UMEÅ UNIVERSITY

Creating access to cancer care

An exploration of patient–provider encounters in primary care, and sociodemographic factors

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Abstract

Background Access to care is widely discussed in both research and practice. However, previous research about access to care has mainly focused on individual behaviors of seeking care, and theories about access have mostly focused on quantifiable dimensions, such as supply and demand. Thus, the possibility that the patient–provider interaction may have importance for patients' access to further care has not been thoroughly explored. Additionally, time to diagnosis and treatment is an important outcome measure and quality indicator related to access to care.

Aim The overall aim was to explore how access to cancer care is created through patient–provider encounters in primary care, and whether sociodemographic factors are related to access to care, after the introduction of Standardized Cancer Patient Pathways (CPPs).

Methods A combination of different methodologies was applied for collecting data, such as participant observations and interviews, as well as data collection from medical records reviews and registers. Initially, primary care encounters between patients seeking care for symptoms that cause suspicion of cancer, that is, alarm symptoms, and their physicians were observed (study **I**). These physicians and patients were then invited to participate in individual interviews (studies **II** & **III**). Lastly, medical records reviews were performed and linked with data from the Swedish Cancer Register on patients diagnosed with colorectal cancer (CRC), and with data from Statistics Sweden and Google Maps (study **IV**). From a social constructivist perspective, the qualitative data were analyzed using grounded theory method (**I** & **II**) and thematic analysis (**III**). The quantitative data were analyzed descriptively, and analytically using Cox regression (**IV**).

Results Access is created through interaction in the patient–provider encounter, and is mirrored through processes of negotiating, embodying roles, and adhering to norms. Patients and physicians create access by negotiating the legitimacy of symptoms through processes characterized by dependency, credibility, and reciprocity (**I**). Second, physicians create access while being pulled between patients and standardized templates, which illuminates the tension between the responsibility physicians have towards their patients and the healthcare organization. It is therefore challenging for physicians to engage in person/patient-centered dialogues, interpret presented symptoms, and match them with standardized criteria (**II**). Third, standardization seems to oversimplify the complexity that underlies patients' interaction with healthcare, downplaying the individual uniqueness of each person's health problem, situation, and needs. Patients experience a need to act as both sellers and

customers when interacting with physicians in primary care and when negotiating symptoms while creating access (**III**). Lastly, even though sociodemographic factors might have impact on the interaction during encounters, sociodemographic factors, such as income, education, and distance to hospital, do not seem to be related to time to diagnosis and treatment for patients with CRC in the study regions (**IV**).

Conclusion Interaction during encounters has importance for patients' access to care, which illuminates the significance of reconciling the patient and the provider perspectives. Patients perceive demands on themselves when presenting their symptoms and use different strategies in order to legitimize these. This seems particularly challenging if symptoms are diffuse. Physicians have the responsibility to assess these symptoms and match them with criteria for CPP-referrals, criteria which are not always easy to access and apply. Furthermore, access measured as time to diagnosis and treatment among patients diagnosed with CRC in the study regions was not related to differences in sociodemographic factors.

Additionally, this thesis demonstrates the importance for physicians to acknowledge the uniqueness of each patient during encounters, to see, listen, and confirm, while operationalizing their medical expertise in order to identify suspected cancer. Such professional skills seem necessary during patient–provider encounters in primary care. Consequently, this thesis contributes to the existing body of literature by recognizing that interaction inevitably affects access to (cancer) care.

Keywords Access to care, patient–provider interaction, primary care, encounters, experiences, symptoms, cancer, time to diagnosis, colorectal cancer, standardization, sociodemographic factors

Svensk sammanfattning

Bakgrund Tillgång till vård har länge varit ett aktuellt ämne inom forskning, praktik, och politik. Tidigare forskning har främst fokuserat på diagnosprocessen samt individuella beteenden och faktorer relaterade till att söka vård, medan teorier främst har fokuserat på kvantifierbara dimensioner, så som utbud och efterfrågan av vård. Däremot har den potentiella betydelsen av interaktionen mellan patient och vårdpersonal inte undersökts tillräckligt. Vidare är tid till diagnos och behandling ett viktigt resultatmått och en kvalitetsindikator för patienters tillgång till vård och behandling.

Syfte Det övergripande syftet var att undersöka hur tillgång till cancervård skapas genom läkarbesök i primärvården, samt om sociodemografiska faktorer relaterar till tillgång till vård, efter införandet av Standardiserade Vårdförlopp (SVF)

Metod Denna avhandling bygger på fyra studier, för att samla in data till dessa användes en kombination av olika metoder. I den första studien samlades data in genom observationer av läkarbesök i primärvården med patienter som sökte vård för symptom som skulle kunna tyda på cancer, samt med deras läkare. Därefter tillfrågades dessa läkare och patienter att delta i en individuell intervju, vilket således var datainsamlingsmetoden för studie **II** och **III**. I studie **IV** inhämtades data från Cancer Registret om alla patienter som diagnostiserats med tjock-och ändtarmscancer under ett år i Region Västerbotten, Region Västernorrland, och Region Jämtland Härjedalen. Dessa data länkades sedan med patientjournaler, samt med data från Statistiska Centralbyrån och Google Maps. Från ett socialkonstruktivistiskt perspektiv analyserades sedan data från studie **I** och **II** med grundad teori, och studie **III** med tematisk analys. I studie **IV** analyserades data med statistiska metoder deskriptivt, samt analytiskt genom att använda Cox regression.

Resultat Tillgång till vård skapas genom interaktionen mellan patient och läkare. Denna interaktion består av olika dimensioner som förhandling, antagande av roller, samt att följa normer. Studie **I** visade att patienter och läkare skapar tillgång till vård genom att förhandla om symptomens legitimitet. Denna process kännetecknas av en ömsesidighet och att patient och läkare är beroende av varandra, samt att båda parter vill visa sig trovärdiga inför varandra. Studie **II** visade att läkare ibland upplever en spänning mellan det ansvar de har gentemot deras patienter kontra det ansvar de har gentemot vårdorganisationen, i form av att följa nya riktlinjer så som SVF. Således kan det vara utmanande för läkare att engagera sig i person-/patientcentrerade dialoger, tolka symptom, och samtidigt matcha dem med standardiserade kriterier. Studie **III** visade att standardisering

verkar förenkla komplexiteten av patientens interaktion med sjukvården, vilket skulle kunna riskera att det unika hos varje patient och dennes hälsa, situation, och behov förbises. I interaktionen med sjukvården, när patienten presenterar sina symptom, upplever hen ofta ett behov av att agera som både ”säljare” och ”kund” för att understryka legitimiteten av dennes symptom och vårdsökande. Slutligen, studie **IV** visade sociodemografiska faktorer, så som inkomst, utbildningslängd, och avstånd till närmaste sjukhus, inte verkar relatera till tid till diagnos och behandling för patienter diagnostiserade med tjock-och ändtarmscancer i de inkluderade regionerna.

Konklusion Interaktionen under läkarbesök i primärvården har betydelse för patientens tillgång till vård, eftersom interaktion kan förena patientens och läkarens perspektiv. Detta innebär att tillgång till vård skapas genom patientens och läkarens gemensamma handlingar under läkarbesöket. När patienter presenterar sina symptom upplever de krav på sig själva och använder således olika strategier för att legitimisterna sina symptom. Det verkar särskilt utmanande om symptomen är diffusa. Som medicinsk expert har läkaren ansvaret att bedöma de olika symptomen, identifiera och matcha dessa med kriterier för SVF, kriterier som inte alltid är lättåtkomliga. Ytterligare, tillgång till vård mätt som tid till diagnos och behandling för patienter diagnostiserade med tjock-och ändtarmscancer var inte relaterat till skillnader i sociodemografiska faktorer.

Denna avhandling belyser vikten av att läkare ser det unika hos varje patient, att de lyssnar och bekräftar patienten under läkarbesöket, samtidigt som de tillämpar sin medicinska kunskap. Sådana färdigheter verkar vara särskilt viktiga i läkarmöten med patienten i primärvården. Följaktligen, genom att visa att interaktion oundvikligen påverkar tillgång till (cancer)vård bidrar denna avhandling till det befintliga kunskapsfältet.

Abbreviations

CPP	Standardized cancer patient pathway
CRC	Colorectal cancer
DI	Diagnostic interval
EMR	Electronic medical record
GTM	Grounded theory method
NE	Nationalencyklopedin
PHC	Primary healthcare center
PI	Patient interval
PPV	Positive predictive value
RCC	Regionalt cancercentrum
RJH	Region Jämtland Härjedalen
RVB	Region Västerbotten
RVN	Region Västernorrland
SBU	Statens beredning för medicinsk och social utvärdering
SCB	Statistiska centralbyrån
SDB	Statistikdatabasen
SFS	Svensk författningssamling
SoS	Socialstyrelsen
TI	Treatment interval
WHO	World Health Organization

Original papers

This thesis is based on the following studies, which will be cited in the thesis by their Roman numerals:

I. Hultstrand, C., Coe, A.-B., Lilja, M., Hajdarevic, S. (2020). Negotiating bodily sensations between patients and GPs in the context of standardized cancer patient pathways – an observational study in primary care. *BMC Health Services Research*, 20(1). DOI: 10.1186/s12913-020-4893-4.

II. Hultstrand, C., Coe, A.-B., Lilja, M., Hajdarevic, S. (2020). GPs' perspectives of the patient encounter – in the context of standardized cancer patient pathways. *Scandinavian Journal of Primary Health Care*, 38(2). DOI: 10.1080/02813432.2020.1753388.

III. Hultstrand, C., Coe, A.-B., Lilja, M., Hajdarevic, S. (2021). Shifting between roles of a customer and a seller – patients' experiences of the encounter with primary care physicians when suspicions of cancer exist. (Manuscript accepted for publication in *International Journal of Qualitative Studies on Health & Well-being*). DOI: 10.1080/17482631.2021.2001894.

IV. Hultstrand, C., Hörnsten, C., Lilja, M., Coe, A.-B., Fjällström, P., Hajdarevic, S. (2021). Socioeconomic factors do not influence time to diagnosis for colorectal cancer in northern Sweden. (Manuscript resubmitted).

Introduction

Jag tänker på den här gamla synen på läkaren också liksom hur man äh alltså våran kanske mor och farförälders generation, hur dom liksom klädde upp sig för att komma till läkaren och sen liksom bockade och bugade och alltså det här var som något slags upphöjd allvetande varelse som ja men alltså sa läkaren att det var okey så var det okey och då behövde man inte ifrågasätta det, men så tänker vi ju inte riktigt nu längre, och det är väl lite grann det där att man är rädd att saker och ting ska falla mellan stolarna för att jamen för att systemet ser ut som det gör för att jag inte får träffa samma läkare varje gång för att jag kan glömma säga saker för att läkaren kan göra ett misstag och då, vems ansvar är det liksom så det är ju som lite så.

Excerpt from interview transcript

I think of this old view of the doctor as well as how one, maybe our grandparents' generation, how they sort of dressed up when they went to the doctor and then bent and bowed, and the doctor was like some kind of exalted omniscient being. Did the doctor say that it was okay, it was okay, you did not have to question that, but we don't think like that anymore, it is a bit like... that you are afraid that things will fall between the chairs because the system looks like it does, because I am not allowed to see the same doctor every time, because I can forget to say things, because the doctor can make a mistake and then, whose responsibility is it? It is a bit like that.

English translation

Access to care can metaphorically be described as a puzzle, consisting of three main pieces, namely, the person in need of care, the healthcare personnel, and the healthcare system. The above paragraph is an excerpt from one of the interviews I conducted with a patient during my doctoral studies that capture these puzzle pieces. From here on, I will try to describe how these pieces separately, as well as jointly, influence access to (cancer) care.

The person in need of care

The first piece of the puzzle represents the person interpreting bodily changes as well as deliberating about seeking healthcare. At first glance, it can appear as the simplest thing to seek care when we experience that we need it, at least here in Sweden. However, this is not always the case. People do not experience a symptom as their first sign of illness; they experience an embodied sensation, a change in their bodies. Camron Hay defines bodily sensations as "*embodied; it is felt experience.*" Symptoms, on the other hand, she defines as "*constructed and socially informed cognitive interpretation that indexes but it is not itself an embodied sensation.*" (Hay, 2008, p. 221). A bodily sensation may transit into a constructed symptom after it has been interpreted as abnormal through a process of interpretation and interaction (ibid.).

When we first notice a change in our body, we engage in exploring that sensation to try to understand what it is, why we feel it, how it proceeds, and whether it goes away by itself. This process is not linear, and it is more than just a matter of recognizing specific symptoms. Rather, interpreting bodily changes and transforming them into symptoms is dynamic, consisting of fluid boundaries, influenced by a sociocultural context and individual conditions (Nichter, 2008; Andersen et al., 2010; Offersen et al., 2016; Rosendal et al., 2013; Hay, 2008). How we interpret bodily changes and how we deliberate about seeking care is multifaceted, influenced by several factors such as earlier life experiences, lifestyle factors, perceived heredity, and the fact that we sometimes trivialize our bodily changes or ascribe them to something benign (Andersen et al., 2010; Macartney et al., 2017; Green et al., 2014; Hall et al., 2015; Jensen Flytkjær et al., 2015). Consequently, the deliberation about seeking care is influenced by our interpretation of our bodily changes and the society in which we are situated.

Healthcare personnel

If we decide to seek care, in Sweden we most often turn to our primary healthcare center (PHC), since that is commonly our first instance of care. This is the second piece of the puzzle, representing healthcare personnel's influence on patients' access to healthcare during encounters, which, for example, includes primary care physicians' (from here on referred to as physicians) communication, interpretation, and medical assessments. When we have reached out to our PHC, the next step is to communicate our experienced sensations, verbalizing them to enable the primary healthcare nurse or physician on the other end of the telephone (or computer screen) to make a first assessment and to prioritize and schedule an appointment with a nurse or a physician, if it is considered medically motivated. As the excerpt illuminates, it seems that we as human beings, sometimes ill and in need of care, feel responsibility for our own healthcare trajectories. Thus, we might feel that

much is at stake when we then encounter our physician, that the outcome of this encounter will depend on how well we succeed in verbalizing our bodily changes, and how these verbalized experiences are interpreted by our physician (Siminoff et al., 2011). Verbalizing bodily changes is sometimes very challenging, especially if the experienced changes are vague and diffuse (Offersen et al., 2016), which symptoms of many cancer diseases often are (Tørring et al., 2013; Neal et al., 2013). Challengingly, symptoms indicating cancer are common among the general population, although seldom connected to cancer diseases (Ingebrigtsen et al., 2013; Rubin et al., 2015).

Communication and dialogue are key features during primary care encounters (Siminoff et al., 2011). We want to be listened to by our physicians and we want them to communicate with us in words and manner that are comprehensible to us (Blackmore et al., 2021; Abt Sacks et al., 2016). Even if these basic aspects of communication are fulfilled, we connect better with some people than others; thus, it is more than the actual verbal communication that counts (Abt Sacks et al., 2016). Johansen et al. (2012) highlight that physicians' thought of malignancy rises from the interaction with their patients, which suggest that interaction may have importance for patients' access to further care. Challengingly, patients' socioeconomic position seems to influence the patient–provider interaction and communication (Verlinde et al., 2012). Besides communication, physicians' medical knowledge and skills (Blackmore et al., 2021; Johansen et al., 2012), intuitive knowing (Johansen et al., 2012), gut feelings and first impressions (Pedersen et al., 2018; Kostopoulou et al., 2017), as well as fear of overlooking malignancy, for example, cancer (Johansen et al., 2012) are traits that seem to influence their accuracy in interpreting verbalized bodily changes, and their medical assessment that consequently influences patients' healthcare trajectories.

The healthcare system

Healthcare professionals, as physicians, are situated within an organization that influences their daily practice, thus, patient–provider interaction is not an isolated phenomenon (Andersen et al., 2015). This is the third piece of the puzzle, representing the healthcare system's role in access to healthcare, such as organizational characteristics, national guidelines and policies, workload, barriers to referrals, and cooperation between primary and secondary care. As Kleinman (1980) proposes, political, economic, social, historical, environmental, and cultural factors shape the healthcare system. From past to present, the healthcare system has changed, as have our views on physicians (Hellín, 2002), just as the interviewee describes in the above excerpt. The paternalistic standpoint is outdated, and the person-centered approach is nowadays the gold standard, emphasizing the importance of

involving patients in their care (Ekman et al., 2011). However, standardization of healthcare is increasingly applied, not least within cancer care, which may have impact not only on the individual patient's health outcomes and healthcare experiences, but also on patient flow and (down)prioritizing other patient groups.

When we are ill, we need sufficient access to care, since a prolonged diagnosis may negatively affect our health and prognosis, notably within a cancer context (Tørring et al., 2017; Neal et al., 2015). Besides, we can all acknowledge that longing for care while struggling with troublesome bodily changes can be challenging, both mentally and physically. However, the emotional distress and physical burden that long wait times may cause could probably be avoided with sufficient access to care; therefore, it is essential that healthcare services are easily accessible when we need them. Interestingly, during interviews with the persons participating in this doctoral project, in conversations with friends and colleagues, and by reading witness reports from media as well as turning to earlier scholars, it seems that even if healthcare services are in some way available, it does not automatically mean that healthcare is accessible.

