a gestational age of less than 15 weeks and offered further testing</td>
<td>Women with a high risk detected by the first or the second trimester serum screening, who were eligible for prenatal testing</td>
<td>Women participating in prenatal screening</td>
<td>Women who went through initial screening and participating in further testing</td>
</tr>
<tr>
<td><strong>Analysis methods</strong></td>
<td>Chi-square test; ANOVA test; multinomial logistic regressions</td>
<td>Chi-square test; ANOVA test; multinomial logistic regressions; thematic analysis</td>
<td>Thematic analysis; t-test; factor analysis; multiple linear regression</td>
<td>Content analysis; thematic analysis</td>
</tr>
</tbody>
</table>
4. Key findings

This chapter integrates the key findings of the four articles. Each article answers some part of the research questions. The findings are organized into the following three subsections:

1. Contextualizing women’s choice in prenatal screening and testing
2. Women’s choice and choice-making in prenatal testing
3. Women’s choice and choice-making in prenatal screening

The first subsection links to the research question “What are the characteristics of patient choice when considering different contexts?” It presents a context approach in characterizing patient choice. The second and third subsections provide answers to the research questions “What are the factors, especially contextual factors, influencing patient preference,” “How do patients make choices,” and “What does the patient experience in the choice-making process?” within certain contexts. Research question “What are the experiential factors in choice-making that influence choice satisfaction?” is covered in the third section.

4.1 Contextualizing women’s choice in prenatal screening

Article 4 outlines the choice points faced by the participants in prenatal screening and testing and applies the DSO framework to contextualize the choice points. It shows that four choice contexts, including Prevention, Cure, Electives, and Care, were present in prenatal screening and testing. Figure 2 visualizes the choice flow and the identified choice contexts. Table 4 summarizes the choice points involved in prenatal screening and testing, the corresponding contexts that were classified by the DSO framework, the possible choice characteristics at each context, and the possible approaches to managing the choices.

The process starts when the woman must decide if she goes to participate in prenatal screening, i.e., choice (0) to screen or not to screen. Deciding to take screening, she must choose the screening methods, i.e., choice (1), to take the first trimester combined screening or the second trimester serum screening. These two choice points are typical for the Prevention mode, where the situation is not urgent, and there is a calculable aneuploidy risk that has not been indi-
vidually revealed. In this context, the medical demand is to get to know the fetus’s risk profile of aneuploidy, and the supply is to screen out the high-risk group and provide information. To screen or not to screen depends on the woman’s values on pregnancy and childbirth, as well as the motivation to get information about the fetus's aneuploidy risk profile. The distinctive features of the screening tests, timing, and reliability may be the woman’s main considerations. Because the aneuploidy risk has not been revealed and the two methods are quite safe, the woman may not spend much time making the choice. For this Prevention context, a woman’s values on pregnancy and childbirth and her motivations to take screening should be clarified; different screening options should be presented with information about the timing and reliability; and because first trimester combined screening has a higher reliability and provides more information earlier, it could be presented as a default choice.

If the initial screening reveals an elevated risk for aneuploidy, the woman will face the decision about whether to participate in further testing, i.e., choice point (2): to take further tests or decline further tests. If she wants to take the screening, she may face choice point (3), which is what test methods to choose: NIPT, amniocentesis, or CVS. If the woman chooses NIPT and the results show normality, no further confirmation is needed. An abnormal result in NIPT needs to be confirmed by amniocentesis. In this case, the woman faces choice point (4): to take amniocentesis or decline it. If amniocentesis or CVS reveal an abnormality, the pregnant woman faces a choice between continuing the pregnancy and terminating it, i.e., choice point (5). Choice points (2), (3), (4), and (5) can be grouped into the Cure context, where an elevated individual risk has been revealed and path-dependent tests with an expected end (pregnancy termination or continuation) are involved. The medical demand in this context is to obtain further or confirmative information about the high-risk fetus regarding aneuploidy, and the woman is offered further tests and a diagnosis. Taking the further testing or not depends on the woman’s motivation to obtain further diagnostic information regarding fetus aneuploidy. The testing methods are different regarding their accuracy, safety, timing, service availability, and rapidness, and these may influence the woman’s choices. Because the aneuploidy or its risk has now been revealed, life may radically change due to the decisions made in this situation. The woman may think about medical, social, and even ethical issues, make trade-offs in the state of high anxiety and uncertainty, and spend much time searching for not only medical, but also social and experiential information. For this Cure context, the path-dependent choices should be presented in sequences and with the information of features; access to social information should be provided; the woman should be allowed to express her values, specifically the values of raising an abnormal baby; and counseling services or social support should be made available.

