

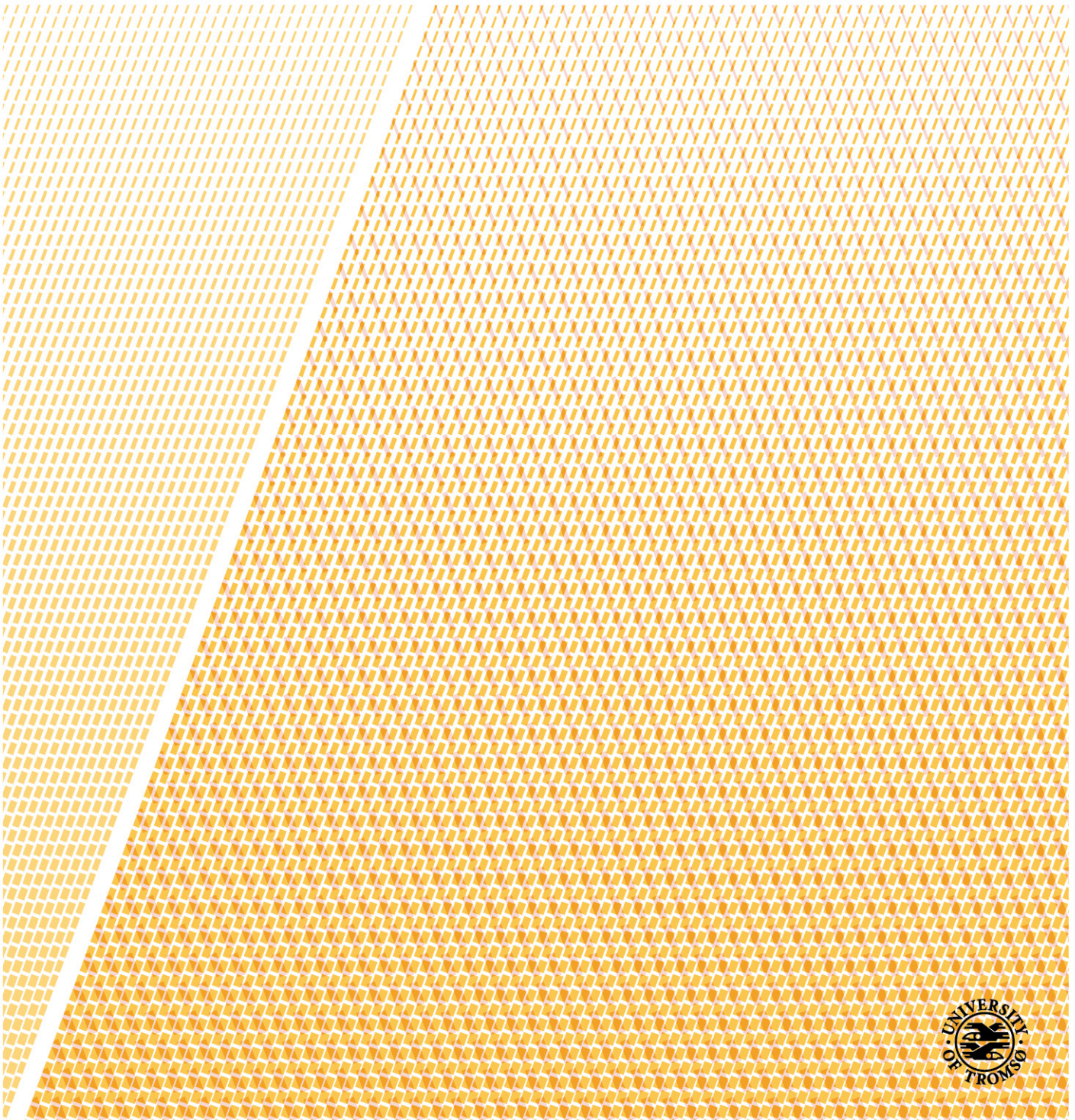
# **Embodied uncertainty**

*Exploring sensorial and existential dimensions of everyday life after cancer*

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## List of papers

Paper 1:

Title: Ignoring Symptoms. The Process of Normalising Sensory Experiences after Cancer

Authors: Tone Seppola-Edwardsen and Mette Bech Risør

Journal: 'Anthropology in Action', Published 2017

Paper 2:

Title: Sharing or not sharing? Balancing uncertainties after cancer in urban Norway

Authors: Tone Seppola-Edwardsen, Rikke Sand Andersen & Mette Bech Risør

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Paper 3:

Title: The sensorial and emotional as pathways to understanding experiences of cancer:  
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## Preface

The writing of this thesis, with its three articles, has been my main path to learning about the field of medical anthropology. I started with a feeling of being quite clueless, searching for the typical fields of interest in medical anthropology and the theoretical ways of investigating them. As I have no health education, and have never worked in health care, I must be considered a lay person in the field of health. However, I have not been unaware of the contested nature of medical science and knowledge, as I have been brought up to be skeptical about public ‘truths’ in general, and in particular to the findings of epidemiology-based research presented in the media, as they always seem to aim at scaring people, or making them feel they are doing things all wrong. Being an anthropologist, I was already aware of theories in the social sciences about governmentality, power, values, worldviews, etc. I had also noticed the increasing attention in the media, and in society in general, to matters of health and illness and to the increasing prevalence of cancer and other illnesses, often indirectly presented as lifestyle illnesses at an individual level. This again fuels arguments about the importance of each and every one of us to do our best to live a healthy life, and avoid risks, whatever that may mean. Hours of discussions with friends, colleagues and others about these matters had made me aware of the vagueness and contested nature of the concepts of health and risk.

Quite by coincidence, my career path had led me closer to the world of health and medicine. First I worked in administration of a Master’s degree in Public Health for a while, and then spent a year and a half in the field of law, considering appeals against decisions on disability pensions on the appeals board of the Norwegian Labour and Welfare Administration (NAV). Part of this job involved reading a considerable amount of medical documents, such as medical certificates and statements from medical doctors, psychologists, physiotherapists, and different specialists in the field of health. My job was to consider legal rights, based on how the physicians had assessed symptoms and diagnoses, but I must admit that the social anthropologist in me often made me reflect about quite different aspects of the cases, such as the meaning of health and illness in society in general, and in the lives of the individuals these documents referred to. A PhD research project to study life after cancer, and sensations and symptoms as they were experienced by the people themselves, then became an interesting angle to consider health and illness from an anthropological perspective. How would life be

perceived after a person had been through a serious illness such as cancer, and how would this affect the person's relationship with his or her own body and with other people?

In connection with my Master's thesis, I had studied a project where Dutch families were recruited to settle in rural areas in Norway. This was a form of lifestyle relocation that made both the new inhabitants and the old ones aware of their wishes and values, and also made them reflect on what they had taken for granted, and what was gained or lost. In the back of my mind, I had some expectation of maybe exploring a kind of journey. At the same time, I did not wish to have any expectations, but to be prepared to explore a completely different world, less material than a geographical area and probably more difficult to access.

My biggest worry when approaching the field of cancer was not my lack of medical knowledge, but my lack of personal experience with severe illness in general, and cancer in particular. Would it be possible for me to gain understanding of another person's experience of living after cancer treatment, and most of all, how could I gain access to another person's perception of embodied sensations and interpretations of these, when I had never experienced this myself? On the other hand, I knew myself as an emotional and easily affected person, so I was also a bit worried about becoming too involved and disturbed by my own emotions, and thus missing important clues. This combination may have made me try to detach my emotions or steer how much I allowed my emotional imagination to be evoked, while also working really hard on my cognitive imagination to try to understand the situations people were telling me about. At the end of a year of interviews, I realized that even though I was aiming at understanding the sensorial, I had not really been able to use this possibility from the start, maybe because I tried too hard to understand it cognitively, and simultaneously tried so hard not to be disturbed by my emotions. Luckily the duration of the fieldwork, and also the methodology, helped me.

I would like this dissertation to show some of the uncertainties and dilemmas present in the life of people after cancer, as expressed by the participants. This involved ambivalence about how to interpret and handle unpleasant bodily sensations, and dilemmas of how much to involve others in the uncertainties of life after cancer. I also wish to show the possibilities of sensorial anthropology in research on health and illness, as well as the importance of the sensorial in intersubjectivity and empathy in the field of illness experiences.

## Summary

In Norway, as in other countries in the northern hemisphere, an increasing number of people survive after cancer diagnosis and treatment. Earlier studies have shown that life after cancer can be challenging in different ways, which makes it important to gain knowledge about this group to be able to meet their needs in the future.

The main objective of this project was to understand the illness experiences and care-seeking processes of former cancer patients as they take place in daily life and social relations. It studied how people after cancer treatment sense, interpret and handle their unpleasant bodily sensations as either normal and part of daily life, or as possible symptoms that might need to be taken care of or investigated further. Research on the interpretation of symptoms within the cancer field has normally examined sensations retrospectively, after diagnosis, in an attempt to understand how they had been interpreted before the cancer diagnosis. Little research in this field has been conducted on the period after the end of cancer treatment.

The general aim of this thesis is to investigate the interpretation process of bodily symptoms and sensations after cancer treatment. A further aim is to explore how the participants handle a state of uncertainty within their everyday management of social relationships by finding a balance in the sharing of existential worries. Another important objective is to show how the sensorial and emotional help to provide insight through empathic understanding.

The thesis builds on ethnographic fieldwork carried out between January 2014 and January 2015, and the main data collection method was repeated semi-structured interviews with eight participants during that period. Depending on when they entered the study, life events during the study period and how much they had to tell, between three and seven interviews/activities were conducted with each participant, 41 in total. I participated in a few activities with four of the participants, and also took part in some activities in the Cancer Society and other settings that stood out as relevant to the participants' life after cancer. The analysis mainly builds on recordings, transcriptions, field notes and memos written in connection with the interviews and activities. The findings are presented in three papers, forming the main analytical arguments of the thesis.

Article 1: Ignoring symptoms. The process of normalising sensory experiences after cancer

This article explores the process of reestablishing the skill of interpreting bodily sensations after cancer treatment. By using the concepts of sensation schemas and sensation scripts, we explored how sensation schemas of cancer dominated in the initial period, while schemas of late effects and reduced tolerance of daily life activities gradually became more important as time went by. When the participants became aware of how their fear of cancer dominated the way they interpreted bodily sensations and how their interpretations amplified their fear of cancer, this opened up for other ways of handling the situation. As their knowledge of late effects after cancer and treatment grew, this allowed them to understand their bodily sensations in a different way. The sensation schemas containing cancer as an explanation were gradually replaced by schemas with late effects as a probable explanation. Ignoring sensations and not seeking medical aid immediately, but waiting and seeing, was a new sensation script and a step along the way towards understanding. This seemed to help to stop the spiral of fear and gradually made way for an understanding of the bodily sensations through alternative schemas. Adapting everyday life to their new health situation by balancing activity and rest became a new main script and strategy.

Article 2: Sharing or not sharing? Balancing uncertainties after cancer in urban Norway

In this article we explore the uncertainties of living after cancer treatment. We refer to this process of managing uncertainty and the social processes involved as an act of 'balancing'. Through our inquiry into who was involved in the participants' interpretation of bodily sensations, health and care-seeking, we found that the participants were keeping most of their uncertainties to themselves. Their main argument was that they did not want to make others worry unnecessarily. On the other hand, participants talked about the need and expectation to inform and involve relevant others and they also described needing an outlet through which they could share worries. These needs and concerns were balanced against a wish to maintain 'normal everyday life' as far as possible. This weighing up of what to share and what not to share was a meaningful mode of acting, as it was an important strategy in managing life within existential uncertainty, without letting the uncertainty dominate social situations. In this way, the participants cared for both themselves and others. What was essentially at stake was a balancing of social relations to be able to preserve these and stay in, or get back to, 'normal' or everyday life, as it existed before their cancer diagnosis.

### Article 3: The sensorial and emotional as pathways to understanding experiences of cancer: Gaining sudden insight during in-depth interviews

This article explores the process of gaining insight into an illness situation through interviews that focus on the sensorial. What first appeared to be one sudden insight obtained through one interview turned out to be one of several insights gained through a process that built on earlier parts of the ethnographic fieldwork, as well as reflections formed during the writing of memos after that particular interview. This process of empathic understanding of the participant's situation came about through sensorial imagination that evoked the researcher's emotions, and emotions became a portal into understanding the existential uncertainty that this participant, among others, had expressed. The process of reaching a deeper understanding discussed in this article was not in itself a complete analysis, but became part of and formed a basis for other analyses. It gave insight into the place of cancer, by providing deeper understanding of the phenomenology of the experience of being ill and under treatment of cancer. This became an important insight that formed the basis for the analysis of how the participants interpreted bodily sensations as a process of adapting to their changed body after cancer treatment (Article 1), and also the analysis of their considerations when deciding whether to share their existential uncertainties with others (Article 2).

This thesis contributes to the field of cancer with enhanced knowledge of how the cancer experience may influence the way bodily sensations are interpreted and handled. It provides insight into the process of regaining everyday health competence, in the light of a changed health situation after cancer. It also makes a contribution to sensorial anthropology in showing how cancer patients perceive and interpret bodily sensations within a context of memories and fear of cancer. It also shows how regaining everyday health competence is possible with new contextualization, built on knowledge of normal late effects after cancer treatment, and the experience gained from living within a 'new normal'. The thesis also sheds light on how existential uncertainty was handled within social relations and everyday life after cancer treatment. All these findings may have general relevance for other severe or chronic illnesses that have the potential to impact life in similar ways. In addition, the thesis shows how the sensorial is an important component of intersubjective and empathic understanding, as well as an important aspect and tool in the study of illness experiences.



# 1 Introduction

## 1.1 The field

In 2015, 32 592 persons were diagnosed with cancer in Norway (Cancer Registry of Norway 2015). At the end of 2015, more than 252 997 Norwegians had had at least one cancer diagnosis, recently or several years ago. The numbers of people being diagnosed with cancer as well as those living after cancer are increasing in Norway. About 70 % are still alive five years after a cancer diagnosis (www.fhi.no 16.04.2015). The increase of people receiving a cancer diagnosis is mainly due to an increased population in general as well as an increase of elderly people in the population. The increase is thus not unexpected, but, as accentuated by the Norwegian Cancer Registry, the increase should not be downplayed, as every incident represents a human being, with his or her life and family situation. It also means that more people will need treatment and follow-up by the health care services and other public services.

To investigate the health care needs of adult cancer survivors in general practice, Hoekstra et al. (Hoekstra, Heins et al. 2014) conducted a systematic review based on both qualitative and quantitative research in the three databases MedLine, Embase and the Cochrane Library of Systematic Reviews. They identified medical, psychosocial and informational needs, where the psychosocial needs were the most frequently mentioned (ibid.: 2). The general practitioner appeared in most studies as an important ‘supporter and someone to share ideas and concerns with’ (ibid.: 3) while the relation to specialists was different, and made the participants feel “too embarrassed to discuss feelings and problems with” him or her (ibid.: 3).

Research shows that after finishing cancer treatment many experience health problems. ‘Many survivors must cope with long-term effects of treatment as well as psychological concerns such as fear of recurrence’ (DeSantis, Lin et al. 2014: 252). These effects can be diverse and vary with the type of cancer, but some more common effects are depressive symptoms, pain, cognitive limitations, physical limitations and fatigue (Harrington, Hansen et al. 2010, Loge 2013). Bower (2014) shows that ‘Studies of long-term cancer survivors suggest that approximately one-quarter to one-third experience persistent fatigue for up to 10 years after cancer diagnosis. Fatigue has a negative impact on work, social relationships, mood, and daily activities and causes significant impairment in overall quality of life during

and after treatment' (Bower 2014: 2). A study among Norwegian 'long term cancer survivors' showed that sick leave rates five years after diagnosis were significantly higher for this group than for the control group (Torp, Nielsen et al. 2012).

Fear of recurrence is another important burden for people after cancer, and is highly relevant to people's quality of life and psychological well-being (Lee - Jones, Humphris et al. 1997, Horlick - Jones 2011). Balmer and Griffit, in their study of people who had completed cancer treatment but lived with a poor prognosis, found that 'a full 'recovery' may be impossible after a cancer diagnosis' (Balmer, Griffiths et al. 2014: 451) as their biographical trajectory and self-identity would be permanent threatened.

Illness in general, cancer and life after cancer have been studied by social anthropologists from different angles, and in concordance with the theoretical discussions that have taken place in anthropology in general. The contribution of social anthropology to the field of health and illness consists of both method and different theoretical perspectives. When medical anthropology started to take form as an individual field, medical pluralism was one of its contributions (Mogensen and Whyte 2007). An important contributor was Kleinman (1980), who pointed out the difference between the understanding of the health professional and the experience of the patient (ibid.). This difference, and the perspective of gaining access to the patient's experience, have been elaborated further by social anthropologists. Within the field of life after cancer, I would mention Frank, who himself has had the disease, and Kleinman (1988), who was one of the first to bring forward the patient's own voice and story. Frank's aim is to prevent people post-illness living 'a life that is diminished, whether by the disease itself or by others' responses to it' (Frank 2013: XVII).

Frank discusses narratives as a way of self-healing and making sense of illness experiences in life after cancer, as well as a way of witnessing the illness situation, and he argues that 'Wounded storytellers tell stories to sustain their own courage and to give others courage' (Frank 2013: 189). The unspecified topic of his book, he says, has been suffering, because his body's suffering during illness created 'a need for stories' (: 169), but he underlines that suffering also has other dimensions than the bodily, for instance social and existential dimensions.



There are shared cultural ways of narrating illness (Frank 2013; Kleinman 1988; Good, Good et al. 1994), and Frank describes three narratives that both ‘storytellers and listeners use to structure and interpret stories’, and simultaneously correspond to ways of experiencing illness (2013: XIV). These are restitution, chaos and quest. Whereas the restitution narrative focuses on the medical story of restitution, where health personnel are actors and heroes, and illness only transitory, the chaos narrative is the opposite, and ‘its plot imagines life never getting better’. It has no narrative order or causality and thus is perceived as chaotic and without connection to a ‘proper life’ (Frank 2013: 97). These stories are ‘hard to hear because they are too threatening’ (ibid). Quest stories are the stories where the ill person accepts illness and seeks to use it (Frank 2013: 115). The ill person is the main character and other sides of the illness experience than the medical story can be told. However, not all can be narrated. In an article from 2001, Frank argues that a problem for ill people is that what he calls ‘ruling relations’ insist that all can be spoken, and ‘refuse to acknowledge that aspects of suffering remain unspeakable’ (2001: 358), and therefore also not researchable.

Frank brings in the cancer patient’s perspective, and sees narratives as a way for the individual to take control of her or his illness story by reclaiming it from the medical expert world and re-embedding it into her or his own world, biographically, socially and existentially. He still points out that there are limits to what can be spoken, as well as what types of narratives listeners will appreciate or even accept as a story.

Another former cancer patient and social anthropologist, Stoller, also tells about his cancer experience in his monograph called ‘Stranger in the village of the sick’ (2004). The title refers to the feeling of entering a new and unknown world when cancer strikes, and is inspired by Sontag’s use of the metaphor ‘Kingdom of the sick’. Sontag claims that we all hold dual citizenship, in the kingdom of the well and the kingdom of the sick. In her book ‘Illness as metaphor’ (1977), she addresses how illness is used as a figure or metaphor, and how the two diseases most described by metaphors are tuberculosis and cancer, both feared and stigmatizing illnesses. In later anthropology on cancer, the metaphors as ways of talking about illness have received less focus, while discourse (e.g. Bell 2012, Willig 2011) and the social context itself (e.g. Jain 2013) have been addressed more.

Stoller (2004) does not discuss metaphors, but makes use of them in bearing witness to his illness experiences. One of his main aims is to show how cancer can create an opportunity for

growth and change by incorporating it and opening up to ‘bring to your being a deeper understanding of life’s forces and meanings’ (2004: 203), which, however, as he points out, does not mean being grateful for the diagnosis. As a way of coping with his illness and life after treatment, he used knowledge gained at earlier fieldwork in Niger, also then being a ‘stranger in the village’, and at that time apprenticed to a Songhay sorcerer. His cancer experience now added depth to his knowledge from the earlier period in Niger, and redirected his gaze to the pragmatic wisdom of the sorcery, which implies accepting the limitations illness presents and working within their parameters, creating ‘a degree of comfort in uncomfortable circumstances’ (2004:191). This made Stoller reconsider, among other things, his obligations as an anthropologist, where he concluded that the most fundamental point is to bear witness and tell accessible stories that shed light on social realities, bringing wisdom that enables people to ‘live well in the world’ (2004: 200). On the other hand, he does not conceal the troubles that come with living in between ‘the village of the healthy’ and ‘the village of the sick’, as living after cancer to him also means living in uncertainty about how long he can live without recurrence of cancer.