The contribution of this thesis

As outlined, the patient, the provider and the system are the three pieces of the puzzle of accessing healthcare. Previous research about access has mainly focused on components found in the first and third puzzle pieces, that is, the individual responsibility of acknowledging bodily changes and seeking care in a timely manner (Pedersen et al., 2013; Andersen et al., 2010), and the healthcare system's influence, for example, quality of care (Adam et al., 2017; Barber et al., 2107), lead times to diagnosis and treatment (Weller et al., 2018), and utilization of resources (Borgsten et al., 2020). Regarding the components of the second piece of the puzzle, physicians have been given much attention in research (Boyer and Lutfey, 2010); for example, research has focused on physicians' communication skills (Ha and Longnecker, 2010), sometimes through conversation analysis (Maynard and Heritage, 2005), or focused on patients' and physicians' shared perception of the communication (Röttele et al., 2020). Thus, the significance of patients' interactions with physicians as well as with the healthcare system has been overlooked in previous research and theories about access. This thesis focuses on the second puzzle piece, and contributes to the existing body of literature by expanding the concepts of access to care to encompass these interactions.

To make this contribution, I have studied access to care through the case of cancer, with particular focus on primary care. Besides exploring patients' experiences of interacting with healthcare, I have from a constructivist perspective explored how bodily sensations are constructed, legitimized, and assigned meanings during encounters in primary care. Finally, I have examined time to diagnosis and treatment as one measure of access.

Background

Understanding access to care

Access to healthcare is a multifaceted and complex phenomenon (Andersen et al., 2014; Gulliford et al., 2002; Norman, 1982); yet, it is an inevitable and vital concept within health policy and practice (Penchansky and Thomas, 1981; Andersen et al., 2014; Levesque et al., 2013). A universal agreement about its definition is lacking, and the terms access, availability, and accessibility are often used synonymously and interchangeably (Penchansky and Thomas, 1981; Ricketts and Goldsmith; 2005; Frenk, 1992).

Some of the most used definitions of access are "dimensions which describe the potential and actual entry of a given population group to the health care delivery system" (Andersen, 1983, p. 51), and "the ability of a client or a group of clients to seek and obtain care" (Frenk, 1992, p. 845). Others have focused on the degree of fit between users and health systems (Thomas and Penchansky, 1984; Donabedian, 1973), or have focused on fulfillment of needs when defining access (Waters, 2000; Levesque et al., 2013). A more recent and somewhat more inclusive definition is suggested by Andersen, Davidson, and Baumeister: "actual use of personal health services and everything that facilitates or impedes their use. It is the link between health services systems and the population they serve. Access means not only visiting a medical care provider but also getting to the right service at the right time to promote improved health outcomes" (Andersen et al., 2014, p.33-34).

Up until the 1960s when Ronald M. Andersen introduced "*The Behavioral Model of Health Services Use*," access had mainly focused on healthcare expenditures and costs. Andersen's (1968) model of access proposes that to use healthcare services there must be predispositions to receive such (e.g., sex, educational level, values and beliefs), there have to be enabling factors to be able to use the services (e.g., income and availability of services), and there must be a perceived need for them (e.g., illness and symptoms).

The original model developed by Andersen (1968) has during the last decades been frequently revised and developed (Andersen and Newman [1973] reprinted 2005; Aday and Andersen, 1974; Andersen et al., 1994; Andersen, 1995). For example, the concept of mutability was introduced, which refers to the extent a component (e.g., social structure) can be altered to influence access (Andersen and Newman, 2005), and the healthcare system was explicitly included (Aday and Andersen, 1974). Furthermore, together with LuAnn Aday, Andersen (1974) recognized that the original framework was limited, since it mainly focused on

characteristics of the users and characteristics of the system. Consequently, Aday and Andersen put emphasis on health policy and consumer satisfaction in their revision, which they then came to name "*Framework for the Study of Access to Medical Care*" (Aday and Andersen, 1974). Later, during more recent years, a sixth version of the model has been developed that puts emphasis on health behaviors and individual and contextual characteristics, together with the feedback loops that continue to be important elements, mirroring how outcomes might alter health behaviors (Andersen et al., 2014).

Roy Penchansky and William Thomas have suggested an alternative approach to understanding the concept of access, theorized as five closely related dimensions: Availability, Accessibility, Accommodation, Affordability, and Acceptability. These dimensions are proposed to describe the fit between healthcare users' needs and the healthcare organization's ability to meet these needs. Availability refers to the fit between existing available health service resources and the volume of patients and their needs. Accessibility refers to the fit between the geographical distance between the location of the healthcare service and the people. Accommodation refers to the fit between the way the healthcare organization is organized and the peoples' ability to accommodate these (e.g., opening hours, drop-in option, waiting time). Affordability refers to the fit between the price for healthcare services and people's ability to pay; it includes the healthcare users' perception of the worth in relation to costs. Acceptability refers to the fit between the healthcare providers' and people's assumptions and attitudes towards each other, including culture and attitudes (Penchansky and Thomas, 1981; Thomas and Penchansky, 1984). Recently, awareness of services has been suggested as a sixth dimension of this framework (Saurman, 2016).

Levesque et al. (2013) contribute to the past and present struggle of defining access by conceptualizing five dimensions of accessibility, namely, Approachability, Acceptability, Availability and accommodation, Affordability, and Appropriateness. These five dimensions have corresponding and interacting abilities related to the person seeking care: Approachability – Ability to perceive, such that people who have healthcare needs can identify that services exist, which is influenced by information, transparency, outreach activities, health literacy, and health beliefs. Acceptability – Ability to seek, referring to cultural and societal factors that influence people's possibilities of accepting healthcare services, such as sex, norms, values autonomy, and knowledge about healthcare options. Availability and accommodation – Ability to reach, referring to healthcare services being reachable, both physically and in terms of time, which is influenced by geographical locations and opening hours, as well as the abilities of personal mobility and availability of transportation, and social support. Affordability – Ability to pay, referring to people's capacity to pay for, and to spend time to use, healthcare services, including direct and indirect costs as well as social capital.

Appropriateness – Ability to engage, referring to the fit between people's healthcare needs and existing healthcare services, including extent of services, timeliness, and quality of care, as well as people's ability to engage in healthcare, for example, through empowerment and shared decision-making (Levesque et al., 2013).

Access to care has previously been studied in a range of different contexts and settings, with a broad variety of outcome measures. However, research about access has mainly focused on quantifiable factors such as financial (Boehmer et al., 2019; Hong et al., 2019; Bustamante et al., 2019) and geographical dimensions (Hong et al., 2019; Johnson et al., 2016; Aboagye et al., 2014; Bergin et al., 2018). Some scholars have used the number of healthcare contacts as a measure of easier or poorer access (Mazzucco et al., 2021; Bustamante et al., 2019), or analyzed whether the supply of physicians influences access (Guttmann et al., 2010). Changes in access over time have been examined (Saunders, 2021). Access has been measured in terms of healthcare usage (Farrants et al., 2016), including regional differencs in healthcare usage (Johansson et al., 2018), and inequalities in healthcare utilization have been analyzed (Wagenius et al., 2019). It has been reported that trust, multidisciplinary teams, medical expertise, and ease of contacting health services are conditions that have importance for adolescents' healthcare accessibility (Goicolea et al., 2018), and interaction during encounters has previously been surveyed by examining patients' experiences of the encounter (Hong et al., 2019). In the context of cancer, access has mainly been measured in terms of patients' time to diagnosis and treatment (Tørring et al., 2019; Baun et al., 2019; Helsper et al., 2017).

To summarize, existing models and frameworks of access highlight geographical, financial, and organizational barriers to accessing healthcare; thus, the focus on quantifiable measures, such as availability of healthcare services, permeates all of the existing theories. My synopsis that the core dimensions of the presented access theories have quantifiable features is not surprising, since today's society is profoundly focused on factors that are quantifiable and measurable to be able to assess indicators of quality of care (Bornemark, 2018). However, "Everything that can be counted does not necessarily count. Everything that counts cannot necessarily be counted" (Albert Einstein).

Even though some of the more recent theories of access to care do include dimensions that address norms, cultures, and attitudes, they fail to address interaction as one dimension of access, which might be especially relevant, since the patient–provider interaction has importance for patients' health outcomes (Hellín, 2002; Mead and Bower, 2000).

Cancer and the importance of access to care

Prevalence and incidence of cancer

The cancer incidence is rising due to an aging population, population growth, and also for some cancers, an increase in lifestyle-related risk factors such as smoking, alcohol consumption, exposure to ultraviolet radiation, and increasing obesity (Hofmarcher et al., 2019; WHO a). In Europe during 2016, more than one in four deaths were due to cancer (Hofmarcher et al., 2019), making cancer the second leading cause of death, after cardiovascular diseases (WHO b; WHO c; Allemani et al., 2018; Hofmarcher et al., 2019). In Sweden, 65,956 persons were diagnosed with cancer during 2019, and 23,452 persons died following their cancer disease the same year. Lung cancer is the cancer disease with the highest mortality (SDB SCB; SoS, 2020).

Besides Denmark, the Nordic countries have among the highest cancer survival rates in Europe, and the survival trends are in general increasing (Allemani, et al., 2018; Hofmarcher et al., 2019). However, in Denmark, the cancer mortality exceeds the deaths from cardiovascular diseases (Hofmarcher et al., 2019). The cancer incidence in Sweden was around 550/100,000 persons during 2018, while Denmark's cancer incidence was one of the highest in Europe (>600/100,000). Iceland had, on the other hand, one of the lowest incidence rates of cancer the same year (400/100,000) (Hofmarcher et al., 2019).

Worldwide, the three most common cancers for both sexes combined are breast (11.7%), lung (11.4%), and colorectal (10.0%) (IARC). In Sweden, for women separately, breast cancer (26.2%) is the most common cancer, followed by colorectal cancer (CRC) (11.2%). Whereas for men, prostate cancer (32.5%) is the most common cancer, followed by CRC (10.5%) (ibid.). In 2019 in Sweden, 8288 women and 10,984 men were diagnosed with breast and prostate cancer, respectively (SoS, 2020). Figure 1 presents an overview of the estimated number of cancer cases for both sexes combined.

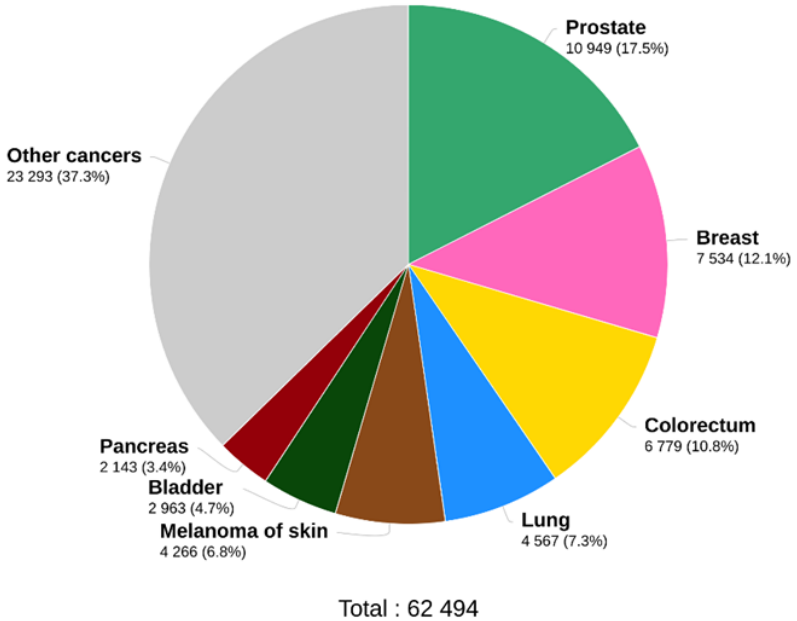

Figure 1. Estimated number of new cases in Sweden 2020, both sexes, all ages. (Graph from iarc.who.int)

Colorectal cancer is a cancer disease with similar incidence for women and men (IARC), even though the incidence of rectal cancer is higher among men (RCC, 2020). The CRC mortality has during recent decades decreased following improvements in treatments (RCC, 2020). Even so, in 2019, 2621 persons died of CRC in Sweden, which corresponds to a mortality of 31/100,000; however, the mortality varies between regions (Folkhälsomyndigheten, 2021). In Europe CRC is the second leading cause of cancer death among men, and third among women (Ferlay et al., 2018); however, survival from CRC varies, even within Europe (Allemani et al., 2018). Colorectal cancer is in particular focus in study **IV**.

Diagnosing cancer: timely diagnosis and the waiting time paradox

Cancer can present with signs and symptoms that are more or less typical; these symptoms are known as alarm symptoms, red flags, or warning signs of cancer. Challengingly, symptoms of cancer are common among the general population, ambiguous, common for benign diseases, and they are seldom connected to cancer diseases (Hamilton et al., 2009; Walter et al., 2016; Adelstein et al., 2011; SBU, 2014, Rubin et al., 2015). On the contrary, not all persons diagnosed with cancer have experienced alarm symptoms, which makes diagnosing cancer

difficult (Hamilton et al., 2009; SBU, 2014). Adding to the complexity, the positive predictive values (PPVs) for many symptoms of cancers in primary care are in general low (Shapley et al., 2010; Ingebrigtsen et al., 2013; Lyratzopoulos, 2014; Rubin et al., 2015), rarely over 10% (SBU, 2014), which means that persons experiencing bodily changes and symptoms indicating cancer will seldom have cancer. For example, the PPV for CRC is low when being presented as a single symptom (Ewing et al., 2016; Huggenberger and Andersen, 2015). In one study, the PPV ranged from 0.9 for abdominal pain, to 3.9 for bleeding, when presented as a single symptom (Ewing et al., 2016). However, it has been suggested that the PPV for non-metastatic CRC is greatest for the combination of bleeding and change in bowel habit, or bleeding with abdominal pain (ibid.). Other research suggests that weight loss and change in bowel habit increase the risk of CRC when rectal bleeding is also present, compared to rectal bleeding alone (Astin et al., 2011). The diagnostic values of symptoms for other cancer, such as esophagogastric cancers (Astin et al., 2015), pancreatic cancer (Schmidt-Hansen et al., 2016), upper gastrointestinal cancer (Rasmussen et al., 2018), and lung cancer (Haastrup et al., 2020) are also shown to be low. Besides clinical parameters, patients' reasons for seeking care, and their statements during encounters, have diagnostic value in themselves (van Boven et al., 2017).

Studies show that patients presenting with vague symptoms often have longer time to diagnosis than patients presenting with alarm symptoms (Neal et al., 2013; Tørring et al., 2013), and prolonged time to diagnosis is associated with more advanced disease for many cancer diseases in general (Rubin et al., 2015; Neal et al., 2015), including CRC (Tørring et al., 2017). Challengingly, there is research that reports a U-shaped association, that the CRC mortality increases with shorter and longer time to diagnosis (Tørring et al., 2012; Tørring et al., 2013). This is probably explained by an aggressive and advanced disease at presentation, as well as tumor biology. Perhaps it is also influenced by patient behavior, and the organization of the healthcare system, which point to the underlying complexity of accessing healthcare and diagnosing cancer.

That patients sometimes seem to have worse health outcomes despite being rapidly diagnosed is known as the "waiting time paradox" (Tørring et al., 2017). It is suggested that the waiting time paradox is related to confounding by indication, which means that patients receive different priorities probably due to their symptomology as well as their physicians' interpretation and assessment of their health condition (Neal et al., 2015; Tørring et al., 2017). Thus, diagnosing cancer and measuring lead times is complex. Lead times in the process of cancer diagnosis are, though, important measures that define various time intervals (previously known as delays) between certain events within patients' care trajectories. The total interval, that is, time from interpretation of a symptom to treatment start, covers a broad period including several time intervals in which

the patient interval, (PI), that is, the time from first symptom to first healthcare visit is one of them, and the diagnostic interval (DI), that is, the time from first symptom presentation/clinical appearance to diagnosis, and treatment interval (TI), that is, the time from diagnosis to start of treatment are others (Weller et al., 2012). These intervals may be interrelated but also separately represent a specific actor's – patient's, doctor's, or system's – main accountability for that specific part of the diagnostic process. Figure 2 presents an overview of the PI, DI, and TI.

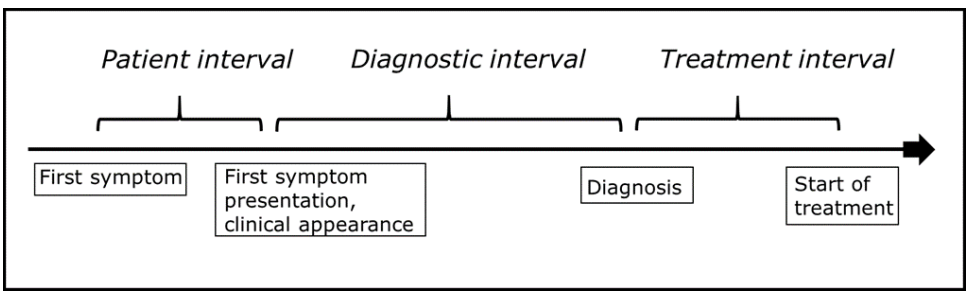

Figure 2. Schematic picture of the patient, diagnostic, and treatment intervals. Inspired by Olesen et al., 2009, and Weller et al., 2012.

Standardized cancer patient pathways to improve access to care

Standardization of care has become more and more common, often stemming from the arguments that standardization can more efficiently allocate resources, improve quality of care, avoid unnecessary testing, and reduce costs, thus having the potential to benefit both patient and providers (Lavelle et al., 2015). At the same time, standardization of care is also criticized for being "cookbook medicine" (Knaapen, 2014), neglecting the intrinsic uniqueness of every person and health condition. Thus, standardization can be perceived as reductionistic, contradicting the holistic perspective (Timmermans and Epstein, 2010; Knaapen, 2014). However, standardization of care is also thought of as an attempt to make care more equal, in terms of reducing regional differences (Wilkens et al., 2016).