If termination is chosen, the woman faces the choices of different termination methods: abortifacient pharmaceuticals or surgical method, i.e., choice point (6). This is related to the Elective mode, where core treatments are usually
standardized with a clear start to the end sequence, and procedures have expected outcomes. In this context, the medical demand is to end the pregnancy based on a precise diagnosis, and the supply is the procedure to end the pregnancy. The relevant information for making a choice may include access, risks, complications, and so forth. The woman may have a high emotional appeal in this context. For this choice context, besides the relevant information of options, emotional support should be made available.

If the decision is to continue the pregnancy, the woman will face choices related to living with a chromosomally abnormal child, i.e., choice point (7) or set of choices. This is akin to the Care mode, where there is no cure that has been known for the genetic disorder, and the end point is not clear. The main demand is to manage the condition and arrest decline, and the supply is to provide a care process that involves issues related to the whole life. The woman and her family may spend much time searching for medical, social, and experiential information about caring for babies with chromosomal abnormalities. In this choice context, the choices should be presented by considering the life-world: diet, activity, support devices, social groups, and so on. Access to social support should be made available.
Figure 2. Choice contextualization in prenatal screening and testing by DSO logic (Article 4)
Table 4. Contextualizing women’s choices in prenatal screening and testing by DSO framework (Article 4)

<table>
<thead>
<tr>
<th>Choice points</th>
<th>Context: demand and supply</th>
<th>DSO mode</th>
<th>Possible choice characteristics</th>
<th>Choice management</th>
</tr>
</thead>
</table>
| Choice point (0): take screening or decline screening | *Non-urgent situations when there is population risk of aneuploidy, but the risk is not individually revealed* | Prevention | • Decision depends on personal values and motivation.  
• Timing and reliability may be the two main considerations.  
• Without revealing the individual risk, people may not spend much time thinking and comparing. | Personal values and motivations should be clarified.  
Information about the timing and reliability should be highlighted.  
Recommendation or default choice may be a suitable choice aid. |
| Choice point (1) screening programs: the first trimester combined screening or the second trimester serum screening | Demand: to get to know the fetus’s risk profile of aneuploidy  
Supply: to screen out the high-risk group; risk estimation | Prevention | | |
| Choice point (2): take further tests or decline further tests | *With an elevated individual risk, requiring path-dependent tests and an expected end point* | Cure | • Decisions and choices are path-dependent.  
• Test options are different in terms of accuracy, safety, timing, service availability, and rapidness, which may influence the choices.  
• As the higher risk is revealed, people may think a lot, not only about medical issues, but also about social and ethical factors, make trade-offs in high anxiety and uncertainty, and spend some time searching for | People should be allowed to express its values.  
Path-dependent choices are presented in sequences and with a benefits and costs constellation.  
Access to social and experiential information should be provided.  
Individual counseling may be necessary. |
<p>| Choice point (3) test methods: NIPT, amniocentesis or CVS | Demand: to get further or diagnostic information about the high-risk fetus regarding aneuploidy and prepare for the further step; anxiety reduction | Cure | | |</p>
<table>
<thead>
<tr>
<th>Choice point</th>
<th>Supply: to provide further information or diagnosis</th>
<th>Demand: to manage the chronical condition and arrest decline.</th>
<th>Supply: to perform the procedure with the expected outcomes</th>
<th>Electives</th>
<th>Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>(4) if NIPT informing abnormality: take amniocentesis or decline it</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(5): pregnancy termination or continuation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(6) termination methods: surgical method or abortifacient pharmaceuticals</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(7): special care for childbirth and after birth</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**With a clear start to end sequence**

