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Siri Christine Kvernmo Næss

Time Is of the Essence

Using Institutional Ethnography to Explore
the Introduction of a Cancer Care Policy

NTNU
Norwegian University of Science and Technology
Thesis for the Degree of
Philosophiae Doctor
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Summary

This PhD project contributes a critical analysis of the increasingly tight standardization and bureaucratic management of professional work. The focus is on the introduction of a cancer care policy entitled cancer patient pathways (CPPs), which assigns fixed time frames to each phase in the diagnostic process: from the identification of a reasonable suspicion of cancer until the start of treatment. Institutional ethnography provides the theoretical and methodological framework for this study. The empirical study is part of a larger project evaluating the introduction of CPPs based on patients' and healthcare professionals' experiences and perspectives. In my study, I take a physician standpoint to explore how physicians' experiences and practices are socially organized. The overarching research question guiding the study is: How do physicians engage with CPP guidelines in their daily work? Based on semi-structured interviews with physicians and other healthcare professionals (N=72), I aim to develop knowledge about some of the work processes connected to the CPPs and trace how different ideological and discursive practices mediate this work.

The thesis consists of three journal articles and one article for a Norwegian anthology on institutional ethnography in practice. In Article I, I explore how general practitioners (GPs) and specialist physicians balance different demands in their work with the referral of patients to CPPs. The analysis illustrates the complexity of the referral process across primary and specialist healthcare. Whether or not a CPP is initiated depends on the interaction between physicians and patients, how the referral is written and subsequently interpreted, and how this work is discursively mediated. Article II focuses on specialist physicians' experiences of how CPPs influence their work with cancer diagnostics. Specifically, it shows how, in practice, the requirement to keep the CPPs' timeframes conflicts with the requirement to achieve diagnostic precision. In Article III, I explore how physicians and other healthcare professionals communicate with patients in CPPs. The analysis illustrates how CPPs, with their explicit focus on deadlines and transparency, generate tensions between biomedical, psychosocial and political understandings of what

constitutes good patient care. Article IV details how I have used institutional ethnography for my thesis as part of a larger research project. Since I have collaborated with other researchers, I have adapted the use of institutional ethnography to accommodate my situation. I use physicians' accounts of their referral work as an example of how institutional ethnography helped me to illuminate the social organization of the initial phase of CPPs.

Sammendrag

Denne avhandlingen bidrar med et kritisk blikk på trenden med økt standardisering og byråkratisk styring av profesjonelt arbeid. Fokuset er på innføringen av en helsetjenestereform kalt pakkeforløp for kreft. Pakkeforløpet angir spesifikke tidsfrister for ulike faser i diagnostiseringsprosessen: fra det etableres en mistanke om kreft og frem til oppstart av behandling. Det teoretiske og metodologiske rammeverket er institusjonell etnografi.

Den empiriske studien er det av et større forskningsprosjekt (EPAK) som evaluerer pakkeforløpet for kreft i lys av erfaringene til pasienter og helsepersonell. Min studie tar ståsted i legers erfaringer med pakkeforløp for kreft og utforsker hvordan deres arbeid er sosialt organisert. Studiens overordnede forskningsspørsmål er: Hvordan forholder leger seg til pakkeforløpenes retningslinjer i sitt daglige arbeid? Basert på semistrukturerte intervju med leger og annet helsepersonell (N=72) søker jeg å utvikle kunnskap om (noen av) arbeidsprosessene knyttet til pakkeforløp for kreft ved å spore hvordan ulike ideologiske og diskursive praksiser medierer dette arbeidet.

Avhandlingen består av tre tidsskriftsartikler og en artikkel som skal inngå i en norsk antologi om institusjonell etnografi. I artikkel I utforsker jeg hvordan primærleger og spesialistleger balanserer ulike krav knyttet til henvisning av pasienter til pakkeforløp. Analysen illustrerer det komplekse arbeidet som er involvert i henvisningsprosessen slik det skjer i samspillet mellom leger og pasienter og hvordan henvisningen er sammensatt, samt hvordan og av hvem henvisningen tolkes, og hvordan dette arbeidet er diskursivt mediert. Artikkel II fokuserer på spesialistlegers opplevelse av pakkeforløpene innflytelse på deres arbeid med kreftdiagnostikk. Artikkelen viser hvordan pakkeforløpets tidsfrister kolliderer med kravet om diagnostisk presisjon nedfelt i handlingsplanene. I artikkel III utforsker jeg hvordan leger og andre helsepersonells arbeider med kommunikasjon med pasienter i pakkeforløp. Analysen illustrerer hvordan pakkeforløpet med sitt eksplisitte fokus på tid skaper spenninger mellom biomedisinske, psykososiale og politiske forståelser av hva som utgjør god pasientbehandling. Artikkel IV handler om hvordan jeg har brukt

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PART SEVEN

Article I: Næss, S. C. K. (2021). CPP or Not, That Is the Question: Physicians' Work With Activating CPPs. *Qualitative Health Research*, 31(11), 2084-2096. <https://doi.org/10.1177/10497323211020708>

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APPENDICES

Appendix I: Interview Guide

Appendix II: Information Letter and Consent Form

Appendix III: Ethical Approval

Appendix IV: Confirmation Article IV

Appendix V: Co-Author Declaration

PART ONE

Introduction

Although questions related to the nature of time have puzzled philosophers and physicists for centuries, there is no disputing that the notion of time significantly impacts human experience (Ellingsen et al., 2015; Wittmann, 2009). A common conception of time is threefold, signifying our experience of past, present, and future (Le Poidevin, 2019). Correspondingly, we often think of a person's life-span in narrative terms, having a beginning, middle, and end (Lachman et al., 2015). This linear depiction of time may very well be a sensory illusion as some suggest (Jaffe, 2018; Ricoeur, 1979), but it has real implications. As human beings, we live with the awareness that one day life as we know it will end. Time will run out. And, for most of us this notion of life as a continuous movement toward an unknown end is a fear-inducing experience that inspires us to facilitate as much alive-time as possible—for ourselves and others (Moore & Williamson, 2003).

According to Becker (1973, as cited in Moore & Williamson, 2003), “the idea of death, the fear of it, haunts the human animal like nothing else; it is the mainspring of human activity—activity designed largely to avoid the fatality of death, to overcome it by denying in some way that it is the final destiny for man” (p. 3). Whether we accept or reject the notion of death as the end of existence, Becker's statement reminds us that fear is a natural and uniting human response to the impermanence of physicality. In the face of serious illness, time turns into a scarce resource for many making the endpoint more tangible, perhaps just a little more real than it was before the disease was made known.

Cancer is such a disease, or rather, a conglomerate of diseases, often depicted as mysterious and evasive—for which a course of development may be hard to predict (Bissell & Hines, 2011; National Institutes of Health (US), 2007). Cancer then is a generic term that covers a large group of different disease trajectories rooted in abnormal cellular activity (World Health Organization, 2022). The Norwegian Pharmaceutical Product Compendium (2016)

describes cancer as a kind of cellular loss of self-control whereby the cells uninhibitedly divide and grow. This anomalous cell growth may or may not spread to other organs in the body—a process called metastasizing. And, once a cancer begins to metastasize, health and prognosis decline (World Health Organization, 2022). This makes *time* an integral component of cancer care. However, while most cancers develop at a slow rate and decades pass before posing any serious threat to the person's health and wellbeing, others are more aggressive and spread at a faster pace (Noble, 2019; Plutynski, 2013). Some people even experience spontaneous remissions without any medical assistance (Jessy, 2011). This fluctuant nature of cancer is both mind-boggling and fear-inducing for most people, medical professionals included (Espinosa et al., 1996; Vrinten et al., 2017). Accordingly, Susan Sontag (2002) remarks that there is something about cancer that is so repulsive to us that it even transcends the fear of death.

Cancer is currently listed as the second leading cause of death worldwide—and the incidence rate is rising (World Health Organization, 2022). There is a never-ending list of possible cancer risks that, in conjunction with the uncertainties associated with current cancer treatments, haunts us on a collective level, whereby the effort to prevent and cure cancer has turned into a shared public and personal responsibility. In Norway, as in many countries, the health authorities are committed to helping people prevent and heal cancerous illness by placing adequate information and enhanced quality of cancer care at the top of the political agenda (Norwegian Ministry of Health and Care Services, 2018). A recent trend in cancer care across continents is the development of initiatives to improve the delivery of timely care (Butler et al., 2013). This goal (timely care) is inspired by a growing recognition that early detection and treatment are beneficial for patients—not only for survival but also for overall satisfaction and well-being (Mæhle et al., 2021).

In this thesis, I explore the introduction of a cancer care policy, entitled cancer patient pathways (CPPs), with a pronounced focus on time—from a physician standpoint. The theoretical and methodological framework is institutional ethnography, which draws attention to the social organization mediating the informants' experiences and actions. I elaborate on three aspects of physicians' work in the context of CPPs: the process of

referral (Article I) diagnostic decision-making (Article II) and communication with patients (Article III). Further, I have written an article (IV) for an anthology of institutional ethnography that explores different ways to engage with institutional ethnography in research. This fourth article details the research process that shaped my project, with a focus on how I used institutional ethnography to explore the introduction of the CPPs.

The empirical fulcrum is thus physicians' experiences of their work with CPPs, and the focus is on the interplay between professional knowledge and practice, and bureaucratic guidelines.

Research Questions and Aims

The empirical study that comprises the foundation of this thesis is part of a larger project, which aims to evaluate the introduction of CPPs from the experiences of patients and healthcare personnel (Melby et al., 2021). The thesis is based on qualitative interviews with healthcare personnel conducted between 2017 and 2020. The aim is to develop knowledge about (some of) the work processes linked to the CPPs. The research question guiding the study is:

How do physicians engage with CPP guidelines in their daily work?

This question captures a relational understanding between policy and practice, which means that I set out to discover how physicians' work is being shaped by their participation in the CPP policy across different aspects of their daily practice.

Cancer Care in Norway

Norway is a small country in the Nordic region that is home to approximately 5.4 million inhabitants (Statistics Norway, 2022). Central to developments of the Norwegian healthcare services is a steadfast desire to ensure equal access, with universal health coverage for all citizens being a fundamental organizing principle (Norwegian Ministry of Health and Care Services, 2016). Universal health coverage is financed through the National Insurance Scheme (*folketrygd*) and is mainly funded by citizens' tax money and "payroll

contributions shared by employers and employees” (Saunes, 2020, p. 159) – patients are, however, required to pay a deductible for certain services and products.

The Norwegian healthcare system is partially decentralized and divided into two main service lines: primary and specialist healthcare. Specialist (hospital) healthcare is state-owned and divided into four regional health authorities, governed by the Ministry of Health and Care Services (Iversen et al., 2016; Ringard et al., 2013). Primary healthcare is drifted by the municipalities (Ringard et al., 2013) In 2001, a general practitioner (GP) scheme was introduced, whereby the municipalities and GPs entered into a contract to provide inhabitants with access to a regular GP. This entails that everyone who lives in Norway has the right to be part of a patient list that is linked to a specific GP. Citizens can freely choose which GP they want as their primary physician (Norwegian Ministry of Health and Care Services, 2021). Following the introduction of this scheme, GPs were assigned as gatekeepers to specialist healthcare; it was decided that all patients who need to see a specialist must first obtain a referral from their GP (Iversen et al., 2016). However, it should be mentioned that there are private healthcare services in Norway that offer specialist consultations without a referral—for a fee (Helsenorge, 2020).

Over the last decades, the Norwegian health authorities have increasingly focused on cancer and improvements in cancer care. The first national cancer plan was presented in 1997. The plan describes cancer as a national challenge and outlines a long-term strategy to prevent cancer incidents both on an individual level and through public screening programs as well as delivering better diagnostic and treatment services (Norwegian Ministry of Health and Care Services, 1997). Successively, new national cancer strategies were presented in 2006, 2013 and 2018. The strategy from 2006 proposed the development of national action plans to improve diagnosis and treatment, while the strategy from 2013 proposed the development of care pathways to improve coherence, predictability and coordination of services. The 2018 strategy suggests that these strategies have been effective. In general, there has been a clear increase in cancer survival due to earlier detection of diagnosis and better treatment. Norwegian cancer care, the strategy concludes, is of high quality (Norwegian Ministry of Health and Care Services, 2006, 2013, 2018).

The Introduction of Cancer Patient Pathways in Norway

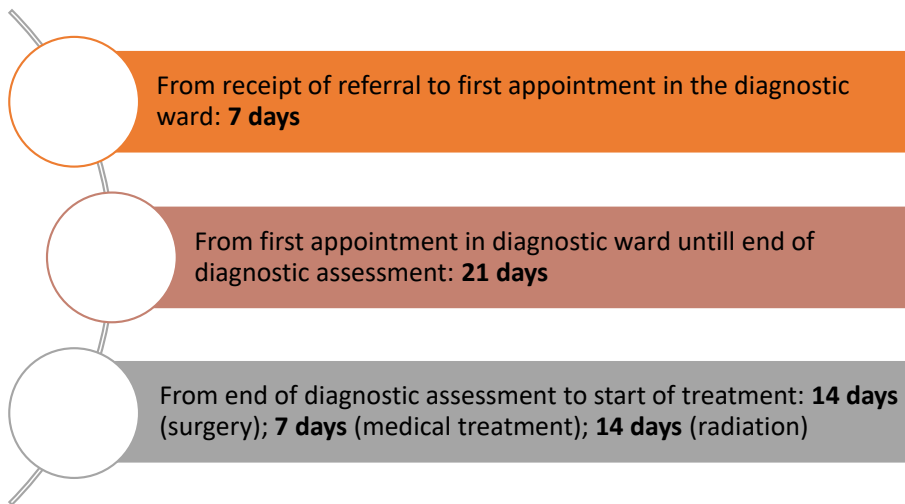
CPPs can be described as a joint Scandinavian project, as the health authorities in three Scandinavian countries—Denmark, Norway and Sweden—have introduced a similar cancer policy to reduce the processing time from suspicion to diagnosis and start of treatment in cancer care (Mæhle et al., 2021). Norway launched its CPP policy in 2015. Currently, there are 28 pathways for different cancer diagnosis, of which, 26 relate to organ-specific cancer diagnoses, while the other two targets unspecific symptoms and metastases of unknown origin (Norwegian Directorate of Health, 2018a).

The CPP policy builds on five goals articulated in the National Cancer Strategy 2013–2017 (Norwegian Ministry of Health and Care Services, 2013), by which Norway will become a leading example for providing good patient trajectories. This includes: (a) offering cancer patients integrated and well-coordinated patient trajectories without unnecessary delays, (b) 80% of all cancer patients shall receive treatment within 20 days of referral to specialist services, (c) installing proper systems for a fast and precise diagnostic assessment for different types of cancer, (d) establishing good interaction, good flow of information and a clear division of responsibilities and tasks within the specialist healthcare services as well as between the specialist and the local/primary healthcare services, and (e) increase the use of individual plans for cancer patients (p. 16). It should also be noted that because Denmark introduced the CPPs in 2008, before the compilation of the National Cancer Strategy 2013–2017, the Norwegian health authorities and other healthcare professionals paid close attention to the CPP policy in Denmark. Thus, the Danish model become a major source of inspiration for the conception of the CPPs in Norway (Melby et al., 2021).

CPPs are based on clinical practice guidelines for medical diagnosis and treatment of specific cancers but—as they are meant to function as a complementary set of guidelines—deal with the logistics of the different phases of cancer care. This includes a focus on efficiency in the form of fixed time frames, multidisciplinary interaction, coordination of services, and patient communication and participation. The goal is to provide cancer patients with “a well-organized, integrated and predictable trajectory without unnecessary

non-medically founded delays in diagnosis, treatment and rehabilitation” (Norwegian Directorate of Health, 2016a, my translation). There are three phases in each CPP defined by maximum time frames for each phase, with slight variations between the different types of cancer. See Figure 1 below for how the phases are organized.

Figure 1: Example of Time Frames for Lung Cancer (Norwegian Directorate of Health, 2016b)



A CPP begins when the hospital receives a referral, usually from a GP, describing a *reasonable* suspicion of cancer. The emphasis on reasonable is significant and denotes that patients must present with a certain set of (alarm) symptoms before being assigned to a CPP. To help the GPs, the Norwegian Directorate of Health (2018b) has made available diagnostic guidelines that outline the symptom-based criteria for including patients in a CPP. Hence, the GP must provide clinical evidence in line with the diagnostic guidelines for the relevant CPP of the suspected cancer for the referral to be classified as a CPP by the hospital. The final decision of whether a referral should be treated as a CPP (or not) is made by the recipient specialist physician (or sometimes a cancer pathway coordinator) at the hospital (Norwegian Directorate of Health, 2016a). The starting point of CPPs is detailed and explored in Article I of this thesis.

The first phase covers the time from referral until the diagnostic assessment begins. The second phase covers the time from the diagnostic assessment begins until a clinical decision of a diagnosis is made. The third phase covers the time from diagnosis to the start of treatment—this time frame varies depending on what type of treatment is best suitable for the patient in question. These time frames are not legally binding, yet they are monitored by a coding system and registered in the patients' medical journals (Norwegian Directorate of Health, 2016a). The results of the coding are made public and published on a national webpage, making it possible to compare the extent to which the hospitals in Norway achieve the CPP deadlines (Melby et al., 2021; Norwegian Directorate of Health, 2014).

Since the process of diagnosing cancer is typically carried out by many different services and healthcare professionals, good communication, collaboration and coordination between the different sites are crucial to realizing CPPs in practice. To ensure that patients in CPPs experience coherence and continuity of care, a new position, entitled cancer patient coordinator, was introduced (Melby et al., 2021). The cancer patient coordinators are supposed to function as the patients' liaisons in the healthcare system. Their main responsibilities are, among other things, to book consultations and examinations within the CPP deadlines and perform the associated coding work, as well as inform and communicate with the patients during the different phases of the CPPs (Norwegian Ministry of Health and Care Services, 2018). Importantly, a well-established and overarching political ambition is to improve efficiency in the healthcare system. This implies better utilization of existing resources (Norwegian Ministry of Health and Care Services, 2009). As a continuation of this aim, no additional resources (money, equipment, or employees) accompanied the health authorities introduction of the package processes. The cancer patient coordinator position was thus assigned to existing positions and are occupied by nurses, secretaries, or other administrative staff (Håland & Melby, 2021).

To further improve continuity and medical quality of care, the CPP guidelines call for consistent interdisciplinary collaboration in the form of multidisciplinary team (MDT) meetings. The purpose of the MDT meetings is to ensure that clinical decision-making happens in an interdisciplinary environment and is thus shaped by multiple medical

perspectives. MDT meetings are usually held in the last CPP phase when the results from the various diagnostic tests are made available. Representatives from the different professions—clinicians,¹ surgeons, radiologists, and pathologists—discuss the findings and make their decision on diagnosis, stage of the disease and choice of treatment. The cancer patient coordinator is also expected to attend the MDT meetings to safeguard the continuity of care (Norwegian Directorate of Health, 2016a).

Furthermore, as emphasized by Håland and Melby (2017), CPPs embrace two, seemingly conflicting, ideals—namely, achieving individualized care in standardized patient pathways. This means that within this standardized process, which promotes a distinct focus on fast and efficient decision-making processes according to fixed deadlines, the idea is that each patient should have an individually tailored process that considers their wishes and individual situation, such as age and vulnerability, and any comorbidity or complications (Norwegian Directorate of Health, 2016a).

Previous Research on CPPs in the Nordic Context

As Melby et al. (2021) note, since CPP policy is relatively new, especially in Norway and Sweden, there is limited research on the empirical workings of this specific cancer care strategy. However, some empirical studies exist, from all three countries, that examine different aspects of the implementation of CPPs. Relevant studies are presented according to four main themes: policy, organization, and design; implications for practice and the perspectives of healthcare personnel; patient experiences; and the effects of CPP concerning the duration and prognostic outcomes. In this presentation, I have included

¹ In this study, the term clinician refers to physicians who oversees the patient's diagnostic assessment in the clinic. Clinicians are medical specialists or surgeons, but the term does not imply medical professionals working in the imaging departments or laboratories.

journal publications that are part of this study's overarching project but are written by other research team members²

Background: CPPs as the Solution to a Problem

Several studies elaborate on the political reasoning and driving force behind the CPPs. According to Probst et al. (2012), the starting point of CPPs in Denmark was the country's struggle with "a higher incidence of cancer and poorer cancer survival rates than many other European countries" (p. 65). This prompted a political focus on eliminating the waiting time for cancer patients and defining cancer as an acute condition. The authors demonstrate how the implementation of CPPs became a success because bureaucrats, healthcare professionals and politicians came together and worked toward the same goal. Tørring (2014) expands upon the reasoning behind the Danish redefinition of cancer as an acute condition in need of urgent care and finds that it is a result of different factors, including the increased focus on the numerical representation of cancer and survival estimates, the circulation of personal stories in media, whereby waiting time was a key

²The following studies are based on the data collected for the overarching project: Andersen-Hollekim, T., Melby, L., Sand, K., Gilstad, H., Das, A., & Solbjør, M. (2021). Shared decision-making in standardized cancer patient pathways in Norway—Narratives of patient experiences. *Health Expectations*. <https://doi.org/10.1111/hex.13317>

Håland, E., & Melby, L. (2021). Coding for quality? Accountability work in standardised cancer patient pathways (CPPs). *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 136345932110138. <https://doi.org/10.1177/13634593211013882>

Melby, L., Brattheim, B. J., Das, A., Gilstad, H., Gjørund, G., Håland, E., Sand, K., & Solbjør, M. (2021). Pakkeforløp for kreft: erfaringer blant helsepersonell og pasienter. Sluttrapport fra den forskningsbaserte evaluering av pakkeforløp for kreft [Cancer patient pathways: Experiences among health care personnel and patients. Report from the research-based evaluation of cancer patient pathways]. (978-82-14-06460-5).

Melby, L., & Håland, E. (2021). When time matters: a qualitative study on hospital staff's strategies for meeting the target times in cancer patient pathways. *BMC health services research*, 21(1). <https://doi.org/10.1186/s12913-021-06224-7>

Solbjør, M., Sand, K., Ervik, B., & Melby, L. (2021). Patient experiences of waiting times in standardised cancer patient pathways in Norway – a qualitative interview study. *BMC health services research*, 21(1). <https://doi.org/10.1186/s12913-021-06679-8>

focus, a growing elderly population, and a kind of cultural polarity between a flourishing economy and fear policies.

The pre-CPP situation was somewhat different in Norway and Sweden. Both countries had comparatively high survival rates and patient satisfaction. However, politicians still saw the potential for improving cancer care by decreasing waiting times, using the Danish model (Mæhle et al., 2021; Wilkens et al., 2016). Håland and Melby (2017) analyze three speeches by different politicians prior to the introduction of the CPPs in Norway. A key finding is that standardization of time and logistical change is elevated as positive and effective strategies to improve the quality of cancer care. The speeches legitimize the notion that new principles for organization and structural changes should be prioritized rather than adding more money to the health and care services (p. 395).

Mæhle et al. (2021) examine and compare CPP policies in the three countries (Norway, Denmark, and Sweden) to illuminate the mechanisms that brought forth the reforms in each country. The empirical data is comprised of 26 interviews in conjunction with examination of documents from national websites. The authors identify three distinct institutional logics inspiring the development of the CPPs: “the medical logic,” “the economic administrative logic,” and “the patient-related logic” (pp. 12-13). In all three countries, cancer had been a political priority for several decades before the introduction of the CPP reform resulting in the successive development of extensive national cancer plans. Yet, a common starting point of CPP reform was a growing critique of the existing system centered around the inequality of access to medical care and new technologies, the growing incidence of cancer in combination with economic constraints, insufficient patient focus and participation, and organizational challenges pertaining to poor coordination between hospitals and departments within hospitals.

In Norway and Sweden, the arguments for eliminating waiting times focused on the experiences of patients and the added psychological strain of unpredictable waiting times, and geographical inequality in access to care (Mæhle et al., 2021). Ultimately, a combination of medical research, the engagement of medical societies and cancer

organizations as well as media coverage of poor patient treatment prompted the discussions in all three countries to be characterized by the need for rapid intervention in cancer care. A call to action was then made by top-level politicians, first in Denmark and subsequently in Norway and Sweden.

Implications for Practice: The Perspectives of Healthcare Personnel

In an evaluation of the Danish CPPs (Vinge et al., 2012), the researchers use qualitative interviews to examine the organizational consequences of the implementation of CPPs for leaders and healthcare personnel. The sample consists of 21 informants. All informants were interviewed twice during the period from 2008 to 2010. The study focuses on the pathway for lung cancer and explores the impact of CPPs on (a) workload and capacity, (b) physicians, their professional autonomy and collaboration, and (c) how healthcare personnel and leaders experience the implications of CPPs for patients.

The findings show that some hospital departments placed greater emphasis on organizational changes than others. Therefore, informants have different experiences of the impact of CPPs on capacity and workload. However, the authors argue that the findings indicate that the CPPs do provide the potential for greater efficacy, as they remove the need for individual adaptations for each patient. Whether this potential is realized depends of the leadership in the respective departments, particularly their ability to motivate and include the staff in decision making processes (Vinge et al., 2012).

Physicians' work is influenced by CPPs in that the policy creates new restrictions on their professional autonomy and work schedule. Physicians cannot use their professional judgment to prioritize between patients or adjust the scope of examinations according to the individual needs of each patient to the same extent as before. While some physicians welcome these changes, others are more critical claiming that it leads to over-examination of patients and removes responsibility, influence, and control from the physicians. The short time to get the patients through creates less flexible work schedules and physicians do not have the same freedom to swap shifts or attend conferences as they used to. However, because the CPP guidelines require that treatment decisions are made via MDTs, it has

strengthened interdisciplinary cooperation. Furthermore, healthcare personnel report that patients appear satisfied with the CPPs, and that there has been a noticeable drop in patient complaints. They underscore that fast-paced trajectories elevates the need for good patient communication to avoid cancellations and delays in the diagnostic trajectories (Vinge et al., 2012)

A Swedish study conducted by Delilovic et al. (2019) explores the experiences of 58 healthcare professionals across six pathways. The study reveals that the informants welcomed the CPP reform. However, many experienced the implementation as challenging due to poor information and a lack of resources to make the organizational adjustments need to meet the CPP time frames. Similarly, Melby and Håland (2021) report that hospital staff in Norway were concerned about—and put much effort into—meeting the time frames. However, healthcare personnel in larger hospitals expressed a greater level of stress and pressure in comparison with informants from smaller hospitals. A variety of strategies were mobilized to achieve the CPP time frames, such as the introduction of new roles (cancer pathway coordinators), hiring more staff, and a reorganization of work processes.

In another article, Håland and Melby (2021) examine different aspects of the work involved in the coding of time frames as “signifiers of quality of care” (p. 15). Based on empirical interviews with 56 healthcare personnel, the authors theorize that the production of codes may be defined as accountability work. Accountability work is comprised of five dimensions: standardization, legitimation, jurisdiction, professional discretion, and compliance. These dimensions cover both similarities and distinctions in healthcare personnel’s understandings, attitudes, and activities pertaining to CPP codes as an expression of the quality of care. A primary finding is that the introduction of a coding system for keeping track of time alters the meaning of what defines the quality of care.

Studies have also focused on the role of GPs in CPPs. Since GPs typically are the patient’s initial encounter with the healthcare services, they play an important part to ensure early diagnosis. The interpretation of cancer symptoms in this setting is challenging work that is shrouded in uncertainty and ambiguity, because patients often present vague symptoms that

could also be interpreted as benign and not necessarily indicative of cancer (Ingebrigtsen et al., 2013). In contrast to vague symptoms, such as loss of appetite, changes in weight, fatigue, bloating, abdominal pain (Vasilakis & Forte, 2021), alarm symptoms are defined as such in diagnostic guidelines, for example, in terms of specific types of breast lumps, blood in stools, urine, moles or sputum (Norwegian Directorate of Health, 2018b).

A Danish quantitative study found that although GPs suspect cancer, they do not automatically initiate a CPP referral. Referral to CPPs is connected to the GP's interpretation of symptoms, with vague symptoms being less likely to lead to a CPP referral than more specific and alarming symptoms. Therefore, it takes longer for patients presenting vague symptoms to receive a diagnosis than patients with alarm symptoms.

Two Swedish qualitative studies highlight the complexity and unpredictability of GPs' interpretation of symptoms and referral to CPPs. Both studies demonstrate how the interpretation of symptoms hinges on the interaction between the GP and the patient. How the patient presents their symptoms and what the patient wants in terms of further diagnostic assessment is central to the decision-making process (Hultstrand et al., 2020a, 2020b). In one of the studies (Hultstrand et al., 2020b), the authors highlight four interconnected processes of negotiation occurring between the GP and the patient. An interesting finding is that patients work harder (put in more effort) to appear credible (i.e., clearly articulate, illustrate and underscore the seriousness of their bodily sensations) when presenting with vague rather than specific symptoms. Simultaneously, GPs pay less attention to patients' verbal presentations when faced with clear and visible symptoms. This confirms the existence of a kind of symptomatic hierarchy, whereby objective medical signs are being prioritized at the expense of bodily sensations that defy immediate medical categorization.

Patient Perspectives and Experiences

As enhanced patient focus and involvement is a major goal of the CPPs, Aasen et al. (2020) examine the discursive construction of patients in the online information available to cancer patients in Norway. Of the 28 CPPs, six web-based CPP brochures were chosen for

analysis that “had different texts and dealt with specific, non-specific and metastatic cancer and pathways specific for women, men and children” (p. 3). The authors conclude that a patient-centered approach is lacking and that the CPPs information constructs the patient as a passive recipient of a standardized treatment program, which is concurrent with the ideology of paternalism.

Correspondingly, another Norwegian study interviewed 19 patients who had been through three different CPPs (prostate, lung, and malignant melanoma) about their experiences with participation in decision-making. Opportunities for participation varied among patients with different cancers. Patients with breast and prostate cancer were presented with treatment options, whereas patients with malignant melanoma were not. Standardization in combination with medical expertise was a source of safety and predictability—patients conveyed that they trust both the system and medical competence of their care providers. However, being presented with and having to make treatment decisions is described as a challenging, stress-inducing experience. The study suggests that patients prefer to partake in logistical decisions, such as pace and choice of treatment location, over medical decisions (Andersen-Hollekim et al., 2021).

Several publications focus on patients’ experiences with waiting time. The studies find that reduced waiting time predominantly influences patients’ experiences and satisfaction with care in a positive manner (Dahl et al., 2017; Malmström et al., 2018; Sandager et al., 2019; Sidenius et al., 2020). According to Malmström et al. (2018), patients are willing to eschew control and power in favor of rapid care. However, as Aarhus (2018) remarks, “for some patients, the pace is indeed too fast” (p. 123). An article by Solbjør et al. (2021) explore patients’ experiences of the waiting times in CPPs. The results indicate that even though patients hold somewhat diverging understandings of what a CPP entails, the standardized time frames generally provide a sense of safety and predictability. A key finding is that the patients’ experiences of waiting time seems to be closely linked to their expectations. The authors highlight that for some patients both delays and unexpected turns of events (i.e., a sudden change of pace in the diagnostic process) jeopardize feelings of safety and protection. Sidenius et al. (2020) demonstrate how CPPs generate ambivalence in patients

with endometrial cancer; the promise of fast care is both reassuring and a source of confusion about the severity of their condition. Moreover, the authors show how patients negotiate their sense of time by participating in different discourses (that diversely frame how quick the diagnostic process should flow) and by embracing a proactive approach to managing their own temporal experiences.

The Effects of CPPs: Duration and Prognostic Outcome

Studies from Denmark and Sweden find that CPPs have successfully decreased the waiting times of the diagnostic intervals in cancer care (Dyrop et al., 2013; Jensen et al., 2015; Schmidt et al., 2018). Nilssen et al. (2019) examine the waiting times for diagnosis and treatment for four types of cancer (colorectal, lung, breast, lung, and prostate cancers) from 2007 to 2016, in Norway. The authors observe a gradual decline in waiting times during the period but could not find a significant change in connection with the introduction of CPPs. Additionally, a Danish study comparing data from 7, 700 patients before, during, and after the introduction of CPPs suggests that the CPPs positively influence prognostic outcome.

To conclude, although other studies have examined the motivation behind CPPs, healthcare personnel and patients' experiences, and the policy's impact on waiting time and prognostic outcomes, the scope of this research are limited. More knowledge is needed on how the CPPs are carried out in practice. In this thesis, using qualitative interviews, I aim to "unpack" the work that is done when physicians engage with the CPPs as part of their professional practice. As my study is guided by institutional ethnography, it fills a knowledge gap by illuminating how physicians' experiences and actions are coordinated by translocal social relations.

Overview of the Thesis

The thesis is comprised of seven parts, three journal articles, and one anthology article. Parts One to Six provide the extended abstract (*kappe*), which aims to contextualize the thesis and demonstrate a coherence between the four articles and the overarching research question. As such, these parts highlight relevant debates and elaborate on the theoretical

and methodological framework. Part One consists of an outline of the research objectives, along with an introduction of the formal description of the CPP procedures and a presentation of previous research on CPPs in Scandinavia. In Part Two, I discuss theoretical perspectives on professional work, knowledge, and quality of care that are relevant to and complement my research. Part Three elaborates on the methodological framework and key analytical concepts of my study. In Part Four, I detail the empirical research process and data material. I provide a summary of the four articles in Part Five and discuss the findings in connection with the thesis' overarching research question in Part Six. Part Seven is a collection of the four articles. Appendices are attached at the end of the thesis.

PART TWO

Professional Work and Quality of Care

This study is based on perceptions and experiences of professional practice in the context of the introduction of a cancer care policy. It is positioned within the field of adult learning which draws on multiple disciplines, including sociology, psychology and education. Notably, I rely mostly on sociological theories and understandings. The formation and development of professional knowledge and competence is an important topic in adult learning and education (Wahlgren, 2010). Specifically, the thesis elaborates on what happens when the theorized knowledge of bureaucratic guidelines intersects with experiential knowledge, professional discretion and autonomy. In this part, I draw on literature to accentuate the discussions and discourses that concern the ongoing development of professional work and professional knowledge, with an emphasis on the healthcare sector and the medical profession.

Work

Essentially, this thesis is about work and work processes. Work is a social phenomenon that has been subject to extensive scrutiny from multiple disciplines and perspectives (Gill, 1999; Håland & Melby, 2021). Perceptions of what work entails are always connected to the social and economic organization of society, whereby some people (in high positions) are have more power to define work's meaning than others. Thus, work can have different meanings in different contexts (Heen, 2009; Star & Strauss, 1999; Wadel, 1977).

This is particularly evident in the way notions about work have shifted alongside the industrial revolution. As Heen (2009) notes, in pre-industrial societies, work was a term used to denote specific forms of activities. The household provided the framework for production, exchange and consumption, and work was an integral part of daily life. Festivities and holidays were often organized following seasonal variability connected to agriculture. During the transition from agricultural to an industrial economy, work-life became separated from home-life, which resulted in a subordination of the household to the

economic market. Work was something done in exchange for monetary wages; it happened outside the home in the public domain and was mainly carried out by men. The home became the private domain, associated with family life, reproduction, consumption and leisure. Domestic activities, which were mainly carried out by women, lost their character of being work, while wage labor became the dominant mode of work in society (Heen, 2009).

Heen (2009) explains that these organizational changes transformed work into both a more general and a polysemantic term. On the one hand, work signifies activities that are being performed in exchange for a salary. In this abstract meaning of work, a paycheck automatically corresponds to work regardless of what this work consists of. On the other hand, the term also denotes specific activities both inside and outside of the labor market. However, in contrast to paid activities, not only is it always possible to debate whether non-paid activities can or should be labeled work, they are also assessed according to certain criteria, such as being useful, necessary, or performed as a service for others

Work is connected to the division of labor, namely, how tasks are distributed between people and between groups of people (Håland & Melby, 2021). The dynamic interplay between formal and informal aspects of work is well-established (Star & Strauss, 1999; Wadel, 1977). According to Star and Strauss (1999), another dimension of work concerns the relationship between visible and invisible work. What counts as “real” work is a matter of making the invisible visible. As an example, the authors highlight the women’s movement, and how it required the mobilization of strong social forces and decades of campaigning for household maintenance and child rearing to be made visible and redefined as work with an economic value.

However, as Suchman (1995) points out, since all work practices are based on lived experiences, they cannot be described in their entirety. There will always be certain activities and aspects of activities, both outside and inside of employment, that go unnoticed. What is important to note is that work descriptions serve interests. They are made up of carefully selected features of work practices that have real implications—work

practices can be represented in a way that protects workers from exploitation, but they can also be represented in a way that enables and justifies control, pressure, and monitoring.

The fluctuating notions and selective work representations across time draw attention to the social, interactive, nature of work. A prominent theoretical perspective, based on social interactionism, conceives work as emerging, essentially, through a process of negotiation (Day & Day, 1977). In relation to work, the term *negotiated order* was first proposed by Strauss and colleagues (1963) who through extensive ethnographic studies in psychiatric hospitals, identified negotiation as a fundamental pattern of everyday work activities. Negotiation is such a substantial part of work that it “enters into how work is defined, as well as how to do it, how much of it to do, who is to do it, how to evaluate it, how and when to reassess it and so on” (Strauss et al., 1997, p. 267).

The negotiated order perspective was developed in criticism of the more “static structural functional and rational-bureaucratic” explanations that had dominated much of the literature on the organization of work to that point (Day & Day, 1977). Eliot Freidson (1976) outlines this backdrop in an article published in *Social Problems*. Here, he notes that much of the literature on the division of labor examines work using general concepts such as *specialization* of tasks, or *apportionment of functions* (p. 305). Nonetheless, the focus is predominantly on distribution. How work is (diversely) distributed and rewarded between occupations and classes of individuals (Strauss, 1985). The problem with these concepts is that they fail to connect with the empirical reality of people’s doings. Namely, the actual work that take place “in the division of labor.” (p. 2).