Good healthcare on equal terms for the entire population is a tenet of Swedish healthcare (SFS 2017:30 3 kap. 1 §), and cancer care in Sweden is in general characterized by good quality and high survival; despite that, the waiting times are long and vary within the country (SoS, 2014; SoS, 2015; Wilkens et al., 2016). To improve accessibility and equity in cancer care, the Swedish government launched the National Cancer Strategy for the Future in 2009. As a response to this cancer strategy, six regional cancer centers were established in 2010, working towards the common goal of promoting cancer care and cancer research across regional boundaries (En nationell cancerstrategi, 2009). Later, in 2015, a national reform of standardizing the diagnostic process was introduced, namely,

Standardized cancer patient pathways (CPPs) (*Standardiserade vårdförlopp*), with the main goals being to reduce waiting times and regional differences, as well as to increase patient satisfaction. When introducing the CPPs, Sweden was highly inspired by a similar national policy in Denmark, which introduced, developed, and implemented patient pathways for 32 cancer diseases during 2008–2009, so-called "Pakkeforløb" (Probst et al., 2011). Not only Sweden was inspired by the Danish policy; in the same year CPPs were launched in Sweden, Norway introduced a similar cancer strategy (Nilssen et al., 2019), but with a more rapid implementation (Wilkens et al., 2016). An even earlier example is the English "two-week-wait," which is a similar cancer strategy on national level that was introduced in 2000 (Dodds et al., 2004).

Standardized cancer patient pathways were initially introduced for five cancers: acute myeloid leukemia, and head and neck, esophageal and stomach, prostate, and ureteral and bladder cancer. Today, there exist CPPs for 31 cancer diagnoses, which were introduced in all healthcare regions between 2015 and 2018 (SoS, 2019a; SoS, 2019b). The most common CPPs are for breast, CRC, ureteral and bladder, and prostate cancers (Regionala cancercentrum i samverkan, 2021).

Each CPP functions as an organizational tool, individually designed for each specific cancer diagnosis with specific sets of indicators and diagnostic procedures that are allocated specific time frames. This means that the clinical guidelines define specific time frames for certain events of patients' diagnostic trajectories. A concept called well-founded suspicion (*välgrundad misstanke*) was introduced alongside the CPPs. These are often based on alarm symptoms and unique for each cancer diagnosis, and constitute an important time point when cancer is perceived as a significant risk. The CPP starts when cancer is suspected, usually in primary or secondary care, and ends when treatment is initiated (Wilkens et al., 2016; SoS, 2019a; SoS, 2019b). Figure 3 demonstrates the diagnostic route for a patient included in a CPP.

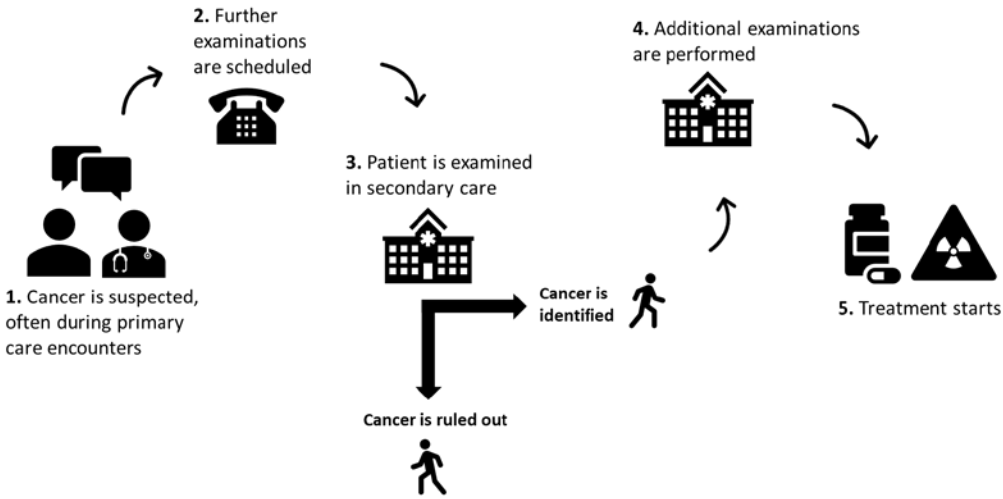

Figure 3. Schematic picture of the route of standardized cancer patient pathways.

The number of patients who are referred into a CPP and have cancer varies between the different pathways (cancer diagnoses); these variations are to some extent explained by clinical and biological indicators (SoS, 2019b). For example, during 2016–2019, 46,030 persons were referred into the CPP for CRC; of those, 27% started cancer treatment (i.e., received a cancer diagnosis). The same year, 43,250 persons were referred into the CPP for breast cancer, and of those, 45% started cancer treatment. Between 2015 and 2019 47,800 persons were referred into the CPP for ureteral and bladder cancer, and 11% of those started cancer treatment (SoS, 2019b), which illustrates the challenges of identifying cancer based on alarm symptoms.

Standardizing cancer care is, however, not that easy, since symptoms of cancer are, as mentioned, common among the general population, ambiguous, and seldom connected to cancer disease (Hamilton et al., 2009; Walter et al., 2016; Adelstein et al., 2011; Rubin et al., 2015), and the PPV for many symptoms of cancer is low (Shapley et al., 2010; Ingebrigtsen et al., 2013; SBU, 2014). Prior to the introduction of the CPPs, the Swedish agency for health technology assessment and assessment of social services (SBU) concluded that there was no evidence of the effectiveness of the CPPs; still they were introduced into the Swedish healthcare organization (SBU, 2014). Furthermore, today there exist, as mentioned, CPPs for 31 cancer diseases. The information tailored for primary care (the short version) about these 31 pathways is 66 pages long. This version, and the original versions, can be found at cancercentrum.se.

Sociodemographic factors and access to cancer care

It is not only factors related to healthcare services that influence people's health; social determinants of health, that is, "conditions in which people are born and, grow, live, work and age" (WHO d) also have significance for health. Thus, social determinants of health, and in particular, socioeconomic factors such as income and education, are reported to shape health and health outcomes (Braveman and Gottlieb, 2014).

There seems to be a social gradient in health, namely, that people with lower socioeconomic positions often have poorer health, both globally (WHO c; Marmot et al., 2008) and in Sweden (Degerlund Maldi et al., 2019). This means that differences in, for example, income and education cause unfair and avoidable differences in health (WHO d). Thus, sociodemographic factors, such as income and education, are important determinants of health (Lindstrand, 2006; Braveman and Gottlieb, 2014). In the context of cancer, there seem to exist sociodemographic inequalities in stage at diagnosis. For many cancer diseases, including CRC (Feller et al., 2018), people with lower socioeconomic position are more likely to be diagnosed at a more advanced stage than people with a higher socioeconomic position (Barclay et al., 2021). Also, people with lower income and shorter education have lower cancer survival in many cancer diseases (Dalton et al., 2019; Teng et al., 2017; Finke et al., 2021; Bergqvist et al., 2018). Previous research also indicates that people in rural areas seem to have longer time to diagnosis (Flytkjær Virgilsen et al., 2019) and poorer survival of CRC (Beckmann et al., 2015) than people living in more urban areas.

In Sweden, it has previously been reported that socioeconomic positions influence cancer care, for some cancer diseases. For example, cancer is often diagnosed in an earlier stage among people with longer education. Also, there exist differences in cancer care and treatment between regions; these differences are greatest for prostate cancer and least for CRC (Vård- och omsorgsanalys, 2019:8). Furthermore, research shows that there exist regional differences in time from referral to start of treatment for patients with cancer. For example, the waiting time in different regions for rectal cancer ranged between 48 and 80 days, while for prostate cancer the waiting time ranged between 117 and 280 days. Differences between different cancer diseases are also reported; for example, the median waiting time for breast cancer was 20 days, for prostate cancer 172 days, and for rectal cancer 57 days (Robertson et al., 2017). Furthermore, research from northern Sweden indicates that people who have longer distance to the closest hospital, and are diagnosed with rectal cancer, report more pain compared with people living closer to the hospital (Näverlo et al., 2021).

Patient–provider encounters in primary care as entrance to access cancer care

In Sweden, primary healthcare is most often patients' first healthcare contact, which means that primary healthcare is in general the instance that manages referrals to secondary care. Cancer in general, and in particular some types, for example, CRC, seem to be extra challenging to identify in primary healthcare (Helsper et al., 2017; Lyratzopoulos et al., 2014). In the context of cancer care, primary healthcare has a twofold function, namely, to swiftly identify and refer patients with potential cancer to secondary care, while holding back referrals for individuals who are most likely healthy (Tørring et al., 2011; Round, 2017; Rubin et al., 2015). Primary healthcare nurses have a key function at primary healthcare centers in Sweden, since they often manage patients' first contact. Primary healthcare nurses often make the first assessment of the patients' health complaint in order to prioritize and schedule medical appointments, or to give medical advice (Distriktssköterskeföreningen, 2019). An international comparison reports that the waiting times for healthcare services, outside emergency care, are longer in Sweden than in other countries, like Australia and Norway, and that there is room for improvement when it comes to continuity and coordination of care in Sweden (Vård- och omsorgsanalys, 2021:4). Sweden has 0.64 primary care physicians per 1000 persons, which is less than, for example, Canada and Norway, which have 1.31 and 0.78 primary care physicians per 1000 persons, respectively (OECD Health Statistics).

Patient–provider encounter

"The patient is not just a group of symptoms, damaged organs and altered emotions. The patient is a human being" (Hellín, 2002, p. 452). Even so, much attention is given to symptoms during encounters. Patients seeking care are expected to express their illness experiences during the encounter, that is, to present their experienced bodily sensations to their physician. Physicians need to have medical knowledge, technical skills, and understanding of human nature (Hellín, 2002) to be able to interpret and assess the presented health issue. Thus, physicians' accuracy in interpreting verbalized bodily changes, in combination with their medical assessment, has importance for patients' future care.

An encounter (appointment) with a physician lasts on average 25 minutes in Sweden (Vård- och omsorgsanalys, 2020:5), including time for administration and documentation, and is scheduled for a patient if it is considered medically motivated. The activities that take place within the patient–provider encounter are transacted through sequences of interaction (Heritage and Maynard, 2006a). Heritage and Maynard (2006b) divide the patient–provider encounter into six parts: (1) opening – patient and physician establish a relationship, (2) presentation of complaint – the patient describes the reasons for care-seeking,

(3) examination – the physician examines the patient, verbally or physically, (4) diagnosis – the doctor evaluates the patient's health complaint, (5) treatment – the physician proposes a treatment, or further examination, and (6) closing – the patient and physician end the encounter (Heritage and Maynard, 2006b; Pilnick et al., 2009).

Patient–provider interaction

During the last decades, patients have become more active and engaged in their health and healthcare; thus, the patient–provider interaction has changed and become more significant for patients' health outcomes (Timmermans, 2020; Boyer and Lutfey, 2010). The patient–provider interaction is therefore fundamental for the provision of healthcare (Boyer and Lutfey, 2010; Heritage and Maynard, 2006a) and possibly for patients' access to care.

Research finds that patients are keen on sustaining a good relationship with their physicians, which means that they might restrict their care-seeking if it were possible that that their physicians might think of them as "hypochondriacs" (Andersen et al., 2011). Illness and the presence of symptoms are not a sufficient measure of what care a patient is in need of, especially since symptoms are characterized by ambiguity. Rather, the patient–provider interaction and relationship are central to healthcare provision (Boyer and Lutfey, 2010; Nettleton, 2013). Consequently, the patient–provider interaction and relationship seem to have importance for patients' care trajectories. Nonetheless, these are not the same thing. The patient–provider relationship does not sufficiently capture elements of actions found within the encounter (Heritage and Maynard, 2006a). The patient–provider interaction, on the other hand, shapes patients' health outcomes, since activities that take place during encounters are transacted through interactional processes (ibid.). Thus, the patient–provider interaction encompasses the complexities existing within the encounter (Nettleton, 2013). Interaction can be understood as an umbrella term for all human communication, verbal and nonverbal, such as words, facial expressions, gestures, and touches, and influences behaviors and the context people are situated within (Benzies and Allen, 2001).

Interaction is defined as "the process where groups or individuals through their actions mutually influence each other" (NE), or as "reciprocal action or influence" (Oxford Dictionary a), often closely related to relation, which is defined as "the way in which two or more people or things are connected; a thing's effect on or relevance to another" (Oxford Dictionary b). It is therefore possible to have a relation to someone without interacting with that person; thus, the main focus of this thesis is interaction.

Patient–provider communication

Communication is a key feature of the patient–provider interaction, with the objectives to create a good relationship between the parties, exchange information, and make medical decisions (Heritage and Maynard, 2006b). Communication can have impact on patients' health and well-being. For example, how patients talk about pain can influence physicians' choice of pain medication (Street, 2013). Physicians engage in different communication strategies to enable patients to understand and make sense of their experienced bodily changes. These are visualization strategies, for example, describing what is possible to see and feel, and may also employ metaphors and contrasting strategies, for example, establishing differences and similarities with previous experiences or with other people (Friberg et al., 2013). During encounters, it is important that patients are given the opportunity to have their illness experiences listened to (Skär and Söderberg, 2012; Lian et al., 2021). Concurrently, research illustrates that patients need to claim their space to be able to express their stories and illness experiences (Lian et al., 2021). Besides gathering and providing information, is it important for physicians to foster the relationships with their patients during encounters (King and Hoppe, 2013), as stress and limited time might impede a fruitful patient–provider encounter (Nygren Zotterman et al., 2015).

It seems that patients with different educational backgrounds have different communicational needs during encounters. For example, patients with shorter education may prefer the expert opinion in the communication with their physician more than those with longer education (Aelbrecht et al., 2015). Scholars suggest that physicians' communication styles depend on their patients' engagement and involvement (Timmermans, 2020), and that physicians' level of engaging in patient-centered communication is influenced by their patients' reasons for care-seeking (Bodegard et al., 2019). Patient-centered communication involves bringing the patient's perspective into the conversation, recognizing the patient as a person, involving the patient, and reaching for shared understanding of the patient's health complaint, as well as ensuring that decisions are based on clinical evidence and are consistent with the patient's values (Street 2013; Epstein et al., 2005).

Power asymmetry within the encounter

Defining illness and disease is a matter of power relations (Burr, 2015). Power asymmetry is vivid within patient–provider encounters (Li et al., 2007). Physicians are often portrayed as the medical expert with the most influence and power, and are the ones people turn to for answers to their questions about their bodily changes (Leder, 1990). Research on health and illness shows that throughout history the encounter between patients and doctors has been characterized by asymmetric power dynamics. In previous research, physicians

have been described as superiors, possessing medical knowledge and power to make decisions for their patients, whereas patients have been portrayed as submissive and passive recipients of care, without autonomy. During ancient times, doctors would treat their patients, despite the patients' own will and desires (Hellín, 2002; Kaba and Sooriakumaran, 2006). Today, patients are and should be involved in their own care, making decisions involving their bodies (Hellín, 2002). However, Swedish patients aged 65 years and older report that they are not as involved in their care as they wish to be (Vård – och omsorgsanalys, 2017:2), similar to what patients report after being referred into CPPs (Regionala Cancercentrum i samverkan, 2019).

Lian et al. (2021) describe that patients and their providers engage in a situation that is underpinned by a set of shared informal rules, for example, patients acting polite and obedient, which foster the interaction during encounters and may contribute to asymmetrical relationships. It is suggested that this power imbalance can be decreased if patients claim their communicative space, and if physicians enable patients to engage in dialogues and listen to their patients' stories and experiences (ibid.). By acknowledging patients' autonomy and involving patients in decisions regarding their own health, physicians can thus decrease the power imbalance (Smith and Hoppe, 1991). Moreover, by acknowledging that patients are more than a set of biomedical signs and symptoms, and recognizing that patients are the experts on their lives and bodies, it is possible to reduce the power imbalances that might be present during medical encounters (Leplege et al., 2007). Even so, the act of seeking care places the patient in a disadvantaged position; the patient–doctor relationship might never be fully symmetrical (Mead and Bower, 2000). Physicians are still the ones who possess the medical knowledge and control patients' care trajectories; thus, the power asymmetry is still present, which may lead patients to self-restrict their care-seeking as well as to decrease their trust in the healthcare system (Andersen et al., 2011).

Theoretical contribution

Existing theories of access to care outlined above have tended to overlook the role of patients' interactions with physicians as well as with the healthcare system. This thesis moves beyond these theories by encompassing these interactions and in doing so expands the concept of access to care. A focus on interactions turns attention to access as an ongoing process that is created rather than something that merely exists. By creation of access, I am not concerned with determining access as an outcome but rather understanding access as a process.

Access through the lens of interaction

Society can be understood in different ways, and for this thesis, I understand society as created through processes in which actors create actions by interacting with one another and interpreting the situation (Berg, 2007). Following the theoretical perspective of symbolic interactionism (hereafter referred to as interactionism), people do not merely interact with other individuals in concrete situations, but also interact with groups through different roles, such as patients and healthcare professionals, and with institutions, such as the healthcare system. Joint action is defined as a societal organization of acts (Blumer, 1986), which is more than the sum of the individual acts (Azarian, 2017). As described by Blumer, "joint action is temporally linked with previous joint action. One shuts a major door to the understanding of any form or instance of joint action if one ignores this connection" (Blumer, 1986, p. 59–60). Thus, interactions cut across all aspects of patients' care trajectories, from interpreting bodily changes to interacting with the healthcare system. In studies **I** to **III**, interaction is studied in the patient–provider encounters in primary care. Meanwhile, study **IV** examines patients' interactions with the healthcare system through the outcome measure time to diagnosis and treatment.

