

Nafkam

‘Will I get cancer again?’

An ethnography of worries, healing landscapes and sensation-to-symptom processes among people living in the aftermath of cancer in rural Norway

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A dissertation for the degree of Philosophiae Doctor – 2019



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Financial support:

The project was financed by the Research Council of Norway, the Norwegian Centre of Rural Medicine and The National Research Center in Complementary and Alternative Medicine.

Acknowledgments

Perhaps this project involved a once in a lifetime opportunity for me in my profession as an anthropologist: During the 11 months of fieldwork, I was able to accompany ten people who shared their time with me and a large part of their personal life story.

Writing did not come as easy to me as conducting fieldwork, but I experienced a lot of support from both of you, Nina and Mette. Nina Foss, your broad anthropological knowledge on Northern Norway was fundamental for the analysis of this dissertation, and your comfort was important when writing was not fruitful. Mette Bech Risør, your accurate way of working and broad overview of journals, scholars, theories and discussions brought me further in each conversation we had. Both of you were always available for me from the start of the project and usually answered my emails within a few hours or within a couple of days – Thank You! And so were you, Rikke Sand Andersen, always available if I needed an opinion, especially during the writing of the third paper. Thank you, Kate Hampshire, for reading through my work - I know how busy you are.

Several supportive environments have contributed to the creation of this thesis. I wish to thank all my colleagues from Nafkam and nifab.no for the many years of support. My contract was extended a couple of times and this secured me financially. Thank you, Agnete Kristoffersen, for our symbiotic relationship over the past years and for helping me out regularly. Thank you, Trine Stub, your structured approach and life experience were an important resource for me in the last few years.

I would like to thank all my colleagues from AFE and NSDM, who made me feel very welcome. The financial support of AFE enabled me to attend the EASA Medical Anthropology Conference in Lisbon. I would like to thank the management team of NSDM for deciding to employ me during my last strokes of the pen. Thank you, Helen Brandstorp, for encouraging me to apply and supporting me with your positive outlook on life, and Frank Remman, for being worried if I would get my salary in time! Thank you, Tone Seppola-Edwardsen, for our professional and personal exchange over the last few years. I admire both your caring side and how you always understand where your limits are.

I would like to thank my dear participants. I stole large chunks of your time. Thanks to those who made a huge effort to integrate me into the local community, fed me seagull eggs, homemade fishcakes, waffles, reindeer steak and many cups of black coffee.

My fieldwork would not have been possible without being able to join all the different leisure groups during fieldwork. Thanks to the members of the knitting club for teaching me the pleasures of handicraft, the local fishing club for letting me join your activities (without me even being a paying member!), to the members of the local brass band for including me, even though my skills were rather poor, and the local choir for the many evenings of singing. Thank you, A., for offering me an entire office in the museum and for all the coffee.

Thank you, Tromsø Museum and the organizers of the course 'BIO-8010 Visualizing your Science' for offering me to exhibit my work for almost ten days.

Thank you, my dear friends and family, for supporting me during the writing process, especially Wienke for running our household and garden plot during this unexpected, very last period of writing.

List of abbreviations

XXX – These letters serve to anonymize locations or names

AFE - Allmenntmedisinsk forskningsenhet/General Practice Research Unit

CCP – chronic cancer patients

EASA - European Association of Social Anthropologists

NAFKAM - Nasjonalt forskningscenter innen komplementær og alternativ medisin/The National Research Center in Complementary and Alternative Medicine

NSDM – Nasjonalt senter for distriktsmedisin/Norwegian Centre of Rural Medicine

GP – General Practitioner

PET-CT or PET/CT - Positron emission tomography/computed tomography

WWII – Second World War

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List of articles

1. Magdalena Skowronski, Mette Bech Risør and Nina Foss

Approaching Health in Landscapes - An Ethnographic Study with Chronic Cancer Patients from a Coastal Village in Northern Norway

Published in: *Anthropology in Action*

2. Magdalena Skowronski, Mette Bech Risør, Rikke Sand Andersen, Nina Foss

The cancer may come back: Experiencing and managing worries of relapse in a North Norwegian village after treatment

Published in: *Anthropology & Medicine*

3. Magdalena Skowronski, Mette Bech Risør, Nina Foss

Sensing possible symptoms of relapse in everyday life: People living in the aftermath of cancer treatment in search of social acceptance for symptoms

Published in: *European Journal of Cancer Care*

Summary

Today, 71% of those who are diagnosed with cancer live five years or longer after treatment. Although the level of mortality varies considerably between different cancer diagnoses, the total number of people who recover after cancer is increasing. There is a need to gain knowledge on how people who live in the aftermath of cancer treatment experience health and illness, bodily sensations, everyday life and relations to the health care system. Several remote municipalities in Northern Norway face challenges regarding the accessibility of specialized health care, which influences the experience of the aftermath of cancer treatment.

This dissertation is part of the overall research project ‘SenCancer - Sensing illness in everyday life: Care-seeking and perception of symptoms among chronic cancer patients’. The main goal of the project was to investigate how people who live in the aftermath of cancer treatment experience bodily sensations, make sense of and act towards cancer illness and health. This involved an exploration of the social processes and relational dimensions of sensations and care-seeking processes.

The study builds upon 11 months of ethnographic fieldwork in 2014 in a rural context, located far off from specialist health care services, more specifically in a coastal village of fewer than 3000 inhabitants in the northernmost county of Norway. Ten people from the village, with different cancer diagnoses and having undergone cancer treatment from three months to ten years earlier, were the core participants in the study. During fieldwork, I took part in the everyday life of participants and in the village in general. The core participants gave monthly semi-structured interviews on experiences of illness and health, treatment, bodily sensations, activities, and relations to family, friends, co-villagers and health care professionals.

The findings of the study are presented in three scientific articles, all published internationally. The articles focus on ways of living, sensing and coping in a small remote village after cancer diagnosis and treatment. They contribute to the understanding of living in the aftermath of cancer treatment in a rural context far away from specialist health care services. The analysis builds upon different analytical approaches to understand social processes of the participants’ bodily sensations, and a) their coping in everyday life in relation to familiar landscapes, b) how

they cope with worries of relapse in relations with others, and c) the social and moral embeddedness of bodily sensations.

The study contributes to the theoretical field of ‘medical anthropology of the sensations’, to an anthropological understanding of emotions and to understanding embodied relations to local landscapes when living in the aftermath of cancer diagnosis and treatment.

Article 1: The significance of cultural norms and clinical logics for the perception of possible relapse in rural Northern Norway – sensing symptoms of cancer; Published in ‘Qualitative Research in Medicine & Healthcare’, Vol. 1 (3), 2017

In this article, we explore how the process from experiencing indeterminate bodily sensations to perceiving them as possible symptoms of cancer relapse is related to clinical logics, and to local values and clinical practice in rural Northern Norway. We show how the high turnover among primary health care staff relates to how and when core participants present indeterminate bodily sensations to shifting GPs. In addition, core participants had certain understandings of what could be presented in a consultation and what is appropriate to ask for from previous experiences with the health care system, and embodied and included clinical routines in their perception and assessment of bodily sensations. The core participants feel that they have to present clear symptoms, so they hesitate to see the doctor for such bodily sensations. Moreover, the personal evaluation of bodily sensations is embedded in local values in the village. Core values are to contribute to the common good, not to be a burden, be positive and avoid focusing on ‘difficult things’. Participants’ inner dialogues with co-villagers and health personnel lead to decisions not to share concerns about bodily sensations which might be symptoms of relapse. We suggest a rethinking and relocation of Hay’s analysis of ‘social legitimation’ in sensation-to-symptom processes in order to grasp the experiences of cancer in rural Northern Norway.

Article 2: Approaching Health in Landscapes - An Ethnographic Study with Chronic Cancer Patients from a Coastal Village in Northern Norway; Published in ‘Anthropology in Action’, Vol. 24 (1), 2017

In this article, we analyze how core participants engage with their familiar surroundings in efforts to counter bad mood, anxiety and symptoms of relapse and to strengthen their health. By drawing on Tim Ingold’s understanding of taskscape, it is suggested that the participants after cancer treatment dwell in and engage with the surroundings of the village in similar ways as before the illness, but after cancer treatment, their core task has changed to coping after

illness and staying healthy. The participants are part of and embody the landscape through the temporality of taskscape, related to their ways of dealing with pain, worries and bodily sensations in everyday life.

Article 3: The cancer may come back: experiencing and managing worries of relapse in a North Norwegian village after treatment; Published online in 'Anthropology & Medicine', 2018

Little is known about how people living in the aftermath of cancer experience and manage worries about possible signs of cancer relapse, not only as an individual enterprise but also as a socially embedded challenge. We contemplate human emotions as arising in contexts of interactions, capable of creating social realities. We highlight how people who recover from cancer construct and experience worries about possible relapse in relation to close family members, friends and co-villagers in the socially closely-knit and relatively isolated village. These emotional experiences emerge through relationships with others, have communicative characteristics and take place in interaction with the social environment of their village. While the participants attempt to protect family members by avoiding sharing worries with them, they express the need to share their worries within friendships. They experience both comfort and challenges in managing their worries in relation to acquaintances in the village. The article enhances understanding of the social embeddedness of emotions in everyday life.

Outline of the dissertation

The dissertation consists of nine parts. The introductory part, Chapter 1, guides the reader through the thematic background. Chapter 2 addresses the aims of this dissertation. The main theoretical and analytical perspectives are presented in Chapter 3. In Chapter 4, I present and discuss the methodological choices of the study. Chapter 5 presents the analytical findings of the dissertation, which result from three different articles. In Chapter 6, I summarize the analytical conclusions and integrate the dissertation's findings with the main theoretical framework. Chapter 7 contains the literature references, Chapter 8 the appendices and Chapter 9 the three different papers of this dissertation.

1 Introduction

This study is part of a research project called ‘SENCANCER - Sensing illness in everyday life: Care-seeking and perception of symptoms among chronic cancer patients.’ The project was divided into two PhD studies, which initially had the same overall research aims, but differed in locus. While the present study has a rural locus, the other study was conducted in an urban area (Seppola-Edvardsen, Andersen, & Risør, 2016).

This chapter will be introduced by an overview of medical issues pertaining to the post-cancer treatment phase (1.1). I will then focus on related research on health care seeking and give an outline of the challenges of cancer diagnostics in primary health care (1.2). This will be followed by an overview of challenges in the Norwegian health care system (1.3). I will then briefly describe how people's identification with outdoor recreation in the Norwegian context is relevant for this thesis (1.4). In 1.5, I will embed this study into a research field that discusses illness in the context of Northern Norwegian culture, followed by a discussion of the use of the terms ‘everyday life’, ‘cancer survivor’, ‘sensation’ and ‘symptom’ in this dissertation (1.6).

1.1 Aftermath of cancer diagnosis and possible recurrence

Cancer occurs in all age groups; however, between 85-90% of patients are more than 50 years old. The total number of new cancer cases in Norway is increasing, and a comparison of 2001-2005 with 2006-2010 shows that the incidence rate has increased by 3.1% for men, and 4.9% for women. 32 592 new cancer incidences were recorded in Norway in 2015. Today, 71% of people diagnosed with cancer live five years or longer after diagnosis (Larsen et al., 2016). Thus, the total number of people who survive cancer and continue living with late effects and new symptoms is increasing (Coleman et al., 2011; Sant et al., 2003), although the level of mortality varies considerably between different cancer diagnoses (Larsen et al., 2016).

Previous studies have investigated the various challenges that may appear in the post-treatment phase (Hoekstra, Heins, & Korevaar, 2014). Experiencing cancer and its treatment can mark one's life after treatment and lead to a variety of physical, mental and social difficulties. Bodily sensations may endure and influence the everyday activities of a person who has had cancer. People who live in the aftermath of cancer can suffer from cognitive limitations, sleep problems,

fatigue, pain and physical limitations, which cannot easily be categorized as new symptoms, late effects or discomfort connected to other illnesses (Harrington, et al. 2010).

People who live in the aftermath of cancer treatment are twice as likely to develop the same type of cancer again as people with no former cancer history. Conventional medicine distinguishes between primary and secondary types of cancer. While primary cancers are those that develop by themselves, secondary types consist of relapses from previous cancers. Relapses usually occur because certain cancer cells have not been fully removed or have been immune to treatment (Nielsen, Nordestgaard, & Bojesen, 2012).

This patient group is repeatedly confronted with having to assess whether bodily sensations could mean a possible symptom of relapse of cancer (Harrington, et al. 2010), due to the uncertain nature of the disease, the phase that follows cancer treatment is therefore often marked by worries about such sensations, indicating relapse (Donovan, Brown, LeFebvre, Tardif, & Love, 2015; Harrington et al., 2010; Mishel, 1988).

In qualitative research, cancer-related worrying has been contextualized from different perspectives. Age, for instance, has been analyzed as a factor that influences how the possibility of recurrence of cancer is perceived by people who live in the aftermath of cancer; younger women experience unique sources of uncertainty and more psychological distress than older women do (Miller, 2015b). Specific communication patterns between life partners can affect how people experience the possibility of relapse (Miller, 2014), and being geared to specific social norms can lead to experiences of intimidation and the belief that expressing concerns is not necessarily favored (Brandes, Linn, Smit, & Van Weert, 2016). Discussing one's continued emotional difficulties may be perceived as weakness and a lack of gratitude for a positive prognosis (Miller, 2015a), and social expectations may be that such worries should be relegated to the past (McKenzie & Crouch, 2004). Humor can help to bear the burden of anxiety; it can enhance problem-solving abilities, safeguard important relationships, communicate difficult topics, restore identity, help significant others to cope and even enable the richness of life to help the person to live with the risk (Roaldsen, Sørli, & Lorem, 2015). The constant interpreting of bodily sensations can become a way to control the fear of a possible relapse (Holmberg, 2014), and balancing what to share may become an important tool to refuse to let cancer dominate social life and contact with others (Seppola-Edvardsen, Andersen, & Risør, 2016).

1.2 Responsible health care seeking

In the context of Western public welfare and a movement towards pre-symptomatic diagnosticity (Rose, 2009), success in the treatment of cancer is often associated with the early detection of abnormal cell growth (Hvidberg et al. 2016). The goal is to keep ‘the patient interval’, i.e. the time between symptom discovery and the contacting of health care services, as short as possible (Hvidberg et al., 2016). Citizens of welfare states are encouraged to become active partners in contributing to their health and to the early interpretation of bodily sensations as possible signs of cancer (Rose, 2009). Current health care promotion is often based on such neoliberal logics of managing risk in the private sphere and the requirement of constant self-improvement and self-examination (Castel, Burchell, Gordon, & Miller, 1991; Lupton, 1995). ‘Typical’ cancer symptoms are also experienced by people who are not diagnosed with cancer, and in daily clinical practice, symptoms can regularly be attributed to other causes (Svendsen et al., 2010). On the other hand, bodily sensations that in retrospect (could) have been symptoms of cancer, are not necessarily ‘alarming’ or painful (Merrild, 2015; Offersen, 2016), but might for example be sensed as discomfort or a soft unusual tingling. Previous research shows that the GP’s gut feeling and long experience in clinical practice is significant in diagnosing cancer at an early stage (Andre, Anden, Borgquist, & Rudebeck, 2012; Donker, Wiersma, van der Hoek, & Heins, 2016; Johansen, Holtedahl, & Rudebeck, 2012).

Recognizing cancer in primary health care is indeed more complex than it immediately appears and several research environments have produced complex knowledge in an attempt to improve diagnostics of cancer. This is often done with an emphasis on how clinical encounters may improve communication. There is a need to gain more knowledge on how sensations are interpreted and presented, how health seeking practices take shape, and how the sociocultural context shapes and informs ‘the patient interval’. Merrild (2015) shows how this large room for misinterpretation encourages both the disregard of significant signs and excessive attention to signs that eventually are shown not to indicate a severe diagnosis after all.

Such research dealing with the ‘pre-cancer patient interval’ and the ambiguities shown above are relevant for this research, because they introduce us to the different processes that people may go through before contacting a health care institution.

Researchers have investigated psychosocial care for cancer patients in primary health care (e.g. Carolan & Campbell, 2016; Pascoe, Neal, Allgar, Selby, & Wright, 2004), and other studies

have focused on information strategies directed at cancer patients and their influence on care-seeking behavior (Bennett, Cameron, Whitehead, & Porter, 2009; Mayer et al., 2007; Mekuria, Erku, & Belachew, 2016).

Care-seeking research in cancer has focused on peoples' care seeking in terms of delay studies (Andersen et al., 2010), satisfaction with patients' and doctors' choices of treatment and experiences of cancer treatment across health sectors (Fogolino et al., 2016). Delay studies have followed various approaches when e.g. trying to investigate and explain aspects of treatment patterns and treatment delay when seen from the patient's perspective. Some studies look at demographic characteristics (Marlow, McGregor, Nazroo, & Wardle, 2014; Tadesse, 2015; Whitaker, Macleod, Winstanley, Scott, & Wardle, 2015), or the protagonists' knowledge of cancer (Dey et al., 2016; Marcu et al., 2016), while others explore more psychological dimensions such as attitudes to health care (Frick et al., 2017), the experience and ascription of symptoms and lack of knowledge of critical symptoms (Andersen et al., 2010; Hall et al., 2015). In general, care seeking is often studied from decision-making perspectives influenced by rational choice and from a retrospective position, although more contextual studies that employ other methodologies are beginning to influence the field (e.g. Elnegaard, Andersen, Pedersen, & Jarbøl, 2017; Khakbazan, Taghipour, Latifnejad Roudsari, & Mohammadi, 2014; MacArtney et al., 2017; Smith, Pope, & Botha, 2005; Walabyeki et al., 2017).

Few studies have addressed processes of illness and care seeking in people living after cancer diagnosis and treatment. Anthropological research has, however, provided analyses of how the public health discourse introduces a logic of efficiency in the clinical setting. Health care users have to deal with ambiguous messages: They are supposed to contact the primary health care services only with health issues that are 'relevant enough' in order to avoid its misuse, and at the same time to act responsibly and be attentive towards possible symptoms of developing illnesses (Andersen & Vedsted, 2015; Offersen, Vedsted, & Andersen, 2017). Such ambiguity in terms of responsibility for interpreting bodily sensations and seeking health care is also relevant for people who live in the aftermath of cancer illness and treatment.

1.3 Primary health care in rural Norway

The majority of people diagnosed with cancer in Norway are treated by conventional therapies such as radiotherapy, surgery, hormone treatment and chemotherapy in a clinical hospital setting (Adams & Jewell, 2007), their disease is recorded in a central electronic system and they get regular calls for check-ups with their GP. GPs are the link between a potentially ill person and specialized health care, as they can refer the patient to a specialist if considered necessary (Abelsen, 2013).

The lack and high turnover of GPs and specialized health professionals in outlying areas and the insufficient quality of primary health services in some regions of Norway has been a major challenge for decades. Hoekstra, Heins, & Korevaar, (2014) have shown that people who live in the aftermath of cancer treatment experience psychosocial needs, a need for support concerning medical issues, and a need for information on recovery, late treatment effects and adjusting to life after treatment; these needs are currently not or insufficiently met in primary health care.

The most challenging circumstance in primary health care relevant to this study is the municipalities' high turnover among primary health care staff, which influences participants' health care seeking when experiencing bodily sensations indicating possible relapse.

Norway has a relatively small population of around five million inhabitants. In some remote areas, especially in Northern Norway, the population is scattered, and there are often long distances between villages and administrative centers. People have to travel far to access specialized health care, and in some places even primary health care.

In 2001, the 'regular GP scheme' [fastlegeordningen] was introduced to entitle all citizens in the National Population Register to get a regular GP. The scheme aimed to improve accessibility and continuity in the relationship between GP and patient, and to gain better control of access to specialist health services (Lidal, Håvelsrud, Mathisen, & Vist, 2012). A stable relationship between GP and patient is linked to better health, lower costs and more appropriate health care (Starfield, 2005).

There are various economic models to run a GP practice in Norway (Halvorsen, Steinert, & Aaraas, 2012). In the villages, the municipality usually employs the general practitioner. Under the regular GP scheme, a municipality may require the GP to be responsible for up to 1500

inhabitants, which is why there is often only one GP position in the small municipalities. This can entail professional isolation, limited career opportunities and professional support (Abelsen, 2013; Abelsen, Gaski, & Brandstorp, 2016).

Unfortunately, many municipalities, especially those with fewer than 5000 inhabitants, experience a lack of permanent health care personnel (Abelsen, 2013; Abelsen, Gaski, & Brandstorp, 2016). More than half of the municipalities without a GP are found in the three counties of Møre og Romsdal, in the west, and Nordland and Finnmark, in the north (Abelsen, Gaski, & Brandstorp, 2016). Such 'GP-less' villages and municipalities depend on the hiring of temporary staff for varied periods of time. Abelsen, Gaski, & Brandstorp (2016) find a statistical correlation between the length of employment of temporary staff and the size of the municipality: the fewer the inhabitants, the shorter the period that temporary staff stay (Abelsen, Gaski, & Brandstorp, 2016). Small places are more vulnerable to the lack of a GP than larger ones, as losing one GP can imply going from one to none, which is a significant difference in availability of health care (Abelsen, Gaski, & Brandstorp, 2016; Sollien, 2016). Andersen, Cacioppo and Roberts (1995) show an additional significant correlation: municipalities with unstable GP coverage are the ones with the longest distance to hospitals with specialist services. Rural location and to some extent long distance to medical services increase the risk of dying, for instance from injuries (Bakke et al., 2013).

The Coordination Reform [samhandlingsreformen] (Norwegian Ministry of Health and Care Services, 2008/09) was gradually implemented from 2012. It entails legal and organizational changes and is referred to as one of the major health reforms since WWII in Norway. Municipalities are to take over more responsibility for meeting the needs of the population for health and care services, and specialist and primary health services are to cooperate more closely. Municipalities are supposed to take over responsibility for patients as soon as they are considered to be treated, and therefore should be discharged from hospital. The aim is to transfer more services from specialist to primary health care, to enable people to have access to more health care services locally. This model is also supposed to save overall health care expenses. The municipalities are required to co-finance specialist health services and are co-responsible

for the financing of discharged patients (Norwegian Ministry of Health and Care Services, 2008/09).¹

The reform has been met with criticism. There have been doubts about the ability of municipalities to provide treatment of the same quality as a specialized hospital, and until now there have been adaptation problems in the municipalities. Previous research shows how communication between hospitals and municipalities did not necessarily improve and the necessary increase in competence and capacity in municipalities has not so far been achieved (Monkerud & Tjerbo, 2016).

Municipalities have been given considerable responsibility for the health status of the residents. GPs tend to have the final word on health-related issues in municipalities.

In 2014, the primary health service in the village which is the locus of the study consisted of a nursing home, including an emergency room, home care services, a GP's surgery, a public health nurse and a cancer nurse. All these facilities are located in the same building close to the center of the village. There is one alternative health practitioner, a massage therapist, who is also located in the center of the small village. A dentist opened a practice during my fieldwork period. A previous study in the village documented that during the five years from 2008 to 2012, sixteen GPs and four physiotherapists started working in the village and left again, interspersed with periods with no such services. The study also showed that patients found that they had to start consultations 'from scratch' when seeing the changing GPs, and to repeat information about themselves.²

1.4 The use of natural surroundings in a Norwegian context

While the geographical region presented here may seem barren to outsiders at first sight, inhabitants of the coastal village of Finnmark in Norway connect a wide spectrum of activities and meaning to the area. The 'harvesting of nature' has always been the basis of existence for

¹ An example of this is that municipalities have to pay 20% of the cost of having a patient in hospital. If they do not receive dischargeable patients, they have to pay a daily fine of NOK 4000, which is supposed to motivate municipalities to have suitable treatment and care facilities, possibly in cooperation with other municipalities (Norwegian Ministry of Health and Care Services, 2008/09).