Later contributions have criticized what they see as a cultural imperative to ‘think positively’ (e.g. Willig 2011) and have thus shed light on one important context of people’s experience of their cancer illness. The work of Bell (2012) is an example of this. She explores cancer survivorship as a biopolitical phenomenon and argues that cancer patients are not only expected to experience personal physical and psychological development, but are also seen to be in need of an externally driven change, if the change does not occur ‘naturally’. This represents a ‘larger ideological shift in contemporary forms of governance’, she argues (: 596), and implies a ‘narrow range of acceptable responses to cancer’ (Bell 2012: 597). Within the discourse of cancer survivorship as positivity and self-growth, the breast cancer movement has been pointed out as presenting this image, and setting a standard for all forms of cancer, especially in the USA, but also in other English-speaking western countries, which has given rise to the term ‘breast-cancer-ization’ (Bell 2014, Solbrække & Lorem 2016). From her interviews with Canadian men and women, Bell (2014) concluded that their accounts suggested that breast cancer provided ‘an important lens through which to understand the effects’ (ibid.: 63) of their own disease. In a study among Norwegian women who had had gynaecological cancer followed by hysterectomy, Solbrække and Lorem found that this was less the case regarding perceived expectations of how to display survivorship.

On the other hand, the women felt that gynaecological cancer had lower status and the bodily site of their cancer was taboo.

Late anthropological research in the field has taken a broader and more macro-oriented perspective on the social relations of cancer. Jain (2013), for instance, argues that we should see cancer as a set of relationships more than as an objective thing, and in her book 'Malignant. How cancer becomes us' she seeks to find a new way of understanding cancer, as she argues that cancer has to be seen 'as a process and as a social field', but simultaneously she explores 'its brutal effects at the level of individual experience' (: 4). Jain shows how cancer is interwoven in most types of social relations as well as areas or sectors of US society; here it contains different meanings for different people, such as a catastrophe for some but a livelihood for others. At the same time, she tells the personal story of her own illness and life after cancer and thus manages to show the individual costs and hardships of cancer as well as addressing the cultural milieu of her illness experiences.

In a recent contribution, Burke and Mathews (2017) argue for applying a global perspective to the anthropology of cancer, as it is a global epidemic, an environmental and economic disorder as well as a transnational phenomenon. The global perspective may help shed light on overarching problems and challenges that reside outside the individual and can be out of reach for single communities or nations to address. In this way, they also wish to achieve a more nuanced body of research than the US-dominated research on a few diagnoses, which they find has characterized research until now. They argue that this could lead to more locally appropriate solutions to treatment.

McMullin (2016) also argues for an intersectional study of cancer, both domestically and globally. The intersectionality applies to diversity in diagnosis, social groups and local contexts, with a particular focus on inequality. In her article, she addresses inequality within topics such as cancer relations, access to treatment technology, exposure to carcinogenic environments and concerns in the use of statistics. In this way and in line with the other studies mentioned, she shows how this perspective can shed more light on the diversity and inequality that are actually part of the social reality.

In short, anthropology has helped to introduce cancer patients' own perspectives to the cancer field, as something different and more than medical understanding could provide. It has also

shown how people who have experienced cancer can use narratives as a way of making sense of their experiences, but within culturally accepted types of narratives and within the discourses available. Living post-cancer takes place within different local contexts but is also influenced in different ways by national and global factors. On the other hand, there are also similarities, one of these being the liminality when uncertainty makes it difficult to return completely to ‘the village of the healthy’, as described by Stoller (2004). This liminality makes it difficult to choose how to term the post-cancer situation or person.

From their study among people who lived with poor prognoses after cancer, Balmer, Griffiths et al. concluded that the ‘constant fear of recurrence created liminality and made “survivorship” ambiguous’ (Balmer, Griffiths et al. 2014: 451). As research shows that fear of recurrence is not limited to a poor prognosis, many experience this ambiguity, which again manifests itself in the contested terminology of ‘survivors’ and ‘survivorship’, which was one of my first challenges when starting the project. How should I name the group I wished to recruit as participants in my study?

## **1.2 When a term contains unwanted assumptions**

As no term is completely neutral, the terms used to define the empirical and analytical object may contain assumptions that are contested and might imply meanings that were not intended. The term ‘cancer survivorship’ was initially used by the medical community in the 1980 to distinguish between the medical needs of people under cancer treatment and those who had completed treatment (Jain 2013: 30). In 1985, Mullan, a medic who had had cancer himself, argued for a three-phase survivorship (Mullan 1985, Loge 2013): The acute - which is after diagnosis and before completed treatment, the extended - which is after completed treatment but still in a regime of regular monitoring and uncertainty, and the permanent - when monitoring has stopped and people see themselves as cured. Today we know more about the risk of new cancer and other illness years afterwards, caused by earlier cancer treatment itself (Loge 2013). The feeling of being cured seems to have faded and uncertainty seems to be more prominent. As stated by the anthropologist Jain (2013: 30) ‘Since then, the term has absorbed new social meanings’. Jain, who writes about her own experience of cancer, calls herself a ‘so-called survivor’, and describes different ambiguities connected to the survivor identity. Uncertainty as to the statistical outcome or ‘living in prognosis’ is one side of it. ‘Would I be in that percentage of people who had a recurrence just two years after treatment

or in the 20 percent who would survive for the next twenty?' (Jain 2013: 27). Another ambiguity is connected to the way an identity as a 'survivor' is 'built on the backs of those people who didn't survive' (ibid.:31). This suggests that your chance of surviving feels enhanced when somebody else dies. Yet another side of the 'survivor' term she mentions is the moral dimension that contains an idea of having had the right attitude, fighting spirit, etc. Even questioning the term might be seen as a lack of the right attitude, as one person in Jain's support group remarked: 'It's as if being against the survivor rhetoric means being against living' (ibid.:30).

Also Stoller (Stoller 2004) discusses the topic. In this case it is the term 'in remission' that is under scrutiny. He concludes that 'in the end, remission means spending years 'being on hold', 'waiting for the other shoe to drop' or 'sitting on your hands'. It is not an easy place to be.' (:182). You can thus never feel safe, cured and finished with cancer. This is further described by his metaphor of the 'village of the sick', inspired by Sontag's 'Kingdom of the sick' (Sontag and Broun 1977) 'You have long left the village of the healthy in which sickness is a temporary respite from good health. Once you enter the village of the sick, as I have suggested, you can never return to the village of the healthy' (Stoller 2004: 183).

Stoller points to the situation as a liminal state (Turner 1995) of being caught in between two worlds or two stages, but where this state is not a transitional one, as described by Turner, but permanent. This is also the topic in Rees' (Rees 2016: 9) article about young women's lives after completion of breast cancer treatment. 'Rather than being categorised as either ill or well, the young women found themselves in a space 'betwixt and between' healthy and ill'.

Participants also described hiding their ongoing fears about recurrence from people around them, and feeling unable to express the reality of their experience to others because of the assumption that they had now returned to normal. This can be understood as 'communicative alienation' (Little, Jordens et al. 1998), a facet of being in a liminal state.

The idea of cancer as an incident or an acute condition does not correspond to these experiences of the illness. Yet the idea of cancer as an acute illness has lately become prominent in public debates and in the media.

### **1.2.1 Acute vs chronic**

An example of how the view of cancer has changed from a ‘biologically and epidemiologically stable illness’ Tørring (Tørring 2014: 16) into an acute condition is the recent Danish debate. Tørring argues that the categorization of cancer into an acute condition in Denmark has been part of a strategy in health policies, aided among other things by the exponential growth of numerical representations of cancer and stories that link time as a delay of diagnosis or treatment to deaths from cancer. This presentation of cancer as one illness that is in need of rapid treatment underlines episodic, acute and dangerous dimensions, but on the other hand the possibility of being quickly cured. This has contributed to prioritizing treatment of cancer patients, with attention to limited waiting time and standardized treatment warranted to all (Tørring 2014). The focus on time as a factor that is linked to survival is also visible and maybe growing in Norway, but not in the same manner as in Denmark (ibid.).

One drawback of the categorization of cancer one an acute condition may be that the chronic suffering and diversity of cancer illnesses become less visible and less acknowledged. Treatment becomes the main focus, and the need of rehabilitation, understanding and managing the suffering in life after cancer receives less attention, as this is more often the focus of chronic illness (Kleinman and Hall-Clifford 2010, Fonseca, Fleischer et al. 2016).

### **1.2.2 Examples of the use of ‘cancer survivor’ in literature**

Hoekstra et al. (2014: 1), in their study of health care needs after cancer, use the term ‘cancer survivor’ about everyone who lives after active cancer treatment: The term ‘covers a wide range of patients: from those who have just finished their active treatment period to patients who have been discharged from follow-up for years’. The broadest definition is used by DeSantos et al. (2014: 252) in their study of side effects and long term effects from cancer treatment. They use the term ‘cancer survivor’ about ‘any person who has been diagnosed with cancer. This includes patients currently fighting cancer and those who may have become cancer free’. On the other hand, they underline that ‘it is important to note that not all individuals with a history of cancer identify with the term cancer survivor’ (ibid: 252). Balmer, Griffit and Dunn, in their study among people who live with poor prognosis, use the term ‘cancer survivor’, but in quotes. In their conclusion they point to uncertainty after cancer as a continuous disruption that prevents people from defining themselves as ‘survivors’ (Balmer, Griffiths et al. 2014: 468).

As I wished to avoid using contested terminology, I have not used the term ‘survivor’ or ‘survivorship’. To recognize the chronic dimension and our focus on living in the aftermath of cancer, I considered using the term ‘chronic cancer patient’, but discarded it as it might be understood as containing too much of a statement about being permanently trapped in cancer and a patient status. Not everybody experiences long-lasting or permanent problems, some experience their life as returning to normal, or even better than before cancer (e.g. Bell 2012, Lillehorn 2013 ). I chose to use terms such as ‘former cancer patients’, and ‘life after cancer treatment’ instead, as I found these to be more neutral, only indicating the stage of a process of treatment when treatment is finished, and we are not making any assumptions about the prognosis of survival or years without recurrence. As my aim was to investigate a certain illness situation, or patient status, I had to choose terms that indicated this stage. The participants were recruited as individuals who lived after cancer, and not as patients in a specific health care situation. On the other hand, people living after cancer regularly seek health care for conditions that are related to cancer, such as late effects or worries about sensations that might be symptoms of new cancer. This way both the illness and patient status can be seen as chronic, and it was within this situation I wished to study how people interpret and handle unpleasant bodily sensations. Health care seeking thus became an interesting focus.

### **1.3 Care seeking**

Research on bodily sensations and symptoms has usually focused on the period before seeking care, often with the delay or waiting time for the diagnosis as the main concern (e.g. Zola 1973, Alonzo 1979, Andersen, Paarup et al. 2010, Brandner, Müller-Nordhorn et al. 2014). In cancer, an early diagnosis and start of treatment will often mean a better prognosis. The aim of symptom research in this field is ultimately to find out how to make people seek medical care earlier. As part of this, it has been important to understand what makes a person interpret a sensation as a possible symptom, and what makes him or her seek medical care. Underlying this is the assumption that bodily sensations do not start as symptoms, but become symptoms through a social interpretive process (Zola 1973, Classen 1997). As little research had been done on the process of interpretation of symptoms after cancer, providing more knowledge on this became one of my aims.

Inspired by Hay's (2008) model based on fieldwork in Lombok I was looking for factors that could be seen as socio-cultural frameworks for making decisions, for instance time and the duration of sensations, how they interfere with activities, as well as ideas about vulnerability (ibid.:198). Investigating 'how and why an individual seeks professional medical aid', Irving Zola (Zola 1973: 677) notes that 'even when there is social agreement to what constitutes 'sickness' there may be a difference of opinion as to what constitutes appropriate action'. One of his findings implied that it was not the worsening of the symptom per se that made people seek help. They sought help when a social situation or a perceived implication of a symptom on social situations became too much for them. This is followed up by Angelo Alonzo (1979) who developed the concept of containment to explain how individuals define illness 'within socially defined situations against the total background of daily life and relations with others' (ibid.:397). This is taken up by Andersen et al (2010: 378) who argue that people sense their bodies and define what is part of life and what could be symptoms, as individuals, within their individual situations, but as part of complex social contexts. By studying life after cancer, I hoped to find out more about the factors in the participants' everyday lives that were important in interpreting and handling unpleasant sensations, both concerning practical life and the social and cultural ideas involved.

Based on interviews with ovarian cancer patients, Brandner et al. (Brandner, Müller-Nordhorn et al. 2014) describe a three-phased triggering process where the three phases are overlapping and non-linear. The first is 'noticing sensations that deviated from normal bodily experiences' (ibid.:126). The second is 'continuously reestablishing normality in sensory experiences' and the third is 'transforming these sensations by gradually replacing this normality with signs of pathology (...) and constructing the need for further care for these symptoms' (ibid. :126). The third phase is reached by a triggering process where the normality of the bodily sensations is gradually destroyed, thus turning the sensations into symptoms. This model provides a detailed description of a process which, even though it is not linear, probably starts with noticing a sensation, and, in the case of seeking medical aid, probably ends with deciding that the sensation is a possible symptom. But an investigation of how this process might be influenced by the cancer experience could add knowledge to how decisions are made both on an individual level and within social interaction.

Andersen et al. (2014) argue that our contemporary society is characterized by sensitization in terms of interpreting bodily sensations as possible symptoms. Contributors to this are



screening programs and informational campaigns to enhance people's alertness to possible symptoms of disease as cancer. We might say that embedded in this focus of public health is a moral obligation of being a good citizen (Petersen and Lupton 1996), who is attentive to potential symptoms and seeks help in time. On the other hand, people who have grown up in the Nordic welfare systems also seem to navigate within a 'moral sensescape' of everyday life (Offersen 2016) and might have internalized a moral sensitivity not to waste the time of the public health care system by seeking medical aid about trivialities. After cancer, most participants expressed this dilemma. When experiencing uncertainty because of unpleasant bodily sensations, they balanced their wish to seek medical care against a wish not to misuse health care resources.

#### **1.4 The Norwegian care context – social welfare**

Cancer patients in Norway undergo the illness with a fairly well-organized network of support addressing both medical issues and personal issues of health and living. Cancer treatment is administered in public hospitals with routine follow-up consultations in the first few years after therapy. The Norwegian Cancer Society is one of the actors in the field.

Financially, a cancer patient enjoys the rights and benefits of the welfare state. Norway has a highly developed welfare system and one of the lowest levels of inequality within the OECD countries (SSB Statistics Norway 2014). The Norwegian welfare system is funded through taxation and features a generous distribution of welfare services, including pensions, sickness and unemployment benefits, as well as health care and education. People are able to live off welfare benefits in their first year of illness, although after this their finances may suffer, in spite of some welfare assistance. As primary and secondary education is free in Norway, patients do not have to worry about how a loss of income will affect their children's education. Economic hardship will therefore probably not be a primary source of uncertainty for the participants in this study, neither in terms of treatment, nor for the future of their family or themselves.

Norway and the Nordic countries score high on social capital, by Wollebæk & Seggaard (2011) understood as networks and trust on macro level as societies and on micro level among individuals. The social capital is conditioned by historic, structural and institutional factors and Norway has had good opportunity to build social capital through being a 'small, homogeneous, egalitarian, and gradually a rich country in the European geography, with quite

an undramatic political history' (Wollebæk & Seggaard 2011: 45, my translation). Norwegian citizens score high on trust in people they know, strangers and institutions. A study from 2010 found that 'having an intimate person to talk to when distressed was among the most important factors predicting self-assessed good health' in adult Norwegians (Gele & Harsløf 2010: 5), which indicates that social relations are important to how people perceive their health. The Norwegian social welfare system, in its present form, is relatively new and has gradually expanded from the 1950s. This welfare system also builds on social trust, as well as helping to maintain social trust through counteracting social differences, which Rothstein (2002) sees as a strong threat to trust between individuals.

These broad dimensions of social trust and the importance of social networks may be reflected in more detailed and local notions of living in Norway. Especially in northern Norway, life has historically been dominated by the hardship of living with the shifting conditions of nature, seasons and weather within family-based fishing, agriculture and husbandry (Brox 1984). Based on these life conditions, the ethos of being one who is able to face hardships caused by weather conditions as well as economic and social misfortune has been important. In northern Norway, this is described by the verb 'stå han av' which has the meaning of being able to 'stand up against the storm', but also to be able to cope with hardship in general. In Høltedahl's (1986: 48) monograph from a village close to Tromsø, being able to 'manage on your own' was an important value for both men and women, and it was also used about the community's ability to cope. This characteristic of small communities, of stamina and interdependence may point to the importance of trust and reliance on close relations, but also to something that may affect how to manage hardship such as critical illness, i.e. sensations and complaints being contained as long as possible to avoid creating disorder in apparently strong but also vulnerable societies.

On the other hand, 'being of use to others' and 'equality' were mentioned as important values by the women in Høltedahl's study (1986). The values reflect a life of hard work where most people struggle to make ends meet. Incidents could make the individual or family unable to cope on their own, and then other villagers would do their best to lend a hand. The villagers were part of each other's networks, and not contributing could be stigmatizing (Høltedahl 1986). In this perspective, we should expect that when in need of help because of illness, people could rely on acceptance and a helping hand, when possible.

In the perspective of social trust, providing help to others could be seen as (among other things) a reciprocal investment, mutually expected and trusted, to be 'repaid' in later situations when in need of help oneself, and thus a help to secure one's own life in uncertain situations. In this perspective, the Norwegian social welfare system can be seen as a national continuation of the local social networks that imply people are equal in value in spite of being different. At the same time, it implies trust, as it is dependent on a considerable workforce that is able to manage on its own and contribute to the common society.

Andersen (1999) has shown that the way people involve others in their illness changes with changed circumstances. In her study from a village in Northern Norway, she found that with improved access to health services, especially the family doctor, the villagers' sharing of worries and knowledge about illness with each other decreased. The local network and knowledge about illness was seen by the villagers to have lost its value as the 'new illnesses' like heart attacks and cancer were different and had made the old knowledge insufficient. The villagers now found that it was of no help discussing illness with others, as the only advice they got from others was to see the doctor. In other words, while there was a high threshold for seeing the doctor in the early eighties, and people only went when it was really necessary, the attitude had changed towards the mid-nineties. Now they found it better to see him or her 'once too much rather than once too little' (Anderssen 1999: 96). This may indicate that alongside the value of being able to 'manage on your own' and only seek help when really needed, a new value of being vigilant, noticing sensations and seeking help in time, had emerged. This could also be a new way of 'managing on your own', where managing your health and being able to sense possible symptoms of the 'new illnesses' in time has become part of it. On the other hand, it seems to have decreased the importance of social relations in the interpretation of sensations, as the doctor has become the only expert in the field. Anderssen (1999) argues that illness now had become a 'private matter' as it was no longer part of the local knowledge network. We may also argue that it had become a national, governmental and expert matter, as health authorities and doctors replaced the networks.

From Anderssen's work, we can see that even when discussing illness was common, there were limits to how it was discussed and with whom. Later work from Northern Norway and other regions shows that some types of illnesses are more difficult to discuss within social relations than others, such as mental illness (Foss 2002) and gynaecological cancer (Solbrække & Lorem 2016).

Another diversifying aspect in Northern Norway is ethnicity, as this region has a considerable Sami population, as well as people descended from previous centuries' immigration from northern Sweden, Finland and Russia. For instance, Sami traditions for handling health, illness and social relations in general have other characteristics than those shown in studies of the majority population. In a study among Sami people, Bongo (2012) found that the norm was not to speak openly about health and illness. These issues were instead to be approached non-verbally and indirectly, respecting the value of being able to cope on your own. Care was not verbally asked for or offered, but simply performed by close ones.

From what has been discussed above, we can see that there are various norms and values that have traditionally been important in northern Norway. The norm to 'stå han av' (be able to handle hardships), also reflected in being able to 'manage on your own' (Holtedahl 1986) has been important, and is still today referred to, though more as a humorous and sometimes ironic comment on hardships. This value may still have an impact on how to manage illness worries and healthcare seeking, some of which is reflected in the above, i.e. being strong and avoiding seeking help unnecessarily.

