

# AIMING FOR THE ORDINARY

Exploring everyday life experiences of bodily sensations and  
symptoms in the Danish middle class

PhD Dissertation

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2016

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**Financial support:**

The project was supported by the Novo Nordisk Foundation and the Danish Cancer Society.

## ACKNOWLEDGEMENTS

Knowing that this part of a dissertation is always the first thing I dig into when opening a freshly printed dissertation, waiting for PhD defence to start, it fills me with awe to write one myself. I have often heard the comment that doing a PhD is a lonely process. My experience of this is quite the opposite, and I am deeply grateful to all the people who has supported, inspired and believed in me along this long and winding road.

First of all, everything I write grows out of the kindness of my informants to generously share pieces of their everyday life with me. Thank you for spending so much time patiently answering my ceaseless flow of more or less meaningful questions, and for welcoming me into your worlds.

The study of this PhD dissertation was carried out during my employment at the Research Unit for General Practice and the Research Centre for Cancer Diagnosis in Primary Care, and I truly appreciate the opportunity to be a part of this lively and ambitious interdisciplinary research environment.

To my supervisors, Rikke, Peter and Mette: Thank you for your enormous patience, encouragement, inspiration, support and, not least, your genuine willingness to always help me with big and small matters. Mette, you ignited the thought in me of doing a PhD in the first place and led me to the Research Unit, which, and I clearly remember this, you described as ‘a good environment’. And you were right. The good environment consists of an open-minded interdisciplinary approach and an ambitious space for doing anthropology within a biomedical setting, also known as Peter and Rikke. Peter, thank you for enduring my anthropological detours, sometimes far away from questions of cancer, and for trusting that I would bring back something relevant and interesting. Rikke, thank you for being always available, kind and calm, for patiently commenting on drafts late at night because I was cutting it close on yet another deadline. You have insistently raised the bar for being an anthropologist in biomedicine – reaching for that bar has made me a better researcher. Thank you. I have learned a lot.

I am also immensely grateful to my supervisor at Harvard, Arthur Kleinman, for granting me the unique opportunity to be part of the inspiring anthropological

and global health community at Harvard University and for mentoring me during my research stay at Department of Global Health and Social Medicine and Department of Anthropology. Thank you, Arthur, for so generously welcoming me and my family and for professional inspiration and encouragement. Your enthusiasm is contagious and will always inspire me to be a dedicated anthropologist. Thanks to staff and faculty at Harvard for interesting discussions and for making me feel welcome. In particular I wish to thank Linda Thomas and Rebecca Grow for making everything practically possible.

The rest of my gratitude I will pour over people who in various important ways have shared the troubles and joys of this part of my life with me. So, here's to my family. To my parents in particular, thank you for always encouraging me to think that I could do whatever made me happy and for your endless support and for doing everything possible to making the last couple of crazy constant writing months a little less exhaustive for us and especially for our children. On that note I also deeply appreciate my mother-in-law's many long trips from Thyholm to take care of Alfred and Marie and for every *frikadelle* and 'grandfather's spaghetti Bolognese' we found in our freezer, making everyday life a little easier.

I also wish here, in a perhaps rather unusual manner, to express my deep appreciation to a very special haematologist who struggles in the background to avoid unnecessary disruptions of my life and the course and opportunities of this PhD. Jesper, thank you for your extraordinary efforts to become as small a part of my everyday life as possible, and for insistently aiming for making my life ordinary in the face of chronic illness.

And, of course, a loud 'thank you' to all my colleagues at the research unit and CaP. And to my fellow knights at 'Riddersalen': I feel so lucky that I have been looking forward to go to work every day because it would just be another day in the company of good friends. I have enjoyed the most fabulous fellowship sharing joys and sorrows, successes and frustrations, intense discussions and great laughs, popcorn, tomatoes, and, once in a while, just a hint of champagne on a Tuesday night. However, one person in particular deserves mentioning: My partner in crime, Camilla, thank you for being in the same boat with me all along. I guess I would have capsized several times without you. I am grateful for your friendship and for all the fun. And, of course, for the many long, loud and very wise anthropological discussions.

At last, my warmest gratitude to my family. Rasmus, other than being my greatest support in all matters, you have been my patient companion in the sometimes challenging journey as a fellow PhD student. I am in particular grateful that you planted the idea of moving to Boston for a while and that we actually made it! Marie and Alfred, thank you for being adventurous and courageous and always trusting that everything will be fine - even when we make you travel to the other side of the world. My proudest moment during this PhD has been watching you two face the challenges of this adventure with an open mind. Thank you for being and for loving. And for so convincingly believing that I am, in fact, a ninja anthropologist! I will do my very best to always remain kind of ninja in your eyes.

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# PREFACE

This dissertation is first and foremost an anthropological attempt to illuminate a question emanating from the realm of biomedicine and public health. The study behind the dissertation is situated in an intersection of different scientific fields sharing the same overall goals and interests in understanding the complexity of cancer in a Danish context in order to reduce suffering due to cancer. In this interdisciplinary intersection I was able to bring my methodological considerations, empirical findings and analytical ideas into play. This, as most researchers working in interdisciplinary environments will know, is not without challenges and epistemological collisions (DiGiacomo, 1999), but at the same time it creates wonder, provocations, curiosity and reflection which all contribute to substantially broaden and challenge the scientific horizons of what can be explored in which ways. Hence, this dissertation is the result of such a horizon-expanding juggling of perspectives, contexts and ways of knowing and producing knowledge. However, it is at same time solidly anchored in anthropology.

Originating from The Research Unit for General Practice and The Research Centre for Cancer Diagnosis in Primary Care, the dissertation is framed within a biomedical and public health scientific context focusing mainly on how to improve cancer survival by reducing the time cancer grows and spreads in the body, unnoticed by patients and healthcare practitioners alike. The primary aim of my study was to provide anthropological perspectives to the question of why people seemed to wait weeks or even months with potential symptoms of cancer before contacting their general practitioner.

Thus marching together with the public health troops to fight cancer with early diagnosis, I took a detour and turned away from cancer, placing myself in and between two analytical contexts; the cancer disease control efforts of public

health policy and research, and the everyday life of ordinary, non-cancer-afflicted (at the moment at least) people of the Danish middle class. This is the position I speak from.

Taking a step back from the cancer agenda to explore the space and time of potential ‘before cancer’ in everyday life is my most central analytical move and provides me with a vantage point to look beyond the cancer agenda and engage critically with public health constructions such as cancer symptom awareness and alarm symptoms from an everyday life perspective. However, my intention is not to question public health research as such, but rather the way we, as society; citizens, patients, researchers, policymakers, healthcare professionals, come to trust and believe in its cultural representations in some reified, unquestionable form. And, while my arguments throughout this dissertation may take a critical stance towards notions of ‘alarm’ symptoms of cancer and cancer symptom awareness, I am by no means suggesting that knowledge of cancer ‘alarm’ symptoms is unnecessary – people are aware of a large amount of symptoms and risk factors and interpret bodily sensations in terms of this knowledge – but I dispute the way we assume causality between symptom awareness and early health care seeking, and the way we do not question the role symptom awareness and alarm symptoms play among healthy people and in the everyday life body.

What I want this dissertation to express, then, is a call for researchers within the field of early diagnosis to expand our explorations from focusing on the specific actions of recognizing a symptom or deciding to call the doctor, to exploring the continuing negotiation and the work of contingencies of what counts as ordinary and extraordinary in the particularities of everyday life, and to reflect on the encounter between public health cancer agendas and ordinary people’s agendas of life. With this detour, far into the banalities of everyday life, it is my hope that this dissertation will be read as a return to, and an anthropological engagement with, my overall public health defined aim with nuances to inspire and broaden our understanding of cancer, healthcare seeking and the experience of sensations and symptoms, thus joining the ranks of interdisciplinary efforts to reduce the sufferings caused by cancer.

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## OVERVIEW OF THE DISSERTATION:

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Chapter 1 introduces and positions the dissertation and its aims in relevant public health and anthropological fields of inquiry. This introductory chapter also includes an elaborate presentation of the field of early diagnosis of cancer and the field of everyday life in the Danish middle class as the two analytical contexts within and between which this exploration is situated. Finally, the introduction briefly presents the overall analytical framework of the dissertation and key analytical concepts. Chapter 2 considers the methodological approaches and implications for the study and presents the ethnographic setting and informants. Chapters 3 to 5 consist of the three papers forming the analytical chore of the dissertation. Chapter 6 draws the main conclusions together and discusses their anthropological and public health implications.

# CHAPTER 1:

## INTRODUCTION

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### ENTERING THE ORDINARY

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Along straight roads with names that are ordered alphabetically lie tract houses side by side with their individual differences in decoration and similarities in construction. The hedges are mostly well-trimmed and cut at a maximum height of 180 cm as determined by the declarations of the neighbourhood. Criss-crossing the area is an extensive network of just as straightly constructed walking paths. There are no pavements along the roads – which indicate that on foot you are meant to use the paths. But it seems like everyone here owns a car. The neighbourhood is characterized by a peaceful and quiet atmosphere. In the middle of the day you do not meet many people here even though many of the inhabitants are retired. The housing style here in one of the largest tract housing middle class residential area in Denmark, frames an everyday life that by most Danes would be stereotyped as ‘typically Danish’. The inhabitants we will meet here are the older generation who has lived here since the 1970’s and 1980’s. Many of them describe how the neighbourhood was just an open, muddy field when they first sat foot here. This is the place in which these people for a variety of reasons chose to settle down and build a home for their families. Inside the walls of these typical 1970’s designed standard houses live families who

are different but nevertheless share the central choice of making this place their home and invest in it their hopes and wishes for their family life and the future.

At one of the houses a smiling woman, Ingrid, waves energetically from the window. She is expecting my visit, opens the door and bids me welcome into a sunlit entrance hall. Without thinking about it I automatically bend down to untie my shoe laces but she stops me and encourages me to keep my shoes on, implicitly expressing that it does not matter that much if the floors get dirty. The house is spotlessly clean, yet Ingrid starts apologizing for not having vacuum cleaned before I came.

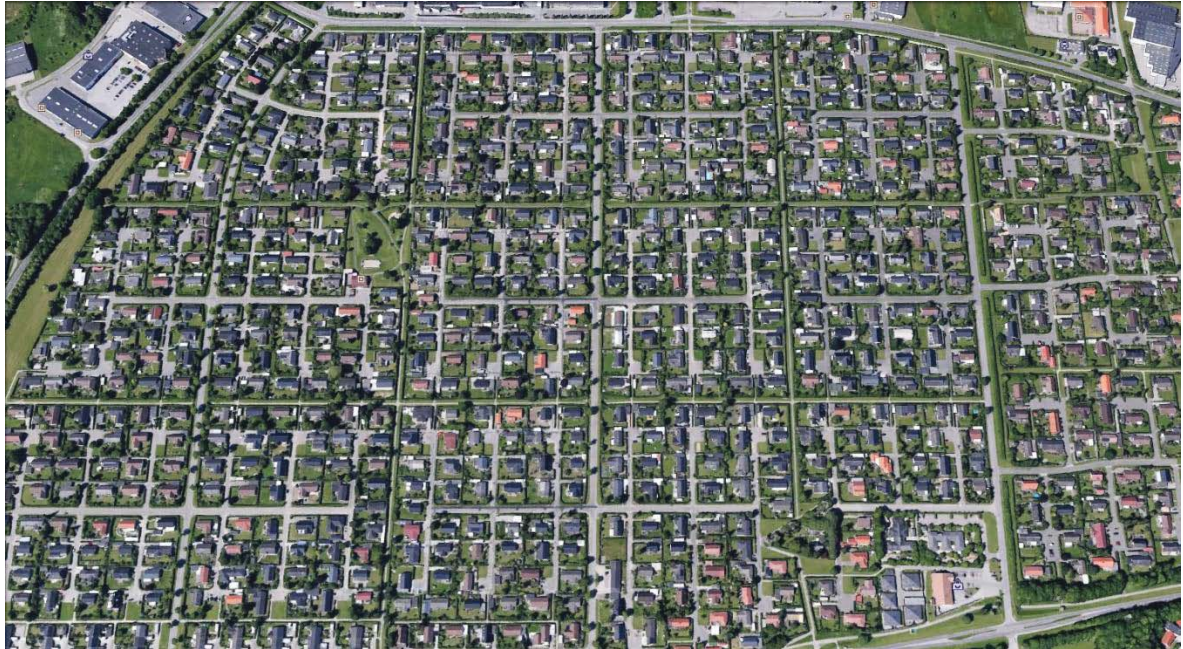
During fieldwork I was surprised to be repeatedly bewildered about the ‘shoe matter’. Should I really keep my dirty shoes on inside the houses of my informants where I in most cases gradually felt less like a formal visitor and more like a friend of the family casually stopping by? As a native Dane my cultural autopilot reached for the shoe laces immediately after entering the front door. As an anthropologist my bewilderment became one step among many in my efforts to understand Danish middle-class everyday life beyond my own cultural autopilot and to ‘descent into the ordinary’ as suggested by Veena Das (Das, 2007) to uncover how illness and health is lived in this particular context; in cultural, historical, sensorial, social, political and biological ways.

Marianne Gullestad observed in her study of everyday life in Norway in the 1980’s<sup>1</sup> that cleanliness and neatness are important cultural values among the Norwegian middle class women. However, it must be balanced between not being obsessive about it and not keeping the home too dirty or messy (Gullestad 2001:117). In a similar vein, Beverly Skeggs also notes how entering a house of someone striving to consider themselves middle class is met by apologies which underline how a middle class home should look like (Skeggs 1997:90). In Ingrid’s entrance hall, as well as in numerous halls in the neighbourhood, the tension between the effort put into the appearance of the house and the downplayed importance of keeping the floors clean by the invitation to keep the

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<sup>1</sup> Gullestad’s informants were young adults in the early 1980’s and thus had more or less the same age as the informants in this study at that time. This is relevant for the comparison of moral values based in historical aspects of the everyday life.

shoes on and the apologies for not having vacuum cleaned a not really dirty floor, roughly sketches a similar balancing that ‘aims for the ordinary’.



The neighbourhood from above. Photo from Google Earth © Google

Quite a distance from these seemingly trivial matters, this study departs in questions related with early diagnosis of cancer; questions such as why people seem to wait several weeks or months with potential symptoms of cancer before presenting them to a health professional or how a bodily sensation is experienced as a symptom or interpreted as something to worry about in everyday life, form the background of the study. In this regard, the question of wearing shoes or not may seem off track. However, as the aim of the ethnographic study behind this dissertation was to explore how the experience of sensations, configurations of symptoms and decisions of healthcare seeking are embedded in everyday life, thick descriptions of the everyday are necessary to understand this embeddedness (cf. Geertz, 1993). As I also argue in chapter 4 it is central to the aim of this thesis to understand how the ordinary body is experienced in terms of its ordinariness and not only of its irregularities, and I would further argue that we miss the point in qualitative health studies if we neglect attending to the ordinary and the both subtle and explicit efforts made to negotiate and sustain subjective, cultural and bodily ordinariness. A similar call is made by Jason Throop to



supplement retrospective, reflective and coherent accounts of experience with an ethnography that focuses on capturing the often pre-reflective, real-time unfolding of social action (Throop, 2003). Thus, by letting the title of my dissertation take form through this quotidian and banal illustration of an ‘aiming for the ordinary’ in everyday life, I wish to draw attention to the centrality of banality and detail when we wish to uncover the significances of the ordinary and thus how the extraordinary such as bodily changes is endowed with significance in everyday life. The transformative process between experiencing a sensorial change in the body and organizing and articulating it as a symptom is a subtle kind of liminality which nuances I have set out to explore in this dissertation influenced by anthropological emphases on the ambiguities, disjunctures, gaps, absences, contradictions and uncertainties of everyday life experience (Arthur Kleinman, 1997c; Throop, 2003, 2010) and by attending to how people aim for the ordinary in socially embodied ways. It is important to stress, though, that I am not implying that the Danish middle class live something that can be termed ordinary lives. The life stories my informants told were far from a similarity that can be described as ordinary. Thus, I am not interested in the ordinary *per se* but in the aiming. I am interested in how the ordinary moves in people’s lives and how bodily ordinariness, and hence bodily extraordinariness, follow suit (Das, 2015; Kirsten Hastrup, 2004).

Kathleen Stewart has described the ordinary as an animate circuit of surging intensities where ordinary affects creates significances in everyday life. ‘The ordinary’, she writes, ‘is a circuit that’s always tuned in to some little something somewhere. A mode of attending to the possible and the threatening, it amasses the resonance in things. It flows through clichés of the self, agency, home, a life’ (Stewart 2007:12). She advocates a slowing down of ‘the quick jump to representational thinking and evaluative critique long enough to find ways of approaching the complex and uncertain objects that fascinate because they literally hit us or exert a pull on us’ (ibid.:4). In my focus on the subtle and vague differences between bodily ordinariness and abnormality Stewart’s perspective makes sense. In an attempt to reach for the kind of insights she demonstrates, the purpose of this dissertation can be said to be a slowing down of the jumping between the experience of bodily ordinariness and ordinary bodily sensations to bodily experiences evaluated as abnormal and represented as potential symptoms and the subsequent reactions on this. In this slow motioned jumping I aim to

catch sight of the subtle everyday ‘modes of attending to the possible and the threatening’ in relation to the body and how surges of affective intensities create significances that resonate in the ordinary.

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#### AIM

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The overall aim of this dissertation is to explore how bodily sensations are experienced, articulated and ascribed meaning as symptoms or as part of the ordinary body in everyday life in the Danish middle class. Theoretically, it contributes to a medical anthropology of sensations and the literature on healthcare seeking practices by exploring the social construction of symptom experiences, and how they are evoked on a continuum between what is considered ‘normal’ and ‘pathological’. Practically, the project on which the dissertation is based is positioned within scientific, political and clinical attempts to ensure early diagnosis of cancer.

In the perspective of cancer and early diagnosis, an idea of symptoms takes centre stage in what has been described as a change in focus towards a ‘symptomatic management’ of cancer disease control in the Global North (R. S. Andersen, n.d.). This includes, according to Andersen (ibid.), among other things an epidemiological delineation of so-called ‘alarm symptoms’ of cancer and a public health rhetoric emphasizing ‘awareness’ of these symptoms. This may at first sight seem like a straightforward tool for people to use when assessing their symptom experiences. However, cancer symptomatology is far more complex than the illusory certainty the list of alarm symptoms expresses (R. S. Andersen, Tørring, & Vedsted, 2015). Many of the symptoms only represents a very low likelihood of being caused by cancer which means that the defined alarm symptoms of cancer are experienced widely throughout the population in benign versions (Hamilton 2009) or, I would say, as part of the ordinary body. Furthermore, the idea of the symptom in itself has been questioned from different perspectives within the social sciences (Eriksen & Risør, 2014; Hay, 2008; Staiano-Ross, 2011). Symptoms, it is argued, have been muted or blackboxed in medical anthropology and an opening and exploration of the idea of what we call symptom is called for.



The anthropological curiosity about what a symptom is in this case thus springs from an intersection between epidemiological representations of cancer which focus on numerical descriptions of e.g. symptoms, risk, mortality and diagnostic timeframes (e.g. Tørring et al. 2013), qualitative health research perspectives of cancer and healthcare seeking which to a large extent focus on health behavior and ‘barriers’ to healthcare seeking (e.g. Whitaker et al. 2015), clinical perspectives on how healthcare professionals should deal with symptom presentations (e.g. Jensen et al. 2014), and policy initiatives aimed at early diagnosis such as awareness campaigns and organizational changes within the healthcare system (e.g. Probst, Hussain, and Andersen 2012; Olesen, Hansen, and Vedsted 2009). Within this intersection, however, there is a scarcity of reflections on the very nature of symptoms; what is a symptom experience? As a consequence, symptoms are often expressed in reifying terms, circulating unquestioned in research, clinical work and at policy-level. This dissertation aims at providing us with clues to how we can understand the processes that shape symptom experiences and healthcare seeking practices in an everyday life context. It contributes to the continuously increasing nuances (Andersen 2010; Merrild 2015) of understanding the lives lead behind biomedically attuned notions of ‘symptom awareness’ and ‘early care-seeking’ in a Danish context. An understanding that challenges these notions that in their cogency amounts to reified slogans of epidemiology and the behavioural sciences of medicine (Good 1994) with an implicit causality between them which is extended to earlier diagnosis and improved survival from cancer; a causality which most of the time goes unquestioned (R. S. Andersen & Risør, 2014). However, both ‘symptoms’, ‘awareness’ and ‘early care-seeking’ take place in everyday life. To shake and unravel these notions it is thus anthropologically sound in this dissertation to turn our attention towards everyday life and to ask the following research questions:

- How are bodily sensations experienced, organized and articulated as symptoms or ‘nothing to worry about’ in everyday life?
- How are healthcare seeking practices shaped in the particular sociocultural context of the Danish middle class?
- In what ways is cancer present in everyday life, bodily experiences and health practices?

In answering these question I follow, on an overall level, Jason Throop’s plea for expanding our understanding of lived experience by attending to the ambiguities

and uncertainties of experience (Throop, 2010) while at the same time attempting to ‘never lose sight of the palpable human realities that exist at the limits of the sayable, the knowable, and the reportable’ (ibid.:4). With a focus on how bodily sensations are experienced, organized and articulated within the ambiguity and uncertainty of everyday life and the body I am additionally inspired by Arthur Kleinman’s works on morality as what really matters to people in their everyday lives (Kleinman 1997b; 1998; 2006;). Together, these theoretical perspectives can be seen as a lens to explore what happens in the slow motioned jumping, inspired by Stewart (2007), between ordinary and abnormal bodily sensations.

Thus, the papers in this dissertation all, more or less explicitly, serve three goals: the first is on an empirical level to provide an ethnographic description of how bodily sensations are endowed with significance and articulated as symptoms and how healthcare seeking is practiced in the Danish middle class. To do this it is vital to also devote a great deal of attention to the particular context of everyday life in which these movements between the ordinary and the extraordinary take place. Hence, focus on the body, health and illness in this regard entails a detailed ethnographic attention to what matters in everyday life and how ordinary and extraordinary registers are configured (Das & Das, 2007). Another goal is, as already touched upon, to ‘open up the idea of the symptom’ by engaging in anthropological discussions of experience as embodied sensations, morality as what really matters, potentiality as what may happen, and uncertainty and ambiguity as the social field of the body in everyday life. The third goal is the attempt to make increased room for (or build a platform for) contextualized and theoretically anchored analysis in biomedical and public health discursive rhetoric on cancer, symptom awareness and healthcare seeking in the ‘patient interval’ in Denmark to broaden our perspectives and inform a way forward.

The remaining part of this introduction will present the two main contexts for the analyses in the dissertation. First, I will present cancer as an overall background for the study from where to take the exploration of the public health defined problems of healthcare seeking and symptom awareness in an anthropological direction. I place the cancer context in the overall framework of health promotion and new public health, and I address relevant anthropological and public health research on the subject. Second, I will describe the ethnographic setting of the Danish middle class as the locus of an aiming for the ordinary in terms of what

really matters, particular in relation to the body, health and illness. Finally I will briefly present the overall analytical framework and central concepts.

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## CANCER AND PUBLIC HEALTH

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As the background of this dissertation it is central to understand the case of cancer in Denmark and how it is reflected in contemporary health promotion discourses. I will present a brief overview of this field, outlining the relevant areas of research that this dissertation feeds into in different ways. First, I will turn to some overall contemporary perspectives on health promotion, followed by a presentation of cancer from the Danish point of view and a depiction of different ways of scientifically approaching cancer which have informed and directed my attention towards illness, health and cancer in everyday life.

### **Health promotion**

With the development of ‘the new public health’, sociologists Alan Petersen and Deborah Lupton write, ‘few areas of personal and social life remain immune to scrutiny and regulation of some kind’ (Petersen and Lupton 1996:ix). From this perspective then, the ordinary also becomes a public health matter of governance and control. The governing of bodies can be contemplated within various perspectives such as surveillance medicine (Armstrong, 1995), medicalization (Conrad, 2008), risk (D Lupton, 1993), technomedicine and ‘the politics of life itself’ (Rose, 2007) and is in everyday life primarily encountered in the shape of a public health rhetoric emphasizing healthy lifestyle and illness prevention. In Denmark this rhetoric is to large extent conveyed through different health promotion campaigns, of which focus on early care-seeking is one among many. The main thread through the new public health is the establishment of a link between lifestyle and health, consistently involving, from the late 1970s onwards, a shift in health science and epidemiology towards people’s health behaviour as the main cause of disease, entailing a focus on individual responsibility for health (Cohn, 2014; Risør, 2003). This can, I believe, be seen in what I, in chapter 3 of this dissertation, call a moral sensescape of the Danish middle class, in the analysis of different potentialities of embodied sensations in chapter 4, and in the

cancer mythologies described in chapter 5. All three papers discuss some versions of health promotion discourses and public health rhetoric with relation to cancer, partly because they, from a middle class everyday life perspective, are pervasive and discursively powerful in their designation of what bodily normality is and how proper health should be practiced, and partly, from a public health perspective, because despite its power and pervasiveness, health promotion focusing on behaviour change in populations have had limited success (Baum & Fisher, 2014; Cohn, 2014). Simon Cohn problematizes in this regard the prominent public health notion of health behaviour which, according to him, is in danger of becoming ‘so reified that it fails to provide any critical insights in to what people actually do and why’ (ibid.:160). Instead he suggests a change in focus from health behaviour to health practices, entailing a resistance to causal explanations between clearly demarcated actions and kinds of behaviour. Mette Bech Risør shows a similar argument in her study of Danish pregnant smokers’ practical reasoning when faced with health promotion messages of smoke cessation in their everyday life. She argues: ‘Health promotion programs and health science is as embedded in local contexts as any other knowledge practices; it is performed by human actors engaging in human relations, and I find it necessary to take into account different complex levels of social interaction in order not to reduce the empirical studies of health promotion to a simple dichotomy of one knowledge system versus another, in a predictable relationship of power’ (Risør 2003:79-80). In continuation of these views, my wish in this dissertation is to explore the entanglements of the body, everyday life, health, illness, cancer and health promotion discourses without trying to disentangle them but instead slow motioning their interactional movements to pay attention to the ambiguities and uncertainties at play between experience, articulation and organization (Throop, 2008).

### **Cancer in Denmark**

Being the leading cause of death in Denmark (Sundhedsdatastyrelsen, 2015), cancer has immense impact on the organization and prioritization in the Danish healthcare system, the welfare economy, funding of research as well as the everyday lives of the Danish people of whom about a third will, statistically, be diagnosed with cancer during a lifetime (Albrecht, McKee, Alexe, Coleman, &

Martin-Moreno, 2008). While prognosis has improved for most cancers with improved treatment and diagnostic technology, Denmark has a lower cancer survival rate than similar countries (Coleman et al., 2011). Studies indicate that these cross-national differences could be due to more advanced stages at diagnosis and later initiation of treatment in poorly performing countries (Sant et al., 2003; Walters et al., 2013). Political focus on cancer has in Denmark increased during the past 15 years, culminating with a reframing of cancer as an acute condition in 2007 by Danish governmental and health authorities. Concretely, this resulted in organizational changes in the health care system with e.g. the implementation of fast-track cancer pathways where diagnosis and initiation of treatment are guaranteed to happen within a narrow time frame defined in the specific pathway (Probst et al., 2012; Marie Louise Tørring, 2014).

### **Contemporary research in early diagnosis of cancer**

The increasing temporal connotations with cancer has led to public health inquiries into the importance of time in the diagnostic pathway (M L Tørring et al., 2011; Marie Louise Tørring et al., 2012) from first symptom to diagnosis and treatment, consequently investigating all aspects of this pathway by slicing it up into intervals where the ‘patient interval’ covers the time spent from the patient’s experience of a potential cancer symptom till he or she presents the symptom to a healthcare professional (Weller et al., 2012). Thus, how people practice healthcare seeking with potential cancer symptoms has entered the limelight of extensive quantitative and qualitative investigations together with notions of symptom ‘knowledge’, ‘awareness’, ‘(non-)recognition’ and ‘appraisal’ (Hvidberg et al., 2016; Macleod, Mitchell, Burgess, Macdonald, & Ramirez, 2009; Quaife et al., 2014; Walter et al., 2014; Whitaker, Scott, & Wardle, 2015) and ‘barriers’ and ‘triggers’ to healthcare seeking (Birt et al., 2014; Hvidberg, Wulff, Pedersen, & Vedsted, 2014; Scott, Grunfeld, Auyeung, & McGurk, 2009). This research is to a large extent based on the assumed function of e.g. awareness and triggers as magic bullets that would turn the ship around and shorten the patient interval, resulting in improved individual prognoses and national cancer survival rates. Anthropological attempts to broaden these notions and their underlying assumptions (R. S. Andersen, Paarup, Vedsted, Bro, & Soendergaard, 2010; Brandner et al., 2014; Seibaek, Petersen, Blaakaer, & Hounsgaard, 2011)

have provided important insights of how healthcare seeking processes, sensations and symptoms are embedded in a social and cultural context and call for further studies exploring this embeddedness from a prospective perspective, i.e. exploring healthcare seeking practices as they unfold and transformations between sensation and symptom when they happen in the context of everyday life. In her comparative study of social disparities in cancer in Denmark, Merrild takes up this challenge and shows how healthcare seeking is practiced and how embodied experiences of sensations are played out differently in the everyday lives of two different social classes in Denmark (Merrild, 2015). Her study implicates, among other things, that health promotion messages of early care seeking and symptom awareness are appropriated differently and that ‘one size does not fit all’ (Merrild et al., in press). partly because class is embodied differently and express different local biologies where a ‘noisy body’ was characteristic of the study’s lower working class group who tended to have multiple other health and social problems and thus a different, more ‘noisy’, local biology in which sensations and changes in the body are experienced (Merrild, Vedsted, and Andersen, in review). This serves to illustrate the path, this dissertation is also following in the prospective focus on how health, illness and sensations are embodied and practiced in a particular sociocultural context as well as how cancer manifests in everyday life ‘before cancer’.

Embraced by the public health framework and health promotion approach described in the above, cancer awareness has been advocated through different campaigns in different versions during the last decade, alongside the emergence of the epidemiological notion of ‘alarm symptoms of cancer’ which the population is advised to react on by consulting a health professional. However, as briefly discussed in the above, many of the so-called ‘alarm’ symptoms represent in fact a high level of statistical uncertainty with regard to the likelihood of being caused by cancer, and are thus frequently experienced in the healthy population (Hamilton 2009; Hamilton 2010). ‘Symptoms of cancer’, Andersen et al. write, ‘are thus equally invisible and potentially omnipresent’ (R. S. Andersen et al., 2015). The concomitant concerns of time and awareness of cancer alarm symptoms have increasingly turned the focus of cancer disease control efforts and public health research on cancer diagnostics towards the patient interval where it is the hope that time till diagnosis can be positively influenced by symptom awareness, also coined by Andersen (R. S. Andersen, n.d.) as a

symptomatic management of cancer disease control, including a continuous expansion and subdivision of cancer symptoms for people to deal with in everyday life. In engaging with the body in its everyday life ordinariness, one aim of this thesis is, in a conversation with contemporary public health research, to add to our understanding of how this symptomatic management plays out among people who are not (yet) patients. This leads me to consider how issues of illness and cancer in everyday life have been approached anthropologically.

### **Anthropological perspectives on illness, cancer and everyday life**

The title of this paragraph with its not so catchy enumeration of anthropological study fields illustrates very well the knowledge gap this dissertation aims at filling. Naming the paragraph the more linguistically fluent ‘anthropological perspectives on cancer and illness in everyday life’ would have implied that there indeed existed substantial anthropological perspectives on e.g. cancer in everyday life. However, this juxtaposition is only rarely found in anthropological studies. Illness and everyday life are, on the other hand, classic anthropological objects of study, and cancer has been thoroughly studied within anthropology as well. This section will briefly present anthropological fields of illness in everyday life and studies of cancer and position the dissertation within these.

Anthropological work exploring cancer has to a large extent focused on cancer patients and emphasized illness experience and representation (Henriksen, Tjørnhøj-Thomsen, & Hansen, 2011; Hunt, 2000), also occasionally in an auto-ethnographical style (Jain, 2013; Stacey, 1997; Stoller, 2005), often departing in an empirical focus on cancer specific arenas such as the oncology ward (Livingston, 2012), particular patient categories (Aronowitz, 2007), rehabilitation and body changes (Hansen and Tjørnhøj-Thomsen 2008; Manderson 1999), and genetic risk and counselling (Gibbon, 2013; Svendsen, 2005). The area of breast cancer alone has spurred a range of studies, often departing in feminist approaches, arguing against the ‘pink’ breast cancer culture (Jain, 2007), and advances in biotechnologies has given rise to anthropological inquiries into a ‘biotechnical embrace’ of cancer patients and healthcare professionals (Good 2007) and new constructions of ‘at risk subjects’ and pre-states of disease (M. Lock, 1998; Rose, 2007).



In everyday life, the body has been studied mainly in terms of illness and chronic conditions as for example the necessity to move healthcare from the clinic to the home and practice ‘chronic homework’ of the chronic ill (Mattingly, Grøn, & Meinert, 2011). With the sociological anthology, *The body in everyday life* (Nettleton & Watson, 1998), a rather unexplored field of inquiry into empirically grounded experiences of the normal body in everyday was advanced.