Freidson (1976) scrutinizes the literature in search of the *empirical referent* (i.e., the actual social foundation) of the division of labor. He identifies three central ideological principles/perspectives that organize the division of labor in contrasting manners. The first is Adam Smith’s principle by which the free market regulates the division of labor without any social regulation. This is a society dominated by heavy competition, rapidly changing work situations, and unstable wages. The second is found in Max Weber’s theorizing of the rational-legal bureaucracy. In this society, formal organizations regulate the labor market,

work tasks, and the wages of employees. Division of labor is hierarchical and rule-based, which provides stable work situations and career opportunities. An alternative to the market and organization is the notion of professionalism, which implies that practitioners and occupational groups themselves control both their work and set the premises for how the division of labor is organized. Professionalism is described by Freidson (2001) as a *third logic* and a more sustainable way of organizing work, particularly when the tasks require the use of discretion. The concept is underpinned by two key ideas, namely “the belief that certain work is so specialized as to be inaccessible to those lacking the required training and experience, and the belief that it cannot be standardized, rationalized or [...] commodified” (p.17).

According to Freidson (1976), as these three starkly contrasting perspectives are ideologies they are “in a sense separate from the work activities they purport to order” (p. 310). The empirical reality is far more complex than any theoretical perspective can capture. For that reason, all three modes of organization can—and likely do—coexist, at any given moment in time, which is why each continues to be supported by different social science analyses. Moreover, Freidson explains that behind each conceptual curtain (e.g., free market, rational-legal bureaucracy, occupational organization) pertaining to the division of labor, hides an ongoing “process of social interaction in the course of which the participants are continuously engaged in attempting to define, establish, maintain and renew the tasks they perform and the relationships with others which their task presuppose” (p. 311). In short, it is work that shapes the divisions of labor, which in return “form around it” (Strauss et al., 1997, p. xiii).

This captures the basic premise of negotiated order theory. Namely, that society is produced through social interaction (Hall & Spencer-Hall, 1982). The theory demonstrates how the division of labor and work is always in the process of being *achieved* in large organizations, such as hospitals. Attention is given to both formal and informal aspects of work, as well as the dialectic relationships between these aspects—interaction shapes social order, but social order also shapes the conditions of the ongoing interactions. An important characteristic of this interactional organization of society is that the interaction of some

individuals is more influential than those of other individuals. As such, this perspective also accounts for the uneven distribution of status and power that dominate organizational working sites (Day & Day, 1977).

According to Strauss et al. (1963), the empirical fulcrum that identified negotiation as the basis of social order deals with the problem of change: How can order be maintained in organizations when they are constantly subject to change, both by internal and external social forces? If change implies destruction of order, why then does change not result in disorder? The answer, the authors conclude, is that change is integral to social order; all norms, rules, and contracts are temporary. Unforeseen events will arise in any course of action and that will, at some point, lead to a confrontation between the actors involved, whether between individuals or groups of individuals. In their words, “review is called for, whether the outcome of review be rejection or renewal or revision, or what not” (p. 148).

A key point is that both formal rules and guidelines, as well as hierarchical power and authority are insufficient to maintain order (Strauss et al., 1963). The social organization of medical work is complex and involves multiple occupational groups (Strauss et al., 1997). Cancer care, for example, which is the focus of this study, includes healthcare professionals across primary and specialist healthcare. As such, the immediate social organization of cancer care rests on the interaction between physicians occupying various positions (GPs, clinicians, oncologists, surgeons, pathologists, radiologists), nurses, administrators, coordinators, and clerical workers, among others (Melby et al., 2021). This means that people from different professional backgrounds “come together to carry out their respective purposes” (Strauss et al., 1963, p. 150) in a concerted effort to provide the best possible care for the (cancer) patient. However, these groups—and sometimes even members of the same profession—have different training and experiential backgrounds by which they occupy different positions in the organizational hierarchy. Jointly, they represent “a multitude of theories and/or perspectives regarding how the general task of patient care will be conceived, who will perform them, how they will be performed or, in general, how the division of labor will be carried out” (Day & Day, 1977, p. 129).

Diverging ideologies trigger conflicts pertaining both to medical and logistical aspects of care. Formal rules and guidelines are inadequate for solving these problems for several reasons. No one, even those working at the same site, is familiar with all the formal regulations of practice, or know when it is appropriate to use them. Guidelines are also often ambiguously formulated, and thus may be diversely interpreted (Day & Day, 1977). Positional authority also falls short in solving problems because rules and regulations are often “cited selectively and even stretched or “fudged” by persons or groups pursuing their own vested interests” (p. 130). As such, alliances may be formed between professionals across hierarchical positions by which some services and even care modalities are utilized more often than others.

The insufficiency of rules and positional authority give rise to an informal order in which the “involved parties develop tacit agreements and unofficial arrangements that enable them to carry out their work” (Day & Day, 1977, p. 130). Hence, work is organized by an interplay between formal and informal behavior (Strauss et al., 1963). Negotiations can be both planned and unplanned and occur on many levels—between individuals and groups inside an organization as well as between organizations (Nathan & Mitroff, 1991).

Importantly, the conditions (and opportunities) for negotiations are shaped by positional hierarchies, formal rules and policies, which constrain what and how things are done (Hall & Spencer-Hall, 1982). According to Allen (1997), to account for the structural conditions underpinning negotiations, in Strauss’ later writings, he introduced the notion of *negotiation context* and *structural context* to direct attention to the relationship between context and negotiation processes. It is possible to empirically discover what people can negotiate and how this process of negotiation unfolds.

Understanding work in terms of negotiated order presents a relevant perspective to expand on the findings of the articles in this thesis—given that change is the fundamental condition for negotiation, and that negotiations are bound to happen in situations that give rise to uncertainty, ambiguity, ideological diversity, disputes, inexperience, and logistical challenges (Hall & Spencer-Hall, 1982; Strauss et al., 1997). These are key conditions of work in the healthcare sector and are particularly prominent in cancer care. Another

relevant aspect of this perspective concerns the conception of the organization/hospital as multiple work sites and the distinction between different types of work. Strauss et al. (1997) coined the term *illness trajectory*, which refers to the work that is organized around the patient's disease as it unfolds over time. The authors found that the work of managing an illness trajectory involves a vast array of work types, including machine, safety, comfort, sentimental, information, and articulation work (Strauss, 1985; Strauss et al., 1997). This aligns with the generous notion of work employed in institutional ethnography, which is a central analytical concept in this study that I return to in Part Three.

Professional Knowledge and Work

“The professions dominate our world. They heal our bodies, measure our profits, save our souls. Yet we are deeply ambivalent about them” (Abbott, 1988, p. 1).

The above statement underscores the magnitude of professional work in society. In many respects, professional groups (at least the most powerful of them) occupy a privileged position as far as they are trained and licensed to meddle in both our personal and interpersonal lives and hold the power to determine the need for collective action. For example, professionals inform our health and well-being, our beliefs and perceptions, our legal rights and duties toward each other, and may even decide whether we will wage war against other nations (Abbott, 1988; Dingwall, 2008; Schön, 1991).

Physicians, lawyers, clergy, and military officials are often depicted as the four prototypical or “true” professions due to their unique knowledge, high social value, status and power (Abel, 1979; Evetts, 2013). With historical roots in the 19th century, the classic professions (as we know them today) were organized in a distinctly collegial (anachronistic) way, which set them apart from other occupational groups in the newly emerging commercial and industrial division of labor at the time (Abbott, 1988). This means that standards for conduct and regulation of professional practitioners were set from within the professional group, meaning, by professionals for professionals (Freidson, 2001).

The professions have traditionally been considered trustworthy by virtue of their competence, experience, and their devotion to service of the greater good, putting other people's needs before their own (Evetts, 2009). However, over the last decades (from the 1970s onwards), this image of the altruistic professional has been shattered by critical voices pointing out that professionals could and should not be blindly trusted. Professionals, some argue, do indeed engage in both self-centered and counterproductive practices (Noordegraaf, 2016). The extensive literature on professions demonstrates that the ongoing transformation of professional work is complex, accompanied by diverging understandings of what a profession is and where these changes are heading (Abbott, 1988; Evetts, 2011; Freidson, 1994, 2001; Martin et al., 2015; Noordegraaf, 2016).

A Complex Enterprise

In sociology, a long-standing debate has centered on the role of professions, which can be traced back to the work of pioneering scholars such as Emile Durkheim, Max Weber and Karl Marx (Leicht & Fennell, 1997). However, research on professions is more firmly anchored in the writings of Talcott Parson and Everett Hughes and has been extensively elaborated on and theorized by other sociologists (see, e.g., Abbott, 1988; Dingwall, 2008; Freidson, 1994, 2001; Larson, 1979). Yet, defining the concepts of profession and professional knowledge has remained an arduous task. Despite disagreements on the attributes and criteria that distinguish professions from other occupations, most scholars agree that a profession is a knowledge-based occupation of some importance for an area of society (Dingwall, 2008; Freidson, 1994; Smeby, 2007). Abbott (1988) argues that professions are “exclusive occupational groups applying somewhat abstract knowledge to particular cases” (p. 8). This implies a theoretical foundation of knowledge—as Larson (2017) notes, knowledge that is licensed, thus is considered superior to “alternative forms of service” (p. xxv). Correspondingly, Solbrekke and Sugure (2011) adopt a broad understanding of the term *professional* as someone who has completed higher education as a requirement to pursue a profession. In today's society the lines between a profession

versus an occupation are becoming increasingly blurred and, as Evetts (2013) notes, most researchers find it irrelevant to separate the two due to their many shared similarities.

Accordingly, Freidson (1994) argues that it is more fruitful to think of profession as a folk concept and explore how people in a particular society decide who is, and who is not, a professional, how certain activities produce professions and how this influences their sense of self and the way they perform their work, rather than strive to establish a firm definition. He acknowledges that this is a challenging endeavor because contemporary societies are diverse with many occupational groups that likely hold different understandings of what a profession and being a professional entail.

Similarly, Dingwall (2008) argues that the conceptualization of profession should be empirically founded and seek to describe how it (professions) is accomplished in practice. Using his research as an example, he illustrates how the notion of being a professional is activated in the work of health visitors. This includes the personal qualities of health visitors, features of the profession as well as the relationship between health visitors and workers in other occupations. In summary, a professional (health visitor) may be described as someone with ambition and commitment, that moves, dresses, and speaks in a distinct manner. Autonomy and authority characterize the work situation. This means that professionals do not give each other orders, nor do they interfere and give contradictory advice to each other's clients. Furthermore, they are driven by intrinsic motivation, enjoy their work, and maintain a healthy balance between work and leisure (self-regulation of work time). They are members of a self-governing occupation that is rooted in a tradition and have a body of (scientific) knowledge that is continuously developing through new research. Formal qualifications are required. Furthermore, professionals respect each other, within and across, different professional groups, which implies a sense of equality (Dingwall, 2008).

Dingwall's (2008) account shows that although scientific knowledge and educational status form the basis of professional work, it also contains other features, such as respectability, autonomy, self-regulation and control, responsibility, trust, ethics, and service (Larson,

1979, 2017). Moreover, this suggests that professional knowledge, in and of itself, connotes more than formal education and theoretical abstraction, as it requires an application to (unpredictable situations in) practice (Schön, 1991). A well-documented gap exists between theoretical and practical knowledge (Bromme & Tillema, 1995; Hatlevik, 2012). As noted by Duchscher (2009), newly educated nurses often experience “transition shock” at the beginning of their careers because of the mismatch between “what graduates understand about nursing from their education and what they experience in the ‘real’ world of healthcare service” (p. 1104).

Schön (1991) argues that the division between theory and practice is rooted in the philosophical tradition of positivism and the premise that professional knowledge should rely exclusively on *technical rationality*—a term that refers to “instrumental problem solving made rigorous by the application of scientific theory and technique” (p. 21). In this context, professional knowledge signifies a body of knowledge that is “specialized, firmly bounded, scientific, and standardized” (p. 23). However, although technical expertise works perfectly well in many situations, it falls short in others. This is particularly true when the issue at hand presents in an obscure fashion and/or when conflicting paradigms form the basis of professional understanding and practice. Standard techniques are only applicable to cases that are predefined in books and guidelines, whereas reality is often a muddier landscape to navigate than what is outlined in texts.

Schön (1991) refers to the navigation of puzzling and obscure situations as a *problem setting* (pp. 40-41). The term denotes the process by which professionals, interactively, formulate the problem, put it in a context, define the end-goals and the means available to reach them. A key point is that professionals often find themselves in complex situations that elude planning yet they are still able to carry out their tasks. Because this is often an intuitive process, it can be challenging for practitioners to identify and articulate the types of knowledge that form the basis of their daily practice. Schön (1991) illuminates this somewhat mystical nature of professionals’ practical competence through the concepts of *knowing-in-action*, *reflection-in-action* and *reflection-on-action*. Moreover, these concepts demonstrate how reflection can be used as a bridge for uniting theory and practice.

Knowing-in action is a form of tacit knowledge that manifests through our everyday activities, without much consideration and reflection. We often find it difficult to explain precisely what we do because we act on an intuitive knowing that is embedded in (and only becomes visible via) activity—we simply know how to do something without necessarily knowing what it is we are doing, or how we got there. Contrary to the intelligent acquisition of formal/objective (rational/scientific) knowledge, tacit knowledge is internalized through practice and experience, and thus is contextual, subjective, and personal (Schön, 1991).

Reflection-in-action occurs when we reflect on what we are doing while we are doing it, whereas reflection-on-action occurs when we reflect on our actions afterward. According to Schön (1991), a diffuse distinction exists between knowing-in-action and reflection-in-action, which makes it hard to pinpoint when we switch from one mode to another. However, for the most part, reflection-in-action is triggered by unexpected events or outcomes. That means that we begin to reflect on what we are doing when our preconceived understanding of the situation is being challenged in one way or another. In professional work, reflection-in-action can be thought of as the practitioners' deliberate inquiry into their practice while it is unfolding.

Schön (1991) highlights that reflection in and on practice is essential for professional renewal. Routine is an integral part of professional activity. As professionals become more seasoned, their "knowing-in-practice tends to become increasingly tacit, spontaneous, and automatic" (p. 60). A pitfall with the routine activity of professional practice is that the professional may develop tunnel vision and begin to selectively overlook phenomena that challenge their internalized understandings (p. 61). However, through reflection, professionals may explore their own (more or less) tacit understandings and ignite a newfound awareness of their professional practice and decision-making.

Another way to understand the significance of intuition and reflection in professional practice is outlined in the adult skill acquisition model, developed by Dreyfus and Dreyfus (1980). The model, which is based on empirical studies of sensorimotor skills, (such as

cycling, swimming, flying) and cognitive skills (such as chess and language learning) depicts an individual's progress—from novice to expertise (mastery)—through a five-step learning process.

In the first step, the *novice* enters the learning process through rule-based instructions for what to do in a given situation. Learning often takes place in a context free environment (e.g., a classroom) and is often guided by a more experienced teacher. In this initial phase, the focus is mainly on learning—and conforming to—rules. The transition to *advanced beginner* happens when the individual gains real-life experiences. With experience, an understanding of the environment begins to form, and context becomes a key factor in decision-making (Dreyfus, 2004; Dreyfus & Dreyfus, 1980).

As the repertoire of both experience and formal instruction grows, the individual is faced with an increasingly overwhelming amount of information. The move from advanced beginner to *competent practitioner* requires that the individual learns to prioritize, either by themselves or by others, different experiences and single out those elements that are relevant to the manage the situation at hand (Dreyfus, 2004; Flyvbjerg, 1991). Competent practitioners are, to some extent, able to apply discretion in decision-making but still turn to “rules and reasoning procedures” to avoid making mistakes in challenging situations (Dreyfus, 2004, p. 178).

Prior to the fourth stage of *proficiency*, all decisions have been made through conscious reflection on alternatives. This stage represents a break with the decision-making model of the three previous stages. The proficient practitioner is personally involved and emotionally invested in their work and has accumulated such a wide range of experiences that decision-making happens in an increasingly fluent manner. New situations are recognized intuitively and immediately, which means that some aspects of training and experience automatically stand out as more or less relevant for reaching a desired outcome. Proficient practitioners organize and understand their tasks intuitively, however, when new situations emerge, they must pause, reflect and make conscious decisions. Discretion is utilized to a greater extent than competent practitioners (Dreyfus, 2004; Dreyfus & Dreyfus, 1980).

The difference between the proficient practitioner and the *expert* is that the expert “makes more subtle and refined discriminations” (Dreyfus, 2004, p. 180). Experience is now fully embodied, and the action is based on a comprehensive assessment of the whole situation. This means that situations, relevant decisions, strategies, and actions are intuitively recognized and occur simultaneously. Contrary to the previous stages, there is no assessment of facts, analytical problem-solving or monitoring of action. The expert acts without the conscious application of specific rules and simply does what works in the moment—it is the body that responds to the demands posed by the situation (Flyvbjerg, 1991).

It is important to note that these are not isolated stages, rather, progression happens across a continuum. An individual can master some aspects of their practice as an expert, while other aspects are handled as a beginner. What the model does is outline a process of development that moves from logic-based action to experiential action, which happens through a gradual release of rule-based action toward an intuitive and bodily felt approach (Flyvbjerg, 1991). According to Flyvbjerg (1991), the Dreyfus model represents a critique of the tradition of technical rationality. Specifically, its failure to account for the significance of experiential and intuitive forms of knowledge. The Dreyfus model demonstrates how the analytical-rational way of thinking that dominate Western societies is insufficient when it comes to understanding the totality of human activity, both in everyday life and in working life.

Furthermore, Flyvbjerg (1998) emphasizes that rational-cognitive aspects are indeed important. Yet, this understanding is problematic because it treats analysis and rationality as the utmost important aspects of human activity and progress. As such, it suppresses and makes invisible other key aspects of the processes involved in acquiring and exercise of knowledge—namely that which concerns context, practice, trial and error, experience, common sense, and intuition. Moreover, the theories proposed by Schön (1991) and Dreyfus and Dreyfus (1980) illuminate how discretion, autonomy, and responsibility are integral features of professional (expert) knowledge. These theories also support the idea proposed by Freidson (2001) that there are (at least some aspects) of the application of

professional knowledge— which translates to professional work in practice—that eludes systematization and external regulation.

Professionalism Under Attack?

Professionalism is a heavily debated and complex concept. As previously mentioned, professionalism has long been viewed as a distinct mode of organizing and regulating work and workers—one that operates from a logic that sets it apart from the logics that govern the market and bureaucratic organizations (Evetts, 2011; Freidson, 2001). Professional work is, and always has, been changing (Abbott, 1988). However, a characteristic of the last decades developments is that these three levels of organization are merging (Evetts, 2011). A growing number of professionals are now salaried employees, working in a wide range of public and private and profit and non-profit organizations (Evetts, 2013; Leicht & Fennell, 1997). In connection with this, it is worth noting that the striking distinction between professionalism in the Anglo-American context (of self-employed professionals with the freedom to shape their working conditions) and the European context (of a predominantly state-run professional work organization) is also decreasing. A common denominator for both contexts is that professional work and workers are increasingly being subject to organizational and managerial control mechanisms.

A consequence, some scholars predict, is that professionals are increasingly losing control of their work, making it more difficult to exercise judgment in decision-making processes (Evetts, 2009). As Evetts (2011) puts it, professionalism as a distinct occupational value is threatened through transformations moving its foundation from “partnership, collegiality, discretion and trust to increasing levels of managerialism, bureaucracy, standardization, assessments, and performance review” (p. 407). This implies a shift whereby professionalism, rather than being solely shaped by members of the occupational group, is being imposed on the professionals “from above” by their employers and managers (Evetts, 2011) – who likely have their own professional agendas (Leicht & Fennell, 1997).

According to Evetts (2011), these changes make it possible to understand professionalism both as an occupational value and a discourse (ideology). What is happening, Evetts (2009,

2011) theorizes, is that a new type of organizational professionalism is emerging that is distinctively more reliant on institutional structures than (the more relationship-oriented) occupational professionalism.

Although a consensus that the conditions for professional work are changing exists, much debate surrounds the implications of these changes for professionalism (Freidson, 2001; Martin et al., 2015; Noordegraaf, 2007, 2016). Some scholars suggest that this new organizational professionalism implies a deprofessionalization and proletarianization of professionals, such as physicians, because essential professional values (power, autonomy, and authority) are being replaced with increased external and formal regulation (Ritzer & Walczak, 1988). Accordingly, Noordegraaf (2007) mentions that, within this system, professionals must continuously “*prove their added value*” (p. 763, emphasis in original). Moreover, it is argued that this is a system of control that amplifies polarization and power struggles, both within and between, professional associations and groups (Reed, 2007). As Noordegraaf (2007) highlights, opposing parallel processes are happening simultaneously. While established professions, such as medicine and law, are being subject to deprofessionalization, other occupational groups, such as social workers, nurses, and managers, use the same control mechanisms (that remove power from some professionals) to professionalize (raise the power and status) of their work.

However, less pessimistic voices contend, on behalf of the more traditional notion of professionalism, that the professions will find ways to regain their power and status as a leading influence on the organization of work in contemporary society (Reed, 2007). An important point set forth by Noordegraaf (2016) is that discussions focusing on the destruction or resurgence of professionalism generate either–or images, for example, between “professionals and managers” or between “professional” and “organizational logic” (p. 787), that distort the actual reality of the practice field. It is quite common that the professionals in service organizations have managing responsibilities. This is often the case with physicians, including several of the physicians who participated in my study—some were even members of the politically ordained professional groups that were tasked with designing the CPPs. As Webster (2020) underscores, a hierarchy of physicians

(academic versus non-academic physicians) exists, whereby the “elite” physicians form alliances with politicians and other external managing groups—thus become managing professionals over the troops on the ground, so to speak (Timmermans, 2005; Timmermans & Kolker, 2004). It could be argued that these elite professionals ensure that organizational standards and management technologies are sourced from professional perspectives. However, professionals in managing positions often have to balance competing loyalties, whereby managerial interests likely take priority over professional interests (Timmermans & Kolker, 2004).

A central point of discussion concerns how professionals’ respond—whether they adapt or resist—to the growing introduction of standards and procedures intended to make them more accountable and evidence-based in their practice (see, e.g., Leicht & Fennell, 1997; Noordegraaf, 2007; Waring, 2007). The changes to professionalism and professional work in healthcare are intertwined with the ongoing debates and perceptions about what counts as quality of care (Martin et al., 2015). I elaborate on the connection between professional work and quality of care in the following section.

Professional Work and Quality of Care

Quality is a word with multiple meanings. We use it frequently and in relation to a vast array of things and situations, such as clothes, food, relationships, education, healthcare services, research, and so forth—the list is endless. Quality is deemed essential, yet it is a relative concept as “it means different things to different people, indeed the same person may adopt different conceptualisations at different moments” (Harvey & Green, 1993, p. 10, UK spelling in original). Although we, as individuals, can have a clear idea of what quality means to us at any given moment, it is still an ambiguous term because we do not automatically know what quality means to other people. Thus, a key problem with the term quality, at least in the public sector, is that it is often used without ensuring a shared understanding of what it entails (Damsgaard, 2019). A shared, more general, meaning of quality is that it concerns the way things are. For an object or service, quality can be defined as the ability to satisfy the user’s requirements and expectations (Gundersen &

Halbo, 2018). As such, quality is a value-laden concept that denotes whether something is good and preferable (Harvey & Green, 1993).

The introduction of the CPPs is part of a long-standing political strategy to improve the quality of cancer care in Norway (Norwegian Ministry of Health and Care Services, 2018). But what is quality of care? And, how is quality measured, monitored and ensured? These are central, heavily debated, and controversial questions for health researchers, policy makers and professional practitioners alike. Quality of care is often defined positively with regard to the fulfillment of certain requirements, standards or expectations; thus it will be defined negatively if certain requirements, standards, or expectations are not met (Grepperud, 2009). In 1990, the (U.S.) Institute of Medicine, coined a general definition stating that “quality of care is the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge” (Chassin & Galvin, 1998, p. 1001). However, as Blumenthal (1996) notes, over time, the debate about quality in healthcare has become strikingly complex and cluttered with confusing terminology. To illustrate, he lists the following quality related terms:

observed and expected mortality, outcomes and process measures, SF-36, case-mix and case-severity adjustments, profiles, HEDIS measures, control charts, continuous quality improvement, total quality management, critical paths, and appropriateness criteria. (p. 891)

The growing complexity related to quality of care can, at least in part, be attributed to the large industry devoted to the continuous development of quality standards aimed to enhance and monitor professional practice (Kassirer, 1993).

According to Campbell et al. (2000), quality of care is a concept that makes the most sense when it is applied to individual patients, as it is the individual who is the recipient of care. For the individual, quality is predominantly a matter of “access” and “effectivity,” namely, whether individuals receive appropriate care when they need it. Campbell et al. (2000) emphasize that it is important to distinguish between the *structure* that shapes the

healthcare services, the *process* of actually delivering care to patients, and the *outcome*. Structure concerns how the healthcare services are organized in a physical manner (personnel, equipment, and buildings, and how the logistics (distribution of appointments, etc.), including the characteristics of staff members (both their competence and how they collaborate with each other). The process of providing care involves the clinical (biomedical) understanding and treatment of the health problem as well as the interaction between professionals and patients, which also influences the clinical understanding of the situation at hand. Both structure and process can, in different ways and situations, influence the outcome. Correspondingly, the authors suggest that quality at the individual level depends on “whether individuals can access the health structures and processes of care which they need and whether the care is effective” (p. 1614).

At the same time, quality for individuals must also be considered in connection with how healthcare is organized for the population. Individual patients’ access to—and process of—care also depends on what is happening with all the other patients in the healthcare system. On a societal level, organizational incentives and directives pertaining to the prioritization of specific patient groups influence the way resources are funneled into the healthcare system. In return, this generates opportunities and limitations for the individual. In the context of an entire population, quality is mostly about equality, efficiency, and costs in terms of doing what is best for society. The introduction of the CPPs, for example, is meant to improve the quality of care for all cancer patients by targeting equality and efficiency for this particular group of patients. This group-based strategy, as Delilovic et al. (2019) remark, could generate further inequality on an individual level. When symptoms pointing to certain conditions are given precedence, other patients in (perhaps even greater) need of the same resources may suffer as a result.

In this study, the focus is not on measuring or evaluating the quality of cancer care, but on exploring the process of giving care to individual cancer patients—thus what quality may entail in practice, from a physician standpoint. How important is it, for quality, that the patients follow a fixed time schedule? What does it mean, in terms of outcome, if deadlines are broken? How are they (physicians) supposed to negotiate between different quality

indicators on a personal and societal level? These are key questions that the physicians in this study must address daily. The CPPs reflect an ideal of equality on a societal level by granting all potential cancer patients the same access and high priority in the diagnostic trajectory. Yet, the policy also recognizes that quality means different things to different people, and thus requires individual adaptation.

As such, the CPP policy incorporates the two most influential, and radically opposing, overarching ideological movements to inform current strategies for safeguarding and improving the quality of care: standardization and individualization.

Standardization

There is a trend toward increased standardization of different aspects of professional work in the healthcare sector. Standardization refers to the process of constructing and implementing standards (i.e., principles) to increase the uniformity of practice across time and geographical locations (Timmermans & Berg, 1997; Timmermans & Epstein, 2010). It is the consistent action taken both on a national and organizational level to regulate, change and improve healthcare personnel's work. Standards are the "explicit, written and formal" (Ponnert & Svensson, 2016, p. 587) norms of practice that aim to ensure quality of care, right prioritization between patients, and to help solve collaboration and coordination challenges (Isaksen et al., 2018). As such, standards are tools that directs and coordinate work activities (Timmermans & Epstein, 2010). In Norway, the development of standards is closely tied to a long-standing political goal that all citizens are supposed to have equal access to healthcare services of high quality regardless of age, gender, geographical location or economic situation (Norwegian Ministry of Health and Care Services, 2009, 2016).

Clinical practice guidelines and care pathways represent two distinct, yet interconnected, strategies to standardize work processes in the healthcare sector (Zuiderent-Jerak, 2007). Clinical practice guidelines, which are rooted in the evidence-based medicine (EBM) movement, concern clinical issues, and thus provide recommendations for medical decision-making, such as diagnosis and treatment (Timmermans, 2005). Coined in the early

1990s, the term EBM signals a leading medical principle: that all assessments in clinical practice should be informed by the best available evidence, preferably from randomized controlled trials (RCTs) and meta-analyses (Gjersvik, 2019). Part of the larger background for EBM is based on a desire to democratize healthcare or make medical knowledge and medical assessments accessible and open to public criticism and assessment. The emphasis on democratization is particularly prominent in the Norwegian debates (Bondevik & Engebretsen, 2018).

As medical knowledge is rapidly changing, the task of incorporating EBM into practice can be considered a process of “lifelong, self-directed, problem-based learning” (Masic et al., 2008, p. 219). However, the rapid expansion of medical knowledge makes it virtually impossible for the individual physician to stay up to date on the best information available for each patient. Clinical practice guidelines emerged as a response to this challenge and are usually developed by a group of healthcare professionals (sometimes in conjunction with other experts) that “evaluates the scientific literature according to set criteria and then, based on the strength of evidence, offers recommendations aimed at the practicing clinician” (Timmermans, 2005, p. 491).

Although these guidelines aim to make it easier for physicians to incorporate EBM into their daily practice, getting physicians to use them has proven to be challenging. Research consistently demonstrates a gap between recommendations in guidelines and clinical practice (Bosse et al., 2006; Fischer et al., 2016; Gabbay & May, 2004; Greenhalgh et al., 2014; Zuiderent-Jerak, 2007). In many respects, the integration of guidelines into practice hinges on both the willingness of healthcare professionals to adjust their attitudes and behaviors and certain structural modifications of the environment (Fischer et al., 2016). Several studies point out that to succeed with guideline implementation, it is vital to identify possible barriers to compliance and work strategically to overcome these (Evenstad et al., 2021; Fretheim et al., 2015; Grimshaw et al., 2012).

In a scoping review, conducted by Fischer et al. (2016), the authors find that the primary barriers to guideline implementation are linked to (a) *personal factors*, such as lack of

awareness and knowledge of the guidelines as well as disagreement with the guideline recommendation, or low self-efficacy, skills and motivation and (b) *guideline-related factors*, such as complexity and layout, for example, the guidelines are too theoretical, difficult to understand, and not directly applicable to practice. Another major barrier is tied to the perceived lack of evidence, plausibility, and relevance to practice and (c) *external factors*, such as logistical constraints, lack of resources, or that the guidelines violate the department's professional norms and traditions. According to Flottorp and Aakhus (2013), studies show that guideline implementation is more likely to succeed if healthcare personnel are actively involved in the development and consecutive renewal of guidelines.

Moreover, another important barrier, mentioned by Greenhalgh et al. (2014), is that the sheer number of clinical practice guidelines now informing medical practice is both “unmanageable and unfathomable”— which reflects an “overemphasis on following algorithmic rules” (para 9, 13). Notably, evidence suggests that healthcare professionals hold divergent views on the importance of following guidelines, with nurses being more inclined to follow formal guidelines and report violations of clinical protocols, than physicians (McDonald et al., 2005). McDonald et al. (2005) explain that this is rooted in divergent conceptions of how clinical work should be carried out. In contrast to nurses, who embrace a more systematized, less individualistic approach, physicians value professional discretion and autonomy. This does not mean that physicians reject rules per se, rather, they are more likely to follow the unwritten and informal rules of medical practice.

Care pathways, such as CPPs, differ from clinical practice guidelines in that they concern the sequential flow of tasks related to the diagnosis and treatment of a specific clinical condition (e.g., lung cancer). They provide an overview of “essential steps in the care of patients with a specific clinical problem and describe the patient's expected clinical course” (Campbell et al., 1998, p. 133). As care pathways map out the tasks, timing, and sequence of the tasks to be accomplished, they have a broader multidisciplinary target group (as described in the section about CPPs in the introduction).

Care pathways originated in the United States in the 1980s in an attempt to improve efficiency and utilization of resources in accordance with the requirements set by insurance companies (Allen, 2009). In Norway, care pathways came into focus with the coordination reform (Norwegian Ministry of Health and Care Services, 2009), which describes the fragmentation of healthcare services as a major problem that can be solved by implementing care pathways. Although the main purpose of care pathways is to improve quality by ensuring collaboration between professionals and coordination of healthcare services, they are based on—and also aim to improve adherence to—clinical practice guidelines (Faber et al., 2014). As Allen (2009) states, care pathways embody multiple social worlds and organize the relationship between these worlds by mapping the relevant tasks and establishing meeting points between the people that are carrying out these tasks. Their attractiveness lies in their “ability to align clinical, management and service user interests around a healthcare quality agenda” (p. 355). As such, pathways foster cohesion and unified courses of action.

Since pathways embrace and make specific multiple aspects of the organization of healthcare, they have become central tools for accountability and the measuring and monitoring of professional performance. Accountability refers to the work of making professional activities visible and open to scrutiny by external parties, for example managers, politicians, or the public. With the introduction of the CPPs, healthcare professionals are made accountable through a coding system that measures efficiency by counting the days spent on different diagnostic intervals to the start of treatment (Håland & Melby, 2021).

Individualization

Although standardization is highly valued and something worth striving for, it has also been criticized for being an approach that coerces everyone into the same mold, elevating technical rationality to the detriment of the personal needs of each patient (Mannion & Exworthy, 2017). Individualization is a parallel trend that represents a counterbalance to standardization by focusing on the importance of adaptation to provide each patient with

care appropriate for their situation. In line with Ansmann and Pfaff (2018), I view individualization as an umbrella term for a diverse range of processes aimed at adjusting healthcare services to match the patient's unique biological and psychosocial disposition.

It is important to note that individualization is not merely a reaction to standardization and that there has been a continuous, dynamic, relationship between individualizing and standardizing processes throughout the history of medicine. This is reflected in the age-old discussion of the distinction between medicine as a science (standardization) and medicine as an art (individualization) (Håland & Melby, 2017). Nonetheless, individualization is gaining traction through scientific breakthroughs leading to the advancement of medical knowledge and technology, along with a more "commodified and consumerist approach to health and healthcare" (Mannion & Exworthy, 2017, p. 304).

Following Ansmann and Pfaff (2018), individualization can be divided into two main dimensions: personalization and customization. Personalization (also referred to as precision medicine) focuses on the patient's physiology and involves finding the right medical treatment based on the patient's genomic and molecular profile. In this context, individualization is understood in strictly scientific terms and is dependent on medical and technological progress that makes it possible to adapt treatment individually. Customization (also referred to as patient-centered care) directs attention to the psychosocial dimensions of the patients, which includes a focus on the whole person and considering patients' wants and preferences in decision making (Ansmann & Pfaff, 2018). Information, communication, and building a relationship with patients are key components of this work (Mead & Bower, 2000; Timmermans, 2020).

Ansmann and Pfaff (2018) remark that an important catalyst of individualization is that there are limitations to the effectiveness of clinical practice guidelines. It is impossible to make evidence-based recommendations that adequately cover every potentially emerging case. For unique and complex cases, including patients with multimorbid conditions, healthcare professionals must, to a greater extent, rely on experiential and tacit knowledge together with the patient's preferences in decision-making. While standards provide general

rules for the most common and isolated conditions, individualization creates a space to “fill-in the gaps in knowledge for specific cases” (p. 350).

The Competing Logics of Standardization and Individualization

Today’s healthcare sector is characterized by increasing institutional complexity constituted by an interplay between multiple, often conflicting, values and demands (Fincham & Forbes, 2015; Van Den Broek et al., 2014). According to Martin et al. (2021), there are four overarching institutional logics, connected to different societal levels, at play in the healthcare sector: professional, market, corporate, and state logic. These logics diversely inform both the services that are offered and what counts as quality of care. The professions determine what is appropriate care and the standard of quality by applying their expert knowledge and autonomy in medical decision- making, the market regulates care, quality, and professional work through a supply and consumerist oriented framework, corporate organization intervenes by establishing bureaucratic regulations, and the state organizes healthcare through different health policies (p. 3). In countries like Norway, which have a state-run healthcare system, a state logic is particularly prominent (Martin et al., 2021). This logic emphasizes principles connected to both standardization and individualization, as is the case with policies such as care pathways in general (Allen, 2009) and the CPP policy in particular (Håland & Melby, 2017).

In the CPPs, standardization is predominantly facilitated through a logic of efficiency, which holds healthcare professionals accountable to fixed time frames for arriving at a cancer diagnosis (or not) and the start of medical treatment, for each patient (Andersen & Vedsted, 2015). This logic calls for all (potential) cancer patients to be pushed through the healthcare system as fast as possible, and within the same time intervals. The policy also states that, based on the CPPs, an individual care trajectory must be arranged for each patient. Information and dialogue with patients and their next of kin are described as key elements of the CPPs, and patients shall be included in decisions about their care. Moreover, it emphasizes that this communication shall be based on respect and empathy, be carried out in a considerate manner, and adapted to the individual patient’s prerequisites,

such as age, social situation, language, wishes, and needs (Norwegian Directorate of Health, 2016a).

This illustrates the argument made Greenfield et al. (2017) that standardization and individualization are colluding aspects of care, whereby individualization is in the process of becoming a standardized practice. Yet, despite efforts to merge standardized and individualized approaches, they present contrasting and competing macro frameworks for organizing and practicing healthcare, which may be challenging to reconcile in the micro world of everyday professional practice (Mannion & Exworthy, 2017). As Bishop and Waring (2016) show, contrasting logics make professional work and quality of care negotiable in daily practice. Furthermore, the multidisciplinary function of CPPs (Allen, 2009, 2014) augments the conditions for negotiation between diverse groups of professionals by making collaboration necessary to fulfill the guideline criteria in terms of providing effective and efficient care.

According to Ansmann and Pfaff (2018), the MDT meeting is an arena that is meant to promote, what the authors refer to as “individualized standardization” of care. In this setting, negotiations of treatment alternatives are not confined to the standards recommended by guidelines but incorporate perspectives from professionals of multiple disciplines with insight into different aspects of the patient’s illness(es) and life situation. As such, these meetings function as a mechanism for ensuring that both comorbidity and the patient’s wishes and social environment are considered. It is possible to deviate from standardized guidelines if it can be demonstrated how that is in the patient’s best interest. However, the authors stress that studies reveal that how this process is carried out depends on the disciplinary composition of the group and how informed they are about the patient’s overall situation.