On the other hand, the high score on social trust and networks indicates that Norwegians in general have people around them that they expect to be of help. Having somebody to talk to when distressed has been shown to be important to people and seems to be connected to self-rated health (Gele & Harsløf 2010).

The city of Tromsø, which is the site of our study, has around 74 000 inhabitants. It is the administrative centre of Troms County and to some degree serves as a centre for the whole of Northern Norway. Its population is heterogeneous, as a large proportion of the inhabitants have moved in from rural areas in northern Norway, both coastal and inland, with different ethnic backgrounds. In addition, Tromsø is home to people from all other parts of Norway, and in 2013 people from 144 other countries were living in the city ([www.itromso.no/nyheter/article8591989.ece](http://www.itromso.no/nyheter/article8591989.ece), 8.11.2013). Since 1964, the city has more than doubled its population.

It is thus difficult to talk about Northern Norway or Tromsø as one society or one culture in terms of 'A system of common perceptions and ways of being that actors have acquired as members of a society' (Eriksen 1998: 110, my translation), even despite attempts such as that

of Wollebæk & Seegaard. People in Tromsø are likely to be influenced by diverse values, which may be seen as local, national, Nordic, European, etc. Then there is the historical aspect. There has been no recent broad study of present-day values in this region, but it seems likely that the social context of health and illness, in terms of access to healthcare, social notions influencing healthcare seeking, and the notions of body, self and illness will play a role for the perception and management of sensations and symptoms. Thus, it will be interesting to investigate the arguments and solutions regarding how people handle life after cancer, when interpreting bodily sensations, involving others or seeking care.

## **1.5 Outline of the thesis**

In addition to the introduction chapter, this thesis is composed of four chapters. In Chapter 2, I present the theoretical frame, which inspired the research and the analyses performed from the data. Chapter 3 presents the research aims. In Chapter 4, I present and discuss the methodology I used to approach the field through interviews and participation. Chapter 5 presents the three articles that form the core of the dissertation and Chapter 6 contains the concluding discussion, with a brief summary of the main findings in each article, as well as a discussion of some overarching topics within the thesis.



## 2 Theoretical frame

### 2.1 The sensorial

As research has shown that people experience late effects and other health problems after cancer treatment (Lee - Jones, Humphris et al. 1997, Harrington, Hansen et al. 2010, Horlick - Jones 2011, Loge 2013, Balmer, Griffiths et al. 2014, DeSantis, Lin et al. 2014), a main objective of the project was to understand illness experiences of persons who had suffered from cancer. How did they sense their body and how were these sensations interpreted and made sense of within their everyday social life after cancer? This made perspectives from sensorial anthropology important points of departure when formulating research questions and interpreting data from interviews and participation in the field. On the other hand, findings during the research process made it necessary to search for other theoretical angles, and also necessitated interplay between earlier findings, theory, new empirical findings and search for other theory.

The body and the sensorial gained (renewed) interest in the 1990s as a critique of the contemporary discourse and text centered approaches to culture. The anthropology of the senses reinserted 'sensorial perception as a site of knowledge construction' (Porcello, Meintjes et al. 2010: 60). The idea that cultures can be read as a text is represented by Geertz' work 'Deep Play: Notes on the Balinese Cockfight' from 1973, where Geertz suggests that 'The culture of people is an ensemble of texts, themselves ensembles, which the anthropologist strains to read over the shoulders of those to whom they properly belong' (Geertz 1973: 452, ). As Geertz' 'interpretive anthropology' was grounded in hermeneutics, which again was developed for the interpretation of written documents (Howes 2010), the idea of seeing culture as text is relevant. Geertz' concept of 'thick description', his famous tool and methodology for understanding, analyzing and describing the complex context of the events he studies, becomes a way to describe the 'ensembles of text' that constitute the culture. Critique of this has been that the text metaphor makes us miss the dynamic dimension of social life and events and gives priority to observation, as seeing and hearing a performance or spectacle, at the expense of participating and activating other senses. This might prevent us from understanding meaning that is left unsaid, but is situated in the sensorial.

The sensual turn in anthropology, as a move away from the linguistic and textual paradigms, instead treated 'cultures as ways of sensing the world' (Howes 2010: 29). This turn laid the foundation for the 'anthropology of the senses', where an underlying premise is that sensory perception is both a cultural and a physical act, which means that the way people perceive the world through their senses varies, and 'the senses themselves may each be linked with different trains of associations, and certain senses ranked higher in value than others' (Classen 1997: 401). Sensorial studies thus emphasize the dynamic, relational and multimodal nature of our 'everyday engagement with the sensuous world' (Howes 2006: 115). As our sensuous world also encompasses health and illness, the perspectives and insights from the anthropology of the senses have become important in medical anthropology.

In an editorial introduction to a special issue of *Transcultural Psychiatry*, Hinton, Howes and Kirmayer (Hinton, Howes et al. 2008a) aim to give an overview of key terms needed to develop a medical anthropology of sensations. They accentuate the dynamic and contextual dimension of sensations. 'In fact, all sensations come into being and are altered through processes of attention and interpretation' they say, and 'every sensation is a shifting entity, varying moment-to-moment in its qualities and intensity. It is stabilized into percepts through strategies of attention and cognitive processes of abstraction' (ibid: 140). Our representations of the world and our body are constructed through our senses, 'mediated by culture models, others' responses, and personal schemas' (ibid:140).

Sensations can for example be responded to in line with local ideas of physiology and vulnerability: what are seen as normal sensations and what might be illness or in need of treatment? (Lock and Kaufert 2001, Hinton and Hinton 2002, Hay 2008, Hinton, Howes et al. 2008, Nichter 2008). The recognition that sensation experience varies across cultures has inspired a search for ways of understanding that enable cross-cultural studies, and has simultaneously contributed to a medical anthropology of sensations in general. One example is the work of Hinton and Hinton (2002:155) on panic disorder, where they suggest understanding the sensing body as containing seven dimensions. The overarching dimension is 'the sensational body', which again, in short, contains the biological body and the cultural understanding of physiology, then the body as part of the world, being metaphoric and connected to the experience of living in a local landscape, and finally, the body as connected to memories and cognition of fear (ibid). These dimensions contribute in different ways to



how we sense our bodies, and this way of studying sensations also makes us see the cultural and lived context of sensations.

In their contribution to the special issue of Transcultural Psychiatry and the medical anthropology of the sensations, Hinton, Howes et al. (2008) suggest the use of schemas to understand how sensations are experienced differently in different cultures. As we are ‘continually bombarded by sensations’ our ‘attention to them is, necessarily, selective’. To understand the way we direct attention to and interpret our sensations, they propose a heuristic use of the concepts of sensation schemas and sensation scripts. Their aim, as clarified in their editorial introduction, is to ‘trace somatic symptoms from their origins in culturally mediated processes of sensing, attending, and interpreting the body and the world’, arguing that ‘these processes involve complex links among neurobiology, culture, and life history’ (Hinton, Howes et al. 2008a: 141).

Sensation schemas are various networks of meaning (Hinton, Howes et al. 2008: 152) or conceptual models (Classen 1993) that are connected to sensations, which we use to understand the sensations we feel. In line with Hinton and Hinton’s (2002) outline of the seven bodies, the schemas will interact with physiology, attention and imagination, and will be connected to previous experiences, worldviews and metaphors. They can also include ideas of causation and models of process, and they are cultural, building on common ideas and local knowledge of a group, but also individual, being based on the individual’s life experiences. The schemas we choose will indicate sensation scripts that fit the schema (Hinton, Howes et al. 2008: 153). The script suggests what actions to take. When we choose a certain sensation schema, the schema activated will place the sensation in specific social contexts that ‘embed sensation in a larger web of meaning and expectations’ (Ibid.) and thereby indicate certain actions to handle the situation.

These ideas of sensation schemas and scripts provide a simple (heuristic) model and understanding of the complex interplay that takes place when people give attention to and interpret sensations. In research on illness experience after cancer, descriptions, arguments and actions taken to handle unpleasant sensations can shed light on the context of interpretation in everyday life. It is therefore important to pay attention to how bodily sensations are interpreted and handled in everyday life.

An example of a perspective based on people's everyday social life is Hay's (2008) work from Lombok, Indonesia. She looked into the process of transforming sensations into symptoms, and found that decisions about when to attend to a sensation as a potential symptom were the result of cultural ideas and personal awareness. People took account of vulnerability in terms of what were perceived as risky situations that could cause sickness, the duration of the sensation, and the degree of disability as to how much the sensation or situation interfered with their activities. People's normal, everyday state of being was feeling 'less than healthy', but this did not stop them from performing their everyday tasks. As a symptom is a 'constructed and socially informed cognitive interpretation' (Hay 2001: 221), the embodied sensation has to be socially confirmed to become a symptom. If it was not confirmed as worthy of being acted upon, it was ignored and sometimes reassessed later. In this project, I wished to seek out the processes of interpretation of sensations that took place in urban Norway; these would possibly be similar, but I expected the cultural models to be different.

A recent study of the Danish middle class (Offersen 2016) provides a Nordic example of how the interpretation of bodily sensations into symptoms is social, and embedded in a 'moral sensescapes' of everyday life. To be a 'good citizen', the middle class navigate between the responsibility of seeking help in time, but simultaneously not misusing the system by seeking help unnecessarily.

## **2.2 Empathy and the sensorial**

Sara Pink (2009), a social anthropologist with a special interest in visual anthropology, argues for doing 'sensory ethnography', as it could 'account for how multisensoriality is integral both to the lives of people who participate in our research and to how we as ethnographers practice our craft' (2009: 1). Sensoriality is 'fundamental to how we learn about, understand and represent other people's lives', she argues (ibid.: 7). In this way, she focuses on intersubjectivity in general, as well as the task of doing ethnographic research on different topics. She underlines that she sees the senses as one of multiple routes to knowledge. Harris and Guillemin (2012) also argue for the importance of the sensory as 'a portal into the otherwise unexplored' (ibid.: 689) by using sensory questions or prompts that assist participants to recall illness and health care experiences, as the senses are strong vessels for memory (ibid.: 697).

In my project, where I aim to understand the participants' illness situations and the way they interpret sensations, sensorial anthropology is an obvious option. To be able to understand the sensorial in other people's lives, I need to engage my own senses in an attempt to imagine the sensorial of the other, in other words, aiming for a form of intersubjective understanding.

Empathy, however, may be relevant to study as a form of intersubjective and imaginative process where more complex embodied, emotional and cognitive work is needed to try to imagine the experience of another from her or his perspective (Hollan and Throop 2008: 387, Throop 2012). The medical and psychological anthropologists Hollan and Throop both argue for the need of anthropology to engage in theorizing about empathy and its place in human interaction and research. Hollan has researched mental and emotional health, empathy, embodiment and consciousness, and his colleague Throop has a focus on subjectivity, empathy, morality and suffering. Throop argues that empathy is a multimodal process that also involves bodily and sensory aspects of lived experience (Throop 2012 Varieties). He is interested in varieties of empathy that are 'not solely or reliably mediated through strictly visual and talk-based cues, but are instead rooted in alternate embodied and sensory forms of attuning with others' (Throop 2012: 424). He uses a healer on the island of Yap in the Western Pacific as one example of how empathic discernment in the field of suffering can be based in embodied engagement, and in the form of manual manipulation and touch. Even though Throop seems to be mainly interested in how the body discloses information that can enhance empathic understanding without talk-based information, his drawing attention to the bodily and sensory aspects of empathy can also be useful in the planning of interviews and the focus of questions in research concerning others' experience of illness and sensations.

Hollan is occupied with the need for studying empathic work as two-sided, where the one to be understood empathically also has an important role, having the wish and capacity to make him or herself understood (Hollan 2008), emotionally and imaginatively. Hollan also argues for the need of investigating how people 'in different times and places promote or discourage understanding themselves' (ibid.: 475). He uses examples from his own life in the USA, for instance his work as a psychotherapist, where he often realized that the feeling of empathic understanding, or being understood, has rested upon misunderstanding. In the case of interviews, this argument is important, as empathic understanding will need a dialogue where much will depend on both parties' ability to express themselves, to imagine what the other is trying to express or needs to know, and in this way maybe engage in a creative investigation

of the topic. Within this process there will probably be different degrees of empathic understanding, as noted by Throop, when he argues that empathy is not an ‘all or nothing affair’ but a ‘process that is arrayed through time’ (Throop 2012: 772), and is also dependent on our ability to understand ourselves.

To be able to understand illness experiences and the sensorial in research participants’ lives, the complexity of empathic imagining thus seems to serve as an additional tool. Empathy is a ‘form of emotional reasoning’ where, in attempting to view a situation from another person’s perspective, one uses a combination of emotional, cognitive and imaginative understanding (Halpern 2001: xxiii, Hollan 2008). This implies that instead of only imagining that something is the case, one imagines how it feels to be in that situation. This may help us recognize emotions in others and understand how and why emotions arise. This will be a result of our imagination of this perspective, but built on dialogue (Hollan 2008), on interpreting others’ bodily expressions of their emotions (Throop 2012) and knowledge about their life in terms of symbols, meanings, positionality or compelling concerns in life (Hollan 2008). When exploring sensorial expressions that are bodily in origin, but often connected to emotional expressions, empathy may encompass the sensorial in a broader sense and produce further understanding of experiences given meaning through the sensorial.

In addition, Pink proposes that ‘one of the goals of the sensory ethnographer is to seek to know places in other people’s worlds that are similar to the places and ways of knowing of those others’ (Pink 2009: 23). She argues for a ‘more abstract use’ of the concepts of place and space in sensorial anthropology, as this can offer ‘a framework for rethinking the ethnographic process, and the situatedness of the ethnographer, as a multisensory concern’ (ibid.: 29).

Inspired by this, I argue for a metaphoric use of the concept of place and thus see the illness situation of cancer as a place that we as ethnographers should seek to know, also in an empathic way. As mentioned in the introduction, the metaphoric use of place to describe the situation of being ill has been applied before by Paul Stoller in his book ‘Stranger in the village of the sick’ (Stoller 2004). He writes about his cancer, and is inspired by Susan Sontag’s ‘Kingdom of the Sick’ (Sontag and Broun 1977) which is also about having cancer.

In seeking to know the place of cancer, I will use theories from sensorial anthropology, and approach the sensorial as a route to seek knowledge through intersubjective and empathic understanding. Another field where the sensorial could be expected to play a role is within the participants' social relations.

## **2.3 Social relations and therapy management**

Central to my study was to explore how the process of interpretation was embedded in social relations and processes. I thus hoped to expand my knowledge of how considerations and decisions are made in private arenas, outside the Norwegian health care system. According to Hay (2008), the 'transformation from sensation to symptom is necessarily a social one in which symptoms must be socially legitimated in order for the transformation to be complete' (ibid.: 201). So when people in Lombok had decided that a sensation might be a symptom, this was discussed with others to obtain legitimation of a possible illness before seeking help. As I knew little beforehand about how social relations would be involved in the work of interpreting sensations and managing illness, I wished to investigate who would be involved and in what way.

The importance of social relations is also captured in Janzen's (1987) work on the 'therapy management group'. The concept of 'therapy management' covers the process of searching for a diagnosis, selecting and evaluating treatment, and giving general support to the sufferer. The 'therapy management group' is 'the set of individuals who take charge of therapy management with or on behalf of the sufferer' (Janzen 1987: 68). The concept was developed in medical anthropological research in the seventies in Central Africa, but was also based on comparison with research in Canada (Ibid). The aim of the development of the concept 'therapy management group' was to shed light on the social context of decisions and actions taken in connection with the handling of individuals' ill health or their other overwhelming problems.

Nichter (2002) argues for a refinement of the concept 'therapy management'. He examines the social relations and the micropolitics of therapy management, through two case histories, one from India and one from the Philippines. The cases show how studying therapy management provides insight into the values and priorities in household and family and contribute to the anthropology of self. 'Illness challenges a sense of order in one's world and tests the integrity of social relationships' (Nichter 2002: 101). Therapy management

encompasses much more than health care seeking, and is multidimensional, Nichter argues, as it is performed on the micro level of interaction around handling the illness, and within the macro level of cultural meanings and symbols:

‘The afflicted, and members of a therapy management group who coalesce around them, engage in a variety of illness-related “works” that emerge through time. These engagements include the marshalling of material resources, the management of emotions, the performative aspects of “being sick” and relating to the afflicted, participation in the co-construction of illness narratives, and provision of space where healing or the management of sickness takes place. The work of culture involves a reappraisal and reframing of troubles and negative emotions in terms of publicly accepted sets of meaning and symbols’ (Nicher 2002: 82).

Inspired by this wide definition of the concept, I was able to take an interest in a wide range of social activities and interactions, covering fields of management of emotions, illness narratives and the performance and handling of illness in general. Having resources in the form of public health care and social relations will be an advantage, but research has shown that uncertainty is still present in people’s lives after cancer. In studying people’s illness experience and life after cancer, understanding this uncertainty would be important.

## **2.4 Uncertainty**

In the introduction, I discussed how the term ‘cancer survivor’ is contested. One of the main reasons is the risk of cancer relapse, which can be measured statistically, but provides no security for the individual and his or her close ones. Another discussion is whether cancer can be seen as an acute illness - an incident - that can be cured and done with. As mentioned in the introduction, we know that many who have undergone cancer treatment have problems with troubling late effects, which affect their life and sometimes make them need health care services long after completion of treatment (Harrington, Hansen et al. 2010, Loge 2013, DeSantis, Lin et al. 2014, Hoekstra, Heins et al. 2014). Furthermore, we know that it is not only the former cancer patient herself who is affected by cancer, but her family also struggle with uncertainty afterwards. Miller (2014) observed that the

challenges of cancer survivorship demonstrate that newfound health may be bittersweet. While surviving cancer treatment is good news, various looming uncertainties may prevent survivors and family from returning back to their "normal" lives' (Miller, 2014: 240).

Much research shows that uncertainty about recurrence is very present, even when tests show no sign of residual cancer (e.g. Lee - Jones, Humphris; Dixon, & Bebbington Hatcher, 1997). In an analysis of his own general sense of existential crisis after cancer treatment, Horlick-Jones states that being able to function 'on a day-to-day basis necessitates suspending awareness of impending death, in order to find meaning in doing things, planning etc. After cancer this proves difficult' (Horlick - Jones 2011: 890). On the other hand, not all former cancer patients experience this. For instance, in a longitudinal qualitative study of the meaning of breast cancer in a life context from Sweden, Lillehorn (2013) found that the majority of the 71 women in her research experienced that their life after cancer had not changed at all or not changed to the worse. In the group of women that experienced that their life had deteriorated, the main reasons were late effects/side effects of treatment as well as worries about recurrence. Lillehorn argued that how the participants valued their overall experience of breast cancer seemed to be very much a matter of circumstances in everyday life. This is interesting for my study, as it focuses on the participants' everyday life.

Uncertainty is about not knowing the outcome of something, and is often discussed in connection to risk. In anthropology, uncertainty has been researched both within earlier classical studies of misfortune by for instance Evans-Prichard (1937) and Turner (1968) and in recent studies of risk and uncertainty by for instance Douglas and Whyte (Jenkins, Jessen et al. 2005). A tension in many studies has been the gap that separates analyses concerned with structural conditions and studies dealing with individual agency (Ibid.).

In everyday parlance, 'risk and uncertainty tend to be treated as conceptually the same thing' (Lupton 1999: 9), and in sociological theory, uncertainty is usually addressed as a part and a measurement of risk. The anthropologist Boholm (2003: 16), in her article on the cultural nature of risk, also suggests that 'we could say that uncertainty is a fundamental dimension of risk, and without uncertainty there is no risk'. Maybe in line with contemporary Western societies' interest in control, much literature in the social sciences seems to focus on how people try to handle uncertainty by risk management (e.g. Brown, Heyman et al. 2013; Alaszewski, Alaszewski et al. 2006), but there are also voices that argue for focusing on uncertainty in itself. An example is a recent anthropological work in this field, Samimian-Darash and Rabinow, who argue that 'it is vital today to distinguish among danger, risk, and uncertainty, both analytically and anthropologically' (2015: 1). In their view, 'the scholarly

fields that have historically focused on risk assessment and management are inadequate in the face of many contemporary problems, in part because the world is increasingly being populated by forms, practices, and events of uncertainty that cannot be reduced to risk.' They make the case that 'scholars should not focus solely on the appearance of new risks and dangers in the world, (...) but should also treat uncertainty itself as a problem and examine the forms of governing and experience that are emerging in relation to it' (ibid.: 1). Although Samimian-Darash and Rabinow focus on the macro perspective, as they wish to contribute to 'the discussion of risk as a technology and a form of governmentality' (ibid.: 5), their suggestion about 'moving the focus from the control of risk to the management of uncertainty' (ibid.: 5) is of general interest, and is useful in studying life after cancer, as the risk of cancer cannot be handled by the individual, but uncertainty will probably have to be.