**Without clear and desirable end points**

<table>
<thead>
<tr>
<th>Electives</th>
<th>Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Choice is between alternative methods based on performance indicators such as complications, infection rate, access, and so on.</td>
<td></td>
</tr>
<tr>
<td>• Emotional appeal is probably very high in this context.</td>
<td></td>
</tr>
<tr>
<td>• Choices are made for issues related to the life-world.</td>
<td></td>
</tr>
<tr>
<td>• People may spend much time searching for not only medical, but also social and experiential information for the specific life situation.</td>
<td></td>
</tr>
</tbody>
</table>

*Choices are presented with performance indicators such as complications and access.*

*Emotional support should be made available.*

*Choices are presented by considering the life-world: diet, activity, support devices, social groups, and so on.*


4.2 Women’s choice and choice-making in prenatal testing (Cure context)

Article 1 and Article 2 focus on women’s preferences for further testing and study the factors influencing their post-counseling choices between NIPT and invasive tests. The study found that the important issues for the women’s choice included (1) women’s values (keeping the baby and safely obtaining information for preparation, sequential choice from the mild to the strong, uncertainty avoidance, and avoiding having a sick baby); (2) personal situation (gestational age); (3) the features of the test methods (safety, accuracy, and performance time); (4) contextual factors (service schedule). The issues that were insignificant for the women’s choice in this study included (1) medical factors (maternal age, trimesters of screening, medical indications for further testing, and risk scores) and (2) social influence (what other people do in the same situation).

Article 2 and Article 4 provide answers to how the women made choices in prenatal testing and their experiences in choice-making. Six issues outlined women’s choice-making processes, including choice activeness, preferences or considerations, information needs and sources, social influence, emotion status, and choice-making difficulty. Experiencing active choices were important for women in prenatal testing, and most of the participants reported that they did actively choose the tests. The main issues considered by the women for choosing tests were safety, accuracy, test time, service schedule, rapidness, easiness, and comfort. The women had their own understanding and acceptable levels about these attributes, taking their personal situations into account. When choosing further testing methods, the women needed face-to-face individual counseling from medical staff, and some of them sought extensive information from other sources. The women tended to keep the choices in prenatal testing to themselves. In such risk-involved situations, the women rarely shared their experiences with other people (except partners) or followed what other people did in similar situations. A husband or partner was the main person involved as a supportive role in the women’s choice-making process but did not make the final decision. Many women reported that it was difficult to make a quick decision in prenatal testing, and they had to think a lot about their choices. When choosing further tests, women suffered from negative feelings. Coping with negative emotions was a common activity in this context.

4.3 Women’s choice and choice-making in prenatal screening (Prevention context)

Most participants chose the first trimester combined screening because it seemed to be better than the second trimester serum screening. The common reason for women to participate in the second trimester serum screening was that they missed the FTS. Article 3 and Article 4 demonstrate how women made choices in prenatal screening and their experiences in choice-making. Six issues, including choice activeness, preferences or considerations, information needs
and sources, social influence, emotion status and choice-making difficulty were still valid to represent the women’s choice-making in prenatal screening.

Most participants thought consent for health care services was important, but active choice seemed not as important for them when making the choice for prenatal screening tests that were often regarded as routine. The women knew that there was little risk involved in the process. The public health nurse’s recommendation was considered valid and appreciated. Most of the women reported that they did not actively choose the screening tests. Easiness, reliability and accuracy, service schedule, and rapidness were the features of the screening tests most of the women were concerned about. The women preferred what was recommended by professionals. The maternity care unit’s leaflet and public health nurse were the two main information sources. Few women sought more information online. Most women followed the arrangement suggested by maternity care units without much doubt or discussing seriously with other people. The women found it was easy to follow the recommendation given by maternity care units or to do as other women did. But they did not feel much social pressure from others. Generally, the women felt it was not difficult to make a choice in prenatal screening, and their emotional status was quite neutral.

Table 5. Terminology of women’s main preferences or considerations when making choices in prenatal screening and testing.