Acting, Interacting, and Interpreting are three fundamental premises of interactionism (Blumer, 1986). First, people act based on the meanings that things have for them. In the context of this thesis, it means that physicians do not act directly with respect to bodily changes/sensations/symptoms; rather, they act based on the meanings that are attached to these. Secondly, the meaning of those things or objects is derived from interactions, which means that the acting stemming from the patient encounters is assumed to be influenced by the patient–provider interaction. Following the above example, we can say that meanings of patients' experienced bodily changes derive from the interacting process within the patient encounter. Lastly, these meanings are then managed and altered through an interpretative process by the person experiencing them, for example, through communication and reflection during the encounter. To

summarize, human beings act upon things based on what those things and objects mean to them, and the meaning is derived from social interactions, which are altered through an interpretative process (Blumer, 1986).

Interactionism provides a theoretical perspective to guide our understandings about human health behaviors (Benzies and Allen, 2001), and specifically how actions during primary care encounters are shaped by the interactions between patients and providers. Following this perspective, human beings engage in actions to construct self, situations, and societies through interactions that are based on shared meanings, language, and unspoken words (Charmaz, 2014). Through sequences of actions between the patient and provider, meanings, roles, and identities are expressed and interpreted (Heritage and Maynard, 2006a).

Within research and practice, the patient–provider encounter has been understood according to two different perspectives, the biomedical perspective and the patient-centered perspective. Simply described, the biomedical perspective focuses on scientific knowledge about clinical conditions, reducing patients' illness experiences to a set of signs and symptoms, often neglecting patients' own illness experiences and needs. The latter focuses on patient participation and taking the patients' experiences, perspectives, and needs into account (Bensing, 2000; Mead and Bower, 2000). By focusing on interactions in the patient–provider encounter, it is possible to capture what can be thought of as a third perspective, which is all of those things that take place in between the patient and provider, as well as to integrate the biomedical and the patient-centered perspectives. Thus, by exploring interaction, we can gain understanding, not merely about the patient and provider perspective but also of what they create jointly based on their interaction, providing us with a third perspective that might have importance for access to care.

Exploring access through the lens of interaction within patient–provider encounters permits developing a more comprehensive understanding of access to care, since the patient's, the provider's, and their joint perspective are illuminated. Earlier scholars have described how physicians' thoughts of malignancy arise within the interaction with patients (Johansen et al., 2012). This is one example of how interaction might directly influence patients' healthcare trajectories, that is, access to further care. It also illuminates how interaction can be mirrored though time to diagnosis and treatment for patients.

Yet, the role of interaction for access to care is not limited to patient–provider encounters. It also encompasses patients' interactions with the healthcare system, which can be analyzed by examining the relationship between sociodemographic factors and time to diagnosis and treatment. Inequalities are created and (re)produced within social settings, which makes it unavoidable to

separate the study of access from the process in which inequalities are created and (re)produced. Inequalities are rooted within processes and relationships; they are re-produced through behaviors stemming from the meanings people learn to give to things and of how people interpret their surroundings (Schwallbe, 2008). This applies even to outcomes from quantitative studies, such as on patients' time to diagnosis and treatment, which are used to measure access to care. I measure this outcome, but still theorizes about what processes related to patients' interaction with the healthcare system throughout their care trajectories that might have led to this outcome.

Rationale

Diagnosing cancer is a multistep process, influenced by factors related to the patient, the healthcare professional, and the healthcare system. Standardized cancer patient pathways have been introduced as an organizational tool for improving identification of early signs of cancer, promoting early cancer diagnosis, and reducing regional differences in cancer care. These CPPs include criteria, that is, warning signs of cancer, which give the illusion of symptoms of cancer being straightforward and easing healthcare-seeking practices and diagnosis, while in reality they are not (Andersen et al., 2015). Even though standardized templates, such as CPPs, many times guide clinical decisions, they still do not incorporate the complexity of diagnosing cancer (Naess and Haland, 2021). Primary healthcare faces the main challenge of identifying patients in need of referral to further diagnostic check-ups when suspicion of cancer exists, referring patients who present with CPP criteria, while holding back patients who do not. Patients' presentation of their experienced bodily changes and health complaints during encounters may influence their care trajectories (Seibaek et al., 2011). Previous research indicates that opportunities for diagnosing cancer may risk being missed during patient–provider encounters, due to, for example, communication difficulties, patients' failure of presenting symptoms, and physicians' failure related to triage and investigation, and the low PPVs of many symptoms of cancer (Singh et al., 2013; Lyratzopoulos et al., 2014; Lyratzopoulos et al., 2015; Ingebrigtsen et al., 2013). This indicates that interaction within the patient–provider encounter in primary care may have importance for patients' access to further care.

In addition, previous research reports a socioeconomic gradient in cancer mortality and survival (Finke et al. 2021; Dalton et al. 2019), that people with better socioeconomic positions have better health outcomes; however, the body of literature on time to diagnosis and treatment for CRC in relation to socioeconomic and demographic factors is scarce.

Previous research about access to care has mainly focused on individual behaviors of seeking care, and theories about access have mostly focused on quantifiable dimensions, thereby not exploring how interaction might have importance for patients' access to further care. Exploring access through patients' interaction with their providers and with the healthcare system permits developing of a more comprehensive understanding of access to care.

Aims

Overall aim

The overall aim was to explore how access to cancer care is created through patient–provider encounters in primary care, and whether sociodemographic factors are related to access to care, after the introduction of Standardized Cancer Patient Pathways (CPPs)

Specific aims

Study I aimed to explore how presentation of bodily sensations were constructed and legitimized in primary care encounters within the context of Standardized Cancer Patient Pathways (CPPs).

Study II aimed to explore how GPs assign meanings and act upon patients' symptoms in primary care encounters in the context of CPPs.

Study III aimed to explore how patients experience encounters with primary care physicians when they seek care for symptoms potentially indicating cancer.

Study IV aimed to examine whether sociodemographic factors, including distance to hospital, are associated with differences in the diagnostic interval and the treatment interval for CRC in northern Sweden.

Methodology

Epistemological and ontological foundations

As researchers, we always bring philosophical assumptions that often inform our choices and guide our research. These assumptions are rooted in our training and strengthened by the academic community that we are situated within (Creswell, 2013).

This thesis is guided by epistemological and ontological commitments of constructivism. Following the tradition of constructivism, the epistemological assumption is that knowledge is understood as transacted, subjective, and socially constructed, rather than "discovered" (Creswell, 2013; Lincoln and Guba, 2016). Further, the ontological assumption is that reality is understood as in our minds, which means that there are multiple perceptions of realities (Creswell, 2013; Lincoln and Guba, 2016). However, from the constructivist perspective, there exist two forms of reality, the physical reality and the socially constructed reality (Lincoln and Guba, 2016). By acknowledging these two forms, it is possible to understand how constructivist qualitative studies can be joint with a quantitative study, as in this thesis. As I see it, the type of reality that constructivists seek to explore is the meanings that are associated with any given social interaction (reality) (Lincoln and Guba, 2016). In the context of this thesis, it is the reality of the patient–provider interaction (**I**–**III**), while in study **IV**, the focus is on the form of reality that is related to the physical reality, such as income, education, and physical distance to the closest hospital. Consequently, it is possible to combine different methodologies. In fact, different methods can complement each other, and thus, contribute a deeper knowledge and understanding about the studied phenomenon (Dahlgren et al., 2004).

Research design

This thesis consists of four studies. The first study is a participant observational study of patient–provider encounters in primary care; participants are patients and physicians. Study **I** laid down the foundation in terms of sampling for the following studies, since those physicians and patients who participated in study **I** were also asked to participate in individual interviews, in studies **II** and **III**.

In addition, one retrospective cohort study, study **IV,** was carried out with patients diagnosed with CRC in Region Västerbotten, Region Västernorrland, and Region Jämtland Härjedalen. This thesis thus combines qualitative and quantitative methods. Table 1 offers an overview of the four included studies.

Table 1. Overview of studies, with design, method, participants, and analysis specified

Study	Design	Data collection	Participants	Analysis
I	Qualitative	Participant observations collected Dec. 2017 – Mar. 2019	Patient encounters n = 18 Patients n = 18 Primary care physicians n = 13	Grounded theory method
II	Qualitative	Individual interviews collected Dec. 2017 – Mar. 2019	Primary care physicians n = 13	Grounded theory method
III	Qualitative	Individual interviews collected Dec. 2017 – Mar. 2019	Patients n = 13	Thematic analysis
IV	Quantitative	Retrospective cohort study, data from 2017–2018	Patients diagnosed with CRC in Region Västerbotten, Region Västernorrland, and Region Jämtland Härjedalen n = 446	Statistical analyses

Study context

Data were collected in northern Sweden, which is an area that is geographically large but sparsely populated, characterized by many rural areas with long distances to healthcare services. There also exist urban areas where the distance to healthcare services is much shorter than in rural areas. These aspects make the setting of this thesis especially interesting.

Sweden has in total 21 regions, which are responsible for the healthcare provision in each region. These regions are then grouped into six healthcare regions, the northern healthcare region consists of Region Västerbotten (RVB), Region Västernorrland (RVN), Region Jämtland Härjedalen (RJH), and Region Norrbotten. Studies **I** to **III** were conducted in RVB, while study **IV** consists of data from RVB, RVN, and RJH.

Map from Kullberg et al., 2018

The hubs for data collection for studies **I** to **III** were PHCs in RVB. Primary healthcare centers were purposively selected to include a diverse setting, covering urban and more rural areas. Twelve PHCs were initially invited to participate and were introduced to the research plan through an in-person visit and an oral presentation. Six PHCs ranging across urban, semi-urban, and rural areas chose to participate, whereas six declined due to time constraints.

Throughout the period for data collection, I regularly contacted the included PHCs by phone, email, or physical visits to recruit newly employed personnel, to remind personnel of the ongoing study, and to be available for potential questions.

Study **IV** was conducted in three of the four northern regions: RVB, RVN, and RJH. The three included regions had in 2019 a population density of 5.18/km^2, which is notably less than for Sweden as whole (25.4/km^2) (SDB SCB). In RVB there exist 38 PHCs and three hospitals, RVN has 31 PHCs and three hospitals, and in RJH there are 26 PHCs and one hospital (figures from 2021).

Participants

Participants in study **I** were patients and physicians who agreed to have their encounters observed. Twenty-six patients ≥18 years of age who sought care for sensations/symptoms that could indicate cancer and who were Swedish-speaking and with no cognitive disabilities were asked to participate; of these, 18 accepted. Thus, patients were enrolled following purposive sampling, while the physicians were enrolled if their patients accepted participation in the study. An overview of the participating patients' health complaints and sex are presented in Table 2. The participating physicians' work experience ranged from less than one year to 27 years (median 4 years), and their age ranged between 26 and 62 years (median 38 years).

In conjunction with the data collection for study **I** the participating patients and physicians were asked to participate in an individual interview. All 13 physicians accepted participation and were thus included in study **II**. The patients participating in study **I** were asked if they would allow me to contact them to discuss the possibilities around participating in an individual interview about their experiences from the encounter. One patient was perceived to be in too poor health to participate in an interview and therefore was not asked, and another patient did not respond. Sixteen patients of those 18 observed in study **I** were asked to participate in an interview; of those, 13 accepted and were accordingly included in study **III**. Figure 4 presents an overview of the participants in studies **I** to **IV**.

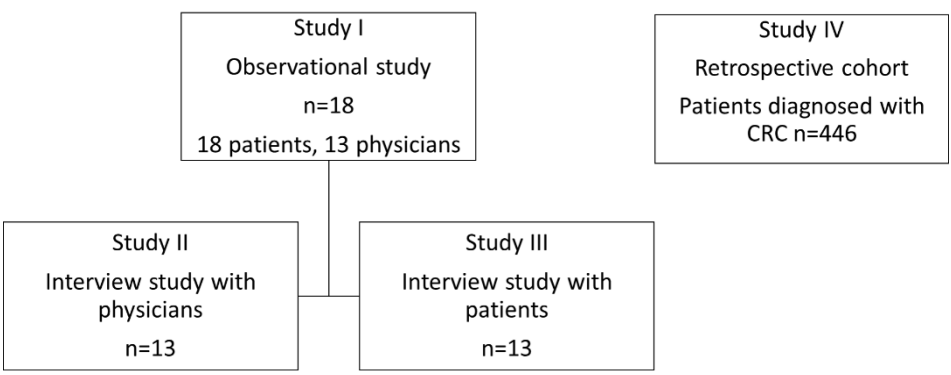

Figure 4. Schematic diagram of participants in the four included studies.

Table 2. Patients' experienced health complaint and sex (**I**)

Health complaint	Sex of patients
Stomach pain	♀=2
Rectal bleeding	♀=2, ♂=1
Blood in urine	♀=1
Lump	♀=3, ♂=1
Weight loss	♀=1, ♂=1
Skin lesion	♀=1, ♂=1
Fatigue	♀=2
Cough	♂=1
Constipation	♂=1

Twelve women and six men participated in study, I with different health complaints. ♀= women, ♂ = men

The data for study **IV** were retrieved from the Swedish Cancer Register on all patients diagnosed with CRC during 2017-07/2018-06 in the included study regions. Four hundred forty-seven patients were eligible for the study; however, one patient was excluded due to having an unreasonably long interval (6230 days) between first contact with care and diagnosis. Thus, 446 patients were included in study **IV**.

Data collection

The data collection for the qualitative studies (**I**–**III**) was carried out between December 2017 and March 2019. All interviews were audio recorded and transcribed verbatim. The data collection for the quantitative study (**IV**) was carried out during 2020.

Participant observations

Data for study **I** were collected through participant observations in combination with grounded theory method (GTM). Prior to the data collection, I conducted a "pilot observation" (within a different context, thus not included in the analysis), which helped me to test the observational protocol that I had developed for the data collection. The protocol consisted of three sections, where the first section was dedicated to events, comments, and actions related to the patient. In the second section, similar events related to the physicians were noted, and in the third section, comments, analytical reflections, questions, and thoughts were written down.

Following GTM, data collection and data analysis were carried out in parallel. Thus, descriptive and exploratory observations were initially conducted to collect data in an as open a manner as possible. Data were gathered on actions, communication (verbal and non-verbal), and other events that occurred during the encounter without making any conscious decisions about what was noted. These descriptive observations were then followed by focused observations based on emergent leads in accordance with GTM (Charmaz, 2014). During the more focused observations, I focused on theoretical categories that had emerged during the analysis of previous observations. This means that I wrote down the emerging theoretical categories in the protocol to explore whether these held up in the subsequent observations. Examples of emerging theoretical categories that I used are Being taken seriously, Looking for and giving recognition, and Balancing expectations and preferences.

Promptly after each observation, the handwritten field notes from the protocol were audio recorded, to be able to extend these written notes with fresh memories of the encounter, these audio recordings were then transcribed verbatim.

In the earliest phase of the data collection four observations were conducted together with another researcher. Thirteen observations were then conducted solely by me, and one observation was conducted solely by the other researcher.

Individual interviews

In study **II**, the physicians' overall perceptions about encounters with patients seeking care for possible signs of cancer were the main focus during the interviews; even so, questions related to the previously observed encounters were also raised. An interview guide with semi-structured questions was used, and additional questions were asked based on emergent leads as well as questions that emerged from the previously conducted observations following GTM (Charmaz, 2014). The interview guide included questions such as "Can you explain what it's like to meet patients with symptoms that might indicate cancer?" "Can you

describe what it's like to listen to patients' symptom presentation?" and "Can you explain what it's like to work with CPPs?"

The interviews were carried out at the physicians' offices at a day and time chosen by them. The interviews were audio recorded and lasted between 31 and 48 minutes (median 39). Twelve of the interviews were conducted by me, and one interview was conducted by another researcher.

In study **III**, patients' expectations and perceived responsibilities of themselves and their physicians, as well as how they perceived their role during the encounter, were research questions this study aimed to answer. Thus, interviews were carried out to explore the patients' narratives of these inquiries. The interviews were guided by an interview guide with open-ended questions such as, "Can you describe the expectations you had before the encounter?" "Can you describe what it was like to tell your doctor about why you were seeking care?" and "How do you experience that the doctor listened and understood your reasons for seeking care?" The word "cancer" was not used by the interviewer unless the interviewee mentioned it. The median length of the interviews was 37 minutes, ranging between 15 and 49 minutes, and the interviews were carried out at a day and time chosen by the participating patients, ranging between 3 and 30 days (median 6 days) after their observed encounter (**I**). Eleven of the interviews were conducted by me, and the remaining two interviews were conducted by another researcher.

Register data combined with medical records and sociodemography

In study **IV**, data from the Swedish Cancer Register, with almost 100% coverage, was used to identify patients diagnosed with CRC during the study period in the three included regions of northern Sweden. Colorectal cancer was chosen, as this cancer disease has similar incidence among women and men. Furthermore, CRC presents with symptoms that are ambiguous and common for many benign diseases; thus, identifying patients with potential CRC, and diagnosing CRC is challenging.

The data from the cancer register was thereafter combined with reviews of these patients' electronic medical records (EMR) for both primary and secondary care. These reviews were carried out by one physician from each region. The dataset was then combined with data from Statistics Sweden (SCB), which consist of data on socioeconomic and demographic parameters. Lastly, Google Maps was used to map the distance between the patients' places of residence and the nearest hospital.

Data analysis

The transcripts from the qualitative studies (**I**–**III**) were input into the software program MAXQDA version 2018 for coding, managing, and analysis. The data for the quantitative study (**IV**) was analyzed using IBM SPSS Statistics version 24, and R version 4.0.5.

Grounded theory method

The data in study **I** and **II** were analyzed using GTM. Following GTM by Charmaz (2014), the process of analysis for study **I** started in conjunction with the first conducted observation. Grounded theory method is a suitable method for exploring and analyzing processes, and enables moving beyond descriptive analysis towards theory generation (Creswell, 2013). Constructivist GTM following Charmaz (2014) was chosen, since the constructivist tradition suits well my epistemological and ontological standpoint, as well as corresponding to the research questions for studies **I** and **II**.

