Managing cancer risk among patients with vague or unspecific symptoms of cancer: a qualitative study in general practice

1. Aim

The overall aim of this project is to study the diagnostic pathway and the clinical encounter among patients with low risk of cancer and no initial cancer suspicion in general practice. Based on ethnographic methods, the aim will be investigated in the research question:

How do GPs manage low levels of cancer risk and cancer suspicions in clinical practice in Denmark?

The research question will be approached and unfolded by answering following working questions:

- Which strategies do GPs use when detecting and diagnosing serious illness (including cancer) based on *known* and *unknown* symptoms, respectively?
- What role does GPs' intuition or 'gut feeling' play in the diagnostic pathways and how do GPs use it in their everyday practice?
- How do cultural variations within understandings and experiences of health and illness affect the diagnostic pathways and cancer suspicion among GPs?
- How do uncertainty and insecurity figure in GPs' daily practices and work and how do they manage these (work) conditions?

2. Background

Annually, more than 40,000 persons are diagnosed with cancer in Denmark, and cancer is the leading cause of death in Denmark (1,2). The prognosis depends on the cancer being diagnosed in an early stage (3). Thus, early diagnosis is a focal point in most Western health care systems, despite conflicting findings on the effect from earlier diagnosis on the prognosis of cancer (4–6).

The majority of cancer patients begin their diagnostic journey by presenting symptoms in general practice (7,8). Emphasis has been made on the importance of diagnosing cancer as timely as possible, and many countries have implemented specific referral pathways when suspecting cancer (e.g. 2-week-wait in the UK and Cancer Patient Pathways (CPP) [pakkeforløb for kræft] in Scandinavia). Use of CPP has been associated with reduced diagnostic delays and overall improved survival (9–11). However, challenges have been stressed (12–15) as referral for CPP often requires specific alarm symptoms to be present, thus patients, who do not qualify for urgent referral risk delay and disease progression before diagnosis (13). Approximately 40% of cancer patients have not gained from CPPs (10); mostly patients who are not initially suspected to have cancer or serious disease due to vague symptom presentation (16).

Three out of ten cancer patients presenting in general practice are not suspected to have cancer or serious illness at the first consultation (16,17). This can be caused by these patients presenting symptoms with low prediction of cancer and the similarities between cancer patients and non-cancer patients with identical vague and unspecific symptoms (18). This requires the general practitioners (GPs) to navigate their clinical assessment of the patient and the diagnostic strategy based on vague and unspecific symptoms, which are rather difficult indicators with low predictive values of cancer combined with other patient factors such as comorbidity (5,17,19). That only a minority of patients with vague and unspecific symptoms turn out to have cancer further complicates GPs' clinical assessment.

Another central aspect of the complexity of diagnosing cancer in general practice is the social organisation of the clinical encounter in primary care which is shown to be dominated by increasing demands of efficiency (20) and competing discourses of what is considered 'good' health care seeking in the local clinical setting (21). Furthermore, anthropological studies have shown how both symptom experience and healthcare-seeking practices are depending on how illness and cancer in particular are perceived in the local context and on how people relate to the healthcare system and the welfare state in general (22–24).

As presentation in general practice is the most common route to a cancer diagnosis (7), this raises the rather paradoxical question of how to suspect the unsuspicious. How do GPs manage low but almost always present cancer risks when they encounter a patient, in whom they do not suspect cancer? How do GPs promote early diagnosis and at the same time avoid over-diagnostics, pressure on the healthcare system and unnecessary patient worries? We need knowledge about the diagnostic strategy and insights into the challenges, potentials and consequences for the GPs in the pursuit of expediting the diagnostic process when cancer is not suspected in general practice.

3. Methods

The study is an ethnographic study based on fieldwork in 3-4 Danish general practices. Fieldwork will run over four months and will consist of participant observation and interviews with GPs, nurses and medical secretaries in order to include perspectives on the topic from all parts of the clinics (26). Each GP is followed by PI for four to five days over the span of one to four months (see time plan). Additionally, one nurse and one secretary from each clinic will be followed for one to two days. Furthermore, PI plans to conduct at least one interview of 40 minutes with nine participating GPs and at least two nurses and medical secretaries. We will focus on how vague and unspecific symptoms and the uncertainty surrounding them are managed in general practice and in the clinical encounter. The project will follow an explorative research design (27), thus allowing unpredictable connections and perceptions to be identified throughout the project, in order to gain insight into the specific challenges and difficulties in the individual GP. Thus, the focus is

prospective and includes a broad range of vague symptoms and low levels of suspicion of serious illness to get insights into the management of low risk but not no risk cancer symptoms.