<table>
<thead>
<tr>
<th>Term</th>
<th>Meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Safety</td>
<td>The issues related to miscarriage risk, complications, or harm from the testing</td>
</tr>
<tr>
<td>Reliability and accuracy</td>
<td>Test scope and the certainty and reliability of the test results</td>
</tr>
<tr>
<td>Test performance time</td>
<td>The time when the test can be technically performed</td>
</tr>
<tr>
<td>Service schedule</td>
<td>The schedule when the test service is arranged by providers</td>
</tr>
<tr>
<td>Rapidness</td>
<td>To get the test and results quickly</td>
</tr>
<tr>
<td>Easiness</td>
<td>Simplicity of the test procedure</td>
</tr>
</tbody>
</table>

Article 3 examines the experiential factors influencing choice satisfaction in prenatal screening. Seven variables were derived from the six issues of women’s choice-making to measure the women’s experiences when making choices for screening tests, including activeness, informedness, confidence, social pressure, difficulty, positive emotion, and negative emotion. Table 6 presents the details of the measurements for choice-making experiences and choice satisfaction. Controlling for the demographic factors, the regression results revealed that activeness in choice-making ($\beta=0.176; \ p=0.023$), confidence in choice-making ($\beta=0.388; \ p<0.001$), perceived social pressure ($\beta= -0.306; \ p<0.001$), and perceived difficulty ($\beta= -0.274; \ p<0.001$) significantly influenced women’s choice
satisfaction in prenatal screening. Activeness in choice-making increased choice satisfaction. Choice satisfaction increased if the women had more confidence when making choices. Perceived social pressure and difficulty in choice-making were negatively affected by choice satisfaction.
Table 6. Measurements of women’s experiences in choice-making (Article 3).

<table>
<thead>
<tr>
<th>Variables</th>
<th>What to measure</th>
<th>Measurement design evidence</th>
<th>Items (statements with 5-point Likert scale )</th>
</tr>
</thead>
</table>
| Activeness      | The extent to which women made an active choice                                | Qualitative study results; Group discussion; factor analysis                                  | • I read all relevant information about the different options.  
• I sought for relevant information from different sources.  
• I actively consulted and discussed with significant ones about the options.  
• I spend much time in comparing different options and thinking about possible outcomes. |
| Informedness    | From the women’s perspective, how much they know about the screening options   | Informed subscale of Decisional Conflict Scale designed by O’Connor; Qualitative study results; Group discussion; factor analysis | • I knew that there were different screening programs offered to Finnish pregnant women.  
• I knew the mechanisms and theories of different programs.  
• I knew the procedures of different programs.  
• I knew features (e.g. timing, accuracy and risk) of different programs.  
• I knew the advantages and disadvantages of different programs.  
• I knew the possible results produced by different programs.  
• I knew nothing about the different programs. |
| Confidence      | From the women’s perspective, whether their preferences are clear, whether the choice is consistent with their preferences, and whether they got enough support from others when making choices | Some items of Informed subscale and Effective Decision subscale of Decisional Conflict Scale designed by O’Connor; Support subscale Decisional Conflict Scale designed by O’Connor; Group discussion; factor analysis | • I felt clear about which benefits matter most to me.  
• I felt clear about which risks and side effects matter most to me.  
• My choice showed what was important to me.  
• I had enough support from others to make the decision and choice.  
• I had enough advice to make the decision and choice. |
| Social pressure | To assess the extent of social pressure perceived by women in choice-making     | Support subscale Decisional Conflict Scale designed by O’Connor; Qualitative study results; Group discussion; factor analysis | • I was deciding and choosing without pressure from others.  
• Someone else (e.g. baby’s father, family members, medical staff, etc.) made the choices for me. |
| Difficulty | From the women's perspective, whether it is difficult to make choices for screening | Qualitative study results; Group discussion; factor analysis | • It was difficult to make decisions and choices for the screening program.  
• I made many efforts to think about the issues and make the choice for the screening program.  
• I spent much time in thinking about the issues and making the choice for the screening program. |
|---|---|---|---|
| Negative emotion | To measure the women's anxiety level when making choices for screening | Qualitative study results; Group discussion; Six-item short-form of the state scale of the Spielberger State-Trait Anxiety Inventory; factor analysis | • I felt something awful was about to happen.  
• I kept thinking about the possible bad consequences or results.  
• I felt I could not control the situation.  
• I felt uncertain.  
• I felt panic.  
• I felt restless  
• I was worried  
• I was tense  
• I felt upset |
| Positive emotion | To measure the women's positive emotional level when making choices for screening | Qualitative study results; Group discussion; Six-item short-form of the state scale of the Spielberger State-Trait Anxiety Inventory; factor analysis | • I felt calm  
• I was relaxed  
• I felt content |
| Choice satisfaction | From the women's perspective, whether they felt satisfied with the choices | Some items of Effective Decision subscale of Decisional Conflict Scale designed by O'Connor; Group discussion | • I expected to stick with my choice and decision.  
• I was satisfied with my decision and choice. |
5. Discussion

