

## **A doctor close at hand**

**A qualitative analysis of GPs' work in cancer care**



**May Lill Johansen**

A dissertation for the degree of Philosophiae Doctor  
August 2012





# UNIVERSITY OF TROMSØ UIT



FACULTY OF HEALTH SCIENCES  
DEPARTMENT OF COMMUNITY MEDICINE

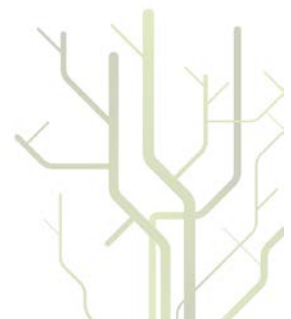
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## Foreword and acknowledgments

The journey of this thesis started during the fall of 2007. I had taken a leave from my position as a GP and had no plans for the following year except doing emergency calls to earn a living. Every month, I used to meet with a group of colleagues for what we called narrative medicine. Carl Edvard Rudebeck was invited to the group and we discussed one of his papers. The next afternoon he called and asked if I would be interested in joining a research project initiated by Knut A. Holtedahl. I had no idea what qualitative research was like, I was not particularly interested in the topic of cancer, but I felt honoured to be asked. The prospect of having a wise thinker like Rudebeck as a supervisor was decisive. I started out as a part-time, freelance researcher. Only a few months later, things grew more serious. A dissertation was suggested, grants were applied for, and from August 2008 I found myself as a full time PhD-student.

Naturally, my first acknowledgment goes to my supervisor Carl Edvard Rudebeck for all the deeply interesting and rewarding conversations we have had. I still have not fully grasped all the gems of wisdom you have presented. I thank Knut A. Holtedahl for sharing your universal wit and historical memory, and Anna Luise Kirkengen for your rigour and endurance as a critical intellect. I am grateful to my colleagues at the Research Group for General Practice, for an inspiring and encouraging working environment. You have all served as models for my probing steps in university life.

There have been other important and supportive groups also. My first academic writing group was founded in 2008 at an interdisciplinary workshop in a Greek monastery and has met quarterly ever since. Thanks to Sissel Lie, Torunn Klemp, Kristin Solli Schøien and Berit Grindland for a great collaboration. In Tromsø, my closest thinking and writing companion has been my friend Ranveig Lind. Our discussions over the years have been invaluable to me. Also, I am grateful to the other members of the Reflector writing group for your feedback. Another rich learning community was a longitudinal session-based PhD seminar led by Aud Obstfelder and Geir Lorem. Your clear epistemological minds helped me find my course, and I also learned much from the other seminar participants.

Last but not least, I am grateful to my friends for all the fun, purpose and beauty you have brought to my life, and to my family for belonging with me. A special reward for saving my mental health during the project goes to Margrethe Aanesen for supportive coffee breaks and Anton Giæver for walking and talking therapy.

During the winter of 2012, my father got seriously and complicatedly ill. During his hospitalizations, the experience of being a family carer with medical knowledge was at times upsetting. I was emotionally shaken, and for two months, I could not concentrate on reading or writing. I lacked the intellectual strength to pull the thesis together. I am conscious that I leave the reader with some fragments and loose ends. Sadly, my father was at times treated exactly the way I discuss at the end, like a disorder. The worthy meeting with a doctor that in a glimpse recognized him as a person and us as a family and made his clinical decision accordingly will forever stand before me as an example of what medicine could be like.





## **Summary of thesis**

The core of medicine, even specialized and high-tech medicine, is a meeting, a consultation, between a human being asking for advice and another human being, whose knowledge and experience is expected to be helpful. This thesis explores how the suspicion of cancer can arise in such a consultation, how general practitioners (GPs) can contribute to cancer care and how GPs might accompany people with cancer towards the end of life.

25 qualitative interviews with Norwegian GPs about diagnosing and attending people with cancer through the course of illness were analyzed. Besides clinical assessments and paperwork, the GPs often acted as intermediaries between the patient and the hospital. They pushed for quick hospital appointments, interpreted and translated discharge letters and were asked for second opinions. In rural areas some GPs offered cytostatic treatments. Knowing the patient and preferably also the family was seen as a premise for being a good GP. In the researcher's interpretation, the GPs were well acquainted both with the patients' world and with the clinical world. They could act as guides for their patients, but their personal knowledge of patients could, even if it was clinically relevant, be given less weight when confronted with hospital routines and criteria. This could lead to conflicting loyalties for the GPs. During end-of-life care in the patients' homes, existential conversations were seen as demanding but rewarding. Palliation of pain was an easy task compared to being a fellow human being, listening and attempting to comfort a person who is afraid to die.

## **Norsk sammendrag**

Avhandlingen tar utgangspunkt i at kjernen i medisin, selv i spesialisert og høyteknologisk medisin, er et møte mellom mennesker: Et som søker råd og et annet som har nødvendig kunnskap og erfaring. Avhandlingen undersøker hvordan mistanken om kreft kan oppstå i et slikt møte, hva fastleger kan bidra når folk får kreft og hvilke utfordringer de ser når de følger noen med langkommet kreft mot livets slutt.

Forskeren analyserte i alt 25 kvalitative intervju med norske allmennleger. De fortalte om pasienter de hadde fulgt gjennom et sykdomsforløp. Ved siden av kliniske vurderinger og papirarbeid var de ofte formidlere mellom pasienten og sykehuset. De ble spurt om behandlingsråd, tolket og oversatte brev fra sykehuset, og var pådrivere for kortere ventetid. I distrikt ga noen også cellegiftkurer. Det å kjenne pasienten og gjerne også familien ble sett på som en forutsetning for å være en god lege. Forskeren oppfattet allmennlegene som lokalkjente både i pasientens verden og i den kliniske verden. Dette var en styrke overfor pasientene, men i forhold til sykehuset kunne fastlegens nærkunnskap bli oppfattet som mindre viktig enn systemets rutiner og kriterier. Det kunne føre til lojalitetskonflikter for allmennlegene. I omsorgen hjemme hos pasienten ved livets slutt var eksistensielle spørsmål både krevende og givende. Å lindre smerter var enklere enn å være et lyttende og trøstende medmenneske for en som fryktet døden.



## List of papers

The thesis is based on the following papers:

1. Johansen, M.-L., Holtedahl, K. A., & Rudebeck, C. E. (2010). A doctor close at hand: How GPs view their role in cancer care. *Scandinavian Journal of Primary Health Care*, 28(4), 249-255
2. Johansen, M.-L., Holtedahl, K.A., Davidsen, A.S & Rudebeck, C.E. (2012) 'I deal with the small things': The doctor-patient relationship and professional identity in GPs' stories of cancer care. *Health (London)* Online first March 7, 2012
3. Johansen, M.-L., Holtedahl, K.A., & Rudebeck, C.E. (2012) How does the thought of cancer arise during a consultation in general practice? Accepted for publication in *Scandinavian Journal of Primary Health Care*



## INTRODUCTION

### Background

The General Practitioner (GP) is the only doctor that ideally could accompany the individual person with cancer through the whole course of illness. GPs often know people before they know what their illnesses will be. GPs claim to be committed to persons, who should feel assured that they will not be abandoned by their GP, whatever may befall them (McWhinney, 2000). However, the diagnosis and treatment of cancer is connected to a highly specialized part of medicine, dependent on a sophisticated use of technology. The association between cancer and technology is pictured at the cover of British Journal of General Practice's cancer-issue (Nov 2011), showing a person on a stretcher and a health worker, both standing in a blue light outside the shining circular opening of a scanning machine. The connection to general practice is not obvious in such a technological image of cancer care. GPs might lose the contact with their patients with cancer during the treatment period, a notion that is captured in the title: "When patients have cancer, they stop seeing me" (Anvik et al., 2006). However, the article also refers to patients who *had* follow-up by their GPs during and after cancer treatment, and who appreciated being taken care of as 'a whole person', with their anxiety and worries, pains and side-effects, concomitant illnesses and issues of family and work.

A Danish study (Aabom & Pfeiffer, 2009) explored this further: Why are some patients in treatment for advanced cancer reluctant to consult their GP? They interviewed people receiving chemotherapy in an oncological outpatient clinic, and found that patients developed a personal relationship with and dependency to the staff at this centre. They consulted the doctor there rather than their own GP. Some patients thought the GP did not know enough about cancer treatment, or that the GP was too busy. As the disease progressed; patients had more psychosocial needs, which were unmet at the cancer centre. The authors concluded that special attention is needed to get the GP involved again during and after cancer treatment, to ensure a good passage to home-based end-of-life care.

Almost every person in Norway is registered with a GP for primary healthcare. Most GPs work as self-employed, in group practices, contracted and granted by the municipalities. Patients need referral from GPs to see specialists, which makes GPs important gatekeepers in the health care system. Out-of-hours, primary care is organized by the municipalities, engaging local GPs according to a roster. There is no formal agreement about the distribution of tasks related to cancer between hospitals and primary care, and there are local variations. Regional centres for competence in palliative care provide training, advice and guidelines. District nurses and, in some areas, cancer nurses are employed by the municipalities, not directly by general practices. Palliative home care is not yet fully developed in Norway, and home death has been less common than in other countries. In 2003, the percentage of cancer related deaths occurring at home was 45 in the Netherlands, 28 in Belgium, 23 in England and only 13 in Norway (Cohen et al., 2010).

GPs are not experts of cancer, but claim to be experts of meeting people who have any common illness, included cancer, or who fear that they have it. GPs could be key persons for the professional interaction around a person suffering from cancer, but often they are not. Some GPs do not engage in palliative care, and a few don't do home visits at all. In Norway, a new health care reform places more responsibility in the municipalities, especially for people

with chronic illnesses. Palliative treatment and end-of-life care should if possible be given in the patient's home or in a local nursing home. Are GPs prepared for this? In a survey to GPs in the Norwegian county of Vestfold, 73% of respondents said they would take medical responsibility for people with cancer who wanted to die at home, but only a minority valued their competence in pain relief as good enough (von Hanno, 2000). Anvik et al (2006) concluded that most GPs in their interview study were prepared to take a more responsible role for people with cancer. The GPs found ways of obtaining the knowledge they lacked, and encouraged a closer cooperation with specialists, especially around the patient's discharge from in-patient care. These were so far the only studies in Norway asking GPs about their work cancer care. In face of the Norwegian health care reform, and also the establishment of palliative teams in many communities, the GPs' roles during the course of a cancer illness are in transformation. There is a need for investigating GPs' possible contribution to health care for persons with cancer.

### **Theoretical considerations**

Cancer is challenging medicine to show its full potential; mobilizing an enormous effort to search for ways of curing, and likewise calling for medicine's utmost caring capabilities. Before looking specifically into a possible contribution of general practice in the face of cancer, we should consider the basic question: What is medicine? According to Pellegrino (1979), medicine is a relationship, a 'specific and unique kind of human relationship', between a doctor (or another clinician) and a patient. Toulmin (1976) asserts that the patient begins and ends as a sufferer, the physician begins and ends as his personal adviser, and the most particular unit in medicine is 'the individuality of the relationship between the patient and his personal physician'. Given this ontological basis of medicine, biomedical science becomes 'only a means to be pursued for the sake of the good that physicians can do to particular patients' (Toulmin, 1976:41). The complex challenges that confront doctors in their daily work and their resulting experience and understanding will according to Toulmin range 'far beyond the boundaries of science' (Toulmin, 1976:49).

Hunter (1991) also holds that medicine is a moral enterprise whose goal is to alleviate suffering. Hunter suggests that the diagnosis of disease is a relatively simple matter compared to the care of the patient. She characterizes medicine as the exercise of practical wisdom in the face of uncertainty, and holds that medicine's identification with science has led to adverse effects for patients, doctors and for the doctor-patient relationship. 'It encourages physicians and patients alike to focus narrowly on the diagnosis of disease rather than attend to what is even more necessary, the care of the person who is ill' (Hunter, 1991:xix). She also claims that 'the idealization of medicine as science offers physicians preparation and support for only a part of their task' (Hunter 1991:25). Malterud (1995) claims that if medicine is defined by knowledge from biomedical science alone, its epistemology fails to include the human interaction and interpretation constituting clinical practice. This is often called *the art of medicine*, which in Malterud's opinion is mystifying, and due to 'a provisional lack of visualization, articulation and documentation' (1995:189). She suggests that if the clinical encounter constitutes medicine, as many authors claim, the specific knowledge generated from this encounter should be a part of the epistemology of medicine: Knowledge about human interaction, clinical judgment and reasoning, and clinical philosophy (Malterud, 1995).

General practice is community based and accessible; offers continuity, a personal doctor-patient relationship and uses little technology. This favours another perspective on medicine than being hospital based, highly specialized and technologically advanced (Rudebeck, 1991). General practice claims to be the only discipline defining itself through relationships,

especially the doctor-patient relationship (McWhinney, 1996). GPs tend to think about individual patients rather than generalized abstractions. They often have difficulties separating diseases from the people they care for who have them, even to talk about general practice without speaking about their patients is difficult. This is, according to McWhinney, due to close doctor-patient relationships, giving a fuller knowledge of the person as particular, and, crucial for caring. Caring doctors should walk hand-in-hand with their patients through the landscape of illness, said McWhinney, challenging the imbalance of intellectual and emotional development in medical education. The cumulative knowledge of a long-term relationship could give the GP great advantages; every new event could be understood in the context of a life story. The relationship to patients could open up a rich experience of life and medicine to GPs, but to achieve this, GPs have to be very good at relationships (McWhinney, 1996).

A person going to the doctor has already been through an interpretative process (Leder, 1990b). Normally, human beings do not actively perceive the body; we are one with and at home in our bodies. Or as Merleau-Ponty (1962) wrote: 'The body is the vehicle of being in the world' (p. 82). When a symptom appears, we might feel torn out of this immediate relation (Rudebeck, 1991) and the body might stand out as a separate entity. The wholeness and homeliness can be lost (Svenaeus, 2000b). Humans do not only have a biological anatomy, but also an existential anatomy, expressed through the meaning each bodily part has in life. Feet, for example, mean standing and walking, keeping our balance, basing our existence, giving us autonomy and freedom of movement (Rudebeck, 1991). Thus, bodily experiences are referring to two levels of meaning, the physical body and the meaning of the body in human life. Symptoms can arise from both levels, and will always affect the other level. The biological anatomy can be compared with the cover, paper and ink of a book. They are necessary physical conditions, but the lived body, the body in its context of life, adds the story to the book. This can seem self-evident in our daily lives, but in scientific thought, self and body has been disconnected for several hundred years. The phenomenological concept of the lived body can help doctors understand their patients' presentation of bodily experiences.

The patient's story is, even if it is adapted to the medical context, primarily a story about the existential aspects of the lived body, about the existential anatomy. The doctor most often listens with the biomedical map of the physical body in mind. As Rudebeck (1991) notes, a question of validity arises: Are patient and doctor talking about the same things? Rudebeck recommends that the doctor attends fully to the patient from the moment of silence that opens the consultation (Rudebeck, 2002). 'Before deciding whether biomedical understanding and measures are applicable at all, the doctor has to grasp the basic character of experience presented' (Rudebeck, 1991:31). In understanding the experiences of the lived bodies of others, doctors can use their own lived bodies as reference. Rudebeck suggests that the capacity to understand another person's bodily experiences is called *bodily empathy*. It is an aspect of general empathy; the interpretative imagination and intersubjective connectedness that makes human beings capable of understanding each other. In the use of bodily empathy, says Rudebeck, there is no split between relating to the patient and making a diagnosis. On the contrary, 'diagnosis is promoted by the accurate apprehension of the symptom presentation' (Rudebeck, 2002).