Mannion and Exworthy (2017) highlight a need for research that examines how the principles tied to standardization and individualization are negotiated and balanced in the daily work of healthcare personnel. This study contributes, in this respect, by using

institutional ethnography to illuminate (some of) the structural tensions that frame negotiations in professional practice, in the context of CPPs.

PART THREE

Theoretical and Methodological Approach

In this part, I present the theoretical and methodological framework guiding my research project. The starting point and research question for this study emerged from an interest in discovering how healthcare personnel experience and engage with a cancer care policy (CPPs) that establishes time as a central indicator of care quality. Since I wanted to explore the introduction of the CPP, from the perspectives of physicians doing the actual work of putting this policy into action, I chose to use a qualitative research approach. Qualitative research methods direct attention to both the subjective aspects and interactional complexity that constitutes social reality. Thus, they are suitable for generating in-depth and contextual data about social phenomena (Gubrium & Holstein, 1997).

Qualitative research embraces a wide array of perspectives and procedures to explore how “human beings understand, experience, interpret, and produce the social world” (Sandelowski, 2004, p. 893). In this thesis, I draw primarily on institutional ethnography, which is a theorized method of inquiry into the social organization that mediates people’s everyday experiences and activities (Campbell & Gregor, 2004; Smith, 2005). As such, institutional ethnography is used both as a theoretical perspective and a method for inquiry into the discovery of how CPPs are actualized in physicians’ everyday work.

Next, I outline the core elements of institutional ethnography, along with some of its orienting concepts, which provide the theoretical foundation of my research. I also detail the specifics of how I used institutional ethnography as a method for examining what happens once the imagined processes of the CPP policy hit the ground of actual practice.

Institutional Ethnography

Institutional ethnography originates in the writings of sociologist Dorothy Smith (1926-), who in the early phases of her academic career, identified a need for a more tangible sociology or a sociology that remains in touch with the reality of people’s everyday living (Smith, 1987, 2005). She developed institutional ethnography as a method of inquiry into

the intricate workings of social relations across different societal levels, with a focus on the way different texts and documents coordinate social action. It is an approach that both begins in, and moves beyond, the actual experiences and activities of individuals (Smith, 2005). Thus, institutional ethnography offers a useful framework for this study, as it seeks to understand how the CPP policy is taken up in everyday work practices.

Notably, institutional ethnography does not present any hard and fast rules for how to accurately apply this approach in practice. As Smith (2006) puts it: “it is important that institutional ethnography not become a sect, a group of insiders who know how to talk and write it, and insists on a kind of orthodoxy in its practice which put hazard its fundamental commitments to inquiry” (p. 1). However, institutional ethnography does provide some principles for empirical investigation, but the “how to” can be diversely realized (p. 1). With that in mind, the research conducted for this thesis is part of a larger collaborative project that evaluates the implementation of CPPs, and that context influenced how I engaged with institutional ethnography. I am the only one in the group who worked with institutional ethnography, and the decision to anchor my study in institutional ethnography was made when the interview process was well underway. This means that there were already some guidelines for sampling, what was to be studied and how, which, it could be argued, challenges some of the fundamental premises of institutional ethnography.

In this section, I outline the theoretical backdrop of institutional ethnography, along with its three essential orienting concepts: ruling relations, standpoint, and problematic. I also clarify the role of these concepts in my study. This discussion will carry over to the next part.

Background: Proposing an Alternative Sociology

The development of institutional ethnography is closely interlinked with Dorothy Smith’s experiences and observations, from the perspective of being a woman in academia from the 1950s onwards. Smith was one of the first women to graduate from the Ph.D. program at the University of California (DeVault, 2021) and received her PhD in sociology in 1963 (Smith, 1963). She gave birth to two children during her doctorate studies, then shortly

after, her husband left, and they divorced. Smith describes the experience of becoming the sole provider of their two sons as a shock (Tremblay, 2007). In an age when most academic positions were occupied by men, Smith defied multiple social conventions when she, as a single mother of two children, went on to pursue an academic career (DeVault, 2021).

Smith's early explorations were tied to her involvement with free speech, anti-war, and the women's movements. Here, she noticed how political protest became construed as disorderly conduct by authorities and how academics turned it into an object of study. Together with a few colleagues, she became aware of the active influence of concepts and texts in people's lives, along with their potential for social control (DeVault, 2021). An important inspiration behind institutional ethnography is rooted in her own experience of a striking tension between the abstract, textual, world of academic work and the hands-on work of mothering her two young sons. A tension that created what she describes as "a bifurcated consciousness" (Smith, 1987, p. 6)—she had to navigate two starkly different modes of being. She recognized, what appeared to her, as an alarming disconnect between the ideological world of concepts (academia) and the concrete world of all the actual activities that went in to caring for her two young sons (mothering).

Especially, the experience of having to shift from one mode of consciousness to another laid the foundation for extensive criticism of the predominant sociological practices of the time. A criticism that grew into a desire to create an alternative—to mainstream—sociology (Smith, 1974). A central argument against what Smith (2005) refers to as "mainstream sociology," is that it is "amazingly cluttered with theory" (p. 50) and, as a result, has lost touch with everyday reality. Another major problem, associated with the theoretical maze of sociology is that it is constructed primarily by and for men; in other words, men that are part of the ruling apparatus that separates practical work from abstract, intellectual work (Smith, 2005; Widerberg, 2015). Institutional ethnography then is Dorothy Smith's response to what she identifies as the distorted role of theory and gender bias in academia. A key premise, as described by Widerberg (2015), is that unless we as researchers dare to set aside existing theories, concepts, and preconceived notions about the world, we will just reproduce the same social order and reinforce existing power dynamics.

So, what is *theory* and what is its purpose in social research? These are bold questions, but a short answer to the former question is that, in social sciences, a theory represents a coherent thought process or interconnected ideas and beliefs about something that is happening in society. Thus, theories are made up of abstract concepts that together provide an understanding and/or explanation of social phenomena (Charmaz, 2014; Swedberg, 2012). As for the latter, in the words of Blumer (1954), “theory is of value in empirical science only to the extent to which it connects fruitfully with the empirical world” (p. 4). However, it is important to note that theories serve different purposes. A broad distinction is usually made between (a) theory as a tool (a conceptual framework) for empirical investigation and (b) theory as the final product, which aims to say something new and substantial about social life and contains statements that can be empirically tested (Mouzelis, 1995).

Mouzelis (1995) underscores that the boundaries between these two types of theory are blurry because “all actual theory contain within them both types of theoretical statements” (p. 1). He explains that an easy way of assessing whether a theory fits with the first or second kind is by its level of specificity. In the first type, the concepts (that make up the theory) are open-ended and function more like a lens for how we can view social reality regardless of context. Such theories prompt us to ask questions and guide the course of study, thus they are closely intertwined with methodological procedures. In contrast, the second type of theory elaborates on a chain of events tied to a specific context. According to Mouzelis (1995), this is significant because a lack of attention to this distinction cause scientists to talk past each other. He argues that misplaced criticism, along with a “persistent failure to link macro with micro, and action with institutional structures” (p. 149) is the reason that sociology today struggles.

An essential challenge for social scientists is to employ and construct theoretical concepts that most accurately represent actual social reality (Sohlberg & Leiulfstrud, 2017). Blumer (1954) suggests that a key problem with social theory is the blatant lack of empirical grounding, which has fostered a somewhat separate theoretical realm where it exists “in a world of its own, inside of which it feeds itself” (p. 3). This theoretical looping, he argues,

is rooted in the ongoing use of ambiguous concepts, which forces empirical data into pre-existing categories. This is the crux of the matter for Smith (Smith, 1990a). The discord in her personal experience of being a woman in academia, along with her involvement in the women's movement from the 1960s through the 1980s and her sociological investigations, led her to realize that conventional sociological texts are written in a way that separates and specializes intellectual work from embodied work and everyday knowing (Smith, 1987).

According to Smith (2005), the problem with sociological theory is that social realities are transformed into external objects or facts residing outside of the actual subjects (people). It is a process by which abstract concepts are ascribed life and agency, which are unconnected to the actualities of real people. The result is a sociology by which researchers study discursive conceptualities (e.g., depression, attitudes, interests) rather than actual subjects. Furthermore, these “textually constituted realities” become authorities over the actual work in society (Widerberg, 2021). Smith (2008a) explains that the distinct sociological language with its extensive use of abstract concepts creates a “transition from being among people to being above them” (p. 418). This entails a practice that conforms to an idea of trying to understand society as a whole but without the perspectives of the actual subjects experiencing that which is attempting to be understood (Widerberg, 2021). The problem is precisely that by replacing the actual with concepts, “the actual becomes selectively represented as it conforms to the conceptual; the conceptual becomes the dominant mode of interpreting the results section” (Smith, 2005, p. 54).

The identification of a disconnect between social theory and the empirical reality of lived experience is a critique of the sociological practices promoted by, for example, Scott (2017) who conceptualize and understand *the social* and *social structures* as independently existing realities (p. 154). According to critics, the conceptualization of structure as something with a life of its own, portrays the social world as something mechanical, beyond human control—people and their interactions are somehow mysteriously orchestrated from behind the scenes (Hart & McKinnon, 2010; Mouzelis, 1995; Smith, 2005)

Smith (2005, 2006) designed institutional ethnography as an answer to this disconnect between theory and reality. It is an approach to the discovery of social reality that aims to ensure that the research remains empirically grounded through and through. The idea is that, by rooting the research in the actual experiences and activities of subjects and maintaining a focus on making the interconnectedness of people across time and place visible, institutional ethnographic research refrains from disappearing into an abstract, distant universe. Since institutional ethnography aims to highlight how it is that things happen the way they do, it is, as DeVault (2021) notes, a potent tool for creating social change – which is why it is often described as an activist approach.

In closing this section, I must stress that critics have challenged Smith's proclamation that institutional ethnography manages to penetrate the theoretical realm and even questioned whether such a project is possible (Doran, 1993; Walby, 2007). As I outline institutional the ontology and conceptual framework of institutional ethnography for discovery in the following sections, I want the reader to be mindful that I do not consider Smith's work as better or more enlightened than the ideological practices she is criticizing. In fact, as Doran (1993) meticulously demonstrates, institutional ethnography also operates from within a particular sociological discourse by which it imposes ideological description on people's experiences— arguably, reinforcing the same ideological loop in the quest for theoretical emancipation.

Furthermore, as Magnussen and Nilsen (2022) highlight, institutional ethnography presents as less alternative (i.e., not so radical or groundbreaking) in the context of the Nordic sociological tradition compared to the North American sociological tradition. For example, in Norway, institutional ethnography fits into a long-standing sociological tradition that both conducts activist research and criticizes, what Smith (2005) refers to as, mainstream sociology. Thus, the uniqueness of institutional ethnography, the authors argue, lies more in the methodology's composition than in its motivation and aims. In this thesis, institutional ethnography serves as a suitable analytical lens for understanding how CPP policy, as a mode of ruling, is taken up by physicians in their daily practice.

Institutional Ethnography as Theory

I return now to Smith's (2005) extensive criticisms of the role of theory in social research, whereby she rejects theory both as a starting point and the conducting of research to build theory. However, she certainly does not suggest that we discard theory in its entirety or proceed without any form of theoretical guidance. I would argue that institutional ethnography is indeed a theoretically saturated approach, with theoretical concepts guiding the research process (Campbell & Gregor, 2004). Although this appears somewhat paradoxical, it makes sense considering the well-established distinction between the two types of theory mentioned above (theory as a tool and theory as the end-product). As DeVault (2021) notes:

What she [Smith] rejects is the type of peculiar formal theory that was so dominant in the functionalist era when she began, and that lives on in so much of contemporary sociology. IE [institutional ethnography] is designed for a different type of theorizing: it does not aim to develop theory, but to theorize about the organization of people's everyday lives as they are unfolding. (p. 12)

Smith (2005) acknowledges a need for theory as a tool for the discovery of how social life plays out. The problems she identified with conventional sociological theorizing of social life became an inspiration for finding a way to examine how the social world works in a more tangible sense: a path to inquiry that remains true to the everyday experiences of actual people. Smith's (2005) commitment to remain true to the actualities of social reality reflects an existential focal point. The question of interest then is, what is the nature of the social? As this is an ontological question, Smith (2005) develops an ontology as the theoretical basis for institutional ethnographic research. Drawing on thinkers, including Marx, Engels, Mead and Bakhtin, she identifies the social as inherently relational and textual, which means that its existential reality emerges from the **coordination** of people's activities. Smith (2005) describes the foundation of institutional ethnography as fourfold: "individuals are there; they are in their bodies; they are active; and what they are doing is coordinated with the doings of others" (p. 59). As noted by McCoy (2021), this is "a

decidedly materialist ontology, in the sense that it brings attention to what is materially there, that is, from people and what they do, rather than from ideas about people, or even their ideas about themselves” (p. 36).

As such, the social as it emerges through coordinated human activity is made the focal point of study. It is here, by allowing this ontological premise (what is actually there; experienced and happening in social reality) to drive the research process forward that institutional ethnography breaks with the “classic” theorized approaches that, according to Smith (2005), selectively organize empirical data to maintain and legitimize a predefined, theorized reality. Smith (2005) emphasizes that she is particularly inspired by the conceptual work of Karl Marx and Engels. These concepts (class and capital) function, in the words of Mouzelis (1995), as tools, rather than end products. Furthermore, they are rooted in actual social relations and material conditions, namely the material conditions that are generated by concrete human activity. It is the actual work of people—their thoughts, feelings and doings— “and the forms of “cooperation” that have evolved among them” (Smith, 2005, p. 54) that concepts such as capital and classes direct attention to. The idea is that, by examining what people do it is possible to uncover the social relations (the ontological foundation) that shapes what is happening in people’s daily lives.

Another fundamental premise is that of *social historical continuity*. This means that there is a social interweaving between people’s past and present activity; the material conditions of our present moment emerged because of other people’s past activity. This is the theorized basis for the concept of ruling relations—the heart of institutional ethnography. The focal point of an institutional ethnographic study is the interconnectedness between happenings. To clarify the coordinating nature of the social, Smith (2005) writes:

the social might be conceived as an ongoing historical process in which people’s doings are caught up and responsive to what others are doing; what they are doing is responsive to and given by what has been going on; every next act, as it is concerted with those of others, picks up and projects forward into the future (p. 65).

This makes it possible to visualize the social as a matrix of interaction. It is, however, important to note that coordination is not a “phenomenon distinct in itself but an aspect of what people do to be explored and explicated” (p. 59). In other words, institutional ethnography tries to maintain a two-dimensional focus: the individual and the social relations the individual is part of and partakes in. The essential elements of the conceptual framework for exploring the social coordination of people’s activities can be described as follows: *Institutional ethnographic research aims to explore how the **ruling relations** operate from a **standpoint** in the everyday world. The inquiry focuses on people’s **work and work knowledge**, and proceeds through the formulation of a **problematic**.* The meaning and role of these four concepts, as I have used them in my study, is outlined below.

Ruling Relations: The Textual Organization of Society

To summarize, institutional ethnography is based on an understanding of the social as something that comes into being in social processes that cut across time and place. Thus, the social can be researched by examining how people’s everyday experiences and activities are coordinated. This means that people’s thoughts, experiences and doings are entangled into a complex web of social relations that extends beyond the local context of (observable) specific chains of events. It is this translocal network of relations that Smith refers to as the ruling relations (and alternately as the relations of ruling). The concept of ruling relations points to social relations that influence and regulate everything we do in our daily lives (Smith, 1999, 2005)

Notably, the term social relations in this context does **not** denote interpersonal relationships, such as those between friends, siblings, or boss and employee, et cetera. Instead, it is a concept that “*directs attention to, and takes up analytically, how what people are doing and experiencing in a given local site is hooked into sequences of action implicating and coordinating multiple local sites where others are active*” (Smith, 1999, p. 7, emphasis in original). Smith (1999) describes ruling relations as a matrix comprised of different forms of social consciousness (i.e., ideas, beliefs) and organization that have been

objectified through their journey in time and place – this means that they have been abstracted and operate independently of specific individuals

Smith's notion of ruling relations draws on Marx's analysis that highlights the social and material nature of social inequality (class) and ruling relations (social forces of power). However, Smith reframes Marx's essential ideas to match the forms of social organization that dominates today. The material conditions and practices of ruling have changed since the era of early capitalism, which formed the basis of Marx's analyses (Rankin, 2004; Smith, 1990b). Today, ruling is predominantly channeled through complex systems of knowledge and information that are distinctly textual in nature. Ruling relations are all the social relations that in one way or another have a textually mediated power to define and mold social reality, such as political and state bodies, various professions, management, and the media (Smith, 1999), including "the complex of discourses, scientific, technical, and cultural that intersect, interpenetrate, and coordinate the multiple sites of ruling" (Smith, 1990b, p. 6).

Importantly, although ruling practices serve certain class interests and are potentially oppressive, the notion of ruling relations does not perpetuate a view of people as subordinate victims of a ruling elite (Benjamin & Rankin, 2014). Ruling relations are enshrined in institutional arrangements recognizable to us as norms, legislation, documents, forms, standards, theories, concepts, et cetera that we (in diverse ways) participate in when we carry out our daily activities. For the most part, we are hardly aware of our participation in (and sustaining of) different modes of social organization, even those we disagree with. The people that developed these arrangements (including the coordination of their activities with those of others) in a different location and at a different time, are not visible to us, yet they constitute a social consciousness that influence and regulate our present lives through various textual mediums (Campbell & Gregor, 2004; Lund, 2015; Nilsen, 2017a). This is what makes ruling both inter-relational and inter-textual and an integral part of the social. According to Smith (2005), texts create material *interindividual territories* (p. 101). This means that when we read a book, follow an instruction, listen to the radio, or watches TV,

we become relationally linked to others reading, listening and watching the same thing. Although I might respond differently to the same textual medium as you, our consciousnesses and actions are, nonetheless, coordinated by our participation in them. A key point is that texts have a particular significance in the social complex because they make things happen. However, the power of the text cannot be considered autonomous or independent of human activity. Rather, they function as institutional coordinators that connect people from different social positions.

Furthermore, discourse is an integral feature of ruling relations (Smith, 2005). As a concept, discourse can be difficult to grasp due to its many distinct connotations. A common understanding of discourse is that it refers to linguistic patterns in our utterances, namely specific ways people understand and talk about something (Jørgensen & Phillips, 1999). Smith (2005) builds on Michel Foucault's understanding of discourse that locates knowledge "externally to particular subjectivities as an order that imposes on and coerces them" (p. 17). From a Foucauldian standpoint, reality is discursively produced, which means that no phenomenon exists objectively or independently "out there" in the world. Foucault (1972) describes discourses as "practices that systematically form the objects of which they speak. In addition, discourses are not about objects; they do not identify objects, they constitute them and in the practice of doing so, conceal their own invention" (p. 49).

Simply put, discourses can be thought of as collective perceptions of reality (worldviews) that present as matter of fact and consequently govern human activity. Smith (1999) emphasizes that discourses, as used in institutional ethnography, "exist in people's socially organized activities" (p. 173). Discourses filters reality and create conditions (and constrain) for human activity. For example, when we consult with our physician, go to therapy, or to a teacher-parent meeting, we will think, feel, talk and act in certain ways. And, by thinking, talking and acting in those context-specific ways we both reproduce and remake the discourse in play at any given moment (Smith, 2005). In line with Håland and Melby (2017), I consider standardization and individualization to be two major overarching discourses that organize professionals work, which are comprised of a number of interrelated discourses (that offer specific ways for people to go about their daily practice).

Standpoint

Standpoint is a particularly important concept in institutional ethnography because it rectifies the problem with abstract sociology that appears to operate with a “view from nowhere” (Lemert, 1992, p. 68). Instead, institutional ethnographic research is firmly grounded in the experiences, puzzles, and activities of people at particular sites. The key aim is to illuminate the workings of the coordinating processes for those people. Thus, standpoint is a concept that is used to establish a concrete viewpoint in the embodied, personal experience of ordinary people and to ensure that the inquiry is conducted from within the local world of real people, objects and experiences (Smith, 2001, 2005).

The notion of standpoint is rooted in feminist standpoint theory, which has been the subject of great controversy and ongoing reformulation for decades. One example can be found in a journal debate about the definition of standpoint theory in *Signs: Journal of Women in Culture and Society* among key feminist academics (Collins, 1997; Harding, 1997; Hartsock, 1997; Hekman, 1997; Smith, 1997a). This debate demonstrates how standpoint theory does not refer to a unified system of ideas and assumptions about the world but functions more as an umbrella term for multiple understandings and approaches to research method and epistemology. Moreover, standpoint theory with its associated discussions has paved the way for new ways of thinking about research and knowledge (Harding, 2004, 2009).

Feminist standpoint theory is inspired by Marxist ideology in conjunction with the growing awareness of the gendered, highly skewed, division of labor and the women’s movement in the 1970s (Smith, 2005). According to Sandra Harding (1997)—who is often referred to as the mother of standpoint theory (Bråten, 2004)—standpoint theory is essentially about the connection between power and knowledge development. The primary foci, at least for the early standpoint theorists, is on uncovering how male supremacy and knowledge production have mutually influenced each other throughout history. As Gurung (2020) notes, standpoint theory emerged in opposition to the patriarchal domination of society in general, and the conventional social sciences in particular. It can be described as a form of

critical social theory, designed with a clear goal of strengthening the life situation of the oppressed—who in the early context were women. The idea is that by examining women’s experiences, it is possible to discover aspects of women’s lives that have been neglected by social policy and theories and produce a type of knowledge that can help women to improve their living conditions.

Harding (2009) underscores that research based on standpoint theory is driven by a two-sided commitment. It aims to (a) produce knowledge that women want and need to overcome their struggles and prosper in their lives, and (b) to free women from oppression by highlighting the high value of women in society. Consequently, taking a standpoint involves interweaving scientific/epistemological and ethical/political ideals. This is the core of the controversy surrounding position theory, as it points to a similar interweaving of male superiority and classical scientific ideals. Harding (2009) explains that although it is rather uncontroversial to be for women and gender equality, it is quite another issue to engage “overtly against male supremacy and regulative ideals” (p. 193) that, according to critics, oppress women and other social groups. It is ultimately a struggle to *matter*—to be of significance. The question remains: “whose experience is to count in formulating ideals of objectivity, rationality, and good method?” (p. 193).

Feminist standpoint epistemology has not only challenged the patriarchal bias and the power structures that shape scientific knowledge but also, as Breimo (2015) puts it, the positivist notion of an “independent, objective, disinterested, universal, classless and genderless research subject” (p. 81, my translation). In contrast, standpoint theorists argue that knowledge is constructed from a specific point of view in the social hierarchy and cannot be value-neutral. Rather, standpoint theorists argue that certain kinds of values can contribute to more advanced knowledge development than others, and that some positions in the social structure provide better access to (and insight into) some aspects of social reality (Harding, 2004).

The evolving nature and diverse use of standpoint are reflected in Dorothy Smith’s work and the development of institutional ethnography. Smith (2005) mentions that she

borrowed the concept from Sandra Harding, but the concept is assigned a different meaning in institutional ethnography than what is common in classical feminist sociology. Smith (1997a) explicitly rejects the notion purported by Hekman (1997) that she is part of a “coherent” group of standpoint theorists. To clarify, Smith (1997) explains that several feminist thinkers were, independently and simultaneously, exploring how women’s experience could be used as a method of inquiry, but her work is different, as it “has nothing to do with justifying feminist knowledge” (p. 393). She also refutes the idea that certain social positions and experiences are epistemically privileged (as some standpoint theorists have been criticized for believing). Furthermore, she insists that power relations and governance should be explored empirically, as they are “themselves people’s socially organized practices in the actual location of their lives” (p. 393). This is the reason she altered her direction: from developing a sociology for women to a sociology for people (Smith, 2005).

Smith (2005) works to establish a more open and indefinite version of standpoint than her feminist colleagues. She writes that standpoint “does not identify a position or a category of position, gender, class or race within society, but it does establish a subject position for institutional ethnography as a method of inquiry, a site for the knower that is open to anyone” (p.10). Smith’s (2005) departure from the notion that standpoint represents a specific category or position in society (e.g., class, gender, or race) is a move that makes standpoint accessible to all researchers and grounds the research in human experience, rather than the conceptual. The focus of inquiry is on what happens in people’s everyday lives and on how activities in one place relate to activities in another place (and time).

Smith (1997a) emphasizes that the contrast she makes between the actual and the conceptual is not meant to imply that the conceptual is located in a realm separate from lived reality. She is not, as she puts it, advocating a move “from concepts to reality” (p. 393). The conceptual is very much a part of reality. However, by taking a standpoint, it is possible to begin an inquiry into the more tacit forms of knowledge that are “the very texture of our daily/nightly living” (p. 394), and from there, to discover and make explicit active social relations via the concepts we use to navigate our daily/nightly living. The

purpose is to show how things work, preferably in a way that is useful to the standpoint informants.

Thus, in institutional ethnography, the concept of standpoint is used as a starting point, a location in the empirical world to look from—and explore what forms of ruling relations people participate in, and how these relations coordinate what happens in that particular part of the social world (Smith, 2005). It is important to note that standpoint is not exclusively about the initial phase of the research, but functions as a benchmark, so that, as the research proceeds, it is possible to continuously assess how things look from the chosen standpoint and how to best illuminate the puzzles and problems of the standpoint group (Campbell & Gregor, 2004).

As previously mentioned, in this thesis, I engaged with the concept of standpoint differently than prescribed in most institutional ethnographic literature. Since the research for this thesis is part of a larger collaborative project and I decided to use institutional ethnography during the interview process, it was challenging to choose a clear standpoint. Thus, the role of standpoint in my project became an issue that I spent a lot of time trying to understand and solve. The difficulty arose in that I wanted to honor the fundamental premises of institutional ethnography, yet I was studying and learning about institutional ethnography while simultaneously trying to use it in practice—in a somewhat predefined and collective research context. It was already decided that we (as a research group) would interview a range of different healthcare personnel. At first, I considered the possibility of taking the standpoint of healthcare professionals as a group. However, after discussing the issue with other more experienced institutional ethnographers, I decided that healthcare professionals as a standpoint group would complicate the research because it is such a diverse group of professions that I would lack a firm anchor to work from.

While contemplating this predicament during the interview process, I decided to take the standpoint of physicians. The reasoning behind this choice is threefold. First, it came as a natural consequence of the distribution of data collection in the research group. I was responsible for organizing and conducting interviews with informants from one of the

university hospitals, and in this particular hospital the majority of the informants were physicians. Therefore, I gained insight into physicians' experiences with CPPs at an early stage of the study. A second important reason is that physicians are the key decision-makers (of diagnosis and treatment) in CPP trajectories. Third, as Vinge et al. (2012) point out, the introduction of CPPs challenges the traditional role of physicians by restricting their professional autonomy, particularly the temporal dimension of their work—both when it comes to professional assessments on the prioritization of patients and the organization of their working day.

Bearing in mind the liberatory potential of institutional ethnography, it might seem odd to take the standpoint of physicians. As a group, physicians are generally considered to hold a high and authoritative position in society (Abbott, 1988; Dingwall, 2008; Freidson, 1994). Many institutional ethnographies aim to illuminate everyday experiences and the work of people “from the margins” and be a tool for change (Smith, 1997b; Webster, 2020). For example, single mothers (Griffith, 2006) people with HIV/AIDS (Mykhalovskiy, 2008), pregnant women with HIV (Ion, 2021), women with cancer (Sinding et al., 2012), people with disabilities (Nordstedt, 2015; Rodriguez, 2021), people in rehabilitation (Breimo, 2015), battered indigenous women (Wilson & Pence, 2006), Asian immigrant women (Grahame, 2003), and transgendered people (Brauer, 2017; MacKinnon, 2019)—as well as frontline workers, such as nurses (McGibbon et al., 2010; Rankin, 2004), kindergarten staff (Jahreie, 2021; Nilsen, 2017b), teachers (Spina, 2017), and social workers (Parada, 2004).

A scoping review (Malachowski et al., 2017) shows that most institutional ethnographies that investigate the work of healthcare professionals take the standpoint of nurses. As nurses are positioned below the physicians in the institutional power hierarchy in the medical field, they have long been perceived as an oppressed group (Chakraborty et al., 2021). Since physicians are part of the medical elite and thus considered to be part of the oppressive regime, few institutional ethnographies have examined the social organization of healthcare from the standpoint of physicians. To my knowledge only two studies have been conducted from this standpoint: A study by Rua (2015) that examines the isolation of

inmates from the standpoint of correctional physicians, and a study by Webster (2020) that examines best practice from the standpoint of physicians working in stroke care.

As physicians' traditionally well-established high position and professional autonomy are being invaded via the continuous introduction of control mechanisms aimed at regulating different aspects of practice, it is, arguably, both relevant and interesting to examine how their work happens as it does. For example, Webster's (2020) demonstrates how variation in physicians' practice (i.e., how stroke care is performed) happens within different forms of social coordination. Thus, the findings challenge the (widely accepted) notion that individual physicians are the problem when there is a breach of best practice protocols.

Cancer care is comprised of physicians that occupy different positions and medical specialties, which means that the physicians in my study represent a diverse group of medical professionals (clinicians, surgeons, radiologists and pathologists as well as GPs). This is also a complicating factor with regards to using a physician standpoint. As Campbell and Gregor (2004) note, different sources of data are needed to uncover the connections between what is done locally and the social organization mediating these actions. As a group, these physicians work in different locations across the institutional setting and meet with patients in different phases of the four CPPs. Thus, a physician standpoint in the context of care pathways provides insight into the connection between these sites from within the standpoint, so to speak. However, the interviews with other types of healthcare professionals, such as nurses, cancer patient coordinators, and administrative staff, were used to enhance the understanding of how the institutional setting (cancer care) works. As this study follows CPP policy into practice, it did not begin with experience per se. It is similar to other institutional ethnographies, for example, a study by Mykhalovskiy (2003) that began within "a set of governing processes and aim at providing an analytical description of professional work activities" (pp. 335-336). This approach implies that I used the concept of standpoint (and problematic) more actively in the analysis of the interview transcripts, rather than during the data collection.

Work and Work Knowledge

Institutional ethnographic research relies on people's work and their knowledge of their work. In line with Strauss and colleagues (Strauss et al., 1997; Strauss et al., 1963), Smith (2005) endorses what she describes as a "generous" conception of work. It is generous in the sense that it embraces "anything done by people that takes time and effort, that they mean to do, that is done under definite conditions and with whatever means and tools, and that they may have to think about" (pp. 151-152). Work is not restricted to that which is done as part of a paid job—or even the formal aspects of paid employment—and includes physical, mental, emotional and linguistic activities. This is a move that bridges the Cartesian split between body and mind, which, according to Smith (2005), produces an artificial separation between aspects that are integral to the human way of being in the world. Thinking, along with mental constructions such as "ideas, concepts, theories, beliefs" (p. 76) as well as feeling and talking is also being done, and thus are intrinsic to the social interconnectivity of people's doings. However, this understanding of work also has its limitations in that it refers to intentional activity.

People are understood as knowers or experts of their practice. They are experts by virtue of their experience with what they do and how (and why) they do it. This means that, in institutional ethnography, experiential knowledge is considered authoritative knowledge, and it is what we can learn from people about their work that is of interest to the inquiry. An individual's work knowledge contains both individual and social aspects. Indeed, individuals have their own experiences, thoughts, feelings and understandings about what they are doing; at the same time, the work and work knowledge of one individual is being shaped in coordination with the work and work knowledge of other people.

Thus, for an institutional ethnography to succeed in the quest for work knowledge, it is important to access people's experiences with their work, both the formal and informal aspects. Smith (2005) points out that this can be challenging because people, especially professionals (Nilsen, 2021), often talk about their experiences using institutional terminology (abstract concepts) that conceal the actual work carried out by the informants

in their local context. Smith (2005) refers to this phenomenon as *institutional capture*. When a conversation becomes captured in institutional terminology, descriptions might end up excluding those aspects of people's work knowledge that do not fit into the discourses, concepts and categories of the institution (Magnussen, 2015). It is important that the researcher is aware of this phenomenon and asks questions that can probe and help untangle the actual from the conceptual (Smith, 2005).

Problematic

The standpoint of informants' work and knowledge of their work provides clues which are used to formulate a research problematic, which provides direction to the research project. This means that the research object in institutional ethnography is constructed by engaging with empirical data. Importantly, the term problematic does not necessarily imply the personal problems of the standpoint informants (although it may overlap with challenging experiences) and is less defined than a research question (Smith 2005). Rather, the problematic is developed from the identification of junctures or disjunctures or tensions between the ruling apparatus and the everyday reality (Campbell & Gregor, 2004; Rankin, 2017b)

Thus, a problematic is found in the intersection between the local and the translocal (Smith, 2005). It is often the identification of contradictions that arise in these intersections that is being taken up as a problematic for further inquiry and analysis (Rankin, 2017b). In this study, the CPPs as a ruling/translocal relation was the primary focal point from the start. I have searched for contradictions between this governing text and lived experience (what the informants say happens) as the basis for direction (identifying what to explore) in my analyses.

PART FOUR

The Research Process and Data Material

The empirical data underpinning this thesis are part of a collaborative research project entitled: Evaluation of Cancer Patient Pathways. The evaluation took place from 2017 to 2020, using a qualitative cross-sectional design. Data were collected through semistructured interviews. The original project explores the experiences of both healthcare professionals and patients and was organized into three working groups that were led by a group leader. One group was responsible for data collection with patients and two groups were responsible for data collection with different types of healthcare professionals. I was assigned to work with the research groups in charge of data collection among healthcare professionals, where my main supervisor was one of the group leaders. The three research groups had joint access to all data material, both patients and healthcare personnel. The Norwegian University of Science and Technology (NTNU) and the Research Council of Norway (project number 272665) funded the studies for this thesis.

In this part, I elaborate on the methods of data collection, materials and analysis as well as the quality of the study.

Interviews

The interview is frequently cited as the most celebrated and widely applied method in qualitative research (Silverman, 2017). For this study, interviews were chosen because of their versatility and potential to obtain in-depth information about a wide range of human experiences, including thoughts, feelings, actions, chains of events, meaning-making, assessments, and decision-making (Miller & Glassner, 2011). Interviews enable us to explore both what people (say they) do as well as the experience and logic embedded in their doings (Holstein & Gubrium, 1995; Smith, 2005).

There are multiple ways to think about and conduct qualitative interviews. A common distinction is made by the desired level of structure (Merriam, 2009). In the highly structured, standardized interview, the questions are predetermined, and the interviewer

follows the interview guide strictly. This entails that the same questions are asked in the same order to all informants. The researcher does not comment or provide any feedback during the interview. As Merriam (2009) points out, the structured interview is an oral version of “the written survey” (p. 90). It draws on positivist assumptions that it is possible to discover “true facts and feelings” (Holstein & Gubrium, 1995, p. 2), that the questions will be interpreted equally by all the informants, and that the interview, with its surrounding circumstances, does not influence the information (Merriam, 2009; Rapley, 2004).

In contrast, although an unstructured interview may be centered around a few broad topics or open-ended questions, it is conducted more like an informal conversation (Merriam, 2009). The data for this study were collected using semistructured interviews. This is the most widespread approach to qualitative interviewing and is a mix of structured and unstructured designs. As such, semistructured interviews are usually guided by a set of topics accompanied by open-ended questions. The order of questions may vary between interviews. The interview style is flexible, so the researcher is free to actively engage and explore new aspects and topics in response to the informant’s accounts. Both unstructured and semistructured interviews draw on constructivist assumptions that meaning and knowledge are constructed in the interaction between the researcher and the informants (Doody & Noonan, 2013; Holstein & Gubrium, 1995).

Furthermore, interviews can be carried out with one or multiple informants at the same time. Individual interviews are suitable for in-depth exploration of the experiences of each informant. Interviews conducted with two or more informants create a different social situation in that the informants can share their experiences, listen, and respond to each other. This could lead to interesting discussions by which nuances, contradictions, and new understanding may emerge (Crabtree et al., 1993). In this study, we used a combination of individual interviews, dyadic interviews (interviews with two informants), and group interviews.

Data Collection and Informants

Sample

The empirical data for this project is based on qualitative interviews with 72 healthcare professionals of different professions. The interviews were conducted from May 2018 to January 2020. Of the 72 participants, 62 informants worked in specialist healthcare in five hospitals across Norway: two local hospitals, and three university hospitals. 12 informants were GPs with their own practice in primary healthcare (Table 1). Notably, the number assigned to the hospitals in Table 1 does not reflect the numbers assigned to the hospitals in the articles of the thesis.

Table 1

Overview of the Informants

Workplace	Hospital 1	Hospital 2	Hospital 3	Hospital 4	Hospital 5	GPs	Total
Number of informants	15	7	5	14	19	12	72
Number of interviews	13	7	5	13	19	5	62
Profession							
Cancer pathway coordinators	3			5	6		
Nurses	6		2	3			
Physicians (clinicians, radiologists, oncologists, pathologists)	4	4	3	5	11	12	
Other (clerical workers, administrators)	2	3		1	2		
Total	15	7	5	14	19	12	72

The sample consisted of cancer pathway coordinators (a position occupied by either a nurse or a secretary), nurses (including cancer nurses), clerical workers in administrative positions and physicians of different professions and positions, including clinicians, radiologists, pathologists and oncologists. Some of the physicians we interviewed also held leading positions in their departments.

Recruitment

As this research project focused on four CPPs (i.e., lung cancer, prostate cancer, malignant melanoma, and breast cancer), we were interested in talking to healthcare personnel working with these four pathways. Since this thesis is part of a larger collaborative effort, the process of recruiting informants was carried out by several researchers, myself included. Informants were predominantly recruited through purposive and snowball sampling. Purposive sampling refers to a strategic approach during which specific informants are selected because they are presumed to have in-depth knowledge of the phenomenon under investigation (Palinkas et al., 2015). Snowball sampling entails asking existing informants to help recruit other informants (Kristensen & Ravn, 2015). The sample could also be defined as a convenience sample (Wu Suen et al., 2014) since some hospital wards declined the invitation to help recruit informants for the study (Melby et al., 2021).