5.1 Contributions to theories and literatures

5.1.1 Contributions to the literature regarding influential factors of patient choice

The current study is a valuable contribution to the growing amount of literature focusing on patient choice, especially to the discussion on the contextual factors that can impact patient choice. Extending the current studies that primarily use individualistic focus as choice models and that focus on personal factors, this dissertation addresses contextual issues and assess their effects on patient choice. In the case study of women’s choice in prenatal testing (Article 1 and Article 2), the test provider’s service schedule (i.e., the NIPT counseling service was provided from Monday to Friday, but the blood drawing service was only offered on Mondays and Tuesdays at the HUS laboratory; invasive tests and counseling service were available all business days) is included in the choice analysis. The result shows that test service availability on a counseling day affects the women’s choice. This phenomenon that the women prefer the test that could be arranged on the same day as the counseling service for convenience is observed by similar studies, e.g., Silcock et al. (2014). The observation that service convenience or arrangement has a strong effect on patient choice highlights the importance of the service context in health service research.

Previous research on patient choice has focused little on the contextual factors (Lawson and Pierson, 2007). The current study indicates that some contextual factors that seem medically irrelevant, e.g., service schedule and arrangement, should not be ignored when helping patients make medical choices. They are probably even more powerful than medical factors in affecting patients’ choices and decisions. In this case, the women strongly preferred a test that could be performed on the same day as the counseling service; they would rather have a riskier test on the same day of counseling than return for a safer test on a different day because of convenience, the shorter waiting time, and getting results earlier.

It seems intuitive that medical factors, e.g. risk status, affect patient choice for health service Many studies in the field of prenatal screening and testing show consistent results that risk indications and levels are significant factors influencing women’s choices in prenatal testing (Godino et al., 2013; Kenyon, 2014;
Lumley et al., 2006; Nicolaides et al., 2005). However, the current study does not have the same observation. Medical risks are not significantly affecting women’s choice for further testing. One possible reason could be that medical risk information was too abstruse for women to understand. It was reported by some women in the interviews that, even with detailed counseling, medical risks given in a ratio form were very demanding to comprehend for persons with no medical background. One exception is the Nuchal translucency thickness detected by ultrasound. Women considered it when making decisions, probably because the information provided by ultrasound is more visible. The other exception is previous pregnancy with a trisomy, which provided personally experiential information of the risk.

It has been claimed that “patient values guide all clinical decisions” (America, 2001; Munro et al., 2016). The importance of values and values clarification in patient choice has been recognized. However, most studies mix values with preferences and narrowly understand values as the preferences on certain attributes of options (Llewellyn-Thomas and Crump, 2013; Munro et al., 2016). Values clarification techniques are mainly used to sort out what attributes matter to an individual (Witteman et al., 2016a; Witteman et al., 2016b). One observation of the present study is that women’s life values, e.g., keeping the baby and safely obtaining information for preparation, sequential tests from mild to strong, uncertainty avoidance, and avoiding having a sick baby, are the determinants of the women’s choice. These values are not situation-specific preferences or preferences on the particular characteristics of options. This dissertation shows that a narrow understanding on values is problematic. Just focusing on a patient’s preference on options and attributes does not effectively promote an understanding of patient choice. Values should be differentiated from preferences and regarded as a higher level concept, referring the overarching ethical, moral, religious, political, or social principles that transcend situations and guide how an individual lives (Feather, 1992; Llewellyn-Thomas and Crump, 2013). Although personally insistent situation-transcending values and situation-specific preferences on the attributes of the options should not be mixed, they are connected, and the congruence of values and preferences is important for patient choice. For example, in the present case study, the women holding the moral principle of keeping the disabled baby would prefer the safer test. To make the choice, women combine their values with their beliefs of the options (Feldman-Stewart et al., 2012).

