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CREATING ACCESS TO CANCER CARE

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

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Akademisk avhandling

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Avhandlingen kommer att försvaras på svenska.

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

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

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

Results Access is created through interaction in the patient–provider encounter, and is mirrored through processes of negotiating, embodying roles, and adhering to norms. Patients and physicians create access by negotiating the legitimacy of symptoms through processes characterized by dependency, credibility, and reciprocity (**I**). Second, physicians create access while being pulled between patients and standardized templates, which illuminates the tension between the responsibility physicians have towards their patients and the healthcare organization. It is therefore challenging for physicians to engage in person/patient-centered dialogues, interpret presented symptoms, and match them with standardized criteria (**II**). Third, standardization seems to oversimplify the complexity that underlies patients' interaction with healthcare, downplaying the individual uniqueness of each person's health problem, situation, and needs. Patients experience a need to act as both sellers and customers when interacting with physicians in primary care and when negotiating symptoms while creating access (**III**). Lastly, sociodemographic factors, such as income, education, and distance to hospital, do not seem to be related to time to diagnosis and treatment for patients with CRC in the study regions (**IV**).

Conclusion Patients perceive demands on themselves when presenting their symptoms and use different strategies in order to legitimize these. This seems particularly challenging if symptoms are diffuse. Physicians have the responsibility to assess these symptoms and match them with criteria for CPP-referrals, criteria which are not always easy to access and apply. Furthermore, access measured as time to diagnosis and treatment among patients diagnosed with CRC in the study regions was not related to differences in sociodemographic factors. Additionally, it is important for physicians to acknowledge the uniqueness of each patient during encounters, to see, listen, and confirm, while operationalizing their medical expertise in order to identify suspected cancer. Such professional skills seem necessary during patient–provider encounters in primary care. Consequently, this thesis contributes to the existing body of literature by recognizing that interaction inevitably affects access to (cancer) care.

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

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