The Aristotelian concept of practical wisdom, *phronesis*, might be useful for understanding clinical judgment. Phronesis is 'an ability to apply general or universal knowledge to particular situations, to see what a unique and particular situation calls for. Phronesis is the rationality for action' (Gatens-Robinson, 1986:174). In clinical judgment, the practical task is

to understand what a given situation requires. To ascertain what is required a wide range of knowledge and skills are involved. Gatens-Robinson explains that ‘the general becomes a way to understand the particular case and the particular case becomes a way of showing how the general could be better put’. She claims that in this hermeneutic situation, neither induction nor deduction is applied, but *dialogue*: The knowledge of the particular arises in a dialogue ‘of well-placed questions and their revealing answers’ (1986:175). To be skilled for this dialogue, the doctor needs many kinds of knowledge. Since persons are temporal subjects, knowledge of their history is essential for understanding. Therefore, the rationality of clinical judgment is both dialogical and narrative (1986).

Hermeneutics for Gatens-Robinson (1986) is not a methodological but an ontological concept. Searching for understanding and meaning are fundamental aspects of being human. In medicine, this search primarily takes place in a meeting; the clinical encounter. Even if the meeting is asymmetrical in powers, it is a search for a shared understanding, through dialogue. Both the dialogue and the clinical examination might deal with intimate matters, which are normally only revealed to very close persons, or maybe not at all. A shared understanding is not possible without a shared language, both verbal and non-verbal, and a mutual attunement, both cognitive and an emotional, which is reached through empathy (Svenaesus, 2000a). Empathy is necessary for understanding another person from a moral point of view (Gadamer, 1979). To understand, in the sense of being able to give advice, means ‘to realize the full moral situation of the other’ (1979:74). This means to understand the deeper meaning of the illness within the unique life story of a person. Understanding both the person and the illness on this level requires ‘the subjective knowledge which comes from empathy and understanding of that symbolic language in which feelings are often expressed’ (McWhinney, 1978). The most essential step in a clinical encounter is *formulating and understanding the patient’s problems*, and this ‘depends above all else on the quality of the relationship established between patient and doctor’ (McWhinney, 1978:299).

How does the doctor think, when relating to the patient and simultaneously trying to solve a clinical problem? According to Polanyi’s theory of tacit knowing, humans have an intention to unify perceived particulars into a larger, coherent pattern. The part is merged into the whole by integration. Human attention has a focal awareness on the whole, e.g. a face, a melody, a diagnosis, and a subsidiary awareness on the parts; the features, the sounds, the signs (Jha, 2002). Human actions occur along a continuum between bodily and conceptual poles. Bodily and subsidiary poles combine to form tacit knowing. Intuition mediates between the focal and subsidiary poles; it brings knowledge from the subsidiary pole into the focal and conceptual realm (Polanyi, 1969). We cannot have explicit knowledge without a tacit background. All our knowing is grounded in tacit knowing (Polanyi, 1983). According to Polanyi, we can know another person’s explicit thoughts only through words, but we can have a subsidiary awareness of the other’s tacit thoughts, through comprehending their bodily gestures and expressions. This knowledge is tacit both for the knower and for the other person (Polanyi, 1997).

Applying this theory on clinical reasoning, the doctor-patient relationship has to be included as part of the diagnostic process. The physician, a human being, can understand the patient as another human being, through an active emphatic stance. Approaching the patient as a person, the doctor’s clinical knowledge will be in subsidiary awareness, and will along with tacitly perceived cues contribute to the initial diagnostic hypotheses. Without this human-to-human understanding of the patients’ experience, through bodily expressions and spoken words, the



doctor can miss important tacit cues for the medical task of diagnosis and treatment, and run the risk of detachment from the patient (Jha, 2002).

In the more analytic phase of clinical problem solving, the patient as a case is in focal awareness and the patient as an existential being is in subsidiary awareness. The focus will be shifting several times during the process. According to Polanyi, it is not possible to attend to both to the biological body and to the existential person at the same moment; one cannot have two foci of attention simultaneously. However, in subsidiary awareness one can have several aspects. The diagnostic process is a shifting between analysis and integration, successively until the problem is solved. Integration means that when turning to curing or healing, both the patient-as-person and the patient-as-case can be in subsidiary awareness, and the patient as embodied mind can be in focal awareness (Jha, 2002).

For Pellegrino (1979), the experience of illness is the most important fact in medicine, manifesting a basic human need to be healed. To be healed is to have the experience of integrity and wholeness; the unity of self and body restored. This restoration may in case of chronic illness 'represent a renegotiation, a newly struck balance, between the self's hopes and the body's capacities' (Thomasma, 1997) p. 177. The word patient has its Latin roots in the word *pator*, meaning to suffer, undergo, experience, while the word profession origins from the Latin word *profiteor*, which means to declare aloud and publicly, to promise. 'The physician is a health professional by virtue of her promise to bring her knowledge, skill and experience to bear on the fulfilment of the patient's ontological need for healing' (1997:178). Pellegrino also holds that clinical expertise is about phronesis, practical wisdom, about experience in 'bridging that epistemological and ontological gap between the abstract, general, and objective laws and rules of biomedical science and the concrete particularity of the individual patient' (1997:183).

Hunter (1991) also sees restoration as the goal of medicine. Se reminds us that although it is often useful in research to isolate a part of the body and attend to it without reference to the whole, this reductionist procedure is not the essence of clinical medicine. If the diseased organ is seen as isolated, this cannot lead to reliable therapy. 'To move toward ameliorating the patient's condition, the part must be recontextualized, considered again as a part of the whole (1991:10). Kleinman (1988) suggests a practical clinical methodology for the care of the chronically ill, wherein the essential words are empathic listening, translation and interpretation. He compares the clinician to an ethnographer, who 'practices an intensive, systematic, and imaginative empathy with the experiences and modes of thought of persons who may be foreign to him (...)' The purpose is 'for the clinician to place himself in the lived experience of the patient's illness.'

## Literature review

On this theoretical background, I will review the empirical research most relevant for our study. At the end of each section, a summary which points towards our research questions will be provided.

### International studies of GPs' work in cancer care

In cancer care, GPs face several dilemmas (Rosser & Maguire, 1982). Being trained in biomedicine, GPs' hand luggage is a medicine aiming to be an objective, physical science, claiming the mastery of natural processes through interventions and dividing strictly between psyche and soma. GPs are located at the juncture between this knowledge of disease and their patients' experience of illness and social suffering. They are aware of the uncertainties and limitations of biomedical knowledge, but also of their own limited knowledge of a particular condition compared to a specialist. A reaction to the rise of hospital medicine and the consequent fall in status for general practice was the emerging in the 1950s of *biographical medicine*, which saw the role of the GP as a 'final arbiter' of patients' care, 'interpreting, modifying, translating and sometimes even rejecting the specialist advice' (Armstrong, 1979). Knowledge should not be seen only as stored in a hospital, but also as contained in the act of general practice. Thus, two perspectives of medicine were co-existing: 1) The application of science to the human body in order to combat disease 2) Care of the individual by attending to the biography and the subjective experience of the sufferer. GPs had both perspectives; and in cancer care, they could conflict (Rosser & Maguire, 1982). In the first perspective, the specialist is the final authority on management, and GPs have a subordinate status. The interviewed GPs (1982) told about several incidents when they felt that their patients were undergoing futile treatment which seemed harmful. Still, the GPs generally did not feel in the position to openly question this treatment. From the second perspective, the patient's experience is decisive, and the GP's primary obligation is to relieve suffering. Thus the GP also had a specific role, which was cooperative, and not subordinate, to the specialist's role. For the interviewed GPs (1982), telling patients about their incurable disease was embarrassing, because it was seen as a defeat both for medicine and for the GP. GPs' ideology of holistic caring would require an advanced understanding of reactions to disease and illness, which was poorly accounted for in medical theory. The attempts of GPs to provide comprehensive care would therefore remain fraught with problems stemming from their position at a crucial juncture in health care, both conceptually and structurally (1982). For our study, the notion of GPs' *place* at a juncture between biomedicine and their patients' life world, GPs' *subordination* to specialists and the attention to *lack of theory* for a holistic patient care, were important contributions.

Still and Todd (1986) picked up the thread from Rosser and Maguire, stating that the conflict the latter authors refer to can be seen as an ambiguity between two roles for the doctor. In the sociological literature, a sick role (Parsons, 1951) and a dying role (Noyes & Clancy, 1983) of the patient have been compared with a curative role and a caring role of the doctor, respectively. Both Parsons and Noyes & Clancy saw the cure of the sick as the primary role for the doctor. The latter assert that society reserves this more important function for the physician, and 'guards against inroads upon the physician's time and energy' (Noyes & Clancy, 1983). The project of Still and Todd (1986) was to explore through interviews the role for the doctor when the patient is not being cured, but is going to die. They found that the GPs shared common beliefs and attitudes towards their dying patients, like wanting to treat

the patients at home and aiming to give them freedom of pain. The GPs told their patients that they were dying only if the patients asked directly, but the GPs varied in their tendency to encourage such questions. They thought that patients had to be told carefully and gradually, to make them accept the dying role and not start a search for miracle cures. More than half of the GPs found care of the dying demanding, but rewarding, while a quarter found it just demanding, without any rewards.

Still and Todd found that the GPs' attitudes revolved around two ideal types: A technically equipped curative agent complimenting the patient's sick role and a caring role complimenting the patient's dying role. The latter involved guiding the patient through the transition from sick to dying role, and then giving palliative care, both physical and psychological support. This role needed social rather than technical skills, involved the doctor emotionally and attended to both the patient and the family. In the caring role, the GP continued to be of primary importance to the patient, as part of a team including nurses and family carers (Still & Todd, 1986). The scripts for roles and ideal types were evolving with social change, so that at any one time they might be in a stable or in a transitional state. Still and Todd assumed that the caring role for the doctor was in a transitional state, resulting in a role ambiguity which would explain why the doctors in their study varied so much in their attitudes towards dying patients. Moreover, they presumed that the doctors who did not find care for dying rewarding had not yet internalized the caring role; instead they were influenced by the values of hospital medicine and university teaching. In my opinion, the caring role of the physician is not a modern invention; rather it is the other way round: Seeing the doctor as primarily a curative agent is probably connected to the success of hospital medicine during the last hundred years, while the caring role is as old as medicine itself, cf. the Hippocratic Oath.

A French study (Aiach et al., 1990) did not agree with Rosser and Maguire's analysis of GPs being in a juncture of dilemmas. They thought that GPs' work towards people with cancer falls so fully within general medicine that it could revive GPs 'mythical image of a practice consisting in devotion and compassion for a suffering world' and make GPs rediscover the vocation of general medicine. Because the GP has little to do in therapy, he can be more personally involved. This corresponds to Still and Todd's caring role. Aiach et al found that GPs had a conception of general practice opposed to medicine as only a technical quest to cure the patient, and that the GPs took their patients' psychological and social characteristics into account. The theoretical contribution of the study was a model for the GP-patient relationship which the authors call a confidence-assistance pact. The GP makes a commitment to handle the patient's case, be by his side and help him cope, while the patient accepts to fully trust the physician. The reasons for a GP's decision to handle the cancer patient's case are, according to the authors, found in the GP's self-image as a physician and as a human being. He has to manage the situation emotionally, socially and medically, and because accompanying a dying person is an extreme situation, the GP might become so deeply involved that he reaches his human and professional limits (Aiach et al., 1990). In the model of these authors, there is no explanation for the divergent views amongst GPs in the British studies. Maybe in France the tradition of looking at medicine as a caring practice was less interrupted by the success of hospital medicine than in the UK. Or maybe the caring role for the GP was already more stabilized by 1990. In our study, we will follow up on their notion of a confidence-assistance pact between the dying patient and the GP and look for a deeper understanding of the driving force behind GPs' commitment to these patients, keeping in mind the notion of an extreme situation which pushes doctors to their limits.

The dilemmas outlined by Rosser and Maguire (1982) provided the rationale for an interview study with British GPs about their care of dying people (Field, 1998). His participants stressed the relational aspects of terminal care in general practice: Knowing the patients before they got ill, being embedded in the family and the community and being known by the patients. The GPs saw themselves as part of a team of health workers, not necessarily in the lead, with the district nurses working in closest contact with patients and family. Most GPs saw themselves as coordinators of care. One reason for this was that they knew the patient longer than anyone else involved. Psychosocial support to patients and their relatives was seen as important, while physical symptom management was treated as a basic and taken for granted aspect of care. Relationships with hospitals were variable, with complaints from the GPs about lack of information about patients. The GPs also expressed a worry towards the palliative care services, a worry of losing control of patient care. The GPs felt that they had the best knowledge about the patients and their families. They welcomed the possibility to call palliative experts when needed, but did not want to surrender terminal care to them. All respondents stressed the importance of honesty to people who were dying and their families. The GPs had procedures for bereavement support, visiting the bereaved relative at home shortly after death. They generally found the work with these patients important, satisfying and rewarding. Just as delivering babies, it created a very special bond with that family. However, the GPs did not regard their work with dying people different from their other work. Communicative, organisational and clinical skills were important for all their work with patients, just as relationship and a holistic view of the person (Field, 1998). Although Field does not comment on it, it seems that the dilemmas outlined by Rosser and Maguire were less predominant in British GPs' work 15 years later. From other studies, we know that by 1998, cancer was less an enigma for biomedicine, treatment was more reliable and there was an emphasis on openness about the diagnosis. The GPs seemed more confident that their role was, in Still and Todd's terms, a caring role, which however, demanded the whole spectre of clinical and professional skills. The fact that they viewed their work with dying people as 'special not different' from their other work indicates that none of them were longer solely a 'technically equipped curative agent'. Following Still and Todd, the caring role for the GP might have been stabilized since their study (1986), and not only so for working with dying patients, but for all patients.

MacLeod (2001) started out noticing that the concept of care, or how doctors learn to care, rarely emerge in the medical literature. He states that care is more than attending to a person's needs. It is to be receptive to and responsible for others, motivated by empathy. The socialization of medical students and young doctors might decrease instead of augment empathy. Presupposing that caring was not learnt at medical school, MacLeod sets out to interview doctors, from internal medicine, general practice and palliative medicine, about how they learned to care for people who are dying. The participants confirmed that they did not learn it at school. The doctors learned the caring of dying people in an intimate and emotional way, from the dying people themselves. As dying people are vulnerable and helpless, they might engender feelings of helplessness and vulnerability in the doctor. Only when doctors accept their vulnerability and are able to express and share it without fear of being judged, they can learn to live with this tension (MacLeod, 2001). The study went in depth into what caring means on an interpersonal level, and also had specific suggestions to how this could be incorporated into a medical curriculum. The notion of doctors learning to care in practice, from their patients, was an important contribution in the context of our study.

A quite different approach was taken by (Mitchell, 2002), who set out to do a review of all the research literature from 1960 to 2000 to find out how well general practitioners deliver

palliative care. The word 'deliver' already suggests that his concept of care is different from that of MacLeod. He defined palliative care in line with WHO as 'the active total care of patients whose disease is not responsive to curative treatment'. He saw the definition of general practice as being in flux, or in Still and Todd's terms, as being in a transitional state. One unstable factor was whether general practice is seen as provided by an individual or by a team, in which the GP is only one member. Palliative care offered in teams of GPs and nurses got better clinical outcomes than GPs alone. When GPs involve in palliative care, their knowledge of patients will add value to the content knowledge of palliative experts; therefore outcomes for patients should improve when generalists and specialist teams work in collaboration, and there was some evidence for this. Some studies in the review showed poor correlation between the symptoms patients' said they suffered and the doctors' identifications of these symptoms. GPs could fail to identify symptoms they found difficult to manage, or less common symptoms. Both Australian and American family physicians felt that psychological symptoms were the most difficult to manage. Many physicians had low confidence in their own palliative care competence. Both involvement and confidence in palliative care augmented with years of experience. In Australia and in the UK, each GP cared for 5-6 terminally ill patients per year. Mitchell concluded that GPs were capable of 'delivering satisfactory symptom control', but should be part of a team approach. GPs would profit from working formally for a while with a specialist palliative care team to learn enhanced from experience, alongside with palliative experts (Mitchell, 2002). In summary, this study's emphasize on a team approach was important; highlighting that nurses, GPs and specialists each had their metiers which, working together, could contribute to a better care for the patients. Focusing on outcomes and performance, it revealed some blind spots on the GPs' side. Knowledge of such blind spots could help GP-researchers to be more humble and critical towards their own profession.