5.1.2 Contributions to the literature regarding patient choice-making process

In the current literature of patient choice-making, the choice-making measurement is underdeveloped, lacking solid empirical support, and patient choice-making experience is granted insufficient attention. Experience, as a value driver, receives increased interest among service researchers (Helkkula et al., 2012a). Patient experience is placed in the center of health service outcome measures (Anhang Price et al., 2014; Manary et al., 2013), but not in the field of patient choice and choice-making. This dissertation takes a multi-dimensional view of the concept of experience (Helkkula et al., 2012b; Helkkula, 2011;
Helkkula and Kelleher, 2010), develops an understanding of patient experience in choice-making, and initiates valid measurements for patient choice-making experience.

Article 3 and Article 4 explore the choice-making process and identify six issues that can represent patient experience in the choice-making process, including choice activeness, preferences or considerations, information needs and sources, social influence, emotion status, and choice-making difficulty. Based on these six issues, a set of measurements are developed to quantitatively evaluate patient experience in choice-making. The variables include perceived activeness, informedness, self-confidence, perceived social pressure, perceived difficulty, positive emotion, and negative emotion.

5.1.3 Contributions to the literature regarding patient choice management

Article 4 applies a context approach for developing patient choice architectures. It outlines the choice points faced by women, analyzes the medical demands and supplies at each choice point, and applies the DSO framework for contextualizing the choice points in prenatal screening and testing. The DSO framework is suitable in contextualizing patient choices, exploring choice characteristics contextually, and applying context-based choice aids. It provides a new insight into patient choice management and opens a path to build choice architectures, aiding with contextual awareness.

5.2 Practical implications

5.2.1 Practical implications for choice architects

The four articles provide evidence for constructing possible choice architectures and designing the appropriate choice aids in prenatal screening and testing. With the empirical evidence, a three-step design approach for choice architectures and aid is proposed to solve the main research problem regarding how to manage patient choice.

The design and construction work starts by defining the goals of choice architecture and aid or the value it aims to deliver. Relevant policies and regulations could help define the goals and identify the value. For the screening programs, the general goal has been shifted from promoting taking the tests to promoting informed and preference-consistent choice, particularly when individuals have different values on outcomes (O’connor et al., 2003; Potter et al., 2008; Wennberg and Wennberg, 2003; Wennberg, 2002; Irwig et al., 2006). In this prenatal screening and testing case, the ultimate goal of the possible choice architectures and aids could be to help women make satisfying choices with a good choice-making experience, which is in line with the core of patient choice policy and patient-centered health service.
Second, the choice context should be defined and classified because in different contexts, patients may exercise their choices differently. This study applies the DSO framework to contextualize women’s choice in prenatal screening and testing, indicating that in different contexts, women may have different choice-making in terms of choice activeness, preferences or considerations, information needs and sources, social influence, emotion status, and choice-making difficulty. After the choice contexts are identified, context-based choice architectures, i.e., the basic constructs of a choice platform, can be built.

Third, within each context-based choice architecture, choice aids are designed to provide information and assist patients in choice-making. Patient preferences and considerations provide evidence of what information should be presented. Articles 1, 2, and 4 indicate that safety, accuracy, test performance time, service time, rapidness, and easiness of the test methods are the important pieces of information that women would consider when choosing testing methods. According to Articles 3 and 4, women are more likely to consider easiness, reliability and accuracy, service time, and rapidness when choosing screening tests. The study on patient choice-making process and experience discloses the problems and challenges patients may face when exercising choices, reveals the factors influencing patient satisfaction, and indicates the help patients may need to make choices. This choice-making evidence enables the design of appropriate choice-support techniques. Article 2 and Article 4 indicate that individual face-to-face counseling was necessary for women in the context of prenatal testing to clarify the values related to this life context and alleviate the burdensome and anxious elements of prenatal testing decisions. Article 3 and Article 4 show that for the women making screening choices, recommendations with backup options presented in a leaflet may work. It could prevent women from becoming overburdened with a lot of reading and thinking while still providing women with the chance to think and make choices by themselves.

