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DECISION-MAKING IN EXTREME CONTEXT

- a case of cancer patients in Finland

Master's Thesis
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“The most critical activity during emergencies or crises is making decisions about what to do next” - Higgins and Freedman (2013)

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Abstract

We all make multiple decisions each day. While some decisions are easy and are done on autopilot, some are difficult to make. In extreme situations, decisions may relate to questions of life and death. Decision-making relating to healthcare and treatment options in situations where your life is threatened, are often complex and further complicated by emotions that step into play.

Shared Decision-Making (SDM) has been shown to lead to multiple positive effects in clinical setting. Cancer is a group of diseases that regardless of the advances in fighting the disease made in the past decade, still raises fear. Due to the emotional affect, cancer diagnosis is likely to impact decision-making processes. Furthermore, the information relating to the disease and the treatment options can be complex. Therefore, this study aims to evaluate the impact of cancer diagnosis on the decision-making process of Finnish cancer patients and to elucidate the readiness of the cancer patients to engage in SDM.

This study was conducted in a qualitative tradition. Eight Finnish cancer patients were interviewed to build a multiple case study. A framework of factors that are assumed to influence the patient's decision-making after cancer diagnosis is proposed.

Across the study set, the SDM model seems not to have been utilized in the decision-making related to treatments. While the study participants perceived a clear role for the physician in the treatment planning, the role of the patients did not emerge clearly from the data set. Patient characteristics such as gender, level of education, and prior experiences with cancer may influence how the diagnosis impacts decision-making. These aspects need further investigated in a large data set.

The findings in this thesis illustrate the need to raise discussion on the benefits of the SDM in Finnish cancer clinics.

Keywords decision-making, shared decision-making, extreme context, crisis, cancer, diagnosis

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ABBREVIATIONS

SDM	Shared Decision Making
EUT	Expected Utility Theory
ANS	Automatic Nervous System
HPA	Hypothalamo-Pituary-Adrenal (axis)
HCP	Healthcare Practitioner
EHR	Electronic Health Record
MDT	Multidisciplinary Team Meeting

INTRODUCTION

In this section I introduce the topic and relevance of this thesis work. I begin this section with a background on the theme aiming to place this thesis in its proper context. Before I move on to discuss my research questions, I highlight the specific gap that exist in literature and that this work sets to begin answering. To bring this section to end, the structure of this thesis is illustrated.

Background

As adult human beings, we make decisions. In fact, the number of decisions an adult is estimated to make per day is around 35 000 (Sahakian & Labuzetta, 2013). Many of these decisions are, however, such routine decisions that we barely notice making them. Consider activities such as staying seated while watching television and keeping our mobile phones close by when we are at work. Other decisions are more involved and multiple factors influence these decisions. Factors that influence our decisions and decision-making include, for example, past experiences (Juliusson et al., 2005) and individual differences such as age and socioeconomic status (Bruine de Bruin et al., 2007).

After a decision is made, the outcome may lead to a multitude of emotions including regret or satisfaction. When the conditions in which the decision is done involves risk and uncertainty, the likelihood of suboptimal decisions is increased compared to those decisions made under certainty. Therefore, information needs gathered to support the decision-making and to enable the evaluation of possible outcomes. Not all decisions are easy and in extreme situations, decisions may even relate to life and death. How do you, for example, make the decision to keep loved ones on life support or take them off?

In the past, medical information was concentrated within the medical profession. The interaction between a patient and a physician was paternalistic – the physician told, and the patient did. The physician's authority was not something that was questioned. Today, the wealth of information that is available to all includes medical information and Google is often first consulted for medical conditions. This shift in the availability of information from an expert group to public gives rise to new types of challenges for the healthcare professionals. What is more, patient laws highlight the patient’s role in the medical setting. The Finnish patient law (1992/785, Laki Potilaan asemasta ja oikeuksista) captures the patients role and rights regarding their medical treatment. Accordingly, patient consent is needed for any treatment. For a patient to be able to make decisions on their own care, they must understand their own interests and the potential consequences of their decisions. They must be able to consider the alternatives. The patient's consent must be voluntary, and the patient must have been given sufficient information to make decisions. The patient, however, also has the right to refuse to receive information. If a patient chooses to refuse a particular treatment or procedure, he or she should, if possible, be treated in agreement with them in another medically acceptable manner. Thus, the fact that a patient refuses one of the treatment options suggested by a doctor does not mean the end of the treatment relationship. In this case, the doctor could suggest another possible treatment, the initiation of which would equally require the patient's consent. Therefore, while the saying “on doctors-orders” is still alive, the treatment decisions should no longer be made in a paternalistic fashion but rather with keeping in mind the patient’s wishes and opinions. Indeed, the value of engaging the patients in the medical decision making is widely accepted. Shared decision making (SDM) has been shown to lead to multiple positive effects such as patients experiencing confidence over treatment decisions and satisfaction with the treatment, as well as trust towards their healthcare provider (Sanftenberg et al., 2021). In cancer care, shared decision making has gained much attention over the past decade as a key element in a patient-centered communication and care (Hull et al., 2021).

Cancer is a leading cause of death worldwide killing nearly 10 million in 2020. While cancer accounts for a significant morbidity and mortality, it is no longer a direct death sentence as today many cancers are curable. (WHO, 2022) While cancer care and treatment options have advanced greatly over the past decade, fear of cancer remains high among the public. As the number of cancer treatments and screening options is growing, so is also their complexity. Therefore, the differences between strategies may not be directly evident to the average patient. Since cancer as a disease causes emotional impact in people, a diagnosis is likely to impact the decision-making processes. What is more, decisions relating to cancer care often relate to high uncertainty about the outcome complicating the decisions further. (Reyna et al., 2015) Emotions have been found to often influence cancer related decision-making more than factual knowledge (Zikmund-Fisher et al., 2010). Regardless of the complexity of the disease and the questions around it Bomhof-Roodnik et al. (2019) among other researchers support the use of SDM in cancer care noting that the patients and oncologists both have their roles when it comes to decisions over treatment and that patients should be supported so that they can fulfil this requirement. Survey results indicate that particularly oncologists are keen on the SDM model (Brace et al., 2010; Pieterse et al., 2008; Schroy et al., 2014). In survey with 60 oncologists from Netherlands, 95% of the responders indicated that patients have a clear role in treatment decision making, and 73% of responders reported preference towards collaborative decision making (Pieterse et al., 2008).

Literature and research gap

In October of 2011, Steve Jobs died with pancreatic cancer. At the time of the initial diagnosis in 2003 he decided on a treatment approach based on the best evidence available to him. (Greenlee & Ernst, 2012) While in some countries, such as the United States of America, prescription medications are advertised directly to the public, in Finland they are not (1987/395, Lääkelaki). While the law secures the safe and appropriate use of the medicines, it also limits the information available in Finnish to the patients.

As described above, the SDM has gained traction in cancer care internationally. In Finland, however, little information or articles around the topic is found using internet search engines. An article discussing the treatment of patients with incurable advanced cancer summarized the SMD method, and notes that there is no systemic use of this method in Finland (Tarkkanen et al., 2020). With the below research objectives and questions, this thesis work aims to address this gap in relation to SDM use in cancer care in Finland.

I have decided to focus on the field of oncology specifically in this thesis project for multiple reasons. Firstly, the shared decision model has been widely investigated within the field of oncology (Baldt, 2020) and therefore, relevant references from literature can be found. Secondly, the decisions within the cancer care continuum are also well researched within studies focusing on SDM (Hawley & Jagsi, 2015; Hopmans et al., 2015; Steffensen et al., 2018). Thirdly, as cancer care is becoming increasingly personalized with a multitude of treatment options tailored towards individual patient, it remains unclear how cancer patients in Finland see their own role in decisions regarding the course of their treatment in relation to the healthcare expert's role. Lastly, research within the field of oncology is highly active, adding on to the wealth of already existing information. Currently multiple pharmaceutical companies are directing their focus towards oncology and the pipelines include various molecules investigated in oncology. If the patient is to have an active role in the treatment planning, how can it be ensured that the patient has comprehension and access to relevant material on the disease and treatment options?

Since evidence of the benefits of SDM accumulates, it is important to study the utilization of this decision-making model in Finnish cancer clinics. Moreover, it is also important to raise discussion around this topic for the benefit of patients and to make sure the relevance of engaging patients in treatment planning is realized. As this study focuses on cancer patients, the observations and results of this study cannot be directly assumed to apply to other patient groups.

Research problem

This research aims to investigate how the decision-making process is influenced by extreme context, here a cancer diagnosis, in the Finnish population. The first research questions my research aims to answer is:

Q1: How do Finnish cancer patients view their role and the physician's role in determining the treatment plan?

Upon answering this question, I explore the willingness of the patients to take part in the treatment planning. The Finnish patient law (1992/785, Laki Potilaan asemasta ja oikeuksista) states that the patient should have an active role in decisions regarding their course of treatment. However, when faced with a diagnosis that is potentially life threatening, the patients may freeze and wish to rely on the expert opinion. Furthermore, the history of paternalistic decision-making in the medical setting may influence the patient's readiness to participate in decision-making. Therefore, with this question I investigate how individuals facing such a diagnosis position their own role in relation to that of the healthcare expert(s) and why. Moreover, by answering this question I will probe on the capabilities the patients have for engaging in a dialogue upon a diagnosis, and their ability to act as an informed participant in the conversation regarding the treatment planning. Answering this research question will shed light into the patient's needs for information regarding their disease and viable treatment options and on the potential needs for decision aids. Importantly, light is also shed on if the professionals seek to engage patients in this conversation relating to treatment planning.

To elucidate the effect of cancer diagnosis on decision-making models, the second research question this work aims to answer is:

Q2: How do Finnish cancer patients' characteristics influence their decision-making process when generating a treatment plan?

With this question, I probe to see if patient features influence how the diagnosis impacts the patient's decision-making. I will focus on three specific features that have been shown to influence decision-making processes in general. Firstly, the influence of patient gender will be of interest. Men and women have been shown to react differently to external stimuli (Bradley et al., 2001; Fischer & Manstead, 2000; Guillem & Mograss, 2005; Kimura, 1999; Wilson, 1992). Therefore, it is expected that men and women will be impacted differently by the diagnosis. Secondly, educational background and the impact it bears is of interest as educational background has previously been shown to influence decision-making (Peters et al., 2006). My focus in this project will be in evaluating if the information needs of patients with different educational backgrounds differ and if enough comprehensible information has been available to the patients with different needs. This is of interest because the literature relating to cancer and cancer care may be complex, and it is important that relevant material is available also for those who have no experience in reading scientific articles. Thirdly, previous life experiences have been shown to have an impact on decision-making (Li et al., 2009). Therefore, I will investigate if previous cancer diagnoses within friends and family influence patients decision-making processes as these prior situations may have taught the patient to cope with such a diagnosis.

Limitations

There are a few limitations to this research project that I want to specifically address. The geographical scope of this study is limited to Finland. While cross-country comparisons could be valuable in generating insights and the differences could pinpoint areas where improvement is needed in Finland, this decision was made due to resources. This is a master's thesis and therefore there are not enough resources to broaden the scope to include other countries into the scope for comparison. Furthermore, limiting the focus of this thesis to Finland allows for more in-depth descriptions of Finnish medical landscape than what would be possible if multiple countries were involved. Furthermore, I am working as a medical advisor in oncology in Finland. While this allows me to have some insights into the

Finnish healthcare system and oncology care, the healthcare systems in the other countries vary from that of Finland. My experience form the industry side of oncology care gives me many tools for conducting humanistic research regarding cancer and cancer patients. However, I am also likely to have biases based on this work experience that may lead to assumptions or generalizations based on my prior knowledge that are not reflective of Finnish cancer patients. Yet, researcher always brings their own biases to the project and with acknowledging that these biases exist, I have aimed to minimize their impact on the neutrality of this research.

I have also decided to limit the scope of this thesis to cancer patients. This decision is based on my prior work experience within the field of oncology and the fact that SDM model has already been researched in oncology care to a degree that allows me to use the prior work as a reference. However, I think research focused on other patient groups in Finland and elsewhere would be highly valuable.

Structure of the thesis

This thesis follows the following structure. First, in the literature review section I provide a comprehensive background on the main topics around the theme of this thesis. The literature review section begins with basics on decision-making and moves forward to describe extreme context and the mental state that such may evoke in human beings. The section is brought to end with introducing cancer diagnosis as an extreme context that influences the patients decision-making processes.

In the methodology section that follows the literature review, I explain the rationale for the philosophical starting point and the methods I have adopted for conducting this research. Once the use of specific methods and my choice of analysis is justified and elaborated on, I move on to present the empirical findings made during this research project. I first describe the study participant demographics and present some cancer statistics on the Finnish population to allow readers to understand the level of generalizability of the results obtained in this research. I end this thesis with a discussion over my observations and findings, and my suggestions for future research.

REVIEW OF THE LITERATURE

In this section, I present a review of the human decision-making. The study of decision-making is rooted in economics but has gained interest also in multiple other fields of study including psychology and sociology. Together the fields have produced multiple models on human decision-making. Therefore, all models and prior research are not visited in this section, rather an overview on decision making is provided. This section moves from the general overview of the topic into situations with uncertain outcomes, and decision making in extreme situations. Next, decision-making in clinical setting is explored and cancer diagnosis is introduced as an extreme context. To end this section, an illustration of the complexity of cancer and its treatment is provided and a framework of factors that influence decision-making in cancer treatment selection is proposed.

Foundations of decision-making

People make multiple decisions daily. While some of the decisions are simple and can be made within seconds, some require more time and thought. The ways in which people make decisions varies greatly, and the more complex the decisions grow, the more information processing is required. Even in simple decisions information needs gathered, combined, and organized. With challenging decisions, this information processing becomes a part of the decision making and decision-making models that can help the processing of information gain importance. (Dillon, 1998; Lehto et al., 2012)

At the core of decision-making are choices between two or more alternatives that lead to differing consequences. Upon deciding the person assigns values to the alternatives that are being considered. A rational decision maker favors the alternative that leads to the more desirable consequences per their judgement. However, alternatives are not always associated with only one type of consequences, rather they may be linked to negative, neutral, or positive consequences all at once. Moreover, all alternatives may be linked with multiple conflicting outcomes. This may lead to a conflict situation and uncertainty over the decision. Such a conflict situation may arise internally within a single decision maker but also in a setting with multiple people. The people involved in the decision-making may have varying goals and objectives. (Lehto et al., 2012) Factors complicating decision-making are hence abundant. What is more, decision context influences the decision making. Contexts have the potential to alter the process by which a decision is made, and hence, shift the choice outcome. As an example, a person may shift from a method aimed at maximizing utility to an emotionally driven choice model due to a context effect. (Thomadsen et al., 2018) Moreover, previous decisions may drive subsequent choices (Lehto et al., 2012). To sum, dealing with uncertainty and conflict resolution both play a key role in decision-making.

Decision-making conditions

In general, decision-making takes place under three types of environments: certainty, risk, and uncertainty (Figure 1). The prevalent conditions determine the probability of making an error in the decision-making process. Many decisions are done in conditions where not all relevant information for making an optimal decision is at hand. In these situations, the decision-maker is dealing with conditions of risk and uncertainty. In contrast, in a condition of certainty the decision-maker is relatively certain of the alternatives and the associated conditions, and the outcomes of each alternative. Risk and uncertain conditions refer to situations where the outcomes of different options are not guaranteed. Therefore, the decision-maker is confronted with a risk of arriving to an outcome that is worse than optimal (Yates & Stone, 1992). In decisions under risk, information about plausible outcomes and their probabilities are, at least in part, calculable or explicitly provided. Consequently, individuals may evaluate options and the expected value of each outcome. Human brain is mostly occupied dealing with conditions of uncertainty. Situations where the decision-maker receives no explicit information on the possible decision outcomes nor of the probabilities of the different outcomes. Therefore, the individual must rely on feedback from prior decisions. (Bechara & Damasio, 2005; Volz & Gigerenzer, 2012) Research shows that risk and uncertainty is often found aversive (Tversky & Kahneman, 1986). As a result, when options associate with differing levels of uncertainty, humans are often seen to prefer safe and sure options over a risky option with ambiguity. This is known as risk aversion. Risk aversive behavior may lead to suboptimal decisions as some options are perceived as "too risky". (Fraenkel et al., 2012) Similarly, a human preference for options that involve known probabilities versus unknown (ambiguous), is known as "ambiguity aversion" (Camerer & Weber, 1992; Ellsberg, 1961).

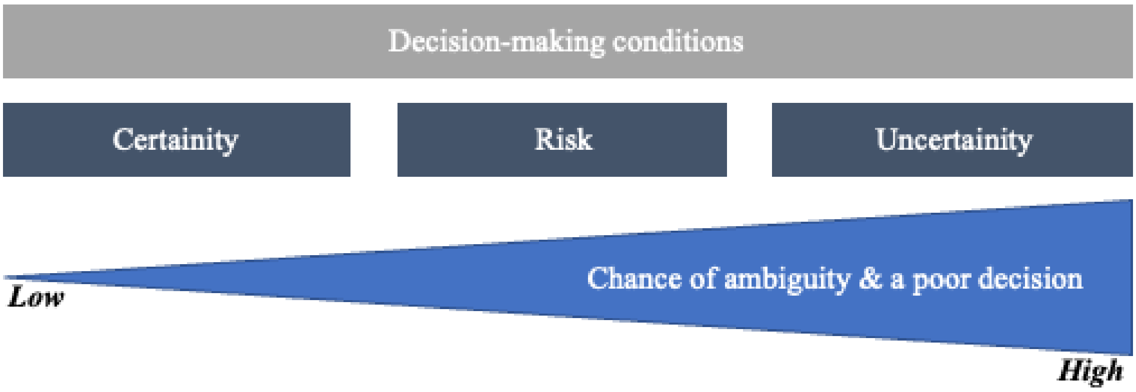

Figure 1. Decision conditions. Decisions made under risk and uncertainty are associated with increased ambiguity and chance for a poor decision when compared to certain conditions.

Decision theories

A vast body of theories and models to aid structured decision-making for situations involving risk and uncertainty have been developed through years. The traditional dichotomy in these decision-making theories distinguished the normative and descriptive sides of decision making. While the former focuses on how decision should be made, the latter is center on how decisions are made.

Normative: What individuals should do.

Descriptive: What individuals do or have done.

Prescriptive theory of decision-making augments the contradiction between the descriptive and normative theories as it blends the theoretical foundation of normative theory with the empirical findings of the descriptive theory.

Prescriptive: What individuals can and should do.

By combining these aspects, the prescriptive theory develops tools to improve decision-making. (Dillon, 1998) Early literature and some authors use the terms “prescriptive” and “normative” interchangeably (Bell et al., 1988). However, as indicated in table 1, not only the descriptive and the normative, but also prescriptive approach have different domains and validation criterions. Therefore, these three approaches are all discussed separately in sections below.

Table 1. Decision theories. Decision theories encompass differing domains, and their validity is evaluated against different criteria (Keeney, 1992a).

