Approaching Patient Delay and Cancer
Anthropological perspectives on concepts and causes
PhD dissertation

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## Contents

**ENGLISH SUMMARY** .................................................................................................................. 3  
**DANISH SUMMARY** .................................................................................................................. 5  
**ACKNOWLEDGEMENTS** .............................................................................................................. 7  
**PREFACE** ................................................................................................................................... 8  

**CHAPTER 1: GENERAL INTRODUCTION** .................................................................................... 11  
  * Reasons for studying patient delay ................................................................. 12  
  * Estimating the extent of patient delay .............................................................. 15  
  * Context ......................................................................................................................... 17  

**CHAPTER 2: FRAMING RESEARCH QUESTIONS AND PRESENTING THEORETICAL PERSPECTIVES** .......................................................................................................................... 21  
  * Symptom recognition ............................................................................................. 22  
  * Social relations ......................................................................................................... 25  
  * Socio-demography .................................................................................................... 28  
  * Aim of thesis and presentation of papers ............................................................ 30  

**CHAPTER 3: METHODOLOGY** ...................................................................................................... 39  
  * Epistemology .............................................................................................................. 39  
  * Validity ......................................................................................................................... 42  
  * The choice of method ............................................................................................... 43  
  * Inclusion ....................................................................................................................... 46  
  * The analytical process ............................................................................................... 48  
  * Ethical considerations ................................................................................................. 49  

**CHAPTER 4: PAPER 1 ‘CONTAINMENT’** ...................................................................................... 53  

**CHAPTER 5: PAPER 2 ‘THERAPY MANAGEMENT’** ....................................................................... 62  

**CHAPTER 6: PAPER 3 HEALTH CARE SYSTEMS** ........................................................................ 81  

**CHAPTER 7: PAPER 4 DISCUSSION OF METHODS** ....................................................................... 93  

**CHAPTER 8: PAPER 5 DISCUSSION OF CONCEPTS** ..................................................................... 101  

**CHAPTER 9: CONCLUDING DISCUSSIONS** ............................................................................... 114  
  * Discussion of main findings ..................................................................................... 114  
  * Symptom experiences ............................................................................................... 114  
  * Social risk and care-seeking .................................................................................... 121  
  * The social relations of care-seeking ....................................................................... 125  
  * Conceptual and methodological challenges ........................................................... 131  
  * Methods revisited ..................................................................................................... 136  
  * Future studies ............................................................................................................ 138  
  * Conclusion .................................................................................................................. 139  

**REFERENCES OF THESIS** .......................................................................................................... 144  

**APPENDICES** .............................................................................................................................. 159  
  * Interview guide .......................................................................................................... 159  
  * Letter of information ................................................................................................. 162  

[2]
ENGLISH SUMMARY

Early diagnosis is a tenet in oncology, and delay in diagnosis and treatment of cancer has been a subject of research for decades. Delay is the term commonly used to describe the waiting time in the diagnostic process, and it is usually divided into patient and provider delay. In this study, we focus on patient delay which is defined as the period from onset of symptoms to the first medical consultation.

Whilst socio-cultural theories of 'lay accounts' on symptom experiences and care-seeking behavior are available within anthropology and the broader social science literature these insights have seldom been applied within the literature on patient delay and cancer. Only few studies have explicitly acknowledged the need for a more interpretive approach, which focus on the complex social and cultural processes by which people experience bodily sensations as symptoms and define how to act properly in response to these. In general there is a need to bridge theoretical insights from the social science literature and our knowledge on patient delay in cancer.

The overall aim of this thesis is therefore, from an anthropological perspective, to explore the social and cultural context of symptom experiences and care-seeking decisions among a group of Danish cancer patients.

The following research questions were addressed:

1) How does the social and cultural context influence the experience of bodily sensations and symptoms and how does this influence time to care-seeking?
2) How does the social and cultural context influence care-seeking decisions and how does this influence time to care seeking?
3) How can anthropological perspectives contribute to the ongoing conceptual and methodological discussions on patient delay?

Method: Semi-structured interviews with 30 cancer patients and their families.

The articles of the thesis address the following five issues:

Article 1: (ad research question 1): 'Containment' as an analytical framework for understanding patient delay. A qualitative study of cancer patients' symptom interpretation process. Published in: Social Science & Medicine, vol. 71, issue 2, pp 378-385. The article takes a situational approach mainly inspired by the sociologist Angelo Alonzo's studies of care-seeking. The main argument of the article is that the timing of care-seeking is influenced by the specific social situation of the individual, where people not only evaluate bodily sensations and symptoms according to their physical manifestations, but also according to their sociocultural context and their social effects.

Article 2: (ad research question 2): Applying 'Therapy Management' as a framework for understanding patient delay among cancer patients. A focus on social risk and gender. Submitted: Qualitative Health Research. By drawing on John M. Janzen's classic concept
of therapy management, the article illustrates how care-seeking decisions are negotiated in a social context and in the latitude allowed to actors in managing their relations with others. It is argued that social risk, defined as risk posed to social relationships and social identity, and gendered practices mediate responses to potential illness, and how social relations are allowed to intervene in care seeking decisions.

Article 3: (ad research question 2): The relation between health care systems and patient perceived access to health care. Submitted: Scandinavian Journal of Primary Health Care. This article raises a series of hypotheses about the relation between organisational aspects of the Danish healthcare system and care-seeking decisions. 1) Gatekeeping introduces an asymmetrical relationship between patient and GP which potentially result in self-restricting health care-seeking, 2) continuity in the doctor-patient relationship (as primarily established through the list-system) potentially shifts focus from the medical issues of the consultation to reflections on how to properly interact with the GP and the system, influencing patient reflections on access to primary care. It is argued that further research is needed on the relation between the organisational structure of healthcare systems and patient-perceived access.

Article 4: (ad research question 3): Patient delay in cancer studies: A discussion of methods and measures. Published in: BMC Health Services Research 2009, 9:189. The main argument of this article is that current studies on patient delay do not take existing theories on symptom interpretation sufficiently into account. It is illustrated that the interpretation of bodily sensations as symptoms related to a specific cancer diagnosis is embedded in a social and cultural context. We therefore cannot assume that respondents define delay periods in identical ways. In order to improve the validity of patient delay studies, it is suggested that research be strengthened on three counts: More research should be devoted to symptom interpretation processes, more research should seek to operationalise patient delay, and, importantly, more research is needed to develop valid instruments for measuring patient delay.

Article 5: (ad research question 3): Anthropological perspectives on the bio-medically defined problem of ‘patient delay’. Published in: The Taste For Knowledge – Medical Anthropology facing Medical Realities, Eds: Fainzang,S., Hem,H.E., Risør,M., Aarhus University Press 2010. The purpose of this article is to illustrate that anthropological perspectives on patient delay raise questions such as whether patient delay is a relevant issue and to whom. The fact that symptom experiences and care-seeking decisions are embedded in a given social and cultural context which potentially hold a number of competing interpretations and interests, raises both normative and epistemological concerns.
DANISH SUMMARY

For at kunne sikre kræftpatienter en god prognose er det vigtigt, at kræftdiagnosen stilles så tidligt som muligt. Forsinket lægesøgning blandt kræftpatienter (patientdelay) har derfor været et centralt forskningsområde i mange år. Mens patientdelaylitteraturen har undersøgt en række patientrelaterede faktorers betydning for lægesøgning (fx psykologiske og sociodemografiske faktorer samt folks viden om kræft), mangler der generelt indsigt i, hvordan den bredere sociale og kulturelle kontekst betinger symptomoplevelser og beslutninger om at søge læge.

Det overordnede formål med denne afhandling er derfor at undersøge den sociale og kulturelle konteksts betydning for symptomoplevelser og lægesøgning fra et antropologisk perspektiv. Afhandlingen behandler følgende forskningsspørgsmål:

1) Hvilken betydning har den sociale og kulturelle kontekst for oplevelsen af kropslige forandringer og symptomer og dermed for tiden til lægesøgning?
2) Hvilken betydning har den sociale og kulturelle kontekst for beslutningen om at søge læge og dermed for tiden til lægesøgning?
3) Hvordan kan antropologiske perspektiver på patientdelay bidrage til udvikling af begreber og metoder inden for forskningen i patientdelay?

Metode: Semistrukturerede interviews med 30 kræftpatienter og deres familier.

Artiklerne i afhandlingen omhandler følgende:


struktureret som et gatekeeper- og listesystem påvirker patienters refleksioner om adgang til almen praksis og potentielt er med til at øge risikoen for forsinket lægesøgning.


[6]
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This work would not have been possible without the many patients with cancer and their families who participated in the interviews on which this thesis is based. My warm thanks go to them for taking the time to participate.

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PREFACE

The rise of science propelled man into tunnels of specialized knowledge. With every step forward in scientific knowledge, the less clearly he could see the world as a whole or his own self... (Kundera, 1988:3).

This thesis offers an anthropological perspective on the medically defined issue of patient delay, and the reader will find that it is written in a reflexive dialogue between health sciences research and medical anthropology.

The degree of collaboration with medicine is often discussed within medical anthropology. Should we practice anthropology of medicine or anthropology in medicine? (Comelles, 2010). As an employee at the Faculty of Health Sciences, my research is institutionally situated within the confines of biomedicine, and it deals with a medically defined problem. It is therefore an example of close collaboration between the two domains, or what some would refer to as anthropology in medicine (Fainzang, 2010). While this does pose a series of challenges as some of the assumptions framing much patient delay research in some ways represent a complete break away from fundamental concepts of medical anthropology (see e.g. further discussions in Chapter 7, 8 and 9), I also believe that the thesis illustrates some of the benefits of practicing close collaboration with medicine. In line with the Danish anthropologist Mette Nordahl Svendsen, I argue that it is important that we obtain what she has called "a critically engaged position through which we continuously discuss our work analysis with our colleagues, the health professionals" (2006:53). Not in order to simplify or downplay the importance of the anthropological perspective, but to be able to transform our results into useful forms of knowledge that work in both areas of specialized knowledge; the health sciences and the social sciences (ibid.).

The act of collaboration and the attempt to present anthropological perspectives on a medically defined problem is evident in several aspects of the thesis, some of which deserve a remark here. As mentioned, some of the assumptions framing patient delay research do not fully correspond to fundamental concepts of medical anthropology. Before entering a wider discussion of such issues, Chapter 1, will, somewhat uncritically, introduce the argument for studying patient delay. This is done in order to situate the study within a collaborative framework, and to underline the fact that the criticism raised in this thesis are not raised in order to denigrate the importance of striving towards improving the prognosis of cancer patients. Rather, it is hoped that a critical comment will stimulate thinking about how the work that has already been done on the subject can be extended and expanded.

Moreover, the thesis by large adopts a series of concepts from the health sciences. Referring to people suffering from cancer, I sometimes refer to them as ‘patients’, I speak of care-seeking decisions not of healing processes, and when referring to decisions to seek health care, I always refer to professional medical care.

Overall, the perspective presented in the thesis is often double. Both inside (to add new knowledge to the issue of ‘delayed’ care-seeking), and outside (to relocate the patient
delay research in a manner that corresponds to basic notions inherent in medical anthropology). I hope that the thesis will be approached with this perspective in mind.

OUTLINE OF THE PHD-THESIS

Chapter 1 is a general introduction to the concept of patient delay and the reasons for studying it. In Chapter 2 I explore selected literature on the causes of patient delay and discuss the background of the three specific research questions of the thesis. In addition, I present the theoretical perspectives applied in the analyses presented in the five papers. Chapter 3 offers a discussion of the methodology of the thesis. Chapters 4 - 8 contain the five papers of the thesis, and, lastly, in chapter 9 I discuss the implications of the conclusions drawn in the papers and address the issue of how we may focus future research.

The appendices contain the interview guide and the letter of information given to potential informants when invited to participate in the study.
THE FIVE PAPERS OF THE THESIS


CHAPTER 1: GENERAL INTRODUCTION

Early care-seeking is a tenet in oncology, and delay in diagnosis and treatment of cancer has been a subject of research for decades (Antonovsky & Hartman, 1974). As early as 1938, Pack and Gallo defined patient delay as ‘the time elapsing between first symptom and first visit with a physician’ (1938). The reasons for delayed care-seeking among cancer patients have since been thoroughly explored. As will be discussed in length below (see Chapter 2), patient delay studies have, however, primarily been concerned with identifying a wide range of patient characteristics such as socio-demographic determinants of care-seeking (Hansen, Olesen, Sorensen, Sokolowski & Sondergaard, 2008; Neal & Allgar, 2005), psychosocial characteristics (Ristvedt & Trinkaus, 2005), the patient’s knowledge of symptoms (de Nooijer, Lechner & de Vries, 2003; Macleod, Mitchell, Burgess, Macdonald & Ramirez, 2009), or the patient’s access to social support (Burgess, Ramirez, Richards & Love, 1998). Only few studies have explicitly acknowledged the need for a more interpretive approach that focuses on the complex social and cultural processes by which people experience bodily sensations as symptoms and define how to act properly in response to these (see e.g. Corner, Hopkinson & Roffe, 2006; Facione, 1993; Levealahti, Tishelman & Ohlen, 2007; Scott & Walter, 2010).

Whilst socio-cultural theories of lay accounts on symptom experiences and care seeking behaviour are available within anthropology and the broader social science literature (see e.g. Garro, 1998; Hay, 2008; Kleinman, 1980; Lock & Kaufert, 2001), these insights have seldom been applied within the literature on patient delay and cancer. In general, there is a need to bridge theoretical insights from the social science literature and the issue of patient delay in cancer.

AIM OF THESIS

The aim of this thesis is therefore to increase our insights on the issue of patient delay in cancer by presenting selected anthropological perspectives on symptom experiences and care-seeking decisions. More specifically, throughout the thesis I will address the following three questions:

1) How does the social and cultural context influence the experience of bodily sensations and symptoms and how does this influence time to care-seeking?
2) How does the social and cultural context influence care-seeking decisions and how does this influence time to care seeking?
3) How can anthropological perspectives contribute to the ongoing conceptual and methodological discussions on patient delay?
REASONS FOR STUDYING PATIENT DELAY

Before entering a wider discussion of the patient delay literature and the reasons for asking these specific questions, I will briefly introduce the medical reasons for studying delayed care-seeking among cancer patients.

Denmark is struggling with problems of high morbidity and mortality of cancer (Sant, Allemani, Santaquilani, Knijn, Marchesi & Capocaccia, 2009; Storm, Engholm, Hakulinen, Tryggvadottir, Klint, Gis lum et al. 2010) (see Fig. 1). In comparison to other Scandinavian countries, Denmark had the highest incidence of cancer between 1992-2003 (Storm et al., 2010) and a lower all-cancer survival than countries with a similar national expenditure on health (Berrino, Ver decchia, Lutz, Lombardo, Micheli & Capocaccia, 2009). The EUROCARE studies, targeting the survival of cancer patients in Europe, furthermore suggest that Denmark had poorer survival rates across a range of cancer types than other Western European countries (Berrino, De Angelis, Sant, Rosso, Lasota, Coebergh et al. 2007; Sant, Aareleid, Berrino, Bielska, Carli, Faivre et al. 2003; Storm et al., 2010). Presenting 5-year relative survival rates among adult cancer cases from 22 European countries, the EUROCARE-4 study shows, among others, that survival in Denmark is significantly lower than the European mean in large cancers such as prostate cancer, lung cancer and colon cancer; and in all cancers combined survival rates in Denmark lie below mean European survival rates (Sant et al., 2009; Ver decchia, Santaquilani & Sant, 2009).
FIGURE 1: TRENDS IN AGE-STANDARDISED INCIDENCE AND MORTALITY RATES PER 100 000 AND AGE-STANDARDISED 5-YEAR RELATIVE SURVIVAL FOR ALL CANCER SITES BUT NON-MELANOMA SKIN BY SEX AND COUNTRY (ENGHOLM ET AL., 2010).
A number of studies have attempted to explain the reasons behind these inter-country differences in cancer survival. Overall, it has been argued that the discrepancies are rooted in a complex set of four intertwining factors: 1) differences in validity and coverage of cancer registry, 2) life-style related differences (e.g. alcohol and tobacco consumption) and differences in co-morbidity, 3) differences in medical technology and available treatment and lastly, 4) differences in time to diagnosis (Berrino et al., 2009; Olesen, Hansen & Vedsted, 2009; Storm et al., 2010).