As observations were carried out, analysis and coding were performed in parallel. Initially, the written transcripts were thoroughly read and re-read, and thereafter initially coded line by line. Focused coding began when patterns among all initial codes were developing; these codes were then sorted and clustered, with emerging categories tested in upcoming observations. Categories were then developed, and relationships between and within these were specified. Throughout the analysis process, memos were taken, which means that analytical reflections, ideas, and thoughts were noted throughout the process. These memos were beneficial, since they enabled me to return to my earliest ideas, for example, ideas and thoughts about specific codes and categories. I also engaged in the method of constant comparison, meaning that I, throughout the process of analysis, compared empirical data, and compared codes and categories. For example, I compared created codes with each other, as well as with the transcripts, to ensure that codes were grounded in the data, and that categories were developed based on specific lines of inquiries.

The analysis process for study **II** started briefly with reading transcripts and taking memos in conjunction with observations (**I**) and interviews (**II**, **III**) being carried out, although, initial coding was performed when study **I** was finished. Otherwise, the process of analysis was similar as for study **I**. An example of the analysis process is presented in Table 3, and the analytical steps of GTM are presented in a schematic figure (Figure 5).

Table 3. Example from the analysis process: transcript, initial coding, focused coding, and theoretical coding (**II**)

Text from transcript	**Initial coding**	**Focused coding**	**Theoretical coding**	
			Sub-categories	**Category**
"… so it facilitates the way that it is, as it turns out, I have a template to go from, well does the patient fulfill these symptoms so that it should lead to a referral and start a CPP prostate cancer or whatever it may be, so that everything becomes standardized and then gets, it becomes equal for everyone, everyone has the same criteria for being included in a CPP, so it facilitates in that way, I think."	CPPs make it simple CPPs facilitate Having a template Checking if patient fulfills symptoms Standardizing Patients having the same criteria	Leaning on CPPs for support Being guided by CPPs Following CPPs is like reading a manual Matching symptoms with criteria for CPPs	Leaning on CPPs for support	**Feeling torn about CPPs**
"… as much within primary care, you can sometimes experience that this is an additional task that has been assigned to primary care without really been given more resources or more time for it, we have the same working hours but we should be doing this, and well its good for those patients who fit in the frame or the template and they get a quick investigation and that is great, but it takes more time for us to do these perfect referrals..."	Getting more tasks Getting no extra resources Having time constraints CPPs are good for patients who fit into the frame CPPs speed up trajectories Writing referrals is time consuming	CPPs as additional tasks Lacking resources to handle CPPs Being frustrated by CPPs	Being frustrated by CPPs	

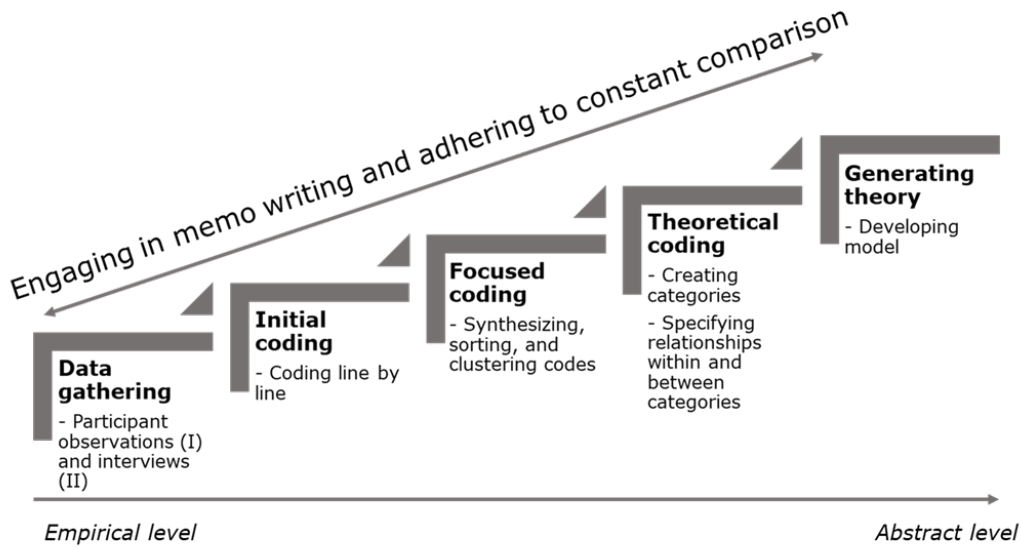

Figure 5. Schematic figure of the analysis process of the grounded theory method (Charmaz, 2014).

Thematic analysis

Thematic analysis, following Braun and Clarke, was used to analyze the data in study **III**. Thematic analysis is a flexible and analytical method to identify meanings and patterns (themes) that are related to the study participants' lived experiences (Braun and Clarke, 2006; Clarke and Braun, 2017). From a constructivist paradigm, the data were analyzed using latent thematic analysis, which means that I searched for underlying meanings and assumptions.

The analysis process follows six steps: data familiarization, initial coding, theme searching, reviewing themes, defining themes, and writing the results (Braun and Clarke, 2006). Initially, to become familiarized with the data, I engaged in repeated readings of the transcripts, and any emerging ideas or thoughts were written down. Ideas that emerged early were, for example, related patients' worries about seeking care unnecessarily, and the difficulties patients face when they try to verbalize their sensations. These emerging ideas supported my understanding of the data. Secondly, I coded the data line by line to create data-driven codes, using words that the participants used to express themselves. Then, codes that were related to each other were clustered, and I started to search for potential themes and subthemes. I also explored the latent level of the data. When the themes then were defined and created, I returned to the data to ensure that they were built on codes of a coherent pattern. Lastly, themes and subthemes were named, and the results written. Additionally, during the final steps, I used the attributes of customer and seller in order to theorize the results. Table 4 presents an example of the process of analysis, from transcript to theme.

Thematic analysis was chosen as a method for analysis in study **III**, since it is compatible with the constructivist paradigm, offers flexibility, and has the possibility to provide a rich and detailed analysis (Braun and Clarke, 2006). Thus, thematic analysis was suitable for analyzing patients' perspectives of their encounters in primary care in order to create patterns and themes.

Table 4. Example from the analysis process: transcript, initial coding, subthemes, and theme (**III**)

Example of text from transcript	**Examples of initial coding**	**Sub-themes**	**Theme**
… Now I got to do this examination and that meant that I was about to get help with my problem, because if they had told me that we don't intend to do this examination, and we do not think that you should go to the surgeon, we don't believe in this, then it would have been hard.	Wanting help Wanting a plan Feeling taken care of when there is a plan Feeling believed when there is way forward	Wanting a plan for my care trajectory	**Expecting a clear plan as an acknowledgment**
… I usually use primary care, I go in and sit down and ask for the things I want, because you do want a referral somewhere…	Expecting to be referred Asking for the things I want Wanting a referral PHCs are only the entrance	Wanting referral from primary care	

Statistical analyses

Initially, normality of data was assessed using Skewness-Kurtosis test in combination with visual inspection of the histograms. The majority of the data were skewed, thus, non-parametric methods were employed in most analyses. Age was although normally distributed, thus the differences in mean age were analyzed using one-way ANOVA. Differences between groups were analyzed using Kruskal-Wallis test, and Pearson's Chi-squared Test was used to examine the relationship between groups of categorical data. Statistical significance for all analyses were defined at $p < 0.05$, with 95% confidence interval.

To be able to adjust for covariate while analyzing the number of observed events (diagnoses and treatments) per observed time unit (DI and TI), I used Cox-regression (Vach, 2013). The measure of number of events per time unit was interpreted as time to diagnosis/treatment. Additionally, to ensure that no violation of the assumption of proportional hazards was made, another researcher assessed the assumption with regression of Schoenfeld residuals against time. A violation of the assumption is made if the curves of two groups cross, which may result in misleading estimates and incorrect models (Stel et al., 2011). No such violations were found. All analyses were performed at a secure platform provided by SCB.

The outcome variables were (i) the diagnostic interval, that is, time (in days) from first presentation/clinical appearance to diagnosis (DI), and (ii) the time (in days) from diagnosis to start of treatment, that is, the treatment interval (TI). Also, the patient interval (PI) (i.e., time from first symptom to first healthcare visit) was used for those patients (67.5%) where these data were available in the EMRs.

Age, sex, and socioeconomic and demographic variables, that is, education, income, and distance to nearest hospital were examined as exposure variables. Income and education were chosen as two of the exposure variables since previous research has identified these variables as important determinants of health (Braveman and Gottlieb, 2014). Income was used both dichotomized and as a continuous variable. When being dichotomized, the income variable was divided across the median. Education was dichotomized into pre- or post-high school education. The 80th percentile was a cutoff when dichotomizing the variable distance to the closest hospital. In addition, clinical parameters were applied as covariates, such as tumor stage and tumor site. Table 5 presents an overview of how the dichotomized variables were defined.

Table 5. Overview dichotomization of exposure variables and covariates (**IV**)

Variables	Dichotomized variables	
Income	*Low income*: < median In data: <166,200 SEK/year ≈ 16,500 €/year	*High income*: > median In data: >166,200 SEK/year ≈ 16,500 €/year
Education	*Short education*: Completed elementary school, or completed elementary school and high school	*Long education*: Completed post-high school education, e.g., university education
Distance to hospital	*Long distance*: ≥ P_{80}, i.e., the 20% with longest distance to closest hospital. In data: 57–248 kilometers	*Short distance*: < P_{80}, i.e., all others In data: <57 kilometers
Metastasis	*Metastasis*: Having metastasis to lymph node, or remote metastasis	*No metastasis*: Having no metastasis
Tumor localization	*Right-sided tumor*: Tumor in the right side of the colon	*Left-sided/rectum tumor*: Tumor in the transverse or left side of the colon, including rectum or unspecified localization

Definitions of dichotomizations exposure variables and covariates

Power calculations

Prior to this thesis project, a power calculation was conducted to inform about the sample size needed in study **IV**. Based on the hypothesis that the time between first visit in primary care and a CRC diagnosis would decrease by 10 days (if referred with CPP), data from 320 patients needed to be included in the study. This calculation was based on the assumption that the standard deviation would also decrease. To calculate the new standard deviation, the same coefficient of variation as in a previous study was applied. In dimensioning, a one-sided test was used, with significance level 5% and strength 80%.

Results

Summary of main results

The overall aim of this thesis was to explore how access to cancer care is created through patient–provider encounters in primary care, and whether sociodemographic factors are related to access to care, after the introduction of CPPs. The results reveal how access is created through interaction in the patient–provider encounter. Patients and physicians create access by negotiating the legitimacy of symptoms through processes characterized by dependency, credibility, and reciprocity (**I**). Secondly, physicians create access while being pulled between patients and standardized templates, which brings into focus the tension between the responsibility physicians have to their patients and their responsibility to the healthcare organization. It is challenging for physicians to engage in person/patient-centered dialogues, interpret presented symptoms, and match them with standardized criteria (**II**). Third, patients experience a need to act as both sellers and customers when interacting with physicians in primary care and when negotiating symptoms while creating access. Standardization seems to oversimplify the complexity that underlies patients' interactions with healthcare, downplaying the individual uniqueness of each person's health problem, situation, and needs. (**III**). Lastly, sociodemographic factors do not seem to be related to time to diagnosis for patients with CRC in the study regions, even though these factors, including distance to hospital, might have impact on the interaction during encounters and patients' access to care (**IV**).

The significance of interaction and its various dimensions – a synthesizing of results

The results of this thesis depict the complexity of the interaction when creating access to cancer care. The creation of access is mirrored through processes found in patients' interactions during encounters in primary care, as well as through interactions with the healthcare system.

Looking back on the three puzzle pieces, which can be understood as three parts of patients' access to (cancer) care and are connected to each other but can also be under scrutiny individually. The focus of this thesis was the second puzzle piece, which encompasses attributes related to the healthcare provider and the encounter and its influence on patients' access to care. The results of this thesis add dimensions of interaction to the second puzzle piece, which highlights that negotiating, embodying roles, and adhering to norms are important dimensions of this interaction. These dimensions are visualized in a conceptual model of patients' access to care, which is presented in Figure 6.

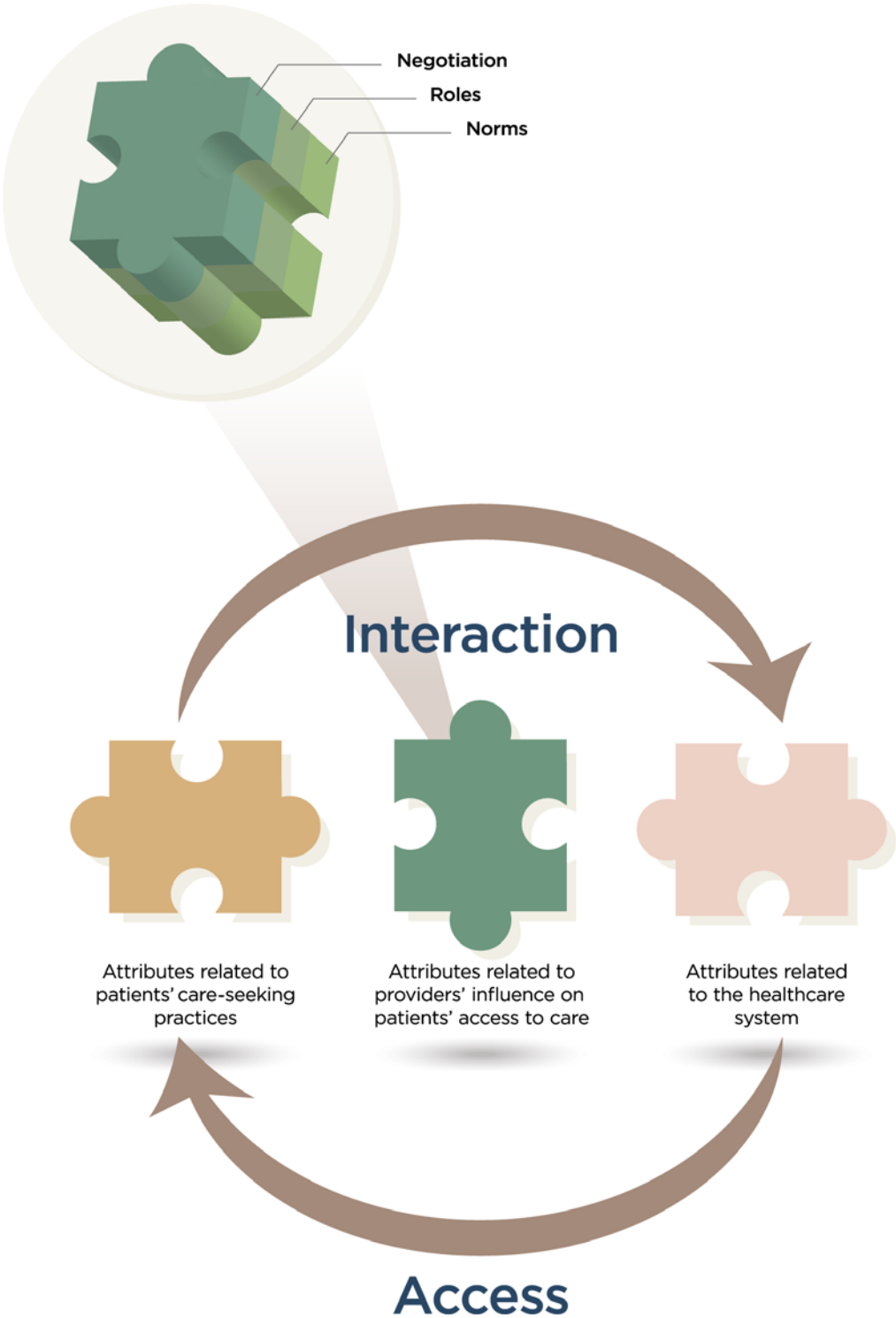

Figure 6. Conceptual model of access to (cancer) care based on the results from this study.

Negotiating, embodying roles, and adhering to norms are related to each other and are often actualized in parallel; as such, they do not stand alone as isolated phenomenon. Even so, the results will from here on be presented with three subheadings; Negotiation and communications during encounters, Roles and norms during encounters, and lastly, Time to diagnosis and treatment and sociodemographic factors.

Negotiation and communication during encounters

Negotiation and all forms of communication are important aspects of the ongoing interaction within the encounter, in which patients and their physicians are mutually dependent on each other. Patients' expertise about their own bodies needs to be reconciled with their physicians' medical expertise, which underlines the importance of negotiation and communication within the patient–provider interaction (**I**). Patients describe how their experience of the interaction with their physician can influence the communication. As one patient related:

> *If you feel that it is easy to talk to a person, then it's easier to express yourself, then you can describe how it feels, your symptoms and so on, but if you feel that there is a wall between you and the doctor it is a bit more difficult.* (Patient, interviewee C)

During encounters, physicians are to a great extent dependent on the information their patients present to understand the health complaint from the patient's perspective, assess, and make judgments. On the other hand, patients seem to be aware of the significance of negotiation and of delivering of information about their reasons for care-seeking, which seems to make patients feel pressure and demands on themselves when they communicate (sell) their experienced bodily sensations to their physician (**I**–**III**). One physician expressed the significance of patients' presentations as follows:

> *Well, 80-90% of my ability to diagnose or make a plan for investigation is dependent on what the patient describes. The anamnesis is very important, how they describe their problem, and then sometimes you have to steer [the dialogue] a bit. It depends on the patient. (Physician, interviewee 8)*

When negotiating with patients, physicians ask questions, control, and appraise the information they receive in order to interpret and assess the patient's presented health complaint in the process of creating and legitimizing access (**I**). Challengingly, physicians experience contradictory aspects of the communication with their patients. Even though patients' presentations of their reasons for care-seeking are important for physicians, physicians have expectations about how

and what patients should present. On the one hand, physicians want and expect detailed, precise, and structured presentations from their patients. On the other hand, physicians filter patients' presentations when they perceive that their patients talk too much or talk about irrelevant things. Consequently, physicians juggle giving their patients room to speak and listening without interfering, and being the one leading and steering the dialogue (**II**).