Theory	**Domain**	**Validation Criterion**
Normative	All decisions	Correctness
Descriptive	Classes of decisions	Empirical validity
Prescriptive	Specific decisions	Usefulness

Normative theory

The normative theory of decision-making is concerned with making decisions that have optimal consequences for specific actions. The theory is rooted in the application of economics and statistics (Savage, 1954; von Neumann & Morgernstern, 1947), and relies on rationality (Savage, 1954). Normative models suppose the decision-maker to have all information to weigh the different alternatives, and to behave rationally. Therefore, following the normative models, the decision-maker has a comprehensive data set to weigh the alternatives and select the one alternative with consequences most in line with personal preferences. (Doyle, 1998)

The classical decision theory is an example of a normative model which uses four basic elements to represent choice and preference problems:

1) potential actions (A).
2) events or world states (E).
3) possible consequences (C) for each combination of actions and events.
4) probabilities (P) for the different combination of action and event.

In this model, the probability (P) of an event (E), influences the chosen action (A) to arrive at the most lucrative consequence (C). (Lehto et al., 2012) Similarly, other normative models are based on basic axioms of rationality which are, on individual level, intuitively appealing and that aim to maximize expected value (Stukey & Zeckhouser, 1978).

As most decisions involve uncertainty, mere value maximation is not enough. The Expected Utility Theory (EUT) (von Neumann & Morgernstern, 1947) is a well-known theory of rational behavior under situations of uncertainty, where maximization of expected utility is seen as the goal. Most of the axioms in EUT rely on assumption that decision-makers are both rational and have well-defined preferences.

These normative decision axioms, however, are not realized in daily decision-making as consequences of routine habitual decisions are not always driving decisions. Moreover, not all people have clear objectives or preferences, to base their decisions on. To add, human preferences may change with context and with time. (Doyle, 1998) Moreover, due to cognitive limitations and lack of background information, decision-maker may not be able to account for all options and their possible consequences. (Lehto et al., 2012) Specifically, in today's information society, a broad range of information is available to people. According to traditional view of unbounded rationality, decisions should be made utilizing all this information. Although artificial intelligence tools can either be used to gather and shower people with all available information, or even to suggest best possible solutions, this view does not capture the way people make most decisions in real life. As a result, this idealistic theory may not work well as a basis for the decision-making models currently being developed. (Todd, 2007)

Descriptive theory

Descriptive theory of decision-making is concerned with describing and elucidating the regularities in people's choices in real life situations. These theories stem from the empirical experiments that show people's behavior to be inconsistent with the normative theories. Descriptive analysis of decision-making is highly empirical and does not seek to modify or influence behavior nor moralize on behaviors (Bell et al., 1988).

According to Bell, Raiffa, and Tversky (1988), human-decision making is characterized by choosing alternatives that are good enough, but not optimal. These "satisficing" decisions are at the center of 'bounded rationality', a notion which refers to rational choice that accounts for the decision-makers cognitive limitations. These limitations include both computational capacity as well as knowledge. (Simon, 1990)

The usual assumption is that the limitations with our rationality are internal. However, the external world imposes constraints on human decision-making as well (Todd, 2007). Firstly, the environment is everchanging – every situation is unique, and hence, mental mechanisms generalize from prior instances to the new. Consequently, a bound of simplicity may be imposed by the external uncertainty. Secondly, many decisions need to be quick to succeed in daily life and the competitive environment of today (Todd, 2007). The more time is spent of deliberating on decisions, the less time for other activities. To make quick decisions, the information and alternatives must be minimized. Therefore, the external world also imposes constraints of frugality to decision-making. (Todd, 2007)

The prospect theory by Kahneman & Tversky (Kahneman & Tversky, 1979; Tversky & Kahneman, 1992) is a recognized descriptive model for decision-making. The theory replaces utility from EUT with value and deviation from reference point. The theory implies that decision-makers and people in general, are risk-averse with prospects to gains, and risk-seeking in relation to losses. This leads individuals to systematically underweight large probabilities and overweight small ones. What is more, in contrast to EUT the framing of the problem is seen to influence the decision-making.

Prescriptive theory

The prescriptive decision analysis can be described as "the application of normative theories, mindful of the descriptive realities, to guide real decision making" (French & Rios Insua, 2000). Therefore, prescriptive approach to decision-making process bridges the gap identified in between the normative and descriptive theories (Bell et al., 1988; French & Rios Insua, 2000; Keeney, 1992b).

French (1995, p.243) describes prescriptive decision analyses as "normative models to guide the evolution of the decision-makers' perceptions in the direction of an ideal, a consistency, to which they aspire, recognizing the (supposed) limitations of their actual cognitive processes." Prescriptive decision aids are a real-world illustration of how human limitations and cognitive illusions observed in the descriptive discipline can be corrected (Brown & Vari, 1992). Moreover, prescriptive analysis can also be used to reason a real-world problem by using a theoretical model to increase understanding of the specific situation and by creating incentives for gathering additional information to help decisions (Larsson, 2008).

Keeney (1992a) stresses that, unlike normative and descriptive theories, the focus of prescriptive decision analysis is to address one decision problem at a time. Moreover, this approach recognizes that decision-makers are individuals with differing emotions, needs, and competencies, and hence, aid should be tailored to the needs of the specific advisee. (Bell et al., 1988)

Decision-making process

According to Kahneman (2011), there are two basic types of decision-making processes that are also frequently recognized in psychology:

- System 1 process where decisions are made quickly with little consideration.
- System 2 process where decisions are a result of a conscious process evaluating different alternatives.

The decisions that are made quickly (system 1) rely on gut instinct or pattern recognition and these are shaped by previous experiences. The system 2 decision-making process aims to arrive at a decision that is based on best possible evidence for an individual case. This is done by considering factors that influence the decision. These decisions require attention as different options are evaluated, as are the possible outcomes of these.

Decisions formed in the system 2 process are more systematic than decisions from process 1. These two systems are, however, continuously interacting as both are active during awake hours (Figure 2). In short, most of the time system 2 accepts the suggestions by system 1 turning impulses into voluntary action, system 2 is mobilized upon situations where system 1 has no answers to offer.

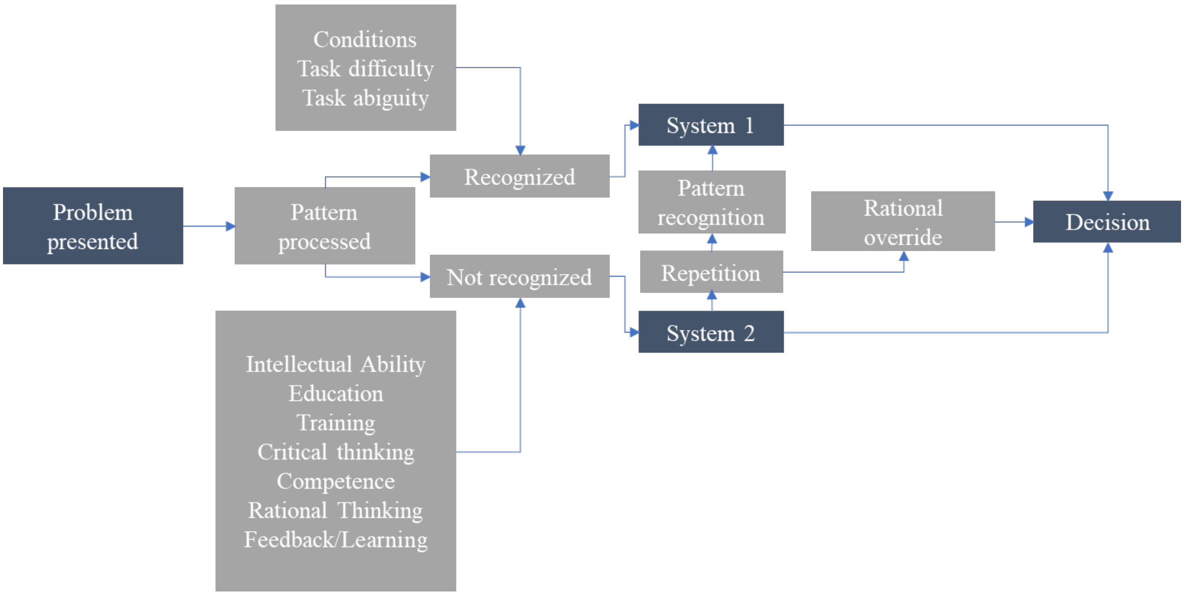

Figure 2. Two decision processes. System 1 and 2 are continuously interacting. Modified from Woodford (2015).

Heuristics

The process by which system 1 decisions are implemented by is called heuristics, a simple procedure helping to find adequate, yet often imperfect, answers to challenging questions to save the mental energy of our deliberate, system 2, brain (Kahneman, 2011).

According to Simon (1990) humans need to make approximations to handle many tasks due to our cognitive limitations. This introduction of heuristics, mental shortcuts for quick and efficient decision-making, relies on the concept of bounded rationality – individual's cognitive limitations in making rational choices. This has been interpreted in two distinct ways. On one hand, it has been suggested that cognitive limitations do not necessarily lead to poor decisions, but rather the use of heuristics often leads to good outcomes (Gigerenzer & Selten, 2001; Gigerenzer & Todd, 1999; Payne et al., 1993). What is more, according to this view, the boundedness of our rationality can be of benefit (Hertwig & Todd, 2003). If a successful decision can be made on limited amount of information, greater amount of information would come at a cost of efficiency. The core of this view is in figuring the pieces of information that is important for the specific decisions. On the other hand, the limits of our cognition were accepted, but it was assumed that this led to suboptimal decision-making. Accordingly, use of heuristics (Table 2) can be seen to lead decision-makers astray to form biased decisions, create cognitive illusions, and stray to fallacies of reasons (Piattelli-Palmarini, 1996). Therefore, work has been conducted to right the erroneous heuristic decision-making (Tversky & Kahneman, 1982). Heuristics often play a contributing role in the formation of cognitive biases, systematic errors in thinking that affect the decisions and judgments. While some biases are related to erroneous memory, some are related to human limits in attention (Table 2). Biases may be implicit, associations outside of conscious awareness, or explicit, recognized associations of prejudices and attitudes. While heuristics often contributes to cognitive biases also other factors such as emotions, social pressures, and individual motivations have been linked to biases. According to Kahneman (2011), system 2 much more resistant to cognitive biases that system 1 is.

Table 2. Types of heuristics & cognitive biases.

Type	**Description**
Availability heuristics	Decision-making influenced by retrieval of one own's memories which may not reflect the reality.
Representativeness heuristics	Decision-making influenced by comparisons to representative mental example.
Affect heuristics	Decision-making influenced by emotions / mood.
Actor-observer bias	The tendency to attribute own actions to external causes and other peoples to internal causes.
Anchoring bias	Tendency of first bits of information to overinfluence decisions.
Attention bias	Tendency to pay attention to some factors while simultaneously ignoring others.
Confirmation bias	Tendency to favor information that conforms to existing beliefs and dismiss evidence that does not.
Framing effect	Tendency of choices to be influenced by the way information is presented.
Halo effect	Tendency for a positive impression of a person on one area to influence the assessment of other areas.
Optimism bias	Tendency to believe that oneself is less likely to experience a negative event.

Emotions in decision-making

According to Bechara and Damasio (2005), the role of emotions in decision-making has long been underestimated. In fact, modern economic theory on decision-making is built on rationality and Bayesian utility maximation, while the role of emotions is largely ignored.

However, human decision-making is subject to emotional affect (Lerner et al., 2015). Many daily decisions serve as channels through which emotions are guiding human attempts at increasing positive feelings and conversely, avoiding negative ones (Keltner & Lerner, 2010; Loewenstein et al., 2003). What is more, we tend to feel new emotions once the outcomes of our actions materialize (Coughlan & Connolly, 2001; Mellers, 2000; Zeelenberg et al., 1998). Emotion and decision-making are therefore hard to separate.

Indeed, many psychological scientists today suggest that emotions are the dominant driver of most meaningful decisions in life (Ekman, 2007; Frijda, 1988; Gilbert, 2006; Keltner et al., 2014; Keltner & Lerner, 2010; Loewenstein et al., 2001). Multiple studies show people in positive (negative) affective states to be (less) influenced by heuristics, (Bless et al., 1996; Bodenhausen et al., 1994). To add, according to prior research increased systematic processing from negative affect can intensify anchoring effects due to increased focus on the anchor (Bodenhausen et al., 2000).

Emotions seem to constitute pervasive and predictable, sometimes beneficial, and sometimes harmful, drivers for decision-making. The effects of emotions on decision-making are neither epiphenomenal nor random as consistencies are seen in the mechanisms of how emotions influence judgement and choice across different types of decisions. Although multiple mechanisms may contribute to how emotions influence decisions, effects seem to occur via changes in (a) content and (b) depth of thought, as well as (c) content of implicit goals. (Lerner et al., 2015)

As Lerner et al. (2015) describe research on emotions and decision-making has been on the incline in the 20th century. While work remains done in elucidating the exact role of emotions in decision-making, the field has accumulated evidence allowing inclusion of emotions in decision models (Figure 3).

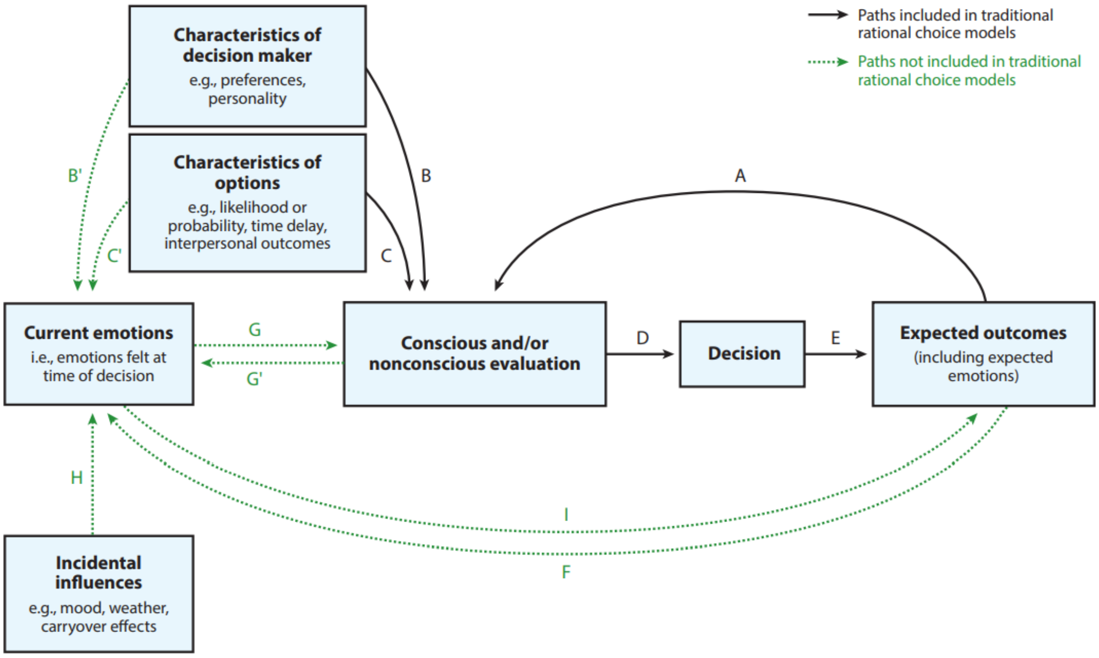

Figure 3. Inclusion of emotions. The emotion-imbued choice model as suggested by Lerner et al. (2015).

Expert opinion in decision-making

Many important decisions are influenced by advice from others. Indeed, the value given to advice is illustrated by the billions of dollars that is paid to consulting companies every year (Statista, 2022). The advice affecting the daily life decisions range from opinions coming from experts with in-depth knowledge to peers with little information to ground their advice on.

In their research on brain activity Meshi et al. (2012), suggest that advice-taking from others is a three-stepped process (Figure 4). First, the advice is valuated. The advisor's expertise on the topic is evaluated. Next, the "opinion difference" is assessed. The decision-maker evaluates how great the difference between the advisor's opinion is compared to their own. Lastly, the prior two are combined resulting into advice utilization. The study shows that expert opinions have a greater chance to result into advice-taking, and even with a large "opinion difference" expert advice is likely to impact decisions. The results of the study conform with prior evidence that people hold expert advice to a higher regard than that of novice when making decisions. The more knowledge on the topic the advisor is perceived to have, the more the advisor's opinion counts in decision-making (Harvey & Fischer, 1997; Jungermann & Fischer, 2005; Sniezek et al., 2004), and the lesser the opinion difference, the more likely the advice is to be followed (Campbell-Meiklejohn et al., 2010; Klucharev et al., 2009).

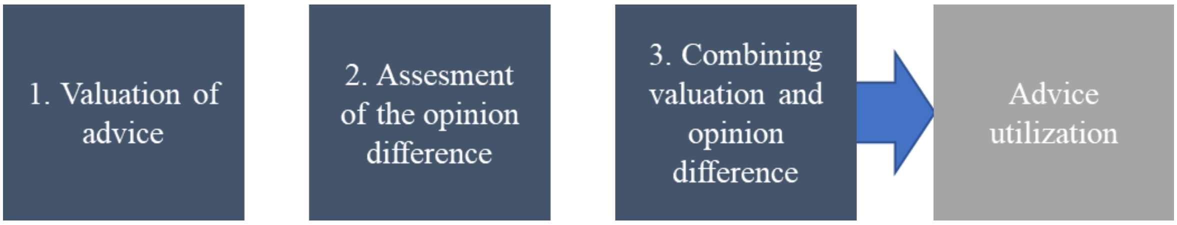

Figure 4. Advice-taking. Meshi et al. (2012) suggest that advice-taking consists of three neurocognitive processes.

However, as illustrated by Kahneman (2011) experts show several of the same biases that everyone else does. Indeed, no one is immune to bias (Dror et al., 2016). In fact, the very process of becoming an expert through training and experience may give rise to certain biases (Dror, 2011). Experience, for example, may lead experts to rely on heuristics and give expectations that arise from past experiences. To add, experts have a tendency for confidence or even overconfidence, which may cause experienced experts to perform worse than novices (Soller et al., 2020).

Physicians are trained experts in their fields. A systematic review of articles focusing on healthcare professionals' preconceptions towards patients found evidence of implicit biases (FitzGerald & Hurst, 2017). According to the evidence gathered in this review, implicit bias is manifested by both physicians and nurses to a comparable degree as within the general population. The biases were seen to influence either the diagnosis or the treatment decisions. The socio-demographic characteristics (such as gender, type of healthcare setting, and experience) were seen to correlate with the level of bias exhibited by the healthcare professional. However, the patients alike are prone to bias. The biases of one party of the interaction may well trigger the biases of the other, causing a snowball effect (Burgess et al., 2004).