The focus on patient delay is part of this general focus on the time to diagnosis as a means of improving cancer prognosis. Research exploring time to diagnosis has traditionally been divided into studies on patient delay and provider delay, where provider delay refers to the waiting times for which health care systems can be made accountable. In Figure 2 below, this is divided into doctor delay and system delay. The full period of delay is usually referred to as total delay and includes the period from first symptom until start of treatment or diagnosis (Hansen et al., 2008).
ESTIMATING THE EXTENT OF PATIENT DELAY

Before presenting the estimated extent of patient delay, a few clarifications on the definition are needed. The term delay has normative connotations, and as mentioned above, Pack and Gallo originally distinguished between undue and reasonable patient delay, ‘undue’ meaning that a person had experienced symptoms for three months or more before seeing a physician (1938). Defining ‘undue patient delay’ as three months or more was an arbitrary distinction, and, as it was since pointed out by the physician Henry B. Makover, patient delay should ideally be identified in terms of:

"knowledge of a specific pathogenesis of specific cancers, rather than using a broad, arbitrary unit of time which does not account for varying growth rates and danger periods" (1963:420).

Makover therefore suggested that we speak of avoidable and unavoidable patient delay, roughly suggesting a distinction between what could be symptoms of minor illnesses, commonly self-treated, and more serious symptoms severe enough to incapacitate the individual (ibid.). Makover’s suggestions, however, never caught on, and today the discussion of when to ‘make the clock tick’ in relation to defining when it is reasonable to speak of patient delay has more or less subsumed within the literature.

More recent discussions have been occupied with terminology, and the concept in itself is sometimes met with criticism (see e.g. Scott & Walter, 2010 for further discussions). In a study of care-seeking for symptoms of lung cancer, Corner, Hopkinson, and Roffe (2006) for example argued that the term ‘delay’ seems an inappropriate description as it had not occurred to patients that they may be unwell. Others have suggested alternative concepts such as ‘timelines’, ‘intervals’ or simply ‘time till diagnosis’ (Scott & Walter, 2010). Below, I return to a discussion of issues related to terminology and whether delay is an appropriate concept from the patient’s perspective (see Chapters 5 and 9). Suffice it here to say that, today, there is still no standard definition of ‘undue delay’, and the discussion of when to ‘make the clock tick’ in relation to defining when it is reasonable to speak of patient delay has more or less subsumed within the literature.

While few studies are still reporting delay in terms of the percentage of patients having delayed care-seeking for more than three months (see e.g. Barber, Jack & Dixon, 2004; Mor, Masterson-Allen, Goldberg, Guadagnoli & Wool, 1990), the majority of patient delay studies simply report the amount of days from first symptom until care-seeking as the delay period. Estimating the extent of patient delay in the Danish context, a recent study of more than 2,000 consecutive incident cancer patients with all cancer types thus reported a median patient delay of 21 days. One quarter of all cancer patients in the study waited for 56 days or more, and 15% waited three months or more before seeking care (Hansen, 2008) (see Fig. 3).
Similarly, a study of patient delay among Danish colon cancer patients showed a median patient delay of 18 days, and it was illustrated that 25% of the patients waited three months or more before seeking care (Korsgaard, Pedersen & Laurberg, 2008). A series of Western European studies reported median patient delays of 43 days (lung cancer) (Koyi, Hillerdal & Branden, 2002), 16 days (breast cancer) (Arndt, Sturmer, Stegmaier, Ziegler, Dhom & Brenner, 2002), 31 days (lung cancer) (Lovgren, Levealahti, Tishelman, Runesdotter & Hamberg, 2008) and 56 days (malignant melanoma) (Faye, Helsing & Langmark, 2000). Others have suggested that approximately 18-25% of all cancer patients wait for three months or more before they seek care (Arndt et al., 2002; Mor et al., 1990).

As will be touched upon below there are a series of methodological issues related to estimating patient delay. How we ought to understand these estimates and approach the issue of patient delay in general will be touched upon in depth below. Suffice it here to say that the main argument for exploring patient delay is that time is considered an important factor in improving the prognosis of cancer patients, and that a vast amount of studies have illustrated that patients often experience symptoms for some time before they seek professional care.

FIGURE 3: PATIENT DELAY IN A COHORT OF 2,000 INCIDENT CANCER PATIENTS WITH ALL CANCER TYPES
A brief introduction to the medical care system in the Danish context is necessary in order to understand the wider societal constrains of care-seeking. Denmark has a population of approximately 5.5 million people. As part of a well-developed welfare system, Denmark has a publicly funded health care system, and free health care is ideally a basic right of citizenship. The only expenditures to be privately covered are dental health care and medicine, and medicine is partly subsidised by the state (Vedsted, Olesen, Hollnagel, Bro & Kamper-Jørgensen, 2005). The health care system is functionally divided into primary and secondary care, where the primary sector serves as a gatekeeper system that operates a comprehensive list system (see Fig. 4). General practitioners (GPs) are thus responsible for initial assessments and only refer people to hospital or outpatient clinic work-up and treatment if necessary. The only specialists accessible without a referral from a GP are ear, nose and throat specialists and eye specialists. The GPs are self-employed on a contract basis with the Regions and nearly all Danes (98%) are registered with a particular practise (the list system). Each practitioner list encompasses approximately 1,600 patients, and everybody is free to enlist with available GPs (Vedsted et al., 2005). In regard to understanding care-seeking decisions, this means that GPs are available for any health problem in any person, and because people themselves define when and for what they need to consult their GP, there are – ideally - no limits of access.

Figure 4 The Danish Medical Care System


CHAPTER 2: FRAMING RESEARCH QUESTIONS AND PRESENTING THEORETICAL PERSPECTIVES

Having presented the medical argument for studying delayed care-seeking among cancer patients, the following section will lay further grounds for clarifying the specific focus of this thesis. This is done by discussing selected studies on patient delay and by clarifying in which areas an anthropological perspective may further improve our understanding of the issue. Furthermore, I present the theoretical perspectives applied in the analyses presented in the papers of the thesis.

Patient delay in cancer is by no means a novel area of research. Several studies have broadened our view on the complexity of delayed care-seeking. It is not possible within the confines of a single thesis to elaborately address the contents of this research tradition. For example, a vast amount of literature explores psychological causes of delayed care-seeking among cancer patients (Andersen & Cacioppo, 1995; Scott, McGurk & Grunfeld, 2008; Bish, Ramirez, Burgess & Hunter, 2005; Hunter, Grunfeld & Ramirez, 2003). Some of these studies are only briefly mentioned here, and it is beyond the scope of this thesis to fully present and discuss these aspects. For the sake of clarity, the following discussion of selected studies has been divided into three categories:

1) A series of patient delay studies has reported that people do not recognise symptoms or trivialise potentially malignant symptoms, and therefore delay seeking care. This inspired me to further probe how the social and cultural context may influence symptom experiences.

2) A series of studies on patient delay have highlighted the influence of social relations on care-seeking. This inspired me to further probe how care-seeking decisions are negotiated in the social and cultural context.

3) A series of studies on the relation between socio-demographic factors and delayed care-seeking have proven inconsistent, and the patient delay literature rarely integrates social science theories on symptom experiences. This inspired me to reflect on a series of methodological problems potentially related to the estimation of patient delay.

In the following, the subjects raised will be discussed consecutively.
Non-recognition of symptoms is an often reported factor resulting in patient delay (Andersen & Cacioppo, 1995; Safer, Tharps, Jackson & Leventhal, 1979; Macleod, Mitchell, Burgess, Macdonald & Ramirez, 2009; Ristvedt & Trinkaus, 2005; Smith, Pope & Botha, 2005; Scott, Grunfeld, Auyeung & McGurk, 2009; Lovgren, Levealahti, Tishelman, Runesdotter & Hamberg, 2008). Much of this research is well-grounded within the psychological tradition, where differences in symptom recognition or appraisal have been explained with reference to different psychological dimensions such as an ‘optimistic bias’ (Andersen & Cacioppo, 1995), individual coping strategies; (Ruiter, de Nooijer, van Breukelen, Ockhuysen-Vermey & de Vries, 2008; Zervas, Augustine & Fricchione, 1993; Tromp, Brouha, de Leeuw, Hordijk & Winnubst, 2004), differences in cognitive structures (Facione & Facione, 2006) or fear (Sheikh & Ogden, 1998; Smith et al., 2005). Leventhal and colleagues’ ‘self-regulation model’ has also been applied to explore the causes of patient delay (Scott et al., 2008; Bish et al., 2005; Hunter et al., 2003). Hunter et al. (2003) illustrated that care-seeking is mediated, partly, by cognitive representations of the identity and consequences of cancer and by attitudes towards care-seeking and perceived behavioral control (Hunter et al., 2003; Leventhal, Safer & Panagis, 1983).

The issue of symptom recognition is, however, also touched upon in a series of largely descriptive, a-theoretical studies. A large review of qualitative studies, exploring care-seeking for cancer symptoms, for example concluded that people who delay care-seeking either fear consultation or tend to trivialize symptoms (Smith et al., 2005). In other studies, ‘delayers’ have been shown to ascribe symptoms to everyday causes (Chapple, Ziebland & McPherson, 2004), misinterpret them as minor or transient problems (Corner, Hopkinson, Fitzsimmons, Barclay & Muers, 2005; Jones, Gregory, Nehill, Barrie, Luxford, Nelson et al. 2010) or lack knowledge about the symptoms to which they should pay attention (de Nooijer, Lechner & de Vries, 2001). While Corner and colleagues advocated for a broader focus on the social context as an explanatory factor in understanding why people with lung cancer do not recognise symptoms as potentially malignant (2006), the majority of such studies either provide no explanation as to why people do not recognise symptoms, or they conclude that lack of information or knowledge on cancer-related symptoms is the main culprit of non-recognition. An Australian study of women who had experienced breast cancer symptoms (Jones et al., 2010) thus concludes that:

“The primary reason for not seeking medical advice in response to a potential symptom was the belief that breast cancer was not present [...]. Health promotion efforts need to continue to aim at increasing community understanding of potential breast cancer symptoms.” (2010:945).

While these studies provide us with valuable information on the variety of what is considered normal in response to bodily experiences, it could, however, also be argued that they reify symptoms (Hay, 2008) in the sense that they neglect the social process
of interpretation that lies ahead of defining bodily sensations as symptoms. Simply referring to a lack of knowledge as the main culprit of non-recognition may leave out important explanations as to how people experience and correspond to bodily sensations as symptoms in their daily lives (Garro, 2000). In order to learn more about the reasons for delayed care-seeking, rather than concluding that people normalise or trivialise symptoms, we need to ask ourselves why they may have been reported to do so. In this thesis, this is done by examining how the social and cultural contexts shape peoples’ understanding of bodily sensations and how these sensations are interpreted as potential symptoms. This question is mainly dealt with in Paper 1 (see Chapter 4).

THEORETICAL PERSPECTIVES IN PAPER 1

A series of anthropological and sociological studies have shown that symptoms should not just be viewed as individual responses to the onset of illness that people may recognise if they have the right kind of knowledge. Rather, symptom experiences are embedded within social and cultural processes that determine how and when bodily sensations become interpreted as symptoms of a specific illness (Alonzo, 1979; Garro, 1998; Hay, 2008; Kleinman, 1980; Zola, 1966; Zola, 1973; Broberger, Tishelman & von, 2005). Symptom experiences should be understood as a part of a collective activity that makes the ailing body sensible in terms of cultural practices and meanings (Alonzo, 1979; Hay, 2008; Kleinman, 1980). The act of interpreting bodily sensations is therefore not linear in the sense that it is only a matter of recognising these sensations as symptoms of potential illness. Overall, this research suggests that we should think of bodily experience and culture as in a continuous feedback relationship where a specific cultural and social context contributes to different expectations and experiences that influence how bodily sensations are understood and acted upon.

This is exemplified in the sociologist Angelo Alonzo’s studies on symptom experiences. Central to Alonzo’s theory is that the process of symptom interpretation not only involves perceptual recognition. Symptoms should not merely be viewed as physical realities to be recognised, but rather as something that emerges from the interaction of individual bodily sensations and the processes of “social objectification or selection, interpretation and evaluation” (Alonzo, 1984:502). This implies that the process of interpreting bodily sensations as symptoms is not only related to the individual, but evolves and is shaped by the relationship between the individual and a given social situation. Of particular importance in Alonzo’s theory is the concept of containment, which is further elaborated on in Paper 1. Containment is defined as a principle that underlies both interpretation and actions related to bodily sensations. Firstly, the interpretation of bodily sensations as symptoms that require care always takes place in the situational context in which they occur. Secondly, containment refers to the social process of negotiation where individuals keep body state deviations and normal processes “at the level of a side involvement, in order to sustain the definitional and participatory integrity of the situation for the individual and others” (Alonzo, 1984:502).
Hence, social situations differ in terms of the contextual constraints they potentially impose on the individual’s interpretation of bodily sensations, which implies that they may not necessarily be recognised as potential symptoms requiring care-seeking.

The present account does not aim to examine Alonzo’s theory in detail, but seeks to demonstrate the usefulness of the notion of containment as a conceptual framework for understanding symptom interpretation as a process grounded in the context of day-to-day life situations. Overall, the concept is found useful as it gives more emphasis to the influence of the social and cultural context and less emphasis to recognition as the prerequisite for care-seeking. Thus, it avoids the shortcomings of merely referring to knowledge as a ‘magic bullet’, which has occasionally limited patient delay studies to an assessment of whether people are competent at recognizing illness signs.
Another line of explanations of patient delay often presented is what could broadly be defined as the social relations of care-seeking. Overall such studies have shown that social relations are important mediators in care-seeking decisions. A review about breast cancer patients has e.g. suggested that role demands such as devoting time and attention to the needs of someone else and taking time to make domestic arrangements prior to having a biopsy taken may delay care-seeking (Facione, 1993). Similar results were reported in an interview study of patients with oral cancer by Scott, who showed that competing responsibilities may be a barrier to care-seeking (2006). Facione and colleagues likewise showed that partner and employer-perceived constrains potentially cause delayed care-seeking among breast cancer patients (2002).