With regard to cancer, anthropological explorations into what happens outside the confines of cancer specific arenas, and before individuals are transformed into cancer patients, have been limited. Thus, we do not know much about how cancer is imagined, embodied, and practiced in ordinary everyday life among healthy, i.e. non-cancer afflicted, people. Healthcare seeking, not specifically with symptoms of cancer, has been explored particularly in the work of Linda Garro with a cognitive anthropological approach to illness and healthcare seeking in everyday life (Garro 1998a; Garro 1998b; Garro 2003) and with her development, together with James C. Young, of a prospective empirically grounded model for healthcare seeking in a Mexican village (Young & Garro, 1994). Garro has also approached the kind of embodied experience of sensations, this dissertation is concerned with, in a processual perspective as narrations of ‘troubling experiences’ (Garro 2003) and is thus in a similar fashion as this dissertation directing attention towards symptoms in the making. But it is with Cameron Hay’s work on sensation to symptom transformations in Indonesia (Hay, 2008), Marc Nichter’s call for a sensorially engaged medical anthropology (Nichter, 2008), and Veena and Ranendra Das’ analysis of ‘how the body speaks’ among New Delhi’s urban poor (Das & Das, 2007), all of them encompassing the dynamics between the ordinary and the extraordinary in different ways, that we are finally entering common analytical ground as these analyses can be seen as primary sources of inspiration to this study.

With its primary focus on exploring sensations and symptoms as they happen among healthy middle-class people in Denmark and how healthcare seeking is practiced from an everyday life perspective, this dissertation adds to the growing inclination in anthropology to explore varieties of articulations of experience, from the pre-reflective to the reflective, from the inaccessible and vague to the most explicit (Throop, 2003, 2010), and enactments of health in everyday life



and how this relates to health promotion discourses and ‘official accounts’ (Garro 2010; Garro 2011b).

Moreover, in continuation of these perspectives on ordinary and extraordinary sensations, this dissertation adds cancer as an ambiguous presence in everyday life and in the experience of embodied sensations. Cancer, in this view, becomes a cultural representation, contingent upon both global discourses and local moral worlds (Kleinman and Kleinman 1991). With inspiration from Susan Sontag (Sontag, 1991), Sarah Lochlan Jain (Jain, 2013) and Jackie Stacey (Stacey, 1997) among others, I engage in discussing cancer as cultural phenomenon and how it affects potentialities in the experience of sensations in an everyday life context. I am thus not looking at cancer illness experiences and how people deal with cancer as an illness. I am looking at how people deal with cancer before cancer; with what I in chapter 5 have called ‘cancer mythologies’.

Departing this exploration in a public health problem of early cancer diagnosis, I thus attend to these matters within what in the public health lingo is termed the patient interval. A somewhat paradoxical focus since I am trying to shift the focus from patients to persons, which I will elaborate on in the following.

### **The patient interval: symptom awareness and early care-seeking**

With the dominating temporal conceptualization of cancer, public health research in cancer diagnostics has zoomed in on the diagnostic processes in an effort to control the disease by understanding what is going on in these processes that recently have been termed intervals in exchange of the former notion of ‘delays’ to avoid implying stigma and notions of intent to the patient who did not come in time, to the doctor who was not quick enough to suspect cancer and refer to specialist care, and to a slowly responding healthcare system (Dobson, Russell, & Rubin, 2014; Weller et al., 2012). The study presented in this dissertation inscribes itself into the exploration of these processes focusing on what is going on the patient interval. Within a diverse range of social science health research the concern with symptom awareness and healthcare seeking has spun a number of studies also investigating this. However, as Cohn also stated in his critique of the behavioral approach to health and illness, ‘...as social scientists often working alongside other disciplines in health research environments, we have,

ourselves, in many instances accepted the concept of health behaviour far too readily' (Cohn 2014:158), thus, in relation to cancer, in many cases implying a decontextualized and simplified causality between cancer awareness and healthcare seeking (R. S. Andersen & Risør, 2014). This has, according to Andersen and Risør resulted in a range of merely descriptive qualitative and quantitative studies of symptom awareness and healthcare seeking emphasizing 'barriers' to healthcare seeking such as lack of knowledge and non-recognition of symptoms (e.g. de Nooijer, Lechner, and de Vries 2001; Forbes et al. 2014), self-management of symptoms and not wanting to waste the doctor's time (e.g. Whitaker et al. 2015; Scott et al. 2009), and fear of cancer (e.g. Smith, Pope, and Botha 2005). While providing valuable insights about how people describe what is at stake in the patient interval, these studies, Andersen and Risør state, may be criticized for not looking further than to what patients verbally state in interviews or answer to a questionnaire survey, and neglecting how historical, cultural and social contexts of everyday life and the healthcare system inform this process and the definitions of the ordinary and the extraordinary. Also, research into the patient interval has a retrospective lopsidedness where the majority of studies are investigating how already diagnosed patients describe their patient interval with the risk of e.g. recall bias and lacking exploration into how people become patients in the first place. The inclination to study the patient interval retrospectively may be reinforced, I believe, by the retrospective construction of the patient interval in itself. To be able to scientifically explore, compare and develop our knowledge on health practices in relation to cancer symptom awareness and healthcare seeking, a construct such as this is necessary. However, it seems in the retrospective inclinations and often unquestioned causal assumptions in research designs, that we are predisposed to forget that the patient only exists in retrospect; that it is a construction of everyday life defined backwards from the moment of cancer diagnosis and that it entails a conflation of persons and patients. This means that people wander around in their everyday life and experience bodily sensations of which some may be perceived and interpreted as potential symptoms that will lead to healthcare seeking where it might be something or it might be assessed as nothing to worry about. In most cases it will not have much to do with cancer and people will not consider themselves wandering everyday life patients. Nevertheless, when cancer is diagnosed, all this becomes a patient interval with some possibly very vague and elusive bodily sensations as starting point. But as it happens, it is just life. So,

with the patient interval turned upside down and no symptom appraisal pathways to trace backwards, how should we understand the myriad of ways people experience, interpret and act on their body in their everyday life? And how does cancer and symptom awareness fit into this? To start exploring these questions, I will now turn to unfold the empirical background of the dissertation.

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## THE ETHNOGRAPHIC SETTING

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While sitting in a nice and orderly living room drinking coffee and looking out at the carefully orchestrated garden encircled by the well-trimmed hedges, informants tell me their life stories where we are taken back in time to childhoods and youths in often poor circumstances in both urban and farming families and to their struggles to do better until they ended up here in this neighbourhood:

When I was 25 I bought a tenement property. Because I needed a place to live, and I had checked the buying prizes of flats and I figured that they were expensive. If I bought a whole property then the prize per square meter was way cheaper. So I bought a whole building....The first year I rented it out to someone I knew. In the beginning I needed a little more money and things like that. And I had two jobs at that time. I had a driver's license for driving a taxi. I had started to do some taxi-driving. I guess it was because I didn't want to be such a poor bugger as my parents. Because I knew that they had financial problems since only my dad was working. My mom, she was a housewife. She always was. Which is fine, acutally. But the money could only just cover the expenses. I can remember every Thursday when my dad came home and they sat there and made the budgets one week at the time and found whatever could be left of a little pocket money for themselves. They didn't spend much but my dad, he would like to have just a little bit to be able to go to the trotting course. He liked to play a little out there. But that thing about the money being short, I didn't want that. I knew that there needed to be some money and then I took two jobs to get going on everything. I bought that building in the city when I was 25, and when I was 29 I bought this place and then I moved out here. And I drove taxi at night. Yes, that's how it started.

Christian, 66 years old, works as a machine operator

One shared characteristic of the everyday life for most of my informants in this (stereo)typical Danish middle class neighbourhood is that they enjoy a standard of living markedly above the conditions under which they were raised, and they have worked hard for it. Scarcity of money during their upbringing and their parents struggle to make ends meet seems to have induced a focus on obtaining economic security and creating possibilities in terms of jobs and education and on using money well in a way reminiscent of a protestant ethics morality (Weber, 1930). The people living in this neighbourhood are schoolteachers, office workers, general labourers, craftsmen, social service workers. All have in different ways made their own way and they are proud of what they have accomplished. They talk about their work and present their everyday life with a pride of 'being able to manage' that mimics Bonnie Urciuoli's finding in a study about class in the United States that 'being middle-class is a generic, and morally loaded, cultural identity, representing the triumph of individual virtue which includes good money management' and 'knowing how to manage' (Urciuoli, 1993: 206).

Is it still relevant today to talk about class at all in a supposedly egalitarian nation such as Denmark, where an 'indeterminate 'middle-classness' has almost become the norm' (Jenkins, 2012: 44)? The redistributive system of the Danish welfare state ensures that basic needs are met across the population and that differences between rich and poor are sought diminished, regulated by social benefits and the relatively high taxes in this small European country with a population of less than six million people. Healthcare is free for all, likewise is higher education in principle available to everyone, including an economic grant to cover living expenses provided to all Danish students, giving everyone, at least in principle, equal opportunities in terms of education to accomplish what they consider 'a good life'. It is common among Danes to describe our place in the world as a *smørhul*<sup>2</sup> – a nice little corner of the world or an El Dorado (of welfare). However, social divisions persist and one of the clearest examples of this is perhaps found within the perspective of health and illness, where class becomes evident in morbidity and mortality rates (Dalton et al., 2008) which are also lived and embedded in everyday life and takes the form of different local biologies

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<sup>2</sup> Literally: a butter hole

(Merrild, Vedsted, and Andersen, n.d.). Thus, class divisions matter in Denmark but they are in many aspects disguised and muted (Faber & Prieur, 2013); hiding in what Merrild describes, with Gullestad's notion, as equality as imagined sameness (Merrild, 2015) and in their effects just as related to morality as they are to socioeconomic variables such as income and education (Faber & Prieur, 2013).

But why the middle class then? As argued with Jenkins, 'middle-classness' becomes a moral norm against which people identify themselves. As several studies have shown, people from all ends of the social spectrum tend to identify with being 'ordinary' or 'middle class' (Gullestad 2001; Faber 2008; Linnet 2011; Larsen 2013). In a descriptive sense the kind of lives people lead and the 'morally loaded cultural identities' they employ, make this social category encompass a wide spectrum of identification as being 'ordinary Danish' within the Danish society (Jenkins, 2012). The aim of this dissertation is to dive directly in to this 'ordinary' to unfold how the ordinary is lived and pursued and how health and illness are embedded in this. On this background, my choice of fieldsite is based on the idea of class. However I am not looking at class as such; as 'economic class', a structuring concept or as identification but rather as social and cultural class; and as 'middle class-ness' as a set of social practices and values (Gullestad 1989:77). I am interested rather in the question of how 'the ordinary' of the middle class is pursued than external identifications and differences. One exception to this, however, is the case of differences in time taking the form of an upwards social mobility from working class to middle class that the majority of informants have experienced and which is expressed in their life stories and in comparisons between then and now such as Christian's case above shows. This is a central aspect of the analysis of how bodily sensations are noticed and articulated, and how or when moves to seek care unfold; and which this dissertation suggests is about balancing moral possibilities in relation to the welfare state and their own moral concerns about being 'good citizens' (see chapter 3).

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THE LOCAL MORAL WORLD OF THE DANISH MIDDLE CLASS: WHAT REALLY  
MATTERS

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This section of the introduction is devoted to more extensive elaborations of the empirical background of the Danish middle class and the analytical context of everyday life. This description is meant to supplement and anchor the analyses presented in this dissertation by providing ethnographic detail and analytical excursions into the ordinary and what really matters in the field on which I build my analyses. This is done in order to deepen understanding on the background against which sensations are experienced, organized and articulated and healthcare seeking decisions are established.

Robert and Kirsten live in one of the houses on a small side road in the neighbourhood. They are 73 and 70 years old and have lived here for more than 40 years. They both look fit and healthy. They laugh a lot and tease each other all the time and overall, they seem pleased with how everything has turned out for them. Both of them have grown up in the city close to where they live now. As a child Kirsten lived in a back yard building in a two room apartment and she refers to herself at that time as an ‘alley cat’, knowing everyone in the neighbourhood and always finding someone to play with. Kirsten never finished her education as language secretary in German because she met Robert and had children but she has had a range of different jobs including office work, cleaning, eldercare, and cooking, sometimes with periods of unemployment in between. Robert grew up as an adopted child in a family he later abandoned. Robert is educated as machine operator but has also been in the army and has been a sailor and ended up working in the same company for 35 years. During his sailing time he met Kirsten who was living in a small attic flat in the city at the time. They now have three adult children. They met at a night out in the city where Robert was celebrating his discharge from the army and Kirsten was going out to have some fun with her cousin. Kirsten tells:

‘It was crowded at Maritza but something had to happen because now we were all dressed up with make-up and everything. And those high heels! Ten centimetres’ heels of steel! And the hair. I had really long hair at that time and then it was styled with a hair pad as we did in those times. A kind of textile thing. Some girls actually used a loaf of bread. But well, we decided

to go to Rico. It was not really the place to be at that time but at least we could get in. And there weren't too many people, so we started looking around to see if there were any good prospects, and in the other end of the room sat Robert and his friend'.

This is the start of Kirsten and Robert's story together. Robert went sailing after this but after writing letters to each other for years they ended up together and moved to Copenhagen where they lived in different small rented rooms and where they had their first two of three children. After four and a half years they moved back to Jutland and lived in different rented places until one day they came across a small house they could just afford. They bought it and for several years spent all their money and time on renovating that house. In the approximately six years they lived there the house had increased its value times six and they finally bought the house in the relatively newly established suburban neighbourhood in the late 1970s where they now sit around their coffee table telling their story which is full of ways to get by and how to manage and make progress. These days, as retired, they mainly spent their time bowling, housekeeping, gardening, seeing their friends and preparing and eating food. They go on vacations not so regularly that it is taken for granted but no so seldom that it is a very big thing. I listen to their stories wearing guest slippers which I was offered after entering the house through the backdoor behind the carport. This house is also spotlessly clean and my gesture to leave my shoes in the back corridor is welcomed by a choice of guest slippers in various sizes so that I won't have cold feet during my visit.

Everyday life can to a large extent be seen as a striving towards an idea of 'the good life' as this is defined and understood in the particular local moral world (Mattingly, 2014). Watching the good life unfold through stories of how it was built, of successes and failures, gives a sense of what really matters to these particular people in the particular time they have been and still are building what they consider a good life. Everyday life in this sense is a moral endeavour, because, as Arthur Kleinman writes:

...for each and every one of us, life is about the things that matter most to us. Just carrying on our existence, negotiating important relations with others, doing work that means something to us, and living in some



particular local place where others are also passionately engaged in these same existential activities – all this is, by definition, moral experience (Kleinman 2006:1).

Taking a relational approach to what really matters in this particular middle class field site, people are morally related on different levels or layers of society such as for example: family relations and individual social relations (friends), close community networks (neighbours, friends, the neighbourhood, work place and colleagues, sports club etc.), larger ‘imagined communities’ (the nation, the welfare system, their generation, their class). Within these relations values, concerns, meaning and morality are communicated and felt as what really matters in everyday life in the face of happiness and success as well as threats, tragedy and sorrows. This is the local moral version of the ‘good life’. Let us now take a closer look at some of these relations that carried moral concern and created significances in the everyday life of my informants. Returning to Stewart’s argument (2007) of ordinary affects, which I in many ways find related to the idea of what really matters, these significances can be seen as intensities or surges of ordinary affects which I believe we can find in some of the following aspects of everyday life in the Danish middle class where significances amassed.

### **Family, home and *hygge***

Most houses I visit have walls or shelves decorated with photos of children, grandchildren and in one case, great-grandchildren. There were mothers, fathers, siblings, husbands, wives and even dogs. When talking about their lives, the photos are often drawn into the stories by a nod towards whoever we are talking about or a particular anecdote connected to a particular photo. Danish middle-class everyday life revolves to a large extent around the nuclear family. This relates to how to build and sustain a home and a stable base for family life to unfold and for children to grow up. However, since the main group of informants were above 60 years old and had adult children and the nuclear family had changed form, everyday life concerns relating to family has had to be redefined. To many of the informants an appreciated task was taking care of their grandchildren. Some of them travelled far distances to be of help in the busy everyday life of their adult children by e.g. staying at home with grandchildren when they were sick while others picked the grandchildren up from daycare or



school on a regular basis. They expressed enjoyment having the chance to be close with the grandchildren and at the same time a feeling of being of help to their children. The role of being a grandparent on these terms seemed to be central and meaningful to most of them and one of their main concerns regarding health and illness was in fact related to this, as the fear of getting sick and die and thus miss out on watching their grandchildren grow up often was presented as central when considering their health. At the same time, most informants also told about problematic relations within their families; conflicts between siblings, children refusing contact with their parents, disagreements over inherited properties, and too much pride to be able to reconcile. Stories of alcoholism, depression, anxiety, stress and other mental illnesses were weaving threads of troubles and worries that expose deep concerns of love and care as well as the fragility of what really matters.

Related to the centrality of family, the home, materialized as the house, the garden, and in some cases a summerhouse, still formed the locus of informants' life and identification with shared moral concerns. This was for instance evident in the introducing example of presenting a clean and orderly house while at the same time presenting oneself as not being too obsessed about cleanliness. The importance of the home as social and cultural marker, loaded with cultural value and moral concerns, is emphasized widely in general literature on class and everyday life (Gullestad 2001; Skeggs 1997; Hamnet 1995; Linnet 2011; Sjørsløv 2009) and fits with the experience of a neighbourhood where houses were similar with individual differences in appearance and the gardens neat and well-kept almost everywhere.

Kirsten is proud of her garden and she loves gardening. We sit in the covered patio where the different plants in pots have been placed and covered for the coming fall and winter. 'I know it is still a little early to that but then it is done', she says. After finishing yet another cup of coffee I suggest that Kirsten shows me the garden. The garden is not really that big but it takes more than half an hour to just show me around. There seems to be a story connected to every tree, bush and even the ground cover plants. Kirsten tells enthusiastically a story about some green ground cover plant which is named something I do not recognize or remember long enough to be able to note down but it is clearly a plant that ordinary gardeners are

supposed to know. She had too many, she told, and then she advertised in a newspaper ad that people could come and dig them up for free. They are very useful and popular to use for ground cover. And those who came were so impressed with her garden that one of them came back only to show the garden to her daughter! She also shows me the hole in the hedge to the neighbouring garden where the kids used to run back and forth between the houses.

Being able to take proper care of one's garden was of great importance in a neighbourhood such as this. Comments about people who did not cut their hedges at the appropriate height or did not weed properly so that unwanted plants spread to other gardens, were common. The declarations of the local homeowners' association clearly states how many and which kind of trees can and cannot be planted in which parts of the neighbourhood, adding to the sense of similarity you get when walking around in the neighbourhood where I lost my way several times. The structure of the main roads, side roads and walking paths was mathematically logical but was a maze of indistinguishable ways to follow with houses, hedges and gardens that to some extent seemed to aim for the same ordinary. But gardens were by no means just about appearance. They were meant to be used. Informants often showed me their favourite spots to sit and enjoy a long summer evening or the spot for reading the newspaper with a cup of coffee in the morning sun. And I ended up losing count of how much fruit and vegetables I carried home with me from field visits; a bag full of apples, a bunch of flowers, parsley, grapes, cucumbers, tomato.



Growing your own vegetables relates to another important concern of the nurturing and flourishing home; food and eating was mentioned and practiced during my visits as central to informants' values and ideas of a good life and good health. Everyday life in the Danish middle class is to a large extent structured around food and meals. Activities are stated as 'before lunch' or 'after dinner' and meals are phrased as 'we take our coffee on the patio'. *Our* coffee, *our* lunch, *our* dinner. Consistent with Jenkins' descriptions of Danish food culture (Jenkins, 1999), these pronouns highlight the communal character of eating in Denmark. We eat together which Jenkins argues is more important than the actual food and drink consumed, thus drawing attention to the centrality of the processes and the cultural significances of food and the social conventions surrounding it. Jenkins states that 'enabling conventions' around the meal makes a relaxed togetherness and sociality possible (Jenkins 1999:44). Only by looking really hard I found myself in the interview transcriptions as the native anthropologist I was, drawing extensively but unconsciously on enabling conventions by drinking several cups of coffee to maintain a relaxed atmosphere in the interview setting that always involved some kind of food or drink (there was not a single interview without coffee), or by accepting a beer for lunch even though I considered myself 'at work' because saying no to both beer and schnapps would create too big differences in the communal feeling over lunch.

Consider for example this casual talk with Kirsten and Robert about eating and drinking routines at lunch:

Robert: Every day we have to half pieces of rye bread and a schnapps, and then we share a beer. We have that every day.

Sara: That is cosy [*hyggeligt*]

Robert: Yes. That is, like... with pickled herring or something else.

Kirsten: Just what we feel like. So well, yes yes. More coffee?

Sara: Yes, please

This interview excerpt is a kind of small-talking break between deeper elaborations on health and everyday life, but as Billy Ehn et al. points out: ‘...when nothing seems to be happening, a lot is actually going on. There is an invisible world at the end of your nose: objects you no longer see, words you no longer hear, tastes that are overfamiliar, tasks that have turned into mere reflexes’ (Ehn, Löfgren, and Wilk 2015:1). Such is for example my automatic response about their lunch sounding like something *hyggeligt*. The notion of *hyggeligt* is derived from the Danish phenomenon *hygge* which has gotten rather famous for not being translatable but ‘which in Denmark has an almost iconic status in representing a style of being together that ‘ordinary people’ often consider to be distinctly Danish’ (Linnet 2011:21). *Hygge* runs through everyday life and is of paramount importance in Danish middle class culture and in national identification processes (see also Jenkins 2012; Sass 2013). When I commented that their lunch routines sounds *hyggeligt* it is not as much something I ascertain from what they are telling as it is an engaging of a communal cultural understanding between all three of us that this type of being together over lunch is a time and space that matters to Robert and Kirsten. And then, on another level of engaging the same atmosphere-creating practice, Kirsten offers me, in an almost automatic manner, slightly lifting the coffee pot before she gets my answer, more coffee. I reply in a just as almost automatic manner, and our talk continues as if this interruption had not been. It really was a *hyggeligt* interview.

*Hygge* can, in my view, be seen as the effort made to create a specific and valued atmosphere in which some kind of food or drink is often implicitly assumed. Eating and drinking are thus closely related to *hygge*, community and sociality as

culturally specific moral concerns that deeply matter in everyday life interactions among the Danish middle class, and among Danes in general, I would argue. The relation between *hygge*, eating and drinking becomes especially evident in cases where the enabling conventions for a *hyggelig* atmosphere are disturbed, for instance by health promotion discourses aimed at lifestyle changes concerning food, drink and their consumption:

Robert: That schoolmasterish way (*skolemesterfacon*), I don't like that.

Kirsten: The preachy pointing finger (*Den belærende pegefinger*)

Robert: Yes, the preachy pointing finger...We would not, for example, be able to drink a schnapps every day for lunch and share a beer, and then once in a while have a beer with someone else, then we will get over the limit. Or a bottle of red wine every other day. Sharing it. Then you will quickly be over the limit. I am just such a person then, that I believe that you are only an alcoholic at that point where you can't do without it.

Health promotion messages concerning weekly alcohol intake in this case potentially disables the conventions for creating *hygge* in the ways this is related to the time and space of lunch that matter to Robert and Kirsten, if they were to comply with the official alcohol recommendations from the Danish Health Authority. On the other hand, however, health promotion seems to be deeply incorporated into food and eating concerns in the middle class and does not seem to disable conventions regarding food. Rather, it was often emphasized how informants had changed their diet towards eating more vegetables and less fat and sugar because 'it is good for you'. Healthy food and eating habits were in general presented as important to people in the neighbourhood, either as something they already practiced or wished to accomplish. But again, it was presented as a fine balance between eating healthy and at the same time not overdoing it by e.g. 'healthifying' food to the extent that it compromises taste or still valuing individual 'health sins' rendered important, like smoking for smokers, butter on the bread or a schnapps and a half beer with lunch (see also Risør 2003).

## Worklife

Opposing the deep concern with homelife, informants' worklife is another central aspect of what really matters. Since most of the informants were retired, their worklife and work place community was not immediately important. However, many of them considered their former colleagues close friends and they often stated them as part of their close networks. And their former jobs seemed to play a central role to their life. When asked to just simply tell me about themselves and their life at our first encounter, I was primarily told a story structured by their way through their worklife: Which deliberate choices they made and which coincidences that got them going in different directions. One informant, Michael, told an exhaustively detailed story that starts with him failing first grade at school because he was dyslectic and then tells the story of how he and his brother started sharing a route as newspaper boys until each of them got their own route when he was about 10 years old. Then he got a job as delivery boy at a market gardening, but one day during summer he was walking down the street *Otte Ruds gade* to get to *Stockholmsgade* and he saw one of his classmates and best friend, John, sitting on some stairs in front a factory that was placed where there now is a supermarket. 'What are you doing here, John?' he said. And John answered: 'Well, I am eating my packed lunch' and told that he had got a job at this door fabric until both John and Michael were going to start on a boarding school after the summer break. Did Michael want a job, too? They could use some more people. So Michael quit his job at the market gardening and started working at the door factory. Because he had failed first grade he was a year older than John and was earning five Danish kroner (less than one US dollar) more per hour than John. They laughed about that. The level of detail presented here continued in his story about how he had different jobs and was trained as a metal worker and became shipbuilder by coincidence before he ended up at his present workplace where he works with machines at a large waste incineration plant.

Stories like this are stories about how informants have managed and made a living. They were intertwined with the stories of their housing career; where and how they lived, how they got their first apartment and then moved on in terms of bigger and better accommodation until they ended up in this neighbourhood. In their narrations these stories are at the same time descriptions as much as evaluations (cf. Gullestad 2001:35) in accordance with the 'morally loaded, cultural identities' of a middle class grown out of the working class emphasizing



their ability to manage. In this regard they must then be seen as carefully constructed stories of this ability to manage; of success, as for example when Christian proudly states: 'I have never been out of work'. Unemployment periods are mentioned in several stories but more as further descriptions of how to manage well, as a kind of pause with no morally evaluated content. Uncertainties and worries of economy, family, status, material goods etc. that often accompanies unemployment were absent in these retrospective accounts; in the bigger picture it all turned out well.

All the informants in the study were working or were retired from work. Thus, I met no one who had been stay-at-home housewives for example. However, some women had had part-time positions and many emphasized the importance of being able to devote time and care to their children when they were young, as for example being at home when the children returned from school every day. Besides that, the women's stories were unfolded in the same manner, structured around choices, coincidences and efforts to manage well with regard to their work-life and housing career.

### **The imagined community of the Danish welfare state**

The individual pride in being able to manage well, described above, also contains notions of contributing to 'the running' of society – the economy and the welfare state. Denmark is known for its extensive welfare system where its citizens pay one of the highest income taxes in the world (OECD, 2015) and in return get e.g. free healthcare, free education, student allowances and unemployment benefits. As this study focuses on healthcare seeking, the informants' relation to the imagined community (Anderson, 2003) of the welfare state, in the shape of the publicly funded healthcare system, is of central importance.

As shown, most of my informants were above the age of 60 and their own social mobility from working to middle class has been temporally intertwined with the development of the present Danish welfare society throughout the latter half of the last century (see also Jöhncke 2011).

With the focus on health and illness in this study, the relation to the welfare society or the imagined community of the nation was most evident with regard to

the healthcare system and informants' attempts to for example seek healthcare properly, i.e. by not burdening the system with trivial matters and at the same by reacting timely on symptoms and risks as a responsible person and good citizen. This balance is further analysed in chapter 3 where it is argued that a mutual moral relation between the welfare state and its middle class citizens is reflected in how people experience, articulate and act on bodily sensations and symptoms. This relation is interesting in the Danish context because of the extensive welfare system that grows out of, maintains and bestows Denmark's high levels of social coherence and trust which contribute to the regular nomination of the nation as the happiest nation in the world (Helliwell, Layard, & Sachs, 2016; Wiking, 2014). The Danish welfare state, according to Jenkins (2012:45), is leaning on pervading ideas of egalitarianism and homogeneity that have become so powerful in their taken for granted-ness that they sink into the background of everyday life. This sketches the background on which to understand the sense of being morally related to the imagined community of the welfare state. Jenkins connects this with the Danes' extensive use of the verbal expression 'thank you' (*tak* in Danish) in everyday social interactions and infers that 'Danes might have a lot to be grateful to each other for' (Jenkins 2012:44). This is in accordance with sociologist Christian Albrekt Larsen's argument where national social cohesion is defined as 'the belief held by a country's citizens that they share a moral community, which enables them to trust each other' (Larsen 2013:194). In particular, Larsen highlights how the sense of belonging to the middle of society and an imagination of most fellow citizens also belonging to the middle are central to the levels of social cohesion and trust in a society. He further relates this argument to traits perceived to belong to the middle class such as honesty, moderation, tolerance, and helpfulness as well public imaginations of the trustworthy hard-working families of the middle class (ibid.:195). In the case of my Danish middle class informants these aspects are particularly profound when informants compare themselves with fellow citizens not perceived to belong to the homogenous middle. It can for example be in relation to the use of the healthcare system. One informant, Jane, tells about how to be a responsible citizen, also quoted in chapter 3 of this dissertation: 'I do my best so that I will not need to use the healthcare system. I keep fit, and I eat healthy food. But when I look at how [overweight] people waddle around in the supermarket and what they buy!... And then they also go out and smoke before getting into their cars and all the other factors. Then I can see why the expenditures of the healthcare



systems are high!’ A disharmony with the middle of society is also at play when Robert and Kirsten for example discussed an episode in Danish politics, which was widely presented in the news media in October 2013, where the liberal opposition leader at that time (who was in June 2015 elected prime minister), Lars Løkke Rasmussen, severely stepped off the imagined egalitarian middle and its traits of hard work and moderation. The then prime minister of Denmark and social democrat, Helle Thorning-Schmidt, was questioned by the opposition as to whether it was economically profitable to have a job compared to being on public benefits. Rasmussen argued that it should pay off, economically speaking, to work and that the government was not doing enough to ensure that. He referred to numbers indicating that to a quarter of a million Danes it was not profitable to have a low-paid job compared to public benefits. Thorning-Schmidt replied that her government had, with the newest tax reform, ensured that to half of these people there would henceforth be a profit of at least 2000 Danish kroner<sup>3</sup> a month to take a job, and did Rasmussen not consider this an appreciable amount? The opposition leader then made his blunder with the reply: ‘2000 kroner. That depends on who you are. Some places you can probably get a pair of shoes for that kind of money....That’s not a profit worth mentioning’(Hansen 2013). The political discussion in itself is a prime example of the fine balance, institutionalized in the Danish society, between contributing to and gaining from the welfare system, between the rights and responsibilities of its citizens. But Kirsten and Robert primarily react on Rasmussen’s disregard for the economy of ordinary people and the value of moderation so apparent in my encounter with middle-class everyday life. 2000 kroner is a lot of money, they tell me. They are more concerned with the opposition leader’s mistake than with the actual discussion of the financial redistribution system which can be considered a cornerstone of the welfare state. This example also draws on the feeling of homogeneity that runs through the Danish welfare state and its citizens and which is explicitly, and famously among the Danes, expressed in novel of Aksel Sandemose as ‘The Law of Jante’ which outlines a mode of conduct where no one should consider themselves above or better than anyone else (Sandemose, 1972), again placing a firm emphasis on a moral striving for the ordinary.

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<sup>3</sup> Equivalent to approximately 300 US dollars

**The ordinary as what really matters**

Titling this dissertation 'Aiming for the ordinary' somehow implies that the ordinary is equivalent to the good life in the Danish middle class. However, ordinariness is not an explicitly stated value among the informants. No one wants to be explicitly ordinary but people does not want to be 'sticking out' either (cf. Linnet 2011). It runs between the lines throughout field notes and interview transcripts and can be seen in examples like the question of wearing shoes inside the house or not as balancing the moral value of keeping the home, or it can be seen in the dissociation from a politician's disregard of ordinary life and of moderate spending on a pair of shoes. Similarly, looking in the driveways in this neighbourhood there is a remarkable 'lack' of new and big cars among the older generation and informants often made remarks about the functionality of the car even though it is not new. Some of them proudly explained how this particular car had lasted for 10-15 years without trouble. In the cases where informants bought a new car it was chosen from practical and economic considerations, not something big or ostentatious, balancing a concern between need, comfort and superfluous luxury, signalling not too much, not too little (see also Linnet 2011). As a similar aiming for the ordinary Daniel Miller argues in his study of blue jeans wearing in London, that blue jeans wearing is a way of putting oneself into a category of being ordinary although this is mostly expressed as a concern of being comfortable (Miller, 2010). What is defined as ordinary is always culturally and relationally constructed and often not explicit. In this regard there is no fixed entity we call ordinary and we are back at the agency inherent in the 'aiming'. This aiming can be seen as intrinsic to a striving for the good life consisting of what really matters to us. In many ways, what really matters in the Danish middle class can be found in the ordinariness of everyday life; in the well-known and the certain, protected from the threat of moral tragedy (Mattingly 2014) or dangers and uncertainties that may hit a comfortable everyday life at any time (Kleinman 2006). The ordinary can be seen as a cherished way of being in the everyday lifeworld. Cheryl Mattingly describes in her study among vulnerable African American families how their lives are so pervaded with turbulence, uncertainty and drama that the ordinary becomes 'a fragile achievement, a hard won moment of mundaneness' (Mattingly 2013:323). In comparison with her informants, mine are not facing the same everyday dramas, but I find that against the background of social progression from working to middle class the ordinariness of suburban middle class everyday life

is not a given. It has been won over time and with determined hard work, and in the context of the Danish middle class, the ordinary can thus be seen to have the same kind of ‘special moral weight’ as Mattingly found among her vulnerable African American families (ibid.), and it is worth to continuously aim for. Facing, as we all do, an existential uncertainty of being in knowing that everything we hold dear can crumble away with misfortune, mistakes, illness, and death, the aiming for the ordinary becomes a moral enterprise circling around striving for the good life, maintaining its stability and developing and trusting one’s personal integrity in knowing how to manage this enterprise. Striving, stability and integrity, I believe, are key concepts to sum up what is at stake and constantly balanced in the local moral world of the Danish middle class.