Physicians' attitudes towards patients are subjective as Protière et al. (2010) illustrate by discussing an age limit that constitutes an elderly person. They note that French oncologists reported vastly different age limit on their views of "elderly", as the answers ranged from patients from 60 to 90 years of age. This statement is notable as prior research has shown treatment disparities to be based on chronological age rather than on co-morbidities (Bailey et al., 2003). Moreover, the results by Protière et. al. (2010) reveals a tendency to associate elderly patients with comorbidities, and hence, assume a lower tolerance to treatment. This is illustrative of a possible anchoring or halo effect within medical professionals.

Steps in deliberate decision-making

Numerous decision-making models have been developed over the course of several decades. The underlying issues and cognitive processes are, however, common to most, if not all, of the decision-making models. Decision-making from a general cognitive point of view is the process of considering a set of alternatives and the subsequent choice of action. Many of the illustrative models describe this as a multistep process (Figure 5) including gathering of the information, evaluation of the alternatives, deliberation, and decision selection. (Azuma et al., 2006)

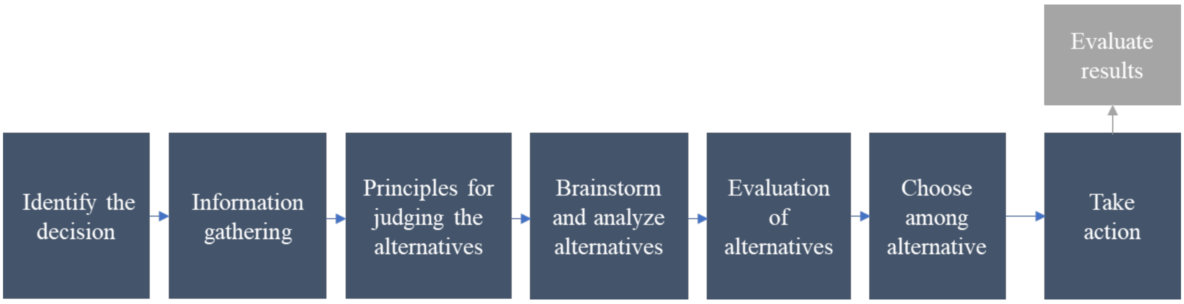

Figure 5. Steps in decision-making. Modified from Berisha-Shaqiri (2014).

Group decision-making

In groups preferences may vary between its members, and it may be impossible to find outcomes that align with everyone's preferences. Hence, group decisions often involve trade-offs. What is more, in groups, other people's actions may influence the return to other members. Individuals in a group may decide to take actions to maximize their return even if this reduces return to others. Alternatively, individuals may decide to take actions that benefit all equally. The reasons for these cooperative behaviors are varied (Dawes et al., 1988). According to Bazerman (1998) fairness considerations at times explain actions for common good which are in contrast with self-interest. Some people may even be willing to accept costs to themselves to right an "unfair" group member, and the research by Bolton and Chatterjee (1996) further confirms the important role of fairness in interactions. On the other hand, cooperative solutions may be imposed by the group by application of punishments for those who deviate. (Lehto et al., 2012)

Multiple models on how decisions in groups are reached exist. Generally, groups are seen to move through different stages before the decision is reached (Ellis & Fisher, 1994). Tuckman (1965) describes this process to comprise of the following:

- Forming i.e., the initial organization.
- Storming i.e., potential conflicts.
- Norming i.e., group cohesion forms and opinions are voiced.
- Performing i.e., when solutions are obtained.

Although the term conflict raises negative connotations in many, conflicts are a natural part of group interacting and expected to occur. Furthermore, conflicts may serve a positive role in group decision-making. Specifically, substantial conflicts, opposition at intellectual level, are especially linked with positive effects as this may promote better understanding of the involved issues. Affective conflict, emotional disagreements, may also improve decision making in the group by increasing involvement, interest and even cohesiveness in the group. However, such conflicts may influence the group decision making negatively, for example, by reducing cohesiveness. (Ellis & Fisher, 1994)

From a psychological perspective, a group can be defined as several people who (1) interact with each other, (2) are mentally aware of the presence of others in the group and (3) distinguishes themselves as a representative of the group (Schein, 1965). A team, on the other hand, is defined as several individuals accomplishing designated objectives through working interdependently. Teams have a joint goal or purpose, and the mission statement for the purpose is clearly defined. The desired results are known to team members and progress towards the goal can be measured. (Topchik, 2007) Therefore, while group members are individuals with common interest, team members share a common goal (Carter, 2009).

While a group differs from a team, the forms of decision-making in these arrangements do not. The steps of group and team decision-making follow the illustration in figure 5**,** where the process in team/group setting is seen as collaborative process to arrive at a mutually accepted decision. While the choice of action between alternatives can ideally be reached in unanimity, the decisions may result from voting or by one person of high authority. Team decision making is characterized by a collaborative process that involves gathering, processing, integrating, and communicating information to arrive at a mutually accepted decision. (Reader, 2017)

Influence of contexts on decision-making

Context is nowadays widely recognized to influence decision-making (Griffin et al., 2005; Kahneman & Tversky, 1984; Kelman et al., 1996; Tetlock, 1985; Thaler, 1999; Tversky & Simonson, 1993; Zeithammer et al., 2017). Historically, context was long used to described merely the composition of the choice set, but today the definition is broader. No uniform characterization for the term, however, exist. For this thesis, contexts include all factors that may shift the choice outcomes through altering the decision-making process (Thomadsen et al., 2018). According to this definition, contexts affect choices in multiple ways. These include, for example, the social network where the decision is made in (Ben-Akiva M, 2012), and habits that have been formed through repetition (Wood & Rünger, 2016). Moreover, the decisions made by others (Bollinger & Gillingham, 2012; Gardete, 2015) as well as the presence of default options (Johnson & Goldstein, 2003), may shape the choices made. Both the nature of context dependence as well as context susceptibility are likely heterogenous. Some of this heterogeneity may reflect heritable differences as demonstrated by twin studies by Simonson and Sela (2011). What is more, experimental studies have found boundary conditions and moderators that influence the effect of specific contexts (Karmarkar & Bollinger, 2015).

Context effect may intuitively first be associated with system I decision-making process. Hereby context effects would equate with deviations from rationality (Wernerfelt, 1995). The systems I and II, however, continuously interact (see p.19). Indeed, as Evans (2012) and Thomadsen et al. (2018) suggest, both systems seem influenced by context effects.

According to Dhar and Gorlin (2013), some specific context effects seem to primarily associate with system I decision-making process and others with system II process (Table 3). Those contexts that seem to serve as intuitive perceptual cues are seen to affect system I process, while those that require more processing to have an impact on decision-making process, associate with system II processing. Although some contexts may initially influence the other decision-making processes, the decision-maker may learn to shift from one system to another. (Thomadsen et al., 2018)

Table 3. Context effects. Examples of context effects affecting system I and II decision-making processes.

Context Effect	Description	Effecting
Compromise effect*	By adding of an extreme option to the selection set, the original option will become a compromise option and become more attractive	System 2
Attraction effect**	The addition of a decoy, or dominated, option to a choice set increases the relative choice share of the dominating option	System 1

*Li (2020); **Tsuzuki et al. (2019)

According to the traditional view contexts originate exogenously from the choice environment. However, contexts may also be endogenous i.e., chosen by the decision-maker. (Thomadsen et al., 2018) Shaping and choosing contexts seems to be an important component of self-regulation, that allows people to meet their long-term goals by forming habits triggered by contexts in their lives (Galla & Duckworth, 2015).

Extreme contexts

In all aspect of human life change is inevitable. While we welcome some changes, some we do not. Yet, unwanted changes are expected, and these may evolve abruptly or over time. The changes in life may lead to situations with new, unfamiliar contexts. Indeed, industrial pollution, war, and global pandemics increasingly take space in media headlines. Moreover, forest fires and other natural disasters add on to the list of potentially dangerous situations that we are faced with. Research on such extreme contexts has surged but the terminology is not uniform. Rather, different terms are used to refer to similar phenomena (Hällgren et al., 2018). Indeed, terms used to refer to unanticipated, sudden, event or series of events include, for example, *adverse events* (Vegt et al., 2015), *unusual events* (Beck & Plowman, 2009; Garud et al., 2011), *non-routine events* (Waller, 1999); *extreme events* (Buchanan, 2011), *edgework* (Lyng, 1990), *extreme situations* (Bouty et al., 2012), and *extreme environments* (Lanzara, 1983), to name a few.

Hannah et al. (2009) suggest that in defining extreme events, the following must hold: "the event(s) must 1) have potential for massive physical, psychological, or material consequences that occur in physical or psycho-social proximity to organization members, 2) the consequences of which are thought unbearable by those organization members, and 3) are such that they may exceed the organization's capacity to prevent those extreme events from actually taking place" (p. 898). Indeed, an *extreme event* is defined by Hannah et al. (2009) as "a discrete episode or occurrence that may result in an extensive and intolerable magnitude of physical, psychological, or material consequences to—or in close physical or psycho-social proximity to—organization members" (p. 898). Moreover, they consider an *extreme context* to be "an environment where one or more extreme events are occurring or are likely to occur that may exceed the organization's capacity to prevent and result in an extensive and intolerable magnitude of physical, psychological, or material consequences to—or in close physical or psycho-social proximity to—organization members" (p. 898).

Hannah et al. (2009) distinguish extreme events and contexts from *crisis* situations. According to a dictionary (Merriam-Webster, n.d.) the essential meaning of the term crisis is "a difficult or dangerous situation that needs serious attention". However, as illustrated by Hannah et al. (2009) the term crisis is used to refer to a broad scope of situations. The authors suggest that while the term is mostly associated acute situations, the threats referred to vary greatly in their levels of magnitude and extremity. In crisis, a high priority goal is threatened. Hannah et al. (2009) define extreme contexts with a stricter qualification for *high priority* than that of crisis. While losing one's job may constitute a crisis, an extreme context deals with matters of life or safety, i.e., with goals imperative to individuals. Furthermore, whereas crisis as a term considers situations to occur with a low probability, this is not the case for extreme events nor contexts.

Risk and threat perceptions have been shown to be subjective and socially constructed. Indeed, risks and threats are perceived subjectively by individuals and are socially constructed in various ways by people with different reference frames (Bernhardsdóttir, 2015). Therefore, extreme as a concept is subjective. Moreover, through normalization people frequently exposed to "extremity" may be able to develop coping mechanisms to help attenuate the extremity (Hannah et al., 2009).

For this thesis, the terms *extreme event* and *extreme context* follow the definitions by Hannah et al. (2009) and extend the notions from organizations to individual level. While organization in its broadest sense refers to any association of two or more people, Hannah et al. (2009) approach the topic of extreme events and contexts form a point of view that relates to a group of people that share a particular purpose, such as a business or health care workers in hospital. However, extreme events are present also in lives of individuals, and these may affect the persons themselves but also their friends and family. Hence the definition for extreme contexts becomes as follows: an environment where one or more extreme events are occurring or are likely to occur that may exceed the individual's capacity to prevent and result in an extensive and intolerable magnitude of physical, psychological, or material consequences to the individual or people in close physical or psycho-social proximity to the individual primarily affected.

Stern (2017) suggests that extreme contexts and crisis share more similarities than Hannah et al. (2009) accept. The notion of crisis, for example, can be seen to encompass not only the acute episodes but also enduring contexts. Moreover, the core tasks in crisis leadership (Boin et al., 2017; Stern, 2013) overlap extensively with and draw on mutual or corresponding literature to key themes in leadership in extreme contexts (Stern, 2017). Therefore, the similarities in the behavior elicited by crisis and extreme contexts are recognized in this thesis. Literature on crisis will next be explored together with extreme situations to inquire how these situations influence behavior and decision-making.

Reaction to extreme context

Fear is an emotion that arises from threat, and it reflects the expectancy of something aversive. To respond to danger, one may need to attack, escape, or if possible, avoid the situation. (Maack et al., 2015) Fear is the emotion that is associated with the activation of all these motivational states (Blanchard et al., 2001; Ohman & Mineka, 2001). Indeed, fear is proposed to be the underlying emotion of the fight, flight, freeze response which is part of the body's defensive motivational system (Gray & McNaughton, 2000). The physiological changes elicited by the response allow action to be taken to eliminate the danger (fight), escape the danger (flight), or become immobile (freeze). The response is fueled by the body's autonomic nervous system, and it takes around 20-60 minutes for the body to recover back to its normal state. (West, 2021)

In her paper focused on assumed reactions of the public in emergencies, Wester (2011) notes that fear is a common reaction in crisis situations. Accurate and meaningful information may be efficient at reducing the feelings of fear and therefore, information shared with the public should focus on the threat rather than reducing anxiety (Helsloot & Ruitenberg, 2004). According to prior research the feeling of fear can lead to hopelessness and helplessness, if allowed to grow (Benight & Bandura, 2004). A hopeless person feels that no means can make the current situation better. The threat is perceived to be real, but so large that the situation feels hopeless. Helpless person, on the other hand, feels that they themselves cannot improve their current situation or protect themselves. If these emotions take over people are less motivated and less able to change the situation for better. Anxiety, confusion, and intense dread are other emotions that may arise during crisis while denial can result from failure to acknowledge such an emotion or the prevailing context. Denial may be caused, for example, by the lack of information or misinterpretation of the received information. Reactions are rarely completely irrational (Sellnow & Seeger, 2013). However, a lack of or presence of conflicting information is likely to create heightened anxiety and emotional distress (CERC, 2019).

Perry and Lindell (2003) note that individuals have the tendency to act in crisis situations rather than wait and do nothing. However, Small et al. (2006) note that the cause of the crisis affects how people react and respond to crisis. A crisis resulting from a terrorist act, for example, may elicit different reactions than a natural disaster will. Moreover, not all risks are perceived equal. Risks with potential benefit and reduction of harm are, for example, more readily accepted than risks with minor or no perceived benefit or reduction of harm.

Similarly, statistical risks are better tolerated than risks represented by individuals. (Covello, 2007) Different individuals and groups of people also perceive threats differently. Characteristics such as age, gender, and level of education have been shown to influence these perceptions (Lemyre et al., 2006). Additionally, people in crisis exhibit optimism bias (see Table 2) (Weinstein, 1989).

As crisis and extreme contexts are often characterized by uncertainty, people seek information to be able to determine their opinions and evaluate beliefs. Information plays a key role in a crisis response, and hence, information is needed quick once in the situation. According to prior research individuals turn to multiple channels for information and do not rely solely on official channels. (Wester, 2011) However, people under intense stress process and act on information in a different way than in stable situations, partly as the fight, flight, or freeze response kicks in. (Covello et al., 2001; Glik, 2007) Firstly, people tend to miss nuances. Perhaps the information shared is not fully heard or remembered, or the message is misinterpreted. To cope, logical decision-making is subdued by reliance on habits and practices or following examples that are set by others. (Hill, 2003) Secondly, under intense stress changing pre-existing beliefs to adapt to the surrounding context may be difficult. People have also been shown to exploit unclear and conflicting messages by interpreting them as consistent with current beliefs. Moreover, people may take advice from a familiar source that is perceived as trusted regardless of the source's expertise. (Andreasen, 1995; Brehm et al., 2005) Thirdly, people in crisis tend to confirm information received by seeking additional information and opinions before they act. (Brashers, 2006; Sellnow et al., 2009) Forth, the information that is received first is often accepted. Indeed, it may be difficult accept information received later if it is not in line with the prior information. (Solso, 2001)

Of note is that extreme contexts and crises do not only generate negative emotions and behaviors, but also associate with positive responses such as coping, relief, altruism, and elation. Moreover, feelings of excitement, increased self-worth, growth, and strength may originate from the experience. The extent of positive emotions and responses greatly depend on the efficacy of crisis management and the length of the crisis. Generally, crisis changes the way future is viewed and necessitates new evaluation and understanding of risks and ways to manage them. Moreover, people not directly affected by the crisis may mentally rehearse coping in similar situations. Such behavior may prepare for future hardships and reduce both anxiety and uncertainty. (CERC, 2019)

Stress inflicted by extreme contexts

Potential threats to our bodily homeostasis are referred to as "stress". In general, stress ensues when a demand surpasses organisms' regulatory capacity, and particularly in unpredictable and uncontrollable situations (Dickerson & Kemeny, 2004; Koolhaas et al., 2011). The human brain is responsible for the interpretation of the experiences and the interpretation leads to behavioral and physiological responses to these situations. Upon stress the autonomic nervous system (ANS) and hypothalamo-pituary-adrenal (HPA) axis are activated. The degree of the activation depends on both the severity of the stressor, but also individual variety based on genetics and prior experiences (de Kloet et al., 2005). In responding to stress, the serum levels of multiple hormones change. For example, the secretion of glucocorticoids, catecholamines, prolactin, and growth hormone is enhanced leading to increased mobilization of energy reserves, and thus, allowing individuals to adapt to the new circumstance. While some of these changes are beneficial and drive adaptation, some changes, especially when prolonged, can lead to harmful consequences and even pathogenesis. (Ranabir & Reetu, 2011)

In extreme events, contexts, and situations of crisis, stress is inflicted upon individuals as these situations are often both unpredictable and uncontrollable and threaten individual's capacities to survive without negative consequences. The following section therefore focuses on deciphering if stress impacts decision-making to further elucidate the magnitude of the impact that an extreme context plays in decision-making. What is more, since information processing plays an important role in decision-making, the impact of stress on memory retention is explored.