The basis of our uncertainties is often 'anxiety created by disorder, the loss of control over our bodies, our relationships with others, our livelihoods and the extent to which we can exert autonomy in our everyday lives' (Lupton 1999: 3), thus a loss of control over areas that are important to us. We can imagine situations where people cannot do much to keep control or order, for instance in managing the risk of cancer relapse. It will then be interesting to study to what extent uncertainty prevails and how the state of uncertainty in itself is handled, i.e. how the participants handle and cope with the situation of living with uncertainty. The uncertainty may vary as to whether one will experience recurrence, or live for years without it (Stoller 2004, Jain 2013). It may also vary according to one's state of health after cancer treatment, how much one's health is affected, and the prognosis for the cancer. Overall, we should be aware that uncertainty may also differ according to different types of cancer, different physical, mental and existential dimensions of late effects, and, especially in our study, according to temporal aspects of sensing the body. Having had cancer and noticing e.g. unspecific pain or bodily changes may arouse uncertainty in the moment but not necessarily dominate one's life at any time. As with risk, uncertainty may be prioritized and the expression of uncertainty is culturally determined.

Samimian-Darash and Rabinow argue that the concept of uncertainty 'reflects a way of observing the future' (ibid.: 7), where precaution, preparedness for scenarios and surveillance become important. Within health, an example is developing ways of monitoring exceptional morbidity to detect a possible pandemic even before diagnosis.



Also at an individual level, we may expect that precaution and preparedness may be in the foreground when handling uncertainty, and may manifest in diverse pragmatic measures. As the risk of cancer recurrence itself is not possible to control at an individual level, the individual is left with trying to limit the spreading of any new cancer by surveillance, early detection and starting treatment as soon as possible. This requires awareness. On the other hand, to be able to live a life after cancer, it is important to be able to ‘bracket off’ (Brown and de Graaf 2013) worries about cancer recurrence. In this way, coping with life after cancer is not about managing the risk of recurrence, but managing the state of uncertainty. Both the kind of uncertainty and the need to find means to deal with it are pointed out by Jenkins et al. (2005) in the introduction to the book ‘Managing uncertainty’:

Matters of life and death are self-evidently at the heart of human existence. When sickness calls into question that existence we are confronted by the uncertainties of life. In such situations our concerns are not only with the physical body and experiences of physical pain and fragility, but also the social and symbolic aspects of life and death. (...) Sickness in particular and crisis in general pose questions of our very sense of existence and non-existence, and thus raise questions about how to deal with the uncertainties of living and the means with which we try to maneuver when the waters of life are troubled.’ (Jenkins, Jessen et al. 2005: 9).

Possibly, serious illness like cancer calls into question people’s existence, and reminds people of what is ‘at stake’ (Kleinman and Kleinman 1991) in life and in daily situations. Kleinman suggests that our existential fear is rooted in our feeling of threats to what matters most to us, and he points to common daily life values as ‘just carrying out our existence, negotiating important relations with others, doing work that means something to us’ (Kleinman 2006: 1).

However, capturing exactly what it is that matters most to us is not always possible, as Jackson and Piette point out (Jackson and Piette 2015: 4), as it is precisely ‘those forms of human life’ that are difficult to capture in language, for instance the human struggle for love, recognition, respect, dignity, and well-being, that are existentially most imperative for humanity, and are at stake in the critical moments that define human lives. To be able to grasp these forms of human life, they argue that anthropology needs to restore ‘a sense of the small and tangible things that make life viable’ (ibid.: 5), such as the everyday details of how we interact with others. I find these points important as a reminder to be aware of the values that

are often not verbalized, but may be underlying other topics in conversations. Inspiration for how to approach these kinds of questions can be found in Whyte's work, where she argues for the pragmatic approach to uncertainty, which requires that we 'see people as actors trying to alleviate suffering' (Whyte 1997: 20) by using 'meaningful modes of acting on the problem' (Whyte 2005: 246).

Whyte is inspired by Dewey's pragmatic approach which 'requires that we see people as actors trying to alleviate suffering rather than as spectators applying cultural, ritual or religious truths' (Whyte 1997: 20) and she argues that the way troubles demand intervention in Africa makes this approach particularly suitable. The interventions are means to deal with misfortune within a cosmology of witchcraft, but do not necessarily exclude any use of biomedically based health care.

Whyte bases her analyses on research among the Nyole people in Uganda from the 1960s, with repeated subsequent visits. She describes uncertainty connected to what she terms misfortune and suffering, which also, but not solely, concerns health and illness. She shows how the process of questioning the source of misfortune and trying out means of dealing with it are embedded in social relationships as well as concerning the individual. To the Nyole, social relationships, also including family, are both potential sources of misfortune and suffering in the case of conflict and sorcery, as well as potential contributors of resources needed to gain access to means of healing or handling a difficult situation. Actions are chosen and tried out pragmatically, based on the resources and ideas available. Whyte argues that, through this focus on the Nyole's pragmatic actions and how they talk about them, we gain knowledge of their notions of 'value, power, personhood and social identity' and we can 'only understand the experience of suffering by seeing subjects in their "local moral worlds" and asking what is at stake for them (Kleinman and Kleinman 1991)' (Whyte 1997: 4).

Even though Whyte's research is based in a very different empirical setting, her point of pragmatic approach to uncertainty and its management through enacting social relations is an inspiring way of thinking that resonates with my interest in how existential uncertainty may be embedded in social relations.

Based on what I have already highlighted in the introduction about the Norwegian welfare context, we can expect that access to health care and provision of means to basic material

needs will probably not be the most important sources of uncertainty. On the other hand, cultural values connected to the self and its social roles, for instance being hardworking and able to manage on your own, as well as being somebody others can count on, will probably be at stake in the case of cancer illness, and life after cancer. These values concern existential matters and what Jenkins et al. (2005: 9) term ‘the social and symbolic aspects of life’. Uncertainty about the ability to fulfil social roles within the participants’ lives can be expected to be important, among other reasons, because they form a base for ‘recognition, respect, dignity, and well-being’ (Jackson and Piette 2015: 4). These values are connected to different arenas in life, both private and public, and may influence how people handle their contact with the health care system as well as their social relations in everyday life. The uncertainty that we can expect to be present in people’s lives after cancer in the context of northern Norway will probably be forms of existential uncertainty, concerning whether one will live or die, what kind of life one will be able to live, and who one can be after cancer.

In an attempt to briefly summarize my theoretical inspirations, I will mention only a few directions related to the research aims to follow. This research project aimed at studying different aspects of living after cancer treatment, and my work has been inspired by many topics and scholars, only a few of which I can mention. With the intention of studying people’s illness experiences and their processes of interpreting and handling unpleasant bodily sensations, the sensorial became an important factor, and I have been inspired by theories about how the sensorial is a fundamental way of experiencing the world (e.g. Howes 2006) and of learning about the world and experiences of others (Pink 2009, Howes 2010). This approach has a methodological dimension as a portal into otherwise unexplored experiences (Harris and Guillemin 2012) as well as being a way to get to know ‘places in other people’s lives’ (Pink 2009), such as an illness situation. Empathic and sensorial imagination (Hollan & Throop 2008, Halpern 2001) became an important way of gaining insight in interviews.

Another aim was to explore the social dimension of interpreting sensations, making decisions and handling care and illness. The importance of people’s everyday social life became a key focus area, inspired by Hay (2008). Within this area, I maintained a broad scope on social activities and relations, inspired by Nichter’s (2002) perspective on Janzen’s ‘therapy management group’ (Janzen 1987).

In the end, the extent of uncertainty became an important aspect to explore, for instance as worries about cancer relapse, or health and ability to cope with life after cancer. My focus on what this uncertainty was about or what was at stake or really mattered was inspired by Kleinman and Kleinman (1991), (Kleinman 2006), as well as Jackson and Jenkins' interest in the existential matters that assume importance when illness calls our very existence into question. In investigating how the uncertainty was handled, I became inspired by Whyte's pragmatic approach (Whyte 2005; Dewey 1929), which accentuated the importance of looking into people's practical everyday handlings of the uncertainty.

### 3 Aims of the study

As most research on interpretation of symptoms and care seeking focuses on the period before diagnosis and treatment, this project wishes to study former cancer patients and their illness experiences after the end of treatment. The overall aim of the project is to understand the illness experiences and care seeking processes of former cancer patients, within everyday social relations. More specifically, the study wishes to provide in-depth understanding of context-based processes of bodily sensations, sense making and (inter-)action towards cancer illness and to contribute to an understanding of former cancer patients' therapeutic pathways.

The project is one of two under the overarching project SenCancer – sensing illness in everyday life: care seeking and perception of symptoms among former cancer patients. The two projects share the same main focus of study, but differ in the locus. The study that laid the foundation for this thesis was conducted in an urban community.

Following the above overall aim, the three specific research aims are:

- 1) To explore the social process of interpretation of bodily symptoms and sensations after cancer diagnosis.
- 2) To explore to what extent uncertainty is fundamental to former cancer patients and how it is managed and handled in everyday social relationships.
- 3) To explore how the sensorial and emotional may help to provide insight of illness conditions, through empathic understanding.

The thesis makes a contribution to the theoretical fields of medical anthropology of the senses, care seeking and coping with illness and uncertainty, and illness as a social and contextual field. It provides an example of how a heuristic use of the concepts 'sensation schemas' and 'sensation scripts' can develop understanding of how and why memories from cancer treatment and worries about recurrence, influence the process of reestablishing an everyday competence of interpreting bodily sensations after cancer. This is a field where these concepts have not been used before. The thesis also extends knowledge of how the interpretation of bodily sensations and worries about possible symptoms, are handled within social relations after cancer in a Norwegian context. Instead of seeking advice and confirmation by social relations, the research participants mostly kept the worries to

themselves, this way seeking to protect everyday life and social relations from cancer worries. In addition, it contributes with methodological reflections within the field of medical anthropology of the senses, as it shows an example of and reflections on the important role of sensorial imagining in gaining empathic understanding of another's illness experience and the fundamental difference between cancer and common ailments, both concerning the illness experience and the existential uncertainty that follows.

## 4 Methodology

In this chapter, I will present the design and methods used to investigate the research questions, and the implications of the choices. I will start by presenting the field and discussing the approach of ethnographic fieldwork. I will present the process of recruitment and the participants of the study, as well as describing and discussing the methods I used, and the analytical process. I will discuss the strengths and limitations of my choices, but will evaluate validity in terms of transferability, usefulness and relevance, as well as ethics separately at the end of the chapter.

### 4.1 The field

In order to investigate former cancer patients' illness experiences and care-seeking processes after cancer, decisions had to be made concerning the focus and locus of the study, or, termed in another way, the empirical and analytical object (Hastrup 2003: 15). I wished to investigate the period of life after completion of cancer treatment, when the former cancer patients had started reorienting and living a life again, outside the health care system. This way I chose a point in time connected to an idea of an illness trajectory, and directed the research at the situation of starting or reestablishing life again after cancer. I was looking for participants who had finished cancer treatment, and were presumed to be free from residual cancer. For a discussion of why I chose to term the participants 'former cancer patients', see the introduction chapter. I will return to the practical sampling when presenting the participants in the next unit; first I will elaborate on other important decisions.

The spatial locus was already decided to be an urban setting, as a contrast to the rural setting of the co-project. The town of Tromsø was chosen, as it is the biggest town in the region and a center for many services. The idea of choosing two different locations in this way was based on expectations that daily life, social relations and health care services might be organized differently in urban and rural settings (Hannerz 1980, Lien 2001, Johnson, McDonnell et al. 2011), which again might influence life after cancer. The research topic itself is not primarily tied to a spatial arena, but involved investigating the situation of living after cancer, and the situation I wished to study should be placed within everyday life.

Everyday life can be seen as a representation of 'ordinary' life, or the life of 'ordinary' people, in opposition to for instance more public, organizational and political life (Gullestad

1989). Everyday life is not tied to any specific institution or locality, even though people's homes are of particular importance (ibid.). The term 'everyday' contains different dimensions, such as for instance the practical dimension of the daily organization of tasks and activities, which is located in place and time. Another is the more phenomenological dimension of the everyday as part of people's life world and experience (ibid.). Both these dimensions are important to my research questions, as they aim to explore sensorial and cognitive processes of perception, interpretation and understanding of illness and bodily sensations, as well as more practical organizational dimensions of how interpretation and handling of sensations take place within social relations and everyday life.

## **4.2 Ethnographic fieldwork**

In social anthropology, ethnographic fieldwork is a 'mark of disciplinary distinction' (Clifford 1997: 216). A typical example of ethnographic fieldwork is one where the researcher moves into a village for a long period, learning about people's lives from the inside, taking the 'native's point of view' (Geertz 1974). This method was originally used in small-scale societies where the researcher was able to take part in people's everyday lives by staying in their village. A typical example is Malinowski's fieldwork among the Trobrianders in Papua New Guinea, by Gupta and Ferguson (1997) seen as an archetype of anthropological fieldwork. This method is suitable where public life is taking place in few, transparent and easily accessible arenas, and where people's public and private lives are not strictly divided. It has major limitations for other types of societies, such as for instance contemporary urban Norwegian society, where everyday life takes place in a wide array of arenas and activities, some not open to everyone to join; such a society is not at all suitable for maintaining an overview of any individual or group in everyday life.

The solution to this has been to make social relationships the site for fieldwork rather than a place. Clifford (1997) refers to Brown's (Brown 2001) study of the life of a vodou (voodoo) priestess in New York, where Brown's 'ethnography was less a practice of intensive dwelling ("the tent in the village") and more a matter of repeated visiting, collaborative work' (Clifford 1997: 188). Brown's ethnography is thus situated by an 'interpersonal relationship – a mixture of observation, dialogue, apprenticeship, and friendship' (Clifford: 189) with the person she follows. Her field is 'wherever she is with Alourdes' [the vodou priestess]. There is, however, a difference between this fieldwork situation and mine, as the vodou priestess



had specific arenas or activities where she regularly played out her vodou priestess status and role, and where the anthropologist could take part in relevant activities. The social relationship as a site gave access to arenas in the form of situations and activities that were specific to the vodou religion in everyday New York, and allowed for observation of its practice. This practice was the phenomenon of interest. In my study, the phenomenon of interest was less observable, as illness experiences and the way they influence interpretation of bodily sensations are only 'observable' as they are expressed verbally, e.g. discussed with anybody.

Important questions regarding participant observation are highlighted by Wolcott: 'A first question to ask is; can whatever I want to study be seen by a participant observer at all? And, if so, am I well positioned to see what I hope to see? These questions need to be followed by another: What are my own capabilities for participating and observing in this situation?' (Wolcott 2005: 81).

There are no specific cancer arenas where we can gain an overview and be positioned to observe all we need as a participant observer. Post-cancer life takes place within a person's life as a whole, at work, in public and in private life, and in all social relations and all activities. In the lives of the former cancer patients, only a few arenas could be seen as 'cancer arenas', where cancer was the context of the activities and tasks taking place. These could for instance be activities arranged by the Cancer Society, visits to the doctor or other health care services, but the participants visited these only sporadically. Cancer was otherwise an omnipresent, but still mostly invisible, part of everyday life as a whole, and there was thus no specific and relevant cancer field to place myself inside, as a spatial unit and arena for interaction to be observed. In order to conduct my research, I needed to be able to talk to the participants and this required a method which would allow the establishment of trusting relations to lead to open sharing and reflection.

The study was designed as longitudinal research (Johnson 1998), where the principal fieldwork method was repeated semi-structured, one-to-one qualitative interviews (Kvale and Brinkmann 2009). This, in turn, facilitated observations of any changes or developments in people's situations. The interview is a talk or a conversation, but is more concentrated and focused than habitual conversations, as it has a purpose and the interviewee's story has the focus and priority (Rubow 2003). The anonymity can also enhance access to stories and

meanings that otherwise would not have been shared. Such a conversation has the potential to create a certain temporal relation that gives room for reflections and perspectives that the interviewee has never previously reflected upon or verbalized (ibid.). Kvale and Brinkmann (2009) also find that ‘interviews are particularly well suited for studying people’s understanding of the meanings in their lived world, describing their experiences and self-understanding, and clarifying and elaborating their own perspective on their lived world’ (ibid.:116). In interviews, the senses can form a portal to understanding, as the interview can be seen as a process where we ‘might learn (in multiple ways) about how research participants represent and categorise their experiences, values, moralities, other people and things (and more) by attending to their treatment of the senses’ (Pink 2009: 81).

However, interviews have aspects of participant observation, as stated by Hammersley and Atkinson (Hammersley and Atkinson 2007: 120): ‘whatever their form, interviews must be viewed as social events in which the interviewer (and for the matter the interviewee) is a participant observer’. The effect of audience and context on what is said and done cannot be avoided, they argue. This points towards many dimensions of the interview situation, for example, how the setting and situation can be observed and provide intake for other reflections than merely what is said. What is said can be affected by the way the researcher shows interest in specific topics, her personal way of asking and responding, what the participants have learned about her life, etc. In this project, the interview situations sometimes varied as to others present in the room (a young child staying home from kindergarten, a teenager returning early from school, a grandmother or a neighbor dropping by), the location of the interview (home, at work, outdoors) and our other concerns of everyday life at that moment. All these aspects also gave additional possibilities to observing people’s everyday lives after cancer.

I will return to the practical implementation of methods, but first I wish to present the sampling process and the participants.

### **4.3 Sampling**

Sampling was conducted through family doctors in three different practices in the northern Norwegian town of Tromsø. The family doctors had agreed to distribute information about the project, together with a letter of consent, to patients in their records who had finished cancer treatment and started their life again.

As my focus was on life after cancer in general, I wished to sample people who had received different cancer diagnoses and who were at different stages in the process of life after cancer. The only requirement was that they had finished their cancer treatment and had recommenced a form of everyday life again, supposedly free from cancer. Due to suggestions from the family doctors, I chose not to restrict sampling to people only in the first years after completion of cancer treatment, as the cancer experience might affect people's lives long after finishing treatment. Such an open selection also allowed for insight into different stages of life after cancer, and actually led to the finding that many of the challenges of life after cancer are present many years after treatment.

Six persons responded and agreed to participate. One other person heard about the project from a friend who was participating and asked to join it, and one relative of another participant was asked by me and agreed to participate. Together we included 8 participants, 6 women and 2 men. They joined the project between January and May 2014 and they all continued until the end of the year, as planned.

All participants were middle-class ethnic Norwegians. Six of them had a bachelor degree and five of these degrees were in the field of health. Apart from the one who was asked by me to participate, they were all between 40 and 63 years old, and they had similar stories about how they struggled with life after cancer treatment. The last one, asked by me, was 75 years old, and differed in a number of ways from the rest. She did not have complaints that she connected to cancer or its treatment; instead, she perceived changes as due to age, and a more inactive life than before the operation. She had had an operation without complications and no radiation or chemo treatment after. These differences provided contrasts or nuances that contributed to the analysis of the other stories of life after cancer.

#### 4.3.1 Presentation of the participants:

<i>Sex</i>	<i>Age</i>	<i>Civil status</i>	<i>Children/age</i>	<i>Diagnosis</i>	<i>Treatment</i>	<i>Work/%</i>
					<i>years past type</i>	
1 – F	45	single	1 u 10	cervical	2 y, s/c/r	H - 80%
2 – M	53	single	2 o 18	prostate	3 y, s	O - 0, volunteer
3 – F	63	couple	3 o 18	colon	6 y, s/c/r	H - 60%

4 – F	58	couple	2 o 18	ovarian	2 y, s/c/r	O - 0
5 – F	40	couple	2 u 10/u 18	lymphoma	9½ y, c/r	H - 50%
6 – F	59	couple	2 o 18	breast	½ y, s/c/r	H - 80%
7 – M	55	couple	3 o 18	lymphoma	7 y, c/r	O - 50%, volunteer
8 – F	75	single	3 o 18	colon	3 y, s	H - 0, retired

*Years after finished treatment/type of treatment: Surgery/Chemotherapy/Radiation*

*Work: Occupation within Health or Other/Workload/hours in percentage of full employment*

I handed out 40 envelopes with participant information to the family doctors and received three back that were not sent out. I do not have exact numbers of how many people they all asked or how many envelopes were distributed; perhaps more than three were not handed out. Further, I do not know how the family doctors decided who should be asked. Together with the project leader, I had a meeting at each practice where most of the family doctors attended, where we informed them about the project. Some of the family doctors said that they would not like to just send out the papers, but would prefer to call or talk to the patients to inform them about the project before handing them out. In general, we had problems getting access to family doctors at all, as they have tight schedules and regularly receive requests to participate in different research projects. To ensure their collaboration, I wished to keep their involvement at a low level, and I therefore did not see investigating their decision-making process as a realistic alternative, even though it could have been interesting.