² The source of this information has to remain undisclosed due to anonymity.

people in the region (Strøksnes, 2016), and is today seen as a useful activity. It provides access to valued 'pure food' [ren mat], and the harvesting may involve collecting berries, fishing salmon, hunting snow grouse and collecting seagull eggs. Nature has particular resources to offer and not making use of those resources may seem wasteful to some. In a Northern Norwegian context, many people grew up with these ideas of being in and using nature and such terms are metaphors for how body and healthiness are imagined. Pure food, especially fish, is considered as particularly healthy; the term indicates the absence of additives like preservatives or other chemical substances that are considered unhealthy. How people understand and use nature is a product of their socialization, and concepts like 'pure food' and 'harvesting nature' are culturally constructed examples of the positive associations with the pure and original that nature has to offer. In many parts of Norway, the collocation of 'nature', 'freedom' and 'purity' is positively associated with health (Witoszek, 1998). Relevant for the context of this dissertation is that such harvesting activities are also considered useful physical exercise. In general, outdoor recreation is a significant part of the Norwegian identity and is an important part of school education (Nedrelid, 1992). Outdoor activities today are part of complex processes where local identity is formed with reference to both local traditions and global trends. In the Norwegian context, there is often an understanding of right and wrong behavior connected to the use of natural surroundings and to how these are internalized by friends, family and neighbors in the local communities (Svensson, 2012).

1.5 Culture, health and illness in Northern Norway

During fieldwork, the local village culture was often illustrated to me through anecdotes referring to Norway's north-south distinctions. From a historical perspective, Northern and Southern Norway developed differently; for many centuries, inhabitants in the north had a lower standard of living and a more limited access to public services. Health care services, higher education and other public and private institutions were established late in the region (Eidheim, 1993; Saugestad, 2012). The otherness of the Northerners was described in different ways, depending on the desired projection by others, from 'dirty' and 'lazy' to a more romantic picture of 'emotional' and 'friendly', to 'rough' and 'strong' (Drivenes, Hauan, & Wold, 1994; Saugestad, 2012; Wold, 1985).

People with higher education usually came from the south, including teachers, judges and doctors. This has changed in recent decades with the development of higher education in the region since the 1970s (Saugestad, 2012). Nevertheless, smaller municipalities today cannot offer education after 10th grade, and young people often have to move away from their home villages to continue school.

Aspects of remoteness, institutional accessibility, attributes ascribed by others and the north-south distinction in general are intertwined with how people experience illness and the health care system. For instance, studies have shown how people may feel disadvantaged in access to certain health care services when living in remote areas (Abelsen, 2013; Abelsen, Gaski, & Brandstorp, 2016).

Researchers have investigated how Northern Norwegians partly include some of the above stereotypes in their own self-image (Brox, 1966; Strøksnes, 2016), and how such attributes stimulate and are reflected in conceptions about dealing with illness and the body. Foss (2008) examines the term 'å stå han av' (from the expression 'stand up in the storm'), and derives its meanings as 'we'll manage', 'we'll get through' or 'we'll survive', based on her ethnography of decentralization of psychiatry in a small coastal community of Northern Norway. It is an old expression on how to deal with the hardships of life connected to a hard climate and poverty. She argues that today it can be seen as a symbol of Northern Norwegian identity and values, associated with people's strength, resilience and strong social cohesion, qualities which people are proud of. Foss investigates how this and similar cultural traits influence villagers' understanding and handling of mental illness in a small Northern Norwegian municipality (Foss, 2008).

Studies of how to deal with mental challenges, or the local term 'nerves' in small communities in Northern Norway have shown that '...the local sociocultural context can shape and reflect social action in ways that affect the experience of nerves and the consequences for those who suffer from them in a significantly different fashion' (Davis & Joakimsen, 1997: 370). Foss (2002) shows how '[n]erves are a way of naming personal problems, while drawing on people's knowing of the pain that is a part of being socially connected.' (2002: 205)

The ongoing discourse about Sami identity and the Sami movement in general, which focuses on preserving and developing Sami culture, language and the Sami community on their own terms, have stimulated health care research on the Sami population in rural Northern Norway to contribute to culture-sensitive treatment (Dagsvold, Møllersen, & Stordahl, 2015; Stordahl, 2004). Studies have focused on the experience of mental illness in the specific culturally mixed

local context (Kiil & Salamonsen, 2013), and on how health care professionals meet and treat Sami patients, and have shown that they have knowledge and respect for traditional spiritual healing practices (Langås-Larsen et al. 2017).

In cancer research related to rural areas and Northern Norway, the challenging accessibility of health care services is a recurrent central issue. Elderly people in remote areas with incurable cancer struggle with fatigue from the stress of a long journey to a specialist, and the lack of local health care services makes such patients vulnerable (Andreassen Devik, Hellzen, & Enmarker, 2016). Other research points out how inhabitants in some parts of Northern Norway lack proper access to Positron emission tomography-computed tomography (better known as PET-CT or PET/CT) (Norum et al., 2015). Seppola-Edwardsen and Risør (2017) explore the interpretation process of bodily symptoms and sensations after cancer diagnosis in urban Northern Norway. The authors show an increase in the knowledge of late effects among people living in the aftermath of cancer, where they were introduced to new ways of understanding bodily sensations. Such sensations-based schemas which included a new cancer diagnosis as a possible explanation for specific bodily sensations were gradually replaced by other schemas with late effects as possible explanations. More knowledge is needed on socio-cultural everyday life processes related to people who live in the aftermath of cancer in Northern Norway.

1.6 Terminology

1.6.1 Everyday life

In this dissertation, ‘everyday life’ is a core term. Sztompka (2008) understands everyday life as repeatedly occurring routines, often in (real or virtual) social contexts, including rituals, deeply internalized scripts and habitual actions. It is localized in space and usually takes place in certain locations, for instance at home, in the street or in church, and often includes habits and routines of which the actors are not fully aware (Sztompka, 2008).

I am interested in studying former cancer patients’ prospective sensations, perceptions and interpretations, and their care-seeking processes in everyday life, because they have usually resumed their everyday life without active cancer treatment, and generally live a life outside the health care system. Offersen (2016), who has studied how bodily sensations are experienced, articulated and ascribed meaning as symptoms or as part of the ordinary body in everyday life in the Danish middle class, states that bodily sensations ‘...are so embedded and

immersed in everyday life that they resist disentanglement and objectification' (2016: 141). She argues for studying participants' everyday lives prospectively to understand how bodily sensations are interpreted as possibly alarming, because such interpretational processes take place in day-to-day logics and routines. Equally, Hay (2008) writes how such interpretations are difficult to reconstruct when studied from a retrospective position. Bodily sensations never start as symptoms, they only become symptoms through a social interpretive process (Classen, 1997). Such processes have their starting point in everyday life, even after a diagnosis. Furthermore, everyday symptom and sensation 'work' does not only belong to the individual, but includes and engages family, friends and other day-to-day social contacts. Such everyday assessments in relation to others have implications for when and where people seek treatment. They instigate comprehensive health initiatives, health discussions and health networks among people before, during and after consulting professional help. The everyday processes of assessing and negotiating sensations: 'When is something "something"?' (Offersen, 2016: 88) or for what to seek medical advice (Andersen & Vedsted, 2015) are crucial in understanding the possible transformation of bodily sensations into symptoms, and the related processes of coping and health care seeking.

1.6.2 Cancer survivor, or living with chronic cancer?

In research on cancer, scholars use varied terminology to name the phase that follows cancer treatment. 'Cancer survivor' or 'cancer survivorship' are currently commonly used terms (Bell, 2012; Bell & Ristovski-Slijepcevic, 2013). From a clinical point of view, 'survivor' is a distinct term used to refer to individuals who have had a life-threatening disease but have remained disease-free for a minimum of five years (Foster, Wright, Hill, Hopkinson & Roffe, 2009). It becomes blurred when used *outside* the clinical context, as it might elicit misleading associations. 'Survivor' may arouse connotations that those who 'survived', fought more than those who did not (Ehrenreich, 2010), or suggest a self-realizing and positive experience, close to a significant 'rite de passage' (Dyer, 2015; Ehrenreich, 2010). Core participants in this study partly experienced being ascribed circumstances associated with cancer which they did not actually experience; terminological labeling may intensify this.

Researchers who work in this field discuss such possible confusions in the concept of ‘survivorship’ and in relation to cancer in general, and some of these authors draw upon their own experience with cancer (Schattner, 2010). Susan Sontag (1979) was one of the first to criticize the victim-blaming language in descriptions about cancer, and challenged the common image that those who suffer from cancer have a repressed and resigned personality. Jain (2013) analyzes how e.g. the Lance Armstrong story may come with real costs for people who are in the aftermath of cancer treatment, and his iconic status overshadows the struggles ‘normal’, non-rich or non-famous people experience during the phases following treatment.

Furthermore, ‘surviving’ may also be associated with ‘closure’. Stoller, an anthropologist who himself experienced cancer and treatment (2004), emphasizes the non-closure character of cancer. In his autobiographical memoir, he develops insight into his experience of living with a cancer diagnosis while moving between an American and a West African context. In the African context, cancer is seen as an ever-present companion, while in the US or other Western contexts, terminology is connected to getting rid of cancer from lives and bodies. His arguments support the use of terms such as ‘people with chronic cancer’ or ‘people who live in the aftermath of cancer’.

Based on considerations of the terms used in research and my own experiences during fieldwork, two main descriptive terms of people who live after cancer treatment used in this dissertation are: ‘people who live in the aftermath of cancer’ or ‘people with chronic cancer’.

The terms leaves room to explore what people going through this phase experience, feel, sense, and how they relate to others and to professional health careers. Some core participants of this study live without late effects and few worries, while others are more uncertain about bodily sensations that cannot easily be classified, they feel tired or worried, and/or live with late effects. The terms indicate that former cancer patients do not suddenly change from being ill to being cured, even if no new symptoms have developed. The terms suggest that cancer may continue to be present in the participants’ lives, both as illness experiences, late effects of treatment and as a potential uncertainty and risk.

1.6.3 ‘Sensation’ and ‘symptom’

In understanding sensation-to-symptom processes, the terms ‘sensation’ and ‘symptom’ are core terms. I apply an anthropological understanding of the two terms that builds upon Hay’s (2008) definition:

‘A sensation is embodied; it is felt experience. By contrast, a symptom is a constructed and socially informed cognitive interpretation that indexes but is not itself an embodied sensation’. (2008: 221)

Processes of how bodily sensations transition into symptoms often occur before any consultation with a doctor, for instance when the individual or others interpret sensations as worrisome (Hay, 2008; Meinert & Whyte, 2017). This dissertation is based on an understanding that specific moral, societal and personal embeddedness and context inform transitions of sensations into clinically relevant symptoms. Bodily sensations may remain (only) bodily sensations, if they do not change into a relevant indicator for a specific disease within the person’s particular life context (e.g. Hay, 2008; Brandner et al., 2014). Then again, they may introduce actions, e.g. further examinations, when protagonists’ experience or communicate discomfort or other bodily signs as symptoms (Risør, 2011), even when these do not actually suggest a specific disease.

This research is located in a branch of medical anthropology with a special interest in the careful exploration of sensation-to-symptom processes among people who experience(d) cancer, partly because this may provide important information about reasons for delay in health care seeking (Andersen et al., 2010; Brander et al., 2014), and the challenges of this particular patient group in general. This dissertation is an attempt to contribute to research that examines such processes regarding people who are in the aftermath of cancer (Seppola-Edvardsen & Risør, 2017; Seppola-Edvardsen, Andersen, & Risør, 2016).

2 Aims of the study

Cancer may continue to be present in the lives of people who live in the aftermath of cancer, both as an illness experience, in connection with late effects of treatment and as a potential uncertainty and risk (Harrington et al., 2010). In many Western welfare states, the health care system is orientated towards the early diagnosis of cancer (Hvidberg et al., 2016; Rose, 2009), and people who live in the aftermath of cancer are often confronted with ambiguity in terms of being responsible for the early interpretation of bodily sensations indicating possible relapse, and trying not to contact the health care services unnecessarily (Offersen, Vedsted, & Andersen, 2017). Recognizing cancer in primary health care is known to be complex: in daily clinical

practice, symptoms which individuals may associate with a possible cancer diagnosis can regularly be attributed to other causes (Svendsen et al., 2010); on the other hand, cancer symptoms are not necessarily ‘alarming’ or painful (Merrild, 2015; Offersen, 2016). This study was conducted in a remote Norwegian coastal village in Finnmark, which suffers from the lack and high turnover of GP’s and specialized health professionals, like many municipalities in that area. This is relevant, as anthropological curiosity has generated research that shows how such aspects of remoteness, institutional accessibility and people’s identification with the Northern Norwegian culture are relevant to consider when studying approaches to situations of illness and experiences with the health care system (Abelsen, 2013; Abelsen, Gaski, & Brandstorp, 2016).

The goal of this study is to understand the illness experiences of people who live in the aftermath of cancer treatment and their interpretation and management of bodily sensations, including how these are mediated and transitioned into possible symptoms of illness, by participating in their everyday life. The study aims to explore if and how care seeking involves social and cultural norms, pragmatic solutions and relational dimensions, and to add new insights to how rurality, small village dynamics and the partly problematic access to health care services in Northern Norway relate to people’s exposure to chronic cancer.

The dissertation contributes to current anthropological discussions in which scholars call for further understanding of people’s experience of bodily sensations and their transition into symptoms, as well as processes that initiate people’s health care seeking in the context of cancer (e.g. Brandner et al., 2014). It enhances understanding of sensation-to-symptom processes in the cultural context of rural Northern Norway with its particular challenges.

On this basis, the first aim of this dissertation is to explore how the challenging local health care situation, clinical logics and the shared values in the village are embodied by the participants and form part of their sensation-to-symptom processes. This aim is discussed in Paper 1: ‘The significance of cultural norms and clinical logics for the perception of possible relapse in rural Northern Norway – sensing symptoms of cancer’.

During fieldwork, my attention was drawn to people’s varied references to nature, particularly how specific ways of using and moving in nature are seen as beneficial for health in the area. I became particularly interested in finding out if and how participants’ sensation-to-symptom processes connected to cancer can be studied in the familiar environment in and around the

remote village. Against this background, the second aim of this dissertation is to analyze how the effort and desire to stay healthy is linked to dwelling in familiar landscapes. How are bodily changes and health and how are approached in those familiar landscapes by people living in the aftermath of cancer? This question is discussed in Paper 2 of this dissertation ‘Approaching Health in Landscapes - An Ethnographic Study with Chronic Cancer Patients from a Coastal Village in Northern Norway.’

In the course of listening carefully to the interviews, I gained further insight into core participants’ sensation-to-symptom processes by studying their descriptions of worries and similar emotional experiences connected to bodily sensations as possible symptoms of relapse. I wanted to explore more closely emotions in the phase after cancer treatment, especially in such a locus as presented here. How do worries about possible relapse arise and how are they modified in everyday contexts? How do people who live in the aftermath of cancer experience and manage their worries in different everyday relations? Based on this, the third main aim of this dissertation is to unravel and understand how worries about bodily sensations and possible relapse in people living in the aftermath of cancer treatment configure and relate to various social relations and contexts. This aim is discussed in Paper 3: ‘The cancer may come back: Experiencing and managing worries of relapse in a North Norwegian village after treatment’.

Specific analytical approaches shape the research questions, design, interpretation and conclusion in this dissertation. My approach is based on a medical anthropological interest in trying to understand the social experience of illness. I am interested in studying everyday lives of people living in the aftermath of cancer, in order to understand how bodily sensations are interpreted as possibly alarming. Such interpretational processes take place in day-to-day logics and routines (Offersen 2016). I apply different theoretical approaches as analytical tools; these are grounded in either philosophical or the socio-anthropological traditions. All analytical discussions are based on and guided by the attempt to understand peoples’ everyday experience of bodily sensations and of processes of transition into symptoms.

In Paper 1, I specifically include Hay’s (2008) model of sensation-to-symptom processes, through which she analyzes how interpreting bodily sensations is always influenced by cultural information and it is socially legitimated whether such sensations should be turned into possible symptoms. Hay’s model provides a comparative basis for the exploration of how core participants’ experience bodily sensations and of processes of transition into symptoms.

In Paper 2, I continue tracing the participants' experiences of bodily sensations and possible symptoms of relapse, this time by analyzing how they strengthen their health and counter bad mood and anxiety in familiar surroundings in and around the village. The analysis builds upon Ingold's (1993) idea of 'landscape', a term that refers to a practiced, lived space, dwelt in and embodied. Additionally, I am inspired by his concept of 'taskscape', which he uses to refer to the entire ensemble of tasks carried out by skilled agents in specific surroundings that are part of their everyday life; these tasks continue as long as people are engaged in activities related to dwelling in specific surroundings. Also relevant to this dissertation is his idea of 'temporality', which can be imagined as part of the experience of those who, while conducting their activities, carry forward the process of social life. This will serve to elicit core participants' experience-near accounts and intentions in their being-in-the-world.

Paper 3 is an attempt to understand the social embeddedness of emotions regarding bodily sensations that might be signs of relapsing illness. I will be theoretically guided by anthropologist Geoffrey White's (1997) perspective on emotions. He suggests that emotions arise in social contexts or transactions and may be seen as shaping the course of events and defining social relations.

The thesis contributes to the field of 'anthropology of the senses', which calls for the integration of lived bodily experiences when approaching and analyzing culture (Porcello, 2010), and the involvement of the senses to portray the embodied representation of culture. It also adds knowledge to an anthropological understanding of emotions and to an understanding of the embodied relations to local landscapes of people living in the aftermath of cancer diagnosis and treatment. Together, these theoretical perspectives can be seen as a lens to explore how core participants in this study respond, experience, articulate and act on bodily sensations and symptoms in the specific cultural context.

3 Theoretical approaches

This dissertation is a medical anthropological study that aims broadly at understanding social and cultural experiences of illness. Medical anthropology studies medicine as a cultural phenomenon and examines how medical knowledge and medical practice are socially and

culturally embedded. Scholars in the field analyze how interpersonal relationships, cultural norms, institutions, micro and macro politics, globalization and other factors condition health and illness of individuals or groups in local worlds (Good, Fischer, Willen, & Good, 2010).

This dissertation is rooted in the methodological basis of social anthropology, the ethnographic fieldwork, which focuses on ethnographers' participation in the 'everyday life' of people they study, in order to understand e.g. practices, local institutions and cultural beliefs. 'Everyday life' is often seen as representing an authentic image of people's lives, which anthropologists hope to identify through fieldwork and participant observation. They have a particular interest in understanding human meanings and interactions as they unfold; these are based in the perspectives of individuals who are 'insiders' in particular situations and settings (Dewalt, Dewalt, & Wayland, 2000; Flick, 2012; Hammersley & Atkinson, 2007; Spradley, 1980).

Questions, perspectives and analyses emerged and developed from the data during the research process of this study, although the theoretical field of 'anthropology of the senses' inspired the formulation of the project proposal and initial research aims. However, all analytical discussions in this dissertation are guided by a central discussion in the field of 'anthropology of the senses' concerning the understanding of the transformation of bodily sensations into symptoms. My work aims to understand the cultural and social processes of people's lives in the aftermath of cancer and their interpretations and management of bodily sensations, including how these are mediated and transitioned into possible symptoms of illness.

In Chapter 3.1, I will present the field of 'anthropology of the senses', with a focus on medical anthropological studies on sense-to-symptom processes. Hay's (2008) model of sensation-to-symptom processes will be given special attention.

In Chapter 3.2, I will present research fields that link chronic cancer to activities in nature and physical activity in general, and trace the relation to nature by drawing on Ingold's discussion in his article 'The Temporality of the Landscape' (1993). I adopt Ingold's (1993) idea of 'landscape', a term that refers to a practiced, lived space, dwelt in and embodied. Additionally, I am inspired by his concept of 'taskscape', which connects tasks carried out by skilled agents in specific surroundings of everyday life. Also relevant to this dissertation is his idea of 'temporality', which can be imagined as part of the experience of people who, while conducting their activities, carry forward the process of social life.

Additionally, I will introduce Leder's perspective on 'The Absent Body' (1990), which focuses on how people's perceptions of their body might change after illness and treatment.

In Chapter 3.3, I will give an outline of social anthropological perspectives and analyses of emotion, in order to understand the social embeddedness of participants' reactions to bodily sensations that might be signs of relapsing illness. Such anthropological perspectives on emotions developed when working with participants' experiences and descriptions of their emotional states connected to previous cancer treatment and associated uncertainty, and I looked for ways to interpret how they related these emotional experiences to friends, family and acquaintances.

I mainly draw on the perspective of the anthropologist Geoffrey White (1997), who suggests that emotions arise in social contexts or transactions and may be seen as shaping the course of events and defining social relations.

3.1 Anthropology of the senses and sensation-to-symptom processes

The field of 'anthropology of the senses' is rooted in a call for greater integration of the lived bodily experience when approaching and analyzing culture (Porcello, 2010). The field as a whole calls for approaching the senses as a possible way of understanding how knowledge is constructed and how the senses may portray the embodied representation of culture (Howes, 2014). The theoretical direction developed from the idea that sensory perception, for instance touching or hearing, is both a physical and a cultural act, and can be studied as a reflection of cultural expressions and values (Classen, 1997). Scholars in anthropology in particular developed discussions motivated by the wish to take the cultural embeddedness of bodily perceptions and experiences into consideration when analyzing culture and society.

Different genealogies have developed in the field of 'anthropology of sensations'. Scholars date the beginnings back to the 1980s (Andersen, Nichter, & Risør, 2017; Porcello, 2010) and to an interest in the contextualized body (e.g. Scheper-Hughes & Lock, 1987). Analyses in the field focus on e.g. including varied sense interpretations among different social-cultural settings (Hay, 2001; Kleinman, 1980), on questioning the Western five-sense model (Geurts, 2002; Pink, 2009; Porcello, 2010; Stoller, 1997, 2004) or on how the senses may function as a record keeper of past events, worthy to be integrated in interpretations of history (Seremetakis, 1996). Within the anthropology of the senses, medical anthropologists took an interest in studying the social and cultural processes of how bodily sensations transformed into symptoms. They argue against the biomedically oriented perspective that sensation experience is congruent across

cultures (Hinton, Howes, & Kirmayer, 2008), and instead argue for studying the detailed context in which sensations transition into symptoms in order to be able to work in a critical and holistic manner (Risør, 2011). Others encourage studying sensation-to-symptom processes as ethnographic objects, e.g. as bound to local knowledge, everyday experience and power relations, and as acts of communication and interplay of values (e.g. Martinez-Hernández, 2000). A number of scholars (e.g. Hay, 2008; Hinton, Howes, & Kirmayer, 2008; Nichter, 2008) published in a special issue of 'Transcultural Psychiatry' (Vol. 45, Issue 2, from 2008) in order to focus on this specific field of understanding bodily sensations and processes of transition into clinically relevant symptoms.

For my analysis, Hay's article 'Reading sensations: understanding the process of distinguishing "fine" from "sick"' has been particularly inspiring. Hay (2008) argues that processes of how sensations transition into symptoms have not been adequately explored. She finds that studies often build upon retrospective narratives of people who are already patients. In line with Kirmayer (1992), she argues for a prospective perspective, in order to grasp social contexts and ongoing interpretive processes (Kirmayer, 1992). Hay (2008) argues that the interpretive process itself, through which experienced sensations transition into symptoms, occurs prospectively.

Hay (2008) mapped the cultural and social processes of how sensations are turned into symptoms during her fieldwork in Lombok among a rural community of 800 Sasak people between 1993 and 1995. In examining the material from her fieldwork, she finds that the following three cultural variables inform when and how sensations are turned into symptoms: 'self-perceived vulnerability', 'sensation duration', and 'disability'.