Impact of stress on decisions

While a large interindividual difference in stress reactions exists, stress is seen to elicit behavioral, physiological, and psychological reactions in individuals (Kudielka et al., 2009). Starcke and Brand (2012) argue that stress alters decision-making and may influence both daily decisions as well as life-altering choices. They indicate that brain regions associated with decision-making are sensitive to stress-induced changes. The link between stress and decision-making has indeed been studied on the neural level and the results show brain regions associated with intact decision-making to be sensitive to changes induced by stress. It is thus reasonable to assume that stress has an influence on decision-making. Stress effect should, for example, lead to increased sensitivity to reward through increases in specific brain areas. Stress effect may also influence decisions associated with a risk, as changes in such settings are seen in brain regions controlling functional strategy use. Stress seems to also impact decisions associated with moderate uncertainty through changes in brain activity in areas that control the interaction between deliberate calculative responses and automated emotional responses. Moreover, decisions associated with a high degree of uncertainty seem influenced by stress through changes in the brain regions controlling the feedback-processing abilities. Therefore, much evidence is gathered indicating that stress does influences the decisions made. Whether stress leads to decisions that benefit or damage the decision-maker is, however, likely to vary depending on the situation. Moreover, decision-making may also be impacted by increased susceptibility to framing effect that the neural changes initiated by stress are likely to cause. (Starcke & Brand, 2012)

Impact of stress in memory retention

Upon the experience of psychological or physical challenges, information-gathering behavior is heightened to evaluate the threat potential of the stressor. Comparing the ongoing event with the cognitive representation that is based on previous experiences will stimulate alertness, arousal, focused attention, and vigilance, and requires mnemonic processing. (Joëls et al., 2006) The influence of stress in learning and memory has been examined in multiple studies (Lupien et al., 2005; McGaugh, 2004; Shors, 2006). While it is largely recognized that stressful events are well remembered (Oitzl & de Kloet, 1992; Oitzl et al., 2001; Roozendaal & McGaugh, 1996; Sandi et al., 1997; Sandi & Rose, 1994) stress has also been associated with weakened cognitive performance such as unreliable memory for details (Christianson, 1992). Multiple variables seem to play an important role in the memory and learning process under stress including age (Lupien et al., 2005; Shors, 2006), gender (McGaugh, 2004; Shors & Miesegaes, 2002; van Stegeren et al., 1998), context (de Kloet et al., 1999), and the memory phase in which stress is experienced. Although the increases in stress hormone levels (corticosteroid hormones in particular), within the context of the learning situation generally link stress with enhanced memory, convergence in time may lead to an opposing outcome (Joëls et al., 2006). Indeed, stress hormones that generally facilitate learning when present around the time of the learning, have the reverse effect when present in high amounts before or a significant time after a learning task. Declarative memory, for example, is impaired when individuals are exposed to high levels of cortisol (a corticosteroid) 15 minutes or experience stress one hour before the learning task (Kirschbaum et al., 1996). Moreover, individuals that receive a high dose of hydrocortisone (a corticosteroid) or experience stress 24 hours after a verbal task, have been shown to exhibit poorer memory than control subjects (de Quervain et al., 2000; Kuhlmann et al., 2005). To add, the nature of learning task and the influencing stressor also play a role in determining how memory is impacted. Different stressors activate different brain circuits. Joëls et al. (2006) propose that memory facilitation will occur only if stress hormones exert their actions in the same areas as activated by the stressor. Taken together, Joëls et al. (2006) argue that for memory facilitation the physiological signals (hormones/neurotransmitters) released by the stressful situation must reach the same neuronal circuits involved in the information processing at roughly the same time as these circuits are triggered by the event. Should the increases in corticosteroid hormone levels be separated in time from the event to be remembered, suppression of learning content is observed (Figure 6).

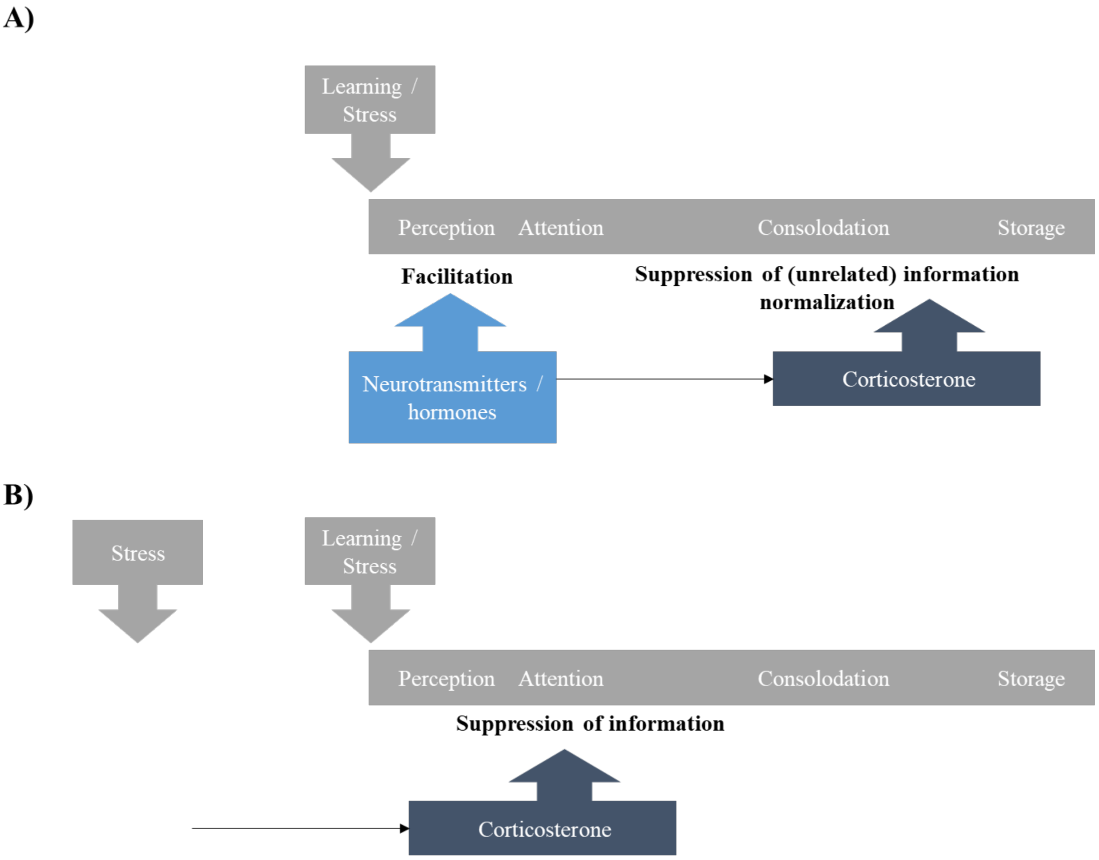

Figure 6. Stress may have opposing effects on learning. A) Stress in the learning situation leads to the release of neurotransmitters and hormones that facilitate learning. Corticosterone initiates a mechanism that results in elevated threshold for input unrelated to the initial event and delays the restore of the neuronal activity (normalization). B) If the exposure to stress occurs prior to the learning process should take place, the mechanism initiated by corticosterone that leads to information suppression is activated already upon the acquisition of the information for learning occurs. Therefore, learning processes is impaired. Modified from Joëls et al., 2006.

Medical care and decision-making

Decision-making in clinical setting is a complex and knowledge-intensive process. Treatment decisions, for example, involve a careful evaluation of not only the benefits but also risks associated with the different treatment options (Kushniruk et al., 1995). The next sections explore how decision-making in medicine has evolved through years and illustrate the diverse team structures that exist in healthcare setting today. Thereafter, the focus will shift to oncology as the remainder of this section is focused on cancer and cancer patients specifically, with a further focus on Finnish population.

Decision-making in medicine

In medicine, decision-making is continuous as questions such as "Is this examination necessary?", "Do other physicians need to be involved?", "What is the best treatment?", and so on, need assessed. Moreover, healthcare decisions are often characterized by uncertainties such as considerations on the true effectiveness of a proposed treatment, important adverse effects, applicability of the clinical research data on the specific patient, and associated costs. When dealing with such uncertainties, clinical decision-making often involves cases where no consensus on the best decision exists for individual patients (Forman & Ladd, 1989; Logan & Scott, 1996). What is more, clinical decisions regularly involve consideration of multiple factors simultaneously including the clinical problem, clinical data, patients' values and social circumstances, price and practice environment, legislation environment, as well as healthcare practitioners (HCP) capabilities and values (Gartner et al., 1990; Higgs, 2008). Still, clinical decisions often associate with long-term consequences, high stakes, and competing priorities.

According to the dual-process theory of decision-making by Kahneman (see p. 18), cognition occurs in two ways: 1) automatically and quickly by system 1 process where little if any voluntary effort is needed, 2) requiring a deliberate attention and mental activities by the system 2 process. The clinical decision-making is suggested to occur with an interactive combination of both system 1 and system 2 thinking (Graber et al., 2012).

Clinical decision-making models – engaging both physicians and patients

Decision-making is, in general, influenced by many factors including individuals' experiences, values, skills, personal perceptions and habits, and availability of information and time (Evans, 2003; Kahneman, 2002). Clinical decision-making may likewise be influenced by the HCPs personal and professional values (Smith et al., 1991). Such values result in biases which may decrease the quality of patient care. Aiming to reduce the influence of HCP biases and to facilitate patient's own involvement in decision-making, current practices endorse patient-centered and shared decision-making (SDM) models where the preferences, values, and social circumstances of the patients are incorporated into clinical decisions (Deber, 1994; O'Connor et al., 2004).

In the SDM model, physicians and patients are anticipated to agree on medical matters together (Elwyn et al., 2000). Although the model is associated with some limitations (Whitney, 2003; Woolf, 2001), the benefits outweigh the disadvantages in most cases as the engagement to the treatment and outcome of both the patient and physician are seen to increase (Drolet & White, 2012).

The SDM is characterized by three key elements: First, the patient and the treating physician shall recognize the need for a decision-making process. Second, both shall be aware of the relevant clinical indications. Third, the patient's values shall be incorporated in the model. (Légaré & Witteman, 2013). Values, as described by Hogg and Vaughan (2013, p. 175) are higher-order concepts that have broad control over individual's specific attitudes. The SDM model proposes that if the patient is aware of their values, the decisions are made in line with these values (Abhyankar et al., 2011). Consequently, a patient who is aware of their values is likely to recognize and share their preference from treatment options.

Considering the history of medicine, the inclusion of the patient and the patients' values in the decision-making process is a rather new development. The paternalistic model where the physician is the sole decision-maker and decides what is best for the patient was prevalent in the field for over 2000 years (Will, 2011a). The paternalistic model was gradually replaced by the informed consent model after the disturbing medical research and practices encountered in World War II were recognized (Will, 2011b). In the informed consent model the patients should be provided with relevant medical information that enables them to make informed decisions (Faden et al., 1986). Therefore, in this model the responsibility for medical decisions is on the patients themselves and not the professionals. Today, the SDM model is becoming increasingly popular in the clinical setting. In this model, the patients and the caregivers work together to reach decisions about care. (Baldt, 2020) Studies show that patients indeed wish to decide if they take part in the decision-making process regarding care or not (Bastemeijer et al., 2017). Patients are likely to voice their values if asked directly.

Therefore, to gain insights into patient perspectives, the physicians may need to provoke the patient values for these to be subsequently incorporated into the SDM (Baldt, 2020).

Today, patient autonomy is at the core of medical decision-making in many nations worldwide, and this right is encoded in the laws of respective countries. The Finnish patient law, for example, states the patients' rights for self-determination, right for good care and access to information. At the core of this law are patient consent, mutual understanding, and respect in care. While the physician is the one able to discern the patients' medical needs, the law necessitates the patient to be heard in treatment planning. (1992/785, Laki Potilaan asemasta ja oikeuksista) Patients right for autonomy is, however, not an obligation as Birnbacher (2012) reasons. While in SDM patients are encouraged to engage in the decision-making together with their physicians to ensure that the course of action is per the patients' values, the patient cannot be forced to reflect on their values and to take part in the decision-making process.

What is more, physician's values may exert influence on medical decisions. A study by Van Kleffens et al. (2004) on cancer patients indicates that the treatment goal influences the physicians willingness to try and persuade the patient to undergo a particular treatment. In curative setting physicians try harder to influence patients to follow their recommended treatment than in non-curative setting. To add, a study by Sanders et al. (2017) found physicians reluctant to engage in SDM if the patient prefers treatments not recommended by the clinical guidelines. Furthermore, Baldt (2020) suggests that physicians may preselect treatment options that are presented to the patient based on their values. This means that the patient does not get all viable options to choose from, which constitutes a violation of the patient's right to an autonomous decision (Beauchamp & Childress, 2001). Baldt (2020) also proposes that physicians may influence patients during the decision-making process according to their own values. Physicians are required to share medically relevant information with the patient (Légaré & Witteman, 2013). Patients regularly also ask for the physician's opinion in medical decisions (Elstein et al., 2005). While a patient's decision is likely to be influenced by the physician's recommendation, physicians should not try to influence patients' decisions with their own values.

Information overload facing the physician

The clinical picture may be incomplete when decisions need to be made, and complications such as limited resources may further complicate the decision-making process (Laker et al., 2018). To rid errors that stem from lack of patient specific health information, the healthcare industry has invested heavily in clinical information systems such as electronic health records (EHRs) over the past years. Although the goal with such systems is to ease the caregivers' decision-making by providing better access to patient information, these systems can also induce information overload where the user's decision speed and quality is lowered. Eppler and Mengis (2004) describe information overload to occur when the intensity of the task increases in such a way that the required information-processing exceed that of the engaged individuals' capabilities. The authors note that information overload greatly influences decision-makers ability to process information and results in decreased decision-making performance. Indeed, a study by Singh et al. (2013) found that specific test results may be missed in the records when the physician is faced with an overwhelming amount of information that may be available in the EHR system. Although decisions that are made with vast background information often lead to good outcomes, human capacity to absorb and process information is limited as described by the theory of bounded rationality (Croskerry, 2005; Simon, 1957; Simon, 1990). Although the EHRs and the information they hold, may lead to more efficient clinical decision-making and increased quality in patient care, these systems also associate with risks and may even contribute to errors in the clinical decision-making (Ash et al., 2004; Kuperman, 2011; Singh et al., 2013). On top of the EHR information that the physicians need to absorb and process, at the 2020 year-end 362,518 clinical trials were running (*ClinicalTrials.gov*). Moreover, already in 2012 7,508 clinical guidelines had been published (Upshur, 2014). Today this number is ever-increasing as information accumulates faster than ever. As no single individual can absorb, handle, and use all this information, teams of specialized professionals are becoming more prominent in the healthcare setting.

Teamwork in healthcare

To provide best possible patient care teamwork is often needed. In fact, Babiker et al. (2014) acknowledge how effective teamwork has immediate positive effects on patient safety and the treatment outcome. The authors suggest that the increasing amount of patient co-morbidities and the ever-increasing complexity of the medical field due to the accumulating medical knowledge necessitates teamwork. While in the past the treatment of a patient may have been in the hands of one professional, this is no longer feasible if aiming to quality patient care.

Teams play a central role in how work is conducted and accomplished in different fields including medicine (Kozlowski, 2018). In clinical settings there is a wide variety of teams and team configurations. These range from tightly coupled surgical teams to teams of consultants contributing to a diagnosis, from teams loosely coupled to manage chronic care to translational science teams that work to integrate basic science into the clinical setting. The teams delivering medical care involve different types of professional roles, each with specific expertise and assigned tasks. Moreover, team sizes range vastly. On one end, a team may be composed of one healthcare provider and a patient interacting in shared decision-making. On the other end, a team may be an extensive multiteam system where different stakeholders work towards a common goal. Healthcare teams responsibilities range from complex problem solving (e.g., diagnosis) and planning (e.g., treatment planning in multidisciplinary team meetings) to intensive procedures requiring coordination such as surgery. (Rosen et al., 2018) Since the quality of teamwork is increasingly linked to the safety and quality of health care delivery (Schmutz & Manser, 2013), much research is focused on further strengthening the understanding of teamwork processes in healthcare settings.

Decision-making and cancer

Multiple decisions are made along the cancer continuum. These decisions begin with some of our lifestyle choices that can serve as preventative measures. A healthy diet, elimination of tobacco products, and attending recommended cancer screenings are all examples of choices that individuals can make to reduce their cancer risk. Still, regardless of the choices made, cancer may arise. The outcomes of cancer prevention are realized in long-term and associate with uncertainty. As individuals evaluate outcomes experienced with specific behaviors to determine if the behavior warrants continuing, such delayed outcomes in behavior choices poses a challenge. (Rothman, 2000)

Decisions relating to the treatment are complicated by multiple factors such as uncertainty around the efficacy of the treatment and potential adverse events. With the number of treatment options on the rise, the patients and physicians are facing an increasingly complex decision. Patients may wish to weigh the benefits of different treatments with respect to efficacy data such as overall survival, duration of symptom-free survival, and time to relapse, or focus on the safety profiles associated with different treatments. As an example, the active surveillance with prostate cancer involves multiple invasive procedures (Cooperberg et al., 2011; Tosoian et al., 2011). While men choosing active surveillance avoid potential side-effects of treatment, living with a fear of the cancer potentially progressing might create unnecessary anxiety (van den Bergh et al., 2012). This fear possibly explains why many men with low-risk prostate cancer still choose active treatment (surgery or radiotherapy) regardless of the associated risk of significant side-effects (Fagerlin et al., 2005). What is more, with cancer care long-term side-effects may arise further complicating the decision-making. Patients that are, for example, considering chemotherapy may be concerned about how possible treatment related cognitive dysfunction would affect their future (Ganz, 2012). Some patients need to decide about fertility preservation (Quinn et al., 2011). Furthermore, it has been shown that our ability to anticipate emotions and preferences is limited (Wilson & Gilbert, 2003) and therefore decisions relating to future are difficult to handle.

Cancer patients who are at the end of life are also faced with multiple challenging decisions. Firstly, they need to recognize that they indeed are entering their end-of-life phase. Once the prognosis is accepted, decision is needed on whether to elect palliative rather than life-sustaining or curative goals. Thereafter multiple decision points arise. Furthermore, difficult decisions must often be made already early in the course of the disease, well before death is imminent. While ethically justified, this can be psychologically daunting as the patient is asked to envision unfamiliar health states and outcomes, and to formulate values and preferences.

Decisions relating to cancer and cancer care should ideally be based on a thorough understanding of the potential benefits, uncertainties, and harms that are associated with each alternative courses of action. Information and understanding are, after all, the basis for informed decision making (Rimer et al., 2004). However, despite ethical desirability this ideal is difficult to achieve in cancer care given the complexity of the topic. Information overload to the patient may even lead to negative outcomes as too much information may confuse or overwhelm the patient, potentially leading them to focus on information with little importance and missing the key elements (Peters et al., 2013). What is more, according to Zikmund-Fisher et al. (2010) emotions may play a key role in decisions over factual knowledge. Cancer related decision making is also subject to heuristics and biases (see page 21). For example, the uncertainty that is associated with cancer decisions may lead to risk aversive behavior as patients may be inclined to choose treatment options that associate with less risk or less ambiguity (see pages 14-15).

Decision-making criteria in oncology

In oncology decision-making often involves attention to a variety of uncertainties. These uncertainties include those related to diagnostics, the therapeutic options, and the prognosis of individual patients. Therefore, considerable disagreement on best course of action may arise as multiple options are usually available for oncological problems. (Panje et al., 2018) For a single case of metastatic renal cell cancer, for example, an overall of 11 international oncology specialists were consulted, and these consultations resulted into six different preferred courses of action (Rothermundt et al., 2015).

Glatzer et al. (2020) use three domains to categorize decision-making in oncology (Figure 7). Firstly, they focus on the criteria related to the decision-maker characteristics. In line with the SDM, they highlight that both the patient and the physician characteristics influence decision-making.