As the sample was dependent on whom the family doctors decided to provide with information about the project, and who then decided to take part, we could expect that people who regularly saw their family doctor, and who experienced problems in life after cancer, were likely to become participants. The sample was thus by no means representative of all people who have finished cancer treatment. Instead the study provides an analysis of how some bodily sensations, uncertainties and dilemmas are experienced and handled by a group of individuals who have restarted 'everyday life' after cancer treatment. The problems, dilemmas and solutions are based on circumstances and values that are likely to share similar

features with other severe illness or crisis situations in comparable socio-cultural contexts. In this sense, I sought to provide insights into the values and concerns at stake, and how these were handled. The longitudinal dimension facilitated a much deeper grasp and analysis of each participant's situation.

The participants that contacted us expressed a wish to make a contribution. They hoped that their story could be of help to others, and enhance knowledge and understanding of cancer and life after cancer. They also mentioned that they felt there was too little knowledge to date, so more research would be positive. This wish can explain some of the similarities in the group of seven participants. They all found they had a story to tell, and therefore wished to take part. Their stories were often about hardships and areas in need of improvement during the process between searching for a diagnosis and completion of treatment, or about hardships after cancer. Some stated that the hardships after cancer were not part of the 'official version' of 'being cured and getting back to life again'.

## **4.4 Conducting fieldwork**

### **4.4.1 The interviews**

Between January 2014 and January 2015, I conducted 41 interviews with eight participants, varying between three and seven interviews with each, depending on when they joined the study, life events during this period, and how much they had to tell. In the summer vacation period, we had a break in interviewing between the end of June and the beginning of September. No one withdrew from the study before the end, and most participants had all interviews at home. One wished to be interviewed in our office and one had the first interview at home and the rest at work. All interviews lasted from one to two hours, mostly two. I had told the participants beforehand that we would limit the interviews to two hours, because I did not want them to become too tired and maybe hesitate to continue taking part in the project. Several also admitted that they felt tired at the end of the interview and needed, or had planned, to rest afterwards.

The interviews began with a rather loosely semi-structured (Wolcott 2005, Kvale and Brinkmann 2009) part, where the participants were asked to tell their story about cancer. The subsequent interviews were semi-structured, using an interview guide and follow-up

questions. I usually had relatively few, but open-ended, questions, aimed at covering specific topics but still leaving the interviewee free to formulate her/his thoughts.

There are many suggestions in the literature on how to pose interview questions and what kind of questions to ask. A common opinion is that the less structured and more open-ended interviews should be planned around a few big issues with non-directive questions and with follow-up questions based on the interviewee's answers (Wolcott 2005, Hammersley and Atkinson 2007, Kvale and Brinkmann 2009). I followed this idea, but had planned some additional questions as an aid to deeper exploration of the topics, if needed. These were rarely used, as I needed the time to follow up the interviewees' responses. However, the additional questions had a mission, as a way to prepare for the interviews and maintain focus during them. Sometimes I also used them as a rough check list at the end of the interview to affirm to myself that we had not missed important topics.

During the year I used four different interview guides. The first was used until the summer break, and the foci of the questions were physical, cognitive and social aspects of life following cancer treatment. They covered aspects of practice, such as recent activities the interviewee had engaged in, who he/she had spent time with, or more existential matters about life satisfaction, or issues, thoughts or emotions that had been preoccupying the person. The more physically-oriented questions concerned health, sensations and symptoms. In cases of unpleasant sensations or worries, I asked if these had been discussed with anybody, and to what extent they had been tackled.

One of my worries before starting this project was that the repeated interviews would become a monotonous task, maybe boring for both the researcher and the participants. But I found that focusing on topics and a few but open-ended questions made it possible to follow up each participant's individual situation, and pursue the topics she/he wished to talk about. Additional tools that I will present in the next paragraph also provided interesting angles for discussion. In addition, the preliminary analysis and subsequent follow-up of this made the topics and interests develop during the year in a way that was seemingly acceptable to all parties. This was mainly confirmed by the participants in their final interview when they were asked about their experiences of taking part in the project.

To provide an overview and aid the participants in recalling their everyday life activities and their social network, we used the drawing of social and geographical maps (Hägerstrand 1985, Aquist 2003). We usually did this in the second interview. After the drawing was done, I used the social map as a starting point to ask who were the ones involved or included in their post-cancer management and reflections on life. Whom did they discuss with or ask for advice or practical help? In other words, who made up their ‘therapy management group’? (Janzen 1987, Nichter 2008).

In the second or third interview, I also introduced a voluntary health diary. They all received it, but I underlined that it was voluntary and by no means should be felt as ‘just another task’ to be performed. As inspiration for what could be noted down in the book, I formed questions that were quite similar to the main questions and topics of the interview guide at the time. At least half of the participants used the diary for a while, some until the end of summer, and during interviews they used it as a tool to remember what had happened since last time we talked. From their writings, which they sometimes quoted, and comments during our talks, it became clear that the diary gave rise to reflections about their activities, priorities and situation as a whole. One commented that when reading it, he realized how much of his spare time he actually had to spend on the sofa. Another commented that she could see that the periods she prioritized to get her rests were those when she felt most well and happy.

The plan was to change the interview guide after the summer, to follow some of the ideas that arose during the preliminary analysis I performed during the summer. But the most obvious thing to do was to get updated on summer happenings and activities, so this first post-summer interview mainly had the same topics as the previous interview guide, but with a focus on summer and vacation and its opportunities and challenges: Had it been as planned or hoped for? This made us miss the opportunity of an extra round of exploring further my findings from the preliminary analysis, but discussing the summer, with its expectations and reality of passing by quite rapidly, also added to my insight. It became a looking glass into how limited capabilities and vulnerabilities after cancer easily disturb plans or make joys come at a price to be paid afterwards in the form of needing extra rest, feeling unwell and maybe worrying about the unpleasant sensations that follow.

The third interview guide followed up the preliminary analysis, and attempted to examine the liminality and distinction between illness and health, the bodily sensations of feeling ill and

well (Hay 2008), or in between, and the experiences of being ill from cancer compared to life after cancer, and maybe uncertainty about the future and a possible new illness. I also ascertained who was involved and which paths to health they had tried during and after cancer. These questions were on a more abstract level. They were less open, but built on previous interviews. They were also more detailed, but I still used the approach of the semi-structured interviews in letting the interviewees' answers inspire the topics I most thoroughly probed. I only used these questions in the penultimate interview. In retrospect, I see that it could have been interesting to develop these topics and questions further through one or two extra interview rounds, on the basis of the analysis performed between them. However, my attempts at exploration through this third interview guide were based on my preliminary analysis and the patterns I had discovered in the earlier interviews, and could not have come much earlier in the process. Also, to extend the period of fieldwork was not within the time limits of the project, so further exploration of illness experiences and how these might affect the subsequent interpretation of sensations must be left for later projects.

In the final interview, I maintained a focus on the health situation, social life and activities, as well as asking about their use of and satisfaction with the Cancer Society, as possibly the most important interest organization and provider of services outside the ordinary health care system. I did this to achieve an overview and possibly be able to give some feedback to the Cancer Society about their role for former cancer patients. We also asked the participants about their experience of taking part in the project, and all said that it had been of value to participate. Some felt that it was good to have the opportunity to talk and reflect about their illness and situation afterwards, and it also brought back memories that they had forgotten. One had at first been doubtful about the number of interviews planned, but found that because they had different topics and angles every time, it had been interesting to take part in all of them.

#### **4.4.1.1 Reflections**

The interview has a relational aspect that can be crucial to what is obtained from it. Different forms of interviews or dialogues can lead to very different types of relationships and questions. One example is the philosophical dialogue, with its confrontational style, aiming at exploring contradictions in the respondent's concepts, ideas and values (Kvale og Brinkmann 2009:38). Another example is the therapeutic interview, which has a non-confrontational style, aiming at emotional and personal change (ibid:41) Following Elton Mayo's method of



(therapeutic) interviewing, one should never argue and never give advice, but listen to what the person interviewed 'wants to say, what he does not want to say and what he cannot say without help' (Kvale and Brinkman 2009:45). The qualitative research interview, which I used, will probably come in between these two. 'The research interview is based on the conversations of daily life and is a professional conversation; it is an inter-view, where knowledge is constructed in the inter-action between the interviewer and the interviewee.' (ibid. 2009: 2). My role was not the role of a therapist, and my aim as an anthropologist was to explore and not to confront or change. On the other hand, the questions one asks, and the way one asks them and responds to the interviewee's answers, can feel confrontational, or at least start reflections with the potential to cause changes. The role of the interviewer thus has some ethical aspects that make it important to be sensitive to how you invite yourself into people's life worlds.

During the interview period, I faced dilemmas about my role as interviewer and interlocutor. I do not usually find it difficult to get in contact with and have conversations with people and one probable reason for this is that I easily share thoughts and stories from my own life with others. In the interview situations, I had to take care not to make my person and my life a topic. On the other hand, repeated visits in people's homes, or regularly spending hours together, talking about their personal and intimate experiences sometimes made me feel a wish, and maybe an expectation from my interlocutor, to also share a little of my own life and experiences, or at least some opinions on certain topics. For instance, I sometimes felt that the participant was struggling with too great demands on him or herself, like being a perfect parent, being active, etc. In that case, I sometimes uttered an opinion or a question like 'Maybe we sometimes ask too much of ourselves? Maybe the most important thing is not to let our kids take part in a wide range of organized activities, but instead just spend time together?' On occasions, I sensed that the person I was talking to might need help with what appeared to be returning depressive thoughts. I did not want to appear as an expert making a diagnosis or maybe causing offence, as mental issues can feel stigmatizing. I emphasized that I only made a comment as a fellow human being, not as a researcher. Then I asked if he or she had considered seeing a psychologist about the problem, as it sounded as if she had the kind of problematic thoughts that a psychologist might be able to help with. Sometimes my questions were taken as an opinion, as for instance when I asked one of the participants if he had talked to his employer about the workload he was struggling with. I was primarily

investigating whether this was a topic of discussion at all at his workplace, and if so, how it was handled or talked about, but at the end of our talk, the interviewee stated that now he was going to have a talk with his employer about it. Another participant commented in the final interview that the topics we had gone through during the year had led her to reflect on her situation.

#### **4.4.2 Participation by the researcher**

As already mentioned, only a few arenas could be seen as ‘cancer arenas’, where cancer was the context of the activities and tasks involved. Two participants did some occasional voluntary work for the Cancer Society. Most of them said that they had not prioritized, or had been unable to take part in, the activities offered. Some said they were done with this part of their lives, and wanted to focus on other things.

Because of this only sporadic activity in such arenas, I usually only got to know about it afterwards, during the interviews. In general, any participation on my part, especially in an arena where cancer or the participant’s health would be a topic, would have the potential to add valuable insight to my research. In not participating, I might have missed valuable data that could have added to or nuanced my insights. Such participation might have provided insight into how the perception of cancer illness and the associated interpretation of bodily sensations are discussed in these arenas. The participants might also have revealed other thoughts than those expressed in the interviews.

On a few occasions, I heard about an appointment with the health care services in advance, but I did not ask if I could join, as I felt it too private and intrusive to ask. Probably I would have been invited to take part on some occasions if I had asked. But my own hesitation to intrude got in my way. Getting access to people’s lives demands sensitivity in being considerate about their privacy, and I had already chosen a modest style in the information form. To increase the chance of recruiting participants to the study, it was important not to make participation too demanding on people’s everyday lives. In the information form and request to the participants, I therefore only asked for participation in interviews, and indicated very vaguely other possibilities:

‘If it is all right for you, the researcher might ask permission to interview other people that are important to you regarding your health. She may also ask permission to take part in activities

you consider important for your health or your experience of being in your current phase. This is voluntary, and we are very grateful for your participation, also if you only wish to take part in the monthly interviews.'

There were also everyday arenas that I felt to be too private to ask admission to as a participant. One was family life. Much of people's everyday life takes place here, and this is the most intimate, private and 'backstage' (Goffman 1978) arena, and therefore not easily accessible, without disturbing its character. To be able to take part in this arena as a natural 'part of the family' would require a considerable amount of time spent in the family, which I considered too much to ask of them. This also applies to other private and intimate relations, which cannot easily be observed without disturbing them. An important factor when I considered participation was the realization during fieldwork that the former cancer patients were very considerate about protecting both their children and partner from worries about cancer recurrence and tried not to discuss their worries too much with them. It could of course have been interesting to observe how cancer might be a topic not discussed, yet still present somehow. But my very presence in the situation would be a reminder of the family member's cancer illness. While interviews could be understood as an interest in cancer as past experience, taking part in family life would more easily be a reminder of cancer as relevant today, still present, and still a possible threat.

It was easier to suggest taking part in less private everyday activities, or doing them together. As my aim was to study the interpretation of sensations in everyday life, and cancer is part of life in general, any of the participants' activities would be interesting, as a window into their life, and provide a more informal portal into talking about life, health, illness and cancer. I participated in activities with four of the participants. The activities were representative of the type of activity each enjoyed in everyday life and were usually chosen on the basis of a suggestion by the participant. With a male participant I made an eight-hour cross-country ski trip at the end of April, and in the autumn I joined him and his team for a day of elk hunting. The skiing trip was his suggestion, but I suggested the day of hunting, because I knew this was an important activity to him on which he spent many days every autumn. I was not sure if this was too much to ask, but he seemingly found it a good idea. On another occasion we went to different shopping centers, buying furniture and drinking coffee. With a female participant, I went to buy summer flowers at a garden center outside town on a chilly and rainy day in June, and with another female participant I went on a trip to a country café on a

sunny summer day. With yet another female participant, who lived in the countryside, I went for short walks in her neighborhood, and we met for a talk in a shopping center café. From my field notes, I can see that taking part in these activities brought me additional insight into the practical side of how some of their health problems were present in daily activities. An example was when bowel problems made it necessary to return home from an outdoor coffee break quite soon after finishing our small meal, as usual. Walking around in the market garden triggered painful hips, and made carrying heavy weights a problem. The positions available in the team of elk hunters became constrained by physical limitations. These represented abilities normally taken for granted, which at the moment were lost, and were uncertain in the future. Observing this might have been difficult without the knowledge the participants had shared with me during interviews. But in fact, being in situations with participants which revealed the practical implications of their health problems made it easier for me to imagine the feeling of being in a similar situation.

To explore the cancer field in general, I took part in some activities on my own that I considered part of the field: social activities in the cancer society, an open meeting in town organized by the cancer society, a nutrition course for cancer patients and a conference in mindfulness and trying out yoga. I attended the latter two because they were activities often tried and sometimes practiced by the participants. In addition, I searched the internet and other media for data about the ‘macro’ context of cancer, e.g. discourse and information, and I have paid attention to how people around me talk about health, illness and cancer. All these ‘additional’ activities have been important sources for understanding the phenomenon of health, illness and cancer, and for a greater insight into the cancer world of the participants (Rubow 2003. 243, Hammersley and Atkinson 2007).

## **4.5 Analysis**

The analysis was based on the semi-structured interviews as well as field notes from participatory activities between January 2014 and January 2015. All interviews were recorded and the first round of interviews was fully transcribed. Later interviews were recorded, partly transcribed and/or further studied through field notes. I also made field notes during interviews, and wrote memos after interviews and activities. In addition, each participant had drawn a geographical activity map and a social map showing family and friends they regularly spent time with.

Applying a broad definition of what the task of analysing contains (Maxwell 2013; Hammersley and Atkinson 2007), my analytic process started already with the planning of the fieldwork, and definitely from the start of conducting the first interview, by reflecting during and after interviews as well as by writing memos. My third article presents an example of how sensory and empathic interaction within an interview situation was part of the analytic process. Through the whole interviewing and fieldwork period, I developed tentative ideas about themes or categories (Maxwell 2013) and relationships between and within these categories. In addition, a more intensive preliminary analysis was performed during summer 2014, as a midway analysis. The aim was to go systematically through the material that I had so far, and adapt the interview guides to the topics or relationships I wished to investigate further.

When the fieldwork was over, I had thus already started a process of analysing, making way for a more focused attempt to sort data into broader themes or categories, such as 'Interpreting sensations', 'Involving others' or 'Being ill vs. being healthy'. The categories referred to meaningful units in the data and were connected to my research questions and interest in the understanding of life after cancer, interpretation of sensations, involvement of social relations and health care seeking. They were also linked to dimensions that emerged as important in the participants' lives, for instance existential matters. I compared data within each category to see patterns of similarity and difference within the interviews of each participant, as well as between participants, trying to confirm categories or identify new categories within them, all the time moving back and forth between new ideas and data (Hammersley and Atkinson 2007). In the process, I used drawings and displays (Maxwell 2013) to grasp the overall picture. Most of the displays I used during the process of analysing were to remember or keep an overview of a topic, data or theoretical perspectives.

During the analytic phase, I discussed my data and theoretical perspectives with my supervisors, who provided comments and inputs on alternative perspectives and literature. I consulted literature on different theoretical approaches, finding that frameworks for e.g. the sensorial, uncertainty, pragmatism and intersubjective understanding resonated with the empirical findings, thus offering theoretical support in unfolding what at an embodied and intersubjective level is at stake when living with cancer. In practice, I moved back and forth between empirical findings, categories and theories to nuance and refine my understandings. As the analysis moved on, it developed from a mainly thematic approach towards a higher

theoretical level of interpretation, and turned into a more abductive orientation – understood as analytic strategies that attempted to ascertain why the participants experienced and handled their sensations and their social relations the way they did by ‘uncovering the largely tacit, mutual knowledge, the symbolic meaning, intentions and rules, which provide the orientation for their actions’ (Blaikie 2007: 90). Searching for perspectives that could provide insights into sensing, for instance, I looked into theories about different modalities and varieties of sensory experience (e.g. Hinton et al. 2008) and about the social dimension of interpreting sensations, such as the notion of a ‘therapy management group’ (Janzen 1987), which contributed concepts that could be used to compare the themes and contexts I had identified in the data.

The articles and their analyses are based on my research questions, and these again were based on relevant research and theoretical perspectives that seemed useful before I started the project. This of course had the potential to make my observations biased, and influence the way I interpreted what I saw, but testing the material for connections and oppositions helped paying attention. The participants’ focus and priorities were sometimes different from what I expected, which necessitated searching for other perspectives to use in my analysis; for instance, I did not expect the participants to be more occupied with keeping their worries to themselves than with discussing interpretations of symptoms with others.

On the other hand, in research material there will probably always be data enough to perform analyses and write articles about more topics than can be completed within the available time. Choices have to be made, and these will be influenced by many factors, such as the researcher’s personal scientific interests, what is seen to fulfil the aims of the project, the researcher’s sense of duty to give voice to the participants’ priorities, and what are the most debated topics in the public or scientific spheres. I could have focused on other aspects of the data, or chosen to look at it through other perspectives. For instance, I could have considered how leisure activities, especially being outdoors, were important to the participants, their wellbeing, and sense of uncertainty, or how the participants related to discourses about cancer as well as other discourses in coping with life after cancer. In the end, it was a matter of choice within many interesting possibilities.

## 4.6 Contribution, usefulness and relevance

How to judge validity or overall quality in qualitative research is an ongoing discussion, also found within medical anthropology. Three main positions emerge in the general literature on qualitative validity (Rolfe 2006). The first group argues for the use of the same criteria as in quantitative research (Morse, Barrett et al. 2002). Another group argues for using a different set of criteria, more adapted to qualitative research, while those in the third group ‘question the use of any predetermined criteria’ (Rolfe: 304). Rolfe places himself within this last position, and argues that when there is no unified qualitative research paradigm, it does not make sense to use a set of generic criteria for judging qualitative research studies. Each study is unique and must be appraised on its own merits. I agree with this view, but find that sets of criteria or an agenda with themes (Stige, Malterud et al. 2009) that are created for qualitative research can be used as guidelines for what might be relevant to discuss. The use should depend on the particular study, and other elements might need to be added. One example of a late contribution that invites reflection and which I find close to the anthropological tradition is Stige, Malterud et al. (2009) who have developed the evaluation criteria EPICURE (Engagement, Processing, Interpretation, Critique, Usefulness, Relevance, Ethics). The themes of this model that I have not yet touched upon are usefulness and relevance.