It seems that Mitchell did not include a study that was quite encouraging for GPs and their teams (Jones et al., 1993). Out of 207 bereaved family carers of people with cancer dying at home in three British health districts, 150 considered the care at home given by mainly GPs and district nurses as excellent, 45 as good, 8 moderate, 2 poor and 2 without comments. The carers reported that pain was well controlled, but 25 per cent of patients had no relief from other symptoms like nausea and vomiting, dyspnoea, dysphagia and confusion. Many lacked early domestic and practical support, financial advice and information about resources outside the health service. The carers own problems largely went unnoticed. A later English study (Grande et al., 2004) found that the family carers in retrospect mainly focused on the basic support that had enabled them to sustain care in the home. Key issues were accessibility of the GP and district nurse, help from other agencies and provision of equipment and supplies. The attitude or approach during interactions and relationship with the professional, especially support from the GP, was important. It seemed quite common that GPs gave their mobile numbers to the family at the end-of-life, and this was greatly appreciated. These two studies emphasize the significance of both practical and relational help. Making the GP's mobile number available includes both these aspects.

In a Dutch study (Groot et al., 2005), GPs were asked in focus groups about how they perceived and performed their tasks in palliative care. Their descriptions are similar to those in Field (1998); they found palliative care responsible and difficult, but rewarding. They described it as complex and typical GP work, combining crucial aspects of general practice; medical care as well as supportive care, in close relationship to patient and family. They saw themselves as coordinators of the patient's care, which was quite consuming. Their work was a mixture of somatic, psychosocial and coordinating tasks. From the group discussions, the

authors identified barriers to palliative care on a personal, relational and organizational level. On the personal level the themes were competence, emotions and time, on the relational level it was communication with the patient and relatives and with other health professionals. The organizational level had barriers in the form of bureaucracy, lack of continuity in homecare and lack of flexibility of specialized personal to perform tasks in the persons' home.

In summary, dilemmas arise from GPs' *place* at a juncture between biomedicine and their patients' life world. If seeing themselves as curing agents, this might result in GPs' *subordination* to specialists. If seeing themselves as caring doctors, they might experience a *lack of theory* guiding a holistic patient care. Nevertheless, GPs have to manage the situation emotionally, socially and medically. Because accompanying a dying person is *an extreme situation*, GPs might become so deeply involved that they reach their human and professional limits. It is in these situations that they *learn to care*, from their dying patients. GPs have some blind spots when giving palliative care; *working in a team* with nurses and having access to specialist advice can improve outcomes for patients. Both practical and relational help is important in palliative home care, and the *accessibility* of the GP is crucial. Dutch GPs saw their work in palliative care as *a mixture of somatic, psychosocial and coordinating tasks*. This summary leads up to some open questions: How do Norwegian GPs see their place in cancer care, today? What might be the GP's special contribution for a patient with cancer? How do GPs perceive accompanying a person through a cancer illness and towards death?

#### International studies of how people with cancer wish to be cared for

How do people with cancer wish to be cared for in primary care, during the whole course of illness? One of the first studies to explore this took place in Scotland (Kendall et al., 2006). People with cancer and their carers met monthly for a year in discussion groups with researchers. They identified five key times in the cancer journey as being especially significant, and made recommendations to primary care for each of them. The key times were: Around diagnosis, during treatment, after discharge, at recurrence and the final weeks. The researchers concluded that people with cancer and their families see an important and unique role for primary care throughout the cancer journey, valuing continuity of care and information that is patient-centred and holistic. This is one of the few studies asking for people's views on GPs' work during the whole illness journey. There are also some studies on GP's specific role in follow-up after cancer treatment and in rehabilitation. Otherwise, most studies concentrate on diagnosis or end-of-life; the two points where GPs until now have been most involved.

In the Netherlands, a research group asked both patients and their GPs what good end-of-life care meant to them (Borgsteede et al., 2006). The starting point for the study was that most people in Western countries prefer to die at home, surrounded by their relatives, implicating that GPs will provide end-of-life care. They found that patients and GPs had similar conceptions of good end-of-life care. GPs should be available, by doing regular home visits and also available on mobile phone out-of-hours, in case of an emergency. GPs should have medical competence, both in treating physical and psychological symptoms and communicate and cooperate well with other health professionals. Attention to the patient and continuity of care was also highlighted.

A Belgian study (Michiels et al., 2007) asked terminally ill people with cancer about the role of the GP in communication and care at the end-of-life. Continuity of care emerged as an important aspect of GPs' involvement. Drawing on previous theory (Haggerty et al., 2003), the authors highlighted relational and informational continuity. Relational continuity meant

having an ongoing relationship with the same GP who knew the history, not only of the patient but also of the family, engendering a relationship of trust and mutual understanding. The GP would know the patient's preferences and be personally responsible, which encouraged individualized care and sensitivity in truth telling. Informational continuity meant that the GP was a mediator and interpreter of information from the specialists, but also one who prepared the patients emotionally and practically for the next phase of illness. GPs should consider patient values and preferences, psychological aspects, social support and context. GPs' lack of time, lack of initiative and lack of knowledge were seen by some patients as barriers to continuity of care (Michiels et al., 2007). It seems that in this study, patients' wishes fits well with GPs' aspirations as quoted in other studies, but it also points to some painful lacks perceived by patients.

We saw that in the Dutch study (Borgsteede et al., 2006), terminally ill patients expected their GPs to be accessible also out-of-hours. This did not seem to be the case (any more) in Scotland, where a study explored patients' and carers' experiences with out-of-hours care. (Worth et al., 2006) found that it was difficult for patients and carers to decide whether to call the regional out-of-hours services. They worried if they were needy and did not want to bother the doctor. Good information about out-of-hours care, being known to the service and empathic responses from the staff was helpful. The authors conclude that regular out-of-hours care is based predominantly on acute illness situations and biomedical criteria, and that special arrangements are needed to ensure integrated out-of-hours care for people at end-of-life (Worth et al., 2006). Their conclusion is important and questions about the organization of out-of-hours care for these patients should be included in our study.

In summary, people with cancer and their families saw an important and unique role for primary care throughout the cancer journey, valuing continuity of care and information that was patient-centred and holistic. GPs should consider patient values and preferences, social support and context. GPs should be available and accessible and have competence in dealing with bodily and mental suffering, as well as communicating and cooperating well with other health professionals. We will return to these wishes and challenges from patients and families to their GPs when discussing the results of the current study.

#### Studies of diagnosing cancer in general practice

In all human thinking, categorization is a basic process. In medicine, certain clusters of symptoms and signs have been assigned to clinical pictures or patterns. Recognizing such a pattern depends on presented cues, which in the majority of cases are, in McWhinney's (1972) terms, not certain but probabilistic. Presented with probabilistic cues, the clinician forms hypotheses about the category to which the patient's illness belongs. In terms of diagnostic challenges, general practice differs from other disciplines: Problems are diverse, illness is seen early, cues are fewer and less certain, decisions are made at lower levels of probability and a background of personal knowledge is often present (McWhinney, 1972).

Diagnostic reasoning in primary care can be split into three stages: initiation of diagnostic hypotheses; refinement of the hypotheses; and defining the final diagnosis (Heneghan et al., 2009). What might trigger the GP's thought of a certain diagnosis early in a consultation? Building on a long research tradition on clinical reasoning (Elstein, 2009; Norman, 2005), four possibilities have been suggested (Heneghan et al., 2009), and most often more than one is active. First, an instantaneous *spot diagnosis* based on pattern recognition of for example acne or a barking cough. Second, *self labelling* by patients of their own diagnostic suspicion,

which immediately directs further refinement of the diagnosis. Self labelling can in some conditions, like recurrent cystitis in women, be quite accurate. Third, *presenting complaint* like head ache or stomach trouble is often used as an outset of a consultation by GPs. Forth, elements in the history or/and examination can, held together, function as a *pattern recognition trigger*, and initiate a hypothesis (Heneghan et al., 2009). In the refinement stage, strategies like *restricted rule out*, *stepwise refinement*, *probabilistic reasoning*, *pattern recognition fit* and *clinical prediction rule* are used. In the study of Heneghan et al. (2009), a known diagnosis was reached in 50 % of consultations, while for the rest, defining the final diagnosis was either attempted by ordering further tests, or undertaking a test of treatment or a test of time.

In the research field of cancer diagnosis in primary care, Norway has two notable pioneers: Magne Nylenna and Knut Holtedahl. Nylenna (Nylenna, 1986a, b) found that in 429 out of 10.000 consultations in general practice (4,3 per cent), cancer was suspected by the GP. After two years, 30 of these patients (7,8 per cent), were registered with cancer. Even if 11 out of 12 suspicions were false, Nylenna found that the strength of GPs' suspicion correlated well with the risk of having cancer. In as much as one in five GP-consultations, patients were worried about cancer (Nylenna, 1984). If patients feared that they could have cancer, the risk of having it was four-fold, while when the GP suspected cancer, the risk that the patient had it was eight-fold (Nylenna, 1986a). Holtedahl (1990, 1991) found that half of the patients who were diagnosed with cancer in Tromsø in 1976 had a delayed presentation to their GP. There was also a delay for half of the patients from the first consultation to diagnosis. About two thirds of the latter delay was attributed to the GP, and one third to the hospital. Altogether, 74 % of the patients had some kind of diagnostic delay. Holtedahl found an association between so called warning signals and the diagnosis of cancer, but altogether warning signals did not discriminate well between cancer and non-cancer. He therefore suggested a more systematic cancer diagnostic strategy for general practice, a two step model. In the first step, the GP should identify whether the patient was in some risk category for cancer, leading to a higher prevalence. In the second step, symptom clues should be scrutinized and diagnostic pitfalls considered. He concluded that reducing the GPs' delay in cancer would be possible with better diagnostic strategies. The usefulness of alarm symptoms for the diagnosis of cancer in primary care has been a main focus of research ever since. In recent years, research has provided numbers that facilitate the utilisation of Holtedahl's suggested strategy. For example, below the age of 50 years, rectal bleeding is almost never due to colorectal cancer, while in people between 70 and 80 years old, the likelihood rises to one in five (Wauters et al., 2000).

Another pioneer in this research field, William Hamilton, asserted that in cancer diagnosis, there are some misconceptions; one is that GPs are not very good at diagnosing cancer. Attempting to clear up this misconception, he wrote:

*One thing most doctors have – which is almost impossible to research – is an innate sense that their patient is ill. The precise diagnosis may not be apparent, but the fact that there is one is apparent. (...) The most powerful predictor of cancer is not a particular symptom or test, but a GP's summation of all the subtle clues present in the consultation. A clue of how strong this summation is comes from studies of the GPs' records of patients with lung, colorectal or prostate cancer. When a variable for a GP's note of possible cancer (generally written as '? cancer') was added to a multivariable equation containing all the other significant symptoms*



*of cancer, the odds ratio for this new variable much outweighed all the other variables. (...) This may represent GPs identifying clinical features not conventionally considered relevant – like the patient’s tone of voice, or a subtle change in their appearance. Clinicians understand such subtleties, which make up the art of medicine, rather than its science (Hamilton, 2009:443).*

Summing up this section, the research by Nylenna and Holtedahl confirmed that on a GP’s list; only a few people will develop cancer every year. To find these cases in the jumble of problems that are presented to a GP is a real challenge. Research on clinical reasoning for the last 40 years and also the model of Heneghan et al. suggests that clinicians engender diagnostic hypotheses very early in the consultation and that these will frame further approach. Hamilton’s notion of the high predictive value of GPs’ summation of subtle clues and also his statement that this is nearly impossible to research, and therefore makes up the art of medicine, made us very interested. We were encouraged by Malterud, who argued against a mystification of the art of medicine, and encouraged the investigation of GPs’ tacit rationality (Malterud, 1995).

Considering the background, the theoretical considerations and the present empirical knowledge, our studies are formulated.

### **Aim of the thesis**

To explore GPs’ views of their contribution to health care for persons with cancer

#### **Aims for each study**

1. To explore how GPs perceive and describe their place in health care for people with cancer, including the challenges and dilemmas that they face.
2. To explore in depth the experiences of being a GP for people with cancer at different crucial points in the course of the illness, including end-of-life.
3. To explore how the thought of cancer arises during a consultation.

## METHODOLOGICAL CONSIDERATIONS

### Choice of method

According to McWhinney (1989), family medicine is a human science, and should learn from the methodologies of other human sciences. Human science is about meaning; the meaning of experiences, practices, events, behaviour, utterances and so on. One way to explore what an experience means to a person is to enter into a dialogue, in which meaning is interpreted and both participants can gain new insights (McWhinney, 1989). Qualitative research is a suitable method for inquiry into phenomena regarding particulars like human beings. The aim of qualitative research is 'to investigate the meaning of social phenomena as experienced by the people themselves' (Malterud, 2001). A qualitative interview is a way of entering into a dialogue with the other about meaning, like McWhinney described. Or as, Kvale & Brinkmann (2009) put it: 'If you want to know how people understand their world and their lives, why not talk with them?'

As context is crucial in general practice, generalisations with explanatory and predictive power can often seem detached from experience. The concept 'particulars' was introduced by Gorovitz & MacIntyre (1976) as entities that 'occupies a region of space, persists through time, has boundaries, and has an environment...' (1976:56). Particulars can be living organisms like human beings, a collective like a city, an ecosystem like a desert etc. The behaviour of particulars cannot be fully explained or predicted by general scientific laws. Their history, context and environment will be decisive. The more complex the particular, the greater is the uncertainty regarding the application of general principles, said Toulmin (1976), and added that a sick person is a very complex particular. Medicine can be seen as a science of particulars, attempting to apply the general laws of the basic sciences to human beings with a unique history. The low-level abstractions of clinical science itself, like diseases and syndromes, are mostly mediated through case histories, which comprises a literature of particulars. For doctors, experience is an 'acquaintance with particulars' (McWhinney, 1989) which might lead to clinical wisdom.

For our research aim, qualitative interviews with GPs seemed the most appropriate method. Other possibilities would have been doing observations and/or recordings of clinical encounters and then interviewing afterwards. In this way the researcher would have had both her own observations of the GPs' encounters and additionally the possibility of interviewing. Observing encounters gives the possibility of analyzing interaction in vivo, but 'even observed firsthand, (events) are not inherently endowed with meaning, nor is their meaning unequivocally available for inspection' (Atkinson & Coffey, 2003:427). Interviewing has the advantage of asking questions, discussing, confronting, attending to stories, learning more about background and context, intentions, explanations and ideals. Combining observations and interviews, they could reciprocally illuminate each other. To get the longitudinal perspective that we wanted for the second study, such an approach would have required an extensive fieldwork, thus limiting the number of GPs that could be participating. For the third study, we would have had to record or observe a high number of consultations to capture the ones in which the thought of cancer turned out to be an issue. There is a question if it is ethically justified to intervene in a lot of consultations when just a few of them are relevant to the research question. We concluded that given the limits of being a single novice researcher in a PhD project, just conducting interviews was a pragmatic choice which still could give valid answers to our questions and contribute to new knowledge.