This part of the introduction has tried to establish an understanding of the context of Danish middle-class everyday life with all its matters, concerns, and ordinary affects. With this as a background I will now turn in the direction of health and illness in everyday life and thus close in on the questions I initially raised in this project, and thus encircle where the analytical contexts of cancer and of everyday life meet.

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HEALTH AND ILLNESS IN EVERYDAY LIFE

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I believe in plain, wholesome food and in exercise. And not too many toxins and things like that you can stuff yourself with. Yet, also a life where you can have a glass of red wine once in a while and a beer. Even though it is poison I believe in the mental value of it....I believe that. Moderation in all things, the golden mean. I believe in that.

Karen, recently retired, 61 years old

As the quote from Karen shows, the ordinary is also seeping through matters and concerns of health, illness and well-being. Health is in the Danish middle class roughly translated into eating healthy food, as already touched upon, and/or exercising regularly. This is in tune with dominating health promotion discourses aimed at reducing lifestyle-related risk factors, and acting in accordance with this serves both the hope of a good health and the moral relation to the welfare state by doing what you can to avoid being a burden on the healthcare system. Well-being, on the other hand, can be seen as a broader perception of health in accordance with middle class notions of moderation and an aiming for the ordinary as this introduction so insistently keeps on returning to. Well-being, as presented by informants, is about feeling good in the body as well as in the mind. And if well-being means having a glass of wine – or a whole bottle, this out-does health concerns, at least as long as it is perceived as moderate (see also Risør 2003).

A good health is in many ways considered a prerequisite of ‘the good life’ in the Danish middle class. However, the horizons of what is considered a good life are dynamic and change with changing circumstances, as for example an aging body or a chronic illness which again affect how a good health is perceived. Some of my informants for instance had chronic pain due to rheumatoid arthritis and a surgery gone wrong. And I choose my words very carefully when I write that they had chronic pain instead of writing that they suffered from chronic pain. From their point of view they were not suffering – they had pain. Kirsten, for example, had chronic pain due to a surgery gone wrong and said: ‘Well, I can choose to just go to bed and whine and feel sorry for myself, or I can choose to live a relatively normal life. So that’s what I do’. Kirsten, like most other informants, stated that she was of good health. For most people a good life and

good health does not include being in constant pain but for people like Kirsten the horizon of their good life includes pain. In fact, there was in the empirical material a remarkable insistence on being of good health, to a large extent circling around a kind of refusal of illness in informants' everyday lives, concerning the threat of illness in general, their relation to the work-life and their relation to the welfare society in the shape of healthcare seeking practices.

### **'I am never ill'**

This phrase, in various versions, is the aspect of health and illness in everyday life that most clearly stands out from the empirical material. Stating a good health is a way of addressing relations that matter and should be seen more as an evaluative act than a descriptive one. It evaluates how one is able to manage the body and navigate a landscape of individual health and illness that obviously matter to the individual and their close social relations but which is also a concern to society as a whole in terms of the welfare state where individual health becomes a public matter because poor health eats into what is considered a common good of the welfare state: the publicly funded healthcare system: 'If you fail your own body, you are failing the entire body of the nation, seems to be the dictum here' (Oxlund 2012:44). The 'never ill'-statements are also often expressed in versions such as 'I am not the kind of person who goes to the doctor all the time' and 'I don't even know the name of my general practitioner'. As will be touched upon later, this relation between citizens and healthcare system/welfare state can be seen as a mutual moral relation that affects how bodily sensations are experienced, articulated and acted upon. Returning to the example of food and eating, described in the above, the moral imperative to eat healthily is both resisted and followed, also complying with Danish middle-class values of moderation and personal integrity, which also indicates a more local concern in the 'never ill' statements. A good health is important to most people but what is subjectively considered good health differs. Illness threatens what really matters and, hence, what really matters can be said to define what kind of good health is important in a particular social context. In the Danish middle class as it has been described so far, health is central to people's ability to manage well as middle-class citizens, workers, grandparents, spouses, parents, neighbours, pensioners, homeowners etc. As an example, Kirsten and Robert, along with

many other informants, went on vacation at least once a year. I spent a whole afternoon in their office where each of them sat by their own computer, shopping for the best deals on their next vacation. Kirsten and Robert often went to Southern Europe whereas others went on package tours to more exotic destinations in Asia or South America. The possibility to go on vacations matters. It matters as part of their accomplishment of an everyday life where it is economically possible and culturally acknowledged to allow oneself this kind of pleasure and enjoyment. Illness hampers this possibility, which was evident in stories of people they knew who were just about to enjoy the pleasures of retirement such as being able to travel whenever you feel like, but then they got cancer or some other serious condition. Christian, who was diagnosed with and treated for prostate cancer during the course of my fieldwork, for example insisted to invite me out for brunch in the city the day after his final day of radiation treatment because, as he told me, 'we should also just enjoy and have a nice time'. After our brunch he went straight to a travel agency to hear about the possibilities for taking a vacation with his wife in the coming spring. He was looking for a good offer but in a nice place, and somewhere with good food. Perhaps Greece.

Practicing health and illness thus works on different levels in everyday life. Karen shows this perfectly well when she tells about why her husband never wants to go to the doctor or follow health promotion directions of how to live well:

Karen: You could label it a lot of things. It is pride: 'No one should control me' and 'Well, there is nothing wrong with me' and things like that. 'I want to decide how to live my life' and so on. Where I think in different ways... I would like watch my grandchildren grow up. If I can do anything to accomplish that. And my husband wants that too, actually. But he doesn't want be dictated by norms and all that nonsense with all the focus on... You simply just get so sick from it, he says. That's his opinion about that. A lot of people are made sick from all the focus on health and diet and... We have a healthy diet. We eat really healthy food. Exercise and smoking and... overweight [her husband is overweight]. But now there's something about overweight not being as bad as it used to be....And now the new man ideal is... but this is not health-related...



Sara: Oh yeah, the dad body<sup>4</sup>... (laughs)

Karen: Yes. It is the man who stays at home. That is also a value. Instead of racing around... They run marathons and I don't know what. And exercise all the time. You are a lot away from home then. It's kind of an extra job. I wouldn't want such a man – who was never at home. That would be really annoying.

Balancing personal integrity (no one should tell me what to do) and the wish of doing what they can to stay healthy and hopefully live a long life and be able to follow their grandchildren's life, is a recurring disagreement between Karen and her husband concerning healthy lifestyle and healthcare seeking. Karen also explicitly weaves values of home and family in to her reflections as oppositions to more extreme health activities. Here, she points to an increasing tendency, visible in topical newspaper articles and debates circulating the Danish media landscape (Knudsen, 2015), to exercise a lot at the presumed cost of time and presence with the family. Karen herself is a very physically active woman and do some form of exercise every day. She is the trainer of a work out group, she swims or she goes for a walk. At the moment of fieldwork, however, she is recovering and in rehabilitation therapy after she stumbled, fell and broke her hip. In this situation she was very careful to follow medical advice about when, how and how much she should exercise to be able to have her body return to normal. This example again takes us towards something ordinary. It is important to Karen and her husband to eat healthily and they follow official health advice regarding food. However, Karen's husband, in Karen's perspective, also explicitly resists 'dictating norms' of how to live his life, addressing the matter of individual integrity discussed earlier. Karen, more implicitly, follows suit by emphasizing values related to home and family as superior to a healthy and fit physical body. This mixture of compliance and resistance to health promotion discourses aims for the similar kind of ordinary we saw in Robert and Kirsten's lunch where personal 'health sins' are allowed with reference to personal integrity in an enactment of health, inspired by Garro (2011), that balances

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<sup>4</sup> Around the time where the interview took place there had been stories circulating in the media about the new ideal male body being the 'dad body' implying a not so fit and well-trimmed ideal body.



normative ideas of healthy lifestyle and a harmonious emotional atmosphere which in the Danish middle class context often will be described as *hyggelig*.



A notice board in one of my informants' kitchen displaying various health informations together with mailing price list, a hairdresser's business card, measurements for a new cushion, and some beloved dogs.

As another part of the striking refusal of illness in their lives, many informants stated like this that it took a lot for them to stay home from work. A common cold was simply not a valid reason for taking a sick day. As shown earlier, informants' worklife and their ability to manage a social mobility and create opportunities for their lives are central to everyday concerns among the informants. This also affects their perceptions of health and illness:

Jens: Honestly speaking, I am born in 1945 and I have never had the flu.  
Why should I...

Sonja: Jens, that is not true.

Jens: But I sure can't remember it.

Sonja: No but I can (laughs). When you are lying down, whining, on the sofa or in the bed. Yes, you had it.

Jens: While I was still working... You know, we sat in these rows. We sat there sorting the papers in a kind of long row. When there was a flu epidemic, then these people were sick and those people were sick. Then he got sick and he over there got sick. In the end I was the only left, sitting there all by myself. Everyone else was replacements. Because all my colleagues were just simply sick. And I never had it....My dad he said that illness should be fought by working. So he went to work no matter what. So I don't know if... perhaps I did have the flu but not enough for me to stay home, that's for sure. Maybe that's the difference.

Another informant even stated that 'my generation, we are not really that ill' and she further elaborated that 'these young people, they stay at home for nothing! My sick days are not many. But yes, I have learned to take a couple of days'. Turning the issue into a matter of generational differences propose similarities to what Gullestad (1996) described in Norway with regard to transfer of values in the upbringing of children and changes in work-life theories and production regimes as a generational conflict between values of 'obedience' and 'being oneself' where a sense of community gradually turns into more individualism. Similar to my experience among in the Danish middle class, Gullestad emphasize values of responsibility, a Protestant work ethic, being of use, hard work and modesty among the older generation in her analysis (ibid.:27). When my informants highlight that they never took any sick days unless they really could not get out of bed it can be seen as a similar valuing of responsibility for a sense of communality and social coherence which is seen in opposition to increasing individualism.

Another example is Christian who underwent treatment for prostate cancer while still going to work. In the waiting room at the urology department, where he went regularly for radiation treatment, he told about how the other men in the waiting room were complaining about how it took up so much time every day they had to go there: 'But then I also told them: "what about going to work then?" I could get

a whole working day out of it before I had to be at the hospital. They didn't get anything else out of their days'.

Not even facing cancer was Christian willing to 'succumb' to illness. He was concerned about keeping things as normal as possible which included going to work early in the morning and continue to the hospital afterwards, and the complaint from the others in the waiting room only confirmed his strategy of keeping things close to the ordinary.

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## THEORETICAL PERSPECTIVES

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The final part of this introduction will present the overall analytical framework of sensorial anthropology and the directions it provided for the different analyses before I briefly present and discuss my use of central analytical concepts.

### **Sensations and symptoms in everyday life**

Finally, to hinder the description of illness in literature, there is the poverty of the language. English, which can express the thoughts of Hamlet and the tragedy of Lear, has no words for the shiver and the headache. It has all grown one way. The merest schoolgirl, when she falls in love, has Shakespeare or Keats to speak her mind for her; but let a sufferer try to describe a pain in his head to a doctor and language at once runs dry (Woolf 1993:200).

So wrote Virginia Woolf in 1926 about the relation between illness and language, and I could describe the experience of my fieldwork in very similar ways. Setting out to explore sensations and symptoms in everyday life in a prospectively oriented research design of 'when they happen' I was at first deeply frustrated and bewildered because nothing really happened, or rather, things happened but neither the informants nor I was able to put this into words or any form communicable understanding (see also Ehn, Löfgren, and Wilk 2015). The subtleties of bodily experience on the verge between normal and abnormal resisted language (Scarry, 1985), and as soon as something could be verbalized it had already transformed into something else, something less subtle. I often had

the experience of circling around a bodily ‘something’ together with an informant without being able to make this something intelligible. The harder I tried to ‘catch’ these elusive, vague and ambiguous experiences, the more demanding became the insufficiency of words that at best provided the contour of an intersubjective attention towards a ‘something’, and at worst seemed to distort or violate experience. This is not necessarily a problem and it was also not completely unexpected. Instead it forced me to attend on all the things around it: What was the something not? How did time and place interfere in the embodied experience of the sensation? Why was this ‘something but nothing’ sensation remembered and discussed? And ‘what really mattered’ (Arthur Kleinman, 2006) around the bodily sensation? And it turned my focus towards the ordinary body in the understanding that bodily ordinariness is shaped from a culturally defined ordinary in the particular local moral world. Hence, I turned my attention to the culturally contingent moral concerns of the Danish middle-class community where I was accepting yet another cup of coffee while gradually realizing how even the details of coffee-drinking during an interview would have to be subject to my ethnographic scrutiny.

In Kathleen Stewart’s amazing book (2007) of ordinary affects she draws an image of the ordinary as animate circuits and surges of affects that create intensities of significations from immanent potentialities and resonances. Following this way of thinking trying to escape the anthropological urge to find coherence and explanations that adhere to categories and labels (Stewart, 2007; Throop, 2010), as I partly was trying to do in the beginning, it makes sense to attempt to follow Stewart and stay ‘in the middle of things’(Stewart 2007: 128) and attend to ‘the ambiguities, the confusions, the gaps, and the ambivalences that arise in the midst of our own, and our informants’, experiences as lived’ (Throop 2010:3). In the case of this study the attempt has been made through the focus on experience of sensations, trying to slow down and stay in the middle of the surging processes, which potentially transform a sensation into a symptom or absorb it into the realm of the ordinary, and attend to the details, the ordinary affects, in these surges. What are the significances that are created from ‘bodies literally affecting one another and generating intensities: human bodies, discursive bodies, bodies of thought, bodies of water’ (Stewart, 2007:128).

**Sensorial anthropology**

To do this I initially turned towards an increasing anthropological interest in the senses and bodily sensations (e.g. Hinton, Howes, and Kirmayer 2008; Nichter 2008; Hay 2008; Howes 2005; Classen 2010; Throop 2010; Geurts 2002). It is argued within this sprouting branch of anthropology that ‘The human sensorium....never exists in a natural state. Humans are social beings, and just as human nature itself is a product of culture, so is the human sensorium’ (Howes 2005a: 3) and that ‘in fact, all sensations come into being and are altered through processes of attention and interpretation’ (Hinton, Howes, and Kirmayer 2008:140). Insights like these became my analytical starting points and proved ‘good to think with’ along with the eloquently phrased definition of a sensorial anthropology by Marc Nichter: ‘sensorial anthropology explores how sensations are experienced phenomenologically, interpreted culturally, and responded to socially’ (Nichter 2008: 166). While I found it a little more difficult to work with than to think with in directly applying its general insights to my empirical material, both during fieldwork and in the phase of analysis and writing, it served me well as an overall analytical framework guiding my ethnographic focus in the field and the questions I could raise to my empirical material in my analytical thinking. However, as one of the first prospectively oriented studies of how sensations are experienced and articulated as symptoms, Hay’s (2008) model of sensation to symptom transformation among the Sasaks on Lombok, Indonesia, inspired me to attend to the nature of culturally defined thresholds between sensation and symptom (ibid.:200) and the local particularities of sociocultural frameworks informing the sensation experience (ibid.:222). But in trying to zoom in on the thresholds between sensation and symptom it became clear that these were as elusive and always out of focus as the sensations themselves, which is also illustrated by the non-linear and multidirectional transformative processes in Hay’s model. To understand this, it is necessary to underline that the threshold between sensation and symptom must be considered an analytical distinction, and that, as chapter 4 in this dissertation in particular argues, it might be fruitful to look at transformations between sensation and symptom as happening on a seesawing continuum between what is considered normal and not normal. Also, we might consider phrasing these processes in a less linear fashion than ‘sensation to symptom transformations’, and rather ‘transformations between sensation and symptom’. As such, this dissertation treats symptoms as an emic category, applied by informants to empirically described bodily sensations,

defined by an analytical distinction between sensation and symptom. The sensorial and interpretive process of distinguishing between ‘fine’ and ‘sick’ as Hay phrases it, takes its point of departure in what is considered ordinary with the ultimate aim of being able to refer a bodily sensation to the realm of ordinary bodily processes. I concur with Veena Das and Ranendra Das (2007) that we should not be looking for ‘culturally standardized breakpoints’ on the continuum of health and illness but that we should rather be looking at illness, and, consequently, sensations and symptoms, as movements between registers of the ordinary and the extraordinary. These movements, or what I, in my analysis, have called a seesawing continuum, are affected by the uncertainty, ambiguity and morality as what really matters in everyday life in a particular local moral world. This understanding thus leads us back to everyday life as unfolded in this introduction. In terms of health and illness, everyday life, I argue, is lead on a continuum of bodily normality and your position on this continuum is affected exactly by what is understood as ordinary or normal which in turn also affects how we sense, perceive and interpret the body. Therefore, noticing a bodily sensation and positioning the severity of it between ordinary, extraordinary, and potentially serious, is not an individual process (see also Nichter 2008). It is highly influenced by shared cultural understandings of the ordinary, both in terms of ordinary bodily sensations and of shared ideas of what counts as the ‘valued ordinary’ in the pursue of ‘the good life’ (Mattingly, 2014).

### **Analytical key concepts**

With sensorial anthropology as the lighthouse guiding my analytical explorations, I have elaborated the sensorial perspective, aided by different analytical concepts, each of them used in my attempt to uncover layers of the experience of sensations.

Directly fishing in the pool of sensorial anthropology, I find that Howes’ presentation of the idea of a sensescape (Howes, 2005b) provides a good way of exploring how informants were navigating the merging of the sociocultural context of the Danish middle class with their sensorial experiences. In analysing this navigation, themes of morality kept on surfacing in the empirical material, and with inspiration from Kleinman’s focus on morality as what really matters to people (Arthur Kleinman, 1998, 2006) and Mattingly’s notion of moral



possibilities (Mattingly, 2014), the sensescape of Danish middle class everyday life can be seen as essentially moral, showing how culturally contingent moral compass is directing somatic modes of attention (Csordas, 1993) and accompanying articulations and actions.

In trying to further dissect the transformations between sensations and symptoms, the concept of potentiality is a central analytical concept in my explanation of some of the dynamics in these transformations in terms of what I describe as a weighing of different potentialities in the experience of sensations. Anthropological interest in potentiality is a relatively recent orientation that gains footing especially in medical anthropological areas focusing on biomedical potentials and their social consequences such as biotechnological advances (Gammeltoft, 2013; Svendsen, 2011), genetics (Gibbon, 2013; Lee, 2013), diagnostic constructions of risk, biomarkers and pre-states of disease (Brown, Lyson, & Jenkins, 2011), and more political questions of the organization of rights and priorities in the healthcare sector (Kaufman, 2013). It can furthermore be argued that potentiality is present in a range of other anthropological conceptualizations such for example the concept of ‘the biotechnical embrace’ (Good 2007) and ‘the political economy of hope’ (Good et al. 1990) developed by Good and colleagues . Moreover, it has been applied with regard to experience and interpretation of impending conflict in areas characterized by high levels of violent conflicts and uncertainty, in terms of a negative potentiality inducing a state of hyper-vigilance in the inhabitants of a violence-prone social setting (Vigh, 2011). Vigh’s analysis of hyper-vigilance related to negative potentiality resonates with my perspective on the potentiality of bodily sensations in chapter 4 where I with Taussig et al. investigate potentiality as ‘that which does not (yet and may never) exist’ (Taussig, Hoeyer, and Helmreich 2013:S4) with regard to the experience of sensations and their potential for being part of the ordinary or a sign of something extraordinary, touching, in some cases, upon a hyper-vigilance towards the ordinary body.

My wish of merging the sensorial everyday life framework directly with cancer as it is imagined, practiced, affecting and affected by everyday life resulted in a focus on cancer as mythologies. This approach has some perilous pitfalls when applied in the midst of anthropology, biomedicine, public health and medical anthropology, the main being the risk of reinforcing, especially within the fields



of biomedicine and public health, stereotypical dichotomies between ‘native’ or ‘lay’ illness representations opposed to scientific biomedical truths. This dichotomy is also reflected in Sontag’s seminal work on cancer mythology and metaphor (Sontag, 1991) which therefore serves as an interesting vantage point from where to explore contemporary cancer mythologies. Sontag believed that increasing scientific knowledge of cancer would replace myth and metaphor, liberating cancer patients from a metaphorical and demoralizing iron grip. Chapter 5 in this dissertation argues against this prediction by showing how cancer mythologies in everyday life do not distinguish between ‘subjective beliefs’ and ‘objective knowledge’ but rather consists of a bricolage of knowledge, attention and experience contingent upon subjectivity and context. The notion of mythologies also provides me with the means to explore how public health constructions such as symptom awareness plays into the dynamics of cancer mythologies unfolded in the context of everyday life.

## CHAPTER 2:

### METHODOLOGY

This chapter is a description and discussion of the design and the methods used in this study and their implications for the findings. First, I will attend to the research design in terms of ethnographic fieldwork, recruitment and description of informants and the empirical material on which the analyses are based. Second, I will discuss my main analytical challenge related to the research design, the empirical data and the theoretical aims of the analyses. A discussion of strengths and limitations is continuously interwoven into my methodological considerations.

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#### ESTABLISHING A FIELD

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Aiming for the ordinary is not confined to be an empirical finding and an analytical perspective. Aiming for the ordinary is central to the methodology of this study as well. As argued in the introduction, approaching bodily sensations before they might turn into symptoms and healthcare seeking requires a prospectively oriented focus and a broad perspective on everyday life in which sensorial experiences and decisions of healthcare seeking are embedded. The retrospective orientation in many existing studies may introduce what in public health vocabulary would be termed ‘recall bias’, and in anthropological terms it

would introduce a meaning and coherence in the narration that were not present at the time of the event or ambiguous experience (Linda C. Garro, 2000). It would, I believe, tell about thresholds of interpreting sensations as symptoms. Thresholds that I, as argued earlier, were not able to find in the uncertain and ambiguous everyday life experiences of bodily sensations. Furthermore, the research design of this study follows the premise that to understand illness, we must also understand health in the particular social and cultural context under study (Hay, 2008). Consequently, the design of this project purposefully let the broad notion of everyday life take centre stage rather than my more narrowly defined interest in sensations, symptoms and cancer.

Thus equipped with a temporal frame (the prospective perspective), a background context (the public health defined field of cancer and care seeking), and a rather broad frame regarding focus and content (health and illness in everyday life), combined with the already described choice of the empirical setting of the Danish middle class, the interweaving empirical and analytical objects that constitute an anthropological field (Hastrup 2003), broadly took form as a methodological aiming for the ordinary in terms of ordinary bodies, ordinary sensations, ordinary life, and some old-fashioned virtues of good old ordinary ethnographic fieldwork as called for by Paul Atkinson (Atkinson, 2015) in a time of increasing popularity, particularly within the health sciences, of various qualitative research methods that cannot, according to him, be equated with ethnography. Ethnography, he argues, is a very special way of doing social research, characterized by ‘a thoroughgoing commitment to understand other people’s social worlds’ (ibid.:5) with ‘a close attention to the particularities of social life; an equally close attention to the forms of their representation; the reflexive attention to the productive work of the artist, writer and ethnographer; an awareness of the work of biographical and autobiographical construction’ (ibid.:4-5).

The unique anthropological methodology of fieldwork, and especially the distinct anthropological method of participant observation, is continuously scrutinized as changing global and local circumstances demand new ways of engaging with the world around us (Hammersley and Atkinson 2007; Gupta and Ferguson 1997). The global and the local merge in ethnographic experience and we are long past the view of societies and cultures as distinct and enclosed entities to be

ethnographically investigated (Hastrup 2012), and field sites are no longer confined to this view but can better be described as a following of both ethnographic and empirical interests in diverse settings (Hannerz, 2003; Marcus, 1995).

### **The neighbourhood as field location**

Having defined my study in terms of an interest in middle class everyday life, the question of how to define the Danish middle class came to the fore. In Denmark, housing is a still more significant marker of social status as both higher and lower classes seem to congregate in ‘enclaves’ with increasing differences in house prices as a consequence (Olsen, Plough, Andersen, & Juul, 2012). Thus, ‘class takes on a spatial form, revealing itself in perceptions of different neighbourhoods and areas and of the people living there’ (Faber & Prieur, 2013). The prevailing perception of a middle class neighbourhood in Denmark will often be a suburban residential area, planned and built primarily in the 1960s and 1970s with single family detached houses. This form of living is in fact how the majority of the Danes live (J. B. Jensen, 2006) and came to be the primary characteristic and point of departure of my ethnographic *location* of the Danish middle class. My ethnographic interest in everyday life as it unfolded, and a middle class aiming for the ordinary, followed my informants’ everyday doings, concerns and histories and thus transcended the location of fieldwork and constituted my ethnographic *field*.

### **Anthropology at home**

The fieldwork of this study is conducted ‘at home’ in my own cultural backyard of everyday life in the Danish middle class. This introduces particular methodological advantages and challenges which are also well described in the literature, often centring around to what extent it is possible for the native ethnographer to distance oneself enough from the field to be able to look beyond, and yet identify, her own cultural assumptions of the social reality she is studying (Ginkel 1998; Hastrup 1993).

The Danish middle class to a large extent resembles my own background and distancing the familiar of everyday life proved challenging (Gullestad 1992:28-33), and the feeling of bringing ‘nothing particular’ home from the field was often overwhelming, and fieldnotes were difficult to write with the inherent familiarity in the field experience. Distancing oneself from the familiar is a methodological and an analytical process, and as Hastrup argues: ‘there is no way in which one can simultaneously speak from a native and an anthropological position. It is logically impossible to speak from an inside and an outside position at the same time’ (Hastrup 1993:157), thus implying that the idea of native anthropology is a contradiction, and that anthropological scholarly disciplining of its practitioners, by a largely implicit practical knowledge and acknowledgement of certain standards of scholarship, ensures that anthropological thinking and practice always transcend local knowledge (ibid.:156). Thus, the analytical reflection in the writing of fieldnotes and concentrating on paying attention to details and significances that so easily slipped my attention, and especially in reading and re-reading the notes and interview transcripts was a way of distancing myself from the very familiar setting of coffee-drinking in living rooms; a performance I indeed am able to manage perfectly as a native, while I in my writing and analysis attempt to transcend this local know-how and present the ordinary as an anthropologist.

An advantage, worth mentioning, of doing fieldwork at home is the ability to ‘read between the lines’ in social situations. While some details will be hidden in all their familiarity, some aspects of the social will be more easily ‘read’ by the native anthropologist. I draw extensively on this ability in paper 3 where I claim a presence of cancer in several social situations where cancer is not mentioned, solely based on my sense of the situation. To some extent I can trace where this sense comes from in my ongoing interactions with individuals over time, but part of it is not traceable and relies, I believe, on the culturally habitual interaction between the particular informants and me.

### **The ordinary as ethnographic field**

With the aim of exploring health, illness, sensations and symptoms in the complexity of everyday life without any strict empirical direction such as a particular diagnosis, pre-defined symptoms, or specific conspicuous living

conditions, such as very poor or very rich, fieldwork became as ordinary as it gets for a native Danish anthropologist. Plunging myself into this ordinariness thus forced me to consciously attend to the details, to the very texture, of everyday life and how the body, health and illness were perceived through this. Sjaak van der Geest has recently argued, in a plea to study the ordinary in and of itself, that anthropologists doing fieldwork ‘at home’ tend to search for the drama and the exotic in the familiar settings of their own cultural contexts (van der Geest, 2015). We do this, he says, by selecting other study populations than our own closest cultural relatives, by focusing on specific topics or events within that population, and by raising particular questions, because our own ordinary is too elusive, implicit and boring to study and capture in writing (ibid.:84-87). In Denmark this is evident in a remarkable lack of anthropological interest in e.g. the middle class and their neighbourhoods (S. R. Andersen, 2004). By floating around in familiar, implicit and non-dramatic ordinariness on the verge of boredom in this fieldwork and trying to give this ordinariness a voice in my analyses, I have attempted to counter the first two exoticizing temptations. However, I would indeed find it hard to conduct an ethnographic exploration, even of the ordinary, where I did not raise particular questions, and my study is thus also an attempt to give the ordinary a particular relevance to public health questioning. I adhere to the call for studies of the ordinary and I find its elusiveness intriguing, but in establishing a field of the ordinary without confining it to location of the neighbourhood, I lean more towards Hastrup’s notion where ‘fields are as emergent as are anthropological interest...To have ‘enough’ ethnographic material is not a simple function of the long term [or of the number of informants, I might add in also addressing a public health research framework], but more of the questions asked’ (Hastrup 2012:146). Furthermore, Sarah Pink has argued that the assumed lack of anthropological interest in the ordinariness of everyday life is not so much a lack of interest, since anthropologists have always studied the lives of people in their everyday both ‘at home’ and ‘away’ (whatever form that takes), as it is perhaps a lack of a joining of the existing and flourishing bodies of both theoretical and empirical work on the everyday, leaving to some degree everyday life to be an anthropologically assumed and uninterrogated, rather descriptive category (Pink 2012:6-8).

Studying everyday life has the distinct implication that everything is at stake and nothing is at stake; it is at the same time ‘a set of banalities and a deep mystery’

(Kalekin-Fishman & Low, 2010). It is all-encompassing but specific, unfocused but existential, and micro and macro, local and global at the same time, and thus requires a what Hastrup calls scaling of the fieldworkers attention: ‘a profound matter of putting a particular perspective to work, and of identifying the complexity of any detail or fragment’ (Hastrup 2012:148-149). In this study it can be argued that approaching the ordinary with questions of how bodily sensations are experienced and articulated serves as a scaling, letting the sensorial perspective work on the ordinary. However, from the point of view of the analytical context of cancer and the background questions this study emanates from, concerning symptoms and healthcare seeking practices, the scaling, I would argue, is turning the other way around: the ordinary becomes a scaling of cancer in Denmark, encompassing all levels from the local to the global as they are expressed in a particular field. In this way, no matter from which angle you look at it, scales of attention raise particular questions arising from particular research interest; we are always looking at something from somewhere thus constituting the anthropological field. Either way, I believe, these scales of attention help me to ‘unassume’ and interrogate the ordinariness of everyday life.

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#### INTRODUCING THE INFORMANTS AND THE ETHNOGRAPHIC SETTING

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The single family detached house as a way of living is predominant in Denmark (S. R. Andersen, 2004; J. B. Jensen, 2006). It has grown out of the industrialization where new industry was built outside the cities. The workers came along, and the suburbs emerged (Lind & Møller, 2014). As I have already described, the middle class informants of this study likewise grew out of primarily working class families along with the building boom in single family house neighbourhoods in the 1960s which since then has been the dominating way of housing in Denmark. However, from being a sign of progress and development, these neighbourhoods and the lives lived within them are now often stereotypically considered static and monotonous in their status as so-called ‘golden wedding neighbourhoods’ implying that these neighbourhoods are inhabited mainly by older people approaching their 50 years wedding anniversary (termed golden wedding in Denmark). However, during the last decades, the neighbourhoods of this kind is experiencing a generational shift where younger



families give the houses a makeover and reinvent everyday life in this distinct but typical Danish housing form.

The particular single family house neighbourhood that framed the geographical point of departure for my study was built in the 1970s and had thus not yet experienced a profound generational shift. It was rather a mixture of retired people above the age of 60, young families, and what my informants termed 'well-integrated foreigners' who had opted for a different kind of everyday life than in the neighbouring immigrant enclaves of housing in grey concrete apartment properties. Yet, perhaps due to my method of recruiting, I ended up with a group of informants of mainly people above the age of 60 who were retired or on the verge of retirement.

Recruitment of informants was initially done by going door to door, giving out leaflets about participation in the project and asking for permission to call people later. This way of contacting people gave potential informants time to consider their participation in the project, and it was at the same time in compliance with Danish law on how to approach people with research purposes. Where no one answered the door, an information letter, encouraging them to call me, was left in their mailbox. No one responded on this way of contact, but approaching people face to face paid off, and I soon got a handful of key informants. Especially on one of the side roads, people were willing to participate, and I thus ended up including people from half of the houses on this small road, comprising a particular kind of social community which was specific for living closely together on the smaller roads as opposed to a seeming lack of a sense of community of the whole neighbourhood as such. This side road provided the empirical material a broader common context for the individual informants' stories and accounts but it also became a well-known writing challenge in terms of anonymization of informants 'at home' who will potentially read the results of their participation in the study. People on this side road know each other and would relatively easily be able to recognize each other. Since some of the things disclosed to me were of a private character it has been necessary to hide details of their lives and stories that no doubt would have enriched the ethnographic writing.