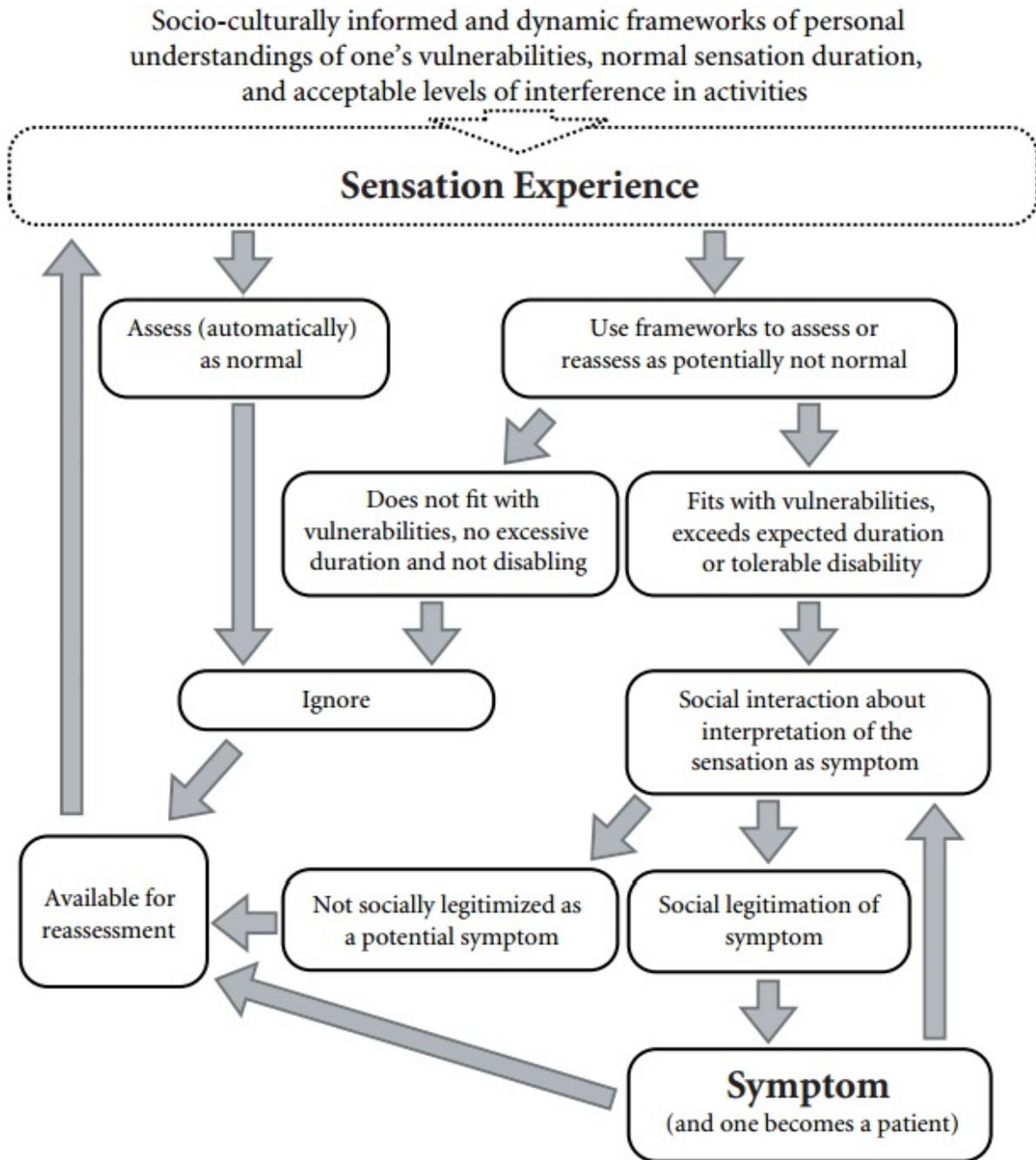
'Vulnerability is the personal sense or awareness that one is open to harm and illness' (Hay, 2008: 209). '...[N]ot every person feels themselves equally vulnerable or vulnerable in all of these arenas. A person's sense of vulnerability results from a dynamic interplay among personal past experience (i.e., "I became ill after speaking with that person before"), the warnings or scoldings of others (i.e., "it's not allowed to go out at dusk"), and one's interpretation of current sensations.' (Hay, 2008: 210). A person's understanding of vulnerabilities, of acceptable levels of disability and of what is normal sensation duration therefore varies, due to the reactions of others and other information in the world surrounding them (Hay, 2008).

Even though the understanding of time varies in different cultural contexts, Hay argues that the seriousness of a bodily sensation is usually judged by referring to time. If a person assesses the

sensation as exceeding her or his personal understanding of a certain timeframe, it may turn into a relevant clinical symptom.

Further, sensations are assessed in relation to how much they interfere with the person's everyday activities. When they do not prevent the person from conducting certain tasks, they will most likely not turn into symptoms. Those sensations that disrupt a person's daily activities are more likely to become symptoms that require outside attention.

Figure 1: Sensation to Symptom Model, Hay (2008)



Hay accompanies the model with her own empirical data, and shows how bodily sensations, when assessed as not normal, are transformed to conscious awareness and may cause the protagonist concern. In her model of analysis, she divides into interrelated elements the process of how bodily sensations become worth worrying about. She suggests social and cultural criteria

in these processes. Hay argues that sensations become worrisome if the person experiences them as ‘...(a) exceeding normal expectations for duration; (b) disabling beyond what could be considered normal; or (c) fitting with and therefore augmenting one’s sense of vulnerability (Hay 2008: 222).’ If none of these criteria are exceeded, such sensations are ignored and/or reassessed later. If at least one of the criteria is met, a sensation becomes worrisome and is presented to others, to assess whether it could be a symptom or not. Depending on other people’s opinions or recommendations on the presented bodily sensation, the person concerned either defines it as a symptom and seeks further expert help, or judges it to be a bodily sensation that may be ignored or assessed at a later point in time.

Hay was one of the first to make such careful fragmentation of the sensation-to-symptom process within a prospective approach. Her model serves as a point of departure to understand the sensation-to-symptom processes of people with chronic cancer of this study and is used as an analytical tool in Paper 1.

After Hay’s analysis and model, other medical anthropologists have studied the processes of transforming bodily sensations to symptoms specifically connected to cancer.

In order to gain more insight into delayed health care seeking, Brandner and colleagues (2014) use Hay’s analytical perspective to understand the social contexts of ovarian cancer patients’ pre-diagnostic bodily sensations and illness experiences (Brandner et al., 2014). In line with Hay (2008), the authors analyze how their interviewees’ interpretations of bodily sensations as clinically relevant symptoms are bound to specific socio-cultural contexts. The authors show how delayed health care seeking in the context of ovarian cancer is not solely linked to the non-specific nature of ovarian cancer symptoms, but also to contextual and social triggers that influence how sensations transition into symptoms. The considerations of Hay (2008) and Brandner and colleagues (2014) were a relevant theoretical inspiration for the analysis in this study, raising my awareness of how bodily sensations are intertwined with the sociocultural context and normative behavior of people who live in the aftermath of cancer.

Offersen’s (2016) study of a suburban middle-class neighborhood in Denmark provides an analysis of how study participants act on bodily sensations within the rhetoric’s of current public health care. In her analysis, she presents how they meet conflicting moral possibilities: They feel responsible to avoid misusing the health care system, are concerned about appearing as hypochondriac and about a ‘timely’ presentation of symptoms. Offersen developed Howes’ (2005) concept of ‘sensescape’ further into ‘moral sensescape’, ‘...an embodied terrain of the

shared social and cultural history of the people inhabiting it' (Offersen, 2016: 139), in which participants experience, organize and articulate bodily sensations. Further, she develops an analysis of how unusual bodily sensations are experienced within what is culturally and morally determined as 'not-normal' and 'normal' in the context of the Danish middle class (Offersen, Risør, Vedsted, & Andersen, 2016). Offersen's work is inspiring for this dissertation inasmuch as her work is based on similar research questions and deals with the assessment and negotiation of 'When is something 'something'?' (Offersen, 2016: 88) or for what participants seek medical advice for bodily sensations that may indicate the first signs of cancer.

Merrild, Andersen, Risør and Vedsted (2016) and Merrild, Vedsted and Andersen (2017) ask how the interpretation of bodily sensations is connected to class and social status. The authors provide an analysis of how sensations that may indicate cancer are perceived and dealt with differently among different social classes, how health care-seeking practices are contextually grounded and how the lower working class resists the moral obligations of staying healthy (Merrild 2016). Although social differences in the rural periphery of Norway vary somewhat from those of suburban Denmark, the author's work initiated reflections on how the interpretation of experienced bodily sensations is bound to social status, common values and morality, and on the kinds of values and relations involved in these processes in a small coastal village in Northern Norway.

Seppola-Edwardsen and Risør (2017) explore the interpretation process of bodily sensations to symptoms based on ethnographic fieldwork with people who live in the aftermath of cancer in urban northern Norway. In their analysis, Seppola-Edwardsen and Risør apply the analytical concepts 'sensation scripts' and 'sensation schemas', showing how the knowledge of late effects of people with chronic cancer increased, and their interpretation of bodily sensations gradually changed. Sensation schemas including a new cancer diagnosis as a possible explanation for specific bodily sensations were gradually replaced by other schemas with late effects as a possible explanation.

Andersen and Vedsted (2015) base their study on ethnographic fieldwork in different clinics in Denmark. Andersen observed around 400 doctor- and nurse-led clinical encounters, and participated in other clinically relevant settings, e.g. front offices, laboratories or home visits. The authors found that, in local clinical settings, logics of efficiency shaped study participants' health care-seeking practices. The background to their article is that health care services in Northern Europe have become more efficiency-oriented in the past few years, which leads to increased demands for individuals to act responsibly towards the detection of symptoms. How

do villagers experience consultations and clinical practice in a rural area which is the least popular location for health personnel to work, partly because GPs often have sole responsibility for the entire area?

3.2 Changing bodily perceptions and taskscapes in familiar surroundings

'Nature' is socially constructed. There is no such thing as 'nature' per se, including certain characteristics, e.g. specific trees or a certain degree of air moisture in a particular geographically demarcated realm (Descola, 1996). Nature is defined by the eye of the beholder, but is for many symbolized by natural surroundings that are considered relatively untouched or where a need for recreation is being fulfilled. In the course of the fieldwork, I gradually learned that being outside in the natural surroundings of the village was part of the core participants' everyday handling of bodily sensations, staying healthy and dealing with worries of relapse.

Against this background, the dissertation became inspired by a research field that investigates experiences in nature of people with chronic cancer. Many of these studies are conducted in the field of health research, and point out the health benefits of physical activity and nature-based interventions for people who live in the aftermath of cancer (Ray & Jakubec, 2014).

Certain activities can improve quality of life (Harris & Niesen-Vertommen, 2000; Lane, Jespersen, & McKenzie, 2005; McDonough, Sabiston, & Crocker, 2008; McKenzie, 1998; Mitchell & Nielsen, 2002; Mitchell, Yakiwchuk, Griffin, Gray, & Fitch, 2007; Parry, 2008), counteract late effects such as attentional fatigue (Cimprich & Ronis, 2003), encourage a sense of belonging and self-esteem (Epstein, 2004; Stevens et al., 2004) and reduce state anxiety (English, Wilson, & Keller-Olaman, 2008). In these studies, cancer, 'nature' and health are linked to a focus on health-promoting interventions and their effects. Research that links chronic cancer to physical activity in general also confirms the health-beneficial effects of certain types of activities for those affected. Scholars have shown that physical activity has preventive effects on cancer recurrence (Baumann et al., 2018), diminishes and prevents late effects from treatment (Armbruster, Song, Gatus, Lu, & Basen-Engquist, 2018; Devin et al., 2018) and has a positive effect on the cardiovascular fitness and strength in people with chronic cancer in general (Toohey, Pumpa, McKune, Cooke, & Semple, 2018). Certain activities offer a

possibility to negotiate physical, emotional and social needs (Bennett et al., 2018) and to manage depressive symptoms (Patsou, Alexias, Anagnostopoulos, & Karamouzis, 2017) in people with chronic cancer.

When searching for a theoretical perspective that would help to understand participants' relations to and use of their familiar landscapes after cancer, I decided to build my analysis on Ingold's (1993) perspective on relations between people and landscapes. His theoretical discussion provides an opportunity to understand participants' relations to the natural environment, both how they have used and ascribed meaning to the natural environment around the village before and after having been diagnosed and treated for cancer. Ingold (1993) understands 'landscape' not only as a geographically and mathematically measurable category, but sees it as formed by the activity of dwelling by humans over time. His understanding of 'landscape' refers to a practiced, lived space, dwelt in and embodied. The way people use certain places and areas, and 'tasks' that they perform, always refers to use and tasks that have been established over generations and time. Ingold uses the term 'remembrance' when analyzing how people perceive 'landscape': People recall internal images and engage with an environment that owns a storied past; they refer to this past when they dwell in landscapes. Places have unique significances, which are established by people's relational engagement in the(ir) world.

Ingold presents his analysis based on the painting 'The Harvesters' by Bruegel from 1565. His description of a tree particularly illustrates how landscapes embody the history of people who have dwelled in them.

'And for those who are gathered there [next to the tree], the prospect it affords, which is to be had nowhere else, is what gives it its particular character and identity. For another thing, no other tree has quite the same configuration of branches, diverging, bending and twisting in exactly the same way. In its present form, the tree embodies the entire history of its development from the moment it first took root. And that history consists in the unfolding of its relations with manifold components of its environment, including the people who have nurtured it, tilled the soil around it, pruned its branches, picked its fruit, and - as at present - use it as something to lean against. The people, in other words, are as much bound up in the life of the tree as is the tree in the lives of the people. Moreover, unlike the hills and the valley, the tree has manifestly grown within living memory. Thus its temporality is more consonant with that of human dwelling.

Yet in its branching structure, the tree combines an entire hierarchy of temporal rhythms, ranging from the long cycle of its own germination, growth and eventual decay to the short, annual cycle of flowering, fruiting and foliation (Ingold 1993: 167/8).

This quote illustrates how places owe their character to people's dwelling and performing of specific activities there.

Further, Ingold (1993) develops the concept 'taskscape', which he connects to the entire ensemble of tasks carried out by skilled agents in specific surroundings. 'Taskscape' is part of everyday life, and continues for as long as people are engaged in activities of dwelling in specific surroundings. A third relevant important analytical concept in his thinking is the idea of 'temporality'. 'Temporality' can be imagined as part of the experience of those who, while conducting their tasks, carry forward the process of social life; people's past and present engagements in landscapes are inherent in 'temporality' (Ingold 1993).

With these different terms, Ingold argues for seeing human life as processual including the passage of time. Such human life processes form the landscapes in which people live. '...[T]he landscape is constituted as an enduring record of - and testimony to - the lives and works of past generations who have dwelt within it, and in so doing, have left there something of themselves.' (Ingold 1997: 152)

I will use Ingold's concept as a lens to understand participants' use of familiar surroundings in dealing with bodily sensations and emotional experience after cancer and treatment, and to elicit their experience-near accounts.

Ingold's (1993) perspective has been applied as an analytical tool in other anthropological analyses (Chua, 2015; Palmer, 2017; Stead & Dominy, 2018) and by scholars in other disciplines such as anthropological archeology (Martínez-Tagüeña & Torres Cubillas, 2018; Pluckhahn, Thompson, & Cherkinsky, 2015) or archeology (Brück, 2005; Cosgrove, 1997; Ingold, 1997). Dunkley (2009) applies the concept of taskscape in ethnographic research of 'Camp E-Wen-Akee', a therapeutic camping program for troubled youth in Vermont. She shows how ongoing activities and relations in the health care setting of the camping program institution produce specific meanings or even therapeutic experiences. She argues that the idea of taskscape '...asks those concerned with health and place to identify key health-giving activities in order to theorize how well-being is produced from relations and activities. Rather than searching for elements of health in a static landscape, we may do better to catch glimpses

of health-giving interactions in a moving taskscape (2009:95).’ Dunkley thus provides a central inspiration for the analysis in Paper 2 in enhancing understanding of core participants’ actions in landscapes surrounding their village and how such actions connect to health and illness.

To understand participants’ relations to landscape and bodily sensations, I was further inspired by Leder’s perspective on ‘the absent body’ (1990). He shows how a healthy person’s awareness of his or her body often changes when the person becomes ill. According to Leder (1990), people often pay little attention to their bodies in everyday life when healthy, but bodily awareness and perceptions change after or during illness. For example, most of the world around us is made by hands, and even for hands (e.g. door handles, kitchens, or all kinds of tools). However, hands are transparent because people hardly ever pay attention to their hands while they do things with them. Thus is the healthy body in everyday life, transparently caught up in the world of engagements and involvements. Only when there is a dysfunction or a moment of breakdown does the flesh enter our awareness (Leder, 1990). The unfamiliarity of changes in the body that occur during illness demands reorganization, reinterpretation and repair. The meaning of certain actions changes when illness connected to uncertainty, pain or discomfort occurs; making plans, playing sports or chatting to friends may become linked to the body, which has changed due to illness and is perceived differently (Leder, 1990).

Leder’s underlining of the change from absent to present contributes to an understanding of how familiar activities may start to include new ‘healthy’ tasks, i.e. how many of such activities become attached to the awareness of the body and the task of staying healthy.

Both Ingold’s (1993) and Leder’s (1990) perspectives contribute to my analysis of participants’ experiences of bodily sensations and possible symptoms of relapse, in familiar surroundings in and around the village.

By applying these perspectives to the empirical data of this study, Paper 2 also touches upon the theoretical concept of ‘therapeutic landscapes’ (Gesler, 1992), which was developed in the field of geography; it intertwines place, wellbeing and social environment, and connects the two disciplines of geography and anthropology (Winchester & McGrath, 2017). It has recently re-emerged in anthropological analysis (King, 2017; Mokos, 2017; Williams, 2017). However, our analysis will involve a more process-orientated approach, treating landscapes as configuring people and being configured *by* them.

3.3 Anthropology of emotions

Studies that deal with emotions in anthropology often focus on the socio-cultural and relational embeddedness of emotions. Lutz (1988) conceptualizes ‘emotion’ ‘...as serving complex communicative, moral, and cultural purposes rather than simply as labels for internal states whose nature or essence is presumed to be universal’ (Lutz 1988: 5). Anthropological monographies, in which the empirical data on emotion-related topics guide interpretations, have analyzed culture-specific emotional expressions (e.g. Abu-Lughod, 1986; Briggs, 1970), the ethno-theoretical contextual interpretations of emotions (Wikan, 1989) and on distinguishing how classifications of emotions are culturally constructed (e.g. Scheper-Hughes, 1992).

Such and similar anthropological writings on emotions served as inspiration for this dissertation, because previous research has shown how the phase that follows cancer treatment may involve a wide range of emotional experiences, due to the uncertain nature of the course of the disease (McKenzie & Crouch, 2004; Mutsaers et al., 2016; Vickberg, 2003). Analyses on the increase in the transfer of care practices from institutions to families in Scandinavian countries show how this development leads to changes in emotional experiences for patients and families (Olsen 2015). It is reasonable to assume that such changes may also increase in the context of chronic cancer, with the increase in the total number of people who survive cancer and continue living at home, with late effects and possible new symptoms. Foss (2002) examines emotions within a Northern Norway-specific locus, and shows how emotions of feeling sad or weak were traditionally seen as a rather private matter not to be expressed in rural parts of Northern Norway, and that the expression of such emotions are still embedded in cultural common values of being able to manage and not complain about difficulties (Foss, 2002).

The analysis of Paper 3 will be based on an analytical understanding that emotional experiences mold social reality and at the same time are constituted *by* social reality (White 1997). I will focus on how emotions are experienced in dynamics with others and develop understandings of the meaning and handling of emotions in a Northern Norwegian context connected to chronic cancer.

White’s (1997) article ‘Affecting Culture: Emotion and Morality in Everyday Life’, is central to my analysis. He joins a discussion in cultural psychology on an adequate theory of ‘emotion’ that takes the relevance of social interactions into account when studying emotional processes

(e.g. Bruner, 1990; Howard, 1985; Shweder, 1990). White suggests that emotions arise in social contexts or transactions and may be seen as shaping the course of events and defining social relations:

‘Research in a wide range of languages and cultures indicates that when people talk about emotion, they are not talking primarily about states inside the individual, nor are they talking about responses or events outside the person. Rather, they are talking about processes that mediate or link persons, actions, and events. [...] [T]he shared models of emotion that lead people to make inferences jointly and interactively about the antecedents of emotion make it possible for people engaged in conversation to use emotional expressions (linguistic and non-linguistic) to appropriate or transform the meaning of social situations. In this manner, emotions are used, both consciously and unconsciously, to mediate actively social relations in much the same way in which any set of cultural signs or symbols may be used to structure interaction or manage impressions [...] (White 1997: 236-7)

In his article, he argues in favor of taking into account the specific meanings and uses of emotion in people’s everyday lives to interpret the significance of emotion in individual lives and social interactions. Emotions involve other people and do socio-moral work in everyday life, as they are always embedded in a field of interpersonal relations and actions. They are moral because they possess evaluative and behavioral elements (White, 1997). Including his observations in the analysis of this study enhances our access to participants’ processes of how bodily sensations transition into symptoms, through an analytical entry to their worrying about possible relapsing illness.

My analysis is further influenced by Hochschild’s research on ‘emotion work’ (Hochschild, 1979; 2003), which shows how people perform emotional manipulations in order to meet ‘feeling rules’ in terms of emotional intensity, direction (e.g. positive or negative) and duration in a particular situation. Hochschild discusses how private and public expectations are connected to such manipulation of feelings. These expectations are informed by a complex interplay between social structures, cultural norms, organizational climates and individual roles. In other words, emotions are shaped and signified by the social emplacement, e.g. the family context (1979; 2003).

Scholars argue how the post-cancer treatment phase is often experienced in dynamics with others (Olsen, 2015; Rasmussen, Hansen, & Elverdam, 2010; Seppola-Edvardsen, Andersen, & Risør, 2016; Tighe, Molassiotis, Morris, & Richardson, 2011), or within a ‘joint ownership of cancer’ (Illingworth, Forbat, Hubbard, & Kearney, 2010). Tighe, Molassiotis, Morris and Richardson (2011) analyze how former breast cancer patients’ day-to-day relationships with family members, co-workers, friends and care professionals influence how they make sense of

specific symptom experiences, and show how social encounters are part of shaping the ‘cancer journey’. Illingworth and colleagues (2010) emphasize the influence of close interpersonal relationships when analyzing cancer patients’ experience of bodily sensations and symptomization processes, and argue that they are core mediating features in how illness is experienced. Rasmussen, Hansen, and Elverdam (2010) show how relatives and friends can experience helplessness in terms of how they ‘are supposed to react’ to the former patient’s changed body, marked by treatment. Seppola-Edwardsen, Andersen, and Risør (2016) show how former cancer patients balance the sharing of uncertainty in order to find a strategy for ‘...managing the state of living within existential uncertainty, without letting it dominate social situations. This way former cancer patients [...] care[...] both for themselves and others’ (2016: 382).

In general, such analyses contribute insights of how people with experiences connected to cancer handle their changed body, role and vulnerability when meeting others.

From a perspective of understanding worries as occurring relationally between people and as an intrinsic part of the social, I explore worries as a phenomenon, based on experience-near stories, and consider how worry exists not only as a particular emotion in itself, but as relationally embedded and structured, organized and articulated in particular settings (White 1997; Hochschild 2003; Lutz and White 1986). Studying core participants’ emotional experiences, with a focus on their worries about possible relapse of cancer and their dealing with such worrying within their various social contexts, will shed further light on processes of how bodily sensations transition into symptoms.

4 Methodology

4.1 Developing the research design

Ethnographic fieldwork involves similar processes to those involved in ‘normal’ life: we act, communicate and seek interpersonal relationships. The difference is that during fieldwork, ethnographers usually do all they can to produce relational knowledge, developed either through observations or through verbal communication. In addition, fieldwork is embedded in epistemological premises of social anthropology, and thus follows not only the practical logic of the social, but specific disciplinary logics that formulate the theoretical framework, research

aims and use of methodology. Fieldwork can be seen as social practice that links the protagonists' social life contexts with their scientific elaboration (Sökefeld, 2008).

Studying people's 'everyday life' is often a significant part of ethnographic fieldwork, because social anthropology as a discipline has a particular interest in understanding human meanings and interactions as they unfold from the perspective of individuals who are 'insiders' in particular situations and settings (Dewalt, Dewalt, & Wayland, 2000; Flick, 2012; Hammersley & Atkinson, 2007; Spradley, 1980).