### **Researcher's perspective**

The pragmatism of choosing an interview design was also related to my professional background as a PhD student. As Kvale & Brinkmann (2009) write, interview research may to some appear as a simple and straightforward task. As a GP, I was used to interview patients for diagnostic and therapeutic purposes. I thought that my background knowledge from general practice would be valuable in an interview situation. I imagined that I more easily than a researcher from other backgrounds could understand what the GPs talked about and maybe even ask better questions. I could use my own experiences from cancer care as a resonance for the GPs' stories. 'An interview is literally an *inter view*, an inter-change of views between two persons conversing about a theme of mutual interest' (Kvale & Brinkmann, 2009:2). I felt that I was qualified by profession and experience for this inter-change, and I thought that the participating colleagues would regard me as a qualified conversation partner. However, I also suspected that in some issues, I could be blinded by having undergone the same professional socialization as the participants and having shared most of their working conditions. Collegial sympathies and mutual professional interests could easily lead to a lack of critical distance and an idealization of the GPs work. Their perspective of looking at health care would probably to a great extent coincide with mine only that for now, I had put on the spectacles of a researcher. Going to visit the GPs, I would have to combine the knowledge and credibility of an insider with the openness and curiosity of an outsider. The challenge of creating a distance was even greater in that my supervisors were also GPs.

More over, the larger research group also contained mostly academic GPs. Our parent department of community medicine was constituted mainly by epidemiologists and statisticians, to whom qualitative research was a rarity. From the start, it seemed important to get input into this project from other sources as well. Taking part in PhD courses given by other departments, other faculties and other universities was valuable, but most important was the continuous participation in two different study groups with researchers from several fields, like pedagogy, anthropology, arts and nursing science. In these groups of mainly PhD-students, we discussed qualitative research literature on method and theory, but most importantly we read and commented on each others proposals, drafts and manuscripts. Likewise I took part in a longitudinal, session-based PhD-course at the department for health sciences, where senior researchers, a sociologist and a philosopher, amongst others, commented on our proposals and drafts. As a guest researcher for a semester at The Research Unit for General Practice in Copenhagen, I also took part in a rich interdisciplinary discussion. To counteract the danger of professional inbreeding, I have very actively searched for a dialogue on matters like epistemology and methodology and also subjected this project to interdisciplinary criticism on several occasions. Such discussions could affirm that we were on the right track, but also point to serious faults, like the risk of heroizing GPs.

## **Epistemological considerations**

An important epistemological question that has been considered throughout the project is: What kind of knowledge can we get from interviews? From an empirical perspective, knowledge comes from observation of facts. Interviewing can from this point of view be seen as a *collection* of data, as illustrated by Kvale & Brinkmann (2009) in a metaphor of mining:

*The knowledge is waiting in the subject's interior to be uncovered, uncontaminated by the miner. The interviewer digs nuggets of knowledge out of a subject's pure experiences, unpolluted by any leading questions. The nuggets may be understood as objective real data or as subjective authentic meanings (2009:48).*

An alternative understanding would be the researcher as a traveller in a foreign country, telling a tale upon coming home.

*The interviewer-traveller, in line with the original Latin meaning of conversation as "wandering together with", walks along with the local inhabitants, asking questions and encouraging them to tell their own stories (...). The potentialities of meanings in the original stories are differentiated and unfolded through the traveller's interpretations of the narratives he or she brings back to home audiences. The journey may not only lead to new knowledge; the traveller might change as well (2009:49).*

As the mining metaphor concerns not only empiricist data collection, but also to some extent Socrates' pursuit of the truth or Husserl's search for phenomenological essences (Kvale & Brinkmann, 2009), these complementary epistemologies were continuously debated in our research group, and will also be discussed throughout these chapters. Reading the thesis, I think you would find traces of both ways of looking at interviewing, revealing both a minefield of epistemological stumbling stones and a traveller in transition.

On the way to a PhD, the researcher not only wanders with her participants, supervisors and other researchers, but also with philosophers and theoreticians. Perceiving only bits and pieces of their assertions at the outset, towards the end of the journey I will now refer briefly to their respective influence in this project. The synthesis below draws on Kvale & Brinkmann (2009), Alvesson & Sköldböck (2009) and my own literature studies.

*Phenomenology* was originally a continental philosophy of consciousness, experience and the human life-world, founded by Husserl, elaborated in an existential direction by Heidegger and towards a philosophy of bodily perception by Merleau-Ponty. With Schütz, phenomenology travelled on from Europe to America and from philosophy into the social sciences, influencing amongst others Berger & Luckmann and Garfinkel. With phenomenology, the life world of human beings was rehabilitated in relation to the world of science. The approach of phenomenology coined our interest in understanding a social phenomenon (cancer care) from the actors' (GPs') own perspectives and 'to describe the world as experienced by the subjects, with the assumption that the important reality is what people perceive it to be' (Kvale & Brinkmann, 2009:26).

Another influence in this project was the American philosophy of *pragmatism*, originally developed by Pierce, James and Dewey, emphasizing the primacy of practice and the utility of scientific knowledge. Presuming that language and knowledge are not copies of reality but means of coping with a changing world, conversation is seen as a basic mode of knowing.

Pragmatism inspired the theoretical perspective of *symbolic interactionism* developed by Blumer and Mead. They assumed that society, reality and self are constructed through interaction; language and communication. Seeing this interaction is inherently dynamic and interpretive, symbolic interactionism addresses how humans create, enact and change meanings and actions. The qualitative research approach of Grounded Theory, developed by Glaser and Strauss (1967) were inspired by symbolic interactionism. The thorough and rigid methodological advices of Grounded Theory, developed further in a more constructivist direction amongst others by Charmaz (2006), have been inspiring also for this project. Pragmatism fits well with being a practitioner, and a main theoretician of practice, Schön (1991), which I refer to, can be seen as writing in a pragmatist tradition.

*Hermeneutics* was originally the study of interpretation of texts. Central to hermeneutics is the interpretation of meaning. A basic assumption is that the meaning of a part can only be understood in relation to the whole. Conversely, the whole can only be understood from the parts. These relations constitute the concept of the *hermeneutical circle*. The contradiction of terms inherent in the concept indicates that logic cannot fully explain the workings of understanding. To grasp the meaning of the parts and the whole, an intuitive and creative 'leap' is necessary (Palmer, 1969). Meaning was in classical hermeneutics seen as a search for the author's intention, which the skilled interpreter should unveil.

According to philosophical hermeneutics, understanding is not only the peak of scientific effort, but the basic existential condition for every human being, a necessity to survive on an everyday basis. Language is not mainly representative, but constitutes human reality. Human beings are always already interpreting an ever-changing life world, and our practices are laden with theory and temporality. Thus a second hermeneutical circle appears; an iterative dialogue between our pre-understanding and an emergent new understanding. Without pre-understanding there is no understanding. However, pre-understanding can preclude understanding (Gadamer, 1960). The notion of text has been extended to all human meaningful action (Ricoeur, 1984). Moreover, every text derives its meaning from a con-text. History, tradition, place and perspective provide contextual interpretive horizons.

The epistemologies outlined above share some assumptions. Life world experience is always prior to scientific knowledge. Knowledge does not reside inside a person or outside in the world, but in relationships between people and the world. Knowledge is not a mirror of reality, but is interpreted and negotiated in a social web, and validated through practice.

On the background of the insights above, some features of the knowledge gained from qualitative interviews can be outlined. Interview knowledge is produced, relational, conversational, contextual, linguistic, narrative and pragmatic, as is the social and historical world of human interaction (Kvale & Brinkmann, 2009). Learning is better explained by a qualitative change in a person's way of viewing, understanding and conceptualizing something in the world, than as an increase in the amount of knowledge (Barnard et al., 1999).

Interview knowledge is constructed first through the social interaction of interviewer and interviewee, through questions and answers, then restructured through transcription, analysis and reporting. Inter-viewing creates inter-relational knowledge, through conversational negotiations about meaning. The meanings of interview statements relate to the interpersonal interview context and to the local life context of the interviewee. Interview knowledge is mediated through language, and the participants' use of linguistic means is often also

analyzed. Interview knowledge is often narrative, as stories make sense of incidents and participation in social life. The pragmatic aspect of interview knowledge concerns the ever human search to perform effective actions and master a practical situation; good research enables us to understand and thereby cope with the world (Kvale & Brinkmann, 2009).

Each of the mentioned features of interview knowledge points to its possibilities, but also to its limitations. Interview statements cannot automatically be taken at face value, but should be critically considered in its context of inter-relations. Interview knowledge is not context-independent and cannot automatically be transferred to other situations. Interviews are not primarily reports from which a social reality can be retrospectively reconstructed. Stories should be treated as ways of making sense of events, not as accurate reports of what has happened. The reliance on verbal language complicates the access to tacit, emotional and bodily interaction and knowledge. Sitting down to talk can seem detached from meaningful action and practice.

Planning our study, we tried to consider these features of interview knowledge. As McWhinney remarked, GPs have difficulty speaking about general practice without speaking about their patients. To explore how general practitioners perceive and describe their place in health care for people with cancer, asking for stories about their care for individual patients throughout the course of illness seemed highly relevant. Case stories are generally the way doctors pass on and discuss medical information (Hunter, 1991), hence the format would be well known to both interviewer and interviewee. The unusual now would be for both to focus on the doctors' side of the story, and on the interaction between doctor and patient. Asking for stories was a pragmatic way of keeping the GPs close to the original experience of having cared for a special patient over time, without having to observe or record it all the way.

## **Sampling and interviewing**

The sampling for our study was already done before I was engaged as a researcher. The process has been explained to me as follows: The participants were recruited through survey questionnaires about cancer and primary care, which were sent to municipalities throughout Norway. The questionnaires dealt with GPs' participation in care for individual patients with cancer throughout the course of illness and also had a question about the GPs' willingness to take part in an interview. The results of that survey are not yet published. The response rate was low, while the percentage of the participants who opted for an interview was 67 per cent (Professor Knut Arne Holtedahl, personal communication). GPs who had indicated in the survey that they had been involved in many tasks during several phases of a patient's illness, including palliative care, were preferably chosen, assuming that they would have rich sources of experience to draw on in a conversation. Moreover, the sampling aimed for a variation in gender, place of practice and years of experience as a GP. Hence, the sample was purposive, counting 16 GPs. The participants had already received a letter from the university, and had already supplied written consents to an interview. I received the consents, together with copies of the GPs' completed survey questionnaires. Each questionnaire addressed the illness course of one particular patient, and how the GP was involved. Most GPs had filled out one form, but several had filled out forms for two patients.

### First study – papers 1 and 2

During the fall of 2007, I contacted the GPs, first by e-mail and then by mobile phone, to make appointments, and started on several interesting journeys around Norway to undertake the interviews. It turned out that one of the GPs had quit and moved to another region, and another was located at a place difficult to combine with other interviews. For practical and economical reasons, these two GPs were not visited. Thus, encounters with 14 GPs comprised the basis for the two first studies in this thesis. A table containing our reflections before the interviews and the interview guide for this first interview round is found in Article 1, as is a table containing information about the participants. Most interviews were conducted in the GPs' office. One interview took place in the researcher's office, and another interview in the GP's home.

In this first interview round, regarding the GPs work during the whole course of cancer illness, I brought copies of the completed patient questionnaires from each GP, and asked if they wanted to tell me about these patients, or if they had other, more recent patients with cancer that came more readily and vividly to their mind. In most interviews, the participants chose to talk about the same patients as in the questionnaires. In four interviews, we talked about two different patients, in the other ten interviews we talked about one patient. Thus, the GPs told about altogether 18 patients. As stated in paper 1, ten patients had died by the time of the interview with their GP: four died at home, four in hospital and two in a nursing home. Six were receiving palliative treatment and only two were survivors. They were suffering from a variety of cancers, located in the breast, lung, gastro intestine, prostate, ovary, kidney, liver and brain.

The starting question was broad and open: Tell me about this patient's story and how you were involved. Such open-ended questions let the interviewees choose the dimensions of the questions they want to answer, which is interesting in itself (Marton, 1988). Secondary questions were placed when they fitted into the developing dialogue. For a list of themes that I tried to touch upon in all the interviews in the first round, see paper 1.

### Second study – paper 3

For the third study, the same GPs were contacted again during the spring of 2010. Since 2007, one GP was retired and one had moved to an administrative job, so 12 GPs received information about the new study by ordinary mail. One GP did not return the enclosed sheet with informed consent, resulting in a second encounter with 11 GPs. Two of the interviews were this time conducted as a videoconference, due to long distances and a limited budget. A third interview took place outdoors and a fourth in the GP's home. All interviews lasted for about one hour and were recorded digitally.

I sent an e-mail to the GPs as a preparation, inviting them to think about consultations during which the thought of cancer arose, see Fig. 1 in paper 3. It turned out that few of the GPs had taken time to read this beforehand, so many interviews started with me reading the short letter aloud to them. Most of the interview consisted of the GPs telling me stories about patients in whom they had thought of cancer, and some in whom they had not thought of it, who turned out to have it. I tried to get some basic information about the patients and the diagnostic process in each story, and had a list of secondary questions to fit in, see Fig 1 in paper 3. As there were around 70 patient stories during the 11 interviews, the space for each was limited.

I had some questions in the guide which turned out to be sensitive. One was about intuition, a subject not often discussed in medical education. Still, the question was discussed in all but one interview, either on the initiative of the participant or the interviewer. Two other questions were about GPs' bodily reactions during consultations, and how they managed to enter into the patients' stories. These topics were, due to their sensitive character as perceived by the interviewer, touched upon only in a couple of interviews.

### Unplanned interview settings

In the second round of interviews, I could build upon the acquaintance from the first round. This led me to opt for two interviews per telecommunication, due to long distances. In one case, the interview was done via Skype while the GP had lunch in her office. The other interview was done with the GP sitting in the local telecom studio. Both worked quite well, but I think that both interviews would have profited qualitatively from a face to face setting. There were two other unplanned interview settings. One participant had quitted his job as a GP in a rural village shortly before the interview. He therefore received me in his new home in a larger city, and the interview became an interesting reflection, thinking back on the five years he had worked in the small community. Another participant was doing a hospital rotation, and was on night call the night before the interview. As this was a fine summer morning, we agreed to meet outdoors, bringing coffee and biscuits to a green hill outside a churchyard. On the recording, I could hear the birds singing, and also, at the end of the interview, this young doctor's tale about the illness and death of her own father under unworthy circumstances. I doubt that this personal story would have been told if we had met in a surgery or a hospital. I asked myself in afterthought if the timing and setting had been inappropriate for the interview; placing a doctor bare feet in beautiful surroundings when being thin-skinned after a sleepless night. The improvised interview settings were, however, also results of the tight schedules of most GPs. For many of them, finding an hour's time for an interview was difficult, and it was an advantage if interviewing could be combined with some other necessary or pleasurable activity, like eating or taking a break.



### **Ethical formalities**

As part of a larger project about cancer and primary care, initiated by professor Knut A. Holtedahl, this study received a formal ethical approval from the Regional Committee for Medical and Health Research Ethics of Northern Norway in 2005 (Ref 200503439-10/IAY/400) and later also from the Data Inspectorate of Norway (Ref 05/01607-9/CGN). In the mean time, Norwegian health research legislation has been changed, and from 2009, a study that neither does direct research on patients, biological material nor personal health information might not require such approvals at all.

Informed consent from the GPs had been obtained in several rounds. As explained in the previous section, the participants were sampled from people who already had consented informally to an interview. Through a personal postal letter, enclosing a consent form, they were briefly informed again, and had another possibility of saying no or not to answer. However, all invited GPs returned a written consent for the first interview, and all but one of those who were eligible for a second interview did so. It should be remarked that the survey was not anonymous. Norway is a small country, and many GPs knew the initiator of the study. Answering the survey with their full names, it might have been difficult for some GPs to say no to an interview, presuming that non-participation could be seen negatively by the research group or by the university. Also, withdrawing when contacted personally by a colleague is not easy; completing might feel like a moral obligation.