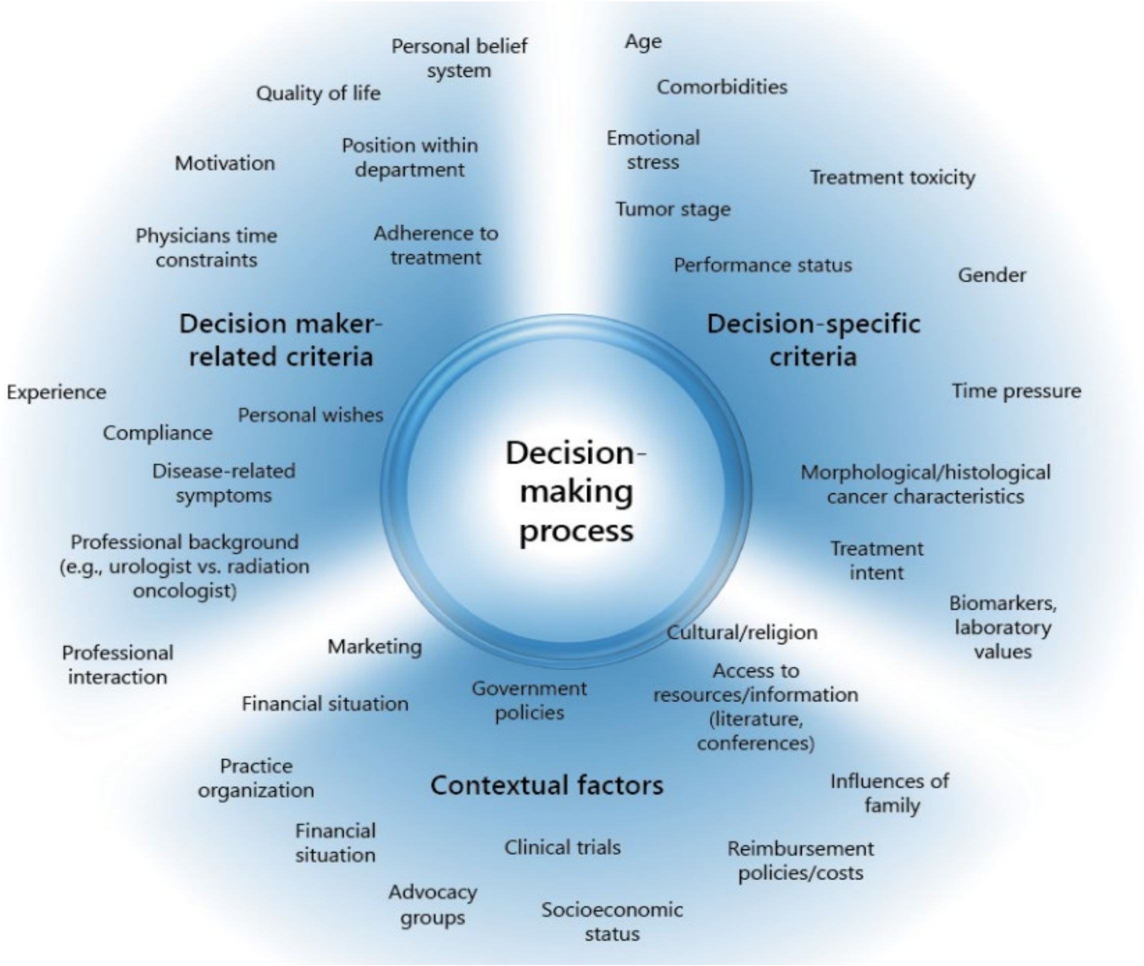

Figure 8. Decision-making criteria. The conceptual model for decision making criteria in oncology as proposed by Glatzer et al. (2020).

Consideration of different treatment options involves many psychological factors for the patient. These include prior experience, life expectancy, quality of life both during and after treatment, family preferences, and the opinions of the care provider. From the physician's perspective their experience and knowledge level affect the process of treatment decision-making. Decision-making is ideally based on high-level evidence. Therefore, informed decision-making requires understanding of current evidence together with the ability to apply the information in clinical setting for individual patients. What is more, the professional background of the physician has been shown to play a role in treatment related decision-making. According to prior studies, for example, surgical specialists prefer surgery as a treatment option while an oncologist may suggest radiotherapy or systemic treatments instead (de Jong et al., 1999; Fowler et al., 2000; Rich et al., 2011). Lack of resources may also influence treatment recommendations (Glatzer et al., 2020). Although shared decision making is the goal and is becoming more and more incorporated in the routine medical decision-making, there are limitations as the model is exposed to biases (Ozdemir & Finkelstein, 2018). Particularly if poor evidence exists, clinicians may revert to the paternalistic model (McKinstry, 1992; Rodriguez-Osorio & Dominguez-Cherit, 2008). What is more, in SDM the physicians often have control over information and therefore also on the decision-making. This may lead to a situation where the patient can only comply with the physician's recommendations. A study of patients with advanced non-small-cell lung cancer found that only 30% of the patients were sure on their treatment decision between chemotherapy or best supportive therapy (Fiset et al., 2000). Indeed, significant proportion of patients who consider preference-sensitive decisions experience decisional conflict. Optimal communication between the physician and the patient potentially helps the patient to regulate their emotions and facilitate the understanding of shared medical information. Furthermore, this allows the physician to better identify the patients' needs, their perceptions, and expectations. A positive physician-patient relationship may lead to not only higher quality outcomes but also increased satisfaction, decreases in the costs of care, increased patient understanding of their health issues, and increased adherence to treatment (Ha & Longnecker, 2010).

Secondly, Glatzer et al. (2020) discuss decision specific criteria and their influence on decision-making. These are characteristics that relate to the nature of the decision to be made. A frequently used decision specific criterion in oncology is age. The treatment recommendations for adults differ from those of or under the age of 18. Similarly, age impacts the treatment decisions for the elderly (Wildiers et al., 2007). Emerging evidence shows that patients perceived as elderly often receive less intensive treatment as younger patients are seen to tolerate such treatments better (Glatzer et al., 2017; Hurria et al., 2003). The interpretation of what constitutes “an elder” is, however, widely varying (Hundsberger et al., 2016). As this population has been underrepresented in clinical trials, the tolerability of different drugs is not well assessed in this population. Similarly, comorbidities have been associated with conservative treatment while little evidence for such need exists. Yet another decision specific criterion is the performance status of the patient. A good performance status is a prerequisite for many treatments. While such measurements may be consistent in experienced hands, wide variation in the cut-off values in clinical routine exist (Hundsberger et al., 2016). Multiple other criteria are included in this category as illustrated in figure 8.

Thirdly, Glatzer et al. (2020) include contextual factors in medical decision-making in their categorization. Contextual criteria include factors like patient’s socioeconomic status, treatment costs, the health care system, and influence from the pharmaceutical industry. The healthcare systems vary in different countries and in some settings, the best possible treatment option may not be available due to the system. Even if clinical benefit is recognized, the reimbursement of a medication may be rejected by national authorities due to insufficient cost-effectiveness (Kreeftmeijer et al., 2015). The coverage of the reimbursement system or insurance also influences the implementation of tests and procedures. Figure 8. illustrates other examples of contextual characteristics that may affect decision-making.

When patients and oncologists are faced with options, the decisions made are influenced by multiple factors that extend beyond rational and analytical decision-making models. Whether the decisions are made by individuals or teams, it is challenging to process and evaluate all relevant information. As a first step to aid and improve decision-making to be possible, it is vital to acknowledge the complexity and influence of the different decision-making criteria.

Cancer diagnosis

In 2020 cancer was the number one leading cause of death killing almost 10 million people worldwide. (Ferlay et al., 2020) Although 70% of the deaths occur in middle- and low-income countries, in Finland cancer is also on the rise (Syöpärekisteri, 2021). Aging population is one of the underlying factors for the increasing cancer incidence. Today, approximately one in three Finns receive a cancer diagnosis at some point of their life, and hence, cancer is seen to affect all Finns either directly or indirectly. (Syöpäjärjestöt, 2021; Syöpäpotilaat, 2021)

Today, cancer diagnosis is no longer a death sentence. The active research and development within the field has led to multiple advancements and while some patients may find cure, some have many high-quality years ahead. However, cancer still invokes fear in many people (Begley, 2019; Reyna et al., 2015) and the diagnosis may be difficult to take. This is well illustrated by the first reactions to diagnosis noted by Mazzocco et al. (2019): "*I was so afraid. I was sure I was going to die when I found out I had cancer. It was terrifying. I could not think about anything but what I was going to miss…*" and "*my family and I were so scared when the doctor said 'cancer'; I don't think I heard anything else that was said.*" This fear associated with cancer and cancer diagnosis is likely to impact treatment related decision-making (Reyna et al., 2015). What is more, cancer as a topic remains a taboo subject for many, and thus, discussions related to the disease and treatment selection may be difficult.

Information overload in oncology

To be an active participant in the decision-making, the patient should understand their disease and treatment options. With cancer, this would encompass understanding the disease and its effects on the body and absorbing a broad spectrum of information on different treatment options. The amount of information available is vast and complex.

Cancer is a term that is used to refer to a group of diseases that may affect any part of the body. Hence, cancers originating from different areas of the body are different from one another. In general these diseases arise though a multistep process, driven by interaction of genetic and external factors, where normal cells in pre-cancerous lesion transform to tumor cells (WHO, 2022). The etiology of the disease is often complex, and more information accumulates continuously.

What is more, the research and development pipelines of pharmaceutical companies are growing. Since the success rates in pipeline trials are historically high, the number of new products launched is expected to increase with an average of 54 new active substances expected to enter the pharmaceutical markets every year until 2023. Oncology alone is expected to represent approximately one third of these new product launches. By contrast, these figures in 2008 were 33 and 17%, respectively. In 2018, the global oncology pipeline included 849 products in late-stage development phase, an expansion of 19% from the previous year. In between the years 2014 to 2018, 57 therapies were launched into oncology market worldwide. Together, these are indicated for 89 patient populations across 23 cancer types. (IQVIA, 2019) Some of the indications include a requirement for biomarker testing underlying the move towards personalized medicine where one size does not fit all. On top of the marketed molecules, investigational drugs that have been carefully assessed in preclinical trials, enter the clinical trial phase where the safety and efficacy in human population is tested. Clinical trials are studies that aim to verify or discover the effects of investigational medicines and that are often run by pharmaceutical companies (EMA, 2022).

Decision-making after cancer diagnosis

Based on the above presented review of the literature, I propose a framework of factors that influence decision-making related to cancer treatments (Figure 9). This framework is based on the communication between the patient and the treating physician. It assumes physician to have responsibility over considering the scientific and medical evidence and sharing this information with the patient. Meanwhile, the patient is assumed responsible for sharing their understanding of the situation with the treating physician along with their wishes regarding the treatment. The patient's characteristics are likely to influence the patients' perception of the situation and willingness to take part in the treatment decisions.

The degree to which different factors influence the decision outcome vary between patients. Factors such as family and socio-economic background may influence the patient in their decision-making. It may, for example, be difficult to go against the wishes of one's family. The socio-economic background may influence decisions on multiple fronts. As one clear example, some treatments not included in the treatment selection in the public hospitals may be available through the private sector, but these come with a price tag. The patients' reaction to diagnosis, the stress it may inflict, and the patient's readiness to engage in discussion for treatment planning may also vary. The framework proposes emotions and expert opinion to also influence the patients' decision-making.

The framework assumes physicians to be likewise influenced by numerous factors. The scientific evidence together with the patient specific characteristics is expected to form the basis for the physicians' decision-making. The specialization, however, is likely to influence how the patient's situation is perceived and is likely to influence the physician's perception of most suitable treatment option. Knowledge over the healthcare setting may indicate some limitations on the treatment possibilities, hence playing into the decision-making. The framework also supposes the physician to be impacted by the opinions of other healthcare professionals and the discussion in the MDT meetings as well as the patients' preferences.

Values, biases, age, and prior experiences are factors that likely influence both stakeholders in the decision-making process. The framework also proposes that cultural tendencies may play a part in how the interaction between these two parties evolves.

This thesis investigates the applicability of this framework in the cancer patient population in Finnish cultural setting.

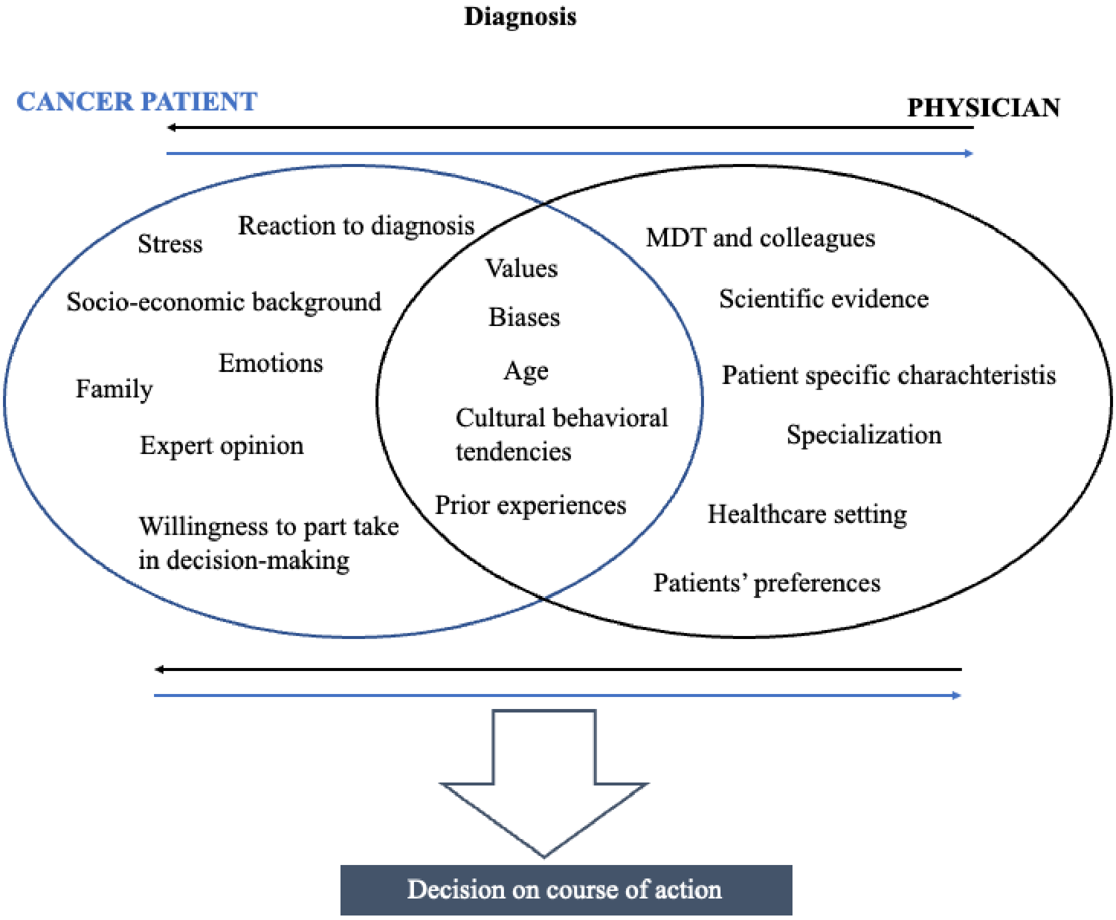

Figure 9. Factors that influence decision-making. A proposed framework of factors influencing decision-making after cancer diagnosis.

METHODOLOGY

In this section of the thesis, I describe my methodological choices for conducting the empirical part of this study. First, I touch upon the philosophical background that guided the planning of this project. Second, I present the rationale for conducting this study in a qualitative tradition and highlight the importance of this type of study in the healthcare sector. Third, I discuss the data collection and analysis in detail. I close this section with a consideration on the validity and reliability of this research.

Research approach

My underlying worldview for conducting this research is that reality cannot be directly measured. Rather, reality is relative - people construct their realities through their experiences, time, and context (Wu & Volker, 2009). Maps, for example, differ in their perspective of the world based on the geographical location of its drawer. Simultaneously, regardless of time and context, water molecules are formed when two hydrogen and one oxygen atoms share electrons regardless of location. This suggests the world to exist as a constant structure. Therefore, it seems that events in the unobservable world give rise to knowledge that we then interpret through our experiences and context. This worldview aligns with the critical realist underpinning, which forms the basis for this research. Indeed, critical realism attributed to the books by Roy Bhaskar (1994, 2013; 1979) postulate that while an observable world does exist, it is independent of human consciousness. Knowledge about the world is therefore socially constructed on individual perspectives and experiences. (Eriksson & Kovalainen, 2008) Critical realist perspective distinguishes between the empirical (human perceptions) and the actual (events occurring in space and time), while also seeking to discover the causal mechanisms. This not only has the potential to identify interesting phenomena, but also may help in understanding why things may change. (Vincent & O'Mahoney, 2016)

Aligned with the critical realist focus on understanding the social reality (Vincent & O'Mahoney, 2016), the aim of this research is to gain further understanding on how Finnish cancer patients view their role and that of the treating physician's in treatment planning, and how the diagnosis influences the patients decision-making process relating to the treatment planning. While medical decisions used to be made in a paternalistic fashion, today the SDM is gaining support in the clinical setting. This research will shed light on if and how patients feel engaged in the decision-making. Applying a critical perspective in this study allows me to take "an outside view" (Eriksson & Kovalainen, 2008) on the interaction in treatment planning that occurs between the clinician and the patient, which potentially leads to identification of problems with actionable components.

Research design

In the guideline on incorporation of psychosocial care in the routine infertility care published in 2015 (Gameiro et al., 2015) it is stated that 'qualitative research has significant value to assess the lived experiences of infertility and fertility treatment'. Yet, the authors exclude such research from the guidelines as qualitative research is 'not generally hypothesis-driven and not objective/neutral, as the researcher puts him/herself in the position of the participant to understand how the world is from the person's perspective'. Indeed, quantitative and qualitative research methods are at times seen juxtaposed, and in health services field the latter is underrepresented when compared to other fields of study. Research in the health sector is traditionally rooted in evidence-based medicine paradigm where changes in the clinical setting are based on the results of randomized clinical trials, a study design considered the golden standard. Research results from studies with a "lesser" design are accepted if practicality or ethical considerations do not allow for better study designs. The idea of hierarchy in research designs and the resulting data generated is therefore clear in the healthcare sector. It is, however, argued that objective hierarchy is an illusion. Therefore, the research methodology should be chosen to best fit the research question. (Berwick, 2008; Christ, 2014; May & Mathijssen, 2015) Qualitative methods suit well, for example, when research questions go beyond the question "what works" towards identifying what works to whom, why, when, and how. Moreover, qualitative methods are useful in elucidating the non-numerical ("soft") side of medical treatment such as patient stress (Busetto et al., 2020), and in asking questions to understand patient experience, and the everyday realities of specific social phenomena (Cleland, 2017). Indeed, as a general distinction between the two traditions, Eriksson and Kovalainen (2008) point out that the focus in multiple qualitative approaches is on understanding and interpreting different phenomena, while quantitative approaches tend to focus on explanations behind the phenomena.