Others have shown that social networks are central triggers for care-seeking, (Smith et al., 2005; Cardol, Groenewegen, De Bakker, Spreeuwenberg, van Dijk, & van den Bosch, 2005), Burgess, Potts, Hamed, Bish, Hunter, Richards et al. 2006; Macleod et al., 2009; Burgess, Ramirez, Richards & Love, 1998). Burgess et al. showed that breast cancer patients who do not disclose their symptoms to someone else within a week have longer patient delay (Burgess et al., 2006). A study of patients with testicular cancer showed that wives are of particular importance in persuading men to visit their GPs (Gascoigne, Mason & Roberts, 1999); and Tromp and colleagues found significant correlations between ‘less seeking support’ as a coping style and patient delay among head and neck cancer patients (Tromp et al., 2004). Similarly, a few studies have suggested that GP-related factors may be a barrier to care-seeking. It has been shown that negative attitudes towards the GP potentially influence the time of care-seeking (Scott et al., 2009), and a recent English study reported that ‘worry about wasting the doctor’s time’ is a barrier to care-seeking (Robb, Stubbings, Ramirez, Macleod, Austoker, Waller et al. 2009).

While these studies witness that interaction with others forms an essential element in decision-making, the social interaction preceding the decision to seek care is often ‘black boxed’ within the patient delay literature. Many studies reveal only sparse information on why these different social elements are reported to be barriers to or triggers of care-seeking. Sociologists and anthropologists working with decision-making have argued that the understanding of decision-making implies a focus on humans as social individuals who interact and perform in relation to other positioned, social individuals, who influence and shape each other through action and being (Pescosolido, 1992; Hay, 2008; Kleinman, 1980; Janzen, 1987). Studying care-seeking from this approach means studying symptom experiences and care-seeking decisions, and how they are influenced through relations and the social and cultural settings in which they unfold (Pescosolido, 1992; Janzen & Leslie, 1978). In order to fully understand delayed care-seeking, we should therefore not only ask if social relations such as wives or GPs mediate care-seeking decisions or act as barriers to care-seeking. Rather, we should ask how and why they mediate decisions taken. In Papers 2 and 3, I
therefore explore how care-seeking decisions are negotiated in the social and cultural context (see Chapters 5 and 6).

THEORETICAL PERSPECTIVES IN PAPER 2

Anthropologists have always been concerned with questions of connections between people, most clearly demonstrated by the central disciplinary concept of kinship. In studies of care-seeking and how people navigate in mainly plural health systems (Choi, 2008; Garro, 1998; Holroyd, 2002; Janzen & Leslie, 1978; Kleinman, 1980; Young & Garro, 1981), medical anthropologists studying care-seeking have studied the role of social relations, framed variously as lay referral systems (Mechanic, 1978), therapy management groups (Janzen, 1987), healing relationships (Kleinman, 1980), or more broadly as ‘family and significant others’ (Alonzo, 1986; Hay, 2008; Holroyd, 2002).

Such studies place focus on the importance of social relations both in the healing process and in navigating between healing options. This focus on social relations is in many ways summarized in the psychiatrist and anthropologist Arthur Kleinman’s portrayal of the health care sectors.

Kleinman identified three overlapping and related sectors: the ‘popular sector’, the ‘folk sector’ and the ‘professional sector’ (1980). The ‘popular sector’ refers to the largest part of the activities and social processes that take place around illness and health. This sector is a nonprofessional layperson arena in which initial ideas and activities related to potential illness are formulated and carried out. The ‘professional sector’ relates to the organised and authorised health professions, while the ‘folk sector’ includes therapists who do not have an officially sanctioned position, but who, nevertheless, are acknowledged as healers and often offer treatments that are rooted in other knowledge traditions than the treatments represented in the professional sector. According to Kleinman, the popular sector, which is the nonprofessional layperson arena, is the primary and most important location for perceiving and experiencing symptoms, valuating diseases, sanctioning a particular kind of sick role and in deciding what to do about it (1980:52). In presenting the popular sector as the place where access to the other sectors are mediated and in placing the family as the main arena of health care, he illustrated how all forms of illness are defined and dealt with in the social arena. From an anthropological perspective, the question regarding care-seeking and social relations is, thus, not so much an issue of whether social relations are of importance for care-seeking decisions, but more how and why they contribute to decisions taken.

Paper 2 mainly draws on the anthropologist John M. Janzen’s concept of therapy management in order to understand care-seeking decisions in what Kleinman called the ‘the popular sector’. Janzen presented the concept of therapy management in describing the social process of defining the illness, supporting the sufferer and selecting and evaluating treatment (Janzen, 1987). The constellation of individuals who partake in the therapy management process was named ‘the therapy management group’:
“The therapy management group coalesces whenever an individual becomes ill or is confronted with overwhelming problems. Various maternal and paternal kinsmen, and occasionally their friends and associates, rally for the purpose of sifting information, lending moral support, making decisions, and arranging details of therapeutic consultation. The therapy managing group thus exercises a brokerage function between the sufferer and the specialist” (Janzen & Leslie, 1978:68).

Janzen’s original analysis of therapy management was presented as a new and critical angle on the social context of decisions. Many studies have since applied the concept of therapy management focusing on ‘survival strategies’ among the poor in third world countries, and the idea of social relations and community as important resources for poor people is a cornerstone in this concept (Bossart, 2003; Nichter, 2002). In Paper 2 I have attempted to use the concept for furthering our understanding of care-seeking decisions in the context of a welfare state which are not necessarily framed by questions related to material resources. Overall, it is argued that studying care-seeking decisions through the lens of therapy management invites a focus on how social relations mediate decisions taken. More specifically, what the therapy managing approach illustrates is that decision-making is a dynamic, interactive process fundamentally intertwined with the structured rhythms of social life, and it is therefore suitable as a theoretical framework for understanding the ‘black box’ of social relations and care-seeking referred to in many patient delay studies.

THEORETICAL PERSPECTIVES IN PAPER 3

In Paper 3 I address aspects of what Kleinman called ‘the professional sector’. The analysis draws implicitly on a series of studies arguing that the structures of health care organisations should be incorporated into our analysis of interaction in the clinical setting (Seidl & Becker, 2006; Pappas, 1990; Shilling, 2002). Overall, these studies illustrate that neither the doctors’ actions nor the interaction between doctor and patient is properly understood without reference to the structural constrains under which these actions unfold (Shilling, 2002). All contexts, including family practices, are structured by rules and norms, which implicitly form a series of social boundaries to action (Hayward & Lukes, 2008). As stated above, patient delay studies have illustrated that some patients delay care-seeking because they ‘worry about taking the doctor’s time’. In order to improve our understanding of such findings, a more contextually oriented framework may prove expedient because it will downplay a unitary focus on either the patient or the doctor as the cause of delayed care-seeking, and help us identify how wider societal issues such as the economic and organisational structures of health organisation influence power and interaction in the clinical setting.
Lastly, patient delay studies have examined the socio-demographic determinants of care-seeking. These otherwise exemplary studies have, however, presented varying and contradictory results. While a series of studies found no association between patient delay and patients’ age, sex or socio-economic status (Mitchell, Macdonald, Campbell, Weller & Macleod, 2008; Mor, Masterson-Allen, Goldberg, Guadagnoli & Wool, 1990; Amir, Kwan, Landes, Feber & Williams, 1999), other studies have suggested that age is associated with patient delay among breast cancer patients (Bish et al., 2005; Arndt, Sturmer, Stegmaier, Ziegler, Dhom & Brenner, 2002; Ramirez, Westcombe, Burgess, Sutton, Littlejohns & Richards, 1999) and patients with non-Hodgkin’s lymphoma (Neal & Allgar, 2005). Low educational level has been shown to be associated with patient delay among colon cancer patients (Macleod et al., 2009) and a study suggested that female work-status may be indicative of delayed care-seeking (Hansen, Olesen, Sorensen, Sokolowski & Sondergaard, 2008). In respect to gender, it has in general been hypothesised that men are more reluctant than women to visit their GP when experiencing symptoms, but patient delay studies have also proven inconclusive on this front (Addis & Mahalik, 2003; Lovgren et al., 2008; Schnurr, Pippan, Stuetzer, Delank, Michael & Eysel, 2008, Hansen et al., 2008).

We can only raise hypotheses about why studies on the association between patient delay and socio-demographic variables present with varying results. Firstly, it could be hypothesised that multivariate studies leave us with a straightforward and static conceptualisation of care-seeking that neglects the dynamic and contextual nature of how bodily signs and sensations are interpreted as symptoms of decision-making (Pescosolido, 1992). That is, socio-demographic factors may be part of a complex interplay of factors influencing patient delay, and it is doubtful whether any single variable can be identified as a sole determinant of patient delay.

Secondly, the inconsistencies could be hypothesised to be due to a series of methodological problems. As discussed above, social science literature has widely documented how symptom interpretation is embedded within social and cultural processes and how such processes determines how and when bodily sensations are interpreted as symptoms of a specific illness. This may lead us to think that we do not really know how people perceive and define the time intervals they are asked to report in patient delay studies. Patient delay studies usually estimate the delay period by asking people to retrospectively report when they first experienced symptoms of their cancer, and when they first presented these symptoms to a medical professional. However, cancer symptomatology is complex. It may be problematic to treat cancer as a single entity due to the complex mixture of different cancers as they represent with a vast variety of symptoms or bodily signs (Hamilton, 2010), which may again be differently experienced and interpreted by different people (Hay, 2008). The lack of consistency in results could therefore also be related to methodological difficulties in measuring patient delay. Before further probing the extent of patient delay and how it
is associated with socio-demographic variables, we may need to further discuss the methodological implications of measuring time from ‘first symptom till care-seeking’. In Papers 4 and 5, we discuss how social science and, in particular, anthropological perspectives may contribute to ongoing methodological and conceptual discussions of patient delay (see Chapters 7 and 8).
AIM OF THESIS AND PRESENTATION OF PAPERS

Summing up, it could be argued that much of the literature exploring patient delay among cancer patients provides only fragmentary information on the contextual causes of delayed care-seeking. One of the root notions of anthropology is that thought and behaviour cannot be properly understood outside the context in which they are situated. It is knowledge of the context that renders these notions intelligible. In order to broaden our understanding of patient delay, the aim of this thesis is therefore to explore the social and cultural context of symptom experiences and care-seeking decisions among Danish cancer patients.

The following research questions are addressed:

1) How does the social and cultural context influence the experience of bodily sensations and symptoms and how does this influence time to care-seeking?
2) How does the social and cultural context influence care-seeking decisions and how does this influence time to care seeking?
3) How can anthropological perspectives contribute to the ongoing conceptual and methodological discussions on patient delay?

THE MAIN FINDINGS PRESENTED IN THE PAPERS:

Paper 1 (re research question 1):


This paper explores a group of Danish cancer patients’ pre-diagnostic symptom interpretation processes, and how these processes potentially delay care-seeking decisions. It adopts a contextual approach inspired mainly by the sociologist Angelo Alonzo’s concept of containment. Alonzo’s theory is supplemented with recent anthropological and sociological literature on how people establish the relation between bodily sensations and symptoms and decide how to respond adequately to these sensations and symptoms.

We present an analysis illustrating that bodily sensations and symptoms are potentially contained in a dynamic interplay of factors related to specific social situations, life biographies and life expectations and their accordance with culturally acceptable values and explanations. A retrospective analysis as the one presented here may therefore establish analytic grounds for separating mind, body and social context; grounds which do not fully allow us to go beyond the individual perspective and to take account of the implications the wider social and cultural structure have for bodily
experiences and care-seeking. Ideally, future studies of patient delay would have to draw on a wider range of methods that integrate both prospective perspectives and a macro-social analysis.

**Paper 2 (re research question 2):**

*Title: Applying ‘Therapy Management’ as a framework for understanding patient delay among cancer patients. A focus on social risk and gender. Submitted: Qualitative Health Research.*

Much literature on patient delay discusses the role of social relations in mediating care-seeking, and it has been shown that social relations are important ‘triggers’ of care-seeking that potentially reduce the delay period. The role of social relations in care-seeking decisions is, however, a ‘black box’. We know only little of the processes by which it unfolds and how it works as a trigger of care-seeking.

The analysis in this paper is inspired mainly by the anthropologist John M. Janzen’s classical concept of ‘therapy management’. Janzen’s concept is supplemented with recent anthropological and sociological literature on social relations and illness experiences. It is illustrated that notions of social risk and gender mediate responses to potential illness and that social relations may invite both passive and active responses towards symptoms and care-seeking decisions. The main argument of the paper is that the decision of when to seek care is established in a social process of negotiation and the paper illustrates that it is too simple to regard social relations as ready-made structures with distinct functions.

**Paper 3 (re research question 2):**

*Title: The relation between health care systems and patient-perceived access to health care. Submitted: Scandinavian Journal of Primary Health Care*

This paper explores the relationship between patient-perceived access to health care and the structure of the Danish health care system.

It raises two hypotheses on the relation between organisational elements of a health care system and peoples’ care-seeking decisions: 1) Gatekeeping introduces an asymmetrical relationship between patient and GP which potentially results in self-restricting health care-seeking, 2) continuity in the doctor-patient relationship (as primarily established through the list system) influences patient reflections on access to health care, as the focus potentially shifts from the medical issues of the consultation to reflections on how to properly interact with the GP and the system in which s/he is situated. It is argued that these hypotheses form a sound basis for further primary care research on how the organisational structure of health care systems influences patient-perceived access to medical advice for symptoms on cancer.
Paper 4 (re research question 3):


There is no validated way of measuring the prevalence and duration of patient delay, and we do not know how people perceive and define the time intervals they are asked to report in patient delay studies. This lack of a validated measure hampers research in patient delay and is counterproductive to efforts directed at securing early diagnosis of cancer.

The main argument of the paper is that current studies on patient delay do not sufficiently consider existing theories on symptom interpretation. It is illustrated that the interpretation of bodily sensations as symptoms related to a specific cancer diagnosis is embedded within a social and cultural context. We therefore cannot assume that respondents define delay periods in identical ways. In order to improve the validity of patient delay studies, it is suggested that research be strengthened on three counts: More research should be devoted to symptom interpretation processes, more research should seek to operationalise patient delay, and, importantly, more research is needed to develop valid instruments for measuring patient delay.

Paper 5 (re research question 3).


Patient delay studies are framed within the epistemological principles of biomedicine. Many patient delay studies depart from what Byron Good has called an empiricist approach to the body; an approach where symptoms are given the status of objects which exist independently of and prior to the patient’s perception of them. Moreover, it could be argued that the concept of patient delay and how it is approached are influenced by a normative assessment grounded in an ideology of health services research; namely that it is both possible and reasonable to make people react early on symptoms.

These principles, the paper argues, contradict anthropological perspectives on symptom experiences and care-seeking decisions in two ways: 1) The act of interpreting bodily sensations as genuine symptoms of illness and defining how to respond adequately to these symptoms always takes place in a socio-culturally informed context. In many cases, only a retrospective perspective therefore allows us to define bodily sensations as cancer-related symptoms. Experience and recognition are not in situ separable entities. This may pose a challenge to empiricist notions of
symptoms and the often predefined focus on knowledge as a solution to the problem of patient delay which it produces. 2) The understanding of and acting on symptoms combine with social norms and expectations and involves aspects of self-preservation. This complicates the process of making sure that people behave 'satisfactorily' in a situation of potential illness. This may to some extent challenge normative notions inherent in the patient delay literature that place sole focus on the material body as an indicator of proper action.

An anthropological approach to care-seeking and symptom interpretation indicates that patient delay may not be a relevant issue when viewed from the patient’s perspective. This critique is not placed in order to denigrate the fact that patient delay is a meaningful concept from a biomedical perspective; rather, it springs from a concern to initiate cancer treatment as quickly and efficiently as possible. However, the discussion brought forward exemplifies how different epistemological assumptions create different kinds of knowledge and potentially produce different kinds of solutions to health-related problems.
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Approaching Patient delay and Cancer. Anthropological Perspectives on Concepts and Causes


CHAPTER 3: METHODOLOGY

This chapter discusses the methodological foundation of the thesis. Firstly, I discuss the epistemological basis of the research project, the choice of methods and how the issue of validity was approached. Secondly, I describe the analytical process and the ethical considerations adopted in the thesis.