Usefulness can be valued in relation to practical contexts, as applied in everyday settings, and include new and enhanced understanding (ibid.). Usefulness is related to transferability, i.e. how the findings from this study could be transferred to other situations or phenomena, and is dependent on the research process of collecting, systematizing and analysing the empirical data. I have reflected on some strengths and limitations that also have implications for transferability in this methodology section, and I will now comment on some of the specific practical and analytical points I believe to be transferable.

In a practical context, this study is useful in showing the need for more information for patients who have finished cancer treatment, both about common late effects and how these can influence life after cancer. This also includes awareness of the way the illness experience and worries about recurrence can influence how people sense and interpret bodily sensations. In addition, people may need more information about what sensations to be aware of as possible symptoms of cancer recurrence, because this can help them make decisions about when to see the doctor, and when to ‘wait and see’ how it develops. On this background, and

bearing in mind the insight that close ones are often not included in interpreting worrying sensations and uncertainties about life after cancer, this study shows that public health care still has an important role to play in former cancer patients' lives even after completion of treatment. They may need information and guidance about how to live with a new body and life, and some have proposed a rehabilitation stay similar to that offered to many heart and lung patients in Norway. An organized course of this type may also be of help in providing an arena for getting to know others with similar experiences to share thoughts with, as such conversations were valued and sometimes felt to be missing by the participants in my study.

In terms of academic relevance and relation to existing theory, this study places itself within and has relevance to the anthropology of the senses by focusing on how former cancer patients experience health and illness through their senses. It does not have the cross-cultural concern and focus on the senses per se (Howes 2010) which have been an important part of the field, also within the medical anthropology of sensations (e.g. Hinton, Howes et al. 2008). On the other hand it continues the task argued for by Hinton, Howes et al., as well as Nichter (2008), of bringing anthropology of the senses into medical anthropology of sensations and symptoms by tracing 'somatic symptoms from their origins in culturally mediated processes of sensing, attending, and interpreting the body and the world. Inspired by the work of Hinton, Howes et al. (2008), my research contributes with an example of how the use of schemas (which is based on a theory of how the interpretation of senses occurs) can enhance understanding of how and why sensations are experienced the way they are by former cancer patients, not in a different culture, but in a different situation. This understanding, because it builds on more general theories of how the sensorial interacts with attention and interpretation (Hinton et al. 2008), can probably be useful and contribute to understanding of similar situations of living under uncertain prognoses of severe illness, especially if there is reason to be vigilant about symptoms.

In addition, my research places itself within methodological reflections on how to comprehend another person's bodily sensations and illness experiences; this contributes to medical anthropology as well as anthropology of the senses in general, by showing how attention to the sensorial gives access to other stories, in line with the argument of Harris & Guillemin (2012), and provides a more multidimensional understanding of a situation. Compared to the ethnographic methodology of participation usually argued for in anthropology of the senses in general (e.g. Pink 2009; Stoller 1989, Ingold 2000), my



research could not be based on taking part in activities and situations where sensorial experiences could be similar, shared and maybe explained underway. It could also not be based on shared illness experiences, as the anthropologist had no experience with her own cancer illness (e.g. Stoller 2004; Jain 2013). Because of this, interviews became of prime importance.

Pink (2009) argues for the use of interviews in understanding sensory experiences of research participants, but her aim is to learn how they attend to their senses in terms of how they categorize and give meaning to the senses. In other words, she uses interviews to learn about the local way of thinking about the sensations per se, instead of trying to understand the participants' actual sensing and experiencing in specific situations. In this way, Pink uses interviews to gain access to the participants' concepts of the senses, but in order to imagine how the participants experience the world through their senses, she uses the ethnographic method of participant observation (and sensing) in specific activities or situations, and hereby uses her own sensorial experiences to imagine the other's sensorial experiences.

Following this, my research provides an example of the use of interviews as a main tool to gain access to people's sensory illness experiences. It also gives insights into how interviews can contribute to research on the sensorial. This is in line with Harris and Guillemin's (2012) arguments for a more extensive use of interviews, as 'sensory awareness can also extend beyond ethnography'. They refer to Mason and Davis (2009:), who point to verbal recounts as sometimes preferable to the researcher's own attempts to sense things 'first hand'. Harris and Guillemin make an important point on how the sensorial could help interviewees to recall and describe broader experiences and perceptions that otherwise would have been unexplored, by 'tapping into' sensory memories by asking questions about specific sensory experiences such as how the hospital bed felt. My work gives an example of this, but goes a little further, as it also focuses on the work of the researcher to obtain understanding from the participants' descriptions of their sensorial and illness experiences. In this way, it sheds light on the intersubjective aspects of anthropology of the senses. These aspects are also touched upon by Pink (2009), when she describes interviews as social encounters and events that are routes to understanding 'other people's emplacement through collaborative and reflexive exploration'. But as her focus during interviews is on understanding people's concepts and not their specific sensorial experiences, we may thus say that Pink is more occupied with 'reflecting along with' than 'feeling along with' during the interview.

As my research had to be based methodologically on activating my own sensory imagination, when trying to understand how the participants experienced their illness and life after cancer, it is also placed within and contributes to research on empathy. Hollan and Throop define empathy as a 'first-person-like perspective on another that involves an emotional, embodied, or experiential aspect' (2008: 391-392). They refer to Halpern's (2001) perspectives on empathy, where she argues for the emotional aspect as essential for empathic understanding.

Halpern, who is a physician, deals with the importance of empathy in medical practice and argues for empathy as a form of emotional reasoning, as opposed to detached, scientific reasoning; it involves being open to the painful emotional states that patients communicate. The goal is 'to discern the particular meanings that a symptom or a diagnosis has for an individual' (:40). Halpern is thus interested in finding out how it feels to be in a situation, but does not emphasize the sensorial and its bodily aspect. This does not necessarily mean that it is not seen as part of empathic imagining, but that it is taken for granted and not verbalized within her perspectives. On the other hand, it can mean that it is a blind spot, as it may need to be detached or tuned out from the patient's bodily pain and suffering in order to practice the medical work which sometimes even itself might inflict pain.

My work exemplifies how the sensorial can be a portal to the emotional, which made it possible to grasp more of the painful existential dimension of cancer. Hollan (2008: 480) emphasizes the embodied aspect, as he notes that 'it is the felt, embodied aspect of empathy that gives us a more first-person-like perspective on another's circumstance, that helps us understand how and why a person feels or experiences what they do, not just that they do'. He does not discuss the sensorial any further. Throop (2012: 408), on the other hand, argues that 'empathy should be considered a multimodal process that not only involves perception, intellection, affect, and imagination but also the bodily and sensory aspects of lived experience'. He discusses the bodily and sensory aspects of empathy by using an example from the island of Yap in Oceania of a therapist's 'reading' of the body during therapeutic treatment. This situation includes tactile aspects of interaction, and is a situation where pain is not, or cannot be, verbalized. Compared to this therapeutic example, my research provides a more general perspective on how the sensorial imagining that comes about through verbal communication can broaden our understanding of the embodied experience of an illness situation. It also contributes perspectives on how the researcher's process of empathic

understanding can be enhanced by sensorial imagining, aroused by the interviewee's accounts of her or his sensory experiences.

Adding to research on empathy I argue that my studies accentuate the importance of activating the sensorial to help understand emotions and gain a deeper empathic understanding of an illness situation, since this will normally be essentially embodied and sensorial. I argue that the understanding of illness probably will be limited if the sensorial aspect is not introduced when trying to understand 'how it feels like' (Halpern 2001: 85) to be in the situation. On the other hand, as pointed out by Hollan, we can never know if we understand the other or if the other understands us (Hollan 2008). In research that is dependent on the participants' capacity to articulate sensorial and emotional experiences, as well as the researcher's capacity to use empathic imagination to gain insight into such experiences, there is of course a possibility of misunderstanding. Throop and Hollan (2008), along with Halpern, argue for the importance of ongoing dialogue to secure the best possible understanding.

My article about gaining insight through interviews (Seppola-Edvardsen & Risør unpublished) is an example of what we may term an ongoing research dialogue. The analysis in this article was based on my idea of having gained sudden insight during a semi-structured interview with one participant. One might question the transferability of a personal experience, based on one specific situation of interaction between only two individuals. However, during the analysis, I realized that my original idea of the delimitation of both the insight gained and the interview situation as one specific event was wrong. When I went through the recordings of the interview, my research notes and diary again, I realized that the insight I gained was built on a process of many realizations that expanded my understanding. My understanding also built on previous interviews, in a process of connecting information and insight. In this way, the process of testing my theory and understanding against my recordings and diary to determine their consistency with other findings in my research, as well as with analytical points in the work of other researchers, can be seen as an ongoing research dialogue and thus strengthens the reliability, transferability and relevance of the analysis and the findings.

## 4.7 Ethics

The study was based on informed consent from all participants, who could withdraw at any time. None did and many stated that their participation had been of value to them.

Throughout the process, I strived for transparency and respect by being open about my aims of the research in general and for the different topics and activities I suggested. The participants received an information letter about the project with the invitation to participate and the letter of consent. In the first interview, they were also given the project description (in English). During interviews, and especially when I introduced a new interview guide/topic or suggested tools such as a health diary or drawing of a map, I explained what the aim was and what research questions or topics I wished to illuminate with these tools. At the end of an interview, I usually asked if there were additional things they wished to talk about. After the year of fieldwork was completed, I occasionally informed the participants about the topics and progression in the analysis and writing of articles, and they were all asked to read and accept, or suggest changes in, the quotes and descriptions I gave of them and their specific situation. I had promised to do this, as some of the participants expressed concerns about anonymization during our talks. When the first article was published, I sent each one a copy, with a summary and translation of some parts into Norwegian. I also invited them to have a talk and discussion about the articles and project after the time I expected the dissertation to be handed in. I plan to contact each of them to make an appointment if they would like to, and I will continue sending the published articles with partial translations and a Norwegian summary.

During the research, I tried to find a balance in how much to ask around worries about unpleasant sensations. I attempted to make it a topic that was accepted and relevant in the interviews, but not a main topic. I tried to be considerate in not triggering their fears too much, as it also became clear that most of them sometimes struggled with fear of recurrence and worries about the future. My solution was to ask the main questions I had planned, and use the answers to make decisions about the further progression. When my interlocutor wished to talk in length about this, I did not limit it in any way, but strived to respond in an empathic and interested way, without signaling any form of opinion about risk. But in cases where participants somehow rejected the topic, for instance by stating that they did not worry about such things, I did not ask for more detail, but proceeded to the next topic. This

happened on occasions in the first interviews. The longitudinal dimension provided more complex data, as the participants could nuance the picture in later interviews, when talking about situations or sensations that did cause worries, or worries could shine through other statements, such as a lack of belief in many more years to live. With one of the participants, I once became afraid that my focus had caused her to worry, as she seemed to become more tense after a while. When I asked about this, she explained that it was about her upcoming first follow-up check at the hospital. Most participants mentioned increased worries in connection with the regular checks, and other cancer research shows similar findings (Lillehorn 2013: 50), so hopefully my focus was not the cause of her worries.

In my first meeting with the participants, I underlined that my education was not in the field of health, and I did not feel that any of the participants assigned me the role of a health specialist. One reason for this may have been that all participants were well educated, five of the eight in the field of health. As a researcher in social sciences, however, I sometimes sensed some expectations of being knowledgeable about social relations or about how others experienced similar situations. I tried to make it clear through the year that my interest lay in how they experienced their situation, and that I did not have opinions on how such a situation should be dealt with. However, we do of course always express opinions in some way; for instance, the questions we ask will reveal what we see as relevant and important, as already discussed in the interview section.

I anonymized all the data and archived it according to established procedures. The overarching project was presented to the relevant Ethical Committee (REK) and found not to be within their jurisdiction as a health scientific project. It was also reported to the Norwegian Data Protection Authority.



## **5 Results**

**Paper 1**

**Paper 2**

**Paper 3**

## Concluding discussion

In this final chapter, I will draw together the main perspectives and findings that have been raised in the thesis and articles. I will first give a short presentation of how the articles answer the research questions. As the main objective of the project has been to understand the illness experiences and care-seeking processes of former cancer patients, within everyday social relations, the aims of the articles are related to this: 1) To investigate the process of interpretation of bodily symptoms and sensations after cancer diagnosis, 2) To explore how the participants handle a state of uncertainty within their everyday management of social relationships through balancing the sharing of existential worries, and 3) To show how the sensorial and emotional help to provide insight through empathic understanding.

The findings in all three articles shed light on aspects of the main objective and I will briefly summarize the articles according to this. Then I will discuss four topics that overarch the articles and give interesting perspectives to the research aim. These are: 1) From sensations to symptoms, 2) Health care seeking and the therapy management group, 3) Uncertainty, and 4) Empathy and the sensorial.

The first article explored the process of reestablishing the competence of interpreting bodily sensations after the end of cancer treatment. By using the concepts of sensation schemas and sensation scripts, we explored how sensation schemas of cancer dominated in the first period, while schemas of late effects and reduced tolerance of everyday activities gradually became more important as time went by. When the participants became aware of how their fear of cancer dominated the way they interpreted bodily sensations and how their interpretations amplified their fear of cancer, it opened up for other ways of handling the situation. As their knowledge of late effects after cancer and treatment grew, this led to a different understanding of their bodily sensations. Ignoring sensations, not seeking medical aid immediately, but waiting and seeing became a new sensation script and a step along the way to alternative interpretations. The sensation schemas containing cancer as the explanation were gradually replaced by schemas with late effects as the probable explanation.

In article two we explored how the participants managed their existential uncertainty as part of their everyday management of social relationships. We found that the participants were



keeping most of their uncertainties to themselves, as they did not wish to let their worries disturb social situations and everyday life. Everyday life was a context for social relations and a basis for living a good life. The participants' main argument concerning their closest relationships was that they did not want to make others worry unnecessarily. With friends, they did not wish the topic of cancer to dominate their interaction, and at work, they tried to protect their professional role. In this way the participants were caring both for themselves and for others. However, some sharing was expected and needed, for their own well-being and as part of reciprocity in social relationships. As a consequence, the participants often had to balance what to share and what not to share.

The third article explored the process of gaining insight into an illness situation through interviews that focus on the sensorial. What first appeared to be one sudden insight obtained through one interview was revealed as one of a number of insights gained through a process that built on earlier parts of the ethnographic fieldwork, as well as reflections that were formed during the writing of memos after that particular interview. The process of empathic understanding of the participant's situation came about through sensorial imagination, which provided insight into the deeply troubling physical aspects of cancer. This evoked my emotions, and emotions became a portal into understanding the existential uncertainty that this participant, among others, had expressed. The article explores the process and points at how the insights gained in this process became important to the analyzes of the other two articles, as they contributed to understanding the existential backdrop of the dilemmas and decisions made by the participants.

## **5.1 The four overarching topics:**

### **5.1.1 From sensations to symptoms**

In this project we see that after cancer the participants' perception and interpretation of unpleasant bodily sensations was influenced by their cancer experience. Their embodied memories of sensations before cancer treatment that might have been symptoms of cancer, and their embodied memories of being ill from cancer and side effects from treatment, influenced what kind of sensations they noticed when monitoring their bodily sensations after cancer. These sensations are easily interpreted as possible signs of cancer recurrence, which might cause a spiral of increased anxiety, and increased sensitization to possible symptoms. In the first article we looked into this process, and found that this way of sensing and

interpreting became less dominating as time passed, but that some participants made a considerable effort to change their way of thinking. This was done by trying to ignore sensations and postponing visits to the doctor, to see if it would go away by itself. Also in the second article, which examined how uncertainty was shared with others, the attempt to ignore sensations was seen in the attempt not to 'make it a topic'. The argument in this case was that it was part of the strategy of not focusing on sensations, as it could keep alive or even increase the worries, both of the former cancer patient and the family. Finally, explanations were sought within late effects of cancer, such as fatigue and low tolerance of stress. This provided other ways of handling the sensations, such as being careful not to take on too much work but instead balance activity and rest.

The dimension of the participants finding balance in their new life was also by some connected to the fear of stress and tiredness as a cause of cancer or a factor that increases the chance of getting it by weakening the immune system. This idea about exhaustion and imbalance as causation is also sometimes expressed in popular media and it fits in with what Mildred Blaxter names the 'ancient idea of homeostasis – the idea that the normal state of the body is order' (Blaxter 2010: 7), and also today the biomedical model of health is compatible with an idea of equilibrium, or balance, she argues. I would also argue that ideas of balance are to be seen in other areas of society, such as in the focus on ecological and sustainable living and in activities like yoga and 'mindfulness' that are popular today. This can thus be seen as an example of how ideas of biology, health and illness are cultural (e.g. Hinton and Hinton 2002, Nichter 2008).

The first article showed how the ideas of sensation schemas and scripts can contribute to understanding the way former cancer patients continue to interpret sensations in a cancer context long after treatment is finished. This also provides a meaningful way to understand how new scripts can help to replace schemas that dominate but may be unhelpful. Hinton et al. (2008) argue for a heuristic use of the concepts as a contribution to the medical anthropology of sensations in psychiatry, and which can be used to understand and treat panic disorder. Our analyses have shown the usefulness of the idea of sensations schemas and scripts to understand the process of learning to live with a changed body after cancer treatment.

On the other hand, these perspectives, being meant for heuristic use, do not provide tools to analyze how and why the process of change happens, with its ambivalence and going back and forth between old and new schemas and old and new scripts in a process that can be understood as learning a new ‘everyday health competence’ (Horlick - Jones 2011), as the former has been lost after cancer. This nonlinear process is featured by a going back and forth between cancer and late effects as explanation, testing out ways of handling sensations: seeing the doctor, or postponing it and seeing if the problem passes, avoiding stress and becoming too tired from too many plans or activities, but on the other hand still taking some exercise, being outdoors, etc. Looking into this process with the help of perspectives on uncertainty, as we discussed in the second article, can give further insight and we will return to this later. Another angle is to look at the process through the cultural values expressed by the participants. The value of protecting everyday social relations is one of these, also discussed in the second article.

Another interesting angle is to explore the ambiguity in the cultural values that influence how people sense their bodies and try to handle, or prevent, unpleasant bodily sensations. One side of this is how interpretation and care seeking take place in a ‘moral sensescape’ (Offersen 2016), where the expectations of the ‘good citizen’ (Petersen and Lupton 1996) in general within the Nordic welfare model are on the one hand to be aware of possible symptoms of cancer and seek help as soon as possible, and on the other hand to avoid wasting the time of an already overburdened public health care system. After cancer, people have their own urge to be vigilant and seek help, but some participants still expressed the moral stance of not seeking help unnecessarily. Some commented that they did not wish to ‘cry wolf’ all the time. They did not want to appear hypochondriac and have everything checked, and those who knew health care from within, as employees, commented that they knew that the workload in the health care system was high already. This indicates how strong the moral intention of not burdening the welfare system still is in Norway, which may be related to being over 40 years old and having been raised within a still developing welfare state.

Compared to the process of turning sensations into symptoms as described by Alonzo, Andersen et al. and Brandner et al. (Alonzo 1979, Andersen, Paarup et al. 2010, Brandner, Müller-Nordhorn et al. 2014), the situation after cancer, as described by the participants in this study, is often dominated by an opposite process. It is not one of gradually turning

sensations into symptoms (Brandner et al. 2014) and where the definition of illness is based on ‘socially defined situations against the total background of daily life and relations with others’, (Alonzo 1979: 397) and medical help in the end is sought when ‘a perceived implication of a symptom’ on social situations got too much for them (Zola 1973: 685). After cancer we have seen that the process can be ambivalent, and often the end point is turning the symptoms into normal sensations, after a process of ignoring, waiting and seeing, maybe also after having seen the family doctor. Because of cancer treatment and subsequent late effects, people experience many unpleasant bodily sensations that deviate from earlier everyday life experiences. Fear of new cancer in addition makes people monitor their bodies more than they used to before cancer, and their interpretation of sensations often seems to skip an assumed phase of interpreting sensations as normal, and part of life, or deriving from every life activities. Instead they are immediately interpreted as possible symptoms of cancer; medical advice is often sought, sometimes including waiting time to see a specialist, and normally no sign of cancer is found. Sensations that are still there must then be reinterpreted, and the normality of the sensory experiences must be ‘reestablished’ (Brandner, Müller-Nordhorn et al. 2014). When sensations are frequently interpreted as signs of cancer, causing anxiety, this interferes with people’s social situations and everyday life, and new ways of interpreting and handling have to be sought that can be contained within everyday life. This seems to be learning again how to ‘reestablish normality in sensory experiences’ (Brandner, Müller-Nordhorn et al. 2014: 126), which again implies accepting that normal everyday life has changed into a ‘new normal’ after cancer, also in terms of the sensorial, and a new ‘everyday health competence’ (Horlick - Jones 2011) has to be established.