Physicians do not respond to symptoms as objective things; rather, they assign meanings to patients' presented bodily changes (symptoms) by interacting with their patients. For example, physicians interact with their patients by inviting them to engage in dialogue and by steering the conversation to create a ground for interpretations. The interpretative process is although constantly changing and is open for redefinition, based on the mutual interplay between these different perspectives, that is, the patient's and the physician's perspectives. Consequently, creating access to further care occurs trough dependency and reciprocity within negotiation and communication between patient and physician (**I**, **II**). As one physician described it:

> *Within primary care, the difficult thing is to sort what needs to be investigated, and what does not.... Patients can seek care for what on paper looks the same, but when you meet the patients it becomes obvious that one has a complaint that seems benign and not that much needs to be done, while the other has a complaint that needs to be examined with ultrasound or x-ray or something like that. (Physician, interviewee 6)*

During encounters patients want to be acknowledged and confirmed by their physicians. Patients strive to present themselves as persons who seek care in a timely manner, who "do the right thing," and who try to facilitate their physicians' work, and they want to be confirmed for doing so. Patients also want to ensure that they follow given instructions, that they do what they are told, and in study **I** they apologized if they failed to do so. In these situations, it seems important that physicians are attentive and provide patients with confirmations and feedback, since such reassurance may help patients feel more comfortable in vulnerable situations, for example, during examinations, which illuminates dependency and the importance of communication throughout the encounter (**I**). As one patient expressed it:

> *I think I said that I felt a bit embarrassed.... Maybe he should have told me that I did not have to worry about that, that it is not embarrassing at all, and that he [the doctor] has seen this many times before.... (Patient, interviewee K)*

It seems important that each individual person is acknowledged within standardized systems, and one way of doing so is to strive for accepting and confirming communication during the patient–provider interaction. Patients being referred into a "fast track" such as CPP often feel taken care of by the healthcare system, and describe that CPP reduced painful feelings stemming from long waiting times and worries. On the contrary, patients with symptoms that do not qualify for a CPP referral sometimes have to continuing dealing with uncertainties while striving to find a solution to their health problem (**III**). By communicating, and providing patients with information, patients' feelings of uncertainties can be eased.

Roles and norms during encounters

To feel trust and to be trusted while interacting with each other is important for both patients and physicians. Patients strive to embody the role of a person seeking care in a timely manner and being a credible person with legitimate symptoms, while physicians aim at embodying the role of a competent and trustworthy doctor. To transmit trust and credibility during encounters, patients use sensations and emotions, and reinforce their verbal language with body language by visualizing their sensations, to convey legitimacy and credibility of their health complaints and presentations. To be a credible and trustworthy physician, physicians devote time to carefully listen to their patients' presentations, take notes, and ask follow-up questions. Physicians also engage in giving verbal and bodily receipts of their attention, such as repeating what their patients have said, or nodding in order to transmit credibility (**I**–**III**). Consequently, trustworthiness and credibility are transacted through sequences of communication, but do not solely relate to communication; they have also to do with embodying the roles that are expected of either a patient or a physician.

Physicians strive to be perceived as credible and trustworthy medical experts who make accurate assessments and decisions, simultaneously as they strive to be perceived as empathic and credible listeners, fulfilling the expectations inherent in the role of a competent physician. These expectations, in combination with the willingness to do good, can make physicians perceive demands related to their performances as medical experts: they want to "do the right thing." (**I**, **II**). As one physician put it:

> *If you get a cancer suspicion, you have to go all the way. I want to be sure that the things I do, the examinations I order, are comprehensive for that suspicion I have, so that I don't miss anything, so there can be a demand related to work performances. (Physician, interviewee 2)*

Patients experience demands on themselves when seeking care and when presenting their experienced bodily sensations and health complaints, especially since it seems to be a common trait among patients to feel that much is at stake when interacting with healthcare. Thus, patients feel that they have to seize the opportunity with their physicians, and that they have to "sell" their symptoms while delivering a good presentation in order to access the care they need (**III**). As one patient stated:

> *If I as a patient can describe to the doctor in an easy way it will benefit me as a patient.… It isn't easy, it's not. (Patient, interviewee M)*

Similar to a customer who freely can choose between services and goods on the market, patients verbalize their perceived needs and wants, initiate actions, and ask questions in order to fulfill their perceived needs and expectations. Because besides having expectations of themselves, patients have expectations of their healthcare trajectories. To get a plan for further and coming care is important for patients, as is clear and comprehensive information. Patients often view primary healthcare as only the entrance to the healthcare system, often expecting to be referred above and beyond primary healthcare (**I**, **III**). As one patient described it:

> *Of course, I expected to get help in some way, that the help started there [primary healthcare] and then moved on, so that was the goal, because of course I got worried and thought that it could be cancer, and you can't go with that and believe that it will go away by itself. (Patient, interviewee J)*

As described by the informant in the above quotation, these demands and expectations often stem from the perceived alarming health complaints, that is, the patients' reasons for seeking care. As medical experts, physicians negotiate these expectations by motivating their decisions and actions with medically sound arguments, describing informatively to patients what their next step in their care trajectory will be and why, to reach reciprocity. This has also to do with credibility of the responses. Physicians strive to act professionally and to be a credible physician towards the patients, as well as towards the system. This means that they want to make an accurate assessment and provide their patients with the most suitable option of care, in order to fulfill expectations from their patients, and from the system. However, it is sometimes challenging for physicians to bridge patients' expectations with their medical expertise, which puts additional demands on the negotiation and dialogue between the two parties in order to create access (**I**, **III**). This also relates to situations when patients' and physicians' idea about the health problem differ (**I**). As noted in one of the observations:

[T]he physician sits himself in his chair and says that there are different things to do. The first thing is that you have lost a lot of weight and that needs to be investigated. The patient then responds, "Well, yes, I have, but that is because I have lost my appetite." (Notes from observation 6)

To create and legitimize access, physicians make decisions about their patients' care trajectories based on the assessment and the assigned meanings of patients' symptoms. These assigned meanings are aligned with the physicians' knowledge about alarm symptoms and CPPs. Thus, CPPs are recreated through the physicians' own interpretation of their patients' symptoms. Besides interacting with patients, physicians interact with different tools, recommendations, and guidelines for managing presented symptoms and complaints. Such tools and recommendations can sometimes make them feel pulled between the responsibilities they have towards their patients, and the responsibilities they have towards adhering to recommendations within the healthcare organization. This implies that patients' trajectories toward diagnosis are not as straightforward and not always facilitating for physicians when using CPPs as these were intended, since peoples' complaints cannot be standardized (**II**). Physicians relate that there are some contradictory aspects to the utilization of CPPs. On the one hand, CPPs are considered helpful and valuable for physicians in their daily work, since they can lean on CPPs for support in situations characterized by uncertainties, which diagnosing cancer is. Physicians remark that CPPs increase the credibility of their work, as well as increasing their confidence, since they follow specifically given instructions when using CPPs. CPPs function similarly to a cook book, that is, they provide clear instructions and criteria, as well as providing structure to physicians' daily work (**II**). On the other hand, CPPs are also perceived as limiting, as one physician expressed:

I think that everyone deserves as good treatment as possible and that is when I mean that you must be able to think for yourself in the individual case, and then it is not always possible to follow guidelines. That is how I think. (Physician, interviewee 13)

Thus, it sometimes seems that CPPs have more legitimacy than physicians' clinical assessments, and that CPPs can take away opportunities of investigations as well as devaluate physicians' medical expertise. Physicians reported that CPPs sometimes make them feel hampered by rules, which often generates feelings of frustration. Consequently, CPPs can make physicians feel pulled between adhering to CPPs and following their clinical judgment of what they believe is best for the individual patient (**II**).

Furthermore, the workload in primary care is perceived as having increased since the introduction of CPPs. More tasks, such as to be updated about, and adhere to

CPPs, are expected to be performed by physicians in primary care, which is often perceived as frustrating (**II**). In addition, the extent of information that physicians have about CPPs varies. Limited information about CPPs seem to cause feelings of uncertainty and confusion about how to use them, for instance, how to write referrals, as well as where to access information, which makes physicians hesitant to utilize CPPs. Consequently, there seem to be both benefits and limitations to the utilization of CPPs, although the major shortcoming seems to be the varying degree of information physicians are given about these standardized routines, as well as the great extent of information to be picked up (**II**). As one physician expressed:

> *The difficult thing is that CPPs exist for many, many different cancer diseases, and to be updated on that, for all [CPPs], that is not always possible. (Physician, interviewee 2)*

Time to diagnosis and treatment and sociodemographic factors

The creation of access has to do with physicians embodying the role of a competent medical expert that makes the "right decisions," for example, timely referral for those patients with a well-founded suspicion of cancer, while holding back those without. It also has to with physicians adhering to the norm of striving to make the right clinical decisions in order to provide patients with the best care and treatment, simultaneously with following guidelines and the time constraints specified in the CPPs. Consequently, it also has to do with patients' time to diagnosis and treatment. Based on an analysis with data from study **IV**, it seems that patients who seek primary care as their first healthcare contact have a longer time to diagnosis than those who initially seek secondary care or emergency care, 33 (IQI 14.0–83.5) and 19 days (IQI 2.0–63.0), respectively ($p < 0.005$). However, no differences according to income, education, or distance were found.

Furthermore, as noted in Table 6, patients diagnosed with CRC have a shorter time to diagnosis if they are referred into the CPP compared to those without a CPP referral. The time to diagnosis for patients diagnosed with CRC and referred from primary care into the CPP, was 15.5 days shorter than the time to diagnosis for those patients without a CPP referral (27.5 days, IQI 14.0–54.5, vs. 43 days, IQI 14.0–98.0) (p 0.028).

Based on unadjusted data of the total sample (**IV**), differences were found in the DI on income and distance to hospital. Patients in the high-income group (income >median), and patients with short distance to hospital ($<P_{80}$) had a shorter DI compared with patients in the low-income group and patients with long distance to hospital ($\geq P_{80}$). Patients in the high-income group had 24.5 days (IQI 8.0–56.5) to diagnosis compared with 39.5 days (IQI 13.3–92.0) for those in the low-

income group (p 0.004). Patients with short distance to hospital had 27 days (IQI 8.0–74.0) to diagnosis compared with 39 days (IQI 15.0–76.0) for those with longer distance (p 0.037). These associations remained after adjusting for age and sex in the Cox regression analyses (HR 1.004, CI 1.000-1.007, p 0.039; HR 0.998, CI 0.955-1.000, p 0.049, correspondingly), but not after adjusting for all covariates. In the TI and PI no differences related to sociodemographic variables, including distance to hospital, were found. Consequently, sociodemographic factors, including distance to hospital, do not seem to be related to time to diagnosis and treatment for patients with CRC in the study regions.

Table 6. Patients' time to diagnosis stratified for referral into the standardized cancer patient pathway for colorectal cancer.

	CPP referral (missing = 59, 18.8%)				
	No (n = 147, 47%)	**CI / IQI**	**Yes** (n = 107, 34.2%)	**CI / IQI**	**P**
Age (years) *	71.0	69.2–72.8	73.7	71.9–75.4	**0.042†**
Male sex (%)	77 (52.4)		66 (61.7)		0.140¶
Diagnostic interval (days) #	43.0	14.0–98.0	27.5	14.0–54.5	**0.028 §**
Treatment interval (days) #	29.0	20.0–45.0	33.0	22.0–41.0	0.218 §
Distance to nearest hospital (km) #	18.0	4.0–58.0	24.0	7.0–52.0	0.427 §
Long education (%)	31 (21.1)		23 (21.5)		0.989¶
High income (%)	67 (45.6)		51 (47.7)		0.844¶
Tumor stage (%)	147 (100)		107 (100)		0.859¶
Tx without metastasis	5 (3.4)		2 (1.9)		
T1–T2 without metastasis	23 (15.6)		15 (14.0)		
T3–T4 without metastasis	43 (29.3)		30 (28.0)		
Tx, T1–T4 with metastasis to lympho-node	39 (26.5)		34 (31.8)		
Tx, T1–T4 with remote metastasis	35 (23.8)		24 (22.4)		
missing	2 (1.4)		2 (1.9)		

CPP referrals among those with primary care as first healthcare contact (n = 313). CPP referrals, i.e., patients who either were or were not referred into the CPP for CRC. Values presented are means with confidence intervals (CI) (marked with *) or median values with interquartile interval (IQI) (marked with #), as appropriate. Bold type indicates significant p-values. † Indicates one-way ANOVA, § indicates Kruskal-Wallis Test, ¶ indicates Pearson Chi-square Test.

Discussion

Creating access through interaction…

In the beginning of this thesis I introduced three puzzle pieces of access to care. The first piece illuminates patients' processes of interpreting bodily changes as well as deliberating about seeking healthcare. The second piece illuminates healthcare providers' influence on patients' access to healthcare, which, for example, includes physicians' communication, interpretation, and medical assessments during encounters. The third piece illuminates the healthcare system's role in access to healthcare, such as organizational characteristics, national guidelines and policies, workload, barriers to referrals, and cooperation between primary and secondary care. This thesis has demonstrated that interaction during encounters have importance for patients' access to care, and three components, found in the second puzzle piece, have been highlighted: (1) negotiating and communicating, (2) embodying roles, and (3) adhering to norms. These components are enacted and transacted though interaction, which points to the significance of reconciling the patient and the provider perspectives during encounters. Thus, access to care is created through joint action of the two parties during encounters. Furthermore, time to diagnosis and treatment is analyzed and interpreted as an outcome measure of patients' interaction with healthcare. Consequently, this thesis contributes to the existing body of literature by expanding concepts of access by recognizing that interaction has importance for access to (cancer) care. Interaction is understood to influence all aspects of patients' care trajectories, from deliberating about care-seeking until treatment, because we, as humans, are in constant interaction with our surroundings, with institutions, with technologies, with media, and with other people, and so forth.

… with the healthcare system

From the constructivist perspective, there exist two forms of reality, material reality and socially constructed reality (Lincoln and Guba, 2016). In this thesis, the socially constructed reality is mainly found in the patient–provider encounter, while the material reality is related to aspects such as income, education, and distance to hospital. Even though it is easy to assume that results from quantitative studies are straightforward, they only provide a snapshot of a reality, overlooking many of those factors and aspects that might alter and influence the results, such as interactions in the patient–provider encounter and patients' interaction with healthcare. Thus, it is important to consider that interaction is vivid through all aspects of patients' care trajectories, from aspects found in the first puzzle piece until the third, and that inequalities are shaped within social processes and relationships (Schwallbe, 2008), such as interactions within patient–provider encounters (Timmermans, 2020). Consequently, the

results from study **IV** can be understood as an outcome measure of patients' interaction with the healthcare system prior to, and during, their diagnosis and treatment. Exploring interaction from different perspectives, and acknowledging that patients' time to diagnosis and treatment is a result stemming partly from interaction, unveils the complexity of patients' healthcare-seeking practices.

Study **IV** showed that sociodemographic factors were not related to time to diagnosis and treatment for patients in the study regions. Consequently, it seems that when patients get access to healthcare, the healthcare organization operates equally in these regions for this patient group, in terms of time to diagnosis and treatment. It is, though, important to acknowledge that the study was conducted only shortly after the introduction of the CPP. Even so, the national evaluation of CPPs reports that the assessment of patients' conditions became more equal due to the criteria reported in the CPPs; thus, CPPs seem to increase the preconditions for improved equity within cancer care (SoS, 2019a; 2019b). However, describing alarm symptoms of cancer as scientific criteria might give the illusion that seeking care and diagnosing cancer is easy, when in reality, seeking care for symptoms potentially indicating cancer seem to be imbedded in a multilayered complexity (Andersen et al., 2015). Additionally, previous research suggests that the referral systems "two-week-wait", similar to the CPPs, which are based on symptoms and warnings signs of cancer, are unlikely to improve early detection of CRC (Mozdiak et al., 2019).

Patients do not simply get or do not get access; they are involved in interactive processes in which negotiating, embodying roles, and adhering to norms are actualized. As described by Schwallbe (2008), inequalities are an accomplishment. Inequalities do not merely relate to things (such as income) that people have or do not have; they also have to do with social processes, with defining groups of people as different in some way. Also, inequalities sometimes are reproduced through our learned behavior, without our conscious knowing (ibid.), possibly within behaviors found in the patient–provider interaction. Even though the results from study **IV** did not report any differences in time to diagnosis and treatment for the study sample based on income, education, or distance to hospital, I can only speculate about these patients' interaction with healthcare. Regardless, access to diagnosis and treatment were created without influence of sociodemographic factors. This contradicts results from other studies that indicate that there is a socioeconomic gradient in cancer care, that patients with lower socioeconomic positions are more likely to be diagnosed with CRC at a late stage, to have poorer health outcomes, and to have lower cancer survival than patients with a higher socioeconomic position (Feller et al., 2018; Dalton et al., 2019; Finke et al., 2021). Nevertheless, it is important to acknowledge that these patients already have been accepted into the healthcare system; we do not know anything about those patients who sought care but did not get it. Having

that said, it is important to remember that not all patients seeking care "should" receive access to further care. Physicians in primary care have the important function of gatekeepers, to identify those patients who need referral, while holding back those who do not – all to ensure that the whole healthcare system chain runs smoothly. Consequently, physicians face daily the challenge of deciding which patients to refer to secondary care, and which patients to hold back. Standardized cancer patient pathways have been introduced to promote equity within cancer care, but also to ease these decisions for physicians by providing criteria for referrals. Physicians participating in this thesis reported that CPPs function as valuable tools in primary care, since CPPs were described as easing the referral procedures and providing physicians with structured guidelines, which they explained were easy to follow. Thus, CPPs can provide clarity and structure in situations that otherwise are filled with uncertainty.