EPISTEMOLOGY

Within the health sciences, it has become a tradition in qualitative research dissertations and articles to state the author’s pre-understanding of the research issue explored, often in order to be able to ‘bracket it’ in the sense of avoiding bias. This, it could be argued, is a slightly positivistic research stance that indicates a possible separation between researcher and the researched object (Hammersley & Atkinson, 1983; Guba & Lincoln, 1994). Instead of thinking of a given researcher’s pre-understanding as foundational to certify the validity (Sanjek, 1990) or trustworthiness (Denzin & Lincoln, 2008) of her research, I will side with other researchers who argue that it is more important that we reflect on epistemology as a means of explicating how a researcher thinks she can gain knowledge of the world and how she defines what constitutes proper knowledge of that world (Anfara & Mertz, 2006; Guba & Lincoln, 1994; Denzin & Lincoln, 2008).

The argument for discussing epistemology is made in relation to overall social constructivist notions of knowledge and knowledge production. It is made to underscore that it is an illusion to deny the human touch on research. Objectivity is not a reachable position; rather, all knowledge is partial and situated (Guba & Lincoln, 1994; Anfara & Mertz, 2006, Kvale, 2002). Epistemology is defined in conflicting ways in the literature (Guba & Lincoln, 1994), but here, in line with Carter and Little (2007:1317), it is defined as "justification of knowledge". Thus, the epistemological position taken in a given research project is crucial for understanding how knowledge is produced and legitimised, and, therefore, important for understanding the methodology, here defined as the relation between the methods applied, the theories used and the knowledge or analysis presented (see Fig. 5).
The epistemological foundation of this thesis is influenced by *social constructivism* as it has been defined and discussed by social scientists such as Guba, Denzin and Lincoln (1994, 2002, 2008) Hammersley and Atkinson (1983) and Emerson, Fretz and Shaw (1995). Constructivism has a long history within the social sciences, and there is no formal agreement between proponents about the definitions or implications of this approach (Denzin & Lincoln, 2008:3). Researchers often do not specifically state that they are driven by constructivism. This is also the case with Emerson and colleagues and Hammersley and Atkinson. However, I will argue that their reflexive hermeneutical approach to ethnographic methodology (Hammersley & Atkinson, 1983; Emerson et al., 1995) is consistent with the overall notions of constructivism as it is presented by Guba and Lincoln (1994). Overall, the thesis rests on three epistemological premises which have implications for the research design, the analysis presented and the wider structure of the thesis:

Firstly, as it is presented here, constructivism assumes that science cannot by simply choosing the right methods converge on 'the real truth'. Guba and Lincoln have called this 'ontological relativism' (1994:110). This is not to imply a radical relativist departure, but it means that the social realities under study are regarded as changeable products of human interaction and intellects. As indicated in Chapter two, this has implications for the study of symptom experiences. In much patient delay literature, symptoms are studied as empiricist phenomena available for recognition. From a constructivist perspective, one should not (only) be concerned with the issue of recognition when studying symptom experiences. It is more a question of interpretation – and importantly – a contextually embedded interpretation that rests on the assumption that bodily experiences cannot be separated from the wider context in which they exist. Understanding symptom experiences and care-seeking decisions from a constructivist perspective, one should therefore focus on the process by which bodily sensations are transformed into symptom experiences. As will be further discussed below, the constructivist perspective thus presents a series of methodological challenges to retrospective studies of symptom experiences and care-seeking decisions.
Secondly, it is assumed that there is an interaction between researchers and the objects researched, and that empirical data are created through the interaction between researchers and these objects. Guba and Lincoln have called this 'the interactive nature of the inquirer-inquired' (1994:107). The empirical data presented in this thesis should thus be regarded as the result of an interaction in the specific interview situations, its specific setting and the social position and values of the people present during the interviews. "We cannot escape the social world in order to study it", as Hammersley and Atkinson have put it (1983:17). Additionally, it has been argued that research projects and the analysis produced are influenced by the specific socio-historical location of the research project (Hammersley & Atkinson, 1983; Denzin & Lincoln, 2008). Certain contexts make certain research questions available and configure research practices in a certain way. The specific research questions raised and the analyses presented in this thesis are, for example, influenced by the fact that patient delay as an area of research is developed within a somewhat positivistic epistemological setting. As stated in the introduction, current knowledge on patient delay is often de-contextualised, i.e. presented without reference to the meanings and purposes attached by the people inflicted. This inspired both the formulation of the research questions and the analytical perspectives presented in this thesis. Moreover, the analyses presented in the specific papers are influenced by the audiences they are thought to address and the journals in which they meant to be published. Different papers address different audiences; and different journals have different epistemologically based assumptions on how to generate and represent 'proper knowledge'. The use of theoretical references and the building of arguments are, for example, very different in Papers 1 and 3.

Thirdly, constructivism as it is presented here, assumes that empirical data are not simply gathered and presented in an analysis. These data are created and rendered meaningful in dialogue with theory. That is, 'knowledge' is 'knowledge only' within some theoretical framework (Guba & Lincoln, 1994:107). This means that theory is not considered something that awaits refinement by analytical tests (induction), nor do empirical data stand apart as independent measures of theoretical adequacy (deduction). Instead, there is a close relation between empirical data and theory. In the words of Emerson and colleagues:

"[...] there is a reflexive or dialectical interplay between theory and data whereby theory enters in at every point, shaping not only analysis but how social events come to be perceived and written up as data in the first place." (1995:167).

This is not stated only to explicate that theory is important as a product and language of research. From a constructivist perspective, the point is that it is not possible to produce knowledge from an objective perspective. All research is theory-driven as it is impossible to engage in knowledge production without at least tacit assumptions about what knowledge is and how it is constructed (Carter & Little, 2007; Anfara & Mertz, 2006).
Lastly, as mentioned above, there is no formal agreement between proponents about the definitions of constructivism. I find it important to emphasize that the understanding of reality, as it is presented here, is not a radical anti-realist position. What I have been trying to explicate in the above is that constructions of reality do not reflect an objective truth about reality. As stated by Richard Rorty, there is a (changeable) world out there, but descriptions about the world are not, "To deny the power of reality is not to deny reality" (Rorty in: Cheek & Gough, 2005:303). Rather than being a position explicating anti-realism, it is thus a position arguing for a truth-relativism. In the following, I will discuss the implications such an approach has for the research process and for how one defines quality criteria.

VALIDITY

When objective truth is no longer considered reachable, the idea that it is possible to validate knowledge against an approachable, objective world is necessarily questioned (Kvale, 2002; Hatrup, 2004). The past decades have seen an ongoing discussion within the social sciences on how to define criteria determining the quality of qualitative research (Lincoln, 2002). One example is Guba and Lincoln. In their classic book on naturalistic inquiry (1985), they argued that social science researchers (in their terminology the naturalist) should strive for establishing trustworthiness in relation to the knowledge produced rather than proving the validity of their results. This, they argued, should be done by convincing the audience that the analysis presented could be regarded as trustworthy by presenting the credibility, transferability, dependability and conformability of the study.

Parallel to the process of developing an alternative terminology for establishing criteria for quality in qualitative research, other social scientists have tried to re-integrate or translate the meaning of validity into the social sciences (Sanjek, 1990; Kvale, 2002). Thus, the psychologist Steiner Kvale has further developed the concept of construct validity, which he defines as “an open process where to validate is to investigate” (2002:304). As stated:

“A move from knowledge as correspondence with an objective reality to knowledge as a communal construction of reality involves a change in emphasis from observation to conversation and interaction (...). Validation becomes the issue of choosing among competing and falsifiable interpretations, of examining and providing arguments for the relative credibility of alternative knowledge claims (...) method as a truth guarantee dissolves." (2002: 306-8).

To Kvale, validity is no longer related to the relation between how we approach the world and the empirical data gained (does the method measure what we believe it does and are our results therefore valid?), but validity becomes a question of how we construct new knowledge in the process of generating empirical data and of deciding between “possible competing and falsifiable interpretations” (2000:307). In a similar
vein, but in an attempt to translate the concept of validity into ethnographic research, the anthropologist Roger Sanjek (1990) has suggested three principles for assessing or evaluating the validity of an ethnographic study: Firstly, he argued for a transparent description of the 'ethnographer’s path' through data generation (1990:398). This description will, of course, differ from a traditional ethnographic field study to an interview study like the one carried out here. In the interview study, this principle is considered a means of thoroughly presenting the methods applied, how they were applied, and their potential and limitations. Secondly, Sanjek suggested that one should carefully account for the relationship between ethnographic interpretation and ‘field note evidence’. This implies that voice should be given to the informants in the analysis presented, and one should carefully explicate the analytical process of ‘writing up’ (1990:400). Lastly, Sanjek stated that for an ethnographic study to be valid, the author should ensure ‘theoretical candor’, explicating the theoretical background and choices made during the study (1990:395).

Without going further into a detailed discussion of emerging criteria for quality in constructivist research (see e.g. Guba, 1981; Lincoln, 2002 for further discussions), in the following I will discuss the validity of the present study by following Roger Sanjek’s three principles, which I have modified to suit the discussions relevant for an interview study.

THE CHOICE OF METHOD

In order to understand delayed care seeking, I set out to explore symptom interpretation processes and social interaction. First hand observations, as gained through traditional fieldwork methods of observation and participation, would most likely have provided valuable information. However, having defined that I wanted to learn about care-seeking decisions among cancer patients, it would have been difficult and time-consuming to prospectively identify and follow people in their daily home-settings and wait for them to experience potentially cancer-related symptoms and decide to seek health-professional care. I therefore decided to resort to interviews alone, but played out a series of strategies in order to improve the validity (Kvale, 2002) or credibility of the interviews (Guba, 1981). As will be explicated below, observation was widely integrated in the interviews and provided valuable information.
LIMITATIONS OF THE INTERVIEW

Consequently, according to the constructivist epistemology presented above, relying on interviews alone may present a series of problems, as the story of ‘what really happened’ might not easily be elicited in an interview (Kvale, 2006; Kvale, 1996). Firstly, the empirical data accessed in interviews are the verbalised, retrospective stories of what happened. In such stories, aspects of the illness stories are potentially established in the interview situation. Being asked to reflect on what happened may bring forth connections and interrelatedness which might not have been there at the time of the illness episode (Mattingly, 1998; Kvale, 1993; Kvale, 1996). The fact that our informants had been diagnosed with cancer, a potentially deadly illness, described to be associated with a strong cultural image of death and bodies gone awry (Sontag, 1983:63-71) potentially initiated reflections on ‘causality’ or ‘why me’, ‘why now’, which influenced how informants represented their stories. Because I interviewed people about illness events that took place prior to receiving their cancer diagnosis, one could say that there had not only been a displacement in time, but also an existential disruption that influenced our empirical data. This problem is, for example, evident in Paper 1, which discusses patients’ symptom experiences. In the stories presented, many informants have integrated discourses on cancer risk and different cultural notions on cancer aetiology. It could be questioned whether these cancer-specific reflections were actually present ‘in real time’, i.e. when the informants first experienced the bodily sensations discussed in the interviews.

Closely related to this problem is the issue of normativism. Information obtained in interviews might be predisposed toward a normative presentation of what ought to happen, because researchers inviting informants to re-tell their stories might encourage them to justify their behaviour (Kvale, 1996). In this case, normativism may have been reinforced due to the subject of my research, as informants who had experienced symptoms for a long time may retrospectively have needed to legitimate choices and actions taken. Moreover, the role and the position of me, the interviewer, may also have influenced the information obtained (Hammersley & Atkinson, 1983; Kvale, 2006). The fact that I am situated in a health department may have increased the risk of normativity as it could have encouraged informants to retrospectively justify their health-related behaviour.

Secondly, as explicated by Bourdieu’s concept of doxa, the logic driving social life is often implicit to the people living it and therefore taken for granted (Bourdieu, 1980). This means that a good deal of the informants’ behaviour in relation to their illness episodes would have been accomplished unthinkingly and unknowingly, and it is therefore not easily accessed in an interview situation. Overall, this means that retrospective interview data potentially establish an analytic basis separating mind, body and social context which was ‘not really there’.
JOINT INTERVIEWING

In order to cater for some of these limitations, I applied a series of strategies when conducting the interviews. As has been stated by the anthropologist Cecilie Rubow, interviews contain elements of observation (2007). Interviews are not merely an exchange of words, but just as much a situation of interaction. In order to increase the level of interaction during the interviews, I resorted to joint interviewing when possible (Seale, Charteis-Black, Dumelow, Locock & Ziebland, 2008). Patients invited to participate in the study were encouraged to invite a family member who had been closely involved in their illness trajectory to also participate in the interview. There are different views about the effect of joint interviews on disclosure of personal and sensitive issues such as illness (Morris, 2001). It has, for example, been argued that gender differences are downplayed and that the woman’s perspective is enhanced when couples are being interviewed (Seale et al., 2008). This may well have been the case in this study where women, in general, were more active during the interviews. Setting out to study the social context of symptom interpretation and decision-making, however, I aimed at enhancing the interactional aspect of the interview situations. As will be evident, particularly in the analysis presented in Paper 2, I accessed and was able to observe how decisions were negotiated and often also able to observe how agreements and disagreements on symptom experiences and care seeking decisions were re-enacted during the interview-situation. It is therefore my overall impression that the decision to use joint interviews produced more comprehensive accounts of illness episodes and decisions taken than single interviews would have done because it allowed direct observations of interactions between family members.

In 23 interviews spouses participated, in one interview a sister participated and in one interview both a daughter and a spouse participated. Five were interviewed alone: three because they were living alone, one because he did not want his wife to participate, and one because his wife had fallen ill just prior to the interview.

EXTENDING THE INTERVIEW SITUATION

Extending the interview was another strategy applied to increase the level of observation and interaction during the interview. The interviews took place in the informants’ homes, and when possible I extended the interview-situation by staying for coffee, by having a walk in the garden or watching family photos, etc., after the interview had ended. This often resulted in spontaneously produced information which gave valuable contributions to the more official stories presented during the interview.
THE INTERVIEW GUIDE

The interviews were conducted according to a guide in which I attempted to assess aspects of the informants' situation (work, family life, other illnesses), to obtain detailed descriptions of symptom experiences and, in particular, to make the interviewee give an account of the specific period preceding the care-seeking decision leading to the cancer diagnosis. I also explored how social relations such as family members, friends and colleagues were involved in the process of interpreting bodily sensations and how the decision to consult health professionals had finally come about. Lastly, I probed for detailed descriptions of former illness experiences and the informants' perspectives on their GPs; what they considered to be a good GP and their views on the GP's role in the investigation for cancer. When family members participated in the interview, they were asked to participate actively; they were asked questions directly and often family members and patients on their own initiative engaged in more comprehensive discussions on the subjects raised. The interview guide was developed based on thorough literature studies and was partly refined during the process of collecting empirical data (see appendices).

INCLUSION

Inclusion of patients into interview studies should satisfy the theoretical and analytical requirements of these studies (Kvale, 1996; Morse, 2008). Thus, analytical pre-assumptions must be borne in mind (for example, is gender an interesting analytical aspect to be considered when selecting informants for a study on care-seeking decisions?) and the theoretical understanding of the phenomena under study must be carefully considered (for example, how does the theoretical underpinning of the study approach symptom experiences?).