Confidentiality in our study had to be considered for both the patients whom the GPs told about, and for the GPs themselves. The interviewer did not know the identity of the patients, only their age, gender and type of cancer. However, the full illness story as told by the GP, eventually combined with some contextual information, would make the case recognizable to people who knew the patient. Remembering that neither the patients themselves nor their families have been asked for consent about being part of the research on their GP's practice, special care had to be taken. A table containing patient characteristics was omitted, partly for reasons of confidentiality. In paper 2, dealing with longitudinal stories of the doctor-patient relationship, concerns of patient confidentiality had to be especially focused upon. I chose to make some slight changes in information about the patients or their context to make the stories less recognizable.

The interviewed GPs have, unlike the patients in their stories, consented to be interviewed and deliberately shared their experiences and opinions. However, as a premise for being interviewed, they have been promised confidentiality. Interview recordings have been stored safely, and transcripts have been anonymized. Citations and presentations of one particular GP had to be considered for questions of recognisability. Certainly, most GPs will recognize their own statements, and theoretically, some of their close colleagues or the patients themselves might recognize a story, and then indirectly figure out who the interviewed GP might be. However, these people all know much more than the interviewer about the patient, the family and the GP, and have their own well-founded version of the stories and their own perceptions of the people involved. Still, the researchers' interpretation and presentation of the storied events might be unfamiliar, uncomfortable or even offending to the interviewees and/or other people who might recognize them.

### **Further ethical considerations**

As the human interaction in the interview affects the interviewee (and the interviewer) and the knowledge produced affects our understanding of the human conditions under study, an interview inquiry is a moral enterprise, loaded with ethical issues which by far exceed principles and formalities. Many ethical issues of interviewing cannot be solved by a procedural approach, but requires practical wisdom and situated judgment.

### Relevance

Health service research should serve both scientific interests and human welfare. The social contribution of a study should include increased knowledge of the human condition, human behaviour and people's understanding of themselves and others (Kvale & Brinkmann, 2009). Regarding the aims of this study, they seemed to have the potential to fulfil the claims of a social contribution. GPs are in the frontline of health care, and how they perceive their work in a broad field like cancer has consequences for many people, especially in countries like ours with a gatekeeper system. Norway still needs to develop care for people dying at home, and it is important to know more about GPs' possible contribution to this. Knowledge about how GPs become aware of cancer in a consultation is important because cancer is mainly diagnosed in primary care. Moreover, the study could contribute to more consciousness amongst GPs about their roles, identity and the meaning of their work.

### Interviewing peers

The relationship between interviewer and interviewee is central in qualitative interviewing. Interviewing peers means that both share a similar role or status, a similar body of knowledge and an ongoing professional relationship (Coar & Sim, 2006). '(R)esearcher and researched are bound together by a powerful set of common experiences and attributions of professional identity' (Chew-Graham et al., 2002:287). This equality could result in feelings of professional credibility, confidence, cooperation and solidarity, which could encourage an open and rich conversation, permit vulnerability and open up the possibility of talking about sensitive issues. However, striving for an atmosphere of intimacy and openness may also have side-effects, leading interviewees to disclose stories they may later regret having shared (Kvale & Brinkmann, 2009). A shared understanding of the research field by interviewer and interviewee might be problematic in a qualitative inquiry, 'precisely because such methods are intended to interrogate the tacit, taken for granted understandings that underpin everyday life' (Chew-Graham et al., 2002) p. 287. Qualitative inquiry can, however, also aim at a manifest level of content; see later in this chapter about content analysis.

### Possible harm

In this study, several sensitive issues were already explicitly stated: Challenges and dilemmas in caring for people with cancer, exploring in depth experiences of being a GP for people with cancer at different crucial points in the course of the illness, including dying, and talking about diagnosing cancer, which easily could lead the thoughts to overseeing cancer. 'In an interview with a fellow professional the individual's professional identity is at stake, and steps are therefore taken to protect this identity' (Coar & Sim, 2006:254). To be interviewed by a colleague about one's practice could feel like being under professional scrutiny, like a test of knowledge or an examination (Coar & Sim, 2006), especially if the GP-researcher was a clinical expert in the field under study (Chew-Graham et al., 2002). However, also researchers with other backgrounds could be experienced as an external threat. It is important to acknowledge that 'there *is* an element of assessment or adjudication of quality in studies that seek to explore (...) clinical practice' (Chew-Graham et al., 2002:289). Protecting oneself

from such external adjudication through hesitance to talk about certain topics is understandable, especially if the research is perceived to result in even greater professional demands (2002). This is certainly a concern that our study has to address: What might be the consequences of the study, both for the participants, for the group they represent and for society in general? Could our conclusions and implications contribute to an increased pressure on GPs in the field of cancer care? Or, may our interpretations contribute to romanticize general practice, covering up critical aspects that another perspective would have revealed?

#### Closeness and distance

A practical measure was to stage the interviews in the GPs' surgeries, where they would feel professionally at home, and also have access to the patient files, if needed. One GP was interviewed in the researcher's office at the university. This GP had, however, an affiliation with the university. Some GPs said they felt privileged to be visited by the researcher, and wondered that I had travelled for many hours to reach their surgeries. Some took the opportunity to show me around on their premises and explained about local circumstances. One GP in a rural area invited me to have dinner and stay overnight with her family, before interviewing her at the surgery the next day. Another GP invited me for supper and interviewing in her home, because this fitted better with her schedule. I accepted both invitations, regarding them as expressions of hospitality and opportunities to get acquainted before the more formal interview setting. Interviewing people in their homes is common when the research subject is more of a personal matter, and I guess that researchers often are invited to have a coffee or sometimes even share a meal with their interviewees. Staying overnight is probably uncommon in an interview context; however, in an ethnographic study the researcher might share the dwellings of a community and live in participants' homes for a longer period of time. The balance of closeness and distance between researcher and participants in qualitative inquiry has, like in any human relation, to be continually negotiated. A small country like Norway with a small scene of GPs means that the researcher will inevitably know at least the names and faces of some of the interviewees beforehand, and meeting again in professional or even private circumstances is quite likely. Thus, taking well care of the shared information becomes a personal and professional responsibility towards the interviewees. This might heighten the ethical sensitivity of the researcher but also impair critical interpretations.

#### Interviewing as debriefing

During the 25 interviews, I several times went through a patient history together with the interviewee in a way that turned into a kind of debriefing. Mostly the GPs seemed to be content with their own appearance in the stories. I felt that in some of the cases, the review of the whole course of illness with all its complications and difficult decisions was done for the first time. Sometimes GPs asked themselves if they had done the right things on the way, and feelings of guilt or regret were occasionally ventilated. In one case, the debriefing of one particularly unfortunate history (of lacking interaction between levels of health care) lasted through the larger part of the interview, leaving little time to touch upon the other themes from the interview guide. Particularly in this conversation, I was also asked questions about the legitimacy of moral choices. In these kinds of conversations, I clearly felt the advantage of being a colleague, a professional person found worthy of receiving the stories, and also with the potential of understanding and valuing them. The GPs' emotional involvements in relation to the patients were rarely explicitly mentioned, but could be heard from the tone of voice, repetitions, urgency of speak, silences or choice of words. Interestingly, questions about the GPs' own emotions were not discussed when planning the study and were not included in the

interview guide. I wonder if the omission of explicit emotional themes was due to blind spot amongst doctors, including academic GPs. As implicit themes, emotions take part in any human conversation, also in these interviews, and can be listened for and looked for, which we also did, in retrospect.

### Confrontation and resistance

Research can be seen as a learning experience. The researcher is finding something out, and the research subjects are also learning. During the interview, the 'interviewer works together with the interviewee to bring forth his awareness of undertaking the task', and the interviewee is 'reflecting over his experience in a state of "meta-awareness", being aware of his awareness of something' (Marton & Booth, 1997:130). In our case, one 'task' was to think back on previous consultations, trying to remember when and how the thought of cancer arose. Marton & Booth differentiate between two levels of the interview: First, the interpersonal contact that resembles a social discourse, and second, more of a therapeutic discourse, in which 'the interviewer is trying to free the interviewee of hitherto unsuspected reflections' (1997). To achieve this, one can try alternative questions, bringing the interviewee repeatedly back to the focus of reflection, or offer interpretations of earlier statements. Like in a therapeutic situation, *resistance* might occur; the interviewee can set up a defence and deny further discussion. Bypassing these defences and making the interviewee aware of his own thoughts should only be done with great caution, as it can be painful, but according to Marton & Booth, it might be necessary. Kvale & Brinkmann (2009) include in their book examples of interviewers going this far, like Robert Bellah (p. 37) and Pierre Bourdieu (p.6).

Being a novice researcher interviewing colleagues, I did not intend to be confrontational or bypass their defences. If I experienced resistance, I backed out. A question about the use of guidelines, which was originally in the guide for the first interview round, caused suspicion in an interviewee. He asked if I was coming around to check if they were following guidelines. As this was an early interview and the question was not essential for our research aims, I decided to skip the question from the guide. I also met resistance in one colleague when I asked about his view of intuition. He did not want to use the word at all, so I left it. A more offensive approach would have been to come back to it later, for example asking: I noticed that you did not want to use the word intuition, do you mind telling me about your thoughts on this word? This could have been a way of keeping a certain distance to the interviewee, but still I would try to get closer to what I reckoned as an interesting aspect of his experiences.

Marton & Booth (1997) claim that

*the question of balance in terms of overcoming defences and the issue of distance versus closeness is ever present in the more reflective parts of an interview, in which the interviewer could easily destroy the relationship by pressing too hard or not hard enough, or by getting too close or not close enough.*

How could the relationship be harmed by not pressing hard enough or not coming close enough? A good dialogue can be seen as having a forward movement towards a turning point. This might be perceived as a promise; the participant expects to get the decisive question, and might feel abandoned if it is not asked. Courage is, like knowledge, interactive. When going out on thin ice, one needs the other as companion and rescuer. What also might be harmed is the sincerity and truthfulness of a shared search for understanding, and also the depth and completeness of the themes that are drawn into the light of dialogue.

## Analysis

Analysing interview data starts during the interview. The interviewer both tacitly and reflectively interprets statements from the interviewee, on the background the whole interview interaction and of her own preconceptions. I did this reflective process for example by asking the interviewee clarifying questions or thinking aloud about my interpretations of statements. The analysis goes on as the interviewer thinks back on the conversation, writing down her first impressions in a field note, and further when she several times listens to the recordings. The transcription from oral to written language is also a structuring and analytic process. Unclear wordings are interpreted or given up; para-linguistic expressions are noted or left out; dialect is normalized into standard written language and grammatical devices like commas and full stops are distributed, just to mention some of the many choices taken. The expression 'transcribed ad verbatim' which is a standard in qualitative papers does in my opinion conceal the interpretative and analytic process involved when qualitatively transforming and reducing oral exchange into the written genre. After the first interview round, I performed the transcriptions myself. Due to time pressure, the second interview round was transcribed by an experienced assistant. After transcription, the interview files were entered into the computer software NVivo8, later NVivo9, to facilitate further analysis. For each of the three studies, we decided on a different approach for the further analysis of the transcripts.

## Content analysis

The aim of the first study was going to get an overview on GPs' work in health care for patients with cancer, as seen by the GPs themselves. The analytic approach should be suited for sifting through the whole dataset and favour a descriptive overview more than going into the dept of the GPs' lived experience or build a coherent grounded theory. We opted for an inductive, qualitative content analysis, a design which is appropriate when there is limited theory or research literature on a phenomenon, and the aim is to attain a condensed and broad description (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005). The first steps in this procedure are similar to several other qualitative approaches focusing on meaning, like grounded theory, empirical phenomenology or phenomenography. As a novice, I found the step-for-step introductory books by Malterud (2003) and Charmaz (2006) useful for learning a broad interpretative approach. The steps they recommended were as follows: The transcripts are all read several times, to achieve immersion and obtain a *sense of the whole* (Hsieh & Shannon, 2005). The reader should note her impressions of preliminary themes relating to the research questions (Malterud, 2003). The texts are then approached systematically; line by line or incident by incident, looking for *meaning units* consisting of words, sentences or paragraphs that relate to each other both in content and context (Charmaz, 2006; Graneheim & Lundman, 2004), and looking for words that could capture the key thought or concept of the meaning unit (Hsieh & Shannon, 2005). This can be done in several steps, first *meaning condensation* and then abstracting this further into a *code*, naming the key thought or meaning. Often this whole process of finding meaning units, condensing and abstracting them is referred to as *open coding*. The next step is *focused coding*, using the most significant or frequent earlier codes to sift through larger amounts of data (Charmaz, 2006). Codes are then sorted into meaningful clusters called *categories*, according to perceived relations and linkages between the codes, found by moving iteratively between a single interview and the whole sample of interviews ((Hsieh & Shannon, 2005; Marton, 1988; Marton & Booth, 1997). Ideally, categories should be exhaustive and mutually exclusive. However, human experiences are intertwined and not always dividable into mutually exclusive categories. The process of coding and categorizing is intensive, time-consuming, detailed, demanding and creative brain

work, which is aided both by discussion within the research group and *writing memos* of impressions, ideas and emergent concepts (Charmaz, 2006).

An example of the process of coding and categorization in our first study is found in Article 1, Table IV. We started off coding for a lot of different GP-tasks, roles, actions and qualities. It was not until very late in the process that suddenly, in a joint creative movement, an idea of a pattern emerged from the piles of condensed meanings and codes. The pattern consisted of what we have called the three aspects of GPs' work in cancer care; the practical, the mediating and the personal. To sharpen the understanding of what these aspects were about, we called the GP in these three roles respectively an efficient handyman, a flexible intermediary and a touched companion, see Article 1, Table III. Thus, the results were comprised in a simple conceptual model. According to Hsieh & Shannon (2005), this is as far as one can get with inductive content analysis. The sampling and analytic procedure is not suitable for developing further theoretical relationships between concepts, which was also not our aim.

### Narrative analysis

For the second study, we wanted to explore in depth the experiences of being a GP for people with cancer at different crucial points in the course of the illness, including end-of-life, using the same dataset as in the first study. Thus, the focus was on the third aspect of the GPs' work in study one; the personal aspect; being a companion. In study one; we had already seen that some of the greatest challenges and dilemmas that the GPs told about related to the personal aspect, and particularly the patients' fear of death. How could we take the analysis further to develop a deeper understanding of the GPs' challenges and dilemmas? Obviously, the narrative character of the interviews had not been taken fully into consideration in the first study. In content analysis, the text is broken down to small pieces of 'meaning units' which then are joined with other such small text pieces into clusters with similar meanings. However, the interviews mainly consisted of stories, 18 long ones about the patients already mentioned, but also 18 shorter ones, anecdotes about other patients with cancer that the GPs came to think of as we talked.

Stories or narratives (I will use these terms interchangeably) contain the temporal aspect of a phenomenon, for example of the course of illness and the doctor-patient relationship. Through their plot, stories create a relation between events, 'imposing a meaningful pattern on what would otherwise be random and disconnected' (Riessman, 2008:5). Stories also contain an explicit or implicit evaluation on behalf of the narrator, which points to the moral meaning of the story (Labov & Waletzky, 1997). Through stories, individuals and collectives make sense of events, create order out of chaos, connect with others and construct identities, but also entertain, argue, persuade, engage, mobilize or mislead their audiences (Riessman, 2008). According to Bruner (1987), individuals might *come to be* the narratives they tell about their lives, and this can be taken advantage of for therapeutic purposes (Mattingly, 1998). Personal stories draw on the web of myths and meta-narratives that underlie a particular culture, and also on well-known genres of stories, like the hero's journey (Frank, 1995; Riessman, 2008). Narratives are often compelled by a *breach* in the commonplace.

From the short introduction to narrative theories above, we could assume that the GPs' stories in our material would take us to events that were challenging or represented dilemmas for them. We understood that the narratives would aid their construction of a professional identity

and that they would draw on meta-narratives about what it means to be a good GP. We learned that looking for an implicit or explicit evaluation by the storyteller would lead to a hint about the moral values at stake in the story. A summary of our concrete analytic procedure regarding the interviews is found in the Methods-section of Paper 2.