The notion of *gatekeepers* is well-known in qualitative methods and refers to individuals who hold a key position in the research site of interest and therefore, may grant the researcher access to the population (Kristensen & Ravn, 2015). In this study, the project leader established the initial contact with key persons in the four CPPs at the five hospitals included in the study. The key persons functioned as gatekeepers in the sense that they helped us to identify and ask the staff in their departments if they would like to participate in the project. They occupied different professional positions—physicians, nurses, and cancer patient coordinators, or part of the administrative management—but all played a central role in the introduction of the CPPs in their departments. In preparation for the recruiting of informants, the project leader organized meetings with the key persons to establish contact and provide information about the project. I participated in all the

meetings with the gatekeepers at one of the university hospitals. During the meetings they were given oral and written information about the project and given the opportunity to ask questions. All agreed to assist us in recruiting informants.

I was responsible for organizing and conducting the interviews at one university hospital (see Hospital #5 in Table 1). I began by reaching out to the persons that had participated in the meetings via e-mail. All were positive, agreed to be interviewed themselves, and provided me with the names and contact information of other potential informants in their departments. All the interviews with GPs were organized by the project leader and carried out by multiple researchers.

Conducting the Interviews

Semistructured interviews were carried out from May 2018 to January 2020. The research team conducted four group interviews and one individual interview with GPs, organized in relation to a teaching seminar for GPs from all over Norway. Another 57 individual interviews were conducted with specialist physicians and other hospital staff and three interviews were conducted with two participants simultaneously. I conducted three small group interviews (no more than three informants in one group), one dyadic interview, and 21 individual interviews alone or with a research team member. Two group interviews, two dyadic interviews, and 36 individual interviews were conducted by other research team members. All the interviews were recorded, transcribed verbatim and anonymized, and made available to all research team members.

The aim of interviews in institutional ethnography is to obtain detailed accounts of the informants' experiences and activities, as well as how they interact with others and how these actions are coordinated through textually mediated relations. Thus, the interview questions must be formulated in a way that captures what people do and how they think about what they do (DeVault & McCoy, 2006; Nilsen, 2017b). The commitment to explicating action and the textual interconnectedness of different activities is what sets institutional ethnographic interviews apart from other types of qualitative traditions. For

example, the phenomenological tradition where the main focus is on exploring people's inner lifeworld (Nilsen, 2017a).

In an article about the use of interviews in institutional ethnography (DeVault & McCoy, 2006), the authors recommend an open, conversation-based interview form that allows for new questions and topics to emerge as the interview process unfolds. However, for this study, all the researchers interviewing healthcare professionals used the same semistructured interview guide (appendix #1). The interview guide was structured around topics we wanted to discuss, followed by open-ended questions (Kvale & Brinkmann, 2009). This means that although all the interviews contained a set of predefined questions, there was also room to ask spontaneous follow-up questions during the interviews and as the process progressed.

Importantly, the interview guide was composed by the project group before I decided to ground my study in institutional ethnography. We had also started to interview informants, so I was already committed to following the protocol designed for the main project. Before making a final decision about using institutional ethnography I assessed the questions in the interview guide. The questions revolved around the informants' perceptions, experiences and work with the CPPs. Questions also covered how and with whom they interact and communicate, including communication with patients, as well as on prerequisites, challenges, and consequences of CPPs in their daily practice. As such, I deemed the interview guide to be fairly consistent with the aim to gain access to informants' work knowledge and practice (Smith, 2005)

All the interviews, except for a few phone interviews, were conducted in person by one or two researchers. I participated exclusively in face-to-face interviews. Below, I describe and reflect on my experiences with the interviews I organized and led at Hospital #5, and the three group interviews I participated in with the GPs. At Hospital 5, I conducted eight interviews alone and ten together with another researcher. One interview at this hospital was conducted solely by another researcher. The interviews lasted between 30 and 90 minutes.

The interviews with hospital staff were conducted in their office or a meeting room organized by the informants. Most informants had received written information about the project prior to the interviews (appendix #2). However, as some informants were recruited and interviewed on the same day, they received the information letter in the interview setting. I/we started all the interviews by providing a short description of the project, consistent with the information letter. This included how we wanted to learn about their experiences with cancer diagnoses and treatment and the CPPs, and that the questions would focus on three main topics: (a) patient satisfaction and participation; (b) interaction between the different healthcare personnel involved in the CPPs; and (c) management and organization, including distribution of tasks pertaining to cancer diagnosis and treatment in hospitals. I emphasized that participation was voluntary, anonymous and confidential. I also reminded them that they could withdraw from the project without explanation at any time. All the participants agreed to the use of an audio recording device and signed a consent form (appendix #2).

I/we strived to establish a good connection with the informant(s), and create a comfortable and confidential atmosphere (Rapley, 2004). The interviews began with a few “warm-up” questions about the informants’ background and their work practice (their job position, work experience, the purpose of the CPPs, and work tasks in relation to cancer diagnostics and CPPs).

As the interviews progressed, I kept in mind that it is particularly challenging to gain detailed descriptions of professionals’ work processes (Nilsen, 2021). Professionals often use a language that is “filled with words concepts, phrases and abbreviations that give some kind of meaning within a specific professional context, while for an outsider they may appear theoretical and abstract” (Nilsen, 2021, p. 359). Professional concepts and discourses conceal the experiences and work practices that professionals carry out in their name, so to speak. To move the accounts beyond the professional language, I/we would consistently ask questions such as, “What does that entail?” or “How do you do that?” during the interviews. I/we would also explain to the informants that we might ask questions that may appear silly because we needed to ensure that we understood them

correctly, and it was important that we, the researchers, did not fill in the gaps with our presumptions (Campbell & Gregor, 2004).

Since texts are at the heart of institutional ethnography, it is important to hone in on “texts and text-based knowledge forms in operation” (DeVault & McCoy, 2006, p. 33) during the interviews. A text can be “any kind of document, on paper, on computer screens, or in computer files; it can also be a drawing, a photograph, a printed instrument reading, a video, or a sound recording” (p. 34). Predominantly, this study revolved around the CPPs, which is a standardized text that is activated by professionals working in different institutional sites, both in primary care and different hospital departments, across the country.

However, I also tried to be attentive to other textual clues in the informants’ descriptions. DeVault and McCoy (2006) highlight that texts appear with varying degrees of visibility in the informants’ descriptions. This was also my experience. Sometimes informants talked about specific documents, such as cancer brochures, patient journals, and clinical practice guidelines. Other times, I had to ask more probing questions to find out what text informed the work practice they talked about. One example of a more implicit textual clue was when hospital staff referred to “a different deadline,” than the CPPs. All the informants that, in one way or another, mentioned this deadline seemed to take it for granted that I knew what they were talking about (I did not). When I asked them to clarify what is this deadline and where does it come from, I learned that they would alternate between the CPP deadlines and another priority-setting guideline with defined deadlines for treatment of different conditions. Also, they informed me deadlines set by this policy carried more weight than the CPP deadlines.

All interviews involving two or three informants, were conducted in collaboration with a co-researcher. As previously mentioned, interviews with several informants provide a different, less predictable social context than individual interviews (Wilkinson, 1998). A central concern raised in the literature (which also applies to all forms of interviewing) pertains to the characteristics of the data—or what extent the data can be considered

naturalistic—given that the information is produced as part of a group dynamic. Do the data reflect the informants’ own experiences and perspectives (Halkier, 2017)? From my viewpoint, the informants spoke openly and honestly, considering that all shared information and voiced agreements as well as disagreements with each other. An interesting aspect of the group interviews is that the informants assisted the research process by asking each other probing questions and discussing and clarifying their viewpoints using concrete examples from their own work practice (Wilkinson, 1998). Simultaneously, I recognize that the information is filtered and emerged as part of the unique group dynamic of each interview, which, as noted by Wilkinson (1998), is a different context than the informants’ daily work context. Also, this applies to the individual interviews as well.

Data Processing and Analysis

With 72 individual and group interviews, I had access to an extensive amount of interview data. All the individual and group interviews were recorded on audio tape and transcribed verbatim in their entirety. I transcribed 31 of the interviews with physicians and other healthcare professionals, while a research assistant transcribed the rest. It can be difficult to capture the emotional and social expressions that are present in the audio recordings in the transcriptions, but I tried to incorporate such aspects by marking pauses, hmms, laughter, sighing, et cetera, in the transcripts (Kvale & Brinkmann, 2009).

As Kvale and Brinkmann (2009) remark, transcribing interviews can provide useful learning opportunities. For example, I noticed several missed opportunities to ask probing questions to access more detailed work descriptions, both in the interviews I participated in and in the interviews done by other researchers. Especially, it made me more aware of the importance of tolerating silence without quickly jumping to another topic. Interviewing and transcription were carried out in an overlapping process, and I noticed that my interview style evolved. As I gained more experience, I became increasingly more confident in my role as an interviewer, which likely influenced the interaction with informants.

Since the data collection was carried out over 20-months, I engaged with data collection and analysis in an overlapping process. All the hospital interviews were conducted prior to the interviews with the GPs. This means that the analytical process began with the experiences of hospital staff. In the initial stages of analysis, I organized the hospital interviews according to the professional groups. I read carefully through all the interviews, beginning with the different specialist physicians followed by the other professional groups, such as coordinators, nurses, and administrative staff. In a sense, the interviews with specialist physicians could be considered, what in institutional ethnography is called, “entry-level informants” (Campbell & Gregor, 2004, p. 60).

However, I would like to point out that analysis in qualitative research (even with guiding principles) is far from a straightforward procedure, rather, it is a time-consuming and, at times, messy undertaking (Roller, 2009-2022; Tanggaard, 2013). Upon working with the hospital transcripts more systematically, I had both conducted and transcribed interviews with informants representing all the professional groups included in the study. GPs were included as standpoint informants at a later point in the study. I chose to include them as standpoint informants mainly because I consider them part of the physician group and because GPs have such an important role in CPPs.

While carefully reading the empirical material, I highlighted words, sentences, and paragraphs that stood out as interesting or “puzzling” (Smith, 1987, p. 91). Guided by the concept of problematic, I searched for disjunctures or tensions in the interviews with the specialist physicians. At different times throughout the analytical process, I discovered multiple tensions that pointed me in the direction of three key problematics located in physicians’ descriptions of their referral, diagnostic, and communication work. This means that physicians’ engagement with CPPs, in relation to these three aspects of their work with cancer patients, became the foci for further analytical exploration. The problematics along with the accompanying analyses are presented separately in the three journal articles.

Once I had identified an aspect of physicians’ work for further analysis, I followed the analytical strategy outlined by DeVault and McCoy (2006) and created folders to organize

the material—one for referral work, another for diagnostic work, and a third for communication work. This helped me read the interviews more systematically. As I read all the interviews, I gathered all the accounts that somehow dealt with the particular aspects of physicians work under examination in files, one for each occupational group (one for physicians, one for nurses, et cetera). Furthermore, I organized the selected data material in a way that resembled the “indexing for a book” (p. 39) by identifying related topics and work processes (in a generous sense of work; Rankin, 2017b). For example, in analyzing the accounts related to diagnostic work, I noticed that many informants reported an experience of time pressure. I made a heading entitled “work associated with time pressure,” and gathered all the relevant accounts under that heading, which I then sub-indexed using empirical key words or sentences. Indexing was done across professional groups.

A central element of indexing is that it “must be oriented to the materiality of the data” (Rankin, 2017b, p. 6), that is textually mediated perceptions, experiences, and work practices. Thus, the analytical process proceeded by searching for descriptions of the work that is being done that contained traces of ruling relations and discourses. This also involved looking for what Rankin (2017b) refers to as small problematics, which entails noticing “when the knowledge generated in the daily doing of work is subordinated by, or in tension with, other (abstract) knowledge that is used or supposed to be used to decide and to act” (p. 7). These small problematics were used to write accounts that focused on making visible how physicians’ lived experiences take shape within translocal relations (DeVault & McCoy, 2006; Rankin, 2017b).

In Article IV of this thesis, I have detailed the analytical process. Let me reiterate that qualitative analysis is a complex and enduring undertaking. That is, although I have outlined a somewhat stepwise analytical process, the work of grouping the data, indexing, and searching for small problematics was done in an overlapping process over 2-3 years. Also, an important aspect of the analytical process has been alternating between analysis, writing accounts, reading literature, and discussing the analytical discoveries with my

supervisors and other researchers at research seminars and meetings with the overarching project's research group.

Quality of Study

Solbrække and Løken (2015) point out that quality of research is a comprehensive and complex topic that clusters around two essential questions: What does scientific quality mean? And, how to promote it? In line with Heale and Twycross (2015), I understand quality to concern the *rigor* of the study, thus it is not limited to an assessment of the findings. In short, rigor refers to precision and concerns the researcher's effort to raise the quality of the study throughout the research process, including "the strength of the research design and the appropriateness of the method to answer the [research] questions" (Cypress, 2017, p. 254).

It is well known that the criteria for quality in qualitative research is a controversial topic. According to Hammersley (2007), critics argue that the lack of clear criteria for quality assessment means that qualitative research is of "uncertain quality" (p. 287). Hammersley (2007) explains that criticisms of qualitative research are informed by two main assumptions. The first compares qualitative research to quantitative research and assumes that quantitative methods have clearly defined quality criteria and thus is more scientific. Quality in quantitative studies is assessed according to their *validity*, which refers to how accurately the research method examines what it intended to examine, and *reliability*, which refers to the reproducibility of the findings using the same methods under similar circumstances at other times (Hammersley, 1987). The second assumption is that clearly defined criteria are fundamental and that researchers who do not adhere to a set of guidelines produce poor-quality research. Another related argument is that, without criteria, the readers/users of the research cannot judge its quality.

Scholars disagree about the necessity of clearly defined quality criteria, but many have tried to establish concepts and checklists to help assess the quality of qualitative studies (Hammersley, 2007; Thornberg & Fejes, 2009). Hammersley (2007) remarks that standardized checklists should be treated with caution, as they undermine the diverse nature

of qualitative research. The author explains that assessing quality is a complex process whereby criteria “will be applied selectively, depending upon the nature of the knowledge claims and research involved” (p. 289). Quality assessments must be context-sensitive and take into consideration the study’s research questions and theoretical and methodological frameworks

As recommended by Morse et al. (2002), I engaged with different strategies to ensure quality throughout the research process, not just “at the end of the study” (p. 14). Below I discuss the strategies that were employed for ensuring quality in this study in light of the concepts of *credibility*, *consistency*, and *generalizability/transferability*. I also expand upon the limitations of the study, and the ethical considerations informing the research process.

Credibility and Consistency

Credibility concerns the trustworthiness of the research findings and how the findings reflect the empirical reality in question. Credibility depends upon the accuracy of both the information provided by the informants, and the researcher’s representation and interpretation of this information (Guba, 1981; Merriam, 2009; Noble & Smith, 2015). As Merriam (2009) notes, our understanding of “the meaning of reality” determines how we understand credibility in research. Are the researchers investigating what they believe they are investigating? Credibility must be assessed in the context of the study’s ontological assumptions.

Several strategies were incorporated to enhance the study’s credibility. *Triangulation* was carried out to obtain multiple perspectives from informants and investigators to “cross-check the data and interpretations” (Guba, 1981, p. 85). Interview data were collected from physicians and other healthcare personnel working with different phases of CPPs across locations in both primary- and specialist cancer care. This ensured that the findings were interpreted considering a diverse range of experiences and perspectives. Data were collected by multiple investigators, and interpretations of data were cross-checked with the research group regularly. Raw data, in the form of verbatim quotes and longer excerpts

from the interviews, were presented with the findings to illustrate the basis for the analytical interpretations (Guba, 1981; Hammarberg et al., 2016; Merriam, 2009).

Another strategy is often referred to as *prolonged or adequate engagement in data collection* (Merriam, 2009). There are no definitive rules for how many interviews are necessary to develop an adequate understanding of the phenomenon under scrutiny. A general guideline is that data collection should continue until you reach saturation, in other words, until you “begin to see or hear the same things over and over again, and no new information surfaces as you collect more data” (p. 219). The data collection for this thesis spanned almost 2 years and resulted in 72 interviews, which, arguably, is a decent sample for a qualitative interview study (Guest et al., 2006). The later interviews did not reveal any new topics, perceptions, or experiences. However, I will refrain from making conclusive statements about saturation, as cancer care is comprised of such a diverse and complex set of work practices. In line with Fusch and Ness (2015), I understand saturation to be more about depth than numbers. The data material is extensive and provides insight into a diverse range of perceptions, experiences, and practical work in the context of the CPPs. Taken together, the data collection and analysis were carried out in an overlapping process over 2-3 years, which allowed me to stay close to the data, reflecting and adjusting my understanding, over a prolonged period.

I applied the strategy of *peer debriefing* (Guba, 1981) by regularly exposing my research to the wider community of researchers. This included the supervision of experienced faculty members, participation in both national and international seminars and discussion groups, as well as peer review of both the thesis articles and the extended abstract. This provided me with constructive feedback that helped me to improve my understanding and adjust my approach across the different stages of researching and writing.

Lastly, researchers must engage in a process of *reflexivity*. Reflexivity means to develop an awareness of—and make transparent—how researcher positioning, subjective assumptions, and biases may have informed every stage of the research process and the findings. As the researcher is the “primary instrument of data collection and analysis in qualitative research”

(Merriam, 2009, p. 214), reflexivity is part of the process of establishing consistency. I will also address the role of the researcher in the next section about the potential for generalizability/transferability of the study findings.

Consistency concerns the trustworthiness of the methodological procedures and depends upon the researcher's articulation of a "decision trail" (Noble & Smith, 2015, p. 34). In other words, a clear and transparent demonstration of how the research process was carried out, from beginning to end. Consistency enhances credibility by making visible the coherence between the investigative approach, collected data, and findings (Morse, 2015). A study can be deemed trustworthy if the findings are consistent with the research questions, collected data, and interpretative framework (Merriam, 2009).

I have tried to enhance consistency by being as transparent as possible about the entire research process underpinning this thesis—which, as previously described, was guided by institutional ethnography. As Bisailon (2012) remarks:

[The criteria for rigor are not] explicitly addressed in the institutional ethnographic literature [but]

an institutional ethnography is rigorous (and successful) when the researcher clearly and convincingly shows *how* things are organized to happen in the material circumstances of people's day-to-day lives; where an explication of the ruling relations that shape or coordinate people's circumstances are produced. (p. 111, emphasis in original)

My use of institutional ethnography was shaped by the circumstances and boundaries of my project. I did not take up the full procedure but used it partly and in a modified way. This has been a source of concern with regards to quality assessment. Paradoxically, the literature conveys mixed signals about whether it is appropriate to use institutional ethnography in diverse and creative ways. Dorothy Smith (2006), the pioneer of institutional ethnography, explicitly states that institutional ethnography is not a dogmatic method of inquiry. Yet, as noted by Mathiesen and Volckmar-Eeg (2022), much literature on institutional ethnography promotes a formalistic and recipe-based understanding, which

implies that there is a right, and a wrong, way to do institutional ethnography (See e.g., Rankin, 2017a, 2017b).

I empathize with Mathiesen and Volckmar-Eeg (2022) who found that the experience of institutional ethnography as a closed tradition with strict boundaries was difficult to deal with. That is, I have also spent much time contemplating (and doubting) whether my research falls within or outside the confines of institutional ethnography. It was, to be honest, quite daunting to include the words “institutional ethnography” in the subtitle of my dissertation. Lund and Nilsen (2020) confront these predicaments in their anthology of the use of institutional ethnography in the Nordic region. The anthology illustrates how researchers have utilized different aspects of institutional ethnography in their research projects. There is even a section dedicated to research that has used it in conjunction with other theoretical frameworks—which is a major point of contention considering that the rejection of abstract theory is an integral part of institutional ethnography.

Accordingly, the body of diverse—or, as some may argue, deviant—institutional ethnographic literature is growing. I have, therefore, as recommended by Mathiesen and Volckmar-Eeg (2022), chosen not to downplay the significance of institutional ethnography for my study, nor that my use of institutional ethnography reflects a process of “learning by doing” (Reese, 2011). Institutional ethnography constitutes the main theoretical and methodological framework in the thesis articles. The theoretical perspectives presented in Part Two in the extended abstract is used to discuss and place the results within a wider research field and theoretical landscape. I have chosen to engage with literature and methods of data collection and analysis that I consider to be relevant for the thesis topic and research questions. Furthermore, I have maintained a “decision trail” (Noble & Smith, 2015) by detailing the theoretical and methodological perspectives and how the research and analysis were carried out, including how and where my study departs from the “classical” methodological tenets of institutional ethnography. I also elaborate on the methodological choices and my use of institutional ethnography in Article IV of this thesis.

Generalizability and Transferability

An assessment of generalizability and/or transferability is essential to all research and concerns the question of whether the findings apply to other people and settings besides those who directly participated in the study (Hellström, 2008; Payne & Williams, 2005). However, generalization and transferability are distinct concepts; transferability is used as a reformulation of the quantitative notion of generalizability to fit the qualitative research context (Merriam, 2009).

It is heavily debated whether it is appropriate to assess the findings of qualitative studies using the term generalization (Mayring, 2007). In quantitative research, generalization refers to how significant the findings from a (representative) sample are for an entire population, regardless of context (Payne & Williams, 2005). In contrast, transferability is a context-sensitive term and refers to how relevant the findings in a specific context are to another, very similar, context (Guba, 1981). As such, these concepts serve different purposes, which are rooted in the different ontological and epistemological assumptions underpinning the quantitative and qualitative research paradigms. Quantitative research is based on positivist assumptions of a determinate social reality (out there) and that it is possible to uncover universal social mechanisms (causal relationships) and make objective knowledge claims. Qualitative research, on the other hand, is (mostly but not always) based on interpretive and constructivist assumptions that reject the existence of a law based social universe; social reality is perceived as inherently indeterminate and knowledge is perceived as constructed and context dependent (Hellström, 2008).

A related argument for using the term transferability instead of generalization concerns the sample size in qualitative studies. Since qualitative studies are often based on relatively small sample sizes (i.e., they are not representative) many contend that it is not possible to make generalized knowledge claims (Kvale & Brinkmann, 2009). Using the notion of transferability, I aimed to provide rich descriptions so that the reader/recipient of the information can determine how transferable and applicable the knowledge is to a new setting (Hellström, 2008; Thornberg & Fejes, 2009).

However, Smith (2005, 2008b) uses the term *generalization* in her writings on institutional ethnography, arguing that the approach aims to produce a different type of knowledge than other qualitative methodologies. Thus, it circumvents many of the problems associated with abstract generalizations. Institutional ethnographic research uses people's subjective experiences as a lens to discover how generalized and standardized social processes coordinate people's activities. (Widerberg, 2015). As Smith (2008b) puts it:

Institutional ethnographies do not just produce case studies. As institutional ethnographies reach into the translocal ruling relations, they engage with and explicate relations that are generalized and that generalize, create commensurabilities, and standardize. Generalization appears in what is described and analyzed. It is there in the ethnographer's data. Each study creates a window from a different angle into the generalizing social relations that rule our societies. Even though each may address a different institutional function, it contributes to our knowledge of how the ruling relations work. (p. 435)

As noted, assumptions about knowledge (epistemology) rely upon assumptions about reality (ontology; Walby, 2007). Interestingly, Smith (2005) boldly states that the ontology of institutional ethnography makes epistemological questions "largely irrelevant," because the "findings are in and of the same world that it investigates" (p. 52). By treating the informants as "expert knowers" of their work practices and by searching for generalized processes, evidenced by textual clues in informants' accounts, the findings are of a generic social nature. Social reality, it is presumed, is always coming into being, yet transcends the here and now through the textual interconnectedness of human activity. This is essentially a socially constructed reality.

The epistemic assumption that follows is, as Rankin (2017a) remarks, that "all knowledge is socially organized; knowledge is socially constructed and carries particular interests that are embedded in its construction" (p. 2). Thus, there is no such thing as neutral knowledge. The informants are situated in a distinct social environment (e.g., a hospital ward, classroom, kindergarten, or bus). The aim is to gain knowledge about the way things look

from their particular viewpoint within that context, and from that viewpoint, to make visible how translocal (discursive and organizational processes) social relations operate across different local perspectives (Nilsen, 2017a).

Accordingly, my focus has been on the social processes at play in physicians' work with cancer diagnoses and CPPs. I have tried to make visible how these are ongoing processes that are part of a larger discursive organizational context. Although I recognize that institutional ethnography produces knowledge about the ongoing generalizing processes of social reality, I agree with Nilsen (2017a) that this is not a total generalization in the positivist sense of the term, but is more in line with what Payne and Williams (2005) refer to as *moderate generalization*. By using a moderate form of generalization, the researcher may identify certain aspects of the studied phenomenon as instances of something more general that extends beyond the case—which, in this thesis, is the particular ruling documents and discourses that coordinate the informants' work with cancer diagnoses and treatment decisions. Moderate generalization also considers the contextual and temporal constraints of the findings.

A related epistemic aspect pertains to the role of the researcher and the researcher's awareness and transparency of the extent to which their preconceived notions, attitudes, and feelings intersect with, and shape, the process of data collection and analysis and the findings (Sciarra, 1999). In accordance with Walby (2007), I disagree with the argument set forth by Widerberg (2015) that institutional ethnography's rejection of theory and focus on translocal social relations enables the researcher to bypass predicaments tied to the subjective nature of the dialogue between the researcher(s) and the informants (interviews) and the dialogue between the researcher and the transcribed interviews (data analysis).

Since I had limited knowledge of both CPPs and the organization of cancer care prior to the investigation and I have never worked in the somatic healthcare services, I consider my position to be an outsider in relation to the informants (Corbin Dwyer & Buckle, 2009). There are both advantages and disadvantages to outsider research. For example, it can be more challenging to gain the trust and acceptance of the informants, so they may not be as

open and forthcoming as if the researcher were a member of the same social group. However, the distance between the researcher and the informants could also be fruitful as the informants are the experts and are treated as such. For example, an outsider may find it easier to ask naïve questions that could produce more detailed information (Chhabra, 2020; Corbin Dwyer & Buckle, 2009). As recommended by Widerberg (2015), I strived, to the best of my ability, to set aside preconceived notions and maintain an open, curious, and questioning attitude throughout the entire process of data collection and analysis.

Nonetheless, I acknowledge that the interviews were produced in a hermeneutic exchange (i.e., the interpretation of talk and behavior) between the researcher(s) and the informants (Walby, 2007). I understand the particular textual clues that were identified and made relevant during the interviews and in the data analysis to be a result of my interpretation. The three problematics explored in the thesis journal articles were analyzed in dialogue with relevant literature, which also informed my interpretation. Although I believe it is likely that other researchers would have identified the same forms of social organization as I did, it is also possible that they could have focused on other forms of social organization and thus made different analytical choices. For example, they could have posed different follow-up questions, followed different textual clues, and found different puzzles, which would have illuminated different aspects of physicians' work with cancer diagnoses and patient care, in the context of CPPs.

However, although I do not believe that this multitude of possible interpretations undermines the findings of this study (Merriam, 2009), I also deem it important to acknowledge that the findings illustrate certain aspects of how the ruling apparatus coordinate physicians' daily work practice. The generalizability of the results lies in the knowledge of how individuals' experiences and activities are tangled up in social processes that extend beyond their immediate surroundings (Nilsen, 2017a). Physicians work with the CPPs depend on their "interpretative practices" (Smith, 1990b, p. 121) of the CPP guidelines in conjunction with other, both formal and informal, rules and regulations that govern practice at any given moment in time. Furthermore, the concept of transferability is also relevant as the study is transferable to the extent other healthcare professionals

(perhaps even patients) and researchers consider the findings applicable to their own experiences. Importantly, the textual landscape in cancer care is continuously changing, revisions to the CPP policy as well as the development of new policies and standards will eventually create new conditions for practice (Guba, 1981; Hammarberg et al., 2016).

Ethical Considerations

Adherence to ethical principles is an important quality aspect of all research, which aims to ensure scientific integrity, and appropriate treatment of both informants and the collected information (Guillemin & Gillam, 2004). In line with recommendations from The Norwegian National Research Ethics Committees (2019), I ensured that the research process was carried out in accordance with the principles of informed consent, confidentiality, respect, and responsible storage of data. Ethical approval for this study was obtained as part of the overarching project from the Norwegian Center for Research Data (project number 58724; appendix 3).

As described, all informants received both written and oral information about the project and signed a consent form (appendix 2). All personal and contextual data that could potentially identify the informants were anonymized in transcriptions of the tape recordings. This involved replacing all mentions of names with XX, including names of people, geographical references, and the names of the hospitals or other institutions. As Norway is a small country with a limited medical community, to further ensure anonymity, I refrained from describing how many informants participated from each medical specialty. The translation from Norwegian audio recordings and transcriptions to English quotations in the journal articles further enhances anonymity—the exception is Article IV, which is in Norwegian but contains few verbatim quotations. The audiotaped interviews were immediately transferred to a SharePoint Cloud Storage for Research (administered by SINTEF) and deleted from the audio recorder. The SharePoint stored audio recordings were deleted by the end of the overarching project on September 30, 2021.

Strengths and Limitations

This study set out to examine how the introduction of a cancer care reform (CPPs) is taken up in practice from the perspectives and experiences of physicians across primary and specialist healthcare services. By using institutional ethnography, one of the strengths of this study is that it highlights various types of work, including work that is often concealed and undisputed, yet is a central part of physicians' daily activities. Another strength is that the study illuminates how this work is coordinated by their participation in different ruling relations, which often collide in practice. As such, this study considers how the work related to CPPs does not happen in a vacuum, detached from other ruling mechanisms—but rather how it connects to a larger discursive context.

However, there are limitations to the findings in this study. First, I was not able to conduct observational studies. In the original research design, we had planned to observe MDT meetings but this was rejected by the Regional Committees for Medical and Health Research Ethics (REK) due to patient confidentiality concerns (Melby et al., 2021) The data material consists exclusively of in-depth interviews, and I did not have direct observations of interdisciplinary work and diagnostic assessments. However, although many institutional ethnographers' triangulate methods, Smith (2005) emphasizes that interviews are essential: We need to hear people speak about what they do to access their subjectivity (experience, thoughts, and feelings) and for understanding their work.

Another limitation is connected to the sample and uneven representation of the different professions and professional specialties. There is more data from specialties than GPs, as it was harder to recruit GPs than hospital physicians. The 12 GPs in the study had different experiential backgrounds: some were at the beginning of their medical career, whereas others were seasoned medical professionals. This is usually considered a sufficient number of interviews for a qualitative study (Guest et al., 2006). However, although the GPs' diverse experiential backgrounds make it possible to assume that a wide range of experiences with CPPs has been covered, additional interviews with GPs could have strengthened and possibly nuanced the findings (Melby et al., 2021).

As Melby et al. (2021) point out, the scope of the study, covering only four of the existing 28 CPPs, is also a potential limitation. The study covers three of the most common types of cancer (breast, prostate, and lung cancer), which gave access to informants with substantial experience with the CPPs for these patient groups. Malignant melanoma is less prevalent but was chosen because less effort had been directed toward achieving an integrated organization of this diagnosis prior to the introduction of the CPPs. Thus, this CPP offered an opportunity to gain insight into a pathway in which the policy (hypothetically) has a greater organizing potential. Physicians and healthcare professional who work with other CPPs may hold different experiences. However, since the focus of this study is on overarching experiences with the organization of cancer diagnosis and patient care in the context of CPPs, the findings are presumably relevant for professionals working with other cancer diagnoses.

PART FIVE

Presentation of the Articles

In this chapter, I present a summary the four articles contained in this thesis. The content of the journal articles will be connected and discussed in relation to each other and the research question in Part Six.

Article I

CPP or Not, That Is the Question: Physicians' Work With Activating CPPs. *Qualitative Health Research*, 31(11), 2084-2096.

<https://doi.org/10.1177/10497323211020708>

In the first article, I examine the starting point of CPPs, namely the process of making and interpreting referrals of potential cancer patients to diagnostic assessments. The findings are based on qualitative interviews with 37 physicians, 12 GPs, and 25 specialists in Norway. The analysis explicates the social organization of physicians' referral work and demonstrates how the starting point of CPPs cuts across primary care and various hospital departments.

Patients qualify for a CPP referral when there is a reasonable suspicion of cancer. In official terms, this means a suspicion that can be documented in accordance with the Norwegian Directorate of Health's diagnostic manuals for CPPs (Norwegian Directorate of Health, 2018b). However, as many of the symptoms associated with cancer overlap with other, more benign conditions, physicians express that it is difficult to know when it is appropriate to initiate CPPs. The first part of the analysis demonstrates how GPs navigate various dilemmas related to establishing reasonable suspicion of cancer. In this work, GPs participate in different, sometimes contradictory, institutional discourses, which create variation in referral practice, whereby some patients wait longer or have been through more diagnostic tests than others before being included in a CPP.

The second part of the analysis demonstrates how the specialist physicians interpret and prioritize patients based on the referral document. The referrals from GPs are described by the specialists as good, bad, or insufficient. The extent to which specialist physicians require that the referral fulfills the CPP guidelines for inclusion varies. The CPPs enable patients to bypass waiting lines which are organized according to another set of priority guidelines. The analysis illustrates how specialists in different departments juggle different priority guidelines with clinical practice guidelines when interpreting the referral document.

Article II

Between diagnostic precision and rapid decision-making: Using institutional ethnography to explore diagnostic work in the context of Cancer Patient Pathways in Norway. *Sociology of Health & Illness*, 43(2), 476-492. <https://doi.org/10.1111/1467-9566.13235>

The second article is co-authored with Erna Håland. In this article, we explore a set of tensions that arise in specialist physicians' work with cancer diagnosis. The article is based on interviews with 27 physicians of different medical specialties (clinicians, radiologists, nuclear radiologists, surgeons, and pathologists) who partake in the diagnostic process. We draw attention to two conflicting organizational processes in cancer care: increased complexity and demand for efficiency in diagnostic assessments.

In line with the development of new medical knowledge and technology, clinical practice guidelines for cancer diagnoses are regularly revised to ensure greater diagnostic precision. This means that physicians must, to an increasing extent, identify genetic markers and subgroups of disease categories and offer personalized treatment modalities. At the same time, the CPP policy has introduced a shorter time frame to execute this work. Informants explain that while one set of guidelines generates more extensive work processes, the other set demands that this work is done within a reduced timeframe. The analysis illustrates how physicians negotiate between compliance with the CPP time frames and the demand of diagnostic precision within clinical practice guidelines.

Article III

“Don’t freak out if you get a letter saying cancer patient pathways!”:

Communication work in cancer care. Submitted for publication in *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*.

The third article focuses on patient communication in the context of the CPPs. The article is based on interviews with 72 healthcare professionals (12, GPs, 27 specialist physicians, 14 cancer pathway coordinators, 11 nurses, and 8 administrative staff) and illustrates the interdisciplinary organization of patient communication during the process of diagnosing cancer. Emphasis is placed on the way physicians and other healthcare personnel balance different forms of knowledge (medical, psychosocial and political) in their communication with patients. Four aspects of communication work are explored: communicating continuity, communicating (or dodging) the dreaded C-word, communicating patient participation, and communicating the relevance of time.

Article IV

Å bruke institusjonell etnografi til å utforske hvordan en helsetjenestereform møter praksis [Using institutional ethnography to explore how a healthcare reform is taken up in practice]. Accepted for publication in A.C. Nilsen & M-. L. Magnussen (Eds.), *Institusjonell etnografi i praksis*.

The fourth article is a chapter in a Norwegian anthology of institutional ethnography in practice. Here, I detail the context of my research and how I engaged with institutional ethnography as part of a larger project. As I collaborated with six other researchers who did not use institutional ethnography as a methodological framework, I had to adapt the use of institutional ethnography to my research context. This entails that the data material was collected both by myself and other researchers without institutional ethnography as a starting point. I highlight the experienced tension between the formalistic and dynamic promotion of institutional ethnography in the literature. I also provide an example of how the concepts of standpoint, problematic, ruling relations and work guided my analyses. The

article contributes to the ongoing debate about the diverse use of institutional ethnography in the Nordic region.

PART SIX

Summarizing Discussion

In this thesis, I set out to examine the following research question: *How do physicians engage with CPP guidelines in their daily work?* As institutional ethnography is the study's methodological framework, attention is placed on the social organization of the informants' experiences and activities. I developed the research question from a relational understanding between ruling documents and practice. This means that I view physicians as active participants in the institutional structures that govern their work practices. My analyses revolve around three distinct, empirically grounded, aspects of physicians' work with cancer diagnoses and patient treatment in relation to CPPs: the process of referral (Article I), diagnostic decision-making (Article II), and communication with patients (Article III). Jointly, the analyses illuminate the social organization of physicians' work across different phases of the CPP trajectory—from the initial suspicion in the GP's office to diagnosis and treatment decisions in the hospital. Each article examines a specific research question and therefore contributes in different ways to answering the overall question of how physicians engage with CPP guidelines in their daily work.

Next, I discuss and connect central elements of the findings across the three articles and consider how these, in light of previous research and relevant theories contribute to knowledge. I close the discussion by highlighting the implications of the study and provide suggestions for future research.

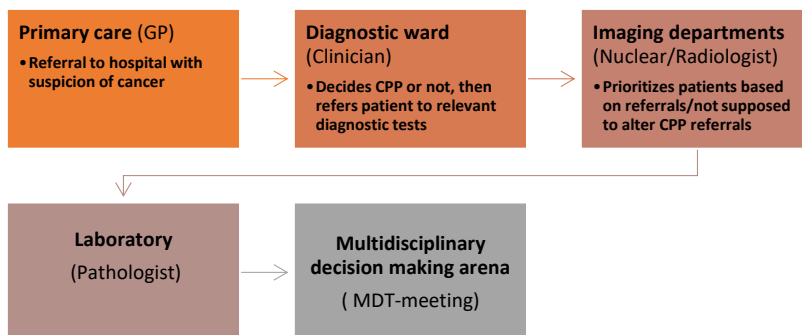
Coordinating Work Practices in Cancer Care

The CPP policy is part of a long-standing political strategy to improve cancer care in Norway. Specifically, it ties into the well-established ambition to make Norway a leading country in the delivery of good care pathways (Norwegian Directorate of Health, 2016c; Norwegian Ministry of Health and Care Services, 2013, 2018). This ambition evolved in response to the ongoing changes in disease conditions, medicine, and technology—namely the growing prevalence of chronic diseases. This trend, alongside the development of new

medical knowledge and technology for diagnosis and treatment, generates increased fragmentation of specialist healthcare services (Norwegian Ministry of Health and Care Services, 2009; Strauss et al., 1997). A major problem with fragmentation, Strauss et al. (1997) remark, is that it can lead to a sense of dehumanization for patients, as they are shuffled back and forth between machines and people “performing tasks on” them (p. 5). Moreover, a high probability exists that something can go wrong due in the logistics of scheduling. A lack of continuity between services could be an added stressor for patients in an already challenging situation.