We conducted semi-structured interviews (Kvale, 1996) with 30 newly diagnosed cancer patients and their family members. Informants were purposefully sampled (Bernard, 2006:186) based on age, cancer diagnosis and gender. Only patients above the age of 18 were invited to participate as illness episodes and care-seeking decisions have shown to unfold differently among children, adolescents and adults (Inhorn, 1995; Hepworth & Featherstone, 1998). The youngest informant was 32 years old and the oldest was 84 years at the time of the interview. Moreover, informants were selected based on cancer diagnosis. We invited patients who had been diagnosed with lung cancer, malignant melanoma and colon cancer. These cancers were chosen for a number of reasons. Firstly, they represent large cancer groups (Karim-Kos, de Vries, Soerjomataram, Lermans, Siesling & Coebergh, 2008), and they potentially present with a vast range of symptoms (e.g. coughing, rectal bleeding, haemoptysis, birthmark or mole changes, pain, tiredness and digestive disturbances), which provided us with data on a variety of symptom experiences. Moreover, by including patients from only three categories of cancer, we were able to make comparisons across different as well
as similar illness episodes. Lastly, studies have implied that gender may influence how people interpret bodily experiences and reflect on health care-seeking (Bendelow & Williams, 1998). It was therefore important to have the perspectives of both genders presented. For each cancer we included both men and women. Overall, 14 female cancer patients and 16 male cancer patients participated.

RECRUITMENT

Informants were recruited through relevant hospital departments where they received written information about the study by hospital staff immediately after they had been informed of their cancer diagnosis. Hospital staff also informed potential informants that they could invite a spouse or another close relative to participate in the interview. Those who were interested in learning more about the study then gave verbal permission to the hospital staff that someone from the research group could call them by phone, provide further information and invite them to participate in the interview. Due to their newly received diagnosis, informants were in a vulnerable situation. In order to give them time to discuss the participation in the interview with a spouse or another relevant family member, and for ethical reasons (see further discussion below), we waited two to three days before calling to make the final invitation. Two thirds (66%) of the patients invited by the research group participated in the study. The majority of the patients who declined to participate explained that they lacked energy to do so, or they felt that investigations and treatment took up all of their time and energy. Ten patients from each cancer group were interviewed.

The interviews took place between one or four weeks after the informant had been informed of their cancer diagnosis. Some had already started treatment and others were still waiting for final investigations to determine which kinds of treatment they should receive.

The informants are anonymised throughout the thesis. No real names are revealed in the cases, and in the case-descriptions, I have made sure not to reveal information that would potentially help identify informants. When informants appear more than once in the thesis, they are referred to using the same fictive names.
THE ANALYTICAL PROCESS

When conducting the study, we followed ethnographic principles of analysis, meaning that the analytic process was not a confined process undertaken separately from reviewing literature, interviewing, coding, interpreting and writing (Emerson et al., 1995; Sanjek, 1990). This process is sometimes referred to as the research cycle (Wadel, 1991), which illustrates the intimate connection between research question, method and analysis (see discussion on epistemology above).

Stating that the research process is like a research cycle is, however, not tantamount to saying that there is no progress. Indeed, the research circle may be said to have a “funnel structure, being progressively focused over its course” (Hammersley & Atkinson, 1983:206). This funnel structure is evident in the way the relation between literature studies, theoretical insights and the development of our research questions was described in Chapter two. It is also evident in the way I progressed from posing research questions to presenting the final analyses in the papers. The analytical process undertaken for each of the papers in the thesis can be divided into four overlapping phases, which took place every time I started to write up a new manuscript. Throughout the process, we continually employed researcher triangulation (Hammersley & Atkinson, 1983:231).

1) In the first phase, I carefully recorded early analytical insights that evolved during theoretical and empirical literature studies. This process is similar to what Emerson and colleagues has called ‘writing initial memos’ (Emerson et al., 1995), and it inspired both the development of specific research questions and the development of the interview guide.

2) When data was collected and had been transcribed, all material was read and re-read in order to initiate a more intense reflection and to review earlier insights recorded in the memos. During this phase, the first ideas for analytical themes evolved.

3) This phase was followed by a more systematic coding process (assisted by Nvivo) of all the transcribed empirical data, where themes and patterns were established across events and informants, hence allowing for comparison at different levels of analysis.

4) The fourth phase was the phase of writing up. In this phase, the interplay between theory and empirical data was strengthened and combined through a both creative and interpretive mode of thinking (Emerson et al., 1995).

It should be noted that all phases of the analytical process were equally influenced by the specific contents of the empirical data as well as the empirical and theoretical insights established during literature studies. Hence, the analysis was both an inductive and a deductive process.
ETHICAL CONSIDERATIONS

According to the Central Denmark Region Committees on Biomedical Research Ethics, the Act on a Biomedical Research Ethics Committee System and the Processing of Biomedical Research Projects do not apply to this project, as the project does not involve the use of human biological materials (jr.nr:73/2007). This, however, does not mean that ethical considerations are of no importance (Hoeyer, Dahlager & Lynoe, 2005; Oeye, Bjelland & Skorpen, 2007). Research can sometimes create anxiety or worsen an already stressful situation. Interviewing and studying people who have recently been diagnosed with cancer clearly requires careful considerations of its likely effects.

In accordance with the Code of ethics of the American Anthropological Association (http://www.aaanet.org/committees/ethics/ethcode.htm), informants received letters of information and they were verbally informed about the aim of the study. In all aspects of the research process, informants were guaranteed anonymity. Informants were, however, never presented with the concept of ‘patient delay’, nor were they comprehensively informed that the indirect purpose of the research project was to gain knowledge on how to make people respond more quickly to potentially malignant symptoms (see appendix for letters of information). This may to some extent conflict with ethical notions in traditional biomedical research, in which it is expected that informants or respondents are ‘accurately and comprehensively informed’ (Hoeyer et al., 2005).

From an anthropological perspective, it may however, be argued that what is ethically appropriate and inappropriate largely depends on the specific context of the study (Hammersley & Atkinson, 1983:279). In this case, it seemed unethical to present informants with full information on the background of the study. This is not an argument placed in order to legitimize coveryness. Instead, it is argued that the research process and the means through which we conceptualize or present our studies may have an impact on the informants’ wellbeing. Following the advice of Hammersley and colleagues, we carefully situated the ethical decisions within the confines of our study and decided that it was of no importance for the participating informants to lean that they participated in a research study on delayed care seeking. Instead, informants were informed that the aim of the study was to learn of symptom experiences and reflections on care-seeking decisions among cancer patients. This was done to downplay the potentially stigmatizing and worrisome reflections that they had acted deviantly or in some ways were to be blamed for the seriousness of their own situation. The decision to invite family members to participate in the interviews was also made for ethical reasons with a view to ensure that the informant would have emotional and social support during and after the interviews.
REFERENCES CHAPTER 3


CHAPTER 9: CONCLUDING DISCUSSIONS

In this chapter, I present the concluding discussions of the thesis, discuss its methodological shortcomings and make suggestions for future research. Initially, in referring to the research questions given in Chapter 2, I discuss the overall findings of the thesis; how they may contribute to our knowledge on the timing of care-seeking and to our notions of the concept of ‘delay’. Then, I proceed to a brief discussion of the methodological problems of the thesis, and offer suggestions for future research. Lastly, a short conclusion is given.

DISCUSSION OF MAIN FINDINGS

The following is a discussion of the overall conclusions of the thesis; how they may add to our knowledge on delayed care-seeking and inspire future research. Firstly, I discuss how the thesis has contributed to our insight on symptom experiences and then I return to discussing ‘knowledge’ as a magic bullet in patient delay. Secondly, I raise a discussion on social risk, and argue that the facing of illness has a social dimension, which should remind us that merely focusing on recognition of symptoms is a one-dimensional strategy when care-seeking decisions are explored. Thirdly, I return to a discussion on therapy management and the social relations of care-seeking. Fourthly, by referring to the arguments presented in Paper 3 on the relation between health care organisations and care-seeking decisions, I briefly touch on structural dimension of decision-making. Lastly, I discuss the methodological and conceptual challenges presented in the papers of the thesis, and address how they may be met in future research on patient delay.

SYMPTOM EXPERIENCES

Intrigued by the many reports in the patient delay literature of patients delaying care-seeking because they trivialised or normalised symptoms (Smith, Pope & Botha, 2005), this thesis set out to explore how bodily sensations are transformed into symptoms, and how people decide how to deal with them. Overall, the thesis suggests that we think of bodily experience and culture as a continuous feedback relationship where a specific cultural and social context contributes to various expectations and experiences that influence how bodily sensations are understood and acted upon (Hay, 2008; Lock & Kaufert, 2001; Alonzo, 1979; Alonzo, 1984). As explicated in the analyses presented, more than being physical realities to ‘be recognised’, symptoms are expressions of the reality of the patient’s world composed of the specific context and experiences of that person. Bodily sensations therefore potentially signify a range of meanings that are all rooted in the particular context in which they appear, and where most people have access to multiple and often contradictory explanations.
**Box 1: Processes of Containment Presented in Paper 1**

<table>
<thead>
<tr>
<th>Unfolding situations</th>
<th>Life biographies</th>
<th>Life expectations</th>
</tr>
</thead>
<tbody>
<tr>
<td>potentially contain bodily sensations when they conform with culturally suitable explanations related to:</td>
<td>potentially contain bodily sensations when they conform with culturally suitable explanations related to:</td>
<td>potentially contain bodily sensations when they conform with cultural values related to:</td>
</tr>
<tr>
<td>Physical constraints</td>
<td>Risk perceptions</td>
<td>Self image</td>
</tr>
<tr>
<td>‘rectal bleeding was due to changes in work functions and heavy lifts’</td>
<td>‘no cancer in our family’</td>
<td>‘I did not want to be a liability to my family’</td>
</tr>
<tr>
<td>‘back pain was due to work in the garden’</td>
<td>‘I am never ill’</td>
<td>‘I do not want to appear weak’</td>
</tr>
<tr>
<td>‘coughing was due to dust in my daughter’s house’</td>
<td>‘we have strong genes in our family’</td>
<td>‘I am not one of those female hypochondriacs’</td>
</tr>
<tr>
<td>Social stressors</td>
<td>Age</td>
<td>Social obligations and relations</td>
</tr>
<tr>
<td>‘stomach trouble was due to my stressful situation’</td>
<td>‘I thought it was because I was getting old’</td>
<td>‘work ethic’</td>
</tr>
<tr>
<td></td>
<td>‘Such ‘body-noise’ is normal when you get older’</td>
<td>‘my wife was ill’</td>
</tr>
<tr>
<td></td>
<td>Life style choices</td>
<td>‘I had a family reunion to attend to’</td>
</tr>
<tr>
<td></td>
<td>‘I lived a healthy life’</td>
<td>‘I did not want to upset my children’</td>
</tr>
<tr>
<td></td>
<td>‘I have always had a good sense of my body’</td>
<td></td>
</tr>
<tr>
<td></td>
<td>‘I never smoked’</td>
<td></td>
</tr>
<tr>
<td></td>
<td>‘I have not sunbathed that much’</td>
<td></td>
</tr>
<tr>
<td></td>
<td>‘coughing was due to my COPD and my cigarettes’</td>
<td></td>
</tr>
</tbody>
</table>

In Paper 1 this was illustrated in the way that bodily sensations were experienced within the patient’s entire life-world (see Box 1). Current time, as the specific situation, past biographical experiences and life expectations coupled with suitable explanations afforded by culture all influenced whether bodily sensations were interpreted as symptoms in need of professional care or not. Cultural notions related to the process of aging or life style choices thus potentially contained bodily sensations as non-significant and thereby influenced time till care-seeking. Likewise, in Paper 2 it was demonstrated that the act of responding to various bodily changes was negotiated in the context of gendered practices and notions of social risk, often resulting in diverse and conflicting interpretations of ‘what was the matter’.
Overall, it is illustrated that bodily experiences are complex matters in which the conversion of a bodily sensation into a symptom introduces an interpretive dimension that goes beyond the bodily referent. In the words of Alonzo, symptoms should not merely be viewed as physical realities to be 'recognized', but rather as something that "emerge from the interaction of individual bodily sensations and the processes of social objectification or selection interpretation and evaluation" (Alonzo, 1984). In the previous chapters, it has been argued that in explaining and preventing patient delay we should therefore be careful to avoid the shortcomings of the 'knowledge perspective', which is often referred to as a 'magic bullet'. In order to further clarify this discussion and to offer alternative suggestions of how we may approach the issue of patient delay, I will return to discuss the issue of knowledge.

**KNOWLEDGE AS A MAGIC BULLET**

Researchers exploring patient delay have often drawn the inference that delay is caused by a lack of knowledge, and that augmenting people's knowledge of potential cancer symptoms will result in changes in health behaviour (Ruiter, de Noijer, van Breukelen, Ockhuysen-Vermey & de Vries, 2008; de Nooijer, Lechner & de Vries, 2003). In this context, knowledge refers to people’s ‘knowing’ about epidemiological knowledge on so-called ‘alarm’ or ‘red flag symptoms’ as indicative of cancer. As indicated in the papers, such a perspective on knowledge may be criticised for referring to knowledge as an objective phenomena predictive of care-seeking, which one may either possess or not possesses (see e.g. Hastrup, 2004; Garro, 2000).

**KNOWLEDGE IS RELATIONAL**

Without entering the rather complex discussion on what constitutes knowledge and how it is diffuses within society (see e.g. Pelto & Pelto, 1996; Barth, 2004; Good, 1996), I will exemplify in a few words what is meant when referring to knowledge as relational or situated (Hastrup, 2004; Garro, 2000). According to the Danish anthropologist Kirsten Hastrup, knowledge is not an objective phenomenon in the sense that it can be detached from the situation in which it is either produced, communicated or received. Knowledge, she says, is contextual and relational “...both in the sense that it attaches itself to relations between people, or people and objects in the sense that it emerges within a dialogical field” (Hastrup, 2004:456). In relation to the material presented in this thesis, this may be further clarified by returning to the case of Linda who had been diagnosed with malignant melanoma (see Paper 2). Linda had experienced an itchy and growing mole for more than a year before seeking care. During the interview, she tells me that her niece had been diagnosed with this same type of cancer years earlier.
“We have a niece, now she is 34, but when she was 21 years old, she had a mole removed. But she was one of those, you know, who would be in the solarium for an hour at a time. She had the mole removed; actually, in the same place as I had mine removed. After that she has had others removed, and I have talked to her about it, because she has been handicapped in some way because of it. On the back, the doctors had to remove a lot, and some of her nerves were damaged. Well, I guess, I did not think that mine was so serious. I did not sunbathe that much.”

Linda’s husband adds:

“The problem is that she [Linda] was not ill, not like that, you know. One of our friends has been very ill for a while. She lost weight and could not manage anything in the end. If she [Linda] had suffered from a great weight loss or been tired...then you would have reacted, right? This, it was just like a wart that grew and was itchy.”