Critical realism is methodologically ecumenical due to its emphasis on ontological rather than epistemological questions. The decisions on research design for critical realist largely depends on two dimensions. Firstly, the focus of the research may range from intensive to extensive. The former is associated with qualitative methods while the latter associates with quantitative research. The second dimension is the detachment of the researcher, in other words, if the role of the researcher is engaged or detached. (Ackroyd & Karlsson, 2014)

Reflecting on these two dimensions, my aim with this project was to generate rich, detailed accounts regarding Finnish cancer patients. Therefore, the study is intensive rather than extensive. As I sought to gather the patient perspectives from their point of view, I chose to take a detached position, and acted as an outside observer when conducting the empirical part of this study. With these positions on the dimensions, I conducted the research in a qualitative fashion as guided by Ackroyd and Karlsson (2014). Approaching my topic and research questions with qualitative methods, I sought to elucidate patient experiences and discover the reasons behind their views. The utilization of qualitative methods in this study bears the potential to reveal actionable insights in cancer patient care.

Ghauri and Grønhaug (2005) suggest qualitative studies to be especially useful when little prior research and insights exist. To date, little social science research has been conducted on the decision-making process of cancer patients after their diagnosis, especially within the Finnish population. This study therefore aimed to fulfil this identified research gap. Moreover and in line with Silverman (2001), this research may serve as a hypothesis-generating first phase study for a potential quantitative study where the findings of this project can be further investigated in a large data set.

Data collection

A multitude of methods are used in critical realist research. However, case studies have been suggested to be the most common and useful form of critical realist research. (Vincent & O'Mahoney, 2016) Case study as a research method refers to an empirical inquiry where a current phenomenon is investigated in its real-life context (Yin, 2009). An essential feature in case study research is the building of case(s) and answering research questions related to understanding and solving the built case (Eriksson & Kovalainen, 2008).

As my study focuses on how the decision-making process is influenced by a cancer diagnosis, I chose case study as the form of inquiry for answering my research questions.

Afterall, I wanted to collect and closely examine data within the context of Finnish cancer patients after their diagnosis and produce 'thick descriptions' of the decision-making process in this situation. Since I believe reality to be subjective, I studied multiple cases rather than just one. This decision is supported by Eisenhardt and Graebner (2007) who suggest that theories built on multiple case studies are more convincing than single case studies. For my multiple case study one patient equals one case.

Since qualitative interviews allow for the collection of in-depth information from the research participants (Brönnimann, 2022), they were utilized to collect the primary data to answer my research questions. Next, I evaluated the number of cases needed for the project to produce valuable insights that can, at least to some extent, be generalized. Eisenhardt (1989) advises to hold the number of cases studied in case studies flexible with starting from four to ten interviews. Only if new insights are still discovered after the tenth interview, more cases should be added. What is more, Clarke and Braun (2013) suggest masters level projects to include from six to fifteen interviews. With these two opinions as my guide, I decided to aim for around ten interviews. To gain access to cancer patients in Finland, I received help from the Finnish Colorectal Cancer Association, Colores ry, a Finnish patient advocacy group that posted a recruitment message on their Facebook-site and on another Facebook-site for cancer patients called 'eniten vituttaa syöpä' (freely translates to 'cancer annoys the most'). The recruitment message included a link to a webpropol-site with more information on the project and the possibility to share contact information as a sign of interest to participate in the study. Once the message was posted on the Facebook-sites, within three days I had received eight registrations to webpropol. The registration link was open for an additional week, but no new participants signed up. I concluded that unless the recruitment message is reposted, no further sign ups are to be expected. I estimated that eight participants would likely be enough to produce a good amount of data, and it matched my initial aim for the number of interviewees.

Before I started the interviews, I carefully considered the interview process and the approach to take. Silverman (2001) proposes three types of interview studies: positivist, subjectivist, and constructionist. Each approach focuses on different type of research questions, therefore, different interview questions are needed for each approach (Eriksson & Kovalainen, 2008). To holistically approach my study topic and research questions, I used both positivist and emotionalist interview approaches. With positivist approach I was able to elucidate facts (Eriksson & Kovalainen, 2008) from the participants' patient journey. This served to build a common understanding of the sequence of events and as a chance for the patients to share their experience. The patient pathways may be complex and vary from one another. Therefore, it was important for me as an interviewer to get a good understanding of each specific case to be able to relate the specific questions of their experience to correct phases of the individual paths. With the emotionalist approach I gained insights into the study participants' experiences and emotions (Eriksson & Kovalainen, 2008) throughout the patient journey up until the interviewing point.

The interviews were conducted in a semi-structured fashion whereby open-ended questions were used to cover the predetermined topics (Tod, 2006). The use of semi-structured interviews allowed for exploring spontaneous issues that arose during the interviews. Moreover, the semi-structured fashion allowed for variation in wording and sequencing of questions (Eriksson & Kovalainen, 2008). Hence, the interviews ended up conversational but guided. I chose this style for interviewing the patients for multiple reasons. Firstly, I asked the participants to share personal information that is hard to process. Thus, I wanted to have a conversational tone in the discussion to make the interview atmosphere pleasant. Secondly, I did not want to waste the participants' time and hence wanted to have a clear idea of all questions I wanted to address. Third, because the patient journeys vary, I needed some flexibility in the interview to ask additional questions. Moreover, the patients had differing ways of sharing their story, and so I needed the flexibility to rephase questions and reorder them. Once I had compiled the list of interview questions and finalized the interview guide for use, I conducted two pilot interviews to assess the structure, clarity of questions, and the time it takes to go through the interview. Since I had access to a limited number of cancer patients, I utilized my personal network to find two people with prior medical diagnoses to conduct these pilot interviews with.

I conducted the interviews through telephone and one by one. While I think the optimal setting for this type of interviews with a sensitive topic would be face-to-face, the interviews were conducted via telephone. This decision was taken because I expected the interviewees to live in various part of Finland and travelling around the country for a master's level project is not feasible timewise nor financially. Moreover, due to the COVID-19 pandemic I preferred to avoid unnecessary face-to-face meetings with people who are potentially immunocompromised. The reason for not utilizing an internet communication platform for the interviews was to ensure all interested candidates have the means to participate and not all are familiar with the different internet-based platforms. What is more, the topic for my research is, in my opinion, sensitive. Therefore, I wanted to make sure the participation threshold was as low as possible. This further guided my decision to conduct the interviews through telephone that is a familiar form of communication with an easy access. Some are shy to share a video image, and I did not want that to limit any candidates and their interest to participate. Simultaneously, however, I did not want to end up with a situation where some of the interviews included video material and some did not as I wanted all to have the same format for equality.

The interviews were conducted one by one to create an intimate environment for the interview. This sought to allow the patients to freely share their experiences and perceptions without being influenced by other people. Again, as the topic is rather sensitive, I expected the one-to-one nature interview setting to be of lower participation threshold than that of a group interview. All interviews were taped for the purpose of transcription and data analysis with the participants consents.

To protect the interviewees personal and sensitive information, I collected limited personal information during the interviews. I did not, for example, ask the full names of the participants nor other information that could easily identify the person in question.

Data analysis

While abduction in the form of theory building is embraced by many critical realists (Haig, 2005), in this research I moved from data to theories by following the inductive process of theory building. Through analyzing gathered observations, I aimed to discover patterns that point to features that explain the decision-making process of cancer patients in Finland. With this approach I sought to better understand the situation and to identify possible problems where strategic recommendations could be suggested.

I utilized thematic analysis (Braun & Clarke, 2006) to analyze the interview data. Thematic analysis is a common method for analyzing semi-structured interviews where the aim is to find patterns of themes in the data gathered in interviews. Thematic analysis is not tied to specific epistemological or theoretical positions. This theoretical freedom makes thematic analysis a useful research tool that can produce a detailed account of various types of data. As the method can be modified to suit various types of studies, detailed theoretical knowledge is not required for its utilization. Consequently, the method is accessible to also researchers in the early steps of their careers. What is more, the method is useful when research is seeking to generate unanticipated insights and to examine the research participants individual perspectives and the differences and the similarities within.

In the analysis I followed the six steps developed by Braun and Clarke (2006). Accordingly, I began the analysis process by familiarization. Transcription process is seen as a good way, if not the key, to get to know the collected data (Bird, 2005; Riessman, 1993). Therefore, I transcribed the data myself. I had eight interviews all of which were less than an hour long, and I considered this amount of data manually manageable. No data analysis software was therefore needed.

Before I started the transcribing process, I evaluated the degree of detail to include in the transcripts. As Mishler (2003) and Packer (2017) illustrate, the format of transcription is likely to influence the interpretation of the data. Therefore, it is important to utilize uniform format through the transcripts. Because my research questions are not interested in studying the language used, I decided to drift away from verbatim transcription and rather utilize intelligent verbatim. As I decided to use intelligent verbatim, I was able to translate the quotes from Finnish to English. To make sure that I did not distort the interview accounts, I made sure to include non-verbal cues in the sidenotes of the transcripts if these seemed to convey meaning. I closely evaluated my translations for accuracy. During the transcription, I made sure that all information is anonymized in the final transcript to protect the participants' anonymity. Instead of using gender based pronominals, I use they/their/them to refer to single participants.

Once I had transcribed the interviews, I moved to the step two of the thematic analysis, the coding. During this phase, I highlighted sections in the text and assigned labels that described these highlighted phrases and sentences. Moreover, for each code I used a different color to make the codes visually distinct. Once all transcripts were coded, I moved the codes and the respective text from Microsoft Word files to Excel as it is easier for me to group and organize data in Excel cells.

Next, I entered the step three of the analysis, generating themes. The themes emerged as I grouped the codes. Those codes that did not appear in at least half of the transcripts were discarded during the theme generation to focus on the main themes relevant to my research questions. Afterall, the intention was to find insights that are potentially generalizable.

In step four of the analyzing process, I reviewed the themes for their usefulness in my study. Before the last step of the analysis process, the write up of the analysis, I named the themes that made it through the revision in step four. The themes that remained after step five are: roles in treatment planning, access to information, and reactions elicited by cancer diagnosis. These themes are further explored in the empirical findings section of this thesis. As I also aimed to investigate if gender, educational background, and/or prior experiences with cancer influence the decision-making processes in the study participants, I reorganized and regrouped the data multiple times to evaluate any possible correlations with the listed characteristics.

Limitations and ethical considerations

To illustrate the rigor and validity of the methodological choices I made for this project I will next briefly discuss the limitations with the chosen approach.

Qualitative research stems from the notions of reality being socially constructed and inquiry being value laden (Denzin, 2008). Therefore, reality cannot be directly measured, and reality is dependent on individual perceptions. This notion supposes reality to be relative. (Carson et al., 2001) The fact that people interpret, understand, and experience the world differently also influences the research process, making it value laden. It is therefore possible that this research project would look very different if it was by another researcher. I am working as a medical advisor in oncology in a pharmaceutical company. This may have influenced how I built the project, and I am likely to have had multiple assumptions over the topic when I embarked on this project. This may have led me to disregards somethings that others may have held as valuable insights. On the other hand, without a strong background in oncology I think this topic would have been very difficult to handle.

I chose to conduct this study as a multiple case study. A limitation is introduced by adding cases to the project as more cases means that there is less observation time for each specific case (Gerring, 2004). Yet, I decided to interview eight participants instead of just one or two to increase the likelihood of finding generalizable insights.

I conducted qualitative interviews to gather empirical data. These are, however, always affected by the researcher and hence do not provide ‘naturalistic’ talk (Silverman, 2001). To limit the impact my experiences and assumptions to the interview, I made efforts to conduct the interviews as neutrally as possible and utilized an interview guide. I also asked questions to which I assumed to know the answers. This allowed me to find out how wrong my assumptions were at times, and hence, further highlighted the importance of trying not to frame any questions during the interview to not influence the answers. An additional limitation is introduced due to interviews being the chosen means for data collection. Interviews intrinsically include subjective perceptions which might change over time and depending on circumstance.

The study provides insights into a small number of cancer patients. Therefore, it is questionable how much their views represent a larger cohort and to what extent the results can be generalized. Furthermore, the questions I asked the participants during the interviews may have affected the data gathered and led it.

When utilizing thematic analysis as a junior researcher, the rigor of the analysis can be questioned. This is because the method is rather flexible and includes much freedom for the researcher. To avoid producing inconsistent and uncoherent insights, I sought to clearly define my philosophical starting points to underpin the relevancy of this research.

Yet another consideration involves the transcription process where the medium of data changes from verbal to written. This is a concern as nuances may not be easily transferred to text format. Moreover, the tone and pauses are easily lost in transcripts. However, throughout the conducted interviews, the tone was quite consistent through the interviews and the interviewees. I also made notions in the sidelines regarding emotions and other observations to minimize the loss of cues of emotion.

When it comes to the ethical considerations, all participants consented to participate in the study by sharing their contact information and the data gathered was anonymized. Moreover, a research data privacy notice has been provided to all participants that details the personal information gathered in conducting this study and informs on the participants rights in accordance with General Data Protection Regulation (GDPR).

EMPIRICAL FINDINGS

In this chapter of the thesis, I discuss the empirical findings of my research. I begin by introducing the participant demographics and thereafter move on to elaborate on the insights gathered during the interviews that are relevant for my research questions. The insights are divided under the three main themes that arouse from the data analysis: roles in treatment planning, access to information, and reactions elicited by cancer diagnosis.

Participant demographics

Eight Finnish cancer patients participated in and were interviewed for my research project. The participants were accrued through Facebook groups with the help the Finnish colorectal cancer association, Colores ry. The study participants resided in various regions of Finland. The interviews took place in the end of 2021.

Out of the eight participants five had a gastrointestinal tumor, while three had a primary tumor elsewhere in the body (Table 4). Within the study participants the median age of cancer diagnosis was 48,5 years, with the youngest being 37 years old and the oldest 63 years old at diagnosis. While the median ages for onset of cancer varies depending on the cancer type, the median age of cancer diagnosis worldwide is at 66 years (NIH, 2021).

Table 4. Patient characteristics.

Characteristic	Number (n=8)
Gender	
Felmale	6
Male	2
Level of Education	
Primary	1
Secondary	1
Post-secondary	6
Familiarity with cancer prior to own diagnosis	
High	5
Low	3
Tumor type	
Gastrointestinal	5
Non-gastrointestinal	3

Out of the eight study participants two were male (Table 4). The cancer incidence in Finland is depicted in figure 10.

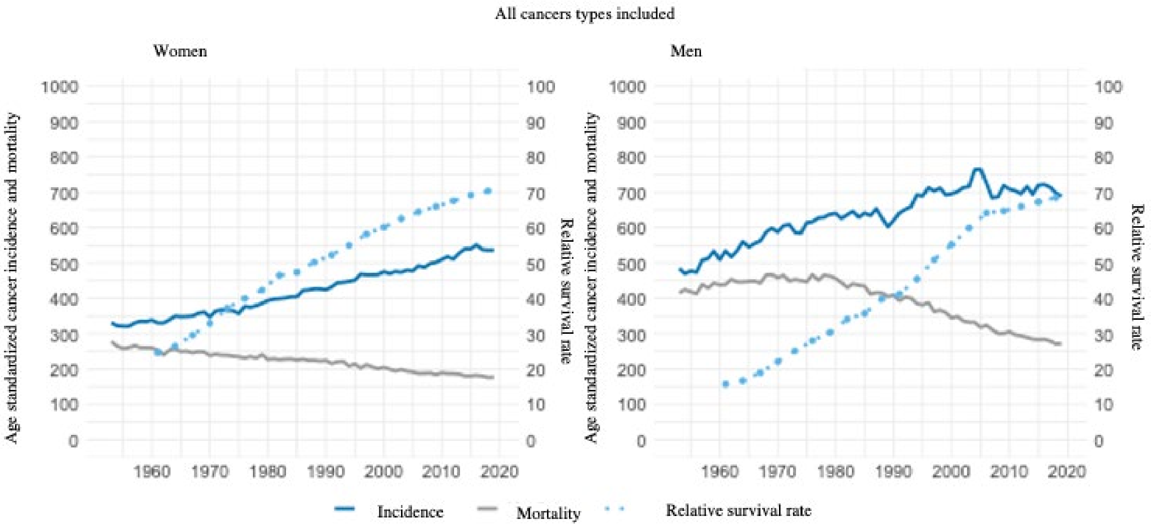

Figure 10. Cancer statistics. Cancer incidence and mortality (per 100 000 person-time and age standardized to the Finnish population in 2014) and age standardized five-year survival rate (5%) based on gender from 1953 to 2019. Modified from (Pitkäniemi et al., 2019).

Out of the eight participants, six had completed post-secondary education, one had completed secondary education and one had completed primary education (Table 4). Figure 11 illustrates the cancer incidence in Finland per level of education.

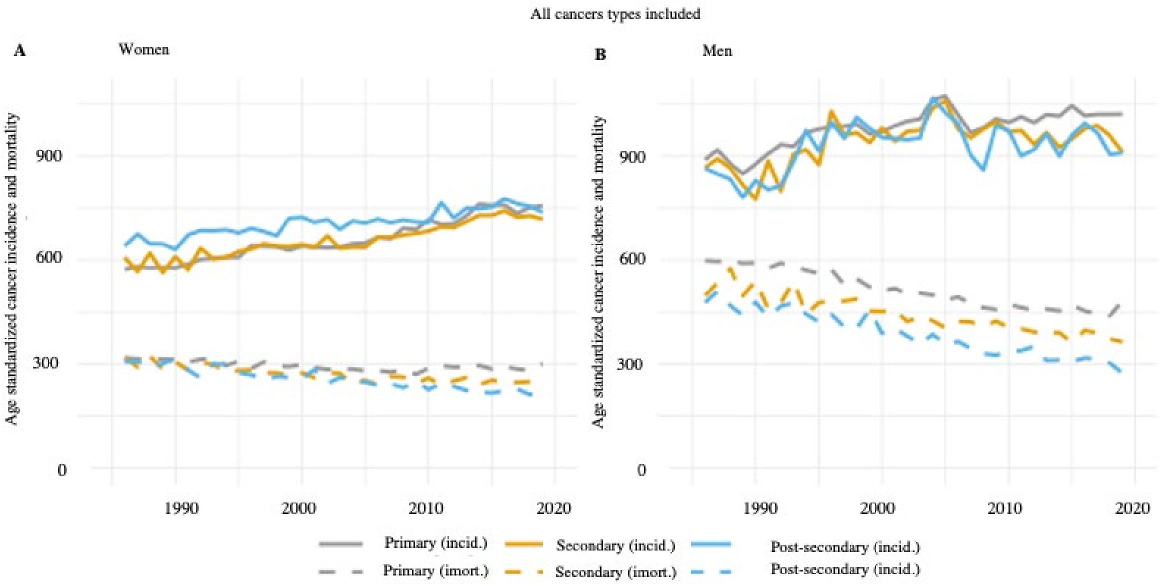

Figure 11. Cancer statistics and education. Cancer incidence and mortality (per 100 000 person-time and age standardized to the Finnish population in 2014) in population over 25 years of age per gender and level of education during the period from 1986 to 2019. Modified from (Pitkäniemi et al., 2019).

Out of the eight study participants, five considered cancers as a familiar group of diseases already prior to their own diagnosis. Out of the three study participants to whom the disease group was not familiar to, two mentioned that there had been cancer in the family but decades ago and therefore the memory of the disease is distant and did not influence their reactions to their own diagnosis.