Today’s health authorities seem to increasingly recognize the risks fragmentation poses for the quality of care. The introduction of care pathways, such as CPPs, is meant to counter the “untoward effects” (Strauss et al., 1997, p. 5) of fragmentation for patients by ensuring efficient and integrated diagnostic trajectories in cancer care (Norwegian Directorate of Health, 2016a). The work of achieving a cancer diagnosis (usually) involves professionals of different specialties across different locations—what Strauss et al. (1997) refer to as multiple work sites. A flow chart of the work sites involved in a CPP is depicted in Figure 2.

Figure 2: Work Sites Involved in a CPP



A central aim of the CPPs is to improve coordination and professional collaboration between these work sites to deliver fast, predictable, and holistic cancer care. It establishes compliance with time frames as a unifying principle between the professions. An important

discovery in this study is how different institutional discourses and guidelines collide in physicians' everyday practice. The analyses illustrate the complexity of achieving a cancer diagnosis across primary care and the different work sites of the hospitals. Informants' accounts of the work involved in detecting cancer challenge the official documents' theorizing of cancer diagnosis as a clear-cut and linear process that can or should be performed within relatively short time intervals. A key problem with cancer detection is that many types of cancer often present vague, and not necessarily concerning, symptoms. Another issue is that advancements in medicine are continuously moving towards more intricate diagnostic testing and decision-making procedures. As such, the introduction of CPPs, with their emphasis on time, creates a situation whereby the institutional discourse of efficiency comes into conflict with the institutional discourses of precision/personalized medicine and patient-centered care. This results in a set of tensions that coordinates physicians' work in different ways across the CPP trajectory; it is visible in the process of establishing reasonable suspicion of cancer, making a diagnosis, and in their communication with patients. Using institutional ethnography, I have shown how physicians' engagement with the CPPs involves a diversity of physical, mental, and emotional activities that are socially organized.

I have untangled how concerns about cancer are handled across primary and specialist healthcare services and the assessments physicians make to clarify and legitimize a concern for cancer. This is the work of transforming a concern into a reasonable suspicion that justifies the activation of the CPP policy. As Nilsen (2017) remarks, it is by examining people's experiences and actions one can discover how political principles are followed in practice. The initial diagnostic assessment of the patient, performed by the GP, involves obtaining evidence that legitimizes further medical assessment in the hospital. A significant aspect of this work involves translating patients and their bodies into text (referral document). The referral document must be written convincingly and contain the right evidence for the specialist recipient to take further action—otherwise, the patient will be denied specialist assessment. This highlights the power that lies in texts to make things happen (Smith, 1990b, 2005). A medical diagnosis is achieved when an empirical

observation, for example, a lump in a breast, is written down and “translated” into a medical diagnosis by employing discursive concepts that enable medical intervention. To move from concern to reasonable suspicion to medical diagnosis, physicians engage in a recurrent textualization of the patients. Ultimately, it is the text that justifies the choice of action.

An important aspect this study demonstrates how physicians’ work with cancer diagnoses and treatment is relational and socially organized. How physicians interpret, understand, and act in relation to a patient is woven into translocal relations of ruling. This happens in the direct interaction between physician and patient and in the interaction between physicians and various forms of texts (referral documents, medical journals, X-rays, lab reports, et cetera).

Integrating Guidelines into Professional Practice

Physicians’ professional practice is driven by the quest for medical certainty, namely the identification of diagnoses and appropriate treatment (Jutel, 2009; Pienaar & Petersen, 2021). The purpose of guidelines is to help eliminate uncertainty by promoting compliance with collectively recognized standards for best practice (Buetow, 2011). However, international literature consistently shows that the introduction of guidelines is, in and of itself, insufficient to change practice, and that physicians’ attitudes, knowledge and use of guidelines vary (Gabbay & May, 2004; Grol & Grimshaw, 2003; Timmermans, 2005; Woolf et al., 1999). Moreover, physicians are often portrayed as opposing guidelines because they represent a kind of “cookbook medicine” that undermines the importance of professional autonomy and discretion in clinical assessments (McDonald et al., 2005; Woolf, 1993).

Consistent with other studies on Scandinavian CPPs (Delilovic et al., 2019), the physicians in this study highlight that they consider the introduction of the CPPs to be positive. GPs express that the CPPs have increased a sense of safety along with a shared responsibility of patients; now they can trust that when they send a referral conveying a suspicion of cancer, it will be rapidly assessed by a specialist. Specialists express that the CPP policy has

initiated work processes that have helped to improve coordination and collaboration between different specialist services. In many respects, these findings reflect the political rhetoric that the introduction of CPPs is a good thing (Håland & Melby, 2017). Further, from an experiential point of view, the CPPs have supported changes to professional practice, at least in terms of organizational aspects (Melby & Håland, 2021).

This (seemingly) lack of resistance can be understood in light of the work context, purpose, and guideline implementation is carried out (Fischer et al., 2016; Flottorp & Aakhus, 2013). In the hospitals, the CPPs were introduced through a collective effort between different healthcare professionals, primarily driven by a cancer patient coordinator (nurse or secretary) and a leading physician. As noted by Håland and Melby (2017), the CPPs did not represent a radical break with existing work practices but entered into ongoing work processes directed at standardizing patient trajectories. Another important aspect, emphasized by the physicians in this study, is that the logic of efficiency underpinning the CPPs makes sense from a medical perspective: time is of the essence when it comes to detecting and treating cancer (Whitaker, 2020).

Although there is a general agreement that the CPP guidelines are beneficial and have improved care for patients, it can be challenging to incorporate them into practice. Physicians draw upon multiple sources of knowledge in their professional work with cancer diagnosis and treatment, whereby guidelines play a (more or less) significant role depending on the situation at hand. Primary and specialist healthcare provide different contexts for cancer care. The GP's job is to determine when it is appropriate to make a referral for diagnostic assessment by specialists, while the specialists job is to determine (or rule out) a cancer diagnosis (Norwegian Directorate of Health, 2016a). Accordingly, the findings of this study suggest that there is a difference between the way GPs and specialist physicians relate to—and actively use—guidelines in their daily work.

Within the group of GPs, different perceptions and the use of guidelines were evident. In line with the adult skill acquisition model developed by Dreyfus and Dreyfus (1980), novice GPs both embrace and use the CPP guidelines to a greater extent than more

experienced GPs. Experienced GPs echo the point made by Greenhalgh et al. (2014) that it is an insurmountable task to keep up with all the guidelines regulating medical practice. Also, the rule-based logic of guidelines is considered contradictory to the actualities that play out in clinical practice where decisions are formed based on an interplay among formal, informal and tacit knowledge (Dreyfus & Dreyfus, 1980; Schön, 1991). This includes the use of guidelines in combination with intuition, experience, knowledge of their patients' medical history, and the patient's preferences (depending on the extent these are articulated). Although specialists also mention that these are vital aspects of the decision-making process, they consistently emphasize that their work is principally rooted in the clinical practice guidelines of the cancer diagnosis in question. However, physicians activate different types of guidelines according to their place in the textual hierarchy as they align with the characteristics of each patient. This means, as emphasized by Smith (2005), that some texts have more power, authority and, influence than others.

Clinical practice guidelines, which aim to ensure that physicians practice EBM, are described by the physicians as more important to follow than standardized care pathways. However, as it is the CPP time frames that are monitored and measured (not the use of clinical practice guidelines), physicians increasingly experience tension between different bureaucratic standards. What happens in practice is that the thoroughness required to fulfill the diagnostic precision recommended by the clinical practice guidelines is being challenged by the narrow deadlines required to fulfill the goal of efficiency recommended by the CPPs—or vice versa. This manifests as problematic because compliance to timeframes becomes the foremost visible expression of care quality.

In addition to the clinical practice guidelines and the CPPs, physicians must manage a third set of guidelines: priority-setting guidelines. The priority-setting guidelines preceded the CPPs (introduced from 2008 to 2012) and are judicial guidelines by which the hospitals can be held legally accountable. The priority-setting guidelines express the last deadline for when medical help must start to ensure a safe patient trajectory. The start of medical help can mean both the start of diagnostic assessment and for treatment depending on the seriousness of the patient's condition, expected benefit of medical care, and the amount of

resources the expected care consumes (Norwegian Directorate of Health, 2019). Seemingly, these guidelines leave more room for prioritization based on the use of professional discretion and autonomy than the CPP guidelines, which group all potential cancer patients into the same urgent category. Thus, (in theory) CPP patients are automatically given precedence over other patients and considerations.

The picture that emerges from this study is one of work practices being reshaped as physicians negotiate between different guidelines that change the organizational context of their work in conflicting directions (Day & Day, 1977; Strauss, 1963, 1997). Physicians use their professional discretion and judgment to resolve managerial tensions by stressing the importance of one guideline over the other. These findings support the idea that professionals have the opportunity to resist, at least some aspects of, governmental infiltration (Noordegraaf, 2016), but that this resistance takes place within the governmental control system. In this context, “professional and organizational logics” are deeply “intertwined” (p. 787) and discretion appears to play a greater role in professional decision-making, than autonomy (Evetts, 2002). When physicians talk about the way they engage with the CPP guidelines in their work, their overall accounts reflect Evetts’ (2002) definition of professional discretion as a balancing act between a wide array of organizational factors in conjunction with the individual needs of patients:

Professional discretion enables workers to assess and evaluate cases and conditions, and to assert their professional judgement regarding advice, performance and treatment. To exercise discretion, however, requires the professional to make decisions and recommendations that take *all* factors and requirements into account. These factors and requirements will include organizational, economic, social, political and bureaucratic conditions and constraints. Thus, professional decisions will not be based solely on the needs of individual clients, but on clients’ needs in the wider corporate, organizational and economic context (p. 345, emphasis in original)

According to Evetts (2002), although external forms of regulation are part of the exercise of discretion, discretion is still essential to achieve individual adaptation of standardized services. However, it is relevant to question whether the increased emphasis on standardized procedures and governmental control are threatening to diminish both professional control and the opportunity to make individual adjustments. The CPP policy is a form of managerial control that aspires to safeguard both standardization and individual adaptation (Norwegian Directorate of Health, 2016a). Yet, it is the physicians' compliance to the standardization aspect that is being monitored; as such, it signals that achieving standardization is of greater importance than individual adaptation. Arguably, this places some restrictions on the physicians' use of professional discretion to make individual adjustments that deviate from the standardized principles.

Individualized Care in Standardized Patient Pathways

I discovered that physicians' engagement with the ruling ideals embedded in the CPPs creates a set of tensions in their work across the CPP trajectory—from the initial suspicion to diagnosis and treatment decisions. The health authorities' aim is that the introduction of standardized guidelines will contribute to a more precise and efficient administration of cancer care across the country. While the time intervals for physicians to complete various diagnostic work processes are shrinking, the amount of work physicians are expected to “do with, and for, patients” (Rankin, 2004, p. 224) is growing. In this thesis, I have brought attention to and argued that the demands for efficiency organize physicians' work in ways that challenge the exertion of their professional expertise/discretion to achieve individualized care.

As described in Part Two, individualized care is a multilayered concept that signals adjustments to healthcare to match the individual characteristics, needs, and preferences of each patient (Ansmann & Pfaff, 2018). Individualized care covers two distinct institutional discourses: (a) precision medicine, which is the identification of the most effective treatment for the patient's biological and molecular nature; and (b) patient-centered care, which is an approach that is sensitive to the whole patient, including the patient's

perspectives and psychological/emotional needs and wants (Ansmann & Pfaff, 2018; Davis et al., 2018; Diamandis et al., 2010; Faber et al., 2014).

Precision medicine is receiving increased scientific and political attention, and the idea of delivering tailored cancer medicine to each patient has become the prevailing vision for what cancer treatment should look like in the future (Collins & Varmus, 2015; Nilsen et al., 2022). Accordingly, Norwegian health authorities have made the development and implementation of precision medicine an important focus to achieve health policy goals such as strengthened quality, patient safety and good research. Precision medicine is still in an early phase but is rapidly advancing through scientific developments in molecular biology and technology (Norwegian Directorate of Health, 2016d).

I discovered that revisions of clinical practice guidelines to accommodate these developments generate more comprehensive diagnostic work processes and intricate logistics between different specialist work sites. Moreover, I found that physicians' engagement with the CPPs has changed the way they work to achieve precision-medicine. A troubling new practice connects to the discourse of excess testing (Brownlee et al., 2017; Schattner, 2009). Whereas before the CPP policy, physicians express that they would wait to see the results of the first round of diagnostic testing before deciding if more testing is necessary for a diagnosis; now, patients are being referred to multiple diagnostic tests at once to ensure that physicians have as much information about the patient as possible within the CPP deadline. In accordance with the literature (Hoffman & Kanzaria, 2014; Schattner, 2009), some physicians remark that this practice produces unfavorable consequences for both the healthcare system and the individual patient. Not only does it risk wasting already limited resources, but it also increases the logistical pressure on the various diagnostic modalities. While this creates longer waiting times for other (non-cancer) patients, potential cancer patients risk having to undergo unnecessary, physically and psychologically strenuous testing.

It is evident that the physicians strive to achieve both the requirement for precision and the requirement for efficiency (CPP time frames). However, despite the efforts to rapidly move

the patient through the required examinations, there is an element of uncertainty in cancer diagnostics, which sometimes comes into conflict with managerial deadlines. When uncertainty arises, physicians must negotiate between the logic of precision and the logic of efficiency. Typically, in this situation, the patient has been through the standard examination trajectory, but the physicians still experience some doubt as to whether they have enough information to establish the most accurate diagnosis. Do they order another diagnostic examination with all the additional work and waiting that entails? Or just take the chance and diagnose the patient based on the available information? Which form of ruling counts the most? Physicians underscore that, for now, they opt for precision over reaching time frames, but it is relevant to note that they associate the achievement of good CPP numbers with “being best in class.” This signals that physicians’ professionalism is being challenged by the CPP coding system.

The GPs grapple with a similar, precision-related dilemma in their work to establish reasonable suspicion of cancer. How much testing needs to be done? How much uncertainty is acceptable upon referral to CPPs? This aspect of GPs’ work is, at least partially, coordinated by a discursively mediated fear of cancer in society. Being assessed for—and getting—a cancer diagnosis is a frightening, serious and life-changing situation, both for the patient and their family and friends (National Cancer Institute, 2021). Cancer has received much public attention over the last decades, and although survival rates for cancer have increased (Norwegian Ministry of Health and Care Services, 2018), much of the cancer discourse in the media is shrouded in fear-inducing metaphors; cancer is often portrayed as a dangerous enemy that must be conquered in a battle between life and death (Clarke & Everest, 2006; Stibbe, 1997). The widespread fear of cancer in society (Vrinten et al., 2014) impacts the thinking and reasoning of both physicians and patients and has become part of clinical decision-making (Stibbe, 1997).

Accordingly, the GPs in this study describe that managing fear and uncertainty is a major part of their work with establishing a reasonable suspicion of cancer, thereby qualifying patients for CPP referrals. The GPs explain that they invest time and energy in distinguishing between what they describe as rational and irrational fears and between

concrete and more intangible symptoms. The findings suggest that GPs have different uncertainty tolerance and perceptions of when it is appropriate to initiate a CPP and, in line with Evetts (2002), that patients' needs and wishes are considered in a larger institutional and economic context.

Uncertainty is particularly demanding to manage within an institutional context that assigns conflicting responsibilities to GPs in terms of being both the patient's advocate and gatekeeper of the healthcare system. This is a matter of granting or denying patients access to care—and symptom interpretation. Since GPs are often the patient's first encounter with the healthcare system, they are an easy target for blame if they fail to make a necessary referral for specialist assessment based on vague symptoms. At the same time, they worry that if they make “baseless” referrals, they will lose respect in the medical community. Thus, central to GPs' engagement with the CPPs is an experience of having to safeguard their reputation and professional integrity where different institutional discourses shape what it means to be professional in a contradictory manner. A more lenient referral practice is associated with professionalism when GPs activate the advocate and/or patients' rights discourse, whereas a stricter referral practice is associated with professionalism when GPs activate the gatekeeper and/or excess testing discourse. Moreover, it is evident that negotiations within this, somewhat disjointed, institutional context is also mediated by the physician–patient relationship. Specifically, the patient's level of assertiveness in communication could sway the GP to activate one institutional discourse over another in the decision-making process.

At the heart of the physician–patient relationship is the question of what is in the best interest of the patient (Kilbride & Joffe, 2018). The patient-centered care movement works to enhance and ensure patient autonomy to create a more even balance of power in the physician–patient relationship (Quill & Brody, 1996). Thus, in a patient-centered approach, tending to the question of what the patient wants, becomes essential to best-interests assessments (Sandman & Munthe, 2009)—a question that hinges on information sharing and communication between physician and patient (Hargraves et al., 2016). I discovered that, from a physician standpoint, what is in the best interest of the patient with regards to

power and autonomy differs among patients. This implies that a patient-centered approach means different things in different situations. Specifically, it means that physicians practice different levels of openness, what in the literature is described as “truth-telling” (Zolkefli, 2018), in their communication with their patients.

This study suggests that although today’s patients can easily find medical knowledge via the internet and social media (Kilbride & Joffe, 2018, p. 1973), physicians still use their medical expertise as a source of power in the decision-making process. With the public’s increasing access to updated medical information in mind, perhaps the most important power of physicians lies in their authority to choose when, what, how, and how much they share their professional assessment, as it relates to the unique situation of the patient in question.

My analyses make visible how physicians activate the two somewhat related institutional discourses of patient-centered care and patients’ rights to justify the concealment of information from patients. The activation of the two discourses serves divergent interests. Concealment (e.g., by avoiding the word cancer or making clear recommendations in the face of alternatives) within a patient-centered perspective is done to protect the patient from the physiological and emotional strain that accompanies cancer diagnosis. However, physicians highlight that patients who are presumed to be more resilient are given more in-depth information and insight into the physician’s professional assessment. Concealment within a patient’s rights discourse is a physician-centered act that serves to protect the physician’s interests and autonomy, which suggests that informed patients are being perceived as a threat to physicians’ autonomy.

This practice of regulating information, whether it is with the patient’s or physician’s best interest in mind, has implications for patients’ opportunities to participate in the decisions about their care (Hsieh et al., 2016; Zolkefli, 2018). It is timely to ask who gets to decide what is in the best interest of the patient, the physician or the patient? How do physicians assess the individual patient’s resilience and coping abilities upon choosing what to disclose or conceal? These questions remain unanswered, but the findings are consistent

with previous studies that not all cancer patients prefer autonomy and participation in decision-making (Gattellari et al., 2001; Sinding et al., 2010; Thorne et al., 2013). The complicated nature of cancer makes patient participation particularly challenging; many cancers do not provide a set of treatment alternatives to choose from, and when options exist, it can be stressful for patients to be confronted with them. A key ethical question, raised by the physicians in this study, is whether it is appropriate to place decision-making responsibilities on the patient. According to Mazor et al. (2013), the answer depends on how the physicians communicate and present their professional assessments. Patient participation is not limited to presenting patients with options. Patients can feel like they are part of the decision-making process if physicians share their “rationale for favoring a particular course of action” (p. 2491).

As Andersen-Hollekim et al. (2021) point out, cancer patients seem to be more comfortable participating in decision-making about the logistical—rather than in the medical—aspects of their care. However, the introduction of the CPPs makes it increasingly difficult for physicians to include patients in time and scheduling decisions as the overall negotiating space is shrinking

Time as Quality

This thesis contributes to the quality debate in Norwegian cancer care. Based on my empirical findings, my main argument is that the CPP policy with its focus on efficiency interrupts physicians’ professional knowledge by diminishing the discretionary space they need to treat patients as unique and whole individuals. Reaching deadlines is at the center of a successful CPP practice, whereby quality is being presented as something that can easily be measured using a stopwatch. This is conspicuously illustrated in that the CPP coding system is now one of the quality indicators for the Norwegian healthcare system (Norwegian Directorate of Health, 2022).

This has implications for physicians’ professional work and professionalism. Physicians know, based on their medical expertise and experience, that cancer is not a standard disease by which an equal distribution of waiting time to diagnosis and treatment results in the

same good quality of care. Cancers both progress and are experienced differently from person to person and there is room for variation in the temporal flow of the patient trajectory without compromising the medical prognosis and continuity of care. Indeed, variation in time—and breaching of CPP time frames—may be necessary to achieve both medical precision and patient-centered care, which are high-quality components of care.

I argue that a key problem with the CPP policy is that what is being counted and measured, then made visible in the official coding reports, is what is being made to count as quality (Star & Strauss, 1999)—namely the number of days spent to achieve a diagnosis and start treatment. These reports are, as Eastwood (2021) notes, always “disconnected” from the actual work “people do to create them” (p. 196). The negotiations physicians engage in to achieve “good” or “bad” numbers become invisible when translated into coding reports. A related discovery is that, by engaging in the CPPs, physicians’ temporal flexibility in discretionary decision-making at the different junctures in the diagnostic process is shrinking. As the physicians in this study express, there is simply less time to think, assess and discuss (prior to the MDT meetings) because there is such a prominent collective focus on reaching deadlines.

As mentioned in the introduction, CPP coding statistics are published on the Norwegian Directorate’s website, which makes it possible to compare (this aspect of) quality between the different hospitals. This is, according to Evetts (2009), a variant of professionalism that draws on discourses about individualization and competition so that “individual performance is linked to the success or failure of the organization” (p. 255). By making deadlines a key indicator of quality, individual physicians’ can be held accountable for how the hospital is rated. A vitally important point, articulated by the physicians in this study, is that any a breach of a deadline in the coding reports is still a breach regardless of the time that has elapsed. This means that the reports do not distinguish between missing the deadline by 1 day or 50 days, suppressing to what extent the deadlines are breached as well as the underlying reasons behind the numbers. As this study shows, for the individual patients that experienced these missed deadlines—resulting in poor numbers, which becomes a reflection of poor quality on a societal level—this (poor numbers) could in

actuality reflect conscious decisions leading to good quality care on an individual level (Campbell et al., 2000).

Importantly, I do not aim to discuss whether individualized care is somehow “superior” to standardized care (Cortés-Puch et al., 2020) or vice versa (Sevransky et al., 2021). Thus, it is worth repeating that even if physicians’ professional work—and the meaning of professionalism—are being challenged and redefined through tighter bureaucratic management, physicians consider the CPPs to be of value. The CPPs are anchored in the biomedical discourse stating that early detection provides a better chance of survival as well as the psychosocial discourse of waiting as a source of distress. It is crucial to intervene before the cancer begins to spread. The physicians in this study stand united by this principle.

However, as this study suggests, something happens in the process by which this professional ideal (of early detection) becomes a political tool for organizing healthcare and measuring quality that is distorting professional practice. In this process, the biomedical discourse that things should happen fast hooks into the managerial discourse of efficiency and it is being used to justify a push toward speedier work processes within a framework promoting the redistribution of old, rather than adding new, resources. Put differently, with the introduction of the CPPs, the medical discourse of time is being used to legitimize a political discourse on time and quality at organizational and societal levels, which might lose sight of the individual patient. Significantly, this happens within a textual framework that incorporates governing principles aimed to safeguard that care is adapted to the individual patient’s unique needs, precisely because measuring and monitoring becomes a domineering point of practice. In this framing, the political discourse of time comes into conflict with the biomedical discourse of time, which, according to physicians, contains a more nuanced perception of the relevance of time. If my analyses can be said to warrant a warning, it is that physicians’ engagement with the CPPs could risk becoming a battle against time—at the expense of more substantial notions of quality that are equally, if not more, important to quality for individual patients. However, this depends on how quality will be made to matter in the future by different groups of stakeholders.

Concluding Remarks

This thesis contributes to the sociological and pedagogical discussions connected to the changes (characterized by increasing textual mediation) of professional work by illuminating how physicians negotiate tensions and contradictions using different types of guidelines in their work with cancer diagnoses. Using institutional ethnography as a framework, my research shows how the identification of tensions in physicians' experiences of their work can illuminate how experience and practice are coordinated by different modes of text-based ruling. This study demonstrates how physicians are not being passively ruled over and still use their discretionary power to resist the activation of principles, that in specific situations, promote unsound practices. Yet, it also suggests that resistance becomes more difficult in a work environment characterized by the introduction of increasingly specific regulations for practice.

Furthermore, the thesis highlights how it is possible to use institutional ethnography differently than studies anchored in institutional ethnography from the start. As I see it, this is particularly relevant because it is increasingly common to partake in project collaboration and commissioned research. I hope my thesis succeeds in demonstrating that institutional ethnography can serve as a valuable framework for inquiry in somewhat constraining research contexts. For me, engaging with institutional ethnography has been an interesting and inspiring learning process. It has provided me with suitable concepts in the analyses of a large body of data collected by multiple researchers. By taking a physician standpoint, institutional ethnography has helped me to highlight how different ruling relations and their associated discourses coordinate physicians' work with cancer diagnoses, thereby shaping how patients' symptoms are interpreted and prioritized.

The findings of this thesis suggest that policy makers and guideline developers should carefully consider how flexible standardized care processes ought to be to safeguard the discretionary space professionals need to accommodate individual adaptations across medical and organizational aspects of care. Attention should be placed on the actual implications of the interplay between new developments that organize the professional

work of physicians. This study has opened a window into some of the tensions physicians negotiate in their work with cancer diagnoses that would benefit from future research. One possibility is to design a broader qualitative study that combines interviews and observations to produce more detailed information about the activities and negotiations that occur in physicians' interactions with colleagues and patients across the CPP trajectory. It would also be fruitful to begin an institutional ethnographic study using the standpoint of patients to explore the social organization of their experiences with cancer care. Following the introduction of CPPs for cancer diagnosis, the Norwegian health authorities have developed CPPs for other conditions, including stroke, psychiatric conditions, and substance abuse. Thus, another possibility is to expand on the issues raised in this thesis by exploring the social organization of professional work in the above-mentioned contexts – or even other contexts—for example, social work and education.

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PART SEVEN

Articles I–IV

Article I

Næss, S. C. K. (2021). CPP or Not, That Is the Question: Physicians' Work With Activating CPPs. *Qualitative Health Research*, 31(11), 2084-2096.

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CPP or Not, That Is the Question: Physicians' Work With Activating CPPs

Qualitative Health Research

1–13

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Abstract

The Norwegian government has launched a policy titled cancer patient pathways (CPPs), which assigns maximum deadlines to the various phases of the diagnostic investigation. In this article, I examine the starting point of CPPs through the lens of institutional ethnography—that is, how physicians work with the referral of patients in the context of CPPs. Based on qualitative interviews with physicians in both primary and secondary care across Norway ($N = 37$), the findings reveal that the distinction between CPP or not is by no means clear-cut for either primary or specialist physicians. The starting point of CPPs is mediated by the interaction between physicians and patients and how the referral is composed, as well as how and by whom the referral is interpreted, in conjunction with overarching discourses, policies, and guidelines for practice. The findings challenge the notion that all potential cancer patients can and should be equally prioritized.

Keywords

institutional ethnography; cancer; standardized cancer patient pathways; referral work; primary/specialist care; qualitative interviews; Norway

Introduction

Despite the absence of a clear connection between a timely cancer diagnosis and survival, there is a growing body of evidence suggesting that early detection and treatment of cancer are likely to influence the prognosis positively (Neal, 2009). Consequently, significant attention is being paid to the importance of accelerating the diagnostic process (Malmström et al., 2018; Rubin et al., 2011; Wilkens et al., 2016). In Norway, as well as Denmark and Sweden, the notion that time can be used as an essential strategy to fight cancer inspired the development of a policy titled cancer patient pathways (CPPs), implemented in 2015. The intention is to improve the quality of cancer care by providing all potential cancer patients with a standardized set of time frames, from suspicion of cancer to diagnosis and the start of treatment. There are 28 CPPs for different types of cancer. The CPPs are anchored in the clinical practice guidelines, which provide recommendations for diagnostic procedures but are concerned with the logistics (Norwegian Directorate of Health, 2016). In this article, I examine how primary and specialist physicians, balancing diverse demands, work with the referral of patients to CPPs.

For most patients, the path to diagnosis starts with noticing symptoms and presenting them to a general

practitioner (GP). How the GP responds is decisive for further action (Lyrtzopoulos et al., 2012; Macleod et al., 2009). Because knowing when and where to refer a patient is not a clear-cut science, there is great variation in referral practices between physicians (Greenhalgh, 2002; Thorsen et al., 2012). Greenhalgh (2002) points out that clinical decision making is a delicate process whereby the principles of evidence-based medicine merge with the experience-based and intuitive gaze of the physician, which she describes as “the science of intuition” (p. 399). Furthermore, physicians’ referral practice is contextual and relies profoundly on interactions with patients, the way patients present their unique concerns and experiences, and how these are interpreted by physicians in conjunction with national guidelines, previous experience (both their own and their associates in the medical community), and the organizational structures framing

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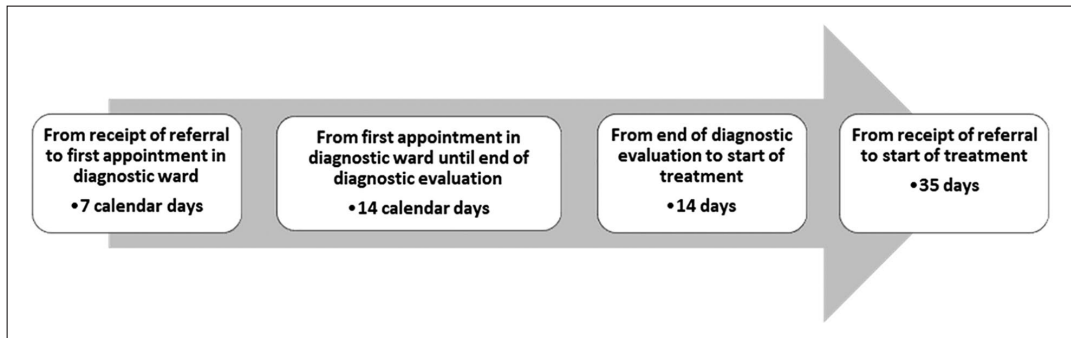


Figure 1. Example of CPP time frames for malignant melanoma.
Note. CPP = cancer patient pathway.

their practice (Gabbay & Le May, 2004; Greenhalgh, 2002; Shaw et al., 2005; Thorsen et al., 2012).

This inherent variation in practice, coupled with the tricky nature of cancer symptoms—they are often diffuse and overlap symptoms of other, more benign conditions, which makes it difficult to decide whether it is more appropriate to make a referral or to wait and see how the symptoms progress—makes the transition from primary to specialist care particularly vulnerable to delays in cancer diagnoses (Andersen & Vedsted, 2015; Green et al., 2015; Hamilton, 2010; Hultstrand et al., 2020; Macleod et al., 2009). Studies demonstrate that there is great variety in the number of primary care visits before patients are referred to the hospital for suspected cancer, and thus many patients will consult their GP several times before a referral to specialist assessments is made (Ewing et al., 2018; Lyratzopoulos et al., 2012).

Because referrals of patients for cancer diagnoses are so varied, more knowledge is needed to better understand how this process is actually carried out. In other words, how a reasonable suspicion of cancer is achieved in reality. How do physicians work with the referral of patients to cancer diagnoses, and what regulates their practice? Although GPs play a pivotal role in early diagnoses by promptly referring patients to specialist care, the priority assigned to referrals by health care providers in specialist health care also interferes with the length of time from suspicion to diagnosis (Olesen et al., 2009). This makes researching what happens in the interface between primary and specialist care physicians particularly relevant in the context of policies such as the CPPs, which targets the rapid detection and treatment of cancer. Although some studies have investigated CPPs from the perspectives of health professionals (Delilovic et al., 2019; Hultstrand et al., 2020; Melby & Håland, 2021; Næss & Håland, 2021), there is no study (to my knowledge) targeting the interface between primary care and specialist care as it relates to the starting point of CPPs.

As with other Nordic countries, the Norwegian health care system is predominantly tax financed and provides universal access. All Norwegian citizens have the right to a dedicated primary physician (GP) of their own choosing (Iversen et al., 2016). The GP is the primary starting point for a CPP. GPs may initiate a CPP, but it is the specialist who ultimately decides (based on the referral) whether the patient is assigned to a CPP.

The CPPs consist of four time frames, as illustrated in Figure 1. The first time frame, which is the focal point of this article, is activated when the hospital receives a referral documenting a “reasonable” suspicion of cancer. In national policy documents, this is depicted as a linear movement with a clear starting point (Norwegian Directorate of Health, 2021). However, I aim to demonstrate that the work involved in starting CPPs is complex, with several overlapping interfaces between primary care and different hospital departments. As the inquiry is guided by institutional ethnography, it illuminates aspects of the broader social organization shaping these work processes. The article aims to contribute to knowledge of the tension between bureaucratic processes articulated through policy documents and what happens when policy documents, such as the CPPs, hit the actualities of clinical practice.

Theory and Method

Institutional Ethnography

The study is theoretically and methodologically underpinned by institutional ethnography. Conceived by sociologist Dorothy Smith, institutional ethnography is an approach to inquiry designed to uncover the social organization of people’s activities—what Smith (1987) refers to as “the relations of ruling/ruling relations” (pp. 4–5). The concept of ruling relations anchors institutional ethnography in a power perspective, as it refers to all the

social institutions (e.g., government, bureaucracies, laws, financial management, educational institutions, mass media, textual discourses) that in one way or another weave their way into people's everyday activities, shaping the social world as it happens in a particular location (Smith, 1987, 1990b, 2005)

Because ruling in contemporary society is predominantly channeled via texts and documents, texts are essential to an institutional ethnographic inquiry. Smith (2005) articulates the interconnectedness of ruling, texts, and human action, she writes,

Institutions exist in that strange magical realm in which social relations based on texts transform the local particularities of people, place and time into standardized, generalized, and, especially, translocal forms of coordination people's activities. Texts perform at that key juncture between the local settings of people's everyday worlds and the ruling relations. (p. 101)

In that sense, texts, in their various forms, function as binding elements, connecting people across time and space, coordinating what they do. A crucial premise in institutional ethnography is that ruling is relational and enacted. People participate in—and reproduce—the complexes of ruling by engaging in certain texts, discourses, ideologies, concepts, theories, and standards in their local setting (Smith, 1990a, 1990b, 2005) According to Smith (2005), Foucault's notion of discourse is a central aspect of ruling relations, as it locates knowledge "externally to particular subjectivities as an order that imposes on and coerces them" (p. 17). Discourses are not confined to statements *about* something but understood as systems of meaning embedded within people's everyday practice. In this conception of discourse, meanings and doings are interconnected and interactive—meanings shape what we do, and our doings shape the meanings of what we do (Foucault, 1972; Smith, 1987).

Institutional ethnography is a project that turns the sociological enterprise upside down, by reinstating the subject as the starting point of inquiry, yet proceeding beyond the experiences of the individuals in a particular setting and into the examination of the formation of these experiences (DeVault & McCoy, 2006). The objective is to discover the way things "are actually put together" and "how it works" (Smith, 2006, p. 1) from a concrete standpoint within an area of everyday life. It is important to note that a standpoint does not reflect a specific position within society such as gender, class, and race: Instead, it denotes a place to start the investigation in the "local settings of people's everyday experience" (Smith, 2005, p. 49). For example, one study by McGibbon et al. (2010) begins with the experiences of nurses and illustrates how various aspects of nurses' stress, thematized as "emotional distress; constancy of presence; burden of

responsibility; negotiating hierarchical power; engaging in bodily caring; and being mothers, daughters, aunts and sisters" (p. 1357), are linked to particular modes of ruling.

In this study, I take the standpoint of physicians. This is a somewhat broad adaption, as the standpoint represents physicians in distinct professions who are positioned differently within the institutional setting, but whose work intersects or congregates around the referral document and the CPP policy. Hence, I follow the making and interpreting of the referral document as it pertains to the start of a CPP from the standpoint of physicians located at different points in the referral interchange.

Data Collection and Materials

The study is part of a larger collaborative qualitative research project evaluating the implementation of CCPs in Norway. Jointly, the project explores how the CPPs are put into practice and experienced by patients, health care providers, and managers affected by the reform across four cancer pathways: lung, prostate, breast, and malign melanoma. Ethical approval was obtained from the Norwegian Center for Research Data (project number 58724). Semistructured interviews were conducted from May 2018 to January 2020.

The article builds on interviews with 12 GPs and 25 specialist physicians ($N = 37$) who have firsthand experience of working with CPPs. A combination of purposive and snowball sampling (MacDougall & Fudge, 2001) was used to ensure geographical variation and the inclusion of different groups of specialist physicians. The sample of specialists includes clinicians, surgeons, radiologists, nuclear radiologists, and administrative managers working across five hospitals, both local and university hospitals. All the informants received written information about the project prior to the interview. This information was repeated orally on the day of the interview before they signed the consent form.

We employed a combination of individual and group interviews. Four group interviews and one individual interview were conducted with GPs, whereas 23 interviews with specialist physicians were carried out as individual interviews. In two interviews, the specialist physician was accompanied by an administrator colleague. The author participated in both individual and group interviews, conducting three interviews with specialist physicians alone and 10 together with a research team member. Other research team members conducted 12 interviews with specialist physicians. Furthermore, the author conducted three group interviews with GPs together with a research team member, whereas one group interview and one individual interview with GPs were carried out by other research team members. All interviews were recorded and transcribed verbatim, and

the research team members were given access to all data materials. The author has developed the findings and analysis for this particular article.