Studying the interviews with narrative lenses opened up for new analytic insights. It was impressive to realize what actually had been blended out by the content analysis. For an example, look at the citation of dr. S on p. 6 in paper 2, and her use of evaluative statements: Strange, bizarre, very unpleasant, one of worst things I have ever experienced... This story refers to a deep breach in the commonplace, and decisive values for this doctor seem to be at stake, maybe threatening her identity as a GP. The most obvious conflict referred to here is between the judgments of a local practitioner and a distant specialist, which again involves important aspects of the history of medicine, see for example Jewson (1976). To understand the depth of this and other stories, it was important for us to review the moral and historical foundations of medicine and also the development of the doctor-patient relationship, as seen in the introduction of this thesis and also in the introduction of paper 2. Thus, every text derives its meaning from a con-text, and history, tradition, place and perspective provide contextual interpretative horizons.

### Phenomenography

The third study was methodically the most challenging, as it set out to explore a tacit phenomenon: How the thought of cancer arises during a consultation. The aim of the study was loaded with epistemological challenges, and the choice of analytic approach was decided on this background. We needed an approach that in its foundations clearly reflected on epistemological issues. Phenomenography has a relational view of knowledge, seeing the researcher as a learner who seeks the meaning and structure of her phenomenon by asking people about their experiences of it (Barnard et al., 1999). Phenomenography implies that we cannot gain knowledge about phenomena like learning, thinking or discovering *as such*, these psychological entities are epistemologically unattainable. However, we can aim at describing, analyzing and understanding people's *experiences* of phenomena like learning, thinking or discovering (Marton, 1981). Phenomenography has *a way of experiencing something*, a conception, as the unit of enquiry, and the *variation* in ways of experiencing phenomena as the object of research (Marton & Booth, 1997:111). Phenomenography is related to empirical phenomenology. The ontological assumption of both traditions is that the only world that we can communicate about is the world that we experience. While phenomenology studies how world and subject mutually constitute each other on a perceptual, preconceptual level, phenomenography mostly studies conceptualized phenomena in a socially constructed world. While phenomenology searches for an essence in people's experience of a phenomenon, the epistemological assumption of phenomenography is that humans experience the world differently, but that these differences can be described, communicated and understood by others (Sjöström & Dahlgren, 2002).

*A way of experiencing*, a conception, represents the interrelationship between the person experiencing and an experienced phenomenon. Experiences are seen as neither mental nor physical entities, neither as located in the individual nor in the world, neither in the mind nor in matter, but as a relationship between the individual and the world –experiences are essentially non-dualistic (Marton & Booth, 1997) p. 122. Thus the world, and our experience of it, is both subjective and objective at the same time, and between them there is a tension that gives both positions a meaning (Barnard et al., 1999). The objective of a phenomenographic study is to reveal the variation of ways of experiencing a phenomenon,

regardless of whether the differences are between individuals or within individuals. The way in which a person experiences a phenomenon constitutes *one facet* of the phenomenon. When the researcher describes the different ways of experiencing a phenomenon, she is *partially* describing the phenomenon, through *categories of description*. Assuming that the qualitatively different ways of experiencing a particular phenomenon relate to each other, the categories of description are ordered in an *outcome space*.

The step-wise process of text analysis is very similar to that of content analysis, which was described earlier. However, the purpose of a phenomenographic analysis is to look for variation. A helpful question might be: Which perspective makes a certain statement about the phenomenon become logical? For example, in our material, the general fear of overseeing cancer was something qualitatively different from a gut feeling of unrest regarding a specific illness presentation. According to Marton & Booth (1997), the number of ways that we are capable of experiencing any phenomenon is limited; otherwise we would not be able to communicate about the world. Ways of experiencing, or conceptions, draw on our history, culture, education, ideals and values. Even if conceptions are fundamental to the way that we enquire, judge, practise and live, they are seldom identified. Different conceptions can be found both between and within individuals. 'To be aware of conceptions is to be aware of our social reality and ourselves' (Barnard et al., 1999:219). Conceptions arise from the interaction between our presumptions, social imperatives, expectations and experience. Just as there are differences in conceptions, there are also similarities; convictions that are reiterated and used as criteria for judgement. They represent individual and group hierarchies of values, beliefs and ways of thinking, which might be called a collective mind, or a collective anatomy of awareness. 'To reveal this collective anatomy of awareness is the path of phenomenography' (Marton & Booth, 1997). According to this, we may say that we have studied partial aspects of the collective mind of Norwegian GPs, regarding their experiences of becoming aware of cancer during a consultation.



## RESULTS

In order to explore GPs' views of their contribution to health care for persons with cancer, we started out looking for descriptions of how GPs perceived their *place*, and also which challenges and dilemmas they faced (Paper 1). The GPs saw themselves as the nearest doctor for their patients, also when the patients had cancer.

The sense of being the nearest doctor had three aspects:  
The practical, the mediating and the personal

Staying in a spatial image, we could say that the perceived place was to be

- close by (the practical aspect)
- between the patient and the clinic (the mediating aspect)
- by the patient's side (the personal aspect)

In diagnosis, palliation and end-of-life care of cancer, the GPs worked from all three positions, each of them containing a manifold of tasks to be solved. Most GPs would have preferred to stay in touch with their patients also during the period of treatment and follow-up in hospital, but were not sure if the patients were in need of this. Some GPs wrote letters or called by phone in these periods, to tell that they were still there if the patients needed them, but they could be hesitant if this was right to do. The GPs especially wanted to secure that they met and got to know their patients personally before they were going to give end-of-life care in the patients' home.

The practical aspect included many concrete ways of being close at hand. The GPs wanted to be the first doctor to be called in case of symptoms, at any stage, a notion we called *first aid*. The notion of the GP as first aid was an expansion of the word's colloquial meaning, and included all the clinical practical actions that the GPs undertook in order to alleviate their patients' suffering. According to our interviewees, knowledge and skills in palliative treatment was quickly obtained in practice and should therefore not be regarded as an obstacle to be the nearest doctor. Relief of pain was seen as easy to learn, while alleviation of other symptoms like nausea or constipation could be more complicated. Especially elderly patients had to be asked directly for each possible symptom, as they would not always tell about their troubles. Simple palliative measures could augment life-quality considerably. A barrier to the work as first aid was that GPs were often not notified when their patients were discharged from hospital, and the discharge letter could arrive with a delay that in some cases was seen as hazardous by the GPs.

The practical aspect also included being the nearest place for health service, like laboratory tests and decentralized treatments. This notion of being a local dispensary of health services we called *corner shop*. This aspect was particularly important in rural districts with a long distance to hospital, where some GP surgeries also offered simple cytostatic treatments. The practical aspect also included a function which could be seen as routine, but nevertheless important to patients; filling out forms, applications and medical certificates that gave right of sickness benefits etc. We called this function being a *secretary*. Many GPs also saw themselves as *team workers*; e.g. in a local palliative team. GPs talked about themselves as members, consultants, or leaders of local teams. We thought that the different ways of being a practical GP could be pulled together in the metaphor of the GP as an *efficient handyman*, dependent on dexterity, improvisation, learning by doing, prioritizing and planning ahead.

The GPs had various interfaces to mediate between: The everyday world and the clinical world, the patient's story and the medical history, the patient and the hospital, amongst others. *Interpreting* was an important task at all interfaces, for example when the patient had received a cancer diagnosis at the hospital and came to the GP for a translation into an everyday and existential life context: What does this mean? The other way around, GPs had to translate the everyday troubles of their patients into a specific clinical language that gave the patients access to hospital care. Being an *advocate* for the patient was sometimes necessary, as the clinic was seen as an anonymous system and the GPs often felt a personal responsibility for their patients' investigations. The GPs could also be asked by their patients for a *second opinion* regarding treatment in hospital. They saw themselves as someone in whom the patients had confidence, but they could lack the specific knowledge that the patients asked for. As interpreter, advocate and second opinion, the GP had to be a *flexible mediator*, using tools like asking advice, often from difficult-to-reach hospital colleagues.

The personal aspect was seen as the most difficult, but also most rewarding aspect of being a GP. The GPs saw themselves as *supporters*, *guides* and *consoling* conversation partners for their patients with cancer. They depended on relation, respect and personal knowledge and used tools like offering time, listening and adjusting to the needs of the person and the situation. The collective term for this aspect of the GP was a *touched companion*. Exploring in depth the experiences of being a GP for people with cancer (Paper 2), we found a strong *loyalty* towards patients suffering from cancer, a stance that went beyond the normal duties. A strongly expressed dilemma for some GPs resulted from their position as mediators; when loyalty to the patient and family conflicted with loyalty to the system of the clinic and the judgement of specialist colleagues. Other matters of judgement regarded the degree of *honesty* about the prognosis and whether death should be openly spoken of. The greatest challenge for some GPs was how to help patients who were afraid to die. Human beings themselves, the GPs own feelings about death could be activated. The notion of *shared humanness* also pointed to how GPs got personally and emotionally involved with the patients and their family and how this involvement often lacked a closure when the patient died. We chose the ironic notion of *dealing with small things*, a GP's own words, as an expression of how GPs' work; the practical, the mediating and the personal, might be seen if medicine is viewed as a hierarchy with specialized, clinic-based biomedicine at the top.

One of the crucial points in the GPs' stories was about diagnosing cancer; of coming to think of it, and not overseeing it, in the first place. In the expanding research field of early cancer diagnosis, there has been a focus on epidemiological studies aiming at refining the predictive value of single symptoms, which again can be used as a basis for guidelines about alarm symptoms and red flags. Exploring more broadly how the thought of cancer arises during a consultation (Paper 3), we found that *practising* such *basic knowledge* was one way the GPs might become aware of cancer in a consultation. However, there were other contexts of attention, in which the thought of cancer could arise. One was about *interpersonal awareness*, of being alert to changes in the patients' appearance or behaviour and of cues in their choice of words, on a background of basic knowledge, experience and often personal knowing. Another context of awareness was *intuitive knowing*, a tacit feeling of alarm which could be difficult to verbalize, but nevertheless was helpful. Intuition built on the earlier mentioned contexts: Basic knowledge, experience and interpersonal awareness. The existential context of awareness, which we called '*fearing cancer*', could affect the thoughts of both doctor and patient during a consultation, and thus the challenge could be how not to think about cancer all the time, or finding ways for both patient and doctor of living with the insecurity without becoming over-precautious.

## DISCUSSION OF RESULTS

### **GPs' practical cancer care in the community**

This thesis aims to tell health care professionals and researchers, including GPs themselves, about how a group of interviewed Norwegian GPs view their work in cancer care. Asking for stories about actual patients and how GPs were involved during the courses of illness, our focus was not on general opinions but on experiences of having cared for individual patients over time.

Paper 1 was intended to give an overview on the GPs work in cancer care. We thought it would be useful for collaborating clinicians, home care nurses and for patients to know more about how GPs view their contribution to cancer care. The main message to all of them is that these GPs saw themselves as the nearest doctor, also when their patients had cancer. When the patients were "away", attending hospital for treatment or follow-up, this was thought of by the GPs as a temporal departure from primary care. It was mainly during this departure that the GPs were unsure of their possible contribution.

I found it fruitful to divide the tasks that the GPs saw for themselves into the three main aspects of the practical, the mediating and the personal. How do these terms compare to other attempts in the literature to make overviews of GPs work in cancer care, seen from the GPs own perspective? Groot et al (2005) summarize from their focus group study with Dutch GPs that in palliative care, GPs performed a mixture of somatic, psychosocial and coordinating tasks and that barriers experienced in daily palliative care were on a personal, relational and organizational level. Field (1998) found that communicative, organisational and clinical skills, just as relationship and a holistic view of the person, were important for GPs' work with all patients, including patients with cancer. Compared to both Field and Groot et al, our three main aspects are wider and include more elements from the many tasks that GPs see for themselves in cancer care.

While we described a broad range of tasks that the GPs were involved in, not all of these have been mentioned and discussed in the GP-literature before. These include the notion of being a local dispensary of health services which we called corner shop, and also the GP as a secretary. The latter was a term for filling out forms, referrals, certificates and reports, suggested by one of the participants. She did not refer to it in a pejorative sense, but rather as one of the necessary things that had to be done, and that should be easy for the patients to get done, without the GP making much fuss about it. The corner shop service of GPs in some rural parts of Norway giving cycles of simple cytostatic treatment might be quite unique in the world. Chemotherapy in the community was given either by cancer nurses in cottage hospitals, or by the GPs themselves in their surgeries. Especially the latter was, according to our participants, a fragile service based on local enthusiasm, without the necessary practical and financial support from the health care system.

Inter-professional enthusiasm to establish good cancer care in the local community seemed to be a driving force at several of the places I visited. The GPs at these places could speak with admiration about their collaborating partners. This could be nurses at the local nursing home where some patients with advanced cancer would live; it could be cancer nurses or district nurses that worked in peoples' homes, or local physiotherapists and occupational therapists. There was often a pride regarding what the local health services might achieve, on the team level and the organizational level. The GPs in Field's study (1998) were worried to loose control of patient care to hospital based palliative care services, as they felt that they had the

best knowledge about the patients and their families. Secondary care palliative teams are about to be introduced in Norway at the moment. When I did the interviews in the fall of 2007, this had not been initiated, so I could not ask the participants about their experiences of shared care. Anyhow, several of participants were located so far from a hospital that they would probably not be able to work with a palliative team. They will still have to rely on their local team and their own competence.

I was surprised that the GPs, even the youngest one with only one year of professional experience after internship, seemed to feel quite competent regarding palliative treatment. Several said explicitly that they felt treatment of pain was easy. Some said that they had learned this well in medical school, others were grateful about using a palliative online handbook and all had learned from experience and discussing with colleagues. Relieving other symptoms than pain, like nausea or constipation was regarded more difficult. These findings are in line with other studies. Jones (1993) found that pain was seen as well controlled by family carers of people with cancer dying at home, but other symptoms was seen as less well relieved.

The overall impression from our study is that palliative competence was seen as grounded in medical school and then developed in practice; learning by doing, learning from colleagues, and learning from patients. Mitchell (2002) found that many GPs had low confidence in their own palliative care competence, but that both involvement and confidence in palliative care augmented with years of experience. While von Hanno (2000) found that only a minority of GPs viewed their competence in pain relief as good enough, in Anvik et al (2006), many GPs felt comfortable with palliative care and found ways of obtaining the knowledge they needed, for example from specialists. Also in our study, most participants seemed to have confidence in their palliative competence. Generally, our participants focused on making everything possible, for example so that patients could die at home, and talked little about barriers to palliative care. Lack of knowledge or lack of experience was rarely mentioned as a barrier. Our interpretation was that knowledge and experience in this field, included being a personal companion at the end of life, was mainly seen as something one obtains through practice. The message from Anvik et al and also from our study is that an initial lack of knowledge and experience should not stop GPs from engaging in palliative care.

The time around discharge from hospital has been characterized by patients as being left alone (Ervik et al., 2010; Kendall et al., 2006). It is also a critical time for GPs, as at this point, they might have taken over the care of the patient with cancer, without having been notified and informed. Norwegian hospitals normally do not admit patients without a letter of referral, and in the case of emergencies, also a telephone call from the GP to the doctor on call. However, patients can be discharged from hospital to primary care without any of these forms of immediate communication. As one of the interviewees remarked; the GP is the only non-anonymous actor in Norwegian health care. The medical responsibility for the patient in primary care is personified, while in secondary care the recipient is an anonymous system. Examples of this in our material were referral letters that disappeared and departments that disagreed about whose responsibility the patient was. Our interviewees had the impression their patients' hospital care could be fragmented. Professor Per Fugelli (2010) coined the term 'disposable doctors', referring to the many doctors that patients meet only once during a course of illness, and advocated that chronically ill people should have their personal hospital doctor, just as they have their personal GP. Such a doctor could also be a collaboration partner for the patient's GP.