Moreover, to get different access point into the field of middle class everyday life, I entered a physical exercise group for older people in the suburb. The first

half of my fieldwork I participated on this team every week, sometimes twice a week. This provided me with other perspectives on everyday life and expanded the location of the neighbourhood to encompass the wider community of the suburb. I also became part of a local 'people's choir' in the nearby church in the same manner. Both of these activities furthermore had a bodily dimension; a more condensed attention to bodily practices than the broad exploration of everyday life in the location of neighbourhood. I recruited additional informants from both activities and ended up with 18 key informants.

Door to door recruitment was done during daytime, and, logically, the people I met were those who did not go to work anymore. When I occasionally met younger people or families with young children, they were interested in the project but declined participation primarily due to lack of time. So even though I had defined a lower age limit of 40 years, I only recruited two informants in their 40s whom I met through the local choir. Thus, my recruitment of mainly the older part of the inhabitants of the neighbourhood to a large extent shaped the field with respect to the particular questions it seemed interesting and relevant to raise. This became especially obvious in the contrast to the inclusion of the two markedly younger informants, Charlotte (46) and Peter (49), who fell within the rather open predefined inclusion criteria of being above 40 years old and owning their own house in the neighbourhood. The differences between Charlotte and Peter and the rest of the informants regarding e.g. life stories, levels of education and everyday life were unmistakable and served to further encircle my field around the distinct age group above 60 and reinforce ideas of some common concerns expressed in particular ways within this group of people, such as for example the notion of the good citizen, as will be discussed later. Charlotte and Peter are thus explicitly absent in the analyses and are my 'least used' informants. However they are implicitly present in very distinctly directing my attention to the particularities of age and the weight of the historical contexts that life stories depart in. In this way, what turned out to become a rather narrow age group, with these mentioned exceptions, can be seen both as a strength and a limitation of this study.

**Overview of informants:**

<b>Informant</b>	<b>Age</b>	<b>Occupation status</b>	<b>Marital status</b>	<b>Number of children</b>	<b>Recruited from</b>
Betty	74	Retired <sup>5</sup> , used to do administrative work	Widowed	3	Neighbourhood
Jens	67	Retired, used to work as general labourer	Married to Sonja	2	Neighbourhood
Sonja	65	Retired, used to work in the healthcare sector	Married to Jens	2	Neighbourhood
Finn	72	Retired, used to work in communication technology	Married to Doris	2	Neighbourhood
Doris	66	Retired, used to work as a medical secretary	Married to Finn	2	Neighbourhood
Kirsten	70	Retired, different former positions	Married to Robert	3	Neighbourhood
Robert	73	Retired, used to work as machine operator	Married to Kirsten	3	Neighbourhood
Erik	75	Retired, used to work in the public service sector	Married	2	Neighbourhood
Jette	63	Retired, used to do administrative work	Married	2	Physical exercise team
Michael	64	Works as machine operator	Divorced and married again	2	Neighbourhood

<sup>5</sup> I use the term retired to refer to a withdrawal from the labour market, getting retirement pension or early retirement pension (*efterløn*)

Christian	66	Works as machine operator	Married	2	Neighbourhood
Helen	77	Retired, used to do office work	Married	2	Physical exercise team
Ingrid	66	Retired, used to work the public service sector	Married	2	Choir
Elisabeth	64	Retired, used to administrative work	Married	2	Choir
Christine	65	In the process of gradually retiring from working in the public service sector	Divorced and married again	1	Choir
Charlotte	46	Working as computer programmer	Married to Peter	0	Choir
Peter	49	Working as consultant	Married to Charlotte	0	Through his wife
Karen	61	Retired during fieldwork from working in the public service sector	Married	3 + 1 from husband's former relationship.	Choir

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#### CONDUCTING FIELDWORK

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The design of this study was an attempt to engage with everyday life with ‘an ethnographic sensibility and an ongoing engagement with lives unfolding in real time and through time’ (Back, 2015: 834); making the familiar strange and paying attention to the seemingly unimportant (Back, 2015; Ehn et al., 2015) by being consciously alert to everyday life concerns (Barth, 1993), and what really matters to the people in this particular setting (Arthur Kleinman, 2006). The big methodological question concerning this then became the question of how to get and construct access to unfolding lives, seemingly unimportant details, and

substantial concerns (Hammersley and Atkinson 2007:41-62). Having included 18 informants willing to participate was only the first step among many to continuously negotiate access to e.g. their wider social networks and activities (where would it be okay to bring an anthropologist along?), intimate bodily details and worries (is this too private to tell? And will I be anonymous?), and all the seemingly unimportant details that everyday life consists of. In fact, the latter proved most difficult and deserves some elaboration, since I soon realized that the way of life I was studying and the way the fieldwork was designed did not fit my wish of participating in the most ordinary of everyday life very well. Plans were made, appointments noted in their calendars and in mine, resulting in field visits being characterized exactly by this; a visit. This entailed, as touched upon already, a lot of coffee-drinking, often at already made tables where cups and plates were only waiting for my arrival. Informants also explicitly made their plans so that they could finish all their housework of that particular day before my arrival so that we would 'have time' (to discuss the, from the informants' view, seemingly important) and it was clear that they considered ordinary tasks such as housework self-evident banalities that could not possibly be of any interest to me even though I tried to convince them of the opposite. This was characteristic throughout the fieldwork period but at the same time I also experienced a transformation over time where our appointments in most cases became less formal. This was for example evident in how I was welcomed into the house and the naturalness of which rooms I had immediate access to. In many first visits I was for example lead directly to the living room but as the fieldwork progressed I often had the experience that the tables and the coffee were not quite as prepared, and the conversations often started in the kitchen while making the coffee. Throughout fieldwork I was thus gradually negotiating access to banalities which in a Goffmanesque sense of impression management belongs 'backstage' (Goffman, 1990).

Being interested in vague and elusive bodily sensations before they turn into something else or into nothing also posed a difficulty of accessing information. Empirically, I was trying to grasp something which almost did not exist, and analytically, I was looking with a perspective of some kind of sensory-cultural thresholds at a kind of experience which is not demarcated by thresholds but continuously experienced and negotiated. Furthermore, as already described, I

was exploring something which resists language and hence could not immediately be derived from interviews and conversations.

I have tried to embrace these challenges by a range of different research methods, which can be seen as different ways of getting access to information about how health, illness and sensations were experienced and articulated in the everyday life of my informants. In the next section I will briefly discuss my use of these methods and the empirical material derived from them one by one.

### **Participant observation**

When doing participant observation the levels of participation and observation are always varying and negotiable. I did not move to the neighbourhood with my family to do full-time participant observation, and as I have stated, I found it difficult to just casually tag along as informants were so eager to participate that they cleared their schedules for me. Coming home from the field facing the writing of fieldnotes thus proved an immensely frustrating task since I did not know where to start, and it seemed to me a matter of writing nothing or writing everything. My lack of a tangible focus made everything potentially relevant while at the same time being so familiar that I at times felt 'home blind' (Ginkel, 1998). I therefore used different strategies to help making the familiar strange. Spending a lot of time in and around the houses in neighbourhood was an opportunity to start noticing how significances attached to the house and the surroundings in different ways, such as for instance the question of whether to wear shoes inside or not and what it meant – a very familiar issue that I have never considered before. Thus, reflecting on the materiality of spaces shared with informants became a way of noticing everyday life significances. Another strategy was to get out of the house and encourage informants to invite me into their everyday tasks of grocery shopping or walking the dog as well as leisure activities such as golfing or bowling. At times I also accompanied informants to appointments at their general practitioner or at the hospital. Writing of field notes were exclusively done after each visit in the field in order not to intrude on the friendly relationships that gradually developed between the informants and me (Emerson, Fretz, & Shaw, 1995).

One important perspective to highlight in this fieldwork is also the time shared with informants, most prominently, the timeframe of the fieldwork. In trying to access the elusive, non-verbal, almost non-existent, phenomena of bodily sensations that might be articulated as symptoms, sharing occasional time of everyday life, over a long period of time, together with informants, I believe, is key to get closer to an understanding of sensorial and moral weighing between the ordinary and the extraordinary.

### **Interviews**

During the course of fieldwork I conducted three interviews with each informant. The couples were interviewed together. All three interviews had different themes, but overall they all kept returning to the same themes, issues and questions concerning the body, health and illness to the extent that I often found myself embarrassingly confused in the middle of an interview, doubting if this was not the same interview as last time. However, this proved very fruitful in uncovering emergent concerns and inherent paradoxes, since answers concerning the same themes and episodes could be different and self-contradictory and also completely alike. The time frame of my study, in comparison with single interview-studies, also allowed me to devote a whole interview to informants' life stories providing me with a historical contextualization of how health and illness for example is experienced and practiced in everyday life. Another interview were focusing on specific sensorial experiences and healthcare seeking, while the final interview had an overall aim of understanding in what ways cancer is present among people not immediately afflicted by cancer in their everyday lives. Interviews were transcribed verbatim and coded in Nvivo in the analytical process.

### **Diaries**

In a period of six months, informants were asked to fill in a 'health diary'. They were supposed to note any bodily change or unusual sensation in their bodies, as well as any contacts with the healthcare system. They were instructed in noting down every time they felt something or at least every second week where I would send them a text message reminder. Even though this turned out to be a difficult



task and that many diaries were returned relatively empty, it was of great importance in showing how difficult it is to ask people to determine when something is unusual. The diaries were used as points of departure of discussing experience of sensations in one of the interviews, and were an attempt at getting access to more of the unnoticed sensations that pass by in an everyday life. It can be argued that this is just as well a retrospective orientation inside my ambition of exploring the transformations between sensations and symptoms as they happen. It is, indeed, from the perspective of the interview situation and it is not unproblematic but it was a way of accessing a problematic phenomenon, the transformations between sensation and symptom, by trying to capture a broader range of sensations than only those which are actually interpreted as symptoms of potential illness and thus easily are ascribed significance retrospectively. In several interviews based on the diaries the informants for instance expressed how they had already forgotten about some of the less significant diary entries.

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#### ANALYSING THE MATERIAL

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The ongoing process of analysing fieldwork material deserves a final comment here, because I want to address the point of analytical categories. I have throughout this dissertation and in the papers argued for a perspective, inspired by Throop (Throop, 2003, 2010), that attends to the ambiguity and non-coherence of experience instead of trying to ascribe it coherent meaning. In the field I was met with ambiguity, uncertainty and non-coherence, and particularly with regard to the experience, organization and articulation of sensations, this was profound. In my interest in sensations, I thus agree with Howes that 'rather than attempting to 'free' ideas from the knot of the senses, we should try to understand how meaning and sense are one' (Howes 2005a: 9). And I believe, leaning on Stewart (2007) that this entangled knot of the senses and sensations is where to find intensities of ordinary affects creating significances of the body, sensations, everyday life and also of health promotion discourses and biomedical ways of knowing. I have argued that we should try not to disentangle various ways of experiencing and articulating sensations but instead try to understand the entanglement in itself.

This position, however, seemingly contrasts what I am analytically doing in each of my papers where I delineate moral possibilities in paper 1, categorize potentialities of sensations in paper 2, and describe different mythologies of cancer in paper 3. The anthropological urge to classify has resulted in something that resembles coherence and meaning from something which was not experienced as meaningfully coherent, neither by the informants nor the researcher. On the other hand, what I hope to show in my analyses by slicing up experience in categories is that by scrutinizing the slices one by one and putting them back together again, properly entangled in each other, new understandings about the ambiguity and non-coherence of the embodied experience of sensations take form.

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#### ETHICAL CONSIDERATIONS

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All key informants signed a letter of informed consent upon agreeing to participate in the study, accepting that their information would be used for the purposes stated in the letter. In the activities at the physical exercise team and the local choir, I presented myself and the project to properly inform all participants of the purpose of my attendance. Thus, several levels of information and consent interact in the course of the fieldwork, since more peripheral informants such as the other participants in these activities than my key informants, indirectly contributed with information to the study, from being part of these activities alone, without signing letters of informed consent. Fieldwork is in this regard a complex undertaking and the ethnographic knowledge is produced in relations and shared experience, where also stories of unknown others; friends or family, interweaves in social experience and personal stories and naturally becomes part of the empirical data material. Informants have been anonymized and given fictive names, and information that would compromise this anonymization has been omitted.

Another ethical area of consideration, when studying potential symptoms, is the moral obligation to intervene when encountering something that e.g. could be defined as an alarm symptom of cancer. While not being a health professional my assessment of such symptoms rests in principle on the same ambiguous and uncertain fundament as the informants, and when discussing potential cancer

symptoms, I made it clear in which situations I, as an ordinary middle class person myself, albeit perhaps, with additional attention towards cancer symptoms due to my project and place of employment, would consider presenting my worries to my general practitioner.

Finally, it is important to address a common objection I have met when presenting my study, especially in biomedical settings, concerning the potential effect my questions and focus on sensations, symptoms and illness has on informants' bodily attention and interpretations of bodily experience. This potentially amplified experience of sensations as symptoms due to participation in the research project is a methodological consequence of doing fieldwork where the anthropologist's research interests and questions will naturally affect informants' direction of attention. This calls for continuous methodological and analytical reflection and is a fundamental reflection of anthropological knowledge production (Hastrup 2003), and a fundamental reflection to keep in mind in any kind of research that involves interaction with individuals.

Overall, the fieldwork was conducted in accordance with the internationally approved ethical guidelines by the American Anthropological Association (American Anthropological Association, 2012). The data collection was approved by the Danish Data Protection Agency (Journal no. 2012-41-1275).

## CHAPTER 3:

### PAPER 1

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‘THE GOOD CITIZEN’: BALANCING MORAL POSSIBILITIES IN EVERYDAY LIFE  
BETWEEN SENSATION, SYMPTOM AND HEALTHCARE SEEKING

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Accepted for publication in *Anthropology in Action*

## Abstract

This article explores how healthcare-seeking practices and the transformation of bodily sensations into symptoms are embedded in what we term a ‘moral sensescape’ of everyday life. Based on fieldwork in a suburban middle-class neighbourhood in Denmark, we discuss how a moral relation between the Danish welfare state and the middle-class population is embodied in a responsibility for individual health. Overall, we identify a striving to be a ‘good citizen’; this entails conflicting moral possibilities in relation to experiencing, interpreting and acting on bodily sensations. We examine how people meet the conflicting moral possibilities of complying with current public health rhetoric on proper healthcare seeking, including timely presentation of symptoms, and simultaneously try to avoid misusing the healthcare system and be characterized as overly worried or even as a hypochondriac; this challenge constitutes complex navigational routes through the moral sensescape of the Danish middle class.

## Introduction

This article explores how moral possibilities for acting as ‘a good citizen’ are reflected in the bodily practices of the Danish middle class. In particular, we pay attention to the ways in which notions of morality are embedded in perceptions of bodily sensations and thereby create possibilities for interpretations and actions regarding the body, health and illness. Most prominently, these possibilities include concerns about the common good of the Danish welfare state, which may legitimate decisions in either direction in the question of whether or not to seek healthcare. The moral possibilities available to ‘the good citizen’ thus open different possible routes of navigation in what we conceptualise as ‘the moral sensescape’ of the Danish middle class.

As an analytical background, we draw on David Howes’ concept ‘sensescape’ (Howes 2005), through which Howes directs attention to how the experience of an environment is “produced by the particular mode of distinguishing, valuing, and combining the senses in the culture under study” (Howes 2005:143). By looking at everyday life in the Danish middle class as a distinct sensescape, we aim to explore the social and cultural embeddedness of bodily sensations and their potential transformation into symptoms.

Denmark is a small country known for its egalitarian Scandinavian welfare model. As the Danish public system is financed by income tax, one of the highest in the world (OECD 2015), the Danes ideally have free and equal access to

healthcare and education. Denmark is often characterized by a strong civil society, social cohesion and high levels of social trust (Wiking 2014). The development of the welfare state along with social cohesion and trust in the population compose a relevant background for our analysis of the moral sensescape of the Danish middle class. Many of the informants' life stories are characterized by social progression from working class, lower-middle class or farming families into owning their own home in a suburban middle-class neighbourhood. Their stories are thus intertwined with the formation of the Danish welfare state in the second half of the twentieth century, and the development of a large middle class that has benefitted greatly from the welfare state (Jöhncke 2011; see also Olsen et al. 2012). With the aim of understanding the making and management of symptoms in this context, the article addresses the relation between the middle-class body above the age of 60 and the Danish welfare society, which is also described as, '...held together not just by the mutual identification and trust of the inhabitants of the country, but also by culturally defined mutual interests in certain economic and practical arrangements...' (Jöhncke 2011:35). We propose that this mutual trust and common interests turn into welfare practices that 'become embodiments of particular forms of ethical orientations and normative expectations' (Langer & Højlund 2011:1), which, in this paper, we find in the notion of 'the good citizen'. This social trust and sense of community thus provide the foundation for the moral sensescape that people bodily navigate when experiencing bodily sensations.

### **Methodology**

The analysis presented in this article draws on long-term ethnographic fieldwork carried out by Offersen from December 2012 to February 2015. The study is part of a large research programme aimed at improving organizational and clinical aspects of cancer diagnostics in Denmark. The fieldwork took place in a suburban middle-class neighbourhood in Denmark, where 14 households (18 key informants) were followed through 1-1½ years. The majority of informants were aged 60 or above, which had distinct significance for the analysis and the notion of 'the good citizen' as we argue that this notion stems from the contemporary social progression of the informants with the development of the Danish welfare state.

Overall, the fieldwork consisted of approximately six planned visits, three of which included a semi-structured interview, with each household. Furthermore, Offersen participated regularly in different community activities (local choir, sports and gymnastics). On some occasions, she followed informants to consultations with their general practitioner (GP), at the hospital and to the pharmacy. Interviews were recorded and transcribed verbatim, and fieldnotes were written immediately after each home visit or activity. For a period of six months informants regularly noted down bodily sensations and healthcare contacts which were elaborated upon in interviews.

### **The good citizen**

The retired couple Jens and Sonja is serving coffee and freshly baked bread in the living room. The house is neat and clean. They spend a lot of time in and around the house, taking care of the carefully orchestrated garden, repairing the car in the garage, watching television, solving Sudoku puzzles or baking bread. These everyday life doings provide a striking contrast to the stories they tell of their upbringing. Jens grew up in the city in a small apartment with his parents and 6-8 siblings. He is not sure how many siblings he had. He recalls how one little sister died from pneumonia: “She died from cold. Yes, that is what I believe. It was so miserable...In winter it was difficult to get out of bed because the duvets had frozen on to the wall. I remember this happened many many times.” Sonja, on the other hand, tells of a happy childhood. Her parents owned a smallholding in the country and to describe how every penny was turned she opens an old book with her father’s budgeting where every tiny expenditure and income is carefully noted.

As mentioned the informants’ life stories are characterized by social progress; they have been able to provide their own children with an upbringing under more socially and economically stable circumstances than they had experienced themselves. Indeed, they are stories of a different time but the contrast between then and now also illustrates the increase of the middle class alongside the development of the Danish welfare state in the last part of the twentieth century. Looking at these stories of social mobility, welfare state development and the sense of social cohesion and community, the relation between individual and



society becomes a mutual moral relation with inherent rights and responsibilities as for example expressed in relation to healthcare by another informant:

‘I do my best so that I will not need to use the healthcare system. I keep fit, and I eat healthy food. But when I look at how [overweight] people waddle around in the supermarket and what they buy!... And then they also go out and smoke before getting into their cars and all the other factors. Then I can see why the expenditures of the healthcare systems are high! But I have done everything I could. If I should fall ill, I sincerely hope they [the healthcare system] will take care of me then!’

Jane, 65 years old

The concern of this informant, who is a recently retired and physically active woman, is encapsulated in what we think of as the notion of ‘the good citizen’. Jane is aware that social welfare benefits, like free healthcare, come at a cost; not at the level of the individual, but at the level of society as a whole. Thus, she articulates the mutual interests in economic and practical arrangements as mentioned earlier. Along with most of the other informants, she voices an individual responsibility for taking good care of her body in consideration of a sense of community and cohesion of the Danish society, which is built on the mutual trust that everyone contributes with what they can and requests only what they need to ensure the common good of the welfare state. This moral relation between the body and the Danish welfare state is also described by Oxlund as a relation of debt which, at the same time, is imprinted at the biological level, ‘If you fail your own body, you are failing the entire body of the nation, seems to be the dictum here.’ (Oxlund 2012). In her disapproval of the overweight and smoking people in the supermarket, Jane clearly demarcates proper citizen behaviour from improper behaviour. It becomes a matter of balancing the rights and responsibilities that are inherent in the Danish welfare state and in the normative expectations of its citizens. A sense of national social cohesion seems to be at stake here, and improper behaviour puts this cohesion at risk. Social cohesion defined as ‘the belief held by citizens of a given nation state that they share a moral community’, where ‘citizens believe they share the norm of not cheating each other’ (Larsen 2013:11), is characteristic of the Danish society

according to Larsen. The belief in a shared moral community can be seen as the background of everyday actions towards what is perceived as ‘the good life’. Yet, individual perceptions of the good life vary and so do the ways in which people enact ‘the good citizen’. While ‘the good citizen’ exists as a shared normative expectation in Danish citizenship, people or different social groups may relate to it in different ways. For example, a recent Danish study suggests that expectations to comply with public health rhetoric translate into everyday forms of resistance (Merrild et al. in press). Forms of resistance to acting ‘properly’ as a good citizen are also present among our informants in the middle class, but the key point is that people *are* morally related to the welfare society and *do* address the idea of the good citizen whether they resist or comply with it. Let us turn to show how normative expectations expressed in the notion of ‘the good citizen’ translate into experiences of embodied sensations.

### **The embodiment of the good citizen**

During fieldwork, statements like ‘I am the kind of person who doesn’t go to the doctor’ and ‘I am never ill’ or ‘I have a strong health’ were often heard. Nevertheless, over time, illness episodes and healthcare seeking showed that this is not necessarily in accordance with what actually happens. Most of the informants do see their doctor once in a while, and they do have at least minor episodes of illness or symptoms. What is then at stake in these statements? As Gullestad describes: ‘Statements like “I am such and such kind of a person” imply ways of categorizing persons and *certain standards for the evaluation of their behaviour*’ (Gullestad 2001:35, emphasis added). In light of the moral relation between the middle-class body and the Danish welfare state, the ‘strong health statements’ should, therefore, be seen as more of an evaluative than a descriptive character and can be understood as a cultivation of the moral relation to the ‘common good’ of the welfare society. An example of an attempt to live up to the ideals of being a good citizen when experiencing bodily sensations is demonstrated by Sonja when she tells about a time when she had some heavy bleeding and low levels of haemoglobin:

‘I went to work the day after. I was on weekend duty that Saturday. It was not really comfortable, I was super super tired, but I did my job.’

She also expresses the difficulty she has in deciding whether some present bodily sensations could be symptoms of disease or not:

‘Sometimes I feel some stomach pain and then suddenly it disappears again. And you think: How long time should pass before it is over? Well, I better wait a little longer. But then again, I could also... It is because we have these old friends, and some years ago she had colon cancer. She is well over it now, but... This can make me think because when I hear about her symptoms... But then I also thought that this does not mean that I will get it as well. But on the other hand, no one says that I wouldn’t get it. At the same time, I also thought when I stopped working that I would not be one of those...who would just be a hypochondriac; then you would go to the doctor with this, then with that. I don’t want to be that kind of person. But I also think: Is there something or not? I hope there isn’t anything if I go, you know? But on the other hand, you should not wait until there is something. We know that.’

The complexity of healthcare-seeking processes is evident in Sonja’s stories. There is no right path to follow when juggling so many concerns of which remarkably few are about the actual sensations. By highlighting her ability and wish to keep working, even when she is ill and even when the absence from work is legitimized by her GP, she draws on a culturally valued sense of agency – of being productive, working and busy and being heroically able to overcome illness. This is very similar to what Cameron Hay has termed the ‘John Wayne Model’ in the US (Hay 2010), and this ideal is also inherent in our idea of the good middle class citizen who contributes to ‘the common good’.

The multiple concerns in healthcare-seeking practices and sensation-to-symptom transformations can be seen as multiple possibilities for acting in a morally ‘correct’ way. This multiplicity of moral possibilities often entails an uncertainty which is sensorial and moral at the same time; when a bodily sensation is a symptom ‘worthy of healthcare seeking’, it is a moral assessment as much as a sensorial assessment. This uncertainty is often voiced in the informants’ efforts to legitimize healthcare seeking decisions. For example, during most field visits, Sonja’s husband, Jens, a retired general labourer, emphasizes that he is the type of person who would not go to the doctor until ‘the very last minute’. When it turns out during an interview that he recently got his

lungs checked, he is asked if he did that because of worrying about the consequences of his smoking habit, and he explains:

‘No, it was because I thought that when you had used the body for so many years then it would be a good thing just to be checked. To see whether it was still functioning the way it was supposed to. That was actually the reason. Then, of course, I was also nervous that something would be discovered. In case anything...I can’t deny that. Of course you are.’

Jens insists that this happened as a part of a 60-year health check even though his wife corrects him on the matter, suggesting that he went to the GP out of worry for his lungs. A general observation was that informants legitimize healthcare seeking in relation to health checks which are commonly referred to as ‘60,000 miles’ check’ indicating an occasion for checking the status of the body. By using the metaphor of keeping a car running, informants highlight the morally unquestionable necessity of this particular visit to their GP. In this way, they are provided with a comforting certainty about their health status without the need to consider the moral legitimacy of potential worries; they behave like good citizens by taking care of their health and yet, not overusing the common good of the healthcare system. In a similar fashion, many informants also stated in relation to actual symptoms that they would have their doctor look at it ‘the next time I’m going there anyway’. This may imply that the moral legitimacy of the symptom is uncertain and, to stay within the confinements of the good citizen, they better not express their sensorial concerns until a legitimate occasion occurs, as for instance a control consultation for blood pressure.

### **Navigating the moral sensescape**

What is at stake then, when people experience sensations and ‘bodily navigate’ the environment that we suggest may be a moral sensescape of the middle class? Mattingly argues that ‘moral pluralism characterizes ordinary life’ (Mattingly 2014:9). In this sensescape, where ‘the good citizen’ is a key shared value, moral pluralism can be considered as the different and sometimes conflicting moral possibilities that are available to the middle-class body to sustain a place in the category of good citizens. Seen from an analytical perspective, this entails that navigating the sensescape with regard to health does not only concern what actually happens in a particular event, but also involves consideration of the

whole range of possibilities; what might happen as well as what might have happened (Mattingly 2014; see also Zigon 2009). People thus navigate in a sensescape of different possible moral routes.

This is particularly evident in the light of contemporary public health rhetoric, which emphasises individual responsibility and ‘symptom awareness’ as central strategies to disease control (Petersen & Lupton 1996), thus socializing people into a body politic taking the shape of healthy citizens who are capable of conducting proper healthcare seeking. Being a good citizen thus implies that you are responsible for taking good care of your body, you are expected to comply with authoritative messages of proper healthcare seeking (which also assumes proper and timely interpretation of bodily sensations as symptoms) and, at the same time, you should not misuse the system by being a ‘hypochondriac’ as shown in the case of Sonja. Adding fear of illness and death as well as more experience-near moral obligations to one’s immediate and close personal relations, the pathway from bodily sensation to healthcare seeking can take many directions.

This is demonstrated in the case of Jette, a retired woman in her early 60s, who talks about which kinds of symptoms that would make her visit her GP:

J: ‘...if you have a lump in the breast, and you feel that there’s something unusual there, then it would be quite fair to ask your doctor if he could take a look at it or run a test. I wouldn’t have a problem with that.’

S: ‘Ok. Would you make an appointment to have it checked? We have talked about this before...’

J: ‘Yes, we have talked about it before. It is that thing with my moles. I haven’t done anything about that yet, but I will. I will, but it is not something I am afraid of. I just don’t think I will get cancer...’

S: ‘But you have the thought of having it checked?’

J: ‘I have the thought. I need to have it checked at some point. The next time I’m going there [to the GP].’

S: ‘But you said earlier that if you found a lump... and that you know this is... [something you should react on]’

J: ‘Yes, I would feel that. But as you get older, you get all sorts of spots on the skin here and there. That doesn’t have to be anything...I also have something here. You just get that. It is this thing about wasting the doctor’s

time. I really respect this. You should be careful not to come when it is not necessary. It is quite alright to come if you are afraid. You shouldn't go around being afraid. But I am not afraid, so I... You just don't go to the doctor every time you feel something. I don't.'

Jettes story illustrates how the experience of a bodily sensation – the mole – opens possible moral routes for its transformation into a symptom of illness or an absorption back into an ordinary embodied being-in-the-everyday-life-world. The moral possibilities at play here are complex interactions between the various perspectives on everyday life morality, such as taking good care of your body and the common good of the healthcare system simultaneously. It can be seen as a moral compass of the body used to navigate its everyday life context. Jette describes the moral possibility of what might happen if she discovered a lump in her breast, a well-recognized symptom of breast cancer. In this case, the socially legitimate moral route would take her straight to the doctor; it would be 'quite fair' to do so, that is, she would embrace the moral relation to the welfare state by seeking care appropriately and thereby also fulfil the normative expectations of being a good citizen. However, in the case of a mole that has changed appearance, which Jette does not consider as alarming although she is aware that this may also be a symptom of cancer, a whole range of other moral possibilities become visible. When trying to explain the contradiction between what she has just said about the hypothetical breast lump and the actual changing mole, Jette applies different moral possibilities. First, she refers to a moral possibility of bodily ordinariness, 'as you get older you get all sorts of spots on the skin'. Second, she states, 'I need to have it checked at some point', and, although this does not take her straight to her GP, this moral possibility is related to the public health rhetoric of seeking care 'in time'. Yet, inherent in this sentence, we also find the uncertainty of the moral legitimacy of the symptom, as discussed earlier, which transforms 'in time' into 'at some point'. Third, she again applies the moral possibility of being a good citizen; this time by the responsible choice not to 'waste the doctor's time', which can be seen as a commodified 'common good' of the welfare state.

Bodily navigation in this moral sensescape thus requires balancing of the moral possibilities at play. This balancing is a continuous process; Jette has not presented the mole to her doctor, but she has not ruled out the possibility to go

there in the near future either. Thus, an ongoing moral and sensorial balancing effort is taking place in her everyday life.

### **Concluding discussion**

We presented the contextual background for ‘the making and management of symptoms’ as a moral sensescape of the middle class, which encompasses a moral relation to the Danish welfare state that extends to individual bodies in a responsibility for individual health. We showed that this is expressed as a striving for acting like a ‘good citizen’, who ideally cares for and aims at protecting the ‘common good’ of society. In this case, this is done through appropriate use of the healthcare system, which also entails the way bodily sensations are endowed with significance as symptoms of possible illness.

With the overall aim of exploring the making of symptoms and thus attempting to ‘open up the phenomena we name symptoms’ (Eriksen & Risør 2014:90), we suggest that morality embraces the processes of distinguishing ‘normal’ from ‘worrying’ sensations and that healthcare seeking is an essentially moral process, which is navigated along culturally shared moral possibilities.

On the basis of our findings, we see two main implications. First, as a practical implication for understanding the healthcare seeking practices that many public health interventions seek to influence, we showed how moral possibilities for perceiving, interpreting and acting on bodily sensations create different, sometimes even opposing, navigational routes throughout the moral sensescape of everyday life when it comes to ‘the making and management of symptoms’. People can seem less concerned with the actual bodily sensations than with their moral possibilities for agency around it. However, the rhetoric of proper healthcare seeking is profound, and it feeds into the continuous construction of the moral possibilities that are available to ‘the good citizen’ when distinguishing between ‘fine’ and ‘sick’ (Hay 2008). The cases primarily focused on how the embodiment of ‘the good citizen’ implies that healthcare-seeking practices are based on considerations about both the ‘common good’ of society and about timely healthcare seeking with ‘legitimate’ symptoms.

Second, in terms of theoretical discussions, our study feeds into recent efforts of a medical anthropology of sensations to challenge the taken-for-grantedness of symptom categories (e.g. Risør 2011; Nichter 2008). Symptoms should not be confined to be ‘natural signs’ indicating a real relation to disease (Staiano-Ross 2011). Rather, symptoms are complex, interactive and point both



forwards and backwards in time as well as inwards and outwards of the human body. Looking in all directions is a way of avoiding to uncritically adopt the prevailing biomedical conceptualisation of the phenomenon, and this forces us to rethink ‘what is called symptom’ (Eriksen & Risør 2014).

Placed in the context of the Danish middle class, this study highlights relations between a welfare state and its citizens in a particular local moral world characterized by social trust and the belief that inhabitants in this relatively small and homogenous nation share a moral community. The perspectives of moral sensescapes and possibilities are likely to take very diverse forms in less homogenous settings, larger communities or different age groups. Therefore, further studies on morality and sensations exploring e.g. moral sensescapes across generations, class, gender or different healthcare and welfare systems could be of interest to both medical anthropology and public health research informing our understanding of symptoms, healthcare seeking and public-health interventions.