This project was designed as an anthropological study. Ethnographic fieldwork conducted for about one year included participant observation and various types of interviews (Hammersley & Atkinson, 2007; Spradley, 1980). In order to study the everyday life of people who live in the aftermath of cancer and to explore their social experiences of bodily sensations and illness in general, I engaged in and sought contact with this specific group and their social surroundings. The reason to focus specifically on everyday life is that the perception and assessment of bodily sensations often occurs in day-to-day logics and routines (Offersen 2016), and most people with chronic cancer have resumed their everyday life without active cancer treatment, in one way or another.

The initial planning involved a longitudinal qualitative approach, aimed at following villagers' practices and especially the project participants' continuity and/or changes of health status over time. Longitudinal qualitative approaches have previously been used to explore trajectories towards a diagnosis of cancer, and have attempted to understand people's transitions and experience of processes along their pathways of illness (e.g. Calman, Brunton, & Molassiotis, 2013; Maher & McConnell, 2011). I was interested in understanding if and how people with chronic cancer experience changes in modes of symptom monitoring, in the development of their interpersonal relations or in how they seek care. In other words: Is it possible to observe developments in their interpersonal relationships due to the former and/or still present state of illness? How does assessing and reacting to bodily sensations and the seeking of health care change over time in the aftermath of cancer? Do they continue during the time span of the study?

In order to examine a longer period of time and to approach these questions, the longitudinal approach used here involved participant observation and conducting a regular series of interviews over 11 months on the same repeated topics and with the same core participants (Caruana, Roman, Hernández-Sánchez, & Solli, 2015; Grosseohme & Lipstein, 2016). The

advantage of accessing data through series of interviews was to meet participants regularly throughout almost a whole year.

The detailed planning of ethnographic fieldwork is impossible, as access to people and arenas usually develops based on getting to know people and establishing trust (Hammersley & Atkinson, 2007). There are no specific ‘cancer settings’ which can be studied or observed in the village; living in the aftermath of cancer is imbedded in a person’s life as a whole (Powers, Gullifer, & Shaw, 2014). Specific interview questions were prepared before I moved to the village, but unplanned conversations on the street, spontaneous inquiries during and after interviews, closer interpersonal relationships and possibilities of my participation in activities where I could grasp core participants’ sense-to-symptom and care-seeking processes, all developed during fieldwork.

4.2 Into the village

The locus selected for the study was a rural one, contrasting with the urban setting of the co-study in the overall project. We decided to choose a small coastal village in Finnmark County for the fieldwork, some hours’ drive from the Russian and Finnish borders. The area of the whole municipality is large, but the settlement is concentrated in the small village, covering only a few square kilometers. People also live in other areas of the municipality, but in small numbers. The access to the sea is a central factor for the village, and the harbor with the different activities, mainly connected to the fishing industry, is the heart of the village. Leaving the village by car or a short walk means being immediately in hilly, grassy and tree-less surroundings for many kilometers, without passing any settlements. The municipality is often described as isolated and barren, due to such characteristics and its distance to other settlements. Other villages similar to the one described here are at least two hours’ drive away. Geographically, the area can be described as a mixture of stony ground and tundra.

The tiny village almost disappeared from the map several times. The heavy swell of the Barents Sea caused repeated flooding until engineers came finally up with constructional solutions. The fishery crisis in the late 70s and 80s, when many villagers chose to leave, affected the village too. The 90s meant the peak of the crisis for the municipality; new entrepreneurs and owners of the fishing settlements (fiskebruk) came to the village and left again. The whole economic

infrastructure threatened to collapse during that time. Today this situation is more stable, since other economic sectors have developed over time.

Most people in the village work in the service industry, the secondary sector of the economy, or the local health and care services (Statistics Norway 2016 - Hva innbyggerne arbeider med). Even though the fishing industry has diminished over the years, it is still considered the main industry in the village.³ The village has a primary and secondary school to 10th grade. Like many of the small coastal villages in the region, this village has only one of various institutions: one health center with one GP, one church with one vicar, one police station, one hotel and one museum. Two small grocery stores, an electrical shop and a tiny shop that sells products from a sheltered workshop are also located in the village.

Houses are built closely together in the village and neighbors are just a few meters away; the Norwegian term 'tettsted' [lit. dense place] describes the infrastructure of the place well. 'Tettsted' was introduced in the Norwegian language in the 1950s as a geographical term for an area of settlement with continuous agglomeration, in contrast to countryside with scattered settlements (Engelien & Steinnes, 2004). Because the history of the place is related to the fishing industry and fish processing, and this is still an important economic source of income, the place is often also referred to as a 'fiskevær' [fishing village].

There is a higher proportion of men in the village, which is most notable in the age range of 65-69 years; in January 2018, there were twice as many men as women in this age range living in the village.⁴

³ The source of this information has to remain undisclosed due to anonymity.

⁴ According to the 2016 statistics, approximately 16% of the inhabitants in the municipality had a migration background (Statistics Norway 2016 – Personer med innvanderbakgrunn).

During my fieldwork in the village in 2014, I did not meet anyone who identified as being part of the Sami population. I often noticed something unspoken when topics related to the Sami culture were mentioned. On the one hand, many in the village remember their grandparents or great-grandparents speaking Sami, but on the other, they found my question as to whether they would identify as being part of the Sami population to be unnatural. At this point, it would be too simple to merely state that the 'fornorskningsspolitikk' [Norwegianization] had left its mark, as processes of identifying as Norwegian or Sami in the area are more complex and need more background to be understood. (From about 1850-1950, the Norwegian authorities had a policy of assimilating the Sami population in much of Northern Norway (Skogvang 2013). This is not the topic of this dissertation but is still necessary to mention, as the village is in the traditional Sami area (Sápmi) in Northern Norway and individual discussions and the public debate about who can (or should) identify as Sami are currently present.

The closest village with a Sami population is about two hours away from the village, but the pasture area of the reindeer herds of some Sami families is very close. Some villagers would explain to me some of the Sami health seeking practices. Even though the villagers seemed to make a clear distinction between themselves and the Sami, many had had occasional experience of traditional Sami practices, such as blood-stopping, healing and "læsing". Other villagers would describe some peoples' belief in how ancestors paved the way for each person. A

In most years, the winter lasts from mid-October until May. The other months are known as summer months - spring and autumn are usually very short. Strong winds, hardly ever warm, are typical of the climate, and residents usually own several sets of thick clothes, wearing them throughout almost the whole year. Residential houses, of which most are detached, usually have a little hall with a heated floor right at the entrance, where clothes, boots and reflectors for the cold and dark period are stored and dried.

Almost 80% of the inhabitants (Statistics Norway 2016 - Religion) are members of the (Lutheran) Norwegian State Church, but villagers would often not define themselves as religious, but say 'Jeg har min barnetro', (I have my childhood faith). A few villagers go regularly to church on Sundays. Others attend services only on specific holidays like Christmas, All Saints' Day or for a confirmation. Most of the fewer than 3000 inhabitants speak a broad Northern Norwegian dialect, including specific local terms and sayings, quite different from the Norwegian spoken in the capital Oslo.

4.3 Defining the ethnographic field

The small community is typified by challenges in recruiting a minimal number of primary health care professionals, like many such small municipalities in the county. Additionally, the two-hour flight from the village to specialized health care services with doctors specialized in cancer and the isolated geographical location in general suggested that people in the aftermath of cancer have particular challenges in accessing medical services. According to the Norwegian Cancer Society, this specific patient group is recommended to see their GP when bodily changes last for over three weeks (Kreftforeningen, 2018). How do such particular geographical conditions affect the lives of people who have undergone cancer treatment, how do they assess bodily sensations and how does this influence their choices in contacting health care services? In the project group, we assessed this particular municipality as a suitable locality for the ethnographic exploration of these questions, as it is far away from specialized health care

stomachache may for instance be a sign of a person who died a long time ago who is guiding the person concerned in the 'right direction'. Nevertheless, it is rather rare for people to connect such non-conventional healing methods to acute cancer. Villagers usually find out about their cancer diagnosis in a conventional clinical context, and for the main treatment, their GP refers them to a specialist in the hospital.

(regular check-ups after cancer treatment are usually conducted in Tromsø (reachable by plane) or in Kirkenes (several hours' drive in good weather conditions).

The geographical, institutional and social conditions in the village are similar to other peripheral, coastal villages in Northern Norway facing current challenges in primary health care (Abelsen, Gaski, & Brandstorp, 2016).

In addition, scholars have shown how bodily sensations are embedded in cultural knowledge and social processes; research on care seeking has pointed out how relational and situational contexts are relevant for deciding what action people take when they feel ill (Alonzo, 1984; Andersen & Vedsted, 2015; Garro, 1998; Kagawa-Singer et al., 2002). This theoretical background suggested that the social density and other features connected to living in such a small village might influence how people who live in the aftermath of cancer experience the life phase that follows treatment. Anthropological research in Northern Norway has focused on studies in small communities, but only a few have had an analytical focus on a contextualized perspective on illness and health (Davis et al., 2013; Foss, 2002, 2008). This dissertation provides further knowledge on small communities in terms of the phase after cancer treatment, including new bodily sensations and late effects from treatment.

The geographical distance to Tromsø's medical specialists and the lack of stable health personnel in the primary health care was important for choosing this village as the locus of the study, as I was interested in understanding relations to health personnel and health care seeking practices for people who live in the aftermath of cancer in rural remote conditions of health care. This made it tempting to see the remote village, with its few square kilometers, as the actual ethnographic field, or as 'locus' and 'focus' at the same time. In this way, it was useful to remind myself that ethnographic settings are not simply there, but need to be distinguished, and are not isomorphic with the physical fieldwork location (Hammersley & Atkinson, 2007); however, my supervisors and I were assuming that participants' everyday lives and illness experiences were strongly connected to the characteristics of the village, including the distance to specialized health care services and social density. Nevertheless, the local, geographical boundaries of the village were regularly exceeded, in e.g. studying the participants' relation to the Norwegian health care system and their identification with biomedicine and clinical care. Such categories cross the village boundaries and place participants and their experiences in a much larger context.

4.4 Identifying core participants

Purposive sampling was conducted through the local cancer nurse and the GP of the only local practice in the village. This meant that I would rely on their judgment in choosing who would take part in the study.

Initially, I aimed at recruiting people within four years of finishing treatment. I assumed that this would represent a timeframe in which they would easily recall the time before, during and after diagnosis and treatment and all events connected to cancer, and that challenges related to the illness might still be present in everyday life. Within this frame, participants would have restarted their everyday life without active cancer treatment, following their daily routines, which, however, did not necessarily mean the same kind of everyday life that participants had before their cancer diagnosis. I aimed at understanding such processes of moving ‘into the village of the sick’ when diagnosed and having treatment, and (trying to) move back to ‘the village of the healthy’ after finishing treatment (Stoller, 2004). I was interested in studying experiences of living in the aftermath of cancer diagnosis and treatment, and if and how this influenced bodily sensations, everyday life and health seeking. I was not interested in understanding one specific cancer type, but sensations and everyday life in a small community of people who had experienced cancer and treatment.

Accessing this specific village was without difficulties, due to previously established relations with the local health care services through an earlier research project conducted by the Faculty of Health Sciences of the University of Tromsø.

Together with my main supervisor, we met with the local GP, cancer nurse and head nurse in December 2013. During the meeting, they responded with interest to the project and we agreed that fieldwork could be conducted in the village. The meeting and two further days staying in the village gave me access to the fieldwork; I started to get to know the medical staff of the local health care center and was introduced to other villagers.

The GP and the cancer nurse agreed to select participants and invite them to join the study, based on the GP’s records, according to the criteria. They suggested expanding the timeframe of 1-5 years after treatment, pointing out that the experience of treatment, late effects and occasional new sensations due to cancer may be still be present even longer after finishing treatment. They also doubted that I would be able to recruit as many as ten participants who

fitted the five-year frame in the village. We agreed, and they started recruiting participants who had completed their treatment 1-10 years earlier.

Ten core participants, I presumed, would give access to varied accounts, and provide enough time to follow up on each participant, to get to know them over time and hopefully allow for detailed understanding of each of them. The GP, cancer nurse and I agreed on trying to recruit everyone who lived in the municipality at that time, fulfilled the above-mentioned criteria and were fit enough to take part in the study. Initially, they were able to name nine potential participants from their records, whom they contacted and invited to participate. I then contacted these nine through an information letter, which included detailed information about the study and the processes of interviewing and participant observation (see appendix) and a written consent that they were asked to sign. Two had changed their minds, but seven of them still wanted to take part in the study. I was then able to recruit two participants through an advertisement in the local newspaper (see appendix). Those two called me and showed interest in the study. Parallel to this, I talked to new acquaintances in the village, who then came up with names of people who might fulfill the criteria. In this way, I recruited another participant, through a process that can best be described as snowball sampling⁵.

These last three participants also received the information letter and a written consent that they were asked to sign.

The sample is not a representative cross-section of people who have finished cancer treatment, but rather of those who were in the aftermath of cancer treatment and fit and motivated enough to take part in such a study to share their stories. I am not sure why the GP and local cancer nurse did not originally suggest the three participants whom I recruited myself. I was grateful for the GP's and the local cancer nurse's input and help as I knew that being employed as core health personnel in the village was often stressful work.

The participants were four men and six women, all Norwegians⁶, between 41 and 82 years of age, with different diagnoses (see table 1) and different career and socioeconomic backgrounds. Nine of the ten had completed conventional cancer treatment. One participant had been

⁵ In fact, the core participants did not recruit others, but the selection of participant Ines (see table 1) was based on my mingling with the community and on relying on my own judgment to select her based on the research aims (Fetterman, 2010; Hammersley & Atkinson, 2007).

⁶ All of them had Norwegian citizenship and identified as Norwegians.

previously diagnosed with 'non-Hodgkin's lymphoma', which was being kept at bay by three different radiotherapies when I met him. He rated his illness as being on 'standby' for the time being. They had all previously received surgery, radio- or chemotherapy or a combination of these. Some participants had added alternative medicine, e.g. distant healing, mindfulness, yoga or silver shark oil during and after treatment to support the healing process and alleviate late effects.

All ten main informants had resumed aspects of everyday life that were similar to before their diagnosis. Some participants were back to work, while others had to either reduce their working hours or retire after treatment due to late effects. Regular check-ups at intervals of 3, 6 or 12 months, were a feature of this period. They were fit enough to spend time with me and give interviews, but had varied experiences related to the diagnosis, ranging from an uncomplicated operation four years ago to the experience of relapse and living with complications. Almost all of them expressed worries about the cancer coming back.

Name/ Sex	Age	recruited by	Occup ation	Civil status/living situation/no. of children	No. of interv iews	Meetings outside interviews	Year of diagnosis
Jan/ Male	62	local health center	retired	couple/lives most of the year by himself/2	5	One long walk; once met by chance at the store; several dinners with family/friends; chatting on the phone; met at local village party; collecting seagull eggs; one spontaneous visit to my house	2011
Siri/ female	42	local health center	works fulltime	couple/lives with partner/0	6	Several times met by chance in the street; met at local village party	2010
Kari/f	50	local health center	works fulltime	couple/lives with youngest son/ 3	6	We practiced a hobby together once a week; several times met by chance in the street; met at local village party	2010
Ole/m	77	local health center	retired	single/lives by himself/2	5	Spending time together at local café/kiosk with others	2009
Synnøve /f	57	local health center	works 50% part- time	couple/lives with husband/2	3	One long walk	2002 and 2003
Ines/f	57	acquaintan ce	works full- time	single/lives by herself/0	4	One short walk	2013
Björg/f	41	local health center	works full- time	couple/lives with children and partner/2	3	Several times met by chance in the street/café/ grocery store; visits at her work several times	2013
Terje/m	82	local health center	retired	single/lives by himself/1	4	Several long walks; several times drinking coffee and chatting in his home	2014
Gro/f	69	local newspaper	retired	single/lives by herself/0	3	Met by chance at grocery store once	2011
Torleif/ m	64	local newspaper	retired	couple/lives with partner/2	4	Met by chance at local concert once	Not cured but kept at bay

Table 1. Overview of informants (status in 2014)

To understand more of core participants' everyday life, I was hoping to spend time with their families at home or at their workplaces, i.e. time not dedicated to the regular interviews. Work and home, I imagined, are two important arenas of everyday life. This turned out to be difficult as some participants preferred to meet me alone, and I partly sensed that I might invade participants' privacy if I spent time with them beyond the planned interviews. One participant made it clear that she would like to keep her family out of the study, especially her husband who does not feel at ease when getting involved in cancer-related topics again, after the family went through a stressful period due to her treatment.

Visiting participants at work was also difficult. Five participants were retired. One participant had to change from a full-time to a part-time position, due to late effects like fatigue and joint pain, and I did not want to challenge her even more during her work. Two of my participants were rather unhappy with their work, and it might have meant additional strain if I were to accompany them. In the end, I visited one participant at work from time to time.

Two participants were very interested in meeting me regularly and I spent a great deal of time at their homes or in outdoor activities with them. One of them simply enjoyed being accompanied on his long walks and often explained to me the history of the village and its surroundings. The other one liked to illustrate the local traditions and the geological history of the region and to introduce me to all his acquaintances. We also used to take long walks together, I had several dinners with his family and friends, we chatted on the phone and once we collected seagull eggs together.

After some weeks in the field, my circle of acquaintances and friends enlarged and I started to meet participants and recognize familiar faces in the street, in the two local grocery stores, at social events in the village or during free time activities, due to the small size of the village. Even though I met participants occasionally, I would only receive scattered data from those short meetings where we would chat for two or three minutes, and I assessed it as insufficient to be called 'participant observation'. Initially, I wanted my work as participant observer among core participants to take place spontaneously, in line with ideals of a natural environment and first-hand actions (Spradley, 1980). However, it developed, not surprisingly, into involving planning, such as agreeing on meetings first, and often setting a limited timeframe, which is not an unusual way of socializing in Western societies. I decided to try to schedule and organize particular activities like walking or coffee meetings with core participants. People would try to make me fit in 'time slots' after work, after dinner or before lunch in the morning when they

had a day off. In this way, I was able to spend time with participants outside the interviews, apart from three of them, who wanted to keep to the interview meetings.

The informal gatherings included 'question-observation' (Spradley, 1980), which meant that I regularly inquired by asking questions, and sometimes tried to lead conversations to topics that could add to my understanding. I talked with participants about topics such as sensations, pain or symptoms, since some core participants actually used walking to get rid of late effects or act upon possible extraordinary bodily sensations and psychologically difficult moments.

4.5 Transparency, isolation, engagements in the village

During the fieldwork period, I tried to spend as much time outside my house as possible. I usually searched for public settings to find opportunities to talk to people, I visited and spent time with core participants and villagers or left home in the mornings to go to the office in the tiny local museum that I was offered to use during my stay. I wanted to use the time well, and made an effort to make written notes of all encounters and observations, of everything that struck me as important in terms of my observation guide/themes, while trying to become more specific and focused on health-related topics as time passed. The following paragraphs contain relevant descriptions of the life context of the villagers, including the core participants presented later.

One day in September, after I contacted my landlady to tell her that a water pipe had to be fixed, I found two tenors from the choir that I was singing with every week standing at my door. They were two of the few craftsmen in the village who could fix the damage. While I was busy with the thought of whether it was strange that they would repair my toilet, they had already made their way into my bathroom - they apparently knew the house already. I learned that people in the village interact with each other through multiple relations; one meets the same persons regularly through e.g. family gatherings, work, voluntary organizations, or at the local training center.

The house that I rented was only a few steps from the main road, which runs parallel to the coastline. Along the main road, in the center, the only kiosk is located - an indispensable spot in the village. People do not only constantly pass it, but also regularly enter the kiosk, because

it is at the same time a pharmacy, snack bar, video store, café, supermarket, bookstore and an important social meeting spot. From time to time, I sat down on one of the five chairs in the corner by the door of the kiosk and chatted with some women. The villages' only pharmacy is inside the kiosk, which makes it impossible to miss what the salesperson would say to customers. This sometimes turned purchasing drugs into a public event. When someone dies, when a store changes its owner, when the reindeer start coming over the mountain pasture down to the village, when someone has to be flown to the hospital or when a pupil is bullied at school – these different events or news find their way sooner or later to every villager, for instance in conversations in the little corner of the kiosk between the women who have known each other their whole lives.

'I haven't seen any light lately in his kitchen window, maybe he has gotten worse again?', one lady asked, while knitting at an incredible speed on a Wednesday evening in the local school, where I regularly met with 10 to 20 women for knitting. People care about their co-villagers and exchange news and discuss changes in other villagers' activity, health or treatment, especially when something unexpected or dangerous may have occurred, such as any illness or health event. The only emergency ambulance has a permanent parking space in a little side street off the main road, and it is impossible not to notice when it passes by or when it is not at its usual spot, meaning that somewhere in the village a medical emergency must have occurred. Nevertheless, chatting and commenting or sharing thoughts about illness also has limits. When I talked to an acquaintance from the weekly choir practice about my work over a cup of black coffee during our break, he could not refrain from telling me how difficult it was for him to deal with the cancer diagnosis of one of his in-laws. 'I must honestly admit that I was avoiding her – I didn't know how to react and what to say.' I also encountered people's involuntary dealing with challenging situations such as illness on their own, contrary to the above-described atmosphere of the lively exchange of information. Ole, who suffered prostate cancer in 2009, tells how he misses having a close friend of his age who is in a similar situation, meaning with a similar diagnosis. With such a friend he could exchange experiences and worries: 'Men who are of my age here are embarrassed to talk about it when something down there is not working.' Ole also participates in the 11 o'clock coffee klatches in the only café in the village, which take place every morning from Monday to Friday. There he meets and chats with other men of his age, and I joined him for three of those mornings. He is single and retired, and these daily get-togethers provide respite from the many hours that Ole spends on his own. He enjoys going there and does not like coming late. I saw him several times getting out of his car and hurrying

up the few steps of the café in the mornings. The cafe is decorated in a simple style and the smell of fried food is constantly hanging in the air. Whenever the temperature would reach more than 10 degrees Celsius, the owner would put a table and two chairs outside the café. When I showed up for the first time in the chatty atmosphere, it initially created a rather long silence, as I was female and far younger than the usual members. The group of men talks about everything, including health, death, illness or for instance the high number of single men in the village. Even though many villagers live in a household consisting of a mother, father and their children in a detached house, and this seems to be the ideal, many residents also live alone. Ole, Jan, Ines, Terje and Gro, i.e. half of my core participants, were living alone and spending large parts of their lives by themselves. On the one hand, some of the men at the 11 o'clock café chats talked about the difficulty of finding a life partner in the small village, especially at a certain age. On the other hand, they emphasized their satisfaction with living in the village, as they had found a good life, were able to own an affordable house and enjoy all the space of the far north of Norway. Not only the regulars at the café meetings but also other villagers felt dedicated to the rural north and identified with having a kind of 'opposite' life style to city dwellers, for example in Oslo. The village symbolizes safety; one can leave the doors open and meet new people in an open manner. People appreciate letting their children play anywhere without worrying. Cities are associated with uncertainty, crime, anonymity and the fact that inhabitants of such crowded areas have no choice but to develop a skeptical attitude in order to protect themselves.

During one of my café visits, one person was speaking about an acquaintance who was struggling with ventricular fibrillation, while another mentioned a villager who had to take the morning plane to the hospital. I realized that it was actually more common to talk about others going through difficult times than to ask directly the people present about their health problems or potential difficulties. By this indirect way of exchanging e.g. health news, 'everyone' is actually informed about 'everyone'.

Nevertheless, the villagers are aware of the disadvantages of living in the small isolated place, for instance the real strain caused by the lack of specialists, e.g. medical staff, teachers, pastors or organists that would stay for a long period.

'Honestly, I'm really unsure. I mean anyone can be a teacher here! If we stay, that means he'll go to school here.' In 2014, I became friends with a woman who was a few years older than I was, and who seemed quite concerned about having to send her boy to the local school. She originally comes from a different part of Norway, moved to the remote area as an experiment

and stayed. Will her son get the education she wants him to get in a place where the amount of lessons has to be reduced regularly, due to staff shortages in the local school?