Traditionally, choice architectures are designed as “widgets” to deal with cognitive limitations and implicitly intervene, aid, or nudge people’s choices and decisions (Nease et al., 2013; Sunstein, 2015; Thaler and Sunstein, 2008). The present study broadens the traditional view and understands choice architecture as a platform, structure, or framework that can manage individual choice and optimize choice-making. Choice aids are the designs within choice architectures, providing information and assisting people in choice-making. This understanding provides the possibility of systematically developing choice architectures and designing choice aids in health care, from the structure development to the inner design.

5.2.2 Practical implications for choice-supported service

Developing an assumed optimal style decision that forces decision makers to adopt normative or systematic modes of reasoning has been regarded as problematic (Cohen, 1995; Michie et al., 2008), betraying the principle of “patient-centered care.” One recommended approach to promote patient choice is to
start with the understanding of the patient’s preferred way of making a choice, examine the bottleneck(s) of the current choice environment, and then develop supportive choice techniques (Michie et al., 1997). The findings of the present study add to the body of knowledge about patient choice-making and provide new insights into how to communicate with patients suffering from unexpected situations and how to assist them in arriving at a satisfying choice.

Creating an active choice environment
The current study indicates that patients appreciate the chance to make active choices and want to be part of the decision-making process, even though sometimes they would ask for professionals’ suggestions and follow the default choice. Therefore, although patients may desire recommendations or default choices, there is a need to create an active choice atmosphere, provide information about the options, allow patients to think about the choices, and prevent paternalistic routinization. This may cause dilemmas and challenges for health professionals in providing information and giving advice (Ahmed et al., 2014; Ahmed et al., 2013b). Therefore, the guidelines and procedures of supporting a patient’s choice-making based on his or her preferences, capability, and willingness of being involved in the decision should be formulated and clarified (Ahmed et al., 2014; Ahmed et al., 2013b).

Clarifying a patient’s values
One of the findings is that personal values, referring to the overarching ethical, moral, religious, political, or social principles that guide how an individual lives (Feather, 1992; Llewellyn-Thomas and Crump, 2013), strongly affect the patient’s medical choices and decisions. When the patient’s values are clear, the choice can be determined straightly, easily, and with less decision burden. This suggests that given a patient’s values and beliefs, health service providers can more effectively assist the patient in the decision-making process. In the present case, the women’s attitudes toward the tested-for condition (baby with a chromosomal abnormality) can predict the testing decisions and behaviors (Bryant et al., 2010). Therefore, the first task of health service providers should be to clarify patients’ values relevant to the choice rather than simply asking about their preferences for different options. Patients should be allowed to express, discuss, and clarify their values. Inquiring about personal values requires an intimate exploration (Eves et al., 2015). Face-to-face individual counseling is a possible approach by which patients are encouraged to articulate their values, prioritize these values, and even reconcile the conflicting ones (Eves et al., 2015). Having a values checklist, presenting a list of values to patients and asking patients to tick and assess the significant values for them, could be a useful method in preparing and conducting a choice-supported counseling service. With the clarified values, eliciting patient’s preferences would become easier.

Presenting medical information
This study indicates that medical information, e.g., the risk figure, is abstruse for lay patients to understand, not to mention making decisions with. Thus, if
the objective is to help women focus more on the medical factors, medical information should be communicated in a more concrete, visualized, comparable, experiential, and understandable way. The way of communication should vary according to patients’ numeracy, health literacy, and cognitive capability.

**Including social support**

The survey of this study reveals that social support helps to build strong confidence and increases a patient’s choice satisfaction. According to the interviews, patients tend to privately cope with the medical issues, e.g., high-risk status, with close ones (for instance, partners) and get decision support from important people in their lives. Therefore, the service provider should build a socially supportive choice environment, allowing their important people to be involved in the choice-making process or allowing patients to seek help and support from others.

**Concerning emotion status**

A patient’s anxiety level may be high in a medical situation, especially when a high risk is revealed and the diagnosis has not been given. Anxiety is exacerbated when waiting for results. Uncertainties and confusion cause fears. Talking with professionals or discussing with close ones helps to alleviate the pressure. Face-to-face individual counseling should be available to allow patients to express their anxious feelings, address their confusion about the medical status, and relieve their stress.