Roles in treatment planning

The aim for this study was to investigate how Finnish cancer patients view their own and the physician's roles in determining the treatment plan. Moreover, I wanted to investigate if some of the patient's characteristic's influence their decision-making process in the treatment planning. To gather insights relating to these roles and how they are perceived by the cancer patients, I asked multiple questions to make sense of how the treatment planning evolved for the study participants. The answers were quite uniform across the study group and none of them felt like they had been well engaged in the decision-making. One of the study participants described the planning process by noting that "*I was not asked anything, the physician just told me what we are going to do.*" One out of the eight study participants had also an experience where they had been involved in the decision-making. Having first experienced a treatment planning where they were not even totally sure what all was selected for them, the experience of being engaged in the planning was of a vast difference according to the interviewee. They recounted "*together with the doctor we went through the options, discussed, and considered what we can do for me. If I did not understand something, the doctor explained, and we proceeded with our discussion. Together we decided how to treat my cancer. I was 120% satisfied and still thank the doctor for this approach.*"

One of the interviewees noted having been satisfied with the physician making all decisions. As the interview proceeded, they however mentioned: "*I was asked if I trust the treatment plan that the hospital chose for me. I said that not 100%, maybe 90%."* One of the study participants noted that: "*It makes a difference in the customer experience whether you as a patient are engaged in the treatment planning as then the decisions are "ours". Of course, most patients would not deny the options suggested by the expert.*" Indeed, engaging patients in their treatment planning would likely result in the same treatment path while increasing the patients' feelings of being heard and involved. While the study participants reported not having been engaged in the treatment planning for most of the experiences, three recount that they felt heard and had the impression that they could have brough forward their own opinions if they would have had the need.

An insight that becomes apparent from the interview data is that the patients experience differences between departments. The study participants seemed uniform in their opinions that while in the oncology ward there would have been opportunities to express own values and opinions, this was not necessarily the case with other specialists involved in the treatments.

While the study participants experienced a rather paternalistic decision-making model where the physician is the one making the decisions, they mostly seemed quite satisfied with this approach (Table 5). One of the interviewees first mentioned that they were not engaged in the treatment planning and continued to note: "*I was satisfied with how the decision related to treatment planning were made. I felt safe.*" As the interview proceeded some of the interviewees noted that they had not even considered that there could be any alternatives to that of paternalistic decision-making. One of them mentioned: *"I did not even think about being able to have a role in making the decisions. The doctors are so wise so what could I have said?"* she paused and continued: *"However, now that I think about it would have been nice if I was engaged in the discussion and had known how to bring forth my voice."* As the interview proceeded, they mentioned that a discussion guide for shared decision making would be beneficial if that would guide the patient in voicing their values and concerns. One of the study participants who agreed that a discussion guide is needed to enable patient participation raised the concern that patients might possibly get judged by their own beliefs if these do not coincide with those of the doctors. They said: "*I think there is a need for a discussion guide to ensure patient perspective is heard. However, if the patient do not share the physician's values, they need to be ready to be judged. Is this something the patients can handle? Afterall in the healthcare system, us patients, we are at the mercy of the doctor.*" She further noted it would be for the benefit of all parties if the treatment and other medical topics were discussed openly and in a two-way format.

Table 5. Treatment decisions. Most of the treatment decisions were made by the HCP, and the patients were mostly satisfied with this model of decision-making.

N=9*	Felt engaged in treatment planning	Was satisfied how decisions were made
Yes	1	6
To some extent	0	2
Not really	2	0
No	6	1

*While the data set includes eight participants, the total number of engagements was nine as one of the patients had two separate experiences.

The roles of the patient and the physician

According to the data gathered for this study, the role of the physician(s) in the treatment planning seems quite clearly to have been to make the treatment decisions for the patient in all the eight cases.

- "*Oncologist then told me that this is the treatment we will start for you.*"
- "*The doctor made all the decisions regarding the treatments.*"
- "*I knew there are treatment options, and then they chose one based on my mutation status.*"
- "*The doctor told me that we are starting with this treatment.*"

Three of the participants specifically mentioned that they felt like it was directly assumed that the treatment is to begin once it has been chosen for the patient. The treatment decisions were most likely made by a team of doctors in most of the eight cases. Some of the study participants recalled their treating physician directly referring to multidisciplinary team meetings (MDT) where the treatment options had been discussed for the cases. MDT decisions have been associated with potential improvements in quality of life for the cancer patients and in some indications also to improved survival (El Saghir et al., 2014; Hung et al., 2020; Selby et al., 2019). While the interviewees mostly expressed satisfaction with the decision-making approach (Table 5), some mentioned that they would have liked to be more active in the process. One of the interviewees mentioned: "*I was slightly dissatisfied with how the decisions were all made by the doctors. I would have liked to be engaged more and hear more on why they chose the treatments they did. I would also have had the capabilities to part take in the decision-making.*" Indeed, multiple interviewees considered that they would have had the capabilities to engage in SDM had such been initiated by the physician.

The exact role of the patient is not as pronounced in the interview data. A deep dive into the interview data revealed that two of the interviewees did not bring forth any specific responsibilities or roles for the patient. Four of the participants raised the topic of providing support to their family and making sure they do not break under the stress where they felt they had an important role to play. One of the interviewees recounted: "*My friends and family, they were in shock. I wanted to look strong on the outside and support all my loved ones. I tried to make sure they do not worry about me.*" Especially those study participants with small children had the urge to avoid bringing worry to the family. While the interviewees brought up their role in staying strong to protect their family and friends, also the converse was mentioned. The support received from family and friends was deemed highly valuable by multiple of the interviewees.

Five of the participants expressed that role of the patient is in asking questions and collecting information for themselves. The participants mentioned:

- "*The patient's role is in gathering information cannot be forgotten. The doctors are not there to discuss with the patients for hours.*"
- "*I have the facts here and now I need to ask questions. I was very focused.*"

Patient behaviour after diagnosis

While it seems that the physician(s) was (were) mainly responsible for making the treatment related decisions in these patient cases investigated in this thesis, the decision to rely on the professionals and to accept the suggested treatments are ultimately still made by the patients. I inquired the study participants for their own perceptions on if their behavior was altered by the diagnosis and the context in comparison to normal impact bearing decision-making situations.

Five out of the eight study participants reported having behaved differently than they do in situations where their health is not on the line (Table 6). One of the interviewees said: "*I was very rational. I would say my rationality was accentuated. I took emotions out, as I needed to be focused and it was not the time to do as feels best.*" Another participant mentioned that they were more trusting in others in this context that they normally are. They mentioned: "*I don't normally trust people readily, but here I just decided to follow the orders I was given*." This increased trust to others and the expert opinion was echoed by three other respondents one of whom said: "*I had no better answers, so I felt like I had to just trust the system.*" A similar sentiment was expressed by yet another respondent. They recounted: "*I usually* *deliberate more on options and decisions than I did here. That's mostly because I only had the treating physician to discuss with. Back then I was not connected to patient associations and none of my family or friends had expertise or experience.*" This sentiment of having no outside person with whom to discuss and to whom to turn to was shared by one other study participant who mentioned having had an increased trust to expert in this context. Indeed, five out of the eight study participants reported increased reliance on expert opinion after diagnosis (Table 6). Only one of the five study participants who reported the diagnosis to have changed their behavior did not report increased reliance on experts.

Table 6. Impact of diagnosis on behavior. Patients' perceptions on if the diagnosis impacted their behavior.

	Diagnosis impacted my behaviour	Diagnosis increased reliance on expert opinion
Yes	5	4
Only little	1	1
No	2	3

One interviewee described their behavior to have been closely aligned with other situations where important decisions need made (Table 6). The difference was the scale of emotions which was much broader in discussions regarding cancer and the related decisions. Two of the interviewees saw no changes in their behavior (Table 6). One of the two said that they had been exposed to similar situations before and thus this was not a new situation to them.

Access to information

To be able to make informed decisions regarding one's own cancer care, information must first be ingested. While cancer associations have produced well-written and clear patient guides to many common cancer types, much of the information that is available online for patients especially regarding the tumor type and treatments may be quite complex. Moreover, the bulk of the peer-reviewed research articles with the latest scientific findings are in English. Therefore, in this study I aimed to investigate the Finnish cancer patient's perspective on if there is enough material available that was also readily understandable for them. I also inquired on the study participants own activity on finding information online and the access to information granted through the treating healthcare professionals.

Firstly, the patient needs information on the diagnosis. For most of the study participants various endoscopic examinations revealed the presence of a tumor in their bodies, the results from imaging and pathology led to more precise diagnosis. Contact from the clinics were made via telephone, and some received the upcoming appointments via mail. Some of the study participants mentioned that the information flow regarding next appointments flowed well, while some had taken a more active role in ensuring that the next appointment follows shortly after the prior. One of the study participants mentioned: "*Approximately three years ago I had visited the doctor for this same reason and then they did an ultrasound and saw something. They ordered further tests for me and wrote a referral to specialized healthcare. No one then contacted me, and then three years later my cancer had advanced. So, I can't help wondering what happened?*"

Upon inquiring if there was enough material about the tumor type and treatment possibilities as well as other information regarding support networks etcetera available from the clinic to the patient, the answers seemed to vary between tumor types. For the more common types enough, if not too much, material had been available but for the rare cancer types this seems not to have been the case. One of the study participants with a common cancer type within the Finnish population said: "*There was so much information available and sometimes I felt like it was information overload for me*." An interviewee with a less common cancer type on the other hand had received very little information on the disease and the treatment options. They felt that the only information that was relayed to them was regarding the appointment times and answers to questions the patient realized to ask. What is more, three of the participants, all with a common cancer type, mentioned that a lot of the information was received right in the beginning:

- "*It was an information overload in the beginning as all information was poured right in the beginning.*"
- "*I got a big bunch of papers with the diagnosis, but I did not read those. It felt like it was too much, too soon*."
- "*I received information at the endoscopy examination already. It was confusing information, and I did not know what to do with it*."

Similar views on the timing of when the information was provided were exhibited:

- "*Especially in the beginning it was difficult to say what my needs for information or support were, but there seemed to be everything available. The clinic could have followed up with the possibilities later like, in the beginning you did not need this, but how about now?*"

- "*I was not too satisfied with how information was provided to me, but it is difficult to concretely say when I would have needed what.*"

Two of the study participants mentioned that it would have been beneficial to receive specific information about the upcoming appointment and the goals for the appointment. This information would have allowed them to prepare properly to discuss with the doctors and give them time to come up with specific questions. One of the interviewees even mentioned: "*It is frustrating that the appointments are used to cover topics that I could read about. And reread if something was unclear. Now I was hearing the stuff for the first time at the appointment, and it was too little time to digest it and then ask questions and discuss."* While the study participants mostly said that the information, they received from the clinic was in a language and format that they were able to readily understand, half of the participants referred to this fact that there was little time to digest it and then come up with questions. One of the interviewees said: "*The questions came after a day or two.*"

Some of the interviewees pointed out that more information specifically relating to their disease and treatment should have been shared with them:

- "*I had read that the radiation of the pelvic area may cause infertility. This was, however, never brought up by the healthcare professionals although I was in childbearing age at the time of my diagnosis and treatments."*
- "*Right from the beginning I had the feeling that everything will probably go well but I am told too little, so I felt that the information flow was not functioning. I was feeling a bit low during the treatments, so I did not complain or even write up the problems for my own reference.*"
- "*The doctor told me very little and only what was going on right then. It was basically only one of the nurses that told me what the treatment looks like as a whole. I mostly knew what to expect through Google, Duodecim, and support groups.*"

Two of the study participants were satisfied with the information flow from the clinic. Moreover, one of those who expressed dissatisfaction concluded: *"In the end, I am not sure if it would have been good to know all that I would have wanted to know."*

All study participants searched information from various internet sources (Table 7), some more and some less. The main goal for finding out more information within the interviewees was to prepare for what is to come. The patient association groups internet pages received appreciations from many on their clarity and the link to support groups. Multiple of the study participants brought forward the complexity of the material that is available online in various sites with the most recent findings. This information is in English and academic in nature.

Table 7. Sources of information. Study participants searched for information mainly from multiple sources.

	Primary source of self-study material used
Material intented for patients*	2
Material intented for professionals**	1
None	0
Both	5

*Including patient association groups webpages, Facebook sites and other patient materials

**Including physician magazines (Duodecim) and peer-reviewed research articles

One of the participants mentioned: "*It was not easy to read the materials in the beginning. Like what is adenocarcinoma and what is a flat cell*?" Also, the surgical techniques and understanding the procedures was mentioned by some of the participants as an added challenge to understanding the treatment path. One of the interviewees recalled visiting the internet sites of the different specialized healthcare regions and being confused the treatment paths seems to vary in each area by a little. They said: "*It was challenging to get a holistic view of what I am about to go through as all clinics told their own version.*"

Information retention

Since stress may impact learning processes, I sought to inquire the study participants if they felt like they were able to take the information shared by the oncologist and retain it. Out of the eight study participants, two felt like they were able to retain most of the information while the others mentioned difficulties associating to the retention of information (Table 8).

Table 8. Information retention. Patients' perceptions on if they were able to retain information that was discussed at the appointments and the use of memory aids to ensure no vital information is missed.

	Able to retain information dicussed at appointments	**Utilized a memory aid**
Yes	2	6
No	6	2

One of the study interviewees with whom the information stuck from the appointments had a healthcare professional background. They remembered retaining most of the information that was covered in the appointments, but still she mentioned: "*I always had pen and paper* *on me.*” The other one of the study participants who did not struggle with retaining the information that was shared said: “*I remembered most of what was discussed during the appointments but struggled with not being able to ask questions right in the moment.*” She continued to explain further: “*Sometimes I did not understand what was being said to me, but I did not realize this in the moment but rather after a couple of days. This is when I would have needed to ask the questions.*”

Six of the study participants mentioned issues with information retention from the appointments (Table 8). One of them mentioned: “*There was so much information coming towards me at the appointments that I was not able to retain it. Also, there is something odd in discussing cancer that makes the information hard to remember.*” Another interviewee mentioned: “*I was not able to really retain the information. This was a problem. Also, I received information here and there and sometimes it did not really go through to me, and I did not always understand what was said to me either.*” They mentioned that one of the reasons why it was difficult to retain the information was that the situation discussing their cancer was stressful. They continued: “*I had my partner with me in one of the appointments, that really helped as the partner was able to retain the information.*” Indeed, six of the study participants mentioned using memory aids, pen and paper or family member to accompany them to the appointments (Table 8), to ensure no vital information would be missed. One of the participants who always had their spouse at the appointments to write all the details down, even mentioned: “*Memory aid is definitely needed, I think.”* One of the participants who recalled actively taking notes at the appointment mentioned that: “S*ometimes I still needed to call back after the appointment and make sure I had the correct information.”* Additionally, the materials provided at the appointment worked as memory aids together with Kanta.fi internet site where information about the appointment will appear in about two weeks after.

The influence of educational background on information needs

Multiple of the study participants mentioned that much of the information available online about the different tumor types and treatment options is complex and takes time to understand. Three of the interviewees who specifically mentioned reading information form Duodecim (a physician’s magazine in Finnish) or international peer-reviewed research articles mentioned that their academic training allowed them to take on this task to figure the information out. The information on the patient association groups pages and that is available through support groups was, on the other hand, in a format that is easily understandable.

Out of the study participants, six had completed post-secondary education, one had completed secondary and one primary education (Table 4). The study participants are more educated that what could have been expected from the national distribution of cancer diagnoses in each educational level (Figure 11), and therefore, it is difficult to use the data gathered in this project to illustrate the differences between the levels of education. However, in this data set those with post-secondary education were more active in seeking out information and utilized more complex information sources. Due to the low number of participants without a post-secondary education, this may be due to chance.

Reactions elicited by cancer diagnosis

Many people still view cancer as a death sentence, and this emotional affect is likely to impact the decision-making processes of patients after diagnosis. In the sections below, insights on the study participants feelings and emotions at different phases of their path with cancer will be presented.

Emotional responses to diagnosis

A theme that emerged clearly from the interview data is the role of emotions that arise with the diagnosis. Many of the interviewees mentioned words like shock, stress, and crisis upon diagnosis or suspicion of cancer. One of the study participants mentioned: "*When I received the diagnosis, I was shocked. The doctor kept talking about a tumor, and then in the papers I saw the word 'cancer'. I needed to call the clinic to double check that do I really have cancer.*" For many of the study participants, the cancer diagnosis came as a surprise. These participants described having had mild symptoms that they had attributed to other causes. "*Shock depicts how I was feeling. I was not prepared that they would find something. We have barely any disease in my family history, and I am in a good shape. Therefore, I had this false sense of security.*" They continued to describe feelings of denial: "*I decided, I will not accept being sick.*" Furthermore, one of the interviewees recounted: "*The diagnosis was a shock; I did not feel sick at all.*"

One of the participants had experienced more severe symptoms and recalls: "*In the back of my mind I remember thinking that this is probably cancer, and I was so scared. I should have gone to the doctor sooner, but I kept postponing because of the fear of cancer* *diagnosis*." Fear was brought up by other interviewees as well. It was mentioned that "*fear was constantly present. But fear of what? I do not know. At some point I feared because the survival rate for me was poor.*" For two of the interviewees fear was present due to cancer having killed one of their parents. Therefore, they knew what could follow the diagnosis and both feared having to leave their family. One of them said: "*The fear took the form of 'I can't leave my children'.*"

One of the participants mentioned that the diagnosis did not seem to cause any impact: "*It was weird, I remained very calm when the diagnosis was discussed.*" They continued to describe: "*I went out and saw my son. He was shocked, but I remained calm. I was sure that all was going to be okay.*" They, however, later discussed having had difficulties in retaining information and other details that implied this initial reaction to have been a result of repressing of emotions. Such behavior was expressed verbally by some of the interviewees:

- *"I stopped thinking and repressed all my feelings. I acted upon orders and did not think."*
- *"I was not able to feel or think straight. I paralyzed and just was in the situation."*
- *"It was easy to repress feelings in that moment."*
- *"I was depressed and paralyzed. I did not know what to think or do. I was just digesting the news. The situation actualized when i needed to start telling people about my situation."*

Other feelings that appeared in the data set multiple times included disbelief, uncertainty, emptiness, and depression. Some had wondered: "*Why is this happening to me?*"

One of the interviewees had first received an incorrect diagnosis, and therefore, arrival to the final diagnosis was a relief: "*Now we knew how to treat it.*" This relief was preceded by feelings of disbelieve and certain death, as the initial diagnosis did not fit the symptoms and would have been a near certain death sentence.