As noted also in Groot et al (2005) and Field (1998), the competences needed for a GP in palliative care are very broad. The challenges in cancer care for the interviewed GPs seemed to be mainly in two fields, namely as mediators between the patient and the hospital and as personal companions of people at the end of life. On a superficial level, one might say that in both these fields, the issue is at stake is 'communication'. It is noteworthy that this technical term was rarely used in the interviews. To understand what is at stake when GPs act as mediators, we should rather consider the different perspectives of medicine that are favoured by working in general practice and in a hospital, see Introduction. To comprehend the challenges of being a personal doctor for a patient at the end of life, we suggest departing from the notion of shared humanness.

### **Theoretical issues rising from the study**

*The physician is concerned ... (unlike a naturalist)...with a single organism, the human subject, striving to preserve its identity in adverse circumstances*  
(McKenzie, 1927: 532).

I will attempt to see the results of this thesis in light of a wider discussion on what medicine and general practice is about. For the reader, it might be unaccustomed to find long citations from other authors at this stage of a thesis. This was, however, the way I had to go to insert the study into a broader theoretical context. While Paper 1 gave a pragmatic overview, Paper 2 went into the dept of the doctor-patient relationship. The latter paper already has a quite comprehensive discussion of the personal aspect of doctoring. Starting from the very first moments of the consultation, Paper 3 touched only briefly upon several theoretical considerations from the introduction, which could merit further discussion.

Human beings are reflective, meaning-seeking, relational and purposeful organisms (Getz et al., 2011). The biographical experiences of persons are inscribed, for good and for bad, deep into the flesh of the human body (Kirkengen, 2001). However, in illness humans often experience that the flesh, their body-as-nature, go against them in a meaningless way (Rudebeck, 2012). Primordially, medicine is a meeting, a consultation, between a human being asking for advice and another human being, whose knowledge and experience is expected to be helpful. Within the frames of today's comprehensive and highly specialized health services with advanced technological mediations; this original core of medicine has to be excavated in each clinical encounter.

Paper 3 dealt with retrospective interviews about such encounters in general practice, as remembered and recounted by GPs. For the interviewer, these were stories about cases of possible cancer, according to her research question. For the participants, the stories were about their patients, people they knew; with names, faces, families and life stories, and about themselves, as professionals and persons. What the interviewer could possibly grasp of the doctors' stories was necessarily limited. Just like a doctor chasing a presumed disease concealed in the patient's body, the interviewer seemed to be pursuing a hidden thought in the doctor's head. Her questions might be heard as stubbornly purposeful: What made you think about cancer, or other serious disease, in this case?

The truth was that the GPs were not always able to tell. In some stories it was easy, at least in afterthought, to say that the patient had had some alarming symptoms or signs; reminiscent of

a textbook model. But what about all the other stories; where did the thought come from? We know that out of the richness of perceptions, interactions, feelings and associations in a human encounter, only a small part will be consciously attended to and lend itself to verbalization. However, all the subconsciously perceived impressions do not get lost; they play tacitly into our judgments. We know more than we can tell (Polanyi, 1983).

Just as the interviews in Paper 3 about the thought of cancer were constructed in the relation between interviewer and participant, the diagnostic ideas they tried to recall arose in the relation between doctor and patient. And before deciding to consult, the patients had had encounters with themselves, and often with significant others, trying to interpret their unfamiliar bodily experiences. Thus, prior to my analysis, there had been a sequence of *hermeneutic moments* (Leder, 1990a), and for each of them only a small part of the richness of perceptions, interactions, feelings and associations had been consciously accessible and possible to verbalize.

The interpretative task of the doctor is twofold, according to Rudebeck (2012). Trying to understand the patient's experience is always the primary, as long as the situation is not immediately acute and life threatening. The meaning of the patient's experience is not necessarily explained by biomedical science. Likewise, empathy with the patient does not develop automatically from questions directed at the nature of diseases. First, the doctor must overcome the intersubjective gap of knowledge, which is valid for all human contact: How can she be sure that the patient experiences what she perceives that he experiences? Formulating bodily experiences into words can be very difficult. The doctor should help the patient express what he feels and thinks about. At this stage, Rudebeck says, the patient's own recognition of the experienced is most important. The doctor should try to enter into the patient's story, without judging or listening selectively to descriptions sounding like disease. Then she could compare to her own experience as a bodily and conscious being, included the special preconditions of being a doctor. Thus, Rudebeck (2001) encourages the doctor not only to observe how the patient presents his symptoms, but to share his experiences, through interpersonal imagination; also called empathy.

Do doctors normally do this? According to the observations of Agledahl et al (2010), doctors, including GPs, generally do not attempt to share their patients' concerns, but quickly pick out information from the patient's story that they consider clinically relevant. That is, doctors tend to concentrate from the beginning of the consultation on the construction of a medical story. But even observing has its limitations, as subtle interchanges between persons might escape the analytic gaze of the researcher.

Interestingly, Rudebeck (2002) wrote:

*An observer — at least not on video — may not even perceive it. But whether I accept the patient's invitation to share her experience, or whether I choose to dismantle the possible disease piece by piece, is a choice between two very different realities. And it is a choice made in a millisecond (p.452).*

This could be a choice between turning the attention directly towards possible diseases and keeping the attention on the person who comes to seek advice. A holistic view of medicine does not mean for the doctor to see 'the whole person', which is impossible. It means meeting the person without an inner cleft, without seeing him as just a body sending messages about its condition (Rudebeck 2012). Symptoms do not go visit the doctor. What a doctor listens to

are not the symptoms, but a patient's symptom presentations (Rudebeck, 1991). The symptom presentation is an account of lived experience, rather than a correlate of bodily derangement. The physical body of the patient cannot speak for itself, without human emotion and reflection (Rudebeck, 2002).

The first interpretative step of the doctor; attempting to understand the experience of not feeling well, regardless of the cause, is the specialty of the general practitioner, according to Rudebeck (2012). Often, the first step suffices; both patient and doctor might realize in a flash that the problem belongs to life and not to medicine (Balint & Norell, 1973). Only secondly comes the other interpretive task of the doctor; the scientific gap of knowledge: How can she objectively verify the patient's experience?

Hunter (1991) is also concerned about the double importance of the patient's story:

*The patient's story is not only the raw material for medical interpretation but a thing in itself. It is the presentation of the patient's illness experience (an often an epitome of a life) and not merely the precursor of the medical "truth". The physician's recognition of this is narrative's first contribution to medicine's healing task (p.132).*

My interpretation of Hunter is that because the patient tells about his bodily experience from within a life, the eventual bodily derangement which the physician finds should also be seen in the context of that life, both when the patient is informed about the physician's medical interpretation of his story, and also when planning possible treatment together with the patient. It follows that shared decision-making in medicine will only find its full meaning when the original problem of the patient was also shared, or at least acknowledged in its context, the patient's life.

Fearing cancer was a category of description in paper 3. A symptom might be so worrying that the patient's life feels changed. What has become evident then is the factual condition of human life, of being a vulnerable and finite bodily existence. Professionally, this is the doctor's home ground and power base. Medicine works in the ambiguity between the most private and the most general. Biomedicine deals with the general while the doctor is faced also with the private and existential (Rudebeck, 2012). As human beings, patient and doctor share these conditions. Through this shared humanness the doctor can be capable of understanding the patient, and through bodily empathy she has the possibility of sharing the patient's vulnerability. The better the doctor knows herself, the further imagination could lead her towards the patient.

*My glands, my openings, my death are my most private things, and yet they are my most general. This paradox is the bridge on which doctor and patient meet. Biomedical expertise is the difference between doctor and patient, but the more that GPs exert their expertise in terms of bodily empathy, the more equal are the doctor and patient, and the more the patient feels to be seen (Rudebeck, 2002:452).*

In paper 3, we did not discuss empathy, but used the concept of interpersonal awareness (Hall, 2011) which seemed closer to the interviews. Interpersonal awareness might be seen as the step before empathy; embracing the attentive presence and passive receptiveness that contributes to clinical sensibility (Nortvedt, 2008) in the consultation.

Direct questions about empathy were not included in the interview guide due to the equivocal meaning of the concept. Today, also in medicine, empathy has mainly an emotional connotation. The original meaning of the German philosophical concept of *Einfühlung* included perceptions, emotions and cognitions; which are integrated dimensions of any experience (Rudebeck, 2002). This original meaning of empathy would fit well for the first interpretative step of the doctor. Reidar Pedersen also suggests this in his thesis (2010), where he, in line with philosophical hermeneutics, defines empathy as ‘an appropriate understanding of the patient’. Surprisingly, he does not comment on the German philosopher Edith Stein (1891- 1942), whose work on empathy could be relevant for an investigation of the doctor’s interpreting task.

Empathy, according to the interpretation Thomassen (2000) does of Stein (1989), happens when I turn towards another person. The other’s feeling, of for example sadness, pulls me towards him, so that I end up side by side with him, at the same place of experience. I do not grasp the other’s experience, I am grasped by it. I am touched by someone else than myself, who make himself known. Empathy is an experience integrating knowledge and emotion, separateness and shared experience. Without empathy I would have been trapped in the world as it appears to me. Through empathy I overcome my own perspective of the world and experience an intersubjectively available, existing world. According to Stein, empathy is the only way to reach the other as a living human being, and not as just a physical thing. Stein maintains that empathy is a direct and irreducible act that breaks down the distinction between the exterior and interior. Empathy precedes and preconditions cognitive acts like inference, assessment and comparison, connecting emotion and knowledge on a more basic level.

If this is what happens when two people meet, it certainly should happen also between doctor and patient. Otherwise, the patient would just be a physical thing to the doctor. But is that not what many patients complain about – that they do not feel recognized and treated like human beings by doctors? Is this because doctors often omit what Rudebeck calls their first interpretive task, and foremost commit themselves to the physical thing, the body-as-nature, which is also the matter they have studied during most of their education? Medical school does not only mediate knowledge but also patterns of thought and action. Within seconds of the patient’s story, the doctor starts thinking about possible diagnoses. Rudebeck (2012) calls this ‘the biomedical reflex’ which convenient in acute situations, when the seconds count. Otherwise ‘the biomedical reflex’ might be disturbing, because it seems to overrule the natural human attitude, which would be the empathic stance towards the other as a human being.

In paper 3, we saw something like ‘the biomedical reflex’ as the first context of awareness for thought of cancer to arise. Logically, interpersonal awareness is the context for all human interaction and would therefore precede the more specific professional attention to alarming symptoms. And maybe *fearing cancer* should have been the second category, as it brings so many people to their GP and also many GPs to refer their patients on. Then we would have *practicing basic knowledge* as the third category and finally *intuitive knowing* at last, but not least. Intuition is supposed to integrate different forms of knowledge (Plessner et al., 2008; Polanyi, 1969), (in our case: biomedical science, clinical skills, professional and personal experience and interpersonal awareness), and might be seen as the highest form of knowledge (Larsson, 1892).

Here it may be necessary to state more precisely that the patient does not come to the doctor to be generally understood as a person, but to get a professional advice about a problem which



he himself has defined as within the realm of illness, otherwise he would not go to a doctor. Hunter (1991) depicts the doctor's task as threefold: 1. To acknowledge the patient's subjective experience – the patient's story. 2. To formulate it as a medical version, matching taxonomic abstractions and biomedical laws – the doctor's story. 3. To return that interpretation back to the patient, 'still to understand and affirm the life narrative of which it is now a part' (p. 147).

It seems that the doctor's first interpretative task (the patient's story) has another ontological and epistemological status than the second task (the doctor's formulation of a medical story). While the first rests on the assumption that humans are relational beings sharing a common, intersubjective, everyday world and thus can understand each other empathetically, the second rests on a clinical ontology seeing diseases as real, physical entities that have invaded the patient's body, revealing themselves as 'clinical pictures' for the doctor to recognize.

*The patient presents himself as a patient, a sufferer, in the expectation (the hope, the dread) that the physician, an expert, will detect characteristic features, perceive him as a "case", for it is only when a "case" has been delineated (...) that an appropriate "treatment" can be suggested. Thus the first act of medicine is to listen to a personal story, extract or abstract from it a (...) "case", and exclaim "Migraine!", and "Parkinsonism!" with all that this implies (Sacks, 1986:17).*

In biomedicine, the classical symptoms of disease are the patient experiences that have high status. Not their particular character gives them status, but the fact that they can be attributed to a specific disease. The patient is expected to confirm biomedical theory through their symptoms (otherwise symptoms might be seen as vague). Diagnosing such classical symptoms and attributing them to a specific disease has a high status for the doctor; it makes her a 'real doctor' (O'Flynn & Britten, 2006; Rudebeck, 2012). Such classical and high status experiences are relatively rare in general practice, both for patients and doctors. Maybe that is why general practice has been a low status specialization in medicine, and why many patients demand to be referred to higher status specialists, hoping to be diagnosed with ditto diseases?

Hunter (1991), in line with Sacks, recognizes that the ill person undergoes an impersonalization, necessary to the medical interpretation of illness.

*The act of becoming a "patient" is itself a first step in assuming a nonpersonal, medicalized identity. The translation of the patient's story into the medical discourse involves the substitution of the case for the person: the patient is impersonalized, represented in the medical arena by an objectifying medical narrative. This generalizing view of the individual aids diagnosis and may even offer the patient some comfort. (...) The case narrative that represents the patient to the medical world comes in that world to be the patient (p. 134-5).*

The case as a stand-in for the patient in medical problem-solving can be useful. Patients hope to be recognized as a case not only because of the prospects of treatment. The diagnosis is a recognition of the patients' own experience (Rudebeck, 2012) and an explanation of what is happening to them. To get to know the truth about one's predicament can help people to preserve a sense of control (Hunter 1991). For this sake, people are willing to undress and open up their bodies and lives to medical scrutiny. Hunter suggests that people accept their medical objectification in an act of trust:

*We undergo this impersonalization trusting in the privileged nature of the patient-physician relationship – what is discovered will be held in confidence – and in the common humanity of the physician who, we presume, will recognize in us a fellow creature asking on this occasion for help (p. 133).*

Here, Hunter takes the patient's perspective, suggesting that his trust relates both to the institutional level, the ethical and juridical obligations of, amongst other, professional secrecy, and also to a perceived moral obligation emerging immediately from the shared humanness of doctor and patient. To be recognized as a fellow creature, a human being, might mean to be seen as more than a case or a physical thing, as Stein explained, through the act of empathy. The many reports about patients who wanted to be recognized in this way (Arborelius & Bremberg, 1992; Frederiksen et al., 2009; Kvåle & Bondevik, 2008; Thorne et al., 2005) suggest that, in Rudebeck's words (personal communication), when a patient is *treated* as an object, it becomes much more difficult to *be* an object.

Seeing the patient as 'a case of ...' might be a pragmatic and useful bridge between shared humanity and professional objectivity, as long as it is recognized as a medical construct rather than a natural object. Further reification of the patient as *being* the diagnosis or the disease itself might be characterized as an ontological and epistemological collapse, a metonymy of person and disease, which has only harmful effects for both patient and doctor. When nothing more can be done against the disease, treatment might be seen as a failure, the doctor's work as over, and the patient might end up abandoned (Hunter 1991).

*The tendency to see the patient as an object with only a medical existence and only a diagnostic meaning (...) fosters avoidance or automatic, unfeeling care, and, by precluding careful observation, it makes possible, even probable, inadequate treatment and misunderstanding of further symptoms. The patient in effect is deserted. The living spirit is ignored in its reduction to a morbid body. Not only do physicians lose their patients, first to inattention and then to death, they are deprived of restorative contact that can validate their life work and the possibility of further learning (Hunter, 1991:137-8).*

Why does this collapse, the reification of the patient, happen? Hunter (1991) thinks it is mainly due to physicians' need for emotional protection. Why then do doctors, also in our study, feel that accompanying patients with incurable cancer until their death is meaningful and rewarding? Agledahl (2011) acknowledges that objectification of the patient is necessary in medicine, which I agree to. Further, she suggests that attending to the existential meaning of illness is not a medical issue and not necessarily the doctor's task. Because rejecting the patient as a fellow human being in this way is a moral offence, doctors should excuse themselves to their patients for not treating them as human beings. In this line of argument, medicine is seen as what doctors are observed to be doing, and as a practice that intrinsically leaves a moral residue.