Data material and analysis
Empirical material from the fieldwork will consist of interview transcripts and field notes, which will be coded in Nvivo. An initial thematic analysis will provide the basis for a workshop where researchers and GPs can interact with the themes and examples from this preliminary analysis. The final phase of fieldwork (in 1-2 GP clinics) will be informed by the insights from this interaction, and final analysis will be based on this as well as relevant theory.

Workshop
A workshop among clusters of GPs [kvalitetsklynger] in the Central Denmark Region will be organised and conducted with the following format: 1) presentation of initial findings from the fieldwork 2) Facilitated discussion of practical, ethical and everyday considerations in the general practice setting of patients presenting with "low risk" symptoms. The GPs will be encouraged to use a case from their own practice for this part, to maximize the clinical relevance for each participating GP. The workshop will provide an opportunity for the GPs to exchange experiences and develop their skills and reflections within cancer diagnostics among patients presenting with low-risk symptoms. Thereby, the workshop will be an important part of the final data material.

We propose a project process in four main steps:

Step 1: Researchers develop and initiate ethnographic fieldwork.
Step 2: Researchers and general practitioners discuss and further develop the study in a workshop format carried out with clusters of GPs.
Step 3: Based on insights and feedback from the workshop, researchers reengage the field of research and finalize data collection.
Step 4: Researchers write and publish scientific articles. The results obtained from the project will be presented at the Nordic Congress for General Practice and at after-work meetings among GPs in the Central Denmark Region [kvalitetsklynger].

4. Implications

The study will provide insights into the under-studied area of the diagnostic process in cancer patients who present with vague symptoms in general practice and do not trigger cancer suspicion. Combined with new insights from observations and interviews in general practice and perspectives from everyday clinical practice, the project is expected to provide a synergetic effect ensuring relevant and useful insight to general practitioners. The obtained new knowledge and experiences from the collaboration with GPs via '*kvalitetsklyngerne'* will be used to ensure high-

quality continued medical education in early cancer diagnostics for GPs in the Central Denmark Region.

5. Study group

The project is a joint venture by employees from the Research Unit for General Practice in Aarhus and Cancer in Practice - Central Denmark Region including:

- PI: Postdoc Anne Sophie Grauslund Kristensen (ASGK), Master in Anthropology
- Senior researcher Line Flytkjær Virgilsen (LFV), PhD, Master in Public Health
- Senior researcher Sara Marie Hebsgaard Offersen (SMHO), PhD, Master in Anthropology
- Postdoc Michal Frumer (MF), PhD, Master in Anthropology
- Postdoc Linda Aagaard Rasmussen (LAR), PhD, Master in Health Science
- General practitioner and clinical consultant and medical leader at Cancer in Practice - Central Denmark Region, Rikke Pilegaard Hansen (RPH), PhD, MD

6. Viability

The project will be situated at the Research Unit for General Practice in Aarhus (RUGP) and conducted in close collaboration with Cancer in Practice – Central Denmark Region (CiP). RUGP will provide office space, overhead, access to support from secretary and data-manager and secure expenses for running costs. CiP will provide logistic assistance in contacting participating GPs and in organizing the workshop for the GPs in the Central Denmark Region. ASGK will plan and facilitate the workshop in close collaboration with RPH. The research group has extensive expertise in the studies' methodologies, gained from previous studies within this field (25). RPH will contribute with clinical and organizational insights as a GP and as clinical consultant and medical leader in CiP.

7. Economy

The project will be co-financed by resources from the RUGP, who will hold expenses for project administration, office premises and running costs not covered elsewhere. CiP has granted the project with DKK 450.000, which will cover salary for PI ASGK, and other members of the research group (MF, LFV and LAR). Further, the grant from CiP will cover expenses for transcription. The project has received funding from 'M.L. Jørgensen and Gunnar Hansens fond' and 'Vissing Fonden' to cover the remaining salary for ASGK.

8. Time schedule

Study preparations and recruitment of general practices will begin in November 2022. The official study period starts on 1 December 2022 and will run over an 18 months period. See time plan table.

		Months																	
Tasks	**Activity**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**	**17**	**18**
Literature studies	Reading																		
Fieldwork	Recruting																		
	Fieldwork in clinic 1																		
	Fieldwork in clinic 2																		
	Fieldwork in clinic 3																		
	Fieldwork in clinic 4																		
	Transcription and coding																		
Workshop	Preparing and conducting workshop																		
Writing/Output	Reporting to CiP																		
	Article in medical anthropological journal																		
	Article in Månedsskrift for Læger																		

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