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# CHAPTER 4:

## PAPER 2

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AM I FINE? EXPLORING EVERYDAY LIFE AMBIGUITIES AND POTENTIALITIES OF  
EMBODIED SENSATIONS IN A DANISH MIDDLE-CLASS COMMUNITY

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Accepted for publication in *Medicine Anthropology Theory*

## **Abstract**

In this article we explore the uncertainty and ambiguity in the space between bodily sensations and symptoms of illness. In terms of the potentiality of bodily sensations becoming symptoms of disease or being absorbed into the ordinary, we illuminate processes of ascribing meaning to sensations in the context of middle-class everyday life in Denmark. We identify four different forms of potentialities: illness potentiality of sensations, non-potentiality of sensations, potentiality of non-sensations, and moral potentiality of sensations. We show how these different potentialities of ambiguous sensations are weighed against each other on a culturally and morally contingent continuum between normal and not normal, uncovering the complex interplay between the body, everyday life, and pervading biomedical discourses focusing on health promotion, symptom awareness and care-seeking.

## **Introduction**

‘In theory, anything could be cancer. My elbow hurts right now – it could be something, right? I do think about it. Now I’ve had this aching elbow for three, four ... seven days and wondered what exactly is this? But then it disappears and that’s it’. (Jens, 67-year-old retired general laborer)

The essential uncertainty Jens expresses when he states: ‘it could be something, right?’ captures the complexity between knowing about the possibility of serious diseases like cancer ‘hiding’ in the body and the everyday attribution of meaning (or no meaning) to bodily sensations. The aim of this paper is to explore and unfold this complexity and uncertainty, which are characterized by an innate potentiality of the bodily sensation becoming something else. We focus on how this potentiality is shaped by the intersection between everyday lifeworlds, pervading biomedical discourses, and the subjective bodily experiences emerging from this, contingent on the time and space of their context, in this case Danish middle-class citizens above the age of 60.

Recently described as the happiest people in the world, primarily due to high levels of social trust and security (Wiking 2014), Danes generally enjoy a peaceful, safe, and wealthy society, where social welfare benefits and a relatively

fine-meshed social safety net markedly reduce everyday basic uncertainties compared to most places in the world. The majority of Danes do not face the uncertainty of not knowing how and when they will get their next meal, of whether they can pay for their children's education, and whether they can cover their healthcare expenditures should they fall ill. The Danish welfare state, designed to make citizens 'fare well' through life (Langer and Højlund 2011), diminishes this kind of uncertainty. However, the Danish middle class – like all human beings – still faces the very roughness of being, i.e., the risk of illness and suffering disturbing the course of faring well throughout life. Moreover, in the context of a society designed to support this faring well of its people, the bodies and health of citizens are matters of substantial political, economic, and ethical concern to the governing power and have, in Denmark, been subject to increasing political focus and a diverse range of interventions aimed at improving health, promoting healthy life styles, and using the public healthcare system correctly. In Foucauldian terms of bio-power, bodies in the well-regulated and regulating Danish welfare society are carefully governed by the state (Foucault 1990).

Everyday life in the Danish middle class is largely centered round the nuclear family. Most of the informants in this study settled down in the suburban neighborhood that constitutes the ethnographic field site when they were in their 20s and 30s. They got married, had children, and worked hard to create a safe and stable environment for their children to grow up in and develop. As most of them are now retired or close to retirement, everyday life now mostly revolves around grandchildren, friends, travelling, and leisure activities such as biking or golf. A major concern is therefore being able to do these things and being able to enjoy some of the good things in life after a long and often strenuous working life. If we see the ordinary uncertainty of everyday life as threats to 'what really matters' to these people, health and illness are major and very present concerns in everyday life (Kleinman 2006).

The point of departure for this article is the desire to understand how bodily sensations are attributed meaning in this everyday life context, with a focus on the potentiality of sensations. Inspired by a medical anthropology of sensations that particularly started taking form in 2008 with a special issue of *Transcultural Psychiatry* (cf., Hinton, Howes, and Kirmayer 2008a; Hay 2008; Throop 2008) emphasizing the need to know more about the process that turns bodily

sensations into possible symptoms of illness, this paper asks the simple question ‘When is something “something?”’.

Illness and suffering can destroy and remake everyday life (Scarry 1985; Kleinman, Das, and Lock 1997; Kleinman 2006). In this regard, bodily sensations can be seen as potential re-makers of everyday life. In this way, they are social events (Staiano-Ross 2011) endowed with cultural significance. Some sensations, however, pose no immediate social event of suffering. This makes sensations, and especially vague and elusive sensations that are not (yet) translated into a symptom category, interesting but also difficult to study. As Jason Throop argues in his study of pain among the Yap, the ambiguities, confusions, gaps, and ambivalences in lived experiences have often been overlooked in our anthropological search for certainties, coherences and structures. He suggests that we expand “our view of experience to include a spectrum of articulations that range from the most formulated and explicit to the most inaccessible and vague” (Throop 2010, 3). Our analysis attempts to unfold this range of experience from the perspective of the Danish middle class, with particular attention paid to the vague and ambiguous sensations that are both part of everyday life and can turn into potential symptoms of disease. The study of everyday – more or less vague – bodily sensations relates to and differs from, e.g., the extensively studied and more explicit sensation of pain (e.g., Good and Brodwin 1994; Scarry 1985; Throop 2010; Kirmayer 2008; Hinton 2012; Morris 1991). Scarry, for example, argues that pain is essentially unshareable and resists language; for the sufferer ‘having pain’ is the same as ‘having certainty’, whereas for the other, this pain cannot be known for certain (Scarry 1985). In comparison with pain, vaguer bodily sensations are likewise difficult to share and, for the most part, resist language, but they do not necessarily demand attention the way pain does and they produce ambiguity and doubt rather than certainty for the ‘potential sufferer’. To explore this ambiguity and uncertainty in the liminal space between sensation and symptom in the middle-class body in everyday life, we suggest that adding the dimension of potentiality – the ‘What if?’ – of bodily sensations is useful when we wish to illuminate the spectrum from the explicit to the vague in the interconnectedness of the socio-cultural context and the experience of bodily sensations.

In this paper, we will shed light on two areas that are at play in the potentiality of bodily sensations: 1) everyday life as the local, predictable ‘ordinary’ and as the site of essential uncertainty and ambiguity, experienced and described by informants in the middle-class neighborhood; and 2) biomedicine and health promotion as pervading discourses that take local form, including technological and scientific progress, clinical practice, and public health rhetoric. From this point of departure, we will explore the forms of embodiment that appear from the interaction between the ‘uncertain ordinary’ of everyday life and emergent health promotion discourses. Or borrowing inspiration from Foucault, the paper explores how a focus on sensations may provide insights into how the organization of bodily attention is affected by biomedical semiotics and contemporary forms of technologies of the self (cf., Throop 2010; Foucault 1985), reflected in a symptomatic management of the population present in contemporary public health promotion rhetoric on, e.g., cancer diagnostics (Andersen, n.d.), and the apprehension of risks and pre-states of diseases (Rose 2007).

One of the aims of our analysis of the potentiality of sensations is to add to contemporary discussions of the configuration and use of symptom categories in the health sciences as well as the social sciences. Within the behavioral sciences of medicine, a focus on symptom awareness as a strategy for, e.g., cancer disease control, tends to treat symptoms as reified entities to be discovered (cf., Quaife et al. 2014; Whitaker et al. 2015). The prerequisite for our study, however, is that we should attend to symptoms as biosocial phenomena that are configured in processes of embodied experiences, attention, and interpretation (cf., Hay 2008). This perspective is also evident in the growing interest in sensations within medical anthropology, with calls for a more comprehensive questioning of the idea of the symptom based on phenomenological, philosophical and semiotic perspectives (Hay 2008; Eriksen and Risør 2014; Staiano-Ross 2011). In line with this, our analysis explores the ‘coming into being’ of symptoms in terms of the concept of potentiality of sensations. Inspired by Taussig, Hoeyer and Helmrich (2013, 4), we think of potentiality as ‘that which does not (yet and may never) exist’, and we treat the space between sensation and symptom as a transitory or liminal space that is characterized by potentiality in different ways (for elaboration on potentiality, see also Vigh 2011; Gammeltoft 2013; Gibbon 2013; Svendsen 2011). The concept of potentiality can be employed with respect



to different aspects of life and the body and with a variety of meanings that overlap and interact. Distinguishing between the use of potentiality as an analytical perspective and as an object of study (Taussig, Hoeyer, and Helmreich 2013), we mainly take potentiality to be our object of study by concentrating on the question of how potentiality is perceived on the continuum between – as aptly phrased by Hay (2008) – ‘fine’ and ‘sick’ when people experience bodily sensations. Potentiality is closely related to notions of risk. However, in this paper, we employ the concept more in relation to uncertainty and ambiguity. We believe that it is in the uncertain and ambiguous “What if?” of sensation experience that socio-cultural context, subjectivities and the pervading discourse of biomedicine interweave and produce meaning to bodily sensations and configure symptoms. Hence, this article also aims at providing general perspectives on how uncertainty and ambiguity are lived by seeing the uncertainty and ambiguity of the body as an essential source of moral concern in everyday life.

As a result, we treat symptoms in this article as an emic category used by informants as a specific way of ascribing meaning to bodily sensations. Sensations, on the other hand, are seen more as an analytical construct that helps us ‘open up’ the concept of symptoms by focusing on the processual aspect of symptom making.

### **Methodology and field**

This project was carried out as ethnographic fieldwork consisting of repeated field visits and semi-structured interviews with 18 key informants over a period of approximately 18 months.

The fieldwork took place in one of the largest of what we characterize as a ‘Danish middle class’ residential areas. Broadly defined as working or retired citizens who own their own single-family home in this neighborhood, the middle class group in this study is characterized more by the particular space and time the informants occupy and the images they invoke than by socio-demographic variables. We chose to weigh the characteristics of the neighborhood heavier than the socioeconomic variables across individuals in our struggle to describe Danish middle-class culture as it is lived. However, the recruitment of informants to this

study is based on ownership of a one-family home in the area in question, which can be socioeconomically characterized as suburban middle class and working class (Olsen et al. 2012).

Informants were recruited partly from an exercise group for older or retired people that the first author participated in and from the local choir she joined during fieldwork, but also partly by going door to door in the neighborhood. A minimum of six field visits, three of which included an interview, were used to follow the 18 key informants throughout the period of study. Furthermore, everyday life activities such as exercise (e.g., fitness, walking, exercise, golf) and grocery shopping were followed, but most of the fieldwork was conducted in the homes of the informants over meals, coffee or in their yards. Fieldnotes were almost exclusively written after every field visit rather than during the visit to be able to be fully present in the relation with the informants. Over a period of six months, informants kept a health diary to record any bodily sensations, symptoms, or contacts with the healthcare system. The diary was used as a point of departure for one of the interviews, which focused on the experience of concrete bodily sensations. During the interview, the diary made it possible to discuss experiences of bodily sensations that informants said they had already forgotten about. Reminded by the diary, they recounted the experiences, enabling us to access some of the bodily sensations that are constantly experienced and absorbed into the ordinariness of everyday life as ‘something normal’, which is a crucial part of our argument. As Das and Das (2007) also note, varying between methods, such as between frequent interrogations into everyday bodily sensations and long open-ended interviews, allows the opportunity to look at how people’s experience of sensations moves between registers of the ordinary and the extraordinary.

With the intention of exploring a process of transformation from sensation to symptom, doing fieldwork in what turned out to be a largely undramatic experience of the body in everyday life was at times frustrating. Only occasionally would a bodily experience or interpretation stand out from the flow of the ordinary. The culturally defined thresholds between sensation and symptom (Hay 2008) that we were looking for were only visible in hypothetical examples that the informants gave, e.g., of a lump in the breast. Every actual sensation that occurred during the fieldwork was ambiguous and did not surpass

any certain threshold. It instead went back and forth between normal and abnormal, influenced by the cultural ordinariness of the everyday life context, and could thus be seen more as a continuum of bodily normality. In this way, the ordinary – with all its predictability and its uncertainties – takes center stage because it is in itself the process of ascribing significance to sensations and not just the cultural background upon which to understand bodily sensations.

### **The ordinary uncertainty of everyday life**

The stories informants tell in this paper are most often told to the researcher over coffee while eating homemade bread in the living room or around the kitchen table in standard single-family home built in the 1970s. In Denmark, this counts as an almost stereotypical image of middle-class everyday life for people approaching retirement age. We are in a suburban neighborhood where similar types of standard houses, each with a yard, stand side by side along meticulously straight roads and a corresponding system of pathways for pedestrians and bicyclists. Named after Danish islands, the roads are in alphabetical order and the hedges are cut no higher than the allowed maximum height of five feet nine inches as stated in the declarations of the area. The geographical predictability of the neighborhood is reflected in the rhythms and routines of everyday life as it unfolds during fieldwork:

Kirsten and her neighbor Elsa arrive at the fitness center together. I take two rounds on the machines together with them. They talk a lot while warming up on the exercise bikes, but as we switch between the different machines, they stay focused on their training. After that, we sit down at a table in the center for coffee, as Kirsten and Elsa always do. ‘They make great coffee here’, Kirsten remarks as they tell me about how they come to the center every Monday, Wednesday and Friday morning to work out and socialize with each other. We go outside and Kirsten and Elsa light their cigarettes while rather non-enthusiastically discussing the possibility of quitting their smoking habit. Back from the fitness center, I sit at the kitchen table with Kirsten and her husband, Robert. Kirsten has prepared a typical Danish lunch with rye bread, pork liver pate, canned mackerel in tomato sauce, and a choice of

various sliced lunchmeats. We all drink a beer, and Kirsten and Robert also have a glass of schnapps as they usually do. They tell me how important it is to eat fish every day and how much they enjoy a daily schnapps and beer with their lunch ... Later in the afternoon we have a cup of coffee and Kirsten serves a cake purchased from the bakery: 'We almost never eat cake or white bread. White bread is the worst [most unhealthy]', she says, clearly indicating that this is a special occasion because I am there. However, we all enjoy the cake, and before I leave Kirsten picks flowers in her yard and arranges a nice bouquet for me to take home. (Fieldnote excerpts, 9 October 2013)

In the familiar and the certain, there seems to be a valued sense of confidence and security that is underlined by the physical living space. However, as informants sit in their living rooms drinking coffee while looking out at their neatly orchestrated gardens, they tell life stories that are also full of the unpredictability, uncertainty, and ambiguity that everyday life is made of (Kleinman 2006). The contrast between the seemingly predictable and 'ordinary' everyday life of the neighborhood and individual stories of tragic accidents, loss of loved ones, illness, poverty, crime, violence, disabling pain, and a lurking fear of all those things, is striking. The tension between everyday life's essential uncertainties and the efforts we make to control them are important aspects of understanding the connections between bodily sensations and the wider socio-cultural context. With regard to health and well-being, there is a consciously defined rhythm in the random everyday of Kirsten's life described above. The choice of exercising three days a week and the claimed avoidance of cake and white bread (which were commonly referred to among informants as dangerous, following a long and insistent focus in the media and among the general public on the possible hazards of carbohydrates to one's health and bodyweight) are examples of how everyday routines are proactively built to sustain a safe and predictable life. In an apparent contradiction, well-known health hazards, such as cigarette smoking and daily alcohol intake, are valued and actively defended as part of Kirsten and Robert's everyday life well-being. The potentiality of sensations should be considered exactly here; i.e., as emanating from embodiments of the merging of powerful discourses on health, illness, and the body and the ordinary uncertainty of everyday life along with the effort to control it and make everyday life livable. We experience bodily sensations constantly in the middle of all this. How we

perceive and act upon them is contingent on local context and global discourses, and the way subjectivities are cast between them. Before digging deeper into the potentiality of sensations, let us just briefly consider contemporary health promotion and symptom awareness discourses in Denmark.

### **Health promotion and symptom awareness**

We are said to live in an age of biology (Rose 2007), where technological and scientific progress turns people into biological citizens (Rose and Novas 2008) and somatic individuals, who are given increased responsibility for managing and monitoring their own health (Petersen and Lupton 1996). With notions of healthcare seeking behavior and symptom awareness, health promotion discourses pervade everyday life as an important arena of disease control and are bolstered by biomedical and epidemiological research, delineating ever more vague bodily sensations as symptoms of disease, and by public health interventions aimed at increasing awareness of early signs of disease and at reducing the time from onset of symptoms until healthcare is sought (Andersen, Tørring, and Vedsted 2015).

Health promotion and symptom awareness discourses thrive on a potentiality for cure, treatment, and control of diseases or on what has been described, especially in relation to the cure and treatment of cancer, as a ‘political economy of hope’ (Good et al. 1990). In Denmark in recent years, the political economy of hope has taken the form of organizational changes in the healthcare system with a politically prioritized focus on ensuring early diagnosis and treatment, as well as various national campaigns advocating symptom awareness and early care seeking, especially with regard to cancer (Tørring 2014). In contemporary orientations toward disease control for major diseases such as cancer or cardiac disorders, the past decade has thus witnessed a shift in direction in health promotion towards what can be termed symptom management strategies (Andersen, n.d.), which adds individual responsibility for symptom awareness to existing health behavior expectations for lifestyle choices in the population (Risør 2003). The everyday life body is encircled and infiltrated by these efforts to control disease and improve individual and societal health outcomes.

Similar to this encirclement and infiltration, Good (2007) uses the concept of ‘biotechnical embrace’ to illustrate the intersection between bioscience, biotechnology, and their societal institutions in subjective experiences of disease and treatments. Potentiality is inherent in the idea of the biotechnical embrace which ‘fundamentally link[s] high-technology medicine and bioscience to the wider society’ (ibid., 367). Looking at the biotechnical embrace from the perspective of everyday life, we propose that everyday sensations are being embraced by biomedicine and biotechnology both in terms of the potentiality of disease that comes with biomedical knowledge and increasing accessibility to knowledge, and the potentiality to escape disease and minimize risk by means of the same knowledge and corresponding awareness of the body and diagnostic technology. The biotechnical embracing of bodily sensations is an act of amplifying and of ascribing potentiality to the sensations as possible symptoms of illness. Striving to trace this potentiality in the subjective embodied experiences, let us turn to the everyday perception of bodily sensations and explore how the biotechnical embrace is met in the everyday life body.

### **Potentialities of sensations**

In the following section, we will argue that bodily sensations contain different forms of potentiality. Depending on the specific time and place where a bodily sensation is experienced by an individual subject, and thus constituting the liminal space between sensation and symptom or ‘non-symptom’, the various potentialities will take on different weight and constitute the perception of potentiality of the sensation. Potentiality as ‘that which does not (yet and may never) exist’ contains not just the potentiality of illness – the parentheses emphasize how uncertain and ambiguous the potentiality of sensations are (is this sensation leaning towards ‘yet’ or ‘may never’?). Moreover, as we shall see, the different forms of potentialities of sensations are often at play simultaneously. To illustrate, take the case of one of the informants, Jette, who talks about a mole that has changed appearance but that does not worry her too much: ‘...well, I’m not that foolish – if it oozed or turned into a sore ... it just doesn’t. But then I know it could be something awful. It doesn’t have to be, but it could be.’ So, how do ambiguous sensations like this move between ‘yet’ and ‘may never’? When is the potentiality for illness downplayed as ‘may never’ and amplified as ‘yet’? We

identify and focus on four forms of potentiality of sensations that have implications for how sensations are perceived in everyday life: the illness potentiality of sensations, the non-potentiality of sensations, the potentiality of non-sensations, and the moral potentiality of sensations.

*The illness potentiality of sensations*

Ingrid: I had something here that I got removed, and my doctor told me that it was absolutely nothing. That it looked benign.

Sara: A mole?

Ingrid: No, it was a brown spot – red and wrinkled. So I thought that I'd better have it checked. And then it takes a long time before you get the result, because when they think that it's nothing, it's not so important [acute]. But it turned out that it was ... if it hadn't been removed, it would have turned into cancer.

Sara: No!

Ingrid: Yes, and I was put at the back of the line because she initially didn't think it was anything, and I understand that. I didn't expect it to be something either. But now they told me to keep an eye on my brown spots to see if anything changes. So I have one here on my back that I need to have checked. Olaf [husband] says that it's just ... Well, I just thought that I better have her look at it.

Sara: So you've become more aware of it?

Ingrid: Yes, I have. You have to be. And I've never used as much sunscreen as I do now. You have to do that as well.

Sara: So, have you scheduled an appointment for the ...?

Ingrid: No, no. I looked at it this morning and it was brown. And I thought that I have an appointment soon. Then she can have a look at it when I'm there anyway. I need to have my cholesterol checked.

Ingrid's story shows an illness potentiality of a bodily sensation – the brown spot. It is a potentiality on different levels. From being one among many brown spots that appear with age, this particular spot has developed into something 'red and wrinkled' that has caught Ingrid's attention. Even though she did not believe that



it was ‘something’, she responded to the potentiality of the brown, red, and wrinkled spot as being a symptom of disease. She does not mention cancer in this initial part of her story. However, its presence as ‘something’ that is seemingly ‘benign’ is somehow invisibly woven into the story. The potentiality of the sensation is taken to a different level when the spot is analyzed and cancer then explicitly enters the story as ‘that which does not (yet and may never but possibly would) exist’. With this discovery, Ingrid’s other brown spots also change potential and Ingrid has already ascribed potentiality to another brown spot. Her increased vigilance towards spots on her skin adds signification to bodily marks and changes, and she is ready to act on them.

Other examples show how illness potentiality is immediately recognized when noticing sensations, almost as an underlying ever-present explanation of sensations:

Erik suffers from multiple chronic disorders, which worry him primarily because they prevent him from carrying out the everyday senior life that he had hoped for. Chronic disorders and increasing bodily discomfort seem to be widely accepted among the informants as part of aging. Erik, however, also states that ‘... all symptoms can present the question “could this also be cancer?” and it spans from the stabbing pain in my head that I told you about to the chest pains that I believe are my lungs, etc., which can give rise to [thoughts of] whether you have an early-stage cancer, then it can also be something like this. I have no idea what an early-stage cancer feels like.’ He goes on to explain how he has had thoughts about cancer with these sensations, but that he has pushed them away because his regular ‘blood tests look good ... and, without knowing too much about it, I think that this would be the place to discover it’.

Erik’s example shows how the significance of bodily sensations is woven in and out of potentialities of incipient cancer, part of aging, part of chronic conditions, the side effects of medications, and a biotechnical embrace assuring him that if it is not visible via biotechnological measures, it is probably not there. The weight shifts between worry and dismissal and eventually sensations disappear, persist, or amplify, demanding additional scrutiny and possibly action. Among other things, this process depends on the extent to which it interferes with Erik’s

everyday life, resembling what Hay (2008) found in her study of sensations and symptoms among the Sasaks of Lombok in Indonesia.

The last example provided here of the illness potentiality of sensations demonstrates how the potentiality of a bodily sensation spans from severe to innocent, often in one step. Christine explains: 'If, for example, I feel tension in my lower body. Like ... not exactly like contractions but more like menstrual cramps. If there's something like that, then I can find myself thinking: Oh... that thing, ovarian cancer, it's difficult to detect. Does this tension mean something like that? But then, if I don't feel it anymore and I just go to the toilet and it stops, the thought disappears. It can be exposure to cold – I can sense that I get this aching in my lower body from that.'

The above examples show how health promotion and symptom awareness discourses and the ordinary uncertainty of everyday life are embodied when people pay attention to bodily sensations. In all cases, the sensation has clearly surfaced into conscious awareness and, in these cases, it is possible to trace the potentiality for illness as an ever present resource for the perception of sensations. This also indicates a relatively extensive amount of knowledge and awareness of symptoms in the Danish middle class – especially of cancer, as illustrated in the examples above. As a consequence, the cases presented here demonstrate a hyper-vigilance towards the body and a hyper-signification of bodily sensations that span from being caused by exposure to coldness to hard-to-detect ovarian cancer. Ingrid, Erik, and Christine are all embraced by biomedicine and cancer awareness in their perception of sensations, but the embrace is being dismissed by both Erik and Christine and the sensations absorbed back into the ordinary uncertainty of everyday life and thus illustrate how illness potentiality is interlaced into the ordinary or what we could term the non-potentiality of sensations. A constant weighing of potentialities is going on in a seesaw between what is normal and what is not.

### *The non-potentiality of sensations*

Perhaps even more telling than the sensations that are embraced by illness potentiality are the sensations that are not. This non-potentiality differs from the illness potentiality presented above, where sensations were clearly noticed before

they were deemed normal or not, by adhering to the constant everyday life flow of ordinary and, hence, almost unnoticeable sensations. This constant absorption of sensations into the realm of the ordinary is where bodily normality is defined from shared cultural ideas of the normal body. Moving on the edge of attention and perception, these sensations are often barely noticed, and even when they are, they seem difficult to articulate. Trying to capture these elusive moments of attention towards a bodily sensation, we turned to the health diaries, where informants were supposed to note down every time they noticed any bodily sensations or changes. In many cases, however, they only noted something when they had already embraced the illness potentiality of the sensation, or when they could explain the reason for the sensation. Many diary entries were, for example, characterized by sensations of muscle tension and tiredness explained as resulting from hard work, housekeeping, or yardwork. Other sensations were framed by personal bodily experience and known symptoms of chronic conditions:

Sonja noted down an episode where her body was aching and writes that it is due to her ‘climbing up and down the ladder to pick apples, holding a heavy bag with apples on one side’. When asked about it, she explains that this, of course, creates sore muscles, but she loves to pick apples and work in the yard. She continues recounting how her husband, Jens, was baking his favorite cake, a white cake with a brown sugar topping, and this time he added apples, which she had just given him while she was standing on the ladder, to the topping. It was really nice to come inside from the cold to freshly baked cake, and the apples only made it better.

A closer look at Sonja’s diary shows that she noted several accounts of headaches and body aches, all ascribed to different household activities or yardwork. If the aches and pains bothered her too much, she notes having taken one paracetamol, ‘just to take the worst of it’, as she explains. Before retirement, she worked in the healthcare sector, and she knows that a doctor would recommend taking two tablets, but she explains matter-of-factly that she only takes two if it is really bad because ‘taking them is not so good for you’.

Similar to Sonja’s examples of non-potentiality of sensations, most of the informants tell different stories of bodily sensations related to work tasks,

household activities, or yardwork. This comes as no surprise since these can be seen as hallmarks of everyday life in the Danish middle class. The attitude that taking medication such as painkillers is not good for you is also commonly found in the majority of the participating households. But what do these explanations tell us about the perception of sensations' potentiality? First of all it shows how the body 'takes place' in everyday life or, in other words, the simple finding that bodily discomfort is part and parcel of everyday life. The manner in which Sonja's story about her aching body naturally turns into a story about her husband's cake, which she could enjoy after her hard work in the yard, illustrates how body and everyday life are completely intertwined. It also indicates something about what count for valid discomfort and legitimate explanations in the cultural context of the Danish middle class. If shared cultural ideas outline the normal body, the perception of the potentiality of bodily sensations is based on the cultural context in which the sensation occurs. When informants significantly emphasize physical activity, especially in the house and yard or at work, as the cause of bodily sensations and discomfort, it connects to Danish middle-class moral concerns about work and home, which are also manifested in the carefully cultivated yards and spotless houses that typically characterized the neighborhood. The determined reluctance to take medication supports this perspective by hinting at values that involve how to cope with pain or discomfort and not to whine about it.

These non-potential sensations are not embraced by biomedicine and symptom awareness, but they draw on socio-cultural concerns. They are not social events endowed with cultural significance like symptoms, but their non-eventful status is in itself definitely social and clearly culturally significant. Non-potentiality might not seem to be the most obvious place to look for embodiments of symptom awareness and cultural configurations of symptoms; however, since this is the everyday lifeworld by which vague and ambiguous sensations are organized and articulated as symptoms, it is in fact central to our aim to also understand the ordinary body in terms of its ordinariness and not only in terms of its irregularities.

### *The potentiality of non-sensations*

During a discussion with some people from the exercise group, one of the men talks about how he goes for regular health checks: ‘... and you just have to follow the controls. It’s been put into a schedule and then you come, and they say that it’s fine and so on. And you owe it yourself to do that! Some people just say “I don’t care. I’m feeling fine” Yes, they are. But only until a certain point in time!’

The examples of using health checks ‘to know that you are fine’ are plentiful. This can be seen as a potentiality of what can be termed non-sensations relating to an understanding of the body as the potential carrier of invisible disease. The feeling that disease may hide and grow in the body without producing any symptoms ‘until it is too late’ creates a constant potentiality of non-sensations that is expressed as a hyper-signified body, where people ascribe significations to their body without experiencing signs or sensations. But does this mean that people are in a constant state of vigilance and worry? This potentiality, which is fully a biotechnical embrace, stands in striking contrast to the non-potentiality described in the above paragraph, demonstrating that the awareness of potential ‘invisible’ serious illness is also part and parcel of everyday life. As many of the informants found it easier to see their general practitioner for a general health check based on the well-established knowledge of potential disease hiding in the body than based on actual bodily sensations with an uncertain and ambiguous status as a symptom, the diffuse presence of potentiality is a powerful legitimizing factor in seeking healthcare, which is also reinforced by the healthcare system and public health interventions such as health promotion and awareness campaigns, screening programs and the categorization of risk groups, risk behavior and pre-states of disease.

This non-potentiality is also evident in Helen’s story, which is about when her regular physician retired and she had to find a new one:

After careful consideration of what was a reasonable distance from home and the options for parking her car, which can be an issue with clinics in the city, she ends up choosing her new physician primarily based on the amount of parking available. At her first visit, she is offered an annual health check. Helen repeatedly claims during field

visits and interviews that she is never ill but complies and goes for a health check, which shows that she has ‘something on her lungs’. She goes through additional clinical tests at the hospital that show a spot on one of her lungs. Cancer is a possibility, but they claim that it is nothing to worry about as long as she continues to be monitored regularly at the hospital. Helen expresses how grateful, amazed, and lucky she is that her rather randomly chosen new physician coincidentally led her to discover this potentiality for disease, which she can now actively make an effort to keep at a minimum.

Existing as a biological fact inside her, the spot on Helen’s lung had not manifested sensorially and thus did not exist until the concept of the regular health check brought this particular illness-potentiality to life as risk in her life. Helen’s example shows how a non-sensation, or a state of bodily normality, is turned into a very real illness potentiality that is institutionally nourished and reinforced by her now regular control appointments. This is not to deemphasize Helen’s risk of developing a serious medical condition but quite simply to show how the normal can turn into something pathological only by means of the diffuse potentiality of non-sensations.

Apart from suspecting a lung disease and having a gynecological problem, which she has actually been quite worried about, Helen insists that she is actually never ill. The insistence on being in good health is a common tendency among the informants, leading us to take a closer look at the role morality plays in the potentiality of sensations.

### *The moral potentiality of sensations*

The way the different potentialities play out in everyday life also indicates something about everyday life morality, about what is at stake for its participants. As ‘what really matters’ to people (Kleinman 2006), morality is an intrinsic component of the ‘at-stakeness’ of everyday life. From this perspective, bodily sensations can thus arguably be said to possess a moral potentiality that has an important part to play in the liminal space between sensation and symptom. When Helen, for example, insists that she is practically never ill despite her illness and symptom episodes, it is more an evaluative statement than a

descriptive one (see also Gullestad 2001). It relates, for instance, to specific Danish middle-class moral concerns about acting responsibly in relation to common public goods (such as free healthcare) in the Danish welfare society ("Author", in review). It can also be argued that the focus we found among informants on physical activity, either in the direct form of regular exercise or in the everyday keeping oneself busy, is central to the moral potentiality of sensations. An example of this is when Kirsten and her neighbor attend their fitness program and explain how it can really make them feel a positive difference in their bodies. This story is repeated in a variety of versions among people in the neighborhood, all of whom emphasize either their dedication to physical activity, which felt good for their bodies, or their lack of physical activity, which they figured would make their bodies and health better. As the non-potentiality of sensations shows, culturally shared ideas of the normal body and non-potential sensations chiefly revolve around physical activity, where sensations are more or less consciously perceived to be normal. Sonja, for instance, explained that her body ached because it has been exhausted from picking apples and working in the yard. While framed as a normal bodily sensation relating to how the body was used, she also remarked that she would probably not have as much pain after working in the yard and be less at risk of illness if she exercised 'like some people do'. In this way, physical activity encompasses both the normal middle-class body as a body in use – with the valid, subsequent discomfort – and the ideal middle-class body as a useful body that is functional and well-kept due to exercise and healthy eating. This illustrates how Danish middle-class everyday life norms of working and housekeeping are embraced by the biomedical and health promotion discourses in a normative idea of physical activity.

Physical activity is an example from the normative end of the moral potentiality of sensations. Our aim, however, is also to show that the potentiality of bodily sensations must be understood in light of the overarching concern with what really matters, as Kleinman (2006) defines morality. To illustrate this point, consider the way time is lived and perceived in everyday life. In our discussions with informants about symptoms and healthcare seeking, time is often phrased as a matter of great moral concern. Many informants tell stories about people who presented their symptoms to a doctor 'too late'. But what does 'too late' mean? First of all, 'too late' most often refers to the idea that serious diseases such as



cancer may be hiding and growing within the depths of the body. Temporality in terms of pathological growth and temporality in terms of 'being aware' thus feed into the potentiality of sensations and shape new moral contexts for bodily experience.