If standardized care is the future for the healthcare organization, the infrastructure of CPPs needs to be improved. For example, the premise for successful utilization of CPPs could be that the healthcare organization ensures that personnel are thoroughly informed about CPPs, which physicians participating in this thesis were not fully. These indications are supported by a recent published study finding that physicians' knowledge about CPPs is insufficient (Backman et al., 2021). Furthermore, physicians could benefit from an ongoing discussion about how to balance adherence to CPPs with making decisions based on their expertise and clinical assessment, since this thesis has shown this to be a source of stress and tension for physicians. Furthermore, as Wells et al. (2021) suggest, it is important that the healthcare organization cooperates within and across different levels. Such cooperation has been in focus alongside the introduction of CPPs (SoS, 2019a); however, there is still room for improvement. For example, physicians report lack of communication and lack of routines regarding referrals, and experience being questioned by secondary care (Wells et al., 2021).

Previous research shows that competing discourses within the healthcare organization, such as the discourses of providing person/patient-centered care while adhering to standardized routines, challenge healthcare practices (Blanchet Garneau et al., 2019). As the results from this thesis portray, there is no such thing as a standardized patient with standardized symptoms; thus, it seems challenging for physicians to engage in interactions based on person/patient-centered dialogues, interpret presented symptoms, and match them with standardized criteria. Standardizing care might risk neglecting the individual variety and uniqueness of each person and each health condition, and thus, person/patient-centered care might risk being impeded by standardized routines, such as CPPs. Nonetheless, patients referred to a CPP report that they are satisfied with the shortened waiting times. However, they also report that their involvement and

participation in their own care needs to be improved (SoS, 2019a). This is especially relevant, since previous research shows that patients want to be respected and involved in their healthcare processes (Hultstrand Ahlin et al., 2018; Lundberg et al., 2020).

The subgroup analysis in study **IV** showed that patients referred from primary care into the CPP for CRC had shorter time to diagnosis than those who were not referred into the CPP. This probably indicates that CPPs facilitate referrals of patients with alarm symptoms when these are identified in primary care, and that these patients are thus more rapidly diagnosed compared with patients with symptoms that do not qualify for CPP referrals. On the other hand, a recent study from Sweden reports that the CPP for CRC in another region did not improve the health outcomes for this patient group (Andersson et al., 2021). Furthermore, a meta-analysis from the UK finds doubtful benefits with their fast track referral pathway for CRC ("2-week-wait"), similar to the Swedish CPP. This because only 7.7% of those referred into the pathway were later diagnosed with CRC, and that no beneficial effects on tumor stage at diagnosis were found (Mozdiak et al., 2019). In Sweden, the national evaluation of CPPs concluded that time intervals for patients with CRC have had a more modest decrease in time to diagnosis, in comparison with time intervals for patients with, for example, prostate cancer or bladder cancer. Colorectal cancer was, however, closer to the target levels regarding time intervals to diagnosis prior to the introduction of CPPs, which possibly offers a part of the explanation. On the contrary, for some other cancers, the time to diagnosis has increased since the introduction of CPPs (e.g., pancreatic cancer, brain tumor) (SoS, 2019b). However, the body of literature about the outcomes and effects of the introduction of the CPPs is scarce, and more research is needed.

During recent decades, traits from the field of economics have had the attention of the healthcare organization, focusing on increasing effectiveness and quality of care (where standardization is one example). Also, the market logic defines patients as customers, insinuating the possibility of individualized tailored care, while, in reality, standardization of care is increasingly adopted (Mol, 2011; McLaughlin, 2009). The northern parts of Sweden are characterized by abundant rurality with long distances to healthcare services, combined with urban areas where the availability of such services is greater, which influence peoples' access to healthcare. Healthcare provision in rural areas differs from that of more urban areas due to different prerequisites. Following the trends of market logic in healthcare, previous research indicates that there is a contradiction between the provision of rural healthcare and creating a competing market. There are challenges in rural areas to providing healthcare, and market logic is not well suited in such areas, since it might impede equity in access to care, due to, for example, the low stimulus to introduce healthcare facilities in rural areas

(Kullberg et al., 2018). Thus, it seems important to tailor healthcare services to match local preconditions and healthcare needs (Hultstrand et al., 2019), since rural areas face different challenges than urban areas.

... within the patient–provider encounter

Existing theories and frameworks about access to care have up until now overlooked the significance of the patient–provider interaction, even though it is known that patient–provider interactions have importance for patients' health outcomes (Hellín, 2002; Mead and Bower, 2000). Access is created through the interaction between patients and physicians, in which communication is an essential aspect. Presenting symptoms that are vague and ambiguous (e.g., not qualified as alarm symptoms) seems to increase patients' perceived need to justify their healthcare-seeking and to appear credible. Being credible and trustworthy, that is, being a legitimate patient, is not a role a patient can take; rather, this role is a position that is conferred by physicians (Mik-Meyer and Obling, 2012). That physicians trust their patients is important for the patient–provider interaction. Patients are enabled to verbalize their health complaints without fearing to be disbelieved, if they feel trusted by their physicians (Rogers, 2002). Thus, trust has significance for the patient–provider encounter in general, and for communication in particular.

Physicians use verbal language and body language to communicate and embody the role as a credible and competent medical expert while interacting with their patients. Previous research reports that physicians' technical skills and how they communicate with their patients can enhance trust during encounters. Trust is, among others, related to whether physicians engage in person/patient-centered care, are honest and caring, thoroughly describe what they are doing, and refer their patients to secondary care when needed (Fiscella et al., 2004; Thom, 2001; Hillen et al., 2011). Practicing patient-centered clinical communication has been described as an essential part of contemporary medical education. Physicians in study **II** described that they sometimes become frustrated if they perceive their patients' stories as long and irrelevant. Larsen and Neighbour (2014) report that such frustrating situations arise if the physicians do not summarize what their patients have said, since a lack of summary can result in patients' presentations going in circles. The communication during patient–provider encounters can be divided into three parts, according to Larsen and Neighbour (2014): (1) the Patient's part, (2) the Physician's part, and (3) the Shared part. During the first part, it is important that patients are given the opportunity to present their ideas, concerns, and expectations, while the physicians responds to these by giving receipts, that is acknowledging their patients, and summarizing what has been said. Receipts have a crucial role, since such acknowledgments and confirmations show the patients that the physician has recognized the accuracy and importance

of their presentations. Such receipt has to be clear: according to Larsen and Neighbour, a simple nod is not sufficient. Summarizing what the patients have presented is also important to ensure that the presentation is interpreted correctly, and by doing that, the patient is shifted from being the active narrator to being the listener (Larsen and Neighbour, 2014). Still, it is not merely the verbal communication that counts; non-verbal language and tone of speech significantly influence patients' experiences of encounters, and can make patients feel either confirmed or ignored, which the results of this thesis also showed. For example, if the physician's body language is perceived as busy and stressed, patients can feel ignored or feel like a burden. On the contrary, body language and eye contact that signify full attention and concentration make patients feel welcomed and listened to (Timmermann et al., 2017). Previous research finds that people seeking care seem to be willing to wait an extra 3.5 weeks to get an appointment with a physician perceived as a good listener. Thus, improving physicians' communicative and listening skills may have the potential to encourage people to seek care when they experience bodily changes (Whitaker et al., 2017), which potentially influence patients' time to diagnosis.

Patients have left the role of passive recipients of care and entered an active and more engaged role, in which they are more vocal about their preferences, advocating for their health, but also having the responsibility to advocate (Timmermans, 2020), which this thesis also has shown. Thus, patients are frequently described as customers, consumers, or clients, who have not only demands and preferences but also responsibility for their health and healthcare (McLaughlin, 2009; Mol et al., 2010; Nettleton, 2013). Patients have gained power due to, for example, the increased availability of medical information (especially online), and have thus become "informed consumers" rather than "acquiescent patients" (Jutel, 2011). Patients are increasingly being treated as customers who have demands of their care and healthcare providers (Nettleton, 2013; Mol, 2010). However, patients do not only have demands related to their healthcare providers and trajectories; they also experience demands on themselves when interacting with healthcare, as this thesis has portrayed.

The results from this thesis showed that the patient–provider encounter is complex for both parties. Patients and physicians want to fulfill the expectations that are embedded in their specific roles. Patients want to come across as credible and trustworthy when describing their bodily changes and reasons for care-seeking in order to embody the role of a "good patient." That patients perceive a need to appear credible during encounters with their healthcare providers (Werner, 2011), and that patients want to be trusted as well as to feel trust (Lundberg et al., 2020) is reported in previous research. It is also reported that patients sometimes put in a lot of effort to appear credible during encounters (Werner and Malterud, 2003), and that patients' satisfaction with care is related

to their perceived trust and the credibility of their healthcare encounter (Yavorskyy, 2016; Chang et al., 2013). Consequently, patients' perceived demands on themselves to appear credible needs to be verbalized within the medical profession, and actions need to be taken to ease these demands. In the literature, social rules have been used to describe the shared ideas that people adhere to in order to avoid problems for themselves and others; hence, rules are used to guide peoples' behaviors (Schwallbe, 2008). These rules resemble the roles and norms that patients and physicians embody and adhere to within the patient–provider encounter, to fulfill what is expected from them, which this thesis has demonstrated. Following the current norms related to care-seeking, patients face, for example, the norms of being responsible for their health and healthcare (Timmermans, 2020), being attentive to bodily changes without being hypochondriac, and seeking care in a timely manner but without wasting healthcare resources (Ziebland et al., 2019). Previous literature suggests that people understand "the rules of the game" when interacting with institutions, such as healthcare systems, differently, which influences the interaction (Lareau, 2015). Thus, knowing these rules influences how patients interact with the healthcare system. Furthermore, when physicians accord patients the role as legitimate patient, they do not merely take into account the patients' conditions but they also consider societal norms (Mik-Meyer and Obling, 2012), such as the obligation to work when not being sick (Parson, 1964; Mik-Meyer and Obling, 2012).

Challengingly, what happens with those patients who do not have the cultural health capital to engage? That is, those who fail to adhere to organizational norms or lack skills and resources that may have importance for the patient-provider interaction. Skills and resources such as medical knowledge, skills to communicate, ability to adapt one's interactional style, and the ability to take an instrumental attitude towards one's body (Shim, 2010). This means that patients' ability to present their reasons for care-seeking, by, for example, using biomedical language, might influence physicians' interpretations and assessment of the patients' health condition, and consequently, the patients' future care (ibid.). Furthermore, previous research finds that patients' socioeconomic position, and their style of communication, influence the patient–provider interaction and communication (Verlinde et al., 2012; Aelbrecht et al., 2015), which might influence patients' health outcomes (Siminoff et al., 2006) such as further access to care. At the same time, it is important to consider that even if patients have power in terms of skills and knowledge, some do not want to be actively engaged in decisions involving their care (Joseph-Williams et al., 2013). It is therefore important that physicians are attentive to the individuality of each patient during encounters, and increase their awareness of patients' communicative differences (Verlinde et al., 2012).

Lastly, this thesis has demonstrated that interaction is a significant dimension of patients' access to care. Challengingly, there seem to be many factors that might influence interaction. For example, scholars report that cultural health capital (Shim, 2010), communication (Verlinde et al., 2012), norms related to healthcare-seeking (Ziebland et al., 2019), and patients' social network (Gage-Bouchard, 2017) influence and shape how patients interact and navigate the healthcare system. Nevertheless, there are possibly many more dimensions that are omitted in this thesis and need to be explored in further research. Still, this thesis has demonstrated that negotiating and communicating, embodying roles, and adhering to norms are important dimensions of interaction, which illuminates the significance of reconciling the patient and the provider perspective during encounters. With that being said, it takes two to tango! Thus, the healthcare organization has a great responsibility to be a compliant dance partner.

Methodological and ethical considerations

Methodological considerations

Study I
Physicians are often portrayed as gatekeepers, meaning that they are the ones who have power over patients' access to further care. However, patients who have been given an appointment with a physician have, most often, already had their sensations and symptoms primarily legitimized by a primary healthcare nurse. Thus, even though we have conducted observations of patient–provider encounters in primary care, we have not managed to capture patients' initial contact with healthcare, which can be seen as a limitation. Consequently, in future research it would be of great interest to study patients' first contact with healthcare, including contact through telephone or Internet (e.g. 1177.se).

That we had no specific inclusion criteria in regard to work experience for participating physicians could be seen as a limitation. In study **I**, physicians were eligible for participation if they had a booked appointment with a patient seeking care for symptoms indicating cancer, and if they consented to participation. To include physicians with, for example, a certain length of work experience or length of employment at that specific PHC might have been favorable. However, that all physicians who worked at the PHCs were eligible to participate does portray the reality that patients seeking healthcare face, meaning that sometimes patients meet assistant physicians and other times they meet senior ones.

By using participant observations as a method for data collection, it is possible to gain understandings about complex and dynamic situations (Yanes et al., 2016) such as interaction during patient–provider encounters. Observations also enable exploration of non-verbal and verbal communication (ibid.); however, there is always a risk that observed participants could be influenced by the observers and that they might change their behaviors. Even so, Roter and Hall (2006) state that observed participants in previous studies forgot that they were being observed. Furthermore, medical students often participate in encounters; thus, we assume that patients felt comfortable having an extra person in the room. In addition, the participants in study **I** were informed multiple times that participation was on a voluntary basis and that they could withdraw from participating at any time. One patient asked me to step out of the room during the physical examination, which increased my belief that the participants felt comfortable having us in the room and that they would let us know otherwise.

During the encounters, I and the other observer were visible but passive, meaning that we observed the encounter without engaging in any activities, and we placed

ourselves in the room so that we would not be in the way or interfere in the patient–provider interaction. I have positioned myself within the outsider perspective, since I have no experience of working within a clinical setting, nor am I medically trained. In contrast, the other researcher who conducted some of the observations and interviews has contributed the insider perspective, since she is a registered nurse with a lot of clinical and medical experience. Consequently, I argue that our perspectives were complementary to each other during analysis. Also, focused ethnography enables explorations of the participants' emic view of the world, and etic insight to the meanings behind their actions (Roper and Shapira, 2000), and to first observe an activity, followed by asking the participants about it, enables a deeper understanding (ibid.).

Studies II and III

The purpose of interviews is to enter the interviewees' world, to get to know their experiences, and to gather their stories described with their own words (Patton, 2002). By using interview guides, I was able to prepare questions that were simple and clear, which were facilitating for the interviewees to respond to (Kvale, 2014). These interview guides also structured the interviews around predetermined lines of inquiries (Patton, 2002), which facilitated keeping the interviewees and me on topic. To be a good interviewer takes practice, one learns from listening to one's own recorded interviews, from feedback, and from doing interviews (Kvale, 2014). Based on personal reflection, each interview differed from the other, and I had to learn to be attentive and responsive, which highlights the significance of research being created between the interviewee and the interviewer. After each interview I listened to the recordings, sometimes with my supervisor, and reflected about what I could improve next time, which developed my interview skills.

By synthesizing the results from studies **I**, **II**, and **III**, it is possible to gain a deeper understanding about the interaction within the patient–provider encounter and what seeking and accessing care entails. Thus, one major strength of this thesis is that the interview studies (**II**, **III**) succeed from study **I**, the observational study. This means that patients and physicians who participated in study **I** were invited to participate in individual interviews. Kvale (2014) underlines the importance of the first minutes of an interview, that is, when the interviewee assesses the interviewer and creates a first impression of her/him, which can significantly influence the interview. Therefore, I consider it as beneficial that the interviewees had met with me before and were thus familiar with me. Also, that I had observed their encounter provided me with a preunderstanding that enabled me to develop interview questions, recognizing the participants' narratives, as well as it increased my understanding about the participants' experiences of the encounter. Even though I am aware that this preunderstanding also can impede and influence my interpretation and analysis,

my personal reflection about this process is that the preunderstanding I attained during the observations was beneficial for the interviews, rather than limiting. I especially perceived the interviewees to be more comfortable talking about their experiences, as they already were familiar with me.

Study IV

That not all four of the northern regions are included in study **IV** is a potential limitation. Region Norrbotten was not included because we failed to find a key person from this region who could assist with performing medical records reviews. However, there is no reason to believe that socioeconomy or the results would differ in Region Norrbotten compared to the included regions. Additionally, that data on CPP referrals was missing in almost 20% of the cases is also a limitation.

Cox regression is one of the most used statistical methods for analyzing "time to event" in medical and epidemiological research, most often for survival analysis (ElHafeez et al., 2012); thus, it could be seen as a limitation that we have used Cox regression outside the context of survival analysis, especially since there were no lost participants at follow up. However, it is important to recognize that Cox regression can be used for any type of time-to-event data. For example, one can use Cox regression for analyzing time until a patient leaves the hospital after surgery (Vach, 2013; ElHafeez et al., 2012), or as we did in this study, the time elapsed until diagnosis and start of treatment. One advantage of using Cox regression is that this method allows for adjusting for covariates (ElHafeez et al., 2012; Stel et al., 2011), and that Cox regression closely approximates the results from parametric models (Kleinbaum and Klein, 2005), which makes this choice of method suitable for our data.