The excerpts illustrate that: 1) Linda was aware of malignant melanoma, 2) she was aware of cancer risk (sunbathing), 3) her husband referred to alarm symptoms of cancer (tiredness, weight loss). These bits of knowledge on cancer expressed in the interview-situation, however, allowed for them to infer that Linda had not shown clear signs of illness. This illustrates how knowledge inter-relates with specific experiences of bodily sensations (an itchy mole), biographical notions (the story of the niece) and broader risk perceptions related to her life style choices (Linda did not sunbathe that much, but the niece did). To this should be added that a previous presentation of the case informed us that Linda had also discussed the mole with her mother and a friend, which exemplifies that the act of relating epidemiological knowledge on cancer to a personal experience is an interactional process that involves numerous actors and rationales. Linda’s knowledge on cancer was not easily detached from her wider social situation. Before further clarifying how this relates to the problems of referring to knowledge as a magic bullet in patient delay, a discussion of epidemiological knowledge on cancer is required.

THE COMPLEXITY OF CANCER SYMPTOMATOLOGY

The fact that knowledge is situated or relational is further complicated by the complexity of cancer symptomatology. Referring to a lack of knowledge on alarm symptoms as a cause of patient delay is a difficult proposition both because research has suggested that only half of all cancer patients report an alarm symptom when first presenting to their general practitioner (Nielsen, Hansen & Vedsted, 2010), and for the reason that no symptoms have proven exclusive to a cancer diagnosis. Research on cancer symptomatology has illustrated that ‘alarm symptoms’ such as rectal bleeding, weight loss or diarrhoea have a positive predictive value to colon cancer of approximately 1-5% among patients in primary care (Hamilton, Lancashire, Sharp, Peters, Cheng & Marshall, 2009). The positive predictive value of known alarm symptoms to ovarian cancer (Hamilton, Peters, Bankhead & Sharp, 2009), lung cancer
and prostate cancer have proven just as low (Hamilton, 2009b). A person presenting in primary care with a symptom of coughing has for example less than 1% risk of having lung cancer, while haemoptysis indicates a risk of cancer of approximately 3-5% (Shapley, Mansell, Jordan & Jordan, 2010; Hamilton, 2009b) (see Box 2 for a list of alarm symptoms).

- An unusual lump or swelling anywhere on your body
- A change in the size, shape or colour of a mole
- A sore that won’t heal after several weeks
- A mouth or tongue ulcer that lasts longer than three weeks
- A cough or croaky voice that lasts longer than three weeks
- Persistent difficulty swallowing or of indigestion
- Problems passing urine
- Blood in your urine
- Blood in your bowel motions
- A change to more frequent bowel motions that lasts longer than six weeks
- Unexplained weight loss or heavy night sweats
- An unexplained pain or ache that lasts longer than four weeks
- An unusual breast change
- Bleeding from the vagina after the menopause or between periods

**BOX 2: ALARM SYMPTOMS (SOURCE:CANCERRESEARCH.UK)**

While the positive predictive value of alarm symptoms presented in primary care increases when studied in relation to specific age and sex groups (Shapley et al., 2010), it is likely that their predictive value is much lower in the ‘background population’, (Hamilton, 2010), in which we measure and explore causes of delayed care seeking. In reference to rectal bleeding, research has e.g. suggested that a single episode of rectal bleeding has a positive predictive value to colon cancer of 0,1% when experienced in the ‘background population’ while it arises to 2-3 percent when presented in primary care (Hamilton 2010). Hamilton has referred to this increase in risk as the gradient of risk, and it is a clear illustration of the fact that only a minority of those experiencing symptoms ever rightly refer themselves to medical care.

What is more, a recent Danish study has explored the incidence of alarm symptoms related to the breast, the lungs and the digestive system. This study demonstrated that approximately 15% of the adult Danish population experience an alarm symptom within one year (Svendsen, Stovring, Hansen, Kragstrup, Sondergaard & Jarbol, 2010). Only a small minority of these are expected to develop a cancer disease.

The fact that alarm symptoms have a low positive predictive value, that they are widely distributed within ‘the healthy background population’ and that an estimated 50% of all cancer patients report an unspecific symptom as the onset of their cancer feeds into the wider discussion of knowledge as relational (Garro, 2000, Hastrup, 2004) and
consequently to the status of ‘knowledge’ as a magic bullet in explaining patient delay. Epidemiological knowledge is numerically accumulated knowledge, established at the level of populations (Gifford, 1986). Alarm symptoms on cancer thus provide quantified probabilities on the risk of having a particular cancer given that one experiences a given symptom. This coupled with the fact that knowledge is relational or situated illustrates that knowledge on cancer epidemiology does not easily translate into the level of the individual. Rather it demonstrates:

1) The challenge faced by the individual person in deciding whether he or she may be experiencing a malignant symptom in need of professional care (when is rectal bleeding or coughing a potential symptom of cancer in need of professional care?).

2) The simplicity inherent in the argument that a lack of knowledge causes patient delay (when did a given patient ‘wrongly’ interpret coughing, tiredness or an itchy mole as non-significant?).

That knowledge on cancer epidemiology does not easily translate into the level of individual people's life-worlds may improve our understanding of the general inconclusiveness of cancer awareness campaigns (Simon, Waller, Robb & Wardle, 2010; Austoker, Bankhead, Forbes, Atkins, Martin, Robb et al. 2009). The discussion brought forward here on the complex relation between epidemiological knowledge on cancer and bodily experiences is, however, not raised in order to denigrate the fact that knowledge on cancer may be an important prerequisite for improving time to diagnosis in general. It is brought about in order state that simply referring to knowledge as a magic bullet in explaining patient delay is an act of simplification that obviates the need to go beyond knowledge strategies in exploring the wider social and cultural context of care-seeking.

Only few studies have explicitly explored how knowledge on cancer is mediated by the specific context in which it is applied (Sheikh & Ogden, 1998). In order to learn more about bodily experiences and how they relate to knowledge on cancer symptoms and care-seeking decisions, we may benefit from engaging in more prospective studies on how bodily sensations are experienced and interpreted as symptoms in need of care-seeking.
Summing up: Symptom experiences, knowledge and patient delay

- Bodily experiences are embedded within a wider social and cultural context, which may contain bodily sensations as non-significant and negatively influence time till care-seeking.

- Knowledge is relational and there may be considerable variability and flexibility in how epidemiological knowledge on alarm symptoms is related to bodily sensations.

- Cancer symptomatology is complex. The low positive predictive value of alarm symptoms and the high prevalence of symptom experiences in the background population make it difficult to properly translate epidemiological knowledge on cancer symptoms into subjectively useful knowledge.

- We should be cautious to conclude that people delay care-seeking because they lack knowledge about symptoms to which they should respond.

Suggestions for future research

- In-depth field studies on how bodily experiences are embedded within local life-worlds would prove beneficial in providing us with further information on how people experience bodily changes and how sensations are transformed into symptoms in need of care (see e.g. Lock & Kaufert, 2001; Leder, 1999).

- In order to further clarify the role of knowledge in care-seeking decision-making, studies on ‘knowledge’ and how epidemiological knowledge on alarm symptoms diffuses and integrates in people's everyday life experiences would prove instructive (see e.g. Garro, 1998; Barth, 2004).
The issue of social risk recurred throughout the papers presented and therefore deserves to be further discussed on its own. The issue was approached differently in the papers of the thesis, and before entering a wider discussion, I will briefly offer a few clarifications. The concept is defined by Marc Nichter as risk to social relations and social identity (Nichter, 2002:82). Overall, in the thesis, the concept is used to refer to a process where the facing of illness is conceived by informants as a process of social de-stabilisation, where change is brought on one’s sense of self and where the current order and meaning ascribed to social relationships are at stake.

In exploring the social relations of therapy management in Paper 2, I argued that gendered practices and notions of social risks medicated advice given on care-seeking. The analysis illustrated that social relations are important means through which bodily experiences are made sensible and for deciding what to do about it. More importantly, however, it was argued that the notions of social risk placed restraints on how others were allowed to function as triggers of care-seeking. The facing of illness was referred to by some as a process of de-socialization that endangered one's social identity and relations with others. In continuing to act like a healthy person, the individual retained the status of a healthy person.

In Paper 1 the issue of social risk was indirectly referred to in discussions of life expectations such as social obligations and self-image, and how they contained bodily sensations as non-significant. For some informants, the process of interpreting bodily sensations as symptoms of potential illness implied a change in conduct, and identifying oneself with potential illness was seen as a disintegration of the different tasks and opportunities which constituted their lives. That is, the act of facing illness was considered a process of marginalisation and social exclusion which influenced care-seeking decisions.

Throughout the literature, it has been widely documented that illness has social implications (Kleinman, 1987; Whyte, 1997) and that it threatens people’s integrity and sense of self and the body (Charmaz, 1995; Radley, 1989). Cathy Charmaz, e.g., illustrated that suffering in the form of facing illness is a moral as well as a physical experience. She argues that the status of being ill confers relative human worth, and often illness equals social devaluation (Charmaz, 1995; Charmaz, 1999). This corresponds to how informants in our study revealed experiences in facing potential illness, and the thesis suggests that one need not be a patient in order to cautiously explore the social consequences of illness. Notions of social risk related to illness may influence the timing of care-seeking. Let me further clarify this by briefly discussing the case of Erik, a 62-year-old man soon to be retired, a busy business manager who had been diagnosed with malignant melanoma. Erik’s wife participates in the interview, and according to her, Erik had had a growing mole on his back for two years, and before he showed it to his GP, his wife had encouraged him on several occasions to contact a
medical professional. Erik contested his wife's interpretation, claiming that the mole
had neither been as big as she said, nor that it had been growing for a very long time.
Erik presented the situation like this:

“Well, it was not that big a deal. I did not think it was important or that I
was ill. I was feeling fine! His wife interrupted and said: “Yes, well, and you
agreed that you would see your physician once you stopped working and
when we had moved to another house. But all the time you kept putting it
off.” Turning towards the interviewer, she continued: “He was all into his
work – he just would not listen.”

After the interview, we were in the hallway and on his own initiative Erik
continued our discussion on how he had approached is his illness. He said:

“Well, one has to be careful not to become a liability to one’s surroundings.
I have decided to see things from a positive angle. I do not want this [the
cancer] to put my life on a standby.”

Overall, these findings show that responses (such as care-seeking) to bodily sensations
are not simply determined by either the nature of symptom experiences or individual
motivations. Rather, they combine with culturally defined values, where the facing of
illness for some people seem the opposite of being able to fulfill obligations, upholding
social relations and retaining a warranted social identity. As concluded in Paper 2 on
therapy management, the aspect of managing when experiencing potential illness is
twofold: it is equally a question of managing therapy (deciding whether to go to the
doctor or not) and a matter of managing the social risks imbued by the facing of
potential illness.

The discussion on social risk thus adds to the argument placed above: that a sole focus
on recognition and knowledge of alarm symptoms as a means of improving patient
delay is a one-dimensional strategy that neglects the fact that illness experiences have a
social dimension. How people respond to bodily changes is not limited to the
experience of the individual, nor is it based on experiences related to the material body
alone. Rather, in accordance with Kleinman:

“[…] we experience symptoms not just with sensations of pain, but with
unsettling questions of bafflement and suffering that are freighted with
feelings, beliefs and relationships that cannot be divorced from sickness
because they are integral to psycho-physiological processes constraining
both the course of the disorder and the response to treatment” (Kleinman
1982).

That the facing of illness is influenced by notions of social risk gives us important
information about the logic of care-seeking. Early research on patient delay has
occasionally suggested that people who do not seek health care act irrationally (Aitken-
Swan & Paterson, 1955). This inference stems, in part, from the assumption that people
ought to think in medical terms (Radley, 1994), and from a particular perspective on
rationality as being structured solely on experiences of the material body (Good &
Good, 1981). However, the fact that the facing of illness is imputed with notions of social risk explicates that ‘not responding to sensations’ may be regarded a pragmatic, even rational, responses to a perceived life change. Current strategies in preventing patient delay have often been occupied with raising people’s awareness of cancer and with discussing how we may ensure that people recognise potential alarm symptoms. Care-seeking decisions, however, are influenced by notions of social risk which should inform us that we may just as well benefit from examining how to improve people’s readiness to face illness. How may we downplay or limit the social consequences of facing illness? In order to answer such questions, it would prove fruitful to further explore the cultural values or the meanings attached to illness experiences (Herzlich, 1995).
Summing up: Social risk, care-seeking and patient delay

- The process of facing and dealing with potential illness is related to notions of social risk, which may negatively influence time till care-seeking.
- The act of delaying seeking care is therefore not necessarily an act of irrationality, but a pragmatic response to a perceived life change.
- Symptom recognition is not the only prerequisite of care-seeking. Care-seeking is equally a matter of 'being ready' to face illness.

Suggestions for future research

- It would prove beneficial to study the wider social constraints of facing illness and how they are reproduced at macro-level. How do work ethics, a political focus on production and various forms of body technologies influence the way people respond when experiencing bodily sensations and facing illness? (see e.g. Lupton, 1993; Lupton, 2003; Shilling, 2002).
- Moreover, in-depth interviews on the meaning of illness in general and cancer in particular (Herzlich, 1995; Sontag, 1983) would provide us with further knowledge on the value structure framing illness behaviour and the patient role.
THE SOCIAL RELATIONS OF CARE-SEEKING

So far, it has been argued that the timing of care-seeking decisions is influenced not only by symptom experiences, but also by notions of social risk. The facing and dealing with potential illness thereby becomes a social event. Turning to discuss matters related to research question two, on the social relations of care-seeking, this point deserves further discussion.

As discussed in Chapter 2, evidence within the patient delay literature suggests that social relations are important mediators of care-seeking. Studies have suggested, on the one hand, that time to care-seeking increases when people disclose information on symptom experiences to someone in their vicinity (Burgess, Ramirez, Richards & Love, 1998) and, on the other hand, that others such as partners or colleagues (Facione, Dodd, Holzemer & Meleis, 1997) and GPs may act as ‘barriers’ of care-seeking (Robb, Stubbings, Ramirez, Macleod, Austoker, Waller et al. 2009). The social interaction preceding the decision to seek care is, however, often ‘black boxed’ within the literature. In order to further explore how social relations mediate care-seeking, this thesis set out to explore how care-seeking decisions were negotiated in the patient’s wider social and cultural context. This subject was particularly touched upon in Papers 2 and 3, the findings of which will be discussed below.

THERAPY MANAGEMENT

Through a focus on therapy management groups (Janzen & Leslie, 1978) Paper 2 in correspondence with other studies suggests that social relations are important means through which bodily experiences are made sensible and for deciding what to do about it (Kleinman, 1980; Hay, 2008). The therapy management groups in our material mostly consisted of closely connected people such as family, close friends, colleagues and neighbours, and overall, the interaction between therapy group members took place on a continuum between presenting diffuse interpretations on ‘what might be the matter’ to placing direct and explicit pressure to consult medical professionals.

More importantly, however, it was argued that health care decisions do not occur in isolation from other forms of social action; and how others mediate care-seeking decisions is restrained by contextual elements. In Paper 2 this was exemplified by the way gendered practises and notions of social risk (Nichter, 2002) influenced how therapy group members interacted.

Firstly, in line with social constructivist approaches to gender, it was suggested that illness-related practices are a means for demonstrating masculinities and femininities (Courtenay, 2000). That is, gender is something that is ‘done in daily interactions’ where illness-related practices are used in the social structuring of gender, and where masculinities are often constructed in opposition to the health-oriented beliefs and behaviours of women. By large, men and women therefore go through different decision-making processes where men to some extent rely on women
to be active in challenging care-seeking decisions, and where women more frequently take part as active therapy group members than do men.