Moreover, for people who fear life-threatening diseases, 'too late' is often an expression of unavoidable death, consequently disrupting what really matters and often voiced as concerns about not being able to watch grandchildren grow up or missing out on realizing the hopes and dreams they have had about the rest of their lives. However, between the ultimate potentialities of life or death, moral potentialities of sensations also disturb what really matters in various other ways in relation to time. Consider, for example, how the duration of a sensation can affect how the potentiality of the sensation is perceived. This is also a moral potentiality in the question of legitimizing a sensation as a symptom and eventually legitimizing seeking healthcare in the local moral world of the Danish middle class (see also "Author", in review). Or we could look at the time of day, the time of year, or the phase of life when the body and its sensations are noticed in different ways due to different concerns. Many informants, for instance, describe how they worry about specific sensations while lying in bed before going to sleep or how they notice something is different when they wake up in the morning. Or that their bodily sensations change with the seasons or with age. The moral potentiality of sensations can also be seen in the informants' concerns about the quality of their time. A strikingly large number of the informants stated that they would not opt for treatment if they got cancer after having seen friends and family suffer severely from chemotherapy. Two male informants would rather not know if they had cancer. In most cases, these statements were in direct opposition to other potentialities at play for them and also to their healthcare seeking practices, where they readily went to their doctor with worries and gladly participated in available screening programs and health checks. The moral potentiality also encompasses the wider society and organization of the healthcare system, with several stories of general practitioners who did not suspect serious illness and delayed diagnosis or of organizational aspects of the system where mistakes were made and people were diagnosed too late.

Everyday life in the Danish middle class can be seen as the efforts that through a life course have been put into creating basic certainty and a space that allows

dreams and aspirations to evolve and unfold. Everyday life consists of the sum of our endeavors towards the life we wish to live. Illness threatens everyday life as well as hopes and aspirations. As a result, symptoms of illness are loaded with morality. In the liminal and ambiguous space between sensation and symptom, moral potentiality, therefore, adds ‘at-stakeness’ to sensations. As Das and Das explain: ‘illness experiences move between the registers of the ordinary and the extraordinary, centered in one’s social and material worlds, yet carrying the power to propel one outside of these worlds’ (Das and Das 2007, 70). Thus, having showed how bodily sensations are constantly weighed between different forms of potentialities, we believe that a moral potentiality of sensations is always present and of key importance in the balancing act between normal and not normal.

### **Concluding discussion**

In our attempt to delineate various potentialities of bodily sensations, what most clearly stands out is how deeply entwined they are (see also Das and Das 2007). We argue that a weighing of potentialities takes place when people experience bodily sensations and suggest that the outcome of this weighing is contingent upon the local moral world in which sensations are sensed. In the context of the Danish middle class, ‘the good (everyday) life’ emphasizes creating and sustaining a socioeconomically stable and secure foundation for ‘what really matters’ (Kleinman 2006) or for ‘well-faring’ (Langer and Højlund 2011). The notion of ‘well-faring’ connects individual well-being to collective and political concerns about how to live well throughout life within a specific cultural context. This paper explored how the uncertainty and ambiguity of bodily sensations and ideas of health and illness interrupt well-faring and threaten what really matters in middle-class everyday life. We showed how the Danish welfare state’s health promotion rhetoric pervades everyday life concerns and influences the potentiality of bodily sensations as well as individual well-being and morality. Looking at everyday life potentialities of bodily sensations reveals how the subtleties of the biotechnical embrace appear in the ordinary uncertainty of everyday life and in the mostly non-eventful experiences of the body in the Danish middle class. In this way the potentiality of sensations casts light on the many subtle ways biomedicine and health promotion discourses structure the

everyday organization, articulation, and experience of the body. However, the perspective of potentiality also shows the complexity of subjectivities spanning the political economy of the welfare state and the local moral world of middle-class everyday life in the experience of bodily sensations. The uncertainty of the liminal space between bodily sensations and symptoms is thus not only biotechnically embraced but also embraced by notions of morality (see also "Author", in review). Our point here is to equally emphasize the role of the non-drama and the moral concerns of ordinary uncertainty in the perception, experience, and articulation of sensations next to the more easily discernible and extensive discursive influence of the biomedical field and health promotion rhetoric, which we must be careful not to treat as 'a ready-made peg on which people can hang their illness [and sensorial] experiences' (Das and Das 2007, 90) in this biotechnically embraced modern Western society.

Viewing the subtle perceptual organization and articulation of sensations as symptoms as continuously happening on a seesawing continuum, where the balance shifts between normal and not normal, rather than as the more rigorous image of crossing a threshold at a certain culturally defined point, acknowledges and allows us to explore the ambiguities of experiences embedded in the socio-cultural context, such as is called for by Throop (2010).

An understanding of this ambiguity provides new perspectives on how health promotion discourses, such as the focus on symptom awareness, feed into and affect the body in everyday life. This understanding questions the idea of sensation to symptom transformations being somewhat linear interpretive processes, where rational decision making can be influenced by awareness and knowledge of symptoms, present in what has been termed the behavioral sciences of medicine (cf. Good 1994). Our perspective instead illustrates the non-linearity of ascribing meaning to bodily sensations and shows how health promotion and symptom awareness provide just some of the nuances in the complex palette of potentialities of bodily experience in the ordinary uncertainty of everyday life. Indeed, biomedical and health promotion discourses are significant in everyday life, and we believe that the present public health rhetoric on symptom awareness in Denmark does expand the illness potentiality of sensations as described in this paper. However, this expansion probably merely rearranges the landscape of uncertainty, ambiguity, and potentiality – it does not reduce it. In accordance

with Das and Das who dismiss the idea of ‘symptoms and diagnostic categories as arising from culturally standardized practices of classification’ and instead suggest that we ‘shift the weight of explanation to the regimes of labor through which both body and temporality are being produced and consumed in local settings’ (Das and Das 2007, 80), we perhaps instead need to direct our attention to how potentialities of sensations are weighed against each other and to the local cultural and moral concerns this weighing is contingent upon.

### Acknowledgements

The authors are grateful to Arthur Kleinman for his inspiration, insights, constructive comments, and encouragement during the writing of this article while on a research stay at the Department of Global Health and Social Medicine, Harvard University.

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# CHAPTER 5:

## PAPER 3

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### CANCER BEFORE CANCER: MYTHOLOGIES OF CANCER IN DANISH MIDDLE CLASS EVERYDAY LIFE

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Submitted to *Ethnos*

## **Abstract:**

This paper explores the various ways cancer is present in everyday life among healthy Danish middle-class people. Approaching cancer presence as mythologies, the paper argues against Susan Sontag's prediction of increasing scientific knowledge 'de-mythicizing' cancer. Based on ethnographic fieldwork in the suburban Danish middle class, different and paradoxical cancer mythologies are described and show how these provides multiple ways of understanding and dealing with cancer in everyday life. Special attention is paid to the relation between biomedically informed notions of symptoms and bodily processes and a ghostly and muted presence of cancer, particularly when faced with actual cancer worries. The paper suggests, based on analysis of dissolving processes that silences uncertain cancer worries, that health promoting constructions such as 'symptom awareness' and 'cancer alarm symptoms' are difficult to fit with ambiguous bodily experiences in everyday life, because they create an unintended illusion of certainty that does not correspond with the essential uncertainty of being and nuances of everyday life. The paper thus both contributes to contemporary anthropological writings on illness mythologies and uncertainty and adds to anthropological conversations with the field of public health, emphasizing the need to attend to the interaction between cancer mythologies to understand how symptoms are managed and health care seeking is practiced in everyday life.

## **Introduction**

“Well, cancer is a horrible disease but fortunately it mainly strikes older people. But of course I am afraid of it and I often think of it when I feel some kind of twinge or stab of pain or a symptom from my body. And I think of my future: When will I get this kind of sentence? It is a kind of a... what can we call it?...a scary monster that attach to your life with this disease...Because I am this age and I feel really lucky that I have come this far without discovering anything. But that is the thing: that this disease, it is not something you notice until it reaches a certain stage. It is a coincidence if someone discovers it before it starts giving

symptoms. So it is a scary disease. A sneaking one that you can carry around without knowing it.” (Christine, 65 years, recently retired)

In spite of the growing scientific understanding of cancer and an increasing array of treatment opportunities during the last decades, cancer is still in many aspects considered an enigma to be solved and, as the introductory informant quote shows, a monstrous creature threatening to rupture and alter life worlds and societies. Recently, President Barack Obama in his presidency’s final State of the Union address aligned America’s effort to find a cure for cancer with a moon shot, implicitly drawing on the ethos of Neil Armstrong’s famous words of “a giant leap for mankind” (Obama 2016). The *cure rhetoric* and *the war on cancer*<sup>6</sup> metaphors can be seen as global symbolisms that unite across countries and culture the many uncertainties and interrelations of the cancer complex into one single, almost caricatured, global quest of solving the enigma and eradicating the disease. But defeating – and understanding – cancer is all but a unified quest. As Julie Livingston aptly shows in her depiction of cancer in Botswana, cancer manifests very differently under different social conditions (Livingston 2012). In Denmark, and generally in the Global North, the complexity of cancer disease control has increased during the past decades. In terms of aetiology, prevention and treatment, cancer has become an increasingly multifaceted social field where focus on lifestyle factors and carcinogens in our environment interacts with genetic dispositions and viral infections. A sense of fate and notions of morality are often read into this complex field as well. Preventive measures in the effort to take charge over cancer must play into this complexity, resulting in various biomedical discursive arenas of e.g. genetic testing and counselling, screening, vaccination and the ‘behavioural sciences of medicine’ (Good 1994) focusing on lifestyle changes, symptom awareness and healthcare seeking practices. Cancer is at the same time a highly political and economic field where decisions and prioritizations provide a framework for what counts as significant in what we in this article choose to look at as contemporary cancer mythologies.

Cancer mythologies emerge between the cancer complexity with its uncertainties, ambiguities and paradoxes permeating society in most aspects, and the ‘cancer caricature’ where the monstrous, heroic and miraculous characters of cancer

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<sup>6</sup> Politically introduced by US President Richard Nixon in 1971 but as Susan Sontag most prominently argues cancer conceptualizations are imbued by war metaphors (Sontag 1991).

stories are amplified to illustrate a battle of winning or losing. The illness experiences of cancer among people directly affected by cancer have been widely investigated globally (Manderson, Markovic, and Quinn 2005; Henriksen and Hansen 2009; Livingston 2012). Yet, the scope between caricature and complexity also includes the everyday life of the populations whose health behaviours are subject to exhaustive public health interest and a diverse range of health promotion interventions aimed at e.g. cancer prevention, cancer awareness and healthcare seeking with symptoms of cancer. Cancer, then, is not just a disease affecting its victims. It is a cultural phenomenon that reaches far into society at large and into intimacies of everyday life (Stacey 1997). Cancer mythologies carry moral significance in their ultimate dichotomy between life and death. As argued by Sarah Lochlann Jain in her semi-autobiographical work, cancer's complexity lies between these polar endpoints pointing towards imagined futures and counterfactually questioned pasts (Jain 2007). Jain investigates the temporality of cancer in the United States through the perspective of 'living in prognosis', and we argue with her that "all of us in American [and Western European we would add] risk-culture live to some degree in prognosis" (Jain 2007:79) and with the contours of impending disease that is implicitly assumed in titling this article 'Cancer before cancer', we imply a presence of cancer as a cultural representation in everyday life without the presence of disease. A presence, however, which in turn affects how the disease is perceived and embodied in the uncertain and ambiguous landscape of potential disease. It is a different landscape in terms of both uncertainty, morality and temporality when we turn our focus from the village of the sick (Stoller 2005) to explore cancer in the village of healthy (Andersen, n.d.), but it is no less relevant since most cancer stories take their beginnings in everyday life with people experiencing bodily sensations as symptoms of potential illness, among other things in the light of contemporary cancer mythologies. In Denmark, as well as in other parts of the Global North political and scientific focus on cancer symptom awareness and 'timely' healthcare seeking has intensified in recent years, marking a change in public health rhetoric towards a reconceptualization of cancer as an acute condition (Tørring 2014) and what can be termed 'symptomatic management of cancer disease control' (Andersen, n.d.). However, assumptions driving public health interventions have been criticized for creating a causal link between recognizing cancer symptoms and healthcare seeking based on assumptions of decontextualized rationality (Andersen and Risør 2014). We

will argue further that this creates an illusory certainty of what cancer symptoms are (Douglas 2001), which is not easily translated into the ambiguous and uncertain sensorial experience of health, illness and everyday life (Offersen et al., n.d.).

In this article we aim to show how cancer is imagined and manifested in everyday life among Danish middle-class citizens who, although presenting various other health problems, did not have a cancer diagnosis at the initiation of fieldwork. Cultural studies of cancer tend to focus on people just diagnosed with or living with cancer but with increasing societal focus on preventive strategies for controlling cancer, it becomes interesting to also focus our attention towards the role cancer plays in everyday life among the 'healthy'. Cancer is present everywhere and the aim of this article is to explore how we are living with it and dealing with it. This is explored with two perspectives. One is, in the first section, to outline and describe contemporary cancer mythologies in everyday life of the healthy population. Another is to discuss how we can understand the public health notion of cancer symptom awareness and its embodied effect on symptom experiences and healthcare seeking practices in the perspective of cancer mythologies. The final part of the article analyzes and discusses this, especially with regard to ambiguous, non-verbalized cancer worries. To begin with, we will elaborate a bit on our use of the concept of mythologies.

### **Defining mythologies**

In Susan Sontag's classic critique of cancer myths and metaphors first published in 1978 she predicts that with an increased understanding of cancer and improved treatments cancer will be partly de-mythified (Sontag 1991). Contemporary literature on cancer culture argues against Sontag's prediction (e.g. Lock 1998; Stacey 1997; Clow 2001) and questions to some extent her argument, showing how it has itself been turned into the latest mythology on cancer (Clow 2001). Our analysis partly leans on Sontag's use of ideas of mythology and metaphor to conceptualize cancer manifestations in everyday, partly joins the questioning of her predictions and sharp distinction between objective, scientific knowledge and mythified metaphorical (subjective) conceptualizations of cancer in the public in her idea that cancer can be de-mythified and freed from metaphor (Sontag

1991: 3-9, 86-87). We do not distinguish between objective and subjective ways of knowing cancer, but in the cancer manifestations that appear in our empirical material we show how various bits and pieces of objectified knowledge such as survival rates, risk factors and genetics become entangled with emotions, narratives of hope and tragedy, sensorial perceptions and morality. In what Levi-Strauss might call a bricolage of knowledge, experience and attention at hand (Lévi-Strauss 1966) we here treat cancer mythologies as the diversity of cultural representations of cancer which configure in the interface between biomedical objectified forms of knowledge and individual everyday life experiences, mirroring its cultural contexts.

Mythology, the paper thus suggest, does not consider mythology as something which is false, subjective and based on beliefs opposed to positivist objective knowledge based on science about the true nature of things. This distinction has long been dissolved within anthropology and may in itself be considered a myth when considering e.g. the epistemological grounds of scientism (Loughlin, Lewith, and Falkenberg 2013), the processes and implications of scientific reductionism (Lock 1994), the idea of local biologies (ibid.) and an empiricist theory of medical language (Good 1994). Turning to classic structuralist perspectives on mythology, we find that Lévi-Strauss also reminds us that ‘the same logical processes are put to use in myth as in science’ (Lévi-Strauss 1955: 444). While emphasizing the equal grounds on which we find mythology and science from different angles, we wish here to use the concept of mythology in an attempt to ‘account for the synthesizing activities by which disease is made an object of personal, social, political, and medical significance’ (Good 1994:167) from the perspective of Danish middle class everyday life.

Margaret Lock subtitled her ground-breaking comparative analysis of menopause ‘*Mythologies of Menopause in Japan and North America*’. While not specifically defining mythologies, she looks at menopause as ‘a concept with boundaries and meanings that shift depending upon the viewpoint and interests of speaker and listener’ (Lock 1994:xviii) The same can be said about cancer and is an expression of a fundamental uncertainty surrounding the disease – an uncertainty that has not diminished with increased knowledge as predicted by Sontag. It can be argued that increased understanding of cancer and scientific breakthroughs merely rearranges the landscape of uncertainty and ambiguity, rather than

reducing it (Offersen et al...). You can know your statistical risk and genetic disposition of getting cancer. You can calculate the probable effect of your years of cigarette smoking on your average life expectancy, you can be aware of cancer symptoms, you can go for a run every day, and you can choose screening, health checks and HPV vaccination. But you cannot know if you will get cancer and why you got it or did not get it. The span between statistical probabilities and individual lives and bodies is the locus of this uncertainty. As biologist Stephen Gould reasoned when faced with a median mortality of his own cancer diagnosis of eight months: 'Variation is the hard reality, not a set of imperfect measures for a central tendency. Means and medians are the abstractions' (Gould 2013:79; see also Lock 1998). Gould lived for 20 more years in *the right skewed tail* of variation to the median mortality. Thus, life in some general sense can be considered lived *in prognosis* but individual life is lived in the variation. The magnitude of cancer as a disease worldwide makes its inherent uncertainty and ambiguity an essential cultural matter with unstable boundaries and meanings and which synthesizes personal, social, political and medical significance in its culturally specific everyday life manifestations. This is what we call cancer mythologies.

### **Accessing cancer mythologies among the suburban middle class**

The analysis in this article is based on 18 months of ethnographic fieldwork in a suburban middle-class neighbourhood in Denmark. Fieldwork consisted of a minimum of six visits in each participating household out of which three included a semi-structured interview. Beyond interviews Offersen did participant observation, following everyday life activities in the house and in the neighbourhood and health related activities such as visits to the GP, physiotherapy, following informants to appointments at the hospital and going to the pharmacy. 18 key informants (11 women and 7 men) participated in the project. Some of them were married couples who were interviewed together while participant observation could follow one or the other. All informants were more than 40 years old, most of them were aged 60 to 70 and were retired or on the verge of retirement.



The anthropological study behind this article departed in the question of how people ‘read’ their bodily sensations as possible symptoms of disease (cf. Hay 2008) and when they decide to seek healthcare with potential symptoms. Thus, the fieldwork in itself was not concerned with cancer but with sensations, symptoms and healthcare seeking in general. However, the underlying reason for conducting this fieldwork was to deepen our understanding of why Danish citizens have a lower cancer survival compared to similar countries (Coleman et al. 2011). One probable reason among many is that people wait too long with symptoms of cancer before presenting them in the healthcare system which results in worse individual prognoses and poor national cancer survival rates. With this point of departure then, it is inevitable that the fieldworker, Offersen, from the beginning has been attuned to the ways cancer was verbalized and enacted within the myriad of health and illness concerns in everyday life. This particular way of paying attention to the subject as a ‘side focus’ to the main focus is precisely what enables us to unfold cancer presence in everyday life as mythologies composed of and embedded in medical, political, social, cultural and moral concerns. However, a principal part of the analysis in this article is built on ethnographic field experience of a non-verbalized cancer presence, or a ‘cancer elephant in the room’, derived from the ethnographer’s sense of the situation or habitual ‘feel for the game’. In this kind of experience the ‘side-focus’ on cancer may also influence the way cancer becomes present in the mind of the ethnographer. However, this ‘absent presence’ of cancer seemed overwhelmingly clear during fieldwork and again in reading and re-reading interview transcripts. It is also not unknown from the literature where the difficulty in saying ‘the C-word’ is often emphasized as part of the cultural phenomenon of cancer (Stacey 1997 m.fl...). The empirical descriptions we present of a non-verbal cancer presence can thus be said to be grounded in tacit knowledge (Polanyi 2009) and in what Michael Taussig has called ‘implicit social knowledge’ (Taussig 1984).

### **Cancer mythologies in the Danish suburban middle class**

Detached single-family houses lie as core symbols of middle class social and economic achievement (Sjørsløv 2009) side by side along a ruler-straight system of roads and side roads in the middle class neighbourhood that is the empirical vantage point of our exploration into everyday cancer mythologies. People are

mowing their lawns, weeding their flower beds and helping neighbours pack a trailer with garden waste to take to the waste disposal site. You can almost hear the chirping birds from this idyllic somewhat stereotypical image of walking through a neighbourhood of middle class everyday life. In colder times of the year the gardens lay bare and the houses take centre stage with candles in windows and electrical chains of light exuding an atmosphere of cosiness and warmth inside. This is the context in which we will explore cancer. Cancer is present in different ways in everyday life here in the Danish middle class. It resides in the perplexed but warm hug to a friend not seen for a long time at the golf course where he and his wife used to play before cancer and illness uprooted routines of golfing and lawn-mowing. It ‘runs’ in families and worries of afflicted family members and inherited risks, and it is narrated in glamorous TV-shows collecting money for the fight. It faces people every day from health promoting commercials at bus stops and in leaflets fixed to their kitchen pin boards with phone numbers of where to call if you are affected by cancer next to phone numbers to services of acute medical assistance. We want to address how all the various, concrete and abstract, cancer manifestations mould cancer mythologies and how they are dealt with in everyday life. Let us elaborate with a closer look at the case of Elisabeth, a retired woman in her 60s:

Sara: Is cancer something you can be worried about when you sense something in your body?

Elisabeth: Yes yes...Skin cancer and things like that. I believe one of our friends she has had... she had something on her nose that she went to get scraped and stuff a couple of years back...And one of our other friends, I think she has had a little bit of this skin cancer. But they say the thing about, if you are fair-skinned, rather reddish perhaps...if you...I can’t count the number of times I had sunburns as a kid, so yes... There is something sometimes. You should look after yourself. That thing about the sun. Yes.

Later Elisabeth tells about one of her visits at her GP where she has gone to have her cholesterol checked. When pressed a little she hesitantly starts telling about how she had given birth to some very big babies which has resulted in her having occasional troubles with haemorrhoids. However, her story gradually unfolds in still more vague

and downplayed formulations: "...but at that time I also thought that I... I felt that I had had some kind of problem. I thought that I had gotten some blood where I... I guess I believe that I had that...But I don't think that I told this to the secretary when I made the appointment, no."

There is a pronounced paradox in the ways in which Elisabeth relates to cancer. It ranges from talking matter-of-factly about the risk of getting skin cancer and telling about a close friend who had it, to discussing actual worries of cancer with a simultaneous hesitancy to use the word 'cancer'. Elisabeth has earlier mentioned rectal bleeding as a well-known symptom of cancer, but as the conversation narrows in on concrete but ambiguous personal experience of the same symptom, we are talking about 'some kind of problem'. All over our empirical material we find this paradox between how cancer manifests as a disease you are statistically likely to get, especially as you get older – you and everyone else live in the prognosis of this likelihood – and how cancer manifests as a more concrete threat when bodily sensations might turn into symptoms of cancer and an illness-potentiality is evoked (Offersen et al., n.d.), marking a change of prognostic character from the statistical probability of getting cancer at all to the likelihood of *this* symptom being a sign of cancer. Interestingly, we find that the more abstract the experience of risk is, the more concrete are the cancer manifestations whereas the more concrete worries people have, the more abstract, ambiguous and uncertain cancer seems to be. As Jain also phrases: 'The word's tangibility dissolves in sheer bafflement, for doctors and patients alike, over what, exactly, it describes' (Jain 2013). In our perspective the paradoxes and contradictions inherent in everyday life cancer manifestations emerge from the 'bricolage' of cancer mythologies and consequently frame embodiment of risk and cancer symptom awareness as well as agency of preventive strategies such as healthcare seeking with potential cancer symptoms. We will now turn to a description of some of the most profound mythologies found in the neighbourhood.

*'Cancer is a lot of things'*

Our cells start to divide uncontrollably. And they generate metastases and tumours. Untreated, this can continue and then it can infect organs.

It can infect the brain and it can destroy the bones. Yes, it can destroy it all.

Erik, 75 years old, retired

As if singing a well-known chorus, almost every informant responded to the question of ‘what is cancer?’ with a version of the ‘uncontrolled cell division’-story. Those who did not, took a more character-describing and consequential approach and told that cancer is ‘ugly’, ‘serious’, ‘deadly’ and ‘frightening’. Being able to account for an abstract fear and for bodily processes involved in cancer is, however, not the full story of cancer before cancer in everyday middle class life in Denmark. ‘Cancer is a lot of things’ as several informants told, but it is also such a singular powerful phenomenon that Elisabeth’s story above diffuses into talking around cancer, not phrasing it as an explicit worry. Cancer, we argue, should be seen in Lock’s phrasing as a cultural representation ‘with boundaries and meanings that shift depending upon the viewpoint and interests of speaker and listener’. So what forms and figures does cancer mythologies take between the rather mechanical recitation of the cell-story and the spooky sense of a ghostly figure that is too terrifying and too elusive in its appearance to name?

### *Death, suffering and a positive attitude*

First of all, death and suffering takes a prominent position in describing cancer. During fieldwork a friend to one the couples, Finn and Doris, was diagnosed with and died from lung cancer. The course of his illness was described as ‘violent’ in terms of how quick he became really sick and died: ‘It went so fast that we couldn’t...we couldn’t even imagine... Every time we spoke with him which was once a week – Good Heavens! We couldn’t even count till three before... it just went so fast’. Doris’ narration of their experience with their friend’s illness and death is a story of cancer as a matter of time. In fact, the relation between cancer and time is so strong that Doris in this story is able to euphemize this close and shocking encounter with cancer and death solely in terms of its temporal unfolding. Another example is Jens and Sonja who housed Jens’ brother, ill with cancer: ‘He was not well. Actually, it was horrible. It started in the throat, all the way from the tongue bone. Tube feeding and things like that...’ In talking about cancer Jens and Sonja keep returning to the horrors of the brother’s cancer. They

don't really describe in any further detail what these consisted of but in general the horrors of encountering cancer in person is reflected in informants' responses to the question of what type of cancer they feared the most where most answers contained a cancer, they have encountered face to face in their immediate social network. Arising from these encounters a different narrative also took form. A common theme was the story of coping with cancer with a positive attitude and 'fighting back' – the moral underpinning of being a good cancer patient. One informant, Christian, was diagnosed with prostate cancer during the fieldwork of this study. Talking about the process he cites a book he has read about the 1<sup>st</sup> World War, saying that 'a big heart does not fear death if it is honourable' and tells that he just wishes to 'take it like a man' like his father did when he was diagnosed with and died from cancer. This is in accordance with what we call the cancer caricature where cancer heroism is praised (see also Stacey 1997; Harris 2015).

Robert: It makes me laugh a little bit, talking about this, because I think of the article we read many years ago by now: An American who was diagnosed with cancer. 'Cancer', he says to himself and he went and bought a lot of comic books and then he sat down and read them and laughed.

Kirsten: And movies! Everything he found funny.

Robert: Then he didn't have cancer anymore.

Kirsten: He healed...

Robert: He healed himself with a positive attitude. By being positive all the time. Positive, positive... Laugh and so on.

Somewhat caricatured in this tale from Kirsten and Robert, the cancer heroism is evident in several accounts of people 'living positively with cancer', as Jette e.g. also states after telling about a friend with bone cancer: 'Of course you will also get the dark thoughts. But to get the most positive out of it, I believe that is life-prolonging'.

### *The absent presence of cancer*

One of the most profound mythologies of cancer in everyday life turned out to be its simultaneous apparent absence and ghostly presence. More or less everyone had a sense that cancer could be invisible and hide and grow in the body, and combined with the temporal imperative of the importance of discovering cancer at an early stage this was a pressing concern for many. Karen, newly retired, explains how she had precursors to breast cancer some years back discovered in the breast cancer screening programme. She had not felt anything herself. She had some tissue surgically removed and had preventive radiation therapy and guessed that she is 'one of those people where it would not have grown into something serious'. Nevertheless she started wondering about how cancer could be present without any notice:

At that time I thought: 'then it can happen anytime and with anything!....When you find it here, where else do I have cancer? Do I have it somewhere else? And will it not just return? Am I predisposed?' My doctor reassured me that I was in no more risk than anyone else. I don't know if that is exactly true but I found comfort in what she said and that, well, they could start to examine me everywhere but that didn't really make any sense. So I just thought 'well, there is nothing wrong with me, then'. But I also didn't feel ill at that time before. Not at all. I couldn't feel a thing. There was nothing. So that is the scary part. For that reason I go to all the screenings as you are supposed to. But it is not everything in the body that gets screened, right?

Informants tell of people they have known, who have gone to work every day, feeling nothing unusual, and then suddenly a large tumor is discovered and they are dead within a few months. The sneaking, lurking, hiding character of cancer is the most profound fear among people in the Danish middle class and is perhaps also the point that most markedly differs from cancer mythologies in the village of the sick where cancer is an enemy that can be fought out in the open, at least to some extent. This ghostly presence of cancer is contrasted and reinforced at the same time by health promotion focus on early detection of cancer, imposing the understanding that cancer can be detected by paying attention to early signs and sensations. Karen continues her puzzlement over how you can feel completely well and be very ill at the same time:

We are told so much about all the illnesses you can get. My goodness, a lot can be wrong! And if you don't see the doctor in time it is really bad! But well, our healthcare system budget is busted if everyone goes to their doctor even when they don't feel anything wrong but they are afraid that there might be something. Well, you can call it hypochondria. You can get that from all the things we are told....But you also hear about all these people who are suddenly fatally ill without having sensed that something was wrong. That is worrying indeed. ...It is about figuring out a compromise between being alert but not hyper-alert if you can be that. I find this a little difficult to balance sometimes.

The conflict between alertness and hyper-alertness is a conflict between the ability to live a normal everyday life, which is not continuously interrupted by fear of illness, and the fear that fatal illness would ultimately disrupt this same everyday life. Or, roughly speaking, between an enjoyable life and no life at all. The absent presence of cancer, running particularly in stories of cancer-afflicted people in informants' social network, yields momentum to hyper-alertness and fear but also moral resistance to excessive healthcare seeking and medicalization (see also Offersen, Vedsted, and Andersen, n.d.).

### *Aetiology and spread*

When I am feeling well I consider my risk small. And this relates to two things. It relates to the fact that I have not – at least not consciously – consumed excessive amounts of toxins in my lifetime. I have kept myself in good shape. And then it relates to what my sister told me: that it doesn't run in our family. And I can look backwards and onwards and ascertain that this is not what they died from.

Erik, 75 years old.

A final aspect to be touched upon is the middleclass mythologies of aetiology and spread of cancer. First, a characteristic feature of cancer origins in this context is emphasizing that cancer is not something new. People agree that there is increasing focus on cancer but many stress that it is more a matter of focus than a matter of increasing cancer incidence and that 'we just didn't know before'



or ‘it was called something else’. This relates to cancer being perceived as dwelling in the body and that cancer disease happens when the immune system becomes weak or internally originated cancer finds ‘a weak spot’ from where cells will start to grow and spread uncontrolled and unnoticed. Cancer is also widely considered hereditary. When informants told stories of cancer in their family, they almost automatically stated whether the cancer-afflicted family member was on their side of the family or not, i.e. genetically related to themselves. A completely different story that was just as readily told was the story of carcinogenesis. Of environmental circumstances external to the body that causes increasing cancer incidence in contemporary society. Toxins and pollution and the governing bodies that allow these to penetrate our lives and bodies become the culprits.

#### *Vanishing war metaphors and mythological multiplicity*

What we did not find in the everyday life cancer mythologies was an abundance of war metaphors as described at length in cancer culture studies among people affected by cancer (Sontag 1991; Stacey 1997; Williams Camus 2009; Penson et al. 2004). They were not completely absent but they were remarkably vague in comparison with what is described in the literature. This is perhaps an expression of difference between the metaphors landscaping the ‘kingdom of the ill’ (Sontag 1991:3) where cancer becomes an enemy to fight (Stacey 1997:172), and the mythologies running through ‘the village of the healthy’ (Andersen, n.d.) where prevention efforts and ambiguous bodily sensations do not connote the same epic sense of an ultimate, and individual, fight. What is characteristic of everyday life mythologies of cancer on the other hand is indeed, as we initiated this chapter, ‘a lot of things’ grouped together under one frightening but invisible banner. In a call to turn an anthropological lens on all the different forms cancer take and their social impact, Lenore Manderson mentions ‘precancers that are not yet, but might be’ (Manderson 2015) as one of the cancers that need attention. As precancer, or cancer before cancer, our study field seem to be characterized exactly by the all the different shapes and sizes cancer comes in. Being not there yet, it can still be anything. Or nothing at all. In this way everyday cancer mythologies are full of bits and pieces of the whole spectrum of cancer variation and inherent paradoxes and contradictions between these. Consider, for instance,

the contrasting perceptions of cancer as invisible, growing unnoticeable in the body, and the embodied focus on cancer as something that can be detected by being aware of early signs and sensations, creating a difficult balance between being alert and hyper-alert, understood in Karen's explanation as too alert to live a normal life. Or look at the paradox between cancer as ugly, horrible and frightening and then the cancer heroism, laughing cancer away with a positive attitude, revealing a body-mind entanglement that leaves the responsibility to sustain a positive attitude with the individual sufferers and 'pre-sufferers' that are not yet but might be. The contrasting mythologies of cancer as both coming from within the body and from outside the body, shape different moral responsibilities and involve different actions towards prevention. The overall question then is how different parts of the mythologies gains significance, become amplified or downplayed in specific contexts. Everyday cancer mythologies, we argue, adapt to situations and are thus not fixed. Rather, they are used in contextualized individual bricolages to deal with the immense uncertainty and ambiguity these contradictions and paradoxes create.