From the stories that the GPs participating in our study told, it seemed that they viewed the doctor's first and second interpretative task as connected. They saw the translation of the doctor's story back to the patient's story as necessary, and acknowledged how biomedical issues were connected to existential concerns. Having a continual, personal and contextual knowledge of patients was of great value to the GPs in our study. Our participants also valued the relational effects they could have on their patients. Listening to the patient as a fellow human being was explicitly mentioned as a supportive measure. Simultaneously, some of

them suggested that these values have a low status in medicine and that GPs sometimes seem to deal with 'small things'. Whether the GPs succeeded with putting their values into life in their encounters with patients, or not, cannot be inferred from our interview study.

A deficiency in developing and discussing epistemology on a broad basis, beyond philosophical journals, might be an explanation for patients' reification and for the lack of attention to human relation in medicine. Medicine leans itself theoretically on the natural sciences, and within the natural sciences, it leans to the positivistic side. It leans itself more towards the reductionist view that the secrets of life can be found on a molecular level, than seeing the human being as a biological whole, an organism. Further, medicine leans itself more towards objectivism, the ideal of scientific detachment, than acknowledging the indispensable personal participation of the knower in the shaping of knowledge (Polanyi, 1962). Moreover, medicine emphasizes explicit, so-called evidence based knowledge, and underrates the basic importance of tacit and practical knowledge, knowing-how. Furthermore, the significance of seeing the human being as a sentient, reflective and purposeful being is not fully recognized. Thus, knowledge and discussions from the human and social sciences, even from a closely related discipline like psychology are not always seen as relevant for medicine. The effect of this 'thin epistemology' (Zhenua, 2006) is that the human person is not consistently regarded in medicine; the molecules are, to borrow an expression from Fugelli (2010), often left alone. And even if the human person was totally insignificant for biological restoration and survival rates after for example cancer treatment, it would always be very significant for human suffering, which is what medicine is supposed to alleviate.

What can doctors mean to their patients with cancer then, on the relational level? In our study they saw themselves as being companions, guides, supporters and consolers. What might this mean to patients? Salander (2002) found that from the perspective of patients newly diagnosed with cancer, receiving bad news was not an event, but a process in which relationships with doctors and nurses were seen as protection from the threat of danger to their lives. Relationship, and not the information as such, influenced the patients' degree of hope. In a theoretical article, Salander et al (1999) elucidate this by applying Winnicott's (1971) theory about the 'intermediate area'. This mental area 'enables us to assign a meaning to reality that is in accordance with our psychological needs' (1999: 83), acknowledged in creative activities like play, art and culture. Unconsciously, the doctor and other medical staff might be seen by the patient as a protectors against death. The protection is according to Salander et al mediated primarily by non-verbal means, like closeness and touch, and a symbolic 'framing structure' of order that facilitates trust and hope: Availability, continuity and predictability.

Salander et al (1999) suggest that information concerning diagnosis and treatment also belong to 'framing' for the patient. The essence of this information can for the patient be: "I am not left alone – there is someone out there who understands my exposed position, who has put her- or himself between myself and death, with the power to assist. I've come to the right place" (1999:85). Clinical dialogues might also be seen as an environment facilitating the process of patients' psychological survival and reconstruction of reality, by allowing space for patients' positive illusions (Salander et al 1999). Doctors should not give patients false prospects, but they should also avoid the closing of doors, by giving more definite information about prognosis than the patient asks for. Also, giving bad news without giving ideas of possible treatment is a way of closing the door and leaving the patient alone, exposed to death. Treatment, whether curative or palliative, means time and future (Salander et al 1999).

Looking back on paper 2, I recognize a sensitivity that many GPs voiced towards the question of honesty, through awaiting patients' readiness to talk about prognosis and weighing each word carefully. The GPs seemed to acknowledge the need of adjusting the information about prognosis to people's capability of making sense of them in their creation of hope. In paper 1, several of the tools that the GPs used for their work in cancer care could be seen as creating a framing structure for patients, like planning ahead, staying accessible, being comprehensive, and offering time. This was a way the GPs said they preferred to organize their work. It may be called 'an organization for relationship', containing

*the promise in your attentiveness that you'll be there, and the declaration in your attitude that you and they are fellow wayfarers on a road beset by fate*  
(Radovsky, 1985:587).

## DISCUSSION OF METHOD

The generalizability or transferability that might originate from a qualitative study is not dependent on a certain procedure for sampling of participants or the size of the study population. It is created through the qualitative analysis itself, by virtue of a depth understanding of the data. Firstly, this understanding is dependent on a theory level applied in the analysis; the theoretical concepts chosen by the researcher as appropriate to explore the phenomenon in question. Secondly, it is dependent on the validity obtained in the analytic process; the process of applying, probing and developing these chosen concepts during the analysis. Accordingly, the basis of transferability in a qualitative analysis is theoretical (Jørgensen, 1995). On the background of Jørgensen's arguments, I want to critically discuss the potential of generalization from this thesis, and to acknowledge methodological problems.

The epistemological assumptions that played into the design of the first study (papers 1 and 2) were outlined in the Introduction. Summarized, we departed from an interpretative paradigm. The theoretical considerations and the background literature presented in the Introduction were only partly present at the time of creating the first interview guide. Prior to interviewing, we had not chosen specific theoretical concepts for the study. This could be called an open, explorative design valuing descriptions, immediate interpretations and the development of concepts during the analysis in an inductive fashion (Jørgensen, 1995). It could also be characterized as yet another a-theoretical, utilitarian study from general practice (Jaye, 2002). On this background, our concepts were inductively developed. Later, we discussed the possibility of contributing to 'a theory of general practice', drawing on authors like McWhinney, Malterud and Rudebeck.

Concepts should be selected on the basis of their ability to 'unlock' the text and give new insights into the coherence of meaning. *Qualis* means how, and precisely to detect *how* this coherence constructed is the goal of a qualitative analysis. The researcher looks for a conceptual or theoretical structure at work in the text. These concepts should be developed with a 'daring imagination', aiming at a new or a more nuanced understanding of the phenomenon, while still communicating with earlier studies in the field. The concepts should be enriched by the insights attainable in the analysis, and leave the analysis with a revived assertive force. Through a systematic evaluation of the possible explanative power of the concepts, the analysis aims to make probable that the presented understanding is documented and plausible. A step-wise elaboration of the depth structure and coherence hidden in the text, and an argumentation in favour of this structure, should establish plausibility.

In Methodological considerations, I presented the analytic steps for each of the papers, for example content analysis for paper 1. Such a step-wise procedural description is often a requirement when presenting a qualitative analysis. However, it is quite a technical description of rules. It compares to a doctor adhering to a model of, say, 'the seven phases in the consultation' when encountering a patient. Neither a step-wise analysis nor going through certain phases in the consultation secures the quality of the dialogues between the researcher and the text or the doctor and the patient. In Jørgensen's view, the researcher should identify a concept as giving an accurate description of a passage in the text through 'feeling-into' the text. We recognize this as a translation of the German term *Einfühlung*. It is interesting to note that Polanyi called this 'indwelling' (Zenhua, 2006), and also that he thought that this was the method of choice for all science. After the *Einfühlung*, however, the researcher should define the criteria for identifying a concept in the text (Jørgensen, 1995). This

operationalizing might compare to the second interpretive task of the doctor: How can she credibly verify the patient's experience.

When presenting our results in paper 1, we chose an extended use of metaphors, trying to evoke new images of what it means to be a GP for people with cancer. While scientific terminology is often abstract, the work of a doctor is, at first look, quite concrete and perceptible, using the ears, the eyes and the hands. As a practitioner coming into research, this level was what I first recognized in the GPs' stories, and in the first paper, the categories were mainly on this manifest level. We picked several terms from everyday language, like corner shop or handyman, which might seem unusual for a scientific paper. However, in presenting GPs as, for example, the handymen of healthcare, we hoped to bring about a broader understanding regarding what GPs' work might be about and the challenges they might face, also on the literally manual level. Being comprehensive or being all-round would be other possible expressions, lacking the tangibility and dexterity of the handyman. A limitation of using metaphors and self-invented colloquial concepts instead of existing terminology is that comparison to other studies might be difficult.

In paper 2, we wanted to go in depth into the challenges of being a GP for people with cancer over time, which meant that we would have to concentrate on a few themes. Within a rich interview material touching on many themes, how did we choose the ones to analyse? Firstly, I looked for vehemence in the GPs own evaluations of the narratives they told, assuming that in these stories, an important issue would be at stake. Secondly, I noted how many times such an issue were thematized across the interviews. Thus, I used both a sense of the strength of feelings expressed in the story by the GP as an indicator pointing towards a value at stake, and the quantitative distribution of these themes. Herby I wanted to promote correspondence between text and interpretation; aiming to prevent a selective interpretation of the text according to my own assumptions and values. The result of this process was the selection of the three themes loyalty, honesty and shared humanness, and the differentiation of the nuances and variations in the meanings of these themes across the interviews.

After identifying concepts and exploring their correspondence within the text, the researcher should according to Jørgensen look for coherence between the concepts. Hereby, there is a possibility of unveiling a deeper structure in the text. The researcher might face the very special experience of gaining a new understanding, of seeing an interrelationship that never has been comprehended before. In paper 1, the coherence was created through a search for relations and divisions between the different tasks that the GPs told about. The experience of discovering such a perceived pattern, through dialogue with the transcripts and with the supervisor, was very inspiring. In paper 2, the process was different. Loyalty, honesty and shared humanness can be seen as sub-themes of the overarching theme which we explored in this paper, namely the doctor-patient relationship. The search for coherence between the themes might be seen as aiming to understand why precisely these three aspects of a clinical relationship were emphasized in the interviews and if there could be a common explanation for the tensions within them. The notion of shared humanness pointed both to the naked fact beneath the white coat, and to the neglected basis of a clinical relationship. A hierarchy of medical knowledge, leaving GPs' relational and contextual knowledge of patients at the lower end, was suggested as a breeding ground for conflicts of loyalty. Honesty was also discussed in relation to a similar hierarchy, in which biomedical interventions aimed at curing diseases seemed to be valued higher than palliative caring and attending to the existential suffering of persons. Thus, the coherence of concepts in paper 2 seemed to be at work in the tension between different ontologies of medicine, leaving GPs in a squeezed position.

In phenomenography, the coherence between concepts is presented in a structure called outcome space. The discussion of paper 3 aimed at developing the outcome space through elaborating the interrelations between the four categories of description. In the paper *basic knowledge* was the most fundamental category. The logical consequence of the theoretical discussion above would be to put *interpersonal awareness* at the basis for all human interaction, also the clinical encounter. However, because the ‘biomedical reflex’ is so strong in doctors, the sequence chosen in the paper might be quite realistic.

Viewing the thesis in its entirety, one question was what its adequate title should be. Was there a key concept that could open up for an understanding of the whole? I chose ‘A doctor close at hand’ as a title after some consideration. It expresses important values for the GPs like access, availability and proximity. It alludes to both a literal and a figurative meaning and points to both the tangible and the supportive work of the GP.

### **Limitations of the study**

As discussed by many authors, the validity of a study is constructed through all phases of the research process, starting with the relevance of the research question. In the Introduction, I aimed for transparency in describing the design and the steps taken. Before drawing any conclusions from this thesis, I would like to discuss the sampling strategy in more depth. When considering the possibility of transferability, is important to consider the degree of similarity, the ‘fittingness’ between the context the analysis draws on and the context it is supposed to be transferred to (Lincoln & Cuba, 1985).

Patton (2002) describes 15 strategies for purposeful sampling, which have in common the underlying principle of selecting information-rich cases. This was also the rationale behind the sampling done for this study, see details in the Introduction. There was self selection of GPs who took part in a survey and opted for an interview and then a further selection of the survey-responses that indicated involvement by the GPs. This highly selective group might compare to what Patton calls Intensity sampling, consisting of cases that manifest the phenomenon of interest intensely (but not extremely, as in Extreme or deviant case sampling). Within this group there was then attempted a maximum variation (heterogeneity) sampling, aiming at including both male and female GPs with varying professional experience working in both urban and rural areas, resulting in an overweight of rural practitioners. The resulting sample turned out to be a group of GPs who seemed to be highly committed in cancer care; possibly they were generally very committed in their work. In paper 1, I suggested that the informants pointed to the opportunities, and that generalization was possible at the level of what *could be* possible in general practice. Due to the sampling strategy, we lack more information about barriers to cancer care in general practice and we also do not know why some GPs hardly take part in palliative home care. In paper 2, the three themes of loyalty, honesty and shared humanity were voiced by the same committed doctors. However, although the examples analyzed are from dedicated practice, the relevance of the concepts for understanding what it means to be a GP for a person with cancer is in my opinion not reduced by the sampling.

Another concern worth discussing is the sample size. Patton emphasizes that ‘There are no rules for sample size in qualitative inquiry’ (2002:244). According to Lincoln & Cuba (1985), the researcher should aim at ‘informational redundancy’ and terminate the sampling when no new information is forthcoming. This sounds logical and it also often stated in methods sections of papers. I cannot say that this point was reached in our studies. But I can also not

say that it was not reached. In my opinion, to be sure that no new information is forthcoming, the researcher has to perform an ongoing textual analysis parallel to interviewing. Alternatively, she could, after a preliminary analysis, do some more interviews to see if the results are challenged or 'confirmed'.

After analyzing and then re-analyzing the 14 interviews from the first round (papers 1 and 2), I did not feel the need to go out for more information. Within the limits of the Intensity-sampled group, there was a theoretical redundancy emerging from the analysis, as alluded above. For the last interview round (paper 3), only 11 of the prior participants were available. After this analysis, I did not have the same feeling of redundancy. I actually kept the possibility open that a few more interviews could have relieved yet another way of experiencing the phenomenon under study, and that would have added value to the study. On the other hand, our main point in that analysis was that in addition to the application of biomedical knowledge, other contexts of awareness are also important for the suspicion of cancer. In my opinion, that point alone makes the analysis valid for practice.

## **CONCLUDING REMARKS**

This thesis aimed to explore GPs' views of their contribution to health care for persons with cancer. Interviewing a group of GPs who seemed to be very dedicated to their work, we got a picture of what the contribution could be when general practice works at its best. The GP could be a doctor close at hand; proximate, accessible and available; being there for patients with cancer in a practical and supportive way. Reaching for the ideal of being such a doctor was seen as meaningful and challenging work. Palliative care was learnt through practice and experience as a GP seemed to increase professional self-confidence. Surprisingly, even very experienced GPs could have trouble getting access to a senior consultant for discussion when needed, and also have the feeling of possessing less important knowledge about the patient than their counterparts. In their diagnostic work, however, the GPs found their relational and contextual knowledge of patients useful. Such knowledge was a background for perceiving changes in the patients' behaviour or wording that could allude to the possibility of malignant disease.

An interpretation of this picture is that working with the diagnosis and care of people with cancer, combining biomedical and relational knowledge, might fulfil ideals of what it means to be a good GP; hence the perceived commitment, meaningfulness and loyalty. To understand GPs' possible contribution to diagnosis and health care for people with cancer, the concepts of being a doctor close at hand, being a translator between everyday life and the clinic and being a supportive and touched companion through the course of illness might be helpful. These issues belong to a broader debate about goals, values and knowledge in medicine, which merits further attention and research.



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## **Papers I – III**





## Paper I



## Paper II



## Paper III