Some of the continuous variables included in study **IV** were dichotomized, which many times is consider useful (Nelson et al., 2017); however, converting continuous variables into categorical can also cause problems (Naggara et al., 2011). Consequently, it is important to consider how to discriminate between groups when dichotomizing a continuous variable. Clinical motivation, based on prior knowledge and experience, is one preferred method for doing so (Nelson et al., 2017), and was used when dichotomizing variables in study **IV**. On the contrary, creating cut-offs based on, for example, minimizing the p-value should be avoided (ibid.). Consequently, it is important to reflect upon how the included variables were dichotomized. Income was used both dichotomized and as a continuous variable. When dichotomized, the income variable was divided across the median; it is highly possible that the results would differ if the dichotomization were done differently. Nonetheless, in the regression analysis the continuous income variable was used to avoid possible distortion of the results and loss of information (Naggara et al., 2011).

Even though education and income were dichotomized, analyses were performed in more than two groups for the two variables to ensure linearity of the data. Nonetheless, in the analyses comparing groups, only two groups were used, since findings from dichotomized analyses often facilitate the interpretation (Naggara et al., 2011).

Furthermore, there might be intrinsic complexity regarding the variable education. The study sample is in general rich by age, and many of the patients may have a long education. But adding to the complexity, the meaning of "long/high" education has changed during the last decades, what was considered long education before is not the same as today. This change of the meaning of education might cause bias, not only for this study but for research in general.

The 80th percentile was selected as a cut-off when dichotomizing the variable distance to closest hospital to ensure that the two groups were reasonable in size, still minimizing the risk of random variation. Also, as in the case of income, in the regression analysis the continuous variable was used to avoid possible distortion of the results and loss of information (Naggara et al., 2011).

Trustworthiness and quality evaluation

There are different criteria for assessing trustworthiness, depending on methods and epistemologies (Patton, 2002). In the following, studies **I** and **II** are assessed using criteria for GTM studies, then criteria for general qualitative studies are described for study **III**, followed by criteria applicable to quantitative studies, study **IV**.

Studies I and II – Grounded theory method

The criteria of Credibility, Originality, Resonance, and Usefulness are proposed by Charmaz (2014) for use when assessing and evaluating grounded theory studies.

Credibility relates to the logic link between data and interpretations, to saturation, and to systematic comparisons between data and categories. By adhering to the method of constant comparison, by comparing code with code, category with category, and so forth, it is possible to raise the level of abstraction but at the same time maintain the logic link between data and result. Furthermore, providing coding schemes and quotations enables readers to make independent assessments.

Theoretical sampling is advocated when following GTM, which means that the process of analysis starts in conjunction with data collection in order to develop theoretical categories (Charmaz, 2014). Study **I** employed purposive sampling to

enroll patients for participation; patients and physicians were therefore not enrolled based on emergent leads from the analysis. However, the process of analysis started in conjunction with the first observation. In regard to study **I**, it could be argued that it would have been favorable to observe more than 18 encounters; however, data gathering continued until saturation of theoretical categories. The samples in study **II** consist of a total sample, meaning that all physicians who had been observed during an encounter participated in an individual interview, which is considered as a strength.

Originality relates to the significance of the studies. The medical encounter per se is not an original study phenomenon; rather, it has been frequently studied. However, to explore access though patients' interaction with their provider and with the healthcare system provides a broadened perspective. Thus, this thesis provides an extended understanding of access to care, in which patients' interaction with their provider and with the healthcare system is significant, which illuminates the originality.

Resonance relates to whether the results make sense to people who share the participants' circumstances, and whether categories portray the fullness of the studied experiences. During analysis, I coded the data line-by-line, which enabled me to interpret what was happening in the data, as well as allowing me to fragment parts of the data. This coding process enabled exploration of implicit meanings and actions, and provided directions for forthcoming analysis. Also, when coding the material, I used a mix of manifest, latent, interpretative, and in vivo codes, which increased my opportunities to portray the fullness of the studied phenomenon. Whether the results make sense to other people in similar situations is up to the reader to assess.

Usefulness relates to whether the analysis offers useful interpretations, whether the results can guide further research, and how the results can contribute knowledge. The results from studies **I** and **II** (and the thesis as a whole) are useful, as they provide new insights and originated in an understanding about the significance of interaction for patients' access to care. Hopefully, these insights can spark further research and be useful for the healthcare organization, which will benefit patients seeking care for potential cancer symptoms in the future.

Study III – Thematic analysis

The criteria of Credibility, Transferability, Dependability, and Confirmability are commonly used to assess trustworthiness of qualitative studies (Dahlgren et al., 2004; Nowell et al., 2017). In the following, these criteria will be discussed in relation to study **III**.

Credibility refers to how well the results describe what has been explored (Dahlgren et al., 2004). Examples of the process of analysis, enabling the reader to follow the process from text to theme, and to engage in triangulation, are ways to enhance credibility (Lincoln and Guba, 1985). Also, the choice of method influences the credibility (Patton, 2002). Individual semi-structured interviews are a suitable method for exploring patients' experiences of encounters with primary care physicians. Furthermore, triangulation by combining different methods, in this case observations and interviews, enhances credibility. Also, I have presented preliminary findings to colleagues, who have provided me with critical feedback, which is an additional way to increase credibility (Dahlgren et al., 2004).

Transferability refers to the extent to which results are transferable to other settings and contexts (Malterud, 2001), which in quantitative studies is referred to as generalizability (Dahlgren et al., 2004). To enhance transferability, thick descriptions of context and setting have been provided, which enable the reader to assess the level of transferability (Lincoln and Guba, 1985). However, to generalize results to other settings is not the goal of qualitative research; rather, qualitative research aims for analytical generalizability, that is, that results exceed the empirical level and contribute to new theory development, which is applicable across different contexts and settings (Dahlgren et al., 2004).

Dependability refers to the logic of the research process, and the researcher's ability to adjust the research processes in regard to dynamic and changing conditions (Dahlgren et al., 2004). To achieve dependability, an emergent design was employed, and multiple researchers were involved in making decisions regarding the research process.

Confirmability refers to the level to which interpretations that are made are derived from data and not figments of the researcher's imagination (Lincoln and Guba, 1985; Tobin and Begley, 2004). To enhance confirmability, the research process has been described in detail and quotations have been provided; also, triangulation in terms of multiple researchers' involvement has been applied. Furthermore, during the process, memos and notes were taken, which is important for all criteria, not only confirmability (Dahlgren et al., 2004).

Study IV – Statistical analyses

Internal validity is what in qualitative studies is referred to as credibility, that is, that the study has measured what it set out to measure (Dahlgren et al., 2004). That our results showed an expected association between tumor localization and time to diagnosis reinforces the internal validity of our results. Selection bias can often impede the internal validity (Polit and Beck, 2012); however, since the goal was to include all patients diagnosed with CRC in the study regions, and since the

Swedish Cancer Register has almost 100% coverage, I assess that the risk of potential bias stemming from selection bias is limited.

External validity, is what in qualitative research is referred to as transferability, relates to how generalizable the results are to other contexts, settings and populations (Dahlgren et al., 2004; Polit and Beck, 2012). Thus, the similarities between the sample and target population is of great importance. However, I would argue that there are more factors that are important. For example, in this case I believe that the context and organization of the healthcare system has a major influence. Consequently, there are several factors to take under consideration when trying to generalize the results from one single study.

Reliability is what in qualitative research is referred to as dependability. If repeated measures yield consistent results, the reliability of the study is high (Dahlgren et al., 2004; Campbell et al., 2007). Consequently, a high reliability presumes minor random errors (Andersson, 2016). Accuracy and clearly defined measures are important to enhance the reliability. The physicians who performed the reviews of the EMRs had clearly defined measures and thresholds, and regularly discussed potential questions to reach consensus. Furthermore, analyses were made with carefulness, and field notes were continuously taken.

Reflexivity and my positioning as a researcher

Constructivism is my ontological and epistemological standpoint. This means that I view data as a social construct, derived from the interaction between the study participant and the researcher, and the surrounding context. Consequently, findings do not emerge from the analysis; rather, results are created (Braun and Clarke, 2006; Charmaz, 2014). Further, following Burr's argument that "no human being can step outside of their humanity and view the world from no position at all" (Burr, 2015, p.172), I believe that being truly objective is impossible. Consequently, different researchers might interpret and understand explored phenomena differently due to their backgrounds, perspectives, and preconceptions. Reflexivity can be described as "the knower's mirror" and influences the researcher throughout the whole research process (Malterud, 2001). By adhering to GTM and engaging in constant comparison (Charmaz, 2014), I have challenged my reflexivity, since these steps of the analysis process have enabled me to search for alternative interpretations and conclusions. Furthermore, memo writing assisted the analysis process, from my earliest thoughts and ideas to the finalized results.

Preconceptions can be described as "the researcher's backpack," which is influenced by previous experiences as well as theoretical perspectives related to interest and education (Malterud, 2001). As mentioned, I have neither medical

education nor experience of clinical praxis. Rather, my preconceptions about the patient–provider encounter stem mainly from own or heard healthcare experiences. Therefore, I assume that the patient perspective is for me closer at hand than the physician perspective. Even though preunderstanding can be advantageous when asking follow-up questions (Dahlgren et al., 2004), I found it beneficial during interviews with the physicians that I lacked clinical preunderstandings, because this lack of knowledge motivated me to ask more fundamental and detailed questions. This might also hinder interviewees from restraining their answers and thoughts, due to them thinking that the interviewer already "knows" (Kvale, 2014). Consequently, that my background is in the field of health promotion and public health is both strengthening and limiting, although, I do consider the benefits greater than the disadvantages.

Ethical considerations

Ethical approval was granted from the regional ethical review board for studies **I** to **IV** (Dnr. 2017-296-31M; 2018-242-32M; and Dnr. 2018/305-31). Written informed consent was obtained from the head of each PHC, and from all physicians and patients who participated in studies **I** to **III**.

The consequences of qualitative studies must be considered in relation to the potential benefits from the scientific results (Kvale, 2014). The results stemming from studies **I** to **III** strengthen existing knowledge and contribute new insights; however, there are no direct benefits for the participating patients and physicians. Rather, the results from these studies contribute to the existing body of literature, and have the possibility to contribute to organizational and educational healthcare improvements. The benefits stemming from these results are therefore assessed to outweigh the risks and vulnerability of being observed and interviewed.

Study I

Being under observation may be perceived as being placed in a strenuous and vulnerable position. However, participation was on a voluntary basis, meaning that participants could decline to participate or withdraw from participation at any time without offering any explanations. Furthermore, written informed consent was obtained from all participants.

Patients participating in study **I** were briefly informed about the ongoing study when they called their PHC and booked an appointment (but after the booking had been made). Then, in connection to the patients' appointments, they were provided detailed informed by the researchers in the waiting room prior to their appointment. Thus, they had a rather short period of time to deliberate whether they wanted to participate or not. However, even though the time period was

rather short, patients had the opportunity to ask questions, which is considered as essential to ensure an informed consent. In general, the majority of the patients approached were rather quick to decide whether they wanted to participate or not, which could imply that they had deliberated about their willingness to participate prior to the researchers approaching them. There were a few patients who rapidly gave their consent to participate, so rapidly that one would consider their consent as uninformed. In those situations, these patients were provided with extensive information, and were asked once more if they consented to participate. Also, patients were informed that their decision to participate, or not, would not affect their given care, and that they could request the researchers to step out of the room at any time.

It is possible that the physicians who participated in study **I** experienced a somewhat vulnerable situation. To my understanding, their prime concern was that their daily work as clinicians would be assessed and evaluated. Therefore, they were meticulously informed about the aim of the study, which was not to in any way judge their work. It was also underlined that I personally have no medical knowledge, which might have eased their concern. Furthermore, prior to the data collection, the physicians were invited to an information meeting in which they had the opportunity to ask questions.

After each observation, participating patients and physicians were asked for permission to be contacted to discuss whether they would like to participate in an individual interview (**II**, **III**). In conjunction with these interviews, but prior to their start, an additional information sheet was provided, and participants were given the opportunity to ask questions. All participants gave their written informed consent.

Studies II and III

Participating in interviews affects different individuals differently, some might experience emotional stress (Kvale, 2014). Prior to the interviews it was emphasized that there are no right or wrong answers to the interview questions. This is especially relevant for the interviews with the physicians (**II**), since it could be perceived that the interview questions in some way evaluated or assessed their work. That some physicians expressed rather limited knowledge about CPPs could also cause distress, maybe making them feel that they lacked information and knowledge about things that they "should know."

Qualitative methods are highly personal (Patton, 2002). Being interviewed about their visit to the PHC, when seeking care for symptoms that might indicate cancer (**III**), was sometimes emotionally challenging for the participating patients. Some became emotionally affected, while others did not. During those interviews that awoke many emotions for the participants, I strived to be attentive and empathic.

All participants did, though, want to continue their interviews and seemed pleased by having the opportunity to talk about their experiences of seeking care and expressed that the research topic was important. Also, all participants could contact us afterwards to discuss potential issues related to their experiences around participating; however, no one did.

In conjunction with data collection for studies **I** and **III**, based on the information that was raised during the medical encounter, I perceived one patient to be in a rather poor health condition. Consequently, this person was not asked to participate in an interview. Even though it could be argued that I should have given this patient the opportunity to decide about participating him/herself, I did not want to cause this person any avoidable distress.

Study IV

Study **IV** is a retrospective cohort study. It could be argued that not obtaining informed consent from all patients about whom we have collected data would be unethical. However, due to the large sample size it would not have been feasible to obtain such consent. Also, the utility of analyzing such data was considered as greater than the potential harm, something that also was approved by the ethical review board. Furthermore, reviewing medical records can be asserted as violating privacy, as there was also the possibility that those who performed the reviews would recognize the patients. To the contrary, performing medical records reviews is a task that physicians perform on a daily basis, and they also conform to their professional confidentiality. Moreover, during analysis, data were deidentified, which means that there was no risk for individual persons to be exposed.

Additionally, even though the individual persons included in study **IV** do not benefit from having their medical records reviewed or being included in this study, we as citizens demand high quality and cost-effective care. Thus, I argue that the results from this study have the possibility to be beneficial for persons undergoing investigations for suspected cancer in the future, and therefore I consider the benefits outweigh the potential risks.

Conclusions

This thesis contributes to the existing body of literature by recognizing that interaction inevitably affects patients' access to (cancer) care. During encounters, negotiating and communicating, embodying roles, and adhering to norms are important dimensions of this interaction, which illuminates the significance of reconciling the patient and the provider perspective. Thus, access to care is created through joint action of the two parties during encounters.

Patients perceive demands on themselves when presenting their symptoms in primary care and use different strategies in order to legitimize these. This seems particularly challenging if symptoms are diffuse. Thus, a need to be proactive when presenting symptoms during primary care encounters seems crucial nowadays. On the other hand, physicians have the responsibility to assess patients' symptoms and match them with criteria for CPP-referrals, criteria which are not always easy to access and apply. Physicians also need to acknowledge the uniqueness of each patient during encounters, to see, listen, and confirm, while operationalizing their medical expertise in order to identify suspected cancer. Thus, physicians need to juggle interpersonal aspects with medical knowledge, such professional skills seem necessary during patient–provider encounters in primary care.

The results of this thesis shed light on the importance of reciprocity while interacting during encounters in primary care. To reach common ground, patients and physicians need to have trust in each other, they need to engage in accepting dialogues, and be attentive towards each other. Thus, responsive interaction benefits both patients and physicians. This also includes being attentive to those patients who are not vocal about their symptoms and wants.

Moreover, access measured within the healthcare system as time to diagnosis and treatment among patients diagnosed with CRC in the study regions, was not related to differences in income, education, and distance to hospital. Additionally, patients who initially sought primary care had longer time to diagnosis than those who started their trajectory within secondary care and emergency care.

Implications for policy and practice

- The importance of patient–provider interaction in access to care needs to be highlighted in the healthcare organization, as well as within medical education.

- By acknowledging patients' feelings and validating their decision about seeking care, healthcare professionals can ease patients' distress and perceived demands on themselves related to their healthcare-seeking.

- It is important that healthcare professionals are aware that patients often devote time and effort to transmit credibility during encounters. Being attentive to these efforts and acknowledging them might decrease patients' perceived demands on themselves to appear credible. Thus, it would be beneficial if these aspects were advocated in the medical education, as well as within the healthcare organization.

- If standardization of care is to be utilized successfully, it is essential that healthcare professionals are continuously informed, and that channels from which they can access information about CPPs are easily accessible and updated. It is also important that the healthcare organization enable their personnel to be informed and updated, for example, by ensuring that they have time to do so.

- It is important to support primary healthcare personnel in their work to identify patients with potential cancer. Beside ensuring that they have time and that information about the CPPs is easily accessible, it would be advantageous to develop the system for medical records so that it could provide an overview of patients' alarm symptoms and signal patients' potential cancer risk.

Further research

Based on the results from this thesis, new questions have arisen. First, it would be of great interest to develop a framework of access in which interaction is included and operationalized, and to test such framework in future research. Second, this thesis included patients' experiences of their first encounter in primary care when seeking care for symptoms potentially indicating cancer. This means that these persons have already been welcomed into the healthcare organization. Thus, it would be interesting to include patients' first contact with care, that is, via telephone or the web interface (e.g. 1177) in future studies, since that might provide a more thorough understanding about accessing healthcare. Third, to conduct an ethnographic study exploring the everyday life of interpreting and managing emerging bodily sensations, as well as interacting with healthcare, would be challenging, yet interesting. Such study could provide insights of the processes leading up to the decision to seek care. Fourth, that the results of study IV showed that sociodemographic factors were not related to time to diagnosis for patients with CRC in the study regions was surprising. Thus, the results yield questions about how and why; analyzing the underlying mechanisms that contributed to that results would be intriguing. Lastly, to be able to draw conclusions about the effects, outcomes, and consequences stemming from CPPs, more research is needed, especially when more time has elapsed since the introduction of the CPPs. This includes studies similar to those in this thesis, but in other regions and with larger samples, as well as studies including register studies with other cancer diseases.

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