Similarly, villagers were concerned about whether they would get the same medical treatment as people in other parts of Norway. Kari, one of the core participants of this study, who suffered breast cancer in 2010, had one of her breasts removed due to the diagnosis. The atmosphere was tense in one of the interviews, when she explained her anger at the long waiting period to get an implant. She was convinced that she had to wait longer to get this type of plastic surgery than people in other parts of Norway: 'In general, we're less visible here in the North. I feel like we live too far away from everything. If I lived in Oslo, I'd have had the surgery done long ago.'

Indeed, after a while I realized that I had registered my place of residence for the first time in a municipality without a dentist. 'I'll get my teeth checked and done this summer, when we're going to Bulgaria anyway', commented Kari towards the end of one of the interviews when we talked about her holiday plans. Some residents had not seen a dentist in Norway for years, as it seemed to be more profitable for the villagers to get a dental examination done when they were spending their holidays in a cheaper European country anyway.

Not only was the difficulty in contacting specialists a health-related challenge for the villagers, but also the situation of the ever-changing GPs. Terje, one of the core participants, spends as much time outside as possible, walking, at his cabin, berry picking, smoking salmon in his little smokehouse in the garden or fishing. He has never really been outside of Northern Norway and speaks only Norwegian. While we were sitting in his living room and drinking coffee during one of the monthly interviews, he gave an account of how, during one of the consultations at the GP's office, he could hardly understand the temporary GP's pronunciation. He was recruited from Sweden to stay for a few weeks in the village, and had, according to Terje, an Arabic accent. At the end of the consultation, Terje realized that the GP had no idea of his previous cancer, because he had apparently had no time to read his patient record due to the stress of his work as a temporary GP.

The lack of staff and the way the villagers asked me regularly if I liked the place and its people hinted at the village's vulnerable status. I enjoyed living there, and appreciated the opportunity to develop as an anthropologist and people's curiosity towards me, and could easily give them their hoped-for answer, but I sometimes experienced the question as a longing for much-needed self-assurance. In 2014, a long-awaited fish store was opened, and for weeks everyone seemed to talk and be very enthusiastic about it. People are proud of the village's self-sustainability,

but the challenge of people moving away from the area was a repeated topic of discussion. When I was chatting with the deputy mayor while doing my groceries, she asked if I would consider staying and finishing my studies as distance learning. People place their hopes in every new person that arrives in the village, that he or she may start a small business that creates jobs, increases the attractiveness of the little place and makes both locals and newcomers want to stay.

In this context, people comment positively on the involvement of villagers in the many small projects in the village: offering badminton lessons for teenagers, collecting historic material for the museum, planting new plants around the main square, or if someone takes the time and responsibility to help out with whatever may be needed at any particular time.

‘I’ve finally retired, and now I’ll just do things I’ve been wanting to do for a long time’. A few weeks after Torleif, one other core participant, retired, he spent a couple of days at the family plot to do some measuring and initial constructions for a new cabin. When he came back he took over additional responsibilities at the local badminton club. It is appreciated when people are still active and continue tracking their small life projects after retiring, which is why it was interesting to observe pensioners and older people in the village, who seemed busier than those who were in regular employment.

In general, social life is often organized around people’s voluntary engagement in clubs and things that need to be done in the village. Many events, restorations or improvements take place within the frame of 'dugnad', which are usually voluntary and collectively performed activities for the good of voluntary organizations or the village as a whole. The regular participation in the cleaning up of the rubbish on the coastline is considered as one of those important dugnad activities.

Even though people appreciate new people and make newcomers welcome, it was difficult for me to get access to participation in everyday life in families and their close relations, although relationships to family members were central during the phase of acute illness, and core family is significant to villagers in general. ‘Well, it’s better if we keep doing these interviews outside my home, ok? He [husband] is so fed up with all the cancer stuff.’ Bjørg, one of the core participants, tried to avoid dealing with cancer-related issues at home and involving her family; we therefore used to meet at the local health care center for interviews. There was always a small meeting room or corner somewhere, where we could sit down and talk. Most of the other core participants also preferred to meet me alone. Cancer-related topics had taken up too much

space in the families already, and it seemed that the core participants did not want to burden their family members unnecessarily again.

During my stay, I experienced periods where villagers had great difficulty leaving the place by the various means of transport due to the extreme weather. Anecdotes during church services, the lyrics of songs in concerts, the image on the municipality's emblem and the motifs of a local art exhibition are often associated with the weather, nature and storms. There are particularly high expectations concerning the summer. Even in a chilly 15 degrees Celsius in July, the residents may suddenly exchange their winter coats for shorts and t-shirts, in order to expose their transparent-blue shimmering legs and arms to some rays of sunshine. Villagers are very interested in the weather and the seasons and the climate is a constant topic when meeting people.

4.6 Participant observation in voluntary organizations and the outdoor surroundings of the village

My fieldwork in the village also meant spending time walking in the outdoor surroundings of the village with the inhabitants, and participating in and observing conversations with people engaged in specific activities and voluntary organizations. I chose to spend time outdoors and in clubs and voluntary organizations, as the village is known for a high concentration of sports, handicraft and music clubs, and walking in the surrounding countryside is common and considered as healthy. Almost every villager is a member of at least one local club or organization, and such engagement is highly appreciated in the village. In these social situations, villagers would chat about local politics, people's health, work or simply things that happened in the village. Further, the core participants' use of the surroundings became a relevant dimension in understanding their sensation-to-symptom processes.

Talking to people in the village while taking part in different activities helped to gradually reveal e.g. their understanding of 'moral behavior', how they talk about others, in which activities they were engaging and how they were making sense of those activities. Talking about my work in those groups and contexts, and 'using our bodies' while we were walking, sometimes spontaneously initiated health-related stories and discussions.

4.6.1 The outdoor surroundings of the village

The villagers designate the barren area between the houses and surrounding the village creatively; most of the year it is covered with snow, and during the few months of summer with yellowish green grass and shrubs. However, none of the villagers would describe the area as barren. People would rather show me the best spots to have a coffee break after a long walk or explain to me which year has had a good berry season, and where the best spots are to pick them (only the blueberry spots (!); cloudberry spots are top secret due to poor growth in some years). Collecting berries and seagull eggs, hunting, fishing and walking in the areas between houses or in the natural surroundings outside the village are popular activities.

During my time in the field, I often found myself observing and listening to how inhabitants relate to certain outdoor surroundings. I was listening to regular discussions on when the area is in a good condition for skiing and snow scooter trips and when for fly fishing, walking and berry picking. Some villagers invited me to join them for a walk from time to time. I wanted to 'start to work somewhere' as a participant observer and suspected that I would gain access to sensory and bodily perceptions by taking a closer look at participants' outdoor activities, and was happy to be asked if I would join them. In the course of the study, exploring core participants' use of such surroundings became a relevant dimension in understanding their sensation-to-symptom processes, as I was able to observe how such surroundings seemed to represent areas where they act in response to diverse bodily sensations connected to cancer. Some participants contemplate and sense pain or other sensations while they spend time outdoors walking or pursuing other activities; spending time in the natural surroundings sometimes provides space to reflect on what certain sensations could mean, but sometimes the opposite: space to forget about worries connected to relapse and illness.

Spending time with inhabitants or core participants in those surroundings showed me how different my perception of the surroundings was from theirs. I often experienced the place as 'closed off', due to the only main road, which runs either east or west out of the village, but the westward road stops after a few kilometers. In the other directions, the village is bordered by the coastline and hilly surroundings, covered with snow for large parts of the year. The villagers would understand this as wide-open spaces with opportunities for snow scootering, fishing, skiing and they would associate the sea with an expanse of freedom. People relate strongly to the natural surroundings of the village; they would discuss it in everyday talk, and describe and demonstrate how it is relevant for their integrity and their identity as Northern Norwegians.

Villagers define for instance their favorite coffee break place in the countryside, describe in detail the routes of the reindeer walking down the hilly areas in spring and emphasize how important it is to have 'nature' outside one's house.

Similarly, the community comes to official and unofficial agreements about e.g. on which paths and on which side of the road people are supposed to walk or how to behave around dogs; a notebook is kept in which everyone can enter his or her name after walking a certain number of kilometers. In winter, people walk only on the snow-free roads, because they would sink deep into the snow where it is not cleared. Boundaries are also defined by the ski-slope grooming; such slopes are specifically maintained for skiers and cross-country skiing is also recognized as a health-promoting activity. Villagers often have a certain idea of when a particular activity is beneficial for health. The distance covered when skiing should be longer than walking distances, because skiing requires less energy per kilometer than walking.

4.6.2 Participating and observing in voluntary organizations

Many inhabitants have fishing as either a hobby or profession, and conversations we had while making fly fishing lures in the fishing club were sometimes full of jargon to me. Next to the little morgue in the local health care center, we found a free room, in which we used to make the lures, organized by the only local fishing club. We were a group of five and it was one club member's initiative to teach us how to make them, as it was a popular activity to go fly-fishing for salmon in the summer. Villagers who grew up in this remote area, next to the sea and a salmon river, are used to going fishing regularly and having either cod or salmon in the freezer all year round. Villagers use the resources of their natural environment and integrate them into their daily diet or verbally into conversations and vocabulary.

In the knitting club, on Wednesdays, I was able to experience the social density and lack of anonymity in the village, which I use in the analytical considerations of the three articles of this dissertation. For knitting, we met in one of the classrooms of the local school for two or three hours, where we usually chatted and drank coffee. There would be 10 to 20 women of a large age range. This type of handicraft is far more popular among women than men, which is why it appeared natural for me to join this group and why someone recommended it to me in the

first place. We usually sat in a round circle, and every person would bring her knitting project, ready for continuation, and always chocolate, licorice and other sweets.

One of our projects was to knit blankets, little hats and socks for premature infants. We sent these to the humanitarian non-governmental organization 'Doctors Without Borders', and some of the women discussed this as an opportunity to contribute to 'the common good'.

Three members of the brass band arranged a short crash course for me to teach me how to play the baritone, so that I would be able to join them for their practices and concerts. No one has to undergo an audition to be able to join the band; it is rather the opposite. It is appreciated if someone shows interest in playing; and there is a tacit understanding that being too picky about good or bad players would be inappropriate in such a small place. Brass bands have a long tradition in Norway, and most villages have one. Members try to maintain the existence of the band - a dissolution of the band due to too few members or little interest would cause disappointment. The band usually accompanies special holidays or anniversaries, and supports and manifests the integrity and cohesion of the village.

By being part of the local brass band, I was also able to observe activities that partly reflected how villagers value people who care for the common good, participate in voluntary work and care for others. In this context, it seemed appropriate to have most of the villagers organized in leisure-time activity groups: this enabled the chief administrative officer to organize them in weekly shifts every spring and summer to get the beaches cleaned up. Periodically, waste is washed up on the shore and most villagers are used to being involved in this 'spring cleaning'. On one of those late spring days in 2014, it was our turn with the brass band. The villagers usually collect the waste and burn most of it afterwards at a safe place on the seashore. Nobody is obliged to organize or participate in this or in knitting for premature babies, but during my fieldwork I could observe not only that there is an implicit norm to get involved in it (Dahl, 2015), but that people would simply experience a positive feeling and satisfaction when engaging in these charitable activities.

4.7 Qualitative Interviews

During fieldwork, the practices of interviewing and participant observation are not strictly separable from each other, but due to readability, I decided to write separate sections for interviews and observations.

I lived close to the ten core participants and agreed with each of them on an initial meeting, which in most cases included the first biographical interview, lasting between 43 minutes and 2 hours and 20 minutes (Schütze, 1983). From then on, I interviewed each participant roughly every month within a semi-structured framework; these interviews took between 23 minutes and 1 hour and 47 minutes.

I started interviewing five participants in February, one in March, two in April and the last two participants in May 2014. Delays in sampling were the reason for the variations in starting the series of interviews. After each interview, we usually agreed on the next meeting, which I tried to schedule roughly one month later. I conducted between three and six interviews with each participant, either in participants' homes, my apartment/house or in a quiet corner of the local café. In total, I conducted 43 interviews in 2014. Some core participants had more capacity and interest to integrate interviews into their daily routines than others.

All interviews were tape-recorded, except three interviews with one participant who asked me to skip the recording. I took notes during all interviews. They usually consisted of a few key words, to allow me to reconstruct the interview from memory in case the tape recorder did not work.

In the following, I will present in more detail the methodological background of the two different interview types, how the interviews were conducted and what kind of information I was able to access.

4.7.1 Biographical interviews

I was interested in the participants' experience of having had cancer and of undergoing treatment as a background for understanding their present life in the aftermath of cancer. The first interview with each of them was planned as open, biographical interview, focusing on their illness experience from a retrospective perspective (Küsters, 2009; Schütze, 1983). The aim was to gain insight into their retrospective reflections on illness and treatment, relations to

health care services, relevant members of the family, circle of friends and other villagers from the onset of the illness and through the period of diagnosis and treatment.

Further purposes and the procedures of interviewing will be explained in more detail in the following section.

The open, biographical interview is used to elicit individual experiences and to let the interviewees reconstruct them in their internal and individual logic (Flick, 2012). I started each initial interview with the phrase: ‘Today I would just like to hear your illness story. How did it all start?’ In this way, I was aiming to capture participants’ descriptions of what happened and the key moments in their experience of illness and treatment (Küsters, 2009; Rosenthal, 1993; Rosenthal, 1995; Schütze, 1983).

These interviews gave me access to terms and expressions participants used to describe their illness story and revealed who in their social environment had been involved during their disease and treatment period. These biographical interviews provided a thematic base for the monthly, semi-structured interviews (see appendix 8.3). Participants described how the former illness and treatment led to individual daily challenges that still persisted. Many described how they had overlooked certain bodily sensations, and in retrospect assessed them to be symptoms. Participants also related these experiences to their present attentiveness to pain or sensations that could indicate new illness. In these interviews, almost all participants shared their thoughts about death and dying, and their worry about crises in their families caused by their illness.

4.7.2 Monthly semi-structured interviews

Qualitative semi-structured interviews are used to elicit participants’ reflections and experiences that are not quantifiable in numbers or short multiple-choice answers. In contrast to the biographical interviews, however, preliminary assumptions are operationalized as questions and organized in a semi-structured interview guide (see appendix 8.3) (Flick, 2012). When we worked on designing questions for the guide during the project group meetings, we followed suggestions in the methodology literature, which recommends starting by collecting relevant theme complexes in note form in a brainstorming that mirror the overall goals and initial theoretical approaches of this study (Kuckartz, Dresing, Raediker, & Stefer, 2008). Such

theme complexes were not only an orientation as to which topics should be included in the interview guide, but also which themes to cover during the fieldwork as a whole.

The theme complexes were:

- 'Experience of new sensations or symptoms – When/How?'
- 'Which circumstances influence participants' health?'
- 'Activities for better health? How does the illness/ sensations control everyday life?'
- 'What role does the popular/folk/professional care sector play?'
- 'What language do participants use to describe body and illness?'
- 'Any social processes of turning bodily sensations into symptoms? How do these processes change everyday life?'
- 'What is just a sensation, what is a symptom?'
- 'Care-seeking behavior'
- 'Choice of treatment (conventional medicine/alternative/other)'
- 'How do people with chronic cancer experience changes or transitions in symptom monitoring, in the development of social relations or in healthcare seeking?'

From these themes, we formed sub-questions, which eventually became the interview questions (Kuckartz, Dresing, Raediker, & Stefer, 2008; Kvale & Brinkmann, 2009). Following the methodology literature (Flick, 2012; Merton, 1946/1979), I formulated the questions by trying to include the following criteria:

1. Non-influencing of the interviewees. 2. Specificity. 3. A broad spectrum of relevant subjects. 4. Depth. Later, during my time in the field and when conducting subsequent interviews, I also had these criteria in mind. In terms of this study, it meant that...

1. ... participants were regularly reminded that they may add answers and reflections which are not necessarily connected to the interview questions.
2. ... in the interview situation, I tried to ask questions that were specific enough, to encourage participants to give responses that related to specific topics. At the same time, questions were formulated to enable participants to apply their own structure and individual logics to their answers.
3. ... a broad spectrum of topics was probed (the guide included 33 questions - see appendix) and participants were given the possibility to introduce their own topics.
4. ... during the interviews, I made sure that dialogues were becoming deep enough, by asking for specific details and examples.

The guide helped me structure interview conversations and make sure that the relevant topics were covered and that the interview would not deviate too much from the themes (Kuckartz, Dresing, Raediker, & Stefer, 2008). Every month, I asked participants about their well-being, if they perceive any bodily changes and how they contextualize these, the people involved in decisions of care seeking and their role and finally their health system encounters and specific contacts with health care personal. I hardly ever used clinical terms in the interviews; quite often participants explained the processes and treatments in the hospital to me, such as the machines for radiation and the application of chemotherapy and other drugs.

Open-ended, semi-structured interviews allow for flexibility to inquire spontaneously between prepared questions, and the possibility of restructuring questions or adding follow-up questions based on participants' answers. During the interviews, I often asked 'Could you say more about this?'; 'What do you mean by ... when you say ...?'. This gave interviewees the possibility to elaborate, and gave *me* the chance to access more detailed answers (Flick, 2012).

I sometimes added questions to the guide before the interviews, based on answers or issues participants had raised in previous interviews. Sometimes these questions formed the introductory part of the interview: 'Last time you mentioned...'.

I asked the participants the same or at least very similar questions every month, and I could sometimes sense how boredom crept into some interview sequences. I often felt like skipping certain questions, because I suspected that some answers would be the same as last month. However, I always tried to go through the whole interview guide to make sure we covered the same topics regularly.

Some participants became more and more aware of the subjects they were interested in telling me about and found to be important in their lives after having had a cancer diagnosis and treatment. One male participant, for example, asked if we could spend more time on topics connected to communication with health care personnel in the hospital; he related this to his fear of not being appropriately treated and to his worries of relapse. A female participant wanted to reflect on how the illness had changed her relationship, especially the physical contact, with her husband. Another female participant wanted to start her story by telling me about the recent death of her husband, as she had no opportunity to talk about it with anyone else. Talking about her partner became a way of accessing her actual story about becoming ill. I gave space to the

topics suggested by the participants, and could often sense that they felt a need to talk about topics that were inadequately addressed during treatment and in the following phase.

In many of the interviews, I listened to long sequences without interrupting. Most participants relished the possibility of talking about their experiences and worries. Only two participants preferred to keep the interviews and our meetings short and answered my questions in three or four sentences, which sometimes meant that the data emanating from these interviews was less dense, but not necessarily. The others emphasized the lack of opportunity to speak in detail about their experiences in their everyday life, especially in a phase where the ‘worst part is supposed to be over’ and participants often found they were considered as ‘recovered’ by people in their social sphere. The methodology literature mentioned how qualitative interviews often encourage interviewees to reflect upon circumstances that they have not previously reflected about (Flick, 2012; Kvale & Brinkmann, 2009). During the interviews, participants said that they experienced their thoughts about possible relapse as challenging, and that it had become more difficult to share such worries with others with the increased length of time since their treatment.

During the eleven months of fieldwork in 2014, I experienced several changes in my relationship with the participants. We usually had a mutual wish for a meaningful conversation. All participants wanted to contribute to research or provide new knowledge through their participation, and I was interested in listening to their accounts and discussing topics that would lead to increased understanding and analysis. This ‘professional connection’ gradually became more personal. Some participants spent most of their days and weeks by themselves, and so did I in some parts of my fieldwork. I had a few acquaintances in the village, but at the same time, I was new and I lacked an established social environment. Spending time with participants and having a meaningful exchange simply felt good. Sometimes we spent time together talking for a while after the interviews, and our relationship shifted between the defined interviews and simply enjoying spending time together.

With all participants, I developed at least a loose acquaintance, and with some even a relationship that resembled a friendship. Such relations often develop during an ethnographic fieldwork, and the ethical issues connected to friendship have to be considered as an important part of the research process (Ellis, Adams, & Bochner, 2010). I made choices about which information from conversations I ‘allowed myself’ to turn into data, and which was part of a personal exchange between two acquaintances or friends, which I would not include. I chose to

remind participants repeatedly that my stay in the village was connected to the study. If we talked about issues of health or cancer during general chats, I might comment: 'I'll write that down in my research diary if that's ok.' Or: 'That's an interesting remark – can I quote you in my dissertation?'

Tears and anger were sometimes part of the interviews, such as when participants shared emotions connected to changes in their family situation, or to being frustrated with the health care system or being worried about relapse. The literature on socio-scientific research methods discusses the therapeutic sphere of interviewing, as telling stories can also serve to process, balance and evaluate experiences (Rosenthal, 1995; Schütze, 1983). In a cancer-related context, scholars have investigated how qualitative interviews have similarities with therapeutic interviews, as both offer possibilities for reflection, by allowing participants to find a voice or space for repressed emotions (Colbourne & Sque, 2005).

One of the participants strongly identified me with research, which she considered sophisticated and difficult to relate to. Her answers were not necessarily short, compared to the other participants, but I sensed that she was worried about giving 'wrong' answers and that she was usually very nervous before the interviews. Even though I always kept the tape recorder turned off when interviewing her, and this seemed to make her feel relieved, it remained a challenge to communicate that there was no 'right' or 'wrong' in her answers, but that I was interested in learning from her perspective and reflections.

4.8 Everyday lives in the village in the aftermath of cancer

My primary consideration was aspects of anonymity and ethics when deciding how I would present core participants' lives, relationships and coping strategies. A presentation using a short paragraph per person would have provided a useful overview for the reader. Nevertheless, I decided to illustrate information on core participants' lives in a more thematic arrangement in this subchapter, and give only brief information when mentioning specific participants. This restricts the identification of individual participants and preserves the limits of anonymity.

In the following, I will illustrate how core interlocutors differ greatly from each other in many aspects, but at the same time, deal with similar concerns, rely on the same health care system, and have similar experiences of living in the small village. Such similarities between people who live in the aftermath of cancer turned my analysis towards generating themes and developing typologies, which will be described more closely in 4.10.

4.8.1 Core participants' varying diagnoses and life circumstances

Core participants differed from each other regarding diagnosis, scope of treatment and resulting late effects. They ranged from Synnøve, who has had two different cancer diagnoses, undergone complicated surgery and chemotherapy, experienced long phases of being wheelchair-bound and lives now with multiple late effects, to Ole, who had a small prostate surgery, with subsequent late effects for only a couple of weeks after treatment.

Core participants differed also in terms of their life situation; their profession, age and gender varied. In 2013, one of the younger ones had to suddenly withdraw for a while from her active family life with two small children and husband, from a responsible role in her job, and her many daily social contacts, due to the diagnosis and subsequent hospitalization. 'There was no room for me to react to the diagnosis.' This statement during our first interview indicates her initial response to the diagnosis in 2013, which was primarily directed at sorting out how she would find substitutes for her tasks at home and work while she was in hospital for treatment. During acute illness, she and some other core participants had many things they had to keep track of: being ill, having a job that was not automatically taken over by others, their family and not least the desire to be able to have a little space to just be ill and digest the diagnosis.

Other core participants of this study were older and had fewer responsibilities. Terje was over 80, and had a much quieter life than the younger participant described above; he lived by himself and his daughter was grown up and lived far away.

The other core participants lived either by themselves, or with their core families or a significant other. Five were retired, and the other five worked either full- or part-time. Their age or the severity of their diagnosis, however, was not proportional to their level of fitness or state of health.

Correspondingly, core participants had varying time frames available for the regular interviews. The body language of one of them would often hint at her tight schedule and that she had to

continue with her work, which meant that our meetings were sometimes short and hectic. In comparison, my encounters with Terje were quite different. After one of the regular interviews with him, we went for a walk, and while we were coming closer back to his house again, he asked: ‘Well, I made some fishcakes yesterday. You want to try some?’ He did not want me to leave yet, and filled the coffee machine with water and ground coffee in next to no time. While we were waiting for the hot drink, we sat down on the steps outside his house and ate our fishcakes; we were hungry from the walk and the wind.

4.8.2 Sense-to-symptom processes in everyday life

Almost all core participants were regularly worried by bodily sensations, mostly late effects from treatment, but which could also be signs for a possible relapse. They differed in terms of how intensely they experienced such worrying about for instance high blood pressure, the occasional itching of a surgery scar or stomachaches. In this way, the severity of the diagnosis, or how much time had passed since treatment, was not necessarily proportional to the intensity of worrying; more relevant was how core participants dealt with challenging situations in life in general.