Analysis

Guided by the main principles of institutional ethnography, discovering the institutional aspects coordinating the informants' doings remained essential throughout the analytical process (McCoy, 2006). Data collection and analysis occurred interrelatedly, directed by Smith's (2005) notion of identifying a "problematic" to examine. A problematic is something in the informants' accounts that the researcher finds puzzling, such as a tension between the different forms of knowledge drawn upon in everyday practice. The problematic is not necessarily experienced as a problem by the interviewed informants, because people's ways of doing things are usually taken for granted (Rankin, 2017; Smith, 2005); however, it is precisely by making the taken-for-granted activities and experiences of people problematic that it is possible "to examine how these particular things happen as they do" (Campbell & Gregor, 2004, p. 47).

The entry point to CPPs arose as puzzling early in the investigation, as it became increasingly evident that starting a CPP is far more complicated than the standardized procedure outlined in the policies. Taking the starting point of CPPs as a problematic allowed the author to explore how the referral process works from various positions in the setting, spanning both primary and secondary care. Interviews were analyzed by labeling all the work connected to the starting point of CPPs as "referral work." The analysis progressed by indexing the accounts related to referral work. Moreover, the author examined the data for disjunctures/small problematics (Rankin, 2017) between CPP guidelines and everyday practice that could help in illuminating the work involved in starting CPPs and tracing how these activities are coordinated.

Findings

Referral Work: At What Point Is a Reasonable Suspicion of Cancer Achieved?

The findings are presented in two sections, first exploring the making and subsequently the interpretation of referrals, thereby following the natural order of things as they (for the most part) happen—that is, the move from primary to secondary care. Findings suggest that there are different interpretations of how the process of referring patients to a CPP is best realized, a key question being, at what point is a reasonable suspicion of cancer achieved? Physicians have different perceptions of how close to a final diagnosis a patient should be before it is appropriate to start a CPP. The findings also reveal some controversy

over who in the specialist health services should be allowed to convert CPP referrals. Figure 2 establishes how the starting point of a CPP can lie in several interfaces between primary and secondary care, and how the work of starting a CPP is tangled within a complex set of relations that are discursively mediated. How these relations influence the referral process to a CPP is subsequently explored below. This is by no means an exhaustive outline, but it provides insight into some aspects of the social organization of referral work tied to the starting point of CPPs.

Managing patients' worries and establishing a suspicion of cancer. GPs portray cancer as a challenging but common theme of daily practice. For some GPs, the CPPs are a welcome addition to practice because they have made the initial stages of cancer detection more of a shared responsibility between primary and secondary care physicians. CPP is described as a category that "makes things happen." The referral process is said to run more smoothly as patients move quicker through the system. However, cancer diagnostics are also characterized as such a fear-inducing and complicated landscape to navigate that referring patients to a CPP is far from being a straightforward procedure.

Forming a suspicion of cancer: Moving between the concrete and the intangible. A GP can refer a patient to a CPP when there is a reasonable suspicion of cancer. To assist this process, the health authorities have developed diagnostic manuals containing the criteria by which to establish a reasonable suspicion of cancer (Norwegian Directorate of Health, 2019a). As the initial recognition of potential cancer symptoms usually happens through face-to-face communication with the patient, a significant part of the GP's work, as informants describe, involves moving from patient-reported worries and symptoms to forming their own suspicion, ultimately determining whether the patient qualifies for a CPP.

When GPs discuss how they work to identify cancer symptoms, they draw on holistic and patient-centered perspectives (Schneider-Kamp & Askegaard, 2020). GPs express that the fear of cancer is so prominent in society that stress reduction is a significant aspect of discernment. Because patients differ, it is also important to align the approach with the individual needs of each patient. For instance, one GP explains how the patient's mindset and attitude determine how he responds to a concerned patient:

If I doubt that the patient will follow up, because some [people] are so afraid to go to the doctor that they are like, "I finally got myself here, so things has to happen immediately otherwise I'm not going to bother doing anything about it," and if I believe that it could be something serious I often "ok

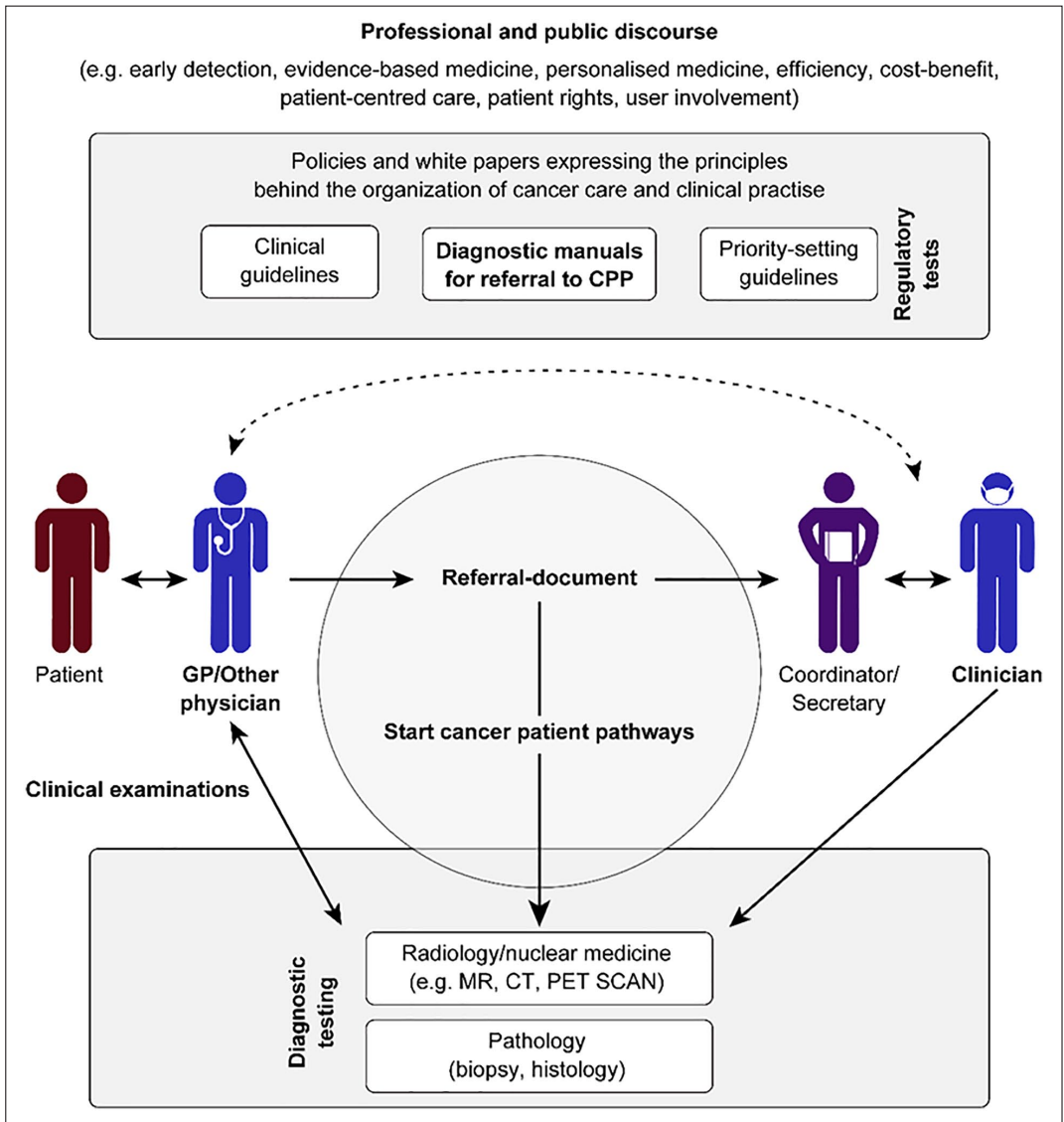


Figure 2. The figure illustrates that the starting point for CPPs relies on interaction between GPs and patients, as well as interaction between physicians in various locations in relation to the referral document.
 Note. CPP = cancer patient pathway; GP = general practitioner.

then, you are going [to the hospital] right away so I can be certain it gets checked, may not be anything concerning but at least we'll know." (GP, interview 5)

GPs emphasize the importance of forming a joint understanding between patient and doctor about the situation in question. This is done by evaluating the specific concerns conveyed by the patient in light of the patient's medical

history, which includes identifying the prevalence of cancer in the patient's family. Many describe this as a tension-filled process, because cancer symptoms range from alarmingly clear to troublesomely uncertain. As one GP puts it,

It is a huge grey area with regards to, I mean, we move between rational and irrational thoughts, our worst fear is

irritable bowel syndrome with loads of diffuse bowel problems and the day it turns out to be cancer we get hanged and we hang ourselves, and that is the chaos we live in, and actually get quite good at, but it is extremely stressful this particular field [cancer], and assessments are made in a kind of bewildering landscape (GP, interview 2).

Although all GPs confirm that they have access to the diagnostic manuals, they describe using them to a variable degree. One newly qualified GP comments, “I often check the criteria; when is it a suspicion, when should I refer, I try to follow it [the manual]” (GP, interview, 3). Others are more critical to guidelines explaining that there are so many guidelines for general practice that there is no way they can stay up to date on all the formal aspects related to the referral of patients. Furthermore, a strict adherence to guideline criteria is described as contradictory to how they practice:

No, actually, I don't [look at guidelines] because there is no room for that, I have far too much to do to sit around and speculate over whether it checks five points or four points, I mean, I don't give a crap. I'm thinking “Okay, this is urological cancer. I mean he pees blood, he is still peeing blood, I can't find anything else, he needs to go in [for examination], it is cancer! Cancer Patient Pathways!” It is cancer, whether it checks five points or seven. I'm not engaging in that. (GP, interview 2)

It is hard, it is very vague what patients present, so let's say the patient has lost weight or experience night sweats, and then they have to display all the symptoms required for CPP referral, that is not going to work, they might experience one symptom, or two, and it could be a full blown metastatic cancer. (GP, interview 4)

According to GPs, limited time combined with a mountain of guidelines for various types of referrals make it both challenging and somewhat irrelevant to practice a strict adherence to guidelines. Many GPs describe employing a combination of guidelines and intuition, as well as interaction with both the patient and colleagues, in forming their opinion. Much in line with the literature on professional discretion (Greenhalgh, 2002; Timmermans, 2005), informants describe the “gut feeling” as a kind of guiding compass, essential for tolerating the many uncertainties arising on a regular basis. A GP articulates it in the following manner:

And sometimes we makes mistakes, we have patients that both exaggerate and minimizes their symptoms, sometimes you take a blood test and can't find anything, you just can't make sense of it, but in most cases I have to trust that I have a kind of gut feeling for these things, otherwise I'm not going to be able to live with the uncertainty this job entails, and if the patient agrees, then I have a confirmation that I'm on the right track. (GP, interview 2)

A key point, underscored by GPs, is that cancer symptoms reveal themselves in such diverse and often vague ways that patients rarely match all the criteria for a CPP referral. The interactive context of establishing a suspicion becomes visible in the statement above. As patients report on their symptoms in different ways (some amplify whereas others downplay their situation), GPs make an active choice to trust their own instincts while searching for confirmation that they are on the right track in the feedback from the patient. Moreover, some GPs underscore that direct communication with hospital specialists is of greater value than formal guidelines because it is effective in sorting out misunderstandings and clarifying expectations. This echoes previous studies identifying the multitude of influences informing GPs' referral practices (Gabbay & Le May, 2004; Greenhalgh, 2002; Nilsen et al., 2011; Thorsen et al., 2012).

“I'm to blame”: *Balancing professional integrity and patients' demands*. The decision to refer is portrayed as being fraught with quandaries, specifically tied to an experience of having a dual responsibility. GPs explain that they are supposed to help patients access the care they want and feel they need, but they do not want to burden the system unnecessarily—a predicament portrayed in the literature as arising from GPs' somewhat conflicting roles as both a patient advocate and a gatekeeper (Matthews, 2012). This friction in answerability organizes the GPs' work in diverse ways.

Informants assert that their ability to filter patients successfully is reflective of their professionalism in the broader community of physicians. This is exemplified below, where two GPs discuss how the lack of clarity over what level of uncertainty is acceptable in a CPP may compromise their reputation:

I was in so much doubt regarding a [female patient] that had stool changes and she had lost some weight; then we took supplementary blood tests that showed serious iron deficiency anemia and she was not that old, [an] otherwise healthy woman, so here I'm thinking “this is cancer till proven otherwise.” And then I began to doubt—is this enough for a CPP or is it somewhere in between? So, I ended up merely describing it . . . but I don't know if the intention is there, that you are supposed to use CPP on those. What do you do? (GP, interview 1)

No, that is a grey area where you feel . . . I feel like it challenges my honor. I'm not keen on referring people for nonsense, and [in that case] you could say it is cancer till the opposite is proven, but at the same time, it may be just an innocent bleeding from the colon, so I don't think I would refer that [to a CPP], but like you, describe it. (GP, interview 1)

What is striking about these statements is that the informants' awareness of how others in the medical

community “judge” baseless referrals enters the equation in such a way that it shapes the decision in favor of not activating a CPP, despite both GPs being convinced that the symptoms should be treated as a likely cancer. Informants explain that the medical community in Norway is so small that they often worry about their reputation as physicians. As one GP states, “you don’t want to be known as one of those GPs that constantly refers patients for cancer assessments and nothing is ever found” (GP, interview 3). And, some patients are more demanding than others. Balancing the needs of each patient with professional integrity is especially challenging when patients persistently refuse to accept the GP’s decision that no further testing is necessary. For example,

We get a lot of pressure from patients. There are so many instances supporting the patient, they have complaints . . . the [Health and Social Services] ombudsman, and they can complain everywhere really, but we sit by ourselves and then, for example, they want an MRI or a CT of their abdomen because they have a pain in their stomach. Bloodwork doesn’t show anything—most likely it is nothing. One in a thousand perhaps has something, cancer or something, and if you persist and deny the patient that CT because . . . or a PSA test, someone with prostate cancer, according to national guidelines there is no point in doing a PSA; suddenly someone gets prostate cancer and then it is us who are bashed in the media or other places. (GP, interview 4)

GPs assert that by being the first medical professional to see the patient, any detection of future illness may potentially be traced back to a past GP consultation. A patient who is denied access to diagnostic tests could at some point face serious consequences for their career. The informants emphasize the power of patients through public institutions such as the Health and Service Ombudsman (Helsenorge, 2019), whose primary mission is to safeguard patients’ interests. To prevent the possibility of patients launching formal complaints, they are willing to set aside their medical authority and follow instructions from the patient.

The extensive anxiety and uncertainties surrounding cancer symptoms makes balancing the aspects of gate-keeping and advocate quite challenging. Pressure from patients combined with concerns about missing a cancer and receiving complaints make it difficult to deny patients the testing they want despite the lack of obvious symptoms. One GP describes this pulling in different directions as a feeling of being held hostage:

. . . then I find myself in a dilemma that perhaps is more on an overarching level, and I agree, we tend to fire away, we over-examine and the carcinophobia out there makes us over-examine. Then I think, I sit down, take an anamnesis and monitor for three weeks, but I experience it as stressful that we have a responsibility not to [over-]examine, and that

will cause us to miss slightly more of that weird, random stuff that an examination . . . and then, I don’t know if you guys feel the same way, but I’m to blame. I think it is both creepy and a bit unfair that I’m being given this hostage role, I’m not supposed to over-examine you, I’m not supposed to under-examine you, and I’m supposed to look after [you], and refer to CPPs, or I’m not supposed to, not too much, not too seldom, but if it goes wrong . . . I’m to blame. (GP, interview 2)

The GP describes feeling trapped by the conflicting demands of the institutional framework organizing the health care services. Ultimately, this becomes a question of compliance with a certain ideal, in this case, a responsibility not to overexamine, which is in line with the institutional discourse portraying excessive testing as a prevalent problem across the world (Bhardway, 2019; Brownlee et al., 2017). The account implies that the choice between leniency or restraint is one of damned if you do, damned if you do not. Choosing to incorporate a strict practice of restraint and hold back on these “just-to-make-sure” investigations requires a tolerance of uncertainty (Hoffman & Kanzaria, 2014). This includes the possibility of missing serious cases of illness, at least in their early stages, which policies such as the CPP are supposed to prevent.

Making the referral. The threshold for initiating a CPP varies between GPs. GPs distinguish between certain and uncertain cases and degrees of suspicion and explain that the decision to refer a patient to a CPP hinges on the level of doubt associated with the case. A definitive CPP referral is often described as “finding a lump in the breast.” However, most patients display far subtler symptoms requiring more extensive assessments. According to one GP, “you use it [CPP] when you are fairly certain, if you have a clear finding on a picture, for example an x-ray or some form of pathology blood test” (GP, interview 1). This is in line with another study (Jensen et al., 2014) showing that GPs may suspect cancer without initiating a CPP, and that patients whose symptoms are interpreted as “vague” are less likely to be referred to a CPP than patients with more telling symptoms.

Informants explain that the referral document is set up in a way that allows them to make concrete priority decisions through check boxes. They may choose between multiple check boxes spanning 1 day to 4 weeks, and there is a separate check box for CPPs. Discussions on the relevance of crossing the time frame box reveal divergent understandings and practices; indeed, although some use them consistently, others say they never cross of the check boxes. A few GPs were not even aware that there is a CPP check box. GPs with experience of using the boxes underscore that the CPP box is the only box worth using as the other time frames in the referral are usually ignored by the receiving hospital.

However, the general agreement is that writing a precise text is the decisive factor. Several GPs explain that they usually write “cancer patient pathway” or “must be checked immediately” in capital letters to make sure that the referral does not slip through the cracks. It is vital that the referral adequately conveys how the patient’s symptoms relate to cancer. The way the text is written, and subsequently read, will determine how fast the patient will receive specialist health care.

Receipt of referral: Prioritizing by interpreting the need for urgency. A CPP starts the moment the hospital receives the referral. The first person to assess the referral in the hospital is usually a cancer pathway coordinator. The coordinator is responsible for scheduling the first appointment within CPP time frames and uses the referrals to ensure that appointments are distributed between patients according to priority, as indicated by the referrals. After assessing the referral, which sometimes includes marking it as CPP, the coordinator passes it on to the physician, who is ultimately responsible for determining whether the referral meets the requirements of a CPP. So, even though it lies in physicians’ domain to decide whether the referral should be categorized as a CPP, in some places, this work is actually done by the coordinators.

The diverse quality of referrals. Consistent with previous research, informants describe referrals as being “good, insufficient or bad” (Thorsen et al., 2013, p. 95). Some are explicitly marked CPP (by text or via the check box), whereas others only contain a description of the patient’s symptoms, therefore leaving it up to the specialist physician to judge whether it signals cancer. Informants explain that this is a problem because referrals marked CPP get “flagged in the system” and are tended to quicker than referrals that are not. Nonetheless, the recipient physician organizes the referrals according to CPP criteria; they must either mark referrals that match CPP criteria but where CPP is not initiated by the referring physician, or reject/deprioritize referrals that are marked CPP but where the description of symptoms does not qualify as a reasonable suspicion of cancer in their opinion.

One physician explains what it means to write a good referral:

That [GPs] have physically examined the patient. Before . . . [the patient] came in and stated that [they have] felt a lump on [their] right or left side and then the doctor would write “lump right breast” and send [the referral] off. Those get rejected. You have to conduct a clinical examination; how large is the finding, upwards, downwards, is it a hard lump, say something about the lump, do other family members have breast cancer? Because that is a criterion for determining whether they should enter the CPP or not. (Physician, hospital 3)

This illustrates the importance placed on distinguishing between patient-reported symptoms and a medically recognizable suspicion of cancer. The referral must document the medical practitioner’s suspicion of cancer as inferred from a physical examination and the patient’s history. Arguably, this shows how the referral process involves a meticulous distinction between “facts and fiction” for defining what kinds of experiences and signs warrant further investigation. Smith (1990b) underlines the social organization constituting facticity; she states that

it is the use of proper procedure for categorizing events which transforms them into facts . . . If something is to be construed as a fact, then it must be shown that proper procedures have been used to establish it as objectively known. (p. 27)

The categorizing of a patient’s experiences and bodily symptoms as cancerous requires a shift from the subjective to the objective, textualized, reality of what counts as symptoms of cancer.

The extent to which specialist physicians adhere to the CPP guidelines for inclusion varies. Although some say that they consistently reject insufficient referrals, others stress the importance of including patients in CPPs regardless, to avoid unnecessary delays for the patient. The uncertainties and possible errors that accompany the interpretation of cancer symptoms make it relevant to provide a speedy diagnostic trajectory for all patients that could potentially have cancer, even those with vague symptoms. A key argument is that CPPs work by bypassing ordinary waiting lists in the hospital. Consistent with a qualitative study on CPPs from Sweden (Delilovic et al., 2019), several informants deemed it likely that the introduction of CPPs has meant longer waiting times for patients who are not categorized as belonging to an urgent priority group. Delilovic et al. (2019) refer to this as the unintended “crowding out effects” (p. 6) of CPPs, which is defined as “situations where lower priority patients are given care before patients who have a higher priority” (p. 6). Arguably, this is highly significant. Longer waiting time imposed on patients outside of the CPP system could compromise the timeliness of care to those patients who are seriously ill but where this is not adequately conveyed by the referral, or who are considered a lower priority by the specialist than the referring physician intended.

Negotiating priority settings. One point of contention (and frustration) raised by physicians working in imaging departments concerns their lack of rights to reject or downgrade what they refer to as erroneous CPP referrals. In principle, they are not allowed to convert CPP referrals, which becomes a problem because of the variable

quality of referrals and the limited appointments available. Several informants express that this an ongoing topic of debate. For example,

We are also responsible for the CPP with serious, [unspecific] symptoms, and I have to say that, in my experience, it's been quite misused, at least in the beginning. I mean, "we want a CT fast, so we just mark it CPP with serious symptoms," and when you read the referral it doesn't really fit the criteria, but it is stamped CPP so . . . I've tried to send them back, but then it became a topic of discussion at the top level, above me, and it was decided that I couldn't do that, so we just have to run [the tests as CPPs] and describe them. (Physician, hospital 2)

The physician notes that there is an inconsistency between guideline criteria and actual practice. He speculates that physicians are using CPPs as a means to secure their patients faster assessments. He also experienced that his professional judgment was overruled by the managers "at the top level." When asked why they are not allowed to alter CPP referrals, informants assume that it is part of the policy. Similarly, others argue for the opportunity to convert CPP referrals, because they embrace such a wide variety of symptoms, from relatively low to high suspicion of cancer, that it defies professional logic to place them all in the same priority category.

However, some say that in their department, the resources are so scarce that they have no choice but to downgrade some of the CPPs to make sure that the patients "that need it the most" are dealt with first. For example,

I don't place all the CPPs at the top—I look for medical indications. For example, lymphoma is urgent. A lymphoma in a 20-year-old is more urgent than an 80-year-old prostate cancer patient, because prostate has a slower progression rate than lymphoma. Lymphoma can kill within a month. (Physician, hospital 3)

The physician explains that she organizes referrals according to medical indications and the characteristics of the patients, as outlined by clinical practice guidelines, rather than the standardized time frames suggested by the CPPs. Clinical practice guidelines provide evidence-based recommendations for decision making related to diagnosis and treatment (Timmermans, 2005). This suggests that by activating another set of guidelines, physicians are able to prioritize referrals differently and in a less standardized way than allowed for by the CPPs. This is deemed necessary because the level of urgency is different between potential cancer patients, even those with the same type of cancer.

One radiologist physician specializing in breast cancer describes how they have solved this predicament in her department:

Physician: It is very frustrating because the hours [appointments] are limited. So, in the beginning we used to call the GP and explain that this is not good enough, we want a new referral, but now we have found a way around it, so we don't do that anymore. We downgrade the CPPs even if we are not allowed to, but then we put it on a list and that list is handled by the secretary. They send a letter to the GP, informing that [the referral] does not fit the criteria and that the GP is free to contact us if [s]he disagrees. It makes it better for the patient because we downgrade it right away in order to give the patient an appointment immediately. Before, we would wait for the next referral, and that caused some delays.

Interviewer: So that means that the patient gets an appointment anyway?

Physician: Gets an appointment, but not within the CPP timeframe, right? Perhaps we consider it to be a lump in the breast that needs to be addressed within four weeks, so she [the patient] gets an appointment within that deadline. (Physician, hospital 3)

This reveals an interesting aspect of the CPPs' time frames—that they are not based on medical indications and are thus not legally binding. Consequently, it is not a patient's right to access specialist care within the CPP time frames, even if the referral is classified as a CPP (Norwegian Directorate of Health, 2019b). The other deadline referred to in the statement is anchored in the priority-setting guidelines, which were introduced prior to the CPPs (from 2008–2012) to align professional discretion better with the overarching political and judicial principles for the prioritization of health care services (Aase-Kvåle et al., 2019). These guidelines specify which conditions give patients the right to specialist care and provide recommendations for the maximum deadlines to start treatment (Tranvåg et al., 2015). By introducing the CPP policy, medical professionals must now juggle two types of deadlines anchored in different policies. An important difference between the two lies in the deadline for assessing referrals; according to the priority-setting guidelines, referrals must be assessed within 10 days, whereas many CPPs require that the patient meets with a specialist physician within 7 days (Norwegian Directorate of Health, 2016, 2019c).

The physician explains how she negotiates between these two policies when she prioritizes referrals for potential breast cancer:

Physician: We must respect [the legal deadline] if there is a lump, even if it appears quite innocent, but we do make an assessment of malignancy potential. So, we distinguish between those that the GP has felt "this one is scary," so they can come straight in, right? A new, unexplained irregular lump with contracture, right? That is highly suspicious.

Interviewer: And you can feel that just by touching?

Physician: A GP will be able to feel that. But, of course, mistakes are made all the time, but [patients] are protected by that four-week [deadline] . . . because if we fill all our CPP appointments with things that aren't important, the entire CPP program will fall apart. (Physician, hospital 3)

This is particularly interesting as all the GPs describe a lump in the breast as undoubtedly a CPP because all lumps are potentially malignant. However, for the radiologist, that is not the case: All lumps should be checked, but not all lumps have the same urgency and they must be prioritized accordingly. In doing so, she uses the medical indications conveyed by the referral to differentiate between referrals according to the criteria outlined by different guidelines.

Apparently, decisions about priority are based on a more fine-tuned medical distinction by specialists than by GPs. However, in discussing the varying quality of referrals and priority settings, it is critical to note that most specialist physicians assert that they understand the difficult position of the GP. They easily imagine that GPs are pressured by patients who are anxious despite a low medical indication that there is anything malignant to worry about. Clearly, it is a significantly different procedure to sit face-to-face with a concerned patient than it is to categorize a document. For the specialist, the referral document is a representation of the patient, and thus the closer the referral reflects the reality of the patient's situation, the easier it is for the specialist to prioritize incoming referrals appropriately.

Discussion

Guided by institutional ethnography, I have investigated the social organization of referral work in the context of CPPs. I discovered that the referral work involved in starting CPPs is complex, with several overlapping interfaces between primary care and different hospital departments. An important analytical point in this study is that "the way things happen as they do" (Campbell & Gregor, 2004, p. 47) depends on the way people interact with the conditions of their practice (Smith, 1990b). The gateway to CPPs relies upon the interaction between physicians and patients and how the referral is composed, as well as how and by whom the referral is interpreted. The inquiry revealed that the distinction between CPP or not is by no means clear-cut for either primary or specialist physicians. Furthermore, the findings have illuminated some of the policies and discourses that mediate the work of starting a CPP.

GPs assert that fear and vague symptoms are major triggers for the frequent concerns about cancer being

raised by patients. The ambiguous nature of cancer symptoms makes it challenging to navigate the border between rational and irrational concerns from a medical point of view. Therefore, GPs invest significant energy in assessing the patient, employing a patient-centered approach upon referral. This is in line with the extant literature (Gabbay & Le May, 2004; Greenhalgh, 2002; Thorsen et al., 2012; Timmermans, 2005), noting that the choice of whether to refer a patient is regulated by a combination of the physician's experience, professional judgment, and collegial relations; the patient's subjective concerns and experiences—how these are conveyed by the patient and interpreted by the physician; and official guidelines for practice.

GPs' work is organized by ruling relations driven by competing interests, whereby the GPs become responsible both for protecting the system's capacity and helping patients to access specialist care. Occasionally—or perhaps, more specifically, when vague symptoms intersect with what they refer to as demanding patients—these interests create a dilemma wherein the GPs must negotiate between the patient's desire for diagnostic testing and their own professional integrity. Interestingly, the practice of restraint—for example, waiting to see how the symptoms develop—is tied to a sense of honor in the wider community of physicians, whereas the practice of leniency is tied to patient satisfaction and the power of patients to launch formal and informal complaints. Either way, the GP's reputation is at stake.

The GPs have different interpretations of when it is appropriate to initiate a CPP. Some refrain from using CPPs in cases where they suspect it might be cancer but do not feel the symptoms can be clearly defined, whereas others see the CPP as an obvious choice in uncertain cases. Because of the GPs' various thresholds for enacting the CPP, some patients may wait longer than others to be referred. In addition, the amount of diagnostic testing performed by GPs prior to patients entering a CPP varies, which means that patients could be at very different stages in the diagnostic process upon entry to a CPP. This, of course, will greatly influence the pace of the entire CPP trajectory.

As with the making of referrals, several tensions between institutional policies and actual work practices come into play in the work of interpreting referrals. These tensions revolve around the diverse quality of referrals, physicians' knowledge of the complicated nature of cancerous diseases, and the freedom (or lack thereof) to apply one's own professional discretion. This work is embedded in the principles for prioritization by which the specialist health care services are organized more generally, as well as cancer care more specifically (Norwegian Directorate of Health, 2019b, 2019c; Norwegian Ministry of Health and Care Services, 2017).

Prioritizing is a natural and ingrained part of the daily work of specialist physicians. In Norway, the authorities have discussed questions pertaining to priorities in health care for more than 30 years; this has resulted in the successive development of policies establishing the premises on which patients should be prioritized (Norwegian Ministry of Health and Care Services, 2016). The CPP policy is thus part of a broader discourse on prioritization in public health care. By specifically targeting potential cancer patients, CPPs enable these patients to bypass the regular hospital waiting lists, which are organized according to another set of priority-setting guidelines. These other guidelines are anchored in the more overarching policies specifying that prioritization between patients is supposed to happen based on the degree of seriousness and need for urgency. This involves a decline in prognosis with regard to life span and quality of life if help is postponed (Bjorvatn & Nilssen, 2018).

The intention of CPPs is to provide every person with a reasonable suspicion of cancer the same care package within a standardized time frame (Norwegian Directorate of Health, 2016). This implies that, in principle, all CPP patients belong to the same priority category. However, the diverse quality of referrals makes the classification and prioritization of patients according to CPP criteria challenging, and physicians engage with referrals in different ways. Ultimately, they use a combination of professional discretion and different guidelines to negotiate prioritization between patients.

Conclusion

As previously mentioned, the scope of this study is too narrow to detail all elements of the social organization that influence the starting point of CPPs. Rather, it highlights some aspects of the ruling apparatus that mediate the experiences of physicians. A limitation connected to the methodological framework is that this study is part of a wider collaborative project and the interviews were conducted by different researchers. Although all the interviewees used the same interview guide, other researchers did not proceed with an institutional ethnographic perspective in mind, and so opportunities to explore traces of ruling relations as they emerged during interviews could have been missed. Also, this study is conducted in a Norwegian context, focusing on experiences tied to modes of ruling particular to this society. However, as many countries have introduced similar reforms and guidelines, the findings may be relevant for other health care systems.

The findings of this study have important implications for further development of the CPPs. Although equal rights to a fast-track care trajectory is a great ambition that is impossible to disagree with, it is evident that not all

potential cancer patients can or should be treated as belonging to one single group. A key point is that cancer is detected in various stages of development, and thus it could be argued that the standardization of time frames for diagnosis and treatment in a “one-package-fits-all”-type model such as the CPPs discredits physicians’ professional authority. Furthermore, it portrays rapidity within the health care services as synonymous with high-quality care, an image consistently disputed by our informants, who argue, from a patient-centered perspective, that patients have diverse needs and desires, which must always form part of the equation.

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Article II

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ORIGINAL ARTICLE

Between diagnostic precision and rapid decision-making: Using institutional ethnography to explore diagnostic work in the context of Cancer Patient Pathways in Norway

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Abstract

Alongside other Nordic countries, the Norwegian government has introduced Cancer Patient Pathways (CPPs) for faster diagnostic assessment and timely treatment to improve the quality of cancer care. A key aspect of CPPs is the introduction of time limits for each phase of the diagnostic investigation. Occurring simultaneously are ongoing advances in medical technology, complicating the process of diagnosing and treating cancer. In this article, using institutional ethnography, we examine: *how does the CPP policy influence physicians' experiences of diagnostic work?* Data were collected from May 2018 to May 2019, through semi-structured interviews with physicians across five hospitals in Norway ($N = 27$). Our findings indicate that the implementation of various strategies aimed at enhancing quality in cancer care collide, compelling physicians to negotiate between diagnostic precision and rapid decision-making. We conclude that attention to interfaces between multiple guidelines and their implications for practice is crucial for understanding and developing quality of care.

*[Correction made on 28 February, after first online publication: A block quote was initially omitted in the 'Resource management between diagnostic precision and demands of efficiency' section due to a production error and has been reinstated in this version.]

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KEYWORDS

cancer, Cancer Patient Pathways, diagnostic work, institutional ethnography, temporality, quality of care

INTRODUCTION

Alongside other Nordic countries, the Norwegian government has introduced Cancer Patient Pathways (CPPs) for faster diagnostic assessment and timely treatment to improve the quality of cancer care. Thus, rapidity is placed at the forefront of what it means to provide quality cancer care and has become a core indicator of healthcare professionals' performance. Consequently, how well (or poorly) they perform in their work is measured according to the time spent on getting the patient through the system. Occurring simultaneously are ongoing advances in medical technology, complicating the process of diagnosing and treating cancer within a fixed timeframe. In this article, based on qualitative interviews, we examine: *how does the CPP policy influence physicians' experiences of diagnostic work?* As the theoretical framework of the study is guided by principles of institutional ethnography (IE), the particular focus is on the social organisation mediating these experiences. IE provides a lens to illuminate the conditions of people's experiences and enhance our understanding of how guidelines are incorporated into practice. The article enters the sociological discussions pertaining to tensions arising with the growing implementation of guidelines regulating professional practice. Specifically, we aim to show how different ruling discourses, articulated in guidelines targeting both precision/individualised diagnosis and rapid diagnosing, intersect and influence physicians diagnostic work.

Diagnostic complexity and regulation of practice

Lawson and Daniel (2011: 403) state that 'one of the most complex problems facing the healthcare profession has been and continues to be that of making correct diagnoses and insuring that optimal treatments follow'. According to Jutel and Nettleton (2011), a diagnosis presents a complex interrelationship between being both a category and a process, whereby both are subject to ongoing changes that are increasingly blurring the lines between healthiness and illness. Characteristic of these developments is the expansion of diagnostic labels to encompass risk factors for diseases, along with the development of new medical technologies to increase the accuracy of diagnoses, consequently affecting both the understanding of diseases and the processes related to diagnostic work.

As such, the diagnostic development is moving towards 'finer-grained and more dynamic taxonomies' (Green et al., 2019: 1) following continued advances in 'precision medicine' (also referred to as 'personalised medicine'), which is 'a form of medicine that uses information about a person's genes, proteins, and environment to prevent, diagnose, and treat disease' (National Cancer Institute, n.d.). Precision medicine is anticipated to be the future of medicine. By enabling medical professionals to accurately identify the underlying mechanisms of a disease, therapeutic interventions may be tailored to match the biological make-up of the individual patient, thus optimising the quality of care (Collins, 2010; Gundert-Remy et al., 2012; Marcon et al., 2018). Precision medicine is deemed especially relevant for cancer treatment due to the vast array of variations between people diagnosed with the same type of cancer, alongside the fact that genetic factors are assumed to play a pivotal role in cancer pathogenesis (Diamandis et al., 2010).

In addition to the evolution of diagnostic tools and technologies related to diagnostic precision and custom-made treatment modalities, medical practice is increasingly regulated through a range

of guidelines, such as clinical practice guidelines and care pathways (Kredo et al., 2016; Nigam, 2012; Timmermans, 2005). Clinical practice guidelines, which are based on expert panels' systematic reviews of available evidence, support decision-making pertaining to diagnostic and treatment processes (Timmermans, 2005). Care pathways, like CPPs, are (usually) anchored in, but are not the same as, clinical practice guidelines. They inform different steps in the care trajectories of patients with specific diagnoses and are more 'explicit about the sequence, timing and provision of interventions' (Kredo et al., 2016: 123) than clinical practice guidelines.

The essential goal of introducing such extensive regulations on health practitioners is to improve consistency, safety, efficiency and the overall quality of care (Kredo et al., 2016). However, given that guidelines 'purport to tell professionals how to conduct their work' (Timmermans & Kolker, 2004: 178), they represent a controversial aspect of medical practice. There are ongoing debates about the extent to which guidelines may undermine professional judgement, discretion and autonomy, which are necessary for accommodating the unique needs of individual patients (Cheraghi-Sohi & Calnan, 2013; Gabbay & Le May, 2004; Greenhalgh, 2002; McDonald et al., 2005; Ponnert & Svennson, 2016; Timmermans, 2005). For example, a study by McDonald et al. (2005) demonstrates that there are diverging views between different groups of professionals, such as nurses and physicians, concerning the relevance of rules and guidelines for quality of care. In their study, nurses' trust and reliance on guidelines clearly outweigh that of physicians who argued that discretion and autonomy are of far greater significance for quality than standardised guidelines.

The development and use of guidelines in health care are inextricably linked to the discourses of evidence-based medicine and new public management (Ponnert & Svennson, 2016; Timmermans, 2005). Hence, multiple actors both inside and outside the medical profession have vested interests in imposing guidelines on health care: for healthcare professionals, they aid decision-making and ensure that their work aligns with the professional standards of the current state of play, while for actors representing powerful institutions such as the state and managed care organisations, guidelines are tools in the quest for increased accountability, efficiency and cost reduction (Nigam, 2012; Timmermans & Kolker, 2004).