### **5.1.2 Health care seeking and the therapy management group**

Before starting fieldwork, I decided to apply a broad perspective to the social field of illness-related work in the participants’ everyday life. I was inspired by Janzen (1987), and especially Nichter (2002), who argues that ‘therapy management’ is multidimensional and contains much more than health care seeking. ‘The afflicted, and members of a therapy management group who coalesce around them, engage in a variety of illness-related “works” that emerge through time’ (Nichter 2002: 82). Some of this will be the work the former cancer patient does himself or herself, termed ‘self-management’ by Henshall et al. (Henshall, Greenfield et al. 2016). I saw this in different activities, some also described by Henshall, for instance

doing yoga and mindfulness, walking and being outdoors, minding one's diet as well as being careful not to exaggerate activities and then becoming too tired.

Taking a broad perspective carrying out everyday life activities can be seen as part of 'illness related work' after cancer. Among the participants, also many years after cancer, everyday life activities still involved extra attention because of their health situation. Sometimes this implied that the family had to take an extra burden of the everyday workload or adapt their activities to the former cancer patient's capacity, which can be seen as part of the 'illness related work'. A lack of attention could lead to increased health problems, such as pain, tiredness/fatigue and subsequent anxiety or even depression.

We may also view 'therapy management' in a more narrow sense, as interpretation of sensations and symptoms, and making decisions about health care seeking. Inspired by her studies in Lombok, Indonesia Hay (2008), argues that the 'transformation from sensation to symptom is necessarily a social one in which symptoms must be socially legitimated in order for the transformation to be complete' (ibid.: 201). After cancer in the urban Norwegian context, our findings show that the 'therapy management group' consisting of family and friends seems to be of less importance when it comes to discussing and legitimizing sensations as possible symptoms. Access to a highly developed public health care system may explain some of this, as professional help is normally available and affordable without the need to involve family and others, and some of the therapy management is this way taken care of by the public health care services.

But this does not explain why the participants mostly kept worries about unpleasant bodily sensations to themselves, as discussed in the second article. Nor does it explain the ignoring strategy already mentioned and discussed in the first article, which can be seen as part of 're-scripting' (Hinton, Howes et al. 2008) the participants managing of sensing, interpreting and health care seeking after cancer. Making worries a topic of discussion with others, was by some seen to make them worse, while others found that it sometimes could be relieving to share worries with others, who could help finding other explanations than cancer. In general, however, the interpretation of bodily sensations before deciding to seek medical advice by professionals was mostly done on their own. Not making others worry, or letting cancer dominate social relations, was important and an underlying aim and value within this was the protection of everyday life and everyday social situations. This way, my study contributes

with extended knowledge of how former cancer patients family and social network is important in urban Norway, not so much in interpreting sensations or seeking therapy, but in maintaining a normal everyday life after cancer.

On the other hand, this way of keeping worries about bodily sensations, and existential uncertainty to oneself, can also have the implication that it hinders intersubjective understanding, as sensory and emotional imagination is the basis for empathy, as shown in the third article. Some of the participants explicitly mentioned that the illness situation could feel lonely at times, and that cancer was a 'lonely illness'. This might be the other side of keeping cancer out of social life.

Compared to the social context of the Asian and African societies described in the works of Janzen (1978), Nichter (2002) and Whyte (1997, 2005), it might be that Norwegian contemporary society is more individual-oriented (Giddens 1991), which could make Norwegians inclined to see their health and illness as their personal responsibility, and not something to involve family or others in unnecessarily. This is also in line with what Peterson and Lupton (1996) term the 'new public health'. Citizenship has long had a biological dimension, they argue, but a new kind of biological citizenship is taking shape. What once was seen as fate, 'becomes subjects of deliberation and decision, a new space of hope and fear is being established around genetic and somatic individuality' (ibid:36). They further argue that in the Western world biological choice has become more important within a 'regime of the self' with a 'prudent yet enterprising individual, actively shaping his or her life course through acts of choice.' (ibid.:36). Within this moral universe, being ill or recovering from cancer may be influenced by discursive ideas about how to cope with these conditions. Willig (2011) argues that meaning is 'made out of discursive resources which are available within one's culture' (Willig 2011: 897). Sharing illness experiences or worries about cancer in this way can entail a loss of control over how to be defined and treated by others in a social context, as for instance 'with unwanted attention, with sympathy or pity when they just wanted to 'blend in', or with unwanted advice or unsolicited opinions about the causes of cancer' (ibid.: 901). In my study, some of the participants told about incidents where they got unwanted and sometimes upsetting opinions from other people they did not know well, for instance on how they should cope with their illness situation. On this background we may wonder if the generous Norwegian welfare system has another side, which contains an expectation about undertaking a 'regime of the self' (Peterson and Lupton 1996) and makes

fellow citizens feel entitled to express opinions about other people's handling of health and illness. Not letting cancer become a topic may this way be an attempt to make it easier to 'blend in' and keep others' worries and opinions out of everyday social situations.

### **5.1.3 Uncertainty**

I will now devote more attention to the aspect of uncertainty. It stood out in the stories of the participants as a topic that was mostly avoided in their everyday interactions and conversations with others, but was probably in the back of the mind of many of them.

Uncertainty forms a backdrop to the stories about how to learn to ignore sensations, or interpret them in another context, as described in the first article. Some of the stories about what to share or not are about shielding family from worrying. In my discussion of this topic in the article about sharing or not sharing uncertainty with others, I underlined that this uncertainty seems to be existential (Jackson 2005). It has its root in the experience of cancer, and in the fear of recurrence, but is about more than living or dying, as it also encompasses the ability to carry on everyday life and social relations, being there for others, etc.

To understand uncertainty we need to look at how the sick and the members of their social network 'encounter, experience, and deal with uncertainty' (Jenkins, Jessen et al. 2005: 12). This is what Whyte does in emphasizing the pragmatic approach to uncertainty which requires that we 'see people as actors trying to alleviate suffering' (Whyte 1997: 20), treating uncertainty as 'something to be managed' (Whyte 2005: 246). Inspired by this, we noticed from the participants' stories that everyday social situations were what mattered most to them (Jackson and Piette 2015), and how they balanced what to share or not with relevant others constituted practical handling of this uncertainty in everyday life. As they could not manage the risk of recurrence in itself, they managed the way uncertainty caused by the risk affected their everyday life. By limiting the sharing of worries, they protected everyday social situations from being influenced by their uncertainty.

I would like to make one further point about uncertainty that I found was very well expressed by one of the participants, and well captured by Giddens (1990), although in another context; this concerns the fundamental dimension of uncertainty, which might be difficult to grasp for anybody lacking a similar experience. The uncertainty is not only about health and illness, but is also more fundamental. As one of the participants explained, she lost the feeling of being safe 'in herself' when she got the cancer diagnosis, and she felt 'uprooted and thrown into

space'. This was a feeling she still struggled with after cancer, and she felt she had to learn again how to master life. Other participants expressed feelings of having lost some of their self-confidence, which affected their relations to others, mostly outside the group of close ones. Inspired by Giddens (1990), we might compare this to what he terms 'ontological uncertainty', which in his perspective is in fundamental opposition to trust. It is not only about distrust of a person or a system, but about losing the feeling of being safe 'in yourself' and in the world you are inhabiting, a world which to some of the former cancer patients appears to have become completely changed and unknown.

To understand the depth, influence and implication of this uncertainty on the lives of some of those who live after cancer is important to understanding what the cancer experience might be. This kind of understanding requires empathy, which will be the final topic discussed here.

#### **5.1.4 Empathy and the sensorial**

My research has shown the importance of the sensorial as a portal into intersubjective and empathic understanding of people's illness situation in several ways. It has been shown to be a portal into what might otherwise have been unexplored (Harris and Guillemin 2012), as a portal into memories through questions about sensory experiences. In this way, it has also been a portal into people's stories about the experience of being ill, and finally, into the researcher's understanding of sensorial ways of being in the world after cancer illness.

Pink (2009: 8) argues for sensory anthropology as one way of knowing, and one route among others to knowledge. Against the background of my experiences in this research project, I would argue that when one aims at understanding an illness situation, the sensorial is an essential approach. I also wish to make a point about the interdependence between the sensorial and emotional as a route to empathy and understanding.

Halpern (2001) has pointed at the importance of emotions when she describes empathy as a 'form of emotional reasoning' where a listener is 'using her emotional associations to provide a context for imagining the distinct experience of another person' (Halpern 2001: xxiii). In this lie both a cognitive aspect of imagining and an emotional aspect. Hollan goes somewhat further and includes the 'felt, embodied aspect of empathy' (Hollan 2008: 480), referring to the perspectives of Rosaldo (1984) and Wikan (1992). Throop (2012) also brings forth the



sensorial aspect of experiences, but discusses this in connection to a therapeutic situation, where the sensorial builds more on bodily interaction than on verbal communication.

My research project brings in methodological reflections on the researchers possibility of gaining understanding through the research participants' reflections and verbal descriptions of their illness experience. I have argued that in order to be able to understand the experience of being ill, only imagining through cognitive and emotional capacities can be insufficient. The understanding of the illness situation may in that case not pass beyond a theoretical level, constructed through empathic imagination of the situational. For instance imagining how it feels to be in a cancer situation, not knowing if one would survive, being hospitalized, missing one's family and being afraid of not being there for them in the future, the feeling of fear, loneliness, etc. I argue that this understanding may be superficial in its lack of understanding the basic physicality of being ill from cancer and treatment. Bringing in sensory imagination thus becomes a method to sense the fundamental bodily dimension of the illness situation.

Awareness of the sensorial dimension to intersubjective, empathic understanding may also be useful in everyday life, both for those who wish to understand another person's illness situation, or who wish to allow for others to understand their own illness situation (Hollan 2008), but as already mentioned, not all social relations encourage or allow for this kind of talk. The satisfaction expressed by the participants in my research project, of finally being able to tell their story and reflect on their situation, may indicate an unmet need for this kind of arena in their everyday life. Some expressed a wish to be able to meet others in the same situation, to be able to discuss their lives, everyday challenges, and maybe learn from other's experiences of what are normal bodily sensations and normal problems after cancer. On the other hand, some participants also expressed an ambivalence towards taking part in activities organized by the Cancer society, as they felt they had left behind this illness related part of life. This ambivalence is illustrative of the situation many experience after cancer, and brings us back to where we started the introduction of this thesis, i.e. to emphasize the liminality described by Stoller (2004) in living in the borderland between the 'village of the sick' and the 'village of the healthy'.

### **5.1.5 Future perspectives**

Based on statements from research participants about unmet needs, and my analyzes showing the participants' experience of having to learn to interpret and live with a changed body after cancer treatment, there seems to be a need of providing good rehabilitation programs. Such programs should provide former cancer patients with information about the treatment they have gone through, and the late effects that may be a result of it, as well as providing information about what sensations or symptoms to be aware of as possible symptoms of recurrence. In addition, the program should offer optional guided physical activity and training on different levels, to help attendants' regain a sense of security and mastering in physical activity. Another important component or possibility offered by a rehabilitation program should be to provide an opportunity for former cancer patients to get to know others in the same situation, and hereby offer an arena for sharing and discussing experiences and thoughts that everyday social situations do not provide.

Future research on life after cancer, and medical anthropology of sensations, might gain new understanding from studying whether programs like this influence former cancer patients' experiences of sensing and interpreting their body after attending the program.

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# Appendices





## Appendices:

- 1) E-post til fastleger
- 2) Kriterier for rekruttering
- 3) Informasjonsskriv til deltakere
- 4) 1. Intervjuguide, første intervju
- 5) 2. Andre intervjuguide vår
- 6) 3. Intervjuguide første etter sommer
- 7) 4. Intervjuguide høst
- 8) 5. Avslutningsintervju
- 9) Spørsmål til helsedagbok

### 1) E-post til fastleger:

Hei

I forbindelse med at vi skal sette i gang et forskningsprosjekt sender vi denne mailen til .... legekantor og lurer på om vi kan få komme på et legemøte hos dere og presentere et forskningsprosjekt: *SENCANCER: Sensing illness in everyday life: Care-seeking and perception of symptoms among chronic cancer patients.*

Dersom en eller flere av dere kan være interessert i å bidra i vårt forskningsprosjekt med rekruttering av deltagere, ville det hjelpe prosjektet enormt.

Vi trenger hjelp til å finne fram til pasienter over 18 år som oppfyller visse kriterier og kan være aktuelle for undersøkelsen. Vi trenger også hjelp til å sende ut et informasjonsbrev og skjema for samtykke til de aktuelle pasientene. Alt vil bli utarbeidet av oss, men må fysisk adresseres og sendes ut fra legekantoret. Vi ønsker å rekruttere rundt 10 pasienter/deltakere til studien, og vil også spørre andre legekantorer om hjelp til rekruttering.

Vedlagt finnes kriteriene for utvelgelse av deltakere.

Forskningsprosjektet er i regi av Universitetet i Tromsø, Institutt for samfunnsmedisin, Allmennmedisinsk forskningsgruppe. Prosjektet er et kvalitativt orientert studie, som skal ha fokus på Tromsø by.

Det vi skal forske på er kort fortalt hvordan mennesker som har vært igjennom kreftbehandling opplever, tolker og forholder seg til kroppslige fornemmelser i en fase der de i utgangspunktet er ferdig med aktiv/intensiv behandling og har begynt å reorientere seg mot et vanlig hverdagsliv. Vi er interessert i de tolknings-prosesser som medfører at kroppslige fornemmelser enten forblir noe man ikke skal bry seg om, eller går over til å oppfattes som mulige symptomer og noe man søker hjelp for. Hvem er involvert, og hvordan forløper disse prosessene?

Vi håper det er i orden at vi - hvis vi ikke har hørt noe fra dere innen en uke - kontakter dere igjen for å høre om vi kan komme og forklare mer om prosjektet, kriterier, og praktisk rekruttering.

Kontakt oss gjerne på telefon 91869779 (Tone)

Med vennlig hilsen

Tone Seppola-Edvardsen  
Stipendiat i medisinsk antropologi  
Adr. osv

Mette Bech Risør  
Prosjektleder  
Seniorforsker, medisinsk antropolog, (+Adresse, tlf osv.)

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## 2) Kriterier for rekruttering av deltakere til SenCancer:

- 1) Vi ønsker deltakere som har avsluttet aktiv kreftbehandling/oppfølgingsbehandling/intensiv behandling og som befinner seg tidsmessig innen for et tidsrom på 4 år etter dette. *(Vi gikk bort fra dette kriteriet etter innspill fra fastleger om at mange sliter med plager langt utover 4 år).*
  - 2) Aktuelle deltakere som tidsmessig går ut over dette tidsrom, kan også bli inkludert, hvis f.eks. kreften er på standby og deltakeren ikke er i aktiv behandling.
  - 3) Deltakerne må ha startet et hverdagsliv igjen, dvs. et liv uten aktiv kreftbehandling. Med dette mener vi at deltakeren har begynt å reorientere seg, uttrykker overskudd og følelse av bedring, tar kontakt med venner osv. Kontroller av sykdommen kan inngå i hverdagslivet; sykemelding (hel eller delvis) kan inngå, og påbegynnelse av jobb eller studie eller f.eks. pensjon. Det er altså ikke nødvendig at man har begynt i jobb. Hverdagslivet trenger heller ikke være definert av det livet som deltakeren hadde før kreftdiagnosen.
  - 4) Krefttyper som ikke inkluderes er: basallcellecarcinom, forstadier til kreft (f.eks. celleforandringer i livmoderhals og konisering).
  - 5) Deltakerne må være over 18 år og helst fordelt på både over og under 50 år
  - 6) Begge kjønn
  - 7) Variert sosioøkonomisk bakgrunn
- 

## 3) Informasjonsskriv til deltakere:

Forespørsel om deltakelse i forskningsprosjektet

### **SENCANCER:**

*Fornemmelser av helse og sykdom i hverdagen: Hjelpsøking og oppfattelse av symptomer blant pasienter som har vært behandlet for kreft*

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- **Bakgrunn og hensikt**

Dette er et spørsmål til deg om å delta i en forskningsstudie som skal undersøke hvordan det er å leve i hverdagen de første årene etter at aktiv kreftbehandling er avsluttet.

Vi ønsker særlig å se på a) hvordan du i hverdagen oppfatter fornemmelser i kroppen, om du opplever ulike symptomer, hva du tenker om symptomer og helse, og b) hvem som involveres i dette, f.eks. familie, venner, helsepersonell og andre behandlere, og hvilken helse-hjelp du søker over tid.

Grunnen til at nettopp du blir spurt om å være med på studien er at du er over 18 år og passer til kriteriene som du finner under kapittel A på side 3. Din fastlege har hjulpet oss med å finne frem til noen personer som kan være aktuelle å sende forespørsel til. Vi får ikke ditt navn før du eventuelt returnerer undertegnet samtykkeskjema til oss. Fastlegen din blir ikke informert av oss om du ønsker å delta eller ikke.

Universitetet i Tromsø er ansvarlig for studien. Studien utføres av ved Institutt for samfunnsmedisin, Allmennmedisinsk forskningsenhet og Nasjonalt forskningssenter innen komplementær og alternativ medisin.

#### • **Hva innebærer studien?**

Hvis du vil være med på studien innebærer det at en forsker vil komme hjem til deg og intervju deg ca. en gang i måneden i et år. Intervjuet kan også gjøres et annet sted enn hjemme dersom du ønsker det.

I det første intervjuet vil forskeren gjerne høre historien om kreftsykdommen din, behandlingen og annet du ønsker å fortelle om i tilknytning til den. I de neste intervjuene vil forskeren spørre om din nåværende situasjon, hvilke fornemmelser av sykdom og/eller helse du har hatt siden sist intervju, hvem du eventuelt har snakket med om dette og om du har søkt noen behandling siden sist. Dersom du i tillegg ønsker å fortelle om andre ting ved helsen din som du er opptatt av, vil forskeren gjerne høre om det.

Dersom det er i orden for deg, kan det hende at forskeren spør om å få intervju andre personer som er viktige for deg i tilknytning til helsen din. Hun kan også spørre om lov til å delta i noen aktiviteter du tenker er viktige for helsen din, eller for hvordan det oppleves å være i den fasen du nå er i. Dette er

frivillig fra din side, og vi er veldig takknemlig for at du deltar, selv om du kun ønsker å delta på de månedlige intervjuene.

Dersom du ønsker å være med på studien, sender du inn samtykke i vedlagte svarconvolutt med ditt telefonnummer. Forskeren tar da kontakt med deg på telefon for å avtale det første møtet.

#### **Mulige fordeler og ulemper**

Studien har ikke andre fordeler for deg enn at du får mulighet til å snakke med en som er interessert i akkurat din situasjon om hvordan du har det. Ved at du gjør det, vil vi lære av dine erfaringer. Det kan bidra til å forbedre tjenester og oppfølging som personer som har avsluttet aktiv kreftbehandling har behov for.

Ulempen for deg er at du blir opptatt den tiden intervjuene tar. For noen kan det være vanskelig å snakke om sårbare temaer. Du bestemmer selv hva du vil fortelle. Hvis du skulle oppleve at du har behov for å snakke mer med noen andre om sårbare tema, kan vi hjelpe deg med å få kontakt.

#### **Hva skjer med informasjonen om deg?**

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjenning opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Det er kun forskerne i prosjektet som har adgang til navnelisten og som kan finne tilbake til deg. Lydbåndopptak

transkriberes i etterkant. Institutt for samfunnsmedisin vil oppbevare opptak til prosjektslutt, deretter vil de slettes. Anonymiserte transkripsjoner og notater fra intervjuer vil oppbevares til eventuelle senere oppfølgingsstudier.