Kari, a former breast cancer patient, is often concerned, and feels like contacting her GP regularly: the high blood pressure, the small spots on the last x-ray - might there be a new tumor? Such concerns often give her difficulty in sleeping. On the other hand, Siri, a former ovarian cancer patient, is less worried, even though her diagnosis does not necessarily seem less severe. She gets a bit nervous a few days before the regular medical checkups. Other core participants referred to similar aspects: before a regular checkup, where they are usually examined for (new) tumors and/or other health problems, some of them become thoughtful or/and nervous. Most of them say that they can relax after the doctor has given them the ‘green light’ and they can return in either 3, 6 or 12 months for a new check-up. Some participants pay less attention to symptoms as the time since treatment passes, while others become more attentive when new bodily sensations appear.

Despite the considerable differences between core participants, the processes of how their bodily sensations transition into symptoms follow similar patterns. ‘You have to be rational - if your blood is fresh and red, everything is fine’, said my core participant Jan, who is a former lung cancer patient, during one of our interviews. We usually spent a lot of time together

talking, and when we were interrupted, it was often due to his strong coughs, which sometimes meant that he had to go to the bathroom and spit out small amounts of blood into the washbasin. Most people who live in the aftermath of cancer in this study are now familiar with the characteristics of their diagnosis. If they suspect that it would harm their body if they do not contact the health care services, they usually make an appointment with their GP.

4.8.3 Medical treatments and health care seeking

All core participants received conventional treatment, consisting of either chemotherapy, radiation therapy and/or surgery. They often used clinical terms in their everyday language and during interviews, such as ‘relapse’, ‘diagnosis’ or ‘metastasis’, which symbolizes how illness and body were experienced in terms of a biomedical understanding. Only one core participant stated that she additionally used a so-called ‘distant healer’ for treatment, when she was in a phase of illness which was about ‘life and death’, and she felt desperate and saw no other way out. Another core participant regularly sought psychotherapeutic support during and after treatment, to counter her fear of death connected to the diagnosis. Some others searched for alternative treatment, such as massage therapy or acupuncture, not for their main treatment, but to counter side and late effects.

All the core interlocutors' different diagnoses were confirmed in a conventional medicine context, usually in one of the Northern Norwegian hospitals, with a prior referral from their GP. They were encouraged to re-contact their GP if they experienced new symptoms. One of the core participants directly contacts the specialists in the hospital in Tromsø. He finds contacting the GP unnecessary since the GP usually does not know his medical history anyway and might send him home again without a referral.

Even though contact with the local GP seems to be tense at times, due to the high turnover, the villagers find that they have no choice but to see the GP when they have complaints. ‘Well, we wouldn’t call it “fastlege”.’ One villager hints at the ironic meaning of the word ‘fastlege’, the Norwegian term for ‘GP’ or one’s ‘regular doctor’, which literally means ‘permanent doctor’. Almost all core participants pointed out the poor local health care situation to me several times. There are varied needs that are not covered, according to participants. One does not feel ‘visible’ because she lives so far north, and is convinced that inhabitants of Northern Norway

have to wait longer for surgeries or interventions that make life in the aftermath of cancer easier to handle. Other participants see challenges in the language; the local health care center quite often employs non-Norwegian health care professionals. Most participants see the biggest challenges as the GP's sole responsibility for the whole municipality and having to present indeterminate bodily sensations to shifting GPs, who do not know the patients well and who sometimes even have to be reminded of their previous cancer diagnoses in consultations.

'The only physiotherapist has died, and I haven't bothered to find a new one since then,' said one of my core participants during one of the regular interviews. She is a former ovarian cancer patient, who grew up in the village and has always lived there. Her statement shows how the physical distance to the health care system influences villagers' health care seeking practices in one way or the other. Another core participant explained that her documents were not forwarded from a smaller hospital to a bigger one, and she therefore had surgery later than planned. One explained how he drove a long way to see a specialist to no avail, because of a misunderstanding about the appointment.

4.8.4 Activities for better health and handling of worries

All participants had an idea that a healthy lifestyle, primarily including exercise, could help to avoid relapse and to relieve pain and other health-related challenges. 'When we go for a walk, we usually push ourselves a little bit towards the airport, against the wind', replied one of my core participants when I asked him how he and his wife would enjoy their new status as retirees. His response reflects the beliefs of core participants and villagers that spending time outdoors and using one's body while standing up to the weather may improve health and fitness.

Occasionally, core participants mentioned how traveling, trying to continue working, pursuing a meaningful hobby, trying to include humor in everyday life as much as possible, or religious prayers helped them during and after treatment to prevent their illness from determining their lives too much. All core participants believed (some just hinted, others said it quite directly) that it is all about having a positive attitude, which facilitates the mastery of cancer and the period after treatment.

Friends, acquaintances or partners played an essential part in providing relief for core interlocutors' late effects or worrying about relapse. Members of such lay referral networks

recommended for instance dietary supplements, hypnosis or mindfulness techniques. Some of the core interlocutors described how close friends and significant others took an active part in providing psychological support and trying to find solutions during painful periods. Core participants' statements range from one woman with late effects from chemotherapy who mentioned: 'I wouldn't be able to walk anymore if he [husband] didn't massage my feet regularly', to a former breast cancer patient who lived by herself and told me: 'I wouldn't have survived without her regular calls', referring to a good friend who consoled the core participant again and again with encouraging words during treatment.

4.8.5 Relation to family, friends and co-villagers

Core participants regularly talked to family members, friends and other villagers about their former diagnosis, mentioning their health status and bodily sensations that could indicate a possible relapse. There were, however, differences in the intensity of such exchanges between core participants and their social contacts. Some people meet many acquaintances, friends and family members every day at work and at home, while others have a quieter life and less contact with other people.

The age and family constellation of core participants bore no relation to their sense of not wanting to burden their relatives and family with matters connected to their past cancer or a possible relapse. Some of them preferred to protect family members by avoiding sharing their worrying, often because they sensed that the family had the need to recover from the illness experience. 'When we talk over the phone, I never tell her that my chest's hurting,' said one former lung cancer patient in one of the interviews, when he talked with me about his long distance relationship with his wife.

Some of the core interlocutors found it easier to share their worrying with friends, especially those who actually had close friends that they could talk to about challenging life situations in general. Others mentioned that they missed having good friends or colleagues with whom they could share their worries.

Experiencing worries in the context of the village and in relation to acquaintances there meant both comfort and challenges for the core participants. Sometimes the size of the village represented reassurance with its non-anonymous social infrastructure, but sometimes villagers struggled with the lack of anonymity, as it is difficult to keep information to oneself and one is

repeatedly confronted with others' opinions about one's health. Many of the core participants experienced both these sides of living in a small community, and saw the non-anonymity and size as both boon and bane.

4.9 Field relations

The methodology literature prepared me for the many different aspects of possible roles I would receive and take up during fieldwork. I was prepared to appear as a novice, that villagers would be skeptical towards me, that there might be a mismatch between participants' expectations of me and my own intentions and that my fieldwork would have to be terminated one day (Hammersley & Atkinson, 2007).

It is difficult to judge what kind of impression interviewees and villagers in general had of me. Even though I sensed that the core participants enjoyed talking to me, the nervous reaction of one of them indicated that she found my interviewing or research to be disturbing (I have briefly described the interview situations with her in 4.7.2).

The first few days, when I was strolling around, people would not necessarily notice that there was a newcomer to the village, as I would not attract special attention through my looks; I adjusted my clothing: saloppes-like pants, fleece and thick winter coats are standard clothes most of the year in the area. In addition, February, the month when I arrived, is dark most hours of the day and the snowy wind simply makes it sometimes impossible to see who is actually passing on the street. I avoided showing up with a notebook to make notes in front of others. On the other hand, I was aware of having a different background and following a different lifestyle than people who grew up in the little village; I was almost 30, not married, and without any plans of settling down with a male partner. The village was small and dense; once people had met me, they knew that I was new.

My first conversations in places such as the village square or the kiosk or at events at the museum were usually positive: 'What work are you doing here?' would be often one of the initial questions. I found people to be curious and interested in my reasons for moving into their small, remote village.

In general, the villagers are used to people coming and going in the village: in the past, fishermen from other villages and countries came, and nowadays it may be curious filmmakers fascinated by the sights and the remoteness or German tourists hoping to find some peace and quiet. So even when people see someone new, they are used to not always exactly knowing who that person is.

My Norwegian still lacked many words in 2014, but it soon absorbed many local words and expressions. I did not have many obligations at home and could take part in events and accept invitations on weekends. I was not aiming to create a specific impression of myself, but tried to present myself as receptive to new information by showing interest in joining different voluntary organizations in the village. In the methodology literature this is described as an opportunity to gain natural access to participants, to work as active participator (Spradley, 1980) and to move from being an outsider to having a more active role during the ethnographic process (Adler & Adler, 1987). Appearing as interested, receptive and flexible to join activities was the key to accessing many of my experiences in the field. I see it also as having been a key to gaining acceptance despite having less life experience, being much younger than the participants, being unfamiliar with all the different features of the region and village, and most importantly not having experienced a life-threatening illness myself (Spradley, 1980).

While my gender influenced my access to some situations, it was less relevant in others. In order to stop sexually motivated approaches made by one male participant, I decided to end our regular encounters prematurely. The fact that I was a female researcher also influenced my contact with the other three male participants. My impression was that I represented, or participants wished to see in me, a 'female understanding and caring side'. Three of the four male participants stated how they had often found it easier to talk to women than to men about emotional difficulties. This influenced my data, as I show in the second article where I discuss the term 'worrying' [å være bekymra] and reflect not only on anthropological concepts of the term 'emotion', but also on my personal contact with participants.

Some participants were dealing with their changed bodily appearance and functioning after therapy and the deviation from societal norms about femininity and masculinity. Such topics seemed to be partly difficult to talk about; this became noticeable through para-linguistic features, e.g. when participants paused several times in their answers, when they were brought to tears or when they lowered their voices. Conversations with female participants about changes in physical contact with their male partners were also part of such 'difficult'

conversations, and I consider that my female gender facilitated my access to this. Interview sections dominated by such topics were characterized by an atmosphere of female connectedness or solidarity between the female participants and me.

In other situations, when we would gather around a table to make tiny flies for fly fishing in a semi-dark room in winter, wrapped in thick woolen sweaters and layers of pants, it seemed irrelevant whether we were men or women. All the thick clothes hiding all body shapes, in combination with the villagers' distancing themselves from the 'superficialities' of cities, created an ambience where gender categories seemed to become blurred.

Having a non-Norwegian background was significant for my data acquisition. I come from a large German city, which I assess as being relevant for noticing things that villagers take for granted, e.g. in relation to activities and values related to nature, being outdoors and 'harvesting nature'.

When I presented how my participants approach health through spending time outdoors and taking walks in their familiar surroundings at a conference in Aarhus, Denmark, I was reminded of the subjective nature of conducting fieldwork and conducting an anthropological analysis (Nagel, 1979). A Norwegian listener commented: 'I would have been blind to all these results - I partly do the things your participants do myself.' Other anthropologists would probably have used different observations as a basis for their analysis.

4.10 Analyzing the material

Almost all the analytical processes were performed in consultation with my supervisors. We had monthly phone meetings while I was conducting fieldwork, and had regular work meetings when I moved back to Tromsø. During fieldwork, I recorded relevant observations and conversations in a diary, which consisted mostly of jotting down situations, dialogues and quotes that I assessed as relevant (Emerson, 2011), and I took the theoretical perspective of 'medical anthropology of the senses' with me into the field, which guided the questions and my general focus. Especially the recognition of the cultural embeddedness of the meanings of sensations, which are mediated by social practices and symbolic systems (Classen, 1993) led me to pay special attention to local cultural values and to how bodily sensations and illness

occur relationally. After the period of fieldwork, other and more concrete theoretical approaches also found their way into the study while I moved back and forth between reading theory and data material, analyzing and writing. Hay's (2008) sensation-to-symptom model, Ingold's (1993) definition of landscape and his concept of taskscape and White's (1997) anthropology of emotions became the main relevant approaches for the analysis, and all analytical discussions were thus based on and guided by the attempt to understand core participants' everyday experiences of bodily sensations and of processes of transition into symptoms.

When reflecting on the analysis, it is necessary to go back to the beginnings of the fieldwork. After spending time with core participants and villagers, and after a few interviews, where the above-mentioned themes (Chapter 4.7.2) were operationalized as questions and inquiries, my decisions on how and where to plan further interviews and ideas about what I would ask core participants, besides the questions in the interview guide, were influenced by my first findings. The participants' concern about experiencing relapse and the challenges of living a life with uncertainty became crucial in understanding bodily sensations, everyday life and care-seeking practices. After some time, the interview data and field notes mostly revolved around their worries about 'relapse' and their experience of the distance to specialist health care services. I assessed this as becoming crucial to the future analysis. My conversations with participants and my inquiries in the interviews aimed to probe how worries of relapse were experienced in relation to bodily sensations and everyday life. Their worrying and dealing with bodily sensations which might indicate possible relapse became approachable for me through my participating in their embodied use of familiar landscapes, in their relationships, in the everyday moral dynamics of the village and through listening to their challenges in relation to local primary health care. The dissertation title 'Will I get cancer again?' mirrors such methodological choices that I took during fieldwork.

The initial planning involved a longitudinal qualitative approach, aiming at following villagers' practices and especially core participants' changes of health status over time and the attempt to understand their transitions and experiences of social processes along their pathways of living in the aftermath of cancer. In other words, I was initially interested in exploring how interactions and practices connected to core participants' experience of illness transform over time. A systematical comparison of time-related regularities was planned (e.g. Calman, Brunton & Molassiotis 2013; Maher & McConnell 2011), and the regular interview schedule was

intended to represent a basis for an analytical procedure that would respond to questions like: Is it possible to observe developments within the period of fieldwork in participants' interpersonal relationships due to the former and/or still present state of illness? How does assessing and reacting to bodily sensations, and the seeking of health care change over time in the aftermath of cancer? Do they continue during the studied time span?

The ethnographic process often involves changes in the choice of methods and analysis during the first steps of fieldwork (Hammersley & Atkinson, 2007). Participants' concerns regarding possible relapse and their experience of the distance to specialist health care services became my two main focus areas; I could thus have used the longitudinal approach to my data to embark on a longitudinal analysis with a focus on change, but instead followed the empirical findings. This turned my analysis towards generating themes, developing typologies and creating topical categories on relapse, worries, healthcare seeking and landscapes. I did make attempts at studying the data as longitudinal data but eventually found it difficult to come up with specific changes over time, and tried to avoid forcing the data to fit into some specific mold (Hammersley & Atkinson, 2007). The data were analyzed inductively, which means that coding took place without trying to fit it into a pre-existing coding frame or analytic preconceptions; I let the data 'drive' my analysis (Malterud, 2011).

I kept looking for an analytical approach that would be suitable for analyzing the rich ethnographic material and I followed a theme-orientated organization of the data, which is a common way to interpret ethnographic material (Hammersley & Atkinson, 2007). Theme-orientated analyses are often used to investigate under-researched areas, as this type of analysis acknowledges the ways individuals make meaning of their experience, and the ways the broader social context impinges on those meanings (Braun & Clarke, 2006).

The interpretation of the data of this study was not a distinct stage of research; rather, during the entire study, I moved repeatedly back and forth between ideas, data and theory, which is a process characteristic of the analysis of ethnographic studies. By thinking things through several times, I partly discovered what 'the research is really about', and adjusted my research aims accordingly (Hammersley & Atkinson, 2007).

The analytical process started already during fieldwork by listening through every interview and reading through all field notes from participant observations at least once. When I returned to Tromsø, I transcribed every first interview conducted with the core participants. I listened through the rest of the interviews, read through the field notes once again and wrote short

thematic excerpts instead of transcribing all interviews, as the interview material was very large. My supervisors also read parts of the transcribed material.

I then sorted my material according to etic categories (Hammersley & Atkinson, 2007). Over forty categories were developed from the interview data and field notes, reflecting my analytical thoughts, such as 'communication in the hospital', 'talking with relatives about worries' or 'physical activity'. Already during categorizing, it emerged that some of the themes would be more relevant than others in relation to the research aims (Emerson, 2011; Flick, 2012; Kuckartz, Dresing, Raediker, & Stefer, 2008). The process of categorizing did not occur statically either, but was accompanied by reading through research articles and literature on theories, and discussing analytical suggestions and themes with my supervisors.

I then combined the relevant categories into overarching themes. Some of the themes were eliminated, as I had not enough data to support them or they merged with another theme into a more general one.

In meetings with my first supervisor, we worked on designing thematic maps. We used paper and pencil to sketch how the different themes fit together, and which overall story they told about the data. These thematic maps were formulated into a text, which was where the paper writing started. At this point, I considered the exact wording of certain sections from the semi-structured interviews to be necessary for my analytical work, and decided to transcribe parts of some interviews in hindsight.

A significant component of writing was moving back and forth between the entire data set, the coded extracts and analysis of the data and relevant theoretical approaches in my discipline (Emerson, 2011). Writing itself catalyzed the analysis; discrepancies often became clear only while phrasing. My writing process was accompanied by new discoveries and analytical conclusions were often only completed when articles were finished (Emerson, 2011; Hammersley & Atkinson, 2007).

During the analytical process, including the writing part, I had to decide which quotes and stories I would integrate in the articles. Some core participants gave very detailed answers to specific questions. A few interlocutors would formulate in an explicit way what others described more incidentally. Some of the core participants' statements even became a point of entry to the indistinct formulations or indications of other core participants. With some of them, I spent more time and got to know them better than others, and thus had more opportunities to inquire and obtain more detailed information. Such details were decisive for how I chose to integrate participants' statements and stories in the different papers of this dissertation.

The most relevant theoretical contributions guiding my analysis during these different analytical steps were those of Hay (2008), Ingold (1993) and White (1997).

Writing Paper 1 brought me to the initial question of the project: How do people who live in the aftermath of cancer experience bodily sensations, make sense of and act towards cancer illness and health?

I took a closer look at certain interviews, such as those with core participant Gro. In our fifth interview, she mentions the tingling and light twitching in the area of her postoperative scar, which sometimes turns into something that she thinks she should contact her GP or a specialist about. She works full-time, walks her dog three times a day, meets friends and her hobby groups regularly and lives with her partner in one of the many detached houses. It is only seven weeks until her next check-up in Kirkenes and traveling to see a specialist before that, in order to be checked earlier, seems to be too much fuss to her. The worst thing she knows is to walk around making other people feel sorry for her. She loves to live in the small village, where in her opinion people seem to take good care of each other. She decides against contacting the doctor in the end: 'Seven weeks... well, that should be ok', she says.

What exactly is the background of this decision? How does a physical sensation become almost a symptom and then not in the end? Approaching these questions became my task during fieldwork and part of the discussion in Paper 1, where we contribute to the anthropological discussion on senses in general, but especially to a better understanding of how social norms and local health care conditions influence sensation-to-symptom processes of people with chronic cancer in rural Northern Norway.

I considered it fruitful to apply Hay's sensation-to-symptom model to the data of this study, because it became clear that I would be able to contribute additional analytical aspects to her suggestions for the exploration of sensation-to-symptom processes.

Embracing Ingold's (1993) theoretical perspective on landscapes, temporality and taskscape provided an opportunity to understand participants' health-related use of the natural environment in reference to their previous routines and the habits of past generations of villagers. The participants' habits of walking around and inside the village and spending time in the countryside close to their homes is unmistakably related to their desire to keep healthy in the period after treatment, which is why I sought suitable perspectives such as that of Ingold. I draw on Ingold's (1993) perspective in my material as a result of my fieldwork, with reference to that there is a need to gain further knowledge associating routines of familiar outdoor

activities of people with chronic cancer with their challenges in handling late effects, worries and newly arising sensations.

Being afraid of dying, being worried about relapse, being cheery and thankful for having survived: the data from my fieldwork was rich in participants' descriptions of their emotional states. During the fieldwork, I learned that core participants' need to share their worrying with others is often accompanied by thoughts about not wanting to become a burden or about other people's expectations of having to show gratitude for having survived, instead of being worried in a phase where 'things are supposed to be back to normal'.

I looked for ways to interpret how participants deal with cancer-related emotional experiences in relation to friends, family and acquaintances, which is why perspectives rooted in the field of the 'anthropology of emotions', particular White's (1997) perspective, are included as an analytical tool in Paper 3.

4.11 Strengths

'...in general my feeling since October is that I have a different contact with people. I get access to stories to which I believe I would not have had access half a year before. People also see that I can contribute with things and they want to me to take part. I believe that this last part of my field research was the most important one and that it has made this research somehow "qualitative".'

My research diary contains this colloquial quote indicating that my long-term stay and participation in the village and the regular interview schedule are strong sides of this study. I participated in the 'everyday life' of people and had the opportunity to collect rich data over 11 months.

The interview schedule and the long period enabled me to follow participants' varied activities in winter and summer, which were often connected to their approach of staying healthy. The regular interviews gave me the opportunity to follow up on participants' experiences of having had cancer, and how they dealt with arising bodily sensations and late effects during the period of interviewing. The schedule allowed me to get to know the participants better over time, and

to spend time together outside the interviews, and to join groups and gatherings in the village. Meeting core participants regularly every month also enabled me to observe how some of them experienced days and weeks of recovery, but could suddenly shift to suffer from late effects and/or new sensations, which sometimes caused new worrying. Another advantage was that participants became more and more aware of the subjects they were interested in telling me about in the interviews and which they assessed as being an important part of their lives in the aftermath of cancer. Getting to know the participants better made me capable of understanding nuances and ‘reading between the lines’. I could, for instance, sense how one of my participants was actually more worried than he verbalized in the interviews. He had been diagnosed with lung cancer and knew perfectly well about the low survival rate of this diagnosis. He would address serious issues ironically or between the lines, or sometimes speak with an exaggerated objectivity about death.

I was able to participate in the everyday life and voluntary organizations over time, which enabled an analysis of common values connected to being a valued villager and ways of dealing with illness.

The first biographical interviews were important for establishing contact with participants, giving access to terms and expressions they used to describe their illness story and revealing the people in their social environment who had been involved during their disease and treatment period. These aspects were important to get to know the participants’ life stories in relation to cancer. These biographical interviews also provided a thematic and relational base for the monthly, semi-structured interviews which focused on their present situation and experiences. Another strength of this study was the previously established contacts with the local health care center through an earlier research project conducted by the Faculty of Health Sciences of the University of Tromsø, which is one reason why the staff from the local health care center was very open-minded towards the implementation of the study in the little village. In addition, we met the local GP, cancer nurse and head nurse already in December 2013. During the meeting, they responded with interest to the project and we agreed that fieldwork could be conducted in the village. The meeting and two further days staying in the village even before I started the ‘actual’ fieldwork in February 2014, gave me access to villagers, gatekeepers and the medical staff. I could relatively quickly start interviewing in 2014.

4.12 Limitations

Although this study was carefully prepared, I am aware of its shortcomings and limitations. First, I was challenged by delays in the sampling procedure, which is why the series of interviews with individual participants started at different points in time. This meant differences in the number of interviews, the data obtained, and my familiarity with the core participants. Varied information and data on the individual core participants was also due to their different motivations in including me in their everyday life. Gaining richer information about some core participants than others was, however, not necessarily congruent with their influence on the analysis. Challenges connected to my role as a female researcher have already been described in the subchapter 'field relations'.

A different limitation of the study is the heterogeneity of the sampling. The ten core participants differ in terms of diagnosis and the time that has passed since treatment (from three months to five years earlier). They also differ in terms of how they sense uncertainty and worrying, which, however, is not necessarily connected to the seriousness of their diagnosis or the temporal aspect, but rather to the personal approach to challenges in general. The heterogeneity of the sampling had also an impact on the analytical process, as the core participants were difficult to compare; I therefore concentrated on identifying similarities and common topics between them. The sampling was conducted through the only local GP and the cancer nurse in the village, and I had to rely on their judgment in choosing who would take part in the study. Later I chose to find three participants on my own, through actual fieldwork and through getting involved in local structures. The sample consists therefore of those who were in the aftermath of cancer treatment and fit and motivated enough to take part in such a study to share their stories. The core participants that took part in this study were most likely motivated by communicating challenges associated with their diagnosis.