Secondly, in line with the discussion raised above, the paper suggests that one need not be a patient in order to cautiously explore the consequences of illness. The process of facing potential illness has a bearing on relationships and social identity, and decisions to seek care are taken in consideration of and in dealing with social risks. Not responding to advice given or wanting to go to the doctor may represent a case where, in the words of Marc Nichter, social risks eclipse physical risk (2002). In continuing to act like a healthy person (e.g. not going to the doctor), the individual retains the status of a healthy person.

Let me further clarify this by presenting the case of Charles. Charles is divorced and lives alone in a small apartment. He is 70 years old, and he has three grown up children, a son and two daughters, who all live in close vicinity to him. He is trained as a manual worker and works as a caretaker at a residence for handicapped. Charles had experienced what he called ‘stomach problems’ such as varying degrees of constipation and bloatedness for more than a year before he went to see his GP. In exploring with whom he had interacted prior to his care-seeking, he told me that his ex-wife had recently passed away due to cancer, and that he had not told any of his children that he had experienced ‘stomach trouble’. Asked why he had not told his children he says:

"Because at first I did not really think it was anything serious. I thought it was my ulcer that had come back. I have been taking strong medications for years, and figured that also played a part. And I know that they [the children] had enough on their minds. But, you know, I did joke with some colleagues about it. I told them that they had to make me a separate toilet, because I had to go so often (laughs). The last two months I was running a lot. But they [the colleagues] were also really surprised when they learned that I was actually ill."

Asked what had eventually prompted him to seek care, Charles told me that it was one of his neighbours who had encouraged him to go.

"Well, I do not know exactly how we started talking about it, but one day I was sitting with some of my neighbours in the garden. I told them that I had to visit the toilet at least five times in a day. “Then something is the matter”, the lady next door told me. “Go to the doctor”. Yehh, yehh, I thought. I have not visited my GP for years. I think some people go too often. One should not show up down there for just anything, right? So I did not do anything. But then a few days later I ran into the lady again, and she asked me if I had done something about it. "You must”, she said. Then I contacted my GP."

After the GP had referred Charles for further investigation, he eventually told one of his daughters and his son that he was ill. The youngest daughter still did not know anything when he was interviewed. "I still want to spare her, he said”.

From this brief example we learn that the determination of whether one is ill or 'ill enough' to seek care takes place in a relationship that is more complex than an
individual judgement about a specific bodily sensation. First of all, to some extent Charles is selective about whom he includes in his therapy managing group. He shares information with his colleagues who do not intervene, but he refrains from sharing anything with his children, because they have just lost their mother. Also, he considers what constitutes legitimate reasons for the use of the health care system, as he does not want to be identified as someone who ‘runs too often’. In the end, his female neighbour triggers his final decision to seek care. As we have no direct observations of how Charles interacted with his colleagues, it is difficult to define whether gendered practices were at stake here; however, as in the above cases, it was a woman who took the leading part in the therapy management group. Moreover, Charles’ strategy of not-involving his children and his reflections on health care use indicate that notions of social risk guided how the therapy managing group was allowed to interact.

The analysis thus illustrates that decision-making a highly relational phenomenon, and adds to our knowledge of why so many patient delay studies have pointed to the importance of social relations in mediating care-seeking decisions (Smith et al., 2005; Gascoigne, Mason & Roberts, 1999; Scott, Grunfeld, Auyeung & McGurk, 2009). However, it also alerts us not to draw premature conclusions on the use of social relations. The case of Charles and the argument presented in Paper 2 illustrates that social relations are not ready-made structures with distinct functions. They may both directly and indirectly trigger or restrict individuals in decisions to seek care (see also Alonzo, 1986). In order to improve time till care-seeking, we may further explore how the social and cultural contexts mediate social relations as triggers. How does work ethics and a focus on productivity influence how colleagues may function as triggers of care-seeking? How are gendered practices played out within households and families and how does that influence time till care-seeking?
Summing up: Social relations of care-seeking

- Social relations are important means through which bodily sensations are made sensible and for deciding what to do about them.

- How therapy managing groups interact is mediated by wider social and cultural processes; here exemplified by notions of social risk and gendered practices.

- Social relations are therefore not to be regarded as ready-made structures with distinct functions.

Suggestions for future research

- In order to learn more of how social relations mediate care-seeking decisions, it would be beneficial to further explore what ‘triggers’ care-seeking. This could be done by carrying out field studies in primary care, interviewing patients in the waiting room and observing GP-patient consultations (see e.g. Zola, 1973).

- Such a study would profit from being supplemented with in-depth case-studies exploring therapy management groups, and how care-seeking and wider treatment decisions are negotiated in the social context of the patient (see e.g. Janzen, 1987; Nichter, 2002).

- In order to learn of care-seeking decision-making, field studies based on household surveys, observations and interviews on illness episodes would be informative in developing decision-making models (see e.g. Garro 1998)
HEALTH CARE ORGANISATIONS AND CARE-SEEKING

As discussed in Chapter 2, negative attitudes towards the GP may influence the time of care-seeking (Scott et al., 2009). A recent English study for example reported that 'worry about wasting the doctor’s time' is a barrier to care-seeking (Robb et al., 2009). In the interviews exploring how care-seeking decisions are negotiated, informants were asked to reflect on experiences with their GP. On this basis Paper 3 raises the following hypotheses: 1) Gatekeeping introduces an asymmetrical relationship between the patient and the GP which potentially results in self-restricting health care-seeking. 2) Continuity in the doctor-patient relationship may negatively influence patients’ reflections on their access to health care, because the focus potentially shifts from the medical issues of the consultation to reflections on how to properly interact with the GP and the system in which s/he is situated.

These findings are presented as hypotheses, because interview material on patient experiences alone does not offer sufficient material for analysis of interactions of the kind taking place in general practice. Patient interviews are representations of patient experiences and they do not fully allow us to go beyond the individual perspective, nor to take account of either the GPs’ actions or the implications which the wider organisational structure have for interaction and care-seeking decisions (Shilling, 2002).

The material, however, did remind about the need for exploring not only the relation between the GP and the patient as indicative of care-seeking decisions, but also the complementary role structure between GPs, patients and the wider structure of health care system (Shilling, 2002). In much research on patient delay or GP-patient interactions, health care organisations appear as if they were little more than backdrops against which action is negotiated (Pappas, 1990). In order to understand why people have been reported to ‘worry that they waste the time of their GP’ (Robb et al., 2009), we need to explore what structures the GP’s time (financial settlements, work load, organisational arrangements?), and how interaction with patients unfold within these structures. In order to further understand how health care organisations influence patient-perceived access to health care, future studies should explore the organisational context of care-seeking decision-making.
Summing up: Health care systems and patient delay

- Gatekeeping introduces an asymmetrical relationship between the patient and the GP which potentially results in self-restricting health care-seeking.

- Continuity in the doctor-patient relationship may negatively influence patient reflections on access to health care, as the focus shifts from the medical issues of the consultation to reflections on how to properly interact with the GP and the system in which s/he is situated.

- There is a complementary role structure between GPs, patients and the wider structure of health care system, which may influence care-seeking decisions.

- Merely focusing on the patient in order to understand care-seeking decisions draws away attention from issues such as power and social control in the clinic, but also from wider societal issues such as the economic and organisational structure of health care.

Suggestions for future research

- In order to learn more about how health care systems structure care-seeking decisions, it would be fruitful to conduct field studies in the health care system; observing GP-patient interactions, interaction and information-sharing between first and secondary care, and interviewing staff/GPs. Inspired by organisational theory, such an approach would help us explore the organisational logic or the culturally preferred patterns guiding interaction and influencing how patients come to think of access to health care.
Having discussed the research questions raised in this thesis in relation to symptom experiences and care-seeking decisions, I will now turn to discuss the last research question examined: how anthropological perspectives may contribute to the ongoing conceptual and methodological discussions on patient delay in cancer.

Overall, the thesis suggests that current approaches to measuring patient delay are invalid, as they have adopted an empiricist view on symptoms as objective clinical realities (Good & Good, 1981), and that the normative concept of delay may not be relevant from the patient’s perspective. The problems will be discussed below.

**MEASURING PATIENT DELAY**

As illustrated in both Papers 1 and 5, there is no simple relation between how people experience bodily sensations and how in retrospect they define these sensations as symptoms related to a specific cancer. Rather, we may be measuring differences in response to bodily sensations and symptoms, and how these are retrospectively linked to specific cancers. We should therefore be cautious to conclude that respondents report delay periods in identical ways. In order to improve the validity of patient delay studies, it was suggested that research be strengthened on three counts: More research should be devoted to symptom interpretation processes, more research should seek to operationalise patient delay, and, importantly, more research is needed to develop valid instruments for measuring patient delay. Below, I will return to discuss why we need more studies on the symptom interpretation process. In so doing, I will briefly develop on the issue of operationalisation and measurement, as some of the issues discussed above may further clarify the roots of these problems.

Operationalisation refers to a process of making abstract notions measureable in the way that they are sensible to informants (Bernard, 2006). When measuring patient delay, we measure a time period, beginning with the time of first symptom and ending at the first presentation to the GP/health professional. While there may be problems with recall bias when estimating the date of first presentation to the GP/health professional (Scott & Walter, 2010), no difficulties arise in the attempt to make the concept sensible and measurable in the sense that all informants may easily understand what is referred to. The problem of measuring patient delay, I will argue, is primarily related to the issue of defining the time of the first symptom.
Based on the discussions raised above, the difficulties related to defining *first symptom* are rooted in the following complex, interrelated issues:

1) Defining first symptom is an act of interpretation
   a. Symptom experiences are embedded within the wider social and cultural context of the individual. People may define ‘first symptoms’ differently.

2) Cancer symptomatology is complex
   a. The positive predictive value of ‘alarm symptoms’ is low
   b. The incidence of alarm symptoms in the healthy population is high
   c. Half of all cancer patients present with unspecific symptoms.

Consequently, cancer diseases may represent with a large variety of symptoms many of which are widely distributed in the healthy population. Moreover, given the low positive predictive value of alarm symptoms, epidemiological knowledge translates poorly into the realm of the individual. These facts are further complicated because people may differently interpret bodily sensations as symptoms related to cancer. The problems may be further clarified by discussing Figure 6.

**FIGURE 6: HOW DO WE DEFINE FIRST SYMPTOM?**

Figure 6 illustrates the symptom trajectory of a figurative lung cancer patient. At some point in time, the lung cancer starts to develop (biological time). This may or may not be noticeable to the patient. After a while the patient experiences back pain, but does not interpret it as a symptom in need of treatment, as he is able to manage with pain
killers. Moreover, he has previously experienced back pain, and attributes the pain to
garden work. ‘At age 72, this is what can be expected’, he reflects. After two weeks, the
back pain disappears, but now he starts to cough more intensively than his cigarettes
usually cause him to do. Finally, he experiences haemoptysis and increasing problems
of dyspnoea. He seeks care after two weeks with haemoptysis and dyspnoea.

The figure illustrates the different time points present in an illness trajectory
which may all influence how the time of first symptom is retrospectively reported. In
respect to the discussion on interpretation presented above, we may not foresee how
the patient in retrospect will report on his delay period. Will he report back pain as his
first symptom, or perhaps consider to report the time when he experienced that his
coughing worsened (retrospective time)? Or will he merely relate his experiences with
haemoptysis and dyspnoea to his lung cancer, the symptoms that in current time made
him reflect on his health? Dependent on what he chooses to do (he may equally refer to
a series of other experiences, unrevealed to the researcher), we may assess a delay
period ranging from several months to two weeks.

Relying on patient-estimated delay is difficult. Given the complexity of defining
the first symptom as referred to above, it could be argued that patients are asked to
think in medical terms. In order to operationalise and improve the validity of patient
delay measures, it is pertinent to discuss whether estimates based on clinical relevance
or rationales would be more appropriate? The objective of monitoring patient delay is
to improve cancer prognosis. In order to do so, we need to make sure that the
estimated time periods received have some clinical relevance. In the words of physician
Makeover; we need to discuss from which point it is reasonable ‘to make the clock tick’
(420:1963).

Time is an important factor in cancer prognoses, and there are weighty medical
reasons for monitoring time till care-seeking (Olesen, Hansen & Vedsted, 2009). But we
need to carefully consider how we operationalise and measure patient delay. The
above serves as an overall discussion on cancer, and it therefore has its drawbacks.
Given the differences in cancers and their symptomatology, the problem of
operationalisation may accordingly present itself to a variable extent (perhaps it is
easier to operationalise patient delay in breast cancer than in prostate cancer?). Suffice
it here to say that, in order to access valid measures of patient delay, future research
should approach these issues in more depth.
THE CONCEPT OF PATIENT DELAY

Besides from touching on problems related to measuring patient delay, the present thesis also suggests that the term delay may not be an appropriate concept when viewed from the patient’s perspective.

DO DELAYERS BEHAVE IMPROPERLY?

As illustrated, the social and cultural frame of understanding bodily sensations (as exemplified in notions on aging and risk perceptions) does not arise in the moment people experience bodily changes, but is there in the apprehension of bodily changes themselves, because the understanding of bodily sensations takes place in a complex interface between a particular person’s cultural context and illness experience.

Coupled with the complexity of cancer symptomatology (Hamilton, 2009b), the fact that only half of all cancer patients represent with a so-called alarm symptom (Nielsen et al., 2010), and the wide distribution of symptom experiences in the healthy background population (Svendsen et al., 2010), it is clear that in some cases only a retrospective perspective may allow for a definition of a delay period. Two people could have experienced identical bodily sensations, but only the one eventually diagnosed with cancer is at risk of being classified as a delayer. The other patient, we would say, had practiced watchful waiting, or rightly attributed rectal bleeding to haemorrhoids or tiredness and pain in the abdomen to stress. Delay is a normative concept, implying that someone behaved improperly (Corner, Hopkinson & Roffe, 2006). When retrospectively identifying someone as having behaved improperly, we need to be able to define clear criteria for proper behavior, which the discussion raised above implies may, indeed, be difficult. It is therefore reasonable to suggest that the term delay is not appropriate viewed from the patient’s perspective.

DELAY AND SOCIAL RISK

Another inappropriateness of the concept of delay lies in the understanding of and action taken on symptoms which combine with notions of social risk.

The act of facing illness has a social dimension that cannot easily be separated from experiencing bodily sensations and determining what to do about them (Charmaz, 1994; Kleinman, 1987). This complicates the process of making sure that people behave 'properly' in a situation of potential illness, and it challenges normative notions inherent in the patient delay literature, which places a sole focus on the material body of the individual as an indicator of proper behaviour. Patient delay, in its current form, it could be argued, tends to focus on the individual's responsibility as it were free of social constrains. Knowing that the facing of illness for some people seems to be the opposite of being able to fulfill social obligations, upholding social relations and retaining a warranted social identity, we need to consider whether we risk adding insult to injury when using the concept of delay in exploring time till care-seeking among cancer patients. As stated in Chapter 1, there are ongoing discussions in parts of
the delay literature exploring alternative concepts. ‘Time till care-seeking’, ‘time-intervals’ or ‘decision time’ have been suggested (Corner et al., 2006; Scott & Walter, 2010). There is currently no agreement on what is the appropriate term to use, and future discussions need to take this subject further.

The argument presented – that the concept of delay may not prove relevant from the patient’s perspective – is not placed in order to denigrate the fact that time till care-seeking is important in cancer prognosis. Nor is it presented in ignorance of the suffering an advanced cancer diagnosis may bring on the individual patient and his or her surroundings. The argument is placed in an attempt to initiate a more critical and context-sensitive discussion on the issue. We need to consider whether we, by simply referring to the material body and the responsibility of the individual as a ‘gold standard’ in defining proper behaviour are placing the bar too high. We need to integrate within our discussions on patient delay considerations on when and on what terms it is reasonable to expect that people respond to bodily sensations as potentially malignant and decide to seek care.