### 5.3 Limitations and prospects for future research

All academic research contains limitations. Concerning the methodology applied, this dissertation relies on single case study that focuses on a particular context. The major limitation of this study is related to its ability to make adequate scientific generalizations. First, the case study was conducted in the Helsinki and Uusimaa district in Finland. The specialty of the health care system, economic development, and culture is presumably reflected in the results. Second, this study was conducted in the field of prenatal screening and testing and investigated women’s behaviors and experiences when choosing screening and testing methods. Patient choice and choice-making in this medical setting have specific characteristics, different from that in other medical situations. However, there is an argument that a case study should be judged based on the naturalistic generalization or analytical generalization, referring to the translation of experiences and tacit knowledge and the possibility for readers to learn, interpret, and judge the results according to their own contexts (Rowley, 2002; Viljakainen, 2015). It differs from statistical generalization, inferring the results from a sample and applying it to a population (Rowley, 2002; Viljakainen, 2015). This study can make the analytical generalization. The core insights gained here can be applied to a similar empirical context, and this empirical experience might be also applicable in other contexts, e.g., cancer screening. Typically, the experience of applying DSO logic for contextualizing patient choice is worth spreading to other medical areas. DSO logic itself can serve as a universal
lens with which to see patient choice and provide some fundamental or general ideas for patient choice management. Of course, to increase the variety of the insights and advance the generalizability of the present study, more cases with different types of medical areas or populations should be added and compared.

Another limitation concerns the FMC test choice database that was used to investigate the factors influencing the women’s choice in prenatal testing. First, the test choice database is limited to a certain amount of medical and service information. Several other factors influencing choices in prenatal testing are likely to be missed, such as intellectual factors and demographic factors. Second, one focus of this dissertation is to increase the knowledge of the contextual factors that may influence patient choice, but only the factor of service schedule is addressed. Therefore, a wider database is needed to improve this study. One possible approach to enriching the database is to request access to registry data held by other medical organizations or medical data authorities and to connect multiple datasets using identifiers. The application for requiring more data access has been a work in process.

The study also has limitations regarding the interview sample (presented in Articles 2, 3, and 4) and survey sample (presented in Article 3). It should be acknowledged that the women who participate in our interview and survey have a high interest in the research, and they most likely have a higher education background. It may cause biases in the results. This kind of sample bias is very common in empirical research and is hard to address. The low response rate of the survey is also a problem. This was probably because women were asked to return the survey by mail with prepaid envelopes, and no deadline was set for returning the questionnaires, which could have led to many women delaying filling in the survey and finally forgetting to return it. Despite the assumedly biased sample and rather low response rate, the study sample still can represent the maternity population in the hospital district of Helsinki and Uusimaa, according to the Finnish perinatal statistics report for 2015 (Vuori and Gissler, 2016). For further study, the sample should be expanded, for example, by inviting more women from other cities, exporting the research to other countries, or even conducting the research in other medical fields to test the generalization of our observations on patient choice and choice-making.
6. Conclusion

The current dissertation aims to contribute to the field of patient choice and add theoretical and practical insight into patient choice management. It applies a case study design, focusing on women’s choice in prenatal screening and testing, contextualizes women’s choice using the DSO framework, and quantitatively and qualitatively investigates women’s choice within different contexts. The main findings include the following: (1) the DSO framework enables patient choice contextualization, and choices in different contexts have different characteristics and require different management approaches; (2) the important factors for women’s choice in a high-risk situation include the women’s values, gestational age, the features of the test methods (safety, accuracy, and test time) and the service schedules; (3) the issues that are insignificant for women’s choice in a high-risk situation include medical factors (maternal age, trimesters of initial screening, medical indications, and risk scores) and social influence (how other people do in the same situation); (4) six issues represent the choice-making process, including choice activeness, preferences or considerations, information needs and sources, social influence, emotion status, and choice-making difficulty; (5) a framework with seven variables, including activeness, informedness, confidence, social pressure, difficulty, positive emotion, and negative emotion, is developed to measure women’s choice-making experiences in prenatal screening; and (6) activeness, confidence, social pressure, and difficulty are experiential factors that significantly influence the choice satisfaction.
7. Reference


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