Further, I see limitations in the difficulty of talking about 'sensations'. Following the overall goal of this study to understand core participants' experiences and management of bodily sensations and to explore how these are mediated and transitioned into possible symptoms of illness meant that I was studying a subject area which is difficult to approach verbally and to capture in text. Even though I was able to participate in different activities and build up interpersonal relationships with core participants over time, which enabled me to grasp their sense to symptom processes, the verbal exchange about being and moving in nature, for instance, and what this is 'doing' to the body, appeared to me rather clumsy.

Another limitation was that it was difficult for me to get access to participation in everyday life in families and close relationships. My analysis therefore builds primarily upon what core participants told me about how health care seeking, emotional experiences and experiences of bodily sensations are dealt with in close relationships. This was similar in interactions with health care personnel; my access to these meetings and relations occurred primarily through participants' retrospective reflections. This means that my motivation to obtain information from a prospective perspective was only partially fulfilled. I was often there when core participants were physically exhausted or experienced pain, and I was then able to fulfill my wish to catch their prospective sensations, perceptions and interpretations. Nevertheless, much of the information in my data includes core participants' stories from a retrospective perspective about events that occurred e.g. two days, three weeks or even months and years ago.

Although some criteria, such as the patient group to be investigated, were defined at an early stage of the project, the observations during fieldwork and the interpretation of the data could have developed into a different direction with a different ethnographer. The point is not that the findings would necessarily have contradicted those presented here, but someone else may have observed some aspects more clearly and others less so and illuminated the data from different theoretical perspectives. For me, an important focus area was the villagers' use of the natural environment surrounding their village. Such activities might not have been relevant to an ethnographer from Norway, as spending time outdoors in natural surroundings is embedded in the Norwegian culture in general. Further, an ethnographer with a clinical background may have paid more attention to the processes and structural challenges at the local health center. Observed circumstances can be turned into data and interpreted in many ways; in qualitative research, there is a risk that interpretations lead to wrong conclusions; the formulation of alternative hypotheses helps to avoid that. Such an examination of internal validity through the formulation of alternative explanations and the subsequent search for confirmation or contradiction can therefore never be complete, since it will never be possible to exclude the existence of unknown and hidden influences, leading to certain alternative findings or conclusions (Flick, 2012). Despite this, my supervisors and I discussed possible other interpretations in regular meetings. Most of the different analytical steps were challenged and repeatedly compared again with the data and individual statements; together, we also questioned my observations in the field.

4.13 Ethical considerations

The American Anthropological Association published a list of ethical requirements for anthropological research in their 2012 Ethics Statement (American Anthropological Association, 2012), which serves as a basis for consideration of the ethics-related topics of this dissertation. Institutional review boards or other review committees are recommended to use these ethical guidelines to verify the compliance with them in anthropological projects.

Before we started the project, it was presented to the Regional Committee for Medical and Health Research Ethics (REK), as we planned to interview a vulnerable patient group, but the project as a whole was found to be outside the jurisdiction of the committee, i.e. not a health scientific project. It has also been reported to and approved by the Norwegian Data Protection Authority.

I tried to ensure that the whole research process was as transparent, honest and confidential as possible. I experienced that dealing with confidentiality was the most challenging ethical aspect during fieldwork and later in the process of analyzing and publishing, due to the small size of the village. I was careful not to inform other villagers when I was visiting core participants for interviews or on other occasions. Descriptions which would reveal the identity of the informants were left out of the dissertation. Instead of presenting contexts sorted by each participant, and using one short paragraph per person, which would have resulted in a useful overview for the reader, I provide information on participants' lives and the differences between them in a thematic presentation in Chapter 4.8. The information that participants provided was treated with confidentiality and was de-identified. All participant names have been changed. The diagnoses of the individual core participants are mentioned in the third paper of this dissertation: 'The significance of cultural norms and clinical logics for the perception of possible relapse in rural Northern Norway – sensing symptoms of cancer', which was a request from the reviewers of the journal where it was published.

The project was based on informed consent from all ten core participants (see appendix), which also meant that participants had the possibility to withdraw from the project at any point or to decide that they did not want to be tape recorded (as already shown above, one core participant made use of this). They were all given a project description in Norwegian, the participants' first language. I would explain the aim of our meetings, when I sensed that a participant was unsure about the purpose of the interviewing or my role as participant observer.

The study consists of confidential records and conversations with people who have experienced a challenging cancer illness and treatment. It addresses the sensual, emotional and relational aspects of their illness experiences. This means that people who live in the aftermath of cancer and their close ones were vulnerable both during fieldwork and by being included in the analysis. During the interviews, I tried to assess whether I could address unpleasant topics or ask further questions, and tried not to trigger fears or other negative feelings. I kept my material inaccessible to third parties. During the scientific exchange about my results, no conclusions about specific people could be drawn. I respected the participants' and other villagers' privacy and treated their vulnerable illness situation with care, always considering whether I may have been invading their everyday life too much. I asked repeatedly if core participants were comfortable with having interviews in their homes.

Since the analysis took longer than initially assumed, all participants were asked to raise objections if they opposed a retention period of the data that was longer than originally planned (see appendix).

All significant individuals and institutions involved in the making of this dissertation were mentioned in the articles.

The fieldwork, the article writing and the dissertation was a thorough process, including revisions by co-authors and multiple checks of references and interpretations, which helped to validate the analysis. I met my supervisors and my research group regularly to reflect on the research progress. This helped to avoid careless errors and negligence and helped me to examine my work carefully and critically.

My constant verbal exchange with other researchers and colleagues from the medical and anthropological fields enabled me to be in a constant process of talking about the study and exchanging criticism, data, results, tools and resources. In this dissertation, I have made several remarks on these conversations.

I made, and continue making, my results accessible through different activities. For example, I enrolled for the course 'BIO-8010 Visualizing your Science' at Tromsø Museum, which was not obligatory but an opportunity to visualize and exhibit the three articles of this dissertation for 10 days in November 2016. My colleague Tone Seppola-Edwardsen, who was responsible for the urban co-study, established contact with the Norwegian Cancer Society, where she presented her results (Seppola-Edwardsen & Risør, 2017; Seppola-Edwardsen, Andersen, & Risør, 2016) to an audience of people who live in the aftermath of cancer. Her presentation also

included the findings of my study. In addition, I informed my participants about the publication of the first and second articles, and they received either a digital or a physical copy of it. They were offered help with translating passages of it into Norwegian. I will continue to inform the participants about further publications connected to the study. The different conferences that I was able to join during the last few years were of great importance in communicating my results, and receiving feedback from a wider scientific audience. During my research stay in Durham, UK, I was able to join a new group of medical anthropologists, to give presentations and participate in discussions of articles and findings in PhD seminars.

5 Results

5.1 Paper 1: ‘The significance of cultural norms and clinical logics for the perception of possible relapse in rural Northern Norway – sensing symptoms of cancer’

In this paper, we aimed to explore aspects of how the challenging local health care situation in a coastal Northern Norwegian village, clinical logics and local shared values were embodied by people with chronic cancer and part of their sensation-to-symptom processes.

The main findings concern how the municipalities’ instability in primary health care staffing influenced how and when people with chronic cancer presented indeterminate bodily sensations to shifting GPs. Moreover, we found that core participants’ personal evaluation of bodily sensations was embedded in local core values such as the idea that people should contribute to the common good, not be a burden to others, be positive and avoid focusing on difficult things. Being anxious, concerned or hypochondriac about a possible relapse can be experienced as negations of these values and the core participants tried to avoid being associated with those attributes. Further, they embodied and included clinical routines in their perception and assessment of bodily sensations.

We integrated Cameron Hay’s (2008) sensation-to-symptom model to develop our analysis and suggested a rethinking and relocation of her analysis of social legitimation in sense-to-symptom processes in order to grasp the experiences of cancer in rural Northern Norway.

The paper is based on participant observation in a coastal village in Northern Norway, where people who live with cancer face challenges due to the isolated geographic location and the

two-hour flight to the nearest hospital with an oncology department. Flights are often delayed or cancelled, which makes access to specialized health care unstable. Four men and six women who lived in the aftermath of cancer illness and treatment were the core participants in the study.

While being part of everyday life and relationships in the village for almost one year, I was able to observe how a culture of trying not to be focused on difficult things in life and one's own worries and negative thoughts was part of how the core participants went through a phase of uncertainty and increased alertness regarding their body and possible processes of bodily sensations transitioning into symptoms. Not wanting to exaggerate, wanting to be seen as a contributor and the value of a positive attitude all played a significant part in how sensations were assessed by the participants. Core participants tried to avoid involving others in their first experience of indeterminate bodily sensations, as it might be connected to being negative and hypochondriac. They felt uncomfortable when misinterpreting indeterminate sensations and had inner dialogues about other people's possible reactions. The participants played down uncertainty and negative feelings and tried to manage to assess the sensations by themselves. We found that for many of the participants, the possible symptoms of the cancer coming back could mean a practical and moral setback in terms of being unable to work, or having to reduce one's work and contributing less to other areas of life, like family and voluntary obligations.

We also found that the municipal local health center was embedded in a health care system based on clinical logics, with requirements of effectiveness and a biomedical understanding of the human body, which also affected participants' sense-to-symptom processes. Participants had certain understandings of what could be presented in a consultation and what was appropriate to ask for from previous experiences with the health care system, and embodied and included clinical routines in their perception and assessment of bodily sensations. Embodying those routines was part of their experience of their body and worries as something atypical and it both questioned and informed the justification of their sensing. In this way, they were either backpedaling from judging a sensation as a symptom and consulting the doctor, or they experienced it as an encouragement or confirmation to actually contact the doctor.

Core participants felt that they had to present clear, clinically relevant symptoms, so they hesitated to see the doctor for such bodily sensations. The often temporary stay of the local GP and his or her unfamiliarity with the patients intensified the requirement for patients to be focused and clear in their communication of possible symptoms during consultation. The consequences for participants' sense-to-symptom processes were that they tended to wait until

they had consulted the doctor or tried to make sensations fit into the clinical setting and connected them to a definite sign of a specific diagnosis, which had the potential to result in a delay in diagnosis and treatment. While the participants referred to how they sometimes experienced their bodily sensations and worries as indeterminate, they conducted inner dialogues with health care personnel, including assumptions about how these might react to the presentation of the indeterminate sensations and how consultations might turn out.

In the concluding discussion of the paper, we considered it fruitful to compare the findings with Hay's (2008) sensation-to-symptom model. Her data suggest '...that people seek care based on their judgments that a sensation exceeds acceptable temporal spans or disabilities, or that it fits within their expectations based on experiences of vulnerability' (Hay, 2008). In our analysis, we were able to locate aspects relevant to the sense-to-symptom processes of the participants of our study, which Hay does not mention in her analytical considerations. We saw circumstances like the atmosphere in the village, with its specific moral values, and the nature of clinical routines, which are reinforced by the high turnover of GPs, as much more decisive for if and how a sensation was turned into a symptom by participants.

Another aspect of Hay's observations is that '[t]hose sensations that are interpreted as worrisome are then presented to others, seeking social legitimation' (Hay, 2008: 223). Hay sees the social interaction around the interpretation of sensations as symptoms as a step that occurs after the individual has considered whether the specific sensation experience fits with vulnerabilities or exceeds the expected duration or tolerable disability. In our analysis, we were able to show how this differed for our participants: when they assessed the significance of a sensation, they were aware of the local healthcare situation and possible judgments by health care personnel. Moreover, their perception of sensations was also strongly influenced by their sense of not wanting to focus on negative things, be hypochondriac or exaggerate excessively, and they therefore conducted inner dialogues concerning the possible judgments of other villagers. For this reason, we analyzed the processes of social legitimation as already a significant part of the assessment of bodily sensations. This is a major difference from Hay's analysis in which she states that '[o]nce a threshold of one of these frameworks is crossed, a person recognizes that "something is wrong here." And at this point, it appears to be crucial that that subjective evaluation is legitimated in a social arena' (Hay, 2008: 218). Even though our participants waited until they actually discussed and verbalized sensations, worries and speculations with others, the imagined potential others, who might have strong opinions, were

already part of perceiving a sensation and not only of legitimating a symptom. In the paper, we suggested that the social and cultural processes influence the sense-symptom process earlier than Hay suggests in her analysis; social legitimation and acceptance were already part of the assessment of bodily sensations and of a process simultaneously informed by sociocultural and medical values.

5.2 Paper 2: ‘Approaching Health in Landscapes - An Ethnographic Study with Chronic Cancer Patients from a Coastal Village in Northern Norway’

In this paper, we aimed to analyze how the effort and desire to stay healthy was linked to dwelling in familiar landscapes and how health was approached in such landscapes by people living in the aftermath of cancer; here, we were inspired by Tim Ingold’s (1993) theoretical understanding of ‘landscape’, ‘taskscape’ and ‘temporality’ to develop our analysis. Our main finding concerns how core participants’ activities in the familiar surroundings of their village changed from enjoying, knowing and harvesting the surroundings, and staying healthy, to additional engagements that actively attempted to relieve pain and handle worries, after cancer treatment. The specific tasks core participants used to perform are relied upon and revived as an assembled part of their changed bodies; their relationship between body and landscapes was reconfigured.

The paper is based on participant observation in a coastal village in Northern Norway, where inhabitants tend to spend much time outdoors, including activities such as fishing, walking or berry picking. They appreciate people who are active outdoors and the closeness and connection to what they understand as ‘nature. While conducting 11 months of ethnographic fieldwork in 2014 in the municipality of fewer than 3000 inhabitants, I joined former cancer patients’ outdoor activities that they had conducted also before they got cancer, and learned how their engagements were shaped over a long lifespan by their experiences and habits.

Through two of the core interlocutors, Terje and Synnøve, we illustrated how moving outdoors in and outside the village acquires additional meanings after cancer treatment; for them it encouraged health-promoting processes. Those processes were experienced as protective against a possible relapse of cancer, and as a possibility to deal with side effects and psychological challenges. The changed focus of being involved in the outdoor surroundings of the village to prevent illness was closely connected to their knowing and embodied

remembering of moving outdoors, what this did for their bodies and how for instance walking influenced their and others' mental state before they got cancer.

In the analysis of the paper, we approached the data by using Ingold's (1993) term 'landscapes', which refers to the concept of a practiced, lived space, dwelt in and embodied. His concept of 'temporality' covers part of the experience of those who, while performing their everyday tasks, carry forward the process of social life; people's past and present engagements in landscapes are connected to a specific timing and history already present in their lives and the way their surroundings are approached. We applied these terms to understand how the villagers used certain places and areas, and how the tasks that they performed always referred to the use and tasks that had been established over generations and time. Certain places in and around the village have unique significances, which are established by people's relational engagement in the(ir) world. Ingold's concept of 'taskscape' specifically contributed to an understanding of how familiar tasks in familiar surroundings are added new meaning for participants who have experienced cancer. They become activities that embody the landscape and in the case of illness they become tasks of staying healthy. The ways the physical surroundings in and around the village created subjective temporalities of the landscape have developed from the many hours of spending time in those surroundings.

Drawing on Leder's theory in 'The Absent Body' (1990), we analyzed how core participants' bodily awareness changed after and during illness. This supplements perspectives from Paper 1, as it facilitates understanding of how individuals often pay little attention to their bodies in everyday life when feeling healthy, but bodily awareness often changes after or during illness. We argue that familiar landscapes may be attributed healing properties because the individual perception of the body changes after cancer treatment.

The findings show how moving in landscapes can take participants' attention away from their potentially ill bodies, but can also focus their attention on a bodily condition and on the circumstances that make them feel healthier. In other words, 'the body-in-the-landscape' is a relational enactment that works both ways, healing the body and restoring the landscape at the same time. The analysis of Terje and Synnøve shows how embodiment can be understood as a movement of incorporation and being-in-the-world rather than the realization of a specific cultural template (Ingold 1993). The analysis brought forth experience-near accounts and the intentions of people while being in the world rather than attributing cultural ideas and beliefs to their specific actions.

5.3 Paper 3: ‘The cancer may come back: experiencing and managing worries of relapse in a North Norwegian village after treatment’

In this paper, we aimed to unravel and understand how worries about bodily sensations and possible relapse in people living in the aftermath of cancer treatment configured and related to various social relations and contexts. Our main findings concern how people who recover from cancer construct and experience worrying about possible relapse in relation to close family members, friends and co-villagers in a socially closely-knit and relatively isolated Northern Norwegian village. These emotional experiences that emerged through relationships with others had communicative characteristics and took place in interaction with the social environment of the village. Analytically, we were mainly inspired by Geoffrey White’s perspective, and thus considered emotions as relationally constituted and as capable of creating social realities (1997). We also drew on Hochschild’s (2003) concept of ‘emotion work’, which describes the emotional manipulation that people perform on themselves and others to meet ‘feeling rules’ in terms of emotional intensity, direction (e.g. positive or negative) and duration in a particular situation (Hochschild 2003; Thomas, Morris, & Harman 2002).

This paper is based on one-year anthropological fieldwork in a coastal municipality, where the two-hour flight to the nearest hospital with an oncology department and the isolated geographic location in general suggested that people with chronic cancer had particular challenges in the aftermath of cancer treatment.

By taking into account how emotions do socio-moral work in everyday life (White 1997), we showed how, for instance, core interlocutors Bjørg and Kari experienced situations in which they attempted to protect family members by avoiding sharing worries with them, and carried out emotion work (Hochschild 2003) to help the family recover from the illness experience. At the same time, they sometimes found it easier to share those worries with friends, since these had a different kind of moral involvement in their lives. Friendships were even strengthened by sharing worries. Experiencing worries in the context of the village and in relation to acquaintances there meant both comfort and challenges for the participants. On the one hand, the size of the village represented reassurance with its non-anonymous social infrastructure, while on the other hand this lack of anonymity was experienced as confining; it was difficult to

keep information to oneself and people were confronted with others' opinions about their health.

6 Conclusion

This final section summarizes the analytical conclusions and integrates the findings of the dissertation with the main theoretical framework. It also shows the contribution of the thesis to the different research fields and implications for further research.

The goal of this study was to understand the illness experiences of people who live in the aftermath of cancer treatment and their interpretation and management of bodily sensations, including how these were mediated and transitioned into possible symptoms of illness, by participating in their everyday life. The study intended to explore if and how care seeking involves social and cultural norms, pragmatic solutions and relational dimensions, and to add new insights to how rurality, small village dynamics and the partly problematic access to health care services in Northern Norway relate to people's exposure to chronic cancer.

In Paper 1, we aimed to explore how the process from experiencing indeterminate bodily sensations to perceiving them as possible symptoms of cancer relapse was related to clinical logics, and to local values and clinical practice in rural Northern Norway. We showed how the high turnover among primary health care staff related to how and when core participants presented indeterminate bodily sensations to shifting GPs. Core participants had certain understandings of what could be presented in a consultation and what was appropriate to ask for from previous experiences with the health care system, and embodied and included clinical routines in their perception and assessment of bodily sensations. They felt that they had to present clear symptoms, so they hesitated to see the doctor for such bodily sensations. The often temporary stay of the local GP and his or her unfamiliarity with the patients intensified the requirement to patients to be focused and clear in their communication of possible symptoms during consultation. Moreover, the personal evaluation of bodily sensations was embedded in local values in the village. Core values are: to contribute to the common good, not to be a

burden, be positive and avoid focusing on ‘difficult things’. Participants’ inner dialogues with co-villagers and health personnel led to decisions not to share concerns about bodily sensations which might be symptoms of relapse. We suggested a rethinking and relocation of Hay’s (2008) analysis of ‘social legitimation’ in sensation-to-symptom processes in order to grasp the experiences of cancer in rural Northern Norway.

In Paper 2, we aimed to analyze how the effort and desire to stay healthy is linked to dwelling in familiar landscapes and how health was approached in such landscapes by people living in the aftermath of cancer. We showed how core participants engage with their familiar surroundings in efforts to counter bad mood, anxiety and symptoms of relapse and to strengthen their health. By drawing on Tim Ingold’s (1993) understanding of taskscape, we suggested that the participants after cancer treatment dwelt in and engaged with the surroundings of the village in similar ways to before the illness, but after cancer treatment, their core task had changed to coping after illness and staying healthy. We analyzed how the participants were part of and embodied the landscape through the temporality of taskscape, related to their ways of dealing with pain, worries and bodily sensations in everyday life.

In Paper 3, we aimed to unravel and understand how worries about bodily sensations and possible relapse in people living in the aftermath of cancer treatment configured and related to various social relations and contexts. By contemplating human emotions as arising in contexts of interactions, capable of creating social realities (White 1997), we highlighted how people with chronic cancer constructed and experienced worries about possible relapse in relation to close family members, friends and co-villagers in the socially closely-knit and relatively isolated village. These emotional experiences emerged through relationships with others, had communicative characteristics and took place in interaction with the social environment of their village. While the participants attempted to protect family members by avoiding sharing worries with them, they expressed the need to share their worries within friendships. They experienced both comfort and challenges in managing their worries in relation to acquaintances in the village. The paper revealed how worrying about possible relapse is a socially embedded challenge.

6.1 Contributions to the research fields

The findings in Paper 1 show how ethnographic approaches in the theoretical field of anthropology of the senses and further discussion of sensation-to-symptom models enhance knowledge of how bodily sensations transition into clinically relevant symptoms, and how additional anthropology-based studies are needed to better understand such processes.

Previous socio-scientific discussions have shown how sensation-to-symptom processes are not universal, but cultural and social norms and personal circumstances shape the experience and understanding of bodily sensations during a phase after cancer treatment (e.g. Andersen, Paarup, Vedsted, Bro, & Soendergaard, 2010; Youll & Meekosha, 2013). In an anthropological study by Brandner and colleagues (2014), the authors demonstrate how ovarian cancer patients experienced bodily sensations within norms set by their specific socio-cultural context, and how such sensations transitioned into clinically relevant symptoms within processes of social legitimization involving significant others. The authors call for further understanding of people's experience of bodily sensations and processes of transitioning into symptoms, as well as processes that initiate people's health care seeking in the context of cancer.

These perspectives are related to the analysis that we elaborated in Paper 1. We show how a particular local culture of trying not to be focused on difficult things in life and one's own worries and negative thoughts in former cancer patients was part of a phase of uncertainty and increased alertness regarding their body and possible processes of bodily sensations transitioning into symptoms. Not wanting to exaggerate, wanting to be seen as a contributor and having a positive attitude are values that are relevant for inhabitants of the little village and all played a significant part in how sensations were assessed by the core participants. They tried to avoid involving others, such as other villagers, in their first experience of indeterminate bodily sensations, as this might be connected to being negative and hypochondriac. Core interlocutors felt uncomfortable when misinterpreting indeterminate sensations and had inner dialogues about other people's possible reactions. Sometimes they played down uncertainty and negative feelings and tried to manage to assess the sensations by themselves. We found that for many of the participants, the possible symptoms of the cancer coming back could mean a practical and moral setback in terms of being unable to work, or having to reduce one's work and contributing less to other areas of life, like family and voluntary obligations in this specific cultural context.

By enhancing understanding of how people in the aftermath of cancer treatment experience bodily sensations within the local values of a small village context of rural Northern Norway, we addressed the need for further knowledge about how sensation-to-symptom processes are bound to normative behavior in the context of cancer. Similarly to Andersen et al. (2010) and Brandner et al. (2014), I argue that the specific socio-cultural contexts in which current or former cancer patients' bodily sensations transition into clinically relevant symptoms have to be studied to increase understanding of health care seeking delays, because playing down worries and sensations may occur within specific normative rules in such contexts.

By comparing our findings with Hay's (2008) sensation-to-symptom model in Paper 1, and suggesting a rethinking and relocation of her analysis of 'social legitimation' in sense-to-symptom processes in order to grasp the experiences of cancer in rural Northern Norway, we made an important contribution to the sensation-to-symptom discussion in medical anthropology.