Cancer Patient Pathways (CPPs)

Cancer is a leading cause of death with increased prevalence in many countries across the world (Bray et al., 2018). The World Health Organization (WHO) estimates that between 2008 and 2030 there will be a 45% increase in cancer deaths on a global scale, and the number of new cancer cases will grow with a staggering 80% in low-income countries and 40% in high-income countries during the same time period (World Health Organization, n.d.). Hence, cancer has turned into a major public health problem, subject to extensive political scrutiny. Through the collective effort of researchers, politicians and patient activists, optimising cancer care is now a top priority in many countries across the world (Timmermann & Toon, 2012). In Norway, there has been a continuous development of national cancer plans and strategies over the last decades. The aim is to reduce prevalence and mortality, and enhance patient satisfaction, participation, and quality of life. A longstanding ambition, explicitly stated in cancer policies, is that Norway will be a leading example of providing good patient trajectories (Norwegian Ministry of Health & Care Services, 2013; Norwegian Ministry of Health & Care Services, 2018).

Inspired by—and based on—Danish experiences with a similar initiative, the CPPs target the logistical and organisational aspects of the diagnostic trajectory (Norwegian Directorate of Health, 2016a). The CPPs were implemented in 2015, and while being a continuation of the work towards providing

exemplary trajectories, they are also a response to the growing recognition by health professionals that identifying and treating malignant cancers as quickly as possible is significant for improving prognosis (Neal, 2009).

CPPs aspire to enhance the quality of cancer care by providing a well-organised and predictable care trajectory without non-medical delays for potential cancer patients. Therefore, a maximum time limit is assigned to each phase of the diagnostic investigation (see the example for breast cancer below). Hospitals' compliance with these timeframes is monitored through a coding system and systematically documented through monthly reports which are published on a national website. There are no explicit sanctions for breaching these deadlines, but the hospitals' reputations are at stake as these numbers are official and frequently conveyed to the media. There are 28 CPPs for different types of cancer diagnoses (Table 1) (Norwegian Directorate of Health, 2016a).

It is important to note that cancer policies, such as the CPPs, are embedded within a wider health and political context which also impacts the implications of CPPs for practice. In 2009, the Norwegian government released a white paper named *The Coordination Reform* (Norwegian Ministry of Health & Care Services, 2009) that highlights evolving trends relevant to future priorities in the public health-care sector. A key concern is that the growing numbers of both elderly people and people with chronic and complex illness is detrimental to the country's economic carrying capacity. The white paper articulates a political development wherein more money is not considered a sustainable solution to the challenges of future health and welfare services, but rather how to develop, run and organise the health and welfare services are explored as alternatives (Håland & Melby, 2017).

Accordingly, the development of CPPs builds on policies where a focus on logistics and organisation is a core health political strategy. For that reason, CPPs did not trigger more funding to aid the accompanying demand for speeding up the work processes involved in cancer diagnostics—a major argument is that the implementation of CPPs does not increase the workload in terms of adding more patients. The success or failure of meeting these new deadlines rests on healthcare providers' abilities to make logistical adjustments and to coordinate smooth transitions between services.

INSTITUTIONAL ETHNOGRAPHY, TEMPORALITY AND AUTONOMY

This study uses institutional ethnography (IE) to examine the implications of CPPs for professional practice. Because CPPs directly targets the temporal dimension of cancer diagnosing, we also engage with concepts of temporality and temporal capital to bolster the theoretical basis.

TABLE 1 CPP timeframes for breast cancer (Norwegian Directorate of Health, 2016b)

Pathway description	Timeframe
From receipt of referral to first appointment in diagnostic ward	7 calendar days
From first appointment in diagnostic ward until end of diagnostic evaluation (decision is made)	7 calendar days
From end of diagnostic evaluation to start of treatment	
Surgical treatment	13 calendar days
Medical treatment	10 calendar days
From receipt of referral to start of treatment	24/27 calendar days

Institutional ethnography

Institutional ethnography (IE) is a method of inquiry designed for the (inductive) investigation of how the social world is organised, from a specific standpoint within lived experience (Smith, 2005). The primary focus is on discovering the way power and dominance—conceptualised as ruling relations/relations of ruling—shape our everyday reality both explicitly and implicitly (Smith, 1990, 1999, 2005). Ruling relations refer to the social relations that coordinate people's activities from locations in other places. This includes all the various sites engaged in regulating and organising society, such as government bureaucracies and media as well as various professions and discourses of a scientific, technical or cultural nature (Smith, 1990, 1999). In contemporary society, virtually all forms of social organisation and exertions of power are mediated by a variety of texts and documents. Thus, IE pays particular attention to texts, such as guidelines like CPPs, as they provide material links between activities in local and extra-local settings (Smith, 1990, 2005). Importantly, the investigative gaze is always on relations. This entails that people are not perceived as subservient victims of domination. Rather, they actively participate in and (re)produce certain strands of ruling by enacting particular texts, concepts and ideas in their local contexts (Smith, 1999). The concept of ruling relations enables us to discover how textually mediated ideas and principles impact people's lives (Campbell & Gregor, 2004).

IE is gaining increased attention internationally, and there is a growing body of IE literature focusing on different aspects of healthcare (Malachowski et al., 2017). Previous studies have for example generated insights into: the social processes related to the formation of knowledge work in multidisciplinary healthcare teams (Quinlan, 2009), nurses' stress (McGibbon et al., 2010), inequalities in cancer care (Sinding, 2010), the transformation of nurses' work following an update of electronic health records (Campbell & Rankin, 2017), and institutional discourses influencing the work of informal carers (Øydgard, 2017). However, as the majority of IE health studies moves from the standpoint of nurses and patients (Malachowski et al., 2017), studies taking the standpoint of physicians, such as this one, are lacking. Arguably, exploring the standpoint of physicians is both interesting and becoming increasingly more relevant as the autonomy traditionally inherent in their profession appears to be challenged by the ongoing implementation of a tighter managerial/policy control (Evetts, 2002; Flynn, 2002).

Standpoint in IE represents the starting point for exploring how ruling relations shape the experiences of people in a particular setting (Smith, 2005). However, IE is a diverse enterprise and researchers engage with IE from different starting points (Devault & McCoy, 2006). In this study, the CPP policy constitutes the entry point into the work processes and activities of physicians involved in cancer diagnoses. By taking the standpoint of physicians, we explore how their work is shaped by different types of ruling relations, namely different forms of guideline authority in conjunction with professional autonomy in diagnostic work. This article contributes to the field of IE and health sociology by illuminating how diagnostic work is influenced by the intersection between CPPs, clinical practice guidelines (both national and international), overarching healthcare policies (such as The Coordination Reform and cancer care strategies), as well as some of the professional discourses embedded within these textual forms of ruling (e.g. early detection, precision medicine, efficiency and logistics, and defensive medicine).

Temporal capital and regulation of autonomy

The implementation of CPPs has made the relevance of time particularly prominent for what it means to provide quality cancer care, treating cancer as an acute state that calls for immediate action

(Sidenius et al., 2020). Zerubavel (1987) highlights the diverse value placed on time in society, and how the amount of time vested in certain social relationships and activities signifies different meanings in different contexts. He argues that waiting provokes a sense of worthlessness, degradation and a lack of respect, and thus, the act of making people wait conveys that they do not really matter. The longer the wait, the less they matter. He states that 'shorter waiting time entails speed [...] The rapidity with which doctors and nurses attend some patients, for example, is indicative of their relatively high priority to them as emergencies' (Zerubavel, 1987: 345).

In the context of CPPs, time (spent on patients) is sliced into measurable parts subject to monitoring and control which arguably introduces a more precise mechanisation (Sabelis, 2001) of physicians' (and other healthcare providers') time. To put it bluntly, the less time spent on a patient, the better. This is justified by the aim of relieving potential cancer patients of the painful experience of waiting and at the same time improve efficiency. The assumption is that by accelerating the pace from suspicion to diagnosis and treatment, time can be mobilised as an ally to improve prognosis (Neal, 2009). That way, speed becomes a significant symbol of what, or rather *whom*, is deemed important and worthy of prioritisation by the healthcare services, as well as a symbol of quality of care (Zerubavel, 1987).

A relevant concept to better understand the relationship between CPPs shrinking timeframes and physicians' work is 'temporal capital' as introduced by Wang (2013). Complementary to IE, temporal capital connects the utilisation of time to social structures of power as it refers to 'the amount of time individuals or groups have under their control, but is necessarily differentiated given one's position within the relevant hierarchy' (Wang, 2019: 1555). Wang (2013) likens the relationship between time and temporal capital to a pie where time makes up the whole of the pie, while temporal capital is a slice of the pie. And some people have more control over these slices of time than others which makes temporal capital unevenly distributed in and across social sites and can be more or less negotiated depending on the conditions of practice.

Physicians can be perceived as having a large degree of control of this capital due to their position in the medical hierarchy (Wang, 2019). However, as the CPPs introduce a tighter timeframe for physicians to conduct diagnostic work, the policy explicitly carves out the temporal capital available. Thus, temporal capital may also be seen as an expression of the temporal dimension of professional autonomy which refers to individual physicians' 'freedom to exercise their professional judgement in the care and treatment of their patients' (Hashimoto, 2006: 126). The introduction of CPPs implies that there is less temporal flexibility in decision-making and the negotiation of what constitutes appropriate professional judgement in cancer care.

Methods and material

The findings discussed in this article are connected to a larger ongoing collaborative project, using a qualitative cross-sectional design with semi-structured interviews, to evaluate the implementation of CPPs in Norway, across four CPPs: lung, prostate, breast and malign melanoma. The aim of the interviews was to gather information on the participants' subjective definitions and experiences (Brinkmann, 2018), focusing on how health personnel experience the introduction of, and practical work with, CPPs. The sample was selected to include different groups of health personnel with experiences in using CPPs within the four cancer diagnoses and consists of interviews with health personnel working in five hospitals in Norway, including both small and large hospitals from geographical regions across the country. Data were collected from May 2018 to May 2019. This article draws on interviews with physicians. The sample consists of oncologists and physicians working in clinics, surgery, radiology, nuclear medicine, and pathology or who were administrative managers ($N = 27$).

The interviews were carried out by one (8) or two research team members (19).

Both authors participated in interviewing and had access to the entire body of data gathered by the research team. The sample consists of 25 individual interviews and two interviews with physicians in which two administrative workers participated. All interviews were recorded and transcribed verbatim either by the first author (13) or research assistants (14).

Ethical approval for this study was granted by the Norwegian Centre for Research Data (Project number 58,724). All participants received written information about the project prior to interview and signed a consent form.

Data analysis

A crucial aspect of IE analysis is to find a procedure that explicates the workings of ruling relations in the investigated setting. In this study, we analysed the interviews by searching for problematics in the data. Problematics refer to disjunctures in informants' knowledge, namely the researcher's identification of something puzzling or paradoxical in the empirical accounts. They do not necessarily reflect the personal problems experienced and conveyed by the standpoint informants but may be grounded in accounts in the data that reveal tensions or conflicts between different types of knowledge, for instance between formal/authorised and practical/experiential knowledge (Campbell & Gregor, 2004; Rankin, 2017).

The analysis revealed a set of tensions in the work processes related to cancer diagnosis shaped by the intersection of multiple guidelines for cancer care, ultimately challenging CPPs' 'ideal' that a strict, timebound care trajectory equals enhanced quality of care for all cancer patients. These tensions/small problematics informed the conception of an overarching problematic located in the disjuncture between concurrent demands for faster *and* more precise diagnoses. Furthermore, the data were sorted by indexing work related to arriving at a cancer diagnosis. As recommended by Campbell and Gregor (2004), we processed the information and expanded our analysis by alternating between discussing, writing and rewriting the accounts presented in the interviews.

BETWEEN DIAGNOSTIC PRECISION AND RAPID DECISION-MAKING

We labelled the overarching problematic, discovered in the analytic process described above 'between diagnostic precision and rapid decision making', informed by tensions/small problematics termed 'diagnosing cancer; interdependency and demands for collaboration', 'sometimes things take more time: when fixed timeframes collide with complexity' and 'resource management between diagnostic precision and demands of efficiency'. Tensions/small problematics are interconnected and build on each other: we start by explicating the collaborative context of diagnosing cancer as described by our informants, before moving on to describe the tensions between diagnostic complexity and rapid decision-making. This is followed by an associated tension in resource management.

Diagnosing cancer; interdependency and demands for collaboration

Inferring a cancer diagnosis from the symptoms observed is often a stepwise and complex process carried out by specialists from various disciplines (Lawson & Daniel, 2011; Lyratzopoulos et al., 2015). Our data

suggest that diagnostic work is performed along two adjoining dimensions: (a) coordination between various specialist services, namely the selection and organisation of necessary tests; and (b) multidisciplinary communication and mutual recognition of findings. Diagnosis encompasses three disciplinary pillars of investigation: clinical testing, imaging procedures and laboratory testing of cellular tissue.

The CPP guidelines recommend regular multidisciplinary (MDT) meetings to ensure diagnostic precision and quality in treatment (Norwegian Directorate of Health, 2016a). This entails that once the necessary examinations are complete, with descriptions of the conclusions from radiology and pathology, representatives from all the disciplines involved in diagnosis and potential treatment are supposed to convene, discuss the diagnostic implications and suggest appropriate treatment. According to informants, the participants in MDT meetings usually include a medical specialist in the field (e.g. lung doctor, urologist), radiologists, pathologists, surgeons and oncologists. Nurses and secretaries may also be present.

When asked to elaborate on how they establish agreement in MDT meetings, physicians express using a combination of diagnostic guidelines and professional discretion. As one physician puts it:

“Everybody uses that [guidelines from NBCG (Norwegian Breast Cancer Group)], and if you, sort of, have done your homework, at least you have a basis to discuss, so that it doesn't boil down to ‘I mean’ because then, you are actually supposed to mean that which is written in that [guideline], and then you could say ‘yes, but you can't make everything fit, so here, yes that isn't, the size [of the tumour], yes it is this and that advanced, yes, maybe, no, we think it should...’ and then we establish agreement in that [MDT] meeting. And it is mostly the surgeons and oncologists, but the radiologists are the ones with the most knowledge of the findings, and it is the pathologist who describes: what does this tumour represent? Yes, it represents so and so, perhaps she [patient] should have hormone treatment, not chemo...at this stage [in the discussion] you can address everything you deem relevant.”

(Physician 19, hospital 3)

We find that, in diagnosing, physicians draw on knowledge that may be traced to a variety of ruling relations vested in the regulation of cancer care. The statement shows that guidelines are central in diagnostic work and not necessarily perceived as something separate or opposing of professional judgement. Statements from other informants echo that professional judgement (when used correctly) is supposed to align with the regulations for practice. In this case, the informant refers to national guidelines developed by NBCG (2020) which is a breast cancer group constituted by professionals representing different disciplines involved in diagnosing and treating breast cancer. Similarly, other informants describe their reliance on national as well as international guidelines and research from organisations such as The International Society of Urological Cancer (ISUP) and the World Health Organisation (WHO). In addition, they draw upon their own and their colleagues experience which together makes up a complex interplay between formal and informal knowledge that is collaboratively adjusted to best serve each patient's needs. Particularly, in cases of distinct polarisation between opinions, the informants state that the final decisions are often made by those with the most experience, or the person that is actually in charge of the discussed treatment.

This is in accordance with literature suggesting that although guidelines may facilitate effective decision-making processes and promote greater uniformity of practice, they are insufficient when physicians are faced with unique variations between patients; indeed, professional autonomy and discretion is an important mediator when physicians negotiate between different interpretations of a patient's condition and/or need for treatment (Gabbay & Le May, 2004; Greenhalgh, 2002; McDonald et al., 2005; Timmermans, 2005).

Although MDT meetings are described by most physicians in our study as a well-established practice long before the implementation of CPPs, the explicit emphasis on MDT in the CPP policy has placed greater demands on radiologists and pathologists to attend such meetings. This is expressed by some informants as creating a paradox in the sense of being a win–lose situation:

“It takes from our time to go to these meetings and prepare and follow up, foremost to prepare and go to the meetings, it is not like we've had this in our work schedule prior [to CPPs], so you could say in quotation mark that it ‘steals’ time from diagnosing, but having said that, it is important that all the disciplines are present in an MDT meeting because we have a lot to contribute.”

(Physician 15, hospital 3)

MDT meetings are portrayed as important; they enhance the quality of care by ensuring that decisions are informed by various perspectives, are professionally interesting and constitute an important arena for learning. However, as illustrated in the statement, for pathologists and radiologists, the requirement to be present in these meetings on a regular basis is time-consuming, taking time away from diagnostic examinations in already highly pressured areas of the diagnostic trajectory. Radiologists and pathologists often work across multiple pathways in a wider scope than most clinicians. Indeed, in one hospital, a manager (also a physician) of the imaging department explained that they (the radiologists) are supposed to attend between 12 and 15 MDT meetings during the week.

This demonstrates that CPPs regulate physicians' temporal capital (Wang, 2019) towards investing time in collaborative meetings, forcing them to engage in new ways to manage their limited amount of time. It also indicates that CPPs, by demanding both rapid decision-making and comprehensive collaboration in the form of MDT meetings, may generate conflicting quality priorities. On the one hand, they improve quality by allowing representatives from each discipline to elaborate upon their findings and viewpoints, creating a comprehensive foundation for decision-making. On the other hand, considering that rapidity is regarded as crucial, the extensive amount of time required by certain professions may adversely impact quality by taking resources away from laboratory work processes.

Sometimes things take more time: When fixed timeframes collide with complexity

The interview accounts in our study provide a complex picture of overlapping processes and negotiations that shape the work related to diagnosing cancer. It is evident that much diagnostic work can be accomplished within a streamlined and predictable organisation of events, in compliance with both CPP and clinical guidelines. However,—by following the principles of IE (Smith, 1990, 1999, 2005) to search for tensions in the data and examine the social organisation of diagnostic work—we find that there is a parallel dimension of contemplations and problems related to change and unpredictability that is deeply embedded in practitioners' daily work.

Physicians express that the CPP timeframes are on a collision course with the dynamic development of new technologies for detection and treatment, and the ongoing changes in national clinical practice guidelines. Accordingly, some speak of CPP timeframes as provoking ‘a loyalty squeeze’ between the desire to comply with the timeframes and the desire to achieve diagnostic precision. One physician says:

“Then there is often, at the MDT meeting, that we see, or discuss ‘perhaps we should do an MR on this one’, we won’t get that the next day, perhaps we can get it after a week, then we do an MR examination and then we surprisingly find ‘Oops, there is cancer in the opposite breast as well’, then she [the patient] has to come for new testing, and she has to be discussed at a new MDT meeting, which will result in poor numbers. On the other side one could have said, if one thinks very... being the good girl in class, let’s skip that MR test, the probability is low, we don’t have time, the numbers will be poor, there is a long wait for MR, and then we just put it straight through to surgery, the numbers will be fine. I don’t think the patient will appreciate that.”

(Physician 10, hospital 3)

The physician conveys that there are often discussions related to doubt over whether there is enough evidence to establish the scope of the patient’s disease. Addressing these doubts poses certain consequences which may conflict with CPP timeframes. The experience of being caught in a loyalty conflict between diagnostic precision and compliance with timeframes suggests that an interesting contradiction emerges in the context of time-based monitoring. Namely, that the political interests of the hospital/government may be detrimental to both professional judgement and quality of care, considering that ‘being the good girl in class’—which is a recurring statement in the interviews with reference to CPPs—connotes reaching deadlines rather than a nuanced and thorough professional approach.

The informants express that shrinking timeframes (CPPs) coupled with changes to the diagnostic criteria outlined in the clinical practice guidelines are difficult to balance. Two physicians, both working with the CPP related to malignant melanoma, illustrate how changes in diagnostic procedures amplify the workload in a way that impacts the temporal aspect of diagnostic work:

“There has been a change in the regulations of who shall receive sentinel node diagnostics, it has dropped to even thinner melanomas, that is, even earlier stages will have sentinel node diagnostics. This is rather traumatic when it comes to resources for us in the plastic surgery department because it means that we can’t simply do it [surgery] in the polyclinic and that extra little piece of skin, now they [patients] have to first be subjected to a radioactive examination to find the lymph node, and we have to book an operating room because it can be more challenging to find such a knot, and it is painful for the patient: he or she must undergo anaesthesia. So, the things we used to be able to do three of in one hour, we now need three hours... or spend a long time in the operating room.”

(Physician 2, hospital 1)

“There are a lot more now, so in that sense we get more patients, yes, but especially, we get more work due to the fact that more people fall within that kind of diagnostic package.”

(Physician 26, hospital 5)

The statements reveal that cancer diagnosis is evolving both as a process and a category (Jutel & Nettleton, 2011)—the criteria for diagnostic testing are changing so that more patients will be included, while the scope of examination increases. Both aspects create more work: greater quantity, as the number of patients and the number of examinations for each patient are growing; and greater demand for precision, which requires more comprehensive examinations. There are two significant ruling discourses involved in the formation of the experiences exemplified above: the idea that early detection yields greater

prognosis for survival (Neal, 2009), and the idea that the best way to cure cancer is through precision/personalised medicine (Diamandis et al., 2010).

Precision medicine, in terms of finding the best treatment to match the genetics of each patient, alters the workload in the laboratory as well. The informants report increased demands for what they termed 'special examinations' that provide 'greater diagnostic opportunities' by enabling physicians to classify subtypes of cancer and detect metastases. These special examinations are described as comprehensive testing, often requiring additional rounds of testing depending upon the quality of the material sent to the laboratory. Frequently patients must undergo extra biopsies so the pathologists can attain an adequate amount of material with which to work.

One physician (pathologist) describes it in the following manner:

"Then [after the pathologist receives the processed tissue sample] this cycle may start all over again because maybe we didn't see, I mean, we don't know how complex a sample is before we see it in the microscope; often we need special examinations and then we have to send an order back to the lab [and say] 'you have to cut more cuts' or maybe even all the way back to the macro-cutting and the initial handling of the tissue and say that 'I need more, I haven't seen enough, you have to take more outwards to the resection rand, to the rand, or to the edges of the preparation, or I don't have enough tumour tissue, we couldn't find the tumour, we have to make a new search'. So, there may be several rounds performed at the different stations."

(Physician 11, hospital 3)

This highlights the complexity and uncertainty associated with calculating exactly how much time is required to make accurate diagnosis. In addition, physicians explain that not all diagnostic modalities that are necessary for diagnostic precision are available in the hospital where they work. Therefore, tissue blocks are shipped back and forth across locations before findings can be included in the final report, which requires that there is some temporal flexibility to work with.

Clearly, cancer diagnoses rest upon an intricate interaction between actors across locations and sometimes even across hospitals. Physicians are negotiating the disjuncture between the demands of complex, time-consuming tests and procedures necessary to achieve diagnostic precision *and* the demands of compliance with timeframes. Considering the notion that waiting symbolises low priority (Zerubavel, 1987), the findings of this study suggest, on the contrary, that the 'dreaded' waiting time imposed on (some) patients might signify dedication, vested time and respect. Sometimes it takes more time to figure out how to best help the patient.

Resource management between diagnostic precision and demands of efficiency

As mention in the introduction, the CPPs are connected to a wider health political goal, outlined in, for example, The Coordination Reform, which focuses on altered logistics to improve health and care services (Norwegian Ministry of Health & Care Services, 2009). We find that the disjuncture (Smith, 1990) between CPP timeframes and diagnostic precision is closely tied to the predicament of how to manage resources. Challenges related to pathway duration and limited availability and accessibility of technology and expertise were frequently brought up in the interviews.

Physicians report that the desire to obtain both diagnostic precision and meet CPP timeframes requires new time-saving tactics to circumvent the long waiting times faced by patients referred to diagnostic technologies. One such strategy involves the ordering of multiple tests at once to obtain a comprehensive image of the patient's illness, within the CPP timeframe. Several physicians

underscore that narrow timeframes, in combination with logistical challenges in the imaging sections of the hospitals, cause physicians to bypass a stepwise collaborative thinking process, thereby putting many patients through unnecessary examinations. This development troubles a physician in a nuclear medicine department. As a nuclear radiologist, she is on the receiving end of referrals for PET scans:

Physician: So, it creates excess exposure to radiation for the patient, extra expenses for society, cost, and it is unnecessary for the patient, perhaps, a young patient, a 30-year-old should not go through CT and PET if it is not necessary because it creates double the amount of radiation dosage, but in order to make the two weeks [in the CPPs] they refer simultaneously, and that is unfortunate.

Interviewer: That is a good point, yes.

Physician: Yes, it's unfortunate, in the old days, they [clinicians] would first refer [patients] to CT, if that didn't provide a clear answer then a PET scan would be ordered, it was like CT doesn't provide a clear answer, what does PET show? It's not like that anymore.

Interviewer: I understand, you just add on to make sure that you will get it in due time...

Physician: We probably conduct 30 per cent more PET scans now, which is costly and exposes them [patients] to radiation.

(Physician 12, hospital 3)

The physician emphasises the ramifications of multiple referrals across individual and collective factors. The practice poses a potentially unnecessary risk factor in terms of irradiations for the person as well as a waste of collective financial resources. The excerpt illustrates how the implementation of CPP timeframes alters practice, as diminished temporal flexibility drives the cultivation of new tactics for bypassing time-consuming mechanisms, including both waiting times for examinations as well as multiple rounds of collaborative discussions. The intention is to gather as much data about the patient's illness as quickly as possible to reach the most precise diagnostic conclusion within the assigned timeframe. However, as the nuclear radiologists warned, this practice comes at a price, affecting both the individual patient and society in general.

Excess testing (and overtreatment) is a highly prevalent and much debated topic, conceptualised as 'defensive medicine', which is presumed to be propelled by physicians' fear of liability as well as a general lack of tolerance for both uncertainty and failure that permeates both the larger medical culture and Western culture in general (Hoffmann & Kanzaria, 2014). Similarly, Schattner (2008) argues that the ordering of unnecessary diagnostic tests is a costly and growing problem that may adversely affect healthcare quality by causing excess waiting times for other patients in greater need of the same tests. The direct association between the implementation of CPPs and increased excess testing noted by our informants indicates that the CPPs' guidelines may push medical professionals towards a more unbalanced and undiscerning approach to diagnostic testing.

Correspondingly, Hofmann and Welch (2017: 1) note that advances in medical technologies are accompanied by unintended harm, such as 'false alarms and indeterminate findings that can worry patients, drive more testing, increase clinical workload, and distract clinicians from more important work'. Discussing the importance of access to medical technology, one physician provides an interesting observation. He explains that a major argument for attaining the funds to establish a PET scanner in their hospital was the inconvenience and logistical challenges associated with sending patients to various locations to undergo the necessary examinations. The idea was that greater accessibility would reduce pressure and waiting times. Reflecting upon this, he describes a different outcome from the one he expected:

Physician: We discovered that time didn't go down, because we, when we had it [the PET scanner] locally we sent a larger number of patients who we selected, you could say we [used to] select the most appropriate [candidates] for transfer to [another hospital], the others maybe we didn't reflect as much upon, while when we had it locally, in this building, it became quick and easy to send them in and we would find a lot more, we had to spend a lot more time examining other issues we found.

Interviewer: You mean, except cancer, or still cancer?

Physician: Yes, with a PET scanner you find a lot of spots here and there, and then you have to make further examinations to find out whether they [patients] have cancer or not, so it yields more examinations, but I think it provides more accurate treatment.

This shows the unpredictable relationship between resources, workload and efforts to reduce waiting times for patients. The experience aligns with other accounts of how greater sensitivity in diagnosis and treatment generates more work. Other informants similarly emphasise that this is a welcome development that signals professional progress and greater patient care.

Much of the work discussed by our informants pertains to resource management, necessary diagnostic modalities, and places where it is possible to make cuts and adjustments. Therefore, resources, or a lack thereof, were highlighted as a major barrier to achieving faster diagnostic assessment, with the respondents consistently arguing that either the CPP timeframes need to be extended or something in the diagnostic process needs to be dropped, lest the system collapse.

CONCLUDING REMARKS

A hallmark of contemporary healthcare is the growing cultivation of diagnostic precision and the regulation of practice through a diverse range of guidelines (Green et al., 2019; Kredon et al., 2016; Timmermans, 2005; Timmermans & Kolker, 2004). Existing literature stress that the use of guidelines among medical professionals has been overestimated, as research demonstrates that guidelines are in themselves insufficient for altering established practices and that individual autonomy outweighs guidelines in terms of significance for practice (Gabbay & Le May, 2004; Greenhalgh, 2002; McDonald et al., 2005; Timmermans, 2005). Contributing to this body of literature within health sociology, our study finds that physicians express that guidelines are both welcomed and essential, yet there is a distinct or more expansive stock of knowledge that is drawn upon to a greater extent in ambiguous cases that remains unaccounted for by the guidelines.

Guided by the principles of IE, this study contributes to knowledge of the complex social organisation of diagnostic work, and how this work is shaped and negotiated by ruling relations through different types of (conflicting) guidelines. Thus, IE has provided us with an analytical lens enabling us to discover and investigate tensions and dilemmas in the interface between multiple guidelines and diagnostic work, expanding existing knowledge in this field. Using IE, this study has revealed that diverse social processes (interests) targeting cancer care management are proving increasingly difficult to balance, compelling medical professionals to negotiate between two types of guidelines: one demanding rapid decision-making (CPPs) and one demanding diagnostic precision (clinical practice guidelines). Furthermore, in cases where guidelines present conflicting demands, physicians rely on their professional autonomy and discretion to prioritise clinical guidelines over CPP guidelines, thus justifying the breaching of CPP timeframes. CPPs play into the very core of professional practice—the possibility of governing and prioritising professionals' own time—and represent a regulation of their temporal capital (Wang, 2013). However, physicians' professional autonomy and discretion, and high position in the medical hierarchy, enable them to 'reclaim' the power of their temporal capital and,

to some extent, prioritise their time as they find medically appropriate. Thus, contrary to previous research in this field (see for example McDonald et al., 2005), we find that physicians do not reject guidelines, but interact with and negotiate between them, however, finding themselves in a 'squeeze' between different targets to an even greater extent than before.

Importantly, clinical practice guidelines are just one of many aspects of cancer care subject to continuous change according to the accumulation of new knowledge and technological advances, complicating the work processes related to cancer diagnostics. Our findings suggest that CPP timeframes are already pushing the boundaries of what it is possible to accomplish with the resources currently available. The pervasive (ruling) emphasis on the importance of both precise and rapid diagnostic assessment creates a situation in which medical professionals must negotiate between conflicting priority demands. Ultimately, these tensions pertain to values concerning what should count as quality of care. The tensions also raise some questions: will physicians always be able to prioritise one over the other? Is it always the right priority? More importantly, who should decide what is most important for quality?

Given that CPPs represent a relatively new reform in Norway, more research into the numerous aspects of work involved in making cancer diagnoses within this framework is required to gain further insights into its consequences for practice. As modern health care is increasingly relying on evidence-based medicine and the regulation of medical practice through guidelines, knowledge regarding the interface of multiple guidelines and their ramifications for practice is crucial in order to expand the sociological understandings of politics, power and professional work.

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CONFLICT OF INTEREST

None.

AUTHOR CONTRIBUTION

Siri Christine Kvermo Næss: Conceptualization (lead); Data curation (equal); Formal analysis (lead); Funding acquisition (supporting); Investigation (equal); Methodology (lead); Project administration (supporting); Resources (equal); Software (equal); Supervision (supporting); Validation (equal); Visualization (equal); Writing-original draft (lead); Writing-review & editing (lead). **Erna Håland:** Conceptualization (supporting); Data curation (equal); Formal analysis (supporting); Funding acquisition (lead); Investigation (equal); Methodology (supporting); Project administration (lead); Resources (equal); Software (equal); Supervision (lead); Validation (equal); Visualization (equal); Writing-original draft (supporting); Writing-review & editing (supporting).

DATA AVAILABILITY STATEMENT

Data consists of interviews and cannot be shared due to ethical reasons/anonymity reasons.

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Article III

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“Don’t freak out if you get a letter saying cancer patient pathways!”: Communication work in cancer care

Abstract

This article explores the experiences of healthcare professionals in their work with patient communication in standardised cancer patient pathways (CPPs). The theoretical and methodological framework for this study is institutional ethnography. Data were collected through semi-structured interviews with 72 healthcare professionals, including general practitioners, specialist physicians and other hospital staff, in five Norwegian hospitals. The study reveals four aspects of communication work that illuminate how the CPP policy mediates the way healthcare professionals interact with patients through communicating continuity, communicating (by dodging) the dreaded C-word, communicating patient participation, and communicating the relevance of time. Healthcare professionals balancing their different experiential realities run as a common thread through the four aspects of communication work identified in this study. The CPP policy, with its explicit focus on transparency, speed, and time frames creates challenges in an already delicate situation.

Keywords: cancer, standardised cancer pathways, communication work, patient-centred care, institutional ethnography

Introduction

Providing high quality care is directed towards continually improving healthcare within the multiple, seemingly contradictory, ideals that shape the notion of what healthcare actually is (Grol et al., 2008). A prominent trend clusters around the discourse of patient-centred care, and the relationship between patients and their care providers. ‘Patient-centred care’ is rooted in a holistic approach to care that focuses on the interplay between biological, psychological, and social factors that contribute to health conditions (Mead and Bower, 2000). It is a broad term that signals a philosophy of care that caters to the unique needs and wishes of the individual patient (Fix et al., 2018). Healthcare professionals are, to an increasing extent expected to build a partner-like relationship with their patients (Beedholm and Frederiksen, 2019). A crucial part of this relational work concerns communication. Caregivers are expected to provide adequate information about all aspects of the condition, encourage patient participation and choice in decisions about their care, and be attentive and considerate of the subjective perspectives and experiences of the patient (Mazor et al., 2013; Mead and Bower, 2000).

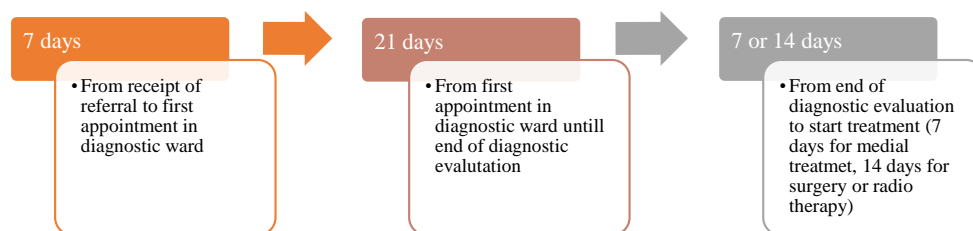
A potentially conflicting trend involves different forms of bureaucratic control and guidelines that regulate clinical practice (Timmermans, 2005). Clinical practice guidelines and care pathways represent two types of guideline that target distinct aspects of care. Clinical practice guidelines emanate from the discourse of evidence-based medicine (EBM) and provide diagnostic and treatment recommendations based on best-available scientific evidence (Kredo et al., 2016). Care pathways function as an extension of clinical practice guidelines and concern the logistics, i.e., “the sequence, timing and provision of interventions” (Kredo et al., 2016: 123). As care pathways aim to promote standardised and efficient care, they may pose a challenge in achieving patient-centred communication. This makes care pathways worthy of study. In this article, as part of a larger study, I explore *how healthcare professionals experience their work with patient communication in the context of standardized cancer patient pathways (CPPs)*. My study is inspired by institutional ethnography. I aim to trace aspects of the social organisation that mediate this work, with the primary emphasis on how the CPPs—as ruling text—inform the way healthcare professionals communicate with patients.

Cancer patient pathways in Norway

The Norwegian health authorities introduced CPP a national cancer policy in 2015. The policy targets the logistics and organisation of cancer care services. Currently, there are 28 pathways for different cancer diagnoses. The policy is anchored in clinical practice guidelines but address the timeliness of care by establishing maximum time frames for the diagnostic process, i.e., from the moment the hospital receives a referral to the starting point of treatment (Figure 1). These time frames are monitored through a coding system and published on a national webpage. This policy places time as a core quality indicator in cancer care (Norwegian Directorate of Health, 2016a).

Figure 1

Example of CPP Time Frames for Lung Cancer (Norwegian Directorate of Health, 2016b).



A new position entitled ‘cancer pathway coordinator’, occupied by nurses or secretaries, was created following the introduction of CPPs. I refer to this group of professionals strictly as ‘coordinators’. The coordinators are responsible for making appointments for diagnostic testing, informing patients about their appointments and monitoring and coding the CPP timeframes (Håland and Melby, 2021).

Most CPPs are initiated through a referral letter from a general practitioner (GP) to the hospital requesting a diagnostic assessment. Within the hospital, coordinators, nurses and specialist physicians (such as clinicians, radiologists, nuclear radiologists, surgeons, pathologists) must cooperate to ensure smooth and timely transitions between the various departments within and across hospitals (Author, 2021). The diagnostic process culminates in a multidisciplinary team (MDT) meeting where the staff involved meet to discuss diagnosis and treatment alternatives (Author, 2021).

The CPP documents also emphasise the principles of patient-centred care by declaring that all patients shall be provided with an individualised care trajectory that considers the patient’s

wants, needs, and individual situation. As such, information, communication, and dialogue are defined as an important part of the CPPs. Håland and Melby (2017) outline how the CPP policy builds on the two opposing discourses of standardisation and individualisation. Standardisation refers to processes that organise practice towards greater efficiency, predictability, and equality in treating patients, with specific guidelines dictating how things should be done and in what order. Individualisation refers to processes found in the patient-centred approach, such as patient participation, shared decision-making, and personalised treatment modalities (Håland and Melby, 2017).

Thus, healthcare professionals must accommodate what may seem like the best of two distinct worlds. How to achieve this is not, however, neatly packaged and delivered in a straightforward procedure. It requires a delicate balance of discretionary judgement. As Timmermans and Epstein (2010: 84) warn, there is a great chance that “one person’s much needed standard causes another person’s suffering”. This underscores the importance of placing good communication at the heart of the clinical encounter. It is the key to establishing mutual understanding and ascertaining the needs and desires of individual patients (Ha et al., 2010; King and Hoppe, 2013).