To build a case for exploring symptom awareness in everyday life, the next chapter is devoted to unfold the absent and muted presence of cancer as people employ cancer mythologies when experiencing and attempting to articulate ambiguous and uncertain bodily sensations and worries.

### **Dissolving cancer**

In Elisabeth's case we see that the cancer presence in her life markedly changes character when she, after a long explanation of the birth size of her children and problems with haemorrhoids, 'admits' that she has been worried about some episodes of rectal bleeding. The casual and commonsensical way of talking about cancer, symptoms and risk has been replaced by a verbally fumbling expression of uncertainty and ambiguity. In this interview, and in many more like it, we were, it seemed, implicitly discussing cancer without saying the word. One informant, Michael, even explicitly refuses it when talking about a work colleague who has been coughing heavily for a long time and now is on sick leave: 'Well, I am not going to say what I think it is!' as if voicing his concern for his friend's potential lung cancer to the anthropologist would actually make

him sick with cancer. But, as Jackie Stacey points out: ‘as the subject is avoided, it enters everyone’s mind’ (Stacey 1997:64). Cancer thus often runs between the lines to the extent that there is no doubt about what Michael’s colleague’s unspeakable potential illness is about, and in many cases like this, it does not take the clearly demarcated shape of a word said aloud. ‘How can we know, then?’ we might ask. The short answer is that we cannot know in the fact-finding sense of the word. And we would not be able to derive this proposed knowledge from e.g. a survey or the interview transcriptions alone. This knowledge is of a different texture which can be most eloquently described in Kathleen Stewart’s words of what she, in her experimental and compelling book, calls ‘ordinary affects’ as ‘the surging capacities to affect and be affected....They can be experienced as a pleasure and a shock, as an empty pause or a dragging undertow, as a sensibility that snaps into place or a profound disorientation’ (Stewart 2007:1-2). The sense of an unvoiced cancer worry presented in this article is thus based on such surging ordinary affects which created intensities of significance (ibid.) in fieldwork situations, as well as on subtle clues from previous discussions or stories told at another time and with another context such as for instance accounts of cancer symptoms or narratives of cancer among friends or family.

People are not unaware of these dissolving processes. An example of a kind of meta-awareness of cancer and symptoms shows how Karen expresses a hope for being able to act on even vague cancer worries instead of ignoring them, and, during the same interview, tells about how she has noticed a concrete bodily sensation that may be a symptom of cancer that she has had for the last couple of years without ever presenting it to her general practitioner:

Sara: When do you think that this is just something you feel in your body or when do you start wondering if it might be...?

Karen: Well...If, for instance, I got a really bad headache or stomach ache...not so much with the hands and feet and so on. That’s something...Well, yes if I had a lot of pain which I could not find explanations to, then I would react. I would definitely do that with all the horror stories I have heard about people who have been really sick without knowing it. They have been walking around with stomach discomfort for some months and then they actually have incurable cancer. These things I think about. I do. I think about it but there just

has to... well, there has to be some symptoms before I would react on it. But then I would react. I would do that for sure.

We continue talking about in which situations she thinks about this and she gives another example where a headache has made her wonder whether she has had a stroke or whether she has just slept in a wrong position which leads her to wonder about her ability to distinguish between normal and severe:

Karen: But I hope that I will react, actually. I hope I would be attentive to it and not just shrug it off. I guess I have a tendency to do that, also when something hurts. I shrug it off then.

Sara: When you say that you hope that you will react in that way...

Karen: Yes, I hope so. That I don't just think that 'well, this is nothing. Don't be hysterical' But I actually think that I have encountered so many who suddenly have started to fall ill without having felt anything other than stomach discomfort or just feeling a bit different in some way. So... but I actually don't know if I then would think that it was just something I ate or something I did or...

After discussing different signs and symptoms of disease and telling about a mole or a freckle or a brown spot on her eyelid which worries her a little bit, the following conversation takes place:

Sara: When were you last in doubt if you should consult a doctor?

Karen: Actually, right now.

Sara: Because of this thing on your eye?

Karen: Yes, and I am glad that you kept on asking because I forget it sometimes. But lately I have been noticing this a little bit. And then suddenly I see in the mirror that I have such a brown blot there which I don't believe I have had before until a couple of years ago. And then I have forgotten about it all winter and then I have thought about it again. Perhaps I should do it. Go there and hear what she (the general practitioner) would say...

Sara: So when you think about having it checked, what is it you want to have it checked for?

Karen: Well, if it is something that can develop into cancer or if it is just a sun fleck or ordinary aging. Or what on earth it is...

Sara: But aren't you then exactly where you told me before that you hoped that you would react?

Karen: Yes yes, I am precisely there.

The symptom awareness that Karen displays in this case is perfectly in accordance with dominant public health rhetoric. However, even though she is (meta-)aware of the risk of her own 'cancer dissolving' and wishes to resist it by actually reacting on vague sensations, her cancer worry seems to easily dissolve, except from when it is prompted and revived by the interviewer's questions. This shows how cancer symptom awareness happens in a context where the straightforward black and white certainty of public health rhetoric dissolves into the nuances and individual concerns of everyday life. It can be argued that Karen's uncertain and ambiguous experience of the mole or freckle on her eye is contingent on impressions of certainty inherent in the list of alarm symptoms of cancer. Yet, even though she recognizes her sensation as an alarm symptom of cancer, her experience does not correspond to the expected certainty by which such symptoms are presented in the public health rhetoric.

### **Discussion – symptom awareness in paradoxical cancer mythologies**

How can we understand these paradoxical cancer mythologies in everyday life? Many informants were themselves baffled over the obvious self-contradictory explanations they often gave. The ethnographically classic differentiation between what people say and what they do, became explicit in questions of perception of and reactions towards hypothetical cancer symptoms and actual ambiguous bodily sensations that could be potential cancer symptoms. Being able to account for public health defined 'alarm symptoms of cancer' did not help people sort out whether a grumbling sensation somewhere in the lower body parts was ovarian cancer or just a grumbling, or if a mole had really changed appearance *that* much. This uncertain and ambiguous embodied landscape is

where everyday life cancer mythologies grow and flow, both separately and together. When presidents then throw moon shots after cancer and people unite under pink ribbons and yellow wristbands to ‘Fight Together’, ‘Support the Breasts’ and ‘Livestrong’ it shows an interesting disparity between the caricatured mythology of a unified global quest and the everyday uncertainty where individual cancer journeys often begin with an ambiguous bodily sensation. In this social field we also find public health rhetoric on cancer awareness and preventive lifestyle, epidemiological representations of cancer and risk as well as both the promises and failures of biotechnology for diagnostics and treatments. All taking part in the continuous configuration of cancer mythologies, shaping the inherent paradoxes in our way of understanding and reacting on cancer and potential cancer symptoms in everyday life that we saw in the cases presented.

This means that there is an inescapable uncertainty of being which is most often not addressed in public health rhetoric on cancer symptom awareness. Instead it can be argued that this rhetoric, together with the ‘cure rhetoric’, the war metaphors and the ‘unified quest’ build illusions of a ‘black and white’ certainty which cannot be met in all the nuances of everyday life’s essential uncertainty (Douglas 2001; Andersen and Risør 2014). The epidemiological delineation of cancer alarm symptoms and the symptomatic management of cancer disease control are themselves prominent examples of our social demand for certainty and control in an uncertain world (Andersen, n.d.), but as Margaret Lock argues: ‘in seeking to avoid misfortune we create new ambiguities and uncertainties’ (Lock 1998:7). Thus, by their notion of being ‘alarming’ and in their use in symptom awareness campaigns cancer alarm symptoms claim a level of certainty that does neither match their high statistical uncertainty in terms of actually predicting the likelihood of a specific symptom being caused by cancer (Andersen, Tørring, and Vedsted 2015) nor the ambiguous experience of a bodily sensation. They become instituted certainties (Douglas 2001) which does not translate easily into the embodied uncertainty of everyday life. This means that when faced with an ambiguous bodily sensation it is difficult to categorize it as a potential sign of cancer because it may not seem certain or indeed ‘alarming’. Following this line of thought, the illusion of certainty inherent in the idea of cancer alarm symptoms might in some situations even prove counterproductive to their purpose and hinder healthcare seeking with early signs of cancer (cf.

Jenkins, Jessen, and Steffen 2005). This was evident with regard to the legitimization of healthcare seeking in the Danish middle class context where a moral concern of being a good citizen of the welfare state and not for instance overuse the free healthcare system made it a difficult decision to schedule a visit with the GP based on uncertain and vague bodily sensations that did not correspond to the solidity of a list of symptoms (Offersen, Vedsted, and Andersen, n.d.). However this does not mean that knowledge of potential cancer symptoms is irrelevant or obstructive. It just shows that cancer is imagined and manifested in everyday life in various ways, and that constructions like ‘awareness’ and ‘alarm symptoms’ do something to our way of understanding and acting upon our bodies in everyday life. Contrary to Sontag’s prediction of a pure objective way of knowing cancer replacing metaphors and myths, we argue that mythological and metaphorical ways of knowing cancer are flourishing in the midst of scientific and technological progress which is itself part of cancer mythologies. In fact, scientific and political focus on e.g. healthcare seeking and awareness significantly feeds into mythologies with illusions of certainty which affect not only *that* we ‘are aware’ but also *how* we ‘are aware’ of cancer and cancer symptoms. This distinction is crucial because it affects available possibilities for how to act on awareness (or how not to act), and consequently renders the causal link between awareness and healthcare seeking seem fragile and oddly hollow. Furthermore, we argue that cancer mythologies not only flourish but that they are necessary for us to grapple with cancer presence in our lives. Consider for a moment how cancer would look ‘naked’, stripped from all its metaphorical and mythical wrappings as Sontag so hoped would happen. Julie Livingston vividly describes how she was shocked to experience ‘cancer without oncology’ in Botswana (Livingston 2012). Oncology is one of our constructions – the biomedical one – to deal with cancer. Another construction is mythologies and metaphors which may differ, like oncology, from place to place. Imagine then, ‘cancer without mythology’, and we are left with not much more than biological processes, biomedical interventions and tacit human suffering. We can perhaps express where it hurts, measure the growth of a tumor and treat and relieve pain, but how we are collectively and individually dealing with the complex presence of cancer among us becomes difficult to describe (cf. Lock 1994:xviii-xix).



## Conclusion

An aim of this paper was to explore and describe contemporary cancer mythologies in the village of the healthy (individuals without a cancer diagnosis). We have outlined a range of different and often paradoxical cancer mythologies in Danish middle class everyday life. However, they should neither be viewed as an exhaustive description of cancer presence, nor as distinct and closed ways of knowing cancer. Rather, we see them as different streams of knowing that merge and divide in people's dealings with cancer presence which consequently takes multiple forms depending on their placement in the shifting terrains of 'cancer before cancer'. Furthermore, we argue that science and mythology (in our usage) are never separate ways of knowing objectively and subjectively. Instead we contend with Lock that these two ways of knowing infuses each other in 'an ongoing mutually reinforcing feedback loop' (Lock 1994:xliv). In line with this, we have argued, like many others, against Sontag's influential depiction of a cancer that can be freed from metaphors and myth. We have tried to turn her argument upside down: Instead of denouncing the mythological aspects of cancer, we argue that understanding cancer presence in everyday life as unfolding within cancer mythologies, we might generate an understanding of a subjectivity that renders human beings as resourceful, enlightened and acting in accordance with contemporary contextualized understandings of cancer.

Our second goal with this paper was to discuss how we can understand the public health construction of symptom awareness detached from public health and as lived experience in everyday life. We showed how the concept of symptom awareness with its accompanying delineation of alarm symptoms creates an illusion of certainty that is challenged by the essential uncertainty of being and the nuances of everyday life. In the intersection between lived uncertainty and illusory certainty cancer mythologies configure and reconfigure. It has been argued (Karakasidou 2015; Stacey 1997; Jain 2013) that war metaphors, cancer heroism, and the global quest to find the cure and fight cancer result in a conspiracy of silence where we are not looking at 'the elephant in the room' in terms of e.g. carcinogenesis and political and economic structures. We argue that similar mechanisms are at play in everyday life 'before cancer' where the illusion of certainty silences ambiguity and uncertainty with a power to turn actual but vague cancer worries in to embodied elephants of uncertainty that only with

difficulty are addressed as potential symptoms. The cancer mythologies laid out in this article further suggest multiple ways of being aware of cancer and cancer symptoms. This entails that public health effort to measure and ensure symptom knowledge and awareness as instituted certainties run the risk of overlooking the variation and multiplicity of being aware of cancer in accordance with contemporary mythologies that may or may not lead to healthcare seeking. By use of the concept of different mythologies, this analysis has tried to spell out the difference between ‘the level of knowledge and awareness’ that public health research of early diagnosis of cancer is eager to quantify and then how this *relates* to the making and management of symptoms and consequently healthcare seeking practices in a not-so causal way.

This is not a contestation of the idea of symptom awareness or of alarm symptoms. It should be seen as an attempt to understand them outside of the seducing illusory certainty in the public health rhetoric. Thus, it is not to question public health research as such – public health does not deny its inherent uncertainty – but the way we come to reify and believe in its cultural representations as certainties. It is also not to question the worth of a global quest to cure cancer but the way it comes to portray cancer as a black and white caricature. It is definitely not to say that knowledge of cancer ‘alarm’ symptoms are unnecessary – people are aware of a large amount of symptoms and risk factors and interpret bodily sensations in terms of this knowledge – but it is the way we assume causality between symptom awareness and early healthcare seeking and the way we do not question the role symptom awareness and alarm symptoms play among healthy people and in the everyday life body. What this is, then, is a call for us to extend our exploration from specific actions such as recognizing a symptom or making an appointment with the doctor to an exploration in slow motion of everyday life cancer presences to be able to catch sight of subtle clues and hidden elephants as well as embodiments and somatic modes of attention (Csordas 1993) in the synthesizing activities of contemporary cancer mythologies.

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## CHAPTER 6:

### CONCLUDING DISCUSSIONS

This final chapter will draw together the main points and perspectives which have been raised in the dissertation and the three papers, and discuss the overall conclusions of the study. The discussion is twofold: On the one hand, I wish to address my basic aim of providing an anthropological understanding to questions related to the public health field of early cancer diagnosis, and in particular how symptoms become symptoms in everyday life, potentially moving people to seek care in the context of the ordinary. On the other hand, the different analyses and perspectives presented contribute to ongoing anthropological theoretical conversations on both bodily sensations and everyday life and their experiential and moral entanglement. After highlighting the main conclusions, I wish here to discuss the practical implications for the interdisciplinary field of early diagnosis of cancer and how the dissertation contributes to contemporary work on sensations, morality, potentiality, and the ordinary.

This dissertation has primarily explored four interrelated areas of health and illness in everyday life; everyday life, bodily sensations and symptoms, healthcare seeking practices, and cancer. In the introduction I primarily provided a thicker empirical description of everyday life in the middle-class neighbourhood than the papers were able to include, together with a presentation of the ordinary as an analytical context. All three papers are grounded in this and touch upon different aspects of the everyday life in their analyses, so the

introductory part of the dissertation should be seen as an elaboration of this to better anchor the different analyses, presented in the papers, in the ordinary which serves as a fulcrum of this study. The introduction also described the analytical context of cancer in Denmark which serves as both starting point and endpoint of the study while it, as an analytical context (Kirsten Hastrup, 2003) weaves in and out of the ordinary in my analyses. The three papers in this dissertation are in many ways different layers of the same theme of sensations, symptoms and healthcare seeking practices in everyday life with an underlying attention towards cancer, while at the same time also serving the three overall goals for the dissertation, stated in the introduction:

- 1) an ethnographic description of the inherent processes in the making and management of symptoms in everyday life,
- 2) an anthropological opening and dismantling of the symptom too look at its parts and their interaction,
- 3) a fashioning of a contextually and analytically informed public health attention.

These aspects are present in all of the three papers as for example in these key points from the papers:

- Sensations are transformed into symptoms or absorbed back into everyday life along navigational routes through a moral sensescape shaped, among other things, by the development of the Danish welfare state in the latter half of the 20<sup>th</sup> century and the growth of middle-class lifestyle. Various moral possibilities are balanced in this process and symptom-making is just one moral possibility among many when experiencing a bodily sensation.
- The organisation of embodied experiences of sensations reflect different ‘potentialities’ that, both consciously and unconsciously, are weighed against each other on a culturally defined continuum of bodily normality when people ascribe meaning and significance to bodily sensations in the context of everyday life.
- Cancer presence in everyday life is characterised by a complex interaction of different and often paradoxical ‘cancer mythologies’ comprised of ‘streams of knowledge’ that run together, merge and divide in the landscape of everyday life with its inherent uncertainty and ambiguity. As



one such stream of knowledge, public health efforts to control cancer by delineating alarm symptoms of cancer and increasing populations' symptom awareness create an illusion of symptomatic certainty which may counteract its purpose of increasing early care-seeking.

In the following I will further elaborate on how these findings relates to my overall goals.

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#### THE MAKING AND MANAGEMENT OF SYMPTOMS IN EVERYDAY LIFE

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By contextualizing the processes of transformations between sensations and symptoms and decision-making regarding healthcare seeking in everyday life, I tried to 'un-focus' on symptoms and instead give way to the ethnographic investigation of the myriad of light and grave concerns that everyday life is made of and in which sensorial experiences and available articulations of symptoms are embedded. Thus, my primary attempt to present empirically grounded description of sensorial meaning-making and healthcare seeking practices has been to direct attention to the nonlinearity of transformations between sensation and symptom and to all the significances and meanings bodily sensations also carry with them in the particular context of the Danish middle class. In paper one of the dissertation, *The Good Citizen. Balancing moral possibilities in everyday life between sensation, symptom and healthcare seeking*, I situate the experience, organization and articulation of sensations in what I call a 'moral sensescape' – an embodied terrain of the shared social and cultural history of the people inhabiting it. By using the perspective of the good citizen, I illustrated this sensescape and related the informants' life stories and the development of the welfare state with embodied experiences of sensations and healthcare seeking practices. Paper 2, *Am I fine? Exploring everyday life ambiguities and potentialities of embodied sensations in a Danish middle-class community*, goes further into a discussion of how the ordinary uncertainty of everyday life infuses sensations with different potentialities for perception, experience and ascription of meaning. The argument in this paper primarily contextualizes the experience, organization and articulation of sensations in ambiguity and uncertainty derived from interactions between health promotion discourses and efforts to protect what really matters in everyday life. In paper 3, *Cancer before cancer:*

*Mythologies of cancer in Danish middle class everyday life*, the ethnographical description of cancer presence in everyday life among healthy (defined as the absence of cancer) people, and the mythological move to throw cancer as cultural phenomenon into this uncertain and ambiguous moral sensescape connects the contexts of middle-class everyday life, biomedicine, national politics and global discourses in an effort to focus specifically on how cancer mythologies are present in the processes of experience and articulation of sensations described in paper 1 and 2. How cancer is experienced (and acted upon) is best understood, I argue, in terms of the phenomenon's dynamic and mutating appearance which depends upon how different parts of the cancer mythologies gain significance, become amplified or downplayed in specific contexts.

The conjoined contextualizing endeavours of the three papers aim to inform the public health problem of ensuring early diagnosis of cancer with a broader understanding of the lives in which health promotion discourses are reflected. I suggested in the introduction that the constructions of 'patient delay', now replaced by 'the patient interval', in cancer diagnostics research subtly and unintendedly reinforces the scientific inclination within public health to view and explore these processes in light of causal links between awareness and care-seeking (R. S. Andersen & Risør, 2014) and imperatives to act 'properly' as patients (Deborah Lupton, 1995; Rose, 2007) instead of viewing it as the chaotic mixture of interacting and conflicting concerns that moral life consists of as it unfolds in real time around what really matters. As for example when Jette in paper 1 is explicitly contradictory in her statements about how a hypothetical breast lump would lead her directly to her general practitioner whereas an actual changing mole did not, thereby exposing various morally legitimate routes to follow through her moral sensescape. And this is exactly what must be acknowledged in public health research and policy on early healthcare seeking; that what would be considered a long patient interval from a retrospectively oriented public health perspective is from an everyday life perspective, as it is prospectively lived, a different but just as legitimate route through the moral sensescape of a particular local moral world (see also Andersen et al. 2010; Andersen, Tørring, and Vedsted 2015; Merrild et al., n.d.). A route that is in accordance with contemporary cancer mythologies, I add with the findings from paper 3 in mind. Thus, the main implication from thoroughly contextualizing sensations, symptoms and healthcare seeking is, overall, to bring an emphasis on

life into the construction of the patient interval and to bring subjectivity of individuals living in local moral worlds to the fore instead of a conception of pre-patienthood. I very deliberately use the word ‘life’ because it connotes something unfolding over time and in real-time in contrast to ‘culture’ which, perhaps due to epidemiology’s ‘distorting effects’ on the concept e.g. in the form of measurable ‘cultural factors’ (DiGiacomo, 1999) or ‘barriers’ and ‘triggers’, seems to connote something more static within public health.

Our problem here is in fact as simple as it is encapsulated in the now hackneyed ‘catchy tune’ from the Danish philosopher Søren Kierkegaard, which can be found as a kind of slogan on fridge magnets, postcards, and in a Google picture search next to images of nature or long empty roads: ‘Life can only be understood backwards; but it must be lived forwards’ (Thielst, 2012). Ascribed to the problem of early cancer diagnosis, we can derive backwards understandings of symptom interpretations and healthcare seeking from cancer patients’ retrospective accounts, but we cannot expect people to have the understanding of the retrospective perspective while ‘living forwards’, i.e. when sensations are experienced and given meaning, just as we cannot expect to achieve an understanding of ‘forward living’ including transformations between sensation and symptom by asking ‘backwards’ in retrospectively oriented studies of the patient interval. There is thus a temporal contradiction between what we aim to investigate (and subsequently influence) and the way we frame those investigations (Andersen 2010). It often becomes a choice of exploring the patient interval either retrospectively or hypothetically, oriented towards imagined reactions to specific symptoms (e.g. Low et al. 2013). But why is it so? In my methodological struggles to position this study in between these two, I realized that it is exactly because bodily sensations that might be symptoms (the object of our interest in terms of reducing patient intervals) are so embedded and immersed in everyday life that they resist disentanglement and objectification. My study design was not at all purely prospective – it included to a large extent retrospective accounts of previous experience as well as questions into hypothetical experience. But by approaching the patient interval as life unfolding in a local moral world, it is possible to draw on previous (and interpreted) experience and action, hypothetical images exposing, for example, moral possibilities for action, and real-time experience where uncertainty and ambiguity becomes primary adjectives. Together, I believe, these temporal ways of

investigating transformations between sensations and symptoms allow us to address the complexity and entanglements of the processes. This leads me to the discussion of my second analytical goal of exploring what symptoms are as concept and as experience, and how we could deal with them anthropologically.

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#### WHAT IS A SYMPTOM?

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Increasing efforts to nuance the concept of the symptom (Eriksen & Risør, 2014; Martinez-Hernaez, 2000; Staiano-Ross, 2011) call for us to ‘open up the phenomenon we name symptoms’ (Eriksen and Risør 2014:90). Following the ‘un-blackboxing’ of the body lead by Margaret Lock’s concept of ‘local biology’ (M. M. Lock, 1994) it is a logical next step to let the symptom follow suit and unfold it as ‘a complex sign form, one that is full of mystery, alive and speaking of something in a language not fully understood, a narrative waiting to be explored through touch, vision, smell and the sensitive ear. It speaks of innocence and guilt and tragedy from within and from without the living person’ (Staiano-Ross 2011:35). By ethnographically unfolding the complexities of symptoms as deeply embedded in their everyday context and analytically dismantling the notion into its sensorial parts and studying their potentialities and moral possibilities up close, both paper 1 and paper 2 suggests a view of the symptom as a dynamic experience assembled from ambiguous sensations and reaching both forwards and backwards in time, and inwards and outwards of the human body, as stated in paper 1. Both papers approach the transformations between sensation and symptom with images of ‘balancing’, ‘see-sawing’ and ‘weighing’ experience, suggesting a never-ending transformative process between the two concepts used here. By situating this process in everyday life and departing the analysis from an idea of the ordinary, it was for example possible to propose a ‘non-potentiality of sensations’ in paper 2 as part of the weighing. Paying attention to everything sensations are when they are not symptoms – or in the reverse way; everything symptoms are not, is, in my view, of crucial importance if we want to understand the complex phenomenon we call symptom. Symptoms, as concept, are interesting because they reach out into the world and from the world into the body at the same time. They are both emic and etic categories which transcend boundaries between lay and professional,

everyday practice and scientific knowledge. Studying symptoms is really an exploration in all directions, not just from the point of view of my informants but also trying to grasp the point of view the epidemiological colleague next to me, the intentions of policymakers somewhere above it all, the medical doctor facing symptoms every day, the health promoter's campaigning and the structural organization of a healthcare system which ends up reflected in the informants' point of view. Thus, symptoms are contested circuits of meaning where who gets to define what is normal and what is not, is never clear, especially from the perspective of the people producing (or not producing) the symptoms. Also, when it comes to cancer, as shown in paper 3, this circuit of meaning becomes particularly evident when it creates elephants in the room, so dense with cancer meaning (which often equals fear) that it 'enters everyone's mind' (Stacey 1997:64) in its verbal absence and ghostly presence.

I suggest an anthropological focus on symptoms that interchangeably focus and un-focus on the symptom, much as with stereogram images where you by simultaneously focusing and relaxing the eye, trying to focus behind the image, will see another, deeper, image appearing. It was already there but it only appears when we change our usual way of focusing. It is sensorial habit that we can consciously alter in the situation. Symptoms constitute an idea so habitual to us that we cannot see the deeper images unless we consciously alter our way of looking.

Thus, looking focused and un-focused at cancer symptoms means that we need to not only look at experiences of rectal bleeding, unusual fatigue or a changing mole for example, but we need to look at the inwards and outwards directions for experiencing these as symptoms of cancer. Cancer symptomatology is complex and dynamic in its continuing colonization of the ordinary in terms of an increasing disease sensitization with still more vague bodily signs being considered 'alarming' (R. S. Andersen, n.d.), rendering embodied registers of both the ordinary and the extraordinary (Das & Das, 2007) unstable. By this I mean that the medical imaginaries of biotechnological possibilities (M.-J. D. Good, 2007) for detection and treatment of cancer, together with the changing conceptualizations of cancer, as visible in e.g. the reframing of cancer as an acute condition (Marie Louise Tørring, 2014), is essentially changing what cancer symptoms, and hence, symptoms in general, are. I will in the following consider

the implications these understandings present to a public health field of cancer diagnostics.

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#### IMPLICATIONS FOR UNDERSTANDING CANCER IN PUBLIC HEALTH

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Broadening the understanding of the symptom as phenomenon relates in many aspects to the implications this study offer public health approaches to cancer. In paper 3 I argue that the so-called ‘alarm symptoms’ of cancer, originating in epidemiological studies, are neither alarming, nor always considered symptoms from the perspective of everyday life. But the idea of some alarming existence that is detectable (and the moral consequence that individuals are supposed to detect it) is not neutral. It does something beyond adding to a pool of symptom knowledge in the population. It affects life, morality and the body in ways that are not always predictable or available to be statistically ‘adjusted for’. Drawing from the findings in this dissertation, it expands the horizon of moral possibilities for action with regard to likewise expanding potentialities of sensations, such as the illness potentiality and the potentiality of non-sensations. Paper 1, for example, illustrated how healthcare seeking is an essentially moral process where public health notions of ‘barriers’ and ‘triggers’ to healthcare seeking must be understood alongside a multiplicity of moral possibilities for agency. In the analysis of potentialities of sensations in paper 2, it is showed how health promotion discourses and public health rhetoric provide nuances to the complex palette of potentialities at play in bodily experience, thus implicating that the focus on symptom awareness actually make people aware, which is also evident in paper 3 on how cancer mythologies configure partly from health promotion messages regarding symptoms and awareness. Throughout the study I have mainly used the public health concepts of awareness and alarm symptoms to fuel my discussions in relation to public health. My discussions with these concepts culminate in paper 3 which, in specifically dealing with cancer, unfolds the concepts and concludes that the delineation of alarm symptoms and the public health rhetoric of symptom awareness create an illusion of a black and white symptomatic certainty that does not translate well into the markedly uncertain and ambiguous everyday experience of sensations that might and might not be symptoms.

Health promotion, such as cancer awareness and alarm symptoms, does not fall into a void in everyday life. It falls directly, as suggested in this dissertation, into the arms of moral possibilities, existing cancer mythologies and an aiming for the ordinary, all circling around what really matters in everyday life. Here it is moulded and mutates into for example socially and culturally specific potentialities of sensations. This collision between an illusory certainty within health promotion conceptualizations and an essential uncertainty of being, give rise to a plethora of confusions, gaps, ambivalences and uncertainties which I argue, inspired by perspectives from Throop and Kleinman (Arthur Kleinman, 1997c; Throop, 2003, 2010), are important parts of understanding social life and bodily experience. It follows, then, that it is pertinent that we acknowledge and attend to this explosion of ambiguity, uncertainty, confusion and disconnected meaning if we do not want to build our scientific questioning and explorations on an illusory fundament of assumed simplistic certainty and causality. I am here not contesting the concepts of cancer awareness and alarm symptoms as such. I am rather attempting to understand them outside of the seducing illusory certainty in the public health rhetoric and suggesting, following Andersen and Risør (2014), that our scientific, epistemologically grounded, assumptions behind them should be subjects of contestation. Thus, this dissertation does not question public health research as such – public health research does not deny its inherent uncertainty – but it questions the way we as society; as citizens, researchers, health professionals, media, policymakers and health promoters, in the various processes of investigating, promoting and communicating health, come to reify and believe in its cultural representations as certainties. On this basis, I would rather propose that we likewise acknowledge and attend to these cultural representations, such as symptom awareness and alarm symptoms, as dynamic, unstable, and continuously negotiated, both within the uncertainty and ambiguity of public health research and within the aiming for what is locally considered the ordinary life and the ordinary body. This dissertation primarily departs in the ordinary of Danish middle class everyday life in this regard, but it leans on inspiring explorations into the shifting terrains and cultural constructions of public health research, policy and clinical practice concerning cancer in Denmark (R. S. Andersen et al., 2015; R. S. Andersen, n.d.; Marie Louise Tørring, 2014).

To sum up, the main contribution of this study to the field of public health research in early cancer diagnosis is a deepened understanding of the so-called



patient interval; or what I would call ‘life unfolding with embodied experiences of sensations that may or may not be symptoms of cancer or other illness’. By its prevalence alone, cancer affects most people in one way or the other, and we must assume *that* cancer is present in everyday life among the healthy in some form; as e.g. an experience, an idea, a fear, or a knowledge construction. This entails *that* people are, to varying degrees, aware of cancer and cancer symptomatology, and we know *that* people, in the ordinary course of everyday life, experience bodily sensations of which some will be an early sign of cancer. In a typical anthropological fashion, I have in this dissertation exchanged *that* with *how* and merely attempted to broaden this knowledge and these basic assumptions by showing aspects of *how* cancer is present and *how* people are aware of cancer and cancer symptoms and *how* they experience embodied sensations as either worrying or not or somewhere in between. It is my hope that these insights can inform the way we think and conceptualize cancer in our eagerness to improve and affect its course and impact on both individual and societal levels. I also hope to contribute to maintaining the solid anthropological bedrock in a medical anthropology that proves itself relevant to both anthropology and public health.

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#### A NOTE ON ANTHROPOLOGY WITHIN PUBLIC HEALTH

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Working in interdisciplinary settings – or ‘at the margin’ of disciplines (Arthur Kleinman, 1997c) – is a well-known challenging task of addressing problems defined on a different epistemological fundament than one’s own (DiGiacomo, 1999). This concerned, in my case, the problem of patient delay which during my project changed into the less normatively infused notion of the patient interval. Sjaak van der Geest argues that focusing on biomedicine is a way for anthropologists to exoticise the ordinary of our own worlds (van der Geest, 2015). However, I would argue that working in an interdisciplinary setting and living in a biotechnically embraced western society, gradually transforms biomedicine into something rather ordinary, where I needed to consciously focus just as hard as I needed to in the to me ordinary everyday life of the Danish middle class, to discover myself taking concepts and frameworks and, more critically, the questions available to ask within these, for granted. And when not

feeling subsumed by public health framework, it was easy to feel provoked by its', in an anthropological perspective, simplistic assumptions. While I find neither position really fruitful for reaching common scientific goals, what I believe is the most important task for anthropologists 'at the margin' is to turn submersion into understanding by using provocations constructively to question the horizons of questioning. Hence, public health engaging fruitfully with anthropology should embrace and practice a reflective questioning of their epistemological fundament and the constructions built upon it to develop ideas and produce knowledge anchored in the complexities of the many possible ways of raising questions about the same matters. Showing how such public health constructions (symptom awareness and alarm symptoms) merge, mould and mutate in epidemiologically unpredicted ways in the complexity of the ordinary has been my way of trying to simultaneously contribute to the public health field of cancer diagnostics and shake its fundamental assumptions a little bit. This relates to my second point of anthropology at the margin, where I concur with van der Geest in his statement, that 'medical anthropology is anthropology and should remain so' (van der Geest 2015:79), sharing my concern with exploring the ordinary but also, not least, advocating a concern for anthropologist to do anthropology. In my case this meant, for example, allowing myself to go beyond the immediate public health problem I was supposed to illuminate and submerge myself in everyday concerns of apple-picking, coffee drinking and proper vacuum cleaning and listen attentively to sailor's stories, love stories and stories of tragedies and loss. Just as naturally as these aspects may be considered part of 'another day at the office' for anthropologists, just as strange and off-track they may sometimes seem within public health where we are often meant to explore well-demarcated health problems. I have in this dissertation thus tried to let apple-picking and vacuum cleaning reflect back on the problem of long patient intervals in a way that resonates with both anthropology and public health.