Så langt som mulig skal ikke noen kjenne deg igjen i det som skrives om studien. Navn, alder og annen sensitiv informasjon vil bli fjernet eller endret i publikasjoner. Det er allikevel alltid en mulighet for at detaljer i publisert materiale vil kunne gjenkjennes lokalt. Du vil ha mulighet for å lese gjennom artikler før publisering, og du vil kunne motta kopi av ferdige publikasjoner basert på materialet.

### **Frivillig deltakelse**

Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dette vil ikke få konsekvenser for din videre behandling i helsevesenet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke uten at det påvirker din øvrige behandling eller livssituasjon. Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte Tone Seppola-Edwardsen på telefon 91869779 eller Mette Bech Risør på telefon 766 23340/93026145.

**Ytterligere informasjon om studien finnes i kapittel A – utdypende forklaring av hva studien innebærer.**

**Samtykkeerklæring følger etter kapittel B. Kapittel A- utdypende forklaring av hva studien innebærer**

### **Bakgrunnsinformasjon om studien:**

Man vet lite om hvordan mennesker som er i fasen etter aktiv kreftbehandling opplever kroppen og helsen sin, og hvem i nettverket og i helsevesenet de søker hjelp hos. Derfor trengs det studier som kan undersøke dette.

Den planlagte studien vil undersøke hvordan følelser og fornemmelser i kroppen tolkes av deltakerne. Hvilke fornemmelser i kroppen anses som ufarlige, hvilke fornemmelser bør undersøkes nærmere eller bør man søke behandling for? Hvem blir involvert i disse vurderingene og avgjørelsene?

### **Gangen i datainnsamlingen:**

Fastleger i Tromsø kommune formidler kontakt ved å videresende brev med forespørsel om å delta til personer som oppfyller kriteriene i studien. De som ønsker å delta og undertegner skriftlig samtykke, vil bli kontaktet av forskeren for å avtale første intervju.

Forskeren vil utføre intervju med anslagsvis 10 deltakere ca. en gang i måneden i 10 måneder av et år. Dersom deltakerne tillater det, kan det bli aktuelt med intervju av personer i deltakerens omgangskrets og fastlege eller andre i behandlingsapparatet.

Dersom deltakerne tillater det kan det også være aktuelt for forskeren å være med deltakeren i noen aktiviteter som kan knyttes til hverdagsliv og helse.

### **Inklusjonskriterier**

Deltakerne skal ha avsluttet aktiv kreftbehandling/oppfølgingsbehandling/intensiv behandling og normalt befinne seg tidsmessig innen for et tidsrom på 4 år etter dette.

Deltakerne må ha startet et hverdagsliv igjen, det vil si et liv uten aktiv kreftbehandling. Kontroller av sykdommen kan inngå i hverdagslivet; sykemelding (hel eller delvis) kan inngå, og man kan være begynt i jobb eller studie, eller motta pensjon.

Deltakerne må være over 18 år og helst fordelt både over og under 50 år, og på begge kjønn.

#### **Formidling av resultater**

Resultatene vil bli formidlet til deltakerne i studien. De vil videre bli formidlet til helsefaglige utdanninger, blant profesjonelle helsearbeidere som arbeider med pasienter som har erfart kreft og kreftbehandling, helsemyndigheter og kreftforeningen. Vi vil også skrive vitenskapelige artikler rettet mot et internasjonalt publikum.

## **Kapittel B - Personvern**

- **Personvern**

Ingen opplysninger om deg vil bli registret i noe register.

Det er kun forskerne i prosjektet som vil ha tilgang til koblingen mellom navn og datamaterialet som er innsamlet gjennom intervjuer og eventuell deltakelse i aktiviteter.

- **Rett til innsyn og sletting av opplysninger om deg og sletting av prøver**

Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede prøver og opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

- **Informasjon om utfallet av studien**

Som deltaker i studien har du rett til å få informasjon om resultatet av studien.

Klipp -----

## **Samtykke til deltakelse i studien**

Jeg er villig til å delta i studien

-----  
(Signert av prosjektdeltaker, dato)

Telefonnummer som forskeren kan nå deg på: \_\_\_\_\_

Forskeren bekrefter å ha gitt informasjon om studien:

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#### 4) Intervjuguide, første intervju:

##### Første intervju (januar 2014 -)

Er det i orden at jeg tar opp samtalen på lydopptaker?

Lydopptak vil kun høres av meg selv og veileder. Opptak er passord-beskyttet og vil lagres innelåst.

*Kort gå igjennom enkle personalia for å få det på opptak.*

- Alder, utdanning, familiesituasjon
- Daglig beskjeftigelse: I jobb, hjemme, sykemeldt, trygd?
- Når ferdig med aktiv behandling
- Diagnose og tidspunkt for diagnose

**Prosjektet** skal handle om hvordan det er å leve med å ha hatt kreft i de første årene etter at man er ferdig behandlet.

Men **i dag** vil vi gjerne høre historien om sykdommen din. Hvordan startet det hele?

*Ev temer om behov:*

**Hverdagsliv** – Sosialt (familie – nettverk)

- Aktiviteter/arenaer (jobb/fritid)

**Symptomer**

**Hjelpsøking**

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#### 5) Andre intervjuguide vår:

##### Gjentakende intervjuer (fra andre intervju)

##### Opplegg for intervjuet

Noen *strukturerte spørsmål* om “siden sist”, [tror ikke det skal være spørsmål i dette som er veldig nærgående, men du velger alltid selv om du vil svare og hvordan].

Så introduksjon av noen *verktøy* som er frivillig å delta i:

1) **Helsedagbok** (per uke – ev. fylles ut før neste intervju for å ha tenkt igjennom litt på forhånd = som hjelp til å huske).

2) **Kart** = tegne en sosial oversikt (personer og arenaer) og tegne kart over “tidsgeografi” – faste mønstre over hvilke områder du bruker å oppholde deg. (= Som hjelp til å bli bevisst på/huske på hvem du omgås og hvem som er viktige personer i ditt liv, og hvilke aktiviteter og arenaer disse er knyttet til. + Det geografiske og fysiske. Hva gjør du og hvor er du da. Hvilke områder av byen/naturen er viktige for deg = aktiviteter og fasiliteter/tjenester).

**Ellers alltid åpent for det du selv ønsker å snakke om.**

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**Formålet** med spørsmålene under er å prøve å favne litt bredt ifht hvordan du har det og hvordan livet er nå. Dessuten hvordan du opplever kroppen og helsa di.

**Forskningsspørsmålene handler om:** Hvordan er det å leve et hverdagsliv igjen når man er ferdig med aktiv behandling etter å ha fått en kreftdiagnose. Hvordan har man det fysisk og hvordan opplever man kroppen sin. Går man rundt og kjenner etter og er bekymret for nye symptomer? Hvilke kroppslige følelser og fornemmelser legger man merke til, og hva gjør man med dem? Hvordan spiller det sosiale livet og hverdagslivet inn? Hvem diskuterer man eventuelt helsa si med?

### **Strukturerte spørsmål: Hverdagsliv og aktiviteter**

- *Er du fornøyd med livet ditt for tida; har du det bra? Går livet "sin vante gang" eller har det skjedd noe utenom det vanlige?*
- *Hva har tiden din gått med til den siste måneden? – Aktiviteter, personer, steder. Hva har du vært opptatt av? – Tanker, følelser, problemstillinger.*
- *Har du gjort noe eller deltatt i aktiviteter som har bidratt til at du har hatt det bra? På hvilken måte gjør dette at du får det bra? Har du gjort tiltak/aktiviteter som du tenker er helsefremmende/sykdomsforebyggende? Har du brukt mye tid eller penger på dette?*
- *Hvordan har du hatt det med familien?*
- *Hvem har du brukt mest tid sammen med siden sist? Er dette som vanlig, eller har det skjedd noe spesielt? Er det noen som har hatt mer behov enn vanlig for at du har hjulpet eller stilt opp for dem? Er det noen som har hjulpet deg mer enn vanlig?*
- *Hvordan har du hatt det på jobben (også frivillig arbeid)?*

### **Helse og symptomer**

- *Hvordan opplever du din helse for tiden?*
- *Har du opplevd smerte, ubehag eller forandringer i kroppen den siste måneden? Hvor ofte? Hvor var du da du opplevde dette? Hva holdt du på med da? Hva trodde du kunne være galt?*
- *Har du opplevd tretthet eller bekymringer for helsen din?*
- *Har dette forstyrret dine gjøremål eller ønsker i hverdagen? På hvilken måte? Hvor plagsomt synes du dette er?*
- *Hva tenker du at smertene/ubehaget/trettheten eller bekymringene skyldes?*
- *Har du snakket med noen om disse fornemmelsene? Ev. Hvorfor ikke? Hvem snakket du med, hva snakket dere om, og hvorfor snakket du med nettopp han/henne? Hva betyr det for deg å dele tanker med noen om at du er bekymret for helsen din? Er det lettere å dele tanker om å ha det bra? Har det med å diskutere helse og eventuelle bekymringer med andre endret seg sammenlignet med hvordan det var før du fikk kreft?*
- *Har du gjort noe med smertene/ubehaget? Har du noen aktiviteter i hverdagen som minsker slike smerter/ubehag? (Eventuelt øker) Hvordan gjør dette at du får det bedre, eller verre?*



*Har du vært hos lege, annet helsepersonell, et alternativ behandling? Hvorfor valgte du å oppsøke/ikke oppsøke behandling? Hvordan søkte du hjelp, og var du fornøyd med møtet og den hjelpen du fikk? Hvem har vært din beste faglige hjelper i denne perioden. Hadde du andre muligheter enn å søke slike typer behandling?*

- Har du blitt oppmerksom på noe annet ved din helse?

#### Målorientering

- Hva ønsker du deg av livet for tida – hva er viktig og hva skal til for å få dette til?

#### Avslutning

- Har du ellers noe du har lyst å fortelle/ta opp.
- Hvordan har intervjuet vært? Som forventet?

#### Neste gang:

Avtale tid.

Noen aktiviteter som jeg kan delta i? Er viktig i livet ditt, for helsa di, eller som bare er en del av det å leve her og nå. Jobb, fritid, (friluftsliv/handle/cafe/på verksted med bilen). Noe du trenger hjelp til?

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## 6) Tredje intervjuguide, første intervju etter sommer:

### Hverdagsliv og aktiviteter (Første intervju etter sommeren)

- Hvordan har sommeren vært? Ble den som planlagt, eller som du håpet?
- Hvilke aktiviteter har du brukt mest tid på?  
(Aktiviteter i vid forstand = også å ligge på sofaen eller slappe av på andre måter).
- Hvordan har du hatt det med familien?
- Hvem har du brukt mest tid sammen med?  
Er det noen som har hatt mer behov enn vanlig for at du har hjulpet eller stilt opp for dem? Er det noen som har hjulpet deg mer enn vanlig?
- Hvordan har du hatt det på jobben/frivillig arbeid?
- Har du det bra for tida?

### Helse og symptomer

- Hvordan opplever du helsa di? Hvordan har den vært i sommer?
- Har du hatt plager som har hindret deg i å gjøre det du ville, eller har du vært i form til mer enn forventet? Eksempler
- Hva tenker du at smertene/ubehaget/trettheten eller bekymringene skyldes?
- Har du snakket med noen om disse fornemmelsene? Ev. Hvorfor ikke?
- Har du gjort noe med smertene/ubehaget?

## Målorientering

- Hva ønsker du deg av livet akkurat nå, og på sikt? Hva skal til for å få dette til?
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## 7) Fjerde intervjuguide (høst)

### Spørsmålsguide høst 2014 (Andre intervju etter sommeren)

*Sykdom og helse/ å være syk og å være frisk, eller midt i mellom/å ha kreft, å være kvitt kreften, eller muligens ha fått ny kreft?*

(Kroppslige) fornemmelser og symptomer

Før du fant ut at du hadde kreft:

Kan du huske hvilke følelser, fornemmelser eller symptomer som gjorde at du oppsøkte lege?

Har du i ettertid tenkt på at det var andre fornemmelser eller symptomer som var til stede, og som du tenker kan ha vært "faresignaler"? (Kroppslige eller psykiske/konkrete eller mer vage)...

Under behandling:

Hvilke fornemmelser/følelser/symptomer/bivirkninger kan du huske fra perioden i behandling?

Tenker du annerledes om dem nå enn du gjorde da?

Etter behandling:

Hvilke kroppslige følelser og fornemmelser er de du husker best fra tiden etter avsluttet behandling og frem til i dag?

- o I hvilke situasjoner kjente du dem?
- o Hvordan tolket du dem?

Kan du si noe om hvordan prosessen med å forholde seg til følelsene og fornemmelsene har vært? Har du noen bilder i hodet som illustrerer prosessen eller endringer i hvordan du følte deg før du fikk diagnosen, under behandling, like etter at du var ferdig, og i dag? (Noen bilder eller noen måter å beskrive følelser eller symptomer på?)

Kommer du på noen "alarmsignaler" knyttet til kreft som du alltid ville søkt lege for, eller som du ville fulgt med på? Noen objektive tegn eller vagere følelser som sier at noe er galt? Konkrete eksempler? Hvor vet du om dem fra? Er det alarmsignaler som du selv har handlet utfra? Hvorfor/hvorfor ikke? Hvilke følelser/symptomer gjør deg redd i dag? Kan du gi eksempler på fornemmelser eller tilstander som du anser for "noe du bare må leve med"? Hvorfor er det slik?

**Følelse av å være syk og følelse av å være frisk, eller følelse av å "ikke være helt i form"**

Kan du prøve å beskrive hvordan du føler deg når du er syk, eventuelt motsatt, når du er frisk?

Har du noen bilder, ord eller uttrykk som dukker opp i hodet når du tenker på det?

Hva er det som kjennetegner "sykdomsfølelsen". Hvilke fysiske følelser forbinder du med å være syk? Kan du beskrive disse? Hvordan føler du deg psykisk når du er syk? Skiller du mellom å være bare "ute av form" og å være "syk"? Kan du forklare dette skillet?

Når du vurderer din tilstand, hvilken rolle spiller: energinivå, humør, fysisk kapasitet, og konsentrasjon? Noe annet?

Er det noen i din familie/omgangskrets/andre som har en avgjørende innflytelse på om du tenker du er frisk eller syk? (diskuterer med/sml deg med?)

Finnes det en "intuisjon" som sier deg at du er syk, selv om legen ikke finner noe? Hva kan ev. denne bygge på? Tror du at din erfaring med å ha hatt kreft har påvirket denne "intuisjonen"?

Flere viser til at "kroppen husker" sykdommen. At man får flash-backs når man føler seg syk. Kjenner du deg igjen i dette? Hva er det i så fall kroppen husker? Hvilke sykdomsfølelser er det ev. som bringer tilbake disse minnene, og kanskje gjør deg redd for tilbakefall eller ny kreft?

Hvordan vil du beskrive din "standard" helse nå for tida? Hvordan var den før du ble syk?

Hvordan opplever du livet eller dagen når du er syk? Hva kjennetegner en normal-dag nå, og før du ble syk? Har du en ideal-dag? Hvorfor er den slik? Er den oppnåelig? Er den en inspirasjon eller en stressfaktor?

Hvordan påvirker det å være syk, "ute av form" eller frisk ditt sosiale liv? Eksempler/utdyp...

**Sosialt - hvem involveres i vurderinger av helsetilstand. Hvem diskuterer man sykdom og kropp med, eller nettopp ikke...**

#### **Proessen:**

Har det endret seg hvem du prater med om kreftsykdommen din hvis du tenker på tiden før du fikk diagnose, under behandling, og etter avsluttet behandling?

#### **Sykdom som tema:**

Er sykdommen noen ganger et tema i sosiale sammenhenger (når flere prater sammen)? Prater man da om din sykdom, eller om kreft generelt, eller om andre som har/har hatt kreft? Hvordan opplever du det at det prates om, eller ikke prates om kreft på denne måten?

Opplever du at andre har meninger om eller forventninger til hvordan man skal håndtere livet etter kreft? Når, og hvordan – eksempler? Hvordan oppleves det for deg?

Opplever du at ditt fokus på helse har endret seg etter sykdommen? Hvordan? Opplever du at fokuset på helse generelt rundt deg har endret seg?

**Helseveier: Fra medisin til livsmestring – balanse?**

Hvis vi følger din sykdomshistorie fra du eventuelt mistenkte at noe var galt, til i dag, - kan du si noe om hvilke helseveier du har fulgt? [I vid forstand – behandling, forebygging, øke/bevare livskvalitet, i helsevesenet og ellers]

Hvilken rolle har fastlegen din spilt i denne prosessen? Hvor mye har du brukt han/henne? Har dette endret seg underveis?

**Fokus på andre veier enn i det tradisjonelle helsevesenet:**

I perioden der du var under behandling – Bortsett fra å motta ordinær kreftbehandling i helsevesenet - Gjorde du noe annet for å lindre plager, øke livskvaliteten eller hjelpe til med å bli frisk? [feks kosthold, kosttilskudd, fysisk aktivitet, avspenning, hvile, psykisk/eksistensielt tankefokus, sosiale eller kreative aktiviteter, annet]. Hvordan fikk du kjennskap til dette? Hvordan syns du det virket?

Etter avsluttet behandling – Har du gjort noe for å lindre plager, øke livskvaliteten, bedre- eller bevare helsa di? [feks kosthold, kosttilskudd, fysisk aktivitet, avspenning, hvile, psykisk/eksistensielt tankefokus, sosiale eller kreative aktiviteter, annet]. Har du brukt dette også før du ble syk? Hvordan fikk du kjennskap til dette? Hvordan syns du det virker?

Hvordan ser du for deg veien din videre – Er det noe du vil fortsette med eller noe nytt du vil prøve ut? Hva ønsker du deg av helsevesenet videre?

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## 8) Femte intervjuguide, avslutningsintervju

- Siden sist:  
Hvordan føler du deg?

Hvordan går det med ...?  
- Andre plager?

Har du vært syk eller hatt noen bekymringer for helsa siden sist?

Har du/dere noen «leveregler» som har som formål å ta vare på helsa? Har dere fulgt disse i det siste?

- Tidsbruk:  
Hva har tida gått med til siden sist?

- Familien; er alt bra, eller er det noe eller noen som krever din energi mer enn vanlig? Har dere to fått vært sammen?
- Jobb; opplever du at din arbeidstid og arbeidsoppgaver er innenfor det du mestrer her og nå?
- Fritid; har du/dere hatt tid/energi til det dere ønsker?

- Kreftforeningen  
Har du/dere benyttet dere av tilbud fra Kreftforeningen underveis eller etter at du var ferdig behandlet?

Hvor fornøyd har dere vært?

Har du/dere hatt nytte av tilbud fra andre grupper eller institusjoner enn Kreftforeningen underveis eller etter behandling?

Har du noen ønsker til Kreftforeningens fremtidige arbeid? Er det tilbud dere har savnet, eller som har vært nyttige for dere?

Har du innspill til andre du har vært i kontakt med?

- Dette er siste intervju

**Hvordan har det vært å delta i disse intervjuene?** Er det noe som ble veldig annerledes enn forventet, eller som du synes manglet? (For eksempel fokus, tema, tilnærming).

Ikke helt umulig at kan føle behov for å diskutere noe eller spørre om noe også etter at jeg har startet med analysen. **Er det i orden at jeg tar kontakt med deg i så fall?**

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## 9) Spørsmål til helsedagbok

### Hverdagsliv og aktiviteter

- *Har livet gått "sin vante gang" eller har det skjedd noe utenom det vanlige denne uka?*
- *Hva har tiden din gått med til og hva har du vært opptatt av?*
- *Hvem har du brukt tid sammen med?*
- *Hvordan har du hatt det på jobben (også frivillig arbeid)?*
  - *Hvordan har du hatt det med familien?*

### Helse og symptomer

- *Hvordan har du opplevd din helse?*
- *Har du opplevd smerte, ubehag eller forandringer i kroppen denne uka?*
- *Har du opplevd tretthet eller bekymringer for helsen din?*
- *Har du blitt oppmerksom på noe annet ved din helse?*

### Hvis ja:

- *Har dette forstyrret dine gjøremål eller ønsker i hverdagen?*
- *Har du snakket med noen om disse fornemmelsene?*
- *Har du gjort noe med smertene/ubehaget?*
- *Har du vært hos lege, annet helsepersonell, el alternativ behandling?*