**Summing up: Methodological and conceptual discussions**

- Patient delay is difficult to measure. Symptom experiences are embedded within the wider social and cultural context of the individual. People may therefore define ‘first symptoms’ differently.

- The understanding of bodily sensations happens in a complex interface between a particular person’s cultural context and illness experience. Coupled with the complexity of cancer symptomatology, this means that in some cases only a retrospective perspective allows for at definition of patient delay.

- The act of facing illness has a social dimension that is not easily separated from experiencing bodily sensations and deciding what to do about them.

- Patient delay may therefore not be a relevant concept when viewed from the patient's perspective.

- We need to integrate within our discussions on patient delay when and on what terms it is reasonable to expect that people respond to bodily sensations and decide to seek care.
METHODS REVISITED

In order to explore patient delay among cancer patients, I interviewed cancer patients on bodily experiences and social interactions that had taken place prior to their diagnosis. In Chapter 3, I touched on a series of problems related to the interview as a method for exploring such issues. In order to lay further grounds for discussing future approaches to delayed care-seeking, I will briefly return to discuss some of these issues.

‘WHAT HAPPENED’

In the context of the interview, informants are asked to retrospectively reflect on ‘what happened’. In order to learn of delayed care-seeking, informants in this study were asked to reflect on their bodily experiences, their reflections on these bodily experiences, and with whom they had interacted. Narrative researchers have argued that the act of retrospectively reflecting on illness episodes brings forth connections and interrelatedness that might not have been there at the time of the experience (Mattingly, 1998; Garro, 2000). As stated by anthropologist Linda C. Garro:

“Remembering is reflexive and generative. It may be long after the occurrence of a past experience that it becomes meaningfully connected to a current illness through a reflexive assessment. Relating pre-existing explanatory frameworks to personal experience is also a generative process, involving the linking of the remembered past to plausible interpretations within the framework of possibilities afforded by culture.” (2000:73).

The many reflections on cancer risk and aetiology presented throughout the thesis may be a case illustrating just this. In the interviews, informants often referred to notions of cancer risk as explanations for why they had not considered that they might be ill. While this demonstrates the flexibility with which epidemiological knowledge integrates with people’s ongoing experiences, it also reveals how the unpleasant incident of being given a cancer diagnosis, may restructure reflections on past events (Garro, 2000). When stating that ‘we do not have cancer in our family’, or ‘we have strong genes in our family’ or ‘I have lived a healthy life’, informants may not have been depicting reflections emanating as a cause of the bodily sensations experienced prior to their diagnosis. Rather, these statements may demonstrate that they are in a process of restructuring past events in the light of the recently received cancer diagnosis. We should therefore be cautious to draw firm conclusion based on these statements.
'THE TAKEN FOR GRANTED'

The problem of accessing ‘what happened’ should be seen in the context of a wider underlying problem related to accessing information on social life. As explicated by Bourdieu’s concept of doxa, the logic driving social life is often implicit and taken for granted by the people living it (Myles, 2004). In probing an informant’s reflections and interpretations on bodily sensations experienced prior to his or her cancer diagnosis, the informant was implicitly asked to present reasons for ‘non-action’. The interview material is full of negations like ‘well I was not feeling sick’, or ‘I did not really give it a thought’. One possible analysis of such statements is that informants ‘normalised’ bodily sensations; or in other words, informants did not think of them as significant. While such a proposition may be true, it could, however, also be argued that the negations explicate the difficulties informants experienced in representing past reflections and actions. Social life with all its variabilities and complexities is not accomplished on the basis of a set of rules or cultural recipes easily accessed or reproduced. People may not always know why they do what they do. This has implications for the interview method when exploring reasons for ‘non-action’, and as discussed below, the validity of the data material obtained in the interview may benefit from being supplemented with material generated through other methods.

NORMATIVISM

Lastly, given the interview context, another important issue that needs to be assessed concerns the extent to which informants feel obliged to provide certain kinds of stories, such as those judged to be compatible with me ‘the health worker’ or wider cultural notions on health and illness-related behaviour, which some argue are indicative of status in the modern western world (Shilling, 2002). When exploring care-seeking decisions, informants were asked to reflect on interactions with their GP and how they perceived access to health care. I continually encountered statements such as ‘I will not bother my GP too much’, or ‘one should not seek care too often’. Moreover, the experiences of bodily sensations were often clothed in remarks like ‘I have been living a health life’ and ‘I did not sunbathe that much’. While such statements may reveal something about the value structure of a given society (notions of access to health care and health as indicative of social status), they may not inform us on why this particular person ‘delayed care-seeking’. Rather, normative statements may be used to retrospectively legitimise actions taken and to illustrate that people do know ‘right from wrong’ in matters of illness and health.
FUTURE STUDIES

Given the arguments presented above and the methodological problems related to the retrospective interview as a means of exploring care-seeking, future studies would benefit from exploring symptom experiences and care-seeking decisions using more prospective research designs. One option is to carry out ethnographic field studies based on participant observation, interviewing and in-depth case studies. Such studies could be done in primary care, interviewing people in the waiting room, observing consultations and interactions between GPs and patients. They could be community-based or designed as house-hold studies (Garro, 1998). It is also an option to do field studies in work-places or opt for other institutional affiliations; study age, symptom experiences and care-seeking in high-schools or in old-people’s homes. Using such an approach, we would learn how bodily sensations are experienced in people’s daily life worlds and how decisions concerning what to do about them are established.

IMPROVING VALIDITY THROUGH INCLUSION

Prospective studies such as ethnographic field studies would improve the validity of our analyses, as engagement with informants who have not yet become patients may reduce the risk of collecting normative or restructured information as people’s needs to legitimise actions taken may be lessened by the fact that they have not yet encountered a serious illness.

Moreover, the complexity of cancer symptomatology discussed above served to remind us that retrospective studies may provide us with information on a highly selected group of informants. Symptom experiences are not mutually exclusive to cancer diagnosis, and we may learn more by studying care-seeking at the level of symptoms (Scott & Walter, 2010). The benefits of conducting prospective studies could be exemplified by referring to Hamilton’s studies of rectal bleeding. As already touched upon, Hamilton has illustrated the very effective selection criteria at stake when people experience an alarm symptom such as rectal bleeding. While the positive predictive value of colorectal cancer with a single episode of rectal bleeding experienced in the healthy population is around 0.1%, the risk of cancer rises to 2-3% once bleeding is reported to primary care (Hamilton, 2010). Moreover, only 41% of those who experience rectal bleeding in a life time ever report it to their GP (Hamilton, 2010). This should encourage us to examine the processes at stake when people do not seek health care. By simply focusing on people who have already become patients, we run the risk of focusing on ‘the faults of the delayers’ (Zola, 1973), and we may wrongly identify a line of ‘barriers to care-seeking’. Barriers which may be widely distributed in the healthy background population and which to some extent may serve us right.
IMPROVING VALIDITY THROUGH TRIANGULATION

Besides providing us with other kinds of information on care-seeking, ethnographic field studies, applying a wide range of methods, would provide more valid analyses because information obtained in for example interview material may be triangulated with information obtained through participant observation (Hammersley & Atkinson, 1983). In this way, we are not analytically confined to rely on informant statements, but may instigate analytical inferences based on researcher-established observations, which will allow us to exploring the aspects of social life that are ‘taken for granted’ by the informants (Hastrup, 1992).

CONCLUSION

In the following, I will present the overall conclusions of this thesis. First of all, it was illustrated that the time of care-seeking is influenced by processes of containment and notions of social risk. Bodily experiences are embedded within a wider social and cultural context that may contain bodily sensations as non-significant and negatively influence time till care-seeking. Moreover, the act of facing and dealing with potential illness may be conceived by informants as a process of social destabilisation where change is brought on one’s sense of self and where the current order and meaning ascribed to social relationships are at stake. In continuing to act like a healthy person, the individual retains the status of a healthy person.

Secondly, it was demonstrated that decision-making is a dynamic, interactive process fundamentally intertwined with the structured rhythms of social life, and that time till care-seeking is influenced by social relations and the wider structure of the health care system. Social relations therefore become important means through which bodily sensations are made sensible and they shape decisions on what to do about them. But the wider social and cultural processes mediate how social relations are allowed to function as triggers of care-seeking. Moreover, it was hypothesised that there is a complementary role structure between GPs, patients and the wider structure of health care system that may influence care-seeking decisions. Danish primary care is structured as a gatekeeping system with a comprehensive list system, and this may have a negative impact on how patients reflect on or legitimise care-seeking decisions.

Thirdly, the thesis raised a series of methodological and conceptual issues related to the concept of patient delay. First of all, it was argued that future research needs to address how the validity of patient delay measures may be improved. Secondly, the thesis touched on the appropriateness of the concept of patient delay. It was argued that the concept of delay is a normative concept that may not be appropriate seen from the patient’s perspective. Lastly, the thesis reasoned that ethnographic field studies may further enhance our knowledge on care-seeking decisions and symptom experiences, and hence our knowledge on time till care-seeking in cancer.
REFERENCES CHAPTER 9


[140]


REFERENCES OF THESIS


Bossart, R. "In the city everybody only cares for himself". Social relations and illness in Abidjan, Cte d'Ivore. Anthropology and Medicine 10(3), 343-359. 2003.


Approaching Patient delay and Cancer: Anthropological Perspectives on Concepts and Causes


Approaching Patient delay and Cancer. Anthropological Perspectives on Concepts and Causes


Pockney, P., Primrose, J., George, S., Jayatilleke, N., Leppard, B., Smith, H., Little, P., Kneebone, R., & Lowy, A. Recognition of skin malignancy by general practitioners:


Approaching Patient delay and Cancer. Anthropological Perspectives on Concepts and Causes


# APPENDICES

## INTERVIEW GUIDE

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subtheme</th>
<th>Suggestions for specific questions (operationalisation)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social context</td>
<td>Description of patient’s life prior to diagnosis</td>
<td>Could you (both) tell me about your life? Where were you born? Children? Work?</td>
</tr>
<tr>
<td></td>
<td>Description of patient’s life at time of diagnosis</td>
<td>How would you characterise your life before you were diagnosed with cancer? (Happy? Stressful? Sorrows?)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>How did you think of your health?</td>
</tr>
<tr>
<td>Illness experiences</td>
<td>Patient reaction, symptom experiences</td>
<td>Thinking back – how and when do you think it all started? When did you first notice any changes or discomforts?</td>
</tr>
<tr>
<td></td>
<td>Symptom interpretation</td>
<td>What was your immediate reaction?</td>
</tr>
<tr>
<td></td>
<td>Reflections on care-seeking</td>
<td>What did you think about the changes? Or symptoms?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Did you consider what it might mean?</td>
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<tr>
<td></td>
<td></td>
<td>Did you search for information? Self treatment?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Did you consider seeking professional advice? When?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>What happened during the time when you decided to consult your GP?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Was there any particular reason why you decided to consult your GP at that particular time?</td>
</tr>
</tbody>
</table>
### Social relations

<table>
<thead>
<tr>
<th>Social interactions</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Will you tell me in detail what happened on that day?</td>
<td></td>
</tr>
<tr>
<td>Did you talk to anyone about your symptoms or discomfort before you saw your GP? (your family? Colleagues, neighbors, friends?)</td>
<td></td>
</tr>
<tr>
<td>What happened?</td>
<td></td>
</tr>
<tr>
<td>What was their/your reaction?</td>
<td></td>
</tr>
<tr>
<td>Did they have any suggestions, as to what you should do? Or what it might mean?</td>
<td></td>
</tr>
</tbody>
</table>

### General Practitioner

<table>
<thead>
<tr>
<th>Experiences with GP</th>
</tr>
</thead>
<tbody>
<tr>
<td>What are your experiences with your GP? Is s/he a good GP?</td>
</tr>
<tr>
<td>What is a good GP?</td>
</tr>
<tr>
<td>What do you think your GP can do for you?</td>
</tr>
<tr>
<td>What kinds of problems do you consult with?</td>
</tr>
<tr>
<td>How do you think your GP has handled this situation?</td>
</tr>
<tr>
<td>Will you tell me what happened when you first presented with these symptoms? What did you say? What did the GP do?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Experiences from the cancer investigation/consultation</th>
</tr>
</thead>
</table>

### Care-seeking

<table>
<thead>
<tr>
<th>Decision-making</th>
</tr>
</thead>
<tbody>
<tr>
<td>Will you tell me about another situation, in which you went to see your GP? Why did you go? What happened?</td>
</tr>
<tr>
<td>What kinds of symptoms or discomfort do you typically see your GP about?</td>
</tr>
<tr>
<td>Have you suffered from serious illness before?</td>
</tr>
<tr>
<td>What do you usually do, when you feel ill? Can you give me an example? (friends? Family? Drug-store? Self-</td>
</tr>
</tbody>
</table>
| Complementary treatment | Treatment choice | Have you ever seen other health professionals or complementary therapists when feeling ill? (than your GP)
What about this time, in relation to the symptoms or discomfort you experienced before you were diagnosed with cancer? (Private hospital, zone therapist etc.) |
|-------------------------|------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Treatment expectations  | Trust in treatment | Did you have any expectations in relation to the national health care system? What to expect? How they might help you in case of serious illness?
And what are your expectations to the treatment you are about to initiate/are receiving? |
| The meaning of illness  | Values            | What is a good life to you?                                                                                                                                                                                                                                                                                        |
|                         | Implications      | What are the implications of your cancer illness? How has it changed your life? What do you expect will happen?                                                                                                                                                                                                 |
| Cancer                  | Responses to the cancer diagnosis | Do you know anyone who has been diagnosed with cancer? Were you surprised to learn that you had cancer? Have you considered why you might have become ill? What was your response when you received the diagnosis? |
Ph.d-projekt om symptomforståelse og lægesøgning

Formålet med projektet
I forbindelse med et større projekt om udredning og behandling af kræft, skal jeg undersøge hvad der får folk med symptomer på modermærkekræft til at søge læge.

Hvorfor vil jeg gerne tale med dig?
Jeg vil gerne vide noget om, hvordan folk forstår deres symptomer, og hvorfor man vælger at gå til læge, når man første gang oplever symptomer, der siden hen viser sig at skyldes modermærkekræft.

Hvad spørger jeg om under interviewet?

Hvad kan vi bruge resultaterne fra projektet til?
Ved at få bedre viden om, hvordan folk tolker deres symptomer, og hvordan de reagerer på dem, kan lægerne få bedre indsigt i patienternes forståelse af sygdom og måske forbedre læger og patienters samarbejde. Vi vil også gerne forbedre oplysningsindsatsen om symptomer på kræft, og måske på sigt gøre det lettere at opdage kræft tidligt.

Hvem skal interviewe dig og hvor skal det foregå henne?
Interviewene vil blive udført af mig, Rikke Sand Andersen. Jeg vil ringe til dig for at lave en aftale, og interviewene vil finde sted i dit hjem på et tidspunkt, hvor det passer dig og din familie.

Projektansvarlige
Rikke Sand Andersen, ph.d.-studerende, antropolog
Jens Søndergaard, ph.d., lektor, alment praktiserende læge
Flemming Bro, professor, alment praktiserende læge,
Bjarke Paarup, lektor, antropolog

Har du spørgsmål til undersøgelsen kan du kontakte:
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