Genders influence on elicited reactions

In the group of interviewees 25% of respondents were male and 75% were female (Table 4). Therefore, generalizations based on the findings in this study may not be appropriate. However, the two male respondents' rationality upon their diagnosis is apparent in the data set. This may however be explained by factors other than gender as well. While the other one of the male respondents calculated survival chances for himself, the other drew sketches of different surgical techniques to gain more information from the treating surgeons. Moreover, the male respondents referenced percentages for survival during the interviews. Such numerical references were not made by the female respondents. Other differences in the reactions to diagnosis other than the increased rational behavior in the male cohort in relation to survival and treatment opportunities cannot be seen in the data set. The emotions and actualization of behavior in the cohorts is aligned.

Coping with the diagnosis

From the interview data, it becomes clearly apparent that after the diagnosis, the patients switched their "work modes" on. One of the interviewees mentioned: "*It was time to treat and take care of the cancer.*" Another interviewee recounted: "*The initial shock was quite something. Thereafter I was task oriented.*" Also, sentiments of distancing their selves from the situation were recounted. One of the interviewees mentioned: "*When the doctor was talking about the upcoming treatments, I felt like we were talking about someone else. I outsourced myself from that situation.*" This feeling was echoed by statement from another interviewee: "*I felt like this was happening to someone else, I was just an observer.*" Moreover, one of the interviewees stated: "*My operating model in crisis is to act. To cope, I focused on performing.*"

In multiple interviews, the topic of trying to stay positive was brought up as a coping mechanism. One of the participants said: "*I did not want to deny my situation, but I needed to find something positive to hold on to so that I wouldn't break.*" This sentiment was echoed by two of the other interviewees. Furthermore, two of the interviewees raised the role of the people around in finding strength to cope in the situation and in bringing positivity to their lives.

Upon inquiring if the study participants ever felt like they were close to reaching the limits of their coping, three mentioned having neared the limits of their physical endurance, two had neared the limits of their mental endurance, one had neared the limits of both, and two had not neared either. One of the interviewees suffering from an incurable cancer said: "*I sometimes come close to the limits of my endurance. That is when I allow myself to take a break, but soon I raise again because I don't want the quality of life to suffer for the days that I have left.*"

The influence of past experiences on coping with the diagnosis

Five out of the eight study participants had prior experiences with cancer to the extent that they described the group of diseases to be familiar to them (Table 4). Conversely three out of the participants described cancers as an unfamiliar group of diseases. All these there reported different behavior in the context under study when compared to common decision-making situations. In comparison with this, only 40% of those familiar to cancers prior to their own diagnosis reported this context to have altered their behavior. Two out of the three mentioned that they considered the treating physician to have been the only discussion partner they had and this in part led them to trust the expert opinion more than what is customary to them. The same sentiment was brought forward in one account where cancers were a familiar disease group. Here the respondent was faced with a new tumor type and would have needed someone to dig deeper into that specific disease, much like they had done when their relative had gotten their diagnosis.

One of the three respondents to whom cancers were not a familiar disease group expressed the emotion: "*Cancers were a distant disease group to me and did not seem like my problem. When I got my diagnosis, I did not know how to react.*" In contrast, one of the study participants to whom the disease was familiar to mentioned having even been familiar with some of the personnel working at the treating clinics. Therefore, this person was able to prepare for the discussions and request physicians that would consider the respondents needs as an individual. What is more, there seems to have been more information relating to cancer support groups and means of peer support already at diagnosis with those to whom cancer was previously familiar to.

Delayed emotions

Multiple of the study participants reported experiences of delayed emotions. While their "work modes" allowed them to focus on the treatments and beating cancer, after the treatments were done, a cloud of distress had appeared to some of the interviewees as they were struck with the realization of all that they went through and the fact that it may have been a close call. One of the interviewees remembers the time: "*It was something horrible! It was a dismay. Each evening during the darkness, I started to cry, and I could not close my eyes.*" She remembered that the thought of death and the fear of it only came months after the treatments were done with. This recount of delayed emotions was brough up by three other study participants. One of them had also learned about this in a cancer seminar, where it had been said that it takes from months to a year for the patients to arrive at the realization of their situation in whole, and this is when the delayed emotions strike. Furthermore, one of the interviewees who was recently out of the treatment cycle also referred to this phenomenon: "*I am sure the psychological effects will come little by little as time passes and I become more aware of what all just happened.*" One of the patients, unfortunately, had recently learned that their cancer had progressed. Furthermore, little time since the ending of the active cancer therapy had passed for some of the study participants. Therefore, not all would have yet experienced these delayed feelings.

Outlook on the future

As crisis situations are known to change the way future is viewed, I wanted to investigate how the cancer diagnosis impacts the outlooks of future. What is more, as prospection has been seen to greatly influence our decision-making and as it might also help people deal with stress and trauma (Allen, 2019), the patient's mindsets over future are an important faucet to study.

Out of the eight study participants five reported that their outlook about the future already during the diagnosis or shortly after the diagnosis was that they can impact their future with their actions although feelings of insecurity were also present. For these interviewees, the mindset seems not to have changed through their path with cancer.

One of the interviewees reported feeling insecure about the future upon receiving the diagnosis, and the outlook towards future is now looking worse and worse.

One of the interviewees reported initial feelings of not being able to impact the future, but currently the feelings about the future have shifted to positive. For one of the interviewees, the disease has recently recurred and the outlook to future is not as bright as one could hope.

An insight that surfaced in multiple discussions is that the live of a cancer patient in follow up is in from one imaging study to the other. One of the interviewees said: "*I think it is true for most cancer patients that when the follow up appointment is approaching, you feel worried, and this may cause some physical symptoms. Once the follow up is clear, the symptoms pass*." Some of the interviewees mentioned that it is hard to forget being a cancer patient, the chance of recurrence is ever present. One of the interviewees mentioned planning their lives with a shorter timeframe now than they did prior to the diagnosis. Another interviewee mentioned making sure to enjoy life in the present and not just plan years ahead.

DISCUSSION

In this section of my thesis, I will reflect upon the general topic of my thesis and the research questions. Furthermore, I will discuss the empirical findings and evaluate their generalizability to cancer patients in a broader scale. The discussion on the empirical findings is divided under the patient demographics and the main themes that arouse from the data analysis, and hence, the structure follows that of the empirical findings section. To end the discussion section, I will specifically consider the relevance of this type of study in the healthcare setting and the benefits to patients.

Patient demographics

The patient demographics in this research (Table 4) do not reflect the Finnish cancer patient medians. Firstly, the median age of participants in this study is considerably low. Colorectal cancer, which is the second most common cancer both in women and men in Finland, is a gastrointestinal cancer where the median age of diagnosis is over 70 years within the Finnish population (Syöpäjärjestöt, 2022). Moreover, this median age is not reflective of the future of the disease as the Finnish Cancer Registry predicts a 6% decrease in cancer diagnosis in the 0 – 64 years old age group by 2030, while within the 65 – 75 and those over 75 years the incidence is expected to increase by 23% and 89%, respectively (Tuomisto, 2020). Secondly, women are overrepresented in my data set (Table 4, Figure 10). Over 35 000 cancers were diagnosed in Finland in 2019, 16 987 in women and 18 340 in men (Pitkäniemi et al., 2019). Moreover, gastrointestinal cancers are also overrepresented in my data set when comparing to the overall cancer burden in Finland (Pitkäniemi et al., 2019). Yet, these deviations from the national medians were expected and are in part, explained by the means of recruiting participants to the study.

As the participants were accrued with the help of colorectal cancer association, I expected gastrointestinal cancer patients to dominate the study population. Since colorectal cancer is the second-most common cancer in both genders after right after breast cancer (women) and prostate cancer (men), gaining insights from colorectal patients is of great value considering how common the disease is within the Finnish population. As the disease landscape between different tumor types varies, it was extremely valuable to have some participants with non-gastrointestinal tumors as well. I also expected more women to participate in my study than men. This was simply based on my own experiences with male and female behavior, and luckily two men also participated in this study to allow some generalizations also to the male population.

The fact that the median age of diagnosis in my study population was as low as 48,5 years came as a surprise to me. This is, however, perhaps explained by the means of accruing study participants through Facebook. According to statistics available online only 5,8% and 3,9% of female and male Facebook users are 65 or over, respectively. Out of all Facebook users 79,8% are, in fact, under the age of 55, matching more to the median age of the data set in this study. Furthermore, in February 2022 45.2% of Facebook users in Finland were male. This may in part, explain the higher number of female participants compared to male in this research. (NapoleonCat, 2022) The fact that the study participants were young cancer patients, leads to assume they have the knowledge and the abilities to use computers and other means to efficiently gather information. Moreover, they are likely able to investigate matters that are not clear by utilizing the information available online. Furthermore, as internet connects people around the world, population with computer skills can seek peers online to share their paths and gain support. In comparison, in 2020 it was reported that only 51% of Finnish people over 75 years old have used the internet. Moreover, only 30% in this age group used internet repeatedly during a day. (Tilastokeskus, 2021)

As figure 11 illustrates, cancer incidence is similar for the different levels of education. Therefore, the study participants with post-secondary education were overrepresented in my data set. According to the cancer incidence per levels of education, I had expected to accrue participants evenly from each level of education. However, as eight participants is a rather small sample size, this may be due to chance. Still this imbalance may bring about biases into the research results, and no concrete conclusions on the information needs for a less educated person can be drawn based on this data.

Five of the study participants considered having been familiar with cancers as a group of disease. Due to the high incidence rates of cancer (Figure 10), this was to be expected.

Overall, while the number of participants in this study is sufficient for a thesis level project, larger data set would allow for more direct generalizations to the cancer patient population.

A larger data set would likely result to a more balanced data set than what was acquired for this study and decrease the impact of chance when drawing correlations.

Roles in treatment planning

The main aim for this thesis work was to elucidate the patient perspective on the roles of the patient and the physician in planning of the cancer treatment. In the data gathered for this project, the role of the physician emerges clearly. The physician’s role seems to have been to make most of the treatment decisions (Table 5). The interviews revealed that some of the participants did not even acknowledge that alternative decision-making models such as the SDM could have been possible. This insight highlights the importance of raising discussion over engaging patients in SDM in Finland to ensure the benefits of this decision-making model (Sanftenberg et al., 2021) are realized.

Importantly, the patients interviewed in this study seemed satisfied with how the decisions relating to their care were made (Table 5). This satisfaction with the decision-making model where the patients have little influence over the course of action, to me, reflects the societal appreciation we hold towards physicians. Physicians are seen as experts whose decisions can be trusted. Indeed, multiple of the study participants mentioned that having relied more on the expert in decisions that related to their treatments than they do to other experts in other areas of decision-making. While it is not possible to gather expertise over all the topics and therefore, the opinions of subject matter experts are highly valuable, it is also important to remember that nobody is immune to bias (Dror et al., 2016). Indeed, the very process of becoming an expert breeds biases that may ultimately influence treatment decisions (Dror, 2011). What is more, as illustrated by Rothermundt et al. (2015) different oncologists can suggest alternative treatment routines for same patient. This leaves room for the assumption that there may be a role for the patients values to be input in the algorithm to find the best treatment for the specific case. The physicians may however, need to provoke the patient to share their values for these to be subsequently incorporated into the SDM (Baldt, 2020).

In Finland, there are multiple clinics where cancer is treated. While in the large university hospitals, the clinicians may be able to specialize into treating certain tumor types, in smaller regional clinics all the oncologists treat most cancer types. A nationwide observational study revealed disparities in glioblastoma survival by case volume (Raj et al., 2020). The article correlates higher glioblastoma case volumes with improved survival. Moreover, the study postulates that there may be differences in the diagnostics capabilities between hospitals. Additionally, cancer care is facing an expansion in the number of therapeutic agents that may be used for treating patients. The cost of the new agents is high, and it is challenging to know who will benefit from the treatment. Hence, making the decisions is multifaceted even for the professional.

When it comes to the role of the patient, two topics emerge from the data set. Firstly, the role of the patient in supporting the friends and family. Especially those study participants with children raised this notion of staying strong for their loved ones. Conversely, accounts on the role of friends and family in supporting the patient were also recorded. It is likely that he patients' characteristics and background influence the assumed role – if they are the ones who consolidate or the ones consoled, or both. Secondly, the patient role in asking questions was brought forward on multiple accounts. The information was mainly used to understand own situation better and to be aware of what was to come.

Access to information

The satisfaction towards access to information varied between the study participants. When it comes to information about the appointments and other practicalities some mentioned that the process worked well, while one of the study participants referrals was lost in space. This variation is likely due to chance and human error. Based on the data collected it seems the practical information flows well enough, while own activity is important in making sure everything moves swiftly.

Information about the tumor type, the treatment options, and support available to patients from the clinic seems to vary between different tumor types. Specifically, those indications that are rare in the Finnish population may not have as much information available as do those that are the most common cancer types. Furthermore, not all indications have active support groups and other activities around them. For the common cancers, multiple participants mentioned the words 'information overload' when describing the number of materials, they received from the clinics. They said there was too much information and for some, it came too soon. Peters et al. (2013) describe how too much information may confuse the patient and lead to negative consequences. Indeed, the information overload led some study participants to disregard the information or led them to focus only on some specific aspects within.

Some of the participants described the initial feelings after the diagnosis as crisis-like situation. While this may result into tendency to act (Perry and Lindell, 2003), this work mode may come into action only after an initial freeze period where information is processed differently than in stable conditions (Covello et al., 2001; Glik, 2007). Therefore, it could be that some of the information that is given right in the beginning of the patient path is not well acknowledged.

Out of the study participants 75% mentioned struggling to retain the information that was covered during the appointments (Table 8). The physiological changes caused by intense stress alter the way individuals process and act on information (Covello et al., 2001; Glik, 2007). Nuances may be missed and indeed, not all information is retained. The message may also be misinterpreted. (Hill, 2003) It seems that the stress of the upcoming appointment and the diagnosis in general leads to changes in hormone levels that influence learning at the appointment negatively (see page 34-35).

All the study participants sought information also from additional sources other than the clinics (Table 7). Indeed, most individuals in crisis situations do not rely only on one channel for information (Wester, 2011).

With this research I sought to see if the level of education influences the information needs of the patients. As six of the study participants had completed a post-secondary education (Table 4), one secondary education, and one primary education, no fair comparisons can be drawn between the different levels. However, three of the study participants themselves brought up in the discussion that due to their academic background they could take on challenging articles, even in English. Since some of the materials regarding cancer are both biologically and statistically challenging, it is possible to grasp them to differing degrees. To get the main gist of the paper, it is not necessary for the reader to understand the statistics in a way that would allow them to repeat the calculations. Moreover, the reader does not need to understand all the specifics on the biology to get the main message of the articles. Yet, familiarity with scientific articles through university studies may make the task of reading these articles less daunting and allow for deciphering the information more in detail. Based on the data set collected in this project, no generalizations on the impact of educational level on information needs can be made. Further studies are needed to elucidate if there is a need to generate different types of materials to ensure patients of different educational levels can be active members of SDM.

Reactions elicited by cancer diagnosis

The participation of the cancer patients in the treatment planning may be complicated by the emotional responses to the diagnosis. Indeed, the study participants described intense emotions that were associated with their diagnosis. Crisis specifically was mentioned by some of the participants and so was fear, an emotion that is common reaction to crisis (Wester, 2011) As Gray and McNaughton propose, fear may trigger the fight, flight, freeze response that leads to physiological changes aimed to eliminate or escape the danger. This defense mechanism interferes with information processing (Covello et al., 2001; Glik, 2007). Accordingly, some of the participants described missing nuances of what was being said to them and most experienced difficulties in retaining all information covered in appointments as discussed above. Also, some recounted having taken some words out of their context and holding on these words as a sense of hope. As discussed above, most of the study participants relied on expert opinions more than they do in other decision-making situations. Such increased reliance on experts even without information on their level of expertise is common under stress (Andreasen, 1995; Brehm et al., 2005).

Crisis situations have been said to influence the way individuals see the future. The study participants largely felt like they can influence the future, which is a sentiment towards the interviewees switching their work modes on to cope with the situation and to change things for the better. Furthermore, the study participants discussed how the diagnosis has changed the way they plan their lives: phased with the follow ups and a shorter span. Crisis situations have been said to also influence those that are not directly affected by the situation as to prepare them to face future hardships (CERC, 2019). In this study all those unfamiliar with cancer reported the diagnosis to have altered their behavior while only 40% of those familiar with the disease reported changes to their behavior. This is indicative that the previous experiences with the disease had prepared the study participants to cope with the disease. However, as the number of participants is low, this correlation needs to be validated in a larger population.

Practical implications

Much of the medical research that is done in Finland is focused on the medical sciences. By conducting a qualitative study on the cancer patients decision-making processes, I wanted to investigate the treatment planning process from the patient’s perspective. Through this project, I have been able to generate rich descriptions of the patients' experiences and have been able to gain a glimpse of what the patient goes through. The information and experiences shared by the cancer patients can be used to improve the patient experience. Through analyzing the patient reports problems in the current practices may be revealed and subsequently acted upon. What is more, even if no direct problems are revealed, areas of improvement are likely to emerge. The resources in the clinics are limited, and as the number of cancer cases each year and the cost of medications are on the rise, it is important that the patient perspective is and will be collected to ensure that all stakeholders voice is heard.

With this specific project, a key insight gathered and contributions to the current literature is the fact that the SDM model seems not yet widely adopted in Finnish cancer care. As the benefits of the model accumulate, it seems that the model has advantages. What is more, it could be that in the years to come the Digi native generations immersed in information that is available, are keen on sharing their values and being an active participant in making the treatment decisions. Therefore, this research serves as an important contribution to the literature by providing a benchmark for future research.

Future research directions

To gain further insights into the decision-making process of Finnish cancer patients, a study with a larger number of patients would be needed. This would ideally lead to insights that are generalizable to cancer patients. Moreover, studies into the use of SDM in other therapeutic areas would provide valuable information on how patients in general are engaged in treatment planning in Finland. While this study is focused on the patient population, research into the factors that influence Finnish physicians' decision-making and their attitudes towards SDM would be highly valuable.

CONCLUSION

While Greenlee and Ernst (2012) describe an active role for Steve Jobs in making treatment related decisions, the patient's role in the Finnish cancer care system seems subdued. The decision-making model across the study participants followed that of the paternalistic decision-making. Therefore, the result leads to an assumption that the SDM model is not yet widely adopted in Finnish cancer clinics. The study participants were satisfied with how the decisions were made. However, they had not realized that the treatment discussion could have been more interactive. Importantly, this finding illustrates the need to raise discussion of the benefits of the SDM in Finnish cancer clinics for its adoption to broader use.

Based on the results in this study, little correlations on the patient characteristics and their influence on decision-making can be drawn. This is due to an unbalanced data set that does not match the national medians. Nevertheless, prior familiarity with cancer as a group of diseases does seem to give some readiness to cope with own diagnosis.

The framework of factors that influence decision-making after diagnosis suggested in this thesis (Figure 9.) seems to include appropriate factors that indeed influence the patient. Further research is, however, warranted to further elucidate how these factors influence the decision-making, and on the factors influencing the physician. Should the SDM gain popularity in Finnish cancer care, the relationship between the patient and the physician proposed in the framework could also be investigated further.

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