Patient-centred communication

A large body of research attests to the relevance of communication in the clinical encounter for patients’ health and well-being (Arora, 2003; King and Hoppe, 2013; Ong et al., 2000). Studies indicate that patient-centred communication positively influences the quality of care across a variety of dimensions, including increased patient satisfaction, adherence to treatment and improvements in both physical and psychosocial aspects of health (Groves, 2010; Mazor et al., 2013; Street et al., 2009). Patient-centred communication is a powerful medium because of its multidimensional potential to influence the patient’s experience. It is communication that aims to nurture the relationships between patients and their professional caretakers; understand the patient’s perspective, needs, and social context; balance emotions and insecurities; make medical information understandable; and that empowers the patient to participate in important decisions about their care (Ha et al., 2010; McCormack et al., 2011).

It could be argued that patient-centred communication is particularly relevant in the context of cancer care due to the often serious and disruptive nature of cancer diagnoses (Arora, 2003; Hansen et al., 2018; Markides, 2011). It is also an aspect of healthcare where inadequate

communication is regarded as a widespread problem (Thorne et al., 2005). As Fagerlind et al. (2008) note, a lack of continuity, due to the many different healthcare professionals involved, is a barrier to successful communication, and patients in general desire more information and more psychosocial and emotional support than they receive.

Much is written about the difficulties that the medical profession has with transparency and truth-telling in disclosing “sad, bad and difficult news” (Fallowfield and Jenkins, 2004: 312). Although there is a move towards greater transparency in medical practice, it is still common for physicians to conceal information from patients about cancer diagnoses and prognoses (Panagopoulou et al., 2008). De Giorgi et al. (2008) assert that many physicians have limited training in talking to patients about difficult topics, such as cancer, and that there are many reasons why certain information is concealed; the patient may not be receptive, or physicians may try to protect patients from psychological distress. However, physicians may also conceal negative information to protect themselves from the emotional distress associated with having to deliver bad news.

Disclosure of information is at the heart of the ideology that promotes patient participation and a more even distribution of power between patients and medical professionals. Notions of patient participation draw on a variety of discourses related to patient autonomy (Quill and Brody, 1996), empowerment (Schneider-Kamp and Askegaard, 2020), consumerism and citizenship (McDonald et al., 2007). In short, these discourses promote the patient’s rights, freedom and competence to be actively involved in all aspects of their care—the actualisation of which hinges on truthful and transparent disclosure of information (Zolkefli, 2018).

Although it is widely accepted that participation is beneficial for patients, empirical evidence suggests that there is a gap between the ideal of participation and the reality of actual practice (Angel and Frederiksen, 2015). In a literature review of health professionals’ perceptions of shared decision-making, Gravel et al. (2006: para 13) identify multiple factors that can present as barriers to patient participation. These range from attitudes and characteristics of both professionals and patients to structural factors, such as “time constraints” and “lack of applicability to the clinical situation”. Solbjør and Steinsbekk (2011: e148) find that although many healthcare professionals value patients’ perspectives and knowledge, they value their own professional knowledge more, “thereby maintaining the hierarchical relation”. Hsieh et al. (2016)

demonstrate how physicians use patient-centered language and perspectives to control patients' preferences and needs. Notably, studies examining patients' preferences for participation in cancer care paint a complex picture of wide variation in patients' desired levels of participation. (Gattellari et al., 2001; Keating et al., 2010; Sinding et al., 2010; Thorne et al., 2013).

Theory and methods

The findings of this article are based on data from qualitative interviews with healthcare professionals working in both primary and specialist care. The study is part of a larger research project evaluating the experience of introducing CPPs from the perspectives of patients and healthcare professionals. The Research Council of Norway and NTNU funded the project (project number 272665). In this article, I explore the experiences of healthcare professionals' work with patient communication in CPPs. The theoretical and methodological framework guiding my contribution to the project is institutional ethnography.

Institutional ethnography (IE)

Sociologist Dorothy Smith developed IE as a methodological approach to uncover the workings of social reality (Smith, 2005; Smith, 1999). IE is based in an ontology that locates the existence of the social in the ongoing orchestration of people's everyday activities. A key premise is that people's activities and interactions are embedded in what Smith (2005) calls the 'ruling relations'. Ruling relations refers to the textually-coordinated interconnectedness of human activity as it happens across time and place. Ruling relations, thus, have a translocal nature. The goal of IE is to discover how different ruling relations shape people's everyday activities. The path to discovery begins in someone's everyday experience: a standpoint. Starting in experience establishes a viewpoint from which it is possible to find traces of the ruling relations that shape (some aspects of) people's lives. Further, the researcher can follow these traces into sites beyond the location of the standpoint informants to illuminate how people's activities in a setting happen the way they do (Smith, 2006b).

Since my study was carried out as part of a larger project, I modified the use of IE to accommodate my research context. This means that IE guided the analysis of the interview material to a greater extent than the data collection process. I had a specific text-based form of ruling (CPPs) as a premeditated focus for the study. I chose to begin the analysis within the

experience of physicians. Because physicians in this study represent a diverse group of medical professionals, they work in different locations across the institutional setting.

To enhance the understanding of the work involved in patient communication beyond the standpoint informants' experience (Campbell and Gregor, 2004), I included interviews with nurses, cancer pathway coordinators and administrative staff. Surely qualitative interviews do not directly access work processes as they happen in real life but provide insight into people's accounts, perspectives and experiences of their work. Although many IE studies draw on observational data, interviews are, according to Smith (2005), crucial to access lived experience.

Data collection and analysis

The article draws on semi-structured qualitative interviews, conducted from May 2018 to January 2020, with a total of 72 healthcare professionals. Ethical approval was obtained from the Norwegian Center for Research Data (Project number 58724). The research group interviewed multiple healthcare professionals working in different hospital departments across five geographical regions. This is consistent with IE's focus on interconnected work processes (DeVault and McCoy, 2006). We concentrated our study on four CPPs: lung, prostate, breast and malignant melanoma. Informants were recruited using a combination of purposive and snowball sampling (MacDougall and Fudge, 2001). We ensured that all potential informants received both written and verbal information about the study, and those who agreed to participate signed a consent form.

The sample consisted of 12 GPs and 60 hospital staff working across five hospitals in Norway, both local and university hospitals. It included 27 specialist physicians (clinicians, surgeons, radiologists, nuclear radiologists, pathologists and administrative managers) as well as 11 nurses, 14 cancer pathway coordinators and eight administrative managers. The research team conducted 57 individual interviews with hospital staff, whereas three interviews were conducted with two informants at the same time. Four of the interviews with GPs were conducted as group interviews, whereas one GP was interviewed individually. The author conducted three group interviews, one dyadic interview and 21 individual interviews alone or with a research team member, while other research team members conducted the other interviews. All interviews were recorded, transcribed verbatim and anonymised.

IE researchers work with their data in diverse ways with a common aim to illuminate how everyday experience is shaped within translocal relations (Campbell and Gregor, 2004; Smith, 2006a). In the analysis of the interview material, I sought to identify how the informants' work processes were shaped by ruling relations and discourses. Discourses are part of the ruling relations and, in short, refer to contextually-regulated collective understandings and practices. I used IE's concept of 'problematic' as a key analytical tool. A problematic is often based on the identification of junctures or tensions—between what is actually done and translocal relations—that the researcher finds valuable to explore (Smith, 2005).

After identifying patient communication as an important aspect to explore, data were further analysed by extracting all reports (including those from other health professionals) that were relevant to patient communication under the heading: communication work. I used Smith's (2005) "generous" notion of work, which includes all forms of activity that take time and effort. This means that thoughts, feelings and talk, on a par with concrete actions, can also be defined as 'work'. Statements were sorted by indexing different types of communication work and small problematics that were found in the data (source). Importantly, the analytical process proceeded in an interplay between reading, writing, reading and rewriting, looking for traces of ruling relations (Campbell and Gregor, 2004; DeVault and McCoy, 2006).

Communication work: A balancing act

I have named the overarching problematic "communication work: a balancing act between biomedical, psychosocial and political realities." This is meant to capture the tension between different forms of knowledge that come into play while healthcare professionals work to establish good communication with patients in a system that is designed to move as quickly as possible. The problematic is informed by four themes pointing to different aspects of communication work in standardised care pathways: (1) communicating to ensure continuity; (2) communicating (by dodging) the dreaded C-word; (3) communicating patient participation; and (4) communicating the relevance of time. Each are discussed in turn.

Communicating continuity

A central aim of the CPP policy is to ensure continuity and predictability in the diagnostic process (Norwegian Directorate of Health, 2016a). Consistently, the informants in this study

emphasise that providing information to the patient about what, how, why, and when things will happen is more important for continuity than fixed time frames. A shared experience among informants is that the CPPs has made it “easier” to communicate in a more consistent manner, as healthcare professionals working in different locations are more tuned into each other’s work processes. As one physician states:

It is easier to get the patient through... and... we think more alike, many of us in the organisation, it is easier to cooperate between departments because we agree that this is how we do things, with the patients... (Physician 13, hospital 1)

This suggests that healthcare professionals’ engagement with the CPPs synchronises their activities across locations (Smith, 2005). The interviews reveal that the work of communicating continuity relies on both consistent interdisciplinary interaction and a clear distribution of communicative responsibilities between healthcare personnel. Coordinators and nurses are responsible for conveying logistical and practical information about time, place and the preparation for examinations, while physicians deliver information of a medical/technical nature (e.g., diagnosis and treatment).

Nurses state that they work to create continuity by being present with the patient in consultations with the physicians, and by talking with the coordinators (and physicians) about what is needed, what has been said, what is being planned and when. After the medical consultation, the nurses continue the dialogue with the patient to provide detailed information about the events to follow. Thus, nurses ensure continuity across both practical and medical information and events. They also stress the importance of a compassion-based approach. This includes taking the time to listen and map out the patients’ personal situation and provide a phone number that the patient can call if they need to talk outside of the scheduled appointments. One nurse describes communicating continuity as a process:

We give them everything we have of forms, give them the brochures, we have a book where we write down what they have received of information, how they reacted, what their family situation is, if they have a job, and then we call them the Tuesday after they received the diagnosis just to check in with how they’re doing and how they’re feeling because then it [the diagnosis] is a bit more processed...because the day they receive the

diagnosis, I mean, it is so much [to take in] that they shut down and just want to go home.

(Nurse 55, hospital 3)

As noted above, continuity in communication is a method to monitor the patient's emotional and psychological well-being in connection with the processing of information. Nurses make sure patients receive information they can digest over time by providing them with written information, such as brochures, about the disease and upcoming treatment, and routinely call patients to check how they are doing. A vital aspect of nurses' continuity work involves communicating their availability. As one nurse puts it:

I tell them [patients] that if there is anything they want to talk about, they can call us.

(Nurse 18, hospital 1)

This reveals a more nuanced approach to the temporal dimension of continuity than time frames. As cancer is often a distressing life-changing event (Mazor et al., 2013), repeated communication over time in accordance with the processing of each patient's care is crucial. However, physicians comment that their schedule is so tightly organised that they simply do not have time to engage with patients outside the confines of scheduled appointments. One physician explains:

I have to deal with the patients that are here, in the hospital, I can't sit half a day talking [on the phone] with patients that are not inside the hospital, although I do understand that they [patients] want that, and their GP wants that because they don't have the details, this is advanced stuff, but...then the hospital needs to organise it.... (Physician 48, hospital 2)

This implies that, for physicians, the demand for medical expertise take precedence over the psychological and emotional well-being of patients. Physicians must rely on other healthcare personnel (such as nurses and coordinators) to create continuity through communication by filling in the gaps in patient-physician interactions. However, nurses and coordinators reported that continuity sometimes breaks down due to a lack of communication from physicians. A nurse remarks:

It is unfortunate [...] I call the patient and say, "you have an appointment in two days" and the patient questions why. "Do I have cancer now?" And it is not my job to inform about that, the doctor should have informed the patient and said, "you have a serious

diagnosis and you will receive an appointment with the oncologist.” (Nurse 72, hospital 5)

In the situation depicted above, the patient’s cancer diagnosis has been identified and the referral for medical treatment has been generated without first informing the patient. This is a breach of the CPP guidelines’ emphasis on patient involvement in decision-making (Norwegian Directorate of Health, 2016a), which puts the nurse in a difficult situation when calling to inform about the upcoming appointment. It is not part of a nurse’s job description to disclose a diagnosis. Other informants report similar experiences along the pathways. For example, coordinators mention that they frequently encounter patients who do not know that they have been referred for diagnostic assessment. Informants argue that this is an area in need of improvement; to further enhance continuity, physicians must consistently make sure that their patients are informed before sending the referral. It is also desirable that they relay (to other healthcare personnel) what kind of information has been disclosed to the patient.

Communicating (by dodging) the dreaded c-word

Before the CPPs were introduced, then you would say to the patient that “we found something that we need to figure out,” right, “we are not quite sure what it is...” right, but once you’ve said the C-word.... (Physician 17, hospital 1)

The quote above suggests that there is something about the CPPs’ reference to the word cancer that triggers a change in the communication with patients. This is tied to the CPPs guideline stating that patients shall be informed about being referred to a CPP (Norwegian Directorate of Health, 2016a). When informants discuss the relevance of providing patients with information about CPPs, the dilemma of truth-telling in medical practice come into play (Zolkefli, 2018; Buckman, 1996). As one coordinator says it:

There are a lot of patients, and I think there are many that still don’t know that there is this thing called CPP and that there is a coordinator who is there and that can help them if they have any questions (Coordinator 58, hospital, 3)

With few exceptions, informants across all professions express the view that information about CPPs is not a priority when communicating with patients. The interviews indicate that there is a lack of clarity regarding who is responsible for informing patients about CPPs. Hospital staff

argue that it is the GP's task to inform patients about the CPPs upon referral to the hospital, thus hospital staff assume that if patients know about CPPs it is because they have been informed by their GPs.

Talking about the CPPs with patients is described as challenging because it contains the word *cancer*, which anticipates a diagnosis. Informants state that there is a pervasive fear associated with cancer in society that triggers a distress on the part of both themselves and their patients. GP 3 illustrates this when he says that: "cancer is a demanding field to be in because "cancer, or cancerphobia, it's like a ghost, constantly haunting patients, and society... so it is a demanding field to be in." The GPs underscore that being referred to a CPP can be a frightening experience for many patients, and they do not want the patient to leave their office more afraid than they were on entering. Because there is so much fear associated with cancer, information must be tailored to fit the psychological make-up of each patient, as people have different thresholds for what they can manage. One GP elaborates:

I guess it depends on the patient, if I know that this is a frail leaf, she'll fall to the ground if I use the word cancer, then I don't, but I use the word pathway and explain that within this number of days, you are supposed to be scheduled for a conversation and examination [at the hospital] and a plan will be made. And I do say that I can't rule out cancer, or I say that unfortunately I suspect that it could be something serious. (GP 7)

The GP above describes a strategy, shared by other GPs, of excluding the word 'cancer' in favour of the word 'pathway' when managing uncertainties about the patient's symptoms or what information is appropriate in the specific situation. However, some GPs did state that they are more open with patients when they suspect cancer. One GP outlines her tactic when referring patients to a CPP in the following manner:

[...] Now in many places in Norway, you can read the referral that your doctor has written about you when you log on [to a digital health platform], so you must be very cautious about what you write so you don't increase the [patient's] worrying. Therefore, before it was easy to be misunderstood, because you're kind of trying to wrap it in, but it still could be cancer, and you don't want to write the word cancer... so now I've kind of just checked off for CPP [a check-box in the referral document], written cancer in the text and told the patient "don't freak out if you get a letter saying cancer patient pathways

because that is a trick we use to get you in fast, and you do want to know if this is something or not, fast, right?” And they just say, “yes I would like that.” (GP 1)

Thus, CPPs seem to create a dilemma in relation to truth disclosure in the patient–physician communication, precisely because of the need to introduce the word ‘cancer’ somewhat prematurely. This problem did not exist before (at least not to the same extent), as GPs could communicate in more obscure language and bypass a (longer) discussion about the likelihood of a cancer diagnosis. Strikingly, most hospital staff agreed that it is not particularly relevant to inform patients about CPPs. What matters is that they do the actual work involved in fulfilling the CPP guidelines. Below, two specialist physicians reflect over whether it is important that patients know that they are part of a CPP:

No, I really don’t know, I’ve rarely mentioned it as a part of this, of patients’ cancer treatment. I think, I believe people have enough to deal with, the fact that there is cancer discovered and it is not important that it is entitled Cancer Patient Pathways. (Physician 49, hospital 3)

It [information about CPPs] will probably lead to some patients becoming more demanding about when they should receive treatment. So, you could say that the consequence of us providing this information would be that they [patients] point out when time frames are breeched. (Physician 47, hospital 3)

In these accounts, two distinct discourses shape how information is concealed from patients. In the first quote, the reasoning is framed as consideration for the patient’s well-being, i.e., not overloading the patients with redundant information. In the second quote, the physician considers the consequences for his own professional autonomy, which raises the question: does a more informed patient lead to a more demanding patient? This is connected to the discourse about patient’s rights and power to interfere with a physician’s work. Consistent with Hsieh et al. (2016), these statements illustrate that, by carefully selecting what information they share with their patients, physicians’ can subdue patients via coded communication.

Communicating patient participation

Most informants talk about patient participation solely in conjunction with treatment decisions, i.e., after the diagnosis is established. One physician, in recalling a recurring dialogue in the

MDT meetings with physicians from a neighbouring hospital, describes how patient participation is diversely valued and practiced:

Well, I mean [the staff at] [name of hospital] are very concerned about that, because they always say, “but what does the patient want?” Now patients are supposed to co-decide, and then we’re at a loss for an answer... “patients, they do what we say,” “yes, ok, but you must ask the patient, are they willing to undergo surgery? [...]” So, I think the [name of hospital] are trying to train those who refer patients [for treatment] that they have to engage in that conversation with their patients prior to [referral]. (Physician 34, hospital 2)

The statement reveals the collision of two opposing discourses: the paternalistic approach referring to the patient as passive and compliant, and the patient-centred approach encouraging active participation (Sandman and Munthe, 2010). It demonstrates the translocal relational nature of textual modes of ruling (Smith, 1990, 2005). When guidelines for patient participation are activated by certain individuals in specific settings, as in this case where the physician in the other hospital consistently reject referrals before the patient has been thoroughly consulted, practices begin to coalesce in a new direction.

How then do physicians practice patient participation? What does that entail in cancer care? The physicians in this study, echoing findings from other studies about patients’ preferences (Gattellari et al., 2001; Keating et al., 2010; Sinding et al., 2010; Thorne et al., 2013), express that patients are so diverse that they range from hardly wanting any information or participation, to scrutinising the internet and wishing to explore every possible avenue before deciding. Physicians highlight the fact that patient participation in cancer care is complicated; not only do the available alternatives differ between cancer types and the cancer characteristics, they also rely heavily on patient factors (e.g., age, comorbidity, overall physical and mental condition, life situation and patient initiative). Here is an excerpt from an interview with a physician speaking about her work with patient participation:

Physician: It is probably different from physician to physician. They could, you’d say that this [cancer] could be treated in different ways, and then it is... if they can have surgery that is the gold standard, and you have to sort of convey that, but if they [patients] are weak or something like that, you’d sort of say “in your case I think it is

appropriate to... the best treatment for you is radiation therapy.” And, it is probably silly to be talking too much about surgery if you know that they could barely handle it, but you do tell [patients] that there are different roads leading to Rome; you try to say that.

Interviewer: Yeah, how does the patient deal with that? I mean, do they ask, want to know as much as possible?

Physician: It’s a bit up and down. Yes, a bit up and down.

Interviewer: Yeah, have they searched online, are they very...?

Physician: Yes, younger patients often search online. They’ve been searching and have learned about different types [of cancer] and ask about that and stuff, yes, but the older [patients] they don’t have as much... they listen more closely to the doctor; it is a different school.

Interviewer: Yes, but do they have what they need to... kind of, is there really anything to co-decide in?

Physician: Well, you could say that, yeah, that you are on the border, kind of, you have a lot of illnesses, we cannot guarantee that you can tolerate surgery very well, it will set you back, maybe it would be better for you to do... and then they just have to make a decision on the basis of what we say. And some ask, “what would you do?” So, they are supposed to [co-decide], but you can’t give them so much co-determination that they end up regretting the choice they made. (Physician 30, hospital 2)

This excerpt illustrates how the work of incorporating the principle of patient participation is tailored to the unique situation of each patient. It reveals an inherent tension between professional responsibility and the ideal of patient autonomy, which can be bent accordingly (Hsieh et al., 2016; Sandman and Munthe, 2010). The physician describes the need to control the situation from a professional point of view in order to protect the patient. She mindfully chooses what to emphasise when talking to her patients about different treatment alternatives. Why would you bring into play something that may be too strenuous, even if is technically possible? On the other hand, why shouldn’t the patient be the judge of their own limitations? These are difficult

questions that physicians balance in their daily work, and that challenge the notion that transparency and patient participation are unequivocally in the patient's best interest.

Several physicians comment that, although they try to not to interfere with the patient's decision, they perceive it as part of their job to provide as clear a recommendation as possible. This is tied in their work ethic and clinical practice guidelines. Physicians are responsible for providing recommendations that aligns with professional standards. Ultimately, they are the ones in charge; patients cannot demand certain types of treatment if they conflict with the physician's professional assessment of what is best in the situation in question.

Communicating the relevance of time

Thorne et al. (2013: 291) remark that it often takes time for cancer patients to develop the confidence to partake in decisions about their care, even though "key decisions are often required during the earliest stages of the experience, when emotionality is intense, relationships are new, and information overload is occurring". The relevance of time in cancer care is multifaceted. According to Maiga et al. (2017), timeliness of care is "among the few modifiable factors" that cancer care professionals can control (p.1796). Similarly, it could be argued that temporality, i.e., the pace at which the sequence of events is carried out, is also one among the few aspects over which it is possible for cancer patients to exert their influence.

The CPPs establish temporality as a core quality indicator of cancer treatment whereby 'faster' connotes 'better' (Malmström et al., 2018). Most informants agree that faster is beneficial for the overall well-being of the patient. Waiting, whether for a diagnosis or to start treatment, is described as a significant source of stress in an already-difficult situation. However, healthcare personnel also experience the idea that faster equals better as a double-edged sword, because patients have different temporal preferences. Sometimes the scheduling can be too tight. Here are excerpts from two informants illustrating this predicament:

Sometimes [patients] ask about waiting times and stuff like that, and sometimes we say that "you are supposed to have surgery within a certain amount of time," right, and patients react differently when they receive a diagnosis. Some are like "oh my God, I am scheduled for surgery within 14 days already, that was very fast," and some get terrified because of that. Then it is important that we tell them why. I mean, we have to tell them

that we have deadlines, right, and then the CPPs might be mentioned, that the government has given us a set of deadlines, and we need to keep to the deadlines. (Nurse 18, hospital 1)

Once I experienced being yelled at by a patient saying, “you don’t allow him to make his mind up!” [...] these people, they were irritated because they meant that he had to breathe on his own, he had to, as he didn’t like all the machinery. He had to approach it at his own pace. (Physician 48, hospital 3)

These statements illustrate that patients can respond differently when grappling with a cancer diagnosis and treatment recommendations, and, although the CPPs deadlines can be helpful, they can also be disconcerting. Some patients, informants note, need more time to process their changed situation. The fast-paced trajectory can signal a kind of danger that elevates fear and anxiety. As one nurse remarks:

Suddenly two weeks becomes crucial, right, and that can create some fear in a patient who has been living with this cancer for months. It’s not like we know—with cancer, it could have been there for months. (Nurse 65, hospital 4)

Cancer is not the only thing that is happening in patients’ lives. Prostate cancer patients, in particular, informants report, regularly request postponing their treatment in favour of, for example, going on a planned vacation. One physician explains that since cancers evolve differently, being diagnosed does not necessarily mean a medical emergency in need of immediate intervention:

Theoretically, it will always be like, I mean, at one particular point in time, that cancer will spread, right, and it’s a matter of intervening before that happens. But it is... most cancers don’t spread from one day to the next. Kidney cancer, for example, right, so if the time frame was three months longer, that would not matter. (Physician 15, hospital 1)

The physician’s assertion highlights the fact that the politically-established time frames do not always mirror the medical or psychosocial reality experienced in clinical practice. In many situations, there is room for greater flexibility from a medical perspective, but accountability to time frames adds pressure to the communication process. Sometimes there is more time, from a medical perspective, than the CPP guidelines allow.

Concluding remarks

By using IE to explore the social organisation of communicating with patients from the standpoint of physicians, a complex picture of interdisciplinary interaction in conjunction with different ruling ideals emerged. It is evident that healthcare professionals work with patient communication is primarily informed by the biomedical paradigm and the organising of events around information pertaining to the process of discovery and treatment of the cancer. However, as cancer is often a stressful and fear-inducing diagnosis, informants across all professions recognised the importance of tending to the patient as a whole person with both biomedical and psychosocial needs. The CPP policy, with its specific focus on transparency, speed, and monitoring of time frames, creates new challenges for an already delicate situation. The increased focus on patient participation challenges the efficiency required by the CPPs, as more informed patients yield more time-consuming communication. In different ways, the balancing of different experiential realities runs as a common thread through the four aspects of communication work disclosed in this study.

The CPP policy compels healthcare professionals to collaborate in a tightly and consistent manner, which, in turn, improves continuity in communication with patients. Continuity of care rests on a clear division of communicative responsibilities between practical and medical information. However, continuity in communication moves beyond providing patients with adequate information about examinations, diagnosis, treatment, and sequences of events. It involves bringing all these different aspects together and assisting patients to process both the information and their situation over time. While (hospital) physicians focus their interaction with patients on the biomedical aspects of care within the bounds of scheduled appointments, nurses (and to some extent coordinators) emphasise their availability, their presence and the psychosocial support they can provide. The study reveals a subtle disjuncture between physicians and other healthcare personnel. Sometimes physicians refer patients for diagnostic tests or treatments without adequately informing the patients about their actions, which complicates the communication work of those on the receiving end of these referrals.

Physicians' accounts of their work with patient communication indicate a sensitivity to the diverse needs of patients, but also that physicians are juggling what might be called 'physician-centred' and 'patient-centred' approaches. This is evident in their emphasis on how information

must be tailored to fit the needs of each patient, and how they choose to use their professional power to restrict certain types of information as they see fit. This is a practice that has implications for the autonomy of patients but is justified as being an act of consideration for the patient's psychosocial and emotional wellbeing. In a different framing of events, however, physicians regulate information to prevent patients from activating their rights and initiating complaints.

The CPP policy signals that, to achieve quality of care, it is crucial for healthcare professionals to get the patient diagnosed and in treatment within a specific time frame. Activating their biomedical knowledge, healthcare professionals argue that although time matters, CPP time frames create an artificial impression that all cancers must be treated with the same urgency, and that all patients have the same temporal needs and desires. This study reveals how CPPs organise physicians' work in a way that can be at odds with their knowledge and expertise in relation to each individual patient. The policy seems to hook people, both staff and patients, into a standardised system through which they might lose touch with their human experiences. An important pitfall is that healthcare professional become actors on a cancer assembly line, whereby their professional judgments as well as the individual preferences of patients, are subordinated to the ruling principles of the CPPs. Paradoxically, this preclusion of relational practices happens inside ideological investments in patient-centred care and collaborative decision-making.

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Article IV

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Appendices

Temaguide

Evaluering av pakkeforløp for kreft

Til helsepersonell sykehus, fastleger, avtalespesialister, Gruppe-/enkeltintervju

Bakgrunnsopplysninger informant

- Stilling
- Arbeidserfaring antall år
- På hvilken måte involvert i pakkeforløp for kreft?

Generell intro

- Relatert til kreftutredning/behandling og pakkeforløp, hva jobber du hovedsakelig med?
- Hvordan forstår du pakkeforløp for kreft? Hva er dette for deg? (kun det som blir målt, hele forløpet fra fastlege til rehab...)
- Hva er myndighetenes intensjon med innføringen, slik du ser det?

Samhandling og kommunikasjon

Kan du fortelle litt om hvordan pakkeforløpet er organisert der du jobber?

- Hvordan ble du informert om pakkeforløp/hva slags opplæring fikk du?
- Hva er likt/ulikt i forhold til hvordan det var før (organisering av kreftutredning og –behandling)? Hva er likt/ulikt i din egen arbeidssituasjon?
- Hvem tar ansvar for hvilke deler av forløpet – hvordan er dette likt/ulikt slik det var før? Konsekvenser (for helsepersonells arbeidspraksis/-situasjon og for pasienter, oppgavefordeling)?
- Har innføringen ført til andre/mer hensiktsmessige/mindre hensiktsmessige måter å arbeide på?
- Hvilke deler av forløpet standardiseres, og hvilke deler er mer fleksible ut fra pasientens individuelle behov/preferanser og ut fra helsepersonells vurderinger? Hvordan fungerer dette/hvordan bør dette fungere? (konsekvenser av å standardisere, profesjonell autonomi)
- Hvilken rolle har ledelsen spilt/spiller ledelsen for innføring og gjennomføring av pakkeforløp? (mer/mindre styring...) På hvilke måter er ledelse viktig?
- Hvilken rolle har forløpskoordinatorer der du jobber? (hvordan organisert, faglig bakgrunn, arbeidsoppgaver...)
- Hvordan har dere organisert MDT? (hvem deltar, hvor ofte, om hvilke pasienter...)
- Hva samhandler du om, og hvem samhandler du med, når det gjelder pakkeforløp for kreft?

Samhandling og kommunikasjon

- Hvordan fungerer samhandlingen? (likt/ulikt tidligere) Samhandlingsutfordringer?
- Har det medført noen nye måter å samarbeide på som ikke eksisterte før?
- Mer tverrfaglig samarbeid? På hvilke måter?
- Hvordan kommer avtalespesialistene inn i forløpet?
- Konsekvenser for pasientene? (bedre koordinerte tjenester?)
- Hvordan kommuniserer du med pasientene gjennom forløpet? Hvilken type informasjon får de og når? Hvordan blir de involvert i forløpet? (brukermedvirkning...)

Forutsetninger, utfordringer, konsekvenser

- Hva er forutsetninger for at pakkeforløp for kreft skal fungere?
- Hvilke utfordringer har dere støtt på? (innføring, daglig drift nå...) Hvordan har dere løst utfordringer?
- Hvilke evt. endringer i kompetanse/behov for kompetanse har innføringen av pakkeforløp ført til? Hvordan har dette blitt løst? (hos deg selv/i organisasjonen)
- Hva er konsekvensene for pasientene, slik du ser det? (tid, kvalitet, medvirkning...)
- Hva med pasienter som ikke er i pakkeforløp, ser du noen konsekvenser for dem?
- Klarer ditt sykehus kravet om 70%? Hva er evt. årsaker til at dette går/ikke går?
- Hvilken betydning har forløpstider for kvalitet, slik du ser det? (konflikt mellom krav om korte forløpstider og kvalitet? Opplevd kvalitet for pasienten?...)

Veien Videre

Fungerer pakkeforløp for kreft slik du ønsker? Hva fungerer og hva fungerer evt. ikke?

Hvorfor/hvorfor ikke?

- Hva bør endres på kort/lang sikt?

Fungerer pakkeforløp for kreft slik intensjonen er fra myndighetenes side? Oppfylles intensjonen om mer forutsigbarhet og trygghet for pasientene, mindre unødvendig ventetid, bedre samhandling?

- Hva bør evt. endres for at denne skal oppfylles?

Avslutning

Er det andre ting du synes er viktig som vi ikke har vært inne på?

Takk for deltakelsen!

Appendix II: Information Letter and Consent Form

Forespørsel om deltakelse i en forskningsstudie

Evaluering av pakkeforløp for kreft – helsepersonells perspektiver

Bakgrunn og formål

Pakkeforløp for kreft ble innført i Norge i løpet av 2015, og i dag er de 28 vanligste kreftformene organisert i pakkeforløp. Dette er en forespørsel til deg om å delta i en studie der det overordnede målet er å få kunnskap om hvordan pakkeforløp for kreft erfarer av pasienter og tjenesteutøvere, og hvorvidt myndighetenes intensjoner med pakkeforløpene oppfylles. Tre hovedtemaer belyses i studien: (i) Pasienttilfredshet og brukermedvirkning i pakkeforløpene, (ii) samhandling mellom spesialisthelsetjenesten og fastleger og avtalespesialister og (iii) ledelse og organisering, herunder oppgavedeling knyttet til kreftutredning og behandling i sykehus.

Studien gjennomføres av SINTEF avdeling Helse, NTNU og NTNU Samfunnsforskning. Prosjektet er finansiert av Norges Forskningsråd (Prosjekt nr. 27265). Prosjektperioden er 1.10.2017-30.9.2020.

Hva innebærer deltakelse i studien?

Du inviteres til å være med på intervju siden du har erfaring med kreftutredning-/behandling og pakkeforløp for kreft. Vi vil gjøre en blanding av individuelle intervjuer og gruppeintervjuer ut i fra hva som er mest hensiktsmessig for arbeidsgiver. Individuelle intervjuer vil ta 45-60 minutter og gruppeintervju maksimalt 1,5 time.

Hva skjer med informasjonen om deg?

Vi vil gjøre lydopptak av intervjuet. Alle personopplysninger vil bli behandlet konfidensielt. Materialet vil bli oppbevart på en forsvarlig måte slik at utenforstående ikke har tilgang til det. Lydopptak vil bli slettet senest ett år etter prosjektslutt. Ingen enkeltpersoner vil kunne identifiseres i eventuelle publikasjoner basert på intervjumaterialet.

Frivillig deltakelse

Det er frivillig å delta i studien, og du kan når som helst trekke ditt samtykke uten å oppgi noen grunn. Dersom du trekker deg, vil alle opplysninger om deg i prosjektet bli anonymisert.

Studien er meldt til Personvernombudet for forskning, Norsk senter for forskningsdata. Prosjekt nr. **XXX**.

Har du spørsmål kan du kontakte prosjektleder for studien: Seniorforsker Line Melby (PhD), telefon 402 24 525, eller line.melby@sintef.no

Samtykke til deltakelse i studien

Jeg har mottatt informasjon om studien og samtykker til å delta i intervju

(Signert av prosjektdeltaker, dato)

Appendix III: Ethical Approval



Line Melby
Postboks 4760 Sluppen
7465 TRONDHEIM

Vår dato: 05.03.2018

Vår ref: 58724 / 3 / AMS

Deres dato:

Deres ref:

Tilråding fra NSD Personvernombudet for forskning § 7-27

Personvernombudet for forskning viser til meldeskjema mottatt 26.01.2018 for prosjektet:

58724	<i>Evaluering av pakkeforløp for kreft - intervjustudie</i>
Behandlingsansvarlig	<i>SINTEF, ved institusjonens øverste leder</i>
Daglig ansvarlig	<i>Line Melby</i>

Vurdering

Etter gjennomgang av opplysningene i meldeskjemaet og øvrig dokumentasjon finner vi at prosjektet er unntatt konsesjonsplikt og at personopplysningene som blir samlet inn i dette prosjektet er regulert av § 7-27 i personopplysningsforskriften. På den neste siden er vår vurdering av prosjektopplegget slik det er meldt til oss. Du kan nå gå i gang med å behandle personopplysninger.

Vilkår for vår anbefaling

Vår anbefaling forutsetter at du gjennomfører prosjektet i tråd med:

- opplysningene gitt i meldeskjemaet og øvrig dokumentasjon
- vår prosjektvurdering, se side 2
- eventuell korrespondanse med oss

Meld fra hvis du gjør vesentlige endringer i prosjektet

Dersom prosjektet endrer seg, kan det være nødvendig å sende inn endringsmelding. På våre nettsider finner du svar på hvilke [endringer](#) du må melde, samt endringskjema.

Opplysninger om prosjektet blir lagt ut på våre nettsider og i Meldingsarkivet

Vi har lagt ut opplysninger om prosjektet på nettsidene våre. Alle våre institusjoner har også tilgang til egne prosjekter i [Meldingsarkivet](#).

Vi tar kontakt om status for behandling av personopplysninger ved prosjektslutt

Ved prosjektslutt 30.09.2021 vil vi ta kontakt for å avklare status for behandlingen av personopplysninger.

Se våre nettsider eller ta kontakt dersom du har spørsmål. Vi ønsker lykke til med prosjektet!

Vennlig hilsen

Marianne Høgetveit Myhren

Anne-Mette Somby

Kontaktperson: Anne-Mette Somby tlf: 55 58 24 10 / anne-mette.somby@nsd.no
Vedlegg: Prosjektvurdering

Appendix IV: Confirmation Article IV



Dato:
18.05.2022

Bekreftelse på at kapittel er antatt av redaktører av bok

Vi bekrefter med dette at Siri Christine Kvernmo Næss' kapittel, som p.t. heter «Å bruke institusjonell etnografi til å utforske hvordan en politisk helsetjenestereform møter praksis», er planlagt som kapittel til en bok som etter planen kommer ut høsten 2022. Bokas tittel p.t. er «Institusjonell etnografi i praksis», og skal utgis på Cappelen Damm forlag. Professor Ann Christin Nilsen og undertegnede er redaktører. Hele boka sendes til fagfellevurdering august 2022, men Kvernmo Næss sitt kapittel er antatt av oss redaktører.

Med vennlig hilsen, på vegne av redaktørene,

A handwritten signature in black ink, appearing to read 'May-Linda Magnussen'.

May-Linda Magnussen,

Førsteamanuensis, Universitetet i Agder

Appendix V: Co-Author Declaration



DECLARATION OF CO-AUTHORSHIP

Siri Christine Kvermmo Næss

..... apply for the evaluation of the following thesis:
Name of PhD candidate

Between diagnostic precision and rapid decision-making: Using institutional ethnography to explore diagnostic work in the context of Cancer Patient Pathways in Norway. Published in *Sociology of Health & Illness*, 43(2), 476-492.

.....
title

*)The declaration should describe the work process and division of labor, **specifically identifying the candidate's contribution**, as well as give consent to the article being included in the thesis.

*)
Declaration of co-authorship on the following article:

Siri Christine Kvermmo Næss is the first-author on the article and Erna Håland is the second author.

The first author has initiated and developed the research question, the analysis and the theoretical and methodological framework, discussing this with the second author at a later stage. The first author has been the main producer of text. The second author has participated in discussions of all parts of the article, contributing to further development of the analysis. The second author has also made comments and suggestions throughout to improve the text. Both authors have conducted data collection. Both authors have approved the final draft of the paper.

Trondheim 07.06.22
Place, date

Erna Håland
Signature co-author

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