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#### SKETCHING A CLOSING IMAGE

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What most clearly stands out from the different analyses and descriptions in this dissertation are words such as 'balancing', 'weighing', 'streams' and 'bricolage', thus drawing a profound image of the findings in this study of being something

dynamic, always moving and never fixed or linear. This goes for sensorial experience, which is always also cultural experience, as well as for how understandings of health and illness, particularly cancer in this case, are at play in everyday life. Stewart's (2007) image of ordinary affects as surges of intensities that create signification in the ordinary is thus reflected in my way of thinking and, not least, picturing the relations and interactions of embodied experiences of sensations, interpretations of symptoms, everyday life moral concerns and the biomedically framed body. A similar image is conjured by Kleinman to explain a being-in-the-world that conjoins cultural, social, physiological and sensorial experience:

‘...experience is a tidal stream of transpersonal engagements in a local world: a family, a network, a neighborhood, a community. That flow of practices and forms of life is....a vital medium of socially constructed gestures, somatosensory communication, actions, reactions, engagements that moves both interpersonally and within the person. It is a tide that rises and falls, sometimes washing in among the objects of inner experience, at other times drawing back outwardly among the participants in the transpersonal world’ (Kleinman 1997b: 326-327).

The images of the dynamic movements of water; of surges, streams and tides, running through what can be termed a moral sensescape of experience in a ceaseless subjective and intersubjective balancing act is profound in the analyses presented in this dissertation. The notion of the sensescape, as borrowed from David Howes (Howes, 2005b), leads the mind to envisage the processes of experiencing, organizing and articulating bodily sensations as the navigating of an embodied terrain of the local moral world where both bodily and everyday life horizons may change depending on when, how and where you are and on the tidal streams and surges of intensities that direct attention within this sensescape. I have added the moral prefix to highlight, following Kleinman (Arthur Kleinman, 1998), that ‘experience is *moral*... because it is the medium of engagement in everyday life in which things are at stake and in which ordinary people are deeply engaged stake-holders who have important things to lose, to gain, and to preserve’ (Ibid.:362). In the perspective of this study I argue that sensation is embodied experience which is also essentially moral (see also Throop 2008), embarking on a navigation of an ambiguous and unstable

sensescape with what really matters as compass towards a hopeful horizon of everyday bodily ordinariness.

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## ENGLISH SUMMARY

Increasing focus on the importance of early diagnosis of cancer for improving individual cancer prognoses and national cancer survival has in Denmark led to a shift in cancer disease control efforts towards a heightened emphasis on symptom-oriented management of potential cancer. This means that the Danes are encouraged to be alert to still earlier and vaguer bodily signs of potential cancer and seek care ‘in time’. With biomedical constructions such as ‘cancer awareness’ and ‘alarm symptoms of cancer’ and the retrospectively oriented definition of life before symptoms-based healthcare seeking as the ‘patient interval’, cancer disease control has firmly entered the domains of everyday life, continuously expanding its presence and likely affects what counts as ordinary and extraordinary bodily experience.

However, most studies of symptom experience and healthcare seeking in this field have been conducted retrospectively among already diagnosed patients. Hence, we do not know much about neither how these processes and changing approaches play out in everyday life among non-cancer-afflicted people, nor about how symptoms in the first place arise out of culturally contingent experience, organization and articulation of bodily sensations, and how decisions about healthcare seeking are established in this context.

This dissertation aims to explore these matters from the perspective of the Danish middle class, mainly focusing on how sensations are ascribed meaning as symptoms and how they are evoked on a continuum between what is locally considered ordinary and extraordinary. Overall, the dissertation argues that inquiries into morality and potentiality provide valuable insights into healthcare seeking practices and the making and management of symptoms in everyday life.

The dissertation is based on 18 months of ethnographic fieldwork in a Danish middle class suburban neighbourhood, using participant observation, semi-structured interviews and health diaries. 18 key informants were followed with regular field visits, interviews and participation in everyday life activities as well as health-related activities.

The findings are analysed in three papers, forming the main analytical arguments of the dissertation:

**Paper 1:** *‘The good citizen’: balancing moral possibilities in everyday life between sensation, symptom and healthcare seeking*

This article explores how healthcare-seeking practices and the transformation of bodily sensations into symptoms are embedded in a ‘moral sensescape’ of everyday life. The article discusses how a moral relation between the Danish welfare state and the middle-class population is embodied in a responsibility for individual health. Overall, a striving to be a ‘good citizen’ is identified; this entails conflicting moral possibilities in relation to experiencing, interpreting and acting on bodily sensations. The article examines how people meet the conflicting moral possibilities of complying with current public health rhetoric on proper healthcare seeking, including timely presentation of symptoms, and simultaneously trying to avoid misusing the healthcare system; this challenge constitutes complex navigational routes through the moral sensescape of the Danish middle class.

**Paper 2:** *Am I fine? Exploring everyday life ambiguities and potentialities of embodied sensations in a Danish middle-class community*

This article explores the uncertainty and ambiguity in the space between bodily sensations and symptoms of illness. In terms of the potentiality of bodily sensations becoming symptoms of disease or being absorbed into the ordinary, processes of ascribing meaning to sensations in the context of middle-class everyday life in Denmark are illuminated. The analysis identifies four different forms of potentialities. It further shows how these different potentialities of ambiguous sensations are weighed against each other on a culturally and morally contingent continuum between normal and not normal, uncovering the complex interplay between the body, everyday life, and pervading biomedical discourses focusing on health promotion, symptom awareness and care-seeking.

**Paper 3:** *Cancer before cancer: Mythologies of cancer in Danish middle class everyday life*

This paper explores the various ways cancer is present in everyday life among healthy Danish middle-class people. Approaching cancer presence as mythologies, the paper argues against Susan Sontag's prediction of increasing scientific knowledge 'de-mythicizing' cancer. Different and paradoxical cancer mythologies are described and show how cancer presence in everyday life provides multiple ways of understanding and dealing with cancer. Special attention is paid to the relation between biomedically informed notions of symptoms and bodily processes and a ghostly and muted presence of cancer, particularly when faced with actual cancer worries. The paper suggests that health promoting constructions such as 'symptom awareness' and 'cancer alarm symptoms' are difficult to fit with ambiguous bodily experiences in everyday life, because they create an unintended illusion of certainty that does not correspond with the essential uncertainty of being and nuances of everyday life.



# DANSK RESUME

## Dansk resumé

Et tiltagende fokus på den centrale betydning af tidlig diagnostik af kræft, i forhold til at forbedre individuelle prognoser og kræftoverlevelse på nationalt niveau, har i Danmark medført et skift i tilgangen til sygdomsbekæmpelse mod en forstærket symptomorienteret håndtering af potentiel kræftsygdom. Dette betyder, at danskerne opfordres til at være opmærksomme på stadigt tidligere og mere vage kropslige tegn på potentiel kræft og søge læge 'i tide'. Bestræbelser på at bekæmpe kræft fylder, med biomedicinske konstruktioner som 'bevidsthed om kræft' og 'alarmsymptomer på kræft' samt den retrospektivt orienterede definition af livet før symptombaseret lægesøgning som 'patient intervallet', stadigt mere i danskernes hverdagsliv og påvirker sandsynligvis, hvad der tæller som normale og unormale kropslige oplevelser.

De fleste studier af symptom oplevelse og lægesøgning inden for dette område er dog blevet udført retrospektivt blandt allerede diagnosticerede patienter. Vi ved derfor ikke meget om, hverken hvordan disse processer og foranderlige tilgange udspiller sig i hverdagslivet hos ikke cancerramte personer, eller hvordan symptomer i det hele taget opstår ud fra kulturelt betinget erfaring, organisering og artikulation af kropslige sensationer, samt hvordan beslutninger om lægesøgning etableres i denne kontekst.

Denne afhandling søger at udforske disse forhold fra et dansk middelklasseperspektiv og fokuserer først og fremmest på, hvordan sensationer tilskrives mening som symptomer, samt hvordan de opstår på et kontinuum mellem hvad der lokalt betragtes som normalt og unormalt. Overordnet

argumenterer afhandlingen for, at anvendelsen af begreber som moralitet og potentialitet skaber værdifulde indsigter i relation til lægesøgningspraksis samt tilblivelse og håndtering af symptomer i hverdagslivet.

Afhandlingen er baseret på 18 måneders etnografisk feltarbejde i et dansk middelklasse-forstadskvarter. Dataindsamlingen benyttede sig af deltagerobservation, semi-strukturerede interviews og helbredsdagbøger. 18 nøgle-informanter blev fulgt med regelmæssige besøg, interviews og deltagerobservation i diverse hverdagsaktiviteter samt helbredsrelaterede aktiviteter.

Resultaterne er analyseret i tre artikler, som udgør hovedparten af de analytiske argumenter i afhandlingen:

**Artikel 1:** *'The good citizen': balancing moral possibilities in everyday life between sensation, symptom and healthcare seeking*

Denne artikel undersøger, hvordan lægesøgning og transformationer af kropslige sensationer til symptomer er indlejret i et moralsk 'sensescape' i hverdagslivet. Artiklen diskuterer, hvordan en moralsk mellem den danske velfærdsstat og middelklassen er kropsliggjort i et individuelt ansvar for sundhed. Overordnet identificeres en stræben efter at være 'en god borger'. Dette medfører forskellige modsatrettede moralske muligheder i forhold til oplevelse, fortolkning og handling på kropslige sensationer. Artiklen undersøger, hvordan folk imødekommer de modsatrettede moralske muligheder for at følge sundhedsretorikken om korrekt lægesøgning, inklusiv rettidig præsentation af symptomer, samtidig med at de prøver at undgå at misbruge systemet; denne udfordring udgør komplekse navigationsruter gennem den danske middelklasses moralske 'sensescape'.

**Artikel 2:** *Am I fine? Exploring everyday life ambiguities and potentialities of embodied sensations in a Danish middle-class community*

Denne artikel undersøger usikkerheden og flertydigheden imellem kropslige sensationer og symptomer på sygdom. Hvordan sensationer tilskrives mening i den danske middelklasses hverdagslivskontekst belyses ud fra sensationers potentialitet for enten at blive til symptomer på sygdom eller for at blive absorberet ind i 'det normale'. Analysen identificerer fire forskellige typer

potentialiteter og viser, hvordan disse potentialiteter for flertydige sensationer afvejes mod hinanden på et kulturelt og moralsk betinget kontinuum mellem normal og unormal. Herved vises det komplekse samspil mellem kroppen, hverdagslivet og gennemtrængende biomedicinske diskurser, som fokuserer på sundhedsfremme, symptom bevidsthed og lægesøgning.

**Artikel 3:** *Cancer before cancer: Mythologies of cancer in Danish middle class everyday life*

Denne artikel udforsker de forskellige måder kræft er til stede i hverdagslivet hos raske danske middelklasse borgere. Ved at se på kræft som mytologier argumenterer artiklen imod Susan Sontags forudsigelse om, at øget videnskabelig viden vil 'afmytificere' kræft. Forskellige og paradoksale kræftmytologier beskrives og viser, hvordan kræft i forskellige former for tilstedeværelse i hverdagslivet udgør mangfoldige måder at forstå og håndtere kræft. Artiklen behandler især relationen mellem biomedicinsk prægede forestillinger om symptomer og kropslige processer og en spøgelsesagtig og tavs tilstedeværelse af kræft, særligt i forhold til konkrete kræft bekymringer. Artiklen antyder, at sundhedsfremmekonstruktioner som 'symptom bevidsthed' og 'alarmsymptomer på kræft' er svære at få til at passe med hverdagslivets flertydige kropslige oplevelser, fordi disse konstruktioner skaber en utilsigtet illusion om vished som ikke er i overensstemmelse med tilværelsens essentielle usikkerhed og hverdagslivets nuancer.

# APPENDIX I:

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## INFORMATION FOR RECRUITMENT OF INFORMANTS

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Invitation til at deltage i forskningsprojektet:

## **”Sundhed og sygdom i hverdagen. Hvordan oplever man symptomer, og hvornår går man til lægen?”**

### **Formålet med projektet**

Formålet med forskningsprojektet er at undersøge, hvordan forskellige danskere forstår og tænker på det at være rask og blive syg. Hvordan du mærker symptomer fra kroppen, og hvad du gør, hvis du oplever tegn på, at du eller nogen i din omgangskreds eller familie er syge. Hvem snakker du med? Hvor søger du eventuelt hjælp og informationer? Hvad betyder sundhed for dig, og hvordan tackler du symptomer eller sygdom i din hverdag?

### **Hvorfor vil jeg gerne tale med dig?**

Projektet foregår som et antropologisk feltarbejde i xxx – primært i xxx boligområde. Jeg er derfor interesseret i at tale med både mænd og kvinder fra boligområdet. Du skal være over 40 år for at deltage.

### **Hvordan foregår det og hvad snakker vi om?**

Jeg vil snakke med dig om, hvad du gør, når du oplever tegn på, at du måske er syg, og hvordan du håndterer sygdom og symptomer i din hverdag.

Jeg vil gerne besøge dig ca. 6 gange fordelt over et år, og det er fuldstændigt op til dig at bestemme, hvor og hvornår vi mødes. Nogle gange vil jeg gerne interviewe dig, men jeg vil også gerne bare deltage i nogle af de ting, du alligevel laver i din hverdag, såsom at købe ind, gå tur med hunden, fritidsaktiviteter eller følge dig til læge, på apoteket, til fysioterapeuten eller til andre former for behandling, som du eventuelt har brug for.

Samtidig vil jeg bede dig udfylde et lille symptomskema hver anden uge igennem et halvt år, så vi får viden om, hvornår man oplever symptomer i hverdagen.

### **Hvad kan vi bruge resultaterne fra projektet til?**

Projektet skal hjælpe os med at få bedre viden om, hvad folk forbinder med sygdom, og hvad de gør, hvis de oplever symptomer eller føler sig syge. Vi vil bruge denne viden i arbejdet med at tilrette sundhedsvæsnets indsatser, sådan at de bliver målrettet almindelige menneskers behov og interesser.

Du deltager anonymt i projektet og kan til enhver tid melde dig ud.

Jeg vil meget gerne fortælle dig mere om projektet, før du beslutter dig for, om du vil deltage. Du kan ringe eller skrive til mig. Ellers vil jeg gerne ringe dig op om et par dage.

Med venlig hilsen

Sara Marie Hebsgaard Offersen  
Antropolog  
Forskningsenheden for Almen Praksis, Aarhus Universitet  
sara.hebsgaard@alm.au.dk  
Tlf. 87168045



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# APPENDIX II:

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## PARTICIPANT INFORMATION

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Tak fordi du vil deltage i forskningsprojektet:

## **”Sundhed og sygdom i hverdagen. Hvordan oplever man symptomer, og hvornår går man til lægen?”**

### **Formålet med projektet**

Formålet med forskningsprojektet er at undersøge, hvordan forskellige danskere forstår og tænker på det at være rask og blive syg. Hvordan du mærker symptomer fra kroppen, og hvad du gør, hvis du oplever tegn på, at du eller nogen i din omgangskreds eller familie er syge. Hvem snakker du med? Hvor søger du eventuelt hjælp og informationer? Hvad betyder sundhed for dig, og hvordan tackler du symptomer eller sygdom i din hverdag?

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Samtidig vil jeg bede dig udfylde et lille symptomskema hver anden uge igennem et halvt år, så vi får viden om, hvornår man oplever symptomer i hverdagen.

### **Hvad kan vi bruge resultaterne fra projektet til?**

Projektet skal hjælpe os med at få bedre viden om, hvad folk forbinder med sygdom, og hvad de gør, hvis de oplever symptomer eller føler sig syge. Vi vil bruge denne viden i arbejdet med at tilrette sundhedsvæsnets indsatser, sådan at de bliver målrettet almindelige menneskers behov og interesser.

Du deltager anonymt i projektet og kan til enhver tid melde dig ud.

Med venlig hilsen

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## **APPENDIX III:**

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LETTER OF INFORMED CONSENT

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### **Tilladelse til at bruge mine oplysninger i forskningsprojekt**

Jeg giver hermed tilladelse til, at den information, som videregives i interviews, samtaler og symptomschemaer må bruges i forbindelse med forskningsprojektet **”Sundhed og sygdom i hverdagen. Hvordan oplever man symptomer, og hvornår går man til lægen?”**

Jeg er bekendt med, at mine personlige oplysninger anonymiseres, og at mine identifikationsoplysninger og cpr.nr. ikke videregives til tredjepart samt at alle oplysninger behandles i henhold til Datatilsynets standardvilkår for forskningsprojekter.

Dato: \_\_\_\_\_ Underskrift: \_\_\_\_\_

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## **APPENDIX IV**

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### INTERVIEW GUIDE 1

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## **INTERVIEWGUIDE 1**

### **Introduktion til interviewet:**

Hvad går det ud på? Hvad vil jeg spørge om? Ok, at jeg optager?

### **Generel information:**

Navn, alder, bopæl.

### **Uddybende:**

Start med at fortælle om dig selv – hvem er du?

- Hvor er du født og hvordan var din opvækst?
- Familie – gift/partner? Børn?
- Uddannelse og job?
- Bolig – hvor længe har du boet her? Hvordan endte du her?
- Omgangskreds? Vigtige personer i dit liv? Familie? Venner?

### **Sygdomshistorie:**

- Har du haft væsentlige sygdomsepisoder i dit liv? Eller i din nærmeste familie/omgangskreds?
- Hvad med din barndom – hvordan eller hvornår var man syg, da du var barn?

### **Hverdagsliv:**

- Beskriv din hverdag. Beskæftigelse, fritid, hjemmeaktiviteter, praktiske ”pligter”
- Hvad er vigtigt for dig i hverdagen? Hvad sætter du pris på?
- Hvad bekymrer dig du om?

### **Krop, sundhed og sygdom:**

- Lever du sundt? Hvordan?
- Hvad er sundhed for dig?
- Hvornår er du opmærksom på din krop/mærker din krop?
- Hvad gør du bevidst for din krop og sundhed?
- Har du prøvet at være bange for, at der var noget alvorligt galt med dig? Hvad skete der?
- Hvor tit går du til læge sådan cirka?
- Hvad skal der til, for at du bestiller en tid hos lægen?
- Bruger du andre former for behandling?

### **Afrunding:**

- Tjek, at jeg har det hele med.
- Har du noget at tilføje?
- Hvordan har interviewet været? Som forventet?

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# APPENDIX V

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## INTERVIEWGUIDE 2

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## INTERVIEW GUIDE 2 – DAGBOGSINTERVIEW

Temaer	Spørgsmål
Dagbogen	Hvordan var det at udfylde dagbogen? At få sms'er?  Var det anderledes end du havde regnet med?
Konkrete hændelser fra dagbogen	Hvem, hvad, hvor, hvorfor, hvordan?
Sensationer	Hvad mærkede du?  Prøv at forklare, hvordan det mærkedes.  Hvad kom du til at tænke på, da du mærkede det?  Mindede det om noget, du har prøvet før?  Hvad skal der til, før du tænker, at noget, du mærker er tegn på sygdom? Hvad er et symptom?  Er der nogle bestemte signaler eller symptomer, der ville bekymre dig?
Forklaringer/sprog	Nu hvor du har fortalt mig om det, synes du så har fået forklaret mig, hvordan det mærkedes?  Kan du sætte flere ord på, hvordan du mærkede det?  Hvilke billeder dukker op i dit hoved, når du tænker tilbage på det?
Lægesøgning	Overvejede du at kontakte lægen i den pågældende situation?  Hvornår tænkte du første gang på at gå til læge?  Overvejede du andre behandlingsmuligheder?  Hvad fik dig til at kontakte lægen?  Hvordan foregår det, hvis du gerne vil til lægen? Telefon? Online? Hvad skriver/siger du? Hvorfor?  Hvordan har du det med din læge? Har du altid den samme eller er det forskelligt? Hvad betyder det for dig?  Hvad er en god læge for dig?

	<p>Føler du at du kan tale med hende eller ham om alting?</p> <p>Er du nogen gange i tvivl om, hvad du kan snakke med din læge om?</p> <p>Er der nogen ting, som du ville tøve med at gå til læge med? (er der konkrete oplevelser eller erfaringer knyttet til nogle af disse refleksioner?).</p> <p>(Hvad var det sidste du var til læge med? Dagbogen...)</p> <p>Hvad er det sidste, hvor du har været i tvivl om du skulle gå til læge?</p> <p>Oplever du at lægen tager godt imod dig og dine bekymringer/symptomer?</p>
Informationssøgning	<p>Snakkede du med nogen? Læste du om det nogen steder?</p> <p>Har du læst eller hørt om noget eller snakket med nogen, der har fået dig til at være mere opmærksom på nogle ting i din krop?</p>
Viden/erfaring	<p>Har du på et tidspunkt oplevet noget, der har fået dig til at være opmærksom på din egen sundhed eller på sygdom?</p>
Fornemmelser/intuition	<p>Et tema, jeg er opmærksom på igennem interviewet, men som bedst kan spørges til i relation til konkrete hændelser. Og som jeg vil forsøge at afdække gennem de andre spørgsmål.</p>
Sundhed og sygdom i hverdagen	<p>Hvad har du i dit medicinskab? Hvordan bruger du det?</p> <p>Har du nogen ting, du bruger til at tjekke dit helbred herhjemme? (Hvordan overvåger du dit helbred?)</p> <p>Synes du det er nemt at leve et sundt liv? At følge de råd og vejledninger, vi bliver oplyst om? Hvad gør du for at holde dig sund?</p> <p>Tænker du på om du er sund/syg/rask, når du fx oplever det her med (dit knæ..? – et eller andet fra dagbogen).</p> <p>Er der nogen særlige sygdomme som du bekymrer dig om at du måske har? Eller som du tænker, du er særligt disponeret for at få?</p>

**Husk eksempler og beskrivelser!**



## APPENDIX VI

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### INTERVIEWGUIDE 3

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## INTERVIEWGUIDE 3

### Tema: Sygdom, sundhed, symptomer, kræft (diskurs)

Start med at forklare præmisserne for interviewet. At det handler om sundhed, sygdom og symptomer igen. Og at det godt kan virke som om, de har svaret på nogle af de her spørgsmål før, men at jeg rigtig gerne vil snakke om de her ting igen for at få dem belyst fra alle mulige vinkler.

Temaer	Spørgsmål
<b>Del 1 – sygdom, sundhed, sundhedsvæsen, sprog for krop og sygdom</b>	
Definitioner Symptomer Sygdom Sundhed	Hvad er et symptom?  Hvad er sygdom? Hvornår er man syg?  Hvad er sundhed? Hvornår er man sund?  Hvad er der imellem at være syg og være sund? (giv evt. mulighed for at kunne tegne det)  Hvornår tænker du, at det, du mærker, er et symptom?  Har du prøvet at tænke om andre, at de havde symptomer på et eller andet? Hvad skete der?  Hvad skal der til for at du bekymrer dig om det, du mærker? Eller om andre?  Har du oplevet at have en fornemmelse, at noget ikke var som det skulle være? Uddyb? Dig selv eller andre. Eller kender du historier om det?
Sundhedsbudskaber – diskurs – tilstedeværelse i hverdagen	Kan du komme i tanker om gode råd, du har hørt eller kampagner om at leve sundt? (billeder, slogans mv??)  Hvor kender du til rådene fra?  Hvad tænker du om det/hvordan opfatter du dem?  Følger du dem?  Hvordan lever du selv sundt?  Hvad er sundhed for dig? Hvordan vælger du mellem alle de forskellige råd og retningslinjer om at

	leve sundt?
<p>Sprog og italesættelse</p> <p>Kan jeg komme nærmere en sproglighed for kroppen og dens signaler?</p> <p>Hvad betyder det, at sensationer bliver formuleret/konkretiseret?</p> <p>Grad af alvor? Hvordan beskrives sensationer mellem lægesøgning, symptom og "ingenting"?</p>	<p>Hvordan vil du beskrive det, hvis du siger, du "har det skidt"? Hvordan har du det så?</p> <p>Kan du komme i tanker om andre ord, du bruger for at beskrive sådan en tilstand?</p> <p>Hvad er forskellen på at "have det skidt"/"være sløj" etc. og så at være syg?</p> <p>Hvordan vil du beskrive det, hvis du siger til mig, at du er syg.</p> <p>Bruger du andre ord om den tilstand?</p> <p>Eksempler – eksempler - eksempler</p> <p>Hvis de ikke selv kommer på noget, så spørg til betydningen af eksempelvis:</p> <p>Sløj Småsløj Skidtmads Nede med... Skidt Dårlig Ikke på toppen Jamsk ...???</p> <p>Hvad betyder det for dig at sige højt (eller skrive/formulere), at noget er galt?</p>
<p>Sundhedssystemet</p> <p>– adgang, erfaring, opfattelse, forventninger</p>	<p>Når du tænker på dine oplevelser i sundhedssystemet, er det så overvejende positive eller negative tanker/oplevelser, der fylder?</p> <p>Hvorfor? Kan du beskrive det nærmere?</p> <p>Hvad forventer du, at sundhedsvæsenet gør for dig?</p> <p>Hvad er lægens/systemets ansvar?</p> <p>Hvad er dit ansvar?</p> <p>Hvordan finder du og/eller lægerne ud af, hvad du fejler? Hvad kan de gøre? Hvad kan du gøre?</p>

Del 2 – Kræft	
<p>Kræft – erfaring, tanker, bekymring, tilstedeværelse i hverdagen</p>	<p>Hvad er kræft?</p> <p>Hvad tænker du på, når du hører om kræft?</p> <p>Kender du nogen, der har fået kræft? Hvordan har du oplevet forløbet?</p> <p>Hvad tænker du selv om risikoen for at få kræft?</p> <p>Er det noget, der kan behandles? Hvor, hvordan?</p> <p>Er du bange for at få/have kræft?</p> <p>Hvilken type kræft frygter du mest? Mindst?</p> <p>Er kræft noget, du bekymrer dig om, når du er syg eller mærker noget fra kroppen?</p> <p>Taler du med nogen om din bekymring?</p> <p>Ville du kunne tale med din praktiserende læge om det, hvis du var bekymret for, om du havde kræft? Hvordan ville du gribe det an?</p> <p>Hvilke symptomer forbinder du med kræft?</p> <p>Hvordan kender du til disse symptomer?</p> <p>Hvis du fik nogle af de symptomer, du nævner, hvad ville du så gøre?</p> <p>Hvordan ville du have det med at blive henvist til videre undersøgelser for kræft, hvis du var gået til lægen med et af disse symptomer?</p> <p>Tager du imod screeningstilbud? Hvorfor/hvorfor ikke?</p> <p>Er kræft noget, der fylder (privat, i samtaler, i samfundet)?</p> <p>Hvad får disse billeder/budskaber dig til at tænke/føle? (vise kampagnebilleder fra diverse kræftkampagner)</p>

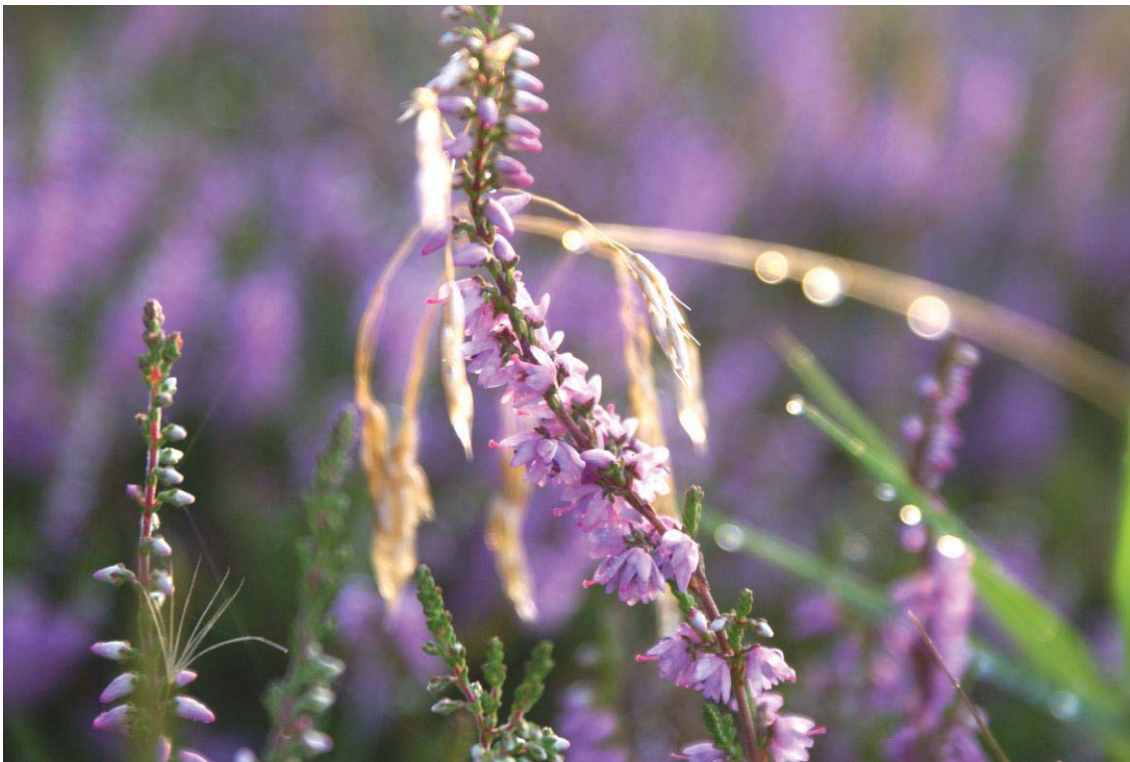
## APPENDIX VII

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HEALTH DIARY

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# Dagbog



## Forskningsprojektet

*"Sundhed og sygdom i hverdagen. Hvordan oplever man symptomer, og hvornår går man til lægen?"*

Navn:.....

CPR. nr .....

Om dagbogen:

I dagbogen skal du registrere, hvordan du oplever din krops signaler i dagligdagen, og hvornår du vælger at gå til læge.

Med "kroppens signaler" mener jeg **alt** det, som du ser eller mærker i din krop, som opleves anderledes end normalt. Jeg vil gerne høre, hvad du tænker om det, og hvad du gør ved det.

Det er meningen, at du skriver i dagbogen, lige så snart du mærker noget, der er anderledes i din krop eller søger læge. Eller mindst hver 14. dag igennem 6 måneder. Jeg sender en sms til dig for at minde dig om det hver 14. dag.

Hvis du har flere besøg ved lægen eller andre behandlere eller har oplevet flere signaler eller symptomer inden for de 14 dage, må du meget gerne skrive dem én ad gangen (én på hver side).

Hvis du har nogle spørgsmål, er du selvfølgelig meget velkommen til at ringe eller skrive til mig.

På forhånd tak for hjælpen!

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**Dato:** \_\_\_\_\_

## Sundhedskontakter

Har du været i kontakt med læge, sygeplejerske, sygehus eller andre behandlere i løbet af de seneste 14 dage?

**Ja / nej**

Hvis ja, hvem?

.....

Hvorfor? Beskriv:

.....

.....

.....

.....

.....

Hvordan foregik kontakten?

☐ Jeg ringede til min praktiserende læge

☐ Jeg besøgte eller bestilte tid hos min praktiserende læge

☐ Jeg benyttede mig af email-konsultation hos min praktiserende læge

☐ Jeg var i kontakt med sygeplejerske, sygehus eller andre behandlere. Hvordan?:.....

.....

☐ Andet. Hvad?:.....

.....

**Dato:** \_\_\_\_\_

## Signaler fra kroppen

Har du mærket noget anderledes eller ubehageligt i din krop gennem de seneste 14 dage?

**Ja / Nej**

Hvis ja, beskriv:

.....

.....

.....

.....

Hvad tænkte du, det kunne betyde?

.....

.....

.....

Hvad gjorde du ved det?

- ☐ Ikke noget
- ☐ Kontaktede min praktiserende læge
- ☐ Tog noget medicin. Hvilken?:.....
- ☐ Søgte information om det. Hvor?:.....
- .....
- ☐ Forsøgte på andre måder at gøre noget (for eksempel ændre spisevaner, motionere, opsøge psykolog, fysioterapeut, akupunktør, healer eller andet).
- Hvordan?:.....
- ☐ Snakkede med familie eller venner om det. Hvem?:.....
- .....
- Hvad sagde de?:.....
- .....
- ☐ Andet. Hvad?:.....

## Corrections in the published version

Page	Original text/content	Corrected text/content
1	Aiming for ordinary	Aiming for the ordinary
85	Submitted to <i>Medicine Anthropology Theory</i>	Accepted for publication in <i>Medicine Anthropology Theory</i>