Hay's data suggests '...that people seek care based on their judgments that a sensation exceeds acceptable temporal spans or disabilities, or that it fits within their expectations based on experiences of vulnerability' (Hay, 2008: 219). In our analysis, we were able to locate aspects relevant to the sense-to-symptom processes of the participants of our study which Hay does not mention in her analytical observations. We saw circumstances such as the village atmosphere described above, with its specific moral values, but also the nature of clinical routines, reinforced by the high turnover of GPs in the village, as much more decisive for how and if a sensation was turned into a symptom by participants.

Another aspect of Hay's observations is that '[t]hose sensations that are interpreted as worrisome are then presented to others, seeking social legitimation (Hay 2008: 223).' Hay sees the social interaction around the interpretation of sensations as symptoms as a step that occurs after the individual has considered whether the specific sensation experience fits with vulnerabilities or exceeds the expected duration or tolerable disability. In our analysis, we were able to show how this differed for our participants: when they assessed the significance of a sensation, they were aware of the local healthcare situation and possible judgements by health care personnel. Moreover, their perception of sensations was also strongly influenced by their sense of not wanting to focus on negative things, be hypochondriac or exaggerate excessively, and they therefore conducted inner dialogues concerning the possible judgements of other villagers. For this reason, we analyzed the processes of social legitimation as already being a

significant part of the assessment of bodily sensations. This is a major difference from Hay's analysis in which she states that '...[o]nce a threshold of one of these frameworks is crossed, a person recognizes that "something is wrong here." And at this point, it appears to be crucial that that subjective evaluation is legitimated in a social arena (2008: 218).' Even though our participants waited until they actually discussed and verbalized sensations, worries and speculations with others, the imagined potential others, who might have strong opinions, were already part of perceiving a sensation and not only of legitimating a symptom. In the paper, we suggested that the social and cultural processes influence the sense-symptom process earlier than Hay suggests in her analysis; social legitimation and acceptance were already part of the assessment of bodily sensations and of a process simultaneously informed by sociocultural and medical values.

Meinert and Whyte (2017) studied sensation-to-symptom processes of people with HIV in Uganda and also question Hay's sensation-to-symptom model. For this reason, the authors make analytical comments relevant to this conclusion. The analysis of their empirical data shows how interlocutors understood their own bodily sensations as symptoms of HIV only after they experienced family members being sick or dying due to an HIV infection. Another interlocutor in the study explained how he did not even notice that he had lost weight; this sign of a possible HIV infection was at some point clearly pointed out to him by others. Through these empirical examples, Meinert and Whyte (2017) show how the social interaction around quite clear symptoms of HIV may even occur *before* they are experienced by the potentially ill person.

Our analytical conclusion concerning Hay's model in Paper 1 therefore differs from the one in the study by Meinert and Whyte (2017). While we analyzed the former cancer patients' perceptions of symptoms of a possible relapse and their inner dialogues with others around such symptoms as processes that often occur in parallel, Meinert and Whyte (2017) show how social interactions around a person's ill body may occur even before the person concerned perceives possible illness.

Comparing their findings with ours also shows that the processes of how sensations transition into symptoms are highly dependent on the characteristics of the particular illness:

'This aspect of the sociality of sensations and symptoms follows from the fact that HIV is a contagious disease contracted primarily through intimate relations – sexual partners or mother-to-child transmission. HIV usually has a long and individually variable incubation period (from HIV infection to AIDS symptoms), which means that infected

persons may not sense anything that might be taken as a symptom for years. It is often after experiencing symptoms in children and partners that they begin to attend to their own bodies for sensations that might be symptoms. This is especially the case if a child or partner has been diagnosed.’ (Meinert & Whyte, 2017: 21)

For future anthropological studies, it might be relevant to discuss the contextual differences between various diseases and draw conclusions for the sensation-to-symptom processes and models.

The findings in Paper 1 also reveal new knowledge about the structures of rural health care in Northern Norway, and I would therefore like to take a look across the anthropological pond, because discussions on the lack of health care personnel in the periphery do not necessarily take place in medical anthropology. Such discussions occur rather in the field of public health oriented research, and I see the findings in Paper 1 as a relevant anthropological contribution to the need for experience-near accounts and insights into people’s sensation-to-symptom processes within the research field that deals with the disadvantages for patients or former patients living in the periphery.

In the paper, we showed how the often temporary stay of the local GP and his or her unfamiliarity with the patients can intensify the requirement to inhabitants to be focused and clear in their communication of possible symptoms during consultations. We illustrated how the consequences for participants’ sense-to-symptom processes were that they tended to wait until they consulted the doctor or tried to make sensations fit into the clinical setting and connected them to a definite sign of a specific diagnosis, and this could potentially delay diagnosis and treatment. While the participants mentioned how they sometimes experienced their bodily sensations and worries as indeterminate, they conducted inner dialogues with health care personnel, including assumptions about how these might react to the presentation of the indeterminate sensations and how consultations might turn out.

Studies that deal with finding solutions for the lack of health care personal in rural areas often approach analytical considerations on a systemic level, for instance how colleges may improve education in medicine to prepare students for work as doctors in rural areas (Stensland, 2016; Wenghofer, Hogenbirk, & Timony, 2017; Woolley, Sen Gupta, & Bellei, 2017). In Norway, discussions often focus on the challenges of professional isolation, limited career opportunities and limited professional support (Abelsen 2013; Abelsen, Gaski, & Brandstorp, 2016). Such systemic challenges are often illustrated by statistical correlations, such as that between the

(short) length of employment of temporary medical staff and the (small) number of inhabitants in a municipality (Abelsen, Gaski, & Brandstorp, 2016), or between the high turnover of medical staff in a municipality and the additional disadvantage of greater distance to hospitals (Andersen, Forsdahl, Herder, & Aaraas, 2001).

Our findings offer further dimensions and insight into the problem of unstable primary health care services in peripheral Norway by revealing the needs of this specific patient group. We elucidate how the lack of health care personnel has relevance for how people who live in the aftermath of cancer perceive and assess bodily sensations. We gain insight into how they sense the dissatisfaction of health care staff in the rural periphery, the partly outdated working conditions and the limited opportunities for professional development, and incorporate this into their perception of bodily sensations. Further research could explore whether the disadvantages of cancer patients or people who live in the aftermath of cancer in remote contexts actually lead to shorter or different sensation-to-symptom processes than for such groups living in urban areas.

By showing how the use of local surroundings are a key site for expressing and responding to sensations in connection with cancer, the findings of Paper 2 contribute to and expand on existing research on people who live in the aftermath of cancer, and to the overall anthropological discussion on sense-to-symptom processes (e.g. Hay, 2008; Hinton, Howes, & Kirmayer, 2008; Nichter, 2008). We show how sense-to-symptom processes are negotiated and contemplated by core participants during outdoor activities; sensations transition into symptoms as a perceptual process which is closely connected to well-known routines, surroundings and localities, i.e. socially embedded and materially embedded in cultural templates of nature and activity.

This paper is thus in line with previous research that analyzes how interpretational sensation-to-symptom processes occur in everyday logics and routines (Offersen 2016); many interlocutors of this study regularly spent time, some even large parts of their everyday life, in the outdoor surroundings of the village, where they experienced dysfunctions and worries related to possible symptoms while being involved in various activities. It is in the nature of things that everyday life spans a broad period of time, meaning that sensation-to-symptom processes may occur within a wide range of activities and moments in a person's life. By capturing additional day-to-day situations and activities, such as those presented in Paper 2, in which people who live in the aftermath of cancer experience, interpret and react to bodily sensations, this dissertation tries to fit further pieces of the sensation-to-symptom jigsaw

together. The paper thus responds to O'Brien and Varley's (2012) suggested use of ethnographic methods to gain important insights into how people perceive their physical body and engage with natural surroundings to gain health benefits, and is in line with other research that shows how the appearance of and dealing with bodily sensations often takes place apart from the official health care system in a private, familiar setting and under local circumstances (e.g. Stoller 2004).

My analysis of conversations and observations while I spent time with core participants in the natural surroundings near the village is in line with other ethnographic research that shows how meaning is not inherent in landscapes, but culturally attributed (e.g. Basso 1996). This analytical conclusion results from approaching the data material with Ingold's (1993) term 'landscapes', which refers to the concept of a practiced, lived space, dwelt in and embodied. In addition, we used his concept of 'temporality', which covers part of the experience of those who, while performing their tasks, carry forward the process of social life; people's past and present engagements in landscapes are connected to a specific timing and history already present in their lives and the way surroundings are approached. With these concepts, we were able to capture how villagers perform tasks in certain places and areas and how the tasks refer to the use and tasks that have been established over generations and time. Certain places in and around the village have unique significances, which are established by people's relational engagement in the(ir) world. Ingold's concept of 'taskscape' specifically contributed to an understanding of how familiar tasks in familiar surroundings are added new meaning for participants who have experienced cancer. They became activities that live and embody the landscape and in the case of illness they become tasks of staying healthy. The ways the physical surroundings in and around the village created subjective temporalities of the landscape have developed from the many hours of spending time in those surroundings.

With an additional theoretical reference to Leder's 'The Absent Body' (1990), we analyzed how core participants' bodily awareness changed after and during illness. We argued that familiar landscapes might be attributed healing properties because the individual perception of the body changes after cancer treatment.

By using the concepts of Ingold (1993) and Leder (1990) in Paper 2, we also made observations on 'embodiment', which often overlap with those on sense-to-symptom processes in medical anthropology. We included Ingold's dynamic idea of embodiment inspired by writings of Goodwin from 1988:

‘Like organism and environment, body and landscape are complementary terms: each implies the other, alternately as figure and ground. The forms of the landscape are not, however, prepared in advance for creatures to occupy, nor are the bodily forms of those creatures independently specified in their genetic makeup. Both sets of forms are generated and sustained in and through the processual unfolding of a total field of relations that cuts across the emergent interface between organism and environment (Goodwin 1988).’ (Ingold, 1993: 156)

What we found when analyzing how core participants conducted tasks in their familiar landscapes is that the tasks took their attention away from their potentially ill body, but also focused their attention on a bodily condition on the circumstances that made them feel healthier. People in the aftermath of cancer reconfigured the relationship between body and landscape, and ‘the body-in-the-landscape’ became a relational enactment that worked both ways: the landscape healed the body and the body restored and shaped the landscape. The core participants of this study conducted tasks that formed the use and meanings of the outdoor surroundings in and around the village and such tasks were molded by the meanings of such surroundings.

Our findings in Paper 2 contribute to research that analyzes embodiment as a dynamic process of contextual engagements where perceptions influence objects and in turn evoke experiences, memories and sensations. We relate ‘embodiment’ and ‘landscape’ in a similar way to each other as other anthropological studies that analyze the reciprocal process of influence between bodies and natural environments (e.g. Basso, 1996; Casey, 1997; Low, 2003). Yet we expand the research literature by setting a thematic focus on people who have had cancer and their responses to bodily sensations in the discussions on the relational enactment of body and landscapes.

This dissertation shows how core participants’ sensation-to-symptom processes take place within a moral fellowship and in relation to weighing up the reactions of family members, friends, acquaintances or the local GP. The findings in Papers 1 and 3 contribute to anthropological discussions on how acting on bodily sensations is connected to moral responsibility and societal images of how specific bodily sensations should be acted upon (Merrild, Andersen, Risør, & Vedsted, 2016; Merrild, Vedsted, & Andersen, 2017). Our study is in line with the work by Offersen, Vedsted and Andersen (2017) and their findings on how people juggle between taking enough care of their own health and body and requirements of not overusing the health care system. Both the study by Offersen, Vedsted and Andersen (2017)

and our study indicate how seeing a doctor for consultations and examinations that are not necessarily required is negatively connoted and supposed to be avoided. On the other hand, not making use of the health system for recommended check-ups is also supposed to be avoided. My findings are also similar to those of the above-mentioned co-study in the overall project (Seppola-Edwardsen, Andersen, & Risør, 2016; Seppola-Edwardsen & Risør, 2017), where the authors analyze how people who live in the aftermath of cancer in an urban Northern Norwegian setting are focused on not letting cancer dominate their social relationships and on avoiding making others worry. The authors show how maintaining a normal everyday life and one's social network after cancer treatment is significant in urban Northern Norway, paralleling our findings in a rural area. Especially the findings of the third paper show how core participants in this study were confronted with similar obligations, such as needing and wanting to protect family members from worries about a possible relapse, and they felt guilty about the effect of their cancer on family and friends, and became careful in day-to-day interaction with them. Moral balancing is performed with respect to expected roles, for instance that parents should be the ones who are worried about their children, not the other way around; the participants are thus very conscious of the effect of their emotional difficulties on others. This kind of guilty conscience may be characteristic of life after cancer treatment, as it is similarly described by Seppola-Edwardsen, Andersen and Risør (2016).

Nevertheless, core participants of this study were confronted with additional moral considerations influencing how they experienced, articulated and acted on bodily sensations and symptoms, compared to other anthropological analyses (e.g. Jain, 2013; Stoller, 2014; Sontag, 1979; Merrild, Andersen, Risør, & Vedsted, 2016; Merrild, Vedsted, & Andersen, 2017; Seppola-Edwardsen, Andersen, & Risør, 2016). The findings in Papers 1 and 3 illustrate how their experience of, and ways of acting on, bodily sensations and cancer in general are not only, or not necessarily, connected to time schedules in clinical practice, neoliberal ideas of health responsibility, a reasonable use of the welfare state system or class. They make morally specific considerations when dealing with new bodily sensations with reference to the particular structures of the small village, which differ from the Danish suburban areas presented in work by e.g. Merrild, Andersen, Risør and Vedsted (2016), Merrild, Vedsted and Andersen (2017) or Offersen, Vedsted and Andersen (2017). This is shown in Paper 3, where we found that core participants' worrying is experienced in relation to the lack of anonymity, the established meeting places and the comfort and support of the village. Knowing that everybody knows is found to be both reassuring and demanding by the core participants in experiencing and

managing worries of possible illness. The paper also shows how core participants experience the phase following cancer treatment in a context marked by difficulty in talking about new alarming bodily sensations. It is difficult to keep information to oneself; one is confronted with others' opinions and expectations about one's health. Participants' strong identification with the Northern Norwegian culture, which is associated with people's strength, resilience and strong social cohesion, qualities which people are proud of, creates a specific moral attitude towards illness or possible illness. They avoided involving others in their first experience of such sensations, for fear of being considered negative and hypochondriac.

Such findings relate to other research that shows how sensation-to-symptom processes are not merely biologically determined, but influenced by cultural and social contexts (e.g. Hinton & Hinton, 2002; Hay, 2008; Hinton, Howes, & Kirmayer, 2008). However, by applying anthropological writings that analyze the tight connection between emotions and morality (White, 1997; White, 2005; Miller & Bersoff, 1992; White, 1990) on empirical data that describe former cancer patients' assessment of bodily sensations, the findings in Paper 3 expand the anthropological discussion. We show how studying the moral, relational and emotional everyday engagements of former cancer patients is a significant part of understanding sensation-to-symptom processes. I argue that it is relevant to develop further perspectives on everyday emotional dilemmas and the relational dimensions of worrying about possible relapse when studying cancer patients' sensation-to-symptom processes, because these are central contexts where such processes are being contemplated and negotiated.

The different analyses of this dissertation have shown how people who live in the aftermath of cancer interpret bodily sensations in relation to local values, reactions of family members, friends or acquaintances, in inner dialogues with the GP or while dwelling in familiar surroundings. In this way, the three different papers of this dissertation, in aiming to enhance insight into the sensation-to-symptom processes of people with chronic cancer, are a contribution to the theoretical field of anthropology of the senses and to research on the social and cultural processes of how bodily sensations transition into clinically relevant symptoms in medical anthropology (e.g. Hay, 2008; Hinton, Howes, & Kirmayer, 2008; Nichter, 2008).

7 Literature

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8 Appendices

a. First email contact with local health center

Hei XXX

Takk for hyggelig samtale på telefon og for at du kan hjelpe til med organisering av møtene!

Vedlagt denne mailen er 2 prosjektbeskrivelser for forskningsprosjektet rundt tidligere kreftpasienter. Ønsker du en rask innføring i forskningsspørsmålene kan du lese introduksjonen i dokumentet "prosjektbeskrivelseFINALMagdalenaSkowronski112013".

Her kommer en oppsummering fra samtalen. Håper jeg fikk med meg alt. Gi meg gjerne tilbakemelding på mail eller telefon uansett hva det skulle være☺

1.

Vi avtalte et *møte mandag 2. desember kl 12-14*. Det vil dreie seg rundt forskningsprosjektet om kreftpasienters opplevelse av sykdom og behandlingene de oppsøker for den (både ved offentlig helsevesen og alternativ behandling). Prosjektet utføres av Magdalena Skowronski med Nina Foss som veileder. Både Magdalena (Magda), Nina og jeg kommer til XXX morgenen den 2. desember og blir til tirsdag 3. desember. Jeg er med i dette møtet siden jeg kjenner XXX fra et tidligere studie og har ikke noe med kreftforskningen å gjøre. Vi er alle forskere ved Nasjonalt forskningscenter innen komplementær og alternativ medisin (NAFKAM), ved Universitetet i Tromsø.

Vi er fleksible i forhold til møtetidspunkt om det skulle bli endringer. Vi kan også møte tirsdag skulle det være ønskelig å ha flere møter enn det ene.

Ansatte som XXX og jeg foreslår blir innkalt til møtet er: Helsesøster XXX, XXX fra psykiatritjenesten, kreftsykepleier XXX, deg og lege XXX. Om du har andre forslag er vi veldig mottagelig for innspill.

Tema for møtet vil være:

Magda og Nina informerer om studiet.

Samtale rundt mulighetene ved å gjennomføre studiet i XXX.

Diskutere spørsmål rundt praktisk gjennomføring av et slikt studie i XXX f.eks; hvordan kan vi rekruttere kreftpasienter ferdigbehandlet 5 år eller mer tilbake i tid, hvem spør pasienter om deltagelse og hvordan kan man gjøre det på en god måte m.m.

2.

Vi avtalte at jeg skulle holde *en presentasjon av prosjektet om muskel- og skjelettlidelser kvelden 2. desember* (du kan bestemme klokkeslett) i kommunestyresalen. Prosjektet har tittelen "Kombinering av konvensjonell og alternativ behandling ved lettere muskel- og skjelettlidelser".

Jeg sender deg en kort omtale av prosjektet som du kan:

- Sende ut på mail til alle ansatte på helsesenter/i kommune
- Legge ut på kommunens hjemmeside og i XXX.

Du skulle booke lokale og ordne prosjektor.

Jeg sender deg en kort omtale av prosjektet i morgen.

Håper både ansatte og innbyggere i XXX vil finne det interessant å høre om forskningen i bygda. Jeg ser i hvert fall frem til å presentere den etter all den gode hjelpen jeg har fått hos dere, både på helsesenteret og ellers.

(This email was written by a former colleague, who has been in touch with the local health care center previously.)

b. Request for participation in the research project (for potential core participants)



SENCANCER:

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

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
- 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. Kommunelegen og kreftsykepleieren 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 eller kreftsykepleieren 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 (ISM), Allmennmedisinsk Forskningsenhet (AFE) og Nasjonalt Forskningscenter innen Komplementær og Alternativ Medisin (NAFKAM).

Hva innebærer studien?

Hvis du vil være med på studien innebærer det at en forsker vil komme hjem til deg og intervjuer 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 viktig 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 svarkonvolutt med dit 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 gjenkjennerende 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. Eventuelle lydbåndopptak transkriberes i etterkant. NAFKAM vil oppbevare opptak til prosjektslutt ved utgangen av 2016, deretter vil de slettes. Anonymiserte transkripsjoner og notater fra intervjuer vil oppbevares i 5 år, før materialet ødelegges.

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. 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 prosjektlederen Mette Bech Risør (tel. 776 233 40) eller forskeren i prosjektet Magda Skowronski (48340823).

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:

Kommunelegen og kreftsykepleier i XXX 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, dvs. et liv uten aktiv kreftbehandling. Kontroller av sykdommen kan inngå i hverdagslivet; sykemelding (hel eller delvis) kan inngå, og påbegynnelse av jobb eller studie eller f.eks. pensjon.

Deltakerne må være over 18 år og 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, biobank, økonomi og forsikring

Personvern

Ingen opplysninger om deg vil bli registret i noe register.

Det er kun forsker 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 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.

Samtykke til deltakelse i studien

Jeg er villig til å delta i studien

(Signert av prosjektdeltaker, dato)

Stedfortredende samtykke når berettiget, enten i tillegg til personen selv eller istedenfor

(Signert av nærstående, dato)

Jeg bekrefter å ha gitt informasjon om studien

(Signert, rolle i studien, dato)

c. Interview guide for semi-structured interviews

- Hvordan har du det for tiden? Er du fornøyd med livet ditt? 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 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 dette forstyrret dine gjøremål eller ønsker i hverdagen? På hvilken måte? Hvor plagsomt synes du dette er?
 - Hva tenker du at smertene/ubehaget skyldes?
 - Har du snakket med noen om disse fornemmelsene? 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 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, el 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? Hadde du andre muligheter enn å søke slike typer behandling?
- Har du blitt oppmerksom på noe annet ved din helse?
 - Har du ellers noe du har lyst å fortelle/ta opp. Hvordan har intervjuet vært? Som forventet?

d. Extension of anonymization phase

Magdalena Skowronski
Forskningsparken, N-9037 TROMSØ
Tel: 48340823
NAFKAM - Institutt for samfunnsmedisin
Det helsevitenskapelige fakultet - Universitetet i Tromsø
E-mail: msk046@uit.no

Siri XXX
XXX Finnmark, Norway

Kjære Siri og deltaker i studien ‘SENCANCER: Fornemmelser av helse og sykdom i hverdagen: Hjelpsøking og oppfattelse av symptomer blant pasienter som har vært behandlet for kreft’.

På begynnelsen av studien fikk du et skriv som inneholdt bl.a. denne informasjonen:

«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 gjenkjennende 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. Eventuelle lydbandopptak transkriberes i etterkant. NAFKAM vil oppbevare opptak til prosjektslutt ved utgangen av 2016, deretter vil de slettes. Anonymiserte transkripsjoner og notater fra intervjuer vil oppbevares i 5 år, før materialet ødelegges.»

Analyseringsfasen tar lengere enn forventet og dermed har vi behov for å behandle og oppbevare personopplysninger til den 01.08.2017, og ikke bare til slutten av 2016 som nevnt før. Etter det, blir opptakene anonymisert.⁷ Jeg ber deg om samtykke av å forlenge perioden fram til endelig anonymisering. Dersom du har noe innvendinger mot en forlengelse av bruk av datamaterialet eller noe spørsmål, ber jeg deg om å kontakte meg, hoved forskeren i prosjektet (Tel. 48340823).

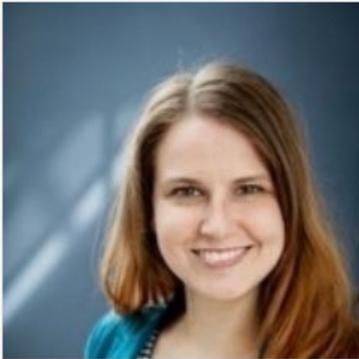
Med vennlig hilsen,
Magdalena Skowronski

⁷ Defensjonen på anonymisering er: For at datamaterialet skal være anonymt må opplysningene ikke på noe som helst måte kunne identifisere enkeltpersoner, hverken direkte gjennom navn eller personnummer, indirekte gjennom bakgrunnsvariabler, eller gjennom navneliste/koblingsnøkkel eller krypteringsformel og kode. Å anonymisere et datamateriale innebærer vanligvis å slette/makulere navnelister, og eventuelt grovkategorisere eller slette indirekte personidentifiserbare opplysninger.

e. Advertisement in local newspaper in order to recruit more participants

Vil du være med i forskningsstudie?

1. mai 2014 • [0 Comments](#)



Kjære [REDACTED]

Jeg gjennomfører en forskningsstudie i [REDACTED] kommune og undersøker hvordan det er å leve de første årene etter en kreftbehandling. I den forbindelse søker jeg etter flere deltakere i studien.

Hvis du har vært i kreftbehandling som er avsluttet, og kan tenke deg å bli intervjuet, så gleder det meg hvis du ringer.

Tel. Magda Skowronski: 48340823